# hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.org


## BREAKING NEWS: BUNDLING MAY AGAIN BE A PROBLEM

Earlier this year Schering put in a request to the FDA to "unbundle" Rebetron (interferon and ribavirin), making it possible to use ribavirin with other interferons that might work better for an individual patient. Schering is now requesting that RebMax, which is their PegIntron + Ribaviriin combo, be approved. Jules Levin from NATAP (National AIDS Treatment Advocacy Project) based in New York, is worried that there could be a problem if the original request to unbundle Rebetron is not followed through. Just in case, NATAP will be asking the FDA for a public hearing where the issue can be raised before the scheduled approval of RebMax in August. Hopefully, the Hep C community in Canada will join together to do something similar here. In the meantime, do what you can as individuals. Every letter helps.

Allan Rock, Minister of Health
Minister's Office - Health Canada
Brooke Claxton Bldg., Tunney's Pasture
P.L. 0913C
Ottawa, Ontario, Canada
K1A 0K9
Fax: 613-952-1154

*Joan King*

## INSIDE THIS ISSUE:



## THE 2ND ANNUAL HEPATITIS C CANDLE LIGHT MEMORIAL VIGIL, MONTREAL QUEBEC

The Hepatitis C Foundation of Quebec and HepCURE were honoured to be able to present the 2nd Annual Hepatitis C Candle Light Memorial Vigil during Opening ceremonies of the 1st Canadian Conference on Hepatitis C held May 1st in Montreal Quebec. Eileen Caldwell-Martin and Marjorie Harris delivered messages of hope, inspiration and remembrance of those who have passed on and those who are now suffering from hepatitis C.

A new world symbol of hope was unveiled for the first time during the vigil. This new symbol is the stained glass Candle of Hope. The stained glass art piece measures 18" by 24" and was designed and made by well-known Okanagan artisans Debra Wilson and Pat Doyle Lightfoot. The candle has two purple eagle's feathers in the flame, representing both Aboriginal peoples and the twin spirits of the HIV/HCV co-infected. The beams of radiance from the flame demonstrate the power of the light of awareness to dispel the darkness of ignorance about hepatitis C worldwide. The

*(Continued on page 8)*

## NEW ALLOWANCE IN BC

*By Darcie Bennett*

The Ministry of Social Development and Economic Security (MSDES) announced low-income people suffering malnutrition, weight loss and other afflictions (as a result of chronic illness) could qualify for a new monthly allowance of up to $300 for pharmaceuticals.

Approximately $6 million has been allocated for the allowance in 2000-2001. The allowance is designed to help offset the cost of items such as vitamins, minerals and other supplements.

Robin Loxton of Advocacy Access/ MHEAP notes that the new health allowance is the ministry's solution to the previous health allowance that the HIV/AIDS community has been obtaining through an arduous appeals process (Schedule C). The allowance is seen as an important victory because it demonstrates the effectiveness of the relentless pursuit of individual rights and how citizens can affect public policy changes.

It is important to note that the new allowance is not available to all people with a chronic illness. Loxton reports that several people have already contacted his office with the expectation that they are entitled to the new allowance since they have a disability. For some, this is not the case, however. People must already be receiving BC Benefits-DB2 in order to be eligible. Individuals must also be suffering from what is known as "wasting syndrome." This includes people with HIV/AIDS and other illnesses such as ALS, Muscular Dystrophy, and certain cancers. This will include about 4,000 people, or 10 per cent of the DB2 caseload.

The precise eligibility requirements have not yet been worked out and the government is currently in consultation with a

*(Continued on page 7)*

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***SUBMISSIONS:*** ***The deadline for any contributions to the* hepc.bull© *is the 15th of each month. Please contact the editors at info@hepcbc.org, (250) 361- 4808. The editors reserve the right to edit and cut articles in the interest of space.***

***ADVERTISING:*** ***The deadline for placing advertisements in the* hepc.bull *is the 12th of each month. Rates are as follows:***

***Newsletter Ads:***
***$20 for business card size ad, per issue.***
***There will be a maximum of 4 ads in each issue, and the ads will be published if space allows. Payments will be refunded if the ad is not published. Ads are also posted to the Web.***

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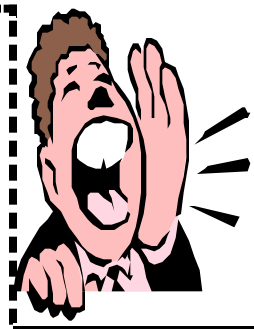
**Victoria BC V8R 4T3**

## 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 4.5 Available NOW!!

**Peppermint Patti's FAQ Version 4 is now available. The new version includes an HIV co-infection section as well as updated Canadian Links and 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.**

**HepCBC Resource CD**: The CD contains back issues of the *hepc.bull* from 1997-2001; the FAQ V4.5; the Advocate's Guide and the Slide Presentations developed by Alan Franciscus. 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!!

**HepCBC would like to thank the following institutions and individuals for their generosity: Lexmark, David Klein, J.J. Camp, Bruce Lemer, Elsevier Science, Blackwell Science, Massachusetts Medical Association, Health Canada, The Legal Services Society of BC, Pacific Coast Net, BC Transit, Margison Bros Printers, Carousel Computers, Island Collateral, David Lang, Alan Franciscus, Arlene & Frank Darlington and Karolyn Sweeting. Special thanks to Danielle Hanna for helping with the pamphlets and the bulletins.**



## 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. Squeeky, 2741 Richmond Road Victoria BC V8R 4T3.** 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.*

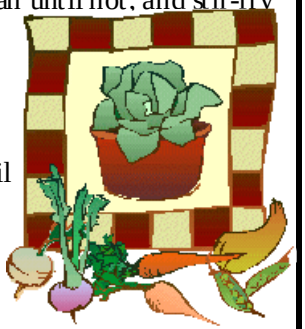
**Got Hep C?... Single?**
**...Visit**
http://clubs.yahoo.com/clubs/ontariohepcsingles
*or*
Alberta Hepatitis Singles web
http://clubs.yahoo.com/clubs/albertahepatitissingles

## *Ask the chef:*

## *Zucchini with Carrots & Ginger*

2 tbsp. *fresh* grated ginger
1 lb. zucchini
1/2 cup grated or diced carrots
1/2 cup diced bell pepper
3 tbsp. peanut oil
salt and pepper as desired

Slice zucchini into thin disks. Heat oil in wok or frying pan until hot, and stir-fry the zucchini for a few minutes. Add the carrots, pepper, and ginger, and stir until the vegetables are slightly soft but still have texture. Add salt and pepper as desired and serve immediately.



# HepCBC
# May Daze Gala

May 6, 2001

Mandolirium

Agnes Stieda & Kate Rhodes

Jimmy Rhodes

Tango Argenta

Jeanette Bernal-Singh & Tony Bernal

Pablo Diemecke

Howie Siegel Auctioning the Queen
(Carolyn Sadowska aka "Laugh with Liz")

Cecilia Valdés & Pablo Diemecke

## Special Thanks to the following donors & to our many volunteers

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# HCV AND BRAIN DYSFUNCTION

*Source: NATAP - DDW Liver Conference, San Diego, May 21-24, Report 11 (thanks to Jules Levin from NATAP)*

We know that HIV enters the brain shortly after a person is infected with HIV. It does appear as though individuals with HIV may experience symptoms related to this, such as reduced alertness or a slower thinking capacity due to HIV. At both recent liver conferences—DDW and EASL—two different research groups reported findings suggesting that HCV in individuals with less advanced disease (non-cirrhotics or mild fibrosis) affects the brain and reduces its functioning capacity. This suggests to me that a person with both HCV and HIV may be affected even more with regards to brain functioning. Over the years people with HIV have complained about experiencing fatigue and/or itching. We now know that many people with HIV also have HCV, and that HCV can cause itching and fatigue. The findings reported at DDW and EASL suggest that HCV related fatigue may be associated with the affect of HCV on the brain.

