

# Canada's Hepatitis C News Bulletin

www.hepcbc.ca

### NATALIE RECOGNIZED



From the time she was a child, Natalie Rock wanted to become a nurse. Her mother, well aware of this fact, greeted Natalie one day when she was arriving home from school with the news, "You have been accepted into nursing school!" Natalie, gratefully surprised that her mother had applied for her, was even more surprised and relieved to find out that her mother had also applied for a student loan for her, since Natalie knew her family wouldn't be able to afford the tuition.

While Natalie was attending her 3rd year at UBC, she gave a talk on hepatitis A and B to her clinical group. At the time, she had no idea that hepatitis would become her specialty. During her 4<sup>th</sup> year, she took a research course, and commented to her parents that she wanted to run her own research clinic. Their dreams of seeing her in a white uniform were fading before their eyes, but she could only see the opportunities that the future held. The flame of her enthusiasm was fanned by her experience in Dr. Anderson's office.

As one of the members of the team at Dr. Anderson's LAIR Centre (Liver and Intestinal Research) in Vancouver, Natalie sees her patients from their first visit, and develops a plan of care for each one, including giving them information about hepatitis, ordering tests and procedures, reviewing the results with the patient, counseling the patient and (Continued on page 6)

### VIRAL LOAD 101

Making Sense of Logs or How to Get the Most out of Your High School Calculator

People unfortunate enough to be infected by a nasty virus like hepatitis C or HIV will go through plenty of medical tests. One of these tests may very well evaluate what is known as a viral load. The result of the test gives an indication of how many viral particles are found in a given unit of serum or blood. While many different types of measurements are given in "normal numbers" such as tens, hundreds or thousands, people who measure how much virus is present usually report their findings using logarithms.

The logarithm is the mathematical operation that is the inverse of exponentiation. For example, take the expression  $2^3 = 8$ . By mathematically rearranging the expression a bit, we arrive at 3 is the logarithm of 8 when the base is 2 or  $\log_2 8 = 3$ . Still with me? Don't worry about it!

Base 10 is usually used and this is so for viral loads. In base 10 we can say that  $2 = \log_{10} 100$ .

We generally do not write the base after the log (in the above case this is the 10). If it is not specified we assume it is base 10.

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### POP'S FIX IT SHOP CLOSED



### **Bavid** Fitzgerald

HepCBC has just suffered a great loss. Dave FitzGerald, long-time member of the organization and member of our board since 2002, died suddenly in his home September 2, 2006.

David Shaw FitzGerald was born in Moosejaw on May 5, 1936. He was the husband of Lorie and his children Deborah, Shawna, Quinn, Marjorie, and Jon. He leaves behind 6 grandchildren, siblings and inlaws.

David, AKA Fitz, Chief, Papa, Dad, or just Dave, joined the Royal Canadian Navy at age 16 and served for 28 years, achieving the rank of Chief Petty Officer First Class, and receiving the Canadian Decoration Medal. He was a member of the Britannia Legion. He ran the Woodwork Shop at the Wilkinson Road prison where he was a corrections officer.

Dave had a booming voice, warm smile and belly laughs that

(Continued on page 4)

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## SUBSCRIPTION/ORDER FORM

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

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

Name:		
Address:		
City:	Prov	PC
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Email:		
□Membership + S		
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□"I want to volun	teer. Please con	itact me."

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

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

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

ADVERTISING: The deadline for placing advertisements in the hepc.bull is the 12<sup>th</sup> of each month. Rates are as follows:

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

#### **HOW TO REACH US:**

EDITOR:
PHONE: 7
FAX:
EMAIL:
WEBSITE:
HepCan LIST: http://healt

Joan King TEL: (250) 595-3892 (250) 483-3368 iking@hepcbc.ca www.hepcbc.ca

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

HepCBC 306-620 View Street Victoria BC V8W 1J6

### LETTERS TO THE EDITOR:

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

### NEW!!! FAQ v7

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

### HepCBC Resource CD

The CD contains back issues of the *hepc.bull* from 1997-2005; the FAQ V6; 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 would like to thank the following institutions and individuals for their generosity: The late John Crooks, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Roche Canada, the Provincial Employees Community Services Fund, Brad Kane, Chris Foster, Judith Fry, S. Segura, The Four Mile Restaurant, Victoria Bridge Centre, Erik, Irene, Chateau Victoria, Victoria Symphony, the Conservatory, the Shark Club, Recollections, Thrifty Foods, Patisserie Daniel, Preview Hair Studio, and the newsletter team: Tanya, Beverly A., Diana Ludgate, Alp and Ernie. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

#### BE PART OF THE TEAM!

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

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

Give us your name, tel. number, and address.

