



hepc.bull

BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

November 1999

Issue No. 17

SCHERING DISCOVERS CRYSTAL STRUCTURE OF HEPATITIS C VIRUS

By Joan King

Schering seems to be doing something productive with the money they get from the combo treatment. At the end of last month, their researchers announced that they had discovered a new aspect in the way the hepatitis C virus is structured. This discovery may provide a target for new drugs. The structure is in the form of a crystal.

"The crystal structure gives us a complete view of the target," Dr. Patricia C. Weber, of Schering-Plough Research Institute in Kenilworth, New Jersey, told Reuters Health. That information will help researchers determine what kind of inhibitor is needed to destroy that target. Dr. Weber, in her interview, went on to explain that this historical discovery provides the first detailed view of an RNA-dependent RNA polymerase.

The crystal enzyme resembles a site encircled by "fingers" and a "thumb," an unusual structure, and the interactions between the finger and thumb areas make up a "relatively inflexible polymerase structure," less likely to change as other polymerases tend to do when they go from inactive to active states.

The Schering researchers have already begun to identify substances which may attack this crystal structure, but they say that it will probably be two or three years before they can start human clinical trials.

Nat Struct Biol 1999;6:937-942.

NEW HCV TEST

AcroMetrix, Inc. Introduces the First Hepatitis C Virus Nucleic Acid Quantification Panel Based on the World Health Organization (WHO) International Standard

BERKELEY, Calif., Oct. 12 /PRNewswire/ -- AcroMetrix announced today that they have introduced the first Hepatitis C Virus (HCV) nucleic acid quantification panel calibrated to the World Health Organization (WHO) International Standard. Because laboratories world-wide utilise numerous testing methods, each having a different standard of measurement for the amount of virus in the patient's blood, the potential exists for misinterpretation of patient results. The AcroMetrix panel was designed to insure a consistent standard across all test methods enabling clinical laboratories and diagnostic manufacturers to assess the performance of the HCV quantitative and qualitative methods they are using with known levels of virus calibrated to the WHO standard. It will also provide an independent standard for the validation of new systems and techniques on any HCV nucleic acid procedure.

"With the enormous impact that HCV has on human health worldwide, assay standardisation is an important step in eliminating potential confusion regarding the test results that will lead to medical treatment decisions," said Michael J. Eck, President of AcroMetrix, Inc.

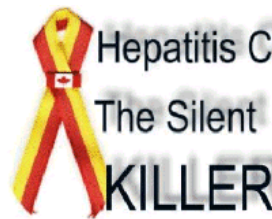
SOURCE AcroMetrix, Inc. 10/12/1999 08:02 EDT <http://www.prnewswire.com>

AN ENCOURAGING NOTE

From the HepCan List:

I just got a call from Dr. A's office and Natalie says that my test results from September 14 are wonderful: AST/29 ALT/16, and I'm PCR **negative**. I did Interferon alone for 6 months—Jan to Aug '97. My LFT's were up and down, but there was not a great drop in my PCR, which was 850,000 at that time. Then from Aug '97 to Aug '98, I did the combo, and, while I was on it, my LFTs came down a lot (from 200/300 to the 50/60 range sometimes), and at midpoint my PCR was 350,000.00, but by the end it was back up to 500,000. Then within 4-5 months my AST/ALT had risen back up to the 200/300 range. That is when I went on Amgen/Infergen - one month of (awful) induction, 15 micrograms daily and then 15/micrograms 3 times a week. I started on 15 Jan 99, so there really is something to "more and soon." I'm going to stay positive that this will hold, and that my own body can fight it off after I end Infergen on 15 Jan. 2000. WOW. I'm Sooooooooooooo Happy - all these side effects really ARE worth it. Hugs.
Anonymous

Victoria Launches HepC Bus Ad Campaign



Have You Been Tested?

HeCSC Victoria, in conjunction with HepCBC and individual sponsors, has signed a contract with BC Transit to place one HCV poster on the inside of every bus in Victoria for a year, beginning Nov 99. As well, there will be 14 giant back of the bus posters during the months of Nov-Dec 99. We have committed ourselves to this project, but we are still short and desperately need donations. We have requested assistance from HeCSC National, and have been refused (see page 3 for details). Please, if you can, help us with this project.

DONATION FORM

Please fill out & include a cheque made out to
HeCSC - Victoria Chapter. Send to:

**Hepatitis C Society of Canada
Victoria Chapter
926 View St.
Victoria, BC V8V 3L5**

Name: _____

Address: _____

City: _____ Prov. ____ PC _____

Home (____) _____ Work (____) _____

One Year Subscription: Donation \$10.00

Member of:

Victoria HeCSC _____

Vancouver HeCSC _____

Okanagan HeCSC _____

HepC BC _____

Other _____

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

I am applying for a grant." _____

"I would like to make a donation so that others may receive the newsletter without charge" _____

(A limited number of newsletters will be available free of charge at group meetings, as well.)

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 HeCSC, HepC BC or of any other group.

