HepCBC

presents

Peppermint Patti's FAQ's

Version 5

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Double Jeopardy: The HIV/HCV Co-Infection Handbook

A big thank you to Frank Montmarquet for permissions for the current research updates; to Ajax Greene of CPS for permissions for *Double Jeopardy*; and to Patricia Johnson for her inspiration.

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Hepatitis C virus resides in the liver of infected individuals for decades, and it is difficult to detect. Giving little notice when entering the body or attacking the liver, the virus has reached epidemic proportions, infecting more than 4 million Americans -- up to 80% of people who have hepatitis C are unaware of its presence.

"Hepatitis C is a blood-borne infectious disease of the liver that affects millions of people worldwide, and is the leading cause of cirrhosis and liver cancer," said David Ciavarella, M.D., Executive Director, Clinical and Medical Affairs, Ortho-Clinical Diagnostics. "It is also the number-one reason for liver transplants in the United States."

"On an average it takes about 10 to 20 years for serious symptoms such as jaundice, fatigue, dark urine, abdominal pain, loss of appetite and nausea to occur," Ciavarella added. "At this point, when patients learn their livers are failing, their only hope is often a liver transplant. But now early detection and treatment is possible through increased public awareness and primary care physician utilization of anti-HCV tests."

Among those at greatest risk for hepatitis C: Hemophiliacs, intravenous drug users, current or past dialysis patients, transfusion-transplant patients, healthcare workers and those engaging in high-risk sexual activities. The CDC estimates that hepatitis C is responsible for eight to ten thousand deaths per year and that this amount could increase substantially during the next ten years.

Source: Ortho-Clinical Diagnostics; Johnson & Johnson, Sept. 28, 2001

HepCBC - HEPV-L HEPATITIS C FAQ v5.1

January 20, 2001

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This FAQ is dedicated to the memory of David H. Kehrer, LTC John Heintz (Peters) and his wife Patricia, Daniel Bodiford, Dr. Horst Irmler, Jude Saucier, Capt. Kevin Donnelly, Ron Thiel, "Uncle" Dave Lang & Guy Thisdelle.

PART 0: ADMINISTRIVIA

PART I: THE BASICS

PART II: MEDICAL ISSUES

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Subject: Part 0: Administrivia
Subject: 0.00 Copyright

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This is a document whose development is in progress. Please make comments to help improve it. Please send suggestions for additions, corrections, or changes privately to the authors (Patricia Johnson) at address clotho@bellatlantic.net, or to C.D. Mazoff at cdm@hepcbc.org.

If you want your contribution to be anonymous, please state so.

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HEPV-L is a list devoted to people with chronic hepatitis, and related liver diseases. Its address is HEPV-L@MAELSTROM.STJOHNS.EDU ; HepCBC can be reached through www.hepcbc.org.

Subscribe by addressing a message to: LISTSERV@MAELSTROM.STJOHNS.EDU and in the body of the message, on the first line, type: SUB HEPV-L FIRSTNAME LASTNAME (substituting your name for the first and last name). Any questions, or problems signing on—or off—the list, please contact one of the listowners at HEPVL-REQUEST@MAELSTROM.STJOHNS.EDU

HepCBC (www.hepcbc.org) is an association of independent grassroots organizations in British Columbia, Canada, and beyond, dedicated to education and prevention of hepatitis C. It is the home of the *hepc.bull*, and the HepCAN list (http://groups.yahoo.com/group/hepcan/messages), a Canadian online information and support network, sister to HEPV-L.

0.01 INTRODUCTION

This document answers frequently asked questions (FAQ) about the hepatitis C virus (HCV), its treatment, and related complications. We have made every effort to provide the most current and most accurate information.

This updated version (FAQ v5) reflects the international nature of the hepatitis C community. Although the home of the HEPV-L list is in the US, many of its members come from other parts of the globe. Patricia Johnson (Peppermint Patti), the original author of the FAQ had asked David Mazoff (squeeky), of HepCBC in Canada, if he could take over the arduous task of revising and updating the FAQ. David lives in Canada, and so this version has quite a bit of information for Canadians. To make the FAQ more accessible to those from countries other than Canada, information relating specifically to Canada has been put in appendices at the end of the document.

Thanks to a grant from the Legal Services Society of British Columbia, this edition now includes information on Disability Benefits for residents of BC. Hopefully, this section will expand to include all of Canada. The reader will also note that there is no list of physicians in the US comparable to the list of Canadian physicians given in Appendix D. Anyone wishing to compile this list is welcome to do so. Please contact the authors of the FAQ.

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 catalogue 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 and HepCAN mailing lists, and from original research published in the *hepc.bull*. 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 and systemic disorders.

Thanks are due to the many contributors to this new official version of the FAQ. Below, in no particular order:

Alan Franciscus (HCV Advocate), Brad Kane (HepCBC), Andi Thomas (Hep-C-Alert), Anne Karim, Bruce Bennett, Bryce Brogan, Paul Harvey, Cindy Torchin, David Lang† (HEP Seattle), Frank Smith, Joe Shaw, Joan King (HepCBC), Kathryn Morse, Eileen Caldwell-Martin (FHCQ), Ken Benjamin, Kevin, Kunga Palmo (USHA), Sue White (Mid Island HepC), Capt. Kevin Donnelly†, Bruce Devenne (HepCNS), Leslie Gibbenhuck

induced, alcoholic hepatitis.

I.0.6 WHAT IS THE FUNCTION OF THE LIVER?

The liver:

- Stores iron reserves, as well as vitamins and minerals
- 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

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I.0.7 HEPATITIS C VIRUS (HCV)

Hepatitis C 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 failure, liver cancer and death. HCV is also a trigger for a host of autoimmune disorders and various other diseases, such as diabetes, non-Hodgkin's lymphoma, retinal complications and thyroiditis. 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".

According to Bruce Devenne of Hepatitis Nova Scotia, governments and medical communities had knowledge of hepatitis C well before 1987, and could have done much to prevent the deaths of thousands. But they didn't. Consider the poisoning of those in Ireland and France with HCV infected blood, and where court cases clearly found criminal liability on the part of blood merchants and governments. Consider also the history of blood safety in Canada, and the current Arkansas Blood Trail scandal (See Appendix E, below).

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

People with abnormal liver function tests with no apparent cause would also benefit from having a hepatitis C antibody test. However, because of the historical inadequacy of sterilisation procedures in dentistry and in the health and beauty industry, we (HepCBC) recommend that anyone who has had extensive dental procedures where blood was present, or who has had manicures or pedicures be tested as well. Recent

studies (2000) show that persons undergoing hemodialysis are still at risk, as are many cured cancer patients.

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@cpcug.org Listowner HEPV-L ---

Most people with hepatitis C contracted it either through a blood transfusion or receiving a blood product (plasma, gammaglobulin, etc.) that was contaminated with hepatitis C, or by sharing needles with intravenous drug users that were infected with hepatitis C. Prior to 1990, the official line is that blood could not be screened for HCV (*see, however, History of Blood Safety, below*). 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 undergoing 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; statistics for vertical transmission are between 5 and 10%. It may occur more readily if the mother is also infected with the human immunodeficiency virus (HIV) that causes AIDS--30% transmission rate.

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. As early as 1956 the *Merck Manual* stated that NANB hepatitis could be spread through the use of glass syringes and other then current medical testing and mass vaccination devices.

Forty percent of all cases of hepatitis C were contracted through unknown means by people who 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 (unless there is deep-kissing and open sores present)
   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 paraphernalia (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 (*see History of Blood Safety below*).

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, no 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 .

Recent studies in British Columbia (1999) show that 90% of the male prison population is infected with HCV.

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 should contact their doctor immediately to have liver function tests performed.

I.1.4 NEONATAL TRANSFER OF HCV

This following is from the HepCBC pamphlet, HCV & Pregnancy. The information was vetted by the BCCDC

Reducing the Risk of Transmission During and After Pregnancy

A woman living with Hep C who wishes to become pregnant may have particular anxieties about the health of her baby. The chance of the virus being transmitted to the baby is 5-10%, and higher in persons who have HIV as well. If a mother also has AIDS, the chances can increase up to 36 in 100. The risk may be even greater in mothers who are infected with both Hep B and Hep C.

Transmission to the baby can happen before or during birth. In parts of the world with lower standards of general health, transmission from a woman with Hep C to her baby is more likely. Most doctors and midwives will be helpful and supportive to a woman with Hep C who wants a child. Pregnancy with Hep C is not officially discouraged.

Viral Load and Mother-to-Baby Transmission

Viral load is the amount of Hep C in the blood. If a woman with Hep C has low viral load (less than 1 million copies/mL), it is less likely that the virus will be passed to her baby than if she has high viral load. However, even if viral load is very low, there is still a chance that Hep C will be transmitted.

Given the low risk of transmission from mother to infant there is not enough information at present regarding the use of Caesarean sections to reduce the risk of transmission. However, it is possible that if a woman has an acute case of Hep C, there is more of a risk of her baby being infected.

Breast Feeding

It is not yet known whether the breast milk of a woman with Hep C contains enough virus to infect a baby during breast feeding. Generally, women with Hep C are not advised to avoid breast feeding. No studies have documented transmission of Hep C infection to infants by breast-feeding.

Children with Hep C *(See also II.8.0 How Does HCV Affect Children?)*

In children, viral infection is usually silent, although children as young as 8 years old can become quite ill from HCV.

Children are less likely than adults to have symptoms of infection with Hepatitis C, and thus may be able to

transmit the virus unknowingly.

Having hepatitis C does not seem to affect a child's growth.

All children, with or without hepatitis C, should be taught proper hygiene.

Children and Advanced Liver Disease

Chronic hepatitis C eventually causes cirrhosis or cancer. However, it can take 10 to 20 years or more before cirrhosis may occur. Liver cancer rarely occurs in children.

Treatment in Children

Few studies exist examining interferon (IFN) use in children with chronic HCV. A recent study suggests that IFN therapy may benefit children with chronic HCV, and indeed, children may respond better than adults, possibly because they have been infected for less time and have a milder disease. Interferon is used in children only in clinical trials in Canada at this time. Another drug, called ribavirin, is being used in combination with IFN in adults and may be recommended for children in the future.

There are still many questions about Hepatitis C in children. More studies are necessary to learn more about how the disease progresses and about different treatments.

Talking to Health Care Workers

Doctors and midwives can be helpful and supportive to a woman with Hep C who wants a child. It can be very hard for a woman with Hep C to tell her health care workers she is pregnant or wants to be, if she suspects they will try to change her mind. Staff with experience of working with women who have Hep C are likely to be the best informed and most supportive.

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), as well as the British Columbia Centre for Disease Control 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 that 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

A report from Health Canada, "Hepatitis C Prevention and Control: A Public Health Consensus," June 1999, p.6, recommends that:

1. People with multiple partners should practice safer sex.
2. Longstanding sexual partners do not need to change sexual practices if one of them is found to be infected with hepatitis C

A recent study in *The Lancet*, 356:9223:42-43 (June 2000) detected the hepatitis C virus in the semen of infected men. The doctors concluded that "the presence of HCV-RNA in semen is a strong argument in favour of HCV sexual transmission from men to women." However, HCV viral loads detected in semen were low, which suggests that the risk of HCV sexual transmission is probably also low.

I.1.5b OCCUPATIONAL EXPOSURE (HEALTH CARE WORKERS)

The general consensus is that HCV is a greater threat to healthcare workers than HIV. The risk that healthcare workers will become infected with hepatitis C virus (HCV) following an accidental needlestick is 20 to 40 times greater than their risk of HIV infection, according to data presented at the International Conference on Emerging Infectious Disease. Sponsored by the US Centers for Disease Control and Prevention and the American Society for Microbiology (July 2000).

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, and firemen 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.

Current recommendations are that "both private and public health providers be made aware of the risk, and above all that all source patient providers be tested for hepatitis C."

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. Recently concern was expressed over the sharing of electric razors in a VA hospital. A study in *Hepatology* showed that 19% of veterans tested in a VA hospital in San Francisco were infected with HCV.

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.

Recent studies recommend regular testing for HBV and HCV among hemodialysis patients Though uncommon, new hepatitis virus infections were detected among patients with normal ALT tests (Harvey S. Bartnof, MD, (www.hivandhepatitis.com, July 9 2000). Reports at the Digestive Disease Week 2000 that was held in San Diego, California between May 21-24, 2000 reveal that in a study of 51 patients with CRF (chronic renal failure), 42 had a normal ALT and ten of them (24%) had detectable HCV RNA. Among the remaining nine patients with an elevated ALT, five of them (56%) had detectable HCV RNA.

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, although antibodies to the virus were (*J Med Virol* 1998 May;55(1):24-27). These findings suggest that body fluids of patients with chronic hepatitis C are rarely, if ever, contaminated with the hepatitis C virus. Another study (*J Med Virol* 1998 Apr;54(4):271-275), however, revealed the presence of the virus itself, and led the researchers to question whether or not the virus could reside in the salivary glands themselves ("Predominance of HCV type 2a in saliva from intravenous drug users." University of Glasgow Dental School, Scotland).

A very recent study in France detected the presence of HCV RNA in the semen of HCV infected men. The researchers had to devise a special test to detect the virus. Ordinary PCR tests are not strong enough to detect the small amount of HCV viral particles in semen. The doctors caution that although the risk of transmission is low because the viral load in semen is low, nevertheless the risk of sexual transmission from men to women remains a possibility (*The Lancet* 356: 9223:42-43, July 2000).

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 (*i.e., acupuncture*), 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).

A cross sectional survey of seropositivity for hepatitis C in Japan found an increased risk of hepatitis C

associated with acupuncture (*BMJ* 2000;320:513, 19 February).

I.1.6e 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. Wiping a surface with isopropyl alcohol and leaving it to air dry will also kill the virus.

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. It is also possible that many persons were infected in the early 50s during mass vaccination programs in schools and camps. As well, programs for the poor often used cost cutting measures which included the recycling of medical devices (syringes, needles) which should have been thrown away. Furthermore, blood products have been used in the making of many vaccines and in the 50s and 60s these products were not screened for HCV.

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 its own DNA. Retro means that the virus 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. (See *Double Jeopardy: The HIV/HCV Co-Infection Handbook*, which we have appended to the printed version of this FAQ). See also Appendix F: "The Double Challenge of HIV/HCV Co-infection."

I.1.7 PREVENTION

Prevention: avoid risk behaviors. Shots of gamma globulin (now supposedly safe) 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?

Eighty-five to ninety percent of all HCV carriers will have it for life, or until a cure is found. All carriers of HCV can transmit the disease to others via his or her blood. 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.

From the* hepc.bull *Dec 1999, Issue 18.

"BLOOD SPILLS: DO YOU KNOW HOW TO SAFELY CLEAN UP A SPILL OF BLOOD OR BODY FLUID? THIS ARTICLE WILL TELL YOU HOW. by Mark Bigham, MD, FRCPC, British Columbia Centre for Disease Control

Hepatitis C virus (HCV) is transmitted mainly by exposure to HCV-contaminated blood. HCV infection is not generally associated with exposure to other body fluids, such as saliva, urine, feces or vomit, but if HCV-contaminated blood is present in these or other body fluids, then the risk of infection will be greater. Therefore, it's important to treat any environmental contamination of blood or body fluid as potentially infectious. The simple principles of cleaning and disinfecting, which are effective against HCV, are also very effective against other micro-organisms.

Viruses can only reproduce inside cells and HCV will not survive very long outside the human body—usually no more than a few hours. Survival of HCV in the environment is limited by such factors as lower temperature and dryness. HCV is also readily killed by standard household products, such as 5% household bleach or 70% isopropyl alcohol.

If you encounter a spill of blood or body fluid, the most important infection control principle is to avoid direct contact. This is easily and effectively achieved by wearing rubber gloves—preferably single use, disposable vinyl gloves, or even household rubber gloves. Litter, such as broken glass should be picked up first. Try not to handle broken glass that could tear the gloves. Pieces of stiff cardboard or newspaper folded over can be used to pick up glass. When disposing of glass, wrap it in a newspaper before throwing it in the garbage bag, to protect municipal waste disposal workers from being cut when handling the bag.

Next, clean up the visible blood or body fluid with plain water and disposable paper towel. Using water will dilute the spill, reduce its infectivity, and facilitate wiping up the spill. Cleaning the visible spill will also remove organic matter that can reduce the effectiveness of disinfectants. The used paper towel can be put in a plastic bag (double bag if very wet and dripping) and disposed of in the regular household garbage.

A disinfectant should then be used. Regular 5.25% household bleach is an excellent disinfectant choice—it is inexpensive; has low toxicity and is not usually irritating to the skin; is fast acting; and is very effective not only against HCV, but also other blood-borne viruses (e.g., HIV, Hepatitis B virus), bacteria and fungi. It can be diluted with water to make a 1:10 to 1:100 bleach solution. The diluted solution should be prepared fresh, since bleach degrades over time when exposed to air or light. It can be wiped onto the surface with a towel and left to air dry, or poured onto the affected area and then wiped up with disposable paper towels after 10 minutes. An effective, alternative disinfectant for use on colour-sensitive fabrics or materials is 70% isopropyl alcohol, full strength, and applied in the same manner as described for bleach.

Gloves can then be carefully removed and disposed of in the regular household garbage along with the used paper towels. Reusable gloves can be rinsed in water and dipped or wiped in disinfectant and allowed to air dry. Finally, don't forget to wash your hands.

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.

A more recent study showed 100% 2-year sustained virologic response with alfa interferon monotherapy for acute hepatitis C. In a small study with seven patients, high-dose treatment for one year (5 mil daily for was 12 weeks, followed by 3 MIU 3-times weekly for 40 weeks. This represents a total alfa interferon dose of 780 MIU. The results were that all seven of the seven treated patients (100%) with acute HCV infection had

a sustained virologic response two years after completing therapy. By contrast, only two of ten (20%) of those with chronic hepatitis C in the comparative arm achieved a sustained virologic response. The difference was statistically significant (Digestive Disease Week 2000).

I.1.8 WHOM SHOULD I TELL?

If you have hepatitis C, you are under no legal obligation to tell others. However, the law may change. Right now, 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 whom they inform, in the 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.

Recent cases where patients have been infected by physicians has raised the ethical issue of whether or not infected physicians should be banned form performing invasive procedures. So far nothing has been done in this respect (*Milbank Q* 1999;77(4):511-29) Infected physicians and invasive procedures: national policy and legal reality; *Rev Med Virol* 2000 Mar;10(2):75-78 Surgeons who test positive for hepatitis C should be transferred to low risk duties).

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.

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), The HEP project in Seattle, the Hepatitis C Support Project in San Francisco, HepCBC in Victoria, British Columbia, or a host of other hepatitis C organizations for a list of doctors near you. If there are no hepatitis knowledgeable doctors in your area and you wish to find an out-of-town specialist contact the organization nearest you for help. For a list of hepatitis C organizations in your area see Part XII of the FAQ.

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. Or you can just give him or her a copy of the FAQ.

See Appendix D for a list of Hepatologists and Gastroenterologists in Canada.

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. Unfortunately hepatologists, especially in Canada, are few and far between.

II.1.0 HOW IS IT DIAGNOSED?

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.

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. Many physicians still assume there is (especially primary care physicians), and this has led to complications and even death because of misdiagnosis. Recent studies show that testing for enzyme level elevation is not an accurate diagnostic for the presence of hepatitis C (Digestive Disease Week 2000).

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 non-viral 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.

II.1.2a WHAT IS A GENOTYPE?

A genotype is the "family" to which our specific virus belongs. Our genotype does not change, but we can be re-infected with a different genotype. The most common 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 anaesthetized, 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.

Some persons, however, have had to be hospitalized afterwards due to extreme pain, shock or puncture of another organ. Many patients have commented that taking an atavan before the procedure helped reduce the pain since this drug will relax the internal muscles and prevent spasms.

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. Some doctors are really hesitant to give pain killers to those with hepatitis C. Please make sure you have some just in case, by clearing up this matter before hand. After my second biopsy, I was in so much pain I was crying for hours, and I had to argue with the nurse to get some medication. The pain subsided after 24 hours, but both Joan and I were very worried (squeeky).

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 non-specific 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. If by advanced we mean cirrhosis, then this is most definitely not the case. Symptoms can occur well before cirrhosis occurs.

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

It is thus possible to have low enzyme levels and few if any symptoms and yet have dangerously advanced liver disease. The problem with this scenario is that the carrier does not know he or she is ill, and does not make modifications to his or her behavior—alcohol consumption, sexual protection, fatty foods, and so forth.

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. The fatigue is often not recognized as such. Many people suffering from this "fatigue" do not have a desire to sleep because they are tired. Rather, they are suffering a very low level muscle pain (which often they do not recognize) that just wears them down. Taking a nap really helps. "It took me years to figure out that it was pain. When nurses would say to me, you look tired, I wouldn't know what they meant. I did not always want to go to sleep. Now much of that has changed. I do get sleepy-tired and must nap often" (squeeky).

A recent study by Goh J, Coughlan B, Quinn J, O'Keane JC, Crowe J Department of Hepatology, Mater Misericordiae Hospital and University College Dublin, Ireland found that fatigue does not correlate with the degree of hepatitis or the presence of autoimmune disorders in chronic hepatitis C infection. The doctors concluded that the perceived functional impact of fatigue on quality of life is significantly higher in patients with chronic HCV genotype 1b infection compared to healthy controls. However, it is unrelated to the degree of hepatitis and cannot be accounted for by the co-existence of autoimmune disorders alone. *Eur J Gastroenterol Hepatol* 1999 Aug;11(8):833-8

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. It varies from a dull ache and bruised feeling, to sharp stabbing pain which is quite different from "gas pains."

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. Sometimes the nausea is caused by disturbances to the inner ear, in which case your doctor might be able to prescribe treatment. Many persons on the list have developed autoimmune inner ear disease as a complication of hepatitis C.

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.

Recently many of our members have taken to using "bag balm," an ointment used on horses. It is apparently effective and harmless. It can be obtained from any equestrian or farm supply store

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II.2.2h VISION PROBLEMS

Some hepatitis patients complain of blurring vision, and dry eyes. This can be especially true while undergoing interferon treatment. Interferon treatment can and does trigger retinal complications, such as hemorrhages, as well as vitreous detachments, cotton wool spots, cataracts and even strokes (infarcts). Be sure to get your eyes tested before beginning treatment. There are products to counteract dry eyes. If you are on treatment, use sunglasses outdoors.

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.

Hepatitis C is becoming increasingly associated with a host of autoimmune disorders. Some of these disorders affect the inner ear. The inner ear regulates balance. Symptoms of autoimmune inner ear disease are dizziness, ringing in the ears (tinitus) and hearing loss.

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?

Over fifty-nine percent of people infected with hepatitis C will remain infected for life, but among those with genotype 1b, that figure zooms up to 92%. 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

Approximately 85% of people infected with HCV will develop chronic hepatitis; ultimately, 20-30% of those will progress to cirrhosis. (*JAMA* Vol. 284 No. 4, July 26, 2000). 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

Progression of the disease depends on several factors: mode of transmission (transfused victims usually progress faster), age at transmission (people infected older progress faster), gender (men usually progress faster than women) and alcohol use.

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

Chronic hepatitis C infection causes problems for parts of the body beyond the liver. The organs most often affected include the blood vessels, skin, joints, kidneys, thyroid gland, heart and brain. The virus itself has been found in the heart, muscles, nerves and lymphatic system. 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, coma, and susceptibility to infection.

During the last years many autoimmune manifestations have been correlated with HCV infection; namely, sicca syndrome, chronic polyarthritis, polydermatomyositis, fibromyalgia, autoimmune thyroiditis, lung fibrosis, and diabetes mellitus. (*Curr Opin Rheumatol* 2000 Jan;12(1):53-60)

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.

Hep C Illness - Outside the Liver

By Paul Harvey

In considering the possible impact of hepatitis C on our health, we should first question our definition of good health. Some clinicians suggest that good health is not so much a specific state such as "absence of disease or illness". They believe that good health is an overall approach: one that accommodates a certain level of illness as normal and has people working positively towards overcoming the physical and emotional problems caused by disease (Lorig et al.). This is quite a useful approach when considering that most people will develop some type of chronic illness in their life.

Our complex biological system

An additional issue before examining the possible impact of hepatitis C on health is consideration of the incredibly complex biological nature of our bodies. Modern technologies are forever changing our world but they remain crude in comparison to the fantastic interaction of electrical, chemical and biological processes that exist within us. Given this level of complex interactions, it is not unusual that a disease most noticeably

causing illness in one major organ or body system will have some level of impact on other parts of the body.

Non-liver HCV illness
Studies suggest that hepatitis C related fatigue is not primarily related to actual liver disease but is linked either to disorders of the immune system (*Eur J Gastro Hept* 1999 Aug;11(8):833-8) and (*Am J Gastro* 1999 May;94(5):1355-60), or to altered neurotransmission (brain tissue) function (*Lancet* 1999 Jul 31;354(9176:397).

The most commonly reported symptom of hepatitis C is fatigue. Clinicians are yet to confirm if this is an extrahepatic condition (an illness affecting parts of the body other than in the liver), or if it is related to actual liver damage (see p16). Aside from fatigue and possible complications of actual liver damage, hepatitis C infection has comparatively little impact on the rest of our body - although several conditions have been observed. Of the range of other health conditions linked to hepatitis C, some have been observed and well documented by clinicians (see below), while the occurrence of many others have been noted in only a small number of cases and may yet be explained as simple coincidence.

The publication Hepatitis C: a management guide for general practitioners (*Aust Family Physician* 1999;28 SI:27-31) recently listed a range of HCV extrahepatic conditions (below). Many of these are reported in *The Hep C Review*, ED30, September 2000, by Dr Bryan Speed (page 12), Dr Tony Jones (page 16), Doug Mellors (page 29), Dr Ed Gane (page 30) and Tina Pirola (page 34).

Arthralgia
Cyroglobulinaemia
Diabetes melitis
Glomerulonephritis
Lichen planus
Non-Hodgkin's lymphoma
Peripheral neuropathy
Porphyria cutanea tarda
Sicca syndrome
Sjogren's syndrome
Thrombocytopaenia
Thyroid disorders
Vasculitis

Summary
The majority of all people in our culture experience chronic illness at some point in their life. So although it's great to have good health, it's probably unreasonable to expect to have perfect health. In a small number of cases, hepatitis C can cause imbalance and illness in various parts of the body - other than the liver. Given the complexity of our bodies, the fact that such extra hepatic HCV conditions can occur should not be seen as abnormal. These "extra hepatic conditions" are not necessarily serious and properly diagnosed and treated, they should not cause alarm if they occur. Certainly, they do not warrant unnecessary anxiety.

If anyone suspects they may be experiencing extra hepatic conditions, they should consult their GP and if necessary, ask for referral to a hepatologist or other hepatitis specialist. Prior to such consultation, people should do a "work up" with their doctor; ie. noting the frequency of possible symptoms and having any relevant blood tests done.

* Paul Harvey is Special Projects Officer with the Hepatitis C Council of NSW, Australia.
Source: *The Hep C Review*, Ed30, September 2000

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; *Rev Med Chil* 1998 Jun;126(6):725-6.

II.4.0d 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. A more recent study (*Curr Opin Rheumatol* 2000 Jan;12(1):53-60) suggests that a causative role of HCV seems to be likely in the development of fibromyalgia.

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 Sjogren's syndrome.

