hepc.bull

BC's Hepatitis C News Bulletin

December 1998 **Issue No. 7**

Report from the National Office

Tim McClemont, Executive Director

Chapter development has increased dramatically in the last few months. You will note from the contact list in this issue that our numbers have doubled. We now have over 40 chapters and telephone support contacts. This speaks to the growing awareness of hepatitis C and our Society, as individuals are coming forward to volunteer to develop chapters in their communities.

Since July, our National Program Director, Hardeep Kaur, and I have visited chapters in Sudbury, Nanaimo, Victoria, Vancouver, Kelowna, Vernon, Sault St. Marie, York Region and Hamilton. Each Chapter has received either or both an introductory presentation about the Society or specific chapter program training, such as "How To Run A Support Group" or fundraising strategies.

We have also had a number of meetings with other groups to talk about research, such as the Canadian HIV Trials Network and the Canadian Liver Foundation. As well, we are in discussions with a couple of funders in both the public and private sectors about funding for an education of health care providers proposal we have developed. We also have submitted a proposal to the Population Health Fund of Health Canada for a youth project for those living with and affected by Hep C.

Earlier this year we applied to the City of Toronto for funding for a pilot project on co-infection of people with Hep C and HIV. That was not approved for this year. However, we sparked the interest of the local health department because they are now holding a workshop on this topic and have invited Hardeep to co-facilitate one of the working groups. Next year, we hope to obtain support for this type of project at both local and national levels by submitting proposals to each funder. Then the chapters could be involved.

The most significant development is the September 18 announcement of funding by the Health Minister Allan Rock for disease prevention, community-based support and research. We will be meeting with officials in November to begin planning how this funding will be distributed. This level of support will strengthen the Society, its chapters, and ultimately people living with and affected by Hep C.

Latest Treatment for Hepatitis C May Not Be Best, According to Patients

NewsWire; Consensus Interferon Effective for Many Patients Who Have Failed Rebetron

PHILADELPHIA, Oct. 27 /PRNewswire/ -- The newest combination drug therapy may not be best for every hepatitis C patient. Many do not respond to Intron A (interferon alfa-2b) with ribavirin, and others may see viral counts lowered but relapse once treatment stops. Consensus interferon (Infergen from Amgen) is worth a closer look for these patients.

A study in the April issue of Hepatology showed that 58 percent of relapsers and 13-17 percent of non-responders achieved a sustained response after 48 weeks of treatment with high dose consensus interferon (15 micrograms three times a week).

Interferons comprise a family of natural proteins produced by the body in response to viral infections. Consensus interferon is a man-made combination of parts of various interferon molecules that has five to ten times the biological activity of natural interferons in the laboratory.

Doctors are pioneering ways to maximize Infergen's effectiveness by modifying the dosing regimen approved by the FDA. Dr. William Boyd, Clinical Associate Professor of Medicine at South Florida School of Medicine and a hepatologist in private practice, uses Infergen with relapsers and with non- responders.

"Infergen is particularly successful with relapsers," says Boyd. "Based on the Hepatology study, they have a 55-60 percent chance of success if they have relapsed after treatment with Intron A."

For non-responders, Boyd prescribes 15 micrograms of Infergen three times a week, either initially or after acclimating the patient with 9 micrograms three times a week. "After three or four months at the higher dose without a dramatic drop in the viral load, we discuss increasing to 15 micrograms of Infergen daily."

Long-term therapy for patients with significant liver fibrosis is a new concept. "In the past, we considered hepatitis a viral illness," says Boyd. "If the virus didn't decrease after three or four months of treatment, we'd try something differ-

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HeCSC: TWELVE MONTHS OF ACHIEVEMENTS AND PROGRESS

A message from Jeremy Beaty, Chairman. Written October 30, 1998

Now is a good time for me as your Chairman to pause and reflect on what our Society has accomplished during the past year.

It was on Remembrance Day in 1997 that our founder Alan Powell, Executive Director Tim McClemont and I met with Allan Rock to present our Society's issues for Canadians living with and affected by hepatitis C. Since that time, and particularly since the first compensation offer in March of this year, the federal and provincial governments have taken the following further actions:

- The Province of Ontario has pledged $200 million and the Province of Quebec $75 million to financially assist hepatitis C blood victims who were infected outside the 1986-90 time period.
- The federal government has committed $525 million (Allan Rock's Regina announcement on September 18). If the provinces buy into these four federal programs they will match them with a further $350 million;
  - improving blood safety through strengthening blood regulation and disease surveillance,
  - helping cover medical expenses incurred by those infected through the blood system,
  - developing programs, with our input, on hepatitis C disease prevention, community based support and research.
  - conducting a "look-back/trace-back" study to identify people who have been infected through the blood system or who have donated infected blood.
- When all these are added together, the determined efforts of our Society have resulted in an additional $1.15 billion being directed to hepatitis C beyond the original compensation offer of $1.1 billion in March.

In other words, governments have committed a total of $2.25 billion to hepatitis C issues, with the promise of more to come. We should

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SUBSCRIPTION FORM

Please fill out include a check made out to **HeCSC - Victoria Chapter**. Send to:

Hepatitis C Society of Canada
Victoria Chapter
1611 Quadra St.
Victoria, BC V8W 2L5

Name: _____

Address: _____

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

Home (___) _____ **Work** (___)_____

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"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: ***Neither*** *HeCSC nor the* hepc.bull *can 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 organisation.*

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,*** joan_king@bc.sympatico.ca, ***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.