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

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

Want a mate? Your Cupid ad could go here!

### Got Hep C? Single? Visit:

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

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

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

### 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 Peginter-feron Alpha-2b and Ribavirin (Pegetron) for treatment of hepatitis  $\mathcal{C}$ .

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 604-875-5122, extension #7 or E-mail

## PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

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### TANYA'S TIDBITS by Tanya Frizzle

#### **VACCINE?**

Working together, Inovio Biomedical Corporation (AMEX:INO) and Tripep AB of Sweden, are hoping to start clinical trials of a vaccine for HCV. So far the vaccine has shown good results in mice and rabbit trials. The next step is to start clinical trials.

http://www.hepatitis-central.com/mt/ archives/2006/08/delivery system.html? eml=hepcen10

#### ANOTHER STEP CLOSER?

A gene that stops HCV replication has been discovered. The gene is called protein kinase R (PKR) and it blocked the replication of HCV in mice. It is also known that interferon stimulates PKR in order to try and stop HCV from spreading throughout the body. The breakthrough will help researchers understand the virus a little bit more and hopefully aid in the fight to find a cure.

http://www.hepatitis-central.com/mt/ archives/2006/09/discovery of ge.html? eml=hepcen10

#### STIGMA OF HCV

The stigma associated with HCV never really hit home until it was in my face from one of my oldest friends. There is a person in my life whom I have known for at least 25 vears, and the first time I met her baby she never even showed her to me. In fact, she backed away from me while my sister was saying, "There she is with her new baby."

She never showed me her face or asked me if I wanted to hold her. You know, at the time it never even clicked in my brain as to why. It was not until later when my sister said to me, all disgusted, "I can't believe she treated you that way just because you have Hep C. She would not touch you last year for her sister's wedding pictures and now she backed away from you when you were being introduced to her baby. She's afraid of you."

Shivers went down my spine. I'm sorry, what did you just say? Is there a person in my life whom I have known practically all my life too afraid to ask me about my virus and how it works, or who won't, at the very least, turn on her computer? In today's day and age of computers and information at a person's finger tips, I never even thought that she would not have looked up the virus and investigated transmission if she was afraid. I know that most of my friends have looked it up on the net, and I am happy that they are intelligent enough to do so.

I want people to feel completely comfortable around me, and to do so they need information. It does not matter how many times I tell people, "Don't worry about it, you can't get it from me," it still feels better to read it to contact me. from a professional.

However, it was shown to me that not everybody will think to read up on the topic. not going to infect them or their children? Sometimes I wish I was a celebrity just so that the world would listen when I talk. Oh veah, and where is the voice of the celebrities of HCV? Every once in a while I hear a bit or two, but not enough. Not enough is said that we are not here to harm others and that we can live healthy normal lifestyles. I think that at the very least what we can do is talk about it with others and be completely open about the virus and how it is transmitted. As best we can we need to educate those who will listen and care. Slowly, word may get out that we are not monsters.

### 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 tanyafrizzle@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

### **HepCBC** ANNUAL GENERAL MEETING

Wednesday, Oct 4, 2006 **6 PM** 

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

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

#### **AGENDA:**

Approve minutes of AGM 2005 Set number of directors Election of those directors

AGM to be followed at 7 PM with a presentation by

Dr. Wayne Ghesquiere, infectious disease specialist.

Public Welcome. Refreshments

#### MARIJUANA AND TREATMENT

It has been found that the use of mari-So what do we do? How do we educate the juana while on treatment may not be detriworld? How do we teach people that we are mental. Seventy-one patients on treatment were studied and one-third of these used marijuana. The people who used marijuana had a 54% SVR compared to 18% of nonusers. Side-effects were similar between users and non-users but the users were found more likely to stay on treatment. However. there is no indication as to how much should be used and the largest user of the group did not do the best. Furthermore, other studies have shown daily use of marijuana can be harmful to people with HCV.

