

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

HOW TO START AN HCV SUPPORT PROJECT: PART 1 Alan Franciscus, Editor-in-Chief **HCV Advocate**

iving with hepatitis C is not easy! In Lorder for people with HCV to successfully manage this condition, it is important that they receive good medical care and support from as many different areas as possible-medical professionals, family and friends as well as from others living with hepatitis C. Peer support in the form of a support group is one of the critical links in helping HCV positive people face the issues in their everyday lives. Education, support, care and services available to HCV positive people will help them make the best possible choices to effectively manage their lives.

I was diagnosed in 1996 when relatively little was known about hepatitis C. The information on hepatitis C was scarce, with more misinformation than accurate information available. Shortly after I was diagnosed, I asked my doctor to recommend a support group in my area, but to my surprise he told me that there were no support groups in my area specifically geared toward people living with hepatitis C. I did attended a local liver support group that was geared towards any type of liver disease, but I didn't feel like it addressed my specific needs for information and peer support on various issues I was struggling with at that time.

A few months after I was diagnosed with hepatitis C, I began interferon monotherapy. It became clear to me early into treatment that I was not prepared to deal with the physical and psychological side effects related to interferon treatment. I became anxious and depressed! Worst of all, I did not recognize the subtle changes in my personality. I also realized how much I needed some form of peer support to help me through treatment. It was during this period that I made a promise to myself that I would start a support group after I completed therapy.

(Continued on page 6)

FEDERAL COMPENSATION FUND MAKES MONEY WHILE VICTIMS DENIED

MEDIA RELEASE — August 31, 2004

Last year the federal government's Hepatitis C Compensation Fund earned \$56 million more in income than it spent on claims and expenses. The fund, set up in 1998 to assist hugely overestimated. More than four years victims of hepatitis C tainted blood transfusions, recently released its 2003 - 2004 annual report which shows that it ended the fiscal year with more than \$1.1 billion still in the fund.

"The compensation fund actually made money while an entire group of victims of tainted blood transfusions has been denied access to the fund," says David Klein of Klein Lyons, a Vancouver BC law firm that has been working on class actions on behalf of pre-86/post-90 Hepatitis C victims for tained in the compensation fund's annual more than six years.

Thousands of persons across the country who were infected with hepatitis C through blood transfusions before 1986 or after 1990 were ruled ineligible for inclusion in the \$1.2 billion federal/provincial/territorial compensation program set up in 1998. The federal government decided that it was responsible for only those persons who received tainted blood between January 1, 1986 and July 1, 1990.

According to then Health Minister Alan

INSIDE THIS ISSUE:

OCTOBER 2004	Issue No. 71
Coming Up	8
Events	7
Caravan of Hope	7
Healthy Gourmet	5
Treatment/Surviving & Coping	4
News	3
Cupid's Corner	2
How to Start a HepC Support Group	p 1

Rock, inclusion of all hepatitis C victims of tainted blood would bankrupt medicare. Current evidence shows that the estimated numbers in both the 86/90 group of hepatitis C victims and the pre-86/post-90 group were after the \$1.2 billion fund was set up to provide compensation for the 86/90 group, there is more than enough money in the compensation program to include the hepatitis C victims who received the virus from tainted blood transfusions before 1986 and after 1990. Those who contracted the virus prior to 1986 are among the longest-suffering and many are among the sickest of the hepatitis C victims.

"In light of the financial information conreport, it is impossible to justify shutting pre-86/post-90 hepatitis C victims out of the fund," says Klein. "The federal government should immediately open the fund to hepatitis C victims in the pre-86/post-90 group. This would provide access to desperately needed financial assistance for thousands of victims across Canada who are struggling with ill health, cannot afford needed medication, and are unable to work and take care of their families."

Klein Lyons, along with law firms Roy Elliott Kim O'Connor, LLP in Ontario, and Lauzon Belanger in Quebec, all of whom have been pursuing class actions, are working with a coalition of community and advocacy groups, the Hepatitis C Compensation Umbrella Of Canada (HCCUC), to urge the federal government to immediately expand the eligibility for the existing 86/90 compensation program to include hepatitis C victims now in the pre-86/post-90 excluded group.

