

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

## MY LIFE AS A HEPPER

In 1976, I was working for INCO at the copper refinery in Sudbury when I had an accident on the job. I injured my lower back that required an operation. In 1978 I had a Pain, breathing difficulties, sleeping probspinal fusion and at that time I was given two units of the Red Cross finest tainted blood.

I did not know that I had hepatitis C until 2002 although I had to leave work in 1981. I had a blood test for my cholesterol. When the test came back my doctor asked me if I drank. My reply was no. He then asked me if I took drugs. My reply was, "Only the ones you give me." He then told me that my liver enzymes were high and he did not understand why. Then he said that he would run a test for Hepatitis A and B. Jokingly I said, "You might as well do C at the same time." not even knowing there was such a thing. He agreed and sent me for more blood tests.

His office called me with an appointment to see my doctor. I went to this appointment and my doctor said with tears in his eyes that I had hepatitis C and suggested I go to the Sudbury Health Unit and they would explain what hepatitis C is. They gave me a little more information about hepatitis C and suggested I go to Access AIDS and join a support group. Now I'm really confused! What does this have to do with AIDS? When I went to my first meeting I soon learned that it has nothing to do with AIDS. After a year of attending the meetings I was getting tired of only three or four of us being the only regular members in the group. Others would come and go. So I did a lot of thinking as to how we could attract new members. I suggested to the group that we ask people involved with hepatitis C, such as the health unit and other organizations, to come and speak to the group. This did attract some of the others that had attended the meetings before, however it did not attract new members, so I decided to put my face in front of the news media. I started off by picketing our Liberal M.P. office with a sign saying

## LIVING A HEALTHY LIFE:

The Chronic Disease Self Management Program (CDSMP) By Samantha Van Staalduinen

Fatigue? Check. Loss of energy? Check. lems, depression, anxiety about the future....the list goes on. Coping with a chronic health condition can be extremely taxing, and while no two individuals' experiences are quite the same, there are a lot of similarities, no matter what the condition might be. This is a cornerstone of the thinking behind "Living a Healthy Life with Chronic Conditions", a free, fun and practical course that helps people with chronic conditions overcome their daily challenges and achieve or maintain an active, fulfilling life. Through information, strategies and techniques, participants learn about healthier ways to live, gain confidence and motivation to manage their health, and feel more positive about their lives.

Some of the topics covered in this highly interactive course include how to manage symptoms and make daily tasks easier, healthy eating and exercise, communicating effectively with physicians and the health care team, and managing emotions like fear, anger and frustration that are often associated with living with a chronic health condition. One of my favorite aspects of the

(Continued on page 4)

## **INSIDE THIS ISSUE:**

oup. Others would		
ot of thinking as to	My Life as a Hepper/Living a Healthy Life	1
w members. I sug- we ask people in-	Kelman/Jesske	1
such as the health	Book Review: Survival Guide	3
ions, to come and did attract some of	Choices	5
nded the meetings	PegCare/Pegassist	5
t attract new mem-	T	
my face in front of	Treatment/News/Cup of Tea	6
d off by picketing with a sign saying	Pitfalls/Magic Mouthwash/Compensation	7
(Continued on page 4)	Coming Up	8

### TOM KELMAN

November 14, 1946-November 29, 2006

Formerly of Gibsons, Tom "will be remembered in our community as a friend without judgment, always ready to extend a helping hand. He was a remarkable man," wrote the Coast Reporter in his obituary.

An HCV activist, Tom was a member of the working group of the BC Hep C Council since 2002. He did notable. innovative work on the Sunshine Coast, and started the Needle Exchange on the Sunshine Coast, with his "client first" approach which served as a model for such services across Canada, and for which he received an award from The BC Association of Substance Abuse Programs.

He was Program Coordinator for a government-funded drug-treatment program in Sechelt which handed out safeuse kits containing vitamins, condoms, educational materials and crack pipes. The crack pipes were assembled by other drug users, working off community-service sentences and given to ad-

(Continued on page 4)

## PERCIVAL "PERCY" **JESSKE**

Percy Jesske, one of our subscribers, a resident of Shawnigan Lake, passed away in Victoria, BC on June 13, 2006. He was 56 years old. Percy was born in Medicine Hat, Alberta. He is survived by Roberta and his children Kendra and Chantal, sisters Myra and Audrey, and many nieces and nephews. A memorial reception was held at First Memorial Funeral Services on June 19. Donations can be sent to Millennium Stars Self Help Group, C/O MS Society, 1004 North Park, Victoria, BC, V8T 1C6. 258204

Source: Times Colonist Obituary

hepc.bull **JANUARY 2007** Issue No. 96 Page 1

## SUBSCRIPTION/ORDER **FORM**

Please fill out & include a cheque made out to **HepCBC** - Send to the following address:

> **HepCBC** #306-620 View Street Victoria BC V8W 1.16

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(Note: The hepc.bull is mailed with no reference to hepatitis on the envelope.)

You may also subscribe on line via PayPal at www.hepcbc.ca

SUBMISSIONS: The deadline for any contributions to the hepc.bull<sup>©</sup> is the 15<sup>th</sup> of each month. Please contact the editors at info@hepcbc.ca, (250) 595-3892. 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 12<sup>th</sup> of each month. Rates are as follows:

Newsletter Ads: Maximum 4 per issue, if space allows. \$20 for business card size ad, per issue. Payments will be refunded if the ad is not published.

## **HOW TO REACH US:**

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http://health.groups.yahoo.com/ group/hepcan/messages

**HepCBC** 306-620 View Street Victoria BC V8W 1J6

#### LETTERS TO THE EDITOR:

The hepc.bull welcomes and encourages letters to the editor. When writing to us, please let us know if you do not want your letter and/or name to appear in the bulletin.

## NEW!!! FAQ v7.1

Peppermint Patti's FAQ Version 7.1 is now available, and Version 7 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 125 pages of information for only \$7 each, plus postage. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

## HepCBC Resource CD

The CD contains back issues of the hepc.bull from 1997-2006; the FAO V7.1; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. The Resource CD costs \$10, including S&H. Please send cheque or money order to the address on the subscription/ order form on this page.