SUBMISSIONS: The deadline for any contributions to the hepc.bull is the 15th of each month. Please contact: **Joan King at (250) 388-4311, jking@pacificcoast.net, Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, hepcbc@home.com or C.D. Mazoff at squeeky@pacificcoast.net**

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:

EDITORS: TEL: (250) 388-4311

Joan King jking@pacificcoast.net

Darlene Morrow hepcbc@home.com

<http://www.geocities.com/HotSprings/5670>

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VICTORIA HeCSC OFFICE: TEL: (250) 388-4311

hepcvic@pacificcoast.net

<http://www.pacificcoast.net/~hepcvic/>

hepcan@egroups.com

COMING UP IN BC:

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

Comox Valley Liver Disease Support Group
Meetings: Third Tuesday of each month, 6-8 PM, St. George's United Church on Fitzgerald. . NEXT MEETING: November 16th. Contact: Ingrid or Nicky, 335-9167 or Jeanne Russell ebus96@island.net

Cowichan Valley Hepatitis C Support Contact: Debbie, 715-1307, mygirl@olink.net, or Leah, 748-3432, r_attig@bc.sympatico.ca

Downtown Eastside Hep C Support Group
Meetings: Wednesdays 7:30-9:30 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: November 28th. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Kelowna HeCSC Meetings: Last Saturday of each month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: November 27th. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Kootenay Boundary Meetings: Second and fourth Tuesday of each month, 7 PM, 1159 Pine Ave. upstairs from Lordco auto parts. NEXT MEETINGS: November 9th and 23rd. Contact: Brian, 368-1141, k9@direct.ca or Pat, 364-1555

Mid Island Hepatitis C Society Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St., Nanaimo. NEXT MEETING: (Change!) November 18th. Speaker: Ian Courtice. Contact: Susan, 245-7654, hepc@nanaimo.ark.com, or Rose, 714-1937.

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

Parksville/Qualicum 1-291 East Island Hwy, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551. dbamford@island.net

Penticton HeCSC Meetings: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: November 17th. Contact: Leslie, 490-9054, bhepc@bc.sympatico.ca

Prince George Hep C Support Group Next Meeting: November 9th 7 PM, Health Unit Auditorium. 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: November 13th. Contact: Brad, 295-6510, citizenk@nethop.net

Quesnel Contact: Elaine, 992-3640.

Slocan Valley Support Group Meetings: Third Tuesday of each month, 7-9 PM, W.E. Graham Community School Youth Centre, Slocan. NEXT MEETING: November 16th. Contact: Ken 355-2732, keen@netidea.com, or Community School Coordinator 355-2484

Sunshine Coast NEXT MEETING: Contact: Kathy, 886-3211. kathy_rietze@uniserve.com

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: November 11th. Contact: the CLF, 681-4588, or Herb, 241-7766, HMoeller@compuserve.com

Vancouver Support Group Meetings: Last Wednesday of each month, 10:30-12:30. NEXT MEETING: **November's meeting is on a Monday due to conflicts for our meeting room. It will be on November 22** from 10:30 to 12:30, CDC Bldg., Building 655 West 12th (12th and Ash, next to the Cambie Street City Square Mall). There will be someone outside the building to direct. Contact: Darlene N., 685-3813, djnicol@attglobal.net, or Darlene M., 987-7378, hepcbc@home.com

Vernon HepCURE Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NEXT MEETINGS: November 2nd and November 16th. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Vernon HEPLIFE Meetings: 2nd and 4th Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. NEXT MEETINGS: November 10th and November 24th. Contact: Sharon, 542-3092. sggrant@attcanada.net

Victoria HeCSC Meetings: Last Wednesday of each month, 1-3 PM and at 7-9 PM, Steve Orcherton's Office, 2736 Quadra (at Hillside) NEXT MEETING: November 24th. Elections will be held. Contact: 388-4311. hepcvic@pacificcoast.net

White Rock Support Group: Meeting Room #2, Peace Arch Hospital. Contact Lisa Peterson at 538-8704.

THANKS!!



HeCSC Victoria acknowledges the personal donations, donations in kind and memorial donations received to date, and the following for discounts, donations of services, or equipment: JJ Camp, David Klein, Bruce Lemer, Woods Adair, David Anderson, Steve Orcherton, Barbara McVagh, United Commercial Travelers, PECSF, CFAV 1070, AM 900, Pacific Coast Net, Microsoft, Symantec, Jim Pattison Group, Paradon Computers, and CompuSmart. We also wish to acknowledge the generosity of the Residents of VIRCC, Uncle Dave and some wonderful anonymous donors. Additional thanks to: Mount Royal Bagels, Howie Siegal, The Pasta Place & Fernwood Home Services.

Reminder: Any change of address, phone number or postal code, please let your phone contact (in Victoria) or your chapter secretary know ASAP

HeCSC Victoria Tel. (250) 388-4311
hepcvic@pacificcoast.net

REPRINTS

Past articles are available at a low cost. For a list of articles and prices, write to the hepc.bull, via Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, hepcbc@home.com



September 22, 1999

Att: Tim McClemont
Executive Director
HeCSC

Tim:

This fax is to apprise you of several items. If you wish to construe them as demands, so be it. If you wish to work with us, just pick up the phone. We need an answer within 7 days.

Despite your constant attempts to silence our efforts, we have recently obtained approval for our pamphlet series, and . . . will print out [80 000] and distribute them province wide. There will be no mention of HeCSC on these pamphlets as per your request, since you refused to help with the project.

Our FAQ project is taking off. Since you also refuse to help with this, there will be no "official" HeCSC logo on this as well.

We have just signed a contract to have an ad campaign on the Victoria buses. On Thursday we will find out if one of our sponsors will help us go province-wide. The art work is done, and we would be glad to share it with you as part of a National campaign, but it's time for you people to pay your dues. You are welcome to share the artwork, if you help fund the project.

If you do not help fund the project, not only will there be no mention of HeCSC on the 200 bus ads that will be up on the Victoria buses for a year, but we will also do our best to let the media know why.

