



hepc.bull

BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

July 1999

Issue No. 14

MONKEYING AROUND

From: AOLNews@aol.com

Most Effective Treatment for Hepatitis C May Lie in Body's Own Immune System

**STANFORD, Calif.--(BUSINESS WIRE)--
April 22, 1999**

In a study funded by Chiron Corporation and National Institutes of Health, researchers Stewart Cooper and other colleagues from Stanford University School of Medicine studied six chimpanzees infected with hepatitis C. Four of the chimps developed chronic infection, but the other two seem to have rid themselves of the virus after three months by their own immune systems' reactions. A year and a half later, the two chimps were still virus-free. By studying these chimpanzees, the researchers have found that it is critical for the cells of the immune system to wage a broad assault at the earliest stages of the infection to successfully ward off the virus.

"Only 15 to 20 percent of people seem capable of terminating hepatitis C virus infection naturally—that means at least 80 percent have inadequate defense against it and become chronically infected," said Dr. Cooper, author of the study reported in the April issue of the journal *Immunity*. "By uncovering how the body is naturally capable of fighting off the infection, we now have a rational target for vaccine development."

When Cooper and his colleagues studied the T-cells from the livers of the chimpanzees, they found an important difference between the cells of the infected chimps and those of the animals who overcame the virus. T-cells from the two chimps that had beaten the virus had gone to work early in the infection. T-cells from the chimps that developed chronic hepatitis C had a delayed response, and the T-cells attacked more limited parts of the virus and utilised fewer of the body's immunological defense molecules.

"These results suggest that unless a certain threshold of T-cell response is achieved during acute hepatitis, infection is likely to persist," said Cooper.

The study has helped show a robust T-cell response over an antibody response, at the time of initial infection is vital. Earlier thinking held that antibodies played an important role, but the Cooper study seems to show that it is the T-cells that are critical in defeating hepatitis C. Knowing this

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VACCINE WOES

by Joan King-Diemecke

I had been hearing some talk on the various Hep C internet lists about people not responding to Hep A and B vaccines, which we know are vital for us. (You do know you are supposed to get vaccinated, right?) So I decided to ask my doctor if he could check to see if my vaccines "took." He said that he could most definitely check, and did so. To our surprise and horror, I found out that in spite of taking the whole series of both vaccines, I was not immune to either. Was this due to my being on interferon at the time of my vaccination, or to the fact that I have hepatitis C? Thus began my investigation.

I posted to the HepCAN list, asking for any information people had, and received some interesting comments. One person mentioned (thanks, Ken) that when he was vaccinated at work, two of his co-workers did not "convert." (I don't know if they had Hep C.) I came across one article, thanks to this same person, which spoke of giving interferon to improve the response to the vaccine [*Infect Med* 16(3):205-210, 1999.]. I also received news from Leslie reminding me that there was an article out by a doctor at Walter Reed which says that those on interferon treatment should not be vaccinated because the vaccine won't take (see Leslie's article, *hepc.bull* 12/99, p 7), and I did see a couple of medical articles that spoke about people with hepatitis C often not responding to the vaccines.

Someone from Schering Canada was kind enough to get back to me by phone about my questions. He explained to me that the vaccines are not supposed to be taken with immunosuppressants, but that interferon is not an immunosuppressant. It is an immune system modifier. He also told me that they simply do not know what the combined effects of the vaccines and interferon are. So I guess we have to tell them.

Natalie Rock, from Dr. Anderson's office, got back to me, and said they have had several people who have been on the trials who have had their Hep A and/or B vaccines, and have been tested and the vaccines haven't "taken," like me. What they are doing is having the patients continue with the interferon, if they are on it, have one booster (of each, if both are needed), and get tested again in 3 months. If the patient still

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IN MEMORY OF PAMELA

by Darlene Morrow

I wanted to say something thought provoking. I wanted to say something that would make some kind of sense of the chaos. I can't. Nothing works.

We have lost another one of our members. You may remember Pamela from Vancouver's story in the February '99 issue of the *hepc.bull*. She was diagnosed with Non-A/Non-B hepatitis early in 1988 following surgery that had required a blood transfusion. She felt great after recovery from the ordeal and was told, like so many of us, that it was nothing to worry about. In 1992 she was told that it was Hep C, but that she was a carrier. Between then and early 1998, she received no treatment, no counseling, no help. She didn't feel sick so there was no pressure from her to further investigate. But then her enzymes rose above the magic marker of 1.5x normal and she was sent to a specialist. Her liver biopsy in October 1998 showed cirrhosis stage 3-4 and autoimmune hepatitis.

Pamela died last month. I only met her once, but talked to her several times on the phone. She was so young—only 38. She was so angry with the medical profession for letting this happen to her. I hope she finds peace now in her final resting place.

The ignorance that let Pamela die must STOP. How many other people are walking around with time bombs ticking away? We have to spread awareness of this disease. Testing for antibodies for HCV is not expensive. It needs to become routine. The BC CDC estimates that 40,000 people in BC have Hep C. Many of those don't know. How many more Pamelas will we see?

