hepc.bull

BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

AUGUST 2000 **Issue No. 25**

TIMOTHEA SINGS FOR HEP C AWARENESS

Photo by: Leni Sinclair ©1999

Well known New Orleans R & B star Timothea Beckerman, a Hep C victim, has launched a campaign to bring the Hep C epidemic to the public's attention. Timothea has been singing professionally since she was twelve years old. Her latest CD, co-produced with Walter "Wolfman" Washington, is called "No Nonsense," produced by Blue Soul Records. Timothea is calling herself "A Siren To Wail," and is quickly becoming one of our major advocates. She has done a series of Hep C public service announcements which are being broadcast on the radio, and she has included Hep C information with ther CD. Last April, she and Hep-C ALERT put on a very successful benefit concert with an all-star cast of New Orleans singers and musicians, and the help of Ochsner Clinic and Tulane Medical Center and many local businesses, who helped with an auction. She hopes to take the show on the road. Good for you, Timothea!! Have you bought her CD yet?

Source: Hep-C Alert

INFO LINE

Do you need copies of medical articles to show to your doctor, or for any other reason, and don't have internet access? Call us at (250) 361-4808, leave a detailed message of what you need, with your complete name and address, and we'll do our best to send you the appropriate articles. This service is free, other than any long distance charge that you might incur.

THE CO-INFECTION SECTION

by Brian D. Klein, MA, LMSW
Hepatitis C Action & Advocacy Coalition

The Double Challenge of HIV/HCV Co-infection: An Update

Approximately 40% of people living with HIV are co-infected with hepatitis C (HCV). At least twice that rate (80%) has been found among injection drug users and people with hemophilia. Compared to HIV and hepatitis B, HCV is not easily transmitted sexually, but, because of its higher rate of replication, it is much more easily transmitted blood-to-blood. HIV produces billions of new virons (virus particles) each day, while HCV produces trillions daily.

An accelerated rate of HCV progression occurs in people co-infected with both viruses compared to those living with HCV alone. One European study of 547 patients with HCV showed that among the 431 who were HIV-, the average time to development of cirrhosis (nonfunctioning scar tissue) was 23.2 years; for the 116 HIV+ individuals, the average time to cirrhosis was 6.9 years. Co-infected individuals also run an increased risk of developing liver cancer and liver decompensation. Many co-infected individuals are surviving HIV only to die due to HCV complications. These complications are the leading reasons for liver transplants. Fortunately, new information is emerging to better understand and treat HIV/HCV co-infection and to increase survival.

Research from UCSF indicates that when an individual with HIV has a CD4 rate <200 cells/ml, HCV is able to mutate more easily. It gets around the defenses of the weakened immune system and evolves new quasispecies (variants) that can survive and multiply, leading to further disease progression. Other research shows that older age and greater consumption of alcohol also lead to increased fibrosis (early scarring which can lead to cirrhosis) in co-infected individuals.

Progress has been made at U. of Pittsburgh regarding liver transplants in a few co-infected individuals. These people were far along in their HCV disease, but early enough in HIV progression to survive both the surgery and the immune

(Continued on page 8)

ASK THE ADVOCATE

CPP DISABILITY BENEFITS
The Canada Pension Plan disability benefits appeal system, Part 4:

WHEN IS A DISABILITY "SEVERE"?

by Sheila Puga, Community Law Clinic, Vancouver Legal *Services Society*

The most common reason why the minister will deny an application for disability benefits is that the medical condition is not considered to be "severe." Section 42(2)(a)(i) states:

> "a disability is severe only if by reason thereof the person in respect of whom the determination is made is incapable regularly of pursuing any substantially gainful occupation."

There are no other sections in the legislation to help us determine what will, or will not, be considered a "severe" disability. Therefore, the best way is to review past decisions of the Pension Appeals Board (PAB), found in the CCH Canadian Ltd. Canadian Employment Benefits & Pension Guide Reports (cited here as CCH).

The PAB, in *Harbhajan Bath v. Minister of Human Resources Development*, (1997), #8666 CCH, pages 6259 - 6260, confirmed that the onus of establishing that a medical condition is both severe and prolonged under the Canada Pension Plan rests with the applicant. The PAB further stated that the "prescribed manner" for establishing these conditions is set out in section 68 of the CPP regulations. Section 68 of the regulations requires the applicant to provide the minister with specific information about his or her medical condition, work history, education, and daily living activities for the purpose of determining eligibility for disability benefits.

About whether a disability is severe, the PAB had this to say in *Bath*:

> "The criterion to be applied is the physical or mental capacity, or incapacity, as the case may be, of the applicant to perform any substantially gainful employment, *not restricted to the type or general nature of the applicant's former employment, but any employment of whatever nature*." (Emphasis added)

It is not enough to show that the applicant is no longer capable of performing his or her usual occupation. The evidence must establish that the applicant is unable to rejoin the work force in any substantially gainful occupation, of any nature. In

(Continued on page 7)

SUBSCRIPTION/ MEMBERSHIP FORM

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

HepCBC
2741 Richmond Road
Victoria BC
V8R 4T3

Name: _____

Address: _____

City: _____ **Prov**. ___ **PC**_____

Home(____)_____**Work**(____)_____

Email: _____

☐Membership + Subscription (1 year): **$20.00**

☐Membership Only **$10.00**
(for those already receiving the bulletin):

☐Subscription Only **$10.00**
(for those already members of HepCBC):

☐"I cannot afford to subscribe at this time, but I would like to receive the bulletin."

☐"I enclose a donation of $_____so that 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.org, (250) 361- 4808. The editors reserve the right to edit and cut articles in the interest of space.***

ADVERTISING: ***The deadline for placing advertisements in the* hepc.bull *is the 12th of each month. Rates are as follows:***

Newsletter Ads:
$20 for business card size ad, per issue.
There will be a maximum of 4 ads in each issue, and the ads will be published if space allows. Payments will be refunded if the ad is not published. Ads are also posted to the Web.

HOW TO REACH US:

PHONE: ***TEL: (250) 361-4808***
FAX: **(250) 414-5102**
EMAIL: ***info@hepcbc.org***
WEBSITE: ***www.hepcbc.org***
HepCAN List ***www.egroups.com/list/hepcan/***

HepCBC
2741 Richmond Road
Victoria BC V8R 4T3

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.

EVER WISH.....?

Have you ever wished your doctor knew more about Hep C? You might consider subscribing him or her to the hepc.bull. It's easy. Just fill out the form here on the left. You may remain anonymous.

WHAT IS BEING DONE TO STOP THE HEP C EPIDEMIC?

REPORTED CASES OF NEWLY DIAGNOSED INFECTIONS IN BC 1992-1997:

Year	AIDS	Hep C
1992	262	232
1993	224	1071
1994	227	2232
1995	212	5153
1996	145	6626
1997	43	8281
Totals	1113	24452

http://cythera.ic.gc.ca/spansweb/ndis/c_dis_e.html

More stats:

Total Hep C cases in BC as of May 2000: 38,528

New cases in BC from Jan-May 2000: 2328

www.bccdc.org/pdf/rpt-0500hu.pdf

USING THE HEPCAN SITE

It has been brought to our attention that there may be some people who are unfamiliar with accessing the features of HepCan on the web through: www.egroups.com/lists/hepcan which you can do by typing it into your address bar or `Find on the internet' box from a program or the start menu. When you sign in, first time users will have to create a password. Check off `Remember me' and if prompted `Do you want Windows to remember this password for future use?' - click `Yes'. Forgot your password? - don't worry - click the `Forgot Password' button and you can be designated a new one. Use the search engine at the top/right of the `Messages' page. Set it to Search "This Archive" and enter a Key word such as `Diet' or `Milkthistle' or `Ribavirin', etc. You can `View by Date' or `View by Thread.'

Enjoy!

Brad Kane

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. Squeeky, 2741 Richmond Road Victoria BC V8R 4T3.** Give us your name, tel. no., and address.

