

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

DON'T INTERFERE WITH MY INTERFERON

By Bradley Kane, HepCBC

Albuferon, Pegasys, Pegintron, siRNA, Ribavirin. What's the diff? Maybe the question "What are they, and what do they do?" might be more appropriate.

I've always believed in understanding situations with realistic expectations of outcomes— "Eyes wide open," so to speak. Tell it like it is. At least then, we can deal with them in realistic terms.

It is well known in the scientific community that the hepatitis C virus is virtually indestructible, and so elusive, that developing a vaccine poses an enormous challenge. and progress has been extremely slow. Pharmaceutical companies turned their attention to interferon-based therapies to market in the meantime. Due to the fact that almost 2 billion people worldwide are now infected with the virus, this market population will represent a \$6 billion-per-year industry by 2010. These interferon-based therapies, to treat people who have HCV, do not actually kill the virus. Ribavirin and siRNA's (small molecule therapies) don't, either. I think any attempt to market them to the public as a "cure" should be treated as fraudulent misrepresentation and dealt with as such. They are chemotherapy class drugs, components of the immune system, and as such, very powerful in nature. Our immune systems respond to a viral infection in a series of events, one of the first of which can be the release of interferons as a barrier, in an attempt to block or slow the spread of the virus by interfering with the process of replication, hence the name "interferon". Then the hunt is on by the rest of the immune system components to seek and try to destroy the virus (antibodies, NK-natural killer cells, Tcells...), quite unsuccessfully, I might add. This virus is incredibly elusive. It seems that, after a year of interfering with replication, circulating virus levels drop to below detectable amounts (<50 ppmu) and the vi-

(Continued on page 6)

ARE YOU DISEASED?

by Tanya Frizzle

I first found out I had HCV at a walk-in clinic near my place of work. I used that one because it was more convenient than my family doctor's office. The first doctor I saw regarding HCV told me I was positive, gave me a sheet to get more blood work done, and sent me out of his office with no more knowledge other than that I had hepatitis C. Oh yeah, I was to come back in a few days for new results. Results for what, I did not know, but I was in shock and would follow orders without question.

I went back in a few days and, because it was a walk-in clinic, I had a new doctor. This doctor opened my file and said, "Oh, you have Hep C. We'd better test you for all the other blood diseases." She gave me a new sheet ordering Hep B and HIV tests. I almost fainted. She stood there and looked at me like my visit was over. I asked her what my results said, and she replied, "Your liver is a little inflamed, but not enough to get treatment." Then she told me to have a good day. HAVE A GOOD DAY? That was the last thing that was going to happen! I asked her, "What do you mean I cannot get treatment?" She told me that my liver had to be more inflamed to qualify for treatment, and again started ushering me out of her office. You should have seen the look on her face as she was doing so. You would have thought I

(Continued on page 4)

INSIDE THIS ISSUE:

Don't Interfere/Are You Diseased?/Lockdown	1
Cupid's Corner	2
Treatment	3
Inner City Health	4
Milk Thistle/Liver Cancer	5
Clinical Trials	7
More of an Issue than Same Sex/Compensation	7
Coming Up	8

LOCKDOWN: Drugs, Prisons & Diseases in Our Communities Vancouver, June 21, 2005 By Karen Dennis, ED—HepCBC

Presenters:

Akbar Bayanzedeh - Dept of Psychology, S.F.U., from Iran David Marsh MD - Vancouver Coastal Health

Howard Spears - Correctional Investigator for Canada

Stephen Smith – Ministry of Health Veronica Sevigny – Matsqui Institution Kathryn Gretsinger – Moderator Gillian Maxwell - Chair

June 21 was a busy day. Not only was it summer solstice and National Aboriginal Day, it was also the Lockdown Event in Vancouver.

"Lockdown: Drugs, Prisons & Diseases in Our Communities" was a one-night presentation hosted by the group "Keeping the Door Open." Keeping the Door Open has a shared vision of the future that problematic substance use is understood to be a complex social, cultural, health and economic issue. Their mission is to prevent the harm associated with problematic substance use in BC and Canada and achieve better health and social justice outcomes for people.

