

# hepc.bull

# BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

## December 1999

#### Issue No. 18

#### **BLOOD SPILLS**

DO YOU KNOW HOW TO SAFELY CLEAN UP A SPILL OF BLOOD OR BODY FLUID? THIS ARTICLE WILL TELL YOU HOW.

> by Mark Bigham, MD, FRCPC, British Columbia Centre for Disease Control

Hepatitis C virus (HCV) is transmitted mainly by exposure to HCV-contaminated blood. HCV infection is not generally associated with exposure to other body fluids, such as saliva, urine, feces or vomit, but if HCV-contaminated blood is present in these or other body fluids, then the risk of infection will be greater. Therefore, it's important to treat any environmental contamination of blood or body fluid as potentially infectious. The simple principles of cleaning and disinfecting, which are effective against HCV, are also very effective against other microorganisms.

Viruses can only reproduce inside cells and HCV will not survive very long outside the human body—usually no more than a few hours. Survival of HCV in the environment is limited by such factors as lower temperature and dryness. HCV is also readily killed by standard household products, such as 5% household bleach or 70% isopropyl alcohol.

If you encounter a spill of blood or body fluid, the most important infection control principle is to avoid direct contact. This is easily and effectively achieved by wearing rubber gloves—preferably single use, disposable vinyl gloves, or even household rubber gloves. Litter, such as broken glass should be picked up first. Try not to handle broken glass that could tear the gloves. Pieces of stiff cardboard or newspaper folded over can be used to pick up glass. When disposing of glass, wrap it in a newspaper before throwing it in the garbage bag, to protect municipal waste disposal workers from being cut when handling the bag.

Next, clean up the visible blood or body fluid with plain water and disposable paper towel. Using water will dilute the spill, reduce its infectivity, and facilitate wiping up the spill. Cleaning the visible spill will also remove organic matter that can reduce the effectiveness of disinfectants. The used paper towel can be put in a plastic bag (double bag if very wet and dripping) and disposed of in the regular household garbage.

A disinfectant should then be used. Regular 5.25% household bleach is an excellent disinfectant choice—it is inexpensive; has low toxicity and is not usually irritating to the skin; is fast acting; and is very effective not only against HCV, but also other blood-borne viruses (e.g., HIV, Hepatitis B virus), bacteria and fungi. It can be diluted with water to make a 1:10 to 1:100 bleach solution. The diluted solution should be prepared fresh, since bleach degrades over time when exposed to air or light. It can be wiped onto the surface with a towel and left to air dry, or poured onto the affected area and then wiped up with disposable paper towels after 10 minutes. An effective, alternative disinfectant for use on coloursensitive fabrics or materials is 70% isopropyl alcohol, full strength, and applied in the same manner as described for bleach.

Gloves can then be carefully removed and disposed of in the regular household garbage along with the used paper towels. Reusable gloves can be rinsed in water and dipped or wiped in disinfectant and allowed to air dry. Finally, don't forget to wash your hands.



The Victoria Bus Ad

#### JUDE SAUCIER

Jude Saucier, from Louisiana, passed away this past month from a massive heart attack. He was 39. We are all saddened by his passing, and had no idea he was so ill. He had been in contact with our group here in Victoria over the years, by telephone and by email. Jude gained fame by starting the Hepatitis WebRing back in 1997, which now links about 150 Websites on the World Wide Web. To the international online hepatitis community, Jude's gift has been precious. He helped give us a voice, and enabled us to come together with that one voice. We all owe him an enormous debt of gratitude. He is survived by his wife Brenda and a daughter, Kaitlin.

Jude was known to everyone as one of the most kind-hearted persons anyone ever met. He would not only give you the shirt off of his back, but his jacket too. He was a very soft-hearted man, who took into his heart everyone else's feelings before his own. Jude was very dedicated to helping others that contracted hep. He felt that perhaps he could make a difference in someone's life.

"It is a sad day." —squeeky

"Jude's love, sense of humour and dedication was an inspiration to all fellow heppers. He will be sadly missed."—Smilin' Sandi.

"I am and will forever be proud of Jude, not for just his accomplishments as a father and husband, but for the help and information he has provided to those he could reach."—Brenda

### **GERARD LANTHIER**

We have lost another member here in Victoria. Gerard Lanthier was 49 years old when he passed away last June 15<sup>th</sup>. He had been transfused in 1988, and his brother Marc, upon learning how sick he was, flew him out here, where he took care of him for the last 9 months of his life. Marc helped Gerard realise some of his dearest dreams by taking him to Mexico, and just before his death, to Tofino and Ucluelet. Gerard left behind his parents, other siblings, and two children in Toronto.

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#### DONATION FORM

Please fill out & include a cheque made out to HeCSC - Victoria Chapter. Send to: Hepatitis C Society of Canada Victoria Chapter 926 View St. Victoria, BC V8V 3L5

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I am applying for a grant."

