

hepc . bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

NEWS

WHAT DOES MILK THISTLE DO?

Researchers now know why milk thistle seems to help some of us with HCV. It has been thought that silymarin, one of the herb's ingredients, had an effect on fibrosis, but actually it has a direct effect on the virus itself. It tends to inhibit the polymerase, and prevents the virus from entering the cells and from passing from cell to cell. It inhibited HCV activity best with genotype 2a, and somewhat with genotype 1b viruses, but it did not inhibit replication of the virus in the genotype 1a, 1b and 2a cell lines the researchers used. It did block cell-to-cell spread of the virus and the production of infectious virions in a cell culture. "Although inhibition of in vitro NS5B polymerase activity is demonstrable, the mechanisms of silymarin's antiviral action appear to include blocking of virus entry and transmission, possibly by targeting the host cell."

Source: <http://onlinelibrary.wiley.com/doi/10.1002/hep.23587/abstract> June 2010, http://www.hivandhepatitis.com/hep_c/news/2010/040610_b.html

PREDICTING RESPONDERS

Soon you may know if you will respond to treatment before suffering side-effects, loss of income, and months out of your life. Merck & Co. has given LabCorp the right to use the IL-28B polymorphism in a test to determine whether or not a patient will respond to treatment with peg-IFN alpha. The association between response and the polymorphism was discovered by Merck, and LabCorp developed the test.

Source: <http://www.genengnews.com>

MILKSHAKE? THINK TWICE

Scientists have noticed that HCV somehow affects the fat cells (lipoproteins) in our blood, possibly increasing the infectivity of the virus. To test this theory, they gave patients a milkshake high in fat. Their plasma (from blood) was measured before and 7 times afterwards. Their viral load peaked

between 2 and 3 hours after drinking the shake, increasing by an average of 26 times. The scientists concluded that triglycerides change the density and dynamic of the virus in the blood, and may make it more infectious. The good news is that the viral load did not stay that high.

Source: www.ncbi.nlm.nih.gov/

GROWING LIVERS

Scientists at Massachusetts General grew a liver in their lab and transplanted it into a rat. The rat lived for several hours. The technology may be available to humans within 5 years, according to researchers.

Source: www.dailymail.co.uk/health/article-1286266/Scientists-grow-laboratory-liver-giving-hope-millions-diseased-organs.html

SPRINT RESULTS

The much-awaited results of the SPRINT-1 phase 2 study was to test the safety and efficacy of standard therapy combined with boceprevir. The regimen was given to 595 patients. Results showed 800 mg three times daily combined with standard treatment can double sustained response rates in some of the groups in both 28- and 48-week regimens. There was a low-dose ribavirin group of patients who had fewer side effects, but their SVR rates did not improve.

Source: www.medscape.com/viewarticle/726685

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Photo: Wikipedia

RICHIE HAYWARD 1946-2010

Richie Hayward is dead from hepatitis C and liver cancer at the age of 64. His passing, on August 12 this year, was blamed in part on the fact he did not have health insurance, and in part to the fact that he started fighting the illness just over a year ago, when symptoms of liver cancer appeared. Unfortunately, since he couldn't work, he had no income. Richie gained fame as the drummer for the group Little Feat.

Symptoms of the final stages of liver cancer can include jaundice (when the skin and/or eyes turn yellow), a fever, loss of appetite, and pain. The patient almost always has cirrhosis, and the cancer may have travelled to other parts of the body. In the final stages, the patient spends most of the time sleeping. Stage IV liver cancer is very difficult to treat. Hayward was married and living on Vancouver Island, and trying to collect money for a transplant when he died. He played at the Vancouver Island Music Fest on July 11, intending to participate in only a couple of pieces, but he actually finished up the night.