DISCLAIMER: The hepc.bull® cannot endorse any physician, product or treatment. Any quests 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 health practitioner before consumering any merapy or merapy prosecut.
The opinions expressed in this newsletter are not necessarily those of the
editors, of HepCBC or of any other group.

#### REPRINTS

Past articles are available at a low cost in hard copy and on CD ROM. For a list of articles and prices, write to HepCBC.

### "HANKS!!

■ HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, Bruce Lemer, Health Canada, the Provincial Employees Community Services Fund, Brad Kane, Chris Foster, Judith Fry, the FitzGerald family, Erik, Irene, S. Segura and the newsletter team: Tanya, Beverly A., Diana Ludgate, Alp and Ernie. Please patronize the following businesses which have helped us: Chateau Victoria. The Mile Restaurant. Lexmark. Recollections, Margison Bros. Printers, Roche Canada, Pacific Coast Net, Patisserie Daniel, Preview Hair Studio, Royal Bank, Schering Canada, the Shark Club, Thrifty Foods, Victoria Bridge Centre, the Victoria Conservatory, and the Victoria Symphony. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

#### BE PART OF THE TEAM!

We need people to summarize articles. HepCBC needs telephone buddies, a librarian and 2 people to help with our website. The HepCan list needs a moderator trainee. Please contact us at 250-595-3892 or info@hepcbc.ca

## CUPID'S CORNER

his 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 15<sup>th</sup> 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 HepCBC, and mail to HepCBC, Attn. Joan, #306-620 View Street, Victoria, BC V8W 1J6, (250) 595-3892.

Give us your name, tel. number, 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 HepCBC cannot be held responsible for any interaction between parties brought about by this column.

Want a mate? Your Cupid ad could go here! \*\*\*\*\*\*\*\*

## Got Hep C? Single? Visit:

http://forums.delphiforums.com/HepCingles/ http://groups.yahoo.com/group/PS-Hep/ http://groups.yahoo.com/group/HepCingles2

> http://groups.yahoo.com/group/ NewHepSingles/

CHAT: <a href="http://forums.delphiforums.com/">http://forums.delphiforums.com/</a> hepatitiscen1/chat

## TIP:

ASK YOUR DOCTOR **ABOUT** THE PNEUMONIA VACCINE

## DIAL-A-DIETITIAN

**604-732-9191 (Vancouver Area)** 1-800-667-3438 (Toll-free elsewhere in BC)

## Hepatitis C - Are you at risk? Get tested...



For more information call: 250 595-3892 www.hepcbc.ca

## PRE-PLANNING YOUR FINAL ARRANGEMENTS?

Please consider arranging for donations to your local hepatitis C organization.

Page 2 hepc.bull **JANUARY 2007** Issue No. 96

## **BOOK REVIEW:**

## The Combo Survival Guide from A to Z

It's January, and typically a lot of us Hep-C'ers will be starting treatment. I want to suggest some reading that will have you ROFL (rolling on floor laughing) in spite of your side effects. Trishamn, Lacey & Freyja have written "The Combo Survival Guide from A to Z". True, it was written in 1999, when the pegylated treatments weren't yet used, but the suggestions on how to deal with the side-effects are still valid. Never before has a dictionary been so fun to read! You can find it at www.hepcsurvivalguide.org/

comboguide.htm, free of charge. And it was written by three of "us"! If you don't have a computer and want a copy, write to HepCBC. I have quoted directly from the book because the website says I can. Here are some delightful and/or helpful excerpts. I have not edited this other than to cut and paste in some of my favorite parts:

Brain Fog: Forgetfulness, lack of coordination, inability to spell and complete sentences in mid conversation. Losing: keys, shopping cart, the car itself, lists, mind, pills, glasses of water, etc. Try to keep a sense of humor. Make lists, lots of them, because you will lose most of them. Write everything down legibly, don't count on your memory to remember what it was.

I have misplaced and found my brain over and over with the help of my homeopath. Here is a link to the NIH's <u>National Center for Complimentary & Alternative Medicine</u>. Always check with your doctor before embarking on any homeopathic or vitamin regimen.

## **Depression:**

Here is an **Online Depression Screening Test** to see if you are depressed:

www.med.nyu.edu/Psych/screens/ depres.html, take this test frequently during your treatment.

Realize that it's the medication not **you** (or your spouse, boss or kids) that is making you feel this way. Ask your doctor to put you on an antidepressant ASAP if you or people around you notice any behavior changes. It will take at least 3-6 weeks to feel better after taking the **Prozac, Zoloft, Xanax** or whatever your doctor prescribes. Talk to other heppers about what is going on, call people, join a chat group, go to your support group.

**Do not** take **St. John's Wort** at the same time you start antidepressants.

#### Fatigue:

Pamper yourself. Let the house and yard go for a while. Only try to do the bare minimum. Take naps. Get a massage. Try to keep your sense of humor! Watch a stupid Mel Brooks movie. Lean on your family and friends, that's what they are there for. If at all possible, take off work for a couple of weeks at the beginning of treatment, if you need to, take some short-term disability or sick leave.

The more active people in my group at NIH seem to do better with the sides. If you are too tired to cook dinner for your family, serve them cereal. Try to keep a positive attitude.

## Lacey's Recipe for an easy Cereal Dinner

Preheat oven to 350 (cause you are so cold all the time)

Go to cabinet, pull out several boxes for them to choose from (you should never scrimp when it comes to your family's nutrition!)

Place bowls on table

Send husband to grocery store for milk Pour and enjoy!

(utensils are optional-if they want a spoon they can wash it themselves!)

## The First Shot - How bad is it? What you can do to get ready:

Ok, so you have not started treatment yet and you are reading the guide so that you can have a general idea of what to expect, especially the first night, which is by far, the worst day (for some people). We call it the "freight train" because you feel like you just got hit by one. The feeling is actually similar to a super bad flu or a New Years Day hang-over from hell. Common sides may include: fever, chills, sweating, severe headache, muscle pain, nausea, vomiting, insomnia, dehydration and overall feeling like crap. Then again, some people don't have any of these symptoms and don't feel very bad on the first night at all. I hope you are one of those, but it's always better to play it safe and prepare as best you can.

