



hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

WITHOUT PREJUDICE

18 June 2007

On the 25th of July, 2006, the federal government made the unexpected announcement that the pre-1986 and post-1990 Hep C victims were finally to be compensated. This was excellent news for all of those whose plight would be recognized at last, but little do we understand that this announcement may possibly cover only a few of us.

Being diagnosed with Hep C does not necessarily entitle us to compensation! Whether or not we are compensated hinges predominantly on lifestyle (background) and mode of infection. Do we actually know where we stand at this point and how we are represented by Klein Lyons throughout the class action suit?

I would like to suggest that, with such a workload, the lawyers should possibly have started off with three different claim categories:

- ♦ To qualify for the first category would require having sufficient evidence to prove the source of infection.
- ♦ The second category would encompass those whose medical records are non-existent, but whose lives reflect being up-standing law-abiding citizens, tax payers, etc., with no prior history of illegal drug use, where the person could only have become infected with Hep C by means of a blood transfusion administered in a medical facility.
- ♦ The third category would be comprised of highly provisional claims, with insufficient evidence, or possibly fraudulent.

The second category is the focal point in this commentary because, within the post-1990 Hep C group, the prospect of being compensated is greater, because some medical records may still exist, or witnesses may be available. With the majority of the pre-1986 Hep C group, however, the possibility of proving the source of infection is more difficult, thus the claims can become cumbersome, simply because their medical records no longer exist. The responsibility of ownership and safe-keeping of medical records rests with the hospitals, blood banks, and other medical entities for approximately

seven years from the last date of a medical entry for each individual, and then legally, the records can be purged. Thus, the burden of proof to establish the right to compensation should not necessarily rest with the claimants, especially for those, who through no fault of their own, have had their medical records destroyed.

What is evidence, and how is it perceived from a legal perspective? It is desirable to have medical evidence in relation to any medical issue, but this is not always possible. For example, it would be nice if the claimant's subjective symptoms could be considered sufficient proof for eligibility, but this is not the case in the majority of claims, and such a claim could produce some speculation.

Evidence, or an inference from evidence, needed to support a proposed conclusion is "speculative", but "speculative" has no uniform meaning. Evidence or an inference that is weak or speculative should be enough to uphold the conclusion that it supports if there is no alternative hypothesis supported by better evidence, or by a stronger inference from the evidence.

Perhaps it should be determined according to the ordinary standard of proof used in civil litigation, i.e., by the *balance of probabilities*, but there is uncertainty about what conclusion should be reached when the evidence (or lack of evidence) on an issue is

(Continued on page 4)

PUBLIC APOLOGY

In a segment of the Sunday night comedy show *Rove*, the comedian Peter Helliar asked what would be the best 40th birthday present for Pamela Anderson, who has everything. "Hepatitis, oh wait, she already got that last year," Helliar said on the program.



"Many of the 260,000 Australians affected by hepatitis C already experience stigma and discrimination on a regular basis, and ignorant 'comedy' like this only adds to the pain," Ms Tyrrell of Hepatitis Australia said.

"I realise hepatitis is a disease affecting many Australians," Helliar said. "The joke ... was not intended to offend those living with hepatitis and if any offence was caused, I sincerely apologise."

"We sincerely doubt *Rove* would have featured a similar joke about giving a celebrity a gift of HIV/AIDS," Ms Tyrrell said. "The fact is it's not acceptable."

Source: www.smh.com.au/news/tv--radio/hep-joke-not-hip-say-rove-critics/2007/07/03/1183351170989.html

TEAM HEPBCBC AT CLF'S "STROLL FOR THE LIVER"



Left to right: Alana (our ED), Joanne, Cheryl, Stephen and family.

"It was really nice to share the day with like thinking people."—Stephen.

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Victoria BC
V8W 1J6

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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

SUBMISSIONS: The deadline for any contributions to the *hepc.bull*® is the 15th of each month. Please contact the editors at info@hepcbc.ca, (250) 595-3892. The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING: The deadline for placing advertisements in the *hepc.bull* is the 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.

NEW!!! FAQ v7.1

Peppermint Patti's FAQ Version 7.1 is now available, and Version 7 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 125 pages of information for only \$8 each. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD

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

DISCLAIMER: The *hepc.bull*® cannot endorse any physician, product or treatment. Any 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.

Do you Have Hepatitis C?

You may be eligible to participate in a Research Study.

TO QUALIFY

We are looking for people who have hepatitis C and had no prior treatment with Interferon.

