



hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HEALING: ALWAYS POSSIBLE

By Karen Marks, RN, BA

Curing may or may not be possible, but healing is ALWAYS possible.

Does that sound like a rather outrageous claim? Probably not, if you understand the difference between healing and cure. Therapeutic Touch is a complementary modality that offers the possibility of healing at the mental, emotional and spiritual levels, even when a physical cure is not possible. Cure involves the elimination of the signs and symptoms of disease, which may or may not correspond to the end of the person's disease or distress. Healing, on the other hand, may occur without cure. It is multidimensional and can occur at the physical level, but also at other levels of the human system, emotion, mind and spirit. Healing is the emergence of right relationship at any or all levels of the human system. Healing can assist one in living life to the fullest within one's physical limitations. Healing is always possible, even when death is imminent.

Facilitating the process of Therapeutic Touch is a natural potential for human beings who have the intent to help and heal. Anybody can learn to do TT if they really want to! Well accepted by the medical community, TT is firmly rooted in a history of practice and research. Developed by Delores Krieger, RN, PhD, in 1972, along with gifted healer Dora Kunz, Therapeutic Touch is a contemporary interpretation of several ancient healing practices. It is a consciously directed process of energy exchange. The TT practitioner uses his/her hands as a focus for facilitating the healing process, and acts as a support system, re-patterning disrupted energy flow. His/her intent is to enable the re-patterning of energy in the direction of health. The practitioner acts out of compassion, recognizing that there is underlying order in the universe.

Therapeutic Touch, used along with stan-

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NEW HOPE: SCH6

Here is a name to remember: Michael Gale, Jr., PhD. He and his colleagues have solved the question of how HCV, unlike most viruses, becomes a chronic infection. It makes a substance that turns off the anti-virus mechanism in a cell. They also found that protease inhibitors, already in development, can beat this mechanism, permitting the body to get rid of the virus by means of its own natural interferon. With this kind of drug, already used for treatment of AIDS, cells already infected can be cleared in about 5 days. While looking for the solution to the problem, McGill University researchers found a trigger which releases interferon, called IRF-3 (interferon regulatory factor 3), and gave some to Dr. Gale for his studies. Gale was able to find the HCV protein, a protease that blocks the IRF-3. Schering-Plough gave Gale some of their SCH6, a protease inhibitor that they are developing.

Working with SCH6 and HCV genotype 1, the hardest kind to treat, Gale found that he could clear the virus, restoring the cells' capacity to fight off the virus. SCH6 attacks the virus and turns on antiviral immunity. It may make IFN treatments more effective, even with lower doses.

Source: Hepatitis C Achilles Heel Found, By Daniel DeNoon April 17, 2003. Original source: Sciencexpress, April 17, 2003. Michael Gale Jr., PhD

HYPERTHERMIA PLUS PEG INTRON/RIBAVIRIN CLINICAL TRIAL:

WEEK 26/80

by Darlene Morrow
The Hague, Holland

Hi Everyone,

Just a short update: I have not had any news about the liver biopsy or ultrasound. I should hear by September, but I don't expect there to be any startling news.

The good news is I can stay in the study. On week 26 they looked over everyone, and if you hadn't met certain criteria, you were excluded. Two out of the ten are gone.

My bone marrow biopsy was not so good. They found a hematological disease. In 1994, before I had any treatments, I had a bone marrow biopsy done because my white count, red count and platelets were low. At that time they found no iron stores in the marrow, but also gave no conclusion as to why. So it was just left.

This time they found a reason. It is "possible" the disease is caused by the drug treatment, and if that is so, then when I stop taking the medication, it will go away. However, because of the earlier biopsy (and other

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JOHN CROOKS

Our friend and supporter John F. Crooks, a resident of Nanaimo, passed away on July 16, 2003. He was in his early 50s. The son of Elizabeth and Cecil Crooks, he is survived by many friends, a brother and an aunt and uncle. John was a retired government clerk and an avid stamp collector. His wishes were that donations be made in his memory to the Hemophilia Society or to a hepatitis C organization of your choice.

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REPRINTS

Past articles are available at a low cost in hard copy and on CD ROM. For a list of articles and prices, write to HepCBC.

Peppermint Patti's FAQ Version 5.6 Available NOW!!

Peppermint Patti's FAQ Version 5.6 is now available in English and Spanish. The English version includes updated Canadian Links and both include the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only \$5 each, plus S&H—but if you can afford more, we'll take it. Contact HepCBC: (250) 595-3892, info@hepcbc.ca

HepCBC Resource CD: The CD contains back issues of the *hepc.bull* from 1997-2003; the FAQ V5.6; the Advocate's Guide; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. The Resource CD costs \$10, including shipping and handling. Please send cheque or money order to the address on the subscription form on this page.

THANKS!

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CUPID'S CORNER

This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad: Write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to HepCBC, and mail to HepCBC, Attn. Joan, #5-915 Glen Vale Rd, Victoria BC V9A 6N1, (250) 595-3892.

Give us your name, tel. no., and address. To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

Disclaimer: The hepc.bull and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.

AD 24: SWM Hep C+ Never married. No kids, 40's, living in Pt. Alberni: Seeking pen pal (female). Maybe leading toward friendship and good company. Previously incarcerated and wish to leave that kind of lifestyle behind. Good looking, 6 ft. 2 inches, 220 lbs. I enjoy music, mountain biking, conversation, walks. Private school educated.