David Mazoff

Reply:

September 23rd 1999

Dr. David Mazoff
Co-Chair, Victoria Chapter
Hepatitis C Society of Canada

Dear David,

Regarding your faxed message of September 22nd, I must inform you that you will receive no reply on this or any other issue you raise when it is accompanied by abusive language and overt or covert threats. What a pity that my first letter to you must, of necessity, begin in this way.

You have a long history of abusive and abrasive correspondence with the National Office, although what you hope to achieve from this is only partially clear. Certainly it has nothing to do with supportive and collegial relationships as, from all accounts, you try very hard to produce the opposite effect. Further, it would seem that when confronted you have the interesting habit of bursting into tears while (unsuccessfully, I would add) attempting to convince us of your sincerity. Whatever underlying dynamics provide the structure for your extraordinary behaviour, it is nonetheless in

(Continued on page 7)

To the Editors, *hepc.bull*

October 12, 1999

Your steering committee has initiated a new education campaign to help identify hep C victims. In conjunction with B.C. Transit, who have given Victoria Chapter a special rate, in the greater Victoria area, information posters will be displayed on the back of 14 buses for the months of November and December and 200 posters will be displayed inside the buses for a year. These posters have been designed by professionals for maximum effectiveness.

Even with the rate, however, we will need a little extra funding to maintain the level of services that we now offer. If every person who receives this bulletin could find it in their heart to contribute a few extra loonies to the bus campaign or to the *hepc.bull*, we will continue to help all of you without cutting back.

The Hepatitis C Society (HeCSC) was approached with an offer to share the artwork, so the campaign could go national, if they would help with the funding. The answer was unequivocal and mean spirited. They have no desire to help our "clients" and "constituents." I thought we were **members** of both the national and local bodies. Obviously, I was wrong.

The reply by the Chairman of the National Board of Directors was also very demeaning to the co-chair of Victoria Chapter. If the national group did one-tenth of the advocacy work your steering committee does we wouldn't be in the position of "poor relations." It seems to me that HeCSC has forgotten why they exist. (I wonder if they ever knew.) Did you know that unless you sit on the national board, your opinion does not count?

If you want to help us educate and inform all victims of Hep C, we would appreciate any donation that you feel you can afford. No amount is too little. The volunteers in the Victoria Chapter feel they have an obligation to the members and they hope the members feel a like obligation to the group.

Thank you in advance for your consideration of our request.

Arlene Darlington

VICTORIA CHAPTER ELECTIONS

Elections for the steering committee of the Victoria Chapter of HeCSC will be held at the November meetings. Nominations may be made in person at the October and November meetings.



Congratulations to Fatima, Jerry and Kyle Jones on the birth of Katherine, October 9, 1999. Kate is the granddaughter of the late Arturo de Torres



DIVIDE AND CONQUER

By Ron Thiel

As one of the thousands of victims of tainted blood who have been victimised again due to the government's phoney "window" period and, in my opinion, betrayed by those whom we trusted to look after our interest, I fail to understand how we could have been let down so badly. When the courts ruled to accept the 1986-1990 compensation package the Canadian press quoted Mr. Jeremy Beaty of (HeCSC) as stating, in part: "This package only covers one group of the hepatitis C victims," said Jeremy Beaty, spokesman for the Hepatitis C society of Canada, in an interview.

"It leaves a whole other group out in the cold and is really unacceptable. The government has taken the legal position and not the humanitarian position."

- Does HeCSC not bear a great deal of the blame for the above situation?
 - Did the Chairman and Board of HeCSC not accept the government's phoney "window" period when it accepted the conditions imposed by the government paid lawyer Marlys Edwardh?
 - Were her conditions not made clear in a letter to the Chairman and the Board of HeCSC dated May 8, 1998?
 - Did the letter, in part, not contain the following conditions: "The Board is not interested in pursuing or putting forward a "fault-based analysis" of why assistance should be extended to persons beyond the periods 1986 to 1990. Thus, for example, the Board is not pursuing a position wherein they are trying to identify other time periods when the Government of Canada, provincial governments or indeed any other actors in the blood system were negligent?"
 - Has this action by the Chairman and the Board not placed thousands of us in a position where we will have to fight a protracted legal battle and did it not lose us the services of three of the most active Board members and the support of many major groups who were working on our behalf behind the scenes?
 - Why were the victims affected by this disastrous decision never informed about it and why didn't the Society contact those members affected before such a decision was made? The Society could have asked these members to donate funds so that we could have paid for a lawyer who would have represented us without conditions.
- Truly the Liberal government has mastered the art of "divide and conquer" to a fine degree.

MEETING MY VIRUS

By Joan King

This "job" has perks. I meet really interesting people. One of those people offered to genotype my virus. Wow! For those of you who don't know, that means to figure out what "family" the virus belongs to. There are around 6 genotypes now discovered and names, and many sub-genotypes. As my anonymous friend explained to me, the researchers don't know which one is the real, "unmutated" virus, but they do know that all of them are slightly different. Someone had to pick a sample virus, similar to most, and declare that one the norm. All others are now variants.



It was very exciting to be able to stare my virus in the face. Well, OK—it was just a series of letters and numbers that repeated themselves in a pattern on a computer screen, but it could also be shown as three coloured, wavy lines, and better yet, it could be compared to other genotypes with coloured, wavy lines. I never knew that a bunch of wavy lines could give me goose bumps. I had that all-too-unfamiliar feeling, "Aha! Gotcha!" My friend was able to point out to me where my virus had "mutated" in a few places, and was able to tell me that it belonged to the family "1b." That confirmed my suspicions, since I knew that 1a and 1b are notoriously resistant to treatment with interferon, and are also the most common genotypes in North America. (They have also probably been around longer, and 1b is reported to be the genotype that has the least likelihood of progressing to liver cancer—so there are advantages.)