DETAILS:

- You will be required to take investigational medication in combination with Peginterferon Alpha-2b and Ribavirin (Pegetron) for treatment of hepatitis C.
- You will be required to give blood samples.
- There will be 1 overnight stay with several out-patient visits.
- If you qualify, compensation will be available.

For more information, please contact the Recruitment Coordinator at 604-639-2608 Or E-mail volunteers@cantest.com



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, tel. number, and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

Disclaimer: The hepc.bull and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.

Ad 28

Got the sustained responder blues? Nobody really believes you're clear? Are you socially stigmatized as well? Am looking for a slender female (30-40) sustained responder for a long-term relationship. I'm an "empty-nester", love more kids. Am open-minded, like to laugh, 185 lbs., 6 ft tall, handsome, ski, tennis, financially secure.

Got Hep C? Single? Visit:

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

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

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

THANKS!!

HepCBC thanks the following institutions and individuals for their generosity: The late John Crooks, A-Channel News, The Ocean, JackFM, Health Canada, the Provincial Employees Community Services Fund, Brad Kane, Chris Foster, Judith Fry, the FitzGerald family, Erik, Irene, S. Segura and the newsletter team: Tanya, Beverly A., Diana Ludgate, Alp, Ernie, and Bruce Lemer. Please patronize the following businesses which have helped us: Top Shelf Bookkeeping, Thrifty Foods, Margison Bros. Printers, The Four Mile Restaurant, Roche Canada (for special support with our newsletter and phone line), Pacific Coast Net, Royal Bank, Schering Canada, Victoria Bridge Centre, the Victoria Conservatory, and the Victoria Symphony. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

HYDRATION PLEASE

I love summertime and all the heat it brings. I wait all year long for the beginning of summer. However, as I sit in front of my computer, feeling like I am going to melt in the first summer heat wave, I am reminded of one thing: the liver loves water. All the summer heat is zapping that water right out of me.

If you have HCV it is important to stay on top of being properly hydrated. However, you must be even more vigilant in the summer. Ensure you have a water bottle with you that you can refill. I have been adding the single packets of juice to my water on occasion to help ensure I am always drinking something.

I used to hate drinking water and I did not know why. I would put a nice cold glass of water at the beginning of my work day and at the end it would still be sitting there full. One day I had a warm bottle of water with me from my cupboard and at the end of the day it was gone. The next day, the same thing. I realized that I do not drink cold water. Whatever trick works for you to ensure you are properly hydrated use it, especially in the summer heat.

WHAT NOW?

After failing two anti-HCV drugs, I felt like there was nothing else I could do to help myself. I felt like all I could do was live with the virus and continue on. There seemed to be no "maintenance" program at all that would help "slow" down the virus. It seems, however, that my feelings may have been incorrect. It has long been theorized that milk thistle (silymarin) may help HCV, however there have not been many studies performed to support this. A new study done by researchers from the University of Washington in Seattle found that milk thistle may have antiviral and anti-inflammatory properties. They concluded: "The data indicate that silymarin exerts anti-inflammatory and antiviral effects, and suggest that complementary and alternative medicine-based approaches may assist in the management of patients with chronic hepatitis C."

http://www.hivandhepatitis.com/hep_c/news/2007/061507_a.html

DO YOU NEED SOMEBODY TO TALK TO?

Do you need somebody to talk to but are uncomfortable going to a group meeting or session? Not comfortable in chat rooms? If you need a shoulder to cry on, a person to rant to, or somebody to understand, please feel free to e-mail me at tanyafri-

zle@hotmail.com. Not only do I live with HCV and have been through failing treatment, I have also lived through my father passing away from HCV. So even if you do not have HCV and are a concerned friend or family member who has questions, feel free to contact me. tanyafrizzle@hotmail.com

VANCITY IS HERE TO HELP HEP C VICTIMS

Vancity branches:

Vancity Centre Community Branch

(Vancouver) 183 Terminal Ave
Janette Hunter, Branch Manager
604-877-7010

Fairview Community Branch (Vancouver)

501 West 10th Avenue
Duncan McGuffie, Branch Manager
604-877-7080

Guildford Community Branch (Surrey)

108-15175 101st Avenue
Rup Sumal, Branch Manager
604-877-7300

Victoria Community Branch (Victoria)

3075 Douglas Street
Charleen Dunn, Branch Manager
604-877-7420

Visit vancity.com for more information.



The Greater Vancouver Support

Group holds drop in sessions at Blenz, 3297 Cambie Street, Vancouver (17th Ave and Cambie St.), on the 1st and 4th Monday monthly from 3 PM to 7 PM. Members of the group will be in Blenz many days of the week, and if you wish to call ahead to see if any members are having coffee, please call Gordon 778-898-7211.