For further information, contact: David Klein at (604) 874-7171.

hepc.bull

OCTOBER 2004

Page 1

SUBSCRIPTION/ MEMBERSHIP FORM

Please fill out & include a cheque made out to HepCBC - Send to our NEW ADDRESS:

HepCBC #306-620 View Street Victoria BC V8W 1J6	
Name:	
Address:	
City: Prov PC	
Home()Work()_	
Email:	
□Membership + Subscription (1 year):	\$20.00
☐Membership Only (for those already receiving the bulletin)	\$10.00
□Subscription Only (for those already members of HepCBC	\$10.00):
□"I cannot afford to subscribe at this tin would like to receive the bulletin."	ne, but I
\square "Lenclose a donation of \$	so that

DISCLAIMER: The hepc.bull[®] cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered medical davice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of these of these of the opinions expressed in this newsletter are not necessarily those of these of the opinions expressed in this newsletter are not necessarily those of the opinions. The opinions expressed in this newsletter are not necessarily those of the editors, of HepCBC or of any other group.

others may receive the bulletin."

SUBMISSIONS: The deadline for any contributions to the hepc.bull[©] is the 15th of each month. Please contact the editors at 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^{th} 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:

EDITORS:	Joan King, Will Lawson, Smilin' Sandi
PHONE:	TEL: (250) 595-3892
FAX:	(250) 414-5102
EMAIL:	jking@hepcbc.ca
WEBSITE:	www.hepcbc.ca
HepCAN List	http://health.groups.yahoo.com/
	group/hepcan/messages

HepCBC 306-620 View Street Victoria BC V8W 1J6

LETTERS TO THE EDITOR:

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

NEWIII 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: (250) 595-3892, info@hepcbc.ca

HepCBC Resource CD: The CD contains back issues of the hepc.bull from 1997-2003; the FAQ V6; 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.

prices, write to HepCBC.



epCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, The Ocean 98.5 for their Public Service Announcements, Durhane Wong-Rieger, Bryce Brogan, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Brad Kane, Chris Foster, Darlene Morrow, Will Lawson, Judith Fry, and the newsletter team: Jeanie and Diana. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

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



CUPID'S

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

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

****** Want a mate? Your Cupid ad could go here! *****************

Got Hep C? Single? Visit:

http://forums.delphiforums.com/HepCingles/ http://groups.yahoo.com/group/PS-Hep/ http://groups.yahoo.com/group/HepCingles2 http://groups.yahoo.com/group/ NewHepSingles/ CHAT: http://forums.delphiforums.com/ hepatitiscen1/chat

LEXMARK

Passion for printing ideas:

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

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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



Management and Treatment A Practical Guide for Patients, Family and Friends

> TO SUBSCRIBE CALL 800-792-6397

or visit us online @ www.hepatitismag.com

DIAL-A-DIETITIAN

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

Page 2

hepc.bull

OCTOBER 2004

Issue No. 71

NEWS

APLIGEN

and its effectiveness as a treatment for patients coinfected with hepatitis C and HIV has been approved.

Hemispherx Biopharma agreed to conduct trials of Apligen(R) on HIV/HCV coinfected patients at their own expense. This was a condition of their right to market the drug in Spain, Portugal and Andorra as a treatment their blood. for Chronic Fatigue Syndrome.

Right now, there is no single product that is considered internationally to be safe and effective enough to give patients with both viruses.

People with both HIV and HCV have a 20 times higher risk for developing liver failure SOURCE: Roy KM, et al. J Med Virol. 2004 than those with HCV alone. Both viruses mutate, or alter themselves, quickly when attacked by medications that block their *injecting drug users* growth, leading to drug-resistant strains of each that mutate more quickly with treatment.

CONTACT: Hemispherx Biopharma. Inc. Dianne Will, 518-398-6222 ir@hemispherx.net www.hemispherx.net or CEOcast Kevin Theiss. 212-732-4300 ktheiss@ceocast.com.

SOURCE: Hemispherx Biopharma, Inc. 07/07/2004

EPOETIN ALFA

For more than a decade, recombinant human causes damage and impaired functioning in erythropoietin (epoetin alfa) has been used the brain, resulting in problems with thinkto fight anemia in people with chronic kidney disease.

As more is known about the devastating effects of anemia on the body, epoetin alfa, is being considered as part of earlier, more the impact of cognitive problems on quality aggressive treatment of mild to moderate of life in HCV patients and to explore the anemia.

Clinical trials using epoetin alfa to combat thinking problems. anemia associated with congestive heart failure and ribavirin-interferon alfa are producing promising results.

