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Canada's Hepatitis C News Bulletin

www.hepcbc.org

HEP C CIRCLE UPDATE: NANAIMO 2002

ADVANCE NOTICE!

BC/YUKON HEP C COLLABORATIVE CIRCLE: SKILLS, EDUCATION & ADVOCACY FORUM Friday, Saturday & Sunday, February 1st - 3rd, 2002

t the end of November 2001, people living with Hep C, managers of related projects, and advocates in British Columbia and the Yukon will receive registration materials for the first Hep C Circle Skills, Education & Advocacy Forum.

Registration, agenda and workshop information will be distributed by fax, email and on a dedicated Hep C Circle web site http://casper.ca/hepcircle, where all forum information will be updated regularly and available for download and feedback.

The Circle Forum is a peer-driven gathering to learn, share information and develop steps to enhance the quality of life for people living with Hep C in the BC/Yukon region. A number of hotel and travel scholarships will be made available to regional applicants; hotel and meal fees for non-scholarship participants will be based on cost-recovery, and are expected to be low (The registration package will clearly state these costs and the scholarship application process).

FORUM LOCATION:

Best Western Dorchester Hotel, 70 Church Street, Nanaimo, British Columbia

ADVANCE CURRICULUM:

Weekend workshops for, by, and about people living with Hep C

- Skills building
- Administrative tools
- Education and advocacy
- Guest Speakers

So mark your calendars for the first weekend in February, and expect your registration package soon.

Best regards,

Erik Ages

Hep C Circle Administrative Desk Erik (250-888-9697) Stacy (250-881-5663)



AASLD CONFERENCE NOTES

The American Association for the Study of Liver Disease (AASLD) held meetings in Dallas November 9-13, where many interesting new trial results were made public. Among these were 13 abstracts on Roche's Pegasys. Pegylation, as you may remember, involves attaching PEG (polyethelene glycol) to a molecule, making it stay in the body longer—in the case of interferon, more than one week. Some earlier Roche studies used smaller PEGS, which required more frequent dosing. These used 40 kilodalton branched PEG, named peginterferon alfa-2a. (Source: 11/07/2001 10:18 EST http://www.prnewswire.com)

We have had access to many studies, thanks to both NATAP's Jules Levin (www.natap.org), and to HCVAdvocate's Alan Franciscus (www.hcvadvocate.org), as they reported back daily.

HCV DRUGS

REBETRON: Preliminary results show that 40% of **non-responders** to previous Rebetron treatment are responding to pegylated interferon+ribavirin, with a 25% sustained rate (SVR)

PEGASYS IN HCV/HIV COINFECTION: Recently conducted studies suggest **coinfected patients can respond**, in a manner similar to patients with HCV alone, to HCV therapy, but study results can't always be duplicated in clinical practice. Other factors include adherence, the prevalence of genotype 1, high HCV viral load, and simultaneous treatment with HAART.

OMEGA IFN FOR GENOTYPE 1: In this study, 16 males and 8 females completed 14 days

(Continued on page 5)

INSIDE THIS ISSUE:

Ask the Chef	3
The Squeeky Wheel	3
HCV & the Immune System	4
Help Your Community	6
Research	6
Where is the Money?	7
Compensation	7
Coming Up	8

GUY THISDELLE

Guy Thisdelle: Guy was only 44 when he passed away from liver cancer. He was, at one time, the head of the Richmond Support Group, but, as his hepatitis C worsened, Guy found it more and more difficult to continue both his volunteer work and his life work as a professional counsellor-work which earned him a prestigious prize. His book, Fathers, Children, Family and Community (1999), was considered such an important work by the Canadian Guidance Counsellors Association that they made him the recipient of their prestigious National Counselling Resources and Training Materials Award in May of 1999. Guy leaves behind family and friends who really loved him. What more can a person ask for? He is sorely missed and fondly remembered.

"APACHE PAT" PAT DAVIS

"Apache" Pat Davis, or "Patchie" as she was affectionately known to her fellow heppers, was taken off the transplant list at her own request. She believed she had arrived at a state where she would no longer survive the surgery. She was surrounded by her loving family on November 1, 2001, when she passed away peacefully a day before her 62nd birthday—much too soon. Originally from Oregon. Pat lived in Apache Junction. AZ, where she was a support person. She was a founding member of the Samaritans, a Hep C group which provides Hep C sufferers in need with care packages, cards and virtual hugs. She was always thinking of others. The Hep groups on the web are in mourning.

IONI HARRIS BROWN

In memory of Joni Harris Brown. Joni was 47 at the time of her death and was diagnosed with hepatitis C approximately 20 years ago. She is remembered by family and friends in New Mexico and Texas.

hepc.bull DECEMBER 2001 Issue No. 40 Page 1

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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.

HOW TO REACH US:

PHONE: FAX: **EMAIL:** WEBSITE: **HepCAN List**

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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 Available IIWOH!

Peppermint Patti's FAQ Version 5 is now available. The new version includes an HIV co-infection section as well as updated Canadian Links 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 V5; 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.