URGENT: Would the gentleman mentioned in the above ad please contact Joan with his name and address. He has received a reply, and his info was lost in a recent computer crash. Sorry! Responder: Please be patient.

AD 25: SF, Indo-Cdn., 35 years old. 5'7", heavy-set. Hep C+, but I still enjoy life, and try to stay active. I love movies, pets, music, traveling, and reading. I occasionally take self-improvement courses. Searching for SM who is confident, caring, would benefit from my company, and can keep me happy. Richmond.

Ad 26: SWF 33, HepC+, nonsymptomatic. College student, gardener. Interests: camping, country/rock music, concerts, nutrition, tattoos, reading, herbs.. Clean & sober, pretty, sensitive, caring. Looking for guy to correspond with; prefer big guy, strong--possibly relationship later--any age. I'm in the Lower Mainland. Must be drug/alcohol free.

Got Hep C? Single? Visit:

<http://nationalhepatitis-c.org/singles/list.htm>
<http://clubs.yahoo.com/clubs/ontariohepcingles>
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<http://groups.yahoo.com/group/PS-Hep/>



WARNINGS

HRT

The article below appeared in the January 2002 issue of the *hepc.bull*. Please note that hormone replacement therapy has since been revisited. We at the *hepc.bull* do NOT recommend hormone replacement therapy (HRT), due to the recent studies showing increased chance of breast cancer, stroke, and other serious health problems in women taking HRT.

PREGNANCIES, ORAL CONTRACEPTION AND MENOPAUSE

Liver fibrosis progresses faster in males than in females, and it is thought that estrogen may be a factor. This study took into account alcohol and tobacco consumption, the presence of diabetes, age at first menstruation, age at pregnancies with or without children, hormonal contraception, age at menopause and its cause, and hormone replacement. The study found that menopause causes fibrosis to progress faster in women with Hep C, and hormone replacement seems to prevent the fibrosis. Pregnancies may benefit liver fibrosis.

Source: AASLD 2001, ABSTRACT #195

ANTIBODY TESTS NOT ENOUGH

This study reports on a regular blood donor who consistently tested negative for antibodies to HCV over almost 5 years. It was discovered that she had been HCV positive from the beginning, when they checked the blood samples by PCR and core antigen tests. Some of the recipients of the blood products were infected. The authors concluded: "The incorporation of RNA detection or HCV core antigen techniques in blood banks may reduce the residual risk of contracting posttransfusion HCV. Measures such as the correct traceability of the components, the existence of a specimen bank, or follow up of the recipients of blood-derived components would help to improve the quality of blood banking with percentage of survivability and case investigations."

Source: Arrojo, IP, et al. *TRANSFUSION*, JUL 2003; 43 (7) : 953-957 *Detection of a healthy carrier of HCV with no evidence of antibodies for over four years*

NALTREXONE FOR ALCOHOLICS WITH HCV?

Dr. Wen-Zhe Ho in Philadelphia warns that his studies with HCV-infected cells in lab dishes show that alcohol makes HCV replicate faster, plus it interferes with interferon

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TREATMENT By Will Lawson

MANAGEMENT OF HCV TREATMENT FAILURE

Until recently, interferon alfa-2b plus ribavirin has been the standard therapy for people with chronic hepatitis C virus (HCV) infection. Interferon alfa-2b (3 million units three times weekly) plus ribavirin (1,000-1,200 mg daily) produced SVR rates of 38% and 43%, respectively.

These studies also showed that patients with HCV genotypes 2 or 3 were more likely to respond to treatment than those with genotype 1 (SVR of 66% vs 29%). Patients with genotype 1 had an increased SVR rate after 48 weeks of therapy (compared with 24 weeks), while those with genotypes 2 or 3 did not see an additional benefit from longer treatment.

The current treatment is peginterferon (the correct generic name, but also commonly called pegylated interferon)—an altered form of interferon that lasts longer in the body and can be injected once rather than three times weekly—plus daily ribavirin. Schering's product is peginterferon alfa-2b (*Peg-Intron*); Roche's product is peginterferon alfa-2a (*Pegasys*).

Initial studies showed that peginterferon monotherapy was more than twice as effective as standard interferon monotherapy (SVR of 39% vs 19% with *Pegasys* vs *Rofeferon-A*, and 23-25% vs 12% with *Peg-Intron* vs *Intron A*). Subsequent studies showed that combination therapy with peginterferon plus ribavirin produces an overall SVR rate of up to 54-61%.

Treatment Failure

Failures to respond to initial therapy include

relapsing, the reappearance of serum HCV RNA after achieving an undetectable level at the end of therapy;

nonresponse, failure to achieve viral clearance by the end of therapy;

breakthrough nonresponse, an increase in HCV RNA after achieving an undetectable viral load during continuous therapy;

no decrease or only a modest decrease in HCV viral load during therapy; and

partial response, a significant decrease in viral load, although it remains detectable during therapy. (These patients may demonstrate decreased serum liver enzyme levels and reduced liver tissue damage.)

Retreatment

Approaches to retreatment include use of higher doses of interferon, longer duration of therapy, use of different types of interferon, and the addition of ribavirin or use of a higher dose. Several factors predict

whether retreatment is likely to be successful:

Relapsers, and nonresponders who had a significant decrease in HCV RNA during initial treatment are more likely to be successfully retreated than nonresponders.