Sources:

www.moderndrummer.com/events_full/700001597/LITTLE%20FEAT%20%20%E2%80%99CRICHIE%20HAYWARD%20BENEFIT%E2%80%9D%20CONTINUES%20TO%20ROCK
www.associatedcontent.com/article/5684466/liver_cancer_kills_legendary_drummer.html?cat=5
http://en.wikipedia.org/wiki/Little_Feat

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"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*® is the 15th of each month. Please contact the editors at jkling2005@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 12th 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.

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

REPRINTS

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

THANKS!!

HepCBC thanks the following 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, Chris Foster, Judith Fry, United Way, and the newsletter team: Beverly Atlas, 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, VanCity, 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

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 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.

TIP OF THE MONTH:

Make sure your medicines are liver-friendly. Check with your pharmacist.

Got Hep C? Single? Visit:

<http://groups.yahoo.com/group/HepCingles2>

[http://groups.yahoo.com/group/](http://groups.yahoo.com/group/NewHepSingles/)

[NewHepSingles/](http://www.hcvanonymous.com/singles.html)

www.hcvanonymous.com/singles.html

www.hepc-match.com/

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CHAT: [http://forums.delphiforums.com/](http://forums.delphiforums.com/hepatitiscen1/chat)
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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.

Hep C Sites on facebook



FIGHT Against Hepatitis C

<http://bit.ly/cvXCGK>



<http://bit.ly/9Nvlw3>

twitter



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>



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 PART 3

By David Squires



I was fortunate to have an R.N. as a significant other, so I was well taken care of by a professional care giver. I was also fortunate to have custody of my youngest son when he was 10. They weren't so fortunate having to live with me through all my treatments. I had depression, anxiety and confusion. I was a wreck! I was loved in spite of my shortcomings, and because of the love and understanding I received, I was able to go on. I truly believe without that, today I wouldn't be alive! It does affect whoever you are with, so knowledge of the side-effects is important with family members.

So on to the next treatment. My local gastroenterologist put me back on Pegasys and again within weeks my virus was cleared. After about a year, my white blood cells dropped very low and I could have received shots for this, but it was decided to drop my ribavirin to 4 pills (800 mg) a day. A few weeks after that I quit taking the pills.

They were having success with full treatments of 18 months so my doctor suggested that I stay on treatment for that long. However I wasn't doing the full treatment by not taking the pills, but my virus was still non-detectable, so I went on with 180 mg of the Pegasys for a full 18 months. After that my doctor truly believed the virus would stay non-detectable, but 2 weeks later, a blood test showed the viral load was again in the millions. I remember seeing my doctor in a hallway with this look of disappointment and sadness telling me that it had returned. I can't tell you how bad I felt. I went through hell for this? If only I could have taken all the Ribavirin doses, I felt I could have beaten it. I then went on the maintenance dose that I mentioned earlier for over 2 years. It kept my viral load down, and the thinking at the time, I believe, was that was until something better was put on the market, that was all that could be done

So it's now been over a year, and I have noticed that I'm having a hard time pushing myself to do what I feel is needed to help me, which is exercising, eating a lot of fruits and veggies, juicing and staying spiritually fit. I've really slacked on these due to stress, arthritis and family problems. You know, it takes a lot of time to eat healthy. Preparing and washing the veggies seems to have taken a back seat, so it seems. So I'm trying to get back on track and take steps to return to what I feel is good for me.

I am now taking "Mindfulness Meditation"

classes along with "Healthy Living: Mind & Body" and "Qi Gong" classes. These have helped me immensely, along with trying to think positively. The mind is very powerful. If I'm thinking, "I'm sick," guess what. I'm probably going to feel sick. Now, with my positive thinking, I just need my body to listen, but really, why do you think they have placebos? Because our minds are so powerful!

So that's my story. We all have our stories—what we went through. This was mine. May your journey with this disease be successful. I know that for me, I learned to trust in my Higher Power and to take better care of myself, so it was a blessing in disguise.

Take care and God bless.