The most important thing that you can do is to hydrate yourself before you take the first shot, drink plenty of water and fluids, especially the day of the shot. It may ease the sides and make it easier on your kidneys. It's better for your system and you will hydrate yourself better if you drink sips of fluid throughout the day rather than drinking large amounts at once in gulps.

Dress warmly, even in the summertime. Have extra blankets by your bed in case you wake up chilled, extra clothes ready in case you soak them with sweat, a water bottle for when you are thirsty and some Tylenol for your headache and fever. Have a thermometer by your bed and if you temperature goes above 102 degrees for an extended period, call your doctor.

Don't plan on doing anything your first shot night except for staying in bed. I know of someone that took the shot, and then went to work. He was a long-distance trucker, needless to say, he regretted not being home in bed, especially on first shot night. If you live alone, plan on having a friend or family member stay the night so they can keep an eye on you.

Before retiring, take a regular strength Tylenol Nightime formula or a Tylenol and some Benadryl. The Tylenol will help with the aches and fever, the Benadryl will hopefully make you drowsy enough so that you will sleep through the worst of it.

First shot night was not fun, but it has gotten better. As I look back, I realize that the anticipation and waiting was worse than the actual shot itself. We hope that it's the same for you also.

#### **Heart pain or murmurs:**

What are you doing reading this! Call your doctor ASAP!!

#### Oral Hygiene (nose, mouth and throat):

This is a doozy of a combination side to get. The interferon dehydrates you and also slows wound healing. When your mouth is very dry, the combination of the dryness and bacteria can run amok and cause all kinds of dental problems including periodontal disease, receding gums, mouth sores, bad breath, gingivitis, cracked molars and loose fillings. Be careful with what you eat so that you don't injure your gums. Stay away from sharp or crunchy foods that can tear your delicate skin. Gargling with very warm strong salt water, Goldenseal or Chamomile tea may be a beneficial aid in mouth wound healing. Don't forget to spit!

Homeopathic: There are many natural products at the market these days, I use "Eco Dent Ultimate Essential Mouth Care-Natural daily rinse & oral wound cleaner", it is available at Whole Foods

or Fresh Fields.

hepc.bull JANUARY 2007 Issue No. 96 Page 3

#### (MY LIFE AS A HEPPER—Continued from page 1)

COMPENSATE ALL HEPATITIS C VIC-TIMS OF TAINTED BLOOD. At that time no one in government was really talking about compensating the pre-'86 post '90 victims other than the undertaking agreement. At that time Ontario never even signed the undertaking agreement, but Tony Clement, as Ontario Health Minister, decided to sign it only to take it away from us and put it into programs that were already in place such as OHIP and lab tests, and he changed Ontario's Trillium program to section 8 for drugs. We are still looking for a place to send our out-of-pocket expenses relating to hepatitis C.

new members. I am proud to say that they are still members of the group. One of them is now our coordinator and is doing a fine job. We have thirty members. Granted, we are still struggling to get all thirty members Hugs, to attend the meetings at the same time because of doctors' appointments, and some are just too sick to attend every meeting.

I met with Jack Layton here in Sudbury in September 2005 and he said that the NDP will not rest until all hepatitis C victims are compensated. I must say that Penny Priddy, the health critic for the NDP, has not given the government of the day any time to rest and we owe her a big thanks for that.

Our group rallied in Ottawa in November 2005 and the Liberals announced the Memorandum of Understanding Agreement. I don't know if we had anything to do with that announcement, but I'd like to think so. They knew we were coming on a Monday and they announced it three days before our rally on Friday. I must say it did take some fire out of our rally, but who cares. We are now recognized as the forgotten ones and as a result we now have nearly a billion dollars set aside for compensation for us.

I was told by a lawyer representing Klein Lyons' office that if they did not make it a political issue we would not be compensated and I told her that if the victims did not rally and show that we were not going away she would not have a job and I did not see her on either side or in back of me in Ottawa. She asked me who I was and I was proud to say, "I'm Ernie Zivny from the Circle C Support Group in Sudbury, one of the seven members that organized the rallies in Ottawa." That was the end of that conversa-

We could not have done this if victims had not phoned or e-mailed their MPs, rallied in Ottawa or at their MP's office showing that we will not go away and we are united. I do hope that this money will give

some peace of mind and a little quality of on an exercise program and was already life.

I know that some have died waiting for Justice. May God be with them and their families. We light a candle at every meeting to remember them. We must not let the government or the Red Cross forget them just because they threw a few dollars at us. Hepatitis C does not discriminate, so why should we? We must push governments to fine a cure and to prevent any one else from this kiss of death. We must push for better testing of our blood supply, needle exchanges for safe IDU, and education in schools to help prevent IDU with drug awareness programs. We have so much to do With all this media attention I got four and with our knowledge, we can educate others. Thank You.

> On behalf of my group, may we all have a very Merry Christmas and a Happy New

Ernie Zivny

Circle C Support Group, Sudbury, ON hepc.support@persona.ca

### (LIVING A HEALTHY LIFE Cont'd from page 1)

course is the action plan, an effective goalsetting tool we use each week. It's been useful for me for everything from eating healthier to planning a trip, and participants often tell us at the end of the course it was one of their favorite tools as well.

I've been a leader with the CDSMP for several years now, and it's been one of the most enriching experiences of my life. Like most course leaders (who are all trained volunteers), I have a chronic condition myself, having been diagnosed with a blood disorder nine years ago. I still use many of the techniques and principles taught in the program, and with every course I'm involved in I find I learn a little bit more, both from the program itself and the people around me.