It is known that individuals with advanced cirrhosis can experience hepatic encephalopathy which can cause brain disorder, but it is important to bear in mind that the participants in the studies discussed below did not have such advanced HCV disease, so the brain dysfunction found was not due to hepatic encephalopathy.

At DDW, Ludwig Kramer and a research group from the University of Austria, reported that "cognitive processing was subclinically impaired in patients as compared to healthy subjects." They studied the impact of HCV infection on sensitive markers of cognitive brain function. Fifty-eight noncirrhotic patients with chronic HCV infection (age, 45±13 years, mean±SD) were studied by P300 event-related potentials (an objective measure of cognitive processing) and by the SF-36 questionnaire for assessment of health-related quality of life. Findings were compared to 58 matched healthy subjects. He found that P300 test results were impaired in patients with HCV compared to healthy volunteers, and concluded that **patients with chronic HCV infection in the absence of cirrhosis exhibit a subclinical neurophysiological impairment**. Cerebral function, however, seems to normalize with antiviral treatment. Although it was not apparent to me if normalization was tied with significant reductions in HCV viral levels, my feeling is that improvements in cerebral function can improve with HCV treatment despite no HCV viral level reductions. More detailed data and discussion are available below at the end of this report.

At EASL, DM Horton presented a talk on brain dysfunction in people with HCV for a UK research group from the Imperial College School of Medicine and St Mary's Hospital in London. First he reviewed two studies. He mentioned a UK study (Foster et al 1998) using the SF-36 questionnaire, and reported that people with HCV, compared to normal controls, scored worse in physical and social functioning, energy and fatigue, and other measures. These results were independent of intravenous drug use. In a large US study (Johnson et al 1998), 309 IVDUs, both with or without HCV, were tested for depression and those with HCV (57.2%) were found to have significantly more depressive symptomatology than those who were negative to hepatitis (48.2%).

In an attempt to further define this neuropsychological syndrome, they administered a battery of neuropsychometric tests to 15 patients with histologically mild hepatitis C, which was determined via liver biopsy. They tested for attention (including simple reaction time, choice reaction time), working memory (numeric & spatial working memory), and secondary memory (delayed word recall). They found that patients with mild or minimal hepatitis C (from liver biopsy) were slower in tests of working memory. He noted that although they were slow their accuracy on these tasks was preserved. This phenomenon has been described in chronic fatigue syndrome. There were no attention or secondary memory abnormalities.

In view of these findings, they asked themselves if HCV infects cells in the CNS (central nervous system), does this cause cerebral metabolite abnormalities, and is cerebral HCV infection the cause of the observed neuropsychological symptoms? They carried out a proton cerebral magnetic resonance spectroscopy study to determine if metabolite abnormalities exist in the brain of patients with hitologically mild hepatitis C. They randomly selected 30 patients with biopsy proven mild or minimal hepatitis due to HCV. As well, they studied 29 matched controls, and 12 eAG+ve patients with chronic HBV. No patient in the HBV or HCV groups had significant fibrosis or cirrhosis. The researchers reported finding metabolic abnormalities in the results of those with HCV compared to both normals (volunteers) and chronic HBV patients. There were no statistical differences between the normals and those with HBV. These abnormalities were not due to hepatic encephalopathy. Johnson et al described the abnormalities as being similar to those abnormalities observed in HIV. Again, no patient in this study had significant fibrosis or cirrhosis. None of the study participants had used IV drugs in the 6 months preceding the study. There was no statistical difference in the study results between those with or without prior drug use. Those with prior drug use had the same abnormalities as those who never used IV drugs. The researchers concluded that prior drug use did not affect the outcome of the study.

*Is there direct infection by HCV of the CNS?*

Dr. Horton presented a potential model by which this could happen. Microglial cells in the brain turn over slowly and are replenished by circulating monocytes, possibly up to 30% in one year. Circulating monocytes are potentially infectable by HCV, and may carry the virus across the blood brain barrier into the brain and the microglial cells. Once in the cells, they become activated and produce chemokines, cytokines, and neurosteroids, which may mediate the neuropsychiatric symptoms described in this presentation. The question still remains—does HCV infect the microglial cells in the brain? The only way to answer this question is to conduct a direct post mortem viralogic examination of brain tissue, a procedure which is being currently undertaken at Imperial College School of Medicine in London.

Horton also suggested that of equal or possibly greater importance is the possibility that the brain may act as a sanctuary site for HCV, allowing immune evasion and protection against antiviral therapy. He suggested that cessation of viral production from the liver may occur during phase 1 of viral decline after starting HCV therapy, but the slower viral decline during phase 2 may be due to a continued release of virus from the brain. He suggested that an alternative explanation for possible brain dysfunction seen with HCV could be that systemic cytokines cross the blood-brain barrier and may exert an effect. But he discounted this theory because in this study patients with HBV had normal spectroscopy. HCV antiviral therapy has been administered to the study patients and results are pending. In the study reported at DDW, and discussed above, the study authors reported therapy improved cerebral function, and **they suggest their data may indicate a direct action of HCV infection on the brain.**

## GUINEA PIG PEN

### VANCOUVER TRIALS

Dr. Frank Anderson's clinic in Vancouver is conducting 3 clinical studies for those with hepatitis C:

1. A pegylated interferon study
2. A maintenance therapy study
3. A study of naive patients (no prior treatment) who have normal enzymes

Contact Dr. Anderson's office: (604) 876-5122

### TRIALS FOR CO-INFECTED PATIENTS

A research trial of an investigational treatment for HCV is being conducted. Volunteers are needed. You may be eligible for this study if you have both HCV and HIV and are over 18 years old. Study visits include physical exams and lab tests. Study medication will be provided to you at no charge.

For further information, please call the Professional Service Center at 1-800-526-6367 for local site contact information www.hcop.org

### LOW PLATELETS?

Metropolitan Research in Fairfax, VA, is actively enrolling Hep C patients who would not otherwise be eligible for IFN-based treatments because of a low platelet count. They are conducting a phase II trial of Neumega + IFN + Ribavirin.

Neumega or IL-11 induces megakaryocyte maturation resulting in an increased platelet production. Patients must have compensated liver disease and a platelet count between 30,000 and 100,000 cells/mm3. As soon as it is approved, patients will be given PEG-IFN. Contact Rachel at (703) 698-9254 ext. 16.

## TIP OF THE MONTH:


## MAY: HEPATITIS AWARENESS MONTH, FINALLY!

Five and a half years of asking, pushing and writing ended successfully on April 30, 2001 when Liberal MP Yvon Charbonneau stood in the House and resurrected Peter Stoffer's Bill making May Hepatitis Awareness Month in Canada. One month to the day after Mr. Charbonneau stood in Parliament and killed Mr. Stoffer's Bill with his "no" vote, he was back on his feet announcing that Allan Rock had proclaimed May as Hepatitis Awareness Month. Peter Stoffer took up the issue in February 2000 at Bruce DeVenne's request and Peter, his staff and many others worked long and hard on it to bring it into the House on March 30, 2001. For some reason the organizers of the Hepatitis C Conference in Montreal refused to announce this at the conference, so this may well be the first public announcement of this long awaited and hard won public recognition. Congratulations to all those who worked on and helped in this cause, and thanks to Peter Stoffer his staff and Yvon Charbonneau.

