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Canada's Hepatitis C News Bulletin

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HEPATITIS C AWARENESS DAY IN MAY

**MAY:
HEPATITIS AWARENESS
MONTH**

**MAY 1st:
HEPATITIS C AWARENESS
DAY**

WHAT ARE *YOU* DOING IN YOUR COMMUNITY?
LET US KNOW. (Deadline: April 15)
info@hepcbc.ca



The Candle of Hope by Deborah Wilson and Pat Lightfoot

UPDATE ON HYPERTHERMIA TRIAL

by Darlene Morrow

Hi Everyone,

As most of you will know, I am in Holland, undergoing a clinical treatment for genotype 1 relapsers. The trial involves a single hyperthermia treatment (which I had February 12th), followed in week six by 10 million units of IFN per day for six days, 5 million units per day for six days, and then high doses of pegylated interferon weekly until week 26 at which time the dosage is reduced to 'normal'. All of this is coupled with 1,000 mg of ribavirin per day.

I am very pleased because the hyperthermia treatment was uneventful. I was told to expect blisters and bruising, and also the possibility of losing (some of) my hair. None of this happened. Because of my neuropathy, I had asked them to move me periodically during the procedure, which they did four times. This resulted in the absence of muscle pain which I had expected to experience.

The only notable side effect was that the anesthetics knocked me out completely for an extra 24 hours, and on the

(Continued on page 5)

FAULTY LOGIC IS DANGEROUS

by W. L., in Victoria

In reference to the March 2003 article on Hep C transmission by dentists (*hepcbull*, p. 6), I would like to relate two conversations I had about this very issue—with a dentist, and a barber.

One day I went to a dentist whom I hadn't visited before. Soon after I had sat down, an assistant came in and proceeded to cover the equipment with plastic.

"Do you usually do this?" I asked.

"No," she replied. "It's because you wrote down that you have hepatitis C."

"What if I hadn't told you?" I asked.

"Well, then we wouldn't do it," she replied.

"But," I said, "I have probably had the virus for decades, and I only just found out. What about all the other people who come in here and have the virus and don't know it? It seems to me that either your normal precautions should protect all patients from one another or you are not protecting anyone."

"In fact, there is more than one strain of the virus, and I don't want someone else's. What you're doing here is just creating a false sense of security. Maybe you've passed the virus on already. Heck, maybe I got this dose from some other dentist."

"Well, this is what *we* do," she said, and kept taping on the plastic.

I got another dentist.

Another day I went to a barber whom I hadn't visited before.

"By the way," I said, getting into the chair, "There's a small pimple on the back of my neck. You should be careful to not nick it, because I have Hep C."

"Whoa," said the barber. "We have to

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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.

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Peppermint Patti's FAQ Version 5.6 is now available in English and Spanish. The English version includes updated Canadian Links and both include the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only \$5 each, plus S&H—but if you can afford more, we'll take it. Contact HepCBC: (250) 595-3892, info@hepcbc.ca

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THANKS!!

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Special thanks to Roche Canada for an unrestricted grant to help publish this newsletter!



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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 HepCBC, and mail to HepCBC, Attn. Joan, #5-915 Glen Vale Rd, Victoria BC V9A 6N1 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 HepCBC cannot be held responsible for any interaction between parties brought about by this column.

AD 24: SWM Hep C+ Never married. No kids, 40's, living in Pt. Alberni: Seeking pen pal (female). Maybe leading toward friendship and good company. Previously incarcerated and wish to leave that kind of lifestyle behind. Good looking, 6 ft. 2 inches, 220 lbs. I enjoy music, mountain biking, conversation, walks. Private school educated.

AD 25: SF, Indo-Cdn., 35 years old. 5'7", heavy-set. Hep C+, but I still enjoy life, and try to stay active. I love movies, pets, music, traveling, and reading. I occasionally take self-improvement courses. Searching for SM who is confident, caring, would benefit from my company, and can keep me happy. Richmond.

Got Hep C? Single? Visit:

<http://nationalhepatitis-c.org/singles/list.htm>
<http://clubs.yahoo.com/clubs/ontariohepcingles>
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\$20 CDN each, including postage. This is a GREAT Fundraiser for Support Groups! Call (250) 595-3892 or email info@hepcbc.ca to place your order

Just a few weeks ago, after basically giving up hope, I had a phone call from Dr. Anderson's office in Vancouver, asking me if I would like to be on a trial. I immediately said yes. I had put my name down before, and I had been interviewed before, but nothing came of it, so I sort of expected the same. To tell you the truth, I wasn't looking forward to getting up at 6 to take a bus to get a ferry to get to Vancouver to sit in Dr. Anderson's office and wait for an hour and a half so that they could take some blood and send me home. Been there, done that. And those trips, especially the getting up early part, made me suffer for days afterwards.

And to tell you the truth, I did NOT really want to go on interferon again, but I was not going to kick a gift horse in the mouth. I had heard only good things about the Roche Pegasys-Copegus combo and, although I would have settled for the Schering product if it was being given for free, I was really hoping it would be the Roche interferon this time around. And it was.

The big worry for me was that the last time I was on treatment (Rebetron), I had developed retinal complications (cotton wools spots—minor stroke in the retina) as well as cataracts and other visual guck, and so the doctors were worried. I have also developed an autoimmune inner ear condition (my hearing cuts out, and I have a hearing aid in one ear) which my hearing specialist believes was probably caused by the HCV, but exacerbated by treatment.

At any rate: I went to Vancouver (didn't forget to get my TAPS form, so that the trip only cost me \$26), and hoped for the best.

As soon as I got there, I was ushered into a room where I was greeted by Paula Cramer and Natalie Rock. On the table was a whole bunch of interferon and forms and I knew that this time I was on the trial.

Natalie and Paula were great—very friendly and very helpful, guiding me through the forms and the implications of signing them. We also discussed the

protocol. During this time, Natalie asked me how my liver was, so I took it out, and showed it to her and she fainted—*see photo*).