Numerous extrahepatic disorders have been recognised in association with HCV infection among which dermatological diseases occupy a central part. Cutaneous necrotising vasculitis, mixed cryoglobulinemia, porphyria cutanea tarda and lichen planus are the major skin diseases frequently associated with HCV infection, but other skin disorders, such as Adamantiadis-Behcet syndrome, erythema multiforme and nodosum, malacoplakia, urticaria and pruritus, may also be linked to hepatitis C. Further studies are necessary to establish or refute an aetiopathogenetic role of HCV in these conditions. Skin manifestations are also part of the clinical picture of other extrahepatic disorders associated with HCV infection, such as thyroid dysfunction and HCV-related thrombocytopenia. The response to interferon alpha (alpha-IFN) therapy in skin diseases is unpredictable with some patients ameliorating, others remaining stationary and others deteriorating. *J Eur Acad Dermatol Venereol* 1998 Jan;10(1):12-21.

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.

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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?

All persons with hepatitis C should be vaccinated against hepatitis A and B. An editorial in the *New England Journal of Medicine* warned that fulminant hepatitis is associated with hepatitis A virus superinfection in Patients With Chronic Hepatitis C. What this means is that persons with hepatitis C who get hepatitis A are at significant risk for fulminant hepatitis and death. From June 1990 to July 1997, the scientists examined 163 adults with chronic hepatitis B and 432 patients with chronic hepatitis C who were seronegative for HAV antibodies; tests were conducted every four months for serum IgM and IgG antibodies to HAV. Over the course of the study, 10 patients with HBV infections and 17 with HCV infections acquired HAV superinfection. Of these patients, fulminant hepatic failure developed in seven of the HCV-infected individuals, six of whom died. All but one of the HBV patients who developed HAV had uncomplicated courses. Since HAV infection rarely has a fulminant course and is usually non-fatal, the scientists note that "the high mortality rate among our patients with chronic hepatitis C and HAV superinfection (35 percent) is thus surprising, as is the even higher percentage of such patients with fulminant hepatitis (41 percent)." The authors suggest, therefore, that individuals with chronic HCV infection be vaccinated against the hepatitis A virus. AUTHOR: Vento, Sandro; Garofano, Tiziana; Renzini, Carlo; et al. SOURCE: *New England Journal of Medicine* (01/29/98) Vol. 338, No. 5, P. 286

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. A study presented at the 3rd International Conference on Therapies for Viral Hepatitis. December 12-16, 1999; Maui, USA and Antiviral Therapy 1999; 4 (Supplement 4), 38. suggested that pre-menopausal women have better response rates to alfa interferon for chronic hepatitis C. Interestingly, menstruation protects women from organ damage until after menopause. This is thought to be caused by the protective effects of estrogen and the lower amounts of iron in the blood in pre-menopausal women.

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

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 whether or not a toddler has the virus. The rate of fetal infections in HCV+ mothers is about 6%. The rate goes up if the mother is co-infected with HIV.

Any woman, or partner of a man, who has taken ribavirin must wait 6 months after the end treatment before becoming pregnant to avoid birth defects.

BREASTFEEDING : There has been no documented case of HCV being transmitted by breastfeeding, and the rates of infant infection are identical in both breast- and bottle-fed infants. There are many advantages to breastfeeding. Breastfeeding mothers should check their nipples before each feed and avoid breastfeeding if they are cracked or bleeding. They may want to consider using breast shields.

It is not known if interferon or ribavirin are passes on to the baby through breast milk.

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

There is a high mortality rate among pregnant patients infected with hepatitis E, which sometimes accompanies hepatitis C. There have been no studies on pregnant women taking interferon.

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. (Leslie Gibbenhuck, President, Children's Liver Alliance, Canada bchepc@telus.net)

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

The most often reported clinical symptoms are: jaundice fatigue abdominal pain loss of appetite intermittent nausea vomiting (CDC)

However, often doctors incorrectly assume that hepatitis C is a liver disease and that the only "real" symptoms of hepatitis C are related to liver disease and liver dysfunction

But the virus itself has been found in the nervous system, the lymphatic system, the muscles and the heart where it causes direct inflammation. Many physicians, unfortunately, do not take this other activity and the stress it subjects us to into account. Rather than relying on the latest tests and literature to help form a diagnosis, they often mistakenly assume that hepatitis C is only a liver disease, and that, unless the patient has obvious cirrhosis, the complaints are psychosomatic

However, just as HIV often causes death by AIDS-related pneumonia, but HIV is not a lung disease, hepatitis C often causes death through liver failure or liver cancer but it is not a liver disease. Hepatitis C is a virus that lives in and attacks many other organs of the body. But hepatitis C is also an active virus which engages the immune system to the point of exhaustion. The high viral activity is called viremia.

When your body is under attack from a hepatitis C viral flare-up, the immune system mounts a defense which produces symptoms much like that of having the flu. The primary symptoms are aches, tiredness, fogginess and maybe a slight fever. These symptoms are the result of the immune system's response to the hepatitis C virus.

For a list of common reported symptoms of hepatitis C see the survey above.

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.

For some reason many physicians continue to assume that if the enzyme levels are low or near normal, that there is no cause for worry or need for treatment. However, the studies which show that **THERE IS NO NECESSARY CORRELATION BETWEEN ENZYME LEVELS IN THE BLOOD AND THE EXTENT OF LIVER DAMAGE** are too numerous to mention. I (C.D. Mazoff) know several individuals who had to insist on a liver biopsy, only to find out that despite the low enzymes, they had grade 2 and grade 3 liver damage. One is dead, another is Joan King. You may post her at jking@hepcbc.org and she will tell you her story.

HEP C AND ALT'S - WHAT IS NORMAL ?

Alan Franciscus

Twenty to thirty percent of people with HCV have persistently normal alanine aminotransferase (ALT) levels. It is currently recommended that HCV+ individuals with normal ALT levels should not be treated with antiviral medications and followed simply by measuring their ALT levels. However, emerging data suggests that it may not be this simple. What does this mean for the patient that has persistently normal ALT counts? Should they be biopsied and treated? This is a 'hot' area of research and some recent findings are changing the way the medical profession views this group of HCV+ patients.

We know that most HCV+ individuals with persistently normal ALT levels have a less serious disease progression and milder disease. The National Institutes of Health (NIH) and European consensus conferences recommended no liver biopsy or antiviral therapy in patients with persistently normal ALT levels outside of clinical trials due to the assumed mild disease progression and low response rates to current antiviral therapy. Some medical professionals dismiss this group as healthy 'carriers' and offer minimal medical follow-up. However, some of these patients with normal ALT's do not fit so neatly into this category and researchers are finding that a small percentage of these patients may have moderate to severe liver damage.

Alanine aminotransferease (ALT's – formally called SGPT) is produced in the liver in response to liver injury or cell death. This injury is not specific to HCV inflammation, but can come from a variety of agents such as alcohol, medications and other substances that can produce liver injury. This is usually, but not always, the first indication that someone may be infected with HCV. Normal values: 0-48 IU/L

It should be noted that many experts believe the normal ALT range value for women should be lower than the range value for men. In fact, women populate a large part of this 'normal group'. The lower ALT levels in women might be explained by the production of estrogen which is believed to lower ALT levels.

Biopsy

In a recent study by Edmund J Bini and others (AASLD abstract #485) 43 patients with persistently normal ALT levels and 96 with abnormal ALT levels were followed. Normal levels were defined by 3 normal ALT readings taken at least 1 month apart. The researchers found that the abnormal ALT levels group had significantly more advanced liver disease than patients with normal ALT's. However, 28% of the patients with normal ALT's had advanced liver disease, which led the researchers to recommend that all patients with normal ALT's undergo a liver biopsy for disease staging.

In a different study by Luis Balart, MD and others, over 300 patients with persistently normal ALT levels defined as 3 normal ALT levels readings taken 6 weeks apart for a period of 6 months were studied. It was found that most of these patients had mild liver disease, but a small percentage had more advanced disease, and some patients were found to have cirrhosis. Based on his study, Dr. Balart recommended that other factors should be considered when evaluating these patients and a biopsy should be considered.

Treatment

This is a much more complex issue. In a recent study conducted by Dr. Mitchell L. Shiffman and colleagues, it was found that response to interferon monotherapy was similar in both normal (58 patients) and abnormal (37 patients) ALT level groups. The researchers concluded that persons with persistently normal ALTs should undergo a liver biopsy and considered for treatment if the liver is damaged. These findings have been collaborated by previous studies.

However, some evidence suggests that antiviral treatment for a small segment of this group could be counterproductive. Some patients do not respond to treatment, but develop elevated ALT levels that continued to be elevated after treatment is stopped. The big questions is – can antiviral treatment for this subset of patients make the disease worse? This is a very important issue that is now being studied.

This area of research is expanding and deserves more attention. It is hoped that a patient with normal ALT values will at the very least be offered additional liver function tests and a liver biopsy if necessary to establish if severe disease is present and given the option for antiviral treatment.

Common tests used to measure liver function:

Liver function tests include a variety of tests to help gauge the health of the liver. Measuring ALT's does not give a complete picture of liver health. A list of the more common liver function tests follow with the normal values listed. It is important to remember that 'normal values' vary from lab-to-lab and can be influenced by the way the blood samples are handled. Treatment decisions should never be made based on one test and always consult with a medical professional to accurately interpret test results.

Albumin is a blood protein produced by the liver. It is responsible for keeping fluids and salts within blood vessels. If the liver does not produce enough albumin, water retention in the form of swelling occurs usually in the feet and ankles. **Normal values: 3.2-5.0g**

Alkaline Phosphatase (AP) is an enzyme mainly found in the liver and is responsible for phosphorus metabolism, which delivers energy to the cell. Elevated levels of AP along with elevated GGT indicate that something is wrong in the liver. **Normal values: 35-115 IU/L**

Aspartate Aminotransferase (AST – formerly called SGOT) is a liver enzyme used for amino acid metabolism. Elevated levels indicate liver injury. Tests for this enzyme and ALT are the most frequently used blood tests to watch changes in liver inflammation. **Normal values: 0-42 IU/L**

Bilirubin is a waste product produced by the liver. A healthy liver will convert these bile salts into water-soluble substances that are excreted by the body. When the liver is damaged it is unable to convert these bile salts into a water-soluble substances leading into a buildup of toxic yellowish liquid which produces jaundice (yellowing of the skin). This is seen in some acute cases of hepatitis C and in end stage liver disease. **Normal values: 0-1.3mg**

Gamma-Glutamyltranspepidase (GGT) is a liver enzyme used in metabolizing glutamate (an amino acid). High levels of GGT may indicate blockage and damage to bile ducts. **Normal values: 30-60 IU/L**

Platelets are blood cells that help the blood to clot. Low platelet counts indicate liver damage. Platelets counts are also followed closely during interferon therapy. **Normal values: 130-400 thousand/MCL**

HCV Advocate – http://www.hcvadvocate.org/

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II.9.1a ELEVATED ALPHA-FETOPROTEIN LEVELS

It is fairly common for alpha-fetoprotein markers to be elevated in patients with hepatitis C. Alpha-fetoprotein 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. In fact a recent study cautions that in anti-HCV positive patients, AFP level is not a good single reference for diagnosis of HCC. Anti-HCV positive patients should be routinely screened for HCC by image studies along with serum AFP level. *Hepatogastroenterology* 1999 Nov-Dec;46(30):3208-11

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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.

II.9.3 HEPATOMEGALY, SPLENOMEGALY

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

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. Certain amino 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. Earlier statistics put the risk for a person with chronic HCV hepatitis developing HCC at 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

The latest studies, however, put the risk for those with advanced liver disease of developing HCC at 13.4% (*Gut* 2000;47:131-136). As well, cirrhosis is NOT a necessary precursor to HCC: it can develop at any time, as the study below shows:

"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)

"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

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

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

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.

"It is suspected that there are, at present, more than 5 million people in the United States that are infected with Hepatitis C, and perhaps as many as 200 million around the world. This makes it one of the greatest public health threats faced in this century, and perhaps one of the greatest threats to be faced in the next century. Without rapid intervention to contain the spread of the disease, the death rate from hepatitis C will surpass that from AIDS by the turn of the century and will only get worse." Dr. Everett Koop, from his webpage. http://www.epidemic.org/theFacts/theEpidemic/

"It is estimated that up to 3% of the world's population is infected with HCV, i.e. up to 170 million chronic carriers." **Canada Communicable Disease Report** - *Supplement* Vol. 25S2 June 1999

"It is reasonably estimated that the prevalence of HCV infection in Canada is about 0.8% (240,000 persons)" **Canada Communicable Disease Report** - *Supplement* Vol. 25S2 June 1999

"Applying U.S. projections to the Canadian situation predicts approximately 2,200 new cases per year in Canada at this time. " **Canada Communicable Disease Report** - *Supplement* Vol. 25S2 June 1999

PART III - TREATMENT (Conventional Medicine)

(A big thank you to Joan King of HepCBC for updating this section)

III.1.0 INTERFERONS

A number of new therapies for hepatitis C are emerging in clinical practice. The combination interferon and ribavirin has proved much more effective than interferon alone, and at this time is considered to be the standard treatment. Trials are being done with combinations of interferon and other substances, with re-treatment, with different types and brands of interferon, with longer-term therapy, long-term maintenance therapy, high-dose induction therapy, and with the more effective pegylated interferons, also combined with such substances as amantadine and thymosin. Promising research is being done on therapeutic vaccines and such things as polymerase inhibitors, protease inhibitors, helicase inhibitors, glucosidase inhibitors, IRES inhibitors, antisense oligonucleotides, and ribozymes, polyclonal antibodies, cytokine inducers, as well as treatments to reverse fibrosis, and to create new liver cells. It is possible that treatment in the future will be tailor-made to fit the patient in terms of genotype and viral load.

III.1.1 Interferon Monotherapy

Interferon alone is no longer considered standard therapy. It is used only when the patient has some condition, such as a heart problem, that doesn't allow the use of ribavirin.

III.1.1a Interferon Alpha 2B, Recombinant (INTRON A)

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. ("Recombinant" refers to a technique that takes a DNA molecule from one organism, manipulates it genetically, and puts it into another organism.) It was approved by the (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 has a sustained response rate of about 12%.

(Note: This FAQ uses "alpha," although some companies use the term "alfa" with their interferon products, and have them patented this way.)

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, therapy with Rebetron (Intron A plus ribavirin) is usually recommended. This "standard" therapy may soon change, now that pegylated interferons are being approved. It is recommended that such patients be referred to specialists with knowledge in liver disease (gastroenterologists/ hepatologists). -- "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.

Patients with genotype 1 are usually treated for 12 months. Those with other genotypes are treated for only 6 months. The treatment is expensive. Many patients also suffer side effects, such as flu-like 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.1.1b 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), mental confusion (encephalopathy), human immunodeficiency virus (HIV) infection or organ transplant recipients on prednisone, cyclosporine and FK-506 are usually treated only in a clinical trial. Others not suitable for treatment are those with symptomatic heart, lung or kidney disease, and patients on antidepressants or with a history of attempted suicide. Interferon should not be given to women considering pregnancy within six months after treatment, nor to the intended father. It is feared that patients with active substance abuse (alcohol or illegal drugs) may not comply with treatment.

III.1.1c Interferon "Breakthrough" and "Non-Response"

Although Recombinant interferon alpha (r-IFN alpha 2) has initially been shown to normalize the aminotransferase levels in approximately 50% of patients with chronic hepatitis C virus (HCV), a few patients experience a relapse during the treatment, 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 alpha therapy in patients with chronic hepatitis C virus infection: prevalence, etiology, and management." (*Hepatology* Vol. 21 no. 3 pp. 645-9, 1995 Mar)

A report in the *Archive of Virology* 1997;142(3):535-544 suggests that an unapparent coinfection (also known as an occult infection) 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.

"The development of neutralizing antibodies to interferon is associated with Breakthrough in about half of the patients; other aetiologic factors such as down-regulation of interferon receptors or development of virus resistance to interferon may be implicated in the remaining cases." Genotype does not seem to make a difference. (*Ital J Gastroenterol Hepatol.* 1998 Jun;30[3]:333-7. Unique Identifier: AIDSLINE MED/98431771)

III.1.1d 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 go the Amgen website, Consensus interferon at a dose of 9 ug administered t.i.w. (3 times a week) 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 9%, according to the results of a phase 3 trial.

In patients failing prior CIFN or IFN alpha-2b therapy, re-treatment with a higher dose of CIFN (15 ug) for 24 weeks results in sustained HCV RNA response rates in 9 percent of nonresponders. Relapsers had a 25% sustained response rate.

Another study on non-responders and relapsers reported that re-treatment with high dose consensus interferon (interferon alphacon-1, Infergen, Amgen) showed a response rate of about 80% in both groups to the optimal dose after 48 weeks, based on those patients who completed treatment (60% of initial patients). --*Medical Industry Today*, November 27, 2000, High-Dose Consensus Interferon Effective Against Hepatitis C, Researchers Say.

In a 1999 study, more than 80% of patients who had relapsed on prior combination therapy IFN + ribavirin cleared the virus after 8 weeks of 15 mcg a day of alphacon-1. For non-responders to previous combo therapy, 37% for those who were treated with 9 mcg a day and 22% for those who received 15 mcg thrice weekly responded by 24 weeks, according to Maria Sjögren, M.D., M.P.H., Walter Reed Army Medical Center, in May 2000. Results released in November showed that, of the prior relapsers who completed 48 weeks of therapy, 83% of patients receiving 15 mcg t.i.w., and 77% on 9 mcg daily were HCV RNA negative. For prior non-responders, 40% on daily therapy were HCV RNA negative compared with 16 percent receiving 15 mcg t.i.w.

Paul Pockros, M.D. of Scripps Clinic in La Jolla, California has presented data showing that consensus interferon combined with ribavirin is a promising option for treating chronic hepatitis C infection. While ribavirin is normally dispensed only "bundled" with interferon alpha-2B, the researchers took the ribavirin out of the package and tested it with consensus interferon. Daily dosing of the combination was as safe and as well tolerated as consensus interferon alone.

III.1.1e 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.

It was thought that the chance of "breakthrough" would be less when using natural source interferon, than with the standard interferon alpha 2b preparation. The results of the first clinical trials were judged as "uninterpretable" and "ambiguous," so the FDA Advisory Committee recommended against approval and has required the company to conduct additional phase 3 trials for the treatment of patients with HIV and HCV.

The product is on the market for genital warts, so a patient who really wants Alferon treatment can get it.

Other IFN alpha-N3's include Alferon A; Alferon Gel; Alferon LDO; Alferon N; Alferon N Gel; Alferon N Injection; Altemol; Cellferon. Cytoferon Alferon is a natural interferon that is being investigated as a possible treatment for hepatitis C.

III.1.1f Beta Interferon, Recombinant (BETASERON, AVONEX AND REBIF)

Human interferon beta-1a has been approved in Europe, Canada, and Latin America for the treatment of multiple sclerosis.

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

Alpha-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.

Hepatogastroenterology 1999 Nov-Dec;46(30):3216-22 reports that beta-IFN therapy was not associated with a significant improvement either in biochemical or virological response in cirrhotic patients with chronic hepatitis C. No significant reduction of cirrhosis related clinical events was linked to treatment.

Clinical trials are still underway for the use of Rebif, Ares-Serono's beta interferon, in hepatitis C, according to Veritas.

III.1.1g **Roferon** INTERFERON ALPHA 2A, RECOMBINANT

In studies in which Roferon-A was administered three times a week for 12 months 12% of the patients experienced a sustained response to therapy. Of these patients, 9% maintained this sustained response during continuous follow-up for up to four years.

Roferon, produced by Hoffman-LaRoche, has US FDA approval for use as treatment for hepatitis C since 1996. It has recently been modified to produce Pegasys, an improved "time-release" treatment that is injected once a week, but this therapy has not yet been approved. (See Part **III.1.2**)

Roferon may be effective in non-repsonders to other interferon products.

III.1.1h Lymphoblastoid IFN

One type of Lymphoblastoid interferon was available until very recently under the brand name Welferon. In December of 2000, Glaxo Wellcome and SmithKline Beecham merged to form GlaxoSmithKline. They no longer produce Wellferon. It was available in most countries worldwide, (except in the USA).

Lymphoblastoid interferon (IFN-alpha-n1) is produced from a human lymphoid cell line and consists of subtypes of IFN-alpha. This is different from the recombinant IFNs, which are single proteins produced from individual IFN-alpha genes and "developed" in *E. coli.*

In 1998 trials on 1,971 patients, comparing lymphoblastoid IFN to IFN Alpha-2b, the lymphoblastoid IFN produced more sustained responders. (*Hepatology* 1998;27:1121-1127.)

III.1.1i **Mochida Interferon** (ALPHA IFN-ALPHA MOCHIDA500)

IFN-alpha Mochida500, a synthetic form of injectable interferon alpha, is produced by Mochida Pharmaceuticals, and is available in Japan. It has not been approved for use in the United States, but is in phase II trials. The company is also developing a Mochida IFN-beta for hepatitis C treatment.

III.1.1j Omniferon Alpha-IF

Omniferon is a multi-subtype alpha interferon derived from human white blood cells. Viragen believes that natural interferons posses several advantages over synthetic recombinant interferons, hopefully having fewer and less severe side effects. This anti-hepatitis C drug is now in phase II clinical trials in Europe.

III.1.1k Veldona Oral Alpha-IFN

Amarillo Biosciences is currently developing an oral formula of interferon alpha, not yet in clinical trials. The company states that low-dose interferon is effective for treating hepatitis C, and oral therapy does not cause the severe side effects associated with injection therapy. The oral IFN can be stored at room temperature, and is less expensive. The company will be doing a hepatitis C study later this year (2001) in Egypt, in conjunction with an antiviral agent.

III.1.1l Omega IFN (BIOMED 510)

Omega interferon is produced by BioMedicines. Phase Ia and Ib testing has been successfully completed in Germany. Phase Ib/II clinical testing has begun in patients with hepatitis C at the Scripps Clinic as well as in multiple centers in Europe. The company is trying to develop a new form of omega interferon that will target only the liver so that it will be more effective and have less side effects that present therapies. (www.biomedicinesinc.com)

III.1.1m Albuferon

Albuferon is a new protein created by fusing the gene for interferon alpha, to the gene of albumin, producing a protein with properties of both interferon alpha and albumin. Preclinical studies indicate that Albuferon should provide patients with a longer acting drug with less side effects compared to recombinant human interferon alpha. In October of 2000, Human Genome Sciences applied to the FDA to begin Phase I clinical trials. (www.hgsi.com/news/press/00-10-18_albuferon_ind.html)

III.1.2 Pegylated Interferon

Pegylated interferons give better results than interferon alone, with seemingly no difference in side effects.

Polyethylene glycol (PEG) is a substance (anti-freeze) with a high "molecular weight" that is easily excreted in the urine, due to its being soluble in water. "PEG" can be linear or branched. It can be attached to interferon alpha, by different types of protein linkages. The larger or branched PEGs lead to a longer, sustained absorption period. PEG attachment to interferon alpha leads to a longer half-life (the amount of time for an original amount to be metabolized by half) of the interferon. In other words, it makes the interferon stay in the body for a longer period of time. This occurs due to decreased "clearance" by the kidney and slower breakdown of protein. In addition, PEG makes it less probable that the immune system would make antibodies against interferon.

Comparisons of the two available pegylated interferons, Peg-Intron and Pegasys have tentatively been made. The two substances differ basically in the size of the molecule involved, (40 kilodalton for Pegasys, 12 "kilodalton" for Peg-Intron) and in the half-life of each product. Peg Intron is distributed widely throughout the body, and Pegasys is distributed to the blood and organs, including the liver. There might be some compartments within the body that Pegasys does not penetrate. Pegasys has a half-life of 50-80 hours, where Peg Intron has a half-life of 30-50 hours, according to San Francisco specialist Dr. Teresa Wright. Roche's Pegasys shows a sustained response rate of 39% compared to 25% for Schering's Peg Intron. Ronald Baker, PhD and Harvey S. Bartnof, MD (www.hivandhepatitis.com) warn that a direct comparison of results is difficult, however. The mean baseline viral load levels in the Peg Intron study were not presented, so it's difficult to compare, and the Peg Intron trial included more genotype 1 patients.

III.1.2a Pegylated Intron A (PEG-INTRON A)

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

"Consistent with previous studies, the rates of sustained virologic response achieved in this study (Phase III clinical trials) were greatly influenced by genotype, and ranged from 11% for patients with genotype 1, the predominant genotype worldwide and the most difficult to treat, to 49% for patients with genotype 2 or 3, compared to 6% to 28% for INTRON A," -- (Christian Trepo, M.D., Ph.D., director, hepatitis research unit, Hopital Hotel Dieu, Service d'Hepatologie, Lyon, France)

Peg-Intron A was approved in Europe in May 2000, and was the first pegylated interferon to be approved, worldwide.

III.1.2b Peginterferon Alpha-2a (PEGASYS)

Pegasys (peginterferon alpha-2a), Roche's pegylated interferon, achieved a sustained virological response in 39% of patients--twice that achieved with the current treatment, interferon alpha-2a. The findings were presented at the 35th annual meeting of the European Association for the Study of the Liver (EASL), in Rotterdam, Netherlands, May 1-3, 2000.

III.1.3 Interferon Combinations

III.1.3a Interferon and Ribavirin Combined (REBETRON)

Ribavirin is a nucleoside analogue, which stimulates the T cells in the body to fight the virus. The drug increases the rate at which HCV, a type of RNA virus, mutates. This process causes the virus' genetic material to change so much that it cannot survive, according to Dr. Raul Andino in a study published in May 2001 in the *Proceedings of the National Academy of Sciences*. Ribavirin alone does not get rid of HCV, although it reduces ALT while that drug is taken. It works in conjunction with interferon, though, allowing more people to sustain their response when the two drugs are combined. The combination of the two drugs is called Rebetron.

Both the U.S. (1998) and Canada (1999) have approved the Rebetron therapy (interferon-alpha2b plus ribavirin) for the treatment of chronic hepatitis C patients who have relapsed following alpha interferon therapy, and for naïve patients. This is presently the standard treatment.

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 ribavirin (Schering-Plough brand name "Rebetol") capsules administered orally in a divided daily dose for a duration of 24 weeks. The drug company Schering-Plough packages this combination therapy of interferon and ribavirin as Rebetron.

A six-month treatment with Rebetron is estimated to cost between $6,400 and $8,600 US depending upon dosage. **In the US, ribavirin alone can be obtained at a lower price through certain compounding pharmacies, making it possible to combine it with other interferons.** 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.

"A virological response at the sixth month after discontinuation of a combination of interferon-alpha and ribavirin in patients with chronic hepatitis C is predictive of a 97.8% rate of long-term complete (biochemical and virological) response." (*Lancet* 2000;356:41).

"Prospective, multicenter, pharmaceutical company-sponsored, randomized clinical trials in the treatment of chronic hepatitis C have shown that clearance of hepatitis C virus (HCV) is more likely in those treated with interferons than in untreated patients. Sustained treatment-induced virological clearance is highly correlated with biochemical improvement, continued absence of circulating virus, improved histology, improvements in health-related quality of life, and most probably, a reduced risk of premature death from end-stage liver disease or cirrhosis-related hepatocellular carcinoma. The combination of interferon-2b plus ribavirin is even more likely to result in sustained virological clearance than is treatment with interferon-2b alone and has become the treatment of choice in previously untreated patients." (*American Journal of Gastroenterology* Editorial June 2000;95[6]:1392-1393)

Recently, it has come to light that there is a direct relation between Rebetron therapy and osteoporosis *Journal of Hepatology* 2000 ; 33 : 812-817. As well, short term memory loss and neurological problems have been linked to combination therapy, and some patients have suffered permanent neurological damage as a result of the combination therapy.