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

"I would like to make a donation so that others may

receive the newsletter without charge" \_\_\_\_

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

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

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

#### COMING UP IN BC:

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

Comox Valley Liver Disease Support Group Meetings: Third Tuesday of each month, 6-8 PM, St. George's United Church on Fitzgerald. NEXT MEETING: December 21st Drop in daily for coffee. Contact: Ingrid or Nicky, 335-9167, nickyrussell@sprint.ca

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

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

Enderby HepCURE Meetings: Last Sunday of each month, 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: December 26<sup>th</sup>. 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 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 Vancouver Support Group Meetings Last Wednesday auto parts. NEXT MEETINGS: December 7<sup>th</sup> and 21<sup>st</sup>. Contact: Brian, 368-1141, k9@direct.ca or Pat, 364-1555

Mid Island Hepatitis C Society Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St., Nanaimo, NEXT MEETING: December 9th, Contact: Susan, 245-7654, hepc@nanaimo.ark.com, or Rose,

Mission Hepatitis C and Liver Disease Support Group NEXT MEETING: November 25th. Pleasant View Care Home, 7530 Hurd St., 7 PM. (short distance past hospital, same street) Contact: Patrick, 820-5576.

New Westminster Support Group Meetings: Second Monday of each month, 7:00-8:30 PM, First Nation's Urban Community Society, Suite 301-668 Carnaryon Street, New Westminster. NEXT MEETING: December 13th. Contact Dianne Morrissettie, 525-3790.

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

Penticton HeCSC Meetings: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: December 8th. Contact: Leslie, 490-9054, chepc@bc.sympatico.ca

Powell River HepC Information and Support: Please call Cheryl Morgan for time and place info. 483-3804

Prince George Hep C Support Group Meetings: Second Tuesday of each month, 7-9 PM, Health Unit Auditorium. Next Meeting: December 14th. Contact Sandra, 962-9630 or Ilse, ikuepper@pgrhosp.hnet.bc.ca

Prince Rupert Contact: April, 627-7083.

Princeton Meetings: Second Saturday of each Month, 2 PM, Health Unit, 47 Harold St. NEXT MEETING: December 11th. Contact: Brad, 295-6510, citizenk@nethop.net

Ouesnel Contact: Elaine, 992-3640.

Slocan Valley Support Group Meetings: Third Tuesday of each month, 7-9 PM, W.E. Graham Community School Youth Centre, Slocan. NEXT MEETING: December 21st. Contact: Ken 355-2732, keen@netidea.com, or Community School Coordinator 355-2484

Sunshine Coast NEXT MEETING: Contact: Kathy, 886-3211. kathy\_rietze@uniserve.com

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Hospital. NEXT MEETING: December 25th. Contact: Signs will direct you. NEXT MEETING: December 9th (Contact: the CLF, 681-4588, or Herb, 241-7766, HMoeller@compuserve.com

> of each month, 10:30-12:30. Please call to confirm. The days may change if there is a booking conflict with the CDC for the room that we use. NEXT MEETING: We have booked a 3 hr meeting on December 15th, BC CDC Building at 655 West 12th (12th and Ash, next to the Cambie Street City Square Mall- park here). This meeting will be a potluck and will be in rooms 70A & B which are downstairs. Everyone is welcome! There will be someone outside the building to direct. Contact Darlene N., 685-3813, djnicol@attglobal.net, or Darlene M., 987-7378, hepcbc@home.com

> Vernon HepCURE Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NEXT MEETINGS: December 7th and December 21st. Contact: Marjorie, 558-7488. www.junction.net/hepcure/

> Vernon HEPLIFE Meetings: 2<sup>nd</sup> and 4<sup>th</sup> Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. NEXT MEETINGS: December 8th and December 22nd. Contact: Sharon, 542-3092. sggrant@attcanada.net

> Victoria HeCSC We will be having a Christmas Potluck and Social for our December meeting. It will be held on December 10<sup>th</sup>, from 7-9 pm at the Victoria PWA office, 541 Herald

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

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

Special thanks to Lisa Harnois for fund-raising at the Fun Run

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 confidence of articles and prices, write to the hepc.bull, via 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, hepcbc@home.com

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## SQUEEKY'S CORNER

#### TO ALL MEMBERS OF HEPCVIC:

When I first came out to Victoria, just over 2 years ago, I was immediately impressed by the creative and sincere energy coming from the group. But I also noticed that you were under enormous constraints (of which I believe you were largely unaware) and thus the true creative potential of this group was not being realised.

First of all: there is the *hepc.bull*, started, maintained and produced by Joan, which, with only a little bit of help (better computers, programs, printing methods, editorial freedom) has become the best known Hep C bulletin in Canada, and is internationally respected. 2 years ago, circulation was around 400. This month we printed 1600.

And there was the pamphlets series, which Joan and others worked on and which remained in a desk drawer rather than in clinics and homes where they belong. Again these could have benefited from better technology, and some encouragement

In my naiveté, I called Toronto, informing them of all the wonderful things that were happening here, and told them what could happen if they were just to give us a small hand.

My hope was that if we all pitched in together we could probably get computer equipment cheaply; or we could work on websites, or mass produce items, facilitate distribution and reduce costs.