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

COMING UP IN BC:

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

Cowichan Valley Hepatitis C Support Services. Meetings: 1st Thursday 7-9 PM. 464 TCH. Duncan. NEXT MEETING: Dec. 3rd Contact: Debbie, 748-5450 or Leah 748-3432. vhepc@hotmail.com

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: Dec. 27th. 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: Dec. 26th. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Nanaimo HeCSC Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Dec, 10th. Contact: Helen, 245-8759.

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: Dec. 14th. Contact Dianne Morrissettie, 525-3790.

Parksville/Qualicum 163 Memorial Street, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551. dbamford@island.net

Penticton HeCSC Meetings: Third Thursday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: Dec. 17th.. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca

Richmond: Meetings: Fourth Tuesday of each month, 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. NEXT MEETING: Dec. 22nd. Contact: Guy, 244-1704. guy@fatherswithoutchildren.com or Carmel at Richmond Health Unit, 279-4069.

Sunshine Coast Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: Dec. 3rd. Guest Speaker will be Dr Loreen Dawson, Naturopathic Physician Contact: Karen, 885-6413. karen_felske@sunshine.net

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: Dec. 10th. Contact: the CLF, 681-4588 or Herb, 241-7766. HMoeller@compuserve.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: Dec. 1st and 15th.. 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: Dec. 9th and 23rd.. Contact: Sharon, 542-3092. sgeegee@msn.com

Victoria HeCSC Meetings: Last Wednesday of each month, 1-3 PM, and again at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex) **NEXT MEETING: Members will be advised by phone. Regular meeting cancelled for Christmas.** Contact: 388-4311. hepcvic@pacificcoast.net

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

NEW GROUP IN RED DEER

National Foundation for Hepatitis-C, Red Deer/Sylvan Lake Chapter. Support group meetings every Thursday night 6-8 PM. at the Provincial Building, room 109. For more info, please call Shane at 1-(403) 887-4066 or 1-888-563-HEPC (4372)
http://www.hepatitis-c.com
e-mail shanehepc@hotmail.com

THANKS!!

Victoria Chapter HeCSC acknowledges the personal donations, donations in kind and memorial donations received to date, and the following for discounts, donations of services, or equipment: Monk Office Supply. CFAX 1070 Radio, Apple Canada, Pacific Coast Net and Island Internet, Inc., Mid-Island Realty, Questar Holdings, Unity Business Machines Ltd., Microsoft of Canada, Jim Pattison Group, Society Press & Graphics, Paradon Computers, DataImage Technology and CompuSmart. We also wish to acknowledge an anonymous agency which has generously supplied us with government surplus computer equipment.

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http://www.pacificcoast.net/~hepcvic/hepcvic~1.htm
hepcan@egroups.com

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

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SQUEEKY'S CORNER

Well folks, it's raining so hard outside, I'm beginning to feel like Noah! Sheesh. Well, at least it was a good summer. It was good in many ways: weather, activism and outreach. But now things have slowed down, and it's time to think things through.

As you know, we tried and tried to get a new office here in Victoria, but it still hasn't happened. And right now things are pretty up in the air because we shall be having our elections on November 25. Hopefully we will elect a competent steering committee to focus on positive and effective strategies for the new year.

Leslie Gibbenhuck has been invited to come to the election meeting to speak on the various projects she is currently involved with. I hope that she will provide us with detailed accounts of the activist movements in the US and the pending tainted blood law suit that is being launched there.

I don't have much to say this time around. I would ask that you all take your participation in the Hepatitis C Society of Canada much more seriously and show up to your local meetings. I would also ask that you remember that unless we keep Hep C in the news, it's going to die. We, here, equals you and me. And tired though we may be, we really don't have any other choice—do we?

Combo Update:

As you may or may not know, I just started the Interferon-Ribavirin combo treatment about 3 weeks ago. I must say that unlike my first time on Interferon, this time is almost painless.

The first time I was on Interferon, I think I was much more ill all the way around. As you know, about 4 years ago I was so sick that I lived in a partial care residence for almost a year. But now, I am regaining a lot of my strength, although my liver damage has progressed significantly.

Because I reacted poorly to interferon the first time (bad sides and eventual "breakthrough") I decided not to take any chances this time around. I did some research on the hepc lists and decided that Zoloft was a good anti-depressant/anti-anxiety medication to take. I started taking it the first day of my treatment, and other than growing dehydration (along with occasional muscle spasms) from the Ribavirin, my response is very good. I now have days where the wooze that debilitated me is almost totally gone, and so are the fibromyalgia-related aches. They do show up periodically though, but not like before.

I do not yet know what my biochemical response is—i.e., whether the damned stuff is working; but I certainly can say that with the sides being what they are at the moment, it's definitely worth the effort.

I hear that Gary Joneson is responding quite well to treatment, as are others in our community, and that the latest Hepatico results are not as promising as expected. We'll give you more when we get more. For the latest information updates check out the list at hepcan@egroups.com.

