

JANUARY 2000

Issue No. 19 MAKE MAY Sample Letter

PHARMACARE PROVIDES IMMEDIATE COVERAGE FOR REBETRON

Dec. 16, 1999 MINISTRY OF HEALTH 1999:426

VICTORIA - A new drug treatment for British Columbians with hepatitis C will be covered immediately by the provincial government, Health Minister Penny Priddy announced today.

"Rebetron is not a cure for Hep C, but it is an effective treatment for some patients," said Priddy. "Unfortunately, hepatitis C is a chronic condition for which there is no cure."

"B.C. has been at the forefront in caring for and treating people with hepatitis C," Priddy said. "I believe this decision is further evidence of our commitment."

Rebetron had previously been made available to some British Columbians through a special Health Canada program, which ended on Aug. 13. As a compassionate measure, Pharmacare continued coverage for patients who had used the drug through this program and who qualified for income or premium assistance. Now that Pharmacare has made a final decision on providing coverage for Rebetron, it is estimated that 1,000 patients per year will qualify for the drug. The total cost of covering Rebetron for these patients is estimated at \$9.5 million annually.

Pharmacare will provide coverage for Rebetron as a full benefit by special authority. To qualify for coverage, patients must undergo two tests—a liver enzyme test and a PCR (viral load) test—which will determine whether they might benefit.

After six months, patients will undergo genotype testing. Depending on the results, they may be approved to continue the full 48 weeks of therapy. In addition, Pharmacare will continue to provide coverage for interferon therapy, another effective treatment for hepatitis C. In 1998, Pharmacare spent \$3 million providing coverage for interferon therapy.

This year, the B.C. government has invested \$541.8 million in Pharmacare, an increase of \$63.8 million over last year's budget.

"I'm concerned about the rising cost of prescription drugs, but we have to ensure patients have access to the treatment they need," Priddy said. "I'm working hard to find solutions that give patients newer drugs while concests."

"HEPATITIS AWARENESS MONTH"

Raising awareness regarding hepatitis across Canada, I think, is important to all of us. Now is YOUR chance to make a difference and help raise public awareness of hepatitis. Bill C-232, which proposes to observe the month of May as "Hepatitis Awareness Month," has received first reading in the House of Commons. It has already received support from 100 MPs, but as a Private Members' Bill it will require unanimous consent from all parties if it is to survive on the order paper.

If you would like to support "Hepatitis Awareness Month," send a letter to your MP and/or circulate a petition. Take a few minutes and be heard. You can find a sample letter, petition, and a complete list of MP contact names at http://www.hepnet.com/hcamletter.html

With thanks....
Michael Betel

From Samantha

ast year my uncle died from hepatitis C. I miss him a lot, but a lot of people say that we should forget our lost love ones. But I don't. I like remembering him. It reminds me how much he cared for me and my family. Last Christmas was the last Christmas we shared together. Now I feel like I should have done something, but I didn't. The day I found out that he died I felt mad and sad I went to do my homework, but I was too sad. I sat there doing nothing, then I gave up. My grandpa and grandma were crying. My mom was trying to be strong but that's what my dad is good at doing. But my uncle is gone now and I want him back.

Samantha Cressman, age 11 years old.
"The victims of this disease are not always
infected, but affected."—Carolyn Caveney

December, 1999

(MP's Name) (Constituency) House of Commons Ottawa, ON K1A 0A6

Dear (MP's Name),

I I am writing to ask your support for Bill C-232,
an Act to provide for a Hepatitis Awareness
Month.

This Private Members' Bill, being sponsored by Peter Stoffer (Sackville-Musquodoboit Valley-Eastern Shore), will focus badly needed attention on a serious disease of the liver. Chronic viral hepatitis has little public awareness because symptoms may not appear until irreversible liver damage has occurred.

Hepatitis C, in particular, has become an epidemic worldwide. According to the World Health Organization (WHO), 170 million people are infected with hepatitis C—8.5 times more people than are infected with HIV/AIDS. There an estimated 240,000 Canadians suffering from hepatitis C. Most of them don't even know it

Hepatitis is a disease that we can do something about. Bill C-232 will heighten awareness of those people who are diagnosed with, or at risk for, hepatitis and encourage Canadians to become actively involved in protecting and prolonging their own health, as well as the health of their communities.

Please give the Hepatitis Awareness Month Act your full support.

Sincerely,

(Your name and address)

cc: Hon. Allan Rock Minister of Health



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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(A limited number of newsletters will be available

receive the newsletter without charge" __

free of charge at group meetings, as well.)

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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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: January 18th. 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. sympatico.ca

Downtown Eastside Hep C Support Group Meetings: Each MONDAY starting January 3rd, 6 to 8 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: January 30th. 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: January 29th. 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: January 11th and 25th. Contact: Brian, 368-1141, k-9@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: January 13th, Speaker: Dr. Jane McKay. Family and friends welcome. Contact: Susan, 245-7654, hepc@nanaimo.ark.com, or Rose, 714-1937.

Mission Hepatitis C and Liver Disease Support Group NEXT MEETING: 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 Carnarvon Street, New Westminster. NEXT MEETING: January 10th. 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: January 12th. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca

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

Prince George Hep C Support Group Meetings: Second Tuesday of each month, 7-9 PM, Health Unit Auditorium. Next Meeting: January 11th. 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: January 8th Contact: Brad, 295-6510, citizenk@nethop.net

Quesnel Contact: Elaine, 992-3640.

