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Canada's Hepatitis C News Bulletin

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MAY: HEPATITIS C MONTH

USER UNIONS AND CASH

S.O.L.I.D.

(Society of Living Intravenous Drugusers)

Carolyn M. Romanow
Victoria, BC, Canada

16TH I.C.R.D.R.H
MARCH 2005

BELFAST, NORTHERN IRELAND

I first applied for this conference in the hopes of attaining two goals: First, to come to Ireland and visit my friend, and secondly, to attend a conference of this magnitude that was relevant to my volunteer work, something that I believe so strongly in—harm reduction. The words themselves in Canada, for some, strike a chord of morality, a sense of indignation or a sense of fear; for others, they cause serious contemplation about the war on drugs. What I see is a war on people who are addicts, a marginalization of a group of people who, by a series of unfortunate timing or events, or just plain life history, have become addicted to drugs, in particular those who have now become visible, generally poor, usually involved in some type of criminal activity and viewed as a social leech and outcast by many.

We then have the pecking order with the addicted groups. It's ok to smoke, frowned upon but legal, and usually considered outright bad by a large segment of the population. Those who continue to hold jobs are the unknown addicts. If the addict is rich enough, the situation is never known. If the addict has money and title, the family gets lots of sympathy and has the ability to ship the addicted person off to an expensive rehab facility.

However none bear so much discussion, with accompaniments of indignation about wasting taxpayers dollars, a strengthening of the courts and policing system and building of bigger and better prisons, as the poor who are addicted. They aren't convicted and jailed for their addiction as a rule, but for

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HEPATITIS C COUNCIL OF BC WORKING GROUP

The Working Group is finalizing the provincial election-related items that it was tasked with by the membership at the Victoria conference. The one page fact sheet, backgrounder, and sample questions for candidates will all be posted on the web site:

www.bcephcouncil.ca

The framework document, which is now titled, 'Managing the HCV Epidemic: A Practical and Cost-effective Approach for BC Communities' has been sent out for review and comment. The final version will also be available on the web site.

These are all tools that can be used to raise awareness about hepatitis C in BC and to educate and encourage our politicians to support and engage in a more active and coordinated response. If everyone reading this prints off copies of these resources and takes the time to attend just one all-candidates meeting and asks a question or two, we can dramatically raise the profile of hepatitis C.

This is a time when a small commitment of time and energy can make a big difference for the thousands of British Columbians who are at risk of becoming increasingly ill, or dying from HCV. Get involved.

—Ken Thomson

*The Candle of Hope by
Deborah Wilson and Pat Lightfoot*



MAY IS HEPATITIS C AWARENESS MONTH

~ *Be Aware, Be Involved* ~

It's Your Future!

May Day! May Day! Why sound the alarm? The services for the hepatitis C community are being decided before our eyes. Decisions are being made that will affect our services for decades and it's time we all got on board and seriously evaluated each contender's proposed "ideal strategy" for our community's services future.

"Double Decade Demographics" impacts will hit our community's limited services and unprepared medical resources as Canada's HCV costs double to \$1 billion annually by 2010 and will continue to climb until at least the year 2030.

BC has even more reason to worry, with 30% of Canada's HCV burden and with close to 60% of cases aged 40-59. Many will discover the disease too late, with need for a transplant.

The strategy for which I would vote would contain a clear goal to radically increase liver disease services and research. Transplant needs will soar into the 1000's with the reality being that only 300 transplants are performed in all of Canada each year. We need strong capacity building and research in liver disease. Even though the pegylated interferon combination treatments have given much hope, raising SVR rates above 60%, the needs of non-responders, relapsers, and others must be met in liver disease services.

In January 2005, the Health Canada/

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

Peppermint Patti's FAQ

Peppermint Patti's FAQ Version 6 is now available, and Version 5.6 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only \$6 each, plus postage. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

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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.

THANKS!

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CUPID'S CORNER



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

To place an ad: Write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to HepCBC, and mail to HepCBC, Attn. Joan, #306-620 View Street, Victoria BC V8W 1J6, (250) 595-3892.

Give us your name, tel. no., and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

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

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HCV COMMITTEE SET UP

George Smitherman, Health Minister of Ontario, says he filled a promise to set up a Hep C task force for the treatment and prevention of that illness, possibly responding to a CBC report that 6 months had gone by with no action. John Plater, the committee chair, had said there had been no meetings. Meetings are now expected to take place before May 15. The committee was created after critics complained that \$66 million set aside for HCV patients had been absorbed into the general health-care budget.

Source: <http://toronto.cbc.ca/regional/servlet/View?filename=to-hepatitis20050331>, CBC News Mar 31, 2005, Smitherman appoints hepatitis committee

CANADIAN VACCINE RESEARCH CENTRE

Canada will contribute \$24 million to a vaccine centre at the University of Saskatchewan, called InterVac.. The immediate cause is a possible flu pandemic, and there will be a focus on avian flu, West Nile virus and SARS. It is scheduled for completion in 2009, and is expected to be one of the largest vaccine research laboratories on this continent. Research will include Hep C, TB, and HIV. There will also be a lab for large animal research, since 79% of newer diseases may be linked to animals. The lab will be able to test several different options at the same time, making research results quicker. The scientists are expecting even more diseases in the future, possibly to the point that a new one emerges every 15 months or so. The scientists hope to create the means to deal with these diseases.