All the best

squeek

CHILDREN NEEDED

There are two ongoing projects (both in the US) that are asking for Hepatitis C input. Both are looking for children with Hepatitis C.

One is for a "Faces of the Disease" poster. The poster project is being coordinated by Angelo Barbiere in San Francisco. He is a record producer who is also working on a concert and recording project to raise money for research.

The other is for children with Hepatitis C to make up 4 1/2 by 5 1/2 drawings of whatever they like and these pictures will be made up into cards. The cards are being coordinated by Sue Simon and she is from Edison, New Jersey

Anyone wishing to be involved with any of these projects can contact me at (250) 490-9054 or fax (250) 490-0620 or send them to me, Leslie Gibbenhuck, at PO Box 21058, Penticton, B.C. V2A 8K8.

INFERGEN

Infergen is not licensed for use in Canada but Amgen is generously agreeing to supply it for free. **Your physician or specialist must handle the negotiations.** I have a contact number or he/she can get in touch with Natalie at Dr. Anderson's office: (604) 876-5122. (Please do not call this number yourself.) This is all thanks to the great work done by Craig and Janice in Windsor, Ontario.

Darlene

HEPATITIS C CONFERENCE OTTAWA '99

In January '99 there will a Hepatitis C conference in Ottawa, Ontario. This conference has been put together by the Medical Research Council of Canada and Health Canada along with the Health Protection Branch. Its objective will be to review critically the full spectrum of research (from the molecule to public health and psychosocial aspects) on HCV and to define a future research agenda for Canada.

(Best Treatment?)—*Continued from page 1)*

ent or wait for better medicines. Now, the goal for patients with significant fibrosis is broader than alleviating the virus. The medicine may slow or even reverse fibrosis, so we plan on a year of treatment, even if the viral load doesn't decrease."

Doctors individualize therapy by weighing several factors: how the patient tolerates the medicine, how motivated the patient is, amount of fibrosis, and what has happened to the viral load. "We may arrive at different dosing schedules for different patients. We don't prescribe by cookbook as we did five years ago," says Boyd.

Dr. Boyd recommends patients find a doctor to spend time with them examining their viral load and biopsy results, their age, their tolerance of side effects, and their expected length of treatment before making treatment decisions. "Working with such a doctor is critical to developing commitment—no treatment works if the patient doesn't refill the prescription," he says.

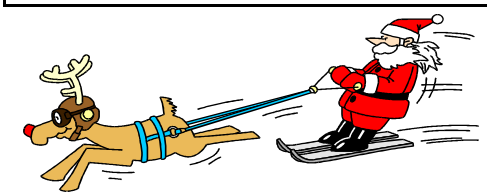
Link to "Re-treatment of Chronic Hepatitis C with Consensus Interferon," Hepatology, April 1998, p.1136-1143, Vol. 27, No. 4:
http://www.hepatology.org/cgi/content/abstract/27/4/1136
SOURCE Patients NewsWire
CO: Patients NewsWire
ST: Pennsylvania

NEW NAME FOR THE HEPSCS LIST List: HepCAN

I am pleased to announce that the hepcsc list has now got a new name: HepCAN. The old list, sponsored in part by the Hepatitis C Society of Canada, Toronto, was good but had a few problems. First, although we had a reduced rate, we still had to pay for the service. Second, options such as archiving and digest were only available at an additional cost. Third, the new list goes back to the original preferred name (the original HepCAN list was started by Rudy, Joan, Darlene Morrow and Marjorie). And last, because there is no official sponsorship of the list, any hint of partisanship has disappeared. We hope that the new list will continue to encourage the open discussion and sharing of important information that were the hallmark features of the old hepcsc.

To subscribe to the new list just send a message to hepcan@egroups.com and I'll get you signed up ASAP.

squeeky



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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 checks payable to **HeCSC Victoria Chapter,** and mail to **HeCSC, Attn. Squeeky, 1611 Quadra St., Victoria, BC V8W 2L5.** 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 check for a donation of $2, if you can afford it. Mail to the same address as above.

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

Ad No. 9

Hi, my name is Shane. I have HBV, HCV. I am 31 years old, 6'3 tall, 170 lbs. If you would like to see a photo of me and read my story, you can go to http://www.hepatitis-c.com, or check out the hepcvic site.

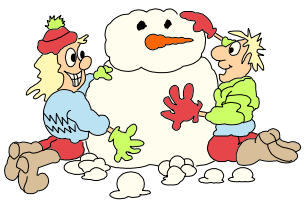
Seeking SF 25-45 for laughter, friendship, sharing and intimacy.
Shane (Alberta)

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. 11

Companion(s) for some fun in the sun this winter. Prefer Eastern Caribbean—Belize, Cozumel, Cuba or ? SWF-61-Christian, healthy lifestyle, is looking for interested support group HCV person(s) to enjoy the great outdoors. Vancouver area.



RESEARCH UPDATES

Early HCV RNA Values After IFN Predict Response.

Wiley, Briedi , Lam, and Layden, from the Department of Medicine at the University of Illinois at Chicago Medical Center report that a PCR test done on a patient at 48 hours after beginning standard therapy with interferon-alpha (IFN-alpha) (3 million IU) may predict response during six months of therapy. In the 17 patients who were positive by bDNA at 48 hr, all were positive at one and three months; and in the nine of nine who continued therapy for six months, there was no further decrease in HCV RNA levels. They concluded that serum RNA values 48 hrs after the first injection predict long-term response.