III.1.3b Pegylated IFN and Ribavirin

In trials where the optimal dose of Peg-Intron was combined with ribavirin, results show a sustained viral response rate of 42% among patients with genotype 1, and of 82% among patients with genotypes 2 and 3, and an overall SVR of 54%.

Preliminary results of a large, phase III study evaluating the benefits of Pegasys (pegylated interferon alpha) plus ribavirin were presented. The sustained virologic response rates will not be presented until June 2001. The end-of-treatment results were presented by Adrian M. Di Bisceglie, MD of St. Louis University in Washington, and showed a response rate of 68%, which included genotype 1 patients. This was compared in the same trial to a response rate of 51% in patients receiving standard treatment of Rebetron, and 58% in patients receiving Pegasys plus placebo.

III.1.3c Interferon and Iron Reduction Therapy

A study published in the *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 procedure is not FDA approved. Trials have proved inconclusive.

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, 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 non-complete responders.

In a report by Hayashi and colleagues (*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.

Studies done since 1998 by Fong and Fontana have shown that phlebotomy (bloodletting), combined with interferon, reduces liver inflammation, but not fibrosis. It seems to reduce the viral load, and may improve sustained response, but the results are not enough to be statistically important. (*Journal of Hepatology* 1998; 28:369-374 and *Hepatology* 2000; 31:730-736) These studies were not done combining the interferon with ribavirin. To do so might be complicated, since ribavirin tends to result in anemia.

Tandon et al. (*Br. J. Nutr.* 1999), have shown that a special low-iron vegetarian diet was able to significantly reduce the serum iron and ferritin levels.

Bovine lactoferrin, 1.8–3.6 g/day for 8 weeks, suppressed ALT levels and viral load in 3 of 11 patients. This could be used with any combination of antiviral therapies, including IFN plus ribavirin, without side effects. (*Jpn. J. Cancer Res.* 1999; 90: 367– 71)

III.1.3d Interferon and Thymosin

Researchers believe that Zadaxin, SciClone's thymosin alpha-1, a synthetic polypeptide, works by boosting the ability of the body's immune system to produce T cells

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 responses in patients treated with combination therapy when compared to the interferon arm.

In 1998, the University of Cincinnati Medical Center reported sustained biochemical responses in 14.2% of patients treated with the combination treatment for 26 weeks, compared to 8.1% in patients taking IFN alone.

In another U.S. hepatitis C trial, 41.9% of those treated with Zadaxin combined with interferon responded while only 16.6% patients responded when treated with interferon alone, according to the SciClone website.

Zadaxin is not yet approved for hepatitis C treatment in the US or Canada. It is still in phase III trials.

When used in combination with IFN, fever, fatigue, muscle aches, nausea, vomiting, and neutropenia were reported at a significantly higher rate than with IFN alpha 2b alone or with placebo (*Hepatology* 1998; 27:1128-35)

A trial combining Pegasys with Zadaxin is planned for late 2001.

III.1.3e Interferon and GM-CSF

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.

GM-CSF is available on a case-by-case, limited "compassionate use" basis from Schering-Plough (201-298-4000, Professional Services Department). Patients who qualify must have low WBC counts due to underlying disease or drug therapy. Schering-Plough representatives will speak about individual cases with the patient's physician.

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 the 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.

Data from another study suggests 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)

"Daily s.c. GM-CSF administration is safe and shows effects against HCV; the GM-CSF/IFNalpha2b combination has an additional-but transient-antiviral activity in chronic hepatitis C." (*Cytokine* 2000 Feb;12(2):165-170)

III.1.3f Interferon and 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, may enhance the response to interferon, but the studies have conflicting results. Most show no reduction in ALT levels or viral load.

According to a report in the *Journal of Interferon Research* (13:279-282 1993), in interferon-unresponsive patients, the addition of 600 mg tid (3 times a day) 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 concluded that NAC enhanced the response to interferon in chronic hepatitis C, and suggested that further studies were needed to determine whether antioxidant therapy would be useful in conjunction with interferon treatment of hepatitis C.

Studies done in 1999 on 147 patients in Spain and Italy concluded that, although the combination treatment showed slightly better results, patients with chronic HCV infection are unlikely to benefit from the addition of N-acetyl cysteine to interferon-alpha.

An Italian study published in September 2000 by S. Neri et al., on 77 patients showed that those treated with IFN alone relapsed sooner, and concluded that "the difference between the results in patients treated with interferon and N-acetyl cysteine and those on interferon alone was significant...[we] recommend wider use of this association." (*Panminerva Med* 2000 Sep;42[3]:187-92)

III.1.3g Interferon and Amantadine

Amantadine, although it has no effect by itself on viral load, can, when combined with interferon, produce an improved virological and biochemical response compared to interferon alone (29.3% compared to 16.8% for IFN monotherapy). (*Hepatology*. 2001;33:989-993) It is now being used in triple therapy trials with IFN and ribavirin, with good results. [See "Triple Therapy", III.1.3m, below.]

III.1.3h Interferon and Ofloxacin

Ofloxacin is an antibiotic. Although it can lower ALTs, "the combined administration of alpha-interferon and ofloxacin to patients with chronic hepatitis C who have not responded to alpha-interferon alone does not increase the primary virological response rate." (*Journal of Hepatology* 29: (3) 369-374 SEP 1998)

III.1.3i Interferon and Histamine Dihydrochloride (MAXAMINE or CEPLENE)

Currently in phase III trials, Maxamine, by preserving the function of natural killer cells and other T-cells, may help improve results with interferon therapy, perhaps getting the same results with smaller doses of IFN. Maxim pharmaceuticals announced that trials with IFN + Maxamine showed that naive hepatitis C patients had reduced viral levels, and that 70% of those patients had undetectable viral loads, compared to 25-40% of patients on IFN alone.

Maxim has released its results from a phase II trial of IFN + Ceplene (which is also histamine dihydrochloride), stating that 44% of patients receiving 10mg of Ceplene a week plus IFN had a sustained viral response at 72 weeks. Up to 50% of patients with genotype 1 had a sustained viral response, using the highest dose of Ceplene, compared to 8% on IFN alone. Studies are being done now with IFN + ribavirin + Ceplene. (Maxim press release April 20, 2001)

III.1.3j IFN and Ketoprofen

A combination of ketoprofen and given for 6 months to IFN non-responders showed no biochemical or virological benefit. (*Can. J. Gastroenterol.* 1997; 11: 294-7.)

III.1.3k IFN and Ursodeoxycholic Acid (ACTIGALL)

Ursodeoxycholic Acid (UCDA) is a highly hydrophilic bile acid, which dissolves cholesterol and fat in the intestines, and has immune modulating factors. It is an approved drug that may limit liver injury and the effect of HCV. Clinical studies have shown that UDCA alone does not significantly reduce viral amounts. Additional studies have shown that a combination therapy of UDCA and interferon may increase the short-term response to treatment. However, the combination did not result in a long-term disease-free response, but it is effective at reducing the risk of relapse after interferon mono-therapy. UDCA, when given for 12 months, was found to be beneficial in patients with chronic hepatitis C with autoimmune features. *(Gastroenterol. Hepatol.* 1999; 14: 413-18)

Tests on 170 patients over 6 months showed that combining ursodeoxycholic acid (600 mg/day) and glycyrrhizin is safe and effective, and improves ALT levels. This combination may be an alternative to interferon in chronic hepatitis C virus infection, especially for interferon- resistant or unstable patients. (*Eur J Gastroenterol Hepatol* 1999 Oct;11(10):1077-83)

III.1.3l IFN and VX-497

VX-497, produced by Vertex Pharmaceuticals, is an inosine monophosphate dehydrogenase (IMPDH) inhibitor, now in phase II clinical trials for the treatment of HCV infection. Blocking IMPDH function prevents viruses from duplicating themselves within host cells.

A randomized study of VX-497 alone in 30 HCV-infected non-responders to IFN monotherapy resulted in decreased liver inflammation and ALT levels. Present phase II studies will look at the effects of longer treatment, especially in non-responders. According to laboratory studies comparing the efficacy of VX-497 to that of ribavirin, the company believes it may be as effective as ribavirin. Studies combining the product with pegylated interferon are being planned for 2001. (www.vpharm.com)

III.1.3m IFN and Colchicine

Colchicine, an anti-fibrotic drug, was combined with interferon in a clinical trial reported by Angelico, et al., in Italy, where 65 patients started out taking 6 MU t.i.w. for 6 months. Then 34 patients took the combination of 3 MU t.i.w. IFN + colchicine, and 31 took interferon alone. The results at 18 months showed

that "The combination of colchicine and interferon-alpha worsens the effectiveness of interferon-alpha alone in HCV chronic hepatitis. These alarming findings prompted us to interrupt the trial at this stage." (*Aliment Pharmacol Ther* 2000 Nov 27;14(11):1459-1467)

III.1.3n Triple Therapy

Triple therapy, with IFN + ribavirin + amantadine, for non-responders, was evaluated by Brillianti et al., in a small randomized study. SVR (Sustained Viral Response) was not seen in any patient with double therapy, but was seen in 30% of patients on the triple therapy. *(Ital. J. Gastroenterol. Hepatol.* 1999; 31: 130-4.) Unfortunately these results were not confirmed during a more recent multi-centre German study, and therefore triple therapy (IFN + ribavirin + amantadine) cannot be recommended as a standard treatment option for nonresponder patients at this time. (*Medscape Gastroenterology*, 3(3) 2001)

III.1.4 Different Dosage

III.1.4a Mega Dosing

III.1.4b Maintenance Dosing

At this time there is only one small study (*Gastroenterology*. 1999;117:1164-1172) that shows hope for antiviral therapy in spite of persisting viremia. This study looked at 53 patients whose liver histology had improved after 6 months of IFN alone. Even though they didn't eradicate the virus, IFN was continued for another 6 months in half the patients. A further biopsy showed improvement in these patients, compared to the others, but no further biopsies were performed. Based on these results, the NIH has begun the HALT-C trials to test long-term pegylated IFN monotherapy in non-responders. The results will not be available for several years.

A trial involving 12 post-transplant patients showed that low, daily dose interferon maintenance was generally tolerable, inflammation (predominantly portal inflammation) improved and fibrosis was stable at end of therapy in treated patients, with no quasispecies diversification in most cases. Controls showed no change or increased inflammation and fibrosis. These findings provide a rationale to study low dose daily or pegylated interferon maintenance therapy for the management of hepatitis C post-transplant. (*Transplantation*. 2001;71:261-266)

III.1.4c Induction dosing

Induction dosing involved giving high doses of interferon once a day. In this trial, all patients with a sustained virologic response had an initial decline in HCV RNA levels of more than 3 logs within the first 4 weeks of treatment. Studies have shown a significant and more rapid reduction in HCV RNA levels among those treated with daily dosing schedules. However, at the AASLD Annual Meeting in Dallas, Texas, in October 2000, it has been shown that a high daily dose of IFN alpha has no significant effect on the long-term results if the treatment schedule is changed to a 3-times-weekly regimen later on during therapy. (*Medscape Gastroenterology*, 3[3] 2001)

III.1.4d Longer Treatment

In an Italian multicenter study on non-responders, patients received either 3 or 5 MU IFN alpha-2b for 6 or 12 months in combination with ribavirin. With the most aggressive treatment regime, sustained responses were significantly higher only among genotype 1 patients, not among patients with genotypes 2 or 3, but the sustained response was only 23%, even in patients treated with 5 MU IFN-alpha 3 times per week in combination with ribavirin for 12 months. (*Medscape Gastroenterology*, 3(3) 2001)

III.2.0 INTERLEUKINS

Early laboratory trials showed that some interleukins might be able to suppress the hepatitis C virus, although more recent studies have shown they are not very effective. Even so, scientists continue trying to develop interleukin compounds against hepatitis C.

III.2.1 Interleukin-10

IL-10 is a cytokine that controls inflammatory responses and hepatic fibrosis. Twenty-four non-responders were given either 4 or 8 µg/kg IL-10 subcutaneously daily for 90 days, and had liver biopsies before and after therapy. Twenty-two patients finished treatment. ALT levels and liver inflammation improved, but there

was no change in viral load, however the improvements in ALTs and fibrosis after 12 weeks of therapy were similar to those seen in IFN therapy after 48 weeks of treatment. (*Gastroenterology* 2000;118:655-660)

III.2.2 Interleukin-12

Interleukin-12 (American Home Products; Yamanouchi, Genetics Institute) is a cytokine that affects immune responses by inducing the secretion of IFN-gamma to fight infection, while increasing production of antibodies. Synthetic interleukin-12 may be able to restore immune responses weakened by the HCV virus. A Phase I/II trial of interleukin-12 showed no advantage over current treatments, but trials continue. It has been shown to decrease fibrosis and stimulate the immune system. (www.veritasmedicine.com; 1st Canadian Conference on Hepatitis C: Dr. Frank Anderson, May 04, 2001)

III.3.0 HCV PROTEIN-BASED THERAPY (or GENE THERAPY or RNA INHIBITORS)

The HCV gene is composed of various enzymes (proteins) that are targets for developing drugs.

III.3.1 Protease Inhibitors

Once HCV enters a liver cell, its genes guide the production of proteins that will become the inner core and surface coat of new viral units. First of all, the HCV makes an immature protein--a kind of unfinished sheet of material, which the Hep C protease cuts into the finished proteins, which then become the virus's outer cloak.

Scientists have developed protease inhibitors, which stick to protease and stop its scissor-like function. These drugs have been used in the treatment of HIV for years and have proved valuable, and hopefully they will be valuable in Hep C treatment, as well. (www.veritasmedicine.com)

Boerhinger Ingleheim reports the initiation of Phase I trials of their HCV protease inhibitor. "Boerhinger PI is the first to go into humans ... none of the other PI programs are that far developed." -(AASLD Conference: New Therapeutic Strategies for Hepatitis C, Chicago, June 15-16, 2001, Reported by Jules Levin)

All of the other protease inhibitors listed here are in the preclinical stage.

Abott Protease Inhibitor, Agouron Protease Inhibitor, Axys Protease Inhibitor, BILN-504 SE BILN-466 SE; BILN-705 SE; BILN-303 SE (Peptide-based molecules that inhibit the NS3 protease of the hepatitis C virus), Corvas Protease, Hoffman-La Roche Ro-32-6167 Ro-32-6168, Vertex Protease Inhibitor (clinical trials possibly in 2001).--(www.veritasmedicine.com)

III.3.2 Polymerase Inhibitors

"A few polymerase inhibitors are in development: two in clinical trials. But there is no data yet and speculation scuttle-butt in the halls here was that these drugs may have limited antiviral activity." (AASLD Conference: New Therapeutic Strategies for Hepatitis C Chicago, June 15-16, 2001 Reported by Jules Levin)

Merck & Co, and Tularik are formulating gene therapies aimed at inhibiting HCV RNA polymerase (www.veritasmedicine.com), as is Biocryst (www.biocryst.com)

III.3.3 Helicase Inhibitors

Vertex Pharmaceuticals is in the preclinical stage of developing an HCV NS3 helicase inhibitor. NS3 helicase is an enzyme that binds to double-stranded HCV RNA and unwinds it so the resulting strands can be used to produce more RNA or translate into proteins. If these strands couldn't unwind, HCV could not reproduce. Vertex has identified the three-dimensional structure of NS3 helicase, and is studying how it works. Hopefully this knowledge will help design potent inhibitors of this enzyme. (www.vpharm.com)

Genelabs Technologies, Inc. On April 20, 2000, Genelabs announced its discovery of a new class of antiviral compounds, which have demonstrated effectiveness against HCV, as well as other flaviviruses. Some of these compounds are helicase inhibitors. Genelabs is currently conducting *in vivo* studies to evaluate the antiviral effect in animals as well as evaluating the *in vitro* antiviral effect on other viruses. (www.genelabs.com)

III.3.4 Reverse Transcriptase Inhibitors

Burroughs Wellcome produces Retrovir (AZT, zidovudine), the first anti-HIV drug approved by the FDA. AZT inhibits reverse transcriptase that the virus uses to copy its genes. It is currently being studied as a possible Hep C treatment. Zidovudine is easily absorbed from the stomach and spreads widely to most body tissues, including the cerebrospinal fluid. Studies have shown that zidovudine crosses the placenta and is present in breast milk. The kidney partly metabolizes zidovudine, so decreased doses are recommended for people with kidney disease. The drug is available in pill form or in IV formulation. (www.veritasmedicine.com)

III.3.5 VP-50406

ViroPharma is currently developing a number of RNA inhibitors for treatment of hepatitis C. Laboratory studies have shown VP50406 effectively inhibits the RNA replication of HCV. VP-50406 is in Phase II clinical trials in naïve patients and non-responders. (www.viropharma.com)

III.3.6 Interferon Alpha Gene Therapy

Interferon Alpha Gene Therapy is a treatment for hepatitis C that delivers genes for IFN alpha-2b specifically to liver cells, hopefully making the treatment more effective. It is currently under development by Schering Plough and Immune Response.

III.3.7 Ribozyme Therapy

Ribozymes, discovered in 1981 by Cech *et al.* (*Cell* 26: 487-496), are RNA molecules capable of catalyzing RNA cleavage in a special way.

Ribozyme Pharmaceuticals' Heptazyme (also known as Ribozyme Gene Therapy or LY 466700) is in phase I clinical trials for the treatment of hepatitis C. It has been biochemically modified to recognize and cut hepatitis C virus RNA at a specific point that is critical for viral reproduction. The product is potent in cell culture, and there is a good safety profile so far in humans, and it is well tolerated. It is administered subcutaneously. Phase II trials will combine the drug with IFN. (AASLD Conference: New Therapeutic Strategies for Hepatitis C, Chicago, June 15-16, 2001 Reported by Jules Levin)

Immusol HCV Ribozyme Gene Therapy Laboratory studies have shown this kind of ribozyme gene therapy inhibits the formation of new hepatitis C virus particles, and may be especially useful in combating some problems with anti-HCV drug design, such as emergence of drug resistant virus types.

Atugen Biotechnology GmbH (Berlin, Germany) The company is developing two technologies: one is proprietary oligonucleotides, small segments of RNA that inhibit expression of genes, in a program called GeneBloc; the other is ribozymes. The company is working together with others, including Roche and Ribozyme Pharmaceuticals.

Other companies that were working with ribozyme therapy were Innovir Laboratories, which went out of business, VimRx Pharmaceuticals Inc., which was its subsidiary, and Nexell Therapeutics Inc., but Nexell is no longer pursuing the ribozyme technology. (www.biospace.com)

III.3.8 IRES Inhibitors

The internal ribosome initiation site (IRES) is a part of the hepatitis C virus that is found in different genotypes. It is an essential part of the replication process, so scientists believe that, by finding an IRES inhibitor, there will be a decreased production of the virus. Several companies are working with possible IRES inhibitors.

RiboGene (QuestCor) is currently investigating small molecules for the treatment of hepatitis C, which will inhibit IRES.

RiboTargets RNA Inhibitor is an IRES-inhibitor, still in lab studies. The company's work is being done by a multidiscipline consortium funded by a Framework 5 award from the European Commision. (www.ribotargets.com)

OSI Pharmaceuticals is working on an anti-IRES inhibitor designated as I70, which showed antiviral activity against HCV in the XTL HCV-Trimera mouse model. (www.hepnet.com/hepc/Mont98/index.html)

Anadys Pharmaceuticals has collected much data about the structure and function of the IRES target and has developed novel screening assays for the identification of antiviral drug candidates. (http://www.anadyspharma.com/home.asp)

PTC Therapeutics "is currently using its TRC technologies to identify small molecules that specifically inhibit the ability of HCV mRNA to function." (http://www.ptcbio.com/big/indexhome.html)

III.3.9 Antisense Based Therapies

ISIS14803 is an antisense inhibitor of HCV produced by HepaSense, Ltd., a partnership of Isis Pharmaceuticals and Elan Corporation. HepaSense has announced the results of a small phase I/II clinical trial with 11 people infected with HCV, all non-responders to previous IFN mono or combo therapy, except one, and all genotype 1. The patients were given increasing doses of up to 2 mg/kg intravenously of ISIS 14803, three times a week, for one month.

Responses, probably dose-dependent, developed after several doses of ISIS 14803 and persisted for 20 to 50 days. In most cases, the responses were associated with a transient ALT flare. ISIS 14803 was well tolerated. Adverse events reported were minor and non-specific. Liver biopsies performed on 2 experiencing an ALT flare revealed no evidence of drug induced liver damage. More studies are being done with subcutaneous injections. -(AASLD Conference: New Therapeutic Strategies for Hepatitis C, Chicago, June 15-16, 2001, Reported by Jules Levin) (www.isip.com)

AVI BioPharma (www.antivirals.com) is also developing antisense technology.

III.4.0 VACCINES

There is no vaccine for hepatitis C...yet.

There has been some discussion as to what type of vaccine would be best for the Hep C virus. Ideal would be a vaccine that would prevent initial infection (prophylactic vaccine), but a vaccine that would prevent the infection from becoming chronic would be sufficient (therapeutic vaccine). The problem is that the virus has so many strains and mutates so easily. An effective vaccine would have to work against at least one genotype of the virus, preferably genotype 1, which is the most common. The other problem is developing a vaccine that confers lasting protection.
(www.brown.edu/Courses/Bio_160/Projects2000/HepatitisC/hcvvaccines.html)

Types of possible vaccines:

Passive Immunization: One would think that having HCV antibodies would cure the disease and protect a person against re-infection, but it doesn't work that way with the hepatitis C virus. Attempts at using this method on chimpanzees have seemingly failed. HCV hyperimmune globulin has worked, but doesn't last and doesn't protect against re-infection.

Envelope Glycoprotein Vaccines: This is the most encouraging vaccine possibility at this time. The vaccine makes antibodies to parts of the virus' outer coating, called E1 and E2. This vaccine seems to be showing promise in chimpanzees. (See III.4.2 InnoVac-C and III.4.3 XTL-002)

Epitope Based Vaccines: This type of computer-generated vaccine is designed to make the body produce a strong immune response (CD4+ and CD8+) using T-cell epitopes. It is hoped that this technology won't allow mutations to escape, and that it will cover several genotypes, not just one. The disadvantages are that the technology requires large computer databases, and an effective vaccine would probably have to include some protein from actual HCV. (See III.4.4 Epimmune Vaccine)
(www.brown.edu/Courses/Bio_160/Projects2000/HepatitisC/hcvvaccines.html)

Naked DNA Vaccines: "Naked" DNA means DNA that isn't associated with a virus. Therapeutic DNA is introduced into a virus to deliver it to the body. The "C" gene of the hepatitis C gene is often used in these experiments, because it is similar in all the genotypes. Side effects of a vaccine of this type may be a problem, and safety may be an issue, although some researchers say there are no viral components to cause unwanted immune responses, infections, or permanent changes in the cell's genetic makeup. DNA vaccines for hepatitis C are still in pre-clinical stages of development, and they show great potential, even for therapeutic treatment. (See III.4.5 Vical)
(www.brown.edu/Courses/Bio_160/Projects2000/HepatitisC/hcvvaccines.html)

***Viral Vector Vaccines*:** These vaccines, like naked DNA vaccines, are designed to place foreign DNA into a cell to stimulate the immune system. Viral vector vaccines have an advantage because they allow specific host cells to be targeted, so that the vector will not enter the genetic material of the cell. Few vaccines like this have been tried, so little is known about how effective they are. (www.brown.edu/Courses/Bio_160/Projects2000/HepatitisC/hcvvaccines.html)

III.4.1 HCV Antibody

Using their Trimera mouse system to produce human antibodies to the hepatitis C virus, XTL Biopharmaceuticals claims that these antibodies are more potent and specific and more effective than previously generated antibodies. (The Trimera mouse has been genetically altered to carry human tissues for *in vivo* [in a living organism] experiments.) These antibodies are now being investigated, and the product is called Nabi-Civacir. Not yet in clinical trials, but tested in chimpanzees with encouraging results, Nabi-Civacir, (a.k.a. H-CIG) is a human antibody to hepatitis C, derived from screened donors. These antibodies neutralize the hepatitis C virus and it is hoped they might prevent HCV infection or subsequent reinfection.

These antibodies are at the pre-clinical phase. In several animal studies, sustained levels of Civacir seemed to reduce viral loads, and possibly eliminate HCV altogether. More studies are required. (www.nabi.com/prodev/corpa5.htm#civacir)

III.4.2 InnoVac-C

Innogenetics is developing InnoVac-C, a vaccine using HCV E1 and E2 envelope protein sequences to produce immunity. These proteins help protect the virus from the immune system and let the virus enter into liver cells. E1 and E2 are the only HCV proteins that can be attacked by the immune system, so they are prime targets for vaccine development.

Phase I clinical trials involving 20 healthy males have been completed. The product was well tolerated and induced an immune response in 19 of the subjects, antibodies in 17, and cellular immunity in 18. Adequate cellular immune response is usually considered to be a key factor in the clearance of a viral infection. In January 2001, Phase II studies began to test safety and efficacy in patients with chronic Hep C. (www.innogenetics.com)

III.4.3 XTL-002

XTL-002 is a monoclonal antibody (an artificially produced antibody, made in the lab by use of an immortalized cell line, that binds to one unique marker on a virus's surface) whose target is the HCV envelope protein. It recognizes many different genotypes. In pre-clinical trials, XTL-002 decreased HCV load by greater than 90% in the HCV Trimera model. XTL has begun phase I trials in HCV infected patients as of July 2001. (www.xtlbio.com/background.html)

III.4.4 Epimmune Vaccine

Epimmune (www.epimmune.com) is developing a vaccine for the treatment of hepatitis C. The company uses their epitope identification system (EIS) to identify epitopes that belong only to the hepatitis C virus. The Epimmune vaccine uses a variety of T-cell epitopes, designed to elicit a strong CD4+ and CD8+ cellular response. Certain peptides are chosen by a computer program that uses a database of sequenced HCV proteins, from which it selects short peptide sequences for use in the vaccine. Often, multiple peptides are found, which can react with as many as three superfamilies of molecules, guaranteeing a broad coverage. Eppimune has developed a group of molecules called PADRE that can be combined with epitopes to use in vaccines against viruses. PADRE can improve the magnitude and duration of the immune response. The company recently announced Phase I and II trials of its vaccine. (www.brown.edu/Courses/Bio_160/Projects2000/HepatitisC/hcvvaccines.html)

III.4.5 Vical technology

Vical is using patented technology to develop gene therapies that involve only the desired DNA ("Naked DNA"), thereby avoiding the complications of using a virus. These vaccines could potentially be used to reduce the chances of contracting the disease, as well as boost the immune response of the body once infection has occurred. Similar vaccines are now in early clinical trials for treatment of AIDS. Vical technology is licensed by Merck & Co.