For those of you who have been following the story in the bulletin, you are aware of what the result of our request for help was, and the trouble it has caused.

Because of our efforts we discovered several things: that the Hepatitis C Society of Canada is not a real "society," but a corporation with a large budget none of which goes to any local initiatives, and most of which is spent on salaries for individuals who, as one of our members has put it, do  $1/10^{th}$  as much as we do here. As well the governing structure is not intended to reflect the wishes of the rank and file members, but the election process is strictly controlled from the top through loaded proxy votes.

We also uncovered the fact that the Board of HeCSC National betrayed the blood injured by backroom dealing with the government, and refused to let the democratic representatives of those with hepatitis C speak. As a result, many of our best loved friends, Leslie, Joe Haché, Ron Thiel, have either been prevented from speaking, or have resigned in disgust from an organisation which does not represent its members.

Now, don't get me wrong. I'm a card carrying, paid-up member of HeCSC. But at heart I'm just a Canadian with Hep C seeking a society of fellow travellers. I will always stand for that vision, and have done my best to bring this fact to National's notice. I would much rather transform HeCSC than destroy or leave it.

As it now stands, because of our aggressive action, we have placed ads on the buses in Victoria,

(Continued on page 7)

# To Hep-C Society Re: Donation to Hep-C Society



Aug. 12, 1999

Dear Editors:

As you know, I am a prisoner at V.I.R.C. C. in Victoria. I am also on your mailing list, and have been for some months, free of charge. At this time I wanted to say that I appreciate very much your newsletter and all you do to help people infected with Hep C.

Each month when I receive your newsletter I read it and put it on the bulletin board in my unit for the other prisoners to read and a lot of them do.

I was trying to think of what I or we could do in here for the Hep C Society and discussed it with other Hep C positive prisoners here. At present we have proposed to the staff that they allow us to make a donation to the Society from our Inmate Welfare Fund that we have from profits from canteen sales. At this time we are waiting for a reply.

If you can think of something we in here can do to show support I myself would be more than happy to help anyway I could.

The donation may take some time but I will do everything possible to make it happen. Thanks again for all you do, and for keeping me on the mailing list.

I hope to have good news about the donation before the end of the month. If you can think of anything else I can do <u>please</u> let me know. Thanks again.

Sincerely, [Anonymous]

[Editors: This letter was somehow lost in the mail, and we just got it recently, AFTER we received the kind donation from the inmates. We are extremely moved by their generosity, and we're pleased that the newsletter is doing some good.]

# VICTORIA CHAPTER ELECTIONS

Elections for the steering committee of the Victoria Chapter of HeCSC were to be held at the November meetings at the time of printing. Results will be announced in the January issue of the *hepc.bull*.

## **Cured?**

By Ken Benjamin Seattle, Washington

[From an exchange on the HEPV-L, reprinted with Ken's permission.]

Sorry, I've just got to throw my 2 cents in. There are two distinct issues that are often being run together, as they are below: Is a person cured?, and Do we have reasonable tools for determining whether or not someone is cured? These are two very different kinds of claims. To say that a person is cured of HCV, I take it, is to say two things: (1) no HCV anywhere in the body; and (2) no ongoing liver damage attributable to HCV infection (it might be, e.g., that HCV starts a causal chain that continues to damage the liver even after HCV is eradicated from the body).

This is a distinct issue from the issue of whether we can determine that a person is cured. The tools we have can tell us when someone isn't cured, of course, but they can't tell us whether someone is. A negative PCR, normal LFTs and a biopsy that reveals no inflammation cannot tell us that a person is cured for a couple of reasons. First, PCRs measure HCV in the bloodstream; they can't tell you whether HCV might be hiding out somewhere else in the body. Second, PCRs are not perfectly sensitive even as a measure of what's in the bloodstream. That is why physicians use the term "sustained remission," rather than "cure." Sustained remission simply means PCR-negative, normal LFT, and biopsy with no inflammation. All that can obviously be measured; more than that cannot.

For this reason, the claim *Bob is in sustained remission* does not imply the claim that Bob *is cured*. That, everyone seems to understand. But it is also important to realise that this means that the claim that *Bob is in sustained remission* does not imply the claim that *Bob is not cured*. Someone who doesn't satisfy the tests for sustained remission is obviously not cured. But a positive judgement about sustained remission has **no** implications, one way or another, about whether a person is cured. She might be or she might not be. The available tools simply aren't powerful enough to enable physicians to tell.

So it is simply wrong to claim that people who are in sustained remission are not cured. And no physician who really understands that notion would tell a person in sustained remission that she is not cured.

As an aside, though, long-term studies of sustained responders suggest (though do not conclusively prove) that they might be cured. There have been a number of studies tracking sustained responders for various periods of time. All but one that I have seen posted here on the list indicate that 90% of people who are sustained responders for a year stay PCR-negative, etc., through the various study periods (4 to 10 years, depending on the study). This has led some researchers to suspect that such persons might be cured—though again, it is important to realise that such studies are indirect evidence for that hypothesis.