PMID: 9790449, UI: 99005109 Dig Dis Sci 1998 Oct;43(10):2169-72

CD81 Protein May Be a Virus Receptor

On October 29, 1998, Chiron Corporation announced its discovery that a protein molecule (CD81) located on the surface of certain human cell types binds to the hepatitis C virus (HCV). This discovery could advance the development of new vaccines and therapeutics designed to prevent and treat this disease through targeted therapeutics and vaccines. It provides clues as to how HCV may penetrate and infect human cells.

BW HealthWire

RiboTargets Enters Into Strategic Collaboration With MSI

On October 23, 1998, RiboTargets Ltd. and Molecular Simulations Inc. (MSI) announced the start of a collaboration to develop software specific to both modeling of RNA Targets and design of RNA targeted drugs.

"This collaboration is particularly exciting given recent advances in antisense drugs," said Dr. Scott Kahn, director of Life Science Product Marketing at MSI. "RiboTargets is pioneering the exploitation of RNA targets and we are delighted to play a role in extending simulation techniques to streamline their research," Kahn said.

RiboTargets has ongoing research programs in HIV, Hepatitis C, and the development of antibiotic compounds for the treatment of infections by drug-resistant pathogens.

MSI is a leading provider of molecular modeling, simulation, and informatics software to the world's foremost research and development facilities. Using MSI's innovative products, researchers can organize and analyze scientific data, share biological and chemical information, and develop novel compounds, materials, and processes.

BUSINESS WIRE

EPIDEMIOLOGY OF THE SEVERITY OF THE INFLAMMATION

by Natalie Rock BSN, RN., Hepatology Clinical Research Nurse
UBC Department of Medicine, Vancouver Hospital and Health Sciences Center

Attempts have been made to determine what influences the degree of inflammation in the liver since not all people with hepatitis C have the same degree of inflammation even with the same length of infection. It appears that route of infection and excessive alcohol intake may both be major factors causing more extensive inflammation. Some studies have shown that hepatitis was more severe and the progression to cirrhosis was sooner in blood transfusion recipients and in persons who consumed alcohol on a daily basis. The interaction between alcohol and hepatitis C is poorly understood, although it is generally accepted that alcohol makes the virus more active and potentiates the progression of liver disease.

There is still controversy as to whether genotype plays a role in the severity of the inflammation; some studies suggest that it does and others found no correlation. While some studies have suggested that genotype 2 caused more active inflammation, patients with genotype 2 were older, and there were differences between the quality and distribution of all the morphological lesions in the liver. As well, viral load as determined by PCR has been studied and appears not to be a factor relative to the severity of liver disease. These authors again confirm that genotype does not appear to be a factor

The time it takes for the progression of liver disease has been fairly well studied. On average it takes 18-20 years for the progression to cirrhosis and 25-28 years for the occurrence of liver cell cancer. It has also been shown that patients over 50 years of age progress more rapidly to cirrhosis and the time period is 1.8 times faster than younger patients.

HEPATICO

News Release Mon 16 Nov 98--Mr. Adolf Huckschlag reports:

Following extensive international clinical and preclinical trials, Alta Natural Herbs & Supplements will now begin distribution of Hepatico in Canada. Upon reviewing 17 independent reports regarding the effectiveness of Hepatico on Hep-C, Alta Natural Herbs & Supplements launched independent human tests in Canada and the United States. Preliminary results have confirmed the overseas findings. Based upon the examination of the preliminary results and after comparisons to the European scientific data conducted between 1992 and 1996, Alta Natural Herbs & Supplements is verifying the validity of the effectiveness of Hepatico as a primary therapy for persons suffering from toxic and viral liver dysfunction.

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(HeCSC—Continued from page 1)

not forget that the Hepatitis C Society of Canada was a major force in getting the governments of Canada to make their original compensation offer to financially assist those infected by the blood system during the 1986-90 time period. Now it is clear that the determined efforts of our Society have played a significant part in the additional $1.15 billion being directed to hepatitis C beyond the original compensation offer.

This is an extraordinary achievement, made possible by the leadership of our Society in concert with other non-profit organisations and concerned Canadians.

There have been many non-monetary achievements that are very significant as well:

- In the past 18 months our Society has contributed to raising awareness about hepatitis C among Canadians, from almost nothing to a level where now nine out of ten understand more about hepatitis C and support our Society's goals for assisting those who are living with and affected by the virus.
- All opposition parties are united in their support for our cause. On September 22, 1998, we achieved a first by getting the four leaders, Preston Manning, Elsie Wayne, Gilles Duceppe and Alexa McDonough, to join us on Parliament Hill and speak in support of the needs of hepatitis C victims.
- The Senate unanimously supports compensating all those infected by the blood system.
- We are at the top of the list with the media, who invite us for comments on stories they are writing about hepatitis C and blood issues. The media always covers our advocacy at government conferences and our rallies. These events have occurred in Ottawa, Kananaskis, Whistler, Regina, Saskatoon, Shawinigan, Victoria and other cities. The Hepatitis C Society of Canada is seen to be a very professional and credible organisation in how it deals with the media.
- Our Society's credibility was further confirmed in April and May this year with two opposition motions voted on in federal parliament. First, our advocacy influenced Reform to ask for a vote in favour of compensating all victims of the blood system. Second, the NDP motion asked that the "Hepatitis C Society of Canada be allowed to participate in the government Working Group". The first failed and the second passed.
- Your Society's image is at an all time high among those working within the blood system and hepatitis C. We are invited to all events and conferences relating to these issues. Here are four recent examples;
  - we actively participated on the steering committee to develop a conference on Research into Hepatitis C to be held in January next year,
  - we are represented on the Consumer Advisory Group to Canadian Blood Services (the organisation that replaced the Red Cross) to provide consumer input to the new blood system,
  - we were a member on the Expert Panel that revised downward the number of victims of transfused blood,
  - we were an active participant in the "Hepatitis C: A Public Health Consensus Conference," which will result in significant recommendations in the areas of education, injection drug use, the blood supply, surveillance and public health.

Of course we are still disappointed that our objective of fair compensation for all tainted blood victims of hepatitis C has still not been achieved across Canada. However, we will continue to fight for as long as it takes, even until the next federal and provincial elections.

It's a time to celebrate with you our members the many successes achieved by the direct actions of our Society. We can be justifiably proud of our achievements. In time they will help make life easier for those with hepatitis C. All these achievements have come from our collective determination and advocacy. We have fought hard to right the wrongs of the past, to demand that our governments do the right thing and to treat all hepatitis C victims equally. It has been a collective effort by our members, countless volunteers and your Board of Directors. On behalf of 240,000 Canadians with hepatitis C I want to thank you all from the bottom of my heart.

DR. ANDERSON'S OFFICE UPDATE

by Darlene Morrow

Susan Campbell, RN, has been added to Dr. Anderson's staff. Susan was the coordinator of the Hoffman/LaRoche project into Pegylated Interferon (PEG IFN—a special type of IFN that requires a weekly injection as opposed to the current three times a week injections). Dr. Anderson was setting up a clinical trial in PEG IFN and convinced Susan to join his staff. Susan is a hepatology clinical research nurse and is in charge of his PEG IFN trial. In addition to that study, Susan is also in charge of three Hep B trials.

As new trials are started at the office, either Natalie and Susan will take charge, depending upon how busy they are at that time. I think this is a very good thing for all of us, as it will ultimately lead to an increase the number of clinical trials that Dr. Anderson can investigate.

Susan specialized in Pediatrics at the Winnipeg Health Sciences Center (Hospital) for 15 years prior to coming to BC. We would like to extend a very warm welcome to her and also express our early thanks for all the help she will undoubtedly be doing for us.

The PEG IFN study should be underway soon. This form of IFN will establish a more stable blood level and through that may be more effective. Interested individuals should contact Susan at (604) 876-5122 to learn more about the criteria for entering into the trial.

TRAVEL COST COMPENSATION About TAP:

The Travel Assistance Program is sponsored by the BC Ministry of Health and Ministry Responsible for Seniors.

TAP was created to help residents of BC to access health care services that they cannot obtain unless they travel.

In other words, if you have to travel to get access to specialists in Vancouver, for example, the TAP program will pay for, or give you discounts for your travel costs, such as ferry fares, for you, your vehicle, and for an escort, if one is needed.

Please ask your doctor for a form to complete. You also need to contact MSP to verify your eligibility and to receive a confirmation number before you travel. (Phone number below)

You are eligible if you are a BC resident enrolled in the Medical Services Plan, and your travel expenses aren't covered by other insurance policies. There are regulations such as arriving at the ferry, for example, one hour before departure.

This program doesn't include meals, accommodations, car expenses, or local transportation. You must make your own travel and accommodation arrangements. You may obtain more information by calling MSP at 1-800-661-2668 from 8:30 am to 4:30 PM, Monday through Friday. You may also call 387-8277 in Victoria.

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SHO-SAIKO-TO

Herbal medicine Sho-saiko-to (TJ-9) prevents liver fibrosis and enzyme-altered lesions in rat liver cirrhosis induced by a choline-deficient L-amino acid-defined diet.

Sakaida I, Matsumura Y, Akiyama S, Hayashi K, Ishige A, Okita K First Department of Internal Medicine, School of Medicine, Yamaguchi University, Japan.

BACKGROUND/AIM: A herbal medicine, Sho-saiko-to (TJ-9), has recently been orally administered to patients with chronic liver disease in Japan and has been reported to inhibit the development of hepatocellular carcinoma. The aim of this study was to investigate whether TJ-9 has an inhibitory effect on the development of preneoplastic lesions and liver fibrosis in rats.

METHODS: The effects of the TJ-9 were examined using the choline-deficient L-amino acid-defined (CDAA) diet-induced liver fibrosis

"Sho-saiko-to (TJ-9) prevents fibrosis "

model in 16-week-old male Wistar rats.