III.4.6 ChimeriVax Vaccine

Peptide Therapeutics has developed a technology for the construction of vaccines against several viral infections caused by flaviviruses. The successful vaccine against yellow fever may help create a ChimeriVax vaccine for hepatitis C, also a flavivirus. Replacing yellow fever genes with the corresponding genes for the Hep C virus will hopefully create immunity to several different strains of the virus. (www.peptide.co.uk, www.acambis.com). Companies involved: Pasteur Merieux, Acambis/Peptide Therapeutics

III.4.7 Chiron Vaccine

Chiron is developing a genetically engineered HCV vaccine. Preclinical studies have been conducted and a small clinical trial with humans is now being conducted. The company is studying two possible vaccines, including a recombinant vaccine and a second-generation DNA vaccine to induce a cellular immune response. (www.chiron.com)

III.4.8 Iscoprep 703 (ISCOM)

Iscoprep 703, produced by CSL Pharmaceutical Companies, is an immune stimulating complex (ISCOM). Laboratory and animal studies have shown that ISCOM may be used to alter the immune response induced by vaccines. Given along with HCV vaccines, ISCOM agents may improve the immune response to HCV. ISCOM is made from saponins that come from the bark of the Quillaia saponaria molina tree, mixed with lipids.

"ISCOMs have been prepared with Quil A (a semi-purified preparation of saponins) or purified saponin fractions. CSL's lead saponin preparation, ISCOPREP703, contains a mixture of the purified saponin fractions." Non-human primate studies are in progress with hepatitis C virus antigens in collaboration with Chiron Corp. (www.csl.com.au/)

III.4.9 Therapore

Therapore, produced by Avant Immunotherapeutics, is a technology that uses a protein delivery system to carry viral proteins into human cells to generate a specific immune response, not only to the Hep C virus, but other viruses, as well. This technology can be used to create vaccines. Avant hopes that this system will be particularly effective in treating chronic infections such as hepatitis C. The company claims that Therapore technology is highly efficient, causing potent immune responses with the use of minute quantities. Therapore is also able to deliver large peptides and proteins to the cell for processing, possibly creating a broad range of immunity. (www.avantimmune.com)

III.5.0 OTHER THERAPIES

III.5.1 Nucleoside Analogs

ANA245 is a nucleoside analog (like ribavirin) in development for HCV, and *in vivo* studies look promising. It is a natural killer cell activator and interferon alpha inducer. It is not yet in clinical trials. (www.anadyspharma.com/home.asp)

ANA246, a type 1 cytokine enhancer, is a nucleoside analog being developed to use in combination therapy for Hep C. *In vitro* (test-tube) studies show that the product induces type 1 cytokine production equal to or better than ribavirin, and is less toxic. ANA246 is not yet in clinical trials. (http://www.anadyspharma.com/home.asp)

Novirio Pharmaceuticals is working on a series of drug candidates to combat HCV. It is hoped that these, alone or in combination, may offer improvements over other drugs. Using SAR (structure-activity relationship) analysis, Novirio has discovered three nucleoside analogs they believe will be active against several genotypes, including genotype I, and clinical trials are being planned for 2002. (www.novirio.com)

III.5.2 ACH-126447 (HELIOXANTHIN)

ACH-126447 (Helioxanthin) is a novel chemotype with potent activity against several flaviviruses. This compound is in early preclinical development with plans for possible development for the treatment of Hepatitis C. (http://www.achillion.com/)

III.5.3 Ampligen

Ampligen (Hemispherx Biopharma Inc) is a form of double-stranded RNA with immunostimulatory and antiviral activity, for the potential treatment of myalgic encephalomyelitis. It is also under investigation for other viral infections including HCV. (www.current-drugs.com/NEWS/AACR91prev.htm)

III.5.4 Enzo Immune Regulator

In November 2000, Enzo Biochem, Inc., announced Israel's approval to start a Phase I human clinical trial to test the safety and efficacy of a treatment for chronic Hep C patients or for those with liver cancer. The product, still unnamed, is a broad-spectrum immune regulation medicine developed by Enzo, which stems from the company's work with EHT899 for treating hepatitis B. Treatment will last 30 weeks, with a 20-week follow up. (www.enzo.com)

III.5.5 Geron Telomerase Activation

Usually the liver regenerates easily, but that doesn't happen in most patients with chronic liver disease. Many studies have shown that shortened telomere (the end of a chromosome) lengths are observed in the livers of these patients. Studies in mice, in which the RNA component of the telomerase gene has been removed, show that these animals have increased sensitivity to liver damage. The Geron Corporation plans to use a gene-based therapy to deliver the telomerase gene into the liver to help it regenerate. An article in the February 18, 2000 issue of *Science* showed that telomerase gene therapy prevents the onset of cirrhosis in mice. This approach is currently under development for preclinical studies. (www.geron.com)

III.5.6 HE2000

Hollis-Eden's HE 2000 is designed to interact at what is believed to be the original source of immune dysregulation, the hormonal balance between corticosteroids and other adrenal steroids, offering basically a hormone replacement therapy that may lead to regulating the immune system. It has been tested for HIV in a Phase I/II clinical trial. Since a small percentage of Hep C patients are able to clear the virus by mounting a strong cell-mediated (Th1) response, and since HE2000 can shift patients from a Th2 immune status back to a Th1 status, the company is considering clinical studies in hepatitis C. (www.holliseden.com and www.current-drugs.com/NEWS/AACR91prev.htm)

III.5.7 Hypericin (VIMRX, HIFRITZEN)

VIMRx Pharmaceuticals Inc. halted development of synthetic hypericin (VIMRxyn) for treatment of HIV-infection, chronic hepatitis C and sterilization of blood for transfusion. (www.bioinfo.com/aabrev98.html)

III.5.8 Immtech Mono and Dication Compounds

Immtech Consortium's scientists have evaluated a series of mono and dication compounds for activity against a surrogate hepatitis C in a cell culture assay. These compounds have proved active against other viruses, including influenza, respiratory syncytial virus, rotavirus and HIV. The scientists at Auburn have used a bovine viral diarrhea virus (BVDV) assay as a substitute for hepatitis C, since HCV does not grow in a cell culture system. The compounds are being evaluated in mice and in a mouse model of chronic BVDV disease to see if they have *in vivo* activity. The Company plans to enter into primate trials in late 2001, into human trials in 2002. (www.immtech-international.com)

III.5.9 IP501

IP501, produced by Interneuron, is a compound related to lecithin, a phospholipid found in cell membranes. It is an anti-fibrotic, taken orally. Scientists hope it will be beneficial to people with liver cirrhosis resulting from chronic HCV infection. A phase III clinical trial involving 800 patients is underway in the US to determine its effectiveness of IP-501 with hepatitis C-related cirrhosis (www.interneuron.com).

III.5.10 Macrokine (WF10)

OXO-Chemie's drug Macrokine is a macrophage-regulating drug, which regulates inflammation and has direct effects on the body's macrophages, immune cells that fight bacterial and fungal infections and "tell" lymphocytes, such as T cells, to fight off viral infections. The drug is in Phase III clinical trials for HIV infection and Phase II clinical trials have begun for non-responders to IFN/ribavirin Therapy. (June 2000) (www.oxochemie.com)

III.5.11 S-28463 (R-848; VML-600)

S-28463 (also known as R-848 or VML-600) is an immune response modifier, discovered by 3M. It is an analog of the drug imiquimod, a cream used to treat viral warts. 3M has partnered with Vanguard Medica to develop it into an oral treatment for hepatitis C. Animal studies have demonstrated that imiquimod may increase the level of endogenous interferon. Currently there is no proof S-28463 can increase the amount of interferon in humans to therapeutic levels. Phase I trials began in 1998. (www.mmmco.be/profile/pressbox/vanguard.html)

III.6.0 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 values 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 are 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. There have also been real successes with Living Liver donors, where a part of the liver of the donor (still alive) is given to another family member.

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. In Canada, it is permissible for HCV positive persons to donate their organs to other HCV positive persons.

Some Statistics: **US:** There are 6,684 on waiting list for livers; there were 3,922 done in 1995; 804 died waiting. **CAN:** (Nov 98) "There are currently more than 220 adults and children across Canada on waiting lists for liver transplants. It is estimated that there are 250,000 to 300,000 Canadians infected with the Hepatitis C virus. Low Canadian organ donation rates mean that 30% of people on waiting lists for liver transplants will die while waiting for an organ to become available." (Canada Newswire.)

III.7.0 OTHERS

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 recognized natural 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 like 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.0.0 KNOWN HERB-DRUG INTERACTIONS

Although the area of herb-drug interactions is under-researched, there are some interactions we do know about.

- **Feverfew:** Feverfew is most commonly used for the treatment of migraines. Non-steroidal anti-inflammatory drugs (NSAIDs) such as aspirin or ibuprofen (Motrin, Advil) may reduce the effectiveness of feverfew. It can also inhibit platelet activity and should not be taken together with blood thinners such as Coumadin. Feverfew contains tannin, which has the ability to inhibit iron absorption, and should not be used for longer than four months without medical supervision. The recommended dosage is 125 mg daily; each dosage unit should contain at least 0.2% parthenolide.
- **Garlic:** Most recent uses for garlic focus on its ability to treat high cholesterol and high blood pressure. Garlic can increase the risk of bleeding and should not be used concurrently with blood thinners. It has been reported to induce heartburn and flatulence, sweating, lightheadedness and allergic reactions. The German Commission E (Germany's equivalent to the FDA in the United States) recommends a dosage of 4 g of fresh garlic daily.
- **Ginger:** Ginger is often recommended for motion sickness, nausea and for loss of appetite. It has also been shown to prolong bleeding time and its use with aspirin or Coumadin should be avoided. Excessive consumption of ginger may also interfere with cardiac and anti-diabetic therapy. It is usually well tolerated but may cause stomach upset or heartburn in some people. For motion sickness it is taken one hour before traveling. The total daily dose is 2-4 g.
- **Ginkgo Biloba:** Ginkgo biloba is one of the most popular plant extracts in Europe and has recently received approval in Germany for the treatment of dementia. There have been reports of spontaneous bleeding in people taking ginkgo and again, it should not be used with blood thinners. People who take anti-convulsant medications, such carbamazepine and phenytoin, or phenobarbital should not take gingko without the knowledge of a physician, because it reduces the efficacy of these medications. Ginkgo is generally safe and well tolerated with the most common adverse reactions being stomach upset, headache

and dizziness. German Commission E recommends a dosage of 40 mg of ginkgo three times daily with meals for at least four to six weeks. Preparations should be standardized to contain 6% terpene lactones and 24% ginkgo flavone glycosides.

- **Ginseng:** Ginseng is used to combat overall debility, as well as lack of energy and concentration. It has also been used as an aphrodisiac. There is tremendous variation in products labeled as ginseng; in one study, only 25% of the commercially available products actually contained ginseng. Nevertheless, ginseng enjoys widespread popularity. Siberian ginseng has been associated with falsely elevated digoxin levels (a heart drug used to treat congestive heart failure) by interfering with the test used to determine digoxin blood levels. Ginseng may also affect fasting blood glucose levels, so people who need to control their blood glucose levels should take ginseng with caution. Concomitant use with warfarin, heparin, aspirin and NSAID's should be avoided. Additionally, ginseng may cause headache, nervousness, and manic episodes in patients with manic-depressive disorders or psychosis or those on anti-depressants, particularly the monoamine oxidase inhibitors (MAOI) such as phenelzine (Nardil). Side effects include high blood pressure, restlessness, nervousness, insomnia, skin eruptions, edema and diarrhea. German Commission E recommends Asian ginseng be taken as 1-2 g of crude herb daily or as 100-300 mg of ginseng extract three times daily. Commercial products should contain at least 4%-5% ginsenosides.
- **Kava Kava:** Kava Kava is recommended for anxiety, sedation and relaxation. Excessive sedation may result when Kava Kava is taken with other sedatives (flurazepam, temazepam) or anti-anxiety drugs, particularly alprazolam (Xanax). The toxicity of kava is increased if taken with alcohol. Until the clinical significance of Kava's action on platelet activity is determined, its use with blood thinners should be cautioned. Long-term use is not advised and is characterized by dry, flaking, discolored skin and reddened eyes. The herb is contraindicated in patients with certain types of depression because it may increase the risk of suicide. The daily dosage is the equivalent of 60 mg to 120 mg kava pyrones.
- **St. John's Wort:** St. John's Wort is most widely used to treat mild to moderate depression, anxiety and seasonal affective disorder. Adverse reactions reported include stomach upset, allergic reactions, fatigue and restlessness. Photosensitivity is usually rare and is associated with higher dosages. Fair-skinned people should be particularly cautious. Concomitant use with other photosensitizers, such as piroxicam (Feldene) or tetracycline should be avoided. St. John's Wort should not be used with MAOIs (phenelzine) or selective serotonin reuptake inhibitors (SSRIs) such as Prozac, Zoloft or Celexa. St. John's Wort has been reported to prolong narcotic-induced (codeine) sleeping times as well as decreasing barbiturate-induced sleeping times and caution is advised when combining these medications. The herb also contains tannin and may interfere with iron absorption. The usual dosage is 300 mg of standardized extract three times daily or 450 mg twice daily. It may take up to four to six weeks to see desired effect.
- **Valerian:** German Commission E recommends valerian for use in the management of restlessness and nervous disturbances of sleep. Valerian may cause headache, hangover, excitability, insomnia, uneasiness and cardiac disturbances. Given its sedative property it would be wise to avoid barbiturates (phenobarbital), sedatives (flurazepam, temazepam) and alcohol while on valerian. Valerian is also a tannin-containing herb and may interfere with iron absorption. Persons currently taking antidepressants should take valerian only under medical supervision. The usual dosage of the extract is 2-3 g, one to several times per day.

Source: When medicine and herbs don't mix by Tammy Chernin, R.Ph. http://www3.healthgate.com

- **Echinacea**, if used for more than eight consecutive weeks, could cause liver toxicity and should not be used with drugs such as anabolic steroids, amiodarone and methotrexate which are toxic to the liver as the affect may be additive.
- **Feverfew, garlic, ginger, ginseng, and ginkgo biloba** all affect bleeding time and should not be taken by patients using warfarin or by patients that have decreased platelet counts.
- **St. John's Wort** should not be taken with monoamine oxidase inhibitors or selective serotonin reuptake inhibitors like Prozac and Paxil until more information is available.
- **Licorice, plantain, hawthorn and ginseng** may interfere with digoxin therapy and valerian root should not be taken when barbiturates are used because it could cause an increase in the barbituate effects.
- **Evening primrose oil and borage** are contraindicated in patients taking anticonvulsants (e.g., clonazepam). Immunostimulants such as **echinacea and zinc** should not be given with immuno suppressants such as corticosteroids (like prednisone) and cyclosporine and are contraindicated in patients suffering from rheumatoid arthritis, systemic lupus erythematosus and autoimmune hepatitis.

Source: Hans Larsen is a health sciences researcher living in Victoria, British Columbia from Alive Magazine *March 1999 with some changes by D. Morrow*

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. Recent studies have shown that HCV may be spread by acupuncture. Please make

certain that your acupuncturist follows proper sterilization procedures.

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

IV.0.7 TRADITIONAL CHINESE MEDICINE (TCM)

We feel it important to caution the reader about Chinese medicines. We know many persons who have found TCM to be very helpful, but there have been many instances of unscrupulous preparation of Chinese medicinal compounds, where herbs and substances other than those indicated were used in the preparation. In some cases this has led to death. Please seek out a reputable practitioner.

The following is from ("Complementary and alternative medicine in chronic liver disease,"* Hepatology *September 2001 Volume 34 Number 3)

TCM has been practiced for roughly 2 millennia, with comprehensive records of Chinese medical theories dating back to 221 BC. CTM comprises multiple forms of ritualistic healing practices. These include the relatively well-known practices of acupuncture and herbal therapy and the lesser-known moxibustion (dermal counterirritation therapy), massage, and exercise therapy (Qi Gong). Chinese herbal therapy comprises over 100,000 recorded treatments, roughly 80% being combination or herbal mixtures. Most herbal mixtures comprise 4 to 5 herbs with 1 to 2 major pharmacologically active compounds (King herb), the remaining herbs playing a "helper function," such as reducing toxicity, promoting delivery to the target site, or working synergistically with the "King."

Regarding chronic liver disease, a limited number of mixtures (approximately 76) have been identified by screening a Traditional Oriental Medicine Database (Tradi/Med DB). A hepatoprotective extract with the highest potency and the lowest toxicity is the Plantago asiatica seed, the active component being aucubin. Aucubin appears to inhibit hepatitis B virus (HBV) replication in vitro and in animals (100 mg/kg daily for 1 month). Its use in a human trial, 10 mg/kg administered intravenously for 4 weeks, led to a 10% to 40% decrease in serum HBV-DNA levels that returned to pretreatment values after stopping therapy.

A second combination of 10 herbs, termed "Herbal Medicine 861 (HM861)," was tested for antifibrotic activity in 3 controlled clinical trials encompassing 107 patients with hepatitis B. ALT levels fell into the normal range in 73% of patients, while spleen size, portal pressure, and serum procollagen peptide and laminin levels decreased in 53%. Liver biopsies, 6 months posttreatment, showed reductions in fibrosis and inflammatory infiltrates and quantitative decreases in tissue hydroxyproline. All patients remained hepatitis B surface antigen (HBsAg) positive. In vitro studies using human stellate cells and in vivo studies using animal models of fibrosis (CCl4 and albumin induced) showed that HM861 inhibited stellate cell activation by blocking cyclin/cyclin-dependent kinase activity in the cell cycle, and that fibrotic tissues were remodeled, with revascularization of liver sinusoids. Transforming growth factor and collagen type I, III, and IV gene transcripts were reduced while matrix metalloproteinase I was increased, suggesting a reversal of early stages of cirrhosis through the correction of imbalance in the dynamics of synthesis and degradation of the extracellular matrix.

CH-100 is a formulation of 19 different herbs developed for treatment of liver disease. In a double-blind, placebo-controlled trial involving patients with hepatitis C, treatment with the product was associated with a significant reduction in ALT levels, although no treated person cleared the virus. NCCAM is currently supporting a study of a 10-herb combination, referred to as 3AR. The trial will assess safety and adverse events, as well as symptoms of fatigue, quality of life, liver function, and HCV-RNA levels in patients who do not qualify for standard therapy of hepatitis C. Thus, there is increasing interest in conducting rigorous testing of candidate CTM compounds (1) as alternatives to standard treatment, (2) to augment conventional treatments, or (3) to ameliorate the side effects of current therapies.

A very good overview of TCM and HCV can be found in Matt Dolan's book, *The Hepatitis C Handbook*

IV.0.8 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

There have been quite a few warnings posted about serious adverse effects from Kombucha Tea in Australia and the United States.

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.

A study of Ganoderma undertaken at Cornell University found that there was a good argument for the use of this substance in conjunction with other medicines in the treatment of Cancer. There was no mention in the literature of HCV. (Role of Ganoderma Supplementation in Cancer Management Meridian Medical Group at the Institute of East-West Medicine and Department of Medicine, Cornell Medical College Raymond Y. Chang, 1997).

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.

Caution should be exercised by anyone with high blood pressure or cirrhosis. ("Complementary and alternative medicine in chronic liver disease," *Hepatology* September 2001 Volume 34 Number 3)

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 its 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 pressure. Garlic contains a natural antibiotic, antifungicide, 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, Thymopoietin, 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

Recently (2000) warnings have been issued against the use and consumption of raw animal parts (glands, testicles, brains) in herbal and alternative treatments, since there is fear that they may spread "mad cow disease."

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 Pauling's 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. It is important to note that Vitamin B12 is not effective when taken in tablet form. It must be injected.

IV.1.12 VITAMIN E

Vitamin E is reported to assist the liver in detoxifying the blood. Vitamin E works best when taken with Selenium, an antioxidant mineral. Too much Vitamin E thins the blood, so those with bleeding disorders should exercise caution.

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 treatment 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.1.15 WATER

Thanks to Alan Franciscus for this important reminder

We've all been told that it is essential for proper health maintenance to drink at least 8 glasses of water (8 oz. each glass) every day. This is especially true for those of us with hepatitis C and, if you are on treatment with interferon and ribavirin, it is even more important to drink plenty of water. In fact, you should try to drink as much water as possible even if you are not thirsty. This will help with the many potentially nasty side effects that may be experienced while on treatment.

The exception to this rule is the person who has ascites (accumulation of fluid in the abdominal cavity) in which case a medical professional will instruct you on the correct diet and fluid intake.

Drinking at least 8 glasses of water can be a problem, but it is not as hard as it appears. Many people fill containers with filtered water so they can track the exact amount of water they drink daily. Frequently, I buy bottled water to take with me when I am on the go. I refill these bottles with filtered water every morning to keep track of the amount I consume daily.

Remember, you are going to have to urinate much more frequently and want to make sure you are near a restroom. If you know that you will not have easy access to a bathroom, you may want to stop drinking an hour or so before an outing.

Even with these obstacles, you will find that the health benefits of drinking large amounts of water greatly outweigh the inconvenience and the frequent runs to the restroom.

Some of the health benefits of drinking adequate amounts of water include:

- Weight loss – suppresses appetite and metabolizes stored fat.
- Digestion – improves the digestive process and can relieve or prevent constipation
- Dry Skin – moisturizes the skin
- Body wastes and toxins – rids the body of wastes and toxins
- Body temperature – regulates body temperature to keep you cool in hot temperatures
- Nutrients – contains many essential nutrients
- Joints – lubricates and cushions joints
- Cancer – helps with preventing some cancers, such as colon and liver cancer

Remember to consume water instead of coffee or colas that contains caffeine. Beverages that contain caffeine deplete body fluids. In order to replace these lost fluids, you must drink two glasses (16 oz) of water for every glass (8 oz) of a beverage that contains caffeine. Additionally, make sure you check the content of the water – you should stay away from any water that contains sodium.

So take that plunge – drink WATER!

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
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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 caries 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 liters 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 sautéed 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), oxidized fatty acids (fried oils) and animal fat, and high in fiber is recommended.

And this from the *Canadian Journal of Health and Nutrition:* "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 fiber 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.

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, reducing 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 carcinogenic 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 and 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.

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 should be off limits for those with HCV. Studies have shown that patients who drink have a higher incidence of cirrhosis. But not only that, patients who drink also have a faster rate of progression to cirrhosis and higher mortality rates. As well, because alcohol interferes with the effect of interferon, those with a history of drinking problems may be denied treatment.

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. As well, recent studies demonstrate that alcohol consumption in cirrhotics can lead to increased bacterial infection (*American Journal of Gastroenterology*, Editorial, May 2000, Volume 95, Number 5, Pages 1124-1125).

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.

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. (*Int J Cancer* 2000 Feb;85(4):498-502).

While many people are aware of smoking's negative effect on the lungs, less consideration is usually given to its effects on the liver. Tobacco and marijuana smoke are rich airborne stews of toxic benzpyrene, polycyclic aromatic hydrocarbons, cyanide, acetaldehyde, tars, acrolein, etc. Since these get into the bloodstream through the lungs, the liver must detoxify them. And virtually all the constituents of smoke are known to be at least mildly liver-damaging (The Liver: Master Organ for Optimal Nutrition).

A recent study biopsied 310 Hep C patients. 176 were current smokers (who were more often males, younger, alcohol consumers, and more often had a history of IVDU than those who had never smoked.) The results were adjusted to consider these factors. The authors concluded that "Smoking increases the severity of hepatic lesions in patients with chronic hepatitis C." Source: *Hepatology* 2001;34:121-125, "Cigarette smoking and hepatic lesions in patients with chronic hepatitis C."

VI.3.0 MARIJUANA

There are plenty of conflicting studies on the benefits/ dangers of marijuana use by the chronically ill. Recent studies show that marijuana can be beneficial for those with AIDS The results of a study released at the XIII International AIDS Conference reports that smoking marijuana helps people with AIDS gain weight, without causing adverse virologic effects (July 2000). But HIV is not HCV. Nor is HCV Cancer, nor are the aches and pains of HCV commensurate with the pain of someone who is dying of a debilitating illness.
Other studies (May 2000) speak of the synthetic marijuana derivative CT-3 as an anti-inflammatory and analgesic therapy intended as a safer alternative to nonsteroidal anti-inflammatory drugs (NSAIDs), the most commonly prescribed analgesic and anti-inflammatory therapy for long-term treatment of arthritis.

One recent studies state that marijuana use increases tumor growth, and another links it to emphysema.

A report from the New South Wales Users and AIDS Association "Hepatitis C and Drug Use" states that marijuana presents no problems for the liver; another report warns that marijuana may interact adversely with antidepressants.

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 he/she has washed his/her 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. An article in *Hepatology*, June 2000, p. 1207-1211, Vol. 31, No. 6, "Hepatitis C, Interferon Alfa, and Depression," the authors note that "two separate lines of evidence support an association between HCV and depression. First, patients with psychiatric disorders have a higher prevalence of HCV infection. Second, patients with chronic hepatitis C may have a higher prevalence of psychiatric disorders including depression."

VII.1.1 MOOD CHANGES

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.

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 judgments, opportunities for personal growth, and a new optimism about life can emerge.

Don't hesitate to seek counseling 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.

VII.1.3 DEALING WITH A LOWER LEVEL OF ENERGY

VII.1.4 IRRITABILITY

Anger is a known side effect of liver disease. And just being sick and tired and achy just about all the time does not help. What helps is slowing down. But most of us can't. If we do we won't be able to eat and pay the rent.

People with symptomatic HCV should be on disability pensions. They should have home care, and day care provided for their children. They should have help cleaning their homes and doing the shopping and cooking.

When you are tired and achy and nauseous and dizzy, getting caught up in the day-to-day aspects of life becomes increasingly difficult. Often you feel like you have cement in your blood. You feel so heavy.

So when you feel overwhelmed by the welfare system, or a doctor, or a bank clerk or whomever, it's no wonder you just might explode.

The best thing is to have a friend who understands. Joining a local support group really helps.

VII.1.5 HOW CAN HCV AFFECT MY SEX LIFE?

What sex life? ☺ See "Loss of Libido" above.

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 your local hepatitis C group 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-Positive 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 traveled this difficult road before you—consider reading from books like the ones listed in Section XII.1.5: Bibliography: Suggested Readings.

VIII.1.0 LIFE PROBLEMS CREATED BY HCV

--- This section will be developed.

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@cpcug.org

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.1.0 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 aleviate 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 usually 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.2.0 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.

A study presented at the AASLD 50th Annual Meeting (Nov 1999) showed that even non-responders to interferon treatment have positive results. Interferon has been shown to halt and even reverse fibrosis in non-responders, and to slow down the rate of progression by reducing the rate of inflammation, and lowering the viral load.

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.3.0 SIDE EFFECTS

IX.3.0a 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 helpful. You can find candied ginger available in the spice department, or in the Oriental foods section of your grocery store.

IX.3.0b 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 dosages 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.3.0c 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.3.0d 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.3.0e 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 a while 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.4.0 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.5.0 STORAGE

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

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

IX.5.0a 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. Since the horror of September 11th, it might be advisable to carry your prescription with you, as proof as to why you are carrying syringes.

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. **Do Not** put ice in a glass Thermos. It can break the glass (personal experience). If possible get a stainless steel Thermos. I don't know if they're as good, but they don't break.

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.6.0 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.7.0 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 going to make a hole. The nursing term is "clean to dirty." You put the pad at the spot where you are going to 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 3mil 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, and push the plunger to the correct level (e.g., .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 quite 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.7.0a 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.7.0b 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 dissolve 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.7.0c 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.8.0 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.9.0 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.

In the US: 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

In Canada: The number to call is 1-800-603-2754 extension 2121. According to Mike Betel from HepNet:

In response to the emails concerning anyone who was on the SAP (special access program) for ribavirin, or anyone who has received a prescription for Rebetron from their Physician, reimbursement assistance is available.

C.A.R.E., (The Canadian Advisory Reimbursement Exchange) is the reimbursement assistance number for patients who were prescribed Rebetron. There is a very easy to read booklet available.