Source: Cotter, John, <http://cnews.canoe.ca/CNEWS/Canada/2005/03/16/pf-963199.html> PM announces vaccine centre, March 16, 2005

TREATMENT IN PRISONS

Ninety HCV-infected male inmates were treated with the standard “combo” therapy (IFN + ribavirin) in prisons on the west coast of Canada between March, 2001 and October, 2002. Of the 90, 8 stopped treatment due to side effects, while 9 were taken off because of non-response at about 6 months. All of the patients continuing the study stuck with the treatment at least 80% of the time, resulting in a sustained virological response (SVR) of 55.9%. In the genotype 1 patients,

response was 31.6%, 100% for genotype 2, and 71.4% for genotype 3. This study showed that treatment of inmates was highly successful and worthwhile.

Source: Farley JD, et al, *Can J Gastroenterol.* 2005 Mar;19(3):153-6.

Treatment of chronic Hepatitis C in Canadian prison inmates. PMID: 15776135 http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15776135

VANCOUVER: FIRST HEROIN PRESCRIPTION

As a result of an exemption of Section 56 of the Controlled Drugs and Substances Act, Vancouver, BC, made headlines in February of this year as North America’s first city to prescribe heroin. The prescriptions are a part of clinical trials. A year and a half ago, Vancouver inaugurated the first safe injection site on this continent.

Source: <http://www.worldpress.org/Americas/2054.cfm> Mar 26, 2005, North America’s First Heroin Prescription Program Introduced in Canada

(MAY DAY—Continued from page 1)

Canadian Institutes of Health Research (CIHR) Research Initiative on Hepatitis C proposed a renewed national initiative which will build an HCV collaborative network to focus on **infectious disease prevention and control**. BC Hepatitis Services is proposing to provide centralized **co-ordination for all aspects of diagnosis, clinical guideline development, treatment expertise, professional education, research and data collection in B.C** and would be linked to B.C.’s Centre for Excellence in HIV/AIDS, and **complement HCV prevention and surveillance activities** of the B.C. Centre for Disease Control. BC Hepatitis Services’ Dr. Yoshida proposes a Liver Disease Center of Excellence.

There you have 3 proposals on the table—one federal and two for BC. Our future is being decided and the writing is on the wall. If we don’t make loud, loud noises right now for liver disease services and research, we will all lose out in the end. Yes, we need medicines, but we need liver services, too. Be Involved! Contact a Hep C organization near you today! Wear the yellow and red Hep C ribbon. Be Aware!

Marjorie Harris, HepCURE
Info Line 1-866-HepCURE

HepCBC

ANNUAL GENERAL MEETING and ELECTION

**Wednesday, June 1, 2005
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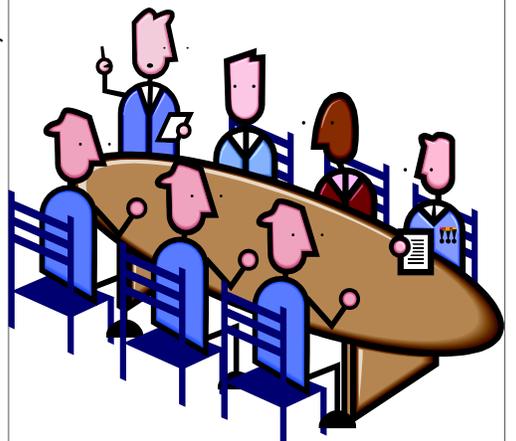
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MANAGING THE HCV EPIDEMIC

The Hepatitis C Council of BC has released a new document, “Managing the HCV Epidemic: A Practical and Cost-effective Approach for BC Communities.”

This groundbreaking document—developed by the Hepatitis C Council of British Columbia—demonstrates that, far from being over, the medical and financial burdens of the HCV epidemic are increasing dramatically and creating a situation that urgently demands a response. The paper also sets out considerations and solutions intended to inform that response.

Click here <<http://www.bchepcouncil.ca/downloads/hcv-renewedfocus-britishcolumbia.pdf>> to download the document directly (PDF) or visit the Hepatitis C Council of BC website for more information at www.bchepcouncil.ca



(USER UNIONS—Continued from page 1)

those crimes they commit in order to feed their addiction, or the violence that erupts and seems to be a part of many addicts' lives. The violence comes from many sources: police, society, jails, the streets, and those who generally think it is acceptable. They are "allowed" to be violent towards others in this life style, particularly towards the women.

Knowing my talk was to be about user unions and cash, when I first began looking at how and what I wanted to say and others heard what I was calling my presentation, the first question I was asked was, "Why call it a union?". I have no ready answer—just that, if a marriage can be viewed as a union, why not a group of people with a common bond: Addiction? Or simply, why not?