> Keep in mind, this is only one study. Further investigation needs to be done before recommendations can be done. And, as my nurse says, "Marijuana will make you loose brain cells."

http://www.hcvadvocate.org/news/newsRev/2006/ HJR-3.15.html

### **INTERFERON COST** REDUCTION

Interferon will be repacked in Egypt in an effort to drastically reduce its price. However, the brief report does not say what this price reduction will be and when it will come into effect. Anybody who has every been on treatment without coverage knows that it is an outrageous amount of money for treatment (approximately \$1700 a month). This cost is mostly to recover research and development costs of the drug. Any reduction in price will help.

http://www.hcvadvocate.org/news/newsRev/2006/ NewsRev-169.html#3



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

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

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



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

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### WHAT IS THE OFFICIAL CAUSE OF DEATH?

My father, David FitzGerald, a long time sufferer of hepatitis C ('86-'90) recently passed. He was very active in the Hep C community raising public awareness about the disease, and sitting on the Board of Directors along with my mother at HepCBC. Dave was a victim of the tainted blood scandal, but strongly believed that everyone, no matter how the disease was contracted, was and is a victim.

As a family, we were very informed about the disease and the Class Action Settlement requirements. He had given us specific instructions that, upon his death, it was imperative that we have a liver biopsy performed and push the medical community to include Hep C as a contributing factor in his death.

In 1999, he wrote to the administrators of the Class Action Settlement that. "With the exception of the Loss of Income section, death due to HCV is used as the criteria for these levels of compensation (Level III-VI). average lay person to obtain as the cause of death on the official death certificate. Like full-blown HIV victims, it is more probable that other causes will be listed, for example, pneumonia, congestive heart failure, renal failure, etc."

"Unless the victim has expertise in this area, and direction is given prior to postmortem autopsy specifically looking for HCV-related indicators and signs, the requirement that death [be] from HCV may be impossible to prove, especially where death has already occurred.'

Also in 1999, he wrote to Price Waterhouse Coopers and spoke on a hearing on the issue.

He said, "I strongly object to the term 'Died of HCV':

- •This will not likely be the listed cause of death on any official death certificate in Canada. Similar to HIV, it is more probable that the victims will die of secondary complications from the disease like pneumonia, congestive heart failure, renal failure, etc., and those diseases will be listed as the
- •Unless the victim or his family has expertise in this area, and direction is given prior to post-mortem autopsy, looking for HCV symptoms and conditions, as listed in the compensation package, the victim's family will not have the proof required for higher levels of compensation after death.
- •The term "Died of HCV" must be re-

moved or re-worded. For example the lies left behind will not have to be victimclause could read, 'If the family member who is compensable dies, and upon auin Compensation Levels III - VI existed, compensation will be awarded."

As you can see, we knew what we had to do. However, the Coroner's office would not perform an autopsy or a liver biopsy. We explained that it was vital for the HCV victim to be recognized for statistical and legal purposes, and they still refused. We left Dad in the hospital and would not allow him be transported until we could contact his family physician. Upon the return of his long time General Practitioner after the long-weekend. we explained the situation to him. This was not about blaming anyone for his death. Simply, he and all sufferers did not deserve HCV in this life, but deserved to be recognized as such in death if that was their final wish. We offered to pay for the appropriate testing. The GP requested that the autopsy These levels will be very difficult for the and biopsy be performed and the Coroner still refused. His GP then had the body transferred into his care, and proceeded to find an independent pathologist to do the proper testing. We contacted the HepCBC Board of Directors for support, and also contacted Dr. Keith Martin, Member of Parliament for Esquimalt/Juan de Fuca, who said that there is definitely a problem with the food, mostly all three. He was a kind man system. Dr. Martin, along with HepCBC, will be assisting us to educate physicians, victims and their families, along with different levels of government on the issue. Dr. Martin told us that patient history, treatment and other testing should be sufficient to allow medical practitioners to put HCV as a contributing cause of death on a death certificate.

In the end, it was determined that my Dad died of several things, and HCV was listed as a contributing factor. He can now rest in peace. We were lucky that we had a GP willing to go through this with our family. We are lucky we were educated to fight this final battle on his behalf with support of the HepCBC Board of Directors and others in the Hep C community across Canada. We are lucky we had the support of our MP, but most of all we were lucky to have a father dedicated to helping others both in life and death. It is our hope that from his death, his story will serve as an example to encourage victims and their families to speak with their family physicians and hepatologists about listing HCV as a cause of death on their death certificates. Only then will statistics and records be more accurate, and the fami-

ized again. Additionally, he would want us to use this experience to change the system topsy HCV symptoms or conditions listed of reporting deaths in cases of HCV and educate the medical community about the importance of this issue. It has always been about public awareness for my Dad, not the money. Consequently, our family will be working with HepCBC and Dr Martin, MP, to change the system from within and get the word out to the public.