The doctor was concerned that I would use my knowledge to refuse treatment. I assured him that I had already been through treatment and had reaped some benefit from it, even though I relapsed. As far as I'm concerned, knowing my genotype ahead of time would have allowed me to push my doctors into prescribing a stronger, longer dose of treatment, had we known, and perhaps I could have avoided wasting some time. Even with less of a chance of responding, I still would have done it. Any chance is better than no chance at all, in my books. Studies show that "high induction doses," or high, frequent doses at the beginning of treatment, often give better results in people with "1" genotypes.

I do hope that our government will approve genotyping in the future. It can help our doctors decide what the best treatment is for us. The more information we have, the better we can fight this disease. BC has the equipment and the knowledge to do HCV genotyping.

(For more information on genotyping, please see Marjorie Harris's article in the May 1999 of the bulletin.)

I'VE BEEN DIAGNOSED. NOW WHAT?

If you're diagnosed with hepatitis C, get informed. Check with your local support group (if in doubt, call 1-800-652-HEPC.)

Make sure that you:

- Get re-rested to confirm the diagnosis
- Get vaccinated against hepatitis A and B, and get tested to see if the vaccinations took.
- Ask about the pneumonia and flu vaccines
- Get sent to a specialist
- Get copies of all tests

The specialist should:

- Order an ultrasound yearly, if your family doctor didn't
- Order an alphafetoprotein test yearly
- Order a liver biopsy. (This is usually done by needle aspiration, but there are other options if there is a bleeding problem, for example)
- Discuss treatment options with you (Get a second or even a third opinion if you don't agree)

HepC Meeting Vancouver, Nov 12th

There will be a Hep C meeting at Carnegie Center, 401 Main Street, Vancouver BC in order to respond to the Vancouver/Richmond Health Boards proposal for Hep C in the Downtown Eastside. If, as usual, this will be a grab of money for the service providers in the area I hope we will all be there to look at this situation.

November 12 from 10:00 AM to 5:00 PM, the facilitators are hoping to have Dr. Anderson, Dr. Sacks and someone else to answer to the current proposal by the Health Board, as well as input from people with Hep C who are living with this illness in spite of the garbage from the province etc.

While much of the proposal is in the area of harm reduction, there are a great many missing components, such as medicine and approval by Pharmacare, Schedule C Benefits for heppers and other needs that are swept under the carpet.

We need an organization that is as strong and as supportive as the AIDS organisations. They have laid the blueprint and we need to understand and have access to the same health measures and quality of life supports as they do!

I, and others like me, need a housing subsidy to allow me to live in decent housing of my choice, I need Schedule C benefits to allow me to purchase needed food items,

CLARIFICATION

The article titled "Complementary and Alternative Medicine in Chronic Liver Disease... A Symposium" appearing in the October 99 issue of the *hepc.bull*, was an edited version of an article written by Pam Ladds, RN MSW, director of WISDOM, an organisation for women dealing with HIV. The editing, done mainly to reflect the interests of our readers in regard to hepatitis C, was done by our friend Sybil, and Pam's name was inadvertently omitted. Our sincere apologies and warm thanks to Pam.

extra laundry, more home support, and access to a center like Dr. Peters or Friends for Life, or Loving Spoonful. I need a transportation allowance that allows me to choose my mode of transportation, especially when I feel really ill.

These are some of the items that are available to people with AIDS. Why not for people with Hep C? We need to have as large a provincial organization with the same amount of funding, over 10 million—this does not include some hidden perks—and definitely the same access to treatment.

With the co-infection rate in the HIV/AIDS community 30% of HCV/HIV, we are all in the same boat when it comes to dealing with a life-threatening illness that robs us of quality of life and forces us to live in substandard conditions.

COME AND SPEAK OUT NOVEMBER 12
1999. 10:00-5:00.

NANNA

PLEASE...

Many of you are under the impression that your membership to HeCSC (\$20 per year) includes a subscription to this bulletin. It does not. We receive no allocation from HeCSC for this, nor does your national membership help pay for this or other publications that Darlene, Joan and Squeeky produce, such as the FAQ's and our new pamphlet series. If you want to continue to receive your bulletin, and you can't afford to subscribe at this time, please fill in the Donation Form on page two, even if you don't send us any money. We don't want anyone to go without the bulletin, but we also don't want to send them out to people who don't want or need them. Please help us to keep track of those who do want to receive the mailing. We would eventually like to remove people from our mailing list who may have got there by mistake. Thanks! *The editors*



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 **HeCSC Victoria Chapter**, and mail to **HeCSC, Attn. Squeaky, 926 View St., Victoria, BC V8V 3L5**. 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 HeCSC cannot be held responsible for any interaction between parties brought about by this column.

Ad No. 10

Respectful, respectable man (49) but looks younger who is very active and loves life. I'm 6' tall, 210 lbs. and considered nice looking, emotionally and financially secure and non-symptomatic. I won't let Hep C rule my life and am looking for a positive female to share a long-term happy life together. Vancouver area.