Seriously though, these two ladies left nothing to chance. They gave me lab test forms with the dates marked on them so that I wouldn't confuse anything, and made me feel very comfortable about what was going on.

The nurses felt that it would be best to inject there, so we did. I was worried that I would get sick on the ferry, but they told me that the pegylated form of interferon took longer to kick in, so that I shouldn't worry.

The protocol that I am on is one injection of Pegasys every Wednesday afternoon, and six tablets of Copegus (ribavirin) a day, for a total of 1200 mg.

And then they sent me home with a cooler full of interferon, etc.

Well, I have been on treatment before, and the way that went was that about 2 hours after the injection I would get a fever and shakes and have to take Tylenol and go to bed.

So when I started feeling ill around 11pm I was ready for it in a way, but it was not fun. I was so chilly and feverish that I had to put on extra pajamas, turn up the heat, and take Tylenol. But all I did was sweat profusely and toss and turn until around 3 in the morning, and then I fell asleep. I woke up the next morning at around 9 feeling absolutely refreshed. Huh? I don't normally wake up at 9 anyways because I'm always too tired, and I never feel refreshed. I was not ready for the unexpected buoyancy I felt. This was

NOT like Rebetron at all.

Later that day I was tired, but not horribly so. I did get some pretty strong headaches for the next 2 days and had to take Tylenol (I normally take around 10 Tylenol a year).

Other than that I was fine. In fact, on some days I didn't feel like I had Hep anymore, and I definitely didn't feel like I was on treatment. The only thing is that I don't sleep as well.

So, I was really curious when the next week's injection came around. Would I get sick? I took my second injection at around the same time—3 pm—and expected to crawl into bed at 11. Well finally at 1 am I gave up and went to bed. No fever, no aches. Didn't sleep well at all though. Up at 3, up at 4, up at 6, up at 8. But I made it through the next day okay, although foggy and unable to play much accordion.

The next day, however, I was fine. The only thing that happens is that out of the blue I will get REALLY TIRED, and I have to lie down or go take a nap; but when this is not happening, I do not feel like I am on any treatment at all, and at times I feel so good that I forget that I even have Hep.

All I can say is that I hope it remains this easy for the full 48 weeks, and that it works. I am genotype 1a/b, and it is my understanding that they are not expecting me to clear the virus, but they are expecting it to reverse my liver damage (I am at early bridging fibrosis).

A big thank you to Dr. Anderson's office and to Roche Canada for this precious gift.



TIP OF THE MONTH

Give your doctor a subscription to the hepc.bull

The Canadian Liver Foundation and HepCBC will be hosting a FREE five-week wellness and educational program for patients and their families affected by liver disease.

LIVING WITH HEP C & LIVER DISEASE PROGRAM

March 13: Naturopathy & Hep C
Dr. Maria Boorman

March 20: Chinese Medicine & Acupuncture
Chris Lam

March 27: Viral Hepatitis and Liver Health
Dr. Denis Petrunia

April 3: Promoting emotional wellness-
Susan Gerard

April 10 Nutrition and Hep C

Victoria Persons with AIDS Society
6:00pm to 8:00pm
541 Herald St. Victoria BC
All sessions are free.
To register, please contact the Canadian Liver Foundation at 1-800-856-7266.

Program subject to change. Call for details.

DID YOU KNOW?
By Inar Hansen, SRN

Studies recently have found that in Chronic HCV patients 25-30% of patients have normal liver enzyme levels. This can mask the inflammation of the liver, as it has been found that in 30% of these cases, liver biopsies discovered inflamed livers.

Source: Normal Liver Enzymes in Patients With Chronic Hepatitis B or C Infection, by David E. Bernstein, MD
<http://www.medscape.com/viewpublication/525>



HCV IN PRISONS

by Rebekah Coopsie

In the past number of years, few efforts have been made to treat chronic hepatitis C among those serving time in American correctional facilities. The rate of Hepatitis C Virus (HCV) infection is significantly higher among this population (up to 1 in 4 individuals out of 2 million), as many of them are affected by psychiatric and addiction illnesses.

Researchers at the Rhode Island Department of Corrections conducted a study on Interferon and Ribavirin combination therapy on the inmates there, and discovered that nearly two thirds (63%) of the people being treated had achieved viral clearance after 6 months of treatment. Further, almost half (46%) of the people remained responsive to that treatment 6 months after it finished. The research team concluded that a correctional facility might be a good place to effectively treat incarcerated persons with HCV.

The Supreme Court in Montana has ruled that providing hepatitis C treatment for inmates in the state's prisons is not a possibility. There are over 900 inmates known to have the hepatitis C virus; however, providing them all with the treatment used most often – interferon and ribavirin combination therapy – would cost the state approximately \$20,000 (USD) per inmate annually. The Court then proceeded to claim that the inability to treat these inmates should not be about cost, yet offered no other explanation as to why the treatment for hundreds of inmates is not an option. Some possible reasons may include the potentially horrible side effects of the combination therapy treatment, as well as the fact that the treatment only has a success rate of about 40%. Justice Terry Trieweiler found the Court's findings unacceptable, and concluded that "Hepatitis C and the state's refusal to treat it is turning Montana's prisons into potential death camps." The state is currently attempting to identify inmates who would be responsive to long-term treatment, as an initial means of dealing with the HCV problem in Montana's prisons.

The Canadian CDC reports that as many as 60% of new HCV cases are linked to injection drug use. A Canadian Correctional facility in Yellowknife has implemented a prevention program to target AIDS and HCV. The new prevention

program was proposed by an inmate and is funded by Health Canada. It involves facilitating inmates to teach their peers in prison about the dangers of AIDS and ways to prevent its spread. It was identified that many inmates were not aware of the disease, nor that they could get it from sharing injection needles. Following completion of their prison sentences, the inmates are sent back to their hometowns with information and education materials in order to spread the word and teach others what they learned in prison. This prevention program has been called an "innovative practice" and could potentially benefit inmates in prisons all over the world.