SOURCE: Arch Intern Med. 2004 Feb gnitive impairment.html 9;164(3):262-76 Epoetin alfa: clinical evolution of a pleiotropic cytokine. Henry DH, Bowers P, Romano MT, Provenzano R. PMID: 14769622 [PubMed - in process]

HCV & PARTNERS OF IVDUs

In Spain, a new clinical trial of Apligen(R) | It is possible that heterosexual partners of injecting drug users may have a high risk of getting hepatitis C, even if they do not inject drugs themselves.

> In this study, it was found that while no homosexual partners of IV drug users tested positive for HCV antibodies, 4.1-6.4% of heterosexual partners had HCV antibodies in

those in relationships with people who inject full study, titled "HLA and NK Cell Inhibidrugs may be at high risk for becoming infected with hepatitis C and should consider being tested for the virus.

Sep;74(1):62-6. Hepatitis C virus among self declared non-injecting sexual partners of

COGNITIVE PROBLEMS

Cognitive difficulties have long been associated with chronic liver disease but were previously believed to be found only in patients with cirrhosis.

About a third of HCV patients suffer from problems with attention, concentration, memory, and motor skills and are saving so. This has led researchers to look at how brain function might be impaired by the hepatitis C virus in those with no cirrhosis. They found evidence that the hepatitis C virus ing through and completing even simple daily household tasks.

The findings of the study are so compelling that researchers want to look harder at role of antiviral therapy to treat HCV-related

SOURCE: Robin C. Hilsabeck, PhD, Hepatitis C and Cognitive Impairment http://www.hcvadvocate.org/hcsp/articles/co

GENE THERAPY

Genetic research into why some people recover from hepatitis C infection is bringing a

closer understanding of how the virus works. John Hopkins researchers found a certain gene combination in twice as many of those who clear the virus as in those who don't, but not at all in those who got infected by blood

Doctors are looking at how gene therapy currently in use for one kind of leukemia might be used for fighting HCV.

transfusions.

SOURCE: HEALTHWATCH August 27, How this happens remains unknown, but 2004 Genes boost hepatitis C defenses. The tory Receptor Genes in Resolving Hepatitis C Virus Infection," and commentary, "NK Cells Lose Their Inhibition," appears in the *iournal Science. (AP)*

VACCINE

Baboons were vaccinated against hepatitis C with HCV-like particles (HCV-LP) in a recent study by doctors studying the safety and effectiveness of the vaccine.

Booster shots after the initial inoculation increased the likelihood of a strong and long-lasting immunity to HCV in the baboons, who remained healthy after being inoculated.

Mice injected with HCV-like particles (HCV-LP) had previously exhibited increased immune responses to hepatitis C.

A study using chimpanzees is now underway, fueled by increasing optimism that a vaccine against hepatitis C can be found.

SOURCE: Will Boggs, MD Reuters Health Aug 03, 2004. Hepatitis C Virus-Like Particles Induce Immune Responses in Baboons Original article: J Virol 2004;78:6995-7003.

MBI-3253 (celgosivir)

A study using MBI-3253 (celgosivir) to treat bovine diarrhea virus (BVDV) provides more hope for a vaccine against hepatitis C.

BVDV is a virus very similar to HCV that can predict the effectiveness of drug therapy for HCV in humans.

This study shows that celgosivir has the potential to become a strong and effective treatment for chronic HCV.

SOURCE: PRNewswire-FirstCall, Jul 20,

(Continued on page 5)

hepc.bull

OCTOBER 2004

Issue No. 71

TREATMENT

NEW ENGLAND JOURNAL OF MEDICINE REPORTS GROUND-BREAKING PEGASYS[®] RBVTM TRIAL RESULTS FOR CO-INFECTED PATIENTS

Results of APRICOT study reinforce patients' chance to clear hepatitis C virus

The New England Journal Of Medicine recently published the results of APRICOT (AIDS PEGASYS[®] Ribavirin International CO-infection Trial)

APRICOT found that Pegasys[®] RBVTM, the combination of PEGASYS[®] (peginterferon alfa-2a) and COPEGUS[®] (ribavirin), achieved a 40 per cent sustained virological response (SVR)—the highest ever reported in a trial of co-infected patients.