Ad No. 14

Victoria area man (48), HepC & B (healthy carrier), non-symptomatic. Brown hair, blue eyes, smoker, non drinker/drugger, 210 lbs. physically fit. Seeking female (30's to 40's) for companionship/possible relationship. Are you, like me, accepting of this affliction, and focussed on moving forward in a positive and healthy manner?

Ad No. 15

X-addict

I'm 5'9", 160 lbs, brown hair & eyes, tattoo's, HIV neg, non-symptomatic, honest & sincere. I've cleared the slate, lost the baggage and starting fresh. I'm looking for that special lady that's been there and made it. Come on take a chance, I might be the one!!

RECIPE BOOK

A while back, I asked you (yes, you!) for a contribution for our recipe book. Think about it! It would be an excellent fundraiser. It would help those living with Hep C to have recipes which are good for them and easy to make. The stories would help spread the word about Hep C. And the sales of the book would bring much-needed money into the organisation.

Please, please, take a bit of time and send me your favorite recipe. It should be original. (You can change an ingredient or two to avoid "plagiarism"). Or it could be a family recipe from a couple of generations back, perhaps even converted to a low-fat version.

We need a little story about you to go along with it. How are you handling the Hep C? How did you find out about it? How does this recipe help? What is your favorite hobby? What would you recommend that others do about the disease (no medical advise, though.) Do you have a funny brain fog anecdote? Anything like that would be great.

Let's get this off the ground. We can't do it with only 7 recipes, guys.

Please send your recipes & photos, if you'd like to:

HeCSC Victoria
926 View Street
Victoria, BC V8V 3L5

or to iking@pacificcoast.net

OTTAWA HEP-C SUPPORT GROUP

The group now meets at 420 Cooper St (Between Bank and Kent) at 7.00 PM. Call (613) 233-9703 for updates and details.

EDMONTON, ALBERTA

HeCSC Informal Support Group Meetings:
Third Thursday of each month, 6-8 PM, 10230-111 Avenue, basement level (parkade level) in Conference Room A or B. **NEXT MEETINGS:** November 18 and December 16

Contacts:

Email: Tracey NitNGale@telusplanet.net

Phone: Jackie: 780-939-3379

KITCHENER

Kitchener Area Chapter **NEXT MEETING:** Nov. 24, 1999 7:30 PM @ K-W Elks Lodge, 38 Bridgeport Rd. E. Waterloo, ON - Tentative guest speaker: Patsy Burns from University Hospital in London to talk about transplants **PLEASE NOTE THAT THIS IS A CHANGE OF NIGHT** (4th Wed. instead of 3rd)

VANCOUVER SUPPORT GROUP

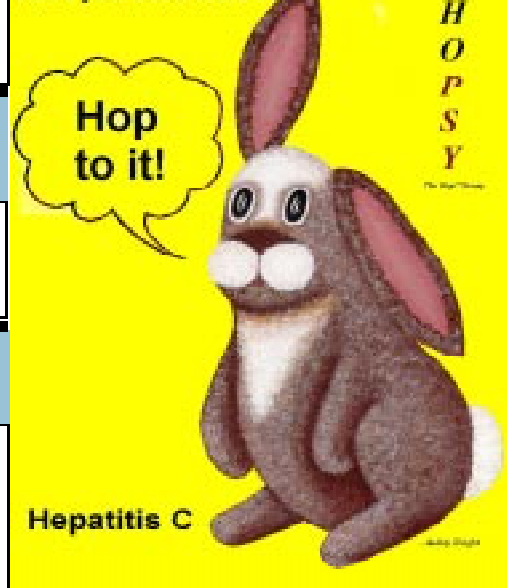
Vancouver Morning Meetings: The meetings will be on the last Wednesday of the month (whenever possible) The next meeting will be on the 27th of October from 10:00-12:00 PM at the BC CDC 655 W. 12th (12th and Ash). Park at the Cambie Street Mall. It's 2 hours for free if you buy something. Pick up stamps or something else you need. Bring your parking ticket with you to be stamped by the merchant.

The CDC building is on the same side of the mall across the street on Ash. Please go to the elevators along the back wall when you enter. Go up to the second floor and turn right as you exit (I think :-)) You'll see the washrooms on your right and at the end of that alcove is the Tom Cox Boardroom.

The October meeting will be on anger and depression in HCV and using Creative Visualisation and Meditation. Please call Darlene N. at 685-3813 or email djnicol@attglobal.net or Darlene M. at 987-7378 or hepcbc@canada.com for more info.

November's meeting is on a Monday due to conflicts for our meeting room. It will be on November 22 from 10:30 to 12:30.

Have you been tested?



HELP

I am beginning to look for funding for a holistic naturopathic protocol for people who are Hep C positive. Do you have any suggestions of organisations such as foundations, or even private individuals who may be interested in funding such a study? Please let me know. Thank you for your help.

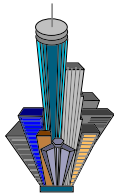
Sincerely, John Ruhland, ND
johnr@BASTYR.EDU

“I’ve never been part of an epidemic...”

USHA

The United States

Hepatitis Alliance Inc. and Hepatitis Education Project of Seattle are proud to announce a Symposium on Hepatitis C in Seattle, Washington at the Seattle Center Olympic Room on November 6, 1999, 11 am to 4 pm. Lunch will be provided at 12:30 pm.