TepCBC 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, Karolyn Sweeting and Alysn Mika. Special thanks to John Hasell and Gordon Mastine for their wisdom and





CUPID'S CORNER

his 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.

Ad No. 20

Positive Attitude and Hepatitis C

Creative, independent, attractive 40something woman, loving and living life, would like to meet active 35 to 40something man. You have a sense of humor and enjoy the good things in life.

Got Hep C?... Single? ...Visit

http://clubs.yahoo.com/clubs/ ontariohepcsingles

Holiday Snack Mix

5 cups Rice Chex 4 cups Corn Chex

3 cups Golden Grahams

1 cup flaked coconut

1 cup slivered almonds

3/4 cup butter or margarine

1 cup sugar

1 cup light corn syrup



Grease two 15-in. x 1-in. baking pans; set aside. In a large bowl, combine cereals, coconut and almonds; set aside. In a heavy saucepan, combine the butter, sugar and corn syrup. Bring to a boil over medium heat, stirring constantly. Boil for 10 minutes, stirring occasionally. Pour over cereal mixture and stir until well coated. Spread onto prepared pans. Cool stirring occasionally. Good to share at our meeting.

Vivian

Page 2 hepc.bull **DECEMBER 2001** Issue No. 40



THE SQUEEKY WHEEL

The Danger of Misdiagnosing Hepatitis C

n November 1st, 2001, the Canadian Medical Association issued a press release on the importance of "getting the diagnosis right": "'We Need to Get the Diagnosis Right,' says CMA."

The article caught my interest for several reasons. First, I have been infected with hepatitis C since 1986. In 1991, after several other theories made by many doctors mostly specializing in the field of psychology or psychiatry, I was finally diagnosed with hepatitis C, which still did not explain a lot of my symptoms at that time. I was one of the many people who were inflicted with many of the very common symptoms associated with this disease, such as fatigue, anger, frustration, and arthritis. As we are all too familiar, fatigue and arthritis are some of the most prominent of all symptoms associated with hepatitis C.

Many patients complain to their family practitioners that they are constantly tired, and can't sleep enough. Their sleep patterns are often disturbed and not routine. A family or general practitioner will often, without thought, diagnose the patient with CFS (Chronic Fatigue Syndrome). No blood test is required for this, but a tilt table test could identify the fact, and it's often overlooked. It would seem to the family practitioner that one with a family, a job and a stressful life, may easily encounter this condition. It's a nice title most likely given to a patient whom a practitioner may believe to be simply stressed out from day to day life, yet is not one that is life threatening.

Others are diagnosed with depression. In my study, I found most women were told that they were depressed and then prescribed antidepressants. The difference between prescribing for depression or chronic fatigue is not a huge difference.

Drugs to assist with CFS that are given frequently include:

- Trycilic Agents like, Doxepin, Sinequin, Elavil, Triavil, Pamelor.
- Antidepressants such as Prozac, Zoloft, Paxil, Effexor and Desreyl are also common

prescriptions for this diagnosis.

 Anti-inflammatory drugs such as Anaprox, Naprosen, Ibupropen, Advil, and aspirin are also on the list.

There are also antimicrobials, Acylovir or antihistamines, which actually cause drowsiness, i.e., Hisminal, Claritin etc. Beta-blockers are in current studies—all those things, just for CFS.

But then what? Many people with HCV who get diagnosed with depression, fibromyalgia, arthritis and migraine headaches are given an arsenal of medication before anyone thinks to check their liver enzymes or liver functions. Maybe they are only being checked because of the amount of medication they have been prescribed, which has been masking the real cause.

One of the people I interviewed was given 26 blood transfusions between the years 1969 and 1980. She was not diagnosed with hepatitis C until 3 years ago, and only now is she on treatment. She is currently in a trial with the latest treatment.

Another girl was told that she must be having problems at home and must be feeling depressed.

Another in the acute phase was diagnosed with having mono; another, just plain old arthritis.

And yes, they were given an over abundance of anti-inflammatories and painkillers, until many of them gave up on these medications and found herbal alternatives.

Women, especially, I find, get overlooked when describing symptoms, and most often are diagnosed with depression, psychosis or other psychological disorders. However, when I interviewed men, I found that, although they were taken more seriously, they were still being misdiagnosed and given medication (mostly sleeping pills) for other things, such as arthritis. Because many of the medical journals associate hepatitis C with symptoms of jaundice, vomiting, nausea, fever and the flu. My favorite quote from the CDC, NIH and other Journals is, "Often there are no symptoms at all." Well there are, and the really common symptoms are often not mentioned in journals, and the ones that are mentioned usually only occur in the acute stage, and then go away. Maybe it's up to us to enlighten our doctors with respect to these real associations with HCV, so others don't get bombarded with liver-threatening medications.

What are the adverse effects of an incorrect diagnosis?

Take, for instance, simple Tylenol, which is often prescribed or recommended for common arthritis on first diagnosis. We

all know the pain arthritis carries with it, and we all know the risks of overdoing Tylenol and what it can do to our livers. But what about the other drugs—the prescription drugs?