The Greater Vancouver Support Group is advising everyone that the 2nd Thursday meeting has moved from 1141 Main Street to 1199 Main Street (around the corner of the building south of 1141 Main Street).

During the spring of this year an exciting new hepatitis C treatment started clinical trials in several study centers. The drug, developed by Vertex Pharmaceuticals, is called Telaprevir. It is also known as VX-950. Telaprevir is a HCV protease inhibitor. The trial, called Prove 3, will evaluate treatment in patients who failed previous treatment with interferon-based therapies such as pegylated interferon and ribavirin. Over 440 patients have been enrolled in this study. What is exciting about this trial is that several Canadian sites have been included.

Previous phase 1 and phase 2 studies called Prove 1 and Prove 2 by Vertex, took place in the United States and Europe. Data from these studies showed the powerful effects of Telaprevir alone or in combination with pegylated interferon. In one small study, 14 days of monotherapy with Telaprevir gave a mean 4 log drop in viral load, and in combination with Pegasys (a pegylated interferon produced by Roche), gave a mean 5.5 log drop in viral load. In a more recent larger study, 88% of patients receiving Telaprevir achieved a viral load less than 30 IU/mL by week 4. 79% went below 10 IU/mL.

It is a bit confusing, but Prove 3 is actually a phase IIb study. One arm of the current Prove 3 trial will evaluate 12 weeks of triple combination therapy with Pegasys, ribavirin and Telaprevir followed by 12 weeks of Pegasys and ribavirin alone. Another arm will evaluate 24 weeks of triple therapy followed by 24 weeks Pegasys and ribavirin alone. Complete data for the study will not be available until some time in 2008, but interim results may be made public before then.

In a statement dated 12 June 2007, Vertex reiterated plans to initiate international phase 3 clinical trials in the last quarter of 2007. I would not be surprised if Canadian sites were included in these also.

Sources: www.vpharm.com/newsreleases.html
www.hivandhepatitis.com/hep_c/hepc_news_alter.html

ERRATA

My group meets in Whitby, not Durham, Ontario. There actually is a town called Durham. Durham Region (The Regional Municipality of Durham) consists of the Towns of Ajax and Whitby, the Cities of Oshawa and Pickering, the Townships of Brock, Scugog and Uxbridge and the Municipality of Clarington.) The meeting location is in downtown Whitby, ON, 50 km. East of Toronto, in close proximity to residents of Durham, GTA and surrounding areas. The *hepc.bull* missed several of our proclamations. Regional Municipality of Durham proclaims that May 1, 2007 is Hepatitis C Awareness Day and May 2007 is Hepatitis C Awareness Month. Individual Proclamations were acclaimed in the Town of Ajax, the Cities of Oshawa and Pickering, the Townships of Brock, Scugog and the Municipality of Clarington.
—Smilin' Sandi :, Oshawa ON.-Durham Region

WHAT'S ON YOUR SHOPPING LIST?

In the previous issue I discussed some of the financial information that needs to be collected, so that both you and the financial planner are able to understand "where you are coming from". Now that we have this information, it can be analyzed so that we can understand the current financial situation and know in which direction to go.

The analysis phase will address many questions, but three major questions that will need to be addressed are as follows:

- The client's needs versus his/her wants
- The investor's profile
- His/her investment portfolio expectations

The first of these three questions is to understand the person's financial needs versus wants. Think of this as the shopping list that you use when you're at the grocery store. There are some items that you must have to maintain a healthy diet: dairy, meat, fruit and vegetables. There are other items that are likely not on the list and are purchased less frequently, but may not be as healthful: cookies, ice cream or candy. The healthful food items are groceries that everyone "needs", but the other items, depending upon your own personal preference are items that you may "want", but could live without, if need be.

The same can be said about an individual and his/her financial goals and objectives; everyone has different financial "needs" and "wants". Some traditional financial needs are rent/mortgage payments, medical costs, or monthly income for personal expenses, while some possible financial wants may include a new car, a fancy vacation or a bigger television. Each individual will have personal wants and needs; it is this relationship of needs and wants that must be understood to be able to provide proper analysis.

With the collection of the financial information and review of the current situation, it is then possible to determine if the needs and wants can be realized. In the event of there being a significant shortfall between the current financial situation and the future objectives, it is these issues that will have to be corrected to ensure that the financial needs and wants are achieved.