Slocan Valley Support Group Meetings: Third Tuesday of each month, 7-9 PM, W.E. Graham Community School Youth Centre, Slocan. NEXT MEETING: January 18th. Contact: Ken 355-2732, keen@netidea.com, or Community School Coordinator 355-2484

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

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: January 13th. (Contact: the CLF, 681-4588, or Herb, 241-7766, HMoeller@compuserve.com

Vancouver Support Group Meetings Last Wednesday of each month, 10:30-12:30, BC CDC Building at 655 West 12th (12th and Ash, next to the Cambie Street City Square Mall- park here) There will be someone outside the building to direct. NEXT MEETING: January 26th. Contact Darlene N., 685-3813, djnicol@attglobal.net, or Darlene M., 987-7378, hepcbc@home.com

Vernon HepCURE Meetings: First Tuesday 12-2 PM and third Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NEXT MEETINGS: January 4th and January 18th. Contact: Marjorie, 558-7488. www.junction.net/hepcure/ index html

Vernon HEPLIFE Meetings: Second and fourth Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27 Ave. NEXT MEETINGS: January 12th and January 26th Contact: Sharon, 542-3092. sggrant@attcanada.net

Victoria HeCSC Meeting: Last Wednesday of each month, 1-3 PM and 7-9 PM, Steve Orcherton's office, 2736 Quadra (at Hillside) NEXT MEETING: January 26th. Elections will be held. There will be a speaker from Victoria Hospice at the afternoon meeting. Contact: 388-4311. hepcvic@pacificcoast.net

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, Kiwanis, CFAX 1070, AM 900, Pacific Coast Net, Microsoft, Symantec, Jim Pattison Group, Alfred E. Neumann, Paradon Computers, and CompuSmart. We also wish to acknowledge the generosity of the Residents of VIRCC, Uncle Dave and some wonderful anonymous donors. Additional thanks to Margison Bros Printers.

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 Margison Bros Printers.







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

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

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SQUEEKY'S CORNER

Living with Hep C

For those of you who don't know me, let me introduce myself. My name is David Mazoff (aka squeeky); I am 50 years of age, and five years ago I was very active. I used to teach and do lots of sports, and I mean lots: run 5 miles in 40 minutes, swim medleys, weight train—you name it.

Then I began feeling very, very weird: achy, heavy feeling, disoriented, fluey. Eventually I became so ill, I wound up in a partial care residence. I rested a lot, finally got my disability and moved to Victoria, where I was able to start walking again, and even jogging a bit—but I went back on treatment and haven't done any workouts for over a year now. Flab city. I can walk now, but not every day.

Today, and for quite awhile now, I am bothered by many symptoms that probably affect many of you, but which you might not associate with Hep C. Sometimes my fingers ache so much that I have a real hard time typing; sometimes when I get out of bed and put my foot on the floor (gently), my toes hurt a lot. Sometimes my limbs tingle, and sometimes I get waves of weakness in my limbs. I am deaf in my left ear now (autoimmune inner ear disease), and get labyrinthitis quite frequently, which makes me so dizzy it's scary; and the vision in my left eye is really bad—I had a minor stroke (infarct) in my eye (the result of IFN, the docs say), but I also have vitreous detachment, cataracts and retinal complications.

My skin has been getting worse. I mark very easily, and I am often very itchy. If I scratch even lightly, sometimes my skin tears unexpectedly, and I bleed. I have rashes, and hives, and lichen planus, and I am prone to other fungal infections. I have asthma now (a known side-effect of IFN). My liver often hurts (not enough to make me cry, but almost) and I have an almost constant nausea, probably from the ribavirin and the Zoloft. I suffer from hypoglycemia.

My last biopsy showed me to be at Grade 2/Stage 2 Inflammation/Fibrosis, but my enzymes are only slightly elevated now, and my bilirubin and albumin and other liver function markers are within range, so technically, there is no reason for me to have all these symptoms—symptoms which I have had to only a slightly lesser degree when I was not on treatment.

The problem is, unfortunately, that many physicians continue to see hepatitis C as simply a liver disease, which it is not. Hepatitis C is a virus which, apart from attacking your liver, also triggers autoimmune reactions and a host of autoimmune related disorders. Thus, if I go into a physician's office with the above symptoms but my liver function tests are within range, the general response up until now has been generally to dismiss the symptoms as figments of the imagination due to lack of any biochemical evidence to the contrary.

(Continued on page 7)

Dear Doctor:

Sometimes, late at night, when I have nothing better to do, and can't sleep, I start thinking of ways I could have been diagnosed earlier. As it was, I wasn't diagnosed until I had probably had hepatitis C for 20 years, but then, that length of time isn't unusual for a diagnosis.

Sometimes, I recall going to your colleagues, years ago, knowing I wasn't going to get anywhere, and complaining, "Doctor, when I wash my hair, my arms feel weak."

Sometimes I remember telling you and other doctors that I just felt miserable all over. I was generally achy. Now, don't get me wrong. I repeat: This wasn't just one doctor. It was many doctors, and I'm not blaming them or you. My symptoms were, indeed, very vague.