The event was a dialogue to explore the broader public health implications of illegal substance use in federal and provincial correction facilities in BC. It was held at the SFU Morris J. Wosk Centre for Dialogue.

Substance use is widespread in the correctional systems of Canada. Offenders who enter the systems often bring with them an existing substance use problem, may develop one, or may become infected with blood borne diseases as a by-product of their incarceration. Evidence indicates that this occurs worldwide.

These circumstances present many challenges to those within the correctional systems, as well as the broader community. For

(Continued on page 5)

hepc.bull AUGUST 2005 Issue No. 80 Page 1

SUBSCRIPTION/ORDER FORM

Please fill out & include a cheque made out to **HepCBC** - Send to the following address:

HepCBC #306-620 View Street Victoria BC V8W 1J6

- I valiic.	
Address:	_
City: Prov PC	
Home()Work()	
Email:	-
☐Membership + Subscription (1 year) \$20	0.00
☐Membership Only (for those already receiving the bulletin)	0.00
□Subscription Only \$10 (for those already members of HepCBC)	0.00
□Peppermint Patti's FAQ \$6	5.00
□Resource CD \$10	<u>0.00</u>
TOTAL:	
☐"I cannot afford to subscribe at this time, be would like to receive the bulletin."	out I
□"I enclose a donation of \$so there may receive the bulletin."	hat
□"I want to volunteer. Please contact me."	
□"I want to join a support group. Please cal	1."

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 12th of each month. Rates are as follows:

Newsletter Ads: Maximum 4 per issue, if space allows. \$20 for business card size ad, per issue. Payments will be refunded if the ad is not published.

HOW TO REACH US:

EDITOR:
PHONE:
FAX:
EMAIL:
WEBSITE:
HepCAN List

Joan King
TEL: (250) 595-3892
(250) 414-5102
<u>iking@hepcbc.ca</u>
<u>www.hepcbc.ca</u>
th.graups yahoo.com/

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.

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

HepCBC Resource CD: The

CD contains back issues of the *hepc.bull* from 1997-2004; the FAQ V6; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. The Resource CD costs \$10, including S&H. Please send cheque or money order to the address on the subscription/order form on this page.

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 advice, 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 the editors, of HepCBC or of any other group.

REPRINTS

Past articles are available at a low cost in hard copy and on CD ROM. For a list of articles and prices, write to HepCBC.

THANKS

HepCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Brad Kane, Chris Foster, Judith Fry, The Four Restaurant, Victoria Bridge Centre, Erik, Irene, Chateau Victoria, the Victoria Symphony, the Victoria Conservatory, the Shark Club, Recollections, Thrifty Foods, Patisserie Daniel, Preview Hair Studio, and the newsletter team: Diana Ludgate, and Beverly A. 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 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. number, 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.

Hepatitis Magazine

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 AUGUST 2005 Issue No. 80

WHAT HAPPENS WHEN PEGETRON DOES NOT WORK?

by Tanya Frizzle

I have been on Pegetron for the last nine months, and by the grace of God, I have had no serious side effects. Unfortunately, the doctor with whom I started Pegetron made some serious mistakes. Fortunately, I have been led into the care of Dr. Anderson and his wonderful team.

I am not responding to the Pegetron, but my viral load is lower than when I started. Usually at this point (actually, the 6 month mark), BC medical stops paying for the ultra-expensive medication, and one simply has to learn to live with HCV-wait and wait and wonder—but I have extended medical, so that gives me more options. I wish everybody with HCV could have extended medical. Dr. Anderson (Vancouver) and his team have given me three options. The first is to stop Pegetron and wait for a new medication in 2-6 years. The second is to stay on Pegetron for 18 months instead of 12 months (as I have genotype 1) on the chance that it might allow me to reach SVR. There is no documentation on whether or not this will work, or the chance of it working. The third option is to switch directly to Pegasys without taking a break in between the two medications. The idea is that the viral load is currently low, so maybe a switch will allow me to reach SVR. Again. Dr. Anderson has never had a patient do this. and there is no documentation on the process seem worthwhile. chances of this working.

I am a gambling girl. I have decided to go with option 3. I will make the switch on June 17, 2005. I'm hoping that, because I have no side effects with Pegetron. I will have no side effects on Pegasys. What have I got to lose, other than HCV?