Russell Gates, died August 7, 98. He was 69. He is survived by his wife, a sister and a brother.

DONATION FORM

Please fill out & include a cheque made out to
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Victoria Chapter
926 View St.
Victoria, BC V8V 3L5

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

DISCLAIMER: The hepc.bull cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the editors, of HeCSC, HepC BC or of any other group.

SUBMISSIONS: The deadline for any contributions to the hepc.bull is the 15th of each month. Please contact: **Joan King-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.

HOW TO REACH US:

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hepcvic@pacificcoast.net
www.pacificcoast.net/~hepcvic/
hepcan@egroups.com

COMING UP IN BC:

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

Comox Valley Liver Disease Support Group
Meetings: Third Tuesday of each month, 7 PM, .
NEXT MEETING: July 15th. Contact: Ingrid or Nicky, 335-9167 or Jeanne Russell ebus96@island.net for location.

Cowichan Valley Hepatitis C Support Services is in desperate need of a meeting place. Contact: Debbie, 748-5450, dduncan@olink.net, or Leah, 748-3432, r_attig@bc.sympatico.ca

Downtown Eastside Hep C Support Group
Meetings: Wednesdays 7:30-9:30 PM, Carnegie Centre 401 Main St., Vancouver. Contact Carolyn: momma@vcn.bc.ca

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NO MEETING THIS MONTH. 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: July 31st. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Kootenay Boundary Meetings: Second and fourth Tuesday of each month, 7 PM, 1159 Pine Ave. upstairs from Lordco auto parts. NEXT MEETINGS: July 13th and 27th. Contact: Brian, 368-1141, k9@wkpowerlink.com or Pat, 364-1555

Mid Island Hepatitis C Society Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St., Nanaimo. NEXT MEETING: July 8th. Contact: Susan, 245-7654, hepc@nanaimo.ark.com

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: July 12th. Contact Dianne Morrisette, 525-3790.

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

Penticton HeCSC Meetings: Second Wednesday of

each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: July 14th. Contact: Leslie, 490-9054, bchepe@bc.sympatico.ca

Prince Rupert Contact: April, 627-7083.

Princeton Meetings: Second Saturday of each Month, 2 PM, Health Unit, 47 Harold St. NEXT MEETING: July 10th. Contact: Brad, 295-6510, citizenk@nethop.net

Quesnel Contact: Elaine, 992-3640.

Richmond Meetings: Fourth Tuesday of each month, 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy, Main Floor, Room 3. NEXT MEETING: July 27th. Contact: Carmel Tanner at Richmond Health Unit, 276-4069.

Sunshine Coast Sunshine Coast Hepatitis C Support Group will be closed for the Summer months. Our next meeting will start up on September 2nd. For more information contact Karen, 885-6413, or e-mail karen_felske@sunshine.net. See you all in September.

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: July 8th. Contact: the CLF, 681-4588 or Darlene N, 685-3813, djnicol@ibm.net or hepcbc@home.com, or Herb, 241-7766, HMoeeller@compuserve.com

Vancouver Support Group NEXT MEETING: Date to be confirmed. CDC Building, 12th and Ash. 1-3 PM. Contact: Darlene Nicolaas, 685-3813, djnicol@ibm.net, or Darlene Morrow, 987-7378, hepcbc@home.com

Vernon HepCURE Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NO MEETINGS THIS MONTH: July 6th and July 20th. 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: July 14th and July 28th. Contact: Sharon, 542-3092. sgrant@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: July 28th. Contact: 388-4311. hepcvic@pacificcoast.net

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

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: JJ Camp, David Klein, Bruce Lemer, David Anderson, Steve Orcherton, Barbara McVagh, United Commercial Travelers, PECSF, CFX 1070 Radio, Pacific Coast Net, Island Internet, Inc., Microsoft of Canada, Jim Pattison Group, Paradon Computers, and CompuSmart. We also wish to acknowledge an anonymous agency which has generously supplied us with government surplus computer equipment, London Life, Uncle Dave and some wonderful anonymous donors.



Reminder: Any change of address, phone number or postal code, please let your phone contact (in Victoria) or your chapter secretary know ASAP
HeCSC Victoria Tel. (250) 388-4311
hepcvic@pacificcoast.net

REPRINTS

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





SQUEEKY'S CORNER

The Editors, *hepc.bull*

Like many of you I have been attending meetings, reading the *hepc.bull*, and showing up at rallies without much thought about how or who was responsible for the organising of all these events. I decided to get more involved a few months ago and I am now completely in awe of the few people who seem to do all the work for the Victoria Chapter. You cannot possibly know how lucky you are in your choices when you elected the steering committee. They are completely dedicated to helping all those who have been unlucky enough to contract hepatitis C (no matter how).

However, unlike the majority of the members, they commit themselves every day to educate, inform, solace and support, not only the victims of this insidious disease, but the general public, politicians and the medical community. What is more, they are doing so with very limited funds. Another fact is that they are also suffering from the effects of Hep C—the insomnia, itches, aches, pains, exhaustion. You name the problem and they probably know the symptoms first hand.