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# Order Your FAQ's Now

More of Peppermint Patti's FAQ are now available. The new version includes an HIV co-infection section as well as updated Canadian Links. Place your orders now. Over 100 pages of information for only \$2 each plus S&H—but if you can afford more we'll take it. Contact Victoria Chapter.



# HONOUR ROLL:

Donors to Bus Ad Campaign:

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Thanks to Jennifer Fetter & Ed Holst of Obie Media for all the help

# HEPATITIS C SOCIETY OF NOVA SCOTIA

6 Nov 1999

As of Thursday of last week, The Hepatitis C Society of Nova Scotia is official. The papers should be in my hands early next week. I am working now to put an official "first meeting" together. I want to hold it in one of the theatres in The QE II complex, feature a guest speaker (hopefully Dr. Peltakian) and also plan to invite Jamie Muir, as publically as I can, to attend to bring the Nova Scotia tax payers up to scratch on what his department is doing to address the many problems that Hep C has and will create in our society. More very soon

Bruce Devenne bdevenne@sprint.ca

# CENTRAL ALBERTA CHAPTER CLF HEPATITIS C SUPPORT GROUP

Meetings every 2nd Thursday 6-8 P.M.
Provincial Building
Room 109 4920 51 St.
Red Deer
Enter at south-east entrance
Everybody Welcome

For more Info call Shane at 309-5483

# KITCHENER AREA CHAPTER

We will be having a Christmas Potluck and Social for our December meeting. It will be held on December 15 starting with the potluck at 6 PM. K-W Elks Lodge, 38 Bridgeport Rd. E. Waterloo, ON.

Season's Greetings to everyone across the country from Kitchener-Waterloo members!



# DURHAM REGION HCV SUPPORT GROUP

"You're not alone..."

#### **Durham Hepatitis C Support Meeting**

Date: Wednesday December 1, 1999
Time: 7:00 p.m.- 9:00 p.m.
Place: Durham Region Health Dept.
1615 Dundas St. E.
Whitby Mall
Whitby, Ontario

**Directions:** 401 to Thickson, N. on Thickson to Dundas (Hwy. 2). Entrance off Thickson to Lang Tower, next to Bell Mobility, 2nd floor, Health Activity Room

Contacts: Jim (905) 743-0319 email tndrhart@idirect.com ICQ# 38912877 or email Smilin' Sandi smking@home.com ICQ# 5259509 "Sandi's Crusade Against Hepatitis C" http://members.home.net/smking/

# HERB WARNING CELANDINE

An article in November's *Gastroenterology* (Nov;117(5),1234-1237) states that 10 cases of acute hepatitis in the last two years were observed which resulted from these people taking preparations of **greater celandine** (**Chelidonium majus**), which are often recommended for treatment of gastric and biliary disorders. The course of hepatitis was mild to severe. Liver failure did not occur. Other causes of liver disease were excluded, and the hepatitis disappeared after stopping the herbal treatment.

# DRINKING, VITAMIN A AND YOU

By Joan King

Through experimenting with the metabolic effects of alcohol and vitamin A in test tubes, these doctors have come to the conclusion that many interactions occur between retinol, ethanol, and other drugs.¹ Therefore, longtime use of alcohol, drugs, or both, results not only in lowered dietary intake of retinoids and carotenoids (included in vitamin A), but also speeds up the breakdown of retinol. The loss of vitamin A affects the liver, and may cause cancer cells to form. Normally, vitamin A supplements are suggested for drinkers, but vitamin A is, to some degree, toxic for the liver, and drinking alcohol increases this toxicity.

On the other hand, beta carotene, a precursor of vitamin A, was considered harmless until recently. Now it is known to interact with alcohol and that stops it from converting into vitamin A. Not only that. The combination of beta carotene and alcohol is toxic for the liver. In people who smoke and drink, beta-carotene supplements can produce lung cancer and perhaps heart problems. The toxicity of beta-carotene was made worse when it was given as part of beadlets.

So alcohol causes vitamin A deficiency and makes both vitamin A and beta-carotene, more toxic. This should be taken into account when trying to correct vitamin A deficiency in drinkers.

<sup>1</sup>American Journal of Clinical Nutrition, Vol. 69, No. 6, 1071-1085, June 1999
Maria A Leo and Charles S Lieber, "Alcohol, vitamin A, and β-carotene: adverse interactions, including hepatotoxicity and carcinogenicity"



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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 cheques payable to HeCSC Victoria Chapter, and mail to HeCSC, Attn. Squeeky, 926 View St., Victoria, BC V8V 3L5. Give us your name, tel. no., and address.

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

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

Ad No. 10

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

Ad No. 14

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

Ad No. 15

X-addict

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

#### **GENE THERAPY**

by Will Lawson

Vaccines may be the greatest achievement of modern medicine. They have eradicated some diseases and protected us from many others. However, a successful vaccine against hepatitis C has yet to be made. One of the most promising alternative strategies creates vaccines out of genetic material.