My stomach hurt pretty much all the time. Sometimes I wonder why I didn't complain about this sooner, because it was that complaint that led to my eventual diagnosis.

I had a remarkably, *wonderfully* low cholesterol count. Now I know that most of us are "blessed" with the same findings, often accompanied by high triglicerides. Sometimes I wonder if I would have responded to treatment had I been diagnosed back then. I wonder how many doctors question a patient's LOW cholesterol levels.

Who should be tested? In my ideal world, doctors would test any patients who has had any of the following:

Risk Factors:

- Has received any blood product—this includes gammaglobulin, Rhogam, or any product from humans.
- Has been artificially inseminated.
- Has had any surgical procedure, including dental surgery
- Has been in the military
- Has been in prison.
- Has used any sort of injected or snorted illicit drugs.
- Has been diagnosed with any sexually transmitted disease.
- Has worked in a medical setting. (Yes, doctors—that means you. Another reason for at-home testing!)
- Has had an endoscopy or dialysis.
- Has had facials, manicures or pedicures, or has performed them.
- Has tattoos or piercings, or has performed them.
- Has had any sort of IV line
- Has had mass immunizations.
- May have had acupuncture with unsterilized needles.
- Has had an EEG.
- Has engaged in contact sports and had contact with blood.
- Is or has been a police officer or firefighter.

Symptoms

- Has complained of fatigue.
- Has complained of fibromyalgia-like aches and pains.

- Has low cholesterol levels.
- · Has diabetes or hypoglycemia.
- Has unexplained abdominal discomfort.
- Complains of itchiness.
- Complains of dizziness.
- Has lichen planus.
- Has an elevation in liver function tests, even if you think they are drinkers.
- Has heart valve problems and/or arrhythmias
- Complains of cold hands or feet.
- Complains of numbness in the extremities.
- Has thyroid or kidney problems.
- Complains of esophageal pain.
- Complains of liver pain. (Yes, an inflamed liver does cause pain when it presses against the other organs.)

Why test?

First of all, with the combo, 40% of patients who can be treated may become PCR negative. The others may improve the state of their livers, their energy levels, and their general well-being, in addition to the fact that they may feel that they are doing something positive to fight the disease. Response to treatment is better the earlier a person is diagnosed.

As well, a person who knows he/she has Hep C can take measures to make lifestyle changes and to avoid transmitting the disease to others.

OTHER GROUPS

Durham Hepatitis C Support Group Meetings: NEXT MEETING: February 3, 7-9 PM, 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. Topic: Nutrition and Hep C. Contact: Jim (905) 743-0319, tndrhart@idirect.com or Smilin' Sandi smking@home.com, http://members.home.net/smking/ Durham Region covers the municipalities of Ajax, Brock, Clarington, Oshawa, Pickering, Scugog, Uxbridge and Whitby.

Central Alberta CLF Hepatitis C Support Group Meetings: Every 2nd Thursday of each month, 6-8 PM, Provincial Building, Room 109, 4920 51 St., Red Deer. Enter at southeast entrance. Contact Shane, 309-5483.

Kitchener Area Chapter Meetings: NEXT MEET-ING: January 19th at 7:30 PM, K-W Elks Lodge, 38 Bridgeport Rd., E. Waterloo, ON.

Edmonton, Alberta Hepatitis C Informal Support Group Meetings: Every third Thursday of each month NEXT MEETING: January 20th, 6-8 PM., 10230-111 Avenue, Edmonton, Conference Room "A" (the basement of the building) Contact: Tracey Peddle, NitNGale@telusplanet.net or Jackie Neufeld: (780) 939-3379 Parking: Meter Parking (underground and surface) roughly \$3 per evening. There is some street parking free if you're willing to walk.

We of the **Sunshine Coast Hep C Group** would like to thank the ladies of the **Sunshine Coast Quilters Club** for donating a beautiful quilt to us. We are thinking of keeping it as a representation of our club. We will use it as a backdrop when we have any public exposure. Thanks, *Kathy*



REAPER RETROSPECTIVE—THE BEST AND THE FUNNIEST FROM OUR OWN RON

THE 12 DAYS OF HEPMAS

On the twelfth day of Christmas Our legal system gave to me Groups of lawyers grabbing Eleven tainted needles Ten liver biopsies A run around on disability Factor 8 from jails Health Ministers lying Blood from Yankee prisons Five months to live No compensation Cretin, Rock and Martin Two bundled drugs And blood laced with hepatitis-C

CANADA FH?

In Kosovo We share your woe

But soon our tax dollars will start to flow

And Yugoslavia We'll be your saviour With dollars to pay for what we did to ya

On the Spanish Main The money will soon flow again

From China to East Timor Our dollars will be coming More and More

And the U.K. With Mad Cow Disease Come and Join us, Please, please, please

Illegal or legal we don't fear Your sure of welcome when you get here With free lawyers, free lodgings and perhaps free

So come and join us in this big land so free But just one warning DON'T GET HEP-C Cause if you do It's nuts to you

LIVING IN B.C. -MY FAVOURITE THINGS

- With apologies to Julie Andrews

Overpriced ferries and budgets so phony Government Agencies full of baloney! Clark and Priddy and other Dingalings These are a few of my favourite things When the tax bites and I can't sleep nights and I'm feeling sad I just remember my favourite things and then I feel twice as bad! Casinos that bring the government dollars despite the anti-Casino hollers Hospital waiting lists with numbers so high if you are on one you're likely to die When I'm stressed out and I turn grev and can't take another day I just remember my favourite things and move to the U.S.A.