The reason I am writing is to request that all the members of Victoria Chapter consider how you can help **your** committee members. There are several events, ongoing and onetime, scheduled for the coming months which require a lot of help. The HepFest in July, the *hepc.bull* monthly, fundraisers like the cookbook, staffing the office, all need your support and assistance. Surely, there is something every one of you can do. I do not think that an hour or two a month is too much to ask of you to ensure that the good works of the committee continue and do not die because of burnout due to lack of support.

A volunteer or volunteers are desperately needed to help with the *hepc.bull*. In case you didn't know, David, Joan and Darlene are responsible for every step of the process of writing, editing, publishing and mailing this bulletin. It does not appear in its very professional form because someone is paid to do it. It is a labour of love by these wonderful people. Maybe you cannot write or do research, but maybe you can fold and stuff and stick on address labels. Maybe you can look after picking up the printed copies and bring them to the office for completion. Maybe you can take care of the mailing, which David has been doing pretty well on his own. It is organised, but many more people are needed each month to make sure it goes out on time. Think about it. Wouldn't it be nice to be part of this worthwhile project? By the way, it serves every province in Canada. It is the only publication of its kind as far as I know.

The HepFest, scheduled for July 16th to 18th in Victoria, is another project that will need willing hands if it is to be a success. There will be something of interest for everyone. A large yard sale is planned. Organisers are needed. Do you like buying and selling? Offer your services for this weekend. A fun run is in the works. Plan to attend. Get an able-bodied person to push your

wheelchair, hospital bed, wagon, whatever. Sign up sponsors. Dress in silly costumes. Have some fun. There will be a potluck. Cook up a storm. Please!

Judith Fry is the office manager of our new office and she is pretty well holding the fort by herself. It does not take physical health to answer the phone for our Society and try to help others in the same boat. There are friendly folks working in the same office, coffee and goodies and conversation. It is more a visit than work. Put your name down for a few hours each week. You will be glad you did.

Can't get out? You certainly can use the phone. Joan could use phoners to let members know about upcoming events. It only takes a half-hour a month of your time. It is something anyone of us can do.

I do not wish to berate anyone. I only wish to educate you as to the running of this wonderful organisation. Victoria Chapter HeCSC is the only line of defence and education for all the sufferers of this disease. **DO NOT** let it fail for lack of support. Every one of you can help in some way. I am begging you to please, please, please offer your support in any way you can.

Arlene Darlington

SPECIAL THANKS

This month, I'd like to take a moment to thank some of our givers. Givers aren't always those who give cash; sometimes givers give products, time or services. This month we were quite fortunate in receiving a large cash gift from [Schering Canada](#) in order to continue publishing the bulletin, and for that we are truly grateful. But we also received other gifts. I would like to thank **Nickolas Burger** and the rest of the staff at [CompuSmart](#) in Victoria for continually being there to help us solve computer problems, and at no cost to us. In the last month, I had to get an older machine internet ready and had no documentation for the modem settings; the staff spent a good hour figuring it out for me. And last week, **Nickolas** spent a good half-hour helping me solve a problem with our Webpage—and all for free. The staff at [CompuSmart](#) know we don't have money to buy the latest equipment, and I'm constantly bugging them; but they help us anyways. I'd also like to thank **Bernie Lambert** at [Paradon Computers](#) for helping us rescue our older donated computers, for waiving the labour charges, and always trying to help us cut costs, and also **Barbara McVagh of London Life** for donating a superb Xerox copier—something really handy for printing out fliers for the Fun Run. Of course, a very special thanks to **Rick Wiertz of AM 900** who has adopted our Fun Run as a personal project, and to **Fatima Jones** for organising the whole thing in the first place. Last thanks to all the volunteers who have helped us this month, and a special one to **Judith Fry** for keeping the office in one piece. What else can I say, but thank you. *squeeky*

Educating the Workforce

By Frank Darlington.

On Tuesday, June 8, 1999, Ron Thiel, co-chair of the Victoria Chapter, Hepatitis C Society of Canada, met with Ernie Iwasco of the Telecommunications Workers Union (Victoria Local 2). Ron was accompanied by Chuck Stark and Frank Darlington, who are life members of the union and are both victims of hepatitis C, as is Ron.

Ernie Iwasco is the current serving officer on the Health and Safety Committee of the union. The TWU has become involved in the safety of its members working in the high-risk area of Vancouver's skid row, installing equipment and collecting coins from pay phones.

Protection from contracting hepatitis C was the primary topic of this meeting. The TWU representatives will be attending a province wide safety/health seminar with BC Tel management to express concerns. They will be demanding that all TWU members be made aware of the dangers of blood to blood contact and that the employer (BC Tel) will make available Hepatitis A & B inoculations and provide safety products (gloves, etc.) and information about hepatitis C.

The Telecommunication Workers Union is one of the largest in BC, with approximately 10,000 members. This health and safety meeting will provide a wonderful opportunity to educate the union members, and most important of all, will continue to open doors and save lives.



TO THE EDITOR

Hi Squeeky!