Next month I will touch on the other two questions which are quite closely related: the investor's profile and portfolio expectations.

If you have questions and wish to discuss your current situation or would like the name

of a local BMO Financial Planner, please contact me directly by email at ross.charlesworth@bmo.com or by phone at 604-665-7187.

Ross Charlesworth BA CFP
Financial Planner
Investment and Retirement Planning
BMO Financial Group



(WITHOUT PREJUDICE: Continued from page 1) evenly balanced.

There appears to be vacillation between the presumption of the negative that is common in the legal and medical professions, and the kinder view that the claimant should receive the benefit of the doubt. In some litigation, the provision, "the benefit of the doubt", has sometimes been read as it applies only where there is some evidence either way. Logically, it would seem to apply also where there is a total absence of evidence either way; but this may never arise in practice because there is always at least some circumstantial evidence. Thus the process of reaching conclusions from the evidence involves a search for the best available hypothesis.

A negative opinion that is based only on the lack of any proof of the affirmative is not evidence to the contrary and if that opinion is the only evidence, the conclusion must follow the presumption. Our federal government has included the provision "the benefit of the doubt" in their Final Settlement Agreement, which in turn becomes more supportive with credible data in your file.

I have concerns how we are represented, since our claims are based on the information submitted to Klein Lyons. This informa-

tion may include medical tests and a liver biopsy from years ago. One of the criteria set out in the Final Settlement Agreement is how far this disease has progressed. Our condition(s) may have worsened since then, so would it not be appropriate to request that your doctor test you again, in order for an assessment to be based on current medical information?

Do the lawyers really know who we are, what we believe in, and what we stand for? Throughout these litigations various questions are asked about us, and we should provide a suitable answer. Is a photo, along with the information submitted, adequate? Can one judge a book simply by its cover and/or by reading the preface? These people have never seen us in person, nor are we present during these litigations.

You may submit the following to Lisa Porteous and possibly add credibility to your claim:

Write down your personal testimony about how your life and family has changed over the years, your symptoms, (which may vary from one person to another), and loss of employment or careers, as well. Your Canada Pension Plan Statement of Contributions can be useful.

- ♦ Ask for a written character reference from affluent people, who have known you for many years. These can be your family physician(s), your pastor, a banker, etc.
- ♦ Personal recognition(s) or certificate(s) you may have received through out your life, perhaps from an employer or a social group, or copies of scholastic records, or letters from your church, military service, etc.
- ♦ If you have no criminal background, you can request a "Consent For Disclosure Of Criminal Record Information" for \$25, at your local RCMP Detachment, which in turn they will send to the Klein Lyons. You provide them with the correct address and ask them to send the information to the attention of Lisa Porteous. Request a copy for your personal records.
- ♦ If you have a clean driving record, request a Driver's Extract Statement of your driver's license at your local Motor Vehicle Branch, usually at no cost to you.

All the above and anything else you think might be beneficial should be part of your claim file, enabling those who are representing you to cast a more accurate persona of you.

Whatever you submit, always keep a copy with the appropriate date for your personal record.

I hope this information has shed some light on the processing of claims and has been of some use to you. I wish you all the best.

Regards
Ric van Ziegler

HIV/HCV RESEARCH NEEDS YOU

By Jennifer Chung

Liver disease is becoming one of the major complications related to HIV infection. In response, researchers at the Canadian HIV Trials Network (CTN) are leading innovative studies that will improve the lives of people co-infected with HIV and hepatitis C (HCV). But clinical trials cannot run without participants – and with more than 30 per cent of HIV positive people living with concurrent liver disease, participation in HIV/HCV studies is invaluable to advancing knowledge in co-infection research.



“Co-infected people aren’t dying of HIV, they’re now dying of liver failure,” says Ian DeAbreu, who has been living with HIV and HCV for the past 20 years. DeAbreu is a member of the CTN’s Community Advisory Committee (CAC). “Research in HIV/HCV is important because we still don’t completely understand the effects of highly active antiretroviral therapy (HAART) on the progression of liver disease. And with the percentage of people co-infected with HIV and HCV, there is definitely a need for research in this area.”

Created in 1993, CAC provides formal community input to the CTN regarding clinical trial research. Members review clinical trial proposals and informed consents and make recommendations to the Network’s oversight body – the Steering Committee. To date, CAC has reviewed more than 220 trials, including two enrolling studies involving HIV/HCV co-infection. One study is currently testing the use of the antidepressant citalopram in the prevention of depression before and during HCV treatment (CTN 194) and another is a cohort examining the effect of HAART on liver disease progression in HIV/HCV co-infection (CTN 222).