### ALBUFERON TRIAL

Albuferon is created by fusing the gene for interferon alpha to the gene of albumin, with the goal of providing patients with a longer drug with fewer side effects than standard therapy. This drug is in Phase I clinical trials with 40 HCV+ patients.

Individuals interested in Albuferon should contact Human Genome Sciences at (301) 610-5790, extension 3550 or via the Internet at http://www.hgsi.com.

*SOURCE: Human Genome Sciences, Inc. Human Genome Sciences Begins Phase I Clinical Trial of Albuferon in Hepatitis C Patients*

## "LIVING WITH LIVER DISEASE"

**The Canadian Liver Foundation will be hosting a wellness and educational program for patients and their families affected by liver disease.**

### LIVING WITH LIVER DISEASE PROGRAM

Monday June 4 ***Traditional Chinese Medicine & Acupuncture***

Stephanie Curran DTCM

Monday June 11 ***Community Resources***- Ann Genovy, Penny Bradford, Hermione Jefferis, Joan King

**Capital Health Region Clinic**
**Multi-purpose Room**
**6:00pm to 8:00pm**
**1947 Cook St. Victoria BC**

**All sessions are *free*.**
**To register, please contact the Canadian Liver Foundation at 1-800-856-7266.**

## WHAT'S NEW: IN POWELL RIVER...

Our June meeting is at Malaspina College—"Hep C and the Internet: Basics and Beyond!" Learn how and where to search for current information. No computer skills required.

Powell River now has a small Resource Library, and computer with Internet access available by appointment. Call Kathy at 485-8864 to schedule time on it. Take advantage of a computer orientation evening with Alice McCallum on Wednesday June 13th at Malaspina College. This is in place of the regular June Support Group Meeting.

## ...AND NAKUSP

The Nakusp Hepatitis C Support Group held its first meeting on May 16th, at the Nakusp Hospital boardroom. It will continue to be held on the third Tuesday of every month at 7:00 PM. There was lots of shared laughter about bizarre food cravings like peanut butter and fish, as well as the complicated mind games employed in vain attempts to avoid the headaches and panic attacks that come with treatment.

Come join us in the Kootenays next month as one person loses their train of thought in mid-sentence, while another goes, "Ooh, ooh, I remember now!"

*Ken Thompson*

# 1ST NATIONAL HEPATITIS C CONFERENCE

Can you imagine being completely immersed in information on hepatitis C? That's what happened to me when several major organizations united to bring about the 1st Canadian Conference on Hepatitis C, held May 1st through 4th in Montreal. I was one of the lucky recipients of a scholarship to attend the event. I wish I could convey the bustle and excitement.

At a lovely ceremony on the evening of May 1st, the organizers were presented, and James Kreppner, a hemophiliac, talked about his experience as an "unlucky" co-infected person who lost a brother infected only with hepatitis C. There was also a Candlelight Ceremony celbrating May 1st as Hepatitis C Memorial Day. Our red and yellow ribbon was displayed prominently during the Conference. Surprisingly, no mention was made that the Canadian Government had just declared May as Hepatitis Awareness Month.

The Conference sessions were divided into three tracks: "Basic and Clinical Science", "Public Health", and "Social Science and Community." A summary of each day's highlights was made available at the end of each day. Several mini-talks given daily during lunch, and there were exhibition booths and displays throughout the Conference site.

The first session was presented by Harvey Alter, MD: "The Natural History of Hepatitis C Virus Infection." Dr. Alter presented statistics on disease progression, pointing out that one quasispecies of the virus can become more dominant than the original strain. He showed a chart of one patient with 20 different quasispecies! He believes that host response is very important. Of interest was the fact that some people clear not only the virus, but also the antibodies.

The talk "Manage the Disease, or It's Going to Manage You," with Mary Giudici, Colina Yim and Vikki Boddy, was geared to patients. Giudici, a nutritionist, insisted on the importance of ensuring a proper balance of proteins and calories, and of keeping the immune system strong through proper nourishment. She discussed brain fog and good bowel functioning, and mentioned a controversial therapy called Branched Chain Amino Acids (BCAA). She reminded us that obesity may be related to fibrosis, of the dangers of alcohol, raw seafood, and aflatoxins, and stressed the importance of vitamin E, snacking, and consulting with a dietician.

Colina Yim gave us tips on fatigue-management, such as getting out more, getting enough sleep, and using a daily journal to record when we feel good, to take advantage of those hours. She stressed the importance of exercise, and that it is more beneficial if done in a natural setting.

After lunch the first day, there was a session for all, "Transmission of Hepatitis C", with Patty Daly, MD, and Bernard Willems, MD, who presented statistics on how and where the disease is spread, needle-sharing being the principal means of infection. *According to both doctors, surprisingly, infection rates are rising in spite of needle exchange programs*. The solutions suggested were: i) use of substance alternatives, ii) making people feel responsible, iii) targeting youth, iv) distribution of cotton and spoons, and v) a vaccine. Other routes of infection were examined, as was prevention.

In the last session of the first day that I attended, "Living with Hepatitis C: Legal and Ethical Issues Affecting Human Rights," Ralph Jurgens talked about prison issues, access to care, treatment and support, discrimination, drug laws, testing and confidentiality, poverty, income benefits, immigration issues, legal and ethical issues and informed consent for clinical trials, drug approvals, "off label" use of drugs, income maintenance, insurance, PharmaCare and medical marijuana.

Jenny Heathcote, MD, opened the next day of the conference with "Treatment Options and Issues," giving us the statistics, extolling the future virtues of pegylated interferon combined with ribavirin, and reminding us that we have three options: Prevent progression, treat, and/or wait.

Next I heard a panel of four speakers, "Co-infections: Which One To Treat First," who compared the two diseases and their individual treatments, and came to the conclusion that, since HIV patients are living longer, the more severe cases need treatment for hepatitis C. According to Dr. Walmsley, if the immune system is restored, HIV viral load is good and it can't be treated, then hepatitis C should be treated first. However, if CD4 levels are low, it's best to treat the HIV first. "We NEVER start by treating both infections simultaneously," she stated. While some of the drugs help each other, others are antagonistic, and the Hep C drugs may harm the immune system, while the HIV drugs can hurt the liver. In the question period, Dr. Peltekian recommended that those who relapse get a repeat biopsy in 1-2 years, and that should the grading/staging be the same, these persons should consider more treatment. If the grading/staging has improved, he recommends waiting for a better treatment to come along.

In her talk, subtitled "Guinea Pigs Unite," to which I could definitely relate, Robyn Sussel discussed all aspects of clinical trials and informed consent, and urged us to request more research (Activist materials: www.hivnet.ubc.ca/ctn.html). At the same time, a talk was being given on pediatric issues, the first of its kind at a hepatitis conference. It was pointed out that fibrosis occurs in 50-70% of infected children 8 to 15 years old, and that children have a better response rate and less side effects to treatment than adults.

That evening, scholarship recipients were treated to a dinner and entertainment cum question session with doctors. The acting was good, but, although it showed us a good example of street theatre, personally, I felt it was a bit patronizing. Since this event was just for "us," people let down their hair, and it became an unexpectedly emotional meeting, fraught with more than a few tears.

Eugene Oscapella, LL.B., opened the third session with "Prevention." He gave a convincing talk on the decriminalization of drugs, and spoke of the lack of prevention in prisons, asking, "Could we have designed a better way to spread infection?" His policy is "Legalize, control, discourage." He has a point, but on the other hand, I couldn't help but think to myself, "So if we all start using drugs, who will pay the taxes to support us?"