LEAKY CONDOS

I bought a leaky condo oh woe is me! But I'll get compensation 'cause I didn't get hep-C!

We overfished the salmon and can't put to sea! But We'll get compensation 'cause we didn't get hep-C!

Our basements did get flooded on the lone prairie! But we'll get compensation 'cause we didn't get hep-C!

We suffered from the ice storm in January! But we'll get compensation 'cause we didn't get hep-C!

We got hepatitis brand name C! But we won't get compensation 'cause there's no money!!!

Ron the Reaper

SURGEON INFECTS PATIENT WITH HEPATITIS C

BMJ 1999;3191219 (6 November) Phyllida Brown, London

Officials at the Department of Health have no plans to introduce routine hepatitis C tests for healthcare workers after the announcement last week that a surgeon had infected a woman patient with the bloodborne virus. The incident is thought to be the third documented case of a patient being infected with the virus by a surgeon.

The surgeon, who had worked at the Pilgrim Hospital in Boston, Lincolnshire, since 1997, is on sick leave. A sample of his blood taken two years ago, before the woman's operation, was found to be positive for the virus. Since the case came to light, another blood sample, taken in 1993 by the hospital © British Medical Journal 1999 that then employed the surgeon, the Torbay District General Hospital, has also been found to be infected.

About 1600 women who have been operated on by the surgeon since then are being contacted and

offered tests.

The Department of Health says that 0.5% of the population are estimated to be infected with hepatitis C virus. In the United States, national survey data suggest that the prevalence there may be about 1.8% making it the country's most common chronic bloodborne infection. The British blood supply has been screened for the virus since 1991.

Some types of surgery increase the risk that surgeons will receive a sharps or needlestick injury, thus potentially exposing the patient to their blood. The women to be contacted in the latest incident have all had gynaecological procedures that are known as "exposure prone," such as hysterectomy and caesarean section.

According to a report by the Senate of Surgery of Great Britain and Ireland, which represents the surgeons' royal colleges and others, gynaecology is one of the highest risk specialties for surgeon injury, with sharps injuries occurring in 10% of all procedures and up to 21% of vaginal hysterectomies.

The two previous documented cases of surgeon to patient transmission of hepatitis C virus involved cardiac surgery, another "exposure prone" specialty.

A spokeswoman for the Department of Health said that its advisory committee on hepatitis did not currently believe that testing of health workers for the virus was warranted because "the risk is so small."

Similarly, the United States does not recommend routine testing of health workers for the virus, saying that prevalence of infection in health workers is no higher than in the general population.

James Johnson, chairman of the Joint Consultants Committee (a committee comprising representatives from the BMA and the medical royal colleges), argues that complete safety could never be guaranteed even if surgeons were tested for the virus four times a year.

Between one test and another, a surgeon could become infected and infect his or her patients. The risk appears to be low, and the costs of testing might not be justifiable, he said. "You are talking big money here, and we can never make it totally safe."

A report by the US Centers for Disease Control and Prevention says that the average incidence of infection with hepatitis C virus after unintentional needlestick or sharps exposure from a source positive for the virus, is 1.8%.

In the case of hepatitis B virus, which is thought to be more infectious, the Department of Health recommends testing for all health workers and immunisation. The department currently recommends that surgeons positive for both the hepatitis B surface and e antigens should avoid performing exposure prone procedures. Surgeons carrying out exposure prone procedures have to show that they are not e antigen positive or that they are immune.

These guidelines are currently under revision after reports of patients becoming infected by surgeons who did not express these antigens.

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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. 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!!



HONOUR ROLL:

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

TO ANYONE WILLING TO HEAR AND SEE

We are a family of four. My husband has not worked in over 2 years. My husband contracted Chronic Hepatitis (Hep C) in 1978 while receiving blood products in Canada. My husband got very sick, and with two young children we found ourselves in need of Social Assistance.

My son, 6 years old has allergies. We recently went to an M.D. of Paediatric Allergies and learned that my 6 year old is allergic to corn, orange, wheat, chicken, carrot, milk, egg white, peanut, and soy bean. The doctor prescribed a treatment plan. My son suffers from chronic sinus problems and has, for the last two months, found it difficult to breathe. The antibiotics prescribed are covered on the drug card, but the three other items prescribed for his treatment are not covered. I forwarded the appropriate telephone number in which the doctor could make a special request for these other items to be covered. Following the doctor's contact with the Ontario Drug Benefits Program, he has told us that these items were turned down by the Ontario Drug Benefit Program. Essentially, my son will not be able to receive his treatment prescribed. The doctor has suggested that we just use the covered item, which in truth is only part of the proper treatment he prescribed. He would like to put my son on massive antibiotics. What my son won't receive is the prescribed friendly bacteria required while stripping his body of all bacteria, friendly and unfriendly. This would undoubtedly create a yeast infection in his body. So I must decline this partial treatment. I can not in good conscience add to and create an even bigger health issue for his young body to cope with.

