



# hepc.bull

## Canada's Hepatitis C News Bulletin

www.hepcbc.ca

### NEWS

#### PEGASYS FAST-TRACKED IN THE US

The US Food and Drug Administration (FDA) has given "fast-track" (priority) review status to Roche's Pegasys (peginterferon-alfa-2a) in combination with the company's Copegus (ribavirin), to treat chronic Hep C. It is hoped that the new combo will be approved during the last part of 2002 so that the treatment will be available early in 2003. According to Roche, in granting the status, the FDA acknowledges benefits of the new treatment over the treatments now available. Pegasys, alone or in combo, was approved in Europe as of July 2002.

*(Continued on page 4)*

#### BRIAN BROWNRIGG

Who was he? A statistic. Someone killed by the hepatitis C virus.

He wanted the final, official acknowledgement of his existence here on earth to clearly state that HCV was what killed him. Not organ failure, internal bleeding or some other non-specific euphemism; he was killed by hepatitis C and he wanted that to be clearly counted.

Brian was not afraid of stigma or controversy. He called them as he saw them. To him, it didn't matter whether you were a teenage junkie or a blue haired dowager. If you had Hep C, what you had in common was a lot bigger than petty differences. And if you didn't have Hep C, he would educate you in such a way that you would ask, "How can I help?", because you knew that could easily be your life.

Brian was a big man with big energy and a bigger heart. He truly loved and believed in people. Whether it was the SPCA, a theatre group, his church or the Hep C community, he had a way of showing people that he genuinely valued them.

*(Continued on page 8)*

### HCV AND LYMPHOMA

by Will Lawson

There is a growing body of evidence indicating a possible connection between the hepatitis C virus (HCV) and non-Hodgkin's lymphoma. Although this is disturbing news for HCV patients, it can be encouraging for lymphoma patients because it offers hope for an additional and effective approach to treatment.

Discrepancies in the findings of studies done in different places suggest that the relationship between HCV and the lymphatic (immune) system may be influenced by regional and racial factors, as well as by genomic variations.

Here are some of the studies:

#### SPLENIC LYMPHOMA

Some French researchers suspect that HCV patients who also have splenic lymphoma with villous lymphocytes may derive anti-cancer benefit from treatment for HCV.

After treating 9 such HCV patients with interferon alfa, they found that 7 patients achieved a complete disappearance of cancer and HCV. When they treated the other two patients with ribavirin in addition to interferon, one achieved a complete disappearance of cancer, and the other achieved a partial disappearance of cancer.

Six other patients, who had splenic lymphoma with villous lymphocytes but did not

*(Continued on page 6)*

### BC Hep C Collaborative CIRCLE

Skills, Communication, Education and Support

Planning has begun on the Collaborative Circle's next meetings, scheduled for November 29th through December 1st, 2002. Conference and hotel space have been reserved at the Residence Inn by Marriott in Vancouver, BC.

Registration and scholarship information will be posted in August.

Website: <http://casper.ca/hepcircle/>

#### ALAN POWELL

Although we have known that Alan Powell was not in good health for some time, it was still sad to hear of his death on July 17<sup>th</sup> in Toronto at age 64. Alan Powell was the founder of the Hepatitis C Society of Canada, or the Hepatitis C Survivors' Society, as it was called then. He made spiral-bound books for the HeCSC support groups, way back when it was almost impossible to get any information about hepatitis C.

I remember when I took the first one home, and kept on reading until I finished it. It was full of medical journal articles and newspaper clippings. I had finally found what I was looking for! He later contacted me to give me support and information about my then upcoming treatment. I had the privilege of meeting him on several occasions. He was a true gentleman, and a man worth much admiration, and one of my personal heroes. The Hep C world owes him a lot.

Alan Powell held a B.A. in sociology from the University of Toronto, and was one of the first teachers at Erindale College, where he instituted its collection of modern Canadian art. He wrote a textbook, *The City, Attacking Modern Myths*

He opened the Major Roberts restaurant in Toronto, known for its poetry readings.

Joan King

Source: *Vancouver Sun / The Province*. Obituaries 07/23/02

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"I enclose a donation of \$ \_\_\_\_\_ so that others may receive the bulletin."

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**SUBMISSIONS:** The deadline for any contributions to the hepc.bull® is the 15<sup>th</sup> of each month. Please contact the editors at [info@hepcbc.ca](mailto:info@hepcbc.ca), (250) 595-3892. 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 12<sup>th</sup> 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:

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HepCAN List <http://groups.yahoo.com/group/hepcan/messages>

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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.

# NEW

## Peppermint Patti's FAQ Version 5.6 Available NOW!!

Peppermint Patti's FAQ Version 5.6 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 1997-2002; 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.

# THANKS!!

HepCBC would like to thank the following institutions and individuals for their generosity: Lexmark, David Klein, Bruce Lemer, Elsevier Science, Health Canada, Pacific Coast Net, Margison Bros Printers, Carousel Computers, Arlene & Frank Darlington and friends, Karolyn Sweeting, Alys Mika, John Hasell, Gordon Mastine, Chris Foster, Ian Campsall, Darlene Morrow, Rick Wiertz, Will Lawson, Judith Fry and Claire Cassidy.

Special thanks to Roche Canada for an unrestricted grant to help publish this newsletter.