This theme was born from my frustration with trying to obtain funding for our group. No one could understand why we choose to have only users, past and current, as members. I guess the answer was the same as for women's groups or men's groups or boys' groups: How can you truly relate unless you have "been there, done, that, got the T-shirt"? We are not eligible for a lot of funding due to our closed membership. Funding is also influenced by the words "addict" and "professional". Who has the experience and understanding and knowledge except the addicts, they who have the T-shirts?

The professionals have a place, a very important one, but not necessarily in these organizations. A professional may be needed for a job in the organization, the first one coming to mind, if we ever get funding, that of bookkeeper; either that, or pay for some training. I'm not a money management person, and don't pretend I ever will be, so that would be a need. A nurse or a doctor may be utilized, but for a specific purpose or need, not necessarily as a member. There are more roles I'm sure others can think of, but primarily it should be a consensus-driven model that could maintain responsibility for the group and work in the field of harm reduction to the extent an individual may be able.

Most of those who are addicts, and all in our group, live in poverty. The majority have health issues, ranging from Hep C to heart disease. Many have mental health issues, but the biggest difficulty is the combination of poverty and addiction.

Trying to do research and present a cohesive, well-researched paper was my goal, however, as time progressed and I began reading papers to see what would be the best and most relevant to quote from, it

struck me how difficult it is just to get through the day as a person who lives in poverty. My group has no cash, and fundraising became a necessity mid-February, when I was informed that there was no scholarship. We have very little money and I live on a disability pension which gives me and income 40 % below what is referred to as the poverty line in Canada.

When my computer and printer screwed up, I didn't have the funds to send them for repairs and spent 5 days piddling around with my friend, who helped get it working in a rudimentary fashion.

I didn't have the money to fly here; my son used his Air Miles. I didn't have the money to pay for a place to stay; HepCBC paid for my bed and breakfast. I didn't have the cost of the conference; contributions from the Methadone Clinic, The Community Solidarity Coalition, L.I.F.E. and The Center for Addiction Research are paying for the conference. Money for anything else is not available and without my friend who lives in Ireland, I would have been sleeping on the streets for a week, as Air Miles tickets give you no choices. As it is, I have to pay to come and go from her home, 250 km away, to the conference. I arrived on the 14th of March and I go back on the 4th of April, with little money for food, taxi fares or any out of pocket expenses. Any souvenirs I buy will come out of my next month's food budget.

In short there is little if any support or help to get users here and help them participate in a conference in which, in reality, they should play a big part. I tried to get 3 or 4 from SOLID over here but it was almost impossible for me. Add in the difficulty of traveling with methadone, or an active addiction, possibly a criminal record or perhaps infection with HIV: that definitely rules out a group going anywhere via the United States.

How in reality can a conference not include those who are the primary focus of discussion? Users should comprise 25 % of the participation because, unless they buy into the plan and it is viable for them, it will be like the war on drugs—a dismal failure. How can you not fund user groups and ensure the process is not so cumbersome most cannot attend? How can this conference charge \$550.00 Canadian funds to a group that has no funding? Fundraising is fine, if one has the time, the energy, an assistant, the health and the tools to do all this work. \$550.00 is a month's money for some on welfare, or for us on disability, 75% of our monthly income. If we can't afford to live in our country of origin, how can we be expected to participate at all?

What do you know about drug users?

Why are they users or addicts first, and people, second? Why is it that no one sees the person, the son or daughter, the mother or father, the auntie or uncle? For some families, addiction isn't admitted or discussed, and many die without family or friends about, save those who are also involved in drug use or harm prevention. What happens that these groups of people are shunned by society, family and almost always have a negative stereotype about them? I have much respect for a group called "From Grief to Action", and I hope they got here, and I certainly hope they are a part of the conference in Vancouver next year. They, as parents, have stood up front with their kids and said to the world, "My child is an addict but I love my child." Addicts and the poor have no protection under human rights, provincially, federally or internationally.

Let's get back to user unions and cash. Funding is almost impossible! Trying to explain the need to have a "voice" and a place at the table is something no one thinks of. We are always told we are allowed to attend, but addicts also need to have financial support to attend workshops or groups. Bus fare or lunch money is important, as most addicts do not have it. Concerning funding for conferences, what are the professionals saying or doing? Who knows, unless you have attended a presentation or conference on the topic? How do the professionals know what is and is not needed unless they have spoken to user groups and found out from the individuals within that group?

Housing, food, clothing, and adequate medical and dental care become a huge part of the complexity of addicts' lives. Bad housing, poor food, used clothing or not enough clothing and lack of medical and dental care is more the reality than not, as are rotten teeth, abscesses, inability to access a family doctor, and inability to have adequate pain management because it is seen as "drug seeking behavior."

Housing for the poor is dismal, even impossible for the visible addict. Welfare rates are too low to pay the required rent. Add in the cost of utilities, and even those on the higher rate pay of disability are paying out more than the allotted amount; many pay out of what is referred to as support, food money. Many live in very unhealthy conditions, run down abodes, owned by slum lords who do little or no repairs or upkeep, with up to 15 persons sharing toilets and showers. Usually there is no cooking area, nor a hot plate or microwave. A 10 by 10 room in which to live ones life: living on the streets is the only alternative for many.