Dr. Frank Anderson, "Future Therapies and Vaccine Development," gave a talk on patient and disease variables involved in treatment, and on current and future treatments, such as the protein-based inhibitors, ribozyme and anti-sense-based therapies, and inhibitory cytokine therapies.

I attended the session given on Compensation, with Sharon Matthews and Mike McCarthy. The following tips were given for filling out the forms: 1) Read the instructions. 2) Check the website. 3) Let your health care drive Compensation, not vice versa. We heard about the provinces receiving 300 million dollars from the federal government over 20 years, and absorbing it into their health budgets, using it for things other than hepatitis C. We also heard that the numbers of people to be compensated are much smaller that expected, lead-

*(Continued on page 7)*

## CONFERENCE

(**CONFERENCE**—*Continued from page 6)*

ing to the question of what will happen to the extra money. Here again, during the question period, tempers justifiably flared, and an unnamed knight tossed his thick pile of "impossible" application forms into the aisle and marched out.

The session entitled "Liver Transplant" made it very clear that we must take care of our livers rather than depend on future transplantation. Waiting times are increasing, however if we doubled organ donations, there would be no wait. The outcomes for people with hepatitis C are similar, but not quite so good as for other patients in Canada. Treatment post-transplant, the use of older organs, live donors, and splitting livers were mentioned. All HCV+ transplant patients remain infected. Many progress more rapidly than before. The normal 5 year survival rate is considered "acceptable," and post-transplant treatment is "sub-optimal."

Dr. Morris Sherman's presentation, "Canadian Viral Hepatitis Network," outlined the new non-profit organization funded and set up by Health Canada, whose projects include a national database, serum and tissue bank, a physician-mentoring program, a nurse/practitioner program, and a virtual research centre. It hopes to include a role for community groups in the near future. When, however, Dr. Sherman was questioned as to what extent community groups will be involved, he changed the subject and did not answer. (While there is uncertainty about how community groups will fit into this Network, the BCCDC has just invited BC community representatives to a strategic planning session June 27, 2001.)

During the last session of the day, Dr. Kelly Kaita gave us a long list of "Extra-Hepatic Manifestations," dealing primarily with cryoglobulinemia (MEC), its symptoms and treatments (mostly interferon). She also touched on diabetes type 2.

The attention given to hepatitis C, and the increasing number of groups and literature available was encouraging. The conference showed me that I'm not alone in my fight. I hope there will be repeat next year, preferably on the west coast.

*Joan King*
*President, HepCBC*
*Editor-in-chief, hepc.bull*

## ALLOWANCE

(**ALLOWANCE**—*Continued from page 1)*

medical advisory committee in order to finalize a definition of "wasting syndrome."

Eligibility will be granted to those with symptoms caused by chronic illness and not by poverty. This means that a person may not claim to be malnourished as a result of receiving the standard $786 currently administered by BC Benefits. The Ministry often receives complaints from recipients that the standard amount, in effect, is the cause of malnutrition, weight loss and the like. The Ministry makes clear that this will not be a valid basis for applying to receive the allowance.

Supplemental treatment will be made available to those whose ill health is a direct result of their chronic condition. Even in the event that a person has been designated as being eligible on the basis of having "wasting syndrome," the maximum allowance of $300 is not automatic. The benefits will be delivered as a customized package of cash allowances and in kind benefits such as vitamins and minerals, making the process discretionary to a certain degree.

It is important to note that it is likely that only those individuals who are eligible for BC Benefits DB2 will able to access the new allowance which is meant to cover illness-related costs. Adequate nutrition, vitamins and minerals, and various over-the-counter products are essential for people with certain chronic illnesses. In order to access the allowance an individual must be beyond the exempt limit and exhausted all other avenues of support. The fact that this allowance is only available through the most stringent of means tested demonstrates there is still a long way to go in advocating for a comprehensive universal health care program.


**The new allowance will be made available beginning July 2001. Contact your local Ministry office for more details.**

*Source: The Long Haul, May 2001, p.8*

## WARNINGS

### TO KISS OR NOT TO KISS…

Those co-infected with HIV/HCV have been found to have high amounts of HCV in their saliva. A study by Dr. D. Rey and colleagues from France, tested blood and saliva samples from 59 co-infected patients by PCR. More than 33% of the patients had HCV in their saliva, interestingly, more men than women.

In the same patients, 76.3% had detectable HCV genetic material in their blood.

"To our knowledge, this study is the first to find significant amounts of HCV RNA in saliva," said the authors, adding that the results "**could have important implications for hepatitis C epidemiology, as the origin of infection remains unknown in up to 40% of cases.**"

*Source: Reuters Health, Mar 07, 2001 Significant Amounts of HCV RNA Found in Saliva of HIV-Coinfected Patients (J Med Virol 2001;63:117-119)*

### ARISTOLOCHIC ACID

The US (FDA) has issued a warning about products containing aristolochic acid, used in traditional medicines or in dietary supplements, believed to be linked to kidney failure and urinary cancer. This includes products with the words Aristolochia, Bragantia, Asarum, Guan mu tong, Guang mu tong, Oval leaf, Dutchman's pipe, Ukulwe, Birthwort, Ma dou ling, Tian xian teng, Mil homens, Ma dou ling, Tian xian teng, Qing mu xiang Sei-mokkou (Japanese), Long birthwort, Guang fang ji, Fang ji, Mokuboi (Japanese), Kwangbanggi (Korean), Fang chi, Kou-boui (Japanese), Indian birthwort, Dutchman's-pipe, Manchurian birthwort, Guang mu tong, Kan-Mokutsu (Japanese), Mokuboi (Japanese), Kwangbanggi (Korean), snakeroot, Serpentaria, Virginia serpentary, Wild ginger, Indian ginger, False coltsfoot, Colic root, and Do-saishin (Japanese). **If you've ever taken any of these products contact your doctor.**

*Source: http://www.hivandhepatitis.com FDA Warns Consumers to Discontinue Use of Botanical Products Containing Aristolochic Acid*

### METABOLIFE

Metabolife International is voluntarily recalling its energy bars, since they **may contain toxic levels (around 32,500 IUs) of vitamin A**, which can cause several problems, including **liver damage**. The bars have a red label and come in the varieties: Outrageous Oatmeal, Raisin, Perfectly Peanut, Downright Chocolate and Lemony Lemon. Metabolife: 1-800-540-7099 http://www.metabolife.com

*Source: Associated Press, Metabolife Recalls Energy Bars, by Seth Hettena*

*(Continued on page 8)*

(**CANDLE LIGHT**—*Continued from page 1)*
flame itself represents the eternal flame of loving memories we carry in our hearts for those who have passed on, and the white candle represents the purity of our caring so that those who are now suffering know they will not be forgotten and that their struggles are not in vain. The red and yellow hepatitis C ribbon represents how the virus taints our blood. The candle can be viewed on the web at http://www.junction.net/hepcure/memorial/candle.htm

The ceremony opened with a collaborative 2 minute and 45 second computer presentation. This wonderful presentation was composed of a voice over of original poetry read by Bill Buckels of HepSEE WPG, slides of the first Canadian HCV Candle Light Memorial Vigil, held in Nanaimo, May 1st, 2000 by Susan White and the Mid Island Hepatitis C Society and instrumental background music. The presentation can be viewed at http://members.home.net/hepsee.wpg/resources/hepclite.zip.

