# hepc.bull

## Canada's Hepatitis C News Bulletin

www.hepcbc.ca

#### **NEWS: ALTERNATIVES**

#### VITAMIN A MAY BOOST STANDARD TREATMENT

Researchers did a small study on 42 patients to see if adding vitamin A to standard treatment (pegylated interferon plus ribavirin) would improve the response rates. Caution: The treatment did not include a placebo, and the doses of vitamin A were quite high, so one would probably not want to add high doses without the results of this trial being confirmed. The recommended daily dose of vitamin A in the US is 2310 to 3000 IU daily and the vitamin can be toxic. The study was presented as an abstract, but has not yet been published in a journal where it has been reviewed by other experts, so the results should be taken as preliminary.

The results of the trial were impressive. After 48 weeks of treatment, 61% of those who added 30,000 IU daily of vitamin A to standard treatment achieved an SVR (sustained viral response) compared to 42.9% of those taking standard treatment alone. Even at 12 weeks into treatment, 70% taking the vitamin A were virus free, compared to about 40% of those on standard treatment alone. There were no side effects from the high dose vitamin A.

Researchers had noted in earlier studies that retinoic acid had a positive effect on liver cancer cells in vitro and increased the effect of IFN and RBV.

A placebo-controlled trial is planned.

Source: Sato S, et al. "Retinol supplements antiviral action of pegylated interferon and ribavirin combination therapy in patients with chronic hepatitis C: Prospective pilot study" DDW 2010; Abstract T2004.

#### VITAMIN E FOR FATTY LIVER?

Nonalcoholic steatohepatitis (NASH or fatty liver) can turn into cirrhosis. At this time, there is no treatment for the condition. Researchers studied 247 non-diabetic patients with NASH, and divided them into 3 groups. One group received 30 mg a day of

pioglitazone, a second group received 800 IU a day of vitamin E, and a third group received a placebo.

Treatment lasted for 96 weeks. The researchers hoped to find improvement based on standard scores for steatosis, lobular inflammation, hepatocellular ballooning, and fibrosis (scarring). 43% of patients in the vitamin E group showed improvement in fatty liver, compared to 34% of those taking pioglitazone and 19% taking placebo. AST and ALT levels were reduced in the vitamin E and the pioglitazone groups, compared to placebo, and both of those treatments showed reduced steatosis and inflammation, but no improvement in fibrosis or portal inflammation. Pioglitazone had improved insulin resistance, patients gained more weight than the other two groups. The insulin resistance returned to baseline levels after treatment, but the weight did not.

The researchers concluded that vitamin E treatment was better than placebo for NASH patients without diabetes, and that there was some benefit related to pioglitazone, as well. It is thought that the patients will relapse if they discontinue the treatments.

Source: Arun J. Sanyal, M.D, et al, NEJM April 28 2010

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#### **INSIDE THIS ISSUE:**

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Coming Up





Dianne passed away May 1<sup>st</sup> 2010. You may not have noticed her or the work she did, but she has been quietly providing support for those in and near New Westminster, BC for over 12 years. Her support group first appeared in the December 1998 issue of our

*hepc.bull.* Their meetings were in the First Nations' Urban Community Society, which used to be on Agnes Street, and later moved to Carnarvon Street, and were held on the second Monday each month. Dianne provided phone and email support.

I met Dianne in person at the Montreal Conference in 2001. I am inserting a photograph of her at that event. It wasn't the last time I was to run into her. We were in contact over the years, and she came to my home for a meeting when I moved to Surrey. She hadn't changed a bit...visibly. She was always elegant and composed, always supportive.

I included her in my monthly calls once we got our support group in the Lower Mainland up and going. By then Dianne was providing only phone support. She had been diagnosed with esophageal cancer. I always hoped she could join us again, but at least we were able to keep in touch.

She was remembered at the remembrance ritual during the World Hepatitis Day celebrations in Surrey, where some of her friends sorrowfully heard of her passing for the first time.

Dianne will be missed by many family members, those she supported, and especially by her husband John.

#### HARRY HOLMES March 7, 2010

Mr. Holmes, of Qualicum Beach, contracted hepatitis C through tainted blood when he was injured in 1976. He was a faithful subscriber to the *hepc.bull*.

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#### 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 1J6	
Name:	_
Address:	
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□Please email me a PDF copy, free of char	rge.
□Membership + Subscription (1 year)\$	\$20.00
☐Membership Only (Doesn't include the <i>hepc.bull</i> )	\$10.00
□Subscription Only (Doesn't include membership privileges)	\$10.00
□Peppermint Patti's FAQ	612.00
□Resource CD	\$10.00
□"I enclose a donation of\$	

so that others may receive the bulletin."

#### TOTAL:

□ "I cannot afford to subscribe at this time, but I would like to receive the bulletin."

□"I want to volunteer. Please contact me."

□ "I want to join a support group. Please call."

(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/orderform.htm

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 jking2005@shaw.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  $12^{th}$  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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#### **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.

#### FAQ version 8.3

Peppermint Patti's FAQ Version 8.3 is NOW AVAILABLE, Version 8 is available in FRENCH and Version 7.1 is available in SPANISH. The ENGLISH version includes the latest treatment information and research from 2009. Place your orders now. Over 140 pages of information for only \$12 each. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

#### HepCBC Resource CD

The CD contains back issues of the hepc.bull from 1997-2010; the FAQ V8.3; 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<sup>©</sup> cannot endorse any physician, product or treatment. Any guests invited to our groups to speak, do so to add to our information only. What they say should not necessarily be considered our information only, what they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the editors, of HepCBC or of any other group.