Retreatment with the same regimen is unlikely to be beneficial unless the previous dose and/or duration of therapy were inadequate. Relapse or nonresponse may have been due to noncompliance with the treatment regimen (in which case, better patient education and monitoring may improve response). Patients who received prior treatment with interferon monotherapy are considerably more likely to respond to further treatment than those previously treated with combination therapy. Lower HCV viral load and infection with HCV genotypes 2 or 3 also may improve response.

Retreatment of Relapsers

In one large study, 48% of relapsed patients retreated with interferon monotherapy achieved an undetectable viral load during treatment, but the SVR was only 5%. In contrast, 82% of initial relapsers retreated with a combination of standard interferon plus ribavirin became HCV RNA negative, and 47% achieved a SVR.

There has only been one published preliminary study on the use of peginterferon plus ribavirin for retreatment of patients who relapsed after initial treatment with standard interferon plus ribavirin. 55 patients were retreated with either peginterferon alfa-2b 1.0 mg/kg once weekly plus ribavirin 1000-1200 mg daily, or peginterferon alfa-2b 1.5 mg/kg once weekly plus ribavirin 800 mg daily. 32% and 50%, respectively, achieved a SVR.

Retreatment of Nonresponders

Several large trials have found that overall, retreatment with standard interferon plus ribavirin benefits no more than about 15% of nonresponders to initial interferon monotherapy. Combination therapy was almost five times more effective than monotherapy.

There are few studies of high-dose induction interferon in nonresponders. However, in a study of 25 interferon monotherapy nonresponders, 33% of the patients receiving induction interferon plus ribavirin achieved a SVR, compared with none of those receiving induction interferon alone.

There are also few published studies on the use of peginterferon plus ribavirin in nonresponders to all prior interferon therapies. Previously untreated patients with

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(TREATMENT—Continued from page 3)

genotype 1 who received high-dose peginterferon alfa-2b (3 mg/kg) experienced a significantly greater reduction in viral load over 48 hours and greater HCV RNA clearance at week 12, compared with those who received a typical peginterferon dose (0.5 mg/kg).

In a current study of peginterferon alfa-2b plus ribavirin in previously nonresponding patients with genotype 1, preliminary data show that 16% of nonresponders to monotherapy achieved a SVR after being treated with peginterferon 1.5 mg/kg weekly plus ribavirin 800 mg daily. 27% of patients treated with pegylated interferon 1.0 mg/kg weekly plus ribavirin 1000-1200 mg daily achieved a SVR. However, the SVR rates with retreatment among the patients who did not respond to previous combination therapy with standard interferon plus ribavirin were only 5-9% with the two treatment schedules.

Preliminary data from a large study previously nonresponders being treated with peginterferon alfa-2a 180 mg weekly plus ribavirin 1000-1200 mg daily shows patients who previously received interferon monotherapy achieving a SVR rate of 34%, compared with 11% for those who initially had received combination therapy.

Management Options for Nonresponders

Retreatment with peginterferon plus ribavirin—or experimental regimens—generally should be reserved for patients with favourable factors that predict SVR. Tolerance of and adherence to prior therapy should also be taken into account, as should the severity of underlying liver disease.

Patients with advanced liver fibrosis or cirrhosis (stage 3 or 4 fibrosis) are at greater risk for developing decompensation or end-stage liver failure in the subsequent 5-10 years. Such people are candidates for additional treatment. Patients with only mild to moderate (stage 0-2) fibrosis can generally afford to wait for newer developments in therapy, although their liver health should be monitored on an ongoing basis.

Maintenance therapy with low-dose peginterferon may reduce the risk of developing decompensated cirrhosis and liver cancer in people with advanced fibrosis. Up to 40% of these patients can experience a histological response (improvement in liver tissue damage) even if they do not achieve an undetectable viral load. Several studies are underway looking at whether long-term peginterferon monotherapy is a beneficial option for people with advanced liver disease.

Source: <http://hepcassoc.org/news/article71.html>

NELFINAVIR HAS LEAST LIVER RISK IN CO-INFECTED PATIENTS

Antiretroviral medications can be toxic to the livers of co-infected patients.

An analysis using a large Canadian database, and concluded recently in Toronto, showed that ritonavir and high cumulative exposure to stavudine (d4T) are associated with a significantly higher risk of severe liver toxicity.

However, patients on nelfinavir-based regimens appeared to be at lesser risk.

Nelfinavir – without accounting for drugs given with it – has about a 70% risk of these patients ever having had a severe toxicity. However, when the effect of other drugs is removed statistically, the risk drops to about 61%.

The biggest risk factor for severe liver toxicity was just the hepatitis co-infection, while both male gender and age were also significant.

Also significant were the extent of exposure to antiretroviral drugs, number of nucleoside analogues, number of non-nucleoside reverse transcriptase inhibitors, and number of protease inhibitors.

Source: www.pslgroup.com/dg/236DAA.htm, Doctor's Guide, July 16, 2003

IFN-131BCB4E.JPG + RBV FOR YOUNG PEOPLE AFTER MALIGNANCY

An Austrian study published in 2000 evaluated the efficacy and safety of treatment with IFN-131bcc52.jpg and ribavirin (RBV) in 12 children and adolescents with chronic hepatitis C and previous malignancy.