*Speech delivered by Marjorie Harris*

Welcome to the 2nd Annual Hepatitis C Candle Light Memorial Vigil. It is my pleasure to be here with you.

Hepatitis C can and will be overcome! Imagine the cure!

Currently, hepatitis C is the leading cause for liver transplantation in North America. The death rate related to hepatitis C may double or triple over the next 10 to 20 years.

This devastating problem must not be ignored. The costs are enormous in human pain and suffering, direct medical expenses and indirect hidden costs to society.

How much will this financial burden be for Canadians?

The costs for Americans were estimated by computer simulation by Dr. John B. Wong in his article titled, "Estimating Future Hepatitis C Morbidity, Mortality, and the Costs in the United States," published in the *American Journal of Public Health*, October, 2000. Using Dr. Wong's model we can estimate the Canadian financial burden by applying a simple population ratio to convert the projected statistics. The burden in direct medical expenses and indirect hidden costs to society for the ten-year period from 2010 through 2019 comes to 9.4 billion dollars US.

Conservative estimates suggest that 240,000 Canadians are currently infected with hepatitis C and that approximately 25% of those infected will suffer from end stage liver disease, liver cancer and death.

If we can prevent 6 people from suffering the consequences of hepatitis C, there is a potential saving of over 1 million dollars.

Intervention is crucial to stem the tide before the social ramifications become overwhelming and catastrophic.

What can we do today to STOP the spread of hepatitis C?

We do not have preventative vaccines and our medicines are still sub-optimal. We need more medical and pharmaceutical research. In the meantime the only weapons we have to combat the spread of hepatitis C are Awareness, Education and Prevention programs.

Live in Light and Love Sheer Compassion. It hurts my heart to remember those who have suffered and passed on and those who are now suffering and need so much care.

It hurts my heart to remember all of the lives and families under stress from hepatitis C.

Honour them. Honour them today in consciousness. Let your hearts and souls collectively come together. Imagine the cure. Let there be no doubt. Know that a cure will be found in our generation. Be hepatitis C aware. Live hepatitis C aware. Look at our children, our genetic immortality. Embrace a future for them that is free from the grief, pain and suffering of hepatitis C. Give hope. Advocate for more research!

Imagine the cure!

Marjorie Harris
www.junction.net/hepcure

(**WARNINGS**—*Continued from page 7)*

## NAPROXEN AND DICLOFENAC

According to a recent study investigating the effect of NSAIDs on the liver, Naproxen and diclofenac were associated with liver injuries. The risk decreased significantly when the analysis was performed after excluding other hepatotoxic drugs associated with NSAIDs (except for naproxen). The main danger seems to be the use of other hepatotoxic drugs at the same time.

*Source: Bareille MP, et al, Therapie 2001 Jan-Feb;56(1):51-5 , Naproxen and diclofenac were associated with a higher frequency of liver injuries PMID: 11322018*



## PEG-INTRON COMBO APPROVED

*COSTA MESA, CA:* Schering-Plough Corporation announced that the European Commission of the European Union has granted centralized marketing authorization to PEGINTRON™ Injection and REBETOL® (ribavirin) capsules as combination therapy for the treatment of both relapsed and naive adult patients with histologically proven chronic hepatitis C. REBETOL, an oral formulation of ribavirin, is marketed for use in combination with Schering-Plough's interferon alfa-2b injection (marketed as INTRONA™). The pivotal clinical study on which the marketing authorization is based demonstrated that PEGINTRON and REBETOL combination therapy was significantly more effective in achieving a sustained virologic response (SVR) in patients receiving the recommended combination regimen than the combination of interferon alfa-2b (INTRON® A) and REBETOL. The study showed that SVR rates were increased if patients were able to maintain compliance.

*Source: PRNewswire March 28, 2001, ICN Pharmaceuticals Says Schering-Plough Announces European Union Approval Of PEGINTRON™ and REBETOL® Combination Therapy for Hepatitis C*

## WEI JIA FOR IMMUNE SYSTEM?

*HONG KONG*: A new drug for the treatment of hepatitis A, B and C and alcoholic liver disease was recently approved by China's State Drug Administration as a Western drug rather than an herbal medicine. Derived from piglet livers, the hepatocyte growth-promoting factor "Wei Jia" is a hormone-like substance that stimulates liver cells to regenerate and repair damaged tissue. Open label clinical trials involved 671 patients at 50 hospitals in China. Patients were divided into two groups: those with "very severe" chronic hepatitis and liver failure and those with "severe" acute hepatitis and hepatitis flare-ups. In the acute hepatitis group, Wei Jia was highly efficacious in 34% and efficacious in 44% of patients. The patients' livers were not biopsied during the clinical trials and there are no histologic data available. Talks are underway to commence clinical trials in other Asian countries where hepatitis B is widespread.

*Source: Reuters Health Apr 04, 2001, Hepatocyte Growth-Promoting Drug Approved in China*

*(Continued on page 10)*

# TRIALS

## IFN + CEPLENE and PEGASYS + RIBAVIRIN TRIALS

Maxim Pharmaceuticals announced the results from its Phase II study of Ceplene (histamine dihydrochloride) plus IFN in naive Hep C patients. It looks like Ceplene may be the same as Maximine, also histamine dihydrocloride, the drug involved in a lawsuit because of its faulty Phase III trial results. (See the February 2001 issue of the *hepc.bull*). The authors of this study claim a sustained viral clearance of 44% with the highest dose of Ceplene (10 mg per week) plus IFN, compared to 16% for those on IFN alone in this study. An encouraging 38% of genotype 1 patients had a sustained response with the Ceplene combo, compared to 8% with IFN alone.

During the same week, Roche Pharmaceuticals announced preliminary results of its Pegasys + Ribavirin trials (not sustained responses) on 1,143 naïve patients. Those in the higher dose Pegasys combo had an end of treatment (48 weeks) response rate of 68%. The sustained response is expected to be lower.

*Source: BW HealthWire http://biz.yahoo.com/bw/010420/0001.html April 20,2001, Maxim Reports 72-Week Results From Completed Phase 2 Hepatitis C Study Demonstrating Benefit of Treatment With Ceplene http://www.maxim.com and Di Bisceglie AM. Highlights from the 36th Annual Meeting of the European Association for the Study of the Liver (EASL 2001) April 18-22, 2001 Prague, Czech Republic*

## IFN + AMA

This study compared IFN plus amantadine (AMA) to IFN alone in 200 naïve Hep C + patients. Patients were treated for 12 months and re-tested 6 months later. A sustained response was observed in 16.8% of patients with IFN alone and in 29.3% of patients who were treated with combination therapy. This new treatment appears safe and well tolerated.

*Source: A Mangia, et al, Hepatology 2001;33:989-993 A randomized trial of amantadine and interferon versus interferon alone as initial treatment for chronic hepatitis C*

## PIVANEX FOR LIVER TUMORS

Titan Pharmaceuticals has begun a clinical study of Pivanex for the treatment of liver tumors. The Phase I/II clinical study is being performed at Stanford University Medical Center at the Palo Alto Veteran's Affairs Medical Center. The study with about 25 patients will assess the safety, efficacy and survival of patients with liver tumors taking Pivanex, an analog of butyric acid. Pivanex causes cancer cells to die, but spares normal healthy cells. The drug is administered through the hepatic artery, hopefully causing less toxicity to the body. The results are encouraging so far.