As a past clinical trial participant, DeAbreu says altruism is one the main reasons he feels it is worthwhile for people to volunteer for clinical trials. “It’s like donating blood - you do it for altruistic reasons so you shouldn’t go into a trial expecting a direct benefit. It may work out that way for you, but it may not,” he says. “But the knowledge in HIV care has to come from somewhere, and without clinical trials, we wouldn’t have it.”

Understanding the risks and benefits of a trial is one of the most important things for potential clinical trial participants to keep in mind, DeAbreu explains.

“The outcome for the participant can’t be predicted so there’s always uncertainty and risk involved. But when you enter into a clinical trial, what you are doing is helping contribute to the body of knowledge that will most likely help people in the future.”

The CTN also publishes a booklet called *Clinical Trials: what you need to know*, a plain-language introduction to HIV clinical trials, including their aims procedures, risks and benefits. For more information on this booklet and CTN trials, please visit www.hivnet.ubc.ca.



HepCBC’s Display Board is on tour, and has already been spotted in several spots in Victoria. It even has “cousins” as far away as Princeton. If you would like the Display Board exhibited at your workplace, library, school, clinic or other location, or if you would like help making your own, please contact HepCBC at (250) 595-3892 or info@hepcbc.ca.

HepCBC ANNUAL GENERAL MEETING

**Wednesday, Sep 12, 2007
6:30 PM**

**Woodward Room
Begbie Bldg
Royal Jubilee Hospital
Victoria, BC**

INFO: 250-595-3892 info@hepcbc.ca

AGENDA:

1. Approve minutes of AGM 2006
2. Set number of directors,
3. Election of those directors

AGM to be followed by a speaker (TBA) and refreshments.

PegCARE

PegCARE is a reimbursement program to help people who don't have third party coverage pay for their Pharmacare deductible for hepatitis C treatment. It is pro-rated, so the less someone's net family income is, the more help they get. Basically, if someone's net family income is less than \$30,000, they will get 100% reimbursement. The more they make, the less of a percent is reimbursed, up to a max of \$100,000 income.

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

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

PegCARE: 1-800-603-2754

PEGASSIST

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

COMPETITION!

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

NM283 TESTS SUSPENDED

Tests on perhaps one of the most promising new treatments, the protease inhibitor NM283 (Valopicitabine), have been suspended because of side effects such as nausea and vomiting.

Source: http://today.reuters.com/news/articleinvesting.aspx?type=hotStocksNews&storyID=2007-07-13T124527Z_01_N13298809_RTRUKOC_0_U_S-IDENIX-COMMENT.xml

R7128

Pharmasset is working with Roche to develop R7128, a polymerase inhibitor, which is being tested in a Phase 1 clinical trial in 24 healthy men. So far it has been "generally well tolerated." Next it will be tested in genotype 1 non-responders.

Sources: www.pharmasset.com and www.natap.com

OCCULT HCV?

Your tests say you have no HCV, and no antibodies, either, but you have unexplainable, abnormal liver function tests. You don't have Hep C, right? Actually, yes, you might, according to new research, which says that you could have too small of an amount of the virus to be detected... yet. A new technique called ultracentrifugation, which concentrates blood serum, is uncovering yet smaller amounts of HCV.

Source: www.ncbi.nlm.nih.gov/sites/entrez?Db=pubmed&Cmd=ShowDetailView&TermToSearch=17475654&ordinalpos=3&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

MILK THISTLE STUDY

Finally a serious study in test tubes, has shown that milk thistle, widely used among Hep C sufferers, is an anti-inflammatory and possibly has antiviral effects. The main problem is that milk thistle has not been standardized. This study used standardized Silymarin extract (MK-001). Better antiviral results were obtained by combining MK-001 with IFN-N1, than by using either alone. Silymarin bought in stores showed some antiviral effects, but not as much as MK-001. The most effective "ingredients" in milk thistle seem to be silybin A, silybin B, isosilybin A, and isosilybin B.22.

Source: www.natap.org Original article: *Gastroenterology*, May 2007, Volume 132, Issue 5, Pages 1925-1936

It was so nice meeting everyone for our "Demo on the Hill" on Thursday, June 7, 2007. It gave us a chance to rub shoulders with some present MP's in order to promote our Pre/86-Post/90 Hep C cause. Many thanks to Bobbi, Bill, Dan, Christine, Keith, and to Vikki for her chosen words backing up Penny Priddy—NDP Health Critic—at her press conference, and for our own Ernie Zivny—organizer and Hep C Pied Piper of the Hill, and his rallying Hep C flag. We got the attention of some, especially when the RCMP threatened to remove us, since we did not have a permit to be there. A discussion with a couple of Liberal MP's and our Penny Priddy seemed to remove the expulsion threat. Quite obviously, Parliament is annoyed at our continual promotion of our Hep C cause!