Speakers will include: Marv Nordquist Jr., CEO of USHA, Dr. Pierre Nader, MD, Liver Specialist, Legislators, a representative from the Social Security Administration, Attorney of Law Jim Douglas, the “Caring Ambassadors,” Dr. Jeff Duchin, MD Chief, Communicable Disease Control and Epidemiology, Public Health, Seattle & King County, Dr. Martha Davis, Ph.D. HCV-HIV Co-infection issues will be addressed. A veterans advocate will speak about the situation with our Veterans who have hepatitis C. Marjorie Harris, “Amberose,” from Canada will speak about how the virus affects the body as a whole.

Contact : Ane Palmo, USHA Washington State Chair, lamapalmo@w-link.net 1 (888) 634-6877 or Dave77@emeraldnet.net

THE GENERAL PUBLIC IS WELCOME AS WELL AS THE PROFESSIONAL COMMUNITY. ADMISSION IS FREE, DONATIONS GLADLY ACCEPTED. Ane will be out of the country 9/14 to 10/4 Contact David Lang during this time with questions. (206) 242-8577.

Who is USHA? We are a national grassroots, non-profit organization formed to assist humans affected by HCV find information and receive support in their local areas. USHA was founded in October 1998 with a grassroots format: For the people and by the people is our creed. “WAKE UP AMERICA” is our theme. It is the intent of the Alliance to attempt to bring together all the varied organizations, as well as individuals themselves who are affected or infected by HCV with the common goal of putting an end to the disease of hepatitis C. We made our first presence known on May 3, 1999 when we held awareness rallies in 24 states at their respective Capitols at the same time. We do not restrict ourselves to the HCV virus. Some of our members have other forms of hepatitis.



Order Your FAQ's Now

We will have more of PPatti's FAQ available in a few weeks. We will include an HIV co-infection section as well. Place your orders now. Over 100 pages of information for only \$2 each plus S&H—but if you can afford more we'll take it. Contact Victoria Chapter.

Virus Breakthrough Offers Hepatitis Hope

Tuesday, October 12, 1999 Published at 0226 GMT 0326 UK—BBC News HomePage

Injecting with dirty needles is the primary cause of new infections

A drug that stops viruses spreading through the body could eventually produce more effective treatment against hard-to-treat hepatitis C.

British experts think that the drug, N-nonyl-BNJ, could be used in combination with other therapies to increase the number of people who can be cured.

So far the treatment has been used with some success against a similar virus to the hepatitis C virus (HCV), as HCV cannot be grown artificially for lab experiments.

But Dr Timothy Block, from the Thomas Jefferson University in Philadelphia, who has developed the drug, believes it could eventually work against both HCV and Hepatitis B.

As many as one in 100 people in the UK are thought to carry HCV, which can damage the liver so badly that a transplant is needed to prevent death.

Sugary secret

Viruses spread by multiplying inside cells, then breaking through the cell wall to spread elsewhere.

To slip through the cell membrane, they develop a sugary coat, and the new drug works by inhibiting this process.

So far it has only been successful against a cow virus, as HCV cannot be grown artificially in a laboratory.

Dr Block said "This is the first drug since alpha-interferon to my knowledge for which there is published experimental evidence against HCV."

However, a British expert said there was still a long way to go before the treatment would be in routine use.

Dr Graham Foster, senior lecturer in hepatology at St Mary's Hospital, Padding-

Chinese Herbs & Enzyme Levels

From JAMA, Letters - July 7, 1999

Liver Enzyme Elevations in Patients Treated With Traditional Chinese Medicine

To the Editor: Traditional Chinese herbs have widespread use outside of China by both emigrants and an increasing number of Western patients. Typically, 3 to 15 different drugs are combined in a prescription based on the patient's individual symptoms. While Chinese herbal remedies appear to be relatively safe, they are not free of risks, and a number of severe adverse events, including death, have been reported. Although hepatotoxic effects associated with Chinese drugs have been described, it is unclear how often such adverse effects occur.

Methods. We investigated the frequency of clinically relevant elevations of liver enzymes in 1507 consecutive patients treated with traditional Chinese herbs at the Hospital for Traditional Chinese Medicine in south-east Germany. Seventy-two percent of patients were female, the mean (SD) age was 52 (14) years, two thirds experienced chronic pain, and the mean (SD) hospital stay was 27 [5] days. Blood samples were obtained at admission and during the last 3 days before

(Continued on page 7)

ton, said it represented a "promising development", and could probably eventually be used in combination with other drugs.

He said "It may stop the viruses getting out of the cell, but if they continue to accumulate, the cell may burst eventually anyway.

"The drug has never actually been used on patients to any great degree."

Costly treatment

He said that HCV was "public enemy number one" in the UK, with an estimated one in 100 people infected.

"The problem is, there are so few treatments."

About 30% of long-term carriers of the virus will develop cirrhosis, or liver cancer. The current treatment, interferon, when combined with another drug, cures about 40% of those carrying the virus.

But a 12-month course costs £10,000, and involves unpleasant side-effects.

The principal cause of new infections is sharing needles for intravenous drug use, and the number of people presenting with symptoms is projected to rise sharply over the next decade to reflect a rise in the number of needle-users two decades ago.