*Source: PRNewswire March 28, 2001 Titan Pharmaceuticals Initiates Clinical Testing of Pivanex(R) For Hepatic Tumors*

## STEROID-FREE LIVER TRANSPLANTATION

Thymoglobulin (ATG), a steroid-free treatment, may decrease organ rejection, diabetes and hepatitis C in liver transplant recipients, according to a study of 71 liver transplant patients done at the Ochsner Multi-Organ Transplant Center, in which half received rabbit ATG, and the other half received steroid therapy. "Four percent of steroid-free patients developed post-transplant diabetes, and only 50 percent developed recurrent hepatitis C. In comparison, 14 percent of steroid-treated patients developed post-transplant diabetes and 70 percent developed recurrent hepatitis C." Survival was the same in both groups.

*SOURCE: May 10, 2001 /PRNewswire/ Steroid-Free Liver Transplantation Shown to Decrease Incidence of Organ Rejection*


# JOURNAL SCAN
*by C.D. Mazoff, PhD*

## MORE PROBLEMS FROM INTERFERON

An article in the April issue of the *American Journal of Gastroenterology* (vol 96, no 4, 2001, p 1311) reports that interferon therapy for hepatitis C could cause *angioedema*, which is a swelling and collection of fluid in the walls of blood vessels. **This condition is a known side-effect of interferon therapy and can be fatal.** Furthermore, the authors warn that, although it is rare, "it may occur at any time, even 5 months after the start of interferon therapy."

## MORE PROBLEMS FROM ACETOMINOPHEN

And while we're at it, hepatic failure and encephalopathy has been attributed to an interaction between acetaminophen and Rifampicin, an antibiotic (AJG vol 96, no 4, 2001, p 1310).

## IS TIPS WORTH IT?

God-forbid you should ever need a portosystemic shunt. The question is, "is the surgery worth it?"

An article in the May 2001 issue of the *AJG* (vol 96, no 5, p1332) reports that while TIPS (transjugular intrahepatic portosystemic shunt) is often used as a last resort for persons awaiting liver transplantation, or who have severe ascites, enlarged spleen, radical bleeding problems or kidney failure, compared to other surgical procedures, it is not the best procedure.

Recent studies show conclusively that the **small diameter prosthetic H-graft portacaval shunt** is much better. Compare a failure rate of 65% for TIPS to 35% in the H-graft; more TIPS recipients suffered major bleeds; more TIPS recipients required more interventions.

## NO MORE PAIN IS NOT A LAUGHING MATTER

Last, doctors worried about controlling pain in liver biopsies have recommended that patients self-administer laughing gas (*AJG* May 2001 p 1327-29). They argue that bleeding from a serious complication would be immediately evident, and that nitrous oxide costs only $4, whereas performing an ultrasound guided biopsy costs about $35-45.

Last month in my journal scan I quoted a recommendation from the American College of Gastroenterology that all physicians use ultrasound to guide biopsies because misses can be fatal. Greed, however, seems to have a hearing problem.. This is **not** a laughing matter.

(**NEWS**—*Continued from page 8)*

## BETTER LIVER CANCER DIAGNOSIS

*BERLIN*: Schering AG, leader in the market for magnetic resonance imaging (MRI) contrast media, announced today that it has received its first approval for the liver-specific contrast agent Resovist® in Sweden. Resovist® is a new and innovative, organ-specific contrast agent used for the detection and characterisation of especially small focal liver lesions, which is relevant for the early detection of hepatic carcinoma or metastases. Resovist® is injected as an intravenous bolus, allows immediate imaging of the liver, and therefore reduces the overall examination time. In comprehensive clinical trials, Resovist® demonstrated an excellent safety profile. Based on the approval in Sweden, which is the European Reference Member State for the Mutual Recognition Procedure, marketing authorisation of Resovist® in the EU is expected within the next six months.

*Source: PRNewswire via COMTEX, March 28, 2001, Schering AG Receives First Approval for Resovist(R)*

## HCV RESEARCH RIGGED

A visiting Japanese scientist, Dr. Tatsumi Arichi, working at the National Cancer Institute, has admitted he rigged part of a vaccine research project and fabricated data. The original paper describing the vaccine work appeared in the Proceedings of the National Academy of Sciences in its January 4, 2000 issue. In its conclusion, that paper said that a DNA vaccine being tested in mice in the experiment was a "potential candidate" for a vaccine to prevent hepatitis C. In the wake of that paper, scientists tried repeatedly to duplicate the results but were unable to do so. The retraction appeared on the PNAS Web site and was published in the May 8 edition of the journal. Retractions such as this are occurring more frequently, said an official of the American Association for the Advancement for Science. Retractions can stem from honest mistakes in experiments as well as data fabrication.

*Source: The Boston Globe 05/03/2001 http://www.boston.com/globe Richard Saltus Hepatitis Vaccine Study Rigged; Report Retracted*

## TATTOOS UNREGULATED

Getting a tattoo could be a key infection route for hepatitis C according to a study at the UT Southwestern Medical Center in Dallas. Participants were tested in 1991 and 1992 in an orthopaedic spinal clinic, unaware that their hepatitis status was being examined. Of the 626 patients studied, 18 percent had a tattoo. Of those with a tattoo, 22 percent were infected with hepatitis C. The study found that people who had several, complex, or large tattoos or tattoos with white, yellow, orange or red pigments had an increased risk of having hepatitis C than those with only black. Hepatitis C can be passed through tattooing by reuse of tattooing needles or dye, inadequate sterilization of tattooing needles between customers, or breaks in sterile technique such as the artist pricking the back of his or her hand to test the needle's sharpness.

*Source: http://www.boston.com/globe, April 4, 2001, Tattooing a major route of hepatitis C infection, UT Southwestern researcher finds. Contact: Mindy Baxter, University of Texas Southwestern Medical Center at Dallas*

## NEUROPSYCHIATRIC SIDE EFFECTS OF IFN

Dose-dependent, reversible neuropsychiatric toxicity is reported in up to 30-40% of chronic hepatitis C patients treated with 6-12 months of interferon-alpha or interferon alpha plus ribavirin combination therapy. Although risk factors remain poorly defined, neuropsychiatric side effects may be severe and dose limiting in as many as 10-20% of treated patients. Diagnosis relies upon the detection of clinically apparent neuropsychiatric symptoms and the emerging use of self-administered mood inventories and questionnaires. Although the cellular basis of the neuropsychiatric toxicity of interferon-alpha remains unknown, several hypothesis involving changes in central adrenergic, seratonergic, opioid and neuroendocrine pathways have been proposed. Recognition and management of the neuropsychiatric side effects of antiviral therapy will be of growing clinical importance as additional patients with chronic hepatitis C are treated and longer durations of therapy are utilized.

*Source: Dig Dis 2000;18(3):107-16 Fontana RJ. Neuropsychiatric toxicity of antiviral treatment in chronic hepatitis c. PMID: 11279329*



## PERSONALITY AND YOUR IMMUNE SYSTEM

A study done at the Western Psychiatric Institute and Clinic at the University of Pittsburgh School of Medicine tested how 84 participants responded to a Hep B vaccine.

They were also given a test to measure neuroticism, indicating people who tend to be moody, nervous and easily stressed. Those participants who were more neurotic tended to respond more poorly to the hepatitis vaccine, possibly showing that these people have less protective immune responses.

*Sources: Center For The Advancement Of Health (http://www.cfah.org), http://www.sciencedaily.com/releases/2001/01/010119080203.htm, http://www.cfah.org/website2/Newsrelease/personality1-19-01.htm*

## THIAMINE

In a small study, Hep B patients were given the B vitamin Thiamine, resulting in normalisation of liver enzyme tests. This could be a cheap and nontoxic way of treating the infection. A bright patient of Dr. Amy Elizabeth Wallace noticed that his AST levels fell when he was taking the vitamin, thus Wallace and a colleague conducted a trial in this patient and two others with HBV who failed IFN therapy. They think that the thiamine reduces the iron load in the liver. The vitamin is inexpensive and has no side effects. It hasn't been tested in Hep C patients.