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

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

Ad No. 17

Attractive, young middle aged male 6'2," 180 lbs. Caring, compassionate, spiritually focused, very outdoors oriented, professional artisan, massage therapist. Loves canoeing, hiking, camping, old movies, beach barbecues. Hep C pos./minimal symptoms. Would love to meet similar adventurous woman for outings, friendship, potential life partner. Vancouver Island.

SINGLE? LONELY?

Alberta Hepatitis Singles web
http://clubs.yahoo.com/clubs/albertahepatitissingles

FREE EMAIL SUBSCRIPTIONS hepc.bull

To subscribe to the hepc.bull free of charge via email, go to www.egroups.com/group/hepc-bull

SQUEEKY'S CORNER

Recently, Health Canada made disbursements as part of its hepatitis C initiative. In comparison to the amounts it has allocated to research and treatment for cancer and AIDS, funding for hepatitis C still remain pitiably low.

Perhaps more troubling is the fact that most of the monies targeting hepatitis C went not to agencies specifically dealing with this illness, but to AIDS and other community organisations whose current target is intravenous drug users.

Granted, these organisations do have experience dealing with the IDU population, and harm reduction strategies are called for, but what about the rest of us?

Recent studies in the most respected medical journals warn of the prevalence of hepatitis C in populations other than IDU, and of the dangers this silent killer poses.

An article in *Harrison's Principles of Internal Medicine* warns that hepatitis C is a serious late complication for those cured of cancer, with 6.6% of the sample group infected. The researchers caution that, "given the long latency of hepatitis C infection, it is persons cured of cancer in childhood or young adulthood who are at greatest risk because of their life expectancy." Since the vast majority of those treated for cancer between 1961 and 1992 have no symptoms, they have undergone no treatment for hepatitis C.

As well, articles presented this May at the Digestive Disease Week 2000 in San Diego reported that new hepatitis virus infections were detected among dialysis patients with normal ALT tests. This again is due to the fact that hepatitis C often presents no symptoms, and standard first line testing is insufficient. The recommendation is that direct testing for the virus be used for those on dialysis.

Last, the latest studies also show that incidences of hepatocellular cancer due to hepatitis C and deaths caused by hepatitis C are almost double the rate given a few years ago. An article in the July issue of *Gut* reveals that '"of the 416 patients, 60 developed HCC with a 5-year rate of 13.4%...and 83 died (including 34 with HCC), with a 5-year death rate of 15.3%.' According to the authors, these results contrast with previous studies, which cite 5-year mortality rates of 9%, and HCC rates of 5% or 7%."

In all 3 studies the population group was not composed of IV drug users. Don't ordinary citizens deserve the same treatment as those more politically correct? After all, it was their tax dollars that funded the grants anyways.

Sincerely,

Dr. C.D. Mazoff, PhD
Executive Director, HepCBC

RESEARCH

TELOMERASE RESEARCH

BMJ 2000;320:536 (February 26, 2000)
Cirrhosis may be amenable to telomerase treatment
Abi Berger , BMJ

An article from the *British Medical Jounal* reports that in Boston, Massachusetts, Professor Ron DePinho and his may have found a new treatment for slowing up liver disease (*Science* 2000;287:1253-8). Cirrhosis occurs after many years of liver disease that results in cell death and regrowth, but there comes a time where liver cells can no longer grow, and this seems to happen at the same time that cells called "stellate cells" are activated in the liver. These cells produce collagen which makes bridging fibrosis, which turns into the scarring called cirrhosis. Some researchers think that end stage liver disease occurs because there are genetic caps on the ends of the chromosomes called telomeres, and these become scarce. There is an enzyme which helps keep the telomeres healthy, called telomerase. In an experiment with mice where the researchers took away the telomerase, the livers became fibrotic. When telomerase was reintroduced into the mice, the formation of cirrhosis was blocked. It is thought, therefore, that telomerase may be a future treatment for cirrhosis.

CHINESE VACCINE

SHANGHAI (July 13, 2000) XINHUA via NewsEdge Corporation - Chinese researchers have designed a compound vaccine after four years of tests on mice, rabbits and monkeys, and found it is resistant to Hepatitis C.

Researchers from Fudan University and another medical college have been working on a vaccine which they have been testing on mice, rabbits and monkeys. The vaccine, which uses gene engineering techniques, seems to resist the hepatitis C virus. There are no immediate plans for clinical trials in humans.

CLONING LIVERS

http://www.newsoftheworld.co.uk/news/1634980
HUMAN ORGANS TO BE CLONED IN BRITAIN By IAN KIRBY, Political correspondent

In a British experiment, a human ear was cloned on the back of a mouse. Cloning of human organs has been approved by the government there, raising hope for cloned livers to be used for transplant within the next six years. Experiments on human stem cells are allowed only for 14 days at this time, but there is a proposal for removing the time limit. Apparently, as the host animal grows, the cloned organ will contain a full human DNA pattern, and will be able to be transplanted. There are, obviously, moral issues at stake here, but it is believed that the great medical advances far outweigh any moral objections.

86 TO 90 COMPENSATION UPDATE

It has been over 2 months since I hosted two very successful "claim form parties" in the Okanagan and Victoria. The turnout was excellent and so far I have been able to assist almost 100 persons through the process.

I have been getting many calls asking "What is next?" - "Will my claim be held up waiting for my traceback?" - "How soon until I get my cheque?"

Well, I will try to answer by telling you what my experience has been so far.

First you send in your claim form. The very early ones got a call from the Administrator's office asking for a fax number they could be reached at. They were faxed a copy of the release forms.

They received a two page covering letter plus a 4 page release letter. The covering letter explains that they will receive Level 1 pay out at 10,156.83 and if applicable a Level 2 pay out at 20,313.65 (less a $5,078.41 hold back).

The letter goes on to say that "You may be entitled to further compensation, including loss of income, loss of service in the home, costs of care, compensable HCV drug therapy, uninsured treatment and medication and out - of - pocket expenses."

So, you return the release forms to the administrator's office by fax and you should receive a cheque by the end of the month you return them in.

If you do not have a fax machine - this will incur additional costs. I am suggesting asking your MP or MLA if you can fax them out on their machine.

If you were **not** one of the early birds, you may have received a letter by now stating...."Thank you for submitting your application for compensation...Response time may vary depending on the total number of claims received and the complexity of the claims submitted." I have no idea how long these will take. I have no idea if uncompleted tracebacks will hold up your claim.

This is the letter that I received, I was not one of the early birds. Unfortunately, it was addressed to the Estate of Jarad Gibbenhuck. The Administrator's caught this mistake but not until after the letter had been mailed. They faxed me a corrected one and they explained there are still many bugs in the system but they are getting smaller. So, if your letter came addressed to your estate and you are not yet deceased, you are not alone.

It appears no matter what level you are assessed at, you will only receive up to the Level 2 pay out at this time. You must sign and return the release forms—in order to learn what you will be entitled to in the future.

(Continued on page 8)

CLINICAL TRIALS

MAXAMINE + INF TRIALS

SAN DIEGO--(BW HealthWire) http://www.maxim.com.Contact: Maxim Pharmaceuticals, San Diego Larry G. Stambaugh, 858/453-4040

Maxim Pharmaceuticals announced its 24-week results from its Phase II study of Maxamine® combined with interferon-alpha in Hep C patients who had not been treated previously. At the end of therapy, the Maxamine + INF combo resulted in a complete viral response in 69% of all patients, compared to 29% in patients who take IFN alone, and about 40% who take IFN + Ribavirin. The principal investigator in the study is Israel's Yoav Lurie M.D. Half of the patients in the study had HCV genotype 1, and patients with high viral loads were also included. Dr. Lurie hopes to do studies combining Maxamine with pegylated IFN and ribavirin. The 129-patient trial is taking place in the UK, Belgium, Israel and Russia, awaiting the next set of results. Maxamine is designed to reverse immune suppression and help the body fight diseases.

ZINC + INTERFERON TRIALS

Takagi H and others. Additive effect of zinc on interferon therapy for chronic hepatitis C. Abstract and poster presentation 229 at Digestive Disease Week 2000; May 21-24, 2000; San Diego, California.