My confidence in our health care system is shaky, to say the least. Mike Harris takes \$114.16 per month from the Social Assistance we qualify for because we receive a Child Tax Benefit on the 20th of each month. That leaves us with \$755.64 at the first of each month to live on. In the last few months Social Assistance has allocated \$138.00 per month for my husband's special diet needs with his Hep C. When we go to fill a prescription at Shoppers Drug Mart, they charge us \$2.00 for each prescription filled. They call this some sort of processing fee. It is a fee that they don't charge to people paying cash for prescriptions. It is exclusive to the poor using drug cards.

Welcome to our country; we have surpluses off the backs of the poor. And for those who think this is just some isolated story from some ungrateful Canadian, this could be you. There are many horror stories. We live in a country very rich in resources, and there is no reason for this. I am just one voice, sceptical of the possibility of being heard. I have stood on Parliament Hill in support of the homeless, lack of health care for the challenged that can't speak for themselves, and for those handed a death sentence with Hep C. I have witnessed riot squads position them-

selves at these rallies, these rallies of people that are primarily so weakened by their health that they pose no threat. I have never heard the Government apologise for its lack of responsibility with the blood products. The blood products still aren't safe in this country, and that affects us all.

My one true wish is that Canadians stand together in numbers and demand consciousness and accountability from our appointed members. So few take this step, and we need so many more to cry out. Otherwise, we will continue to be lead around by the nose, manipulated, and the gap will grow. One day it may be you who wakes up and says, hey this affects my own personal life. It's not just some drama on television.

Marilyn Petersen



WAKE UP! SMELL THE COFFEE!

What goes on, you say? Am I missing something that could be to my benefit? Well, Buddy, you sure as heck are. I assume that you joined the Hepatitis C Society because, from some source, you were infected with the potentially deadly virus. Now, you can, of course, do your own research on Hep C and become quite knowledgeable. The information is out there, and if you can run a computer and get on the internet, you can have bedtime reading for months. But the very best way to gain and GIVE information is by attending your local Hep C, Victoria Chapter monthly meetings.

January is the next meeting planned, and this is election time for the steering committee for the year 2000. Come on out and join the others. We, too, wish it were a club or organisation formed to have fun and social times, but unfortunately it started as a group to pursue compensation for persons infected with the Hep C virus. However, the winds are changing, and we are now more focused on searching out methods to help our bodies deal with this killer virus, and also to give aid and comfort to those who are seriously ill. There are six positions open on the steering committee, and we have six nominations so far. Voting will be by ballot, and all new nominations are welcome. The only stipulation is that you be a member of Hepatitis C Society of Canada.

Come on out! Talk to your candidates! Be a part of choosing your year 2000 executive! Take an active role in the operation of your Victoria Chapter!

Sincerely,

Frank Darlington

LIVER DIALYSIS

We were contacted by HemoTherapies. We thought we should pass the info on. We have more here at the office, should any patient or physician desire it. Their website cites a number of case studies. We have included data from one of those studies involving a Hep C patient at the end of this article.

What is Liver DialysisTM

Liver Dialysis is a medical procedure that helps the liver do its job of removing poisons (also knows as toxins) from the blood. Patients are treated with the Liver Dialysis UnitTM, which is a compact, mobile device that can be used at a patient's bedside for liver dialysis. The Liver Dialysis UnitTM is the only toxin-removal device currently available for routine hospital

What is the need for liver dialysis?

Millions of people in the United States suffer from liver disease, which can damage the liver, suddenly get worse, and require hospital care. Each year, many others suffer liver damage as the result of poisons, drug overdoses, or other chemicals. When liver cells stop working as a result of disease or drug overdose, toxins build up, damage the liver, and can quickly interfere with the brain, lungs, kidneys, and blood pressure. By selectively removing toxins from the bloodstream, the Liver Dialysis Unit diminishes stress on the liver and allows more time for liver recovery. This unique approach to treatment offers new hope for patients whose livers have been affected by illness, alcohol, poisons, or drugs.

What specific types of patients might be treated with liver dialysis?

Liver dialysis is used to treat patients with acute hepatic encephalopathy (a relatively rapid change in brain activity and consciousness that results from worsening liver disease) or severe drug overdose (the ingestion of a dose of drug large enough to have toxic effects on the body, particularly the liver).

How is liver dialysis done?

First, the doctor places a single flexible tube into one of the patient's large veins near the top of the leg or above the collarbone. The Liver Dialysis Unit is connected to the tube and gently draws a small amount of blood into the machine. Inside the Liver Dialysis UnitTM, a special dialysis fluid draws the toxins out of the blood. A patented membrane ensures that the blood never touches the dialysis fluid. The Liver Dialysis UnitTM gently returns the treated blood to the patient and then draws another small amount of blood from the patient into the machine to continue removing toxins. The total amount of blood outside the body at any time is much less than the amount of blood taken when someone donates blood.

Is there any discomfort from the procedure?

No. The Liver Dialysis Unit does not cause significant discomfort or side effects.

How long does the treatment take?

Liver dialysis requires only four to six hours per Liver Dialysis Unit(tm) Treatment. day. Most patients need only a few days of treatment to benefit.

What are the results?