Chronic hepatitis C is a major long-term problem for children who survive cancer. The combination therapy significantly improves the response in adult patients with chronic hepatitis C.

The patients, 7-14.7 years old, were treated subcutaneously with recombinant IFN-131bcc0.jpg-2a 3-times-a-week, combined with daily RBV for 12 months.

At the end of the treatment, hepatitis C virus RNA could not be detected in the serum of 8 of the 12 patients. Two of these patients relapsed soon after therapy withdrawal. 6 patients remained in sustained virologic and biochemical remission after 12 months. Treatment-induced toxicity was moderate and reversible, with influenza-like symptoms and a decrease in blood counts in all 12 patients, alopecia in 5 of the 12, hemolysis in 4 of the 12, and weight loss of >10% in 2 of the 12.

The researchers have concluded that the treatment seems to be an effective and safe

therapeutic option for children and adolescents with chronic hepatitis C after malignancy

Source: *Pediatrics* Vol. 106 No. 4 October 2000, p. e53

STUFFED ACORN SQUASH

3 Acorn squash, halved lengthwise and seeded

2 cups Wehani rice or rice blend

4 cups Water

1 tablespoon Tamari

1 tablespoon Soy margarine or butter

1 cup Carrot -- diced

1 cup Celery -- diced

1 cup Onion -- diced

1/4 teaspoon Dried thyme

1/2 teaspoon Fresh ginger -- minced

2 tablespoons Pecan pieces

1 tablespoon Orange zest -- minced

Sea salt, to taste

Freshly ground black pepper, to taste

-----GLAZE-----

1 cup Orange juice

1 tablespoon Honey or barley malt

1/4 teaspoon Cinnamon

Preheat oven to 375 F.

Steam squash for 20 minutes (not be fully cooked). Set aside.

Boil water and tamari over medium-high heat. Add rice. Return to a boil, then simmer, covered, until rice is tender.

Stuffing: Sauté carrots, celery, onion, thyme and ginger until onions are golden. Toss in the rest of the ingredients and remove from heat.

Put glaze ingredients into a small jar. Shake to combine.

Stuff each squash half to about 2 inches over top of squash. Place squash in a baking pan filled with 1/2 cup of water. Drizzle some glaze over stuffing and brush onto squash. Cover with foil. Bake 20 minutes.

Drizzle remaining glaze over squash. Bake uncovered, another 20 minutes until glazed and lightly browned. Serve immediately.

Source:

<http://www.webvalue.net/recipes/lowfat/lowfat02.htm#aswwaps>

(WARNINGS—Cont'd from page 3)

treatment. He also showed that naltrexone blocked the effect of alcohol on HCV. This drug is used to treat opiate addiction, and Dr. Ho suggests that alcoholics with HCV could be treated with this drug, but that studies are needed in patients.

Source: www.reutershealth.com July 22, 2003, *Alcohol Ups Hepatitis C Virus Replication* Original source: *Hepatology*, July 2003.



IS MY PARTNER AT RISK?

HCV is transmitted through the blood. According to recent statistics from the US CDC, about 15 to 20% of acute cases are caused by "sexual" transmission. If this is true, then sexual transmission would be the most common means of transmission after IV drug use. The data we are used to seeing seems to be very different. Dr. Donovan's article goes into detail, and shouldn't be missed. (If you need a hard copy, please send a SASE to the *hepc.bull.*)

Among the things Dr. Donovan notes is the data from the NHANES III study, showing that 9.4% of those who had more than 49 sexual partners in their lifetime had HCV antibodies. The study did not ask about IV drug use. It did ask about intranasal cocaine and marijuana use, and the infection rate was higher in those people.

He brings up the issue that, just because a partner can become infected, the person may not have been infected through sexual activity. Low levels of HCV have been found in the semen of 1/3 of men with the actual virus. In a study by Chayama, the virus RNA pattern was identical in 2 couples with no IVDU history. There is a study that shows HCV found in cervical smears. Prostitutes, male and female, have a higher rate of HCV infection, even after taking into account IVDU and HIV infection.

Dr. Donovan talks about the actual risk that one's partner will become infected. He takes into account that couples may be infected because of drug use or other risky behaviour. He suggests that "the risk is low but not zero."

A study of 398 couples was done. Each couple had a hemophiliac male partner, of whom 343 men were coinfecting with HIV, 42 with only HCV, 6 with only HIV and 2 with neither. Blood samples were collected over 6 years. 5 couples were eliminated because of prior IVDU. At the beginning of the study, 5% of the women were already HCV positive. Only 1 partner of the men who only had HCV became positive. Of the partners of men who were coinfecting, 20 women became HCV positive. It is thought that sexual transmission is more possible if genital sores exist, as is the case with HIV and HBV.

Dr. Donovan also states: "... if transmission from sexual activity does occur it occurs less frequently from a positive female to her sexual partner than from male to female, or male-to-male." In the case of the 2533 Irish women who received contaminated anti-D globulin after giving birth, none of the 94

male partners of the women who contracted chronic Hep C developed antibodies after 10 to 15 years. The probable rate of a male becoming infected from a female is about 1 in 10,000 per year.

Should you use safer sex? The decision is yours.

Source: <http://www.hcvadvocate.org/>, *Sex and the C Virus*, by Jeremiah Donovan, M.D., F.A.C.P.