Take a simple one, a benzodiazapine given for CFS, fibromyalgia and even some forms of psychosis. A patient lucky enough to be prescribed a drug like this would be checked for liver enzymes, yet still may go undetected for liver disease, since it is a common side effect of the drug itself. Slight, transient elevations of transaminase and alkaline phosphatase are associated with many of the prescriptions listed and may also be one of the mild to severe symptoms that come with our disease.

More complicated and frustrating is the fact that, even if our liver functions are tested for the overload of medicine we may be given prior to the proper diagnosis, our liver functions may be fine.

After the 1998 publicity given to hepatitis C in Canada, I'm amazed that many of our brothers and sisters are still out there, infected unknowingly and still being given many wrong diagnoses and many unwarranted prescription drugs that

can cause liver damage, liver failure and actually increase the viral replication of this disease.

Why won't doctors take the time with patients to get the diagnosis right, especially after 5 years and an unprecepublic compensation for a medical mishap?

How many people do you know in the hepatitis C circles who were given antidepressants, pain killers, muscle relaxants, sleeping medication and even dangerous antibiotics for our compromised immune systems, who were not diagnosed properly?

After all this, the liver is damaged naturally by the disease and further damaged perhaps by all the medications. Then we get to go through interferon treatments, which are often accompanied by the same abovementioned medications. I'm puzzled.

The concern and worry stretches beyond misdiagnosis, as I still see many of my friends with HCV being given liver unfriendly drugs for common problems associated with HCV, one of which is Lipitor for high tryglycerides, which we all know is a common problem for many of us. What are the professionals thinking? Or are they?

Kimberly A. Seguin

hepc.bull DECEMBER 2001 Issue No. 40 Page 3

THE TERRORIST WITHIN

HCV & The Immune System (Summary)

Compiled by Bradley Kane

ur immune systems could be considered as our military and front line of defense from invaders and foreign bodies. Bcells (a.k.a. B lymphocytes) are one of the body's most important cells. Their function is to produce antibodies, which bind to and neutralize foreign particles (e.g., viral peptides). They develop from stem cells in the bone marrow and fetal liver and migrate to the peripheral lymphoid organs (spleen, lymph nodes, blood, lymphoid tissue in GI tract, etc.). Bcells and T-cells are both types of white blood cells. All white blood cells originate in the bone marrow as "stem cells." If a stem cell stays in the bone marrow to mature, it is called a B-cell; if it migrates from the bone to the thymus to mature it is called a T-cell. Each B-cell has its own antigen receptors, called immunoglobulins (antibodies), which bind to a specific antigen (e.g., a Hep C viral particle). There are 6 classes of antibodies, which correlate to the many millions of unique immunoglobulins which can be produced, capable of binding to many millions of specific antigens.

Antigen-specific T-cells are divided into two main categories: Th1 cells promote cytotoxic T-lymphocyte (killer T-cells) activity, and Th2 cells promote antibody response.

When a CD4+ T-cell binds to its antigen, it secretes its cytokines (interleukins), which alert and stimulate the arrival and production of more T-cells. Thus, CD4+ T-cells can be thought of as "helper" T-cells.

In contrast, when a CD8+ T-cell binds to its antigen, it secretes cytotoxins stored in specialized lytic granules. The release of these cytotoxins is very carefully regulated because they include perforin (which creates holes in the target cell membrane) and granzymes (proteases). Thus, CD8+ T-cells can be thought of as "killer" T-cells. This immune response works to destroy the virus's host cell (necrosis), depriving it of a place to replicate, as well as exposing the pathogen to circulating antibodies.

Enter the HEPATITIS C VIRUS. HCV is both a hepatotropic (liver) and lymphotropic (lymph glands) virus and is a heterogeneous, single-stranded, positive-sense RNA virus belonging to the Flaviviridae family. Like many other RNA viruses, HCV has an inherently high mutation rate, resulting in considerable genetic heterogeneity throughout the genome. HCV codes for an RNA polymerase that copies its genome without "proof-reading" or checking for changes, giving it the ability to mutate each time. HCV also replicates at a very high rate therefore increasing the rate of mutations. This genetic heterogeneity subdi-

vides the hepatitis C virus into six major genotypes that vary in distribution worldwide. Quasi-species are closely related variants of a single genotype within a single individual, which arise from mutations that occur during viral replication. Quasispecies diversity may increase with time and contribute to interferon resistance and viral persistence.

HCV is considered by the scientific community to be one of the most "highly evolved" viruses ("smart virus") known to man, having an almost perfect strategy of survival. Because HCV is an RNA virus, it floats around in our bloodstream as a non-living (inert) thing, and because it is coated with all the same glycoproteins as our own bodies (cells) use, it's not even recognized as a foreign object, but appears as though it is actually part of our own structure. This gives it the ability to slide into the nucleus of the liver cell as if it had a "key to the door." It needs our (human) DNA to replicate, and when it unwraps and attaches itself to our genetic material to do so, it is suddenly recognized as being very much alive and invasive. The alarms of our immune system go off, and, as the military rushes in to identify the intruder and destroy it, it mutates.

