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BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

October 1999

Complementary & Alternative Medicine in Chronic Liver Disease... A Symposium

August 22-24, 1999 National Institutes of Health, Bethesda, MD By Pamela Ladds /Sybil Stein

Chronic liver disease is a major problem in the United States and abroad. Treatment of chronic liver disease by allopathic methods has been a difficult issue. Treatment success is only modest, and adverse effects and discomforts from treatment are common. When an opportunity presented itself to attend a symposium entitled "Complementary and Alternative Medicine in Chronic Liver Disease" at the National Institute of Health, I jumped at the chance. The conference was sponsored by the National Institute of Diabetes, Digestive and Kidney Diseases, NIH, and co-sponsored by the National Center for Complementary and Alternative Medicine, NIH, the Office of Dietary Supplements, NIH and the American Association of Naturopathic Physicians. This seemed promising as a place in which holistic care could be discussed and all points of view explored constructively.

The conference was a well-kept secret. Attendance was small and publicity limited to the NIH Website. A quick survey of registrants and participants showed that those in attendance were primarily presenters, posterboard authors and some people with hepatitis who had been brought to the conference as speakers for the Sunday night panel.

The aims of the workshop were stated as follows:

1. To assess the current knowledge on Complementary and Alternative Medicine (CAM) for chronic liver diseases, focusing on the available scientific evidence for efficacy and safety.

2. To identify and prioritise research needs that will more fully define the potential for efficacy and safety of CAM for treatment or amelioration of liver diseases.

From the reading of the aims, it was clear from the start of the symposium that the discussion would be focused on treatment and amelioration of a disease, and not on the well-being of the entire person.

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Matt Dolan and John Tindall

Hepatitis Can Alternative Approach Matt Dolan and John Tindall

The study of hepatitis C is full of opposing opinions and diagnoses. It's very confusing for the patient. In 1994 Matt Dolan, together with another HCV-infected individual, started a support group in London. At this point Matt did his research online and investigated alternative medicine. From this research it appeared that drug therapy was the only answer. However, he met other people who were into alternative therapy and eventually his interest was piqued. He drew up a list of herbs for peripheral symptoms, herbs that were immune modulators and antivirals. He came up with a list of about 40 herbs that he felt were best for Hep C, but when he met an herbalist, he was told not only that these herbs were wrong, but also that perhaps the Western perspective was not the best approach. Chinese medicine became the key for Matt both psychologically and physically. John Tindall has been instrumental in all of this through the Gateway Clinic. Matt's experience at Gateway helped to open his mind to other approaches and he wrote the Hepatitis C Handbook to share what he has learned

The Gateway Clinic in London clinic treats HCV, HIV/AIDS, and cancer. John Tindall is the clinic's manager. They have approximately 1,600 patients and see 70 - 100 patients per day. In London, John and Matt are setting up

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DICLOFENAC WARNING

http://www.medscape.com/SMA/SMJ/1999/v92.n07/ smj9207.09.bhog/smj9207.09.bhog-01.html

Diclofenac-Associated Hepatitis

Anil Bhogaraju, MD, et al., Department of Internal Medicine, University of Illinois College of Medicine at Urbana-Champaign.

Abstract: This patient, who had a history of osteoarthritis, had severe hepatitis 5 weeks after being started on diclofenac for increasing pain in the joints. A week before the onset of hepatitis, the patient complained of upper gastrointestinal symptoms and was treated for gastritis. Seven days later, she had full-blown, severe hepatitis. Diclofenac was immediately stopped, leading to a complete restoration of liver functions over the course of the next few months. We highlight the importance of having a high index of suspicion for hepatic side effects of di-

clofenac and emphasize the need for increased awareness of this rare but potentially serious problem. We also review relevant literature regarding incidence and management.



[South Med J 92(7):711-713, 1999. © 1999 Southern Medical Association]

IN MEMORIAM

Michael Steele of Kitchener ON, formerly of Alberta and a liver transplant recipient passed away August 7, 1999. Apparently the virus came back with a vengence and doctors were unable to help him this time. He leaves his wife Sheila and a son and daughter. Two days later, Sheila's father passed away suddenly as a result of an aneurysm. A double funeral was held on August 12. I'm sure Sheila and the family would appreciate prayers and condolences in this difficult time. If anyone wishes to send condolences, they can send them to me and I will give them to the family.

Send them c/o Carolyn Caveney, 8-1200 Courtland Ave. E., Kitchener, ON N2C 1K7.