IS MY SURGEON AT RISK?

A study published in the September issue of *Gut* declares that the risk of a surgeon contracting the disease through work is low, and depends on three things: The prevalence of HCV in the patient population, the probability of an injury breaking the skin, and the actual injury to the doctor during an operation.

The study, done in two North Glasgow hospitals, determined that 1.4% of their patients had HCV between 1996 and 1997. Injuries to surgeons were tallied. "The estimated probability of hepatitis C transmission from a patient to an uninfected surgeon was 0.001-0.032% per annum." That means there could be a 0.035-1.12% chance of transmission over 35 years, even in an area of a very high prevalence of HCV.

Source: *The risk of hepatitis C virus transmission from patients to surgeons is low*
www.gastrohep.com/news/news.asp?id=2215

(DARLENE—Continued from page 1)

reasons), they felt it necessary for me to realize that this disease is a real possibility. If that is the case, it must be monitored closely as it can become aggressive quickly. I believe, they are looking at Aplastic Anemia.

So two months after the treatment stops (May 2004), I am scheduled for a repeat biopsy. Hopefully it will be normal or I prefer to think of the positive, as there will be plenty of time to deal with the negative, if and when it happens.

Bill, my husband, is here for 3 weeks, so I am having a wonderful time no matter how I feel. We are doing some fun stuff and taking my mind off how things are going. In the third week of September, the PEG Intron will be reduced by 1/3, and hopefully that will mean fewer side effects.

On October 9, I can go home to Canada until Dec 29, which is my next appointment. I can't wait to touch Canadian ground again.

Lots of love to everyone, and I'll be in touch when there is more news.

Dar

(HEALING—Continued from page 1)

ard treatments, can help to manage the symptoms of hepatitis C. The common effects of TT are reduction of pain and anxiety, promotion of relaxation and facilitation of the body's natural restorative process. There is a change in the perception of pain and a boost to the immune system. I have been practising Therapeutic Touch since 1995 and have had many people report that they "feel relaxed", sleep soundly, and feel more energized following treatments. Wound healing is accelerated and pain is eliminated or reduced. TT is not a miracle cure, but it can support one at times when nothing else seems to work. The effects are not always immediately apparent as TT is a process that continues to work following the treatment. Change of mood and attitude can occur over time.

Though TT is not taught in a religious context, as a parish nurse, I understand it to be a body prayer, a way for me to connect with the healing power that is present for all. As a practitioner, I also receive the benefits of this "universal energy" and feel energized and empowered after I have shared a treatment with a client. I incorporate TT into many of my pastoral visits. By sharing a TT treatment, the client feels that they have the total undivided attention of the practitioner for a time. It is a modality that requires presence in the moment and focus on the client. Clients feel truly cared for in this climate of compassion and presence. That, in itself, is healing.

Karen Marks, RN, BA is Parish Nurse at St. Mark's United Church in Whitby and supports the work of the Durham Hepatitis C Support Group that meets there by sharing Therapeutic Touch treatments and other spiritual resources. Karen is a recognized practitioner and teacher of Therapeutic touch by the Therapeutic Touch Network (Ontario).

<http://www.therapeutictouchnetwork.com/>

Karen Marks will be presenting on Therapeutic Touch, along with complimentary treatments, for interested participants at the Durham Hepatitis C Support Group monthly meeting. Date: Thurs., Oct. 9, 2003 Time: 7:00 p.m. - 9 p.m. Place: St. Mark's United Church (Church Hall), 201 Centre St. S. & Colborne St. W., Whitby, Ontario. Email Smilin' Sandi, Co-Founder smking@rogers.com, or visit her site, Sandi's Crusade Against Hepatitis C
<http://members.rogers.com/smking/>

LETTERS TO THE EDITOR

QUESTION:

Dear *hepc.bull*:

I received some newsletters from a friend whose daughter is infected. I am Hep C positive, as well. I had no idea you people were out there. I'm glad you are!

I am left with a problem I don't understand! I have cold spots that surround my body in colour, light red to pink. I've been seen by a specialist some years ago, who told me it was because of my Hep C! I remain many degrees colder, all year round. Winters are the worst!

My family doctor put me on iron pills, Ferrous Gluconate, 300 mg X 3 per day. The specialist I saw was a skin specialist. I'm 51 years old now and have had Hep C probably around the 30 year mark. I just now read in your newsletter *hepc.bull*, Sept. 2000 issue, number 26, that iron is harmful to the liver. Are we now talking about the same iron I am taking? Has anybody realized the cold spots I'm talking about, or am I the only one? It can't be!

A while ago my wife and I ran into a lady whose son died at age 47. He always complained about the cold, she told us. It's quite possible he didn't know that he had these cold spots. If I hadn't checked and noticed these cold spots, I would also simply feel cold!

I believe this is an issue that should be addressed. I have read lots about Hep C but have never read about anything to do with the cold!

If you could get back to me about ANYTHING regarding the above, I would be quite interested. Then again, maybe we should turn this letter into a "Letter to the Editor" and get other input. I will leave this in your trusting hands, and thank you in advance. I remain

Yours Sincerely,
"RW"

PS: The iron pills have been helping very much so! (The cold spots are still there, though.)

ANSWER:

Dear RW,

Iron + HCV = bad

We can even get too much in our diets which is one reason for cutting back on red meat.