Ron noticed ex-MP Don Boudria approaching the front door and spoke to him. Boudria inquired what we were doing and our demonstration was explained. He immediately recounted the story of a tainted blood pre/86 Hep C constituent of his and the Government's inability to assist that person. He said when the brass ring seemed attainable, it was moved. What else has changed?!!

Regards,
Tina & Ron



On June 7, 2007, we had a news conference in Ottawa at the House of Commons. It was scheduled for 11 AM, with Penny Priddy, Health Critic for the NDP Federal party. I think Penny did get the message that Canada does need a national awareness program all across Canada for hepatitis C. However she seemed to be more concerned about compensation and not about other issues. She seemed to have a one-track agenda. She has been working hard and long on getting the victims an interim payment. I do feel that she will work on a national strategy for an awareness program in the future.

Two minutes after we arrived on the Hill we were met by an RCMP officer who

asked us to leave. I asked why and he said that they had a complaint. When I told him that we just got here and asked who complained, he said he didn't know, but we had to leave. Then he asked who was in charge and if we had a protest permit. I told him that we did not have a permit to protest because we were not there to protest, but we had a news conference scheduled at 11 AM in the House. He asked us to wait while he radioed in. In the meantime two Liberal MP's talked to the officer and I told them that we didn't need their help because they didn't help us in the past and I had a bone to pick with them. I called Glenn Ewald from Penny's office. By the time he got there another officer drove up. He asked me who was in charge and I told him that we are all in charge of each other. As I was carrying the hepatitis C flag he asked me my name. He then said that we could stay.

Our conference went well; Penny first spoke about getting an interim payment and a national awareness program. Then our own lovely Vikki, who traveled all the way from Calgary, spoke about a national awareness program and the other issues that have been on the government's back burner for years, and that now that the compensation issue is close, it's time to address the other issues.

I wish to thank all the people that attended this rally-conference. Thank You, Vikki, Tina and Ron, Dan and Christine, Bobbie and Bill, Keith, and all those that wanted to be there and couldn't because of being too sick to travel. I know you were there in your thoughts. I wish to give a special thanks to our most generous contributor who donated and paid all of our expenses, hotel, food, and gas. This party wishes to remain anonymous.

I feel that we have come a long way but remember we aren't finished yet. We can only achieve things when we are united. We all need to keep up the fight for Justice and our needs.

Thank you for allowing me to fight along side of you and with you. Many have fought and died for our cause. Let us not forget them. Let us not be the forgotten ones ever again. Speak out and be heard. If no one can hear you, then shout it out until you are not only heard, but listened to.

Hugs, Love You All.

Ernie Zivny

If you are a person living with hepatitis C you may think that the only issue was compensation. Well, it's over. Compensation is a done deal, with the exception of getting our applications, being accepted and receiving our compensation. I fear that there will be many who did receive a transfusion of the Canadian Red Cross's finest tainted blood who will not be compensated. Crawford has been chosen as the administrator for the pre-'86/post-'90s. They are the same administrator as for the '86-'90s. I understand that there were thousands of '86-'90 victims who applied for compensation, and I understand that a large number were denied.

We must focus on the other issues now. This is why we had a rally in Ottawa on June 7, 2007. This rally had very little to do with compensation, other than to ask for an interim payment, as it could take several months to set up the administration process. The '86-'90s waited over twenty months before it was set up and running, and some time to get applications approved and cheques out. The government does not want to hear about the other issues.

One thing I must say: I was very disappointed at the turn out. I had 8 people who said they would show up and needed assistance, accommodations, travel money and meals. Those 8 never showed up. You know who you are. The rooms were non refundable. I did have one person, Vikki, as sick as she is, drive by herself all the way from Calgary. I had another lady, Bobby, who was in hospital very sick on the 6th, and she still drove all night from Toronto to Ottawa and arrived at 7:30 AM. All who attended were very sick, including myself, and all of us were caring about our and your future. All have said that we will not stop fighting for our and your rights. This was an opportunity of a lifetime. It would have shown the government that there are other issues. It was an opportunity to show them that we're united and not going away. It was also an opportunity to meet each other and know that we are not alone.