Traditional vaccines consist primarily of a killed or a weakened version of an agent that causes disease (pathogen) or of some piece of the agent. Like most genetic vaccines, standard types try to kill pathogens quickly by tricking the immune system into behaving as if the pathogen had already invaded.

When the immune system responds to a real infection, it homes in on foreign antigens (substances produced by the disease). Two major "arms" can come into play, both of which receive help from white blood cells called helper T lymphocytes. The humoral arm, led by B lymphocytes, kills pathogens that are outside cells. The cellular arm, led by killer T cells, kills pathogens that are inside cells.

An immune system armed against a specific pathogen develops memory cells that can repel it in the future.

Standard vaccines based on killed viruses, such as the hepatitis A vaccine, or on antigens isolated from diseases (such as the hepatitis B subunit vaccine) can't get into cells, so they don't activate killer T cells. When they do work, the protection often wears off. Then patients may need frequent booster shots.

Live vaccines trigger an attack by killer T cells as well as by antibodies. That dual activity is necessary to block infection by many viruses. Some live vaccines—the "gold standard" of vaccines—create lifelong immunity.

However, even live vaccines can fail to shield against some diseases. They can at times mutate in ways that restore viral activity. They can also cause illness in people whose immune system is weak. Such individuals may also catch diseases from healthy people who have been vaccinated recently.

Live or dead, whole-organism vaccines have other drawbacks; for example, retaining molecules that are not involved in evoking protective immunity. They can also contain contaminants that trigger allergic reactions.

#### The Ideal Vaccine

The structure of genetic vaccines is quite different from that of traditional ones. The most studied consist of strands of DNA, called plasmids, that come from bacteria but are unable to produce an infection. They have been altered to carry genes that target one or more proteins made by a selected pathogen, but to leave out genes that would let the pathogen cause disease.

Once injected into cells, some of the plasmids enter the nucleus and tell the cell to synthesize the encoded antigenic proteins, which can cause

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#### **IGNORANCE IS BLISS**

by Bob Edwards

Well, I have had one giant step backward in time.

I just got back from seeing my neurologist to see if I have any nerves left. He is an elderly physician and is credible and well known. While discussing my medical background, we finally came around to talking about Hep C. What he said was the same thing that my prior GP told me after I was diagnosed and, it was my opinion, prior to being diagnosed with Hep C.

"Did you get it from IV drug use or a blood transfusion"?

While many people who are part of online support groups can share their negative emotions on other issues with many persons of different cultures, backgrounds and beliefs, the only thing we have in common on the HepCAN list is our blood. Support groups were intended as a forum to allow all people to state their opinion, share experiences and EDUCATE.

Back to the induction tests. If I did not inform him I was HCV positive he may have treated me the same way as I was tested prior to diagnosis: no protection while they stick probes in my skin looking for nerves, and the less you have, the more probing they need to do, the more bleeding I do. However, after I told him he took more precautions to his practice. Well, he put on rubbers. So, well, after he held the towel down until the bleeding stopped, he told me that there is no permanent damage and there is no point in any unnecessary surgery. When he told me to get changed, I saw all this blood on my hand and he had already left the room. So I used precautions that I have learnt on the HepCAN list. I disinfected my hand after finding something to do it with, being aware that my hand was dirty, so I did not contaminate anything. I put a bandage on, but I was a little unsure of what to do with the towel. I should have put it in the garbage.

It is time to educate the population and eradicate this disease. So I am open to any ideas regarding public awareness campaigns. Together we conquer; divided we will all fail. So is the less people know about hepatitis the happier we are? So the question I have is are we better off not knowing about it?

Personally, I am glad that I have found out how to cope with Hep C, and I am trying to prevent the spread of the virus as well as improve my quality of life. Now I am saddened about it.

Thanks. Love you all Bob Edwards



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#### (Continued from page 5)

both antibody-type and killer-cell immunity. Such features raise hopes that DNA vaccines will keep all the positive aspects of existing vaccines while avoiding their risks.

They are also easy to design and to generate in large quantities, and they are as stable as other vaccines (perhaps more so) when stored. They should therefore be relatively inexpensive to hepatitis B), to bolster the impaired immunity of manufacture and distribute. Furthermore, because HIV-infected patients, and to treat a number of they can be engineered to carry genes from different strains of a pathogen, they may provide immunity against several strains at once. This should be very helpful when the pathogen is highly variable.

#### History

Genetic research dates back to the 1950s. In 1992, studies on animals showed that unwanted immune responses to the protein products of foreign genes might be put to good use for vaccina-

Ensuing studies revealed that DNA vaccines delivered into cells could stimulate animals' immune systems to generate B cell, killer T cell, and helper T cell responses against many different pathogens and certain cancers. The studies also showed that immune responses and disease How long do people remain immune? How much protection could be elicited by different methods do the results vary? What are the most effective

of vaccination.

Since the mid-1990s, the number of researchers has grown. The earliest human trial began in 1995 with HIV-infected patients. In 1996, physicians put new genes (for HIV or influenza) into healthy people for the first time.