The new dedicated line is 1-800-603-2754 extension 2121. The people at C.A.R.E. are fully bilingual and available from 10:00am to 6:00pm Monday to Friday Eastern Standard Time. After hours, patients can leave their name and number, and a medical professional will call them back the next day. Everything is always confidential!

Concerns like these will be answered.

- I don't know who is supposed to pay for my REBETRON
- I don't think I have coverage
- I have no coverage and I can't afford to pay for it myself
- I have insurance but I can't afford my co-pay or deductible
- I have insurance but they won't pay for REBETRON
- My government plan is too complicated for me to understand
- My government plan only pays for a portion of my REBETRON and I can't afford the rest
- They tell me that my REBETRON is not covered, what do I do now?

Also in the US: 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.10.0 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 program 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 follow-up 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 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 decompensated cirrhosis, however, 5-year survival was only 50 percent. - National Institutes of Health Statement on Hepatitis C 1997

The latest study shows that incidences of hepatocellular cancer due to hepatitis C and deaths caused by hepatitis C are almost double the rate given a few years ago. An article in the July issue of *Gut* reveals that '"of the 416 patients, 60 developed HCC with a 5-year rate of 13.4%...and 83 died (including 34 with HCC), with a 5-year death rate of 15.3%.' According to the authors, these results contrast with previous studies, which cite 5-year mortality rates of 9%, and HCC rates of 5% or 7%."

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.

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.

The following table is from the website at http://www.frontiernet.net/~monty/hcvpipel.html and was last updated August 16, 2001. © Frank Montmarquet.

HEPATITIS C NEW DRUG PIPELINE

Drugs specific for Hepatitis C

Company	Drug Type	Development	Pre Clinical	Clinical Phase I	Clinical Phase II	Clinical Phase III	NDA
Ribozyme	Ribozyme - Heptazyme	xxxxxxxxxxx	xxxxxxxx	xxxxxxx	4q'01		
Viro Pharma / AHP	RNA replication inhibitor (VP50406 series) Polymerase inhibitor?	xxxxxxxxxxx	xxxxxxxx	xxxxxxx	xxxx		
Isis Pharmaceutical / Elan	ISIS 14803 Antisense	xxxxxxxxxxx	xxxxxxxx	xxxxxxx	xxx		
XTL	Monoclonal antibody	xxxxxxxxxxx	xxxxxxxx	xxxxxxx			
Innogenetics	Therapeutic vaccine	xxxxxxxxxxx	xxxxxxxx	xxxxxxx	xx		
Enzo Biochem	Immune Regulator	xxxxxxxxxxx	xxxxxxxx	xxxx			
Epimmune / Genencor	Therapeutic vaccine	xxxxxxxxxxx	xxxxxxx				
Genencor / Phogen	Therapeutic vaccine	xxxxxxxxxxx					
Anadys	IRES inhibitor	xxxxxxxx					
Avant	Immuno-therapy (Therapore)	xxxxxxxxxxx	xxxxxxx				
NABI	Polyclonal antibody Civacir	xxxxxxxxxxx	xxxxxxx				
Isis / Merk	????	xxxx??					
Corvas/ Schering	Protease Inhibitor	xxxxxxxxxxx	xxxxxxx				
Vertex/ Eli Lilly	Protease Inhibitor	xxxxxxxxxxx					
Vertex	Helicase inhibitor	xxxxxxxxxxx					
Trimeris	Fusion inhibitor	xxxxLD					
CellExSys	T Cell therapy	xxxxxxxxxxx					

Biocryst	Polymerase inhibitor	xxxx??					
Novirio Pharm.	NV08	xxxxxxxxxxx	xxxIND				
PTC Therapeutics	Targeted RNA Chem.	xxxx					
Immtech Int.	Dication	xxxx					
Agouron	Protease Inhibitor?	xxxx??					
Biochem Pharma	????	xx??					
Signal/ DuPont	Gene regulating targets	xxxxxxx					
Chiron	Protease Inhibitor?	???					
AVI BioPharma	Antisense	xx??					
Hybridon	Antisense?	xx??					
Immune Network	Immunomodulation	xx??					
Hybrigenics / XTL	??	xx??					
Triangle / Dynavax	Immunostimulatory - ISS	xx??					
United Therapeutics	Anitviral??	xx??					
Genelabs	RNA antiviral	xx??					
Glaxo Wellcome	??	xx??					
Aethlon Medical	Hemopurifier	xx??					
Hemispherx Biopharma /CIMM	ZSX	xx??					
Immusol	Ribozyme/gene therapy	xx??					
Microcide	Anitviral ??	xx??					
Rigel Pharm	Antiviral	xx??					
Myriad	??	xx??					
Cangene	Hyperimmune product for liver transplants	xxxxxxxxxxx	xxxxxxxx	xxxxxxx	xxxxT		
Bristol-Myers Squibb / AAT	Protease Inhibitor	xx??					

NABI's Civacir will begin Phase I testing to prevent reinfection after liver transplants.

Agouron is a subsidiary of Pfizer. Ribogene has merged with Cypros to form Questcor ; their Hep C research has been licensed to Rigel Pharmaceutical.

Gilead lost a patent suit with Chiron and is no longer developing a protease inhibitor, Chiron is.

The Axys/ Bristol-Myers Squibb protease inhibitor collaboration has been terminated, Bristol-Myers is now developing a protease inhibitor using chemistry from AAT (now merged with Discovery Partners).

Ribozyme has repurchased rights to Heptazyme from Eli Lilly.

Existing drugs and nonspecific drugs being tested for Hepatitis C & Drugs for related conditions

Vertex	IMPDH inhibitor (VX497)	xxxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx		
American Home Prod	rh interluken 12	xxxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx		
Maxim	immune	xxxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx		

	modifier (maxamine)						
BioMedicine	Omega Interferon	xxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx		
Holliseden	cell energy regulator HE2000	xxxxxxxxxx	xxxxxxx				
3M / Vanguard	immune modifier VML 600	xxxxxxxxxx	xxxxxxx	xxxxxxx			
Viragen	Omniferon (natural interferon)	xxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx		
Human Genome Sciences	Albuferon (interferon / albumin fusion)	xxxxxxxxxx	xxxxxxxxxx	xxx			
Achillion Pharm.	ACH-126447 (Helioxanthin)	xxxxxxxxxx	xx				
Interneuron	IP-501 Cirrhosis anti-fibrotic	xxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx	xx	
Viragen/ Valentis (PolyMASC)	PEGylated Omniferon	xx??					
Anadys	Nucleoside Analogs	xxxxxxxxxx	xxxxxxx				
XTL / Pharming	Recombinant human Lactoferrin	xxxxxxxxxx	xxxxxxx				
Millennium / Bayer	Liver fibrosis	xxTI					
OXOchemie	WF10	xxxxxxxxxx	xxxxxxx	x			
Amerillo Biosciences	Oral alpha interferon	xxxxxxxxxx	xxx??				
ICN	Levovirin 2nd gen ribavirin	xxxxxxxxxx	xxxxxxx	IND			
Avigen	Gene therapy liver cancer	xx??					
InetrMune	Interferon gamma-1b For liver cirrhosis	xxxxxxxxxx					
Sci Clone	Immune modifier Zadaxin	xxxxxxxxxx	xxxxxxx	xxxxxxx	xxxxxx	xx	
Enzo Biochem	Broad spectrum antigen Immune Regulation	xxxxxxxxxx	xxxxxxx	xxxxxxx			
Incara	Liver stem cell research	xx??					
Hemispherx Biopharma	2nd gen interferon	xx??					
Organogenesis	Bioartificial liver	x??					
Geron	Cirrhosis -	x??					

	Telomerase						
Immunomedics	AFP-Cide alfa-fetoprotien monoclonal antibody - liver cancer	XXXXXXXXXXX	XXXX				
Interferon Sciences	Alferon N	x??					
Lifetime Pharmaceuticals	beta-alethine	x??					
Genetrol	non-recombinant human interferon-alpha	x??					

Notes: TI = target ID, AD = Assay development, LD = lead compound development, CO = Chemical optimization, numbers = start date of project, ?? = development stage unknown or drug type unknown. IND = investigational new drug application. T = terminated.

The pipelines of the major drug companies could not be determined for compounds not yet in phase II clinical testing. There are probably one or more drugs in development by the majors.

Bristol-Myers Squibb is developing a protease inhibitor. Glaxo-Wellcome + SKB has licensed patents from Chiron, good sign they are working on something. Abbott has several patents related to HCV. Merck has/had? a collaboration with Isis to develop HCV drugs.

More information about drug companies doing research into HCV can be found here:
Research and HCV- How YOU Can Make a Difference
Good site about viruses: All the virology on the WWW
Good antiviral site: Antiviral Agents Bulletin
Biotech information: Biospace, Signals

Links to clinical trial information
Veritas Medicine
Center Watch
NIHs ClinicalTrials.gov
Recombinant Capital Database

This information was gathered from public sources. Accuracy is not guaranteed. If you know of additions or errors please e-mail: hcvpipel@yahoo.com
Last updated 16 AUG 2001

PART XI - EMPLOYMENT AND DISABILITY

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

Note: A Section for Canadians is in the works. Until then, you can find answers on the HepCAN list, and in the hepc.bull.

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 spiraling 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 livable income, whereas if they had gone straight from full-time to disability, the disability payments were much

more livable. 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.

XI.1.4 Winning Your Social Security Disability Claim: 15 Mistakes You Cannot Afford to Make! *by Scott E. Davis, Esq. and Scott M. Harris, Esq.*

This article reprinted with permissions from the Hep C Connection in Denver Colorado. Although written with the US population in mind, the issues raised below apply equally to filing for disability in Canada. In Canada, however, there is a network of community advocates, paralegals and legal aid lawyers in place who will represent you for free if your finances are limited.

Mistake #1: Assuming that what SSA tells you is true.

Unfortunately, some of the advice that Social Security Administration (SSA) employees provide to the public is incorrect. So if you aren't happy with what SSA told you over the telephone, you'll be glad to know it may not be correct. The problem is, many people don't file a disability claim for years (and go without benefits they deserve) simply because an SSA employee gave them bad information.

Advice: Don't give up on your claim until after you have reviewed your case with a disability lawyer. Disability lawyers know more about the law than SSA employees and will give you correct information.

Mistake #2: Assuming the Social Security Administration will approve your claim.

Many people believe that because they have paid into SSA, their claim should easily be approved when they apply for disability benefits. Many people believe it's just a matter of filling out the forms and going through the process. But this isn't true. SSA denies 70 to 75% of first-time claims. SSA denies 82% of claims that are appealed for Reconsideration. However, the good news is that when cases are heard before judges, nationwide over half (53%) are approved.

Advice: Appeal every denial within 60 days of receipt. Build a strong case by understanding what information Social Security requires. Make sure to present your case properly.

Mistake #3: Assuming the disability forms you fill out will win your case.

Usually they will not. Claimants hurt their case by overstating what they can do. In most cases, SSA and judges rely heavily on medical records as well as your doctor, psychiatrist, and/or psychologist's opinion about your ability to work full-time. If the judge isn't happy with you, if he doesn't believe what you're saying, or if he is looking for a reason to deny your claim, he may look for inconsistencies in answers you provided earlier on the forms. For example, if you answer one way on the form and testify at a hearing to something else, the judge may use the answer on the form to undermine your credibility and support a denial of your claim.

Advice: When completing the forms, be honest, accurate, and brief! You should always answer the question in the space provided--do not attach additional sheets of paper or write in the margins. Also, it is important to assume you are back working full-time on a sustained basis (8 hours per day, 5 days per week) when answering questions about what you are capable of doing.

Mistake #4: Assuming that your medical and/or psychological symptoms will be enough for the judge to approve your claim.

Not true. You need detailed medical records, which document your symptoms and limitations and specific opinions from your doctor, psychiatrist, and/or psychologist if you hope to win your case. Their opinions will only be given weight by the judge if you have received continuous and consistent medical treatment. If you are not meeting regularly with your doctor, you are jeopardizing your case!

Advice: It is critical that you receive continuous and consistent medical treatment and care so you can provide SSA and a judge with current and complete medical records which support your doctors' opinions.

Mistake #5: Assuming your diagnosis will win your claim.

It won't. It's true that SSA needs a diagnosis. But SSA also needs medical proof that your diagnosis causes limitations that are so significant and severe that they preclude your ability to work full-time on a sustained basis.

Advice: Disability cases are won based on your limitations, not your symptoms. Make sure you provide detailed medical records from your doctor that reflect your symptoms, the diagnosis, and your limitations.

Mistake #6: Assuming SSA will be persuaded by any type of medical treatment you choose.

It will not. You can choose any alternative therapies and holistic treatments you desire. After all, you should do whatever it takes to try to get better. However, be aware that SSA and judges are most persuaded by mainstream doctors (M.D., D.O., and psychologists) and how you respond or fail to respond to mainstream treatment. If you are not taking medications or are not receiving mainstream treatment by a mainstream doctor, you may be jeopardizing your claim.

Advice: To win your claim, try to exhaust every medical treatment your mainstream doctors recommend, so you can prove that in spite of doing so, you continue to be unable to work full-time on a sustained basis.

Mistake #7: Assuming your family doctor's opinion is the only one you need.

This may not be a good choice depending upon your diagnosis. If your diagnosis is usually made and treated by a specialist (M.D., D.O., Ph.D.), you should treat with both a board certified specialist and your family practitioner. From a legal standpoint, you want to show the judge your diagnosis is correct and that you are receiving the best possible medical care. You have a stronger case when your doctor is a specialist who is skilled and experienced at treating people who have your condition. Social Security law generally gives more weight to the opinions of a specialist than a general practitioner. As a result, SSA and the judge will look more closely at the credentials of the doctor who is providing the opinion.

Advice: Get your medical treatment from a specialist because the more skill and experience your doctor has, the more likely you are to win your claim. Note: If you are a member of an HMO and they will not allow you to go to a specialist, consult with your disability lawyer, who can help you get appropriate treatment.

Mistake #8: Assuming your doctor will support your claim for disability benefits.

He may not. Some doctors refuse to help patients with their disability claims. Many doctors do not know SSA's definition of disability and believe that one has to be bedridden to qualify. In general, doctors are very conservative in their opinion about a patient's ability to work. Because SSA and a judge will want to know if your doctor supports your claim, it is critical you know the same information! After you have established a relationship with your doctor you should discuss with them the fact that you have filed a claim for disability. Ask if they will support your claim, and if they will not, you should consider finding another doctor because their opinion is not likely to change! It is critical your doctor supports your inability to work full time on a sustained basis!

Advice: As soon as practicable, you should learn whether your doctor supports your disability claim. If not, consider finding a more compassionate doctor who will. One place to find a referral is to attend a local support group for individuals who share your diagnosis.

Mistake #9: Assuming you have to go to SSA's doctor for a medical examination.

Often, SSA wants to a claimant to go a disability examination with a doctor/psychiatrist/psychologist it chooses. Unfortunately, the doctor is not really "independent" and probably performs many of these examinations for SSA each month. In my experience, the majority of the time the doctor will conclude you are not disabled and can return to work. Once this opinion is included in your file SSA and a judge will have sufficient evidence to deny your claim.

Here's the good news: SSA rules allow your doctor to perform the disability exam and SSA should pay for all or at least part of it. Naturally, if your doctor supports your disability claim he will probably conclude your condition precludes your ability to work. Once your doctor's exam report is in your file with a conclusion that you are disabled, SSA and a judge may have sufficient medical information to approve your claim.

Advice: This strategy is only possible if you are certain your doctor supports your claim and is willing to do the examination. If you do not have a doctor, or your doctor will not perform the examination, you must go to SSA's doctor or risk having your claim denied or closed out. This strategy really should only be employed by a disability lawyer because complex regulations are involved and must be complied with.

Mistake #10: Assuming an entire year has to pass before you can file a disability claim.

Not true. SSA law requires that before you can be approved one of the following must be true: (1) you have already been disabled and out of work for one year, or (2) your doctors expect that you will be unable to work for a minimum of one year from the date you last worked, or (3) your medical condition is expected to result in death. Too many people have told me that an SSA employee said they could not file a claim until one year had passed since they last worked. This information is totally incorrect and if followed, will almost certainly cost you disability benefits and medical insurance!

Advice: Apply for disability benefits as soon as you or your doctors believe your medical and/or psychological condition will preclude you from working for at least one year. Waiting to file will only cost you benefits that you may not be able to recover.

Mistake #11: Assuming that if you lose before a judge at a hearing, you can simply file another claim.

When you have a hearing before a SSA judge, you do not want to lose. This is because, practically speaking, your best chance at winning is at your first hearing before a judge. True, you can file a second application if you lose at a hearing; however, the second time you go through the process, SSA and a judge will know your first claim was denied. In my opinion, this may have a detrimental effect on your second claim as the second judge will know.

Advice: Make sure your case is properly prepared so you can present your strongest case at the first hearing.

Mistake #12: Assuming you can handle your case without a disability lawyer.

Most people can't. SSA disability laws are complex, even many lawyers do not understand them. To win your claim, you need to very carefully prepare your case from the very beginning. In addition, it

is critical to understand what you need to prove legally in order to win your case; if you do not know what you need to prove, why would you risk going before SSA or a judge without knowing how to win your case? The fact that you and your doctor agree you are disabled is not enough to win your case.

Advice: Retain only an experienced disability lawyer. They will help build your case, develop a case strategy, obtain a complete set of your medical records and critical opinions from your doctor that will maximize your chances of success. More often than not, your doctor will not be familiar with the stringent criteria that SSA and a judge will utilize in determining whether you meet their definition of disability.

Mistake #13: Assuming any lawyer can help you win your claim.

Not true. You want a disability lawyer who is familiar with SSA laws and regulations. Similar to doctors, attorneys generally specialize in a certain area of the law. You wouldn't go to a dentist for a physical examination, so do not pick just "any" attorney to represent you in your disability claim.

Advice: Choose a disability lawyer who's practice is dedicated to representing clients because your odds of winning will increase. A seasoned disability attorney will understand the strategy and tactics that are crucial to helping you win your claim.

Mistake #14: Assuming you should not hire a lawyer until your case has initially been denied.

Not true. You can hire a lawyer any time you wish. Unfortunately, many employees at SSA will tell you that it is not necessary to hire an attorney until you have been initially denied. Following this advice could be fatal to your claim! Why? Because in general, SSA will begin preparing a case against you from the day you file your application!

Advice: You should consult with and/or hire a disability attorney as soon as possible after you file your application. The attorney can explain how the process really works and lay the proper foundation for your case by developing a case strategy. The attorney can also guide your case through the myriad of rules and regulations that are certain to have an effect on your entitlement to benefits.

Mistake #15: Assuming that you cannot afford a lawyer.

Not true. In almost every case, you will only pay the attorney a fee if and when you have won your case and received benefits. SSA law limits the amount of money your lawyer can earn from your disability claim. Generally, by the time you win your claim you will have accrued back benefits. The law mandates the fee can only be 25% of your past benefits and is capped at $4,000. In other words, if your back benefits total $1,000.00, the attorney's fee would be $250.00. The law does not allow your lawyer to charge a fee on your future benefits.

What may be at stake? By way of example, assume a claimant is 45 years old and their monthly disability benefit is $1,000.00. If the person never returns to work before age 65, their disability benefits would total $240,000.00! This amount does not include the value of the lifetime health insurance they would also receive through Medicare or Medicaid.

Advice: Because the amount of the benefits can be staggering, the truth is, you can't afford not to hire an experienced disability attorney!

Scott E. Davis and Scott M. Harris are attorneys who specialize in Social Security and long-term disability claims. More than 50% of their disability practice is devoted to individuals with FMS and/or CFIDS. Mr. Davis and Mr. Harris are located in Scottsdale, Arizona and represent clients throughout the United States. They invite your questions and inquiries about representation by email or FAX at (602) 482-4300.

XI.1.5 HEPATITIS C AND DISABILITY BENEFITS IN BRITISH COLUMBIA

Your Doctor(s):

If you have been diagnosed with hepatitis C you should be under the care of a specialist. If you are not, ask your family doctor to recommend one. Your doctors should be your closest allies, both in your battle with hepatitis C and also in obtaining your disability benefits, should you qualify.

Disability Benefits:

There are several types of Disability Benefits available to residents of BC: Canada Pension Disability Benefits; Disability Benefits from the BC Government; Worker's Compensation; and various private plans. All have very different qualifications, and procedures, which your local advocate can explain to you.

Advocates:

Advocates are community workers who have a great amount of experience fighting for citizens' rights in many areas: housing, income assistance, disability benefits, and so forth. Often advocates can be found at community organisations, such as AIDS organisations, or organisations for the disabled, such as the BC Coalition of People with Disabilities, TAPS or the ACPD. They can also be found at various Legal Services Society offices throughout the province. For help in locating an advocate nearest you, you can call the **Advocacy Access Project** at 1-800-663-1278, or HepCBC at (250) 361-4808.

Often people feel their case is so clear cut that they can take care of it themselves. Big Mistake! Unfortunately, the decision to award disability is not based on how you feel, or even on how you look, but on very special criteria that each disability plan has established. Unless you meet these criteria, you will not get your disability—no matter how deserving you may feel that you are.

Arguing your own case is exhausting. If you are ill, this is the last thing you need. Advocates know the ropes and they are there to help you.

Qualifying for Disability Benefits:

If you are applying for Canada Pension Plan Disability benefits, the most important aspect, aside from your condition, is whether or not you have made enough contributions to the Canada Pension Plan, and when you have made them. If you have not paid into this plan because you have not been working, or have not worked recently, you may not be eligible. Your advocate, or a lawyer from Legal Services, can help you understand whether or not you should apply for CPP Disability.

If you are applying for BC Disability Benefits, it can help if you have applied for and received your CPP, but not having CPP Disability will not disqualify you from getting BC Disability Benefits.

Some of the Issues:

The Runaround:

Getting disability even if you are really sick is not easy. Often you will need to have lots of papers and doctors appointments and interviews. When you are feeling really sick and tired, it is very frustrating to have to go to one appointment after another, all the while not knowing how you are going to eat, let alone pay the rent.

Hep C and Doctors:

Perhaps the single most important document you will need when making your disability claim is your doctor's letter. Unfortunately, many doctors, no matter how sympathetic they may be to your plight, do not know how to fill in the form properly. Your advocate will be able to provide you with guidelines that you can give to your doctor, to help him or her fill out the form more effectively.

Sadly, there are still many doctors out there who do not understand the nature of hepatitis C. Many continue to think that it is only a liver disease, and that, unless you are suffering from end-stage liver disease (cirrhosis, ascites, bleeding), you cannot be disabled.

Other doctors and specialists are beginning to understand that hepatitis C, while it does cause liver disease, also causes a host of other problems related to autoimmunity. In fact an article in the American Journal of Gastroenterology states that "up to 70% of patients with chronic hepatitis C" may suffer from autoimmune related disorders.[1]

It is the presence of autoimmune activity (your body fighting the hepatitis C virus) that causes the fatigue, muscle aches, confusion, bone aches, feverishness, nausea, itching and mood swings from which people with hepatitis C suffer. Often, none of this can be established by a specific blood test, although some autoimmune disorders do have special "markers" in the blood.

When the Federal Government decided to compensate certain individuals who received tainted blood between 1986 and 1990, they concluded that those under the plan with Grade 2 Liver Fibrosis (a stage of scarring in the liver) would be eligible for "loss of income" payments. In making this decision, the government set a precedent which should make it much easier for anyone with Grade 2 Fibrosis (non-bridging Fibrosis) to qualify for long term disability benefits, which is what "loss of income" payments are.[2]

Those under the compensation scheme with Grade 3 Fibrosis (bridging fibrosis) or cirrhosis have been awarded even more because the government recognizes that the more heavily scarred the liver is, the more disabled the person will be.

However, in order for anyone to know to what extent your liver is scarred, you must undergo a liver biopsy, which is not the most pleasant of experiences, but should be standard procedure for everyone with hepatitis C.

Notes:

1. American Journal of Gastroenterology, Vol 96 number 2, 2001: 910-911.

2. Hepatitis C : January 1, 1986-July 1, 1990 Class Actions Settlement, p. 18.

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 a few HCV patients, despite what the drug companies would have you believe. Speaking about cure rates from interferon therapy (1996), Dr. Lerner says this: "Assuming a "cure" rate of 8 - 15% in the 5 - 15% who would potentially benefit from treatment, one comes to an estimated improvement in outcome in only 0.4 - 2.25% of patients. Even this higher number is doubtful since the group with the most aggressive disease tends to have the lowest response to interferon.." From "Hepatitis C – A Silent Epidemic" by Dr. Steven E. Lerner http://www.lectlaw.com/med/med17.htm

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

- 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

- The Hepatitis Foundation International, 30 Sunrise Terrace, Cedar Grove, New Jersey 07009, USA. HIF's toll free line for callers in North America is 1-(800) 891-0707 www.hepfi.org
- 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.
- 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 deductible. 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.1.3 CANADA

HEPCBC

2741 Richmond Road
Victoria BC V8R 4T3
Phone: (250) 361-4808
Fax: (250) 414-5102
Email: info@hepcbc.org
Website: http://www.hepcbc.org/

HepCBC is an umbrella organization comprising a variety of autonomous organisations, each of which is dedicated to educating and advocating for those infected and affected by HCV. Currently these are: ANKORS (Nelson), ARC (Kelowna), Positive Living North West (Smithers), Coast Garibaldi Health (Sunshine Coast), Comox Valley Community Health, Northern Interior Health (Prince George), HepTalk (Chiliwack), Victoria Persons with AIDS, Trail Support Group, Princeton Support Group, HepCure (Armstrong), Mission Support Group, Hepatitis C Foundation of Quebec, HepSEE (Winnipeg), and Action Addiction Services (Sechelt). *HepCBC provides information*, education and support to people infected with Hep C as well as to the organizations caring for them. HepCBC is the home of the *hepc.bull*, and the HepCAN list. HepCBC also distributes and updates the FAQ and other materials. HepCBC maintains the most comprehensive community co-infection library on Vancouver Island, and one of the best in the province of British Columbia. Full text access to major medical journals and other services are available to member organizations.

ATLANTIC HEPATITIS C COALITION

902-443-5140 Halifax
902-857-9093 Hubbards, NS
902-542-4431 Kentville, NS
Email: ahcc@ns.sympatico.ca
Website: www3.ns.sympatico.ca/ahcc

CANADIAN HEPATITIS C COALITION

P.O. Box 21058
Penticton, B.C. V2A 8K8
Phone: (604) 490-9054
Fax: (604) 490-0620
email: bchepc@telus.net

Founded in March 1996 to assist newly diagnosed and their families and friends to understand and live with Hepatitis C. Designed the red and yellow awareness ribbon and supply ribbons internationally.

THE CHILDREN'S LIVER ALLIANCE CANADA INC

P.O. Box 21058
Penticton, B.C. V2A 8K8
(250) 490-9054
(250)490-0620 Fax
email: bchepc@telus.net, http://www.livertx.org/

HEPATITIS C COUNSEL GROUP

(This group is coordinating the class action lawsuit for Hepatitis C infections from tainted blood, which has been launched against the Canadian Red Cross Society, the Canadian federal government and the provincial governments other than British Columbia and Quebec) Contact the Hepatitis C Class Action Line at 1-800-229-LEAD

CANADIAN HEPATITIS INFORMATION LINE:

1-800-363-3422 Press Code 2121 for information. Press 0 to speak with an information nurse.