July 17, 2005: I did it. Thursday I was taking Pegetron, and on Friday, I was taking Pegasys, with no break in between—directly from one medication to another. No patient and Rebetrol (Ribavirin) (800-1,400 mg/ from my doctor's office has done this before. Patients have switched from Pegetron to Pegasys, but no patient in their office has ever done it without a break in between. I was told this information before the switch so I was a little concerned about new side effects. When I first started Pegetron, I had mild side effects that went away around the fifth to sixth month. Since then, my "old faithful" side effects include shortness of breath, fatigue, and a lack of appetite. Compared to what I have heard others have gone through, I have it easy. I have to admit I was afraid that, because of the switch, I would no longer have it easy. When I asked my nurse

that she did not know, as she has never had a patient do this. She did say though, "If I was a gambling girl, I would gamble that the side effects will not change." Thank goodness she was right. I had some minor intestinal difficulties the day after the switch, which may or may not have been related. Everything else has stayed the same, except for the fact that I am a little more tired. I have not gone in vet for any blood work results to see if there are any changes there.

The plan on the new medication is to go six months and then test to see if I still have HCV. If I do, then I will stop the medication. If I don't, then I will go a full year's course.

I'm crossing my fingers and praying to God...

To be continued...

TREATMENT VS. **SIDE EFFECTS: WORTH IT?**

At the University Health Network and the University of Toronto, physicians have located 18 genes that can foretell whether or not patients will respond to current Hep C medication before they start treatment. In non-responders, 16 out of the 18 identified genes were "turned-on". This is the predictor of whether or not interferon will work.

Would it not be great to know that the suffering from the medication was worth it and to hang on? This test could keep more people in treatment—it makes the whole

Source: http://www.hemophilia.ca/en/5.8.15.php Identification of specific genes predicts which patients will respond to Hepatitis C treatment, May 3, 2004

DON'T GIVE UP

Interim results of a continuing clinical study (EPIC 3) has revealed that people with HCV who have failed previous treatment may respond to PegIntron (1.5 mcg/kg/wk) day). 21% of the 978 patients enrolled reached SVR.

Professor Thierry Poynard, M.D., Hopital Pitie-Salpetriere, and lead investigator of the above trial (EPIC 3) stated: "We know that some HCV patients will not be able to clear the virus with the currently available therapies. In EPIC 3, we are researching ways to prevent liver disease progression in these patients using low-dose PegIntron maintenance therapy. Our goal is to keep these patients healthy until the next generation of HCV products become available."

Source: http://www.hemophilia.ca/en/5.8.11.php Clinical Benefits of Retreatment With PegIntron

what she thought would happen, she told me and Rebetol Combination Therapy Demonstrated in Difficult-to-Treat Hepatitis C Patients, April 18, 2005

DAILY CANNABIS USE NOT RECOMMENDED

In France it has been found that daily cannabis use is considerably linked with fibrosis progression during CHC (chronic Hep C). People with continuing CHC should avoid regular cannabis use.

Source: http://www.ncbi.nlm.nih.gov/entrez/ q u e r y f c g icmd=Retrieve&db=pubmed&dopt=Abstract&list $uids=15892090\&query\ hl=2$ Hezode C, et al, Hepatology. 2005 May 12, Daily cannabis smoking as a risk factor for progression of fibrosis in chronic hepatitis C

SHOULD YOU WAIT FOR TREATMENT?

I have heard too many times since being diagnosed with HCV, "You're young, and vour liver enzyme levels are 'normal'. Don't worry about getting treatment now. Why not wait until you are approved by Pharmacare for treatment?", or similar statements along those lines. I am glad I did not listen. Professor Gane of Auckland and Middlemore Hepatitis clinics and the New Zealand Liver Transplant Unit and lead author of a study that was recently offered at a chief international medical gathering stated, "The results from our study confirm that not only do these patients [with normal ALT levels] benefit form PEGASYS combination therapy, they also experience better results when treated at an early age." When patients were divided into two age groups, under 40 and over 40, there was a 20% higher success rate in reaching SVR in the population under 40.

Source: www.hemophilia.ca/en/5.8.12.