Sources:
Great Falls Tribune: Saturday, March 1, 2003 – Eric Newhouse
http://north.cbc.ca/template/servlet/View?file_name=de18ykjailaidsproj12182002
Annals of Internal Medicine 2003, 138: 187-90
<http://www.gastrohep.com/news/news.asp?id=1837>

MOVIE REVIEW: FIX

By Inar Hansen, SRN

On Feb 28, 2003, the movie *Fix: The Story of an Addicted City* opened at the Odeon Theater in Victoria, BC. It is a powerful documentary, which follows a number of drug users and their advocates as they attempt to open the first Safe Injection Site and Drug Treatment Center in Canada. The film presented the issue well, and also touched on the benefits of the Safe Injection Site in reducing overdose deaths, and HIV and HCV transmission. It was presented by the BC Nurses Union, CBC, the Times Colonist, Vancouver Island Health Authority, University of Victoria, Monday Magazine, and the Laurel Point Inn.

The movie also had a public forum attached to the screening. The opening night forum had Mayor Alan Lowe, who, with the support of his counselors, agreed to begin the procedures for implementing this plan in Victoria.

The film was directed by Nettie Wild, starred Dean Wilson and Ann Livingston, and was produced by Betsy Carson. For more information about this film, see the website at www.canadawildproductions.com

RESEARCH

IS NUCLEAR RADIATION RELATED TO HCV-RELATED CANCER?

by Rebekah Coopsie

During World War II, the United States released a nuclear bomb over Hiroshima, Japan. Studies done by scientists in both the US and Japan have raised the possibility that this exposure to nuclear radiation may have greatly increased the risk of hepatocellular liver cancer among those people already infected with the hepatitis C virus (HCV). Scientists at the Radiation Effects Research Foundation in Hiroshima and specialists from the US based National Academy of Sciences studied tissue samples from people with liver cancer, as well as those without. Findings showed nearly a 60% increased risk for liver cancer among those patients without cirrhosis in comparison to those patients who already had it. (This particular study was conducted by exposing the HCV infected tissue with radiation and

observing the changes that occurred within the liver tissue.) The same results were NOT observed when the study was conducted using the hepatitis B virus in place of HCV.

Source: *Cancer Weekly* (via *NewsRx.com*) January 7, 2003. By Sonja Nichols



(*HYPERTHERMIA—Continued from page 1*)

third day, I still was not able to function until later in the afternoon. I have had four operations and never had this reaction before. I spoke to another participant in the trial and she experienced the same side effect making me think it was due to the hyperthermia treatment.

By the way, the hyperthermia treatment was seven hours in the O.R.

I have had two weekly checkups since being released. My platelet count doubled, and is now normal at 150. My white count was up the first week, and is now down to 3. My ALT was a real shocker. Previously it had been 40 and now is 230. I was totally dismayed but Dr van Hattum was delighted. He said this is what we were looking for - activity from the Hep C. The next thing they expect to see is immune system activity in response to the HCV, which should happen between week 4 and 8.

Starting on week 6, March 26th, I will be taking the 10 million units and carrying on from there. I was unaware that I was going to be doing the induction therapy, and I therefore NEED regular interferon DESPERATELY. If

(*Continued on page 7*)

MANAGING SIDE EFFECTS OF INTERFERON TREATMENT

By Will Lawson

Anxiety

Anxiety is a common side effect of interferon treatment. It may be greater among those taking ribavirin. To monitor for anxiety, attend regular follow-up appointments. Any practice that brings a sense of empowerment will help reduce anxiety—meditation, visualization, learning to lean on a greater power. Medication, counselling, a support group, or a combination of these may also help.

Depression

Depression is a common side effect, appearing as sadness, apathy, feelings of low self-worth, or thoughts of suicide. Report any symptoms of depression to the treating physician. Depression is often treatable with medication and may also be reduced with the other methods used to combat anxiety.

Rage

Some patients report that small daily problems that used to "roll off their back" appear large and unmanageable.

If feelings of rage occur, notify the treatment provider.

Tearfulness

Tearfulness and wide swings of emotion may occur within the first few weeks on interferon. Some patients describe laughing or crying spells that are out of proportion to the stimulus. This may or may not resolve without intervention. Inform the treating physician.

Confusion

Mental confusion is especially common within the first few weeks of therapy. Increased intake of water, juices, sports drinks, and non-caffeinated fluids may help reduce this side effect.

Decreased Concentration

Decreased concentration is especially common in the first few weeks of therapy. Increased intake of water, juices, sports drinks, and non-caffeinated fluids may help reduce this side effect.

Headache

Headaches are a common side effect,

and are often at their worst within the first month of therapy, and then improve. Increasing intake of fluids may help, as well as a restricted use of an over-the-counter analgesic such as *Motrin*. (Since these medications are processed by the liver, the treating physician may choose the best pain relief medication and dose based upon the health of each patient's liver.) The longer acting the medication, the better. For patients taking ribavirin, headaches may be a symptom of anaemia, which affects some more than others. Attending regular follow-up appointments is important for monitoring lab work. If anaemia occurs, the dose of ribavirin may be reduced or, in severe cases, discontinued.

Muscle Aches

Muscle aches are a common side effect. They are often worse within the first month of therapy, and then improve. Some patients have muscle

(*Continued on page 6*)

(SIDE EFFECTS—Continued from page 5)

aches throughout the therapy. They are usually managed with an over-the-counter analgesic.

Joint Pain

Joint pains are a common side effect. They are often worse within the first month of therapy, and then improve. Some patients have joint pains throughout the therapy. They are usually managed with an over-the-counter analgesic.