We often come into the course with a wide variety of backgrounds and health conditions--liver disease, arthritis, diabetes, asthma, fibromyalgia, hypertension, depression, heart disease, you name it---but always find we have a great deal in common. We meet as a small group (usually 10-15) for  $2\frac{1}{2}$ hours, once-a-week for 6 weeks, and it's always a warm, supportive, casual environment. I've seen some amazing transformations occur in people over those six weeks, both in terms of attitudes and physical health. I can remember one participant in particular who at the beginning of the course was sleeping until mid-afternoon every day, felt unmotivated to exercise, and was convinced his situation was beyond his control. By the end of the course, he had embarked

seeing/feeling results, and was able to get up earlier. He had even stopped smoking and gotten a new job! Obviously not every participant has experienced changes as dramatic as this after participating in the course, but the wonderful combination of practical tools and social support the program offers ensures there really is something for everyone. For me, the biggest benefits have been the tools for managing stress and the opportunity to work through some of the difficulties associated with having a chronic condition with others who know what it's like.

"Living a Healthy Life with Chronic Conditions" courses are delivered provincewide and year-round in various community settings such as recreation centres, libraries, community health centres and seniors' activity centres. They are delivered by the University of Victoria's Centre on Aging at no cost to participants, and funded provincially by the BC Ministry of Health Services. Details on course offerings around the province can be found by visiting the website at http:// www.coag.uvic.ca/cdsmp or by calling the toll-free information line at 1-866-902-3767.

Note: A special course offering for people with Hep C and other liver diseases, their family members, friends and caregivers is scheduled to begin on Monday, January 8, 2007 at the Liver and Intestinal Research (LAIR) Centre in Vancouver. For more information feel free to contact me at (604) 897-7446 or samannvan@gmail.com, or register directly for the course by calling Natalie Rock at the LAIR Centre at (604) 876-5122 extension \( \) 2224.

## (TOM KELMAN—Continued from page 1)

dicts after they completed a lifestyle survey. The hope was to prevent sharing of pipes which might be contaminated with blood.

Tom disappeared from view around 2002, due to his HCV, but he was spotted at BC Transplant Society offices, wearing the pager that was to let him know when transplant was available. That call did not come.

"Tom passed away on November 29, at approximately 3 AM. His memorial service was held in Sechelt on December 9, 2006, and was attended by more than 50 people. His obituary appeared in the Coast Reporter. He will be missed by many," wrote his friend Brent.

He will be missed by his daughters Jen, Celeste, and Christina, his granddaughters Sarah and Hailey, and his "family" of colleagues on the Sunshine Coast. A celebration of his life was held at the Education Centre. Sechelt Indian Band, on December 9, where memories and stories were shared.

Page 4 hepc.bull Issue No. 96 **JANUARY 2007** 

## **CHOICES**

By Joan King

worry. All of us HepC'ers have a time-bomb when we know that we will die soon. If your ticking away inside of us. It may go off, and again, it may not. The fact is, we are all going to die someday, be it from Hep C, or from something else.

we are going to die, programs called palliapeople comfortable, even in cases where the person is not dying, such as pain from arthritis, and can be combined with treatments to prolong your life or cure your illness. The care can be given in a hospital or at home, or through hospice, where you can also receive emotional and spiritual support. You have a team of support givers—your family, your friends, your doctors-in either place. Remember: Pain killers can shorten the lives of people with hepatitis C. Also remember: At the end of life, we don't worry about addiction. Your doctor has the duty to relieve your pain, and that pain should be re-assessed often.

Another common worry is how to console those who are left behind. If you have children or grandchildren, tell them you are sick, what you have, and what you think is going to happen. Give them only the information they request. If they are your children, tell them who will care for them. You can leave behind things that will comfort them, such as videotapes or letters.

The best thing to do is to plan for end-oflife issues while you are still healthy enough to do so. With that out of the way, you can relax and spend quality time with the people you love. You will feel less burdened, believe me!

Some things you may want to take care of are the following:

- \* Writing a will to distribute your belongings in the way you choose.
- \* Writing a living will—a legal document that tells people what kind of medical procedures you do or don't want if you can't speak or make decisions for yourself. You can copy, paste, edit and format a simple Living Will from the internet. Here's an example: www.ilrg.com/forms/ livingwill.html
- \* Have a medical power of attorney to appoint someone to make medical treatment decisions for you any time you are not able to do so.

Donating your organs: We with Hep C don't usually do that, but we may wish to donate our bodies for research.

Many times we can receive treatments together with palliative care. At some point, we may have to choose between them. Stop-

We rarely talk about it, but most of us do ping curative treatments is an easy choice to help people who don't have third party state of health does take a turn for the better, you can return to curative treatments.

Your culture affects your attitude towards death. Some societies view death as com-One of the worries about dying is dealing mon, while others try to avoid it literally at with possible pain. When it is obvious that all cost. Unlike death in the past, we usually are cared for in hospitals or nursing homes, tive care can kick in. Palliative care keeps not at home. We don't experience the process of someone's death so intimately as a

> Medicine can prolong life in spite of illness or coma, and people forget about quality of life in order to live as long as they can. Discuss your feelings about this with your loved ones so that they are aware of our wishes. It will help to prepare for your death.

> Sources: http://health.msn.com/encvclopedia/ healthtopics/articlepage.aspx?cpdocumentid=100073618 Care at the End of Life http://www.davidkessler.org/html/qa\_death.html

#### LIST OF HAZARDOUS HERBS

- \* Chaparral. Can cause liver inflammation.
- \* Comfrey. At least seven cases of liver complications have been reported in users. Toxic to the liver when taken internally.
- \* Yohimbe. Produces adverse reactions when consumed with certain foods -- liver, cheese and red wine. Is valued as an aphro-
- \* Lobelia. High doses can suppress breathing, cause sweating, speed the heart, lower blood pressure and even lead to coma or death. The source of lobeline, an ingredient in some over-the-counter smoking deter-
- \* Germander. Linked to liver inflammation. including one death. Used as a weight-loss
- aspirin, which could cause stomach irritation or Reye syndrome Is promoted as an the clinics. 'aspirin-free" pain reliever, but no adverse effects have been reported.
- Jin Bu Huan. An overdose can result in severe sedation requiring medical treatment, and in liver inflammation. Is marketed as a sedative and pain reliever.
- \* Stephania and Magnolia. Have been impli-
- pressure, rapid heart rate, nerve damage, muscle injury, psychosis, stroke and memory loss; Used for weight control, enhannced energy and to treat asthma and hav fever. Contains pseudoephedrine, found in decongestants such as Sudafed.