Nutritional food is impossible for those

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(USER UNIONS —Continued from page 4)

who are poor and live on welfare, impossible for an addict. Free food is always around; no one need go hungry. But one also has to have the energy to get to these places, and the nutrition is lacking in most. Free food, designed to fill the stomach, not provide a nutritional balance, is totally inappropriate for those with hepatitis or HIV. With 85% of addicts infected with hepatitis C, nutrition is important.

In short, complicated by the fact I do a needle exchange out of my van twice a week with no funding, and I work on fundraising with a computer, a broken printer and no money to purchase ink or pay for photocopying, I lost sight of my original plan.

Our group meets weekly, no money for bus fare or food or even a bit of tobacco. We have no office; hence I live with rigs, water and condoms stored in my van or my home. Most in our group cannot afford a phone or computer, so getting hold of people may mean a drive to their place or looking for them at a free eating place, or Rev. Al's "Open Door", Rev. Tom's "Mustard Seed", or "The Link".

Funding must happen so that working space can be purchased. Computers need to be available. Addicts need to have some ability to earn money by doing work that is relevant. Office support in terms of a manager or bookkeeper needs to be funded. Users need to be part of the solution, and not a way for the "poverty pimps" to obtain funding and build their own jobs.

Funding must happen so that addicts can take courses as they are able, according to their interest, capabilities and desires. Addicts must be consulted and involved in the process of managing their own lives. Funding needs to happen so that we can meet the "determinants of health". Addicts must have a better quality of life and access to better housing and nutrition, not better access to jails or the streets as a home. Social support programs need to stop attacking the poor and marginalized in the hopes of "saving money", taxpayers' dollars. It only costs more in the long run.

Band-aid programs do not solve anything; they never have; they never will. In Canada, we have over 300,000 persons infected with hepatitis C, most of whom will never be treated; definitely, few in the addict group will be. Our attempts at saving money now will only result in higher costs later, either by hospitalization, increased costs in the penal or court systems, or the loss of human potential via the premature deaths of those we see as "less than" compared to others in society.

TREATMENT

HCV, DEPRESSION and SUBSTANCE ABUSE

Many, if not most, Hep C patients, according to recent research, suffer substance abuse problems and psychiatric disorders. In this study, 293 patients were screened at their first visit to a hepatology clinic in Portland between 2002 and 2003. They were given a questionnaire about alcohol use and another about depression. 93% had a history, past or present, of one or more psychiatric disorders, including depression, posttraumatic stress disorder, substance use, and bipolar disorder. 35% had moderate to severe depression, and 21% had scores showing heavy alcohol use. The depression, as shown by this data, existed before any IFN treatment. The researchers believe it is important to diagnose these disorders before initiating IFN, in order to treat the patient more effectively, thus increasing the number of patients eligible for treatment and improving treatment outcomes.

Source: Fireman M, et al, *Clin Infect Dis*. 2005 Apr 15;40 Suppl 5:S286-91. Addressing tri-morbidity (hepatitis C, psychiatric disorders, and substance use): the importance of routine mental health screening as a component of a comanagement model of care. PMID: 15768336

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15768336

QUALITY OF LIFE

Successful treatment can reverse the negative effect of HCV on a person's quality of life (QOL), according to this study, which also shows that traditional ways of measuring liver disease, such as damage as indicated on biopsy or ALT levels don't necessarily correspond to QOL, which can be affected dramatically by HCV, if there are complications from advanced disease such as encephalopathy, variceal bleeds, ascites (water retention), and liver transplantation. Of course, most people with HCV have no serious liver disease, but they can still suffer from poor QOL. There are other parts of the body, not just the liver, affected by HCV, which can cause conditions like cognitive dysfunction or "psychosocial disorders." Many doctors are not so familiar with how to judge a patient's QOL as they are with using the ALT to judge the extent of the effects of HCV, thus the true burden of the disease is not well understood. The researchers suggest that the doctor ask the patient to fill out a QOL questionnaire to add to his/her chart, which could be compared to another done at a later time. They also recommended a series of courses pointing out the importance of QOL for those with HCV.

To determine how HCV affects the patient, the researchers identified 32 past studies on QOL, where they found that those with HCV were affected in social and physical function, health and vitality. They compared QOL reported by those with HCV vs. those without, and they compared QOL of responders vs. non-responders to therapy, where the non-responders had a predictably worse QOL. They studied how QOL was affected in relation to the degree of liver disease, which was more obvious in patients with cirrhosis, and to neurological, psychological and social factors, causing cognitive problems, depression, emotional problems and stigmatization. They decided how much difference was actually related to HCV in the QOL. The researchers were convinced that treatment might improve QOL and overall health, and that awareness of that fact might result in earlier treatment.