HepCAN

The online support group for Canadians and everyone else. Check us out on the Web at http://groups.yahoo.com/group/hepcan/messages or contact: citizenk@nethop.net. To subscribe send an email message to hepcan-subscribe@yahoogroups.com

Hepc.bull

hepc.bull is a monthly Canadian newsletter about Hepatitis C. The newsletter provides support information primarily in BC but also from across Canada and contains articles on many different aspects of the disease. To subscribe, send a message to jking@hepcbc.org

BRITISH COLUMBIA:

Armstrong HepCure Office and library, by appointment. Contact: Marjorie, 546-2953, amberose@sunwave.net, www.junction.net/hepcure

Castlegar Contact: Robin, 365-6137

Chilliwack BC HepTalk Contact: 856-6880.

Comox Valley HeCSC Meetings: 3rd Tues. monthly, 7-9 PM, St. George's United Church on Fitzgerald Contact: Jayne, 336-2485 or Dan, 338-0913, Rhagen@mars.ark.com

Cowichan Valley Hepatitis C Support Contact: Leah, 748-3432.

Cranbrook HeCSC-EK: Meetings: 1st & 3rd Tues. monthly, 2-4 PM, #39 13th Ave South, Lower Level. Contact: 426-5277 or 1-866-619-6111 hepc@cmha-ek.org, www.cyberlink.bc.ca/~hecsc-ek/

Creston/Golden/Invermere Educational presentation and appointments: Contact Katerina 426-5277

Grand Forks Hep C Support Centre Each Mon, 3:30-5:30 PM, & 1st Mon. monthly, 6:30 PM, 7215 2nd St. (Boundary Women's Resource Centre) Contact Ken, 1-800-421-2437

HepCBC INFO Line. Free medical articles & other info. Contact: David, (250) 361-4808, info@hepcbc.org, www.hepcbc.org

Kelowna HeCSC Meetings: 1st Sat. monthly, 2-4 PM, Rose Avenue Education Room, Kelowna General

Hospital. (Please call to confirm.) Contact Elaine Risely (250) 768-3573 or Merv, 862-2437.

Kimberley Support Group Meetings: 1st Mon. monthly, 1-3 PM. Contact Katerina 426-5277

Kootenay Boundary Meetings: 2nd & 4th Tues. monthly, 7 PM, 1159 Pine Ave, Trail. For individual support, info & materials, contact: Brian, 368-1141, k-9@direct.ca.

Maple Ridge New group starting. Contact Peter or Laura-Lea 604-463-0223 or madclark@telus.net

Mid Island Hepatitis C Society:
Ladysmith Friendship and Support Group.Meetings: Every Wednesday except the 4th, 2 PM, Ladysmith Resource Centre. Contact Sue 245-7635.
Nanaimo Friendship and Support Group
Meetings: Weekly Friday afternoons, 2 PM, Nanaimo Community Building, 285 Prideau Street, Nanaimo. Contact Barb 756-9631 bwreggitt@home.com

Mission Hepatitis C and Liver Disease Support Group Meetings: 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Contact Gina, 826-6582 or Patrick, 820-5576. missionsupport@eudoramail.com

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Contact: Ken, 1-800-421-2437

Nelson Hepatitis C Support Group Meetings: 1st Thurs. monthly. ANKORS Offices, 101 Baker St. Contact: Ken Thomson, 1-800-421-2437, 505-5506, info@ankors.bc.ca, or Ken Forsythe 355-2732, keen@netidea.com

New Westminster Support Group Meetings: 2nd Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. Contact: Dianne Morrissettie, 525-3790.

Parksville Support Group Contact Ria, 248-6072

Parksville/Qualicum 102a-156 Morison Avenue, PO Box 157, Parksville, BC V9P 2G4. Open daily from 9AM to 4 PM, M-F. Contact: 248-5551, sasg@island.net

Penticton Hep C Family Support Group Contact: Leslie, 490-9054, bchepc@telus.net

Powell River Hep C Support Group: Contact: Cheryl at 483-3804, or the Health Unit at 485-8850.

Prince George Hep C Support Group Meetings: 2nd Tues. monthly, 7-9 PM, Health Unit Auditorium. Contact: Gina, 963-9756, gwrickaby@telus.net or Ilse, ikuepper@nirhb.bc.ca

Princeton Meetings: 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Contact: Brad, 295-6510, citizenk@nethop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy: 557-9362, e-mail: wmm@island.net, www.island.net/~wmm/

Quesnel: Meetings last Mon. evening every other month. Contact Elaine Barry, 992-3640, ebarry@goldcity.net

Richmond: Lulu Island AIDS/Hepatitis Network: Meetings/drop-in dinner each Mon. 7-9 PM. Contact Phil or Joe, 276-9273.

Slocan Valley Support Group Meetings: Contact: Ken, 355-2732, keen@netidea.com

Smithers: Positive Living North West Meetings: 2nd Wed. monthly, 7-9 PM, 3731 1st Avenue, Upstairs. Contact: Deb. 877-0042, 1-866-877-0042, or Doreen, 847-2132, plnw_hepc@bulkley.net

Sunshine Coast—Sechelt: Contact: Kathy, 886-3211, kathy_rietze@uniserve.com—**Gibsons**: Contact Bill, pager 740-9042

Vancouver

HepHIVE: Contact: 254.9950 hephive@mdi.ca:
Carnegie Centre Hep C & HIV/HCV Meetings: Each Mon., except holidays, 4:30-6 PM, 3rd floor, room. 2.
HepHIVE and HepC VSG Hep C & HIV/HCV Meetings: Last Wed. monthly, 10:30-12:30, BCCDC Building, 655 West 12th Tom Cox Boardroom 2nd floor. Next meeting Aug. 29th.
VANDU Vancouver Area Network of Drug Users Meetings each Mon., 1 PM, #350 - 163 West Hastings St., (Cambie & Hastings) Bus fare and snack. Contact: Ed or Ann, 683-8595, vandu@vandu.org, annlive@direct.ca, http://www.vandu.org/

Vernon HeCSC HEPLIFE Meetings: 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Contact: Sharon, 542-3092, sggrant@netcom.ca

Victoria
HeCSC Meetings: Last Wed., St. John's, 1-3 PM. Contact: 388-4311, hepcvic@coastnet.com
Victoria Support and Discussion Group Meetings: 1st Wed. monthly, 7-9 PM. Contact Hermione, Street Outreach Services 384-1345, hermione@avi.org
Victoria HepCBC Support Groups Small support groups for men or women. Men, contact David at 361-4808, cdm@hepcbc.org. Women, contact Joan at 595-3882, or jking@hepcbc.org

ATLANTIC PROVINCES:
Atlantic Hepatitis C Coalition, QEII Health Sciences Centre, Bethune Building, Rm 223, 1278 Tower Road, Halifax, TEL: 420-1767 or 1-800-521-0572, r.ahcc@ns.sympatico.ca, www.ahcc.ca Meetings:
Antigonish: 2nd Wed. monthly, 7 PM, St. Martha's Health Centre, 25 Bay St, Level 1 Conference Room
Bridgewater: Last Wed. monthly, 7 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room
Halifax: 3rd Tues. monthly, 7 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110
Kentville: 2nd Tues. monthly, 6:30 PM, KingsTech Campus, 236 Belcher St, Rm 214
Truro: Last Tues. monthly, 7 PM, Colchester Regional Hospital, 25 Willow St, Conference Room
Yarmouth: 1st Tues. monthly, 7 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1—Main level

Fredericton, NB HeCSC Meetings: 7 PM Odell Park Lodge. Contact: Sandi, 452-1982 sandik@learnstream.com

Moncton, N.B. HeCSC Contact Debi, 1-888-461-4372 or 858-8519, monchepc@nbnet.nb.ca

Saint John & Area/HeCSC: 3rd Thurs. monthly, 7 PM, Community Health Centre, 116 Coburg Street. Contact Esmonde, 653-5637, hepcsj@nb.aibn.com, www.isaintjohn.com/hepc/

ONTARIO:
Barrie HepSEE Chapter Meetings: 3rd Tues. monthly, 7-9 PM, AIDS Committee of Simcoe County, 80 Bradford Street, Suite 336 Contact: Jeanie, 735-8153 hepseebarrie@home.com

Durham Hepatitis C Support Group Meetings: 2nd Thurs. monthly, 7 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contact: Smilin Sandi, smking@rogers.com, http://members.rogers.com/smking/ Ken Ng, (905) 723-8521 or 1-800-841-2729 (Ext. 2170); Jim, (905) 743-0319

Kitchener Area Chapter Meetings: 3rd Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact: Carolyn, 893-9136 lollipop@golden.net

Niagara Falls Hep C Support Group Meetings: Last Thurs. monthly, 7 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact: Rhonda, (905)295-4260 , Joe (905) 682-6194 or hepcnf@becon.org

Trenton. Eileen Carlton (613) 394-2924 carfam@quintenet.com

Windsor Support Group Meetings: Each Thurs., 7 PM, 1100 University Ave. W. Contact 739-0301 or Ruth or Janice (Hep-C), 258-8954, truds99@hotmail.com

PRAIRIE PROVINCES:
Alberta
Edmonton: Hepatitis C Support Group. Contact Fox: 473-7600 or Cell phone 690-4076 for further information. fox@kihewcarvings.com

Manitoba

Winnipeg HepSEE WPG Meetings: Each Wed, 7:30 PM, Sunshine House, 342 Maryland St., Main Floor. Contact David: 774-8123, jmoritz12@home.com

Winnipeg Hepatitis C Resource Centre, Inc.,. Meetings: 1st Tues. monthly 7-9PM, RM# 203, 825 Sherbrook St. (south entrance—parking at rear) Contact: (204) 975-3279

QUEBEC:

Montreal: Hepatitis C Foundation of Quebec Meetings: 4th Tues. monthly, 7-9 PM, Montreal General Hospital, room A1.109, 1650 Cedar Ave. 7-9 PM., and 3rd Wed. monthly, 7-9 PM, 4341 Verdun Ave (English meeting) and 1st Wednesday of each month, 7-9 PM, at 4341 Verdun Avenue, Verdun, P.Q. (French meeting). Contact Eileen to reserve (limited seating): 769-9040 or fhcq@qc.aibn.com

Quebec City Region, 1st Wed monthly, 7 PM, 876 rue D'Alençon, St. Nicolas, QC. Contact: Renée Daurio, 836-2467, reneedaurio@hotmail.com

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XII.1.3a AUSTRALIA/NEW ZEALAND

NEW SOUTH WALES: Hepatitis C Council of NSW. Publishes a quarterly newsletter: *The Hep C Review.* A community-based organisation committed to providing high quality HCV information, education, support and referral services. PO Box 432 DARLINGHURST NSW 1300 AUSTRALIA. Ph: 61 2 9332 1853; Fx: 61 2 9332 1730 hccnsw@hepatitisc.org.au www.hepatitisc.org.au. Support Line: 1-800-803-990

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.1.3b 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

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.1.3c 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.1.3d 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

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

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

Residents or citizens of Canada dealing with Hepatitis C may join HepCAN the online support group for Canadians and everyone else. HepCAN has Chat, its own website with easy archive access and a search engine. Check us out on the Web at http://groups.yahoo.com/group/hepcan or contact: kane@hepcbc.org or info@hepcbc.org To subscribe send an email message to hepcan-subscribe@yahoogroups.com

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

Hepatitis & Liver Disease-What You Need To Know, 2000. Dr. Melissa Palmer, MD. ISBN: 0895299224.
Contains information on Hepatitis B, C, and D. Section on AutoImmune Hepatitis, Primary Biliary Cirrhosis, Fatty Liver and NASH (non-alcoholic steatohepatitis), alcohol and the liver, alcoholic liver disease, Hemochromatosis and other iron overload diseases, benign & malignant liver tumors, transplantation, herbals, overview on conventional therapies, more.

The Liver Disorders Sourcebook, 1999. Howard J. Worman, MD. ISBN: 0737300906.
Overview of the normal liver, diseased liver, failing liver, liver transplantation, selecting a liver specialist, research, living with liver disease. Overview on several kinds of hepatitis, fatty liver, autoimmune hepatitis, alcoholic liver disease, inherited liver disease, primary sclerosing cholangitis, liver tumors and cancers-cysts and abscesses, Budd-Chiari Syndrome, pregnancy with liver disease, drugs & toxins, more.

Living With Hepatitis C: A Survivor's Guide, 1999, Revised Edition. Gregory T. Everson, MD, Hedy Weinberg.

Hepatitis C: A Personal Guide to Good Health, 1997. Beth Ann Petro Roybal. ISBN: 1569750912.

HCV: The Silent Killer, 1998. Carol A. Turkington, Joseph B. McCormick, Susan Fisher-Hoch. ISBN: 0809229587.

Hepatitis (Diseases and People), 1994 {young adult reading level}. Alvin, Virginia & Robert Silverstein. ISBN: 0894904671.

The Hepatitis C Help Book: Combining Treatment with Western & Eastern Medicine, 2000. Misha Ruth Cohen. ISBN: 0312252463.

The Iron Elephant-What You Should Know About The Dangers of Excess Body Iron, Roberta Crawford. $12.95 + postage. To read about and order this book go to this site http://www.ironoverload.org/books.html

Natural Liver Therapy

Herbs for Hepatitis C and The Liver, 2000. Stephen Harrod Buhner. ISBN 1580172555.

Foundations of Health: Healing with Herbs and Foods, 1994. Christopher Hobbs. ISBN 0961847085.

Herbs and Other Natural Remedies For a Healthy Liver (with a chapter on Hepatitis C). By: Christopher Hobbs. ISBN: 0961847026.

Liver Cleansing Diet: Love Your Liver and Live Longer,1998 (revised). Dr. Sandra Cabot. ISBN 0646277898.

The Hepatitis C Handbook, 1999. Matthew Dolan, Lain M. Murray-Lyon, John Tindall. REVISED Edition, May 1999 (contains new section on alternatives). ISBN 1556433131.

Hep C: Practical, Medical, Spiritual Guidelines for Daily Living, 2000. Mark Jenkins. ISBN 1568383681.

Triumph Over Hepatitis C, Alternative Medicine Solution, 1999. Lloyd Wright, Lyla Campbell, Dr. John Finnegan. ISBN 0967640407.

Hepatitis C Cookbook {200 recipes, diet tips} Romona L. Jones, CNC, Vonah Stanfield. Inquire about ordering at: Nature's Response, 22 Fairview Lane, Shawnee, OK 74804. 1-800-216-5195. Email to tealady1@aol.com

Spontaneous Healing, 1995. By: Dr. Andrew Weil, MD. ISBN: 0449910644. Includes Dr. Weil's "Eight-Week Program for Optimal Healing Power."

How to Reverse Immune Dysfunction. By: Mark Konlee. To inquire about ordering at: Keep Hope Alive, Ltd. PO 27041 West Allis, WI 53227. (414) 548-4344. Email at Keephope@execpc.com. KEEP HOPE ALIVE http://www.execpc.com/~keephope/keephope.html. Mark Konlee is also the Editor of newsletter *Positive Health News* ($15), and *Progressive Health News* ($20).

Prescription for Dietary Wellness: Using Food To Heal, 1998. Dr. Phyllis A. Balch, MD and Dr. James A. Balch, MD. ISBN: 0895298686.

Miracle Cures: Dramatic New Scientific Discoveries Revealing the Healing Powers of Herbs, Vitamins and Other Natural Remedies, 1998. Jean Carper. ISBN: 0060984368.

The GastroIntestinal Sourcebook, 1998. M. Sara Rosenthal. $16.95 (paperback). ISBN: 0737300817. Overview on GI conditions such as ulcers, GERD, heartburn, pain, cramps, H.Pylori, NUD, dysmotility, bowel problems, eating disorders, more. Discusses correct diet, testing and therapies. Glossary of terms.

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.

Stedman's Pocket Medical Dictionary (ISBN0-683-07921-2) - $22. A good general companion.

Transplantation

I'm Glad You're Not Dead: A Liver Transplant Story, 1996. Elizabeth Parr. ISBN: 0965472817.

Pennies, Nickles and Dimes, 1999. Elizabeth Murphy Melas. ISBN 0929173325.

Strings: The Miracle of Life, 1998. John B. Robbins. ISBN 1880823179.

Defying the Gods, Inside the New Frontiers of Organ Transplantation. Scott McCartney. ISBN 0025828207.

This Is The Story About God: The True Account of Two Men, an Impossible Surgery and The God of the Universe. Ann Kiemel Anderson. ISBN 0834117312.

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!

Coping, Personal Loss & Grief

Site listing books on personal loss and grief http://www.GriefWorks.com/GriefBooks.html

In The Country of Illness: Comfort & Advice for The Journey, 1998. New York Times Writer Bob Lipsyte $24.00. ISBN: 0679431829. Book for anyone facing a challenging illness or caring for ill loved one.

Mainstay: For the Well Spouse of the Chronically Ill, 1988. M. Strong, New York: Penguin Books.

In Search of the Sun: How to Cope with Chronic Illness, 1988. H. Aladjem, New York: Macmillian.

Living with Chronic Illness: Days of Patience and Passion, 1987. C. Register, New York: Free Press.

We Are Not Alone: Learning to Live with Chronic Illness, 1987. S.K. Pitzele, New York: Workman.

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)

XII.1.6 WHAT NEWSLETTERS, MAGAZINES AND VIDEOS ARE AVAILABLE?

Newsletters:

The *hepc.bull,* Canada's most widely-read hepc bulletin is available snail mail and online as well www.hepcbc.org. Current circulation is 1700 a month. It is edited by Joan King, and C.D. Mazoff. Contact jking@hepcbc.org if you would like to subscribe. Read the bulletin online at http://www.hepcbc.org.

The HCV Advocate. An excellent newsletter out of San Francisco. Check them out at www.hcvadvocate.org

HepNews: Another excellent newsletter out of Seattle. Check them out at www.scn.org/health/hepatitis

Magazines:

There is a new magazine out called *Hepatitis Magazine*. Check them out at www.hepatitismag.com. There do a really fine job.

Videos

Hepatitis Foundation International 30 Sunrise Terrace, Cedar Grove, NJ 07009 Phone: 1.800.891.0707 or 1.973.239.1035 Fax: 973.857.5044 - *Respect Yourself - Protect Yourself: Teens Talk to Teens about Liver Wellness - * Silent Stalker : High Risk Video Hepatitis and Abuse Prevention - * Hepatitis C: Cutting Edge Medical Report - http://www.hepfi.org/

HepCBC: HepCBC has a host of up-to-date vides in its library. Videos may be viewed at the library (541 Herald Street, Victoria BC) or borrowed. HepCBC also has on hand videos of the First Provincial Roundtable, with guest speakers, Dr. Frank Anderson, Dr Stephen Sacks and more, and from the Hepatitis C and Your Rights Workshop. For Library hours, please call (250) 382-7927. To order tapes call (250) 361-4808, or email info@hepcbc.org.

The San Francisco Support Project (HCV Advocate) has fantastic resources available. Please give Alan Franciscus a shout at (415) 978-2400. The Hepatitis C Support Project is the home of the HCV Advocate, a great newsletter. Please visit their site at www.hcvadvocate.org or email them at sfhepcat@pacbell.net.

In the Seattle area: Contact HEP. They can be reached at (206) 732-0311, or email hep@scn.org

"Hepatitis C Video," $39 American Liver Foundation , 1-201-256-2550 or 1-800-223-0179

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 (BAKERSFIELD): Kern Hepatitis Association support groups meet weekly in various Bakersfield locations. For schedule and more information, call 661-323-5000 or 661-834-3196.

CALIFORNIA (BURBANK, LOS ANGELES COUNTY): Hepatitis C Support group meets monthly at Providence St. Joseph Medical Center. For schedule and more information, call 919-767-4162.

CALIFORNIA (LONG BEACH): Let's Talk support group meets at the VA Medical Center, 5901 E. 7th St., Long Beach in the H5 Conference Center. For schedule and more information, call Back to Life at 949-654-4250.

CALIFORNIA (LOS ANGELES): American Liver Foundation support groups meet monthly. For locations,

schedule and more information, call the American Liver Foundation, Greater Los Angeles Chapter at 310-670-4624

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 (OJAI): Hepatitis C Support group meets the 4th Tuesday of each month at the Little House. For schedule and more information, call Back to Life at 805-692-2860

CALIFORNIA (ORANGE COUNTY): Back to Life support group meets at the UCI Medical Center, 101 City Drive, Orange in the Associates Conference Room. For schedule and more information, call 949-654-4250 or toll-free in California 1-888-85LIVER.

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): Hepatitis C Support Project. Contact Alan Franciscus, (415) 978-2400. The Hepatitis C Support Project is the home of the HCV Advocate, a great newsletter. Please visit their site at www.hcvadvocate.org or email them at sfhepcat@pacbell.net.

CALIFORNIA (SAN FRANCISCO): HAAC: Hepatitis C Action & Advocacy Coalition. A group of independent committed heppers who haven't copped out. If you want to change things and get involved with the politics of HCV, this is the place to call. (415) 863-5172. Email: haac_sf@hotmail.com. Contact: Brian Klein.

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

CALIFORNIA (SANTA BARBARA): Back to Life Santa Barbara support group meets monthly. For schedule and more information, call 805-692-2860.

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

CALIFORNIA (SANTA MARIA): Hepatitis C Support groups meets the 1st Tuesday of each month in Santa Maria. For schedule and more information, call Back to Life at 805-692-2860.

CALIFORNIA (VENTURA COUNTY): Living with Hepatitis support group meets monthly in Ventura. For schedule and more information, call 805-524-5438.

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.)

CALIFORNIA (YUBA CITY): Hepatitis C Support group meeting the 3rd Monday of each month at the Glad Tidings Church. For schedule and more information, call 530-671-5644.

COLORADO: (COLORADO SPRINGS): Health Learning Center, 1644 Medical Center Point, 3rd Thursday, 7-8:30pm; (719)528-5575 Jane; (719)598-3771 Sharon; or Lance at william@divide.net.

COLORADO: (DENVER): 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: (WHEAT RIDGE): 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, 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, 3rd Tues/mo, 7pm, St. Alphonsus Medical Center, 1055 N. Curtis Rd. Chickee Helms @ 208-382-6400.

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, Prairie 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

Maryland (Frederick) Living With Hepatitis Support Group, Frederick County Health Department, 350 Montevue Lane, entrance C, 7-8:30pm. Tel 301-694-0245. Geraldine Frank, Facilitator, tfrice@erols.com. Meets 4th Thur./ month (except for June, July, Aug. Nov. & Dec.)

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.

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

MINNESOTA (Minneapolis/St. Paul): Liverhope Support Group. Meetings are the 2nd and 4th Tuesday each month 7-9 PM Shepard of the Hills Lutheran Church 3920 North Victoria Street Shoreview, Minnesota 1/2 mile north of I-694 on the Victoria St. exit. LiverHope too Education Group Education for the newly diagnosed. Meetings are the 3rd Sunday each month 7-9 PM 901 Meadowwood Drive Brooklyn Park, Minnesota. http://www.liverhope.com/, Voice mail: (763) 780-0108 Pat Buchanan (763) 566-3839 pat@liverhope.com Helen Clark (952) 933-0932 helen@liverhope.com

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 JERSEY (Summit): Union County, NJ, Support Group Meets last Friday of every month (7:30PM) Overlook Hospital, Conference Rm #2 Summit, NJ contact: susie@hepcesn.net. Also: Hepatitis C Education & Support Network, Inc. Focus on educating the public, promoting awareness and supporting people with HCV Toll-free Support Line (1-888-437-2376) hepcesn@hepcesn.net

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.

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 (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 (PASCO): Hepatitis Support Group. Our Lady of Lourdes Hospital, Pasco, WA held in the Carondelet Room right next to the cafeteria Second Wednesday of every month - 6:30 to 7:30. Contact Person: Cindy Purdin - 509/545-6338. thebreezeone@earthlink.net.

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: (SEATTLE) Washington State, Hepatitis Education Project. Resource Center located at 4603 Aurora Avenue North, Seattle, WA 98103-6513. Local phone number for Seattle area: 206-732-0311, toll free 1-800-218-6932. Sponsors 20 support groups across the state of Washington, call Resource Center for locations. Web site: http://www.scn.org/health/hepatitis, email hep@scn.org.

WASHINGTON STATE: (VANCOUVER). 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.

WISCONSIN (MILWAUKEE): American Liver Foundation support group, Wisconsin Chapter, 710 W. Oregon Street, #7, Milwaukee, WI 53204. For more information, contact Deborah Larkins at (414) 257-7477.

APPENDIX A:

WHERE TO GET THE CURRENT VERSION OF THIS FAQ

E-Mail : send a message to Peppermint Patti at clotho@bellatlantic.net, or to C.D. Mazoff at squeeky@pacificcoast.net and say "Send me the FAQ please!"

http://members.bellatlantic.net/~clotho

http://www.geocities.com/HotSprings/5670/

http://members.rogers.com/smking/

www.hepcbc.org Includes Spanish Version

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, e.g., 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, D, 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/~clotho
HepCAN: http://groups.yahoo.com/group/hepcan
HepCBC: www.hepcbc.org, Email: info@hepcbc.org
HCV Advocate: www.hcvadvocate.org
Hepatitis Education Project: www.scn.org/health/hepatitis
American Journal of Gastroenterology: http://www-east.elsevier.com/ajg/
British Medical Journal: Search All Issues: http://www.bmj.com/all.shtml
Hepatic Pathology Index: http://www-medlib.med.utah.edu/WebPath/LIVEHTML/LIVERIDX.html
Hepatology: Search Abstracts
HIV and Hepatitis.Com: www.hivandhepatitis.com
Journal of the American Medical Association: http://jama.ama-assn.org/
Mescape Hepatitis C Resource Centre:
http://gastroenterology.medscape.com/Medscape/features/ResourceCenter/HepC/public/RC-index-HepC.html
New England Journal of Medicine: http://www.nejm.org/content/index.asp
PovNet: http://www.web.net/povnet/
Reuters Health Information: http://www.reutershealth.com/
Ask Emaliss - Hepatitis Info Support: http://www.askemilyss.com/
The Hepatitis Foundation International Online (NJ): http://www.hepfi.org/
Scotty (the.Reezer) Warren's Hepatitis HomePage: http://tinpan.fortunecity.com/floyd/587/index.html
The Hepatitis Information Network: http://www.hepnet.com
The Canadian Liver Foundation: http://www.liver.ca
"Sandi's Crusade Against Hepatitis C": http://members.rogers.com/smking/
Melissa Palmer, MD, a Hepatologist in New York: http://www.liverdisease.com/
UNOS Website (Transplant): http://www.patients.unos.org/tpd/frm_info.asp?org=LI&tab1=info
CenterWatch Clinical Trials Listing Service: http://www.centerwatch.com
RxList - The Internet Drug Index: http://www.rxlist.com
Schering-Plough (manufacturers of Intron-a): http://www.hep-help.com
Hepatitis Weekly: http://www.newsrx.com/home/main.asp?wasp=03x1mb0852g9vldbb2e7
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://www.aasld.org
American Liver Foundation (ALF) Homepage: http://www.liverfoundation.org
Health Care Information Resources: http://www-hsl.mcmaster.ca/tomflem/top.html
RxMed: http://www.rxmed.com/rxmed/a.home.html
Merck Manual

Natural Pharmacist
PovNet A great Canadian Resource site for disability and human rights issues
http://www.transplant.bc.ca/links.html
http://www.objectivemedicine.com
www.hepcassoc.org.
Medline Plus: http://www.nlm.nih.gov/medlineplus/hepatitisc.html
Alternative Medline: http://www.nlm.nih.gov/medlineplus/alternativemedicine.html

Oh yes: and if you go to this site, http://home.pacbell.net/pwstern/quilt/, you can see the HepC quilt.