APRICOT is the largest and only multinational prospective study evaluating the efficacy and safety of pegylated interferon combination therapy in almost 900 people co-infected with HIV and hepatitis C (HCV), including 33 Canadian patients. In Canada, approximately one-quarter of people living with HIV are co-infected with HCV.¹

"APRICOT was a ground-breaking trial that demonstrated the safety and efficacy of Pegasys RBV in coinfected patients, a difficult-to-treat population. Pegasys RBV is superior to anything we are currently using to treat co-infection," said Dr. Marc Poliquin, specialist in co-infection of viral hepatitis and HIV, Department of Gastroenterology, UHRESS, Hôpital Notre-Dame, Centre hospitalier universitaire de Montréal (CHUM), and an investigator in the APRICOT trial. "I think the impact of APRICOT will be tremendous and it will cause a paradigm shift in HIV-HCV treatment. In the past, many physicians have not treated hepatitis C and HIV because of a perceived lack of response along with unacceptable toxicities. APRI-

COT should lay those fears to rest." The key APRICOT findings were:

• 40 per cent of patients treated with Pegasys RBV achieved a SVR compared to 20 per cent of patients treated with PEGASYS monotherapy and 12 per cent of patients treated with standard interferon/ribavirin.

• Genotype 1 patients, those with the most difficult-to-treat type of the virus, treated with Pegasys RBV achieved a four-fold increase in SVR compared to standard interferon/ribavirin (29 per cent versus 7 per cent). The authors noted that this is the highest SVR that has been achieved in this group of patients.

• 62 per cent of genotype 2/3 patients treated with Pegasys RBV therapy achieved a SVR compared to 20 per cent with standard interferon/ribavirin.

• Pegasys RBV therapy effectively treats hepatitis C in patients with HIV-HCV co-infection—being compatible with antiviral treatment without compromising the virological control of HIV infection."

"Based on this very positive clinical evidence, there is absolutely no reason to delay making Pegasys RBV available to all patients with hepatitis C." said Durhane Wong-Rieger, Secretariat, Canadian Hepatitis C Network. "Some patients have been waiting for years for effective treatment, and we know that the longer they wait, the more difficult it will be to clear the virus. Medically and ethically, it is imperative for all provinces to move quickly to add Pegasys RBV to their provincial formularies."

About the APRICOT study

In this study, 868 patients from 19 countries who were co-infected

with HIV-HCV were randomized to receive either Pegasys RBV (PEGASYS 180 mcg once weekly in combination with ribavirin (800 mg daily); PEGASYS 180 mcg monotherapy once weekly (plus placebo ribavirin tablets), or standard interferon alfa-2a 3MIU three times a week in combination with ribavirin (800 mg daily), all for 48 weeks.

Real world patient population

The patients in this landmark study were predominantly male, middleaged with stable HIV disease. However, patients had a wide range of HIV status; the majority (85%) were on anti-retroviral therapy and they had very high HCV viral loads (10-15 million copies/ml). The very low (12%) response achieved by patients randomized to the arm receiving standard interferon/ribavirin combination therapy is illustrative of the challenging nature of the co-infection present in these patients.

About Pegasys RBV

Pegasys RBV was approved on May 10, 2004 following a priority review by Health Canada. Pegasys RBV is currently going through the Common Drug Review (CDR), a process for undertaking reviews and providing listing recommendations for new drugs to participating federal, provincial and territorial (F/P/T) drug benefit plans in Canada (with the exception of Quebec). The Common Drug Review is overseen by the CDR Directorate, Canadian Coordinating Office for Health Technology Assessment (CCOHTA). A listing recommendation for Pegasys RBV is expected in September 2004.

REFERENCE:

¹Management of Viral Hepatitis: A Canadian Consensus Conference 2004, p. 23. Available on-line at http://www.hepatology.ca/cm/FileLib/ ViralHepatitisCanadianConsensus2004.pdf

OCTOBER 2004

(NEWS—Continued from page 3)

2004. MBI-3253 (celgosivir) Demonstrates Potent Activity Against Hepatitis C Virus Surrogate.

http://www.stockhouse.ca/news/news.asp?ne wsid=2373599&tick=MBI

DIFFERENCES: PEG-INTRON & PEGASYS

A recent study found that the drug PEG-Intron reached maximum concentration levels in the blood of chronic HCV patients after 24 hours and was undetectable 120 hours later

PEGASYS levels, on the other hand, increased steadily and did not reach maximum concentrations until 48-168 hours after injection.