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## CUPID'S CORNER

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

To place an ad: Write it up! Max. 50 words. Deadline is the 15<sup>th</sup> of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to HepCBC, and mail to HepCBC, Attn. Joan, 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://nationalhepatitis-c.org/singles/list.htm>

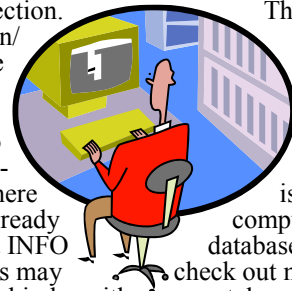
or

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

## HepCBC LIBRARY

We would like to remind those of you in and around Victoria, or just visiting, that we have a library, organized and stocked with books, videos, audio tapes, journals, and pamphlets about hepatitis C for your use at the Victoria PWA office at 541 Herald Street. You can find even more in the HIV library, especially on co-infection.

There is a television/available the vid-a tape in a com-room. There is also an internet ready computer with our latest INFO databases in it. Members may check out materials. There is a binder with a catalog of the library's contents. The office staff is friendly and helpful. We hope you will take advantage of this great resource.



## 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.ca](mailto:info@hepcbc.ca) to place your order

**THESE FOODS CAN KILL YOU**

1. Raw eggs in protein shakes, raw homemade cookie dough, sunny side up eggs, runny eggs or Caesar salad. (Raw eggs can carry salmonella. Ask if dressing has raw eggs.) Cook eggs until the yolk and white are firm.
2. Rare hamburger. E Coli danger. Cook ground meat to at least 160 degrees
3. Turkey and stuffing. Don't cook the stuffing inside the bird. It has to reach 165 degrees in the center of the stuffing to be safe.
- 4 Wild mushrooms. Eat only mushrooms you've bought at the grocery store.
5. Raw or undercooked shellfish, as in some sushi, sashimi, raw oysters, ceviche.
6. Water. Water from wells or streams, or from a swimming pool can contain E. coli. Test your well's water often. It's best to boil it.
7. Raw sprouts. They can carry E. coli. Cook them.
8. Unpasteurized juices, milks or cheeses. They can carry salmonella, E. coli and listeria. Buy pasteurized or boil for 1 minute. Watch out for the juice bar, too.



**Tips:**

- Use a cooking thermometer
- Scrub fruits and vegetables with rinds thoroughly. (Can be contaminated by manure or irrigation runoff, or by bacteria on the peel passing to the inside from the knife)
- Wash hands before and after preparing foods
- Purchase produce in packages (pre-washed and not handled by so many people)
- Cooking food kills the bacteria
- Throw away food with broken skin. (Germs may have entered the pulp)
- Use a food thermometer with meat

Source: 10 Foods That Kill! by Kim Droze  
[http://www.ediets.com/news/article.cfm?article\\_id=6221&code=24042](http://www.ediets.com/news/article.cfm?article_id=6221&code=24042)

**FAST FOOD MEAL? TAKE YOUR VITAMINS**

Researchers in Buffalo, NY, have found that eating a meal with high glucose (sugar) or fat and calories, such as a fast-food meal, causes an inflammatory response in the blood, lasting 3-4 hours, possibly damaging the blood vessels. They also showed that the antioxidants vitamins E and C could cancel out this response, making an "unsafe" meal "safe". To determine this researchers studied the blood of 9 people before they ate a 900-calorie breakfast, and after the meal at 1, 2, and 3 hour intervals. Then they tested for oxygen free radicals and proinflammatory indicators. In another study, 8 people took 1200 IU of vitamin E and 500 mg of vitamin C before taking a large quantity of glucose, and their blood was tested the same way. The free radicals and proinflammatory markers did not increase this way.

Source: *Obesity, Fitness & Wellness Week July 13, 2002 High-fat meal raises blood's proinflammatory factors; vitamins E and C counter that response*

<http://www.newsrx.com/front/weekly-reports-contribution.asp?wasp=4nc6a0bnpa4rundabav0&referrer=thisweekstopnews&backto=thisweekstopnews,26,38&absoluteposition=26>

**ZADAXIN TRIALS**

SciClone Pharmaceuticals' U.S. Phase 3 clinical trials testing thymalfasin (thymosin alpha 1, ZADAXIN) for the treatment of hepatitis C are now open for accrual of patients.

These clinical trials will accrue 1,000 patients in 40 sites throughout the U.S.

To qualify, patients must have received at least 24 weeks of previous therapy with either non-pegylated interferon or non-pegylated interferon plus ribavirin and at the end of their therapy tested positive (non-responder) for hepatitis C virus RNA.

During these trials, patients will be randomized to receive either thymalfasin (thymosin alpha 1, ZADAXIN) plus pegylated interferon or placebo plus pegylated interferon for a period of 12 months.

There will be no cost to the patient for the treatment, the study drugs used, or for study related tests.

For further details, please have your referring physician call 1-866-ZADAXIN (1-866-923-2946)

More details can be found at [www.sciclone.com](http://www.sciclone.com)

**MILK THISTLE + STANDARD THERAPY**

Did you know that milk thistle may hinder your response to standard Hep C therapy? A group of researchers from University of Iowa presented the results of a study of 284 patients from their clinic. About 54% of them were using alternative medicine along with their IFN therapy. Although 39% of the patients were using more than one herb, about 53% were using milk thistle. Comparing responses in therapy of those who used complementary medicine and those who didn't, there were no major differences, but when they looked only at milk thistle, they found suggestions that it may hinder the response rate, but pointed out at their presentation that the size of the group studied was small. They plan to continue collecting questionnaires. Their clinic doesn't recommend alternative treatments, but the doctors do record the patient's use of herbs.