TREATMENT & DEPRESSION

There is a high risk of depressive disorders in the HCV population (37%), and interferon/ribavirin treatment-related depression is common (10%-40%).

Interferon increases plasma cortisol, and possibly also norepinephrine and epinephrine levels. It can also interfere with tryptophan production, which affects availability of serotonin within the brain.

Depression on interferon therapy can appear within 2 weeks; it most commonly appears within 12 weeks.

Psychiatric side effects, including mood disorders, depression, and psychosis account for nine of 21 common side effects, and six of 24 uncommon ones of treatment.

(Continued on page 4)

hepc.bull **AUGUST 2005** Issue No. 80 Page 3

MILK THISTLE SAFE, BUT WORTH IT?

By Tanya Frizzle

Although milk thistle is safe, having no bad side effects, it does not decrease deaths from alcoholic or hepatitis B or C related liver diseases when taking 140 mg three times a day. These were the findings of a research team at the Centre for Clinical Intervention Research at Copenhagen University Hospital led by Dr. Andrea Rambaldi. This was found after studying 915 patients with liver diseases in thirteen randomized trials. The trials evaluated the effectiveness of milk thistle compared to that of a placebo (a fake medication; you believe you are taking a medication) and to no medicine at all. There was no proof that showed milk thistle was more beneficial than the placebo.

However, these findings have been questioned by G. Thomas Strickland, M.D., Ph. D., professor at the University of Maryland School of Medicine. He believes it may be beneficial to study the effects of milk thistle with a higher dose, as it has been shown in animal studies that milk thistle may be beneficial to the liver.

Source: www.hemophilia.ca/en/5.8.14.php

LIVER CANCER—NOT THE ONLY CANCER RISK ASSOCIATED WITH HCV?

By Tanya Frizzle

Researchers studying the Swedish HCV population looked at whether or not people with HCV were at greater risk for different types of cancer other than liver cancer. Of all the different types they looked at, they found that the danger of non-Hodgkin's lymphoma and multiple myeloma were higher than for people without HCV—for non-Hodgkin's lymphoma, 1.99 times higher, and for multiple myeloma, 2.54 times higher. The bulk of the people with HCV having one of the above cancers were estimated to have had HCV for greater than 15 years. Researchers propose that the danger for HCV-related cancers goes up with the length of time one is infected with HCV.

Source: http://www.hemophilia.ca/en/5.8.4.php
Cancer in Patients With Hepatitis C

Original article: Ann-Sofi Duberg, et al, Hepatology; 41:3; March 2005, "Non-Hodgkin's Lymphoma and Other Nonhepatic Malignancies in Swedish Patients With Hepatitis C Virus Infection."

(TREATMENT—Continued from p. 3)

One cause of mood disorders may be treatment-induced hypothyroidism. Pretreatment and ongoing monitoring of thyroid status seems warranted for this reason.

Vigilance for increased symptoms, even in patients already on antidepressants before beginning INF/RBV treatment, is critical, especially in the first three months of treatment.

A study was done comparing several antidepressant drugs in current use on the various forms that psychiatric manifestations can take in HCV patients. Risk factors unique to people on HCV therapy were assessed, and a detailed list of recommended drug interventions are discussed, citing both the benefits and risks of given antidepressant therapies in this population.

It concludes by recommending that an aggressive, comprehensive, multi-disciplined approach to HCV treatment should be taken to minimize the risk of complication from psychiatric illness in patients on IFN/RBV therapy.

Source: James A. Bourgeois, M.D., et al, Psychiatric Times April Bonus Edition 2005 Vol. XXII Issue 5, Depression as Co-Pilot: Clinical Implications of Hepatitis C and Interferon/Ribavirin Treatment

TREATING CHILDREN

A recent study conducted by HELIOS Children's Hospital, Wuppertal, Germany, demonstrated that treatment with peginter-feron-alfa-2b and ribavirin is a well-tolerated and effective therapy for children with HCV genotype 2 or 3. The level of sustained viral response among patients varied, dependent upon the HCV genotype, liver enzyme levels, and the mode of infection.