—David L. Squires



ANNUAL GENERAL MEETING

**Tuesday September 21, 2010
6:30 PM**

**1947 Cook Street,
Victoria, BC
(Victoria Health Unit, Activity Room)**

Schedule:

6:30-8:00pm Welcome and Main Speaker
8:00-9:00pm Annual General Meeting

AGENDA:

- Approve minutes of AGM 2009
- Set number of directors,
- Election of those directors
- President's Report
- Coordinator and Staff Report
- Financial Report

Main Speaker: Irene Barnes, RN, BSN, GNC(C), CPMHN(C) - Consultant, Educator, Author, Workshops about the Brain, especially people with dementia, delirium, and depression associated with chronic diseases.

She is preparing an interactive, fun presentation for those with hepatitis C, caregivers, and other interested people. See Irene's website: www.dementiacare.ca

Refreshments provided. Public welcome. No charge. Must be a member to vote. Hope to see you there.

A member is entitled to one vote at a meeting of members, and must become a member at least 30 days prior to the meeting to be able to vote.

BASICS:

FROM PEPPERMINT PATTI'S FAQs VERSION 8.3
WHY DO WE HAVE PAIN?

WHAT OTHER MEDICAL PROBLEMS CAN BE RELATED TO HCV?

Chronic hepatitis C infection causes problems for parts of the body beyond the liver. The organs most often affected include the blood vessels, skin, joints, kidneys, thyroid gland, heart and brain. The virus itself has been found in the heart, muscles, nerves and lymphatic system. Many problems may arise from the cirrhosis, per se. Potential problems from cirrhosis include fluid accumulation in the abdomen, bleeding into the stomach, jaundice, confusion, poor blood clotting, coma, and susceptibility to infection.

During the last years many autoimmune manifestations have been correlated with HCV infection, namely sicca syndrome, chronic polyarthritis, polydermatomyositis, fibromyalgia, autoimmune thyroiditis, lung fibrosis, and diabetes mellitus. (*Curr Opin Rheumatol 2000 Jan;12(1):53-60*)

UPPER RIGHT QUADRANT (URQ) PAIN (SIDE PAIN)

Even though the liver itself contains no nerve endings, and does not feel pain, many people with HCV experience a pain on the upper right side of their body, just beneath the ribs. It varies from a dull ache and bruised feeling, to sharp stabbing pain which is quite different from "gas pains."

This is thought by some to be "referred pain" from the swelling of the liver capsule due to the disease process. This pain may also be referred to the right shoulder or to the back between the shoulder blades.

CRYOGLOBULINEMIA

One-third to one-half of people with chronic hepatitis C infection have cryoglobulinemia. Cryoglobulinemia is a condition where antibodies which are attached to the hepatitis C virus solidify when cold. Hepatitis C is recognized as the most common cause of mixed cryoglobulinemia.

Most of the people with cryoglobulinemia from hepatitis C have had their hepatitis for a long time or have cirrhosis. People with higher concentrations of hepatitis C RNA in their blood do not seem to have a higher risk of having cryoglobulinemia. Usually the cryoglobulins are in low concentration and cause no symptoms.

About 20% of people with hepatitis C and cryoglobulinemia have symptoms. Symptoms most often associated with cryoglobulinemia include mild fatigue, joint pains, or itching. Occasionally, people with cryoglobulinemia develop vasculitis (inflammation of the blood vessels) which can cause purpura (purple skin lesions), Raynaud's phenomenon (the hands turn white, then blue, and then red from constriction and subsequent dilation of the blood vessels), or numbness in the hands and feet. The presence of cryoglobulinemia does not affect people's response to interferon. In fact, some people with vasculitis have improvement in the vasculitis as their liver tests improve on interferon.