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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.

HepCBC the following thanks institutions and individuals for their generosity: The late John Crooks, A-Channel News, The Ocean, JackFM, Community Living Victoria, Provincial Employees Community Services Fund, Dr. C. D. Mazoff, Lorie FitzGerald, Michael Yoder, Chris Foster, Judith Fry, Ernie, Bruce Lemer, United Way, and the newsletter team: Beverly A., Diana Ludgate, Alp, Judy Klassen, and S. J.

Please patronize the following businesses that have helped us: Top Shelf Bookkeeping, Thrifty Foods, Samuel's Restaurant, Margison Bros. Printers, Roche Canada, VanČity, Schering Canada, Shoppers Drug Mart, and the Victoria Conservatory. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com.

Special thanks to Thrifty Foods for putting our donation tins at their tills in these stores: Greater Victoria: Quadra, Cloverdale, Hillside Mall, Tuscany, Broadmead, Fairfield, James Bay, Admirals Walk, Colwood, Central Saanich, and Sidney. Lower Mainland: Tsawwassen, Coquitlam, Port Moody. Also: Salt Spring and Mill Bay.

#### CUPID'S CORNER

<sup>7</sup>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  $15^{\text{th}}$  of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send a cheque payable to HepCBC, and mail to HepCBC, Attn. Joan, #306-620 View Street, Victoria, BC V8W 1J6, (250) 595-3892. Give us your name, telephone 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.

#### **REMINDER:**

For anyone who was infected with HCV by tainted blood between 1986-1990, the deadline for initial claims is June 30, 2010 or within 3 years of first learning of the infection.

#### Got Hep C? Single? Visit:

http://groups.yahoo.com/group/HepCingles2 http://groups.yahoo.com/group/ NewHepSingles/ www.hcvanonymous.com/singles.html www.hepc-match.com/ www.hepcsinglesonline.com/

> **CHAT:** *http://forums.delphiforums.com/* hepatitiscen1/chat

#### **DIAL-A-DIETITIAN**

(604) 732-9191 or 1 (800) 667-3438

www.dialadietitian.org

Dietitians of Canada: www.dietitians.ca



#### **MEET NEW FRIENDS!**

We need experienced board members to occupy key positions. Also needed: summarizing, telephone buddies, translation English to Spanish. Please contact us at (250) 595-3892 or *info@hepcbc.ca* 

#### **PRE-PLANNING YOUR FINAL ARRANGEMENTS?**

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

**HEPC.BULL** 

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## **Hep C Sites**





# **Against Hepatitis C**







http://bit.ly/9Nylw3

Hey there! hepcbc is using Twitter. Twitter is a free service that lets you keep in touch with people through the exchange of quick, frequent answers to one simple question: What's happening? **Join today** to start receiving **hepcbc's** tweets.

http://twitter.com/hepcbc



**witter** 

#### Transplant Support Group of **British Columbia**

You can join the Facebook group by putting

"Transplant Support Group of British Columbia" in your browser or using this URL: http://www.facebook.com/group.php? gid=311699175404&ref=share



I have been working on my peer support Wendy's Wellness Website and wanted to offer everyone a safe place to get together.

This is the link to my post offering a secure place to blog about Hep C health. I hope to connect with anyone interested in sharing how we cope and manage our health challenges.

Please pass this along to anyone out there who would like a safe place to blog.

http://wendyswellness.ca/

## EIGHT YEARS OF INTERFERON

**By David Squires** 



You read that right: 8 wondering if they've grown an extra pair of ears or something like that! All kidding aside, treatment was a challenge, but if you

are thinking of getting on treatment, don't let any of the horror stories scare you from doing it. They are coming out with better and better treatments now, and in the near future, treatments are going to be more successful with far fewer side effects.

If you're reading this and have gone through some of the earliest treatments, like me, or some of the treatments that they still use today, you can relate. However every person is different and what was hard for some wasn't so hard for others. This is my story, what I have gone through, and what I face today.

I did not clear the virus, but I still have hope that someday this disease will be defeated! I am not on any treatment right now. My doctor took me off the interferon maintenance that I was on for over 2 years. The maintenance was half a dose of Pegasys (90 mg) without the ribavirin, and I believe the thinking at the time was that it might keep the virus from getting any worse. Whether that has been proven I have yet to find out. My doctor had taken me off it, and stated that if I needed a transplant, I should have it before I was 60. I'm 57.

My journey with the HCV started in the early 80's. I was having blood work done and the doctors at the time said some of my levels were high. At some time I believe the virus was called non-A/non-B. In 1991 I had blood test and the doctor said, а "Congratulations. You have America's newest disease, hepatitis C." He referred me to a specialist who took a biopsy. The biopsy showed I had stage 2 damage and stage 2 inflammation. He said that they were having people use interferon and it was showing some promise. He said that interferon was being used at the time to help with the AIDS virus, however many people were having side-effects of depression. He said they were working on other drugs at the time, also, so he left it up to me whether I wanted to get on it. He also said he thought at about age 60, I would have cirrhosis. He stated that the worst things that I could do was to drink or use speed. I believe at that time I gave up, and fell deep into my addiction.

I believe that is where I picked up the years of interferon. If HCV—in the 1960's from sharing needles. If anyone else has been you're reading this and you didn't get the through more, I am HCV that way, I'm truly sorry for you because I did behaviour where that was part of the game. You didn't. But there are many people who don't know how they picked it up. I have been corresponding with some one from the hepc.bull who doesn't know and said that someone else didn't know either, but said he may have picked it up because of unprotected sex with a bull moose. I may have slept with the same moose. I truly don't know how.