By selectively removing toxins from the bloodstream, the Liver Dialysis Unit diminishes stress on the liver and allows more time for liver recovery. If the patient still has enough healthy liver cells, the Liver Dialysis UnitTM can often improve the patient's overall condition. The use of the Liver Dialysis UnitTM also may improve chances for successful • transplant surgery, if needed, by improving the state of health of a seriously ill patient before surgery.

What could I expect from liver dialysis?

Liver disease is a complex condition to treat. Many things can influence the results of treatment. For the most accurate information on your particular situation, talk with your health care provider about the benefits liver dialysis might provide.

Case Report

Effect of Liver Dialysis Unit(tm) on Acute-on-Chronic Hepatic Failure With Hepatorenal Syndrome . Treatment Center: Greater Lafayette Healthcare Systems, Lafayette, IN. Physicians: Drs. C. Cline, Dr. J. Geneczko, Dr. D. Shook, Gastroenterologists

Brief Summary:

A 42 year old white male with hepatitis C infection, distant history of cocaine abuse and modest alcohol intake, developed early signs of cirrhosis. Three months later, the patient suddenly developed hepatic failure with coma, adult respiratory distress syndrome (ARDS), respiratory failure, and renal failure with anuria, concomitant with E. Coli septicemia. In spite of IV antibiotic therapy over the first 24 hours of admission, the patient rapidly worsened and was intubated. During three successive days of treatment with the Liver Dialysis Unit(tm), liver function, renal function, and respiratory function improved, and the patient was extubated. In spite of an elevated bilirubin and ammonium level, the patient returned to reasonable health for the next 8 months, traveled, and even returned to work for a while. Signs of cirrhosis persist, and the patient is now undergoing evaluation for liver transplant.

Patient History.

Three months prior to admission, the patient noted swelling of legs and abdomen and generalized weakness. Two months prior to admission, he was found to have hyperthyroidism and was treated with IV esmolol, then propylthiouracil (PTU) 50 mg/day. The day before admission, the patient had increased shortness of breath, abdominal pain, jaundice, and decreased urination. On admission to the hospital, the patient was markedly short of breath and had Grade 3 encephalopathy and diffuse pulmonary infiltrates typical of ARDS on chest x-ray. Bilirubin was 4, ammonium 73, albumin 1.8, INR 5, and platelet count 20,000. The patient declined rapidly on the day of admission, developed coma, and was transferred to ICU and intubated. Blood cultures were drawn (later growing E.Coli) and IV antibiotics begun. Hepatitis C antigen and antibody tests were drawn (later both found to be positive). Esmolol was begun for pulse of 140. Urine output decreased to zero.

The patient was treated with the Liver Dialysis Unit(tm) for 6 hours daily, starting on the night of hospital admission. Fresh frozen plasma was administered during treatments to normalize the INR. Esmolol was started to lower pulse rate, which decreased from 140 to 100 bpm.

Results of Liver Dialysis Unit(tm) Treatment. **During treatment:**

- Urine output increased.
- Creatinine and bilirubin stabilized.
- Encephalopathy decreased.
- BP trended upward during each day of
- Ammonium decreased to about 60.
- Patient became alert.
- Urea continued upwards, but peaked on the day after the third treatment.

Following treatment:

- Urine output continued to increase.
- BUN and creatinine peaked, then decreased to normal levels
- 2 days after the last Liver Dialysis Unit treatment, the patient was removed from the respirator.
- In spite of continued lactulose therapy, ammonium increased to 100 after the treatments. then ranged from 50 to 100; however, the patient remained alert.
- Coagulopathy improved, with INR 1.8, and platelets increased to 60's.
- Bilirubin increased after the treatments to 9, then decreased just before discharge, 15 days after admission.

Outcome.

Patient was discharged after a 2-week hospital stay. The patient was generally weak but functional, and even returned to work for 10 days. He was readmitted 1 month later with encephalopathy, after discontinuing lactulose for several days. Bilirubin stabilized at about 6, platelets remained in the 70's, ammonium in the range of 50 to 70 mm/L. The patient moved to Florida to live with his sister, then returned to live in Indiana 8 months later. He has persistent swelling of legs and has required two paracentesis treatments for increasing ascites. He was turned down for liver transplant by one center but currently is being evaluated by another center. He has consumed no alcohol and used no illicit drugs.

Founded in 1998, HemoTherapies Inc. is located in San Diego, California.

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RUMOUR HAS IT THE LATEST ON 86-90

Rooters, Dec 14, 1999. 08:52 GST

Well, our man in the field, Terry "Big Ears" Waller has done it again—picking up information where none has gone before. Well done, old sleuth.

Terry called the office (Rilly?) and told us that he heard that the forms that were being sent out to people in the 86-90 group were....(are you ready)50 pages. So much for JJ Camp's statement that the process would be simple and not require a lawyer. I'll I can say is: put a 50 page whatever in front of me and I'll just fall asleep. So there.

Terry also told me that another rumour out there is that the Salem Witch Hunt is about to make a comeback. Apparently the government is establishing procedures to weed out any undesirables from the compensation package by beginning a thorough investigation of our underwear. Apparently, if you ever had sex with more than one person, had a tattoo, have pierced body parts, or smoked a joint (does that include Ham, Bill?) or otherwise had a life, you are in big trubble.