Source: John C. Martin, www.hepatitisneighborhood.com/content/in_the_news/archive_2304.aspx, *Quality of Life Important in Hepatitis Management, Physicians Stress*, 04-06-05.

CHICKEN VEGETABLE ENCHILADAS



- 1 1/4 lbs chicken pieces, skin removed
- 1 19-oz. can red or green enchilada sauce
- 8 corn tortillas, warmed
- 2 C fresh or frozen vegetables (corn, green beans and carrots)
- 1/2 C crumbled queso fresco or shredded Monterey Jack cheese

Place chicken in a large pot. Cover with water. Bring to a boil over high heat. Reduce heat to medium-low. Simmer, uncovered, until chicken is cooked thoroughly, about 30 minutes. Drain and let cool. Shred chicken. Heat oven to 350°F. Place 1 cup enchilada sauce in a shallow bowl. Dip a warm tortilla in sauce. Place 1/4 C vegetables, 1 Tbsp. cheese and 1/3 C chicken along center of tortilla. Roll up tortilla. Place in oven-proof baking dish. Repeat step 4 until all enchiladas are in baking dish. Cover and bake 20-30 minutes or until heated thoroughly. Meanwhile, in a small saucepan, heat remaining 1 1/4 cups enchilada sauce over medium heat. Pour sauce over cooked enchiladas. Serve.

Yields: 4 servings (2 enchiladas per serving).

Source: California Department of Health Services (<http://www.dhs.ca.gov/>)

Jules Levin of NATAP attended the 40th Annual Meeting of EASL (European Association for the Study of the Liver) and made a preliminary report about some of the newer Hep C drugs being developed which were presented at that meeting: NM283; Viramidine; Albuferon; a-glucosidase inhibitors.

NM283 or Valopicitabine

According to a phase II study presented by N. Afdhall, et al, NM283 is being developed to use with peginterferon, combined with ribavirin or Viramidine in genotype 1 non-responders. The drug alone reduced viral load by 94% in a 15 day trial with non-responders, and is now being tested in naïve patients. The study consists of two arms: one with NM283 alone, and the other, combined with peginterferon. NM283 is taken orally. So far, the combination therapy shows good antiviral activity in this difficult-to-treat group.

VIRAMIDINE

Viramidine is a substitute for ribavirin, producing less anemia. In a dose-ranging study in 180 naïve patients, engineered by R.G. Gish and associates, the researchers compared viramidine and ribavirin, each combined with peg-interferon. 64% of the patients were male, 76% were Caucasian, 72% were genotype 1, and the average viral load was 6.5 log10 copies/ml. Anemia was

analysed, but the dose was not reduced. At the end of the study, the results of both products were comparable in antiviral activity, but the patients taking viramidine showed less anemia.

ALBUFERON

Albuferon is a type of interferon fused to human albumin, given by injection once every other week. This phase II study by V. Bain, et al, included 32 naïve patients with genotype 1, some in Canada. It was divided into 3 groups with different doses. There are now two more groups taking still higher doses. The albuferon was well tolerated and showed good antiviral activity.

a-GLUCOSIDASE INHIBITORS

C. Chapell and associates are studying this HCV entry inhibitor, which interrupts a part of the viral cycle that hasn't yet been attacked by other antiviral strategies. The researchers are using a virus related to HCV as a model. They have shown earlier that the a-glucosidase inhibitors could stop viral life-cycles, hopefully that of HCV, as well. They have now demonstrated how these inhibitors produce an antiviral effect.

Source: Levin, Jules, <http://www.natap.org/>, *New Hepatitis C Drugs in Development: EASL Report , 40th Annual Meeting of the European Association for the Study of the Liver, April 13-17, 2005, Paris, France.*

May 1—4, 2005

3rd National Aboriginal Hepatitis C Conference, Regina, SK
All Nations Hope AIDS Network
Toll free: 1-877-210-7622
allnationshope2@sasktel.net
www.allnationshope.ca

June 17, 2005

National March for Awareness
Washington, DC
HMAwareness@aol.com
www.march-on-dc.com 540-248-7324

November 3, 2005

Royal College of Physicians of Edinburgh - Hepatitis C, Edinburgh, Scotland
www.sign.ac.uk/events/index.html

November 11-15, 2005

56th Annual Meeting of the American Society for the Study of Liver Diseases (AASLD)
San Francisco, CA
www.aasld.org/eweb/DynamicPage.aspx?webcode=05_Annualmeeting

March 25--28, 2006

Shanghai - Hong Kong International Liver Congress 2006, Shanghai, China
www.livercongress.org/en/news/20041015.htm

NON-RESPONDER. WHAT'S NEXT?



Question: I have done the Pegylated Interferon and Ribavirin treatments for 6 months. I am genotype 1, and like 50%

of us, I failed to completely clear the virus, and was taken off treatment. Where do I go from here? I have heard about maintenance dosing, but is it effective, or a viable option for those of us who are nonresponders? Do we have any other options at this point?