"In a randomized Japanese trial, "polaprezinc" supplements increased sustained virologic response from 10% to 32% in those with low baseline viral loads." Since patients with liver disease usually are lacking in trace elements, researchers from Gunma University in Japan decided to do tests combining IFN (alone) with zinc. The patients all had genotype 1b (the most difficult to treat) and a viral load of at least 100,000 copies per ml. All were given 10 million units of IFN daily for the first four weeks, followed by every other day for 20 weeks. Half received 150 mg. daily of "polaprezinc." The IFN+Zinc performed better, but only for those with starting viral loads of 100,000 and 199,000 copies per milliliter. For patients with viral loads greater than 500,000 copies per milliliter, 9% of the IFN arm and 13% of the IFN+Z arm tested negative for HCV. However, for those with an initial load between 200,000-499,000 copies per milliliter, the IFN+Z arm had a complete response rate that was twice (36%) that of the IFN arm (18%). The study has its limits, especially with the concern of possible development of zinc toxicity, but the findings are interesting. Do not take zinc without consulting with your doctor!

VX-497 + IFN TRIALS

CAMBRIDGE, Mass., July 3 /PRNewswire/ via NewsEdge Corporation – Vertex's press releases are also available at www.vpharm.com or by fax-on-demand at (800) 758-5804 - Code: 938395 SOURCE Vertex Pharmaceuticals Incorporated CONTACT: Lynne Brum, Vice President, Corporate Communications, 617-577-6614, or Michele Karpf, Manager, Product Communications, 617-577-6259, or Katie Burns, Manager, Investor Relations, 617-577-6656, all of Vertex Pharmaceuticals

Vertex Pharmaceuticals has initiated a Phase II clinical trial of VX-497, which we have reported on in earlier editions of the *hepc. bull*, after proving in Phase I trials that the substance is safe and effective against HCV. This time, researchers will combine it with IFN-alpha in a randomized, double-blind, placebo-controlled dose-escalation trial, enrolling up to 54 adult HCV patients in the US who have not previously received HCV antiviral therapy. Half the patients will receive VX-497 plus IFN, and half will receive placebo plus IFN for four weeks, assessing the safety and changes in the viral load.

PEG-IFN + RIBAVIRIN TRIALS FOR CO-INFECTED PATIENTS

Satellite Symposium at the XIII International AIDS Conference; July 9-14, 2000; Durban, South Africa.

A large (740 patients) randomised, multinational placebo-controlled trial of patients co-infected with HIV/HCV already taking HAART has begun enrolment. There are three arms of the trial: 1) Pegasys - 180 mc. once a week plus oral placebo. 2) Pegasys, same dose, plus ribavirin 800 mg once daily, and 3) Roferon (IFN alfa 2a) 3 MU 3 times a week + ribavirin, 800 mg once daily, all taken for 48 weeks, with testing 24 weeks later to measure sustained response. Researchers are afraid that ribavirin will cancel the effects of HAART, or that there will be bad drug interactions in the patients. In previous studies, Roche's Pegasys has been compared to Roferon, and Schering's PEG-Intron has been compared to Intron A.. Both of the pegylated interferons were superior to the non-pegylated forms. This present study was initiated by F. Hoffmann-La Roche Ltd., and will include patients from Canada.

PEGASYS TRIALS

Filing of PEGASYS with FDA Triggers Milestone Payment to Shearwater. HUNTSVILLE, Ala.--(BW HealthWire)--June 5, 2000 via NewsEdge Corporation - CONTACT: Shearwater Polymers Inc., Huntsville | Stephen A. Charles, 256/533-4201 | sacharles@swpolymers.com | www.swpolymers.com

Shearwater Polymers, Inc. has applied for FDA approval for Pegasys, a pegylated (time-release) interferon. Produced together with its partner Hoffman-La Roche.

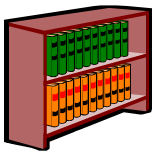
Phase III trials showed undetectable virus load in 39% of patients treated with a 180 mcg of Pegasys once a week of PEGASYS compared to 19% of patients treated with a 12-weeks of 6 MIU of interferon alfa-2a three times a week, followed by 36 weeks of 3 MIU of interferon alfa-2a three times a week. Interferon without induction dosing usually results in response rates of about 10 percent.

In another study which included only Hep C patients with cirrhosis, data showed that PEGASYS may achieve a sustained response rate nearly four times higher than standard interferon. These patients showed improvement in biopsy results, as well.

Pegasys is injected only once a week, compared to the usual 3 tines a week dosing with IFN-alpha.

HEPCBC COMMUNITY LIBRARY NOW OPEN

Thanks to the generosity of Elsevier Science, the Massachussets Medical Association and the San Francisco Hep C Support project, HepCBC now has full access to the following journals.:



- *American Journal of Gastroenterology*
- *The Lancet*
- *Journal of the American Medical Association*
- *Hepatology*
- *New England Journal of Medicine*

Community members are welcome to search these journals online at the computer terminals at our library for the latest information on HCV and HCV/HIV co-infection. Thanks as well are due to the Victoria Persons with AIDS Society where the library is housed. ***The library is located at 541 Herald Street in Victoria. For hours of operation call : (250) 382-7927***.

NEW VICTORIA WOMEN'S SUPPORT GROUPS

let's get together for tea. For more information call Joan: 595-3882

COMING UP IN BC:

Castlegar/Grand Forks/Trail Contact: Robin, 365-6137

Chilliwack BC HepTalk Meetings: 2nd and 4th Wednesdays of each month, 7-9 PM, Chilliwack United Church 45835 Spadina. NEXT MEETINGS: Aug 9th and 23rd. Contact: HepTalk@fraservalleydir.every1.net, or 795 4320

Comox Valley Liver Disease Support Group Meetings: Third Tuesday of each month, 6-8 PM, St. George's United Church on Fitzgerald. NEXT MEETING: Aug 15th. Drop in daily for coffee. Contact: Ingrid or Nicky, 335-9167, nickyrussell@sprint.ca

Cowichan Valley Hepatitis C Support Contact: Debbie, 715-1307, or Leah, 748-3432.

Cranbrook HeCSC : Meetings: 1st and 3rd Tuesday of each month, 2-4 PM, #39 13th Ave South, Lower Level. NEXT MEETINGS: Aug 1st and 15th. Contact: 426-5277, hepc@cyberling.bc.ca

Downtown Eastside Hep C Support Group Meetings: Each Monday, 6 to 8 PM, Carnegie Center, 401 Main St., Vancouver. Contact: Carolyn, momma@vcn.bc.ca

Enderby HepCURE Meetings: Last Sunday of each month, 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: Aug 27th. Contact: Marjorie, 558-7488, amberose@sunwave.net

HepCBC Hepatitis C Education and Prevention INFO Line. Need free medical articles? Contact: David, (250) 361-4808, info@hepcbc.org, www.hepcbc.org

Kelowna HeCSC Meetings: First Saturday of each month, 2-4 PM, Rose Avenue Education Room, Kelowna General Hospital. NEXT MEETING: Aug 5th. Contact: Doreen, 769-6809 or eriseley@bcinternet.com

Kootenay Boundary Meetings: Second and fourth Tuesday of each month, 7 PM, 1159 Pine Ave, Trail. NEXT MEETING: Aug 8th. Contact: Brian, 368-1141, k-9@direct.ca. Meetings for August and September 2nd Tuesday of the month only

Mid Island Hepatitis C Society Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St., Nanaimo. NEXT MEETING: Aug 10th. Contact: Susan, 245-7654, mihepc@home.com, or Rose, 714-1937.

Mission Hepatitis C and Liver Disease Support Group Contact: Patrick, 820-5576.

New Westminster Support Group Meetings: Second Monday of each month, 7:00-8:30 PM, First Nations' Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. NEXT MEETING: Aug 14th. Contact: Dianne Morrissettie, 525-3790.

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

Penticton Hep C Family Support Group Meetings: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: Aug 9th. Contact: Leslie, 490-9054, bchepc@telus.net

Powell River HepC Information and Support: Contact: Cheryl Morgan, 483-3804.