APPENDIX D – A List of Canadian Doctors Specializing in the treatment of HCV (Special thanks to Joan King of HepCBC and Eileen Caldwell-Martin of the FQHC for this)

ALBERTA

Calgary

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APPENDIX E: History of Blood Safety, Canada's Track Record, and Compensation Issues

1940's - Late in the 1940's a study was released warning of the greatly increased dangers of Post Transfusion Infection (PTI) with hepatitis in commercially purchased blood and blood sourced from prisons.

They determined this by using elevated bilirubin levels to detect the hepatitis. This is a surrogate test.

1955 - Dr.'s Worblewski and Ladue publish extensive paper on PTI hepatitis using elevated ALT and AST values. Surrogate testing.

Test to detect hepatitis B is developed. Surrogate testing shows that PTI of hepatitis is still present and it is called Non B hepatitis.
Test to detect hepatitis A is developed and surrogate testing confirms that there is still PTI of hepatitis. There are now three classes of hepatitis: A, B and NonA NonB or NANB. PTI of NANB hepatitis turns out to be a collection of viruses of which hep C comprises 90%.

1965 - West Germany adopts surrogate testing (testing for elevated ALT and AST levels) to screen out hepatitis NonA Non B from their blood systems. Other European countries follow suit over the next 15 years.

1971 - The Canadian Red Cross bans use of prison blood. (this is significant when you read about "clause 32," Continental Pharmaceuticals in Montreal, and the USA prison blood).

1974/75 - Term hepatitis C first coined by Prince but was quickly discarded because they soon realized it consisted of more than one virus.

1979 - Canadian Medical Association journal publishes complete instruction guide on how to use surrogate testing to detect PTI of NANB hepatitis.

1981 - Such world experts in virology as Dr. Harvey J. Alter push for surrogate testing on all blood products in the U.S.A. and while the authorities drag their feet some centers like the New York blood center adopt screening on their own.

1985 - In the spring of 1985 the federal government licensed as an anti-hemophilia agent a product called Haemate P. It was heat treated using the "wet method" which killed both enveloped and non-enveloped viruses and was for treating both hemophilia A (factor VIII) and vonwillebrands disease (vonwillebrand factor and factor VIII). This product sat on the shelves. It does not show up in Nova Scotia until 1992-93 and I didn't hear about until the spring of 96 after I was told I was infected. Sadly I know a young man who was diagnosed with hemophilia A in the fall of 86 over a year after this product was licensed but the Nova Scotia medical profession responsible for his treatment put him on untreated cryo-precipitate for the first four years of his life with the result that he has chronic hepatitis C—when there was no need whatsoever.

1986 - With a supply of HIV tested product in their possession, but unable to get anybody to guarantee payment to cover the cost of destroying the untested dangerous product they have in stock, the Canadian Red Cross puts the untested product in the front to be used before the safer product will be dispensed. I add this HIV incident to the hep C story to illustrate how, in my opinion, little things have changed.

1986 - The U.S.A. becomes the latest and the last of the industrialized nations to adopt surrogate testing to screen their blood supply for NANB hepatitis. Canada joins Spain and Japan in refusing their citizens this extra measure of safety.

1988 - Tests by Harvey J. Alter show PTI of hepatitis NANB to be twice as high in Canada as in the United States despite the USA's use of commercially purchased blood.

1992 - A test for the Hep C virus is introduced. Prior to this they were looking for surface antigens and or antibodies to the disease to detect it in blood. Both of these are surrogate tests in that they use the presence of something other than the virus in to diagnose hep C.

1992/93 - Hamate P is finally introduced into the treatment plan for Nova Scotian vonwillebrands disease carriers. Despite being licensed in 1985 as an anti-hemophilia treatment, young Nova Scotian hemophiliacs born and diagnosed well after the spring 85 date have been kept on Cryoprecipitate, resulting in PTI of hepatitis C.

Nov. 1996 - The first law suit against the Federal Government, The Nova Scotia Government and the Red Cross is launched in Halifax Nova Scotia by five individuals including young hemophiliacs kept on Cryoprecipitate when haemate P was available.

1997 – The Krever Report is published. In it Justice Horace Krever recommends compensation for all victims of tainted blood in Canada, without prejudice. The report is ignored.

1998 – Then Justice Minister Allan Rock announces a compensation package which excludes pre 86 and post 90 people and is riddled with clauses that require the victims to accept all responsibility for the package while forgiving all past and future wrong doings by the government and its agencies. The process involved in filing a claim is so complicated that it exhausts and confuses the victims.
Class Action lawyers suddenly appear and the victims vanish. The lawyers come out from behind closed doors with a package that will enrich them by $50,000,000 plus. Payment to the lawyers occurs well before any victim sees a penny.

Spring 1999 - National convention on CJD infected blood products is held in Toronto. Federal Department of health decides to re-release the contaminated products, despite the World Health Organization's recommendations of 1998.

Summer 1999 Canadian Blood Services CBS tells people that they may have to pay for safer blood products out of their own pockets

Summer of 1999 Canadian Blood Services request permission to be added to the lengthy list of allowed to dip from the Hep C compensation pool. Seems everybody except the victims with Hep C are in the pool.

Aug. 18, 1999 despite the above (spring 1999) Canadian government states that that the blood system is as safe as can be.

To protect ourselves from a lawsuit, we could not go into further detail here about these shocking matters. If you wish to find out more about the issues of government cover-ups and the trade in prison blood, please email Bruce DeVenne at bdevenne@sprint.ca.

COMPENSATION IN CANADA
(Thanks to Smilin' Sandi for this list: http://members.rogers.com/smking/*tainted.html*

Hepatitis C Class Action Suit Line: 1-800-229-LEAD
Health Canada Compensation Line: 1-888-780-1111
Canadian Red Cross Information Line: Lookback programs 1-800-668-2866 for Canada; Lookback B.C. call 1-888-770-4800
Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056
Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362
RCMP Blood Probe 1-888-530-1111 TIPS. Or, 345 Harry Walker Parkway, South Newmarket, Ontario L3Y 8P6 Fax: (905) 953-7747

Pre 86 / Post 90 (before 1986 and after June 30,1990) http://www.pre86hepc.com/
British Columbia:
Contact Klein Lyons in Vancouver (604-874-7171 or fax: 604-874-7180) 1-800-468-4466. www.kleinlyons.com/pages/class_actions/Hepatitis_C.htm

Ontario:
The Ontario Hepatitis C Assistance Plan: Application for Compensation for Ontario residents 1-877-222-4977, In Toronto (416) 327-0539, 1-877-434-0944
Canadian Red Cross Registration Line for Transfusion Claimants prior to 1986 and after 1990. Call 1-800-563-2387 (Ernst & Young Law Office) for a claims package

Quebec:
Contact Lauzon Belanger S.E.N.C. www.lauzonbelanger.qc.ca.
Red Cross Compensation Registration. New phone # effective Oct. 10, 2001 in Montreal. 1-888-840-5764

Other provinces, contact Goodman and Carr LLP at pre86hepc@goodmancarr.com www.goodmancarr.com.

1986-1990 (January 1, 1986 - July 1, 1990)
Hepatitis C Class Actions Settlement 6/15/99 http://www.hepc8690.ca/

APPENDIX F: The Double Challenge of HIV/HCV Co-infection

By Brian D. Klein, MA, LMSW
Hepatitis C Action & Advocacy Coalition
For the ACT-UP Golden Gate Writers Pool

Approximately 40% of people living with HIV are co-infected with hepatitis C (HCV). At least twice that rate (80%) has been found among injection drug users and people with hemophilia. Compared to HIV and hepatitis B, HCV is not easily transmitted sexually, but, because of its higher rate of replication, it is much more easily transmitted blood-to-blood. HIV produces billions of new virons (virus particles) each day, while HCV produces trillions daily.

An accelerated rate of HCV progression occurs in people co-infected with both viruses compared to those living with HCV alone. One European study of 547 patients with HCV showed that among the 431 who were HIV-, the average time to development of cirrhosis (nonfunctioning scar tissue) was 23.2 years; for the 116 HIV+ individuals, the average time to cirrhosis was 6.9 years. Co-infected individuals also run an increased risk of developing liver cancer and liver decompensation. Many co-infected individuals are surviving HIV only to die due to HCV complications. These complications are the leading reasons for liver transplants. Fortunately, new information is emerging to better understand and treat HIV/HCV co-infection and to increase survival.

Research from UCSF indicates that when an individual with HIV has a CD4 rate <200 cells/ml, HCV is able to mutate more easily. It gets around the defenses of the weakened immune system and evolves new quasispecies (variants) that can survive and multiply, leading to further disease progression. Other research shows that older age and greater consumption of alcohol also lead to increased fibrosis (early scarring which can lead to cirrhosis) in co-infected individuals.

Progress has been made at U. of Pittsburgh regarding liver transplants in a few co-infected individuals. These people were far along in their HCV disease, but early enough in HIV progression to survive both the surgery and the immune suppressing drugs needed for recovery. Securing funding for this work is due in large part to the work of community activists.

Only a year ago, researchers were debating which disease to treat first—HIV or HCV. People with HIV have higher HCV viral loads than those with HCV alone. Most research suggests that HCV does not affect HIV viral loads or CD4 counts. The consensus is growing that, other things being equal, it is best to get HIV stabilized first, then treat HCV if serious liver disease is seen.

Some HIV medications such as protease inhibitors (PIs), most notably ritonavir and, to a lesser extent, indinavir, are toxic to the liver. Co-infected individuals tend to be more sensitive to this toxicity. Most research shows that co-infected individuals see increased liver enzyme levels for up to several months after beginning HIV treatment. Most can ride it out and tolerate a regimen containing one of the less hepatotoxic PIs. There is evidence that people using a PI tend to slow the rate of liver fibrosis. The reason for this bonus has not yet been explained. If another combination is needed, different non-protease containing combinations can be used, using current HIV treatment guidelines and always looking for combinations likely to be easiest on the liver.

The only way doctors can tell the extent of liver disease is by liver biopsy. Unlike common blood tests for HIV, common HCV blood tests such as viral load and liver enzyme levels (ALT, AST) do not correlate with disease progression. A liver biopsy is an outpatient procedure. The doctor inserts a needle to take a tiny sample of liver tissue to look at. It is actually easier and less painful than it sounds. If the patient does not have any liver inflammation or fibrosis, and all liver enzymes are in normal ranges, just monitoring your status and waiting for better treatments is one viable option to discuss with your doctor.

Studies have examined the response of co-infected individuals to interferon therapy, an immune system modulator, that is the most common treatment for HCV. Interferon is usually self-injected under the skin three times a week. Results have universally shown that getting a "sustained response" (maintenance of HCV viral load below the level of detection 6 months after treatment has ended) is more difficult for co-infected people than for singly HCV infected individuals. CD4 counts can drop significantly during interferon therapy, so this treatment is not recommended for individuals with CD4 counts below 200. Other co-factors that challenge response to treatment include increased age, increased alcohol use, higher baseline viral load, genotype 1a or 1b (the most common variants of HCV in the US), being male, and being African American. We do not know why African-Americans respond more poorly to HCV treatments than other ethnic groups. Higher doses of interferon and/or daily dosing increase sustained response rates, but usually no more than 28% of those studied with genotypes 1a or 1b. Results are somewhat better for other genotypes.

Combination treatments using interferon with ribavirin in co-infected people are being looked at. Ribavirin seems to make interferon work better. Early reports last November from a small ongoing study by Dr. Douglas Dieterich at NYU showed that, after 12 weeks of treatment, 50% of the individuals taking the combination had undetectable HCV viral loads compared with only 9% of the interferon monotherapy group. Laboratory research early on indicated that ribavirin might interfere with zidovudine (AZT) or stavudine (D4T). This has not been a problem with people using these HIV treatments in this study, but more analysis is needed. Half of the participants on the combination developed hemolytic anemia (low red blood cell count), a side effect of ribavirin. Co-infected people tend to be more susceptible to this effect. Either they need other expensive treatments such as Procrit or Epogen (erythropoetin) for the condition or they need the ribavirin dose reduced. Some studies from singly infected individuals indicate that 600-800mg/day of ribavirin (as opposed to the common 1000-1200mg/day) may actually be equally effective and less toxic.

Dr. Bennet Cecil, a clinician and hepatitis researcher with the VA and Hepatitis Treatment Centers, Inc., in Louisville, KY, makes the following comments regarding co-infection treatment and cirrhosis in his experience:

"If a patient has a platelet count below 150,000 or a prolonged prothrombin time they may have cirrhosis. These are simple blood tests that indicate the amount of damage each patient has. They are not perfect but they are very good and I use them every day treating hundreds of hepatitis C patients. I usually start with 600 mg of ribavirin each day and all of my patients do daily interferon because it has fewer side effects (1.5 MU on Intron is easier than 3 MU). Frail patients and cirrhotics usually start with 500,000 units daily of Intron or Roferon. I treat decompensated cirrhotics successfully with low titrated doses of interferon and ribavirin."

Studies are also underway in co-infected people using pegylated interferons. The two versions being studied (Pegasys from Roche, Peg-Intron from Schering-Plough) are designed to be long acting interferons that only have to be injected once a week and, ideally, maintain an even blood level of interferon in the body. Studies are looking at using these drugs +/- ribavirin. These drugs should be available later this year. Most research with them has been done to date in individuals infected with HCV alone. Schering has released little data on their drug yet. Roche has released study results that show Pegasys monotherapy resulted in a 36% sustained response rate vs. 3% for standard interferon. A small Pegasys + ribavirin study in Europe showed an 80% sustained response rate. This is the highest rate shown in any HCV study to date. This looks promising for co-infected individuals as well.

Investigations are underway with a variety of other drugs. Ribozymes are natural enzymes that can be synthesized to selectively inhibit disease-causing proteins by interfering with RNA production. These are being investigated for use in HIV and HCV. Several pharmaceutical companies are also targeting other enzymes important in the life cycle of HCV (protease, helicase, and polymerase) for development of inhibiting drugs.

The goals of HCV treatment are now changing as well. Even if treatments that use interferon do not achieve complete viral suppression or eradication, such treatment should not be labeled a "failure" as these treatments often slow and sometimes reverse the development of fibrosis. The liver is an amazing organ with the ability to regenerate itself unlike other organs of the body. Dr Thierry Poynard, a leading hepatitis researcher, says:

"The true goal of therapy is to reduce the rate of liver fibrosis progression—this may be accomplished even without reducing the HCV viral load—some patients who have a virologic response to treatment even have regression of fibrosis. **The fibrosis progression rate is for HCV what the CD4 count is for HIV infection"**

A health care provider who knows HIV really well doesn't necessarily know HCV. And vice versa! It is important for co-infected individuals to have doctors with expertise in each disease and urge them to talk to each other to coordinate their medical care.

Research in co-infection is slower than for either HIV or HCV alone, as drug companies look to make sure their new treatments work in the least complicated populations first. Patient and treatment advocates need to urge healthcare providers, public health officials, and local drug company representatives to work for more clinical studies and access to treatments for people living with HIV/HCV co-infection.

For current information on viral hepatitis and HIV/AIDS check out www.HIVandHepatitis.com.

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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.

www.hepcbc.org

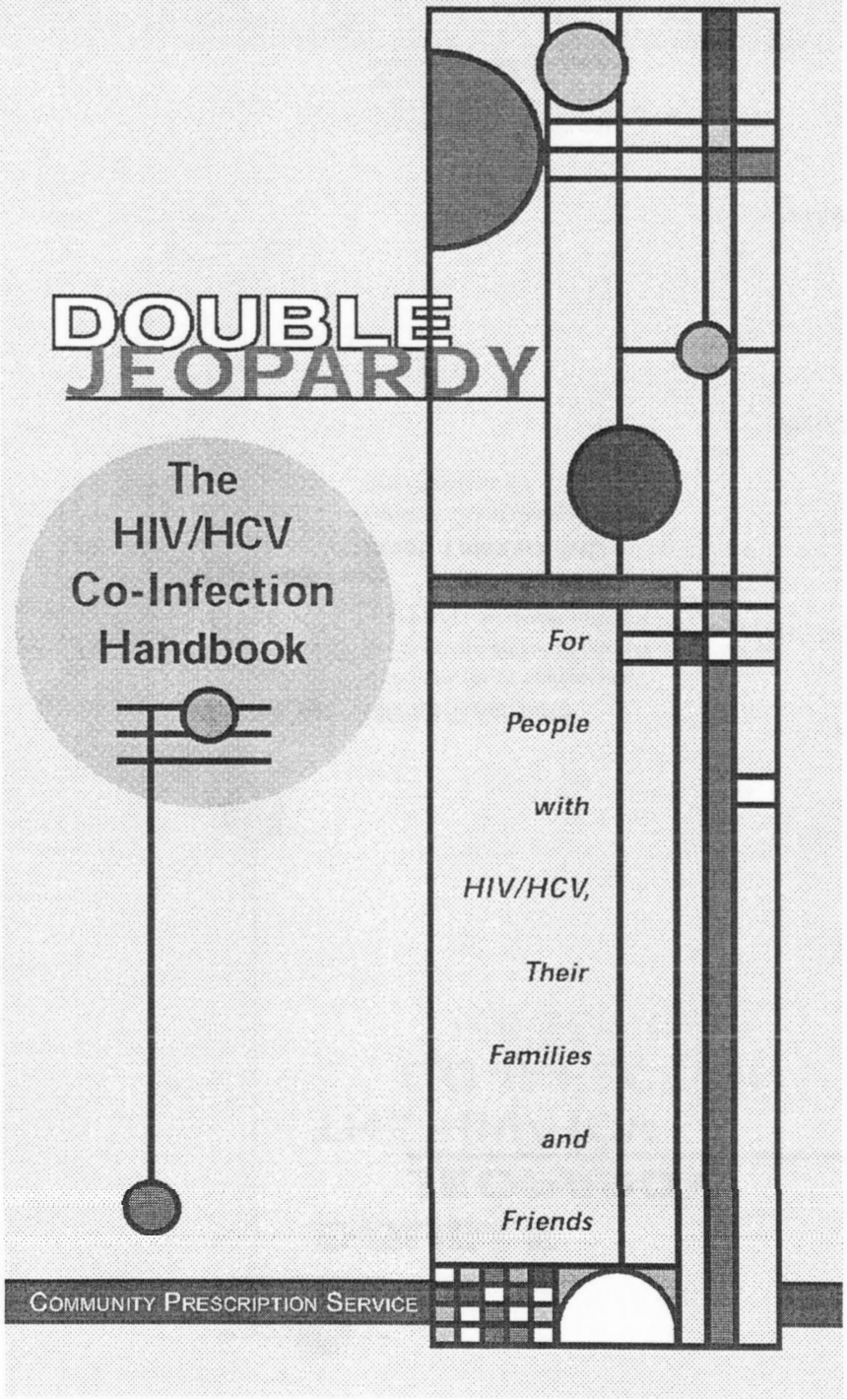
http://members.bellatlantic.net/~clotho

Go soothingly on the greasy mud, for therein lies the skid demon. - Chinese Road Sign

DOUBLE JEOPARDY

The HIV/HCV Co-Infection Handbook

For People with HIV/HCV, Their Families and Friends



COMMUNITY PRESCRIPTION SERVICE

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Welcome

We at Community Prescription Service believe information is key to survival and a better life. This handbook may be a first step towards thinking about treatment for many who read it. As an HIV+ owned and operated pharmacy, we understand the fear you may be feeling as you take that step. Our experienced staff are only a free phone call away. Please don't let fear paralyze you. We can answer treatment questions raised by this handbook, help find you support in your city, and when the time is right for you to begin treatment CPS will be there for you.

800/842-0502.

COMMUNITY PRESCRIPTION SERVICE

DOUBLE JEOPARDY

THE HIV/HCV CO-INFECTION HANDBOOK

For People with HIV/HCV, their Families and Friends

Written by: Lillian Thiemann
CPS Director of Educational Services and Editor of the HIV treatment newsletter InfoPack

in association with
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This educational booklet was made possible by an unrestricted educational grant from
Schering-Plough Corporation

No Need to panic

If you are co-infected with HIV and Hepatitis C you are not alone. There is no need to panic. There are medicines and therapies for HIV that work very well for many patients, and as a result, people live longer today with HIV than they used to. Hepatitis C (HCV) is very slow-developing, long-term chronic disease, and like HIV it can be treated. Many people live 30 years or more with the HCV virus without ever getting sick. Future treatment options for both diseases are being developed.

Just remember: Freaking out never helped anyone get a tough time

You are not alone

One in every 65 Americans is infected with Hepatitis C. That means approximately 4 million—about four times the number of people with HIV.

No one has counted how many people have both HIV and HCV yet, but think about this:
80%-90% of the people who are intravenous drug users (IVDUs), and go into drug abuse programs have HCV. Then imagine all the people you know who are HIV+, and not in treatment for their addiction. They may never have been tested for HCV.

Scientists are beginning to give this group of people the special attention it needs because the number of people who are HIV/HCV co-infected is large and growing.

Who Are the co-infected ?

You may be co-infected:

- **if you have ever shot dope or shared a needle even once;**
- **if anyone you live with, or have ever lived with, has shot drugs;**
- **if you got a blood transfusion or had a transplant (heart, liver, etc.) before 1990;**
- **if you've been pierced or tattooed;**
- **if you are a health care worker.**

Testing is an act of love

> *"Get tested for your own sake!"*

Many people who are HIV/HCV positive, don't know they are infected because they have never been tested. People are getting infected every day because they don't know they are at risk. We all make mistakes—sometimes fatal mistakes. So if you think you might be HIV/HCV positive, get tested. Get tested for your own sake, so you can make the right decisions about treatment, as well as protect yourself and others from infection.

(See Testing on Page 8)

Risky behaviors

HIV and HCV are both blood-borne diseases. That is, they enter the body directly through the blood.

HIV (but not HCV) enters through other bodily fluids, such as vaginal fluid and breast milk. It is much easier to get HCV through the blood than it is to get HIV.

(See HCV is a tough virus on page 6)

Let's Talk about sex

> **"If you don't tell at all, safe, or safer sexual practices will help lower the possibility of infection."**

Sex is a powerful thing. And making choices about how, or if, you'll have sex is taking power in your life. Here are a few tips that will help you make that power your own.

Tell your lovers you are HIV/HCV positive before you have sex with them so they can make their own sexual decisions.

If you didn't tell them before the first time, tell them after. It's not too late. They may not have gotten your HIV, and they probably have not gotten your HCV by having sex with you.

High and low risks

HIV

High Risk

- **Shooting drugs & sharing needles.**
- **Sex—vaginal (pussy), anal (butt) with semen (cum) or vaginal fluid being exchanged.**

Lower Risk

- **Contact with blood at work.**
- **Oral sex—penis in mouth (blow job); semen (cum) in mouth or swallowed; mouth on female genitalia (pussy).**
- **During childbirth—passed from mother to baby (called vertical transmission).**
- **Body piercing, tattooing with unsterilized needles.**
- **Acupuncture done with shared, unsterilized needles.**

HCV

High Risk

- Shooting drugs & sharing needles.
- Body piercing & tattooing with unsterilized needles.
- -- Acupuncture done with shared, unsterilized needles.
- Contact with blood at work.

Lower Risk

- Salon manicures done with shared, unsterilized nail files and scissors.
- Sharing toothbrushes.
- Sharing straws while snorting (sniffing) cocaine.
- If you are HIV+, the risk of you transmitting HCV is greater due to the increased HCV viral loads found in people with HIV.
- Passed from mother to baby during birth. Mothers who are HIV/HCV positive are more likely to pass HCV.
- Breast feeding with cracked or bleeding nipples.

HCV is a tough virus

Unlike HIV, which dies within minutes of hitting the air, HCV can live a long time outside of the body. Any blood that gets on the outside of the syringe, in your cooker, on a tourniquet, the table, or any surface can live for days—even longer.

HCV can live for days outside the body

So even if everyone in the house is not sharing needles, they are at risk for HCV just by living, touching and using things in areas where blood may be.

If, when shooting up at the kitchen table, some blood is dripped or squirted on the table, even if you wipe it up some, HCV will be there waiting for someone with an opening in their skin to come by and pick it up.

(See page 36 for more ways to live safe)

You Try To Do the right thing But Bleaching Needles Doesn't Work

For people who shoot drugs there is an added risk because of outdated information.

We used to think that bleaching needles for two or more minutes would kill any virus.

Many people think that if they swish some bleach around in their works, this is enough to kill any virus.

NOT TRUE

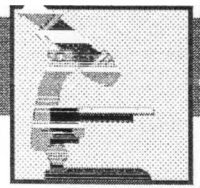
Bleaching needles does *not* do a good job of killing HCV. To kill even HIV, your works have to soak for more than two minutes.

When you are dope-sick, two minutes is a very long time, and many people who think they are waiting long enough are not.

A study on this subject found that 18 seconds is the average time people actually spend soaking their works in bleach.

If you are going to do drugs, there are safer ways to get them into your body

(see page 36)



Testing for HIV and HCV

You probably won't know you have HIV/HCV unless you go for a blood test. When people first become HIV positive they may have flu-like symptoms. But it is easy to mistake the initial HIV infection for the flu. When people get Hepatitis C, they rarely have any symptoms at all until serious liver damage has been done.

A simple blood test (ELISA) that detects antibodies is the first test used to check for both HIV and HCV.

HIV

If the ELISA test for HIV is positive, a Western Blot test should be done to make sure.

If the Western Blot test results are positive, a PCR (viral load) test should be done to measure the amount of HIV virus in the blood.

HCV

If the ELISA test result for HCV is positive, a PCR (viral load) test should be done to measure the amount of virus in your blood.

A RIBA test can also be done to get more detailed information on the level of HCV in the blood.

"Antibodies are cells your body makes in reaction to an infection"

What If It's negative?

If you get a negative test result from your first ELISA antibody test for HCV, but you fall into a high-risk group, testing every 6 months is a good idea. Sometimes, in high-risk groups, the first blood test doesn't find any antibodies because it takes time (sometimes as long as six to eight weeks) for the body to recognize a virus. Or the test may not have been sensitive enough.

So if last night or last week you shared works with someone or had unprotected sex with someone who is HIV/HCV positive or shoots drugs, tell your doctor so he/she can do the right tests to look for the infections.

Two negative antibody tests done over a six-month period (with no high-risk activity during that time) can be considered a true negative.

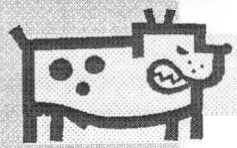
Even though it is very scary to get a test done or to ask someone you care about to have one, it is the best thing to do. The earlier you know, the better. There are more opportunities for successful treatment of HCV if it is caught before your liver is severely damaged.

"If someone tests negative but is in a high-risk group, testing every 6 months is a good idea."

And let's not forget: Sometimes a false positive test result is given by mistake. If in doubt, get another test.

After a positive HIV test:

Find a doctor who has experience with HIV/HCV. Regular blood tests that measure CD4 T-cells and viral load (PCR) are necessary to track how fast your disease is progressing and if the medications you take are working.



CD4 T-cells are the watchdogs of the body

They signal the body's natural fighters (white blood cells) and tell them that they should attack.