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DONATION FORM

Please fill out & include a cheque made out to HeCSC - Victoria Chapter. Send to: Hepatitis C Society of Canada Victoria Chapter

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Okanagan HeCSC П HepC BC П Other _[1]

"I cannot affor	rd to subsc	ribe at	this tin	ne, 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, HepCBC 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-Diemecke 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 jking@pacificcoast.net Joan King-Diemecke Darlene Morrow <u>hepcbc@home.com</u> http://www.geocities.com/HotSprings/5670 C.D. Mazoff squeeky@pacificcoast.net

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- Leslie, 490-9054, bchepc@bc.sympatico.ca 5137

Comox Valley Liver Disease Support Group Meetings: Third Tuesday of each month, 6-8 PM, St. Georges United Church on Fitzgerald. MEETING: October 19th. Contact: Ingrid or Nicky, 35-9167 or Jeanne Russell ebus96@island.net

Cowichan Valley Hepatitis C Support Contact: Debbie, 715-1307, mygirl@olink.net, or Leah, 748-432, 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: nomma@vcn.bc.ca

Enderby HepCURE Meetings: Last Sunday of each nonth, 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: October 31st. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.

Kelowna HeCSC Meetings: Last Saturday of each month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: October 30th. Contact: Michael, 860-8178 riselev@bcinternet.com

Kootenay Boundary Meetings: Second and fourth Tuesday of each month, 7 PM, 1159 Pine Ave. upstairs from Lordco auto parts. NEXT MEETINGS: October 12th and 26th. Contact: Brian, 368-1141, k9@direct.ca or Pat. 364-1555

Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St., Nanaimo. NEXT MEETING: October 14th. Contact: Susan, 245-7654. nepc@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: October 11th. Contact Dianne Morrissettie, 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: October 13th. Contact:

THANKS!!

Prince George Hep C Support Group Next Meeting:

October 12th, 7 PM, PG Hospital, Room 102 Speaker: Darlene Morrow of HepC BC. Contact Ilse: NEXT 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: October 9th. Contact: Brad, 295-6510, citizenk@nethop. net

Quesnel Contact: Elaine, 992-3640.

Sunshine Coast NEXT MEETING: See page 3. 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: October 14th. (Contact: the CLF, 681-4588, Darlene, hepcbc@canada.com, or Herb, 241-7766, HMoeller@compuserve.com

FIRST MEETING: Vancouver Support Group September 29, 10:30-12:30, 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@ibm.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, Mid Island Hepatitis C Society Meetings: Second 3402-27th Ave. NEXT MEETINGS: October 5th and October 19th. 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: October 13th and October 27th. 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: October 27th. Contact: 388-4311. hepcvic@pacificcoast. net

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

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Victoria's Pierre Fontaine for a generous donation and some coffee supplies for our office. Reminder: Any change of address, phone

A big round of applause and many thanks to

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

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Page 2

"Our Readers Ask"

One of our readers, Cian Bulioni, wants us to let you know that he cannot understand why the National Office of HeCSC stated the following in its last newsletter: "Our society at all levels was rewarded for our advocacy, with a federal transfer to the provinces of \$300 million... so that provincial health care programs to people with hepatitis C will be provided."

When Mr. Bulioni telephoned the Toronto office to ask what this meant for him, he was given the Compensation Hotline number. Asking for succour, but feeling like a sucker, Cian forwarded us his complaints and asked that we share this little "incident" with you, our readers.

In case you don't know, our local office in Victoria—one of these "levels"— has seen NONE of this money. Our "individual" members—another level have received no increased health benefits, no extra homecare, no easier access to treatment, no increased subsidies, no food allowances and so forth. Treatment for most of us is inadequate, and for some, non-existent—especially if you are poor and live in BC.

We continue on a shoestring, struggling to get the bulletin out, and to provide literature and help to all who ask. Requests for official funding from the federal government and from our national office for help with our publications and services continue to go UNANSWERED.

On the other hand, we have recently received a cheque from the inmates at Vancouver Island Correctional Centre to help us continue with our work. Now that's what I call all levels. Way to go boys! Thanks for the reward!

PS: Cian, you wanted details about the program. Well keep reading *this* bulletin. Darlene has the latest on our attempts to get treatment for persons in BC (see page 8). As well, as soon as Ron or Leslie hear anything about compensation issues, I assure you we will give you reliable and timely information.

On the level

C.D. Mazoff

In the July issue of the Bulletin, we posted an announcement that both Dr. Anderson and Natalie Rock had joined the medical advisory board of HepC BC. We had spoken to them in their office, where they had requested that we send them an official request by fax. In our enthusiasm we thought that they had agreed to be on our medical advisory board and made that an-

RETRACTION

our medical advisory board and made that announcement prematurely. To date, we have not received official acceptance or refusal from Dr. Anderson or Natalie Rock. They have promised that we will hear from them shortly. We sincerely regret any embarrassment that the premature announcement caused. At such time that we receive an official response from them, we will post this information in the bulletin.