RHEUMATOID ARTHRITIS-LIKE SYMPTOMS

Hepatitis C infection can mirror rheumatoid arthritis symptoms. The predominant clinical findings include palmar tenosynovitis: small joint synovitis, and carpal tunnel syndrome. Risk factors such as transfusions and IV drug abuse or a history of hepatitis or jaundice should be included in the history of present illness of any patient with acute or chronic polyarthritis or unexplained positive rheumatoid factor. In such patients, gammaglutamyl aminotransferase, serologic studies for hepatitis C, and other tests appropriate for chronic liver disease should be performed. (*Journal of Rheumatology, June 1996;23(6):979-983; Rev Med Chil 1998 Jun;126(6):725-6.*)

FIBROMYALGIA

Fibromyalgia is the name for a condition that typically includes widespread muscle pain, fatigue and abnormal sleep patterns.

Until a few years ago, doctors called the condition fibrositis, or muscular rheumatism, and believed mostly that the condition was "all in the patient's head". Today, fibromyalgia is recognized by medical organizations as a genuine and serious problem.

The symptoms of fibromyalgia typically include pain in many muscles, and around ligaments and tendons, persistent fatigue, waking up feeling tired even after a full night's sleep, headaches, bouts of constipation and diarrhea, abdominal pain, painful menstrual periods, sensitivity to cold, numbness or tingling, and difficulty exercising.

Symptoms vary widely among patients and tend to wax and wane over time. An illness, injury, cold weather or emotional stress may

trigger a fibromyalgia episode or make ongoing symptoms worse.

A study at the Oregon Health Sciences University and Portland Adventist Hospital suggests hepatitis C may trigger fibromyalgia ("Fibromyalgia: A prominent feature in patients with musculoskeletal problems in chronic hepatitis C, A report of 12 patients," by A. Barkhuizen, G.S. Schoepflin, and R.M. Bennett, *Journal of Clinical Rheumatology, Vol. 2, No. 4, August 1996*). This study is the first to show a link between the two illnesses. Another study (*Curr Opin Rheumatol 2000 Jan;12(1):53-60*) suggests that a causative role of HCV seems to be likely in the development of fibromyalgia.

It was determined that the relationship between the hepatitis C virus and fibromyalgia followed three distinct patterns:

In nine patients, fibromyalgia developed as a long-term complication of the hepatitis, arising on average 13.4 years after the virus was acquired.

In two patients, fibromyalgia arose simultaneously with the hepatitis C infection. In one patient, pre-existing fibromyalgia was significantly worsened by the hepatitis C.

It is unknown why the hepatitis C virus and fibromyalgia may be linked, but the authors suggest that hepatitis C causes chronic activation of the immune system that leads to muscle aching, fatigue, mental changes, sleep abnormalities, and alterations of the neuroendocrine system.

The patients with both hepatitis C and fibromyalgia could be distinguished from most other patients with fibromyalgia alone because they had symptoms unusual to fibromyalgia. These symptoms included synovitis (inflammation of the membrane around a joint, bursa, or tendon) and vasculitis (inflammation of a blood or lymph vessel). In addition, laboratory findings pointed to a disease process other than fibromyalgia.

SURREY, BC ANNOUNCEMENT:

The Fraser North Hepatitis C clinic previously located at the North Surrey Health Unit has moved to the Charles Barham Pavilion on the Surrey Memorial Hospital grounds. The 1 (800) 308-3318 number listed on their pamphlet is not working yet. Try calling (604) 585-5666 extension 77-3095.

*I have just made my way to the end of Eckhart Tolle's **The Power of Now**. Basically, it is a guide to enlightenment. Practically, he gives tips on how to deal with many of our problems by eliminating the time factor—eliminating the past and the future. Here are some excerpts from that book about illness and pain that I would like to share with you. I realize that they are taken out of context, and this may not be your cup of tea, but I encourage you to read this, and if you find some bit of Truth in it, you may want to buy the book. —Editor*

Surrender is inner acceptance of what is without any reservations. We are talking about your *life*—this instant—not the conditions or circumstances of your life, not what I call your life situation. With regard to illness, this is what it means. Illness is part of your life situation. As such, it has a past and a future [which] form an uninterrupted continuum, unless the redeeming power of the Now is activated throughout your conscious presence. As you know, underneath the various conditions that make up your life situation, which exists in time, there is something deeper, more essential: your Life, your very Being in the timeless Now. As there are no problems in the Now, there is no illness either. By focusing on this instant and refraining from labeling it mentally, illness is reduced to one or several of these factors: Physical pain, weakness, discomfort, or disability. *That* is what you surrender to.