Some Hep C patients have cryoglobulinemia (joint aches, weakness, broken blood vessels under the skin). In such patients, interferon therapy may reduce joint pains as the blood is "thinned".

Sharp Pains

Some patients describe sharp, shooting pains in the abdomen, lower back, or shoulder blades within the first few weeks of therapy. These occur suddenly, last a few seconds, and then disappear. They also disappear completely after the first two weeks or so. They do not require treatment, although any sudden chest pain should be investigated.

Dry Skin

Dry skin is a common occurrence during therapy. Use of mild soap and plenty of skin lotion is helpful. Skin lotion may be mixed in the palm of the hand with petroleum jelly and applied to the skin while it is still warm from a shower or bath, creating a thin, but long-lasting layer of relief.

Itching

Feeling itchy is a common side effect. Oatmeal baths and skin lotions may offer relief. Over-the-counter medications such as *Benadryl* may also be helpful, but use them cautiously.

Rash

Skin rash may occur from interferon or ribavirin. Notify the treating physician if it appears rapidly or is accompanied by welts, blisters, wheezing, or fever. In mild cases, use mild soap and plenty of skin lotion.

Sweating

Increased sweating is common during interferon therapy. Increase fluid intake to replace what has been lost.

Eyes

Interferon may irritate some patients'

eyes.

Itching: Interferon may irritate mucus membranes causing itching. Saline eye drops may reduce irritation. For many patients, this side effect occurs during the first few weeks on interferon, and then resolves on its own. If it persists, or is accompanied by redness, swelling, or discharge, notify the treating physician.

Burning: Some patients describe burning or irritated eyes during treatment. Generally, this improves after the first month of therapy, and may be managed with soothing eye drops.

Blurry vision: Some patients describe blurry vision. Because interferon has been known to cause changes to the retina, notify the treating physician if vision is blurred.

Loss of vision: Loss of vision in one eye (or both eyes), or a sudden change in vision such as a "hole", "tunnel", or "window shade" may be a serious event which requires immediate medical attention.

Nose

Nasal congestion: Nasal congestion is a common side effect, especially within the first month. Interferon may irritate the mucus membranes within the nose and cause congestion. This usually resolves on its own.

Sores: Sores inside of the nose may occur as a result of irritated mucus membranes. Coat the sore with petroleum jelly to relieve dryness. Picking or rubbing it may delay healing and cause nosebleeds.

Dryness: This side effect often lasts for the first month or so of therapy, and then goes away on its own. It may be relieved by saline nose drops, or a light coating of petroleum jelly.

Mouth

Dry mouth: Many patients experience dry mouth soon after starting therapy. This is a common side effect which may be relieved by increasing fluid intake of non-caffeinated, non-alcoholic beverages, or sucking on sugar-free hard candies and mints.

Bleeding gums: Some patients will notice increased gum bleeding during regular brushing. Interferon lowers almost everyone's platelet count. A reduced platelet count can cause gums to bleed when irritated by brushing. Monitor your blood work.

Stomach

Nausea: Nausea is a common side effect, especially within the first month of therapy. Ribavirin may contribute to nausea. Try taking it with food. Also, take smaller, more frequent meals. Low-fat salty snacks such as pretzels and saltines may help too, unless you are on a low-salt diet.

Decreased appetite: Appetite is commonly decreased during the first month, after which it improves dramatically. Continue to take plenty of fluids, eat when hungry, and eat what tastes good, but vary your diet as much as you are able. Nutritional supplement drinks or bars are a temporary alternative.

Cramps: Stomach or abdominal cramps may occur within the first two weeks. They are usually self-limiting and only occasionally accompanied by diarrhoea.

Bowels

Diarrhoea: Diarrhoea sometimes occurs within the first week or two. It does not usually persist. Diarrhoea may be managed by using over-the-counter fibre preparations such as *Ultra-Fiber* (very good) or *Metamucil* (generic psyllium is cheaper).

Haemorrhoids: Haemorrhoids are sometimes found in patients with liver disease. These patients should inform their treating physician. Over-the-counter treatments may help. Otherwise, consult with a surgeon. (Take heart. Surgical procedures are much improved to what they once were.)

Menstrual Cycle

Some women experience abnormal menstrual periods during therapy. This resolves after therapy has been discontinued.

Because of the hazards of interferon and ribavirin to pregnancy, all women of childbearing potential on interferon, with or without ribavirin, should observe two effective methods of contraception until six months after the last dose.

Fatigue

Fatigue is a common side effect, especially during the first month, after which it decreases dramatically. Increasing fluid intake to about a gallon a day may help reduce fatigue. Meanwhile, conserve your energy.

Insomnia

Trouble falling asleep: Insomnia is a

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(SIDE EFFECTS—Continued from page 6)

common side effect. Some patients describe difficulty falling asleep, restlessness, or racing thoughts. Most treating physicians have developed a preference in medication to promote sleep.

Awakening early: Insomnia may take the form of going to sleep as usual, but waking up early and being unable to fall back to sleep. This may be a symptom of depression and may be treated differently from a sleeping problem. The treating physician may prescribe medication for this.

Thinning Hair

Sometimes, hair may thin or change in texture after the first few months of therapy. It will not all fall out, and usually will return to normal after therapy has been discontinued.

Source: <http://www.hopkins-hepc.org/sideEffects/mind/index.shtml>

(HYPERTHERMIA—Continued from page 5)

you or anyone you know has any unopened vials PLEASE get in touch with me by return e-mail: Darlene@v-nieuwenhuizen-adm.nl I have received four weeks of PEG Intron and still need a lot. My dosage is 100 mcg. per week. I would be eternally grateful if anyone can help.

I have successfully received one parcel from the US here in Holland, and also one parcel from the US, shipped to Canada.

I have one offer of PEG in Florida. Should there be any other offers from the US, perhaps we can co-ordinate a mailing address and fly over to take delivery in person. One plane ticket return is much cheaper than having to pay for the meds privately.