RESULTS: TJ-9 (1% w/w) prevented fibrosis, as indicated by reduced hydroxyproline content in the liver and inhibition of the increase in a serum marker of fibrosis (hyaluronic acid), without reducing the increase in serum alanine aminotransferase and aspartate aminotransferase. TJ-9 also reduced the expression of type III procollagen alpha 1 mRNA in the liver, as well as the proliferation of myofibroblast-like cells (activated stellate cells, activated Ito cells). Furthermore, TJ-9 reduced the number of preneoplastic lesions, detected as enzyme-altered (glutathione S-transferase placental form-positive) lesions, in the liver.

CONCLUSIONS: These results indicate that the herbal medicine Sho-saiko-to (TJ-9) prevents fibrosis as well as preneoplastic lesions, not by inhibiting hepatocyte cell death but by inhibiting the activation of stellate cells, which are considered to be the main collagen-producing cells, leading to a reduction in the development of preneoplastic lesions. PMID: 9514543, UI: 98173478

Editors' Note: The National Institutes of Health warn, "Interstitial pneumonia as an adverse reaction to the herbal drug was stated first under Adverse Reactions in the Precautions in April 1 1991. It was then further stated under General Precautions in December 1992. Since interstitial pneumonia was reported in patients with chronic active hepatitis C receiving shosaikoto concurrently with interferon when the indications for interferon were extended to include this disease in the spring of 1991, concomitant administration with interferon was contraindicated in January 1994."

Herbalism and Homeopathy

As a number a therapies use plants in their healing work, confusion exists as to their differences. There are the culturally diverse medical systems of the world that use plants as the core of treatments, such as Ayurveda from India, Traditional Chinese Medicine and Islamic Unani medicine. Amongst western therapies Homeopathy, Aromatherapy and the Bach Flower remedies make extensive use of herbs. The majority of drugs used in orthodox medicine are either derived from plants or are actually plant products.

Homeopathy is the main system of medicine other than Medical Herbalism that utilises plants in the treatment of disease, though in a fundamentally different way to Medical Herbalism. There is a common misconception that these two healing modalities are the same because they both employ plants.

Indeed, herbs are used by both approaches but in radically different ways, reflecting differences of philosophy and therapeutics. The holistic perspective being explored by their practitioners can complement each other, but only when the strengths and weaknesses of each are acknowledged and understood. There is not space here to give homeopathy the attention it deserves, but simply to compare the use of herbs in the two approaches.

As with other approaches to holistic medicine, homeopathy looks at the patients' total picture, both body and mind within the social setting of their lives. The system originated in Germany around 1800, with the work of Samuel Hahnemann. He treated disease with a very low dose of drugs which themselves produced similar symptoms to those of the disease itself. This is the basis of the principle that like treats like.

About 60% of homeopathic remedies are botanical in nature, the rest being minerals, animal products or nosodes. These last remedies are highly diluted extracts of diseased tissue. These medicines are administered in extremely diluted form and are thought to work by influencing the vital force within the human body. The more the dose of the remedy is reduced so the more its potency is enhanced. This is why the homeopathic process of dilution is known as potentiation. The dilation of one part of the active remedy in ten parts of the solvent (usually water) is known as a potency of 1X. A one in a hundred dilution is 2X and so on to 200X dilution. A homeopathic mother tincture is similar to an ordinary herbal tincture.

A problem that gets in the way of mutual understanding between the two. therapies is the application of the concept of like treating like. Many of .the herbs in the homeopathic Materia Medica are prescribed in dilution to treat symptom pictures that a full dose of the herb supposedly causes. This may be the case with very strong or poisonous herbs such as belladona. or gelsemium, but the medical herbalist has problems with the homeopath's ideas about many of the remedies both systems share. An example is the homeopathic remedy pulsatilla, known as Pasque Flower (Anemome pulsatilla) to the herbalist. A comparison of the symptom picture given for the homeopathic remedy is very similar to the indications for herbal dosages of the plant. As both approaches use the herb to treat similar things, this would appear to contradict the core idea.

The value of homeopathy in health care is undeniable, but its use of plants is in no way herbal. Selecting either therapy should be based upon attraction to one or other of their philosophical contexts recognising that there is little or no sharing of botanical medicine.

The Herbalist b*y David Hoffman, (c)1993 David Hoffman, Hopkins Technology*

NEWS FROM HAAC

Excerpt from a letter to Heidi M. Jolson, M.D., M.P.H.
Director, Division of Antiviral Drug Products
From Brian Klein, HAAC-Hepatitis C Action & Advocacy Coalition
November 16, 1998

The FDA should not approve Rebetron for treatment-naive patients in its bundled form. A new advisory committee should be called to publicly review the FDA initial approval of this unprecedented bundled drug combination. This bundling is preventing many doctors and patients with hepatitis C from using these drugs effectively. I call for a review based on concerns of efficacy of these therapies as many patients need to realistically use them.

In an October 15 meeting with patient advocates, Dr. Robert Spiegel, Chief Medical Officer of Schering and Kathleen Hurtado, Vice President of Sales and Marketing, verbally agreed to develop a compassionate use program whereby patients could obtain ribavirin separately from them for use in combinations other than that used in Rebetron. While we wait to see if Schering is actually going to honor the word of their own representatives, the fact that they would suggest a program where HCV patients could obtain ribavirin separately admits to Schering's knowledge that there are safe and clinically effective legitimate uses for ribavirin other than in the Rebetron package; it belies all of their clinical safety and efficacy reasoning they say necessitates the bundled package.