Source Source: Digestive Diseases update, Vol. 38, No. 24, June 18, 2002, Ask hep C patients about use of milk thistle. Commonly used herb may interfere with antiviral therapy, by Lynn Haley

<http://www.medicalpost.com/mdlink/english/members/medpost/data/3824/14A.HTM>

**STUFFED MUSHROOMS**

- 6 ounces of fresh mushrooms
- 1/2 tsp. of olive oil
- 1 tsp. of dried basil
- 1/4 cup of low fat or nonfat ricotta cheese
- 1 tsp. of Parmesan cheese
- 1/2 onion, small
- 1/2 bell pepper

Preheat oven to 350 degrees F. Prepare rice according to recipe, omit salt. Choose large mushrooms: wipe mushroom caps with a damp paper towel and reserve; rinse stems and chop: reserve. Chop onions and peppers: reserve. Heat oil over low-medium heat in a medium nonstick skillet and sauté mushroom caps for 3 to 4 minutes, turning to briefly cook both sides. Remove from pan and set aside. In the same pan, sauté chopped vegetables and basil until the onions are golden. Remove from heat; add the cooked rice and ricotta cheese and stir to combine well. Arrange mushrooms, rimmed side up, on a cookie sheet sprayed lightly with cooking spray. Spoon the rice mixture into the caps, dividing equally, and top with Parmesan cheese. Bake for about 10 minutes and serve with rice and salad.

Source: [www.ediets.com](http://www.ediets.com)

## TREATMENT

by Karolyn Sweeting

### WEIGHT LOSS MAY IMPROVE STEATOSIS

New study findings indicate that steatosis and elevated liver enzyme levels may be improved by weight loss. The pathogenesis of steatosis appears similar to that seen in patients with non-alcoholic fatty liver disease and is related to the presence of visceral adiposity and elevated serum insulin levels.

A 3-month program was conducted from Princess Alexandra Hospital in Australia to investigate if weight loss would improve the steatosis and abnormal enzyme levels seen in 19 patients with chronic HCV.

Liver histology was determined in 10 subjects before and after the weight loss intervention. In most patients, serum alanine aminotransferase levels fell progressively as weight decreased. Furthermore, a significant reduction in fasting insulin levels was also observed. 9 patients experienced a reduction in steatosis and the extent of improvement was directly related to the amount of weight loss. Five of these nine patients also demonstrated a reduction in fibrosis.

Source: Reuters Health. 51: 89-94. Jul 24, 2002, *Weight Loss Improves Liver Abnormalities in Patients with Chronic Hepatitis C. New York.*

### NEW STANDARDS FOR ALT LEVELS

Serum alanine aminotransferase (ALT) activity is used to assess hepatic disease but fails to identify many patients with hepatic injury. Current standards for normal ALT levels were defined by using populations that included persons with subclinical liver disease.

A study was conducted at a university hospital in Italy to update definitions for serum ALT levels. The study group consisted of 6835 people who were first-time blood donors from 1995-1999 and negative for anti-HCV, 209 persons with anti-HCV antibodies who attempted to donate blood from 1990-1999, and 131 with HCV viremia. Healthy ranges for ALT were computed from the population at lowest risk for liver disease.

Serum ALT activity was independently related to body mass index and to laboratory indicators of abnormal lipid or carbohydrate metabolism. Updated upper limits for serum ALT activity were lower than current limits (men, 30 U/L; women, 19

U/L) versus (men, 40 U/L; for women, 30 U/L), respectively.

Source: Prati D, et al. Updated definitions of healthy ranges for serum alanine aminotransferase levels. *Centro Traslazionale e di Immunologia dei. Milan, Italy.*

### TREATING THE OLDER PATIENT

Researchers in Milan, Italy, found 268 patients with hepatitis C who had a documented transfusion and had no other apparent cause of the disease. All underwent biopsies. The results showed that over a period of 30 years, those aged 21 to 30 years when infected are 4.51 times more likely to progress to cirrhosis than those younger than 21. Patients over 30 at the time they were transfused are 12.20 times more likely to progress to cirrhosis in 30 years. The study concluded that aggressive therapy should be used with patients infected at an older age.

Source: Reuters Health, Jul 19, 2002, *Age at Infection Influences Outcome of Hepatitis C Original article: Blood 2002;99:4588-4591.*



### YOU MAY BE ELIGIBLE TO PARTICIPATE IN A CLINICAL RESEARCH STUDY IF YOU:

Have chronic hepatitis C infection

Are between the ages of 19 and 75 years of age

Have already been treated with but not benefited by interferon-a-based **THERAPIES** or such therapy is contraindicated

Are willing to undergo pre and post treatment liver biopsies

IF YOU ARE INTERESTED, PLEASE CONTACT:  
The Research Co-ordinator  
Viridae Clinical Sciences, Inc.