At this point, I would like to thank everyone from the bottom of my heart for their swift action and extreme kindness. Everyone has been so wonderful in responding, that I have enough ribavirin with expiry date 2003 to last me until the end of this year. I still need two months' worth with an expiry date after February 2004.

I am feeling like my ALT is 230. I am experiencing HEAVY night sweats and extreme fatigue. Fortunately my sister has a washing machine and is taking good care of me.

I will be doing my next up-date after I

TREATMENT

RATE OF NATURAL DISEASE PROGRESSION IN PATIENTS WITH CHRONIC HEPATITIS C

by Will Lawson

Researchers from France and the U. S. find that an interval of 4-5 years is needed between liver biopsies to measure changes in patients with mild liver disease. The interval at which liver biopsy should be repeated in untreated patients with chronic hepatitis C is not defined.

In this study, researchers examined fibrosis change in patients who had had 2 or more liver biopsies. They found that the mean interval between biopsies was 3.67 years (3.08 years in the 16 patients who had had 3 biopsies).

The researchers found that the median rate of fibrosis progression per year was 0.04 to first biopsy, 0 between first and second biopsy, and 0.17 between second and third biopsy. The number of patients who increased in fibrosis stage was significantly higher after 4 years.

Age at first biopsy over 40 years, and alcohol consumption of 1 to 50 g per day and more were the only factors associated with severe fibrosis.

Source: *J Hepatology* 2003; 38(3): 307-14 (21 February 2003).

<http://www.gastrohep.com/news/news.asp?id=1865>

start the interferon. Keep all the good vibes coming my way. I am going to need every one of them, at 10 million units PER day.

Dr. van Hattum has told me that the two patients ahead of me that are already on the meds have gone viral undetectable by week 9 (two weeks after beginning the meds). Also, previous data has indicated that there could be a response rate as high as 70% in genotype 1's. Therefore, this misery may be worth it all. That's why we do it, right?

Hugs and prayers for everyone,
Darlene Morrow



INTERFERON THERAPY AFTER TUMOUR ABLATION ASSOCIATED WITH HCV

by Will Lawson

Researchers have found that, after tumour ablation (tissue removal) by ethanol injection, interferon therapy may enhance patient survival in patients with hepatitis C. Tumours frequently develop after surgery, and then the prognosis is poor.

Researchers in Japan found that patients treated with interferon after tumour ablation had a survival rate of 68% at 5 years and 53% at 7 years. Untreated patients had a survival rate of 48% at 5 years and 23% at 7 years.

Source: *Ann Intern Med* 2003; 138: 299 - 306 (21 February 2003).

<http://www.gastrohep.com/news/news.asp?id=1864>,

INTERFERON TREATMENT DURING PREGNANCY

By Rebekah Coopsie

Doctors in Turkey reported findings that it is possible to treat expectant mothers with Interferon during pregnancy, in conjunction with close supervision. A 26 year old Turkish woman received 72 million units of interferon alfa-2b over a period of two and a half months, resulting in a complete virologic response to the treatment. She experienced premature labor, and gave birth to underweight twin infants; however, they were healthy and reached 18 months of age, and showed normal developmental patterns. Both children responded negatively to the hepatitis C serology tests.

Doctors remain cautious about treating pregnant women with interferon due to its action of preventing cell growth, which can easily affect a growing fetus. Extensive studies on the subject of treatment during pregnancy are rare; however, the eight infants born in Turkey to mothers receiving interferon and/or ribavirin during pregnancy were all born without congenital abnormalities or malformations.

For more information on this study, contact E. Ozaslan, Hacettepe University Hospital, Division Gastroenterology, Mektep Sok 7-10, TR-06660 Ankara, Turkey.

Source: *Women's Health Weekly*, Jan. 23, 2003



WARNINGS

AMNIOCENTESIS

By Arthur Ralfs

This article is a "meta-analysis", meaning it is based on an extensive search and analysis of previously published work. For HCV positive women the authors conclude that there does not appear to be a significant risk of transmission of the virus to the fetus. However, it is cautioned that there are not many studies that have properly addressed this issue. In any case, it is recommended that non-invasive screening tools should first be used before considering amniocentesis, and, if amniocentesis is used, special care is taken not to insert the needle through the placenta.

Source: *Amniocentesis and women with hepatitis B, hepatitis C, or human immunodeficiency virus.* *J Obstet Gynaecol Can* 2003 Feb; 25(2): 145-52 Davies G, Wilson R D, Desilets V, Reid G J, Shaw D, et al.

HEP C MAY FLARE IN NEW MOTHERS

By Rebekah Coopsie

Following an uncomplicated pregnancy and delivery, a Taiwanese woman experienced and acute aggravation of her chronic hepatitis. Throughout all three trimesters of pregnancy the woman's viral levels remained low, as did her liver function tests. However, one month following the birth of her child, her liver function test results climbed to 20 times the normal level, and her Hepatitis C virus (HCV) levels soared as well. This abrupt flare of hepatitis resolved itself after two months, however studies have not yet shown why this occurred without warning, one month into the postpartum period. Following this occurrence, physicians should be aware of the potential for women infected with HCV to experience hepatitis flare-ups during the months following childbirth.

Source: *Women's Health Weekly*, July 5th, 2001 (NewsRx Network)

DIAL-A-DIETITIAN

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

WHAT DO THEY DO?