Thanks for your call the other day. Just wanted you to know and please pass it on to all the others in the Newsletter production staff, that the recent pamphlet enclosure GIVE LIFE: BC TRANSPLANT SOCIETY was a great idea! For years I've assumed I could never again be an organ donor because of my HCV infection, just as after years of blood donation, that is also no longer an option.

After reading the enclosed pamphlet, however, I phoned the toll free number and talked at length with a woman there who said that yes, indeed, we could still be on the organ registry, and seemed surprised when I mentioned that many HCV people had the same thoughts as myself. I also let her know that if not for the enclosure in our *hepc.bull*, I still would be under this wrongly assumed notion. So, after filling out the Organ Donor Registry Card and mailing it to BCTS, my day was ended on an even better feeling of perhaps making a difference.

Again, thanks!
Sheila Evanson

Note from squeek: It was Joan's idea

DOWNTOWN GROUP

The downtown Eastside Hep C Support Group will be meeting on Wednesdays, 7:30-9:30 PM, at Carnegie Centre, 401 Main St. in Vancouver, BC—yes, the notorious corner of Main and Hastings, so come on down and visit us. Actually we have some wonderful spots down here. We are not far from Aun Yat Sen gardens, Gastown, and the 2nd largest Chinatown in North America. Our community centre is one of 2400 that Andrew Carnegie built in North America, and we have one. It is a beautiful old building, and we have a lot of programs, including low cost lunches, several support groups: diabetic, AIDS, drug and alcohol, seniors program, plus tai chi, a pool room, library, TV room, theatre, the best staff (most of them) and me !!! :-)

Carolyn
HEP C SUPPORT GROUP
CARNEGIE CENTRE 401

CONTACT INFO FOR NB

Local efforts are underway to form a Hepatitis C Support Group for Saint John, New Brunswick. Meetings are held at 7 PM on the 3rd Thursday of every month at the Community Health Centre - (506) 632-5537 - located at 116 Coburg St., Saint John, New Brunswick E2L 3K1. Contact: Audrey Knight, kknight@nbnet.nb.ca

NEW VANCOUVER SUPPORT GROUP MEETING

Darlene Morrow and Darlene Nicolaas will be hosting a monthly support group meeting in the afternoon from 1-3 pm. The first meeting will be in September. The meetings will take place at the CDC Building on 12th at Ash Street (next to City Square Shopping Mall). The room number and day will be confirmed in August. Please call Darlene Nicolaas (djnicol@ibm.net) at 685-3813 or Darlene Morrow (hepcbc@home.com) at 987-7378 for more info.



Barbara McVagh
Suite 380, 3795 Carey Road
Victoria, BC V8Z 6T8
Tel (250) 475-1100

Freedom 55
The freedom to choose.
The power to get there.

HepC BC The Hepatitis C Education and Prevention Society

Hepatitis C Support Group Members:

We are pleased to announce the incorporation of HepC BC - The Hepatitis C Education and Prevention Society. Please let me introduce the founding members of this group: Joan King-Diemecke is Editor-in-Chief of the *hepc.bull* newsletter, past chair of HeCSC, Victoria, and founding member of the Hepatitis C Clinical Trials Research Group (HepCTRG). C.D. Mazoff, PhD. (Squeeky) is currently co-chair of HeCSC, Victoria, co-editor of the *hepc.bull*, webmaster of *hepcvic*, Victoria's HCV link to the internet, founding member of HepCTRG and co-list moderator of HepCAN, an online support group for HCV. Darlene Nicolaas is past co-chair of the HCV Vancouver Support Group. Ronald E. Thiel is current co-chair of HeCSC, Victoria. Darlene Morrow is webmaster of HepC BC, co-editor of the *hepc.bull*, co-list moderator of HepCAN and founding member of the HepCTRG.

We are in the process of forming the medical advisory board and wish to extend a warm welcome to Dr. Martin Schechter, National Director of the Canadian HIV Trials Network, Dr. Mel Kraiden, Associate Director of the BC Centre of Disease Control Laboratory, and Dr. Frank Anderson and Natalie Rock from Vancouver General.

HepC BC is a legally incorporated not-for-profit voluntary association formed, in part, to increase our fundraising capabilities. It is our desire to join all the support groups within BC so as to provide increased support and networking. We would like to do the following:

1. Provide computers to support groups so that everyone will have access to the Internet.
2. Provide province-wide Internet service so that everyone can keep abreast of news and developments as they happen.
3. Provide support for the computers so that all documents and programs are compatible.
4. Provide the *hepc.bull* monthly along with your support group info as part of that newsletter.
5. Provide FAQs (Peppermint Patti's frequently asked questions) to all newly diagnosed people.
6. Provide the pamphlet series that we have developed to help you promote HCV awareness in your area.
7. Act as a central organisation to help with Disability and other Advocacy issues such as Patients' Rights.
8. Organise a fully co-ordinated provincial team to increase our effectiveness by avoiding duplication of efforts and providing common goals and focuses.

To aid us in this organisation of efforts, we would like to form executive committees made up of elected representatives from each support group.