Prince George Hep C Support Group Meetings: Second Tuesday of each month, 7-9 PM, Health Unit Auditorium. Next Meeting: Aug 8th. Contact: Sandra, 962-9630 or Ilse, ikuepper@pgrhosp.hnet.bc.ca

Prince Rupert Contact: April, 627-7083.

Princeton Meetings: Second Saturday of each Month, 2 PM, Health Unit, 47 Harold St. NEXT MEETING: Aug 12th. Contact: Brad, 295-6510, citizenk@nethop.net

Slocan Valley Support Group Meetings: Third Tuesday of each month, 7-9 PM, W.E. Graham Community School Youth Centre. NEXT MEETING: Aug 15th Contact: Ken, 355-2732, keen@netidea.com

Smithers Contact: Doreen, 847-2132 or aws@mail.bulkley.net

Sunshine Coast — Sechelt: First Wednesday of each month. NEXT MEETING: Aug 2nd—**Gibsons**: Last Thursday of each month. NEXT MEETING: Aug 31st. Both meetings—Health Units, 7 PM. Contact: Kathy, 886-3211, kathy_rietze@uniserve.com

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence, VGH (12th & Heather). NO MEETING IN AUGUST. NEXT MEETING: Sep 14th. Contact: CLF, 681-4588, or Herb, 241-7766, HMoeller@compuserve.com

Vancouver Morning Support Group Meetings: Last Wednesday of each month, 10:30-12:30, BC CDC Building, 655 West 12th (Park in Cambie St. City Square Mall). NEXT MEETING: Aug 30th. Contact: Darlene, 608-3544, djnicol@attglobal.net, or info@hepcvsg.org.

Vernon HepCURE Contact: Marjorie, 546-2953 for Hep C information. amberose@sunwave.net

Vernon HeCSC HEPLIFE Meetings: Second and fourth Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. NEXT MEETINGS: Aug 9th and 23rd. Contact: Sharon, 542-3092, sggrant@netcom.ca

Victoria HeCSC Contact: 388-4311, hepcvic@idmail.com

Victoria HepCBC Support Groups We have small support groups for men and for women. For men, contact Guy at 382-9888, kidsturn@home.com, for women, contact Joan at 595-3882, or jking@hepcbc.org

OTHER PROVINCES

ALBERTA:

Central Alberta CLF Hepatitis C Support Group Meetings: Last Thursday of each month, 6-8 PM, Provincial Building, Room 109, 4920 51 St., Red Deer. Enter at southeast entrance. NEXT MEETING: Aug 31st. Contact: Shane, 309-5483, shane-hepc@hotmail.com

Edmonton, AB Hepatitis C Informal Support Group Meetings: Third Thursday of each month, 6-8 PM, 10230-111 Avenue, Edmonton, Conference Room "A" (basement) NEXT MEETING: Aug 17th. Contact: Cathy Gommerud, yzcat@telusplanet.net or Jackie Neufeld, 939-3379

ATLANTIC PROVINCES:

Cape Breton Hepatitis C Society Meetings: Second Tuesday of each month. NEXT MEETING: Aug 8th. Contact: 564-4258 (Collect calls accepted from institutions) Call toll free in Nova Scotia 1 (877) 727-6622

Fredericton, NB HeCSC Meetings: 7 PM Odell Park Lodge. NEXT MEETING: Contact: Sandi, 452-1982 sandik@learnstream.com

Greater Moncton, N.B. HeCSC Meetings: First Thursday of each month, 7 PM. Place to be changed. NEXT METING: Aug 3rd. Contact Debi, 1 (888) 461-4372 or 858-8519, monchepc@nbnet.nb.ca

Halifax Atlantic Hep C Coalition Meetings: Third Saturday of each month, 1-3 PM, Dickson Centre, VG Hospital, Rm 5110. NEXT MEETING: Aug 19th. Contact: 420-1767 or 1-800-521-0572 or ahcc@ns.sympatico.ca

Kentville Atlantic Hep C Coalition Meetings: Second Tuesday of each month, 6:30-8 PM, Kingstec Campus, Rm 214. NEXT MEETING: Aug 8th. Contact: 1-800-521-0572 or ahcc@ns.sympatico.ca

ONTARIO:

Durham Hepatitis C Support Group Meetings: Second Thursday of each month, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby, ON. NEXT MEETING: Aug 10th. Contact: Smilin' Sandi, smking@home.com http://members.home.net/smking/ or Durham Region Health Department (905) 723-8521 or 1-800-841-2729 Ext. 2170 (Ken Ng)

Kitchener Area Chapter Meetings: Third Wednesday of each month, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. NO MEETING IN AUG. NEXT MEETING: Sept 20th. Contact: Carolyn, 893-9136 lollipop@golden.net

Hep C Niagara Falls Support Group Meetings: Last Thursday of each month, 7-9 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thurold, ON. NO MEETING IN AUGUST. NEXT MEETING: Sep 28th. Contact: Rhonda, 295- 4260 or hepcnf@becon.org

Hepatitis C Society of Ottawa-Carleton Centertown Comm. Health Centre, 420 Cooper St. (Ottawa) between Bank and Kent St. One on one peer counselling Mon. afternoons. NEXT MEETING: Contact 233-9703 or sue.rainville@sympatico.ca

QUEBEC:

Hepatitis C Foundation of Quebec Meetings: Third Wednesday of each month, 7-9 PM, Dawson Community Centre, 666 Woodland Ave., Verdun. NEXT MEETING: Aug 16th. Contact Eileen: 769-9040 or fhcq@qc.aibn.com

WHAT TO DO WITH NON-RESPONDERS

Source: American Journal of Gastroenterology, Editorial May 2000, Volume 95, Number 5,Pages 1122-1124

The author of this letter reports that combined IFN + Ribavirin therapy has increased the sustained virological response (SVR) of naive patients from 10%, with IFN alone, to 40%, but even so, the majority of treated patients fail to achieve the benefits of sustained loss of the virus, and retreatment has been disappointing, even when using higher doses, induction, longer therapy, and combinations with other medications or with phlebotomy, therefore **more effective treatment for these non-responders should be made a priority.** Retreatment with the combo seems to be a good option for about 14% of INF non-responders.

A treatment of IFN + ribavirin + Amantadine resulted in a sustained response for 3 of 10 non-responders, in a trial run by Brillanti, compared to none retreated with only IFN + ribavirin, but other small studies have not confirmed this finding. The good news is that even though non-responders do not clear the virus, there seems to be **lessening of fibrosis** as a result of treatment, **so long-term maintenance therapy with IFN may be beneficial**. There is a long-term clinical trial going on now to test this theory.

NO HCV AT 6 MOS. = 'CURE' FOR MOST

Source: Being Free of Hepatitis C Six Months After Treatment May Mean You're Cured. Six-Month Blood Test Accurately Predicts Outcome by Roxanne Nelson, RN, WebMD Medical News. Reviewed by Dr. Michael Smith. July 5, 2000

Yes, they're beginning to use the word "cured"—although cautiously. French studies on 45 patients receiving the combo show that if you test negative for the virus 6 months after treatment ends, you will remain that way, and may possibly be considered "cured." In this trial, all 45 responder patients free of the virus at 6 months were still Hep C free after 12 months, except for one.

TO SHUNT OR NOT TO SHUNT

Source: SOURCE: The New England Journal of Medicine 2000;342:1701-1707.Shunt may boost survival of liver disease patients. Jun 08

The use of a "shunt" to helps to get rid of fluid from the abdomen and seems to prolong the life of patients with cirrhosis better that repeated draining of the excess fluid (ascites) according to a report in the NEJM June 8th issue.

Draining the fluid using a needle and tubing is one treatment option. The other two are day surgery to shunt the fluid back into the circulation, or a liver transplant. If the fluid is drained, it continues to collect and the procedure must be repeated. A shunt often solves this problem. A liver transplant is more permanent, but there is a shortage of livers. A doctor in Germany, Dr. Martin Rossle, did a trial where 29 patients with ascites received a shunt, and another 31 had their ascites drained. He saw the patients again 3 or 4 years later, and of the patients in the shunt group, 15 had died and one received a transplant. It the other group, 23 died and two received transplants. Statistically, the differences could have occurred by chance, but the general opinion is that **a shunt is better than drainage of ascites** in terms of survival and retreatment.