What do Crawfords do to earn our money? They were supposed to be insurance claim experts, yet, in reality they seem to have very few skills other than creating and shuffling paper loads. They didn't have, nor were they able to develop, the necessary software for the project, so they spent three quarters of a million dollars to have it developed. They are unable or unwilling to do the tax work, Price Waterhouse Cooper have been invited to swim in the pool, and do that. Investment was left up to Royal Trust. We paid \$180,000 plus in the first year out of our fund for this. If I had a billion dollars to invest, I would not deal with a bank or company that was going to charge me and, in the end, put over 70% of it in Canada Savings Bonds. It seems the government is having a hard time letting go of our money. Now they want everybody to re-apply and re-qualify annually. This creates a yearly mountain of redundant paper work for them to read, file, and pass from desk to desk, while charging us for doing so. Last year it was July or August of 2002 by the time we received our lost wages for 2001. I wonder how long Crawfords wait for their money. We know how long the Class Action lawyers waited--they didn't. They were in line being paid before the line was even there for the victims of the blood.

Up to the end of 2001 Crawfords had drained \$4,267,151 of our money. With an average payment to the victims of the blood, the so called winners in the law suit--that means that Crawfords--in one year have consumed enough money to have compensated 65 people on average. This does not include monies for: Delette Touche; Royal Trust; TD Assessment Ltd.; Towers Perrin; Eckler Partners Ltd; Canadian Blood Services; Hema Quebec; Fund Council (ex class action lawyers); Price Waterhouse Coopers. I think we would have been better off being paper shufflers than the victors in this deal.

Bruce DeVenne

(LOGIC—Continued from page 1)

stop right here. I mean no disrespect, but I can't touch it."

"Touch what?" I asked.

"The Hep C," he replied. "We don't touch that."

"But I've been going to the barber for forty years, and I've probably had Hep C for half of that time and didn't know it," I said. "They always cut my hair before."

"Sorry, sir," he said. "We just don't touch it...and I mean no disrespect."

"But half your clients could have Hep C and not know it," I said. "You must cut their hair, otherwise you wouldn't still be in business."

"Yes, but you've told me, and I mean no disrespect...blah...blah..." and much waving of the hands.

"Look," I said. "I'm not offended. But either your precautions work for everybody or they're not good enough for anyone, right?"

"Sorry, sir, but."

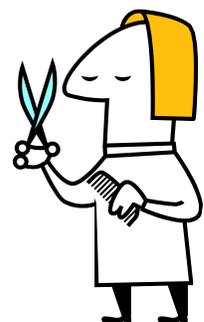
I got a new barber. I figure, we've been married almost twenty-five years, and she doesn't have Hep C.

My point is this: There is a great deal of ignorance out there, and I think it is very, very dangerous. Can anyone really believe that hundreds of thousands of persons with Hep C today all got it from street drugs?

We must look around us for how else the virus is being transmitted. It doesn't have to be on a complex piece of equipment such as an endoscope.

At present, I guess it's up to Hep C patients to monitor and, where possible, to educate.

(Hmmm. I wonder how my wife would be at filling cavities.)



2ND NATIONAL ABORIGINAL HEPATITIS C CONFERENCE

"Weaving the Mind, Body and Spirit"

Chee Mamuk Aboriginal Program is pleased to announce a call for abstracts for the 2nd National Aboriginal Hepatitis C Conference. This is your opportunity to share your experiences, wisdom with others who are infected / affected by the Hepatitis C Virus.



The conference is being held in Vancouver, BC, from May 4th - 7th.

Conference Topics:

- ◆ Palliative
- ◆ End of life
- ◆ Prevention
- ◆ Harm Reduction
- ◆ Youth
- ◆ Addictions
- ◆ Treatment
- ◆ Co-Infection
- ◆ Research
- ◆ Women
- ◆ Residential School
- ◆ Life Skills
- ◆ Self Care
- ◆ Culture, Traditional Medicine,
- ◆ Ceremonies
- ◆ Prison
- ◆ Living with Hepatitis C (individual, family)

FOR MORE INFORMATION CONTACT:

Lucy Barney – Chee Mamuk Aboriginal Program, BC Centre for Disease Control

655 West 12th Ave. Vancouver, BC V5Z 4R4

Ph: 604.660.1673 Fax: 604.775.0808

Toll Free: 1.877.667.6668

Email: lucy.barney@bccdc.ca

Web site: www.bccdc.org

Abstract Deadline was February 15, 2003.
Scholarships are available.

**Are you in the 86-90 Window?
Are you having any problems?**

**Contact: Terry Waller
(250) 642-6766**

(Terry is not a lawyer but a concerned victim)



VOLUNTEER APPLICATION FORM

NAME: _____

ADDRESS: _____

CITY: _____

PC: _____ **PROV:** _____

TEL: () _____

FAX: () _____

EMAIL: _____

**ABILITIES OR AREA OF
INTEREST:**

Library Printing Copying
Phoning Fundraising
Counseling Research
Refreshments Special Events
Publications Computer Help
Errands Grant Applications
Board Member Other

Experience:

Time available:

SEX M F

Date of Birth: ____/____/____

Mo Day Year

Contact: HepCBC

#5-915 Glen Vale Rd

Victoria BC V9A 6N1

**Tel. 595-3892 or Email:
info@hepcbc.ca**

DISABILITIES HELP SHEET

The BC Coalition of People with Disabilities has created a 'help sheet' for filling out the new Disability Benefits forms. Please pass this information on to anyone who is having to reapply for benefits. Hopefully it will reduce some of the confusion and anxiety that this process has created for some people. Here is the link, and another useful page:

www.bccpd.bc.ca/commlert/helpsheets/DesignationReview.pdf

<http://www.bccdc.org/content.php?item=29>

COMPENSATION

LEGAL ACTION

Hepatitis C Class Action Suit Line:
1-800-229-LEAD (5323)

1986-1990

Bruce Lemer/Grant Kovacs Norell

Vancouver, BC

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

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

www.kpmg.ca/microsite/hepatitisc/english/forms.html

Klein Lyons

Vancouver, BC 1-604-874-7171,

1-800-468-4466, Fax 1-604-874-7180

www.kleinlyons.com/pages/class_actions/Hepatitis_C.htm

Mr. David Harvey/ Goodman & Carr

Toronto, Ontario

Phone: 1-416-595-2300, Fax: 1-416-595-0527

Ernst & Young Law Office (Ontario)