So far, human tests are examining vaccines designed to prevent various infections (including cancers. A vaccine against hepatitis B has resulted in levels of antibodies that should be high enough to prevent infection.

However, current genetic approaches will probably have to be combined with generalized immune stimulators in order to elicit the strong immune responses required to shield recipients from future infections.

#### The Future

If first-generation genetic vaccines do well in clinical trials, they may sometimes be combined initially with more traditional vaccines to achieve even better effects. Eventually, though, the needed effects may be achievable from genetic vaccines alone.

However, many details remain to be considered:

doses? How often should they be given? What substances are the best for targeting genetic material to specific cells? Which genes in a pathogen are the most powerful?

Transmitter organisms are emerging as powerful vehicles for gene transfer to the liver. However, they can replicate independently, do not live long within the cell, and are susceptible to the antiviral immune response of the patient. There are few clinical trials in humans involving them, but there is significant ongoing research into improving their effectiveness for liver disease. Therefore, the adenoviral gene delivery system stands to have a significant role in liver-directed gene therapy.

Clinical trials evaluating the effectiveness of the first DNA vaccines may not be completed for five or ten years. Whether or not these specific versions reach the market, though, genetic immunization technologies are likely to prove extremely valuable for research into the immune response and for designing even better vaccines.

References

Genetic Vaccine, David B. Weiner and Ronald C. Kennedy http://www.sciam.com/1999/0799issue/0799weiner.html

Adenovirus-Mediated Gene Therapy of Liver Diseases, Yaron Ilan, M.D, et al.

Seminars in Liver Disease

What are the limitations of clinical application of recombinant adenoviruses for liver-directed gene therapy? http://gastroenterology.medscape.com/Medscape/features/ question/1999/09.99/q661.html

## Dear Editor,

I watch with interest as day after day new ways of treating hepatitis C using natural herbs appear on the screen on HepCan. Many of these remedies, as noted by one member, contain additives. The one he mentioned was Milk Thistle with licorice root and "something else in it." You have to watch the "what else is in it" carefully. Licorice is not recommended for people with high blood pressure, and neither is devils claw, which is an extra in some natural herbs. And what is the "something else mentioned?" This is an unregulated source of medicines and should be considered as such. Talk to your hepatologist before using any of these items and, as well, consult him or her as you add to what you are already taking.

This is of particular urgency if you have another problem, such as heart disease, blood pressure problems or a clotting disorder. One example of natural foods that can harm is the pineapple: it contains a naturally occurring clot dissolving agent. In particular, if you are bleeding from the gums eating pineapple can undo what bit of clotting a hemophilia or vanwillbrands' may have accomplished.

Remember every thing, almost without exception, that goes into your mouth has to be handled by your already damaged liver. When you get prescription drugs your doctor or you should ask if there are any contraindications for people with liver problems, and you would be surprised how many times another drug has to be prescribed for a given problem in a person with a liver disorder simply because the usual treatment is not recom-

mended for people with hepatitis or other liver disorders.

Milk thistle itself has been used since the days of the pharaohs for treating liver disorders perhaps King Tut himself was a consumer—and, while I'm not condemning any "natural treatments," remember the snake oil salesmen who roamed the old west. Many times a need for a treatment where there is none or a slick sales pitch may make something look a lot better than what it really is.

With all the Hepatitis problems around you would think, if any of these things truly helped on a long term or permanent basis, that there would be overwhelming data to that extent by now. When my liver is acting up to the point that I can feel it burning I use milk thistle for a few days and it subsides. I don't know if it is the milk thistle or simply the passage of a few days while I take it.

Here are some natural items that really help, cost nothing, and will only help you in general even if it doesn't cure your Hep C.

- 1 Stop smoking.
- 2 Eliminate salt from diet.
- 3 Lose weight.
- 4 Exercise when able.
- 5 No alcohol.
- 6 Use a good respirator when using any strong chemicals or sprays, bug spray, paint.
- 7 Avoid strong cleaners etc. Even if you breath it in the liver has to filter it out.
- 8 No illegal drug use.

Bruce DeVenne Hepatitis Nova Scotia





# HEPC TALK AT CAPITAL **HEALTH REGION**

David Mazoff gave a talk at the Capital Health Region as part of the Vancouver AIDS Respite Care program on HIV home care. The attendees were all professionals in the field of home care, and expressed concern about their lack of knowledge about hepatitis C. Many were unaware of the nature and scope of the disease, and about various risk factors. Again it becomes increasingly obvious that the information networks we have, such as HepCAN, are absolutely necessary for educating the public. Most were amazed when they looked at the hepc.bull and various fact sheets and the pamphlets we gave them. They did not know this information existed. To all who help produce this material, thank you for your efforts.

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#### (SQUEEKY—Continued from page 3)

are sending out another 400 FAQs, and have had our pamphlets approved by the BC CDC and the MOH. We are in the process of distributing 80 000 of these now.

We have started the HepCAN online information and support service, and have made the *hepc.bull* available world-wide on the web.