The medical advisory board of HepC BC at present comprises Dr. Martin Schechter, National Director of the Canadian HIV Trials Network, and Dr. Mel Krajden, Associate Director of the BC Center of Disease Control Laboratory.

Dr. Aslam Anis, PhD., Assistant Professor of Health Economics, Department of Health Care and Epidemiology at the University of British Columbia is on our Academic Advisory board.

SUNSHINE COAST

Greetings to everyone from the Sunshine Coast! Our September meeting is put on hold for now. If there are any changes, please watch Cable 11. I will be moving to Dean Park on October 1st. and I am hoping someone can give me referrals

for doctors. I would like to find someone who is up to date with information on Hep C and who really cares for their patients' needs. During the month of September ONLY I can be reached @ 383-9234 (Victoria), and as of October 1st. our new phone number will be 655-9468. My email for September is <u>karen_felske@sunshine.net</u>. Thanks for any support! I would like to say farewell to everyone I have met at our meetings on the Coast. Good luck to everyone. Ian, take care of yourself, OK?? Kathy, keep an eye on him!! Good luck to you Kathy. I am sure that everything will work out just fine. Thank you!

I hope the meetings will carry on (I am sure that they will) and I wish all my friends love, health and happiness. You can still e-mail me, and to those who do, I will send you my new address. Bye for now....

Karen Felske

PRINCE GEORGE

The first meeting of the Prince George hepatitis C support group took place on September 7th. HepC BC will be at the meeting on October

12th to answer questions and offer support. 7:00 PM Room 102 of Prince George's hospital.

CENTRAL ALBERTA

Canadian Liver Foundation, Central Alberta chapter:

Hepatitis B&C Support Group Every 2nd Thurday 6-8 P.M. Provincial Building Rm. 109, 4920 51st., Red Deer Call Shane Bower for more Info (403) 309-5483

KITCHENER

KITCHENER CHAPTER CONTACT: <u>annetteb@golden.net</u>

EDMONTON

Edmonton, Alberta Hepatitis C Informal Support Group Meetings will be held the third Thursday of each month (Next Meeting Thursday, September 16th/99) from 6-8 PM at 10230-111 Avenue Edmonton, AB, in Conference Room "A" (the basement of the building). Contacts:

Tracey Peddle: <u>NitNGale@telusplanet.net</u> Jackie Neufeld: (780) 939-3379

Parking: Meter Parking (underground and surface)... roughly \$3 per evening. There is some street parking free if you're willing to walk.

HEPATITIS C MONTREAL

Hepatitis C Montreal meets every 3rd Tuesday of the month at the Dawson Community Center, 666 Woodland Avenue, Verdun, Quebec.

SPECIAL MENTION

In the last Bulletin a number of people were thanked but some were left out, which I feel was a mistake. Both **Gary Lunn**, **MP** and **Dr. Keith Martin** participated in the run and they have both been very strong spokespersons on our behalf in parliament.

Also, **Murray Coell**, **MLA** was present at the fun run. Murray has been present at all rallies and functions we have held and he makes sure the Legislature knows what is going on. I feel these three deserve special mention.

Ron Thiel



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Hepatitis C Vaccines Bv Will Lawson

There is currently no vaccine against hepatitis C virus (HCV) infection, but two research projects which have been ongoing since 1998 may soon change that. The studies are being conducted independently by an American company, Chiron Corporation, and Innogenetics, a Belgian biotechnology company.

Chiron, which discovered the hepatitis genome in 1987, plans to complete data analysis this year on a Phase I trial of its HCV vaccine.

Its vaccine comprises a recombinant HCV antigen preparation in combination with Chiron's MF59 IFN enhancer, which is designed to induce viral neutralizing antibodies as well as other potentially protective immune responses.

The trial was a double-blind, dose-escalating study in which forty-eight healthy adult volunteers received three immunizations over a sixmonth period. It was intended to evaluate the safety and tolerability of two different doses of the vaccine. The company also intends to look at parameters that will indicate whether the vaccine stimulated an immune response within the subjects.

Chiron believes its HCV vaccine has potential both as a prophylactic and therapeutic product.

Developing an HCV virus is also one of the highest priorities of the Belgian firm Innogenetics. In June, 1998, it said its researchers had administered several trial vaccines to chimpanzees known to have been chronically infected with HCV for 10 years.