(Continued on page 5)

MID ISLAND HEPATITIS C SOCIETY

Our great news is we should soon have a downtown office in Nanaimo. We're proud to announce that Gary Korpan (Nanaimo's Mayor) and Reid Elley (our Reform MP) have joined our board of directors. Our NDP provincial MLA, Dale Lovick, has promised me he'll try to arrange for us to have a meeting with Penny Priddy to discuss our concerns. We are looking forward to that and hope he is successful, but he told me she and he are pretty busy, right now. Heh hrrmmm? I told him we only need a little time, while we are living, please. We certainly do appreciate the fact that he is going to try ...

We are in the process of planning a 'fun' fund raising project that will be sure to attract the press and the public ... will keep you informed.

We had a wonderful time and the group truly enjoyed Joan, Squeeky and the Reaper at our last meeting. They brought a lot of information about Hep C and related health issues to our attention, and I just wish we could @copy and @paste all of their information about the disease into our own brains. Thank you, guys, for coming up and sharing. We're planning more meetings with knowledgeable guest speakers for the upcoming meetings.

Thank you, Peter and Pat Dolan, from Tim Horton's Donuts on Bowen Rd., Nanaimo. They quietly and faithfully supply donuts for every monthly meeting. They've never asked for recognition, nor do they know our members; they just do this out of the goodness of their hearts. It's people such as Peter and Pat that give us faith in this world and our fellow humans.

Meetings 2nd Thursday of every month at 7 PM at the Health Unit-Central Vancouver Island, 1665 Grant St. Nanaimo. Next meeting July 8th. Contact Susan: 245-7654

We have an email address now too! Contact Susan: hepc@nanaimo.ark.com

A note of appreciation this month to **Lou** at **J & L Copy Plus** 777 Fort Street in Victoria, for giving us a SUPER DEAL on Fun Run posters.

Tel: 386-3333
Fax: 286-3312

jlcopy@islandnet.com



(HEPC BC—Continued from page 4)

This will happen immediately for the Lower Mainland and Vancouver Island. These executive committees would meet on a monthly basis so that everyone can keep in touch with what is going on, brainstorm, re-energise and problem solve any concerns within the local support groups and plan the agenda for the upcoming month. The meeting will take place electronically, in person or by any means necessary so as not to exclude anyone.

These meetings will take place in the Lower Mainland at the CDC Building at 12th Ave and Ash (next door to the Cambie City Square Mall) beginning in September. Please email us (hepcbc@home.com or djnicol@ibm.net) if you are interested in taking part or call 685-3813 or 987-7378. Those on the Island, please contact hepcvic@pacificcoast.net or call 388-4311.

We invite your ideas and participation and look forward to energising our efforts through the continued support of all people with hepatitis C.

Sincerely,

Darlene Morrow

TO THE EDITOR

I have been a member of the Hepatitis C Society of Canada, Victoria Chapter, for about one year. I was looking forward to travelling to Toronto for our conference this Summer, as I have become rather disillusioned with the head office due to lack of info, lack of support, and no communication. I was completely dismayed when I received my proxy package in the mail. It arrived on May 13th, demanding a reply, along with a \$20.00 registration fee, directions for hotel reservations—Days Inn for example (\$135.00 plus tax per night)—leaving virtually no time to prepare to travel. A plane ticket with Westjet was going to set me back another \$479.00 plus tax, which, because I'm on a pension like so many others, made it impossible to attend. Voting by proxy for people I've never met is out of the question. How is this going to help me deal with hep C?

Thanks a lot, Toronto. Some day I'll figure out just what it is you do. You certainly haven't helped me.

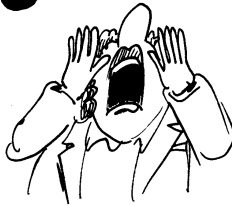
Disillusioned in Sooke,

Ken Crews

“The newsletters are well done, because they are helping patients understand what hepatitis is, and how to better cope with it. Keep it up David!”

Mike Betel HepNet

Volunteers!



(VACCINE WOES—Continued from page 1)

shows no immunity, then they have them get revaccinated with the whole series, but with a different brand of vaccine. She also says that no one really knows, which is what the Schering rep told me, too. The moral: Get tested to see if the vaccine took. And if you haven't been vaccinated, please do so. Good luck. (In Victoria, both vaccines can be obtained free of charge from the CDC on Cook Street through your family doctor, if you have hepatitis C.)

From the Helix Site, Marnie L. Peterson, PharmD

http://12.4.5.24/helix/resc/trends/pharmacy/aug97_in_rereview/ce_text.htm

About the hepatitis A vaccine: Persons receiving immunosuppressive therapy or having other immunodeficiencies may have a diminished antibody response to active immunization. These persons may require additional doses of vaccine or may be deferred from vaccination and may require passive immunization with IG.

About the hepatitis B vaccine: Boosters should be given if antibody levels decline below 10 mIU/mL. Dose 40 mcg (2x20 mcg.)