(604) 689-9404

(NEWS—Continued from page 1)

Source: Roche Wins FDA Fast-Track Review for Pegasys Plus Copegus for Treatment of Chronic Hepatitis C

[http://www.hivandhepatitis.com/hep\\_c/news/071702a.html](http://www.hivandhepatitis.com/hep_c/news/071702a.html)

### HEP C & ERECTILE PROBLEMS

According to a recent study, infection with HCV may put men at risk of erectile dysfunction. The study took into account both liver failure and treatment, both of which are suspected of causing the same problem. The problem has been reported, but it has been unclear as to whether the virus itself is to blame, or the improper functioning of the liver, or the treatment. This study of 414 men, half with Hep C, 39% of those HCV+ had erectile dysfunction, compared with 14% of the healthy subjects. Neither liver failure nor IFN treatment seemed to matter, but possibly contribute, so treatment should be for the individual, according to the researchers. In the long run, IFN treatment should relieve the problem, and a trial should be done to study that. It was recommended that doctors should test patients for Hep C if they are found to have erectile dysfunction

Source: Reuters Health, [www.reutershealth.com/archive/2002/08/13/eline/links/20020813elin007.html](http://www.reutershealth.com/archive/2002/08/13/eline/links/20020813elin007.html) Aug. 13, 2002, *Hepatitis C may cause erectile dysfunction*

### NURSE FINDS OUT 5 YEARS LATER

Cheryl Diehl, a nurse at St. Joseph's Regional Medical Center, was going over her personal medical files one day at work in early 1998, and saw, much to her surprise, that she had tested positive for HCV three times in the previous 5 years. No one ever told her. She is suing, even though she has now cleared the virus, thanks to treatment. Her liver is not badly damaged.

Ms. Diehl suffered a needle stick injury in 1991, and though she tested negative shortly afterwards, she tested positive in December 1992 after another similar injury. After she was exposed to blood at work in 1997, another test came back positive. She was never told, not even after a third positive test in 1998, and never treated. She and her lawyer say that she suffered for years, not knowing how her health would be affected, and for days, not knowing if she had infected her family members. (They were all negative.)

Source: Nurse 'shocked' to learn of her disease, July 02, 2002, by Jennifer V. Hughes

[www.bergen.com/page.php?level\\_3\\_id=50&page=4147358](http://www.bergen.com/page.php?level_3_id=50&page=4147358)

## STEM CELLS GROWN ON HUMAN TISSUE

Researchers in Singapore have found they can grow human stem cells on human muscle and tissue instead of on mouse cells. This finding could speed up future clinical trials on humans, since researchers would not have to test for animal diseases. Stem cells can grow into almost any human tissue, such as liver tissue.

Source: Health Highlights, August 6, 2002, Stem Cells Grown on Human Muscle

## HCV MAY CONFER SOME IMMUNITY

Although, it was believed that a person infected with HCV who has cleared the virus could be re-infected, a recent study shows this may not be true. According to Stuart Ray, of Johns Hopkins University this finding may help in the development of a vaccine. Studies with chimpanzees suggest the animals can be reinfected, but may once again clear the virus with the help of a vaccine. In a study of 164 IVDUs, the 98 who had cleared the virus were half as likely to get a new infection as those never infected, and 12 times less likely to get a chronic infection, especially if they weren't co-infected with HIV.

Source: UPI Science & Technology Desk, Hepatitis C infection may confer immunity 4/25/2002

## VACCINE POSSIBLE?

Researchers from the US FDA and NIH found that 2 chimpanzees who had previously cleared HCV developed what looks like a T-cell mediated immunity when given plasma with clonal HCV. Another uninfected chimpanzee was also challenged with the plasma, and developed a viral load 1000 times higher than that of the other chimps, as well as higher ALT levels. This chimp developed chronic hepatitis. This study may indicate the possibility of developing a vaccine

Source: Sonia Nichols, [www.NewsRx.com](http://www.NewsRx.com) Challenge experiments in chimpanzees imply hepatitis C vaccine not impossible, July 7, 2002 Original article: Journal of Virology, July 2002;76(13):6586-6595

## DL1520 FOR HCC

According to scientists in London, experiments on immunodeficient mice have shown that the E1B-deleted virus dl1520, an adenovirus, prevents and destroys hepatocellular carcinoma (HCC), a kind of liver cancer, independent of p53 status. The cancer cells looked very different after the therapy.

It has been clinically tested for head and neck tumors. It is most effective in cells with divergent p53 status, which could mean that it could help patients with hepatitis from a virus or toxins.

Source: Sonia Nichols, [www.newsrx.com](http://www.newsrx.com) Amended virus kills liver cancer cells, prevents growth of new ones MAY 23, 2002 Original article: Cancer Gene Ther, May 2002;9(5):414-420

## ARTIFICIAL LIVER ADVANCES

If scientists can grow a human ear on a mouse, they should be able to grow a liver, right? Let's hope so. Now researchers have recently discovered how to grow a network of blood vessels, the next step in a very long process of an eventual replacement liver, by copying the structure of the liver. They injected liquid plastic into a liver's blood cells, making a cast which they measure and then use a computer to make a 3D model, which is divided into horizontal slices to make a mold. The slices are put together using heat and pressure, to make a framework for a liver. Several types of cells are then injected into the framework. The trick is to get the right kinds of cells growing in the correct places, and another problem is keeping everything sterile.

Source: Artificial liver 'could be grown' April 25, 2002 [http://news.bbc.co.uk/1/hi/english/health/newsid\\_1949000/1949073.stm](http://news.bbc.co.uk/1/hi/english/health/newsid_1949000/1949073.stm)

## GENE THERAPY + ELECTROPORATION

Scientists from Japan say that transferring the gene of DNA for hepatic growth factor can stop injury to the liver. They injected plasmids with these genes into mice, and used electrical stimulation (electroporation) to make the cells more receptive to the therapy. The mice were challenged with a toxin to induce liver damage. Comparing those mice with others not treated but given the same toxin, liver cell death was much less common, and ALTs were lower.