(Courtesy of Smilin' Sandi from HepCAN)

The Mid Island Hepatitis C group arranged for a meeting with Reed Elley (Federal MP for Nanaimo-Cowichan) and had discussions concerning several areas for people with Hepatitis C.. What he is going to do from the Ottawa end is check and see what he can do to apply some pressure in the saga of Rebetron, re: Tied Sales and the Patent Medicine Price Review Board complaints. He also is doing some work in regards to CPP benefits for people with Hep C and is concerned that far more are turned down than we really hear about. So at your next meetings, would you ask anyone who is having difficulties getting or who has been turned down for CPP benefits and/or is unable to get Rebetron treatment for WHATEVER reason to let Reed Elley know the basic circumstances? Folks can send the info a number of ways:

Fax in Ottawa: (613) 993-5577
 Fax in Duncan: (250) 746-6666
 Fax in Nanaimo: (250) 755-4059
 Fax via Email:
remote-printer.Reed_Elley@16139935577.iddd.tpc.int
 Email in Ottawa: elleyr@parl.gc.ca
 Email in Duncan is: mpoffice@island.net

Hepsi

(Chinese Herbs—Continued from page 6)

discharge. The enzymes measured routinely were aspartate aminotransferase (AST), alanine aminotransferase (ALT), and -glutamyltransferase. A liver enzyme elevation was defined as any elevation over the normal range in patients with normal values at admission, or any elevation over admission values in patients with elevated values at admission. The main outcome measure was the proportion of patients with a more than 2-fold elevation (compared with upper limit of normal values or elevated admission values) of ALT.

Results.

A more than 2-fold elevation of ALT values was observed in 14 (0.9%) of the 1507 patients consuming Chinese herbs. Two of the 14 patients also had temporary clinical symptoms (nausea and vomiting in 1 patient, itching in the second patient). Based on assessments by 2 independent physicians reviewing the records, a causal relationship of elevated ALT levels with Chinese drug therapy seemed possible in 13 patients and likely in 1. All patients were also receiving non-Chinese drug treatment, and, for some of the drugs used (for example, minocycline, mesalazine, and diclofenac), liver enzyme elevations are listed as possible adverse effects. Thirteen patients had started these treatments with non-Chinese drugs before their hospital stays, and the dosages had been kept constant or diminished. When

Can you help us? We are a group of individuals concerned that members of the 1986 to 1990 class actions are confused and in the dark. You are not sure whether you meet the criteria for the class actions, yet face a potential opt out date but do not know what to do. You have heard about the class action in the media, have called one of the toll free numbers but have found nothing, only confusion. You have not been sure where to look or what questions to ask. You found out too late that you were a class member and that you could object to the proposed settlement.

Our plan is to request standing at the approval hearing for the legal fees. We are going to try to prove to the respective judges in BC, Ontario and Quebec that the fees the lawyers are requesting are excessive. (The lawyers have requested \$52,500,000.00 plus the taxes of \$6,000,000.00 for a grand total of \$58,500,000.00!) Plus in BC class members have been advised that, in addition to the fee above, individual class members could also be held responsible for additional amounts as set out in Camp Church's letter to class members dated June 18th, 1999.

It is our understanding you can call the '86 to '90 compensation hotline at 1-(888) 726-2656. They will get you on the list for an application and we believe you do not need the services of a lawyer any longer. The cheques will be issued directly to you out of the administrator's office.

Please pass this along to your chapters to ensure every class member ('86 to '90 victim) gets the proper information.

For further information contact HeCSC (1-800-652-HEPC)

*Joe Hache
 Leslie Gibbenhuck*

(Chinese Herbs—Continued)

the frequency of drugs used in these cases was compared with the frequency in patients who had normal liver enzyme values, an increased risk was observed for formulas containing Glycyrrhizae radix and Atractylodis macrocephalae rhizoma.

Comment.

In the population and setting studied, clinically relevant liver enzyme elevations occurred in about 1 in 100 patients treated with traditional Chinese drugs who also were receiving non-Chinese drug treatments. Based on these findings, we recommend that liver function be monitored in patients receiving traditional Chinese drugs, especially in patients with possible previous liver disease or risk of decreased liver function.

(Continued on page 8)

(SQUEEKY—Continued from page 3)

violation of the Society's Code of Ethics, and as such goes far to negate any possible importance of what you have to say.

With regard to the response of the Victoria Steering Committee of May 26th sent to our Board by Joan King-Diemecke, whether you are aware of this or whether or not you like what you know, the National Board does indeed have the authority to act and make decisions on behalf of the membership. We are not governed by the British Columbia Societies Act. I suggest you seek which Act we come under for yourself. It will give you something useful to do.

David, you are living in a little world of your own and show a remarkable lack of insight into and understanding of legal and procedural issues, of human relations and modern life in Canada. The correspondence you send us has all the tone of directives from a 1917 workers' soviet and very finely ignores the realities of corporations and societies in a stable democracy. It is my belief that you hold a greatly inflated notion of your importance and the impact your abrasive and abusive correspondence might have.

As a local chapter, you quite rightly have a great deal of autonomy in doing what you believe to be appropriate for your client group. As one of the founding directors of HeCSC I speak with knowledge when I tell you that this was our goal for local chapters at the time of the founding of the organization, and remains so. In terms of requesting assistance from us, for the great part local funding is entirely your responsibility. If you have bitten off more than you can chew (your request for funding seems to indicate this, and if you seriously expected financial support from the National Office you should have shared your plans with us in great detail long ago), I would strongly advise that you attach some realism to your plans. It is very easy to "talk big" in terms of what you think you can do. It is an altogether different matter to get things done the way you want. You have many constituents to consider, and if your correspondence with us is anything by which to judge, you do not do a very good job in making these considerations.

So.....good luck with your various campaigns. I have no doubt of your general sincerity in wanting to get things moving in a manner beneficial to our client groups, but your approaches may leave much to be desired.

Incidentally, David, you are *not* Co-Chair of the Hepatitis C Society of Canada, Victoria Chapter, but Co-Chair of the Victoria Chapter of the Hepatitis C Society of Canada. A small, but important distinction as the former clearly provides you with an authority to which you are not entitled. Finally, by all means go to the Press if you feel you must.