Allow the suffering to force you into the present moment, into a state of intense conscious presence. Use it for enlightenment. Surrender does not transform what *is*. It transforms *you*.

Illness is not the problem. *You* are the problem—as long as the egoic mind is in control. When you are ill or disabled, do not feel that you have failed in some way, do not feel guilty. Do not blame life for treating you unfairly, but do not blame yourself either. All that is resistance. Withdraw time from the illness...and see what happens.

Being cut off from your feelings is not surrender. In certain extreme situations, it may still be impossible for you to accept the Now. But you always get a second chance at surrender. Your first chance is to surrender each moment to the reality of that moment. Knowing that what *is* cannot be undone—you say yes to what *is* or accept what isn't. It may look as if the situation is creating the suffering, but ultimately this is not so--your resistance is.

Do not resist the pain. Allow it to be there. Surrender to the grief, despair, fear, loneliness, or whatever form the suffering takes. Witness it without labeling it. Embrace it. Let it become your resurrection and ascension.

by Petra Hoffmann



Today is rough. I feel exactly like the couple of days after my shot. I did my last shot on June 24, and my last pills on June 30. That makes it about 4 ½ weeks now since my Pegasys treatment. I am sitting here on a hot sunny summer day, wearing my usual summer clothing underneath, but with a thick hoody kangaroo jacket, and a blanket on my lap, and of course, the keyboard. In a few minutes, I am sure, I will suddenly find myself drenched in sweat...from one moment to the other, literally. My teeth have been clenched for nights and days now. Teeth that are not even there anymore hurt like hell. My gums and teeth have been bleeding, and I can taste the interferon in my mouth, and smell it coming out of my pores. There is a metal taste in my mouth and on my teeth, almost like the old metal fillings, coming into contact with tin foil.

I took a quick pause just now, to lose the jacket and the blanket, the anticipated heat spell beginning to come on. My scalp is burned from an hour in the sun the other day, because my hair is now so thin. My entire body hurts. I have chest pains, and stomach pains, my legs feel like 100 lb weights, I am sluggish, my brain turns off completely, and sporadically, and of course my mouth is as dry as a popcorn fart! My ears have been either plugged or buzzing, or there has been too much commotion and noise, amplified intensely in my skull. My face is suddenly full of bumps, and acne, and black heads all at once, and anywhere the sun has touched my skin for more than 5 minutes, my legs especially, there are bright red splotches, small mostly, some a bit larger. I have heard that the interferon and the ribavirin come out of the pores of your skin, and that in the sun, they boil on the surface, and that must be the spots. It doesn't hurt or itch though.

I have spoken to a lot of people going through this, or having recently completed

treatment, and this seems to be the general consensus for those who were quite ill on treatment. From what has been explained to me, and from my own experience thus far, it seems as though these drugs leave your system in “bursts” or “pockets,” so to speak.

It is no wonder I have not as yet felt any excitement, or have had any energy to celebrate my “negative viral load results.” Seems as though no one I have spoken to as yet, has been very enthusiastic about finishing treatment, because by then a lot of people feel so crappy, they forget what it was like to feel normal, and the reality is that this stuff can take up to 90 days to leave the system.

No worries though—tomorrow will be better. The days are slowly becoming easier, especially since I have learned to take it easy, and not go crazy with the energy bursts I do get now.

Please come and follow my journey on: <http://www.youtube.com/petrabilities> and visit <http://www.petrabilities.com/> for more information.