From "Ask the Experts" at the Immunization Action Coalition, by Linda A. Moyer, RN, and Harold S. Margolis, MD

<http://www.immunize.org/catg.d/p2021a.htm>

“...hepatitis A vaccine should be given to all susceptible patients with chronic liver disease. Hepatitis A vaccine is very immunogenic and the patient's diminished immune status due to interferon should not affect the immunogenicity and effectiveness of the vaccine, although there are no data to support that statement. Studies still need to be done to address this issue. Current assays are generally not adequate for hepatitis A postvaccination testing as protective levels of antibody produced by vaccination may be at a level that the test cannot detect.”

“...interferon treatment should not preclude hepatitis B vaccination. Postvaccination testing, however, should be done 1-2 months after the last dose of hepatitis B vaccine to assure adequate protection.”

HELP!

Has HeCSC Victoria helped you? Now's your chance to return the favour!

We are planning a rummage sale to help raise funds for HeCSC Victoria, and we need volunteers desperately. It will be held during HepFest, on Saturday, July 17th, at the same time as our speakers, so ideally, we need volunteers to man the tables and sell the items who are not especially interested in hearing the speakers. Do you have family members or friends who would be willing to do this? Please call the office and leave a message: 388-4311.

We also need:

1. Donated items, cardboard boxes, and plastic bags. To drop off items, please call Jean Day at 370-1587, effective immediately. To arrange for pickup of items on July 9th and 10th, please call the office at 388-4311.
2. Strong people with cars or trucks to pick up donated items on July 9th and 10th. Call the office, please.
3. Clothes racks. Contact the office.
4. People to price the items on July 14th. We're having a little Pricing Party. Please call Jean Day at 370-1587 to find out about the time.
5. Strong people with cars or trucks to transport items to the sale early on July 17th. Contact the office, please.
6. People to set up the tables and display the items. Contact the office.
7. People to clean up afterwards, and strong people with cars or trucks to deal with any unsold items. Please contact the office.
8. People to put up signs along the street before the sale. Contact the office.
9. People to take signs down after the sale. Contact the office, please.

(MONKEYING—Continued from page 1)

is important in developing a vaccine against the disease.

Efforts to find a treatment have been hampered by the fact that the virus will not grow in liver cells maintained outside the body, and by the fact that the only animal model for hepatitis C is the chimpanzee, which has an immune system almost identical to a human's. Some people seem to have overcome hepatitis C infection naturally, however these people are difficult to find and haven't been studied in detail. Thanks to his animal research, Cooper has the methods to go back and study the immune responses of people who have spontaneously rid themselves of hepatitis C virus.

CONTACT:

Stanford University Medical Center
Stewart Cooper, MD, 650/723-5469 (For Comment)
<http://www-med.stanford.edu/center/communications>

HERB AND DRUG INTERACTIONS

- **Echinacea**, if used for more than eight consecutive weeks, could cause liver toxicity and should not be used with drugs such as **anabolic steroids**, **amiodarone** and **methotrexate** which are toxic to the liver as the affect may be additive.
- **Feverfew, garlic, ginger, ginseng, and ginkgo biloba** all affect bleeding time and should not be taken by patients using **warfarin** or by patients that have **decreased platelet counts**.
- **St. John's Wort** should not be taken with **monoamine oxidase inhibitors** or selective serotonin reuptake inhibitors like **Prozac** and **Paxil** until more information is available.
- **Licorice, plantain, hawthorn and ginseng** may interfere with digoxin therapy and valerian root should not be taken when **barbiturates** are used because it could cause an increase in the barbiturate effects.
- **Evening primrose oil and borage** are contraindicated in patients taking **anti-convulsants** (e.g., **clonazepam**).
- **Immunostimulants** such as **echinacea** and **zinc** should not be given with immuno suppressants such as **corticosteroids** (like **prednisone**) and **cyclosporine** and are contraindicated in patients suffering from **rheumatoid arthritis**, **systemic lupus erythematosus** and **autoimmune hepatitis**.

Source: Hans Larsen is a health sciences researcher living in Victoria, British Columbia from *Alive Magazine March 1999 with some changes by D. Morrow*



Update on the RCMP Blood Task Force

The following is from a letter to Leslie Gibbenhuck: we ran out of space this issue, so here's the main points:

The RCMP's Blood Task Force Investigation remains on track and is progressing extremely well. While information about "systems and science" is still important, the Task Force is now in a position to concentrate on certain decisions taken about blood and blood product distribution in Canada between 1980 and 1990. It is important that the public understand that, while the investigation has not reached any final conclusions, interviews with key players in the Canadian blood system continue to provide the Task Force with an ever greater understanding.

On June 15th, 1999, an investigator with a medical background will join the Task Force full-time. His involvement will enhance the existing expertise and, as such, be very valuable to the investigation. Sherry Christie, our Victim's Coordinator is now on maternity leave and is being replaced by Heather JAMEISON on June 15.