1-800-563-2387

Lauzon Belanger S.E.N.C. (Quebec)

www.lauzonbelanger.qc.ca

Goodman and Carr LLP

pre86hepc@goodmancarr.com

www.goodmancarr.com

Other:

William Dermody/Dempster, Dermody, Riley and Buntain

Hamilton, Ontario L8N 3Z1

1-905-572-6688

LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC

1-888-332-5663 (local 207)

Lookback Programs, Canada: 1-800-668-2866

Lookback 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, Ont-

ario L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656

Health Canada Compensation Line: 1-888-780-1111

Red Cross Compensation pre-86/ post-90 Registration: 1-888-840-5764

Ontario Compensation: 1-877-222-4977

Toronto Compensation: 1-416-327-0539, 1-877-434-0944

Quebec Red Cross Compensation: 1-888-840-5764

1986-1990 Hepatitis C Class Actions Settlement

6/15/99 www.hepc8690.ca/

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-888-726-2656 or 1-877-434-0944.

www.hepc8690.com info@hepc8690.com

MISCELLANEOUS

Excellent Website!: HCV Tainted Blood, Canada:

<http://members.rogers.com/smking/tainted.htm>

COMING UP IN BC/YUKON:

Armstrong HepCure Office and library, by appointment. Contact: Marjorie, 546-2953, ambrrose@sunwave.net, www.junction.net/hepcure

Campbell River Hep C Support Group Support and information, call 830-0787 or 1-877-650-8787 or email niac_hepc@hotmail.com

Castlegar Contact: Robin, 365-6137

Comox Valley: Contact North Island Hep C Community Support Project 1-877-650-8787,

Cowichan Valley Hepatitis C Support Contact: Leah, 748-3432.

Cranbrook HeCSC-EK: 1st & 3rd Tues. monthly, 1-3 PM, #39 13th Ave South, Lower Level. Next meetings Apr. 1st & 15th. Contact: 426-5277 or 1-866-619-6111 hepc@cmha-ek.org, www.hepcastkootenay.com

Creston/Golden/Invermere Educational presentation and appointments: Contact Katerina 426-5277

Grand Forks Hep C Support Centre Each Mon, 3:30-5:30 PM, & 1st Mon. monthly, 6:30 PM, 7215 2nd St. (Boundary Women's Resource Centre) Contact Ken, 1-800-421-2437

Kamloops (People in Motion) 1st and 3rd Tues monthly 12:30 PM, 6E-750 Cottonwood Ave, North Kamloops. Next meetings Apr. 1st & 15th Contact Pam: 851-7300, pamela.zulymiak@interiorhealth.ca

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Next Meeting: Next meeting Apr. 26th. Contact Elaine Risely (250) 768-3573, erisely@shaw.ca or Lisa Mortell 766-5132 lmortell@silkn.net

Kimberley Support Group 2nd Tue. monthly, 7-9 PM. Next meeting Apr. 8th Contact Katerina 426-5277

Kootenay Boundary 2nd Tues. monthly, 7 PM, Room 108, Selkirk College, Trail. Next meeting: Apr. 8th. For individual support, info & materials, contact: Brian Reinhard, (250) 364-1112, reiny57@yahoo.ca

Mid Island Hepatitis C Society Friendship and support group, 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Next meeting: Apr. 10th. Contact Sue for info 245-7635. mihepc@shaw.ca

Mission Hepatitis C and Liver Disease Support Group 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting Apr. 16th. Contact Gina, 826-6582 or Patrick, 820-5576. mission-support@eudoramail.com

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Next meeting: Apr. 15th. Contact: Vivian, 265-0073 or Ken, 1-800-421-2437

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St., Next meeting: Apr. 3rd. Contact: Ken Thomson, 1-800-421-2437, 505-5506, info@ankors.bc.ca

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, 623 Agnes Street, New Westminster. Next meeting: Apr. 14th. Speaker: Dr. John D. Farley on Hepatitis. Contact: Dianne Morrisette, (604)517-6120, dmorrisette@excite.com

Parksville Support Group Contact Ria, 248-6072

Parksville/Qualicum 102a-156 Morison Avenue,

PO Box 157, Parksville, BC V9P 2G4. Open daily 9 to 4, M-F. Contact: 248-5551, sasg@island.net

Penticton Hep C Family Support Group Contact: Leslie, 490-9054, bchepc@telus.net

Powell River Hep C Support Group Next meeting: Contact: Health Unit, 485-8850.

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Health Unit Auditorium. Next meeting Apr. 8th. Contact: Gina, 963-9756, gina1444@yahoo.ca or Ilse, ikueper@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Next meeting Apr. 12th. Contact: Brad, 295-6510. kane@nethop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy: 557-9362, e-mail: wmm@island.net, www.island.net/~wmm/

Quesnel HeCSC Last Mon. evening every other month. Contact Elaine Barry, 992-3640, ebarry@goldcity.net

Richmond: Lulu Island AIDS/Hepatitis Network: Meetings/drop-in dinner each Mon. 7-9 PM. Contact Phil or Joe, 276-9273.

Slocan Valley Support Group Contact: Ken, 355-2732, keen@netidea.com

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, 3731 1st Avenue, Upstairs. Next meeting: Apr. 9th. Contact: Deb. 877-0042, 1-866-877-0042, or Doreen, 847-2132, plnw_hepc@bulkley.net for times.

Sunshine Coast—Sechelt: Contact: Kathy, 886-3211, kathy_rietze@uniserve.com—**Gibsons:** Contact Bill, pager 740-9042

Vancouver: For information please call HepHIVE at 604-254-9949 ext 232.