*Source: Reuters Health, Apr 13, 2001 Thiamine helps hepatitis patients in small study by Anne Harding*

## BIOPSY SUBSTITUTE?

Liver biopsy is the best way to know the state of the liver in Hep C patients. The researchers in this study looked for a combination of blood tests that could detect fibrosis, even in early stages. They compared these findings with biopsy results by taking blood samples of 205 patients on the day of their biopsies, and then again on another 134 patients. They came up with a fibrosis index sensitive to age and sex differences. The best markers were: alpha (2) macroglobulin, alpha(2) globulin (or haptoglobin), gamma globulin, apolipoprotein A (1), gamma glutamyltranspeptidase, and total bilirubin. The researchers believe that a combination of basic blood tests could reduce the number of biopsies on Hep C patients.

*Source: Imbert-Bismut F, et al, Biochemical markers of liver fibrosis in patients with hepatitis C virus infection: a prospective study. PMID: 11297957 http://www.amedeo.com/lit.cfm?uid=A11297957&aid=B126260&dopt=r&s=chep*

## GEORGE MARCELLO: SCHEDULE

Please check the 500 Day Walk schedule to see when it is coming to your community and help out the campaign by letting your City Hall know that you would like to support the awareness event in your community.

Please call George or David at (416) 540-7872 to volunteer to carry the Torch of Life.

Marjorie Harris, wwwjunction.net/hepcure

*For more information, about organ and tissue donation and liver disease please visit the following websites:*

***Step by Step Organ Transplant Association*** *www.stepbystep.ca*

***BILL C-227*** *http://www.parl.gc.ca/36/2/parlbus/chambus/house/bills/private/c-227/c-227_1/362032bE.html*

***HepCURE*** *(Hepatitis C United Resource Exchange) www.junction.net/hepcure/*

June 1-3 Kamloops
June 4-5 Merritt
June 6 Lytton
June 7 Clinton
June 8-10 100 Mile House
June 11-12 Williams Lake
June 13-14 Quesnel
June 15-17 Prince George
June 18-19 Vanderhoof
June 20-21 Pemberton
June 22-24 Whistler
June 25 Squamish
June 26 Lion's Bay
June 27-28 North Vancouver
June 29-July 1 Port Moody
July 2 Coquitlam
July 3 Port Coquitlam
July 4 Langley
July 5 White Rock
July 6-8 New Westminster
July 9-10 Vancouver
July 11 Harrison Hot Springs
July 12 Hope
July 13-15 Chilliwack
July 16 Mission
July 17 Matsqui
July 18 Abbotsford
July 19 Campbell River
July 20-22 Courtney
July 23 Port Alberni
July 24 Parksville
July 25 Nanaimo
July 26 Duncan
July 27 Victoria

## THE CO-INFECTION SECTION

### HAART MAY ELIMINATE HCV

In HIV/HCV coinfected patients, HAART therapy reduces and may eliminate HCV, according to Dr. Junki Takamatsu and his colleagues. 130 male hemophiliac patients were tested and some were found to be co-infected. Until now it has been thought that HIV therapy did little if anything for HCV, but in this case, it eradicated the HCV in 2 of the co-infected patients who were treated, and in the others, reduced the viral load. The co-infected patients also experienced a rise in B-cell counts, and a decline in serum IgM levels, leading these researchers to conclude that "coinfected patients should be treated with HAART to improve host immune status, followed by treatment with interferon and ribavirin."

*Source: Blood 2000;96:4293-4299.*

## WHERE IS THE MONEY GOING?

The Federal Government claimed that Canadians would give "care not cash" for the victims of the blood infected outside the imaginary '86-'90 "window." To this end, he promised $300,000,000 over the next twenty years. This money would be sent to the provinces, and was to be used specifically to avoid any out of pocket costs to these people. It was and is earmarked to pay for treatments that are not covered by provincial plans for those not covered by "the package."

The Progressive Conservative Government of Nova Scotia is looking at these funds as a windfall from Ottawa. Premier Hamm told people that it would not be used as intended, and that he was not going to create a two-tier health care system for people with hepatitis C in the province. The simple solution to this is to include full treatment for everybody with Hep C under our provincial plan. The logic and long term cost saving of this move seems to have escaped Premier Hamm and his advisors.

On May 14, I received yet another letter from Health Minister Muir re: stating his position that this money would not be spent as intended. I faxed it all to My MP Peter Stoffer, and Peter, once again proving one of our staunchest supporters, has raised this issue in Parliament.

What is your provincial government doing with its allotment? Is it going to prevent any out of pocket expenses for the forgotten victims as intended, or is it being viewed, as it is in Nova Scotia, as a windfall? Local grassroots organisations should raise this issue. Talk to people infected outside the window and find out if they are paying for any treatment. Talk to government and find out how and where they are spending it. Make sure it goes where intended. It's little enough for those the government and class action lawyers chose to ignore. Remember, these people were infected by the same blood supply as us, through the same criminal neglect as us, the only difference is all they are getting is this paltry amount of money for treatment, and already local governments are prepared to take it from them.

*Bruce DeVenne*


## COMPENSATION

**BRITISH COLUMBIA**

**1986-1990**
Bruce Lemer/Grant Kovacs Norell
Vancouver, BC
Phone: (604) 609-6699 Fax: (604) 609-6688

**Before August 1, 1986 or 1990-1991**
David A Klein/ Klein Lyons
Legal Assistants: Carol Anton or Jeanette Cheung
Vancouver, BC (604) 874-7171, 1-(800) 468-4466, Fax (604) 874-7180

also:

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

The toll free number to get you in touch with the **Hepatitis C Counsel** is 1-(800) 229-LEAD (5323).

**ONTARIO AND OTHER PROVINCES**

**Pre 1986/post 1990**
Mr. David Harvey/ Goodman & Carr
Toronto, Ontario
Phone: (416) 595-2300, Fax: (416) 595-0527

**TRACEBACK PROCEDURES:**

**INQUIRIES-CONTACT:**

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

This information is for anyone who has received blood transfusions in Canada, if they wish to find out if their donors were Hep C positive.

**RCMP TaskForce TIPS Hotline**
(Toll free) 1-(888) 530-1111 or 1 (905) 953-7388
Mon-Fri 7 AM-10 PM EST

**CLASS ACTION/COMPENSATION**

*If you would like more information about class action/compensation, or help with a lookback, contact:*
*Leslie Gibbenhuck Tel. (250) 490-9054*
*E-mail: bchepc@telus.net*
*She needs your name, address, birth date, transfusion dates, and traceback number.*

National Compensation Hotline: 1-(888) 726- 2656

**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

***Should you have any questions about the status of your claim (86-90), please contact the administrator. They should answer all of your questions. If, however, they do not, then please contact Bruce Lemer who has promised me that he would answer your questions at no charge.—C.D. Mazoff*

# COMING UP IN BC/YUKON:

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

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

**Chilliwack BC HepTalk** Meetings: 2nd & 4th Wed. each month, 7-9 PM, Chilliwack. Next meetings: June 12th & 26th. Contact: HepTalk@fraservalleydir.every1.net, or 856-6880.