> So-fast forward to December 1998. I was truly dying. I was in jail and my liver was pickled. I was throwing up blood, my stomach was out about a foot (not because I was fat), and I was sick and tired of being sick and tired. To be continued ....

#### (**ALTERNATIVES**—*Continued from page 1*) ALAURSO FOR NASH

There are approved treatments for NASH, but many patients do not respond, so researchers in Prague studied the effects of ALAURSO, which is 400 mg daily of alphalipoic acid (found naturally in your body, and in health food stores) and 300 mg daily ursodeoxycholic acid (UDCA or ursodiol) in 10 patients with NASH, who in addition to a low-calorie diet, took the products for 6 months. None of these patients had Hep B or C. None consumed alcohol, and none had gallbladder stones. All had biopsies before and after treatment. While 10 patients took 400 mg of alpha-lipoic acid, 10 other patients received placebos and ate a low-calorie diet. The diet alone improved the severity of the NASH.

No change was seen in liver enzymes in the placebo group, but there was a notable drop in those taking ALAURSO. AST dropped an average of 17 mg/dL, ALT dropped about 17mg/dL, and GGT dropped about 13.5 mg/dL.

Fibrosis increased in the placebo group, and declined in the ALAURSO group. Researchers believe that R-enantiomer, found naturally in alpha-lipoic acid, may be solely responsible for the benefits of the drug.

Note: This study used very few subjects. The results are preliminary. They have not been peer-reviewed.

Please tell your doctor if you are taking supplements

Source: MedPage Today Published: May 16, 2010 (via natap.org)

#### BASICS: ALTERNATIVE MEDICINE From Peppermint Patti's FAQs version 8.3

There have been few research trials to check the effectiveness of natural therapies, but many people report positive benefits. If you decide to use natural therapies, it's vital that you see a practitioner who is properly qualified, knowledgeable and well-experienced. It's also advisable to continue seeing your regular doctor or specialist. If a natural therapist suggests that you stop seeing your medical specialist or doctor, or stop a course of pharmaceutical medicine, consider changing your natural therapist. Ask searching questions of whichever practitioner you go to:

- Is the treatment dangerous if you get the prescription wrong?
- How have natural therapies helped people with hepatitis C?

• What are the side effects?

- Are you a member of a recognized natural therapy organization?
- How much experience have you had of working with people with hepatitis C?
- How have you measured the health outcomes of the therapy?

• How do you plan to help me?

Most typical health insurance will not cover alternative medical procedures, but that's beginning to change. Many alternative procedures are now covered under medical insurance in the states of Washington and Oregon, and it looks like it's a trend which is beginning to spread.

Alternative Health Insurance Services of Thousand Oaks, California covers both allopathic and complementary/alternative treatments.

Patients may choose any provider, M.D. or N.D., or D.O. or D.C.

Subscribers must meet a deductible of up to \$1000, and the plan pays 80% of the first \$5,000 eligible medical expenses in a year, then 100 percent thereafter, with a \$2 million maximum. The plan includes prescription drug cards, with a \$5 co-payment, as well as "named partner" coverage for homosexual or non-married couples and their families. Alternative Health Insurance Services: 1-800-966-8467.)

Another plan is offered by American Western Life Insurance Co. in Foster City California: Prevention Plus. It covers a full range of alternative therapies. Enrollees use a naturopath as their primary care physician, or the gatekeeper who refers to other alternative practitioners. There is a \$5 co-payment for prescriptions, including herbal medicines. The company also has a 24-hour 800 Wellness Line staffed by naturopathic physicians, saving on doctor visits

where possible. (American Western Life: 1-800-925-5323) for at least four to six weeks. Preparations should be standardized to contain 6% ter-

#### **KNOWN HERB-DRUG INTERACTIONS**

Although the area of herb-drug interactions is under-researched, there are some interactions we do know about.

**Echinacea**, if used for more than eight consecutive weeks, could cause liver toxicity and should not be used with drugs such as anabolic steroids, amiodarone and methotrexate which are toxic to the liver as the effect may be additive.

**Feverfew** is most commonly used for the treatment of migraines. Non-steroidal antiinflammatory drugs (NSAIDs) such as aspirin or ibuprofen (Motrin, Advil) may reduce the effectiveness of feverfew. It can also inhibit platelet activity and should not be taken together with blood thinners such as Coumadin. Feverfew contains tannin, which has the ability to inhibit iron absorption, and should not be used for longer than four months without medical supervision. The recommended dosage is 125 mg daily; each dosage unit should contain at least 0.2% parthenolide.

**Garlic**: Most recent uses for garlic focus on its ability to treat high cholesterol and high blood pressure. Garlic can increase the risk of bleeding and should not be used concurrently with blood thinners. It has been reported to induce heartburn and flatulence, sweating, lightheadedness and allergic reactions. The German Commission E (Germany's equivalent to the FDA in the United States) recommends a dosage of 4 g of fresh garlic daily.

**Ginger** is often recommended for motion sickness, nausea and for loss of appetite. It has also been shown to prolong bleeding time and its use with aspirin or Coumadin should be avoided. Excessive consumption of ginger may also interfere with cardiac and antidiabetic therapy. It is usually well tolerated but may cause stomach upset or heartburn in some people. For motion sickness it is taken one hour before traveling. The total daily dose is 2-4 g.