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HOW DO WE DEFINE CURE?

Long-term histologic improvement and loss of detectable intrahepatic HCV RNA in patients with chronic hepatitis C and sustained response to interferon therapy.
Ann Intern Med 1997;127:875-881[Medline] .

Marcellin et al. studied a cohort of 80 patients with hepatitis C who had a sustained response to interferon alfa (IFN) therapy and were followed up to determine the durability of the response. These patients represented approximately 18% of an overall group of 450 treated with IFN at their institution. Sustained response was defined as a normal alanine aminotransferase (ALT) level each month for the first 6 months after completion of therapy and absence of hepatitis C virus (HCV) RNA in the serum 6 months after completion of therapy. HCV RNA was measured in the serum using the Amplicor assay (Roche, Nutley, NJ). HCV RNA titer was measured using the branched DNA assay (Chiron, Emeryville, CA). Follow-up ranged from 1 year after completion of therapy to 7.6 years (mean, 4 ± 2 years). At least one biopsy was performed in 69 patients after therapy, ranging from 1 to 6 years after therapy. Forty-eight of 69 patients underwent liver biopsies a year or more after completion of treatment. The mean interval to biopsy among these patients was 2.2 ± 1.3 years. Histology was scored using the Knodell scoring system. A 2-point reduction in score was noted as "improved," a 1-point reduction and no change was defined as "no change," and any increase was defined as "worsened." Over the follow-up period, 93% of patients had persistently normal aminotransferase levels and 96% remained HCV RNA seronegative. The overwhelming majority had an improvement in liver histology (94%) between the first and second biopsy. Furthermore, liver biopsy findings became normal or near-normal in 60%. HCV RNA was also undetectable in liver tissue after therapy in all patients who were tested. The treatment regimens were variable. Patients were treated with IFN, lymphoblastoid IFN-n1 or interferon-2a. Fifty (63%) were treated in a clinical trial, and 30 received standard open-label therapy. The majority of patients (75%) received IFN at a dose of 3 million units three times a week for 6 months. There was no deterioration in liver function in the 5 patients with cirrhosis and no progression to cirrhosis among the 75 patients without cirrhosis. Fatigue was present in 60% of the patients, and reportedly improved in all patients after treatment. Serum HCV RNA levels were determined for up to 7 years after completion of therapy. Data were available on 53% of responders at 4 years, 30% at 5 years, 18% at 6 years, and 2.5% at 7 years. Ninety-six percent remained negative for HCV RNA; 1 patient had a transient recurrence of viremia, and 2 patients experienced relapse at 24 and 36 months.

Comment. The study by Marcellin et al. provides important new information about the durability of the response to IFN in patients with chronic hepatitis C. Late relapse was uncommon in patients with hepatitis C who had a sustained response to IFN therapy, defined by the absence of HCV RNA in the serum and normal serum ALT levels 6 months after completion of therapy. Furthermore, liver histology was significantly improved or even normal after therapy in all such patients. This is the strongest evidence yet that a virologic "cure" is possible in chronic hepatitis C and, furthermore, that the natural history of hepatitis C is altered among patients with a sustained response. The only major limitation of this study is the small number of patients with prolonged follow-up and the lack of uniform histological evaluation, but these problems are common to all retrospective studies. Forty-eight patients underwent pretreatment biopsy and a posttreatment biopsy more than 1 year after the completion of therapy. Only 6 of 80 patients (8%) underwent biopsy 4 years after treatment. Liver HCV RNA was measured in a total of 27 patients, but at various intervals after therapy and apparently only once in each case. None of the 27 patients with a sustained response had HCV RNA in liver tissue, although 2 had measurable HCV RNA in the serum; it is not clear whether serum was tested at the same time as the liver. If so, this would provide additional evidence for persistence of extrahepatic replication sites for hepatitis C. The characteristics of the population described in the current report provide important additional insight into the factors predictive of a sustained response to IFN in chronic hepatitis C. The majority of patients was younger than 40 years and had the disease for less than 10 years. Most had serum-glutamyl transpeptidase (55%) and iron levels (83%) below the normal range. Furthermore, most patients were infected with non-genotype 1 (67%) and had serum HCV RNA titers less than 350,000 genome equivalents/mL (29%). Seventy-five of 80 patients (94%) did not have cirrhosis. Hoofnagle and Di Bisceglie recently reviewed the literature and found that genotype (other than 1) and viral titer (>100,000 genome equivalents/mL) were the two most important predictors of response (N Engl J Med 1997;336:347-356). Furthermore, genotype other than 1a or 1b was the best predictor of sustained response, which was greater than 40% in patients with genotype 2 or 3. Marcellin et al. confirm these previous observations and provide additional long-term serological follow-up about response to IFN in chronic hepatitis C. However, their study also shows that even some patients who would be considered poor candidates for IFN therapy may respond to standard doses of IFN. The sustained response was 6% among patients with cirrhosis, 33% in patients with genotype 1 infection, and 9% in patients with a viral titer greater than 3 million genome equivalents/mL. This is all the more impressive considering that the majority of patients (75%) were treated with only 3 million units of IFN- for 6 months. However, it is apparent that the sustained responders in this study generally had mild liver disease and were those probably at lowest risk of progression to advanced liver disease. Only 30% had "severe" chronic hepatitis (i.e., Knodell score >9). Therefore, this study once again confirms the difficult paradox in the management of patients with hepatitis C, namely, that the patients most likely to benefit from treatment with IFN are those who may be at the lowest risk of progression to worsening liver disease. Cost-effectiveness analysis may be one way to address the utility of IFN in patients with mild liver disease.