Please speak to your doctor!

Thank you,

Shawna Farmer (daughter) and the FitzGerald Family

#### (DAVE FITZGERALD—Continued from page 1)

were infectious! Dave was known all over Victoria. He was known for his beautiful baritone voice, he sang in a barbershop quartet and was in HMS Pinafore among other productions. He umpired baseball professionally (one of the best) and he and his wife Lorie coached and rejuvenated the Gordon Head Girls Little League. He always rooted for the underdog, loving the Canucks, Lacrosse and all sports in general. Children filled his life, as he did theirs, with pure joy. When you visited Dave you were always welcomed with a smile, a coffee or some who would help anyone in need. He was at home in Pop's Fix It Shop, making all kinds of projects. Dad made toys for the Children's Ward at VGH: his impact will be felt in the toy rooms of the region for the foreseeable future; a master carpenter who much preferred the title "Jack of all Trades, Master of None".

He dedicated many years and ceaseless effort to the cause of hepatitis C awareness.

"Dave set up the offices of both HeCSC and HepCBC, and made purchases for our group. He was the muscles of our organization. He recruited his family and friends to help us out during our events, and we could always count on him. Dave was a tainted blood victim from inside the window. I met him when we were both involved with HeCSC Victoria. I will miss his support, his big bear hugs, and his wisdom. Most of you probably didn't know him. I wish you could have."—Joan King, Pres. of HepCBC

The family requests that in lieu of flowers, a donation be made in his memory to HepCBC, 306-620 View Street, Victoria, BC, V8W 1J6, telephone: 250-595-3892.

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### TO TREAT OR NOT

### **LICORICE**

Glycyrrhizin, found in licorice root, is a promising herbal therapy for hepatitis C, and has been long used as such in Chinese medicine. Past clinical trials have shown that it lowers ALT levels in Western patients after 4 weeks of treatment. This new trial in nonresponders to IFN showed that those who respond at 4 weeks of glycyrrhizin can maintain the response with a minimum of 3 injections a week, but there is no improvement in the state of the liver. However, patients reported better quality of life.

http://www.hivandhepatitis.com/ Source: hep c.html H, Orlent, et al. Biochemical andhistological effects of 26 weeks of glycyrrhizin treatment in chronichepatitis C: a randomized phase II trial. Journal of Hepatology 45(4): 539-546. October 2006.

### MILD HEP C AND **PROGRESSION**

It is difficult to predict how hepatitis C will progress in patients with little or no fibrosis, and to decide whether or not to treat them. In this study, 106 such patients who were not treated were examined 5 or more years after their biopsies. In 5 to 10 years, progression occurred in 2/3 of patients with stage I. In 1/3 of patients with stage I, progression to stage III occurred. Progression was associated with age, ALT levels, histological activity, fat in the liver, and alcohol use. These researchers believe that Hep C patients with even mild fibrosis should consider treatment.

Source: J of Vir Hep, May 2006 Vol. 13 Issue 5, Page 297 Fibrosis progression in initially mild chronic hepatitis C, S. Boccato, et al.

#### ANTIOXIDANTS

A. Melhem and colleagues researched the effect of a combination of antioxidants on 50 patients who were treated for 20 weeks with glycyrrhizin, schisandra, silymarin, ascorbic acid, lipoic acid, Lglutathione, and alpha-tocopherol, as well as 4 different IV preparations (glycyrrhizin, ascorbic acid, L-glutathione, B-complex).

Viral loads, liver enzymes, the condition of the liver and quality of life were monitored. The results showed that multi antioxidative treatment in these patients is easy to tolerate and may have a positive effect on the inflammation of the liver. Combining them with antivirals may enhance their response rates.

Source: www.therapeuticsdaily.com Hepatitis Weekly - Aug. 21, 2006 Study 3: Synergy between antivirals and antioxidants benefits patients with chronic hepatitis C



The Public Health Agency of Canada has just now approved funding that will enable the Hepatitis C Council of BC to hold a conference on November 17-19, in Kelowna, BC.

More detailed information, scholarship applications for HCCBC members, and registration forms will soon be available at www.bchepcouncil.ca

This is our one opportunity during the year to bring people together from across the province to share knowledge, skills and hope. Help to make it an exceedingly worthwhile experience by taking a minute while you're at www.bchepcouncil.ca | needed. It's only a single page, a simple to answer the quick poll about what needs to be on the conference agenda. Thanks, and see you there.