Because it chooses the liver (the only organ in the body that regenerates itself) to replicate in, it is ensured a long life in a host whose immune system is altered to prevent a successful attack. HCV's survival strategy is almost flawless, which presents an ultimate challenge to finding a cure.

Let's look at this from a military or police point of view. A terrorist sneaks into security facilities and commits crimes. He is identified and a photo is sent out. Each time he commits the crime, his appearance changes. One time he is 64", 230lbs, blonde, Caucasian; next time he's 4'6", 112lbs, bald, Asian-

impossible to catch.

Anergy (a state of refractoriness to optimal activation) is an inability of the T-cell to synthesize appropriate cytokines. The HCV virus may mutate to form antagonist peptides, epiotopes, and lead to anergy and the non-(Interleukin 2) is one of these cytokines. One of its functions is to bind to receptors on a nearby cell (e.g., the infected liver cell which released the original viral antigen discovered by the Bcell) and increase the production of MHC (major histocompatibility complex) class 1 molecules in that cell. (MCH molecules are two proteins and consist of two globular domains: alpha-1 and alpha-2, or beta-1 and beta-2 respectively.) If the RNA region coding for this peptide is changed by mutation during replication, then, if the newly coded peptide is presented by the MHC molecule, the T-cell may only partially recognize the MHC-peptide complex or may not recognize it at all. T-cells will eventually be able to recognize these newly

produced, mutant peptides, but this takes time, and by the time the T-cell recognizes this new MHC-peptide complex, the virus may mutate again and again. The T-cell will not recognize the MHC-peptide complex. Antigen receptors have to be reinvented by every generation.

Patients who developed strong responses to HCV antigens during the initial stages had strong Th1 reactivity and eliminated the virus, remaining seronegative for HCV RNA. In contrast, viremia persisted in those who were unable to develop HCV-specific CD4 T-cell reactivity during acute hepatitis. This leads to the idea that CD4 T-cells are lacking in the CD4 Th1 type, which is responsible for interferon gamma and interleukin-2 production, the latter being responsible for causing a killer T-cell response. CD4 T-cells will recognize viral antagonist peptides in such a way that normal cytokine profiles are altered in favour of the production of Th2 type cytokines, rather than Th1 cytokines. This process would result in the loss of IL-2 and IFN-gamma production. Such CD4 T-cells would display an anergic or Th2 phenotype. B-cell driven antibody production would still be intact due to the levels of IL-2, IL-5, and IL-6. The loss of IL-2 and IFNgamma production would compromise the differentiation of cytotoxic precursor T cells, so that elimination of HCV-infected targets by mature CD8 killer T-cells would be impaired. Such a modification of cytokine production would occur through effects on TCR affinity for MHC-presented HCV peptides, which would result in a defective or incomplete primary signal.

From a military point of view, when you do finally corner the terrorist, he is able to confuse the ranks and the mission or strip you of

all your guns or weapons so you can't attack—and laugh in your face. Viruses can escape T-cell recognition, not only by mutation of the sequences encoding the epiotope (peptide) that is recognized directly by the T-cell antigen receptor (TCR), but also by down regulating the expression of any one of several

synthesis of the appropriate cytokines. IL-2 host molecules that are necessary for efficient T-cell recognition of virus infected cells. Specifically, for HCV this would be the MHC class II molecules, which are recognized by CD4 T-cell receptors. The down regulation of the MHC class II molecule is not done directly. but indirectly, by inhibiting the interferon gamma mediated up regulation of MHC class II molecules. Increased expression of MHC class II by interferon gamma is likely to play a roll in antigen presentation, and interference with this step may prevent the generation of an effective immune response against the virus.

> Given the essential role of the innate immune system in regulating all aspects of immunity, it is conceivable that dysfunction of

> > (Continued on page 6)

Page 4 hepc.bull **DECEMBER 2001** Issue No. 40

(AASLD CONFERENCE—Continued from page 1)

of daily therapy with 15 mg of Omega IFN. (Median half life of elimination of Omega IFN was approximately 9 hours). The study showed that Omega IFN reduces levels of HCV RNA within 48 hours in patients with genotype 1 who failed prior alpha IFN therapy. Side effects were similar to those of other IFNs. Neutropenia was dose limiting in some patients. Prospective trials are needed to determine the role of Omega IFN for the treatment of HCV infection. (Source: McHutchison, John G, et al., Open Label Phase 1B Study of Hepatitis C Viral Dynamics with Omega Interferon.)

OMEGA IFN IN NAÏVE GENOTYPE 1 PATIENTS: This study tested the safety and tolerability of different doses Omega IFN in naïve HCV+ patients. The authors concluded that it is active against genotype 1, inducing undetectable HCV RNA levels in 10 out of 30 pts during the first 28 days of treatment and that further evaluation of higher doses and prolonged treatment is warranted. (Source: Plauth, Mathias et al, OpenLabel Phase II Study of Omega Interferon in Previously Untreated HCV Infected Patients.)

LEVOVIRIN: Levovirin is a second generation ribavirin being made by ICN Pharmacueticals. Testing in monkeys showed that Levovirin gets into the red blood cell less than ribavirin, perhaps indicating **fewer side effects and a better safety profile**. RBV can lead to reduced hemoglobin and fatigue. A study is planned to see if this new version of RBV has antiviral activity in combination with IFN. Phase I clinical trials began in February 2001.