You can use cilantro (Chinese parsley) to chelate the excess heavy metals out of your body.

Cold spots & chills are so common with HCV that it is a wonder why we don't talk about it more.

First I would like to highly recommend

(Continued on page 7)

Note from Joan: In case you don't know, Ian Campsall was one of our editors. Sadly, he has just resigned, and has gone off to Japan. We will miss him greatly, but wish him well. He is one of our unsung heroes. Here is a note from him:

Hello All!

I have survived my first week in Japan quite nicely, and am now enjoying a week of holidays—its Obon all week. First, just a quick little update for the people I have done a bad job of keeping in touch with:

I finished my MA two years ago and stayed in Victoria while Cornelia finished her BFA. I defended my thesis two days before the new budget cut everything that could be cut and then some. I walked into a job market of zero. After handing out more resumes than I want to think about, I got a job at Chapters bookstore, where I languished for about eight months. I was able to get work as a freelance writer and editor, and soon got a position at an ESL college. I also worked for *Momentum Magazine* as their regional advertising and distribution manager.

I arrived in Japan at Narita airport last Monday, and am now settled in Fukushima, about 1.5 hours North of Tokyo. The city is quite small—about 300,000 people. It is a center for agricultural production, especially peaches and rice (in fact if you eat Japanese rice there is a good chance it is from Fukushima). The city sits in a basin and is surrounded by mountains are covered in lush green forest. The mountains protect the city from typhoons, but make for VERY humid weather—up to 75% humidity! I was planning on going on a hike today but it is raining. The skies are cloudy this time of year, in fact, Sunday was the first time I saw blue sky and could see the entire range of mountains and valleys. They are breathtaking. The typhoon that came through on Saturday night brought very heavy rainfall and blew away the clouds for one day at least. The city is an interesting mix of old and new. It was flattened by bombing during WWII so there is not much of old Japan left. However, as you walk down the streets you will come across an old wooden building quietly tucked away in a corner. Many of the houses have the beautiful tiled roofs, but there are certainly plenty of short squat ugly concrete building here too. My apartment is a spacious bachelor style pad with a balcony, TV, PlayStation II, washing machine, full size fridge, and AC (thank god!!). It takes

(Continued on page 7)



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elsewhere in BC)

LETTERS TO THE EDITOR:

The *hepc.bull* welcomes and encourages letters to the editor. When writing to us, please let us know if you do not want your letter and/or name to appear in the bulletin.

PREPLANNING YOUR FINAL ARRANGEMENTS?

Please consider arranging for donations to your local hepatitis C organization.



ARE YOU A GOOD SPELLER? GOOD AT GRAMMAR?

The *hepc.bull* needs a proofreader. This is an opportunity for fame for the qualified individual. Please contact Joan at 250-595-3892 or info@hepcbc.ca

DO YOU HAVE NICE HANDWRITING?

HepCBC needs a Volunteer thank you note writer. Please contact Joan at 250-595-3882 or info@hepcbc.ca

POSSIBLE SURPLUS OF COMPENSATION FUNDS



VOLUNTEER APPLICATION FORM

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ABILITIES OR AREA OF INTEREST:

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- Errands Grant Applications
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Experience: _____

Time available: _____

SEX M F

Date of Birth: ___/___/___

Mo Day Year

Contact: HepCBC
#5-915 Glen Vale Rd
Victoria BC V9A 6N1

Tel. 595-3892 or Email:
info@hepcbc.ca



According to recent reports, there is currently an \$800 million surplus in the funds allotted for those infected with tainted blood. Less than 1/3 of the estimated 22,000 victims have received compensation, and many victims known to be eligible have not yet applied. Officials in charge stress that these figures may be misleading, as applications are still being accepted, and many current recipients will be collecting more in the future. A review of this potential surplus is planned for next year, but critics believe that it's not soon enough. They argue that the leftover money should be distributed as soon as possible among the remaining victims. The package is designated for those infected between 1986 and 1990, and is available until 2010.

Source: *Globe & Mail, Jul. 20, 2003, Tainted-blood*

(Q&A—Continued from page 6)

Calcium + Magnesium /w Vitamin D for cramping of the feet, lower legs and hands, dead nerve spots and red flushes on the skin. It even seems to help with Raynaud's phenomenon.

The thing that causes chills and even hot flushes is an imbalance of 'body temperature regulating hormones.'

At one point in the day I can have cold chills and a few hours later I can run a fever. Night sweats are a problem.

A blood hormone test never seems to show anything, yet because HCV plays havoc with our immune systems' glands, these occurrences are often referred to as transient.

Caution should be used for attempting to treat the problem with hormone replacement therapy of any kind. HGH (Human Growth Hormone), for instance, affects the pituitary (master) gland with a hormone growth factor which will increase the production of ALL of your hormones, which may not be advantageous.

It has been my experience that women suffering from this problem can benefit from primrose tea and men suffering the same can benefit from wild yam.

Other than natural remedies, I don't have a specific medical reference for medication. If researchers would pay more attention to extra-hepatic disorders associated with HCV, then we might see some of these problems addressed, medically.

Best wishes,

Brad Kane (Princeton), Regional Advisor,

(LETTERS—Continued from page 6)

about ten minutes to walk to the school, located in the heart of downtown.

Things I like so far?? The FOOD!! The people are friendly, helpful, and kind. The office staff at the school are very helpful and will take care of any detail you are having difficulties with.