Scientist Geert Maertens said in a statement that the vigorous immune responses recorded turning the severe chronic active hepatitis into more moderate liver disease were "very positive" and without side effects. "Such results have never been recorded before," he said. "Our approach opens new perspectives for the treatment of chronic hepatitis C. Since liver histology markedly improved in the vaccinees, the progression towards more severe forms of liver disease may be halted or even reversed."

Innogenetics intends to start additional preclinical investigations to maximize the potency of the candidate vaccine and to begin human trials as soon as possible.

Enhancing the Effectiveness of Alpha Interferons By Will Lawson

The standard treatments for chronic hepatitis C (HCV), alpha interferons (IFNs), effect a sustained response in only fifteen to twenty-five percent of patients who qualify for treatmentroughly 8% of the total HCV population (Mel Krajden, BCCDC).

Although the causes of IFN resistance in various categories of HCV-infected patients are still unknown, both viral and host factors have been involved, including defects in IFN signal transduction and IFN-alpha/beta receptor downregulation.

In order to improve responses to IFNs, several drugs have been investigated alone or in combination with them.

Of these agents, ribavirin is currently the most promising IFN enhancer. The most commonly used alternatives to ribavirin are amantadine, rimantadine, (or triple therapy with either amantadine or rimantadine plus an IFN and ribavirin), ursodeoxycholic acid (UDCA), and nonsteroidal anti-inflammatory drugs (NSAIDs).

So far these agents have proven ineffective on their own, and the same may be said for the combination of IFN and UDCA. The effectiveness of NSAIDs in combination with IFN is still unclear

In 1997, for example, the UBC Faculty of Medicine administered a combination of IFNalpha 2b and the NSAID ketoprofen on seventeen patients who had been nonresponsive after six months' treatment with IFN-alpha 2b alone. The researchers monitored the patients' ALT, AST, and HCV serum levels before and throughout the four-month study. They found no convincing evidence that the combination had improved any of the patients' responses to IFN.

However, researchers at the University of L'Aquila (Italy) claimed recently (Hepatology 1999 Aug; 30(2):510-16) that at least one NSAID, indomethacin, does potentiate IFN signaling. "Our data indicate," they reported, "that [a] blockade of arachidonic acid (AA) metabolism by indomethacin activates a signaling pathway that converges on STAT1 activation to potentiate IFN-alpha-dependent gene activation.'

(**DOLAN**—*Continued from page 1*)

medical students with children, who are being treated with herbs, and monitoring their progression. They are trying to get funding to set up clinical trials that will look at integrated approaches. They believe that HCV-infected people taking Chinese medicine can improve at the same rate as those in drug treatment, but with no side effects.

The Gateway Clinic is also starting a clinical trial that will look at ways of coping with the side effects of the combination therapy. The US government has funded a clinical trial in San Francisco for a group of prostitutes who are Hep C positive. They are looking at four groups---one that is being treated with interferon, another with Chinese herbs, another with herbs, diet, Qi Gong, and lastly, a group that is not undergoing treatment.

John has made up 4 different Chinese herbal combinations (2nd generation) based on a patient's current symptoms. John and Matt are trying to set up a clinic and pharmacy here in Vancouver. They want to the keep the cost down for the patients. John has found that patients can accurately choose their own Chinese combinations. It is therefore not necessary for the patients to see a practitioner unless they so desire. But the herbal companies in the US will not dispense the herbs directly to the patients. They require a practitioner's prescription. Because the practitioner's fee adds an unnecessary cost to the patient, John is trying to find a doctor who will provide the information on the 4 combinations and the prescription without charging the patients.

Both John and Matt are working closely with Herb Moeller to meet their goals. If you can help, please call Herb at 241-7766.

John Tindall can be reached in London at 01-81-690-9145. This number is both a fax and a phone. If you fax him, he'll get back to you as soon as possible. The internet address for Matt's book is www.hephandbook.com and John's internet address is www.yuancentre.com

Matt has just finished the second edition of the Hep C Handbook. He would like to offer this book to support groups. You could offer the books at cost to your support group members at a reduction of 55%. Matt's publisher's number is (510) 559-8277. You must order one case of books (20 books) and the cost is \$225 US. You can also order a personal copy of the book from 1(800) 337-2605

Darlene Morrow



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. Squeeky**, **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.

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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 longterm 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 "plagarism"). 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 antecdote? Anything like that would be great.

Let's get this off the ground. We can't do it with only 5 recipes, guys.

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

HeCSC Victoria 926 View Street Victoria, BC V8V 3L5

or to jking@pacificcoast.net

HEP C QUILTS

It's not too late for you to add your square to the Hep C Quilts.