EAT YOUR CURRY

Source: Turmeric has anti-inflammatory effects, BEIJING, Jun 08 (Reuters Health)

In a study done of several Ayurvedic and herbal remedies, only turmeric proved to have anti-inflammatory effects. The data was presented at the 9th Asia Pacific League of Associations for Rheumatology Congress. Turmeric is used to make curries. Its active ingredient is **curcumin.**

The study was done by Dr. M.W. Whitehouse of Woolloongabba, Australia. He tested the herbal medicines in rats, giving the animals oral doses. Five of 23 celery-based preparations induced a significant anti-arthritic activity, but the results appear to depend on processing at low temperatures. **Only tumeric showed anti-inflammatory effects**. The doctor urged that herbal products be tested in strict clinical trials.

FATTY LIVER? WEIGHT LOSS AND VITAMIN C MAY HELP

J Pediatr 2000;136:734-738. Vitamin E Normalizes Elevated Liver Enzymes in Children With Steatohepatitis

When 11 children with fatty liver were given vitamin E supplements, their liver enzymes go back to normal within 1 to 3 months, says Dr. Joel E. Lavine from UCSD. These children did not have Hep C, but fatty liver is a common finding in patients who do have Hep C. They were, however, heavier than most children their age, and their liver enzymes were abnormal.

Five children reached normal enzyme levels at the dosage of 400 IU/day, while four required 800 IU/day, and two required 1200 IU/day. Two children who discontinued vitamin E had their enzyme levels rise again within two months.The ultrasound images appeared no different before or after vitamin E therapy, so the doctor speculates that the fatty liver stays the same, but that the inflammation may decrease.

CHECK ALBUMIN LEVELS

Source: What's New In GI, July 2000, Volume 95, Number 7, Page 1627Hepatitis C: Who's at Risk? T. M. McCashland, M.D.Khan MH, Farrell GC, Byth K, et al.Which patients with hepatitis C develop liver complications? Hepatology 2000;31:513-20.

In a fascinating study, 455 Hep C patients were followed for an average of 4.7 yr to find out what factors can predict liver decompensation, liver cancer, death or transplantation. The results showed that having sporadic transmission, fibrosis grade 3 and 4, and albumin less than 3.0 g/dl were associated with decompensation.

Factors usually named when predicting which patients will have fast progression are being older, having a genotype 1, and consuming alcohol. In this study, these factors were not associated with progression. The most striking finding was that patients with an albumin of less that 3.0 g/dl had an 85% chance of developing complications in the next 5 years, and 70% of those patients died within 3 years. Liver cancer was more of a possibility in male patients.

When doctors are asked, "How long do I have left?" they are uncertain, especially since it's hard to know when the patient was actually infected, and mode of transmission is unknown. When the patient's albumin level goes below 3.0, the doctor can predict that the patient has a 70% chance of dying within 3 years.

BRITISH COLUMBIA

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

Before August 1, 1986 or 1990-1991
David A Klein/ Klein Lyons
Legal Assistants: Lisa Porteous and & Candace Wall
Vancouver, BC (604) 874-7171, 1-(800) 468-4466, Fax (604) 874-7180

also:

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

The toll free number to get you in touch with the Hepatitis C Counsel is 1-(800) 229-LEAD (5323).

ONTARIO AND OTHER PROVINCES

Pre 1986/post 1990
Mr. David Harvey/ Goodman & Carr
Toronto, Ontario
Phone: (416) 595-2300, Fax: (416) 595-0527

TRACEBACK PROCEDURES:

INQUIRIES-CONTACT:

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

This information is for anyone who has received blood transfusions in Canada, if they wish to find out if their donors were Hep C positive.

RCMP Task Force TIPS Hotline
(Toll free) 1-(888) 530-1111 or 1 (905) 953-7388
Mon-Fri 7 AM-10 PM EST

CLASS ACTION/COMPENSATION

If you would like more information about class action/ compensation, or help with a lookback, contact:
Leslie Gibbenhuck Tel. (250) 490-9054
E-mail: bchepc@telus.net
She needs your name, address, birth date, transfusion dates, and traceback number.

National Compensation Hotline: 1-(888) 726- 2656

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1(888) 726-2656 or 1 (877) 434-0944. www.hepc8690.com info@hepc8690.com

(**CPP**—*Continued from page 1)*

addition, the PAB has interpreted the legislation to mean that the sole test is the applicant's physical or mental capacity to perform the gainful employment, regardless of whether such employment is readily available, or whether the applicant is actually trained to do such work [*Surjit Bains v. Minister of Human Resources Development* (1997), Appeal C.P. 04153, unreported]. The PAB has routinely held that personal circumstances (such as age, the availability of work, language barriers, etc.) cannot be considered under the legislation to determine whether the applicant's disability is severe (see *Antonio Macri v. Minister of Employment and Immigration* (1995) #8669 CCH, pages 6263 - 64). This is because such personal circumstances do not indicate either the applicant's physical or mental capacity to work.

The PAB's refusal to consider whether employment is readily available, or whether the applicant is actually trained to do such work, leads one to wonder what happens to the applicant who is no longer capable of performing his or her usual occupation, and is prevented from retraining for another occupation because of age, education, work history, or language skills.

In *Goldie Dalrymple v. The Minister of Employment and Immigration*, (1996) #8648 CCH, pages 6226 - 27, the PAB stated that personal factors, "*except in very narrow circumstances*, are extraneous factors that will not avail a claimant if her capacity to work is otherwise beyond question" (emphasis added). Therefore, there may be, in some limited circumstances, cases where such personal factors will be considered in the overall determination of whether the applicant has a severe disability (see *Lidia Ocelak v. Minister of Employment and Immigration* (1995) #8608 CCH, pages 6143 - 45 and *Appleton v. The Minister of Human Resources Development* (1997) #8709 CCH, pages 6381 - 82).

So if the test for "severe" is essentially an inquiry into the applicant's physical or mental capacity to perform a substantially gainful occupation, the next question is, what is a "substantially gainful occupation"? The PAB has attempted to define this term in a number of contexts. In *Germaine Boles v. Minister of Employment of Immigration* (1994) #8553 CCH, pages 6036 - 38, the PAB considered a substantially gainful occupation to be one where "the remuneration for the services rendered [are] not merely nominal, token or illusory compensation but rather compensation which reflects an appropriate reward for the nature of the work performed."

In *Susan Sutton v. Minister of Human Resources Development* (1998), Appeal C.P. 05339 (unreported), the PAB found that the test for a substantially gainful occupation can often be met with less than a full-time job. Therefore, an appropriately paid part-time job may be considered to be a substantially gainful occupation.

However, the test for "severe" requires more than a determination of whether the applicant can perform a substantially gainful occupation. Section 42(2)(a)(i) refers to "incapable *regularly* of pursuing any substantially gainful occupation." In *Minister of Human Resources Development v. Clayton W. Bennett* (1997), #8690 CCH, pages 6319 - 20, the PAB found:

> "It has been held in earlier decisions rendered by this Board ... that the phrase in the legislation 'regularly of pursuing any substantially gainful occupation' is predicated upon the individual's capability of being able to come to the place of employment whenever and as often as is necessary for him to be at the place of employment; that predictability is the essence of regularity. "The requirement that a supportive employer with a flexible work schedule or productivity requirement would be needed (what other cases have referred to as a 'philanthropic employer') is a requirement not reasonably attainable within today's competitive workplace. "It follows, then, that if such a benevolent figure is the sine qua non for the Respondent's return to the workforce, then it can be reasonably said that he is, indeed, 'incapable regularly of pursuing any substantially gainful occupation.'"

Therefore, if the applicant cannot attend at the place of employment regularly, in the absence of theoretical extraordinary steps to accommodate for the disability, it cannot be said that the applicant is capable regularly of pursuing a substantially gainful occupation.