Answer: You know, I'm glad you asked this one because many people are asking the same question. The first thing I would say is don't despair. Hepatitis C is a slowly moving virus (for most of us) and you can protect yourself and even increase your wellbeing by taking some simple steps:

- ◆If you smoke, STOP. Smoking is known to accelerate liver damage and compro-

mise health in general.

- ◆If you drink alcohol, STOP. Alcohol is the single most dangerous thing you can put in your body if you have hepatitis C. If you can't stop or cut down, then consider seeing a counselor.
- ◆Change your diet to include more fresh fruits and vegetables, and cut down on fatty and pre-processed foods.
- ◆Exercise. Even going for a 20 minute walk each day will help.
- ◆Try to avoid stress. Stress is a known cause of flare-ups.

There is an excellent publication on our site (www.hcvadvocate.org) that can help you through this difficult period. Check out: "Next Steps: When HCV Treatment Isn't Working"

Maintenance dosing of pegylated interferon is under research and you would need to know how damaged your liver is before your physician would prescribe

maintenance dosing for you. Since it has not been approved by the FDA, it may be difficult to get it covered by your medical insurance.

We don't expect that any new drugs will be available for the next 5 years or so, and any new drugs will probably be used in combination with pegylated interferon and ribavirin. If you are interested in trying out some experimental treatments, check out our Clinical Trials page to see if there are any new treatments that you may want to investigate. Before you jump into a clinical trial, however, I would highly recommend that you read our publication "A Guide to Understanding Medical Research and Clinical Trials."

CD Mazoff, PhD
Managing Editor, Webmaster
www.hcvadvocate.org www.hbvadvocate.org

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HOUSE VOTE

March 22, 2005 Fletcher's motion to force House vote on Hep C compensation

OTTAWA - Opposition Health Critic Steven Fletcher, M.P. for Charleswood - St. James - Assiniboia, applauded the Standing Committee on Health's support for his motion which passed on Monday. The motion calls on the health committee to report to the House of Commons that the government should extend compensation to all those who contracted Hepatitis C from tainted blood.

Last November, the health committee made a similar report, but the Liberals talked out debate in the House before a vote to accept the report could be put to members. Due to new procedural rules instituted this month, such filibustering will no longer be possible. Now, any committee report must be debated within the House for three hours and then be put to a vote.

"Thanks to the new procedural rules, the government can't keep ignoring this issue like they've always done," said Fletcher, "Even when others suffered, the Liberals have had no qualms about manipulating the system for their own political ends. They can't get away with such flagrant abuse any longer. Victims of Hep C will finally be heard."

Last November, Health Minister Ujjal Dosanjh suddenly announced that the government would reconsider its long-held position that those infected outside of the 1986-1990 window did not qualify for compensation. Stating "changing circumstances", he suggested that new financial options might be considered for those originally left out of the fund. Any additional compensation would depend upon the results of a June audit, which would determine if the fund had an actuarial surplus and if so, how large.

"Since 1998, the Liberals have ignored the suffering of thousands of Canadians infected by tainted blood. Using legal arguments, they tried to absolve themselves of any responsibility to those not infected within the 1986-1990 window," said Fletcher, "For seven years, while victims died, this government refused to accept blame. The Health Minister has essentially admitted his government has acted in error, but is still forcing victims to wait until June. The callousness of it all shocks me."

John Macaulay, Legislative Assistant Office of Conservative Health Critic Steven Fletcher, M.P., 103-S Centre Block, Parliament Hill, Ottawa, ON Tel. (613) 943-8131 Fax: (613) 992-3199

SEQUEL: SHAME!

On Wednesday, April 13, officials wouldn't extend their business day by two minutes, thus preventing a motion calling for compensation of "forgotten victims" of Hep C from going to a vote, according to Conservative MP Steven Fletcher, who put forward the motion on Monday. Mr. Fletcher had introduced a similar motion last fall, which never came to a vote because of a filibuster by the Liberals. Several years ago Jean Chretien defeated a similar motion when he declared it a matter of confidence. Now, under revised rules, the vote will take place around the end of April.

Source: D. Bueckert, Canadian Press, <http://www.halifaxherald.com/stories/2005/04/07/jCanada.html> - An 'inhumane' two minutes - Critics incensed as time runs out on hep C compensation motion

CARE-LINE

A limited patient assistance program, called CARE-Line, is available in Canada for some people receiving Pegatron. Patients can call 1-800-603-2754 extension 2121 to find out if they are eligible for help from this program. Health care providers who wish to make inquiries about their patients access to CARE-Line may call 1-800-463-4636 extension 346.

Source: <http://www.hepcvorkregion.org/docs/352.1.Slide.1>

COMPETITION!