"Naked DNA injection and transfer by electroporation efficiently brings about HGF expression in vivo, which can attenuate acute liver injury," stated the scientists.

Source: Sonia Nichols [www.newsrx.com](http://www.newsrx.com) Gene Therapy Weekly, Gene transfer via electrical stimulus reduces toxin damage to liver cells, April 11, 2002 Original article: Gut, April 2002;50(4):558-562



Once again, Elders in the Downtown Eastside gathered for 4 days of fasting, prayer, and reflection. Vision Quest Elders held the 4<sup>th</sup> annual fast and feast in Oppenheimer Park, August 13<sup>th</sup> to August 17<sup>th</sup>.

As part of the Aboriginal Culture, fasting, hardship and sacrifice have become known to us in many forms such as Sundance, Raindance, Counsel Dance, Winter Camps, and Dances. Other groups and individuals also come together in many similar forms and do so in unity against oppression in all races. Individuals bear these hardships and sacrifice for all those who need the help of the Creator and others in their lives.

The Vision Quest is a place for all, drumming, fasting, and praying. Reading, sharing stories, and reflecting on the hardships that people endure. Praying for justice for those who have none. Praying for health for those whose health is failing. Praying for happiness for those who are burdened with

(Continued on page 8)

## HEALTH CANADA LAUNCHES HEP C "GET THE FACTS" CAMPAIGN

Health Canada has launched a national public awareness campaign designed to inform Canadians about hepatitis C. This infectious disease of the liver is caused by the hepatitis C virus (HCV). It is usually spread through direct contact with infected blood. An estimated 240,000 Canadians are infected with the hepatitis C virus and, because there are usually no symptoms, 70 per cent of them are unaware. The objective of the hepatitis C "Get the Facts" campaign is to raise awareness of the risk factors of this disease.

The campaign's public education materials include a brochure with general information about the virus, a poster and bookmark as well as an information sheet for health professionals.

A website has also been developed to provide information on prevention, risk behaviours and treatment; it can be accessed at <http://healthcanada.ca/hepc>. For more information on the campaign, visit: [www.hc-sc.gc.ca/english/media/releases/2002/2002\\_39.htm](http://www.hc-sc.gc.ca/english/media/releases/2002/2002_39.htm).

To access these materials, or to help distribute them, contact your local support group. In Victoria, call HepCBC at 595-3892.

## CARE from the Heart

For people offering hepatitis C oriented support to others, the concept of networking and sharing is essential for healing on an individual basis and for the wellness of those we are striving to help.

Giving and receiving support is interconnected on the three levels of body, mind and spirit. When a support person continually gives to others without attention to his/her own support needs, eventually a downward turn towards ill health will occur on some or all levels. It may manifest itself physically in a reoccurring illness, or mentally with stress related issues, or spiritually as a sense of emptiness. As volunteers in the area of providing information and experience to those with HCV, we require a space where we can CARE for each other on a personal level; a place where we feel free to interact with each other concerning our own health issues, and an environment where we share resources and information which can in turn be passed on to our various support groups. This is the BODY aspect of good health, where we work with the physical manifestations of this disease, sharing how each of us copes individually. As our collective experience evolves, so does the exchange and distribution of knowledge to others.

The MIND aspect of healing is challenging in a different sense. On a personal level we help each other with how the mind reacts to constantly dwelling on hepatitis C while we offer support to others. We can share the effects this process has on us and our own mental health, as well as coping methods. Here, we are also able to assist each other a great deal by exchanging reliable resources, which are already available. It is energy efficient to make use of the excellent materials compiled by various groups and individuals rather than repeating the same work. To this end, we shall provide a networking

location, which facilitates quick access to resources. Many web sites, newsletters, groups, books, etc. exist which offer this service for those who happen to discover them on their own or through support services. I would like to see a "hub" or center where we collect reference information to pass on to the outer spokes of the healing wheel.

The SPIRIT level of healing also applies both internally and externally as we share with others. One's own personal belief systems come into play as we strive to understand ourselves on a deeper level. The more we give from the heart without thought of competition, the more healing will take place on a personal and global level. Reliable information resources should be freely exchanged and must be provided without the baggage of hidden agendas. Just as with other information providers, webmasters, discussion group administrators, and all volunteers who provide info via the internet, have a responsibility towards those they are helping. When we offer quality information and support from the heart without thought or expectation of personal glory or gain, we show a clear path towards health management. As care givers we must provide safe and nurturing resources for those we are helping.

In October 2001 I founded CARE - an online discussion group that has been slowly growing. My hope is to expand this caregiver network throughout Canada and the world.

CARE stands for Collective Awareness Resource Exchange and lives at <http://groups.yahoo.com/group/CARE-HepC>

All Hepatitis C support givers are welcome to join our CARE family as we work together for mutual support and growth.

Wendy Mackay  
Hepatitis C Support  
Haida Gwaii/Queen Charlotte Islands  
and Northwest British Columbia

(**LYMPHOMA**—Continued from page 1)  
have HCV, did not respond to treatment with interferon alfa.

The researchers concluded that anti-viral treatment with interferon alfa, with or without ribavirin, produces significant anti-cancer responses in HCV patients who also have splenic lymphoma with villous lymphocytes.

The researchers recommend that all patients with splenic lymphoma, or other types of B-cell non-Hodgkin's lymphoma, should be tested for HCV prior to the initiation of any therapy.