## **PegCARE**

PegCARE is a reimbursement program coverage pay for their Pharmacare deductible for hepatitis C treatment. It is pro-rated, so the less someone's net family income is, the more help they get. Basically, if someone's net family income is less that \$30,000, they will get 100% reimbursement. The more they make, the less of a percent is reimbursed, up to a max of \$100,000 income.

The patients must be signed up for Fair Pharmacare to qualify, and they also need to provide a copy of their last year's T4 form to show income level.

Each treating physician and hepatitis support nurse has these forms available to them. There is a toll free number that can be called if there are any questions or if help is needed. It's only a single page, a simple form to fill out.

PegCARE: 1-800-603-2754

### **PEGASSIST**

The PegAssist Reimbursement Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment success-

PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM- 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/ physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating any financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or co-payments.

In partnership with CALEA Pharmacy, \* Willow bark. Contains salicylates, like the program can conveniently deliver the medication directly to patients' homes or to

## **COMPETITION!**

epCBC is looking for writers for the next issue of the *hepc.bull*, and is willing to pay \$50.00 for a featured article. The article should be original, consist of 500 to cated in severe kidney injury to at least 48 800 words, and of course, be about hepatitis C. It may be, for example, about the author's \* Ma huang. Associated with high blood experience with hepatitis C, a study (with references) on some aspect of the disease, or a call for action. Submissions should be in by the 15<sup>th</sup> of next month, *stating interest in* the bonus. If there is more than one submission chosen, the editors reserve the right to print both, or leave one for a future edition. info@hepcbc.ca

## **TREATMENT**

#### **COLCHICINE**

Hepatocellular carcinoma (HCC), a type of liver cancer, is a major cause of death in | 6. Drink plenty of fluid. patients with cirrhosis, so patients with Hep C are especially at risk. Colchicine, an antiinflammatory, has been proven ineffective in slowing the progress of cirrhosis, but in a study described in Gut, September 11, 2006, 116 out of 186 patients with cirrhosis had received colchicine, and all the patients were studied at least 3 years later. It was found that HCC was much lower in those who had taken colchcine (9% vs. 29%). In those who had taken colchicine and did develop HCC, it took them 222 months, compared to 150 months in the untreated patients. The authors concluded that the results suggest that HCC may be prevented or delayed in cirrhotic patients, but more studies are needed. Colchicine is already approved for the treatment of gout and arthritis.

Source: http://www.hivandhepatitis.com/hep\_c/ news/2006/101706 c.html

### **NIGHT CRAMPS**

You are sleeping soundly. Suddenly you awake with a sudden, severe pain in your calf or thigh or foot. Any muscle cramp happens when your muscle tightens and shorten. Common cramps usually happen because of overexertion and dehydration, which can lead to an electrolyte imbalance. Electrolytes are minerals, and the ones that usually are lacking when we get muscle cramps are potassium, sodium and calcium. They can mysteriously occur when you are not moving.

What can you do to relieve a cramp?

- 1. Gently massage the area stretching the muscle slowly but not to the point of pain.
- 2. Drink fluids, either water, a sports drink, or juice.
- 3. Massage the area with ice for no more than 10 minutes. It can relieve inflammation
- 4. If ice is uncomfortable, try heat to improve the circulation and make the muscles more flexible. Use a heating pad for 20 minutes, or take a warm shower.
- 5. Follow ice or heat with massage.

How can you prevent night cramps? Consult with your doctor!)

- 1. Consider taking magnesium. If you do this, check the magnesium in your blood periodically.
- 2. Take vitamin D. 800 units daily should be enough. Too much can be bad for us.
- 3. Stretch regularly.

## 4. Take calcium supplements.

- Take vitamin E supplements.

Sources: http://www.betterbodz.com/library/ muscle cramps.html

http://www.medicinenet.com/muscle\_cramps/ page6.htm

### **NEWS**

## HCV + HAV = 0(IF YOU'RE LUCKY))

We know that some studies seem to show that if a Hep C patient gets infected with Hep A (HAV), as many as 35% of these patients may die. Interestingly, this study found 17 patients with HCV antibodies (out of 3170 at the same centre during a period of 12 years) who were suffering from acute Hep A as well. None of these 17 patients died. HCV RNA was found in 84% of the 3170 patients, but only in 65% of the 17 who had acute Hep A, which seems to indicate that HCV can be suppressed during acute HAV infection. Previous HAV infection did not affect HCV replication, and actually increased in 6 out of 9 patients. Two patients remained HCV negative after clearing the HAV.

Source: Deterding K, et al, J Hepatol. 2006 Dec;45(6):770-8. Epub 2006 Sep 22. Hepatitis A virus infection suppresses hepatitis C virus replication and may lead to clearance of HCV

## **RISK FACTOR:** NON-O BLOOD TYPE

French researchers have noted an association between blood group ABO (non-O) and how much fibrosis occurs in people with Hep C. They think that fibrosis progression takes place when genes interact with factors in the environment, and that a "clotting process" is part of the creation of fibrosis or scar tissue. Since ABO-group blood is linked to thrombosis, or blood clots, they did a study in 346 HCV+ subjects who were biopsied. Non-O patients had more severe fibrosis after taking into account gender, age, length of infection, and alcohol use. They concluded that having non-O blood is vet another risk factor for progression of fibrosis in those with HCV.

Source: Hepatitis Weekly, November 8th, 2006, Chronic hepatitis C fibrosis severity is associated with ABO blood group. Original source: Association between ABO blood group and fibrosis severity in chronic hepatitis C infection. Dig Dis Sci, 2006;51(9):1633-1636).

## A CUP OF TEA, ANYONE

Researchers have been doing some interesting work with compounds found in green tea. Results from studies on antioxidants found in green tea indicate that one may be of use in retarding liver damage from fibrosis necrosis and inflammation.

In one study, rats were injected with carbon tetrachloride (a toxic chemical that affects the liver). The rats that received EGCG (a component of green tea) by injection showed lower levels of ALT and other markers for inflammation and liver damage.