ISIS 14803: an antisense inhibitor of HCV, has shown decreases in viral loads, and temporary ALT flares seem not to be toxic for the liver. The drug is given by subcutaneous injection twice weekly. A study in HCV-infected patients is starting up now.

HEPTAZYME: given by injection once a week, is supposed to **prevent HCV reproduction**. Studies indicate it is safe, and a study of Heptazyme + Infergen interferon in treatment-naïve patients is starting now.

VIRAMIDINE: a potential prodrug of ribavirin, may be more effective and have fewer side effects than ribavirin. It seems to target the liver better, according to tests on monkeys. An oral report was given at the AASLD Conference, called "Immunomodulatory Activities of Viramidine, a Liver-Targeting Ribavirin Prodrug, in vitro and in vivo," by Johnson Yiu-Nam Lau, M. D., co-author of the study. (Source: www.prnewswire.com 11/12/2001 ICN Presents New Data on Viramidine(TM) and Levovirin(TM) At The AASLD Annual Meeting)

EPO FOR LOW HEMOGLOBIN

Many patients have had to stop treatment because of anemia. A study by Doug Dieterich shows **EPO can raise hemoglobin** in patients who had 11.7 hemoglobin during HCV therapy.

Some doctors prefer to hold off unless hemoglobin reaches 10 because the long-term effect of EPO on bone marrow is not known. Others start treatment with EPO to prevent anemia even before therapy has begun.

TMA TEST

The new ultrasensitive HCV viral load test (TMA) may identify who may relapse following therapy. It is not yet FDA approved. Up to half of patients who appear to be HCV negative at the end of treatment have been proven to still carry the virus by the TMA, and may be more likely to relapse. These patients might be better off continuing therapy for another 6 months. A Phase 3 study is in progress. The test may be available through Quest and Speciality.

TMA assay was used to find residual HCV RNA in patients treated with peginterferon a-2a who relapsed after therapy. Stored end-oftreatment and end of follow-up plasma samples from 177 of 267 patients treated with peginterferon a-2a was re-tested by TMA and compared to samples from patients in the same study who relapsed after standard IFN treatment, who served as controls. In patients who relapsed after the end of therapy according to PCR, residual HCV RNA was detectable in end-of-treatment samples by the TMA-based assay in 7% and 33% of cases, respectively. (Source: Christoph Sarrazin, Frankfurt, Germany et al, Assessment of virologic response by transcription mediated amplification in patients with chronic hepatitis C virus treated with peginterferon-a 2A, Abstract 1019)

HALFZYME

A new, low cost way to detect low amounts of HCV is based on Halfzymes, which are ribozymes requiring a target nucleic acid to supply nucleotide sequences for ribozyme catalysis. Halfzyme can both detect and signal in a single step, reducing variability and cost. Halfzyme tests don't need target amplification, so they are rapid, simple, and inexpensive, and avoid problems of cross contamination of samples, common in PCR assays. Halfzyme may provide a good alternative to PCR and RT-PCR. (Source: A novel ribozyme-based method for the direct detection of hepatitis C virus RNA—Abstract #183.)

TREATMENT OF PATIENTS WITH NOR-MAL ALT

Current studies often exclude patients with normal ALT values. 16 HCV RNA positive patients (80% were genotype 1) with normal ALT and one with ALT less than 1.2 times the upper normal limit for at least 3 consecutive months received daily IFN alpha 5 MU for one month, plus ribavirin, followed by standard Rebetron. Those still HCV+ at 24 weeks were taken off therapy. Two patients dropped out. HCV patients with normal ALT values responded well to combination interferon/ribavirin therapy, with a sustained response rate of 47%. (Source:

Ann L Silverman, et al, Chronic HCV patients with normal ALT values respond well to Rebetron therapy, Abstract 668)

IFN REDUCES HCC RISK

A Japanese research group reported that interferon therapy reduces the risk for developing HCC and death, and although we have already heard this, this study was a large one. **Responders and transient responders had reduced risk**, but non-responders did not, when compared to untreated patients. There are studies going on to see how long it takes after stopping therapy for progression of liver damage to resume.

BLACKS PROGRESS WITH NORMAL ALTS

Thelma Wiley from the University of Illinois, reported finding that, in African-Americans compared to whites, cirrhosis was as likely to occur whether ALT is normal or not. Normal ALT usually means less progression, but one can have normal ALT and have moderate or advanced liver disease. This study shows that African-Americans with normal ALT are as likely to develop liver disease as whites with abnormal ALT.

UNDER OUR CONTROL

Excess weight, elevated fats (cholesterol, trigly-cerides), and sugar are associated with HCV progression. These are things that patients can control with diet, exercise, and medical intervention for lipids.

BIOPSY RECOMMENDATIONS

A follow-up biopsy should be done 3-5 years after the first to evaluate progression. If a patient is HIV/HCV co-infected, a follow-up biopsy should be considered 1-2 years after the first, if HCV therapy was not started.