And the sunsets!! They are short, but the entire sky burns like its on fire!

Peace to everyone, Ian Campsall

COMPENSATION

LEGAL ACTION

Hepatitis C Class Action Suit Line:
1-800-229-LEAD (5323)



1986-1990

Bruce Lemer/Grant Kovacs Norell
Vancouver, BC
Phone: 1-604-609-6699 Fax: 1-604-609-6688

Pre-86/Post-90

Hepatitis C Settlement Fund—KPMG Inc.
Claims Administrator
2000 McGill College Avenue, Suite 1900
Montreal (Quebec) H3A 3H8
1-888-840-5764 (1-888-840-kpmg)
HepatitisC@kpmg.ca
www.kpmg.ca/microsite/hepatitisc/english/forms.html

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/pages/class_actions/Hepatitis_C.htm

Mr. David Harvey/ Goodman & Carr
Toronto, Ontario
Phone: 1-416-595-2300, Fax: 1-416-595-0527

Ernst & Young Law Office (Ontario)
1-800-563-2387

Lauzon Belanger S.E.N.C. (Quebec)
www.lauzonbelanger.qc.ca

Goodman and Carr LLP
pre86hepc@goodmancarr.com
www.goodmancarr.com

Other:

William Dermody/Dempster, Dermody, Riley and Buntain
Hamilton, Ontario L8N 3Z1
1-905-572-6688

LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC
1-888-332-5663 (local 207)

Lookback Programs, Canada: 1-800-668-2866

Lookback Programs, BC: 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

Manitoba Traceback: 1-866-357-0196

RCMP Blood Probe Task Force TIPS Hotline
1-888-530-1111 or 1-905-953-7388

Mon-Fri 7 AM-10 PM EST
345 Harry Walker Parkway, South Newmarket, Ontario
L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656

Health Canada Compensation Line: 1-888-780-1111

Red Cross Compensation pre-86/ post-90 Registration: 1-888-840-5764

Ontario Compensation: 1-877-222-4977

Toronto Compensation: 1-416-327-0539, 1-877-434-0944

Quebec Red Cross Compensation: 1-888-840-5764

1986-1990 Hepatitis C Class Actions Settlement 6/15/99 www.hepc8690.ca/

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-888-726-2656 or 1-877-434-0944.

www.hepc8690.com info@hepc8690.com

MISCELLANEOUS

Excellent Website!: HCV Tainted Blood, Canada:
<http://members.rogers.com/smking/tainted.htm>

COMING UP IN BC/YUKON:

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

Campbell River Hep C Support Group Support and information, call 830-0787 or 1-877-650-8787 or email niac_hepc@hotmail.com

Castlegar Contact: Robin, 365-6137

Comox Valley: Contact North Island Hep C Community Support Project 1-877-650-8787,

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

Cranbrook HeCSC-EK: 1st & 3rd Tues. monthly, 1-3 PM, #39 13th Ave South, Lower Level. Next meetings Sept. 2nd & 16th. Contact: 426-5277 or 1-866-619-6111 hepc@cmha-ek.org, www.hepceastkootenay.com

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

Grand Forks Hep C Support Centre—Closed due to lack of funding. Contact Ken, 1-800-421-2437

Kamloops Phone support. Contact Susan, 554-7055, or the Liver Clinic, 851-7300.

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Next Meeting: Sept. 27th. Contact Elaine Risely (250) 768-3573, eriseley@shaw.ca or Lisa Mortell 766-5132 lmortell@silk.net or toll-free 1-866-766-5132.

Kimberley Support Group 2nd Tues. monthly, 7-9 PM. Next meeting Sept. 9th Contact Katerina 426-5277

Kootenay Boundary 2nd Tues. monthly, 7 PM, Room 108, Selkirk College, Trail. Next meeting: Sept. 9th. For individual support, info & materials, contact: Brian Reinhard, (250) 364-1112, reiny57@yahoo.ca

Mid Island Hepatitis C Society Friendship and support group, 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Next meeting: Sept. 11th. Contact Sue for info 245-7635. mihepc@shaw.ca

Mission Hepatitis C and Liver Disease Support Group 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting Sept. 17th. Contact Gina, 826-6582 or Patrick, 820-5576. missionsupport@eudoramail.com

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Next meeting: Sept. 16th. Contact: Vivian, 265-0073 or Ken, 1-800-421-2437

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St. Next meeting: Sept. 4th. Contact: Alex.Sherstobitoff@ankors.bc.ca 1-800-421-2437, 505-5506, info@ankors.bc.ca

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, 623 Agnes Street, New Westminster. Next meeting: Sept. 8th. Speaker: Dr. John D. Farley on Hepatitis. Contact: Dianne Morrissett, (604)517-6120, dmorrissett@excite.com

Parksville Support Group Contact Ria, 248-6072

Parksville/Qualicum 102a-156 Morison Avenue, PO Box 157, Parksville, BC V9P 2G4. Open daily 9 to 4, 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 Next meeting: Contact the Health Unit, 485-8850.