Anyone with information relating to the investigation is asked to call the TIPS line at 1-888-530-1111

HCV AND CHILDREN

By Natalie Rock BSN, RN,
Hepatology Clinical Research Nurse

UBC Department of Medicine, Vancouver Hospital and Health Sciences Center

HEPATITIS C IN CHILDREN

The commonest reasons children receive blood transfusions are for bone marrow transplantation and in the management of other malignancies. A significant number of these children survive their primary disease and may thus be at risk also for hepatitis C.

The extent, course, and management of chronic hepatitis C in children has not been well described, although many studies are currently underway. It is still somewhat controversial as to the progression of chronic hepatitis C in children, although there is less controversy over the efficacy of management. A summary of present knowledge follows below.

INCIDENCE

There have been a few look-back studies to determine the incidence of chronic hepatitis C in transfused children, one of the largest being done in Canada by Dr. Eva Roberts. The incidence of hepatitis C among children is not dissimilar from adults, with seropositivity being from 1.4 to 3.2% of the population. As well, like adults, 80-90% of children exposed to hepatitis C will become chronic carriers.

NATURAL HISTORY

There is some controversy as to the course of chronic hepatitis C in children. There have been a number of European studies that suggest the disease is mild and that progression to clinical liver disease is uncommon. A number of points are important, however; many of these studies only followed the patients for less than ten years, and these patients were diagnosed with hepatitis C after 1990. There are differing reports as to the number with enzyme elevation and the degree of enzyme elevation, but it seems that enzymes are less significantly elevated in children than in adults. It is important to note, however, that none of the above studies included liver biopsies and follow-up was completely clinical. There have been a few studies that have included liver biopsies. These studies have shown that the type of liver pathology seen in children is the same as in adults, and that there is progression to fibrosis and cirrhosis. Although the follow-up in these studies was generally less than 10 years, it is suggested that the course of chronic hepatitis C may be longer in children with a greater tendency for remission and exacerbation. It is thus possible that if followed long enough the occurrence of cirrhosis may be the same as in adults, but this had not been demonstrated clearly in any study.

Many studies of chronic hepatitis C in children have not included liver biopsies. A recent paper, (Guido 1998), has suggested that biopsies are helpful and should be considered. Liver biopsies in children are relatively safe, although actual risk figures are not well-documented.

TREATMENT

There was initially some hesitancy in treating children with chronic hepatitis C, but more and more papers are reporting results. Children do seem to tolerate interferon well, and side effects are short lasting. The response rate to interferon in children is encouraging with reported responses from four centres ranging from 33 to 56%. A response has generally been considered as normalisation of enzymes and a negative HCV RNA, and a sustained response rate was generally obtained. One study did include liver biopsies which confirmed the absence of HCV RNA in the liver tissues of those responding, as well as improvement in the Knodell score (fibrosis). Similar to adults, those children with lower serum HCV RNA levels had the best response to therapy, and also similar to studies in adults, genotype 1b was the commonest genotype.

There have been no reported studies of combination interferon and ribavirin therapy in children.

TROVAN WARNING

From: "Group Seeks Ban of Antibiotic Trovan" by LAURAN NEERGAARD, AP Medical Writer, WASHINGTON (AP)

One hundred forty cases of serious liver damage have been reported among Trovan users since February 1998. While most recovered after stopping the antibiotic, five patients died and three required liver transplants. Trovan is an antibiotic made by Pfizer, Inc. The consumer advocacy group Public Citizen has petitioned the Food and Drug Administration to ban Trovan.

The European Union last week warned Europeans to stop taking Trovan if they experience symptoms suggesting liver damage, such as fatigue, yellowing of the skin or eyes, stomach pain with nausea or vomiting, or dark urine. Officials call the risk rare, since Trovan has been prescribed to 2.5 million people.

The FDA called the liver problems serious. The FDA often approves drugs with liver risks as long as doctors are warned to monitor patients carefully so they can stop the drug if a problem arises.

TRIBUTE TO TONY

As a tribute to the death of our son and brother Anthony John French, who died at exactly 6 p.m. on September 20, 1996 at the age of 37 and one quarter years as a result of contraction of Hepatitis C from a blood transfusion contracted in 1988 when even the Government of Canada admits they had available a test which would have prevented his infection.

Adapted from Tony's Eulogy and presented to Minister of Health David Dingwall on January 18, 1997

Mr. Minister

I became involved with the Hep C cause only in the last year with the sudden death of my little brother. Tony was the best man and best company I ever had. Tony never took advantage of anyone in his life and was scrupulously honest, never mistreating in any way any living thing. He was a scratch golfer, an excellent fisherman, a devoted son and a loving brother. He never drank, never had so much as a marijuana cigarette, and had had relationships with only a handful of women.

Tony had lived with kidney disease and with thrice weekly dialysis for eighteen years. On April 14, 1988 he received a kidney transplant, which promised a healthy future, and was, in our family's case, the best of days.

But for some reason, his health never really improved after the first year or so after the transplant. Although Tony had never drank, and was meticulous in his diet and anti-rejection drug administration, he struggled with jaundice, severe joint pain, weakness and general ill health, and unending bouts of itching and ongoing fatigue. In 1994 he contracted melanoma on his back, which he had cut out in monthly operations for over a year.