While receiving the therapy, 64 percent of patients had no detectable level of HCV RNA, and only five percent of patients relapsed during the follow-up period. The study also demonstrated the following:

- ◆ All children infected with genotype 2 or 3 achieved a sustained viral response; however, less than half of patients infected with genotype 1 had similar success
- Children infected by their mothers did not respond as well as non-vertically infected children
- ◆ Patients with normal liver enzyme levels before treatment responded better that those with above normal levels.

Patients did exhibit side effects that included mild, flu-like symptoms and leucopenia (a decrease in white blood cell counts). There was one incident of diabetes mellitus in one patient.

Although the response rate did not differ from response rates documented by studies using non-pegylated interferon-alfa-2b plus ribavirin therapies, researchers conclude that the treatment is a well-tolerated and effective treatment for children with HCV genotype 2 or 3. The authors emphasize that treatment should be available to children with normal liver enzyme levels, given the high viral response rate observed in this study. In addition, the authors submit that more research would determine if there is a link between mode of transmission and therapy response. Further, the research should focus primarily on vertically-infected children with HCV genotype 1.

Source: Treating Children with Chronic Hepatitis C: PegInterferon-alfa-2b with Ribavirin Shows Promise www.interscience.wiley.com/journal/hepatology.



(DISEASED?—Continued from page 1)

had the plague. I then asked, "What am I supposed to do now?" She replied, "Wait.," with no further explanation. I gave up and took her not-so-subtle hints at leaving. When I got to the hall, she said, "You better get your A and B vaccinations, too." I asked her how to do this. She told me to call some government agency to get them for free, and then said, "I'm sure you know the number," snidely, and again told me to have a good day, and shut the office door. I stood there in shock.

Does having Hep C mark me as a bad person? If doctors are treating me this way, how is the world going to perceive me? I became scared to tell anybody that I have HCV. I had a desire to be open and to educate people about HCV, but was afraid of what people would think of me.

Time has passed, and I have lived and learned. I have become open about my HCV, and tell others that I have it. I have found that, as long as you educate others when you tell them, it is OK. Not everybody will shun you. Some even open their arms wider. I feel comfortable now with who I am and what I live with. I figure, if you don't like me for having HCV, then I don't need you in my life. I need support and love. That will get me through this.

The other moral to this story: Get a good family doctor—one you can tell cares. My family doctor explains everything in detail to me and gives me options. She found a great specialist for me, and follows my case. She also gave me the A and B vaccinations in her office, the way they are normally done.

Page 4 hepc.bull AUGUST 2005 Issue No. 80

(LOCKDOWN —Continued from page 1) example:

- Inmates are more vulnerable to diseases such as HIV and Hepatitis C within the correctional system, and consequently risk of infection in our communities increases.
- Inmates have limited access to addiction treatment within correctional facilities.
- Staff of correctional facilities face serious challenges to providing appropriate health care to inmates who use drugs, and to maintaining the security of facilities.
- Family and friends of inmates face profound negative impacts, including potential transmission of Hep C and HIV.

Here are some stats from the event:

- General population of Aboriginal people in Canada is 3% but 18% of the prison population is made up of Aboriginal people, in some areas, up to 70%.
- It is estimated that at LEAST 80% of incarceration is due to direct or indirect issues with drugs (Gus Richardson, National Parole Board).
- 15-20% of the prison population share drug equipment which most of the time is "home made" (1995 Canadian Inmate Survey).
- 45% of inmates have had tattooing done while incarcerated (Correction Services Canada, who are in the process of a pilot project on Safer Tattooing and Piercing in selected Canadian Prisons).
- 10 20% of inmates start using intravenous drugs for the first time while incarcerated. Most HCV-positive prisoners come to prison already infected, but the potential for health, physical illness and poverty are imfurther spread is high. HCV is much more easily transmitted than HIV, and transmission has been documented in prisons in several countries, including Canada

Recommendations

EDUCATION

Have prisoners and staff develop appropriate materials.

Peer training and education/educators

Safe Tattooing

Remove penalties for giving/receiving tattoos.

Create a safer environment including training.