The PAB has also considered a number of other factors in defining "severe." The PAB has consistently held that full-time attendance at school can be equated to an ability to carry out light, or sedentary, employment (see Ann Lauzon v. Minister of National Health and Welfare [1991] #9202 CCH, pages 6203 - 06 for an example). However, a finding that an applicant is able to carry out household tasks cannot be equated to finding that the applicant is capable of performing a substantially gainful occupation (Loretta Wong v. Minister of Employment & Immigration [1996], #8599 CCH, pages 6126 - 27). In such cases, the PAB acknowledges that household chores can be carried out and completed at the applicant's leisure, something not realistically available in the competitive work place.

Perhaps the case most helpful to advocates involving the determination of disability under the Canada Pension Plan has been Edward Leduc v. Minister of National Health and Welfare (1988), #8546 CCH, pages 6021 - 22. That decision considered what is now referred to as the "realistic versus theoretical approach," or the "real world" test. Specifically, the PAB arrived at the following conclusion in this case:

> "The Board is advised by medical authority that despite the handicaps under which the Appellant is suffering, there might exist the possibility that he might be able to pursue some unspecified form of substantially gainful employment. In an abstract and theoretical sense, this might well be true. However, the Appellant does not live in an abstract and theoretical world. He lives in a real world, peopled by real employers who are required to face up to the realities of commercial enterprise. The question is whether it is realistic to postulate that, given all of the Appellant's well documented difficulties, any employer would even remotely consider engaging the Appellant."

In this case, the PAB concluded that the appellant was unemployable in the real world due to his multiple medical conditions.

The *Leduc* case had a large impact on a number of appeals that followed its release. The realistic approach became very popular, with applicants arguing that they were not employable in the "real world." However, the PAB has recently distanced itself from the test outlined in *Leduc*.

In *Robert L. Crossett v. Minster of Employment and Immigration* (1996), #8618 CCH, pages 6161 - 65, the PAB was asked to apply *Leduc* to find that the applicant was disabled under the Canada Pension Plan. The PAB held that *Leduc* could not be applied to Crossett, because to do so would "extend in significant fashion the special and restricted circumstances in which Leduc was decided and the special and restricted circumstances in which the decisions which followed Leduc were decided." Those special circumstances included: total disability as a result of combined conditions, both medical and non-medical; a limitation on the possibility of control of those combined conditions; a formal restriction on driving an automobile; there being some "unspecified" form of substantially gainful employment; an unqualified acceptance of symptoms; the consideration of slow learning and learning disability; and the disability applicant being well motivated.

Similar comments were made by the PAB about *Leduc* in *Constance M. Osachoff v. Minister of Human Resources Development* (1997), #8684 CCH, pages 6301 - 04. Again, the PAB discussed the very limited circumstances under which the test in *Leduc* may apply. This is not to say that the "real world" argument no longer applies and should not be argued, but the PAB may limit the application of *Leduc*.

The test to be applied in determining whether a disability is "severe" can vary, depending on the specific disability. For example, an applicant claiming to have a severe disability on the basis of a diagnosis of chronic pain syndrome or fibromyalgia must prove that such a diagnosis exists, that it prevents him or her from working, and that he or she has sought all treatment and made all efforts to cope with the pain (*Minister of National Health and Welfare v. Densmore* [1993], #8508 CCH, pages 5971 - 73). If the applicant fails to provide all of the information to meet that test (remember, the onus is on the applicant), he or she may not succeed in obtaining disability benefits.

The above cases demonstrate that there are many facets to determining whether a disability is severe. However, these represent only a few of the cases, reported in CCH, which can be used to formulate an argument that a particular disability is severe. Advocates should familiarize themselves with as many PAB cases as possible to ensure that the applicant has met the onerous task of establishing that he or she has a severe disability.

HEPCBC UPDATE

HepCBC is pleased to announce the appointment of Bradley Kane and Brian Brownrigg to its board of directors. Brian heads up the support group in Trail, and Brad Kane coordinates a group in Princeton. Brad also moderates the HepCAN list.

Joan King and David Mazoff will be visiting support groups in the latter part of August. If you would like them to come and speak to your group, please call 250 361-4808.

(**CO-INFECTION**—*Continued from page 1)*
suppressing drugs needed for recovery. Securing funding for this work is due in large part to the work of community activists.

Only a year ago, researchers were debating which disease to treat first—HIV or HCV. People with HIV have higher HCV viral loads than those with HCV alone. Most research suggests that HCV does not affect HIV viral loads or CD4 counts. The consensus is growing that, other things being equal, it is best to get HIV stabilized first, then treat HCV if serious liver disease is seen.

Some HIV medications such as protease inhibitors (PIs), most notably ritonavir and, to a lesser extent, indinavir, are toxic to the liver. Co-infected individuals tend to be more sensitive to this toxicity. Most research shows that co-infected individuals see increased liver enzyme levels for up to several months after beginning HIV treatment. Most can ride it out and tolerate a regimen containing one of the less hepatotoxic PIs. There is evidence that people using a PI tend to slow the rate of liver fibrosis. The reason for this bonus has not yet been explained. If another combination is needed, different non-protease containing combinations can be used, using current HIV treatment guidelines and always looking for combinations likely to be easiest on the liver.

The only way doctors can tell the extent of liver disease is by liver biopsy. Unlike common blood tests for HIV, common HCV blood tests such as viral load and liver enzyme levels (ALT, AST) do not correlate with disease progression. A liver biopsy is an outpatient procedure. The doctor inserts a needle to take a tiny sample of liver tissue to look at. It is actually easier and less painful than it sounds. If the patient does not have any liver inflammation or fibrosis, and all liver enzymes are in normal ranges, just monitoring your status and waiting for better treatments is one viable option to discuss with your doctor.

Studies have examined the response of co-infected individuals to interferon therapy, an immune system modulator, that is the most common treatment for HCV. Interferon is usually self-injected under the skin three times a week. Results have universally shown that getting a "sustained response" (maintenance of HCV viral load below the level of detection 6 months after treatment has ended) is more difficult for co-infected people than for HCV-singly infected individuals. CD4 counts can drop significantly during interferon therapy, so this treatment is not recommended for individuals with CD4 counts below 200. Other co-factors that challenge response to treatment include increased age, increased alcohol use, higher baseline viral load, genotype 1a or 1b (the most common variants of HCV in the US), being male, and being African-American. We do not know why African-Americans respond more poorly to HCV treatments than other ethnic groups. Higher doses of interferon and/or daily dosing increase sustained response rates, but usually no more than 28% of those studied with genotypes 1a or 1b. Results are somewhat better for other genotypes.

Combination treatments using interferon with ribavirin in co-infected people are being looked at. Ribavirin seems to make interferon work better. Early reports last November from a small ongoing study by Dr. Douglas Dieterich at NYU showed that, after 12 weeks of treatment, 50% of the individuals taking the combination had undetectable HCV viral loads compared with only 9% of the interferon monotherapy group. Laboratory research early on indicated that ribavirin might interfere with zidovudine (AZT) or stavudine (D4T). This has not been a problem with people using these HIV treatments in this study, but more analysis is needed. Half of the participants on the combination developed hemolytic anemia (low red blood cell count), a side effect of ribavirin. Co-infected people tend to be more susceptible to this effect. Either they need other expensive treatments such as Procrit or Epogen (erythropoetin) for the condition, or they need the ribavirin dose reduced. Some studies from singly infected individuals indicate that 600-800mg/day of ribavirin (as opposed to the common 1000-1200mg/day) may actually be equally effective and less toxic.

Dr. Bennet Cecil, a clinician and hepatitis researcher with the VA and Hepatitis Treatment Centers, Inc., in Louisville, KY, makes the following comments regarding co-infection treatment and cirrhosis in his experience:

"If a patient has a platelet count below 150,000 or a prolonged prothrombin time they may have cirrhosis. These are simple blood tests that indicate the amount of damage each patient has. They are not perfect but they are very good and I use them every day treating hundreds of hepatitis C patients. I usually start with 600 mg of ribavirin each day and all of my patients do daily interferon because it has fewer side effects (1.5 MU on Intron is easier than 3 MU). Frail patients and cirrhotics usually start with 500,000 units daily of Intron or Roferon. I treat decompensated cirrhotics successfully with low titrated doses of interferon and ribavirin."