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Health Unit Auditorium. Next meeting Sept. 9th, Contact: Gina, 963-9756, gina1444@yahoo.ca or Ilse, ikueper@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Next meeting Sept. 13th. Contact: Brad, 295-6510. kane@nethop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy: 557-2487, e-mail: wmm@island.net, www.island.net/~wmm/

Quesnel HeCSC 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 Contact: Ken, 355-2732, keen@netidea.com

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, **3862 Broadway (back door)** Next meeting: Sept. 10th. Contact: Deb 877-0042, 1-866-877-0042, or Doreen, 847-2132, plnw_hepc@bulkley.net for times.

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

Vancouver: Healing Our Spirit— Offering Hep C and HIV education and support to Aboriginal People in BC. 100 - 2425 Quebec St. Contact: 1 800 336-9726 info@healingourspirit.org www.healingourspirit.org

VANDU Vancouver Area Network of Drug Users Each Mon., 2 PM, **412 East Cordova** Bus fare & snack. Contact: Cristy or Ann, 604-719-5313, or 604-216-2776 (ask for VANDU). Space limited—come early. vandu@vcn.bc.ca, www.vandu.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Next meetings Sept. 10th & 24th. Contact: Sharon, 542-3092, sgrant@telus.net

Victoria HeCSC Last Wed. monthly. Contact: 388-4311, hepcvic@coastnet.com

Victoria Support and Information Information about support groups and other services: Contact the Needle Exchange, 384-2366, hermione.jeffers@avi.org

Victoria HepCBC & INFO line —Contact: (250) 595-3892, info@hepcbc.ca, www.hepcbc.ca

YouthCO AIDS Society HepCATS Education and information to youth infected or affected with hepatitis C. #205-1104 Hornby St., Vancouver. Contact Caitlin Padgett 604-688-1441 or 1-877-YOUTHCO

Yukon Positive Lives 3rd Wed. monthly, Whitehorse. Next meeting Sept. 17th. Contact Heather 660-4808, fromme@marshlake.polarcom.com, www.positivelives.yk.ca

OTHER PROVINCES

ATLANTIC PROVINCES:

HeCSC NB Meetings:

• **Fredericton, NB** Contact: Bob, 453-1340, bobc215@hotmail.com

• **Saint John & Area:** Information and Support. Contact: Allan Kerr at kerrs@nbnet.nb.ca

Moncton, N.B. Contact Debi, email support only: hepcmonc@rogers.com

The Hepatitis Outreach Society The organization is undergoing reconstruction, for telephone support call: 1-800-521-0572 (902) 733-2214 Fax (902) 733-2043

ONTARIO:

Barrie HepSEE Chapter 3rd Tues. monthly, 7-9 PM, AIDS Committee of Simcoe County, 80 Bradford St, Suite 336 Contact: Jeanie, 735-8153 hepcseebarrie@rogers.com

Durham Region, GTA and Peterborough, ON support. Sept. 11, 2003 Speaker: Tobin Brown, RN, Positive Care Clinic. Topic: Overview of Hepatitis C and Ongoing Care. Contact: Smilin' Sandi smking@rogers.com "Sandi's Crusade Against Hepatitis C" <http://members.rogers.com/smking/>

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S. **NO MEETINGS JULY OR AUGUST.** Kitchener. Contact: Carolyn, (519) 880-8596 lollipop@golden.net

Niagara Falls Hep C Support Group 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 jcolange103@cogeco.ca or hepcnf@becon.org

Trenton ON support. Contact: Eileen Carlton 394-2924 carfam@quintenet.com

Hepatitis C Network of Windsor & Essex County 3rd Thurs. monthly, 7 PM, 1100 University Ave. W. and 1st Mon. monthly, 491 Victoria Ave, 11 AM. Contact Andrea 250-5399 or Michelle, 256-1878, hepcnet@cogeco.ca <http://home.cogeco.ca/~hepcnet/>

PRAIRIE PROVINCES:

HeCSC Edmonton: Contact Jackie Neufeld: 939-3379.

HepC Edmonton Support Group: Contact Fox, 473-7600, or cell 690-4076, fox@kihewcarvings.com

HepSEE WPG: Contact David: hepsee@shaw.ca or 1(204)897-9105 for updates on meeting schedules.

Winnipeg Hepatitis C Resource Centre 1st Tues. monthly 7-9 PM. #204-825 Sherbrook St. (south entrance—parking at rear) Contact: 975-3279, hcre@smd.mb.ca

QUEBEC:

Hepatitis C Foundation of Quebec, Contact Eileen, 769-9040 or hccq@qc.aibn.com. **Meetings:**

• **Hull:** Each Tue. 7-8 PM, 57 Rue Charlevoix.

• **Sherbrooke** 2nd Mon. monthly, 7-9 PM, Les Grandes Coeurs D'Artichauts Au Centre Jean-Patrice Chiasson (2^e etage) 1270 Galt Street West. Contact: 820-7432

• **Verdun:** 1st Tues. (French) & 3rd Tues (Eng) monthly, 7-9 PM. Verdun General Hospital, Room 3121.

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

TIP OF THE MONTH:



Get your flu shot. Ask your

HepCATS/ YouthCO News

HepCATS welcomes Caitlin Padgett as their new coordinator at YouthCO. HepCATS is Hepatitis C Awareness, Training and Skills-building. They provide education and information to youth who are infected or affected with hepatitis C. They also provide peer educators training and information workshops.

Their new address is:

YouthCO AIDS Society #205-1104 Hornby St. Vancouver BC, V6Z 1V8

Vancouver #: 604-688-1441 Toll-free 1-877-YOUTHCO