Ken Thomson, Working Group—Hepatitis C Council of BC



The Canadian Liver Foundation will be hosting a FREE four-month educational program for hepatitis C patients and community health workers.

> DOWNTOWN EASTSIDE HEPATITIS C DROP IN WORKSHOP #2

Wednesday, October 11th So you've tested HEP C+, what next?

Dr. Mel Krajden, MD, FRCPC **Carnegie Community Centre Auditorium** 401 Main Street (Main and Hastings) Vancouver, BC

FREE HEP C TESTING: 5:30-6:30 TALK AND Q&A: 6:30-8:00 Snacks will be provided. Contact

the Canadian Liver Foundation at 604.707.6430

> CANADIAN FOUNDATION









This workshop series was made possible through an unrestricted educational grant courtesy of Schering Canada and Hoffmann-La Roche.

### **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 that \$30,000, they will get 100% reimbursement. The more they make, the less of a percent is reimbursed, up to a max of \$100,000 income.

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

Each treating physician and hepatitis support nurse has these forms available to them. There is a toll free number that can be called if there are any questions or if help is 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!**

**I** epCBC is looking for writers for the next issue of the *hepc.bull*, and is willing to pay \$50.00 for a featured article. The article should be original, consist of 500 to 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 15<sup>th</sup> of next month, *stating interest in* the bonus. If there is more than one submission chosen, the editors reserve the right to print both, or leave one for a future edition. info@hepcbc.ca

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#### (NATALIE ROCK—Continued from page 1)

his/her family, exploring treatment options, and following up on the patients. She encourages her patients to participate in decision-making, thus the patient becomes an integral part of the team. The resulting commitment increases adherence rates. She still sees patients she met 13 years ago, and this is one of the most rewarding parts of her job. This model of nursing is now being adopted in other provinces, and even in Australia.

Natalie is not just a nurse on a team. She is, among other things, a consultant for international pharmaceutical companies. Her involvement in this area has been to look out for the needs and rights of the patient, especially in regard to adherence to treatment and to quality of life. Treatment with interferons can weaken patients. Even though treatment may be effective, the side effects can, in some cases, be worse than the disease itself, even if there is a cure. Natalie is always working to minimize the side-effects. Because of the nursing model developed at the LAIR Centre, their adherence rates to standard treatment and to clinical trials are the highest.

Natalie has been a consultant, working of herbs to complement standard treatments. with three international companies, in developing the collection of data for research studies. She realized early on that it was necessary to have a way to track and monitor her patients, so with the help of a computer programmer, she designed a database, which includes the demographics of the patients, their lab test results, their biopsy and ultrasound results, and their medications and any reason for stopping them, plus depression and quality of life scores. She has over 4000 in the database at this time. She has since helped other clinics and pharmaceutical companies to develop their own databases.

A founding member of the Canadian Association of Hepatology Nurses, Natalie recalls that she and her co-founders formed a group of 5, which has now expanded to almost 100. When she first started, there were only 3 hepatology nurses in all of Canada. She is very grateful for the support and networking possibilities that the Association facilitates.

"By becoming skilled in this area I have been able to make decisions about patient management. I have become an expert in hepatology and have been able to train not only nurses but also physicians in this area. I never dreamt that I would be fielding phone calls from other health care professionals all over Canada asking for my advice. This is simply amazing. I have also been fortunate to be able to attend and pre-

sent at international meetings and conferences." When asked which was the most promising treatment for Hep C in the future, Natalie apologized, saying that they have to sign confidentiality agreements regarding future studies. She did say that historically, the cure rate used to be 6%, and now it is a minimum of 50%, and even 88%, depending on the genotype. This improvement has happened in the last 12-13 years! There are new classes of drugs on the horizon, to be used without IFN or ribavirin.

treatments. Natalie likes to see her patients take a general multi-vitamin, and Vitamin E. which is an antioxidant. She thinks other products may help make patients feel better, but proper randomized trials are needed to prove their real effectiveness. 22 years ago Dr. Anderson sponsored a Chinese doctor to incorporate his knowledge into the clinic. The measure for whether the traditional Chinese medicine did any good or not is difficult to compare to Western medicine. Quality of life has to be considered, not just a cure. Other things to take into account are the treatment of symptoms and combinations

Historically, nurses have never been recognized on this level. When asked about this, Natalie commented, "It's just so awesome! Nursing is the backbone of medical care. Part of the reason clinics like ours function so well is because of the team of nurses. I don't just do what people think of as nursing. Teaching and counseling are also a part of my job. I have trained almost all the hepatitis nurses in Western Canada."