99% RESPONDERS VIRUS FREE AFTER 3 YEARS

A long-term study on more than 300 patients treated with Pegasys found that 99% remain virus free when examined two to three years later. The indication is that if a patient is virus free at 6 months after completing therapy, the virus will not return. Two-thirds of the patients in this study were infected with genotype 1, associated with a lower response to therapy, and 25% had cirrhosis. Patients could not be on any anti-HCV therapy after their original treatment, and all were off original therapy for two to three years.

Pegasys has been submitted to Health Canada for approval and is currently under review. (Source: 99% of patients remain free of hepatitis C virus when tested three years later.)



hepc.bull DECEMBER 2001 Issue No. 40 Page 5

IMPORTANT! HELP YOUR COMMUNITY!

Anonymous

Dear Friend.

t appears that the federal Ministry of Health has made the short-sighted decision to discontinue funding for community support to

people and their families who are affected by hepatitis C. Last year, small "Capacity Building" grants were awarded to a number of community hepatitis C organizations. Many of these groups focused their efforts on helping sick people and raising public awareness about Hep C, rather than doing things to ensure their group's ongoing viability.

It seems that these groups are being punished for responding to the immediate needs of their community, rather than planning for their own future growth. They assumed that there would be time for that kind of "capacity building" in the second year of funding. If you believe that the work done by your community-based hepatitis C organization has been valuable and you want to see it continue, please take a few minutes to write to Allan Rock, the Minister of Health.

Included is a sample letter that you can use as a template. If possible, please send copies to the opposition parties' health critics as well.

Many provincial governments have done very little to address the hepatitis C issue, so a copy to them and their opposition critics that also asks, "What are you doing? Please respond by outlining the steps you are taking," would be appreciated. Letters sent through the mail are taken most seriously by the politicians. If you have access to fax and e-mail, send copies that way as well. We want to see at least 10 people from each community send in their thoughts on what was worthwhile and what they would like to see in the future.

We appreciate that you may be tired and certainly have other priorities, but if we don't act now and flood them with our letters about what we want and deserve, there will be 300,000 Canadians and their families fighting this virus in ignorance and isolation, without the support of an educated community.

Please take the time to spend few minutes on these letters and a couple of bucks on stamps. We deserve cost-effective, community based supports that are accountable to the communities they serve.

Together, we can reverse this decision. Thank you very much.

Below is an example of a letter that can be sent to Alan Rock and the Health Critics in each federal party. Send a copy to your provincial politicians and ask what they are doing.

People should use what fits for them and throw out what doesn't. Add your personal experiences and opinions - that is the most powerful part! Add the services and supports that you have found to be valuable as well as those that you would like to see in the future. If you can, send the letter by Canada Post, fax and e-mail. Thanks!

Allan Rock Minister of Health, House of Commons, Ottawa, Ontario, K1A 0K9



Mr. Rock,

I am writing you to express my appreciation for (insert name of person/organization) and the wonderful work they have been doing.

(Describe the hepatitis C support, prevention and public awareness activities and the person/organization that has been doing this in your community.)

As you are aware, hepatitis C is a very serious and significant health issue for Canadians. Its impact will continue to grow as more people are diagnosed and increasing numbers of people and their families experience the often devastating effects of this viral infection.

I was very disappointed to learn that the Capacity Building grants for community organizations had been discontinued after only one year. People live in communities, regardless of whether they are located in large cities or small towns. When people are sick they rely more than ever on those supports that are close to home. Most people have only four potential sources of support and information when it comes to hepatitis C: Their family doctor, who is usually overworked and overbooked, their specialist, who for most Canadians is many miles away, their public health nurse, who has many other responsibilities, and community organizations such as (insert name) which can provide support and information in a very cost-effective manner. They play an important role in strengthening the responsiveness and understanding of the community as a whole.

I urge you to continue the federal government's investment in community supports for the hundreds of thousands of Canadians infected by this life-threatening virus. We need supports that are accessible, community-driven and accountable at the community level.

Now!

\$20 CDN each, including postage. This is a GREAT Fundraiser for Support

Sincerely, (Your Name)

(TERRORIST WITHIN—Continued from page 4)

the components of innate immunity can contribute to disease. Two general types of genetic alterations could lead to immunologic abnormalities: mutations that inactivate the receptors or signaling molecules involved in innate immune recognition, and mutations that render them constitutively active. The first type of mutation would be expected to result in various types of immunodeficiencies. The second type of mutation would trigger inflammatory reactions, and could thus contribute to a wide variety of conditions with an inflammatory component, including asthma, allergy, arthritis, and autoimmunity. Indeed, mutations in macrophage mannose receptors and mannan-binding lectin of both humans and mice have been associated with increased susceptibility to infection by a variety of pathogens.

As is the case in cryoglobulinemia associated with HCV infection, all manner of autoimmune disorders can precipitate, and the host immune system, in general, is impaired and altered in its functionality. Studies are ongoing and, as previously mentioned, quasispecies diversity may increase with time and contribute to interferon resistance and viral persistence, which may also lead to new and innovative ways that HCV will affect our immune systems to its advantage.