Condoms

Available

Harm reduction materials and education for safer sex

Needle Exchange Programs

Sterile needles, bleach, alcohol wipes, sterile

water for harm reduction (example: Obershchongrun prison in Germany and Hindelbank Women's Prison)

Methadone

Methadone should be made available and administered in prisons

More drug treatment options for prisoners

More drug treatment programs should be available to prisoners Easy access

INNER CITY HEALTH & HEPATITIS C

Vancouver, June 25, 2005 by Karen Dennis, ED—HepCBC

Presenters:

Rev. Allan Tysick - Director, The Open Door Caite Meagher, R.N. - Cool Aid Community **Health Centre**

Dr. Chris Fraser, MD – Medical Director, Cool **Aid Community Health Centre**

Dr. Satish Shrikhande, MD, FRCP(C) - Consultant, Cool Aid Community Health Centre Dr. John Farley, MD, FRCP(C) - Infectious **Disease Specialist**

Jason Grebely, B.Sc - Dept of Pharmacology & Therapeutics, UVIC

On June 25 at the Victoria Conference Centre Rev. Al opened the day with a very powerful message, and he didn't say a word. It was all "spoken" in the slide show he provided: Pictures of his "family", those who lived in the inner city, many of whom are no longer in our world. His message was clear and inspirational: The health of those who have issues such as addictions, mental portant.

With the teamwork of Schering and the Victoria Cool Aid Community Clinic, a great opportunity for networking, obtaining information (and not to mention a great lunch!) was had by all who attended.

The presenters were well versed in their topics, which included:

- An Overview of Hepatitis C
- Hepatitis C and Chemical Dependency
- Managing the Neuropsychiatric Side Effects of Interferon-based Therapy for Hepatitis C
- A Systematic Approach for the Treatment of Hepatitis C Virus (HCV) in the Inner City: No Patient Left Behind

The information provided in both these conferences is available through the office of HepCBC. Please call us at 250-595-3892, visit our website at www.hepcbc.ca or email me at karendennis@shaw.ca



Conference Photos, top to bottom: Veronica Sevigny—Matsqui Institution, Stephen Smith—BC Min of Health Services, Karen Dennis—HEPCBC and Robert—BCPHA, **Howard Sapers**—Correctional Investigator for Canada, Kathryn Gretsinger-Moderator, Gus Richardson-National Parole Board, Gillian Maxwell—Chair, David Marsh MD—Vancouver Coastal Health, Aaron Nelson-Moody-Squamish Nation, Akbar Bayanzedeh—Dept of Psychology SFU from Iran. Photos compliments of Larry Dennis, rawphoto.ca

hepc.bull **AUGUST 2005** Issue No. 80 Page 5

(DON'T INTERFERE— from page 1)

rus seems to quit trying or goes dormant in down quite nicely. "responders". However, 10 -15 year followup of earliest clinical trial participants/ responders and samples taken from them revealed a high level of relapse and low level activity in others. The virus RNA was still completely intact in cells and capable of fully functional replication in all participants tested. Recently, highly sensitive electron microscopy revealed virion particles embedded in tissue samples taken from cadaveric participants from multiple organs and tissues, which contain the entire code of the virus and are able to develop into fully functional and active virus. We have this virus and we are able to transmit it to others for

Interferon alphas seemed to be the most specific to this virus so Pharmaceutical giant Roche patented interferon alpha 2a and the other, Shering-Plough patented IFN alpha 2b. Patients had to have injections at least 3 times per week (or daily) for 24 to 48 weeks. Compliance was a problem because a lot of patients couldn't continue that long, and tion. IF YOU ARE PLANNING TO HAVE would quit and consequently, fail treatment. To make the therapy more convenient, both NOT TAKE RIBAVIRIN. companies wrapped each molecule with a polymer (polyethyleneglycol—also used in antifreeze, runways, tires—for it's excellent coating and thermodynamic capabilities). I'm sure a lot of you agree that our modern plastic packaging of our groceries or chocolate bars can be quite frustrating to open sometimes. It's a lot of extra work for our bodies to unwrap or break down the plastic before it can use the raw interferon inside. The interferon still builds up to therapeutic levels in our systems but the pegylated versions take longer to break down so injections are only necessary once a week.