These differences suggest that PEG-intron be administered twice a week to maintain the drug's stability and efficiency.

SOURCE: 38th Annual Meeting of the 3 tbsp. peanut oil European Association for the Study of the Liver. Istanbul, Turkey. March 28-April 1, 2003. Pharmacokinetics of Peginterferon Alfa-2a (40kd, Pegasys) Compared to Peginterferon Alfa-2b (12kd, Pegintron) in Naive Patients with Chronic Hepatitis C (CHC)

LAWSUITS AND TREATMENTS

The Bush administration has been stopping lawsuits against manufacturers of medical devices and medications, claiming that lay judges should not have the right to overrule decisions made by the FDA's expert research.

Lawsuits arising from such issues as faulty heart pumps and pacemakers, and from suicide deaths while on antidepressants, are at the centre of a controversy over patients' right to sue.

Critics claim that the Bush administration | Prawns is serving the drug manufacturers, not the Black public good, and that there is no legal basis for such intervention.

The Bush administration warns of manufacturers pulling products from the market and of people being frightened away from seeking appropriate medical treatment if they do not intervene and block such lawsuits against drug companies.

A patient's right to sue is not law. Experts on both sides of the issue continue to debate.

SOURCE: http://www.nytimes.com/2004/07/25/politics/ 25DRUG.html?th

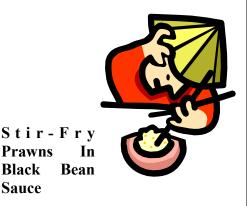
HEALTHY GOURMET



Zucchini with Carrots and Ginger

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

Slice zucchini into thin disks. Heat oil in wok or frying pan until hot, and stir-fry the zucchini for a few minutes. Add the carrots, pepper, and ginger, and stir until the vegetables are slightly soft but still have texture. Add salt and pepper as desired and serve 1. In a small bowl mash together black immediately.



(Yield: 6 Servings)

Ingredients

- 2 tb fermented black beans; rinsed well
- 2 ts minced garlic
- 1 tb grated gingerroot
- 1 lb large prawns
- 1 c sliced onion
- 2 ts peanut oil
- 1 c chopped bok choy
- 1/2 c red bell pepper; julienned

1/4 c shiitake or other Asian mushrooms; sliced 1/2 c Chinese cabbage; chopped

- 1 c whole snow peas; ends trimmed
- 1 ts light miso
- 3/4 c defatted chicken or fish stock 1 ts honey
- 1 ts low-sodium soy or tamari sauce
- 1 tb arrowroot powder or cornstarch
- 2 tb cold water
- chopped cilantro; for garnish

Instructions

beans, half the garlic, and ginger until mixture forms a paste. This can also be done in an electric minichopper or small food processor. Set aside. Peel and devein prawns.

2. In a wok or large skillet over mediumhigh heat, saut, onion in peanut oil until soft but not brown, stirring constantly. Add remaining garlic, bok choy, bell pepper, and mushrooms. Stir-fry for 5 minutes. Add cabbage, snow peas, and black bean mixture. Cover and let cook for 2 to 3 minutes.

3. In a small bowl mix together miso and broth. Add to stir-fry with honey, soy sauce, and prawns. Stir-fry until prawns turn pink. In a small bowl mix together arrowroot and the water and add to stir-fry. Cook until slightly thickened (3 minutes). Serve at once. Pass around chopped cilantro for garnish.

SOURCE: http://recipes.chef2chef.net/ recipe-archive/26/142342.shtml

hepc.bull

(SUPPORT GROUP—Continued from page 1)

Shortly after I completed treatment, I enlisted help from a friend and we started the first HCSP support group in the area. To prepare for facilitating a support group I took a 3 day course about support group facilitation from a local health agency that gave me some valuable information and resources. It wasn't particularly difficult to set up and maintain a support group, but a lot of what I needed to know specific to hepatitis C was learned by hit and miss, and it would have been much easier had I been able to learn from others who were experienced with running a hepatitis C support group.

The importance of support groups can not be overstated. This article is part one in a series of articles designed to help others start a support group and to provide some tools to help people in the difficult job of maintaining an on-going support group. This is by no means a definitive guide for starting and maintaining a support group, but I hope it will be a helpful tool for support group leaders to use and for others to take the big step of starting a support group. The information in this article will not be suited for everyone because different approaches may be needed for different populations. Every individual is unique, as is every support group. A support group leader must always consider the members' needs and take every opportunity available to adapt to the individual and group needs.