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petrabilities@aol.com
Direct: 778.855.6074
www.petrabilities.com

HepC and Me...The Incredible Journey!
<http://www.youtube.com/petrabilities>



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www.adobe.com/products/acrobat/readstep2.html

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ADVERSE EVENTS

Report problems with medical products, product use errors, quality problems and serious adverse events.

www.accessdata.fda.gov/scripts/medwatch/medwatch-online.htm

Reprinted from the *hepc.bull* February 1999, with some edits to bring it up to date.

I am often asked what we are supposed to do when we have a painful episode. One question asked in particular was about back spasms and anti-inflammatories. People are frustrated by the recent warnings about Ibuprofen. Tylenol is out, so what is left?

First and foremost, you have to discuss this with your physician, preferably your specialist. Each body reacts differently to drugs. Our specific stage of liver disease will also play a big role in the decision making. But a little information beforehand will enable you to prepare careful questions for your physician.

At a St Paul's conference, at the time this article was written, Dr Anderson replied to a question about whether Tylenol was okay for HCV patients and he replied that it was the lesser evil—but only 2 regular strength or 1 extra strength. We are talking about short duration episodes—not something that is taken on a regular basis.

Anti-inflammatories have been studied in HCV to see if they would be a useful adjunct to interferon therapy. The rationale was that there can be significant inflammation of the liver so then perhaps the anti-inflammatories would provide a benefit. Studies have looked at both Orudis (ketoprofen) and Indocid (indomethacin). The research found that it didn't make a difference in the response rate. But are these drugs harmful to the liver?

There are almost as many types of anti-inflammatories as there are people. The reason there are so many is that they have a different effect on different people. One anti-inflammatory may totally erase pain in one individual and have no effect on another. No one really knows how you will react until you take it.

One of the biggest concerns with anti-inflammatories is that they cause a reduction in the mucosal lining of the intestinal tract. This allows the acid in your stomach free access to the lining of the tract and the results can be devastating. Many people end up in the hospital or die as the result of a bleeding ulcer. You might think that you would feel pain before this developed to the point of an ulcer but the drug works in pain prevention and can block the very sensation that would alert you.

I think that the dangers for those with hepatitis are probably the worst when the progression of the scarring of the liver has reached a point where portal hypertension exists. Basically the blood can't flow smoothly through the portal vein and it backs up. This causes a back pressure and in a worst case scenario you could see esophageal bleeds. If you couple that with an anti-inflammatory, would it be possible to hasten the onset of a bleed?

If your physician has given you the go ahead on taking anti-inflammatories there are a few different kinds that can help guard against this problem.

First and foremost on the list is Pantoloc (Pantoprazole). It is a very powerful aid in preventing damage to the intestinal tract and in the

resolution of duodenal ulcers. This medication is covered by Pharmacare IF it is prescribed by a specialist. If your GP orders it, it may need pre-approval or it may not be covered at all. You'll need to check. 14 pills cost \$34 but one pill covers the whole day. It is NOT for long term usage.

Other medications to protect the gut include Cytotec (Misoprostol) which decreases acid production and increases mucosal protection, and Sulcralfate (Sulcrat) which reacts with stomach acid to form a thick paste which adheres to the gut lining. One of the problems with these medications is that Cytotec can cause diarrhea initially and Sulcralfate can cause constipation in some individuals. Used as adjuncts to anti-inflammatory usage and for the very short term, the pros may outweigh the cons.

Another medication is Arthrotec which combines Cytotec and Voltaren (diclofenac) in a single tablet. This is paid for by Medicare with pre-approval only. It is a costly drug if you have to pay for it out of your own pocket.

You can always go the other route and several brands of anti-inflammatories are available in suppository form. I find this is often my preferred route as you do not have to have a full stomach to take the medication whereas any of the oral medications require you to eat. Voltaren suppositories are available as is the generic and cheaper make Diclofenac. Indocid (Indomethacin) is also available in suppository form but this is a very strong and potentially damaging drug (even in this form).