All of these endeavours were *actively* resisted by HeCSC National, an activity that continues even now. Just last month, instead of praising Victoria for its successes, or even chipping in to help cover costs, Richard Bond's response was to send faxes across the country in an attempt to discredit the pamphlets. This move was supported by the complete BOD of HeCSC and by Tim McClemont as well. When I called and asked Tim for an apology and a retraction we were treated rudely. I would ask that you, the reader, might phone Toronto and ask why they have not yet apologised to Joan and me and to the Drs of the BC CDC and made a public retraction.

I am glad to say that so far it looks like we have won the fight, but the toll has been great. It has made Ron and me quite ill, and turned me into a nervous wreck, and, as a result, both Ron and I have stepped down from the Chairs at HeCSC Victoria, and Ron from the board of HepCBC.

I am sorry that I have been such a pain; it is not my intention to go around upsetting people. I would really much rather be sitting by the water and looking at the ducks. But that doesn't get much done for the Hep C community, and justice is not served. Thus, I think it is true to say that without our fighting HeCSC and the government in the way in which we have, we would not have made our present gains, but we cannot continue this mode of activity.

I made several decisions along the way to prepare us to be more self-reliant, which perhaps many of you did not understand, but which I would like now to explain.

It was my understanding that to be truly effective we had to be inserted into this community, and not rely on a head office or a government that wasn't listening. An office in the back of a church wouldn't do. Since I am disabled, I got involved with the ACPD (the Action Committee of People with Disabilities), who offered us not only a space, but their guidance and expertise. They help us with grant issues, networking, and most importantly advocacy. In fact it is due to this organisation that I began to become aware of how the everyday rights of people infected with HCV are denied, or ignored.

As well, because most of the HIV community is now co-infected, I felt that it was best to link ourselves with some AIDS groups, who could also teach us the ropes.

It is also my understanding that direct action against the government was not working, and that what we needed was more community support. If we could get the community aware of Hep C, then maybe their collective voice would move the government. The key here was to get

more active and more visible through the media—websites, publications, pamphlets, bus ads, etc.

The end result of our consultation with these other groups led us to believe that we needed to set up a new organisation along the lines of the Persons with AIDS network—an organisation run for and by those with the illness, rather than by a large bureaucracy with a big budget and little sense or compassion.

Because HeCSC National actively thwarted our attempts to educate the public, several of us decided to form a new association—HepCBC.

HepCBC is not a replacement for HeCSC, although it could be, I suppose. It is a voluntary association of independent support groups designed to undertake and/or partner in projects that local groups with their limited funds could not initiate or complete.

Many of the projects we do here in Victoria would be more cost effective if the scope and production were increased. It is cheaper to print and mail out 1600 bulletins than it is to print 900. It is cheaper to design the bus ads once than to redo them in every city.

If all these local groups could come together in an association—some with local funding, and some with none at the moment—then they would be eligible for funding at another level, and from another level of government.

As it turns out, Health Canada has been watching our activities (Ron says, "I knew that!"), and came out to talk with us about HepCBC (several times), an idea actually proposed to us by the BC gov't—thank you Steve Orcherton, Ed Conroy and Craig Knight. It is not written in stone, but it looks like this new provincial organisation will be eligible for a sizeable grant to continue the projects that HeCSC Victoria and HepCBC in Vancouver have already been engaged in. It will continue to service all communities receiving the *hepc.bull*.

HepCBC has already established positive working relationships with organisations such as the BCMA, Kiwanis, and various provincial Ministries and local community groups.

Some of the projects HepCBC has already undertaken and is looking to continue are:

- Bus ads throughout BC
- Computer distribution and networking
- The Hopsy Children's Book
- Production and distribution of the most current and reliable materials for Hep C education and prevention.
- 1-800 number
- Setting up of local Hep C clinics
- An advocacy network for disability and treatment issues
- .....and much more.

Now that things have calmed down around here, and the true colours of HeCSC National are known to us, I have little worry that the progress the Victoria chapter has made will be undermined.

I am quite tired. And my part is done. With Judith, Arlene and Jean in the office, and with future volunteers, I am positive that Victoria will maintain the reputation it has earned. I shall continue with the bulletin and HepCAN, from my home, and

probably come in one day a week to do the database and answer the phones. People say I'm a good fundraiser and speaker—but you all know me under pressure, and I need a rest. Maybe I could continue some of the community links—but still, we need more volunteers.

So: my thanks to all of you, especially, to Joan, and to Ron, Judith, Arlene, Frank, Jean, Fatima and Dave FitzGerald for jobs well done.

It is my intention to formally relinquish the Chair of the Victoria Chapter, Hepatitis C Society of Canada at this month's meeting. I shall not stand for the steering committee.