**Comox Valley HeCSC** Meetings: 3rd Tues. each month, 6-8 PM, St. George's United Church on Fitzgerald. Next meeting June 19th Contact: Jayne, 336-2485 or Dan, 338-0913, Rhagen@mars.ark.com

**Cowichan Valley Hepatitis C Support** Contact: Debbie, 715-1307, or Leah, 748-3432.

**Cranbrook HeCSC** : Meetings: 1st & 3rd Tues. each month, 2-4 PM, #39 13th Ave South, Lower Level. Next meetings June 5th & 19th. Contact: 426-5277, hepc@cyberling.bc.ca

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

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

**Kelowna HeCSC** Meetings: 1st Sat. each month, 2-4 PM, Rose Avenue Education Room, Kelowna General Hospital., Next meeting: June 2nd. Contact: Doreen, 769-6809 or eriseley@bcinternet.com

**Kimberley Support Group** Meetings: 1st Mon. each month, 1-3 PM. Next meeting June 4th. Contact Katerina 426-5277

**Kootenay Boundary** Meetings: 2nd & 4th Tues. each month, 7 PM, 1159 Pine Ave, Trail. Next meetings June 12th & 19th. Contact: Brian, 368-1141, k-9@direct.ca.

**Mid Island Hepatitis C Society** Meetings: 2nd Thurs. each month, 7 PM, Central VI Health Centre 1665 Grant St, Nanaimo **Contacts—Ladysmith:** Sue 245-7635 **Nanaimo:** Barb 756-9631 **Parksville** Ria 248-6072 mi-hepc@home.com

**Mission Hepatitis C and Liver Disease Support Group** Meetings: 3rd Wed. each month, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting June 20th. Contact Gina, 826-6582 or Patrick, 820-5576.

**Nakusp Support Group Meetings:** 3rd Tues. each month, 7 PM, Nakusp Hospital Boardroom. Next meeting: June 18th. Contact: Ken, 1-800-421-2437

**Nelson Hepatitis C Support Group** Meetings: 1st Thurs. each month. ANKORS Offices, 101 Baker St., Next meeting: June 7th. 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. each month, 7-8:30 PM, First Nations' Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. Next meeting June 11th. Contact: Dianne Morrissettie, 525-3790.

**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** Meetings: 2nd Wed. each month, 7-9 PM, Penticton Health Unit, Board rooms. Next meeting June 13th. Contact: Leslie, 490-9054, bdhepc@telus.net

**Powell River Hep C Support Group** Meetings 2nd Wed. each month, 7-9 PM, Next meeting: June 13th Malaspina College: Hep C and the Internet. No computer skills required.. Contact: Cheryl Morgan 483-3804.

**Prince George Hep C Support Group** Meetings: 2nd Tues. each month, 7-9 PM, Health Unit Auditorium. Next meeting June 12th. Contact: Gina, 963-9756, gwrickaby@telus.net or Ilse, ikuepper@pgrhosp.hnet.bc.ca

**Princeton** Meetings: 2nd Sat. each month, 2 PM, Health Unit, 47 Harold St. Next meeting June 9th. Contact: Brad, 295-6510, citizenk@nethop.net

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

**Quesnel**: Contact Elaine Barry. Meetings last Mon. evening every other month. 992-3640

**Richmond: Lulu Island AIDS/Hepatitis Network**: Meetings/dinner each Mon. evening. Contact Phil or Joe at 276-9273.

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

**Smithers: Positive Living North West** Meetings: 2nd Wed. each month. 7-9 PM, 3731 1st Avenue, Upstairs. Next meeting: June 13th. Contact: Deb. 877-0042 or 1-866-877-0042, plnwhepc@bulkley.net, or Doreen, 847-2132, aws@mail.bulkley.net

**Sunshine Coast—Sechelt:** 1st Wed. each month. Next meeting June 6th. Contact: Kathy, 886-3211, kathy_rietze@uniserve.com—**Gibsons**: Last Thurs. of each month. Next meeting June 28th. Both meetings—Health Units, 7 PM. Contact Bill, pager 740-9042

**Vancouver HepHIVE:** Contact: 254.9950 hephive@mdi.ca **Meetings:**

- **Carnegie Centre** Hep C & HIV/HCV Meetings: Each Mon., 4:30-6 PM, 3rd floor, room. 2.
- **HepHIVE and HepC VSG** Hep C & HIV/HCV Meetings: Last Wed. each month, 10:30-12:30, BCCDC Building, 655 West 12th Tom Cox Boardroom 2nd floor. **Next meeting Aug. 29th. (None Jun/July)**
- **Positive Outlook.** 441 East Hastings Street. Hep C & HIV/HCV, 1st & 3rd Thurs. each month, 2-3PM.

**Vernon HeCSC HEPLIFE** Meetings: 2nd & 4th Wed. each month, 10 AM-1 PM, The People Place, 3402-27th Ave. Next meetings June 13th & 27th. Contact: Sharon, 542-3092, sggrant@netcom.ca

**Victoria HeCSC** Meetings: 1st Mon. each month, 6:30-9 PM, CHR 1947 Cook St. Multi-Purpose Room and last Wed., St. John's, 1-3 PM. Contact: 388-4311, hepcvic@coastnet.com

**Victoria Support and Discussion Group** Meetings: 1st Wed. each month, 7-9 PM, Next meeting June 6th. 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

**Yukon Positive Lives** Meetings: 3rd Wed. each month, Whitehorse. Next meeting June 20th. Contact 456-2017, positivelives@yknet.yk.ca or Heather, fromme@marshlake.polarcom.com, www.positivelives.yk.ca

# OTHER PROVINCES

**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. each month, 7 PM, St. Martha's Health Centre, 25 Bay St, Level 1 Conference Room
- **Bridgewater:** Last Wed. each month, 7 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room
- **Halifax:** 3rd Tues. each month, 7 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110
- **Kentville:** 2nd Tues. each month, 6:30 PM, Kings Tech Campus, 236 Belcher St, Rm 214
- **Truro:** Last Tues. each month , 7 PM, Colchester Regional Hospital, 25 Willow St, Conference Room
- **Yarmouth**: 1st Tues. each month, 7 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1—Main level

**Cape Breton Hepatitis C Society** Meetings: 2nd Tues. each month. Contact: 564-4258 (Collect calls accepted from institutions) Call toll free in Nova Scotia 1-877-727-6622

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

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

**Saint John & Area/HeCSC**: 3rd Thursday each month, 7 PM, Community Health Centre, 116 Colburg Street. Contact Esmonde, 653-5637, hepcsj@nb.aibn.com, www.isaintjohn.com/hepc/

**ONTARIO:**

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

**Hep C Niagara Falls Support Group** Meetings: Last Thurs. each month, 7 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thurold. Contact: Rhonda, 295-4260 or hepcnf@becon.org

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

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

**PRAIRIE PROVINCES:**

**Edmonton, AB Hepatitis C Informal Support Group** Meetings: 3rd Thurs. each month, 6 PM, 10230-111 Avenue, Conference Room "A" (basement) Contact: Jackie Neufeld, 939-3379

**Edmonton, AB** Meetings: 2nd Wed. each month, #702-10242 105 St. Contact Fox, 488-5773, 473-7600, or fox@kihewcarvings.com

**HepSEE WPG Winnipeg** Meetings: Last Wed. of each month., 7-9 PM, Young United Church, 222 Furby St., Rm AB, Main Floor. Contact: Bill, 489-1405, bbuckels@escape.ca

**QUEBEC:**

**Hepatitis C Foundation of Quebec** Meetings: Montreal General Hospital 1650 Cedar Ave. 7-9 PM. Contact Eileen: 769-9040 or fhcq@qcaibn.com