Most of the anti-inflammatories are attached to sodium because it makes a very good delivery molecule. But the effect of this is often an upset in the fluid balance. This is particularly important, and one way to counteract that effect is by drinking lots of fluid. There is one anti-inflammatory that does not use sodium and that is Voltaren Rapide which uses potassium. It may not be covered by Pharmacare.

Finally—both the anti-inflammatories and Cytotec are excreted by the kidneys. Long term usage can show problems here. You can help to avoid that by drinking LOTS of water when you take these medications.

You may want to consider a type of anti-inflammatory called a COX 2 inhibitor. Celebrex (produced by Pfizer) is approved in Canada for treatment of both osteoarthritis and rheumatoid arthritis. COX 2 inhibitors are designed to be used as analgesics but do not have the gut damaging side-effects.

When the pain is from arthritis, it is often caused by muscles in spasm. It is possible that muscle relaxants may provide more relief than anti-inflammatories. The only one that I would talk with your physician about is Flexeril (cyclobenzaprine). This is not a benzodiazepine like Valium (diazepam) which is very addicting and also tends to tranquilize. However Flexeril is both metabolized and excreted primarily by the liver so you would want to discuss this very carefully.

Other drugs like Elavil (amitriptyline) have also been found to be effective in some cases of

Chronic Pain Syndrome and Fibromyalgia. It is usually sufficient to take an extremely low dose of this tricyclic antidepressant to obtain pain relief. This drug is extensively metabolized by the liver.

Non-drug therapies are the preference for people with liver disease. It may not be possible to get pain relief from an attack that comes up suddenly but it is something to work on long term and it can decrease the number of painful episodes. The Thorson Pain Clinic in North Vancouver and the Victoria Pain Clinic are two very excellent facilities. You need a referral to the North Van clinic, there is a long waiting list; but once you get in, there is no additional cost to you (above the user fee for massage therapy, etc). They attempt to break the pain cycle and to train you to respond differently to the pain such that it is not aggravated. Biofeedback, autogenics, creative visualization, and meditation are examples of the type of approaches that have proven effective in this way and are taught at the Pain Clinics. They also cover a multi-disciplinary approach using massage therapy, physiotherapy, hypnotherapy, acupuncture, and rolfing to name a few. I spent a year at the Thorson Pain Clinic and found the techniques that I learned extremely helpful in pain control.

UPDATE from the Editor:

Prescription pain medications listed at drugcoverage.ca are the following:

Cymbalta, Celebrex, Codeine Contin, Duragesic, Ran-Fentanyl, Toradol, Demerol, Oxycontin, Ralivia, Tridural, Zytram XL, Tramacet

The cost of some of these drugs may be covered, depending on your provincial drug plan and any private insurance you may have. They may also be paid for if you are signed up for palliative care.

Another tool we now have for pain relief is a nerve block, which interrupts the pain signals being sent to your brain. The doctor injects alcohol or phenol into the spine or into or around a nerve. Usually the blocks are used for chronic pain when other drugs can't control the pain or produce intolerable side effects. They can numb the pain for 6 to 12 months, and may be repeated. Side effects can include temporary paralysis of a muscle or loss of feeling in surrounding areas.

NEW: LONDON, ON GROUP

My name is Nicole Elliott, and I am new to the AIDS Committee of London. I am planning a Hepatitis Peer Support Group for London, Ontario. Our first meeting will be held on Tuesday, September 7th, 2010 at 186 King Street, London, Ontario, and subsequently, the first Tuesday each month, 7-9 p.m. It will be open to those who are infected as well as affected by Hep C.