The second study had rats fed a high fish-oil diet to simulate non-alcoholic fatty liver disease (after a recently described model for NAFLD). Again the rats given EGCG faired better than those that did not get EGCG.

A note however... After having actual work experience with EGCG, ECG, EGC and EC (different polyphenol gallates and epi-gallates found in green tea), I can say that these compounds are rather unstable (which is why they are good antioxidants). Also note that the rats were injected with 85% pure EGCG at a dosage of 50 mg/kg 3 times per week. That would equate to a little over 10 grams per week for an 80kg person. That's one hell of a lot of green tea!! Ingestion of EGCG as tea or a supplement would most likely be far less effective as much of it would be degraded to non-effective byproducts as it reacted with stomach and intestinal enzymes, acids and other contents. This is probably why the researchers had to inject the rats rather than have them sit around at tea parties. They would also have to brew a lot of green tea to get the equivalent of 50 mg/kg EGCG, 3 times a week per rat. In a method described by J.H. Kang, et al, 121 mg EGCG were isolated from 5g of Korean green tea. That works out to about 2.4% EGCG by weight., so if you wanted 10 grams EGCG you would need 413 grams (almost 1 pound) of dry green tea.

Now don't go out and inject yourselves with green tea! There is more than just EGCG in green tea! You don't know what will happen.

So drink your green tea and enjoy.

Sources: www.hivandhepatitis.com/2006icr/aasld/ docs/111406 e.htmlG L Tipoe, et al, 57th AASLD. Boston, MA, October 27-31, 2006. Abstract 1062. cat.inist.fr/?

aModele=afficheN&cpsidt=1509685



Page 6 hepc.bull **JANUARY 2007** Issue No. 96

## PITFALLS IN THE **PACKAGE**

I got a call from Terry Waller from Sooke a couple of weeks ago. (He is a sustained responder, by the way!)

He doesn't have a computer, so can't write to us on the HepCan list, and has asked | Magic Mouthwash was developed at Duke, me to do so for him. Terry was compensated in the '86-'90 group, and realizes that the group outside the window is in negotiations right now. He pointed out that there are some | NDC Number pitfalls in their package, and some things 00143-1254-01 you should know. This is what Terry told me:

- 1. The \$75 million from the Red Cross that has already been paid out is seemingly being | 99999-9999-99 taking off the top of any money going out to those outside the window. (He was talking to More mixtures from Peppermint Patti and the lawyers' office, as I understood).
- 2. He was a tradesman. He is compensated for what he was earning, not taking into account what he would be earning now, which might be \$10/hour more. He does not have a pension plan, or dental or eye care, which he would have were he still working.
- 3. Other costs for diseases that may be a result of Hep C are not reimbursed (heart problems, arthritis, eye problems, etc.)
- 4. Prescriptions must be validated by the doctor that they are, indeed, related to Hep C. They must be validated each time, which becomes a bother for the doctor(s) who have to fill out the forms.
- 5. Terry has tried to get a report of how the money is being disbursed, but has been unsuccessful, and suggests those outside the window make transparency a part of the deal.
- 6. He took his forms to his own lawyer, and his lawyer fills out the necessary forms each year. He believes it is not wise to completely trust the lawyers who are involved in the negotiations.
- 7. Terry says that there is redundancy with the disability deductions. (I hope I got this right). He has to declare disability payments on his income tax return, but he also has to have a form filled out by his doctor each year that he continues to be disabled. Since he has to prove that he is disabled to get the disability payments, he has to prove it twice each year, the way I understood it.

Terry hopes that those of you who are involved will try to get these pitfalls resolved for your package, and if you have any questions, to please feel free to call him: Terry Waller 250-642-6766.

—Joan

## **MAGIC MOUTHWASH RECIPES**

Many of us tend to get mouth sores when we're on treatment. Here are some solu-

and consists of the following ingredients (any pharmacist can do this):

**Metric Quantity** 6.00 Hydrocortisone 20 mg tablet 60.00 Nystatin 100000 000536-1220-85 U/ML Susp 420.00 Benedryl

her FAOs:

First Magic Mouthwash Recipe 1/3 Maalox 1/3 liquid Benadryl 1/3 lidocaine viscose 2% solu-

Second Magic Mouthwash Recipe 1/3 liquid prednisone syrup 5mg/5ml 1/3 liquid Benadryl 1/3 liquid Nystatin

## **HCV-I.E.T. TRIAL**

On August 4, 2006, Transition Therapeutics Inc., based in Toronto, released the 12week results from its phase I/II clinical trial of HCV-I.E.T, an IFN enhancing product plus standard treatment (peg-IFN + ribavirin). The trial evaluated safety as well as effectiveness of of HCV-I.E.T, their EMZ702 plus standard treatment, compared to standard alone in 21 genotype 1 nonresponders to previous treatment.

The study data showed that 6 of the previous non-responders had a greater than 99% reduction of virus levels. The researchers believe that shorter treatment or lower doses may be just as effective. There seemed to be no side effects other than those of standard treatment, other than skin rash which occurred with the highest dose. Four of those patients withdrew from the study. More trials will be done to find the best dosage.

SOURCE: www.transitiontherapeutics.com (416) 260-7770, x.223,

tcruz@transitiontherapeutics.com

Mr. Elie Farah, CFO and VP, Corporate Development, Transition Therapeutics Inc., (416) 260-7770, x.203,

efarah@transitiontherapeutics.com

## **COMPENSATION**

#### LAW FIRMS

1986-1990

Bruce Lemer/Grant Kovacs Norell Vancouver, BC

Phone: 1-604-609-6699 Fax: 1-604-609-6688



Klein Lyons Vancouver, BC 1-604-874-7171. 1-800-468-4466, Fax 1-604-874-7180 www.kleinlyons.com/hepc/intro.html

David Harvey Toronto, ON

Phone 416-362-1989; Fax 416-362-6204

Lauzon Belanger S.E.N.C. (Quebec) www.lauzonbelanger.qc.ca.