Studies are also underway in co-infected people using pegylated interferons. The two versions being studied (Pegasys from Roche, Peg-Intron from Schering-Plough) are designed to be long acting interferons that only have to be injected once a week and, ideally, maintain an even blood level of interferon in the body. Studies are looking at using these drugs +/- ribavirin. These drugs should be available later this year. Most research with them has been done to date in individuals infected with HCV alone. Schering has released little data on their drug yet. Roche has released study results that show Pegasys monotherapy resulted in a 36% sustained response rate vs. 3% for standard interferon. A small Pegasys + ribavirin study in Europe showed an 80% sustained response rate. This is the highest rate shown in any HCV study to date. This looks promising for co-infected individuals as well.

Investigations are underway with a variety of other drugs. Ribozymes are natural enzymes that can be synthesized to selectively inhibit disease-causing proteins by interfering with RNA production. These are being investigated for use in HIV and HCV. Several pharmaceutical companies are also targeting other enzymes important in the life cycle of HCV (protease, helicase, and polymerase) for development of inhibiting drugs.

The goals of HCV treatment are now changing as well. Even if treatments that use interferon do not achieve complete viral suppression or eradication, such treatment should not be labeled a "failure" as these treatments often slow and sometimes reverse the development of fibrosis. The liver is an amazing organ with the ability to regenerate itself unlike other organs of the body. Dr Thierry Poynard, a leading hepatitis researcher, says:

"The true goal of therapy is to reduce the rate of liver fibrosis progression—this may be accomplished even without reducing the HCV viral load—some patients who have a virologic response to treatment even have regression of fibrosis. **The fibrosis progression rate is for HCV what the CD4 count is for HIV infection."**

A health care provider who knows HIV really well doesn't necessarily know HCV. And vice versa! It is important for co-infected individuals to have doctors with expertise in each disease and urge them to talk to each other to coordinate their medical care.

Research in co-infection is slower than for either HIV or HCV alone, as drug companies look to make sure their new treatments work in the least complicated populations first. Patient and treatment advocates need to urge healthcare providers, public health officials, and local drug company representatives to work for more clinical studies and access to treatments for people living with HIV/HCV co-infection.

For current information on viral hepatitis and HIV/AIDS check out www.HIVandHepatitis.com.

(**Compensation**—*Continued from page 3)*

When you are contacted for possible further payment you will have to make an election, at Level 3 to take the lump sum ($30,000.) or to make a claim for loss of income.

I have been told the protocol should all be worked out by mid-July and suspect it may take until about September to actually receive any paperwork from the Administrator's office.

I have been told there are approximately 700 claims processed to date and that 21 cheques have been cut. These should be received by the end of June.

I hope this answers your questions. Hopefully by next month I should be able to report on people actually receiving and cashing cheques. If you have any questions, please contact the Administrators office at

1-877-434-0944 or call me at 1-250-490-9054.

Until next month,
Leslie Gibbenhuck

PS: HepCBC has been speaking with David Klein, the lawyer for those outside the window. As it now stands, David will be coming to Victoria in September (we don't have a fixed date yet) to update those affected by the government's decision to set an arbitrary window of eligibility. We will let you know well in advance. If you would be interested in attending this meeting, please call 250-361-4808 and leave a message to this effect. Remember to leave your name and phone number—squeeky

"CURE" FOR HEP C TO BE APPROVED…??

Source: Medical Resorts International Inc - Street Wire--Medical Resorts sub privately touts AIDS cure. TRAGEDY, CUPIDITY, STUPIDITY: CAPITALIZING ON MISERY by Stockwatch Business Reporter

According to a Stockwatch reporter, an anonymous investor is saying that the president of Medical Resorts' subsidiary International Biotech (IBC) is privately touting a cure for AIDS. The reporter finds it strange and puzzling that an obscure Canadian company with "no relevant expertise" would boast of a cure and play with the emotions of sufferers. Interestingly, the company has not only obtained the rights to this cure, but also for hepatitis C and herpes.

The IBC president has supposedly told about clinical trials in Mexico and Anguilla, and says that the "cure" will soon be approved by the government of Anguilla. The "cure" is said to involve one injection a week for 8 weeks, in the gluteus muscle, and costs only $45,000.00. The doctors who developed the secret serum remained unidentified, but are reported busily buying shares of the company.

The president contacted Stockwatch by E-mail, denying that there is a "cure" for HIV/AIDS, and reminding Stockwatch that a claim for a cure is subject to major fines in the US and Canada. The claims, whatever they were, are being met with extreme doubt by stock traders.

HOSPITAL TRANSMITS HCV VIA SHARED IV SALINE SOLUTION

Source: www.hivandhepatitis.com HCV Transmitted to Five Patients in Miami Hospital. Breach in infection control practices led to "nosocomial" HCV infection, by Harvey S. Bartnof, MD 5/29/00

Five patients were infected with HCV in a hospital in Miami. The only possible common source was saline, or salt water, taken from a vial that was shared by health care workers on the same ward. All five patients had had an IV line that was flushed with saline when they were in the hospital. All patients have the same genotype. Three of the patients came down with acute Hep C about 6 weeks after they were in the hospital. All the patients who had been on that ward were tested, and two more victims were found.

It is important that hospitals stop using multi-dose saline vials and begin using single-dose syringes or vials to avoid unwanted further infection in hospitals.

ELECTRIC RAZORS SHARED IN SOME HOSPITALS

Source: hivandhepatitis.com Hepatitis Viruses May Be Transmitted by Shared Shaving Equipment. Physician finds inadequate infection control practices after observing shared electric razor at VA Hospital by Harvey S. Bartnof, MD

Dr. Colleen R. Kelly was working at a VA Hospital in Massachusetts when she saw a male patient using an electric shaver marked "9C" indicating the ward it belonged to. Then she observed another patient immediately use the same razor without changing the heads or screen and without disinfecting it in any way. When she asked, she was told that the razor was not normally disinfected, and that sharing of electric razors at the hospital was common. Dr. Kelly is worried that such practices could transmit infections, including hepatitis C, even though electric shavers cause fewer cuts than non-electric shavers. She wrote a letter to the NEJM, suggesting that single-use disposable razors be used in hospitals, and that patients be reminded that they must not share them. In a 1991 study in the journal *Hepatology*, up to 24% of VA patients had antibodies to HBV and 19% of 791 veterans tested at the San Francisco VA Medical Center were HCV positive.

DO MOSQUITOES TRANSMIT HEP C?

Source: www.healthcentral.com/drdean/DeanFullTextTopics.cfm?ID=35140&src=n113 June 01, 2000

Can HCV be transmitted by mosquitoes? "French scientists say the virus can efficiently bind and replicate in mosquito cells for 28 days." The study doesn't say if the virus can infect humans through a mosquito bite, though. Dr. Dell thinks that it is a possibility, since the Hep C virus belongs to the flavivirus family, all of which can be transmitted by mosquitoes and ticks. One such virus is dengue. At this point, it is not known if mosquitoes can transmit Hep C or not, but this possible means of infection may explain some of the 20% of cases not related to transfusions or IV drug use. On the other hand, would there not be many more cases of Hep C if it were really transmitted by mosquito bites? Hopefully researchers will investigate soon.

MISS AMERICA HELPS FIGHT HEP C

Source; WASHINGTON, May 24 /PRNewswire

Miss America 2000, Heather French, whose father has Hep C, announced that she will participate with Rolling Thunder members in their 13th annual Ride For Freedom protest, to raise awareness about veterans' issues, including Hep C, which is affecting so many of them.

Rolling Thunder, committed to aiding disabled veterans and to raising awareness about important veteran's health issues, including hepatitis C, Agent Orange and Post Traumatic Stress Disorder (PTSD), has officially made hepatitis a key issue during this year's protest. Miss French hopes to encourage every veteran to get tested.