The Need

Why is there a need for support groups? A person living with hepatitis C must make daily decisions on a variety of issues about hepatitis as a facial expression. In any event, we all C. Some of these issues may include disclosure, stigma, disease management, and treatment issues. Peer support is critical in providing needed advice and information to help a hepatitis C positive person successfully live with HCV.

why people seek HCV support groups:

Newly Diagnosed

When a person is newly diagnosed it is usually a life altering event. Being told you have hepatitis C raises many questions:

- What does it mean to have hepatitis C?
- Am I going to die soon?
- What should I tell my spouse, family, ٠ employer and co-workers?
- How do I tell others I have hepatitis C? ٠
- Do I need to start treatment immediately? ٠ How do I protect others from getting After the shock of being diagnosed with hepatitis C?
- How do I take care of myself?
- How do I take care of loved ones?
- What about herbs?
- ٠ What should I avoid - alcohol/ other

drugs?

How do I cope with a potentially life-٠ threatening disease?

Stigma

Stigma occurs when we attach negative labels to people and make generalizations about certain groups or types of people. Generalizations about people are endemic in our society because we all feel a need to categorize people and situations in order to make decisions in relation to any group. Some people find it easier to generalize about certain groups rather than to take the time and energy needed to discover and understand the differences that make up individuals. These differences may be due to religious, cultural, physical or even pathological reasons. Negative generalizations on a large scale produce prejudice, in which certain groups or populations in our society apy. become stigmatized.

Stigma has two consistent componentsthe recognition of different characteristics in groups of people, and the devaluation of another human being. Feeling different is one of the reasons why people seek out support groups-they need to be with likeminded people experiencing similar situations.

Most people who have been diagnosed with hepatitis C face some form of stigma or prejudice in their daily lives. It could be a phrase like "you people," or a slight pause when you divulge your HCV status. Friends may stop calling, employers and co-workers may act differently, or it could be as subtle know how it feels to be treated differently based on being HCV positive. How you handle the stigma associated with HCV is an important issue because it will greatly affect the quality of life, health (both mental and physical) as well as just about every area of There are generally several major reasons the life of those dealing with this condition.

> Stigma and prejudice affect every one differently and could lead to: · Withholding HCV diagnosis from family, friends, a n d co-workers · Not seeking medical care for fear of being seen at a healthcare setting by others · Loss of employment and livelihood · Friends and family may "guard" their children from coming into contact with a person with HCV.

Disease Management

hepatitis C, a person will have to make a variety of important decisions in order to manage the disease.

Individuals will seek information and ad-

vice about many issues including:

- Alcohol and other drugs
- Nutrition and exercise ٠
- Preventing transmission of HCV to ٠ others
- Medical management
- Depression and anxiety
- Herbs, vitamins and other dietary supplements
- Disability issues
- Sexual issues
- Guidance on their everyday lives

Treatment

Issues about treatment are one of the main reasons why people seek out HCV support groups. People come to hear what others have experienced on treatment as well as to learn from others about effective strategies to cope with the side effects of ther-

Peer support is critical for people taking interferon-based therapy. There are a wide variety of physical and psychological side effects that people may experience on a daily basis. The potential for drug-induced psychological problems is frightening for most people to think about. During HCV medical therapy the side effects can be so subtle that only the people in close contact are able to notice any changes. Support group members who have experience with these side effects are able to help identify and help others cope with these distressing issues.

After Treatment Issues

The side effects of treatment will continue even after stopping therapy. It may take even longer to feel completely back to "normal." The uncertainty of treatment outcome will weigh heavily on most people. Until someone receives the news that their treatment was "successful" or "unsuccessful," they can become quite anxious. In addition, if the hepatitis C virus does comes back after enduring a six month or year long therapy it is disappointing and makes it difficult for people to decide how to move forward.

These are some of the most important issues that I have found that have been raised in support groups, but it is by no means the entire list. The amount of support and the different issues raised by hepatitis C positive support group members is truly amazing.