So I called the Compensation Hotline and requested to speak with a certain supervisor. His name is Mark. We had a nice chat. He said, off the record, that, yes, the application forms package was quite big, but that is because it contains lots of instructions, and, also, it has not yet been typeset. I asked him if the thought the typeset forms would be more at around 35 pages, then, and he seemed to agree...:)

Mark also said that there are still many things to be approved and procedures set in place, so he couldn't tell me much. But he said that he would keep in touch with me, and we spoke about setting up a peer training session in Victoria to help our members fill out the application forms. He thought it was an excellent idea, and I will know more later

Latest update: Well, I called Terry and asked his permission to misuse his name; he chuckled, took a deep breath and said, "There's more. Just call this number for the latest updates: 1-800-229-5323," so I did. The sultry voice on the tape gave me an updated message (Dec 13) in which I was told that: 1) Contrary to what you may have heard. the matter is not closed because the appeal process for Quebec is still open (and with good old Lucien at the helm, who knows what can happen). 2) That the forms going out are trial forms and (according to the Big TW) are not government forms, and thus not official, but forms designed by the lawyers to "streamline" the processs. And 3) Only 100 selected claimants will receive the 50 page application form in the next 2 weeks; the other unlucky ones will have to wait until the office of the administrator assesses how well-oiled it is.

And last, according to the old TW, a call put in to the Traceback people reveals that they are so far behind that any statement to the effect that cheques will be in the mail soon can in no way be taken to mean that most of you will get your money anytime soon.

This just in from Leslie:

"Test compensation applications" are being received by some 1986 to 1990 claimants. The sample contains about 50 pages and is much like a tax form. It offers plenty of instructions, and guides the claimant through the claims procedure.

There are general forms to be completed by everyone, Quebec claim forms, ones that only apply to the transfused, to hemophiliacs, or to persons with thalassemia. There are forms that must be completed by your doctor, forms that must be sworn and witnessed by a lawyer, notary or a commissioner of oaths. Forms that must be signed by a family member.

It is obvious that one will need to have a <u>completed traceback</u> in order to be compensated. There are about 10 forms dealing with your transfusion.

It is reported that you will not require the services of a lawyer to complete these forms. But it is necessary that you have obtained all applicable paperwork. You need to get

1) all medical records pertaining to your transfusion

2) traceback results - *not to be confused with the lookback letter you may have received from the provincial government. A traceback is the confirmation that the Canadian Red Cross or Canadian Blood Services has located the donor of your blood and confirmed that you did in fact receive hepatitis C positive blood

- 3) antibody test results
- 4) PCR test results
- 5) biopsy results
- 6) and anything else that will apply to your claim.

It is important that you contact the Canadian Blood Services. You will need to know the status of your claim and get the traceback claim number from them.

The administrators office is testing the system with these randomly picked claimants (about 100) in hopes of getting all of the bugs out before everything is approved and claim forms go out to everyone. It is not believed that any of these test applicants will actually receive payment, but this question is not yet resolved.

(**SQUEEKY**—Continued from page 3)

This popular approach to hepatitis C, i.e., as only a liver disease, is not only wrong, it is dangerous. For example, let us say that I go to my doctor and I don't have cirrhosis; the doctor might say to me, "Take a multivitamin and don't take Tylenol, take ibuprofen." Well, most multivitamins have iron in them, and iron is what feeds the virus. As well, Tylenol in low doses is fine for a liver that functions properly, whereas ibuprofen can activate the virus. Although I have no absolute scientific proof for this (there have been some studies pointing in this direction), I can assure you that many times our members have come to me saying, "Boy my liver started hurting so much the last couple of weeks, I'm scared." When I question them, it turns out that their physicians have been giving them ibuprofen for arthritis, because the physician believed that Tylenol was bad for them, and that the pain started when they started taking the ibuprofen, and it stops when they stop taking the ibuprofen. The same with aspirin. Aspirin should not be taken if you have advanced liver disease because people with advanced liver disease usually have bleeding problems. Just because you have HCV does not mean that you cannot take aspirin, or that you cannot take Tylenol.

Fortunately, the medical community is beginning to listen. I remember calling the Capital Health Region in Victoria, and during a conversation with one of the officials, I thought I'd ask a question. What is hepatitis C? The official correctly answered that it was an autoimmunetype disorder. Had this individual said "It's a liver disease," I would have gone squeeky.

Recently I have had some meetings with the BCMA who have offered to help us by doing two things: 1) drawing their members' attention to the *hepc.bull*, and 2) working with us to design a physician education program. They are very open to a community approach to medical practice, and I do believe they are genuinely listening.

Many of us have been quite lucky in finding a physician who will listen to and take us seriously; others have not been so fortunate. The problem is that healthcare in Canada in the year 2000 should not be based on luck.

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.

NEW INTERNET CHAT ROOM

he chatroom is for Hep chat and heppers meeting heppers. I have met a few in there that were just diagnosed and know nothing-so sad. Their family has left them, etc. The chatroom is at http://anexa.com/hepatitis

Please come by when you can.