Our next rally is being planned to take place in Toronto to ask for the 3/11s that we did not get in this settlement, and for health care, as we need guarantees that people living with hepatitis C and other blood diseases will have continued care and treatments, as the Ontario Government is continuing to cut back programs and health care services.

Ottawa has the summer to think about our other issues and to respond, or we will rally just before an election is called and we will see who will campaign on our behalf to implement our issues if elected.

The Issues

1. There is no national education and awareness program aimed at getting people tested

and helping them live with and manage the disease.

2. There is no comprehensive strategy for Hep C to deal with legal, cultural, medical, treatment, prevention, harm reduction, age, and other issues.

3. There is no ongoing long-term funding in place for Hep C issues.

4. There is nothing for additional resources for patients to help them deal with their disease, such as alternative and/or herbal treatment, supplements, bottled water, etc.

5. There is nothing available to help patients deal with other costly complications like dental, vision, and home care, or help with drug costs.

6. HCV is not considered a disability, so neither private nor government pension plans allow a claim on those grounds.

7. HCV is not considered a cause of death, so survivors are left out in the cold and statistics are erroneous.

8. There's no big rush to develop a cure as long as there is such a huge and lucrative market for expensive interfering therapies.

9. There's no initiative to actually stop this virus from spreading by doing away with the instruments that spread it.

10. There is no plan by the Centre for Disease Control to actually get a handle on this disease and attack it vigorously.

11. Health care and treatment for Hep C patients are not consistent, accessible, affordable, universal or portable.

12. There is no cure for Hep C so please stop allowing hepatologists to insist that there is. The best any patient can hope for is remission.

13. Let's get rid of the myths surrounding hepatitis C and start working on finding solutions for the realities of Hep C.

14. Stop allowing hepatologists to be the last word and authority on Hep C. It is a systemic disease with unpleasant and often fatal complications that require consultation and treatment with additional specialists who are rarely consulted, resulting in inaccurate patient records and difficulty in treating patients.

15. Allow patients to help you help us. You might be surprised to find that we can be reasonable. We are only trying to find solutions that will work for everyone involved.

These are some of the issues plaguing us and of course they are all much more involved than this simplified list you are seeing. All of these issues have been on the back burner waiting for compensation to get out of the way.

This is an opportunity for us to put these issues out there for you and give you some time to look over them.

Thank you.

Ernie

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/hepc/intro.html

David Harvey
Lauzon Belanger S.E.N.C. (Quebec)
Toronto, ON
Phone 416-362-1989; Fax 416-362-6204
www.lauzonbelanger.qc.ca

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

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

Other:

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

LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC
1-888-332-5663 (local 3467) or 604-707-3467
Lookback Programs, Canada: 1-800-668-2866
Look back Programs, BC: 1-888-770-4800
Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056
Hema-Quebec Lookback/Traceback & Info Line:
1-888-666-4362
Manitoba Traceback: 1-866-357-0196

RCMP Blood Probe Task Force TIPS Hotline
1-888-530-1111 or 1-905-953-7388
Mon-Fri 7 AM-10 PM EST
345 Harry Walker Parkway, South Newmarket, ON L3Y 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
Ontario Compensation: 1-877-222-4977
Quebec Compensation: 1-888-840-5764
ca/en/ms/hepatitisc/forms.html

ADMINISTRATOR

1986-1990

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

Pre-86/Post-90

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

UPDATES

<http://hepccc.blogspot.com/>
www.hepccc.ca/
Agreement: www.reko.ca/html/hepc_settleagreement.pdf



COMING UP IN BC/YUKON:

AIDS Vancouver Island HCV support
 • **Campbell River:** Drop in, harm reduction, support, education. Contact: 250-830-0787, leanne.cunningham@avi.org
 • **Comox Valley** 355 6th St. Courtenay; Contact Phyllis 250-338-7400 phyllis.wood@avi.org Drop in, harm reduction, support, education.
 • **Nanaimo** Each Mon. 2-4 PM #201-55 Victoria Rd. Contact Anita 250-753-2437 anita.rosewall@avi.org
 • **Port Hardy** (Sayward, Port McNeil, Alert Bay, Sointula and Woss) 7070 Shorcliffe Ave, Contact Shane, 250-926-3293 shane.thomas@avi.org. Education, mobile harm reduction, and support.
 • **Victoria** 1601 Blanshard St., 250-384-2366 info@avi.org Harm Reduction.