Part two of this article will focus on identifying experts and resources as well as on one of the most important questions to consider: "Why do I want to start a support group"?

hepc.bull

OCTOBER 2004

CARAVAN OF HOPE

Hon. Carolyn Bennett, Minister of State (Public Health) Brooke Claxton Building Tunney's Pasture Ottawa, Ontario K1A 0K9

Dear Minister Bennett,

We, the Caravan of Hope, a coalition of hepatitis C-mandated groups involved in public policy issues relating to access to comprehensive and integrated care and treatment, are writing to you on behalf of the 250,000 Canadians living with hepatitis C to request that the Health Canada website dedicated to hepatitis C be updated with the latest care and treatment guidelines established by the Viral Hepatitis Network 2004 Consensus Document.

Current care and treatment options for patients in Canada are being limited by the absence of the 2004 consensus document on the Health Canada website.

The guidelines for such treatment have changed considerably since the release of the year 2000 consensus document that is currently used as an outdated expert medical source for provincial health ministries, as evidenced by the use of the Health Canada website as its ministries' resource. To quote the Hon. Colin Hansen, Minister of Health Services for British Columbia, "The use of ALT levels to qualify for therapy is used because, according to current Health Canada guidelines," (<u>http://www.hcsc.gc.ca/hppb/hepatitis_c/pdf/careInfoUpdate/</u> virus.html).

We remind you that hepatitis C is a unique disease that constantly evolves and finds different ways to attack its victims' immune systems. It requires a comprehensive and integrated approach to care and treatment for the best patient outcomes. The drugs are very toxic to take. Patients, therefore, require the broadest array of treatment options and combinations available to them.

Will you please update your website to reflect the current medical treatment guidelines outlined in the 2004 consensus document?



RADIO REQUEST

Dear members,

BC Radio is looking to speak to patients who are enrolled in clinical trials for new hepatitis C treatments. They are trying to gather background information from as many people as possible during the initial research phase for a potential project on the experiences of hepatitis C patients almost ten years after the Krever Inquiry.

If you're interested in helping out, please contact Stacie Bergwerff by phone - (613) 751-3551

or email - stacie_bergwerff@cbc.ca

HEPCBC INFO SESSIONS

epCBC in Victoria, BC, is planning a moderated 8-session pilot group in early October for those who are infected with hepatitis C. Please sign up, leaving your name and phone number at 250-595-3892, or email <u>info@hepcbc.ca</u>. Space will be limited.

YOUTHCO "TRAIN-THE-TRAINERS" WORKSHOP FOR YOUTH

I f you are between the ages of 15-29 and who would like

to learn more about hepatitis C, <u>-</u> harm reduction and how to talk to and support your peers with regards to hepatitis C re-



lated issues, why not attend these work-shops?

The 3-day worshop dates and times are:

- Friday, October 15: 6-9pm
- Saturday, October 16: 9:30-4:30
- Sunday, October 17: 9:30-4:30

The training will be held at youthCO AIDS Society: 1104 Hornby Street, Vancouver, BC

If you have any questions, or would like to register, please contact 604-688-1441, or email <u>caitlinp@youthco.org</u> Space is limited! Register soon!

COMPENSATION

LEGALACTION

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/ Klein Lvons

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

David Harvey Toronto, Ontario 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

Other:

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

LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC 1-888-332-5663 (local 207) Lookback Programs, Canada: 1-800-668-2866 Lookback Programs, BC: 1-888-770-4800 Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056 Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362

Manitoba Traceback: 1-866-357-0196

RCMP Blood Probe Task Force TIPS Hotline 1-888-530-1111 or 1-905-953-7388 Mon-Fri 7 AM-10 PM EST 345 Harry Walker Parkway, South Newmarket, Ontario L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656 Health Canada Compensation Line: 1-888-780-1111 Red Cross Compensation pre-86/ post-90 Registration: 1-888-840-5764 Ontario Compensation: 1-877-222-4977

Toronto Compensation: 1-8//-222-49// **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

MISCELLANEOUS

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

hepc.bull

COMING UP IN BC/YUKON:

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

Campbell River/Comox Valley Hep C Support and information. Contact 830-0787 or 1-877-650-8787, P.O. Box 52, Port Hardy. Contact Dan Webb (250) 902-2238 or 1-866-902-2238 niacph@hotmail.com

Castlegar Contact Robin 365-6137

Comox Valley Mon.-Thurs. drop-in support 9-4 PM. Contact AIDS Vancouver Island Hep C Community Support (250) 338-7400 355 6th St. Courtenay or Del: dggrimstad@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Support Group Monthly meetings. Call for details: Katerina (250) 417-2010, hecsc-ek@shaw.ca or Leslie (250) 426-6078, ldlong@shaw.ca

Kamloops Call the AIDS Society of Kamloops (ASK) at (250) 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 Riseley (250) 768-3573, eriseley@shaw.ca or Lisa Mortell 766-5132 Imortell@silk.net or toll-free 1-866-766-5132.