The squares should measure 12" by 12". For the Canadian quilt, you should use red cloth with a yellow hand print, or yellow cloth with a red hand print. You should use black for your name and any message. You may use different colors on your square for the International quilt, but it should be the same size as the Canadian square. For both quilt squares, please leave a 1 inch border, so that a seam is possible.

You may also make a memorial square for a family member who has passed away with Hep C. You should mention the date of death, and any other pertinent data. A family member may place a square on either quilt, as well, preferably stating how s/he is affected, for example: "My mom has Hep C."

Send your square for the Canadian quilt to: HeCSC

383 Huron St. Toronto, ON M5S 2G5

Send your square for the International quilt to: Marie Stern

4918 W. 135th Street Hawthorne, CA 90250

Thank you, Tim at HeCSC and Marie!

Please Copy and Mail to Penny Priddy

Hon. Penny Priddy Minister of Health and Minister Responsible for Seniors 133, Parliament Buildings Victoria, B.C. V8V 1X4

Dear Ms. Priddy:

The hepatitis C community is deeply in need of action on your part. We must have funds allocated to Pharmacare to pay for Rebetron therapy. This therapy is the only one that has the potential to return hepatitis C infected people to an improved quality of life (QOL). While the success rate is around 42%, almost all people that have been on therapy (even those that have failed) have a notable improvement in QOL. This means that many of these people can return to their jobs and becoming tax paying members of the community and province once again.

As a community, we have addressed the issue of the high price of this drug in two different ways. We are trying to break apart the bundling of the two drugs that make up the Rebetron package (Intron A and ribavirin). In doing so, we hope to bring down the price so that we (and the Province) will not have to pay such an exorbitant amount. We have filed a claim with Industry Canada that Schering Plough (SP) (the drug company that makes Rebetron) is guilty of Tied Sales which is illegal in Canada. We have also filed a claim with the Patent Medicines Price Review Board stating that SP is guilty of excessive pricing because it is possible to get ribavirin for \$0.96 in Great Britain or \$2 in Mexico and SP is asking for over \$7 in Canada. Both of these claims are in process with the respective branches of the Federal government.

But now we must wait. And you know the wheels of government move slowly. In the interim we implore you to move forward and do your part—cover Rebetron so that people infected with Hepatitis C in this province can begin the step that may lead to a better life.

Platelet counts are often low in people who have hepatitis C, especially those with advanced disease. Rebetron has a further depressive effect on that platelet count. There are individuals currently hovering around the cutoff mark. Waiting for treatment, they could drop below that mark and no longer be able to go on Rebetron. You can see, then, the seriousness of this situation and all of its implications including the legalities.

We also wish you to support us in the upcoming proposal for the BC Center for Hepatitis. BC was a leader in Canada when they began the Lookback Program. They became a model for the other provinces to follow. Now there is a chance to do the same again. Be a leader and set forth a model example of health care for people infected with hepatitis. We are in desperate need of such a Centre. The BC CDC estimates that there are over 40,000 people infected with hepatitis C in this province. Direct action is needed so that we might curb the devastation that will surely follow if the quality of care for people with HCV does not improve. Please do what you can to help us.

Respectfully, Darlene Morrow President, HepCBC

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"I've never been part of an epidemic..."

USHA



Hepatitis Alliance Inc. and Hepatitis ⁶ 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, <u>lamapalmo@w-link.net</u> 1 (888) 634-6877 or <u>Dave77@emeraldnet.net</u>

THE GENERAL PUBLIC IS WELCOME AS WELL AS THE PROFESSIONAL COMMU-NITY. 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 USHA was founded in October areas. 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 or 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.

(Continued from page 1)

At no time was there even mention that "complementary" means "to complete."

Leonard Seeff, MD gave the introduction and set the stage for the symposium. Part of his presentation stated that "The medical scientific community has been sceptical about these claims [of the efficacy of herbal remedies] and have tended to either ignore the practice or to disparage the benefit of these products and instead have focused on their potential for toxicity....It is therefore incumbent on the medical scientific community to give proper consideration to the views and anxieties expressed by the public on this issue."

While several presentations discussed the range of patients using complementary modalities and whether they shared this with their allopathic (medical) physicians, the primary focus of the conference was on herbal and botanical medicine. The sessions focused on reviewing literature and determining the scope of use and spectrum of products used, quality assurance, minimum scientific requirements needed for determining benefits of therapeutic agents and exploring whether alternative approaches can be employed, determination of scientific evidence of potential benefit of the preparations and a review of evidence of toxicity of these products—an impressive array of goals for a 3-day conference.