Ginkgo biloba is one of the most popular plant extracts in Europe and has recently received approval in Germany for the treatment of dementia. There have been reports of spontaneous bleeding in people taking ginkgo, and again, it should not be used with blood thinners. People who take anti-convulsant medications, such carbamazepine and phenytoin, or phenobarbital should not take gingko without the knowledge of a physician, because it reduces the efficacy of these medications. Ginkgo is generally safe and well tolerated with the most common adverse reactions being stomach upset, headache and dizziness. German Commission E recommends a dosage of 40 mg of ginkgo three times daily with meals

for at least four to six weeks. Preparations should be standardized to contain 6% terpene lactones and 24% ginkgo flavone glycosides.

Ginseng is used to combat overall debility, as well as lack of energy and concentration. It has also been used as an aphrodisiac. There is tremendous variation in products of the commercially available products actually contained ginseng. Nevertheless, ginseng enjoys widespread popularity. Siberian ginseng has been associated with falsely elevated digoxin levels (a heart drug used to treat congestive heart failure) by interfering with the test used to determine digoxin need to control their blood glucose levels should take ginseng with caution. Concomitant use with warfarin, heparin, aspirin and NSAID's should be avoided. Additionally, ginseng may cause headache, nervousness, and manic episodes in patients with manicdepressive disorders or psychosis or those on anti-depressants, particularly the monoamine oxidase inhibitors (MAOI) such as phenelzine (Nardil). Side effects include high blood pressure, restlessness, nervousness, insomnia, skin eruptions, edema and diarrhea. German Commission E recommends Asian ginseng be taken as 1-2 g of crude herb daily or as 100-300 mg of ginseng extract three times daily. Commercial products should contain at least 4%-5% ginsenosides.

Kava Kava is used for anxiety, as a sedative and as a relaxant. Excessive sedation may result when it is taken with other sedatives (flurazepam, temazepam) or anti-anxiety drugs, particularly alprazolam (Xanax). The toxicity is increased if taken with alcohol. Until the clinical significance of Kava's action on platelet activity is determined, its use with blood thinners should be cautioned. Long-term use is not advised and is characterized by dry, flaking, discolored skin and reddened eyes. The herb is contraindicated in patients with certain types of depression because it may increase the risk of suicide. The daily dosage is the equivalent of 60 mg to 120 mg kava pyrones. Heavy consumption has been associated with increased concentrations of glutamyltransferase, suggesting potential hepatotoxicity. A case of recurring necrotising hepatitis has been reported. Health Canada issued a stop-sale order for kava kava, and it is banned in several European countries.

**St. John's Wort** is most widely used to treat mild to moderate depression, anxiety and seasonal affective disorder. Adverse reactions reported include stomach upset, aller-

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#### (FAQs BASICS-Continued from page 4)

gic reactions, fatigue and restlessness. Photosensitivity is usually rare and is associated with higher dosages. Fair-skinned people should be particularly cautious. Concomitant use with other photosensitizers, such as piroxicam (Feldene) or tetracycline should be avoided. St. John's Wort should not be used with MAOIs (phenelzine) or selective serotonin reuptake inhibitors (SSRIs) such as Prozac, Zoloft or Celexa. St. John's Wort has been reported to prolong narcotic-induced (codeine) sleeping times as well as decreasing barbiturate-induced sleeping times and caution is advised when combining these medications. The herb also contains tannin and may interfere with iron absorption. The usual dosage is 300 mg of standardized extract three times daily or 450 mg twice daily. It may take up to four to six weeks to see desired effect. St. John's Wort should not be taken with monoamine oxidase inhibitors or selective serotonin reuptake inhibitors like Prozac and Paxil until more information is available.

**Valerian**: German Commission E recommends valerian for use in the management of restlessness and nervous disturbances of sleep. Valerian may cause headache, hangover, excitability, insomnia, uneasiness and cardiac disturbances. Given its sedative property it would be wise to avoid barbiturates (phenobarbital), sedatives (flurazepam, temazepam) and alcohol while on valerian. Valerian is also a tannin-containing herb and may interfere with iron absorption. Persons currently taking antidepressants should take valerian only under medical supervision. The usual dosage of the extract is 2-3 g, one to several times per day.

**Evening primrose oil and borage** are contraindicated in patients taking anticonvulsants (e.g., clonazepam).

Echinacea and zinc, which are immunostimulants, should not be given with immunosuppressants such as corticosteroids (like prednisone) and cyclosporine, and they are contraindicated in patients suffering from rheumatoid arthritis, systemic lupus erythematosus and autoimmune hepatitis.

Feverfew, garlic, ginger, ginseng, and ginkgo biloba all affect bleeding time and should not be taken by patients using warfarin or by patients who have decreased platelet counts.

**Licorice, plantain, hawthorn and ginseng** may interfere with digoxin therapy.

**Valerian root** should not be taken when barbiturates are used because it could cause an increase in the barbiturate effects.

Sources: Hans Larsen, Alive Magazine March 1999 and When medicine and herbs don't mix by T. Chernin, R.Ph. www3.healthgate.com

#### The Line in the Sand

**HEP C AND ME: THE INCREDIBLE JOURNEY!** 

by Petra Hoffmann

So then, we keep asking ourselves, who is right and who is wrong? Is there a difference anymore? Who is it, exactly, that has the power or

the authority to draw the line? I think that we all draw our own lines in the sand. I have learned, as my life has whizzed by, that it is a very personal thing. I have redrawn and re-measured and curved the lines, but what has always saved me, and what I truly believe and always will, is that I have never crossed the line, and have stayed true to myself.