VANDU Vancouver Area Network of Drug Users Each Mon., 2 PM, 412 East Cordova Bus fare & snack. Contact: Cristy or Ann, 604-719-5313, or 604-216-2776 (ask for VANDU). Space limited—come early. vandu@vcn.bc.ca, www.vandu.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Next meetings Apr. 9th & 23rd. Contact: Sharon, 542-3092, sgrant@telus.net

Victoria HeCSC Last Wed. monthly. Contact: 388-4311, hepcvic@coastnet.com

Victoria Support and Information 1st Wed. monthly, 7 PM. Hep C Outreach Workers avail. each Wed. 7-11 PM, or weekdays 9-4, Street Outreach Services (needle exchange). Contact 384-2366, hermionejefferis@avi.org

Victoria HepCBC & INFO line General Meetings quarterly, 1st Tues., 7-9 PM, 541 Herald St. Next meeting: May 6th. **Living with Liver Disease program:** Thursdays, 6-8 PM, Mar 13-Apr 10. Contact: (250) 595-3892, info@hepcbc.ca, www.hepcbc.ca

YouthCO AIDS Society HepCATS Hep C advocacy, training and support for youth 15-29 living with Hep C or co-infected with HIV. #203-319 W Pender St., Vancouver. Contact Leahann Garbutt, (604) 688-1441, (604) 808-7209, information@youthco.org, or www.youthco.org

Yukon Positive Lives 3rd Wed. monthly, Whitehorse. Next meeting Apr. 16th. Contact Heather 660-4808, fromme@marshlake.polarcom.com, www.positivelives.yk.ca

OTHER PROVINCES

ATLANTIC PROVINCES:

Cape Breton HeCSC 2nd Tues. monthly. Contact 564-4258

Cape Breton-HepC-CB 2nd Wed. monthly, 7 PM YMCA Board Room, Charlotte St., Sydney. Contact: Maria MacIntosh at 567-1312 <http://www.accb.ns.ca/>

HeCSC NB Meetings:

•**Fredericton, NB** Contact: Sandi, 452-1982 sandik@learnstream.com or Bob, 453-1340, bobc215@hotmail.com

•**Saint John & Area:** Telephone support line: Contact Allan Kerr 672-4372, kerrs@nbn.net

Hepatitis C Moncton Inc. of N.B. Contact Debi, 858-8519, hepcmonc@rogers.com

Hepatitis Outreach Society, Simpson Hall, Suite 452, 300 Pleasant Street, Dartmouth, P.O. Box 1004, NS, B2Y 3Z9. 1-800-521-0572, or 902-420-1767, rahcc@ns.sympatico.ca, www.ahcc.ca

•**Bridgewater:** Last Wed. monthly, 7 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room

•**Halifax:** 3rd Tues. monthly, 7 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110

•**Kentville:** 2nd Tues. monthly, 6:30 PM, Kings Tech Campus, 236 Belcher St, Conference Room A-226

•**New Glasgow:** 3rd Mon. monthly, Aberdeen Hospital, Conference room #1 South.

•**Truro:** Last Tues. monthly, 7 PM, Colchester Regional Hospital, 25 Willow St, Conference Room

•**Yarmouth:** 1st Tues. monthly, 7 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1—Main level

ONTARIO:

Barrie HepSEE Chapter 3rd Tues. monthly, 7-9 PM, AIDS Committee of Simcoe County, 80 Bradford St, Suite 336 Contact: Jeanie, 735-8153 hepsee-barrie@rogers.com

Durham Region, GTA and Peterborough, ON support. Contact: Smilin' Sandi smking@rogers.com "Sandi's Crusade Against Hepatitis C" <http://members.rogers.com/smking/>

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact: Carolyn, (519) 880-8596 lollipop@golden.net

Niagara Falls Hep C Support Group Last Thurs. monthly, 7 PM, Niagara

Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact: Rhonda, (905) 295-4260, Joe (905) 682-6194 jcolangelo3@cogeco.ca or hepcnf@becon.org

Trenton ON support. Contact: Eileen Carlton 394-2924 carfam@quintenet.com

Hepatitis C Network of Windsor & Essex County 3rd Thurs. monthly, 7 PM, 1100 University Ave. W. and 1st Mon. monthly, 491 Victoria Ave, 11 AM. Contact Andrea or Michelle, 256-1878, hepcnet@cogeco.ca <http://home.cogeco.ca/~hepcnet/>

Fri., May 9th—Candlelight Vigil, Dieppe Gardens waterfront, 8-10 PM. Contact Andrea, 250-5399 or Liz, 253-8481 Ext 263

PRAIRIE PROVINCES:

HeCSC Edmonton: Contact Jackie Neufeld: 939-3379.

HepC Edmonton Support Group: Contact Fox, 473-7600, or cell 690-4076, fox@kihewcarvings.com

HepSEE WPG: Contact David: hepsee@shaw.ca or 1(204)897-9105 for updates on meeting schedules.

Winnipeg Hepatitis C Resource Centre 1st Tues. monthly 7-9 PM. #204-825 Sherbrook St. (south entrance—parking at rear) Contact: 975-3279, hcc@smd.mb.ca

QUEBEC:

Hepatitis C Foundation of Quebec, Contact Eileen, 769-9040 or fhcc@qc.aibn.com. **Meetings:**

•**Hull:** Each Tue. 7-8 PM, 57 Rue Charlevoix.

•**Sherbrooke** 2nd Monday monthly, 7-9 PM, Les Grandes Coeurs D'Artichauts Au Centre Jean-Patrice Chiasson (2^e etage) 1270 Galt Street West. Contact: 820-7432

•**Verdun:** Meetings temporarily on hold. 5100 Rue Verdun, Box 28508, QC H4G 3L7

HeCSC

•**Quebec City Region,** 1st Wed. monthly, 7 PM, 876 rue D'Aleçon, St. Nicolas, QC. Contact: Renée Daurio, 836-2467, reneedaurio@hotmail.com