Splenic lymphoma with villous lymphocytes is a slow-growing type of non-Hodgkin's lymphoma, typically marked by an enlarged spleen and the blood disorders anemia and thrombocytopenia. Non-Hodgkin's lymphoma is a cancer of the lymph system. It is thought that splenic lymphoma with villous begins in the spleen. The cancerous lymphocytes grow and crowd the spleen and peripheral blood. It is usually treated by removing the spleen, chemotherapy, or both, with a 5-year survival rate of 80 percent.

Source: *The New England Journal of Medicine*.  
2002;347:89-94.

## VARIOUS CANCERS

HCV can be a contributing cause of tumour growth because it affects the immune system.

Italian researchers screened 495 [presumably HCV] patients with different types of cancer: liver cancer (114), multiple myeloma(41), non-Hodgkin's lymphoma (111), thyroid cancer (130), and Hodgkin's disease (63). The controls were 226 patients with no history of cancer.

Risks were greater for liver cancer, multiple myeloma, and B-cell non-Hodgkin's lymphoma. An association between HCV and thyroid cancer was also noted. There was no significant association with Hodgkin's disease.

They concluded that the high prevalence of HCV in the South of Italy gives reason to expect increases in liver cancer, thyroid cancer, and tumours associated with the immune system.

Source: *Liver*. 21(5):335-41, 2001 Oct.

## LYMPHOPROLIFERATIVE DISORDERS I

Another French study led to different conclusions.

They tested 813 hematology patients in all for antibodies to HCV: B-cell non-Hodgkin's lymphoma (164), Hodgkin's dis-

(Continued on page 7)

### ISVHLD 2003 INTERNATIONAL SYMPOSIUM OF VIRAL HEPATITIS AND LIVER DISEASE

Sydney Convention & Exhibition Centre

SYDNEY, Australia

6-10 April 2003

Contact:

ISVHLD 2003 Congress Managers

GPO Box 128

Sydney NSW 2001

Tel: + 612 9262 2277

Fax: +612 9262 3135

E-mail: [isvhld@tourhosts.com.au](mailto:isvhld@tourhosts.com.au)



*(LYMPHOMA—Continued from page 6)*

eases (34), chronic lymphocytic leukemia (107), multiple myeloma (54), Waldenstrom's macroglobulinemia (12), acute lymphoblastic leukemia (17), hairy cell leukemia (6), bone-marrow diseases (189), solid organ tumours (6), and non-malignant diseases (224). A control group comprised 694 other patients.

HCV antibodies were detected in only 2.46 percent.

The researchers concluded that HCV seems not to play a major role in the pathogenesis of B-cell lymphoma in France. Cofactors should be stressed to explain geographical discrepancies.

*Source: American Journal of Hematology, 67(3):168-71, 2001 Jul.*

## LYMPHOPROLIFERATIVE DISORDERS II

In Israel, between August 1997 and September 1999, 212 consecutive patients were screened for anti-HCV antibodies and hepatitis B surface antigen. The prevalence of HCV in patients with lymphoproliferative (LPD) disorders was compared to that in a control group of patients with bone-marrow disorders.

HCV infection was more prevalent in the group of LPD patients than in the control group, (7.8 percent v. 1.19 percent, and in the general population 0.64 percent). This finding was not considered statistically significant. However, among the different classes of LPD, a significant association with HCV infection was significantly more prevalent than HBV infec-

tion in the LPD group, but not in bone-marrow disorders group.

The researchers recommend that anti-HCV antibodies tests be performed on patients with diffuse large B cell lymphoma.

*Source: Israel Medical Association Journal: Imaj, 4(1):24-7, 2002 Jan.*

## CRYOGLOBULINEMIA

Preliminary studies suggest that there may be an association between chronic hepatitis C, mixed cryoglobulinemia (MC), and non-Hodgkin's lymphoma (NHL).

At the University of Toronto, 16 patients with chronic HCV and clinically active MC underwent bone marrow biopsy and aspiration. Nine (56 percent) had abnormal marrow morphology, 7 (44 percent) were interpreted as suspicious for lymphoma, 2 (13 percent) were interpreted as consistent with lymphoma, 5 (39 percent) of 13 patients had increased B-cell populations, 4 of 16 (25 percent) had marrow morphology and evidence of a monoclonal B-cell consistent with B-cell NHL, and all 13 tested negatively for Epstein-Barr virus.

These findings were considered confirmation of the presence of lymphoproliferative disorders in patients with chronic HCV and MC. Some of these disorders meet the criteria for the diagnosis of malignant lymphoma.

(An earlier study of 17 HCV patients in Italy reached similar conclusions.)

*Source: Hepatology 1999 Feb;29(2):543-7; Blood 2000 Nov 15;96(10):3578-3584.*

## SJOGREN'S SYNDROME

A 2001 paper from a researcher at a Paris rheumatology clinic notes that B cell non-Hodgkin's lymphomas occurring in cases of both Sjogren's syndrome (SS) and chronic (HCV) diseases share a number of characteristics: predominance of low grade marginal zone histological type, frequency of mucosal localization, possible transformation into a large B cell lymphoma, association with asymptomatic low level cryoglobulinaemia, and absence of virus within lymphoma cells, but localization of lymphomas in organs where the chronic viral infection is active in patients with HCV and where the autoimmune disease is active in patients with SS.

The paper proposes that in both diseases the first event of lymphomagenesis is the chronic stimulation at the site of the disease of polyclonal B cells secreting rheumatoid factor.