Roy Elliot

Roy Elliott Kim O'Connor LLP. hepc@reko.ca www.reko.ca

Kolthammer Batchelor & Laidlaw LLP #208. 11062 - 156 Street. Edmonton, AB T5P-4M8 Tel: 780-489-5003 Fax: 780-486-2107

kkoltham@telusplanet.net

### Other:

William Dermody/Dempster, Dermody, Riley & Buntain Hamilton, ON L8N 3Z1 1-905-572-6688

#### LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC 1-888-332-5663 (local 3467) or 604-707-3467 Lookback Programs, Canada: 1-800-668-2866 **Look back Programs, BC:** 1-888-770-4800 Canadian Blood Services Lookback/Traceback & Info

Line: 1-888-462-4056

Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362

Manitoba Traceback: 1-866-357-0196

**RCMP Blood Probe Task Force TIPS Hotline** 1-888-530-1111 or 1-905-953-7388 Mon-Fri 7 AM-10 PM EST 345 Harry Walker Parkway, South Newmarket, ON L3Y

CLASS ACTION/COMPENSATION

Class Action Suit Hotline: 1-800-229-5323 ext. 8296 Health Canada Compensation Line: 1-888-780-1111 Red Cross Compensation pre-86/post-90 Registra-

tion: 1-888-840-5764

8P6 Fax: 1-905-953-7747

Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764 ca/en/ms/hepatitisc/forms.html

#### ADMINISTRATOR

#### 1986-1990

To receive a compensation claims form package, please call the Administrator at 1-877-434-0944. www.hepc8690.com info@hepc8690.com http://www.hepc8690.ca/PDFs/initialClaims/tran5-

#### Pre-86/Post-90

Hepatitis C Settlement Fund—KPMG Inc. Claims Administrator 2000 McGill College Avenue, Suite 1900 Montreal (Quebec) H3A 3H8 1-888-840-5764 (1-888-840-kpmg) HepatitisC@kpmg.ca http://www.kpmg.ca

#### **UPDATES**

http://hepccc.blogspot.com/ www.hepccc.ca/ http://ca.groups.yahoo.com/group/TaintedBlood-TrialsandProceedings/

hepc.bull **JANUARY 2007** Issue No. 96 Page 7

## **COMING UP IN BC/YUKON:**

Armstrong Hepatitis C United Resource Exchange Contact: 1-888-HepCURE

AIDS Vancouver Island HCV support • Campbell River: Drop in, harm reduc-

\*Comport River. Drop III, Infall Teduction, support, education. Contact: 250-830-0787, jeanette.reinhardt@avi.org leanne.cunningham@avi.org

\*Comox Valley 355 6th St. Courtenay; Contact Phyllis 250-338-7400 phyllis.wood@avi.org Drop in, harm reduction support education

reduction, support, education.
• Nanaimo Each Wed 2-4 PM #201-55
Victoria Rd. Contact Anita 250-753-2437

anita.mcleod@avi.org,

•Port Hardy (Sayward, Port McNeil, Alert Bay, Sointula and Woss) 7070 Shor-cliffe Ave, Contact Shane, 250-926-3293 shane.thomas@avi.org. Education, mobile

harm reduction, and support.
• Victoria 1601 Blanshard St., 250-384-2366 info@avi.org Harm Reduction.

Boundary HCV Support and Education. Support, education, presentations. Contact Ken 250-442-1280 <u>ksthom-</u> son@direct.ca

Castlegar Contact Robin 250-365-6137 eor@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 250-748-3432

Cranbrook HeCSC-EK Phone support. Contact Leslie 250-426-6078, Idlong@shaw.ca

Kamloops AIDS Society of Kamloops (ASK) 433 Tranquille Rd. Office 250-376-7558 Support/ Referral. ask@telus.net 1-800-661-7541 www.aidskamloops.bc.ca

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Sep-May, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 250-768-3573, eriseley@shaw.ca, Lisa ljmortell@cablelan.net or 1-866-637-5144.

Kootenay Boundary: Individual support & info Contact Brian Reinhard 250-364-1112 reinv57@vahoo.ca

Mid Island Hepatitis C Society 2<sup>nd</sup> Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Cindy 250-756-4771 midislandhepc@hotmail.com

Nakusp Support Contact. Contact Vivian 250-265-0073 Claire@columbiacable.net

Nelson Hepatitis C Support Group 1st Thurs. monthly 7-8:30 PM. ANKORS Offices, 101 Baker St. Drop-in library M-Th 9-4:30. Contact Alex 1-800-421-2437, 250-505-5506, info@ankors.bc.ca alex@ankors.bc.ca www.ankors.bc.ca/

Mt Waddington Harm Reduction Each Tues. 10-12 8635 Granville, Pt. Hardy. Contact Dan 250-902-2238 mtwreduc@hotmail.com

New Westminster Support Contact Dianne Morrissettie, 604-525-3790 before 9 PM. dmorrissettie@excite.com

Pender Harbour Hep C Support & Info Contact Myrtle Winchester 604-883-9911 or 604-883-0010 myrwin@telus.net

Powell River Hep C Support Group Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact: 604-485-3310

**Prince George Hep C Support Group** 2<sup>nd</sup> Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 421. Contact Gina 250-963-9756, Ilse 250-565-7387 ilse.kuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Public Health Unit 250-624-7480

Princeton Contact the Health Unit (Princeton General Hospital) or Brad at 250-295-6510 CitizenKane@hepcan.ca

Queen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-2487, 1-888-557-2487, wendy@wendyswellness.ca www.wendyswellness.ca Northern BC discussion & info: http://groups.yahoo.com/group/ Network-NW/

Slocan Valley Support Group Contact Ken 250-355-2732, ken.forsythe@gmail.com

Smithers: Positive Living North West Contact 1-866-877-0042 or Doreen 250-847-2132, deb@plnw.org

Sunshine Coast-Sechelt Healthy Livers Support Group Information/resources, contact Catriona, 604-886-5613 catriona.hardwick@vch.ca or Brent, 604-740-9042 brent.fitzsimmons@cgh.bc.ca

VANDU The Vancouver Area Network of Drug Users: Satellite Hep C group at Health Contact Centre (HCC), 166 E. Hastings, each Thurs. 2 PM. Bus fare & snack provided. Contact VANDU 604-683-6061: Fax 604-683-6199 vandu@vandu.org www.vandu.org