HepCBC is looking for writers for the June issue of the *hepc.bull*, and is willing to pay \$50.00 for a featured article. The article should be original, consist of 500 to 800 words, and of course, be about hepatitis C. It may be, for example, about the author's experience with hepatitis C, a study (with references) on some aspect of the disease, or a call for action. Submissions should be in by the 15th of the May, stating interest in the bonus. If there is more than one submission chosen, the editors reserve the right to print both, or leave one for a future edition. info@hepcbc.ca

ATTENTION: ARTISTS

We at HepCBC are looking for a new, bold logo. We are prepared to offer \$100.00 for any logo that is used on our website or bulletin as a result of this contest. To enter, please send your logo design to info@hepcbc.ca



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
<http://www.kpmg.ca/en/ms/hepatitisc/forms.html>

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/hepc/intro.html

David Harvey
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204

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

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

Kolthammer Batchelor & Laidlaw LLP
#208, 11062 - 156 Street,
Edmonton, AB T5P-4M8
Tel: 780.489.5003 Fax: 780.486.2107
kkoltham@telusplanet.net

Other:

William Dermody/Dempster, Dermody, Riley & Buntain
Hamilton, ON 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
Look back 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, ON L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656
Health Canada Compensation Line: 1-888-780-1111
Red Cross Compensation pre-86/ post-90 Registration: 1-888-840-5764
Ontario Compensation: 1-877-222-4977
Toronto Compensation: 1-416-327-0539, 1-877-434-0944
Quebec Red Cross Compensation: 1-888-840-5764
1986-1990 Hepatitis C Class Actions Settlement
6/15/99 www.hepc8690.ca/

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-877-434-0944.
www.hepc8690.com info@hepc8690.com
<http://www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf>

MISCELLANEOUS

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



COMING UP IN BC/YUKON:

Armstrong Hepatitis C United Resource Exchange Contact: 1-888-HepCURE ambrrose@sunwave.net www.hepcure.ca

AIDS Vancouver Island Hep C support.
♦ **Campbell River:** Mon-Thu 9AM-4 PM, 1249 Ironwood. Contact Jeanette or Leanne: 830-0787, jeanette.reinhardt@avi.org leanne.cunningham@avi.org

♦ **Comox Valley** 355 6th St. Courtenay Contact: Phyllis 338-7400 phyllis.wood@avi.org

Castlegar Contact Robin 365-6137

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Support Group Monthly meetings. Contact Katerina 417-2010, heccs-ek@shaw.ca Leslie 426-6078, ldlong@shaw.ca

Kamloops AIDS Society of Kamloops (ASK) 372-7585 for support or referral. ask@telus.net

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 768-3573, eriselev@shaw.ca or Lisa 766-5132 lmortell@silks.net or 1-866-766-5132.

Kootenay Boundary: Individual support & info Contact Brian Reinhard 364-1112 reiny57@yahoo.ca

Mid Island Hepatitis C Society 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Sue 245-7635, mihepc@shaw.ca

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Contact Vivian 265-0073

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St. Contact Alex 1-800-421-2437, 505-5506, info@ankors.bc.ca www.ankors.bc.ca/

Boundary Hep C Support. Contact Ken 250-442-1280 ksthomson@direct.ca

Mt Waddington Harm Reduction Each Tues. 10-12 8635 Granville, Pt. Hardy. Contact Dan 250-902-2238 mtwreduc@hotmail.com

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations Urban Community Society, 623 Agnes Street, New Westminster. Contact Dianne Morrissett, 604-517-6120 dmorrissett@excite.com

Powell River Hep C Support Group Next meeting: Contact the Health Unit 485-8850

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 107. Contact Gina 963-9756, or Ilse 565-7387 ilse.kuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Contact Ted 624-7480 Ted.Rogers@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Contact Brad 295-6510, kane@mehop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy 557-2487, www.island.net, www.island.net/~wmm/ <http://health.groups.yahoo.com/group/CANhepc/>

Salmo Hep C Support Group 2nd Wed. monthly 6 PM, 311 Railway, Contact Giselle Rogers 357-9511, Carol 357-9293 or alex@ankors.bc.ca

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

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, 3862F Broadway Contact 1-866-877-0042 or Doreen 847-2132, deb@plnw.org

Sunshine Coast-Sechelt Healthy Livers Support Group 2nd Monday monthly, 6:30 PM, Sechelt Health Unit, 5571 Inlet. Contact Brent or Bill 604-740-9042 brent.fitzsimmons@cgh.bc.ca

Pender Harbour Hep C Support & Info Contact Myrtle Winchester 604-883-9911 or 604-883-0010

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

VANDU Vancouver Area Network of Drug Users: Satellite Hep-C group, each Thurs. 2 PM, HCC, 166 E. Hastings. Bus fare & snack. 604-658-1224. **H.A.R.M. group** each Mon., 10 AM, 50 East Hasting St. Bus fare & snack. Contact 604-683-8595 vandu@vandu.org www.vandu.org

Vancouver: Pre/post liver transplant support Contact Gordon Kerr sd.gk@shaw.ca

Vancouver Hepatitis C Support Group Meetings: 3rd Tues monthly, 7-9 PM, Lauener Room JPP 2809, Sassafras Cafeteria, Jim Pattison Pavilion, South Level 2, Vancouver General Hospital, and 1st Tues monthly, 5-8 PM, Java Express, 3420 Cambie St. Contact Robert, CLF: 1-800-856-7266