Kootenay Boundary: Individual support & info Contact Brian Reinhard (250) 364-1112 reiny57@yahoo.ca

Mid Island Hepatitis C Society Friendship and support group, 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. 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 Sherstobitoff, 1-800-421-2437, 505-5506, info@ankors.bc.ca http://www.ankors.bc.ca/

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

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations Urban Community Society, 623 Agnes Street, New Westminster. Contact Dianne Morrissettie, 604-517-6120 dmorrissettie@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, room 107.Contact Gina 963-9756, gina1444@yahoo.ca or Ilse 565-7387 ikuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Contact Ted Rogers (250) 624-7480, Ted.Rogers@northernhealth.ca

Page 8

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

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

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

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, 3862 Broadway (behind Panago). Contact Deb 877-0042 or Doreen 847-2132, deb@plnw.org

Sunshine Coast-Sechelt: 2nd Mon. monthly, 6:30 PM at Sechelt Indian Band Health Unit. 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, waterspider@telus.net

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

VANDU Vancouver Area Network of Drug Users Each Mon., 2 PM, 50 East Hasting St. Bus fare & snack. Contact Cristy or Ann 604-683-8595 (ask for VANDU). Space limited. vandu@vandu.org www.vandu.org

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

YouthCO AIDS Society HepCATS #205-1104 Hornby St., Vancouver. For info, contact Caitlin Padgett For support, caitlinp@youthco.org contact Matt Lovick 604-688-1441 or 1-877-YOUTHCO <u>www.youthco.org</u> Brandy Svendson brandys@youthco.org

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

http://www.hepc.vernon.bc.ca/

hepc.bull

Victoria Support & Info Contact The Needle Exchange 384-2366

Victoria HepCBC & INFO line —Contact (250) 595-3892 info@hepcbc.ca, www.hepcbc.ca Library open M-F 306-620 View St. Phone support or private appointment for interviews.

Works Without Words Yukon Hep C Support Group Every Thurs. at 7 p.m., 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. mthly, 7-9 p.m., 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/ 2919 1-800-841-2729 ext. re: HCV testing, free Hep A and Hep B Vaccines and group info. http://health.groups.yahoo.com/group/ hepc-info/

Kingston Hep C Support Group 1st Wed. monthly, 5:30 PM, - 9 p.m. St. George's Cathedral, King and Johnson St. (Wellington St. en-trance) 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, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact: Carolyn (519) 880-8596 lollipop@golden.net

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

Peel Region Hep C Support Group Third Mon. monthly, 11AM-1PM Mississauga Office, 3038 Hurontario St. (Classroom C) Contact (905) 799-7700

healthlinepeel@peelregion.ca

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

Hepatitis C Network of Windsor & Essex County Contact Andrea 250-5399 or Michelle 256-1878, hepcnetwork@mailcan.com http:// hepcnetwork.cjb.net

York Chapter HeCSC 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact (905) 1-800-461-2135. 940-1333, info@hepcyorkregion.org www.hepcyorkregion.org Wed. Oct. 20th -Dr. Danny Chen, Infectious Diseases Specialist, York Central Hospitals "New Develop-ments in Hepatitis C"

OUEBEC:

OCTOBER 2004

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

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

Issue No. 71

ATLANTIC PROVINCES:

Fredericton, NB Contact: Bob, 453-1340

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

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

PRAIRIE PROVINCES:

Regina, Saskatchewan

Contact Doug 306-565-8593 hep-c.regina@accesscomm.ca http://nonprofits.accesscomm.ca/ hep-c.regina/

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, 7 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Contact (403) 527-7099 bettyc2@hivnetwork.ca

Winnipeg Hepatitis C Re-source Centre 1st Tues. monthly 7-9 PM. # 204-825 Sherbrook St. (south entrance—parking at rear) Contact 975-3279, hcrc@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 <u>sking@rogers.com</u> PLEASE inform me of any changes, or of any special events/speakers, etc., in your area, well in advance of the date. -Smilin' Sandi



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