In order to live without fear or guilt or regret, we must draw our own line in the sand, and not allow others to drain that energy by not agreeing with us. I have been told recently by someone very close and dear to me, whom I thought I really understood, and who I thought understood me, that I have lost all credibility in my home town because I told the world the truth about my past. It should be no one else's burden to bear but my own, and it ought to be no one's business to "be ashamed for me." It is my life and my business as to whom I tell, and I am not ashamed, so what gives anyone else the right?

I was also scolded for potentially costing someone else their business and their clients' respect, because "everyone is looking at me differently, since they know you are an addict."

How am I to apologize for wanting nothing more than to help other people, by opening my world and experiences, not for one moment in time, even thinking the thought that it might affect someone else's career? Most of my own business community has turned their back since they have learned that I have Hep C, so I get it...the butterfly effect is large. After careful reflection, I am alright with all this, because I have made a clear choice to help others, as opposed to worrying about being judged. I suppose I have come to terms with the fact that nothing is perfect. Go figure!

What would you do, do you figure, if you were handed these cards? Would you hold your hand out to educate and help the world, or continue to please the people that do not understand, due to nothing more than the lack of knowledge? My vote, clearly, is to give them the knowledge, if they will accept it.

Do you know that you DON'T have it? 170 million people worldwide do, but more than that have Hep C, and don't know it....

Hepatitis C is a growing global EPI-DEMIC....1 in 12 has it....Please HELP spread awareness and tell us your story!

Please follow my Journey: <u>www.youtube.com/petrabilities</u> and <u>www.petrabilities.com</u>

#### **GREEK LENTIL SALAD**

9 oz. can lentils (9 ounces), drained
½ cup calamata olives (optional)
½ cup chopped onion
½ cups grape tomatoes, halved

1/2 cup chopped green peppers

1 cup cucumber, diced



<sup>1</sup>/<sub>4</sub> cup crumbled feta cheese <sup>1</sup>/<sub>4</sub> cup fresh parsley, chopped <sup>1</sup>/<sub>4</sub> cup canola oil (or cold pressed olive oil or grape

seed oil) <sup>1</sup>/<sub>4</sub> cup lemon juice 1 Tbsp dried oregano



1. In a large bowl, combine lentils, olives, onion, tomatoes,

green pepper, cucumber, feta cheese and parsley.

2. In a small bowl, whisk canola oil, lemon juice and oregano together.

3. Add dressing and parsley to lentil mixture and toss to coat.

4. Can be eaten right away or covered and left in refrigerator to marinate for 2 hours before serving. Salad can be made a day in advance.

Inspired by a recipe on a Pharmasave calendar.

If you are receiving this newsletter by snail mail but have a computer and/or internet access, please consider switching to our pdf version. All you need is Adobe Acrobat Reader, free at this site: www.adobe.com/products/acrobat/ readstep2.html

Just send your email address to *info@hepcbc.ca* and say, "Send me the email version, please," and you, too, can enjoy this newsletter in glorious colour, free of charge.

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#### FROM A WIFE'S POINT OF VIEW

When my husband was first diagnosed with Hepatitis C, I automatically thought that I must have it as well. Strange as it sounds, I was the one who seemingly had been experiencing symptoms, and he wasn't. Being completely uneducated about the disease, my first thoughts were, "Who will raise our four year old daughter? We are both going to die". My husband and I have been together for 20 years, and he is my best friend. He is also a son to my mother, and a brother to my baby sister. I asked him if I could tell them about the devastating news, and he said, "I don't care." That proved to be a tragedy of sorts. My brother-in-law had just had a liver transplant, and so I really wanted to talk to my sister. My sister, mom, and I have always been very close. I told my



husband that they would not say anything to anyone else, as they would want to protect us and our daughter from the terrible stigma that HCV carries. My mom had once under-

gone chemo herself, so she was definitely able to relate.

Then, suddenly, having changed his mind about sharing his plight, I had to go back and tell them that his antibody test had turned out to be a false positive. It became even worse when he now felt as though he had to hide things from me as well, and tried to drive off to a few doctor's appointments without me. I jumped in the car anyway, and he ended up driving like a maniac to get there, and then forbade me to go in with him. During the entire one hour drive there, he ranted and raved at me, and nothing made sense anymore.

When I was finally allowed to accompany him to see the gastroenterologist he made it clear that he wished that he had had someone else to go with him. I cannot describe the pain I felt, to know that he felt so betrayed and hurt by me somehow. His own mom suffers from delusional depression, and they have a couple of family members whom have had Hep C and fortunately beat it, so she is familiar with the disease. She came right out and asked him if he had been checked for HCV & HIV. My husband then lied to her, and told her that what he had was a bleeding ulcer that required the need for procrit injections.

I honestly think it's the stigma he's afraid of most. Since finding out that his sister also has Hep C, his mom has told me countless times to have him checked. He blames my family somehow, for his mother's own concerns. He has always been self employed, and that permits him to spend a lot of time with our daughter, who is daddy's girl. Since I recently got laid off, and he is at home sick, we have been able to get very close to her. It has been hard to convince her that daddy's sick and he didn't catch the flu from her. She blames herself somehow, as children often seem to do, and I find myself constantly reassuring her about how much he loves her, and that he will get well again. I feel as though it is my little girl who has held me together, since I have felt so disconnected from my own husband.

I can only imagine how much easier this would all be if we could only tell our friends and family, so that they could help.