YouthCO AIDS Society HepCATS #205-1104 Hornby St., Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Program Coordinator: Brandy Svendsen brandys@youthco.org Support Worker: Matt Lovic mattl@youthco.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Contact Sharon 542-3092, sgerant@telus.net <http://www.hepc.vernon.bc.ca/>

Victoria Support & Info Contact the Needle Exchange 384-2366

Victoria HepCBC Support 1st Wed. monthly, 7-9 PM, 1611 Quadra St. **AGM this month!!** Library open M-F 306-620 View St. Phone support or private interviews. Contact 595-3892 info@hepcbc.ca, www.hepcbc.ca

Works Without Words Yukon Hep C Support Group Every Thurs. at 7 PM., Grace Community Church, 8th & Wheeler St. Contacts: Harry & Debbie 867-667-2402 harry.mckenzie@klondiker.com. Brian: 867-668-4483 P.O Box 31216, Whitehorse, YK.

OTHER PROVINCES:

ONTARIO:

Barrie Hepatitis Support Contact: Jeanie for information/ appointment 705-735-8153 hepcsupportbarrie@rogers.com

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contacts: Smilin' Sandi smking@rogers.com Sandi's Crusade Against Hepatitis C <http://creativeintensity.com/smking/> <http://health.groups.yahoo.com/group/hepc-info/> 1-800-841-2729 ext. 2919

Hepatitis C Network of Windsor & Essex County, Last Thurs. monthly, 7-9 PM. Contact (519) 562-1741 Fax (519) 256-1383 hepc@hepcnetwork.net, <http://hepcnetwork.net>

Kingston Hep C Support Group 1st Wed. monthly, 5:30-9 PM St. George's Cathedral, King and Johnson St. (Wellington St. entrance) Contact: HIV/AIDS Regional Service 613-545-3698

Unified Networkers of Drug Users Nationally undun@sympatico.ca

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Kitchener. Contact: Bob bc.cats-sens@rogers.com

Niagara Falls Hep C Support Group Contact Rhonda (905) 295-4260, hepcnf@beco.org

North Bay HCV Support Group 2nd Monday monthly 7 PM, 269 Main St. West, Suite 201, North Bay. Contact: Gabe Giroux, Hep C Education and Support Coordinator 705-497-3560 ggiroux@vianet.ca

Peel Region (Brampton Mississauga, Caledon) Hep C Support Group. Contact (905) 799-7700 healthlinepeel@peelregion.ca

St. Catharines Contact Joe (905) 682-6194 jcolangelo3@cogeco.ca

York Chapter HeCSC 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact (905) 940-1333, 1-800-461-2135. info@hepcyorkregion.org www.hepcyorkregion.org

CANDLELIGHT VIGIL

On Tuesday, May 10, 2005, the Hepatitis C Network of Windsor & Essex County will be holding our 3rd annual Candlelight Vigil at our waterfront Dieppe Gardens, 7-9 PM. This candlelight vigil is a special one for our network as one of our cofounders, Claudette Dugas, passed away December 7th, 2004. She will be missed deeply by our network and those that knew her. Contact (519) 562-1741 Fax (519) 256-1383 hepc@hepcnetwork.net, <http://hepcnetwork.net>

QUEBEC:

Arundel Contact Andy Aitken chen.alexander@sympatico.ca Canadian Hepatitis C Network <http://www.canhepc.net/>

Quebec City Region Contact Renée Daurio 418-836-2467 reneedaurio@hotmail.com

ATLANTIC PROVINCES:

Fredericton, NB Contact: Bob, 453-1340

Saint John & Area: Information and Support. Contact Allan Kerr kerrs@nbnnet.nb.ca

Cape Breton Island, N.S. The Hepatitis Outreach Society Support Group 2nd Tues. monthly 150 Bentinek Street, Sydney, N.S. 7-9 PM. Call Cindy Coles 1-800-521-0572, (902) 539-2871 FAX (902) 539-2657 hosc@ns.aliantzinc.ca

PRAIRIE PROVINCES:

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

Hep C Edmonton HCV, pre/post liver transplant support Contact Fox 473-7600, or cell 690-4076, fox@kihewcarvings.com

Fort McMurray, Alberta Hepatitis C Support Network—Info and support. #205, 10012A Franklin Ave. Contact Lyn, (780) 743-9200 Fax (780) 943-9254 wbhas@telus.net

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Contact (403) 527-7099 bettyc2@hivnetwork.ca

The Life with Hepatitis Society of Central Alberta Support group meets each Wed. 7 PM Turning Point Agencies 4611-50th Ave., Red Deer. Contact: Chris (403) 341-6026 crthomas@shaw.ca

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

If you have a Canadian HCV support group to list on this page, please send the name of the group, day, time, place, contact name/phone, and email address to info@hepcbc.ca Please inform us of any changes by the 15th of the month —Joan King



BE PART OF THE TEAM!

We need people to summarize articles. HepCBC needs office staff and 6 people to help with our website. The HepCAN list needs a moderator trainee. Please contact Joan at 250-595-3892 or info@hepcbc.ca