Not only the number is important. The percentage of CD4 T-cells is also important, because there are many kinds of T-cells. We need to know how many of the total T-cells are CD4s. In uninfected people, the normal range of T-cells is 450-1200 p/cu.mm with a CD4 percentage of 32%-50%, and there is no viral load at all.

Only when viral load is reduced, is it possible for T-cell counts to go back up to higher levels.

T-cells are considered to be dangerously low when they are below 200.

Standards for viral load change depending on where you live: In the U.S., HIV viral load is considered high when it is over 10,000 copies, but in England the standard is 50,000.

The goal of all treatment is to have a negative viral load.

Because HIV attacks and destroys T-cells turning them into little HIV factories, the number of T-cells goes down.

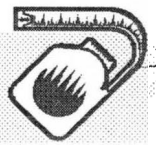
The more virus you have, the faster this happens.

Undetectable viral load test results mean that your virus cannot be found by the PCR blood test used by your doctor. Most PCR tests for HIV cannot measure below 40 copies.

After a positive HCV test:

You and your doctor will have to look after your HCV infection to watch what it does and what damage it is doing to your liver.

> "Regular blood tests are needed to track the disease and see if it changes. To look at the actual damage to your liver as well as its condition, your doctor may want to do a liver biopsy before talking to you about treatment."

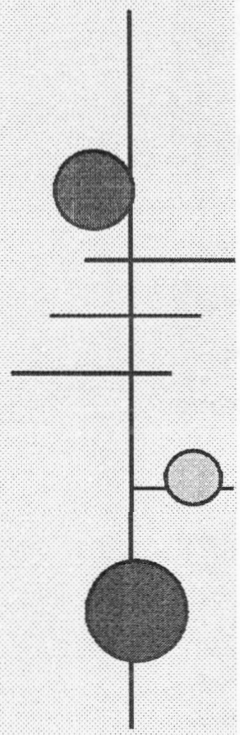


Get your HCV measured regularly

Get a baseline (first test results) reading of your viral load (PCR), but don't get excited if your HCV viral load is a million. What is considered a high viral load in HCV is MUCH higher than in HIV. Depending on the type of test your doctor uses, a score of a million or two is not considered a high viral load. Also get a baseline reading of your liver enzymes (AST, ALT). But remember: These levels can go up to 5-10 times normal without signaling liver damage. These tests will give you a basis for comparison when you get your next test results. The numbers will be helpful when you want to decide on treatment.

A liver biopsy is a test done by inserting a needle into your liver and then taking a small sample out in the needle to be tested under a microscope. Test scores vary depending on the test used, but in one type the results are graded on a scale of 0-4.
0= no damage,
1=mild fibrosis *(scarring)*,
2=medium,
3=bridging
4=cirrhosis fibrosis

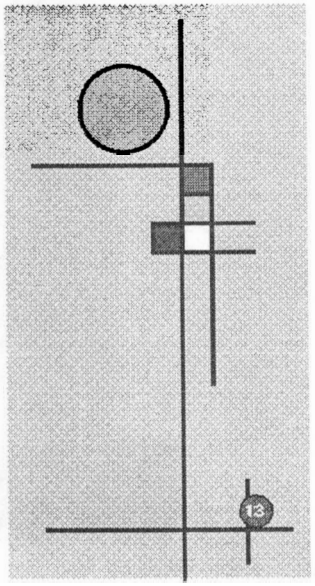
Questions To Ask your doctor if you are HIV/HCV co-infected



Do you have any literature I could look at about the treatment you are recommending?

- Do you have many other co-infected patients?
- Do you keep up-to-date on all the latest changes in treatment?
- Can you refer me to a good liver specialist for my Hepatitis C (HCV)?
- Have you checked to see if I am immune to Hepatitis A and B? Do I need vaccinations for Hepatitis A and B?
- Do you recommend I take medication for my HCV? Which treatment do you recommend, and why?
- Do I need a liver biopsy? If a liver biopsy shows I have fibrosis or cirrhosis would you still prescribe HCV therapy for me? What are the results of my liver biopsy and what does it mean? How will the result effect my treatment?
- Do you exclude patients from interferon treatment because they have some liver scarring? Are you aware that the interferon treatments for HCV have been shown to be of some benefit even when the virus is not totally killed? Do you know that the progression of fibrous scarring in the liver is slowed down by interferon treatment? What are the side effects of these medications?
- What HCV genotype am I? How will that effect my treatment? (some genotypes are harder to treat than others)

- What is my HIV viral load? Was it an ultrasensitive (under 40 copies) test? What's my T-cell count? What is my T-cell percentage? What is my Hepatitis C viral load? What are my liver enzyme (ALT, AST) levels? Can you show me where they are on this blood test? Will you make me a copy of my blood test results every time I get them done?
- Is the HIV I have a drug-resistant virus? Can you get me genotypic/phenotypic tests to see if I have drug-resistant virus? Can you read these types of results accurately? If not, will you send me to a doctor who can?
- Do you recommend I take medications for my HIV? What combination of drugs would you recommend, and why? What are the possible side effects of these medications? How often are they taken and how? How many pills are in this combination? Are they taken with or without food, or does it matter? Can I speak to someone who is on this combination? Can we talk about my lifestyle when making treatment decisions? Do any of the drugs you are prescribing interact with my other medications, such as methadone? Do you believe in saving protease inhibitors for later or not? How will I know if these drugs are working for me? Should I be taking vitamins too?
- Have you tested me for TB or other opportunistic diseases?
- Do you believe in herbal and alternative medicine? Acupuncture? Can you refer me to a good acupuncture person in my area? Can you refer me to a nutritionist? Can you refer me to a social worker or organization that can help me get better food & shelter?



HIV or AIDS?

If you have been HIV positive for awhile and your T-cell count is stable—meaning that your T-cell count has been the same number for some time; and if your HIV viral load is low/moderate and you have no symptoms of illness, then you don't have to decide anything about treatment today.

The HIV drugs on the market today will not cure you. If your doctor says, "The sooner you take something, the longer you are going to live." He may or may not be right.

HIV becomes AIDS only when your T-cell count gets very low (below 200) or you start getting the diseases (opportunistic infections, OIs) that come when your immune system is very weak. Your doctor should check for them.

Take your time

Talk to people, get more information and then you will be more able to make a treatment decision you can live with.

Some common opportunistic infections (OIs) are:

PCP: pneumonia, a lung infection;

MAC: a bacterial infection related to TB in the blood;

Kaposi's Sarcoma (KS): type of cancer affecting the skin and organs;

Displasia and other gynecological conditions in women: pre-cancerous sores or cancer on cervix or uterus;

CMV: a herpes-type virus that in most cases causes blindness but can also affect other areas of the body;

Tuberculosis (TB): A bacterial infection of the lungs that causes wasting and is signaled by coughing up of blood.

Co-Infection— hard and fast

If you are HIV positive, your HCV infection gets worse faster then if you have HCV alone.

The HCV virus in an HIV positive person multiplies faster than in an HIV negative person.

HCV does not make your HIV virus multiply faster than it does on its own.

But when HCV badly damages the liver,

it is hard for the body to absorb HIV medicines. If your body cannot absorb the HIV medicine, then your HIV viral load has a chance to grow because the drugs won't work for you.

People get worse side effects from their HIV medications when they are co-infected with HCV.

People on HIV medications who are experiencing fat changes in their bodies (protease paunch, buffalo hump) have higher fat in their livers.

Some HIV drugs don't mix well with some HCV drugs, street drugs or methadone. *(See page 24 & 25 for drug interactions.)*

"Lowering your Hepatitis C (HCV) viral load and AST/ALT levels takes some of the strain off your liver and makes the possibility of effective HIV treatment more likely."

Pay Attention to your liver health

It's important that you get a doctor who knows a lot about HIV/HCV and all the treatments for both. Policy is in place that excludes HIV positive people from getting on the transplant lists for new livers. There are not enough livers to go around. Over 9000 people, who were not HIV positive, died in 1998 waiting for livers.

The best strategy is to try not to get sick so that you don't need one.

Your liver is a giant filter

and much, much more

- *Every thing you eat, drink, breathe and inject passes through and is filtered by your liver.*
- *Toxic substances like street drugs, alcohol, paint and chemical fumes, some HIV drugs and chemicals in food put a strain on your liver.*
- *Your liver makes proteins to make muscle.*
- *Your liver makes clotting factor, so if you're cut it will stop bleeding.*
- *Your liver stores energy for later use when you need it.*
- *Your liver makes bile, so you can absorb vitamins and other nutrients better.*
- *Your liver makes immune factors to protect you from infection.*
- *Your liver helps detoxify your HIV medications so you can get the most out of them to fight HIV.*

You can't survive without a working liver, so taking care of it makes sense.

Is Your Liver working too hard?

You can tell your liver is working too hard by how you feel

If you take HIV medicines that are working for you, and your liver is not too damaged, the primary symptom of HIV/HCV co-infection is extreme fatigue.

The higher the enzyme level measured by a (ALT, AST) blood test and Hepatitis C (HCV) viral load, the greater the possibility that damage is being done to the liver.

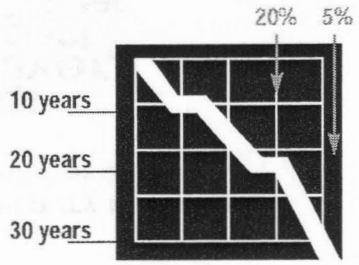
"But there is an exception to every rule: Sometimes in people with very damaged livers, the liver enzymes are very low because the liver is so damaged it can't even make them anymore."

Liver damage control

The road of liver damage is all downhill unless something is done to stop or slow down your progress. Lifestyle changes (such as sobriety, good nutrition, relaxation and stress reduction, moderate exercise), HCV drug therapy, alternative or complementary therapies (acupuncture and herbs) and vaccinations against Hepatitis A and B can slow down or stop your liver damage. *(See pages 30-35)*

Liver damage chart

"If you don't put on the brakes with some or all of the above this is what you have to look forward to:"



- from date of infection to inflammation is immediate
- to fibrosis in 10 years
- 20% will develop cirrhosis in 20 year
- 5% to cancer in 30 years

If you stop drinking alcohol, you will be doing your liver the biggest favor of your life.

Defining liver damage

Inflammation is a condition caused by an insult to the liver (HCV, alcohol, chemicals, etc.) that causes it to get red, swell, heat up and possibly become painful.

Fibrosis is the scar tissue that forms in the liver after it has been inflamed for awhile.

Cirrhosis is what happens when the liver has been inflamed and has been forming fibrosis (scarring) for a long time. At this stage, the inability of the liver to work well filtering blood is due to the loss of liver cells and scarring that blocks blood flow between the cells.

Cancer is the end product of years of inflammation, fibrosis and cirrhosis. Surgery to remove tumors does not extend life for long.

As you can see, liver damage is a process that you have some power to control. How fast you go from HCV infection through this process is in many cases up to you.

Many people successfully make changes that help them to live longer, healthier lives. So Can You!

or changing treatments for: Hepatitis C

If HCV virus is killed off for good (eradicated) as a result of taking this treatment, will I live longer?

If my liver improves as a result of taking this treatment, will I live longer?

More questions to ask your doctor, based on the answers to the questions on page 12 and 13:

- Why should I start HCV antiviral therapy now?
- What are my chances to totally kill (eradicate) all the HCV in my body and keep it away?
- Are there any other reasons to treat my HCV disease besides killing the virus? Even if the virus isn't totally killed off, will this treatment help my liver stay healthy longer?
- What HCV treatment do you recommend, and why? Are there any other treatments that are as good at killing the HCV and keeping it away? How long do I have to take this treatment? How will we know if it is working? How long do we have to wait before we know if the HCV is gone for good?
- How do I take the treatment you are recommending? Is it an injection, pills or both? How often do I take it?
- What are the possible side effects? Are there medications to take or things I can do to help me if I get side effects?
- Can I take this treatment with medications for my other diseases? Is this treatment OK to take with protease inhibitors?

HIV

- Does the combination of medicines you are recommending leave me any future combinations to take? How many options does it leave?
- What side effects can I expect from this combination of drugs? Do other drug combinations have fewer side effects?
- How often do I need to take these drugs? Are there other combinations with simpler dosing schedules?

- Do I have to change how and when I eat to take this combination? In what way must my diet change?
- How does this combination interact with the other drugs I take for other diseases? Are there any drugs I can't take if I'm on this combination?

(See drug interactions page 24)

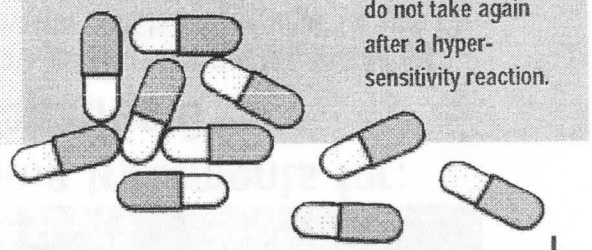
- Can I take birth control pills or get pregnant safely while taking this combination?
- Will this combination be hard on my liver? Is there a combo that is easier on my liver?

Do I need to treat my Hepatitis C before I start on HIV drugs?

HIV drug chart

NUCLEOSIDES REVERSE TRANSCRIPTASE INHIBITORS (NUKES)

Drug	*Adult Dosing*	*Side Effects*
Retrovir (AZT)	2 x 100mg capsules 3x/day or 1 x 300 mg tablet 2x/day	nausea, headache sleeplessness
Combivir (AZT/3TC)	1 x 150mg/300mg tablet 2x/day	headache, nausea, sleeplessness
Epivir (3TC)	1 x 150mg tablet 2x/day	minimal
Zerit (d4T)	1 x 40mg capsule 2x/day	neuropathy
Hivid (ddC)	1 x .75mg tablet 3x/day; should not be used with Videx.	neuropathy
Videx (ddI)	2 x 100mg tablets 2x/day or 4 x 100mg tablets 1x/day; taken on empty stomach.	pancreatitis, neuropathy diarrhea, nausea
Ziagen	1 x 300mg tablet 2x/day	nausea, vomiting, fatigue, headache; do not take again after a hyper-sensitivity reaction.



PROTEASE INHIBITOR (Fat abnormalities for all?)
(PIs)

Drug	*Adult Dosing*	*Side Effects*
Crixivan	2 x 400mg capsules every 8 hrs.; food restrictions (no food 1 hr. before or 1 hr. after and drink at least 1.5 liters of liquid daily.	kidney stones, nausea
Invirase	3 x 200 mg hard gel capsules 3x/day; take with food in stomach.	nausea, diarrhea
Viracept	3 x 250mg tablets 3x/day or 5 x 250mg tablets 2x/day; take with meal or light snack.	diarrhea
Norvir	7.5ml solution 2x/day; take with food.	diarrhea nausea, vomiting,
Fortovase	6 x 200mg soft gel capsules 3x/day; take within 2 hours of a full meal.	nausea, headache, diarrhea

NON-NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS
(NNRTIs)

Viramune	1 x 200mg tablet 2x/day; lead in first 2 weeks: 1 x 200mg 1x/day.	rash
Rescriptor	4 x 100mg tablets 3x/day; at least 1 hr. apart from Videx.	rash, headache
Sustiva	3 x 200 mg capsules 1x day	disorientation, rash, nightmares

Drug interactions

Alcohol and Videx (ddI) don't mix and can bring on severe stomach pain caused by pancreatitis. If you are using alcohol regularly, choose another nucleoside.

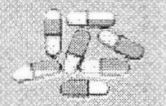
Cocaine stimulates HIV to make copies of itself 20 times faster than usual.

Marijuana: Protease inhibitors may increase THC levels (the active ingredient in marijuana) so a smaller intake of pot may get you just as high.

Heroin: The protease inhibitor Norvir may reduce heroin levels by half.

Amphetamines (Speed, Crystal) and Ecstacy: Norvir is thought to increase amphetamine levels in the blood 2 to 3 times normal.

AZT taken with ribavirin can cause anemia



Protease inhibitors are hard on the liver. Crixivan and Norvir are the greatest offenders.

⚠ *Sedatives: Halcion, Valium, Ambien, and Versed can be deadly if mixed with protease inhibitors with Norvir being the worst offender. Serax and Restoril are safer sedatives to use with Norvir.*

⚠ **Barbiturates: Crixivan may increase blood levels of phenobarbitol (Luminal), Seconal, Tuinal and all other barbiturates so an overdose is more likely.**

interactions

Raise methadone levels by 30%

Ketaconazole (Nizoral) and Fluconazole *(fungal medicines)*
Elavil and Luvox *(antidepressants)*
Valium, Halcion, and Xanax *(anti-anxiety drugs)*

Can raise methadone levels:

Tagamet *(for ulcers and acid stomach)*
Bicitra and Polycitra *(for gout and kidney stones)*

can decrease methadone levels

Rifampin and Rifabutin *(TB drugs)both decrease the level of methadone in the body. Rifampin cuts methadone by 50%, but Rifabutin's effect on methadone is less severe.*
Tegretol and Dilantin *(anti-seizure drugs)*
Viramune *(for HIV)*
Vitamin C *taken in very large amounts can reduce methadone levels.*

With these drugs it can and does go either way:

Norvir *(protease inhibitor) increases the strength of methadone in the test tube, but in real life may decrease it's strength. So if you are on Norvir and your dose of methadone is not holding you, ask for an increase.*
Crixivan *(protease inhibitor) has the same story as Norvir, only less so.*
Alcohol *used regularly first increases but later lessens the effect of methadone.*

Methadone raises the potency of AZT 50%. This means you can take half as much AZT as someone who is not on methadone and get the same HIV-fighting effect. If you are having bad side effects from AZT, it may be you need to cut your dose. Ask your doctor.

Interferon drug therapy for HCV

The current "standard of care" therapy for the treatment of HCV is Rebetron. ("Standard of care" means that a therapy is seen to be the most effective and is prescribed first unless there is a reason not to.)

results

In three large groups of HCV+ people tested (drug trials), one of which was done on people who had relapsed after taking interferon by itself, greatly improved results were seen. On average, 45% of the people who took the Rebetron combination therapy and reached undetectable viral levels (no virus could be found in their blood using a PCR test) stayed that way. When their blood was tested by PCR, six months after the treatment was stopped, no virus could be found.

In another trial of HCV+ people (1744 people) who had never taken any interferon (interferon naive), 41% were cleared of virus in their blood for good after completing Rebetron therapy.

These tests were not done in co-infected people. The benefit of this treatment for HIV/HCVco-infected people is not known because drug trials for co-infected people have not been completed yet, but a lower percentage of eradication is expected.

Combination therapy for HCV

Rebetron

made by Schering-Plough, *is a combination of Intron A (interferon alfa-2b) and ribavirin in the same package:*

Drug	*Adult Dosing*
Intron A	3 MIU (Million Units) subcutaneous (skin-pop) injection 3X a week
	plus
Rebetrol	is in pill form, and you take 1000-1200 milligrams per day depending on how heavy you are. Anyone under 165 lbs. takes 1000 mg. per day, over 165 lbs. takes 1200 mg. Pills are taken twice a day (BID).

Combination therapy has a higher percentage of eradication (killing the virus for good) than monotherapy, but the side effects are more intense using the combo.

> "Women should never take ribavirin when pregnant, and not for six months after the treatment stops"

Pregnancy is not recommended while on interferon.

Interferon used alone in monotherapy

Drug	*Adult Dosing*	*Side Effects*
Intron A *(interferon alfa-2b)* is made by Schering-Plough,	3 MIU three times a week and taken by a subcutaneous injection (skin-pop, shot).	
Infergen *(alfacon-1)* is made by Amgen	9 mcg three times a week and taken by a subcutaneous injection.	
Roferon-A *(interferon alfa-2a)* is made by Roche	3 MIU three times a week and taken by a subcutaneous injection.	

Used alone, all the interferons have similar antiviral benefit while you use them, and a similar percentage (8-15%) of people remained free of virus after completing the treatment. The benefit that delays the progression of liver fibrosis is also similar among the interferons.

> "Alert your doctor to any severe side effects or unusual illness while taking interferon"

Immune diseases such as arthritis may get worse when taking interferon.

HCV Drugs in trial

A new way of delivering interferon into your body is being developed by companies who make interferon. What is called a pegalated form of interferon will be a time-released, longer-acting drug, so you will only have to have one injection per week. There are reports of reduced side effects too.

New

PEG-INTRON *(Schering-Plough)* **and Pegasus** *(Roche)* are two drugs of this type that are close to applying for FDA *(Food and Drug Administration)* approval.

> Helicase inhibitors are being studied for use against HCV. They are enzymes that attach themselves to key areas on the cell so it can't reproduce.

Also in development is Interferon Alfa-n3; a new type of interferon that is being studied in HIV/HCV co-infected people.

Drug trial and Expanded Access Program Information

Company	*Product*	*Phone Number*
Schering-Plough	Intron A, Rebetron	800/526-4099
Amgen Inc.	Infergen	888/508-8088
Roche Laboratories	Roferon-A	800/526-6367
Interferon Sciences, Inc.	Alferon	732/249-3250

(All of the above have on going co-infection trials.)

Alternative or complementary therapies

Alternative therapies are ones people choose in place of FDA approved drug therapies. Complementary therapies are ones that are used along with drug therapy.

Chinese Medicine

Acupuncture is an age-old therapy done by a certified acupuncturist who inserts very fine needles in the skin. This treatment is done repeatedly over time so that healing can take place. Proven to be effective when people are trying to detox from street drugs, it is also a good stress reducer.
Chinese herbs are prescribed by a certified practitioner of Chinese Medicine. The practitioner determines the type of herbs to give you after examining your pulse points, tongue and eyes as well as a discussing your recent symptoms.

> Unfortunately, many alternative treatments cannot be prescribed by a physician and so are not covered by Medicaid or health insurance. Your doctor can prescribe acupuncture, massage, as well as some types of vitamins, and they may be covered.

Resources

AIDS Medicine and Miracles for information and retreats on complementary therapies and the mind, body, spirit connection. Boulder, CO 303/447-8777

Direct AIDS Alternative Information Resource (DAAIR), in NYC, for information about and access to alternative and complementary treatments for HIV/HCV 212/725-6994

Healing Alternatives Foundation (Buyers Club) herbs, vitamins as well as a newsletter and fact sheets. San Francisco,CA 415/626-2316

Groups that help

There are places in cities around the country where you can get help and have some of your questions answered. Some organizations/ support groups for people with HIV/HCV offer 800# hotlines that anyone with questions can call whether you are from that city or not.

HIV/HCV

Community Prescription Service
800/842-0502

Project Inform 800/822-7422

CDC National AIDS Hotline
800/342-2437 (English)

CDC National AIDS Hotline
800/344-7432 (Spanish)

HIV/AIDS Information Service
800/448-0440

Hepatitis Foundation International 800/891-0707

Hepatitis Liver Foundation
800/223-0179

Hep C Connection
800/522-4372

For questions about your treatment rights and HIV/HCV advocacy: The Hepatitis Advocacy and Action Coalition: HAAC/ San Francisco E-mail: HAAC_SF@hotmail.com HAAC/NYC at the PWA Health Group 212/255-0520

Hepatitis A and B

Get a blood test to see if you are already immune to Hepatitis A and B. If you are not immune, vaccinate for your own good.

If you have HIV and HCV, you can not afford another hepatitis infection. As many as 40% of HIV/HCV co-infected people die after being infected with Hepatitis A.

A lot of harm can be done to an already damaged liver if you get a fresh infection of Hepatitis A (HAV) or Hepatitis B (HBV) on top of what you already have.

Hepatitis A

- Hepatitis A (HAV) is spread through oral/anal contact. You get it by putting something in your mouth that is dirty with feces (stool, shit).
- You get it when people who are infected with HAV and do not wash their hands after going to the bathroom, touch your food.
- You get it from unclean infected seafood.
- You can get when visiting countries in the Third World where water is not filtered properly.
- You get it from some types of sex: Rimming (licking butt during sex) someone who has HAV, or having sexual contact with a penis or dildo that has recently been in an HAV infected person's anus (butt).

Symptoms HAV

You may have none, or you may get really sick and turn yellow (jaundice). Other symptoms include: stomach pain, vomiting, nausea, fatigue, fever, dark urine and very light-colored stools.
Children with HAV may have no symptoms, so test for it. Once you have had it, you can't get it again.

Hepatitis B

HBV is 100 times easier to get than HIV.
(HBV can live for weeks in a dried spot of blood)

Approximately 10% of HBV+ people remain chronically infected and can pass the virus to others for life. You can catch Hepatitis B (HBV) by:

Blood

- sharing needles while shooting drugs.
- piercing and tattooing.
- household contact: sharing razors, toothbrushes and nail files.

Sex

- exchanging semen and/or vaginal fluid (cum) with someone who has HBV.

Birth

- HBV positive mother to baby during birth.

Symptoms HBV

You may not feel sick. Some people get mildly sick and feel like they have the flu. Fever, fatigue, dark urine, light stools and turning yellow (jaundice) are all possible symptoms.

Treatment with Epivir, the HIV drug, has met with some limited success against HBV. Combination therapy using Epivir with famcyclovir or gancyclovir may be a better option because becoming resistant to a single drug is very likely when you use it alone. Once you become resistant to a drug, it no longer works for you.

Just for IVDUs

80%-90% of people entering drug abuse treatment have HCV.

32% of all AIDS cases — over 60,000 cases are caused by shooting drugs or by being in contact with someone who shoots drugs.

HIV+ women who have used injection drugs progress to AIDS faster than male IVDUs. They get there with a 38%-65% lower viral load than male IVDUs, and for these women, earlier HIV treatment may be needed.

You can do something else

If you are an addict but not infected yet with any of the infections listed in this booklet, you can remove a lot of the risk from your life by cleaning up your act.

Options
to change your life

- Detox
- Rehab
- 12 step programs
- Methadone Maintenance
- LAMM *(levomethadyl acetate hydrochloride)*
- Support groups
- acupuncture
- spirituality
- therapy

Get Clean
get help

Even If you have every infection you can do yourself a lot of good by getting clean.

Having a place to live where you can rest and eat properly is important. You are more likely to be able to hold on to your house, apartment or room if you are clean.

Trust somebody today

It is hard to work through the health system and life by yourself. If you honestly try to get clean and seek treatment for your drug addiction, people will help you get through it. They will also help you to cope with other parts of your life, health issues included.

> "You will be much more likely to show up at the doctors for your appointment if you don't have to cop first."

There are treatments for HIV/HCV that have a chance for working only if you take them correctly. That means being able to remember to take your pills or injection on time, every time. It means being able to stick with taking your medicines for months (HCV) or years (HIV), a day at a time.

Not Ready
to stop?

If you are not ready to stop shooting drugs there are still thing you can do to reduce the harm you do to yourself and others.

Needle Exchange Programs

have been proven to reduce the number of people getting infected while shooting up. These programs let you trade in old works for new works. Stock up when you can. Make sure the area where you shoot up is clean. (An inside unused section of the newspaper is a clean work surface). Use your own clean works, ties, cooker, cotton and water.

Wash your hands.

Many clinics and needle exchanges provide free condoms, razors and toothbrushes when they have them.

> "*Be sure to use water-based lubricant (like KY or Score) on the condom after putting it on.*"

If you start HIV combination therapy, try not to use street drugs for the first 6-8 weeks. You want to give them time to work before you start using again.

In states where needle exchange is not legal, get a doctor to give you a prescription for needles and syringes. If your doctor will not prescribe for them, find one who will.

Instead of shooting drugs up with a needle, try:

- *Snorting (sniffing)*
- *Smoking (chasing the dragon)*
- *Keestering (inserting them up your butt)*

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