#### **ATTENTION: I Need Your Personal Hepatitis C Story**

This is the blog address that will include everyone's Hep C Story:

http://bettyhepatitisc.blogspot.com/

Please send me your personal Hepatitis C Story so I can include it on this blog and in May, Hepatitis C Month, I will get it out to congressmen, newspapers and all the media I can think of, and any other suggestions you may have. This is one way of making sure our voices are heard. I would like to gather as many stories as possible and have this done soon. I have been clear of Hep C for nearly 5 years and am a patient advocate in New York. Thanks, guys. Together we can make a difference!

Please email me your stories to BettyV444@aol.com I will cut and paste your stories onto the blog.

I wear lots of Hep C Hats:

Hepatitis C Support Group Facilitator Hepatitis C Task Force Patient Advocate Hepatitis C Survivor

## CONFERENCES 2010

XIII International Symposium on Treatment of Viral Hepatitis

1st Meeting on the Management of Liver Cirrhosis of the Brazilian Society of Hepatology 14 - 17 July, 2010 Bahia Othon Palace Hotel (simultaneous translation into English) Tel: (55) (71) 2104-3477 Fax: (55) (71) 2104-3434 E-mail: eventus@eventussystem.com.br www.hepatologiadomilenio.com.br.

> Australasian Viral Hepatitis Conference 2010

6 - 8 September 2010 Sebel Albert Park Melbourne, Victoria, Australia Tel: +61 2 8204 0770 Fax: + 61 2 9212 4670 Email: info@hepatitis.org.au

#### Hepatitis 2010 Viral Hepatitis

World Congress 13-14 September 2010 St Hilda's College, Oxford, UK Hepatitis2010/Home.htm Registration deadline: 5 August 2010 Contact: Dr M Sohail Tel: +44 (0)1865 275743 Email: HepatitisOxford@gmail.com www.libpubmedia.co.uk/Conferences/

#### The Liver Meeting 2010

AASLD's 61st Annual Meeting 29 October -2 November 2010 John B. Hynes Convention Center Boston, Massachusetts Registration: Mid-July www.aasld.org/thelivermeeting/

#### Interdisciplinary Viral Hepatitis Education Workshop

BC Hepatitis Services September 23 & 24, 2010 Holiday Inn Vancouver Center 711 West Broadway, Vancouver, BC

For health and social service providers, who want to increase their knowledge about viral hepatitis and improve prevention and care services.

Please register ASAP Contact Carolyn Timms carolyn.timms@bccdc.ca (604) 707-2423 1(866) 660-1676.

Forms: http://www.bccdc.ca/NR/rdonlyres/ C68426AA-AABA-44E2-A99E-D195BF9AE6EF/0/2010IVHEWRegistrationFilla bleForm.pdf

HEPC.BULL

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#### **THE ACQUISITION OF ERYTHROPOIETIN**

Erythropoietin may be prescribed to some Hep C patients to help reach and maintain a sufficient red blood cell count. However, this drug is very expensive. The following is a summary of the steps I pursued to help alleviate the prescription cost.

Step 1: I contacted my MLA, who sent me to the Ministry of Health.

Step 2: The Ministry of Health notified me of the restrictions in place for Hep C patients requiring the prescription and coverage for Erythropoietin.

Step 3: I contacted the Food & Drug Liaison Office. They suggested I contact the distributors of the drug directly for possible assistance with the prescription cost.

Step 4: I found the brand name and provider of this specific drug prescribed for patients in Canada.

vider. In turn they passed me on to their Pre- ordination assistance for patients who have scription Assistance Program.

where I was put in direct contact with the on, and complete their treatment success-Distribution Manager for Canada, who in fully. PegAssist Reimbursement Specialists turn, was very surprised I had been able to are available (Monday to Friday, 10 AM- 6 contact him directly.

"Compassion Care" program. This would physician to gain access to the program. qualify me to have my prescription at no cost.

Step 8: The drug company faxed a form to my prescribing physician so he could provide the specifications for the drug I needed.

Step 9: My physician submitted the form to complete my acquisition of the drug at no homes or to the clinics. cost.

Note: The above steps were pursued by my own initiative; and were in no way influenced by any other outside source. By A. York

#### EPREX ASSISTANCE PROGRAM

Janssen-Ortho Inc, Canada has a program that may provide assistance in obtaining epoetin. It is the Eprex Assistance Program (EPO) (877) 793-7739

For more info, provincial coverage and forms: http://profiles.drugcoverage.ca/en/ default.asp?DrugID=25

#### PEGCARE

PegCARE is a reimbursement program to help people who have been prescribed Pegetron and need assistance with any copayment they might have, whether through their provincial coverage (i.e., Pharmacare) deductible or their 3rd-party health insurance. It is pro-rated, so the less the family income is, the more help they get. If someone's net family income is less than \$30,000, they will get 100% reimburse-The income maximum ment. is \$100,000. Patients must be signed up for Fair Pharmacare to qualify, and they need to provide a copy of last year's T4 form.