Over the years, she has presented to physicians. The first lecture she gave was for a Victoria audience consisting of about 30 patients in a gym. She remembers feeling really nervous, and she had to sit down to calm herself. Now she speaks in front of hundreds of international specialists.

encouraging me to do this. I field calls from doctors and specialists from all over the world, asking my advice. Nurses are not just doctors' helpers anymore."

To purchase tickets to Natalie's Tribute **Event** which takes place on Saturday, November 18, 2006 at the Four Seasons Hotel & Convention Centre, 6:30 PM-11:30 PM, please call the Canadian Liver Foundation: 1-800-856-7266 or 604-707-6430. \$100/ ticket, \$1000/table or \$2000/sponsorship table. For further information: www.liver.ca



#### (VIRAL LOAD 101—Continued from page 1)

Moving on to viral loads, a viral load of 6 log IU per mL serum means that 1x10° (which is the same as one million) international units of virus are present in one mL of serum. Serum is obtained by processing a blood sample. Viral loads in the millions are very common.

Changes in viral load may be given using logarithms also. A 1 log drop, a 2 log drop, a 3 log drop and so on. A 1 log drop is decrease in viral load by a factor of 10 (10 As far as alternative and complimentary raised to the power 1 = 10). If a patient had a viral load of 6 log in June and a viral load of 5 log later in December, then he would have gone from a viral load of 1,000,000 to 100,000. As 1,000,000 is 10 times greater than 100,000, we can say there was a 10 fold decrease in viral particles from June to December. This would be the same as saying a 1 log decrease or a 1 log drop.

> A 2 log drop is a factor of 100 (10 raised to the power of 2). This patient would have 1/100<sup>th</sup> of the virus that was measured previously.

> A 3 log drop is a factor of 1000 (10 raised to the power of 3).

> Notice something? The "number of logs" and the number of zeros? A 5 log drop would be a factor of 100,000. Count the ze-

> OK, it isn't always so easy to see. For example, Mr. X has a viral load of 6.73 log per mL of blood. How do we convert that to normal numbers? Unless you are Rain Man, you use a scientific calculator. You might be able to do it using a spreadsheet such as Excel, but I always use a calculator.

Type in 6.73, then hit whatever keys that raise 10 to this power. On my calculator I have to push 2<sup>nd</sup> function, then the log button. On your calculator it might be quite different. The log and 10<sup>x</sup> functions often share the same button on a calculator. Some calculators require you to press INV or 2ndF "I am really grateful to Dr. Anderson for before or after, so have the manual ready!

> The answer should read as 5370317.964. Mr. X has 5,370,317.964 viral particles per mL of blood. It would be acceptable to round this number down and say 5.37 mil-

> Try another one to make sure. Mrs. X has a viral load of 7.3 log. Convert to "real numbers". Get 19952623.15? Good!

Now let's have some fun!

Mr. A has a viral load of 6.2 log in January when he starts treatment. 8 weeks later Mr. A has a viral load of 3.3 log. What is the viral load drop?

(Continued on page 7)

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#### (VIRAL LOAD 101—Continued from page 6)

The easy answer is 6.2 - 3.3 = 2.9, Mr. A shows a 2.9 log viral load drop after 8 weeks of treatment.

get the values 1584893.192 for 6.2 log, and 1995.2623 for 3.3 log. I'll round off the decimals for simplicity in writing. Divide adjustment would have to be made to con-1584893 by 1995. The answer is 794. The virus has decreased by a factor of 794 between the two blood tests. Type 794 and hit log. The answer is 2.8998. This is almost equal to 2.9. The difference is due to having rounded off the decimal. (Try it again with the virus is equally distributed in the blood the decimals and you'll see!). This is the 2.9 log drop we calculated the easy way above!

Let's have some more fun.

eliminated in Mr. A? Well he started with 1584893 and ended up with 1995. 1995 divided by 1584893 is 0.00125876. Multiply this by 100 gives 0.126 percent. Now, wait. That's how much virus load he has left: all. I have a fairly good grasp of math but 0.126 percent of the amount he had in Janu-

To find out what percent was eliminated subtract it from 100.100 - 0.126 = 99.874%. Mr. A has cleared 99.874% of the virus