Human Genome Sciences, on the other hand, took a more compassionate approach to the patient and human body and did it in a way that would be more familiar and acceptable to the body, and spliced the interferon onto the correct gene of human albumen. AlbuferonTM is currently in clinical trials. shows fewer and less extreme side effects and adverse events, and shows a good response rate even for genotype 1, with the added benefit of only one injection per month. It can circulate in the blood stream for a long time without breaking down, yet is readily available for use when needed. Albumen is produced naturally in the human body. It's quite nice, friendly stuff (compare to egg white). Raw interferon can be like putting a crushed aspirin in your mouth pretty shockingly bitter and harsh, but put news/20041015.htm

the aspirin in a teaspoon of honey and it goes

siRNA's are "small interfering RNA" (ribonucleic acid)—produced by our immune systems in some circumstances, that, again, only interfere with the replication process. It is very similar to the virus itself, which is a single strand of RNA protein, but the siRNA is harmless, yet it plugs into, or uses exactly the same receptacles that the virus uses to replicate. You could call it a small molecule prophylactic. If the virus can't attach, then it can't replicate.

Ribavirin collects in the liver, so any circulating viruses or the ones in the liver would come into close proximity to it and it would have its effect. It is still unclear how ribavirin works, and new discoveries are being made frequently. A few things that are known about ribavirin are that it can affect almost any genetic material by inducing change or mutation. The virus seems to get looped into a constant mutation cycle until exhausted and consequently, too busy to replicate. Again, it interferes with replica-CHILDREN OR ARE PREGNANT, DO

I strongly feel that activists, support workers and societies involved or concerned for people with HCV should be insisting that governments and pharmaceutical companies focus their efforts on developing a vaccine and true cure for this virus instead of focusing on a perpetual market for expensive interfering therapies.

What do you think? kane@nethop.net

CONFERENCES

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/

CLINICAL TRIALS

By N. Hoskins & Jay P.

IC41

Intercell AG announced that it is ready to launch the next phase of clinical trials of the hepatitis C vaccine, IC41.

Intercell has conducted Phase II trials on patients who do not respond to Interferon/ Ribavirin therapy. T-cell induction occurred after the vaccine was administered which coincided with a short-term reduction in HCV RNA levels. Intercell reported the results of Phase I and II at the conference of the European Association for the Study of the Liver (EASL) on April 14th in Paris.

The next testing phase aims to optimize route and frequency of treatment methods to reduce the levels of infection further. Current testing involves applying the vaccine to healthy volunteers. However, if results from the study meet expectations, chronic HCV volunteers will be included in 2006. Entry into the EUR 3.5 billion market would follow in 2011.

Prof. Michael Manns from the Medical University in Hanover endorses Intercell's research: "I am convinced that the achieved induction of T-cells in chronic nonresponder patients as shown in Intercell's Phase II study has paved the way to the development of a therapeutic vaccine for novel stand alone and combination treatments."

Alexander von Gabain, CEO of Intercell discusses the significance of his company's research: "We belong to the few pioneers working on new treatments against Hepatitis C. Our therapeutic vaccine in this field of high medical need is latest state of the art vaccine technology".

Source: Intercell AG Press release, May 3, 2005, Recruitment completed for optimization trial of therapeutic Hepatitis C vaccine

REPAIR YOUR OWN LIVER

Specialists in Britain have found a way to successfully use patients' own stem cells to regenerate their livers.

This raises the possibility of a cure for liver disease that would negate the controversy over cells harvested from aborted embryos.

A second phase of the trial is imminent, and will test the treatment's ability to actually reverse liver disease.

Source: http://www.telegraph.co.uk/news/main.j Halle, Martyn, The Telegraph - UK, 5-28-05 Doctors Fight Liver Disease With Body's Own Stem Cells

Page 6 hepc.bull **AUGUST 2005** Issue No. 80

"HEP C COMPENSATION SHOULD BE MORE OF AN ISSUE THAN SAME-SEX"

by Darlene Nicolaas, Vancouver, BC

The article reports that "the government has moved closer to passing its controversial budget legislation and voted to press ahead to complete passage of the same-sex marriage bill even if it means asking Speaker Peter Milliken to recall the House next week to drag MPs back from the beginning of their summer recess." The fact the government is willing to take these steps is abhorrent and demeaning to me and many others in Canada. That is because on April 13, 2005, MPs would not extend their business day by just a few minutes, thus preventing a motion calling for compensation of "forgotten victims" of hepatitis C from going to a vote. Those "victims" are people who were infected with Hep C through the blood transfusions before 1986. The artificial compensation window set up by the Liberal government covers only those infected from 1986 to 1990. I received tainted blood in February, 1985. Can readers imagine how I and many others in my shoes felt upon reading that the right of same-sex marriage partners is more important than the quality of our lives? I have now lived with this insidious dragon disease for 20 years. When is the federal government going to do the right thing and compensate those of us who were infected before 1986?