It concludes that the best preventive treatment of lymphoproliferations occurring in SS probably consists in decreasing the hyperactivation of autoreactive B cells when it is present, allowing the use of immunosuppressive drugs such as methotrexate or even tumour necrosis factor alpha antagonists, which in theory could favour other types of lymphoproliferation.

*Source: Annals of Rheumatic Diseases. 60(11):1007-10, 2001 Nov.*



**VICTORIA HepCBC  
GENERAL MEETING  
SEPTEMBER 3<sup>rd</sup> 7-9 PM, 541 Herald  
St.  
Nominations to the Board requested**



Please attend this important meeting. If you like the things that HepCBC has provided you, like the *hepc.bull*, *Peppermint Patti's FAQ*, *Advocate's Guide to Hepatitis C*, HepCAN list, pamphlets, counselling, computers, then we need YOUR help to ensure that these services continue. We are very short of volunteers, and need new ideas, energy, and fundraising efforts.

*(Vision-Quest—Continued from page 5)*

sadness. Listening to those whose hearts and lives are broken. Poverty, addiction, and the ravages of what has happened break lives.

Many only drink water during this time; some do eat, other drop by to say hello; others stay in the park for the 4 days to offer support and ensure safety. Everyone has a role, just as everyone has value in this world

This annual event is held in order to bring awareness regarding the plight of Aboriginal People and combines a spirit of unity among all cultures to end the war on the poor.

The Downtown Eastside is one of the largest unofficial reserves in Canada. Here lives the greatest group of nations of Aboriginal peoples as well as many other ethnicities. The largest common bond is visible, abject poverty.

This year has even more significance due to the massive and punitive draconian cuts ever placed on the poor and marginalized groups by any government in Canada. The referendum resulted in controversy among aboriginals and non-aboriginals alike. With unclear questions, unclear results, and less than 35% of the sent ballots returned, do we really have an answer? Do British Columbians have the right to determine Aboriginal rights? Does the Liberal Government have the right to over rule Federal Contracts? Was any of this even legal? Perhaps it should be like the ballot boat burned on the Songhees Reserve in Esquimalt—just sink out of sight

Poverty exists everywhere, but nowhere is it more visible than in the Downtown Eastside of Vancouver.

Missing women, now finally recognized as “women” not just as prostitutes and junkies, but also as people; mothers, daughter, aunts, sisters, and friends, not just from the DTES, but also from all across Canada—how many would still be alive if they were seen as part of society years ago? How many would have been able to succeed if that “bed” was available at the treatment center when they wanted it, and how many were making extra money because they couldn't live on “welfare”? Will we have vigils, benches and cross-Canada vigils in memory of these, our forgotten sisters?

The greatest rabble of slum housing is not usually seen by the tourists of Vancouver, but may change if we get the Olympic games. Just as Expo created more homelessness, so will this expensive endeavor.

Here we find the highest rate of hepatitis C and B, as well the highest rate of HIV/AIDS, more mentally ill, more TB, and more disenfranchised and marginalized people than should ever exist in Canada, along with less treatment and help available.

*(BROWNRIGG—Continued from page 1)*

When George Marcello was walking across Canada to raise organ donation awareness, Brian drove to a lonely stretch of highway on the BC/Alberta border to welcome him. He would prepare a hundred meals for a community dinner with the precision of General Patton and the good humour of St. Nick. Last year, even though he needed an electric scooter to get around, he drove three hours to our local Fall Fair to quietly show his support for a Hepatitis C Awareness display.

Last month, he needed oxygen to breathe, his face was gaunt and his belly was distended so he used that image to highlight a full-page article in the local paper on the need for early diagnosis and better access to home care.

About three weeks ago he knew he didn't have much time, so he threw a party. There must have been a hundred people in his backyard, along with guitarists, singers, a belly dancer and his crazy collection of disco lights. Smiles and laughter mingled in the warm summer night breeze with an unspoken sense of foreboding.

On August 11, 2002, surrounded by his family, his body quit working. Perhaps he left on that same breeze.

For his wife, Diane, and their two daughters this is a time of heart wrenching loss.

For the rest of us, this is an opportunity to examine our own lives for signs of love and fearlessness.

Thanks, Bri...

*Ken Thomson*

*(Note from the editors: Brian was a beloved member of the Board of HepCBC)*

Poverty has been further increased by the recent cuts by our MLA's Cuts to welfare, legal aid, health care, education, and housing.

Aboriginal People, seniors, people with disabilities, women and children, those who suffer from mental illness, those who live in the throes of addiction and those who have been physically, emotionally and sexually abused will continue to suffer and be part of the carnage left by the inhumanity of the liberal agenda.

If you have a moment to share, a thought to remember, a joy or sadness in life, offer it up. Some have had blessings. Some have had trauma. It is all part of why the Elders gather to hold a Vision Quest in the Downtown Eastside.

All my Relations,

Carol Romanow



**Dear Readers:**

At our last general meeting, I was asked by the membership and Board of HepCBC to contact you to see if you could join with us to help the hepatitis C community. We have noticed that many times when one of us dies, the death does not count as hepatitis-C related. We know that Health Canada keeps the best statistics on the disease in this country, and we believe that the data may be flawed because of the way the death is recorded. Can anything be done to rectify this? Let us know if you have any ideas. Would you please talk to or write to your local MP/MLA to ensure that this is discussed, and to anyone else who might be able to make a difference?

Below, please find a statement from the NIH Conference related to this problem:

**The NIH Consensus Conference on the Management of Hepatitis C: 2002**

*The Course and Outcome of Hepatitis C*  
Jay H. Hoofnagle, M.D.