Yours sincerely,
 W. Richard Bond, Ph.D.
 Chairman of the National Board of Directors

Eds.: We have indeed shared our plans with HeCSC National and were ignored. For those of you with back issues, please see numbers 11 & 12.

NO CASH YET

By Leslie Gibbenhuck

Many Canadians wrongly believe all Hepatitis C victims have received compensation, are getting treatment and have been able to put the whole nightmare behind them. Not so!

No Hepatitis C victim, within the 1986 to 1990 "window," has received a cent! The fund administrator has not been approved by the courts, the hearing to approve the legal fees has not happened and a protocol that applies to those seeking compensation has not been established. Our lives are far from normal!

We have been told we should see cheques in March, then September and now possibly January. People are sick and dying and tired of waiting. Many like ourselves have already been forced to declare bankruptcy, with no emergency aid made available.

Our Canadian Association for the Study of the Liver (CASL) recently released their 1999 report. It dedicated an entire 9 sentences to Children with Hepatitis C and boasts a final statement "**Chronic Hepatitis C in children should not be treated except in controlled trials.**"

This is Canada. I am aware of no controlled trials involving children and a call to Schering or Amgen drug companies confirmed this fact.

So...the Minister of Health, Allan Rock, has given us no care—testing still eludes most infected with Hepatitis C—and no cash! Children and their parents suffer in silence, frightening off much of the medical world, with this unresolved "legal liability" issue.

Even if one decides to accept the proposed compensation package, class action lawyers will be the only ones who will receive a guarantee of payment, with no holdbacks. For everyone else, they simply get a promise—and we know how well the government does at keeping its promises!

Blood injured Canadians should not have to pay lawyers in order to be compensated for the governments' negligence. Compensation should be forthcoming from the fund—one should not have to pay class counsel for compensation, when counsel has already applied to the fund for \$52,500,000.00 plus taxes on that of \$6,000,000.00. Some of these same lawyers will make up the Joint Committee of the settlement fund and they have set a budget for themselves, of an additional 7.4 million dollars.

All class members have not been identified. Most do not understand they are members of the class simply because they meet the criteria (transfused between 1986 and 1990 at a Canadian hospital and reside in Canada). They also do not understand that although they are signed on with other lawyers, they are still members of the class unless they opt out. And they do not understand that they could have expressed their objections to the proposed settlement and still can with respect to the legal fees class counsel has requested from the fund. In addition many class members have signed contingency fee agreements and lawyers can charge them per those agreements! It is time for the lawyers involved to show some honour—

cancel all contingency fee agreements with your hepatitis C clients and assist these people to get the compensation they deserve.

According to the '86 to '90 Compensation Call Centre (1-888-726-2656) one should simply phone to register themselves, receive the claim form, complete the form and await a cheque. I only hope it will be that easy!

There is no accountability with our government and despite having laws to protect against this happening, no authority in the land understands how to enforce these rules. It is my opinion the government has banked on the fact this group could not communicate with each other and could not organise themselves. Does the government hope most victims would be so overwhelmed by the delays and the confusion that they would not even bother to apply for compensation?

The fear factor of victims is running high, "if I opt out....I stand to get nothing"; "if I take a stand against the compensation agreement will the lawyers ask me to leave?" Too many issues and too many questions!

Thousands of Canadians were needlessly poisoned by the inaction of our Federal government. This same government has offered 1.18 billion in compensation, yet admit they have done nothing wrong. A little over a year ago victims of this disaster mounted an effective campaign to prove government negligence. With a promise from the government that **all victims** would be looked after, those groups abandoned the attack.

But we are coming back—louder and stronger. Should you wish more information please contact me:

Leslie Gibbenhuck
P.O. Box 21058
Penticton, B.C. V2A 8K8
(250)490-9054
(250)490-0620
email: bchepe@bc.sympatico.ca

(Chinese Herbs—Continued from page 7)

Authors

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CLASS ACTION SUITS:

BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, BC V6B 1Z5
1-(888)-236-7797



Grant Kovacs Norell
Bruce Lemer
Grosvenor Building
930-1040 West Georgia Street
Vancouver, BC, V6E 4H1
Phone: (604) 609-6699 Fax: (604) 609-6688

Before August 1, 1986
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, BC V5Z 1K1
(604) 874-7171 or 1-(800) 468-4466
(604) 874-7180 (FAX)

also:

Dempster, Dermody, Riley and Buntain
William Dermody
4 Hughson Street South, 2nd Floor
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
200 King Street West
Suite 2300
Toronto, Ontario, M5H 3W5
Phone: (416) 595-2300
Fax: (416) 595-0527

CLASS ACTION FOR CHILDREN

Poyner Baxter Blaxland
Jim Poyner or Ken Baxter
Tel. (604) 988-6321
Fax (604) 988-3632
poyner.baxter@bc.sympatico.ca

or

Siskind, Cromarty, Ivey and Dowler
Michael Eiazenga
Tel. (519) 672- 2121 Local 332
Tel. 1-(800) 461-6166

TRACEBACK PROCEDURES:

INQUIRIES-CONTACT:

The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
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.

CLASS ACTION/COMPENSATION

If you would like more information about class action/compensation, you can contact:
Ron Thiel Tel. (250) 652-0608
E-mail: thielron@pacificcoast.net

National Compensation Hotline
Tel. 1-(888) 780-1111