In early 1995, for some reason, his physicians began doing liver tests and biopsies. Tragically, on Thanksgiving Day of 1995 they advised him that he had hepatitis C, contracted during his transplant.

When he received the gift of life with a kidney transplant, he also received a gift of death by way of transfusion.

Tony had beaten kidney disease, and had cancer cut from his body every month. He had approached all of his illnesses and everyone of his 33 surgical treatments with his approach to life—keep spirits up, fight through it, move on, and look forward to his share of good fortune.

When he called me during Thanksgiving dinner in 1994 the spirit was gone from his voice. The voice of the man who faced cancer bravely was shaking. He explained to me that there was no cure for hepatitis C, nor was there any satisfactory course of treatment. This time he was not the victim of a bad break, or statistical possibility, he was the victim of the actions and inaction of other human beings. Although he had never disappointed another person, others had very seriously let him down.

In 1996 his health got steadily worse, with severe problems and pain in his liver and gall bladder. To do his part in improving his health, he quit smoking and went on a no fat diet and lost 30 pounds from a normal frame.

An operation in September of 1996 to remove a degraded gall bladder, and a subsequent cancer test on his liver resulted in complications that led to his death, and the death of all enthusiasm in an ordinary Canadian family.

Tony spent his last months as a devoted volunteer, helping other people sick and dying with hepatitis C. His commitment to these brothers and sisters was his legacy to our family, and we carry on his commitment to this day.

Tony was buried on Terry Fox Day of 1996. He is our Terry Fox. I humbly make the same request of you, Minister, that I made to the hundreds of my fellow Maritimers at Tony's eulogy. Next September, when you hear Terry Fox's name, please also recall the heroism of my brother, Tony French, and the thousands of other Canadians who are trying to survive sicknesses caused by and associated with hepatitis C.

My colleagues are ordinary Canadians, who share only the commonality of stories like the one I just shared with you. We are activists only in our common mission of trying to make better the lives of hundreds of thousands of Canadians who share the effect of Hep C.

We deeply appreciate the caring and willingness to co-operate that you are proving by being here today. We responded completely and honestly to the Krever Commission. Our purpose in this meeting is not to apportion blame, nor to be anything but a partner with you and your colleagues in solving a major Canadian humanitarian and health crisis.

Our Society decided that we would view this meeting as the first step in a longer journey, not as an opportunity to draw attention to our cause, and not as an opportunity to make you personally an outlet for the frustrations that our members have in the government or in a system.

We promise you that we will be forthright in trying to accomplish our mission, and we pledge honesty and integrity in our dealings with you and the Canadian governments as we work together to improve the quality of life of sick Canadians.

Brian French

CLASS ACTION SUITS:

BRITISH COLUMBIA

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



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

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

also:

Dempster, Dermody, Riley and Buntain
William Dermody
4 Hughson Street South, 2nd Floor
Hamilton, Ontario L8N 3Z1
(905) 572- 6688

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

ONTARIO AND OTHER PROVINCES

Pre 1986/post 1990
Mr. David Harvey
Goodman & Carr
200 King Street West
Suite 2300
Toronto, Ontario, M5H 3W5
Phone: (416) 595-2300
Fax: (416) 595-0527

CLASS ACTION FOR CHILDREN

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

or

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

TRACEBACK PROCEDURES:

INQUIRIES-CONTACT:

The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-(888) 332-5663 (local 207)

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

CLASS ACTION/COMPENSATION

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

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

First Annual Northwest Hepfest: Schedule of Events

FRIDAY JULY 16:

ARRIVAL OF VISITORS FROM OUT OF TOWN

Volunteers needed to billet guests.



BARBECUE AND HOOTENANNY FEATURING THE UNRENOWNED—HEPCATS!

Need backyard for barbecue, and a nanny to hoot.

Come see Joan squeak her fiddle, Squeek bellow on his accordion, Ron reap in anguish, Judith fry, and Ken cruise (naw, sing & strum his geetar!)

SATURDAY JULY 17:

RUMMAGE SALE

First Metropolitan United Church: 932 Balmoral Road **9:00 AM-12 Noon**

Volunteers needed.

SPEAKERS (so far)

Location: Church of St John the Divine Lounge,
1611 Quadra Street

10:00 AM-12 Noon: Transplant Forum. Guests include, David Smith, Michael Bunyard (Prankster), Ed Conroy, MLA, and Sharon Barnard.

12 Noon-1:00 PM: Potluck Lunch

1:00 PM-2:00 PM: Presentation on Chinese Medicine: Focus on natural pain management. Dawn MacDougall & Brian O'Malley from the Can College of Acupuncture & Oriental Medicine.

2:00 PM-3:00 PM: Dr. Bob Hogg, St Paul's Hospital: Overview of the recently published HCV Quality of Life Survey.

3:00 PM-4:00 PM: JJ. Camp, QC on the Compensation Plan & More.

SUNDAY, JULY 18:

FUN RUN

9:00 AM: 2nd Annual Run for Life, Lochside Park



Both the American and Canadian HCV Quilts will be on display.

Come and see them!!