Panels started off with an overview of the spectrum of liver diseases, what Western medicine has to offer and what "patients" are actually doing. Given the statistics produced around the efficacy, or lack there-of, of alpha-interferon and ribavirin and what we know about the side-effects, exploration of alternatives makes perfect sense. However, there was the usual concern expressed about patients taking alternatives without "permission" and, of course, not discussing this with their physicians. This is a debate that has gone around and around in the HIV community for years and ultimately comes down to the quality of the relationship between the medical practitioner and the person living with whatever disease. The conclusion from "experts" at this conference was a need for this degree of openness either through relationship or legislation. As usual it was abundantly clear which of the experts would develop a working partnership and which didn't have a prayer!

Sunday evening featured a panel titled "Complementary and Alternative Medicine in Liver Diseases: Meet the Experts Forum," a forum for individuals to meet and question experts in the field of alternative medicine regarding informed choices for treatment strategies, co-sponsored by the American Liver Foundation and Hepatitis International Foundation.

The patient/expert panel was scary—not because of information shared, but because of the way in which it was set up. The "experts," predominantly allopaths, sat on their raised platform. The patients were trotted out one at a time—4 from one hepatitis organisation and 4 from the opposition. They were introduced by the leader of each pack. After each patient's speech, the patient was to ask the panel two questions. There were no questions from the floor and no discussion!

Thelma Theil, CEO for HFI, introduced one of "her" patients as a "victim" of hepatitis C. Another woman living with hepatitis C introduced herself by all of her hats and credentials before describing her "most important" role—that of patient! She, not surprisingly, chose to go only the allopathic route! Other speakers described their horrendous journeys through the medical system misdiagnosed and mistreated—before finding a medical partner and exploring various treatment options openly. Another woman whose liver disease seemed due to no known cause was offered treatment (long term steroids) that she said her vet wouldn't give to her dog! She finally settled on an assortment of herbal and body oriented therapies. Her liver disease is now non-active. One member of the panel immediately felt the need to negate the treatment protocol by suggesting her liver disease would have resolved spontaneously. At no time was there discussion from the expert panel about the possible importance of attitude, or taking charge of her own treatment or specific herbs. There was no recognition of the disempowering aspect of negating anyone's treatment protocol. It is very easy to forget the power of words, particularly from an "expert."

And so the show went on. In the midst of all of this were some excellent speakers with really interesting information: Ethnobotanists, studying herbs in their habitats, working with indigenous peoples using the herbs according to their cultures; alternative practitioners, treating the whole person, not just a liver disease; and some allopathic practitioners, recognising the limitations of current practice and being open to exploring other options. There were little clusters of alternative and allopathic practitioners developing clinical trials for integrated approaches, combining Western medicine with Traditional Chinese Medicine or standardised herbs such as silymarin. There were discussions about standardisation and efficacy, discussions about growing and harvesting methods and discussions about whole plant versus isolated active ingredients. The plea from the West is, of course, to isolate an active ingredient, standardise it and then test according to a Western paradigm—a double blind clinical trial. Alternative practitioners have pointed out for years that this is not an effective strategy and does not get the information necessary. Just as people are more than livers, plants are more than one active ingredient. A pharmacist and naturopath who now develops and markets herbs handed out lists of plants with all of their components, dozens for some plants. Assuming that one ingredient is "the" ingredient makes no sense. A synergy is much more likely.

What was abundantly clear was that the driving force throughout much of the conference was not efficacy, but came down to market and turf. Much of the rhetoric was disguised under the "we have to help them because they are too simple, unsophisticated, ignorant, and so forth," and therefore what (Continued on page 7)

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we need is more legislation, more controls and more power. It is a tough debate. People who have spent years on a career path with beliefs about entitlement find it very hard to share power. Entrenchment in any belief system or model of the world sometimes makes it hard to be open to other approaches. It is not just in medicine where this is apparent. It is also true that there are snake oil salespeople and frauds out there from all branches of medicine. Greed is an equal opportunity disease. It is also true that some regulation of any product is appropriate for safety reasons. However, how is safety determined? There was considerable lated as food, not drugs, a fact that disturbs many allopaths and some naturopaths. It was clear that neither group was free of conflict of interests. Naturopaths probably have more to gain if supplements are regulated as drugs, a fact that they have clearly registered! 1997 figures for the US market showed prescription drugs out in the lead at \$94 billion supplements at \$10.4 billion and botanicals gaining ground at \$3.2 billion. This is not peanuts nor chicken feed! Many of the pharmaceutical companies also have their own supplement lines, neutraceutical compamost prominent manufacturers of vitamins were recently found guilty of price fixing and artificially maintaining the high cost of these products which are added into cereals, grains, milk, orange juice and other foods.