A 24/7 Nursing Hotline and bilingual assistance is available, at no charge. Other services are access to live translation services (150 languages) and injection assistance from registered nurses. Ask your doctor or nurse to enroll you in PegCARE. It's an easy single-page form to fill out, which they will provide. PegCARE: 1-866-872-5773

#### PEGASSIST

The PegAssist Reimbursement Assis-Step 5: I contacted the drug company pro- tance Program provides reimbursement cobeen prescribed Pegasys or Pegasys RBV. The program will assist in securing funding Step 6: I contacted the Assistance Program, for patients to ensure that they can start, stay PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain Step 7: My request was submitted to their a program enrollment form from their nurse/

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, the program can conveniently deliver the medication directly to patients'

#### **NEUPOGEN** VICTORY PROGRAM

Amgen has a program for patients who have been prescribed Neupogen. A reimbursement assessment is conducted by a specialist who will help you navigate through your personal or provincial coverage options. Dependant on specific criteria, some patients may be able to obtain Neupogen on a compassionate basis free of charge. Please note that Amgen will only provide Neupogen to patients on a compassionate basis as long as it is prescribed and dosed in accordance with the approved product monograph. This service is accessed through the Victory Program: 1-888-7064717.

#### COMPENSATION

#### LAW FIRMS

#### 1986-1990

Bruce Lemer/Grant Kovacs Norell Vancouver, BC Phone: 1-604-609-6699 Fax: 1-604-609-6688

Pre-1986/ Post-1990



Klein Lyons Vancouver, BC 1-604-874-7171. 1-800-468-4466, Fax 1-604-874-7180 www.kleinlvons.com/class/settled/hepc/

Lauzon Belanger S.E.N.C. (Quebec) Toronto, ON Phone 416-362-1989; Fax 416-362-6204

www.lauzonbelanger.qc.ca/cms/index.php?page=108 Roy Elliot Roy Elliott Kim O'Connor LLP.

hepc@reko.ca www.reko.ca/html/hepatitisc.html

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

Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056

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

Canadian Blood Services, Vancouver, BC 1-888-332-5663 (local 3467) or 604-707-3467

Lookback Programs, BC: 1-888-770-4800

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

Manitoba Traceback: 1-866-357-0196

**Canadian Blood Services, Ontario** 1-800-701-7803 ext 4480 (Irene) Irene.dines@Blood.ca

**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 8P6 Fax: 1-905-953-7747

#### **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 Registration: 1-888-840-5764 HepatitisC@kpmg.ca

Ontario Compensation: 1-877-222-4977 Quebec Compensation: 1-888-840-5764 http://www.phac-aspc.gc.ca/hepc/comp-indem\_e.html

#### **CLAIMS ADMINISTRATOR**

#### 1986-1990

Administrator 1-877- 434-0944 www.hepc8690.com info@hepc8690.com www.hepc8690.ca/PDFs/initialClaims/tran5-e.pdf

#### Pre-86/Post-90

Administrator 1-866-334-3361 preposthepc@crawco.ca www.pre86post90settlement.ca

Settlement Agreement: http://www.reko.ca/html/ hepc\_settleagreement.pdf

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

Armstrong HepCURE Contact 1-888-437-2873 Phone support.

AIDS Vancouver Island The following groups provide HCV info, harm reduction, support, education and more:

• Campbell River: Drop in, 1371 C -Cedar St. Contact 250-830-0787 leanne.cunningham@avi.org

· Comox Valley Hep C Support group-Drop in, needle exchange. 355 6th St. Courtenay. Picnic: Simms Park May 18. Contact Sarah 250-338-7400 sarah.sullivan@avi.org

 Nanaimo Contact Anita 250-753-2437 anita.rosewall@avi.org

• Port Hardy (Port McNeil, Alert Bay, Port Hardy, Sayward, Sointula and Woss) Drop-in kitchen. 7070 Shorncliffe Rd. Contact Tom, 250-949-0432 tom.fenton@avi.org.

•Victoria Access Health Centre, drop in, disability applications. 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jefferis@avi.org

**Boundary HCV Support and Educa**tion Contact Ken 250-442-1280 ksthomson@direct.ca

Burnaby HCV Support Contact Beverly at 604-435-3717 batlas@telus.net

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

Courtenay HCV Peer Support and Education. Contact Del 250-703-0231 dggrimstad@shaw.ca

Cowichan Valley HCV Support Contact Leah 250-748-3432 r-l-attig@shaw.ca

HepCBC info@hepcbc.ca, www.hepcbc.ca •Victoria Peer Support: 4<sup>th</sup> Tues. monthly 7-8:30 PM, Victoria Health Unit, 1947 Cook St. Drop-in/Office/Library, 306-620 View St. Contact 250-595-3892 Phone support 9 AM-10 PM. 250-595-3891

•Fraser Valley Peer Support: 3<sup>rd</sup> Wed monthly 7PM, N. Surrey Rec Centre Meeting room 10275-135th St Info: 604-576-2022, petrabilities@aol.com.

•**Surrey Positive Haven Hep C group** 2<sup>nd</sup> & 4<sup>th</sup> Thurs monthly 1 PM. 10697 135A St. Contact Brian or Sam 604-589-8678.

Kamloons ASK Wellness Centre. Chronic illness health navigation/ support. info@askwellness.ca 250-376-7558 1-800-661-7541 ext 232 or Merritt health housing and counseling 250-315-0098. www.askwellness.ca

Kamloops Hep C support group, 2nd and 4<sup>th</sup> Wed monthly, 10-1 PM, Interior Indian Friendship Society, 125 Palm St. Kamloops. Contact Cherri 250-376-1296 Fax 250-376-2275

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 1-866-637-5144. ljmortell@shaw.ca

Mid Island Hepatitis C Society 2<sup>nd</sup> Thurs. monthly, 7 PM (Location to be arranged.) Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Peer Support Group 1<sup>st</sup> & 3<sup>rd</sup> Thurs.

monthly 4-5 PM, AVI Health Centre, #216-55 Victoria Rd, Nanaimo. Contact Fran 250-740-6942. hepctxpeersupport@hotmail.com

Nelson Hepatitis C Support Group 1<sup>st</sup> Thurs. every 2<sup>nd</sup> month, afternoons. ANKORS, 101 Baker St. Library M-Th 9-4:30. Contact Alex or Karen 1-800-421-2437, 250-505-5506, information@ankors.bc.ca alex@ankors.bc.ca www.ankors.bc.ca/

New Westminster DIANNE HAS PASSED AWAY. See page 1.

North Island Liver Service Viral Hepatitis Information, support, treatment, Fanny Bay North to Pt Hardy, Vancouver Island. 1-877-215-7005

Pender Harbour Contact Myrtle 604-883-0010 myrwin@dccnet.com

Powell River Hepatology Service Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact Melinda Melinda.herceg@vch.ca 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 Ilse 250-565-7387

ilse.kuepper@northernhealth.ca

Prince Rupert Hep C Support Contact: Dolly 250-627-7942

hepcprincerupert@citytel.net

Oueen Charlotte Islands/Haida Gwaii & Northern BC support. Contact Wendy 250-557-2487, 1-888-557-2487, wendy@wendyswellness.ca www.wendyswellness.ca http:// health.groups.vahoo.com/group/Network-BC/

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

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@vch.ca

VANDU The Vancouver Area Network of Drug Users. 380 E Hastings St. M-F 10-4 Contact 604-683-6061 vandu@vandu.org www.vandu.org

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

Vancouver Hepatitis C Support Group Contact 604-454-1347 or 778-898-7211, or call 604-522-1714 (Shelley), 604-454-1347 (Terry), to talk or meet for coffee.

Vernon telephone buddy, M-F 10-6 Call Peter, Tel. 250-309-1358. pvanbo@gmail.com

Victoria CoolAid Peer Support each Wee 10-11:30 AM, 713 Johnson St. Support for all stages of treatment (deciding, during, after). Contact Carolyn cshowler@coolaid.org

YouthCO AIDS Society 900 Helmcken 705-522-5156, St, 1st floor, Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Support program manager: Sasha Bennett sa shab@vouthco.org

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

#### **OTHER PROVINCES:**

#### **ONTARIO:**

Barrie Hepatitis Support Contact Jeanie for info/appointment jeanievilleneuve@hotmail.com

Sandi's Crusade Against Hepatitis C/ **Durham Hepatitis C Support Group** 

Contact Sandi: smking@rogers.com www.creativeintensity.com/smking/ http://health.groups.yahoo.com/group/ CANHepC/

Hamilton Hepatitis C Support **Group** 1<sup>st</sup> Thurs. monthly, 6-7 PM, Hamilton Urban Core Community Health Centre, 71 Rebecca St, Hamilton. Contact Maciej Kowalski, Health Promoter 905-522-3233 mkowalski@hucchc.com

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, Teen Health Centre-Street Health Program Office, 711 Pelissier St., Suite 4, Windsor, ON. Contact Andrea Monkman 519-967-0490 or

hepcnetwork@gmail.com. http://hepcnetwork.net

Kingston Hep C Info HIV/AIDS Regional Service. Contact 613-545-3698, 1-800-565-2209 hars@kingston.net, www.hars.ca

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Waterloo Mennonite Brethren Church, 245 Lexington Rd. Waterloo. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

Niagara Falls Hep C Support Group Contact Rhonda 905-295-4260, kehl@talkwireless.ca

Owen Sound Info and support. Contact Debby Minielly dminielly@publichealthgreybruce.on .ca 1-800-263-3456 Ext. 1257, 519-376-9420, Ext. 1257, www.publichealthgreybruce.on.ca/

Peel Region (Brampton, Mississauga, Caledon) Contact 905-799-7700 healthlinepeel@peelregion.ca

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

Sudbury Circle C Support Group 1st Tues. monthly. Contact Ernie

hepc.support@persona.ca or Monique 705-691-4507.

Toronto CLF First Mon. monthly Oct. through June, 7:30 PM, North York Civic Centre, 5100 Yonge Street. More info: www.liver.ca.

Contact Billie 416-491-3353, bpotkonjak@liver.ca

Thunder Bay Hep C support. Contact Sarah Tycholiz 807-345-1516 (or for 807 area only 1-800-488-5840)

Unified Networkers of Drug Users Nationally undun@sympatico.ca

York Region Hepatitis C Education Group 3<sup>rd</sup> Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, 905-940-Unionville. Contact 1333, 1-800-361-5653 info@hepcyorkregion.org

www.hepcyorkregion.org

#### **OUEBEC:**

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

#### ATLANTIC PROVINCES:

Hepatitis Outreach Society of NS. Info and support line for the entire province. Call 1-800-521-0572, 902-420-1767 info@hepatitisoutreach.com. www.hepatitisoutreach.com

#### PRAIRIE PROVINCES:

Edmonton Contact Jackie Neufeld 780-939-3379.

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

Manitoba Hepatitis C Support Community Inc. Each 2nd & last Tues. monthly, 7 PM, 595 Broadway Ave. Everyone welcome. Contact Kirk 204-772-8925 info@mbhepc.org www.mb hepc.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

#### TIP:

**IF YOU ARE TAKING** HERBAL MEDICINE OR SUPPLEMENTS, DON'T **TRUST BLINDLY. FIND OUT EXACTLY WHAT** YOU ARE TAKING AND **INVESTIGATE IT.** 

If you have a Canadian HCV support group to list here, please send details to <u>info@hepcbc.ca</u> by the 15<sup>th</sup> of the month. It's free!

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