References:

The Canadian Asociation for Study of the Liver Consensus Conference on Viral Hapatitis

H. Ghosh, CELLBIOLOGY 2B03 at McMaster University http://mcss.mcmaster.ca/~ghoshh/hepinmunology.html http://mcss.mcmaster.ca/~ghoshh/hepinmunology2.html

The New England Journal of Medicine, August 3, 2000, Vol. 343, No. 5,

Advances in Immunology: Innate Immunity - Ruslan Medzhitov, Charles Janeway, Jr.



Order Your "Hepper Bear" Now!

\$20 CDN each, including postage. This is a GREAT Fundraiser for Support Groups! Call (250) 361-4808, or email info@hepcbc.org to place your order.

Page 6 hepc.bull DECEMBER 2001 Issue No. 40

WHERE IS THE MONEY **GOING?**

Dear Editor:

llan Rock 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 not covered by provincial plans, for those not covered by the compensation package.

Lou Goudreau of the Federal Health Department says that, as well as the money from Ottawa, each province is supposed to kick in an amount equal to Ottawa's, thus doubling the amount available to the victims infected outside the imaginary window.

The Progressive Conservative Government of Nova Scotia has taken 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. Sadly, this logical and long term cost saving to the tax payer 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 with Mr. Rock in Parliament.

What is your Provincial Government doing with its allotment? Is it being used, as intended, to prevent any out-of-pocket expenses for the forgotten victims of the blood, or is it being seen, as it is in Nova Scotia, as a windfall? Your local grassroots organizations should raise this issue. They should 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. It will be interesting to see if the Health Minister allows this theft to take place.

Yours truly,

Bruce DeVenne 122 Phoenix Cres, Lr. Sackville NS B4C 2B4 bdevenne@sprint.ca

Ph 1-902-864-6376 Fax 1-902-864-8512

VGH - 1984

The practitioner arrives to measure my care, She is disguised in white, her eyes are vacant, snow glazed—somewhere else, her lips are sealed, her fangs well hidden, her unholy hands reach into The rivers of my life, —a rich blue vein.

This is her jurisdiction, Her prescription for me, Donor #70094, The letting in of blood, "No, this is unnecessary," I whisper— "my life—a harmony of balance" But, this is her jurisdiction, This procedure is her gift, her blessing at My time of miracles.

Her assertion, a vanity of needs—complete, She leaves only a faded signature card, a traveler's roadmap to the hanged man. As angels turn, their heads in Sorrow Her lips are sealed.

> Anonymous June 14, 2001





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

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

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

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-

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

Ontario Compensation: 1-877-222-3977

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

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

Questions about the status of your claim (86-90)? Please contact the administrator. If you still have questions,please contact Bruce Lemer who has promised me he would answer your questions at no charge.—C.D. Mazoff

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

Page 7 hepc.bull **DECEMBER 2001** Issue No. 40

COMING UP IN BC/YUKON:

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

Castlegar Contact: Robin, 365-6137

Chilliwack BC HepTalk Contact: 856-6880.

Comox Valley HeCSC 3rd Tues. monthly, 7-9 PM, St. George's United Church on Fitzgerald. Next meeting Dec. 18th Contact: Jayne, 336-2485 or Dan, 338-0913, Rhagen@mars.ark.com

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

Cranbrook HeCSC-EK: 1st & 3rd Tues. monthly, 2-4 PM, #39 13th Ave South, Lower Level. Next meetings Dec. 4th & 18th. Contact: 426-5277 or 1-866-619-6111 hepc@cmha-ek.org, www.cyberlink.bc.ca/

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

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

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

Kelowna HeCSC: Last Sat. monthly, 1-3 PM, Rose Avenue Education Room, Kelowna General Hospital. (Please call to confirm.) Next Meeting: Dec. 1st Contact Elaine Risely (250) 768-3573, or Lisa Mortelli, 766-5132.

Kimberley Support Group 1st Mon. monthly, 1-3 PM. Next meeting Dec. 3rd. Contact Katerina 426-

Kootenay Boundary 2nd Tues. monthly, 7 PM, 1159 Pine Ave, Trail. Next meetings: Dec. 11th For individual support, info & materials, contact: Brian, 368-1141, k-9@direct.ca.

Maple Ridge Last Wed monthly, 7-8:30 PM, Health Unit. Contact Peter or Laura-Lea 604-463-0223 or madclark@telus.net

Mid Island Hepatitis C Society Contact Sue 245-7635. mihepc@home.com

- Ladysmith Friendship and Support Group. 2nd Fri. monthly, 7 PM, Ladysmith Resource Centre.
- Nanaimo Friendship and Support Group 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo.

Mission Hepatitis C and Liver Disease Support Group 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting Dec. 19th. 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: Dec. 18th. Contact: Ken, 1-800-421-2437

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St., Next meeting: Dec. 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 2nd Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. Next meeting Dec. 10th. Contact: Dianne Morrissettie, 525-3790.