Dr. C.D. Mazoff



## HEPATITIS C: THE BASICS

AN INTRODUCTION FOR

PEOPLE CO-INFECTED WITH HIV+HepC

by **DAVID MAZOFF** *Executive Director* **HepCBC** 

THURSDAY, DECEMBER 2 at 4:00 PM

VICTORIA PWA SOCIETY 541 HERALD STREET

TOPICS: WHAT IS HEPATITIS AND
WHY IS "C" SO SERIOUS
HOW MIGHT Hep C AFFECT YOUR
HEALTH
HOW TO TAKE CARE OF YOURSELF

IOW TO TAKE CARE OF YOURSE UNTIL THE CURE SOME EXPERIMENTAL THERAPIES

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## HEP C IN THE NEWS

#### SAFER SYRINGES

In June, both houses of the Legislature in the U.S. unanimously passed a bill that would require hospitals to **replace traditional syringes with safer needles** that automatically retract after use. More than 2,000 healthcare workers contracted hepatitis C, 400 got hepatitis B, and 35 contracted the AIDS virus just last year alone. Safer needles were invented a 10 years ago. Several types of needles are available, including ones that retract and others that have protective sheaths. A CDC report says that these safer needles could prevent 76 percent of needle sticks.

http://www.bergen.com/editorials/needl19990930.htm

#### **LOW DOSE MAINTENANCE**

Investigators studied 53 non-responders to interferon treatment, who had improvement as shown by biopsy. Twenty-seven of the patients were chosen randomly to receive maintenance interferon for 24 months, and 26 were randomized to discontinuation of interferon therapy. After 30 months of therapy, the investigators found that **those receiving the maintenance dose had less scarring** than previously, and those who did not have maintenance therapy showed worsening of their liver scarring. Eighty percent of those taking the maintenance dose improved their histology (liver biopsy) score, while 30% of those taking no interferon had worse scores than before the trial.

November issue of Gastroenterology

#### TRANSPLANTING HEP C LIVERS

Researchers from the University of Pittsburgh Medical Center studied more than 200 liver transplant cases performed from 1992 to 1995 and found that 89 percent of patients who got a hepatitis C-positive liver were still alive a year after the operation, compared to 88 percent of those who got healthy livers. After the transplant, the patient has different strains of the hepatitis C virus: one that caused the infection and a second carried into the patient with the donated liver. The two versions appear to interact until one gains dominance. If the donor strain predominates, patients tend to do a little better. They have milder recurrences of hepatitis than patients whose own viral strain takes over.

Gastroenterology 1999;117:149-153.

#### **NEW LIVER TISSUE**

Dr. Bryon Petersen, at the University of Pittsburgh Medical Center, reports that special **bone marrow cells have been shown to change into liver tissue** in rats. He hopes that this may mean that one day a patient's own marrow may be used to repair failing livers.

"Cell Used To Make New Liver Tissue" by PAUL RECER AP Science Writer

#### **HOW HCV HIDES**

Vincent Agnello, MD, who heads the Clinical Immunology Laboratory at Lahey Clinic, performed studies that proved that the **virus combines with** 

**lipoproteins** and enters the cell the same way lipoproteins do - via a doorway called the LDL receptor. The LDL receptor is the primary pathway through which cholesterol, the main component of lipoproteins, enters the cell. The fact that the virus combines with lipoproteins may shed some light on why this virus, unlike other viruses, avoids an immune response.

SOURCE Lahey Clinic http://www.lahey.org/

#### **CLINICAL TRIALS AND INMATES**

There have been several articles in the news this past month about clinical trials and prison inmates. Apparently in the US in the 1950's, prisoners were being injected with many diseases, such as hepatitis, syphilis and herpes, so strict legislation was passed to prevent this. Now, however, inmates with such diseases as hepatitis C and AIDS would often like to be included in clinical trials, so as to reap the benefit of free drugs which may prove beneficial. This has not been permitted in the US, and there is much debate as to whether or not to allow inmates to take part in trials, for which they are sometimes paid. All seem to agree that precautions must be taken to ensure that no one is coerced into participating. Opinions?

http://cnn.com/US/9910/14/inmate.experiments.ap/

#### **CHEAP HEP C TREATMENT**

Researchers at New Mexico State University have found that a combination of alpha lipoic acid (thioctic acid), silymarin, and selenium is economical, safe and effective in dealing with hepatitis C, even in patients with cirrhosis, portal hypertension and esophageal varices. These substances, they say, protects the liver from free radical damage, increase the levels of other antioxidants, and help stop the virus from multiplying. The 3 patients studied avoided transplant and are back at work.

Med Klin 1999 Oct 15;94 Suppl 3:84-9

# TARRY TAKTURKAN

# XMAS SOCIAL

The Victoria Persons With AIDS is having its Christmas Social, and since many of its members are co-infected with HCV we thought that it would be nice to have a joint party. All members are welcome

The POT LUCK is on Dec 10, from 7-9 pm at 541 HERALD STREET, just below Government.

#### **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 or 1990-1991 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

#### 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

Many thanks to the members of the Oak Bay Kiwanis Club in Victoria for their generous donation to the bus ad campaign. Three of our members went to speak at one of their meetings, and they have kindly "adopted" our cause as one of their own. Our bus ad project was one of several proposed at a recent budget meeting, and they remembered us!

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