"...patients most likely to benefit from treatment with IFN are those who may be at the lowest risk of progression."

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NO COST OPTIONS

By Chris Landry, Markdale, ON

Over the past several months, options for a compensation package that my group, my own and your input have developed has been forwarded to all of the Premiers, their Ministers of Health as well as the federal authorities, including leaders and key members of the opposition. Their responses have been somewhat "formatted." However recently I have been encouraged by one response in particular, requesting a follow-up meeting in Ottawa. In the spirit of democracy, I am going to provide you with the correspondence flow to bring you up to speed: First my outgoing letter to the MP:

I have written to you previously.

I too am a Hepatitis C victim of the Tainted Blood Scandal, having contracted this disease in March of 1988 as a result of a motor vehicle accident and the 14 transfusions that I required to save my life during surgery. I have had the opportunity of setting up a support group in my area and we now have 16 members, ranging from the widow of a victim, through members who remain asymptomatic, to members who are on various interferon drug regimens. Their dismay is palpable.

This group has discussed their needs amongst themselves and has come up with suggestions for the government to consider, which might allow for the current package to be expanded to include all victims, with little or no additional cost to our Healthcare system or the Canadian taxpayer. These suggestions have been forwarded to all leaders of all parties as well as yourself—apparently to no avail.

We believe that our Federal Government has not truly considered some "No Cost Options." If the federal and provincial governments offered some or all of the following to the victims, enough might take part such that the funds that have been brought forward and budgeted would become sufficient to meet the needs of all the perishing victims. There are many amongst us who are currently able to continue working. Why not allow us to participate in the process of protecting ourselves, our families and our homes? Where is it written that it must cost so much?

Consider, please, for tainted blood victims:

. Lifetime "Tax-free" status for victim and partner

. Income tax deductions similar to "Disabled Deduction"

. Mortgage payment incentives similar to RRSP deductions or previously available RHOSP

. Reallocation of assets without income attribution via RRSP direct to mortgage pay out

. Increased child tax-credit where the child is a victim or the parent is unable to provide care due to illness

The foregoing are all "No Cost" options to either government, requiring no monies to fund the programs.

Consider, please, for tainted blood victims:

. For those victims who are able to continue working; make available income, mortgage, travel, life and health insurance programs at regular rates, charging the individual and/or by guaranteeing the excess mortality with a private insurer. Is this really different from Employment Insurance? The immediately preceding is a "Reduced Cost," potentially "No Cost" option.

Moreover, no one has assessed the needs of our suffering community on an individual basis. No one knows how many we are and what or how much is needed. The consideration of some of the foregoing coupled with an expression of the willingness to work together might actually serve to repeat a 2,000 year old miracle.

It is the opinion of our group that there are 2 issues here:

1) Tax impacts
2) Insurance aspects

The details of the tax impacts unfold, as do the insurance impacts, into various other areas; yet, nevertheless, we are only discussing 2 issues (from our point of view).

I would like, once again the benefit of your thoughts prior to going to Ottawa and meeting with the MP. While there is probably no need to state this, please recall that my strategy involves developing peripheral, low/non-cost items, in order to expand and spread the existing "announced" programs (whatever they are) to include all of the tainted blood victims (primary and secondary) regardless of the date of disease contraction.

My final point: Just as a matter of interest, I was just speaking with the MP and he will make time available to me when I am able to come to Ottawa (I will try to make time over the next week). My impression is that he may be prepared to present this to Mr. Rock and may direct specific questions during "Question Period" which may serve to re-heat the issue. Also, he stated that he was definitely prepared to use his free mailing privileges to allow for a mailing of a document—questionnaire, suggestions etc (not clarified)—to the HepCAN list. This would serve to respond to the "no money" available position that the Society is currently experiencing.

Please note that this member is not a member of the Liberal caucus, but rather a member of HM's loyal opposition.

CLASS ACTION SUITS:

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Before August 1, 1986
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The toll free number to get you in touch with the Hepatitis C Counsel is 1-(800)-229-LEAD (5323).

ONTARIO AND OTHER PROVINCES

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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:
Tricia Plunkett Tel. (250) 479-5369
E-mail: *plunket@islandnet.com*

(HAAC—*Continued from page 6)*

Schering has no intention of unilaterally interrupting their profits or their plan to boost sales of Intron A through this unprecedented approval of Rebetron. Ethics and realistic patient needs in this case do not seem to be of real concern to them. Since the initial Rebetron approval, the FDA has been given facts from many patients on the insanity of this situation. The FDA has a chance to correct a mistake, and help patients to get appropriate treatment. Now it looks as if the FDA is about to make the same mistake twice, by not taking this chance to unbundle Rebetron and make ribavirin available separately with appropriate labeling.