"Thanks to the powerful political forum that Rolling Thunder has created, those who fought to protect our country will learn that they don't have to suffer needlessly from preventable and treatable diseases such as hepatitis C," said Miss French.

Miss French has been touring the country in support of a national disease awareness campaign entitled Helping Veterans Fight a Silent Enemy: Hepatitis C. Free and confidential screening was provided to veterans during the protest.

HEP C SALIVA TEST

Source: Saliva test for hepatitis C on the drawing board, June 26, 2000, Reuters Health

A saliva test for antibodies to hepatitis C might be available within a year. At this time, a blood test is used to screen for the virus. By making a test for antibodies painless, possible victims may be more likely to get tested. The saliva test would eliminate some danger of healthcare workers being infected from needlestick injuries. The producers, Epitope and LabOne of Lenexa, Kansas, hope to obtain US FDA approval by next summer. They will sell the test to public health institutions such as hospitals, clinics and community health centres, and to drug rehabilitation programs and AIDS treatment centres, both of which serve clients with an elevated risk of contracting the hepatitis C virus. Hopefully they will also sell it to Hep C centres.

The test consists of a flat cotton swab attached to a tube and held between the gum and cheek for about 4 minutes. It is then put in a preservative-filled test-tube and delivered to the lab. Each kit will include instructions, a return air-express mailer and a pa-

(Continued on page 10)

(**NEWS**—*Continued from page 9)*
tient ID form. Negative test results will be available to healthcare institutions within about 24 hours. Positive results will take about 72 hours. The new test could be available to consumers for at-home use in the future.

ALTERNATIVE COMBO APPROVED IN GERMANY

Source: New Alternative Combination Therapy to Treat Hepatitis C Approved, Roche Media Release, Basel, 26 June 2000

Did someone say Canada has one of the best medical systems in the world? Well, can we beat this? Last month Germany approved the use of Roche's Roferon combined with ribavirin. Roferon-A has come out ahead of Schering's Intron-A when both are combined with ribavirin. Unfortunately, Schering has a monopoly here in Canada, and ribavirin cannot be sold alone, so once again, Hep C sufferers are obliged to suffer the unfortunate decisions of higher-ups. In addition to superior results, Roferon-A is a good alternative for patients who have not responded to Schering's treatments, or who cannot tolerate the side effects. Roche has kindly made its drug available with a pen device which makes injection almost painless, and makes loading syringes unnecessary. Another advantage is that the Roferon-Pen can be stored at room temperature for 28 days. Note that this is not pegylated treatment, but the fact that the non-pegylated interferon was approved for use in Germany makes it logical to think that Roche's Pegasys will also be approved there.

DETECTION OF HEPATITIS C VIRUS IN THE SEMEN OF INFECTED MEN

Source: The Lancet, 356:9223:42-43

In a study of semen samples from 21 untreated men with Hep C, researchers detected hepatitis C virus (HCV) RNA in the semen of one third of their subjects. Although the seminal viral loads were low, the researchers still feel that the semen could be infectious and that HCV might be spread sexually.

To study the presence of HCV in semen, the researchers developed a reverse transcriptase PCR method that was highly sensitive and adapted to detecting the virus in semen samples.

Surprisingly, while HCV RNA was detected in the blood of all patients, only eight seminal plasma samples contained HCV-RNA, and semen viral loads, themselves, were low, suggesting that the risk of sexual transmission is low but possible from men to women.

These results should be considered when counselling HCV-infected couples with different genotypes who intend to embark on medically assisted reproduction.

WARNINGS

CHINESE WEIGHT LOSS PILLS

N Engl J Med 2000;342:1686-92 Urothelial Carcinoma Associated with the Use of a Chinese Herb (Aristolochia fangchi) Joelle L. Nortier, et al.

Chinese herbal weight-loss pills containing **Aristolochia fangchi** has been found to cause **cancer** of the urinary tract.

TROVAFLOXACIN

The New England Journal of Medicine -- February 3, 2000 -- Vol. 342, No. 5 Acute Eosinophilic Hepatitis from Trovafloxacin. Henry J.L. Chen, M.D., et al, Massachusetts General Hospital

According to the article cited above, the US FDA has found that **trovafloxacin, an antibiotic**, has been associated with more than 100 cases **of liver toxicity**, with 14 of the patients experiencing liver failure, and 4 requiring a transplant. Five of the patients died. There have been other reports of liver toxicity with quinolones.

ALCOHOL

From: American Journal of Gastroenterology, Editorial, May 2000, Volume 95, Number 5, Pages 1124-1125. Alcohol: "Ice-Breaker" Yes, "Gut Barrier-Breaker," Maybe

It is well known that chronic alcohol use impairs a person's defense mechanisms and immunity, and that nonalcoholic cirrhosis can make a person susceptible to infection, but it was not known if the infections were due to alcohol or the results of alcohol, such as cirrhosis and malnutrition. Since both alcohol abuse and cirrhosis can make people susceptible to infection, the authors assume that people who both abuse alcohol and have cirrhosis will be even more susceptible to infection. In the above cited edition of the Journal, Rosa et al., after studying 383 patients with cirrhosis, reported a more frequent bacterial infection in patients with alcoholic cirrhosis than in those with nonalcoholic cirrhosis. The group with alcoholic cirrhosis had more severe and more frequent infections (61%) than the nonalcoholic cirrhotics (39%). The data from the study clearly show that alcohol is a risk factor for infection in well compensated cirrhotics. The author of the review suggests that the cause may be leaky gut syndrome, and that **patients should avoid things like NSAIDS and abstain from alcohol.**

CHECK YOUR INGREDIENTS!

Source: http://vm.cfsan.fda.gov/~dms/ds-botl2.html About Botanical Products, Including Dietary Supplements, Containing Aristolochic Acid

Beware! The US FDA is concerned about botanical products containing **aristolochic acid**. Some of these botanicals include: **Aristolochia spp., Asarum spp., Bragantia spp., Stephania spp., Clematis spp., Akebia spp., Cocculus spp., Diploclisia spp., Menispernum spp., Sinomenium spp., Mu tong, Fang ji, Guang fang ji, Fang chi, Kan-Mokutsu** (Japanese), and **Mokutsu** (Japanese). Practitioners who prescribe botanical remedies are urged to throw away any products with the above listed ingredients. Cases of nephropathy and end-stage kidney disease associated with their use have been reported. Because of the Chinese tradition of interchanging similarly named herbs, there is a great tendency for many harmless herbs to be accidentally substituted with Aristolochia spp., not only in traditional medicines but also in dietary supplements.

CHOMPERS

Source: Friday June 2 2000, San Francisco Chronicle, Herb Remedies: Panacea or Problem? Kenneth Howe, Chronicle Staff Writer

"Chompers," a dietary supplement made by Arise and Shine of Mount Shasta, is thought to be a natural colonic cleanser. Federal investigators later determined that the plantain in the herbal remedy had been contaminated with digitalis, which can be a lethal poison. FDA investigators found an untold number of people had been affected by the supplement, with resulting lawsuits. Public health officials complain that there is next to no regulation of dietary supplements, and that consumers can't be certain about the ingredients, or if they are contaminated, or even spiked with restricted drugs or even if there are any active ingredients. Australia, Japan and Taiwan, for example, set strict quality standards and manufacturing procedures.

COLD REMEDY: Loxoprofen sodium

Source: Labkorea. Japan Issues Health Alert on Common Cold Remedies. May 29 (Reuters)

An ingredient used in some prescriptions to fight the common cold may cause serious liver problems, Japan's Health and Welfare Ministry warned hospitals and physicians after two patients died. Eight patients who have taken loxoprofen since 1997 have had serious liver damage. Some NSAIDS also include loxoprofen sodium.

RISKS OF VITAMIN OVERDOSE

Source: US panel warns on excessive antioxidant intake, by Tim Dobbyn (1999 Reuters)

A US government advisory panel has warned consumers against taking large doses of antioxidants such as vitamins C and E. The panel warned that high levels of vitamin C can cause diarrhea, too much vitamin E can increase the risk of stroke, and excessive selenium can cause hair loss and brittle nails. At high levels, vitamin E acts as an anti-clotting agent.