Debbie my-girl@home.com

INFO ABOUT DAVID KLEIN'S PRESENTATION

Thursday, December 9, 1999 - Evening Support Group - Vancouver - Guest Speaker: David Klein of Klein, Lyons who represents the pre '86 post '90 group. Disclaimer: Please note that I took these notes in rapid succession at the meeting and I trust that I have all the information down correctly. If you have any questions about the content and want to verify anything please get in touch with Lisa Porteous at David Klein's office (604) 874-7171 or e- mail Lisa at lporteous@kleinlyons.com

simultaneous basis:

January 1, 1986 - July 1, 1990. This is commonly known as the "Endean" class action, and has been certified in BC, Ontario and Quebec. Also, the Hemophiliac Group is included and has also been certified in all three provinces mentioned above. The government promised \$ 1.2 billion in compensation for this class action. No moneys have been paid out to date, and the appeal time has now expired. The settlement is now final and will go ahead. The necessary forms required by the government prior to payouts have not been finalised, but should be done and out in the mail to recipients within the next couple of weeks. The hope is that the first cheques will be in the mail late February or early March, 2000. The government has filed an objection to the lawyers' fees.

Pre '86 - Post '90, commonly known as the "Ted Killough" class action. Note: This is the only pre '86 - post '90 class action that has been certified and that has been done both before the provincial and federal governments. The federal government has provided the lists of documents required by Klein Lyons on behalf of the class action, but to date, BC has not provided these documents. The law firm will cite contempt against BC for failure to produce the documents and negligence in fulfilling their duties. I understand this was to have been heard in court on Dec. 9 and 10, but has now been postponed. No new date has been set at the time of our meeting. The class actions in Ontario and Quebec for this period of time have still not been certified.

Red Cross Insolvency Hearings. It appears that there will be approximately 60 - 70 million dollars left after the Red Cross pays all of its creditors. These remaining moneys will go into a trust fund. The Red Cross is also trying to get their insurers to contribute to the trust fund. There are about 4000 infected registered across Canada with regard to voting on the outcome of the moneys. You can still file a claim against the trust if you have not vet registered, but you will have no vote. It appears that there may be about 1000 out of the 4000 that were IDU (intravenous drug users), and they will not get any money. The final tally of persons who could expect moneys from the Red Cross trust (only pre '86 - post '90 group) could be about 5000 persons, sharing anywhere from 60 to 80 million dollars. The structure of the payout has not yet been set, but it will probably be on some type of sliding scale. I understood from the meeting that the Red Cross plaintiffs will only be paid out if and when the

"Killough" action is settled.

David Klein has about 780 tainted blood clients at this time-190 of which fall into the January 1, 1986 to July 1, 1990 group and 150 of which have proved they contracted Hep C through blood transfusions.

Klein Lyons has an agreement with 110 hospitals throughout BC that, as of one year ago, they will no longer destroy any records they still have until the Hep C suits have been settled.

Children's Hospital and also VGH have many of the records from the old Shaugnessy site. Also, many hospitals have a separate blood division, and they may have records on microfiche There are 3 different groups that are ongoing on a that will not show up in the regular hospital records. It is another avenue to pursue if you are trying to prove you received blood transfusions.

> There is also a Post '90 group. There is no class action slated for this group in BC, and the number of people affected is very small.

Advice from David Klein: If you can prove that you received blood transfusions during any of the time periods mentioned above and you have no other behaviour that would point to having contracted Hep C from another source (i.e. IV drug use, tattooing, etc) do not do the trace back. If you do, and the results were to come back that the donors of the blood you had received had tested negative, you would be out in the cold with regard to compensation. It is not worth taking the risk. If you can prove blood transfusions without other possibilities of having contracted Hep C, that is all you need.

Advice from Lisa Porteous at Klein's: Before any decisions on payouts are made an offer has to be forthcoming from the governments in question, and then the parameters will be set as to where and how and to whom the moneys will be paid out. One thing that Lisa made very clear was that if you have Hep C and feel that you may not be around when a settlement is forthcoming it is EX-TREMELY IMPORTANT THAT YOU HAVE A WILL AND EXECUTOR. THAT IS THE ONLY WAY THAT A CLAIM COULD BE CONTINUED AGAINST WHATEVER MONEYS **BECOME** AVAILABLE.

Darlene Nicolaas Co-Chair, HepC - VSG (Vancouver Support Group)

TCM MEDICATION IN VANCOUVER

I have finally managed to have the herbal medication available in Vancouver. I have been taking the herbs for the past 3 years and have found that my symptoms have been greatly alleviated. This is by no means a cure, but should offer people some relief from the symptoms of Hep C.

There are three formulas available: Peaceful River. Middle Way and Cool & Calm, formulated to reduce the symptoms of Hep C.

In addition to the three main formulas, there is eliminator formulated to be only be used only in conjunction with Peaceful River, Middle Way or Cool & Calm. It is designed to reduce the effect of 'fire-poison' an adjunct designed to offset side-effects, increase tolerability

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)

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: Tel. (250) 652-0608 Ron Thiel

E-mail: thielron@pacificcoast.net

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

and enhance efficacy of interferon, whilst clearing heat and strengthening the immune system. In terms of Chinese medicine it also has the objective of supporting the energy of the kidneys, particularly when taking drug

Contact: Herb Moeller at: Hmoeller@compuserve.com

The product is available from: Eastern Currents Unit 200A 3540 West 41st Ave. Vancouver, BC V6N 3E6

Ph: 604-263-5042 Fax: 604-263-8781

Contact: John Stan