"Mortality statistics in the United States are based on the "underlying cause of death" listed on death certificates. As deaths attributable to viral hepatitis primarily result from chronic liver disease and liver failure and, in those cases, viral hepatitis may not necessarily be listed as the underlying cause of death, it is likely that deaths classified as viral hepatitis underestimate the true incidence of deaths related to viral hepatitis. Further, until 1999, when the International Classification of Disease version 10 (ICD-10) began to be used to classify causes of death, HCV was not given an independent code, making it difficult to estimate the total number of deaths attributable to HCV."

We suggest you send letters to the following opposition MP:

Mr. Svend Robinson  
House of Commons  
Parliament Buildings  
Ottawa, Ontario  
K1A 0A6  
Telephone: (613) 996-5597  
Fax: (613) 992-5501  
Email: [Robinson.S@parl.gc.ca](mailto:Robinson.S@parl.gc.ca)

Joan King  
Editor



## CRAWFORD'S OBSESSION

What is Crawford's obsession with papers? They go out of their way to get us to mail in as many papers as they can. They want your spouse's T4. Why? The lawsuit was by and for the victims of the blood. If your spouse doesn't work, he/she is included on your T4. If they do work, then they submit their own T4. Why do Crawford's need these pieces of paper annually?

We must re-apply—again, more papers. The papers must be printed, sorted, mailed out to us, then we have to mail them back, and then they must be filed and handled. All of our personal and medical information is on file at the click of a button. Again, why this almost fetish-like desire for duplicate papers?

Our doctors have to fill out the same papers annually. Why? If we get sicker and go up a level, we'll be sure to ask for the forms and send them in, because we get lump sum payments as our conditions worsen. If we clear the virus and are able return to work, then that will be reflected in our T4's.

The only reason, in my opinion, is money. The way I see it is that the greater the paper load they can create, the more people they have to employ in their office. The more people, the more money they draw out of our limited fund. The more money they draw, the greater the profit.

The court agreement doesn't call for us to re-qualify annually. From what I've been told, it is the brainchild of the director at Crawford's. The people who contracted AIDS from the blood don't have to re-apply or re-qualify for any of their packages, and I'm sure that none of the lawyers or companies drawing money out of our fund need re-apply annually. That privilege is reserved for us, the victims of the blood.

*Bruce DeVenne*



### VOLUNTEER APPLICATION FORM

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_  
\_\_\_\_\_

CITY: \_\_\_\_\_

PC: \_\_\_\_\_ PROV: \_\_\_\_\_

TEL: ( ) \_\_\_\_\_

FAX: ( ) \_\_\_\_\_

EMAIL: \_\_\_\_\_

#### ABILITIES OR AREA OF INTEREST:

Library Printing Copying Phoning  
Fundraising Counseling  
Research Refreshments  
Special Events Publications  
Computer Help Errands  
Grant Applications Board Member  
Other

#### Experience:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

#### Time available:

\_\_\_\_\_  
\_\_\_\_\_

SEX M F

Date of Birth: \_\_\_/\_\_\_/\_\_\_

Mo Day Year

Contact: HepCBC  
2741 Richmond Rd, Victoria, BC  
V8R 4T3  
Tel. 595-3892 or Email:  
info@hepcbc.ca

### LETTERS TO THE EDITOR:

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

Are you in the 86-90 Window?  
Are you having any problems?

Contact: Terry Waller  
(250) 642-6766

*(Terry is not a lawyer but a concerned victim)*

## COMPENSATION

### LEGAL ACTION

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

#### 1986-1990

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

#### Pre-86/Post-90

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

#### Klein Lyons

Vancouver, BC 1-604-874-7171,  
1-800-468-4466, Fax 1-604-874-7180  
www.kleinlyons.com/pages/class\_actions/Hepatitis\_C.htm

#### Mr. David Harvey/ Goodman & Carr

Toronto, Ontario  
Phone: 1-416-595-2300, Fax: 1-416-595-0527

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

#### Lauzon Belanger S.E.N.C. (Quebec)

www.lauzonbelanger.qc.ca

#### Goodman and Carr LLP

pre86hepc@goodmancarr.com  
www.goodmancarr.com

#### Other:

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

### LOOKBACK/TRACEBACK

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

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

Lookback Programs, BC: 1-888-770-4800

Canadian Blood Services Lookback/Traceback &  
Info Line: 1-888-462-4056

Hema-Quebec Lookback/Traceback & Info Line:  
1-888-666-4362

Manitoba Traceback: 1-866-357-0196

#### RCMP Blood Probe Task Force TIPS Hotline

1-888-530-1111 or 1-905-953-7388

Mon-Fri 7 AM-10 PM EST

345 Harry Walker Parkway, South Newmarket, Ont-  
ario L3Y 8P6 Fax: 1-905-953-7747

### CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656

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

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

Ontario Compensation: 1-877-222-4977

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

Quebec Red Cross Compensation: 1-888-840-5764  
1986-1990 Hepatitis C Class Actions Settlement  
6/15/99 www.hepc8690.ca/

### ADMINISTRATOR

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

www.hepc8690.com info@hepc8690.com

### MISCELLANEOUS

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

## DIAL-A-DIETITIAN

732-9191 (Vancouver Area)  
1-800-667-3438 (Toll-free  
elsewhere in BC)

**LEXMARK**  
Passion for printing ideas.™

HepCBC gives special thanks to Lexmark  
for printing out our Treatment pamphlets!