Boundary HCV Support and Education. Support, education, presentations. Contact Ken 250-442-1280 ksthomson@direct.ca

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 Hepatitis C Support Contact Leah 250-748-3432 r-lattig@shaw.ca

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

HepCBC info@hepcbc.ca, www.hepcbc.ca
 • **Victoria:** Drop-in/Office/Library, 306-620 View St. Phone support, interviews, info sessions. Contact 250-595-3892
 • **Surrey:** Support/info 604-597-3881

Kamloops AIDS Society of Kamloops (ASK) Living Well HIV/HEPC Peer Support Group, each Thurs. 11-2 PM, 433 Tranquille Rd. Office 250-376-7558 Support/ Referral. ask@telus.net 1-800-661-7541 www.aidskamloops.bc.ca

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

Kootenay Boundary: Support & info Contact Brian Reinhard reiny57@yahoo.com

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

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

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

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

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

North Island Contact Sharon Spencer at 949-6735 or Shane Thomas at 949-0432 shane.thomas@avi.org

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

Powell River Hep C Support Powell River Community Health, 3rd Floor-5000 Joyce Ave. Contact: karen.peel@vch.ca 604-485-3310

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

Prince Rupert HCV Support Group 7-8:30 PM 3rd Mon. monthly, board room, Public Health Unit, 300-3rd. Ave. W. Contact: hepcprincerupert@citytel.net

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

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

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

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

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

VANDU The Vancouver Area Network of Drug Users: Satellite Hep C group at Health Contact Centre (HCC), 166 E. Hastings, each Thurs. 2 PM. Bus fare, snacks. 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 2nd Thurs. monthly 7-9 PM, 1199 Main St. near Sky Train -Terminal & Main, and 3rd Wed. monthly, 7-9 PM VGH, Lauener Room, LP2809, near Sassafras Cafe, Jim Pattison Pavilion, South. Contact Gordon 778-898-7211, ohmygodyes@canada.com

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

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Contact 250-542-3092, hepsc@hepc.vernon.bc.ca

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



OTHER PROVINCES:

ONTARIO:

Barrie Hepatitis Support Contact: Jeanie info/appointment hepcsupportbarrie@rogers.com

"Choices" Peer Support Group for those co-infected with HCV/HIV. Survivor trauma, addictions. Every 2nd Wed 5-7 PM, AIDS Committee of Ottawa, 251 Bank St, 7th Floor. Contact: Colleen Price 613-563-0851 coinfection@sympatico.ca www.aco-cso.ca/supportgroups.htm

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Contact: smking@rogers.com <http://creativeintensity.com/smking/> <http://health.groups.yahoo.com/group/CANHepC/>

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

Hepatitis C Network of Windsor & Essex County Last Thurs. monthly, 7 PM, 1078 Goyeau Street (across from Hotel Deiu Hospital). Contact 519-967-0490, amonkman@hepcnetwork.net, www.hepcnetwork.net

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

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Zehrs Community Room, Laurentian Power Centre, 750 Ottawa St. S., Kitchener. Contact: Bob 519-886-5706 bc.cats-sens@rogers.com or Mavis 519-743-1922 elroy222@rogers.com

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

Owen Sound Contact Debby Minielly, 1-800-263-3456, 376-9420, Ext. 257, www.publichealthgreybruce.on.ca/dminielly@publichealthgreybruce.on.ca

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

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

Sudbury Circle C Support Group No meetings in the summer. Contact Ernie hepc.support@persona.ca 705-522-5156.

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

Thunder Bay Hep C support. Contact Kevin Larson 807-475-8210,

Janet Adams 807-345-1516 (or for 807 area only 1-800-488-5840) hepc thunderbay@yahoo.ca

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, 1-800-461-2135. info@hepcyorkregion.org www.hepcyorkregion.org

QUEBEC:

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

ATLANTIC PROVINCES:

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

Cape Breton Island, NS The Hepatitis Outreach Society Support Group 2nd Tues. monthly 150 Bentinck Street, Sydney, NS. 7-9 PM. Call 1-800-521-0572, 902-733-2486 info@hepatitisoutreachsociety.com.

PRAIRIE PROVINCES:

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

HeCSC Edmonton Contact Jackie Neufeld 780-939-3379.

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

Manitoba Hepatitis C Support Community Inc. Each Tues. 7 PM, United Church, Crossways-in-Common, 222 Furby St., side door, Main Floor. Look for signs) Last Tues. monthly: Speaker Meeting. Everyone is 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 bet-tyc2@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.

Victoria & Area S.O.L.I.D. Society of Living Intravenous Drug Users, Wed. (except welfare week) 7-9 PM, 1947 Cook St, Support, info, & referrals Contact: momma@vcn.bc.ca