Vancouver HepCBC: Info and support Contact 604-582-3843 www.hepcbc.ca

Vancouver: Pre/post liver transplant support Contact Gordon Kerr sd.gk@shaw.ca

Vancouver Hepatitis C Support Group 2<sup>nd</sup> Thurs. monthly 7-9 PM, 1141 Main St. near Sky Train -Terminal & Main, and 3rd Wed. monthly, 7-9 PM VGH, Lauener Room, LP2809, near Sassafras Cafe, Jim Pattison Pavilion, South. Contact Robert, CLF: 1-800-856-7266, 778-898-7211, radmin@liver.ca www.liver.ca

YouthCO AIDS Society HepCATS #205-1104 Hornby St., Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Program Coordinator: Stephanie Grant nieg@youthco.org Support Program Coordinator: Brandy Svendson brandys@youthco.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27<sup>th</sup> Ave. Contact 250-542-3092, hecsc@hepc.vernon.bc.ca http://www.hepc.vernon.bc.ca/

Victoria HepCBC Drop-in Office/Library, 306-620 View St. Phone support, interviews, info sessions. Contact 250-595-3892. 604-582-3843, info@hepcbc.ca, www.hepcbc.ca

Whitehorse, Yukon—Blood Ties Four Directions Contact: 867-633-2437 bloodties@klondiker.com

If you have a Canadian HCV support group to list here, please send details to info@hep Please inform us of any changes by the 15<sup>th</sup> of the month.

## **OTHER PROVINCES:**

#### **ONTARIO:**

Barrie Hepatitis Support Contact: Jeanie for information/ appointment

hepcsupportbarrie@rogers.com

**Durham Hepatitis C Support Group** 2<sup>nd</sup> Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Jan. 11th: Volunteers Needed! Feb. 8th Dr. Fung. "Current Treatments for Hepatitis C" Contacts: Smilin' Sandi http://creativeintensity.com/ smking/ 1-800-841-2729

Hamilton Hepatitis C Network Support Group 4<sup>th</sup> Thur. monthly 6:-7:45 PM. Hamilton Urban Core Community Health Centre—Ask reception for the room. Contact Shannon Lane 905-522-1148 ext 312. hepc@sprc.hamilton.on.ca hamiltonhepc.net

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, 1078 Goyeau Street (across from Hotel Deiu Hospital). Contact 519-967-0490, amonk-m a n @ h e p c n e t w o r k . n e t, www.hepcnetwork.net

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, hars@kingston.net, www.hars.ca.

Kitchener Area Chapter 3<sup>rd</sup> Wed. monthly, 7:30 PM, Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Kitchener. Contact: Bob 519-886-5706 bc.cats-sens@rogers.com or Mavis (519) 743-1922 èlroym222@rogers.com

Niagara Falls Hep C Support Group Contact Rhonda 905-295-4260, hepcnf@becon.org

Owen Sound — Contact Debby Minielly, 1-800-263-3456, 376-9420, Ext. 257,

www.publichealthgreybruce.on.ca/ dminielly@publichealthgreybruce. on ca

Peel Region (Brampton Mississauga, Caledon) Contact 905-799-

healthlinepeel@peelregion.ca

St. Catharines Contact Joe 905-682-6194 jcolangelo3@cogeco.ca

Sudbury Circle C Support Group 1st & 3rd Thurs. Contact Cathy 705-522-3352 or Ernie hepc.support@persona.ca 705-522-5156

Toronto CLF 1st Mon monthly 7:30 PM, North York Civic Centre, 5100 Yonge Street, Committee Rm #2. Contact Gina 416-491-3353 glipton@liver.ca

Unified Networkers of Drug Users Nationally dun@sympatico.ca

York Chapter HeCSC 3<sup>rd</sup> Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 905-940-1333. 1-800-461-2135.

info@hepcyorkregion.org www.hepcyorkregion.org

#### **OUEBEC:**

Quebec City Region Contact Renée Daurio 418-836-2307 reneedaurio@hotmail.com

### **ATLANTIC PROVINCES:**

Saint John & Area: Information and Support. Contact Allan Kerr 506-633-4817 kerrs@nbnet.nb.ca

Cape Breton Island, N.S. The Hepatitis Outreach Society Support Group 2<sup>nd</sup> Tues. Tues. Support Group 2 Tues.
monthly 150 Bentinck Street,
Sydney, N.S. 7-9 PM. Call
Cindy Coles 1-800-521-0572,
902-733-2486 Fax: 902-733-2487 <u>hoscb@ns.aliantzinc.ca</u>

#### PRAIRIE PROVINCES:

Regina, Saskatchewan Contact Doug 306-545-1628 hep-c.regina@accesscomm.ca http://nonprofits.accesscomm.ca/ hep-c.regina/

HeCSC Edmonton Contact Jackie Neufeld 780-939-3379.

Hep C Edmonton HCV, pre/ post liver transplant support Contact Fox 780-473-7600, or cell 690-4076

Wood Buffalo HIV & AIDS Society #002-9908 Franklin Ave, Fort McMurray, AB Contact 780-743-9200 wbhas@telus.net ww.wbhas.ca

Manitoba Hepatitis C Support Community Inc. Meets every Tues.7:00 PM, United Church Crossways-in-Common, 222 Furby Street, side door, corner of Furby and Broadway, Main Floor - look for the signs) Contact Kirk: 204-772-8925 info@mbhepc.org www.mbh epc.org

Medicine Hat, AB Hep C Support Group 1st & 3rd Wed. monthly, 6:30 PM, HIV/AIDS Network of S.E. AB Association, 550 Allowance Ave. Contact 403-527-7099 bettyc2@hivnetwork.ca



Victoria & Area S.O.L.I.D. Society of Living Intravenous

Drug Users, Consumers Support Group

Wednesdays (except welfare week) 7-9 PM 1947 Cook St, Health Unit (Cook and Pembroke) Past and Current IDU's welcome, support, info, & referrals Contact: momma@vcn.bc.ca

Page 8 hepc.bull **JANUARY 2007** Issue No. 96