The final day, not only in terms of placement at the conference but also its content, indicated the mindset of the organisers. Panel 1 was a token run through Chinese Traditional Medicine, Kampo (Japanese traditional herbal medicine), Korean herbal use, European use, Ayurvedic and traditional Nigerian approaches to liver disease. Each speaker, most of whom had travelled from his/her country of origin and practice, got to speak for 20 minutes and attempt to translate concepts into Western English, both in literal and Western medicine terms. This seemed like tokenism in the extreme! It was also a set-up to invalidate other wellestablished and effective medical models, some of which can prove they have been around since the 6th century B.C. Makes our Western medical model look pretty infantile! The speakers even attempted to show to offer studies in the Western scientific model. Unfortunately the miserable amount of time allotted meant that those of us in the audience who were interested would only get information through back channels and a wonderful opportunity for dialogue was lost.

They were followed by a group whose job was to describe toxicity and adverse effects of herbs. This panel represented official bodies such as the FDA and CDC, groups not known for their objectivity or balance. Ending the conference on a "this stuff is bad for you" note seemed somewhat gratuitous, particularly as everyone in the room was well aware of the toxicity of Western approaches to liver disease. Of course toxicity is a real issue, but presenting information based on anecdote and those whom they wish to regulate. For example, herb toxicity was frequently described in such clinical and specific terms as "many," "potential" and "possible," a strategy that would be sloppy and invalid if alternative practitioners used it. Case histories where some one deviated from the recommended 3 cups a day of a tea to 17 pots, not surprisingly doing damage to herself, were offered as evidence of the need for regulation. In that case coffee had better be pulled, too. If I drink 17 pots of that a day, it is clearly the fault of an unregulated substance, not my stupidity!!

The American way of "if one is good, more would be even better" was offered as further evidence for the need to control and regulate. Examples were everywhere of how regulation would prevent lay people from harming themselves. One panellist showed photos of mushrooms that would poison foragers. His point was unclear. Did he want to regulate foraging? Should dandelions picked for salad be checked with the narcotics squad first? Maybe we should ask the Feds to regulate prayer, which is often touted as an unconventional therapy.

Controlling of substances has never worked. In fact, in this country,

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forbidding a substance has guaranteed an increased demand. History provides many examples. Prohibition contributed to the love/hate relationship with alcohol. Making some drugs illegal has created big business. Suggest that an herb is about to be regulated and watch the rush. Make Vitamin C available on prescription only and we'll all hit the street corners. As one toxicologist pointed out, the horses left the barn a long time ago. Making government bodies and health care providers, with a vested interest in maintaining the status quo, responsible for regulating herbs and botanicals is about as smart as asking a fox to guard the chickens!

reasons. However, how is safety determined? There was considerable discussion around who regulates what, and why. Many herbs are regulated as food, not drugs, a fact that disturbs many allopaths and some naturopaths. It was clear that neither group was free of conflict of interests. Naturopaths probably have more to gain if supplements are regulated as drugs, a fact that they have clearly registered! 1997 figures for the US market showed prescription drugs out in the lead at \$94 billion (more zeros than I can count), over the counter meds at \$16.7 billion, supplements at \$10.4 billion and botanicals gaining ground at \$3.2 biltion. This is not peanuts nor chicken feed! Many of the pharmaceutical

companies also have their own supplement lines, neutraceutical companies, and are gobbling up botanicals. And to add to the confusion, the most prominent manufacturers of vitamins were recently found guilty of price fixing and artificially maintaining the high cost of these products which are added into cereals, grains, milk, orange juice and other foods. The final day, not only in terms of placement at the conference but

Those of us who walked into the conference, optimistic that this was a place for open discussion and genuine learning about many different approaches, left, muttering. If the National Center for Complementary and Alternative Medicine truly wants to be effective as an NIH entity, then it needs to at least choose its partners more carefully, and select moderators who can open their minds and leave their arrogant assumptions and biases in a box at the door.

So where do people living with liver disease go from here? It was suggested all treatment information should be filtered through experts, meaning allopathic physicians steeped in Western paradigms of medicine.

cal model look pretty infantile! The speakers even attempted to show that they integrated the American approach with their own practices, and to offer studies in the Western scientific model. Unfortunately the miserable amount of time allotted meant that those of us in the audience who were interested would only get information through back channels

> Much of this conference was driven by the public's continued call for more holistic approaches to wellness, instead of the focus on illness and disease. No one wants to be treated by anyone as a kidney, a cataract, a broken bone. This is apparent as more health centres open departments of complementary treatment, give classes on meditation, on yoga, incorporate living well into treatment plans for healing of chronic diseases that some movement has started.

aware of the toxicity of Western approaches to liver disease. Of course toxicity is a real issue, but presenting information based on anecdote and obscured numbers made the regulating bodies as guilty of distortion as those whom they wish to regulate. For example, herb toxicity was frequently described in such clinical and specific terms as "many," speaks of the importance of the rituals of healing instead of the regimes of cur-"potential" and "possible," a strategy that would be sloppy and invalid if

But until the recognised Western medical community can begin to focus on patient wellness and not on the absence of disease, this dialogue will continue to short circuit itself during symposia such as the one just presented.