Parksville Support Group Contact Ria, 248-6072



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

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

Powell River Hep C Support Group 2nd Wed. monthly. Next meeting: Dec. 12th. "Breathe and Stretch Your Way to More Energy and Less Stress,' with Shirtey Floe, Yoga and Qi Gong instructor. Contact: Cheryl, 483-3804, or the Health Unit, 485-

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Health Unit Auditorium. Next meeting Dec. 11th. Contact: Gina, 963-9756, gwrickaby@telus.net or Ilse, ikuepper@nirhb.bc.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Next meeting Dec. 8th. Contact: Brad, 295-6510. citizenk@nethop.net

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

Quesnel: 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, 7-9 PM, 3731 1st Avenue, Upstairs. Next meeting: Dec. 12th. Contact: Deb. 877-0042, 1-866-877-0042, or Doreen, 847-2132, plnw_hepc@bulkley.net

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

Vancouver HepHIVE and HepC VSG Last Wed. monthly, 10:30-12:30, BCCDC Building, 655 West 12th Tom Cox Boardroom 2nd floor. No meeting in December. Contact: 254-9950 hephive@mdi.ca

VANDU Vancouver Area Network of Drug Users Each Mon., 1 PM, #350 - 163 West Hastings St., (Cambie & Hastings) Bus fare and snack. Contact: Ed or Ann, 683-8595, vandu@vandu.org, annlive@direct.ca, www.vandu.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Next meetings Dec. 12th & 26th. Contact: Sharon, 542-3092, sggrant@netcom.ca

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

Victoria Support and Discussion Group 1st Wed. monthly, 7-9 PM, Next meeting Dec. 5th. Contact Hermione, Street Outreach Services 384-2366, hermione.jefferis@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

YouthCO AIDS Society HepCATS Hep C advocacy, training and support for youth 15-29 living with Hep C and/or co-infected with HIV. #203-319 W Pender St., Vancouver Contact Shane, (604)688-1441, (604)808-7209 or shanet@youthco.org

Yukon Positive Lives 3rd Wed. monthly, Whitehorse. Next meeting Dec. 19th. Contact 456-2017, positivelives@yknet.yk.ca or Heather, fromme@marshlake. polarcom.com, www.positivelives.yk.ca

OTHER PROVINCES

ATLANTIC PROVINCES:

Cape Breton-HepC-CB 2nd Wed. monthly, 7 PM YMCA Charlotte St. Board Room, Sydney. Contact: Howie, howiesullivan@accb.ns.ca, http://www.accb.ns.ca/

Cape Breton HeCSC 2nd Tues. monthly. Contact 564-4258

Fredericton, NB HeCSC 3rd Thurs. monthly, 7 PM Odell Park Lodge. Contact: Sandi, 452-1982 sandik@learnstream.com or Bob, 453-1340, bobc215@netscape.net

Greater Moncton, N.B. HeCSC Contact Debi, 858-8519, monchepc@nbnet.nb.ca

Hepatitis Outreach Society, Simpson Hall, Suite 452, 300 Pleasant Street, Dartmouth, P.O. Box 1004, NS, B2Y 3Z9. 1-800-521-0572, or 902-420-1767, rahcc@ns.sympatico.ca, www.ahcc.ca Meetings:

- Antigonish: 2nd Wed. monthly, 7 PM, St. Martha's Health Centre, 25 Bay St, Level 1 Conference Room
- Bridgewater: Last Wed. monthly, 7 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room Halifax: 3rd Tues. monthly, 7 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110 Kentville: 2nd Tues. monthly, 6:30 PM, KingsTech Campus, 236 Belabor St. Pm 214

- Pus, 236 Belcher St, Rm 214

 New Glasgow: 3rd Mon. monthly, Aberdeen Hospital, Conference room #I South.
- Truro: Last Tues. monthly, 7 PM, Colchester Regional Hospital, 25 Willow St, Conference Room
- Yarmouth: 1st Tues. monthly, 7 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1—Main level

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

ONTARIO:

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

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7 PM, St. Speaker Paul Dobbs, John Howard Society, St. Mark's United Church, 201 Centre St. South, Whitby. Contact: Smilin Sandi, smking@rogers.com, http://members.rogers.com/smking/index.htm, Ken Ng, (905) 723-8521 or 1-800-841-2729 (Ext. 2170)

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

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

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

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

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: Last Mon of the month, 7 PM, Crossways and Common United Church, corner Broadway & Maryland, Winnipeg. Contact David: jmoritz12@shaw.ca or 1-204-897-9105 for updates.

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

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

- Montreal: 4th Tues. monthly, 7-9 PM, Montreal General Hospital, room A1.109, 1650 Cedar Ave.
- Verdun: 3rd Wed. monthly, 7-9 PM (English), 1st Wednesday monthly, 7-9 PM, (French) 4341 Verdun Ave.
- Hull: Each Tue. 7-8 PM, 57 Rue Charlevoix.

HeCSC Montreal 3rd Wed. monthly, 7 PM, YMCA 255 Ash Ave. Contact John, 450-926-2237. http://communities.msn.ca/ Hepatitiscmontrealchapter

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

Page 8 hepc.bull **DECEMBER 2001** Issue No. 40