Source: National Post, Friday, June 24, 2005 Re: Liberals survive to rally for Same-Sex, June 22. Reprinted with permission of author.

HepCBC

ANNUAL GENERAL MEETING Part II

Wednesday, Sept 7, 2005

Woodward Room Begbie Bldg Royal Jubilee Hospital Victoria, BC INFO: 250-595-3892 info@hepcbc.ca

AGENDA:

- 1. Approve minutes of AGM Part I
- 2. Set number of directors,
- 3. Election of those directors



GORDON MASTINE

Gordon Mastine was one of our very first board members here at HepCBC. He was a great voice of wisdom and experience, having had much experience in the military and in his church groups. His final public message read as follows: "I love you all and pray blessings upon you. Do pass it on to the global email lists" Dinah, his wife, added: "Gordie died at 1:00 am Wednesday, June 15th. All available family members were there to hold his hand and pray with him. Praise God it was peaceful!" He is survived by Dinah and his children, step-children and many grandchildren.

CARE-LINE

A limited patient assistance program, called CARE-Line, is available in Canada for some people receiving Pegetron. 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.hepcyorkregion.org/
docs/352,1,Slide 1

COMPETITION!

epCBC is looking for writers for the August 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 August, 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

COMPENSATION

LAW FIRMS

1986-1990

Bruce Lemer/Grant Kovacs Norell Vancouver, BC

Phone: 1-604-609-6699 Fax: 1-604-609-



Pre-1986/ Post-1990

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

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)

kkoltham@telusplanet.net

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

Class Action Suit Hotline: 1-800-229-5323 ext. 8296 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 Quebec Compensation: 1-888-840-5764 ca/en/ms/hepatitisc/forms.html

ADMINISTRATOR

1986-1990

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/tran5e.pdf

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.

MISCELLANEOUS

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

hepc.bull AUGUST 2005 Issue No. 80 Page 7

COMING UP IN BC/YUKON:

Armstrong Hepatitis C United Resource Exchange Contact: 1-888-HepCURE amberose@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 ◆Nanaimo Drop-In as of June 1st, each Wed 2-4PM, #201-55 Victoria Rd. Contact Anita 753-2437 anita.macleod@avi.org

Castlegar Contact Robin 365-6137

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Contact Katerina 417-2010, hecsc-ek@shaw.ca Leslie 426-6078,

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, erise-<u>ley@shaw.ca</u> or Lisa 766-5132 tell@silk.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 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, Rm. 107. Contact Gina 963-9756, or llse 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 (Princeton General Hospital), Contact Brad 295-6510, CitizenKane@hepcan.ca

Queen Charlotte Islands/Haida Gwaii: Phone 557-2487. Contact Wendy support. wmm@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 Thurs. monthly, 3-5 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 1-800 Contact 336-9726. info@healingourspirit.org www.healingourspirit.org

VANDU Vancouver Area Network of Drug Users: Satelite 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 <u>vandu@vandu.org</u> <u>www.vandu.org</u>

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 Svendson 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, sggrant@telus.net

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

Victoria Support & Info Contact the Needle Exchange 384-2366

Victoria HepCBC 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 hencsupportbarrie@rogers.com

Durham Hepatitis C Support 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@becon.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) 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 940-1333, 1-800-461-2135. info@hepcyorkregion.org www.hepcyorkregion.org

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 — loan King of the month — Joan King

HepCBC is 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

OUEBEC:

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

ATLANTIC PROVINCES:

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

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

Hen 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



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

Page 8 hepc.bull **AUGUST 2005** Issue No. 80