Rebetron in BC- What's New?

by Darlene Morrow

As many of you will already know—Rebetron has yet to be funded by Pharmacare. We have been very active in this area and need your help. First of all let me tell you what we have already done. At issue here is the high cost of the drug (\$1500 per month) as well as the fact that this is a bundled product of Schering Plough's brand of interferon, Intron A and ribavirin. It is now possible to get different kinds of interferon in Canada—consensus interferon (Infergen) by Amgen and lymphoblastoid interferon from Glaxo Wellcome. We should be able to choose the brand we want.

Let's address the pricing issue first. Intron A costs about \$500 per month. That means that the ribavirin costs \$1000 for a month's supply. Now ribavirin has been around for a long time and, in fact, the patent has just run out on it. If we look to other countries we can see that in Mexico it costs \$2 per 200 mg capsule, and in Great Britain we can get it for less than \$1!! In Canada we are paying over \$7! This is outrageous. So we have filed a claim with the Patent Medicines Price Review Board stating that Schering Plough is guilty of exorbitant pricing. They have received our complaint and just last week they told me that they are continuing to investigate and that our claim has merit. Step 1.

Now, moving on to the bundling issue. We felt that if it were possible to unbundle the two drugs, this would take care of step 1 because the ribavirin on its own could not be so highly priced. So we went to Industry Canada and filed a complaint that Schering Plough is guilty of Tied Sales. Tied Sales are illegal in Canada and are defined as a sale that forces a consumer to buy one brand of a product when they purchase a second product. Industry Canada has been very helpful, and when I spoke to them again last week, they said they are actively looking into our claim and that it has merit. So, we're doing pretty well on both issues.

But having said that, how long will this take? The answer is too long. We don't know for sure, but it is possible that it could take a year. We must do something else in the interim.

So, now I'd like to ask each of you to write a letter to Penny Priddy (see page 5). We have to get Pharmacare moving. BC is the only province that is not funding Rebetron. We have some good news. Ken Winiski worked very hard and managed to get coverage for some of us—if you are on welfare AND were in the clinical trial AND then got cut off when the Health Canada approval came through—you are now covered. But what about the rest of us? Not so lucky. So we need to let the government know that this is not acceptable. Writing to Penny Priddy will help us all.

For a small subgroup of people, this delay could be devastating. If your platelet count is borderline and, while you are waiting for the government to do the right thing, your platelets drop to a level that excludes you from treatment with Rebetron, then you would have a very good legal case

DEATH CERTIFICATES

My mother died a few weeks ago (not of hep C) and I thought the following information might be of interest to my fellow heppers. The doctor who signed the death certificate was not my mother's regular doctor; it was a doctor who, at the time my mother died, was working alone in the emergency department and rushed over when he got a free moment. He was probably tired and made a minor mistake in the certificate. It wasn't of great importance, but I thought, "What if a mistake was made when one of us dies."

I have suggested before that any of us who suspect we may die of liver failure due to hepatitis C discuss the matter with their doctor. My doctor has stated that I wouldn't have the endstage liver disease if it hadn't been for the hepatitis C, and he will put this on the certificate. In my opinion this could be critical to those who are involved in litigation, or at least to their families.

What if it isn't your doctor who signs the certificate, or if your doctor has forgotten his commitment? My suggestion is that to be sure that at least one member of the family be present when the death certificate is signed and try and get a photocopy right away because the official death certificate, at least in B.C., does not indicate cause of death.

I must remind you again that I am not a lawyer, and should you have any doubts, please discuss them with your legal representative. Sincerely,

Ron Thiel

Editor: We at HeCSC Victoria extend our heartfelt sympathy to Ron, our co-chair, and his family in this time of grief.

BC is the only province that is not funding Rebetron.

against the government. Of course that's not what we want to see—we want to see you getting treatment.

While you're writing Penny Priddy, we also need to let her know how much this province needs a Centre for Hepatitis. The proposal will be going to the provincial government sometime this month, so let your voices be heard.

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

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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: <u>thielron@pacificcoast.net</u>

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

hepc.bull

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