Contact: Nicole NElliott@aidslondon.com, aidslondon.com (519) 434-1601 ext. 260, Toll Free: 1(866) 920-1601

CONFERENCES 2010

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 Sohal

Tel: +44 (0)1865 275743

Email: HepatitisOxford@gmail.com

www.libpubmedia.co.uk/Conferences/

Interdisciplinary Viral Hepatitis Education Workshop

BC Hepatitis Services

September 23 & 24, 2010

Holiday Inn Vancouver Center

711 West Broadway, Vancouver, BC

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/0/2010IVHEWRegistrationFillableForm.pdf>

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/

EPREX ASSISTANCE PROGRAM

Janssen-Ortho Inc, Canada has a program that may provide assistance in obtaining epoetin. It is the Eprex Assistance Program (EPO) 1-877-793-7739

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 co-payment 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% reimbursement. The income maximum 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 Assistance Program provides reimbursement coordination assistance for patients who have been prescribed Pegasys or Pegasys RBV. The program will assist in securing funding for patients to ensure that they can start, stay on, and complete their treatment successfully. PegAssist Reimbursement Specialists are available (Monday to Friday, 10 AM- 6 PM EST) by calling: 1-877-PEGASYS or 1-877-734-2797. Patients can also obtain a program enrollment form from their nurse/physician to gain access to the program.

The program provides financial aid to qualified patients, alleviating any financial barriers which may prevent patients from starting treatment, i.e., deductibles and/or co-payments. In partnership with CALEA Pharmacy, the program can conveniently deliver the medication directly to patients' homes or to the clinics.

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: 1-888-706-4717.

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.kleinlyons.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 Elliott

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-Quebec 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



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. 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, peer training. **Support group each Mon, 1:15 PM**, 713 Johnson St., 3rd floor, 250-384-2366 Hermione.jeffers@avi.org

Boundary HCV Support and Education 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

Covichan Valley HCV Support Contact Leah 250-748-3432 r-lattig@shaw.ca

HepCBC info@hepcbc.ca, www.hepcbc.ca

♦ **Victoria Peer Support:** 4th 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 9AM-10PM. 250-595-3891

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

Kamloops 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 4th 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 2nd Thurs. monthly, 7 PM (Location to be arranged.) Contact midislandhepc@hotmail.com

Nanaimo Hepatitis C Treatment Peer Support Group 1st & 3rd Thurs. monthly 4-5 PM, AVI Health Centre, #216-55 Victoria Rd, Nanaimo. Contact

Fran 250-740-6942. hepcxpeersupport@hotmail.com

Nelson Hepatitis C Support Group 1st Thurs. every 2nd 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/

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 2nd 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

Queen 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.yahoo.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

Surrey Positive Haven Hep C group 2nd & 4th Thurs monthly 1 PM. 10697 135A St. Contact Sam 604-589-8678.

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 Wed 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 St, 1st floor, Vancouver 604-688-1441 or 1-877-YOUTHCO www.youthco.org Support program manager: Sasha Bennett sshah@youthco.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 1st 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 Menonite Brethren Church, 245 Lexington Rd. Waterloo. Contact Bob 519-886-5706, Mavis 519-743-1922 or waterlooregionhepcsupport@gmail.com

London Hepatitis Peer Support Group 1st Tues monthly 7PM, 186 King Street, London, ON. For those infected as well as affected by Hep C. Contact: Nicole Nelliott@aidslondon.com, (519) 434-1601 ext. 260, Toll Free: 1.866.920.1601, aidslondon.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 icolangelo3@cogeco.ca

Sudbury Circle C Support Group

1st Tues. monthly. Contact Ernie 705-522-5156, 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 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact 905-940-1333, 1-800-361-5653 info@hepcyorkregion.org www.hepcyorkregion.org

QUEBEC:

Quebec City Region Contact Renée Daurio 418-836-2307 reneeaurio@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 McMurray, AB Contact 780-743-9200 wbbhas@telus.net www.wbbhas.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.mbhepc.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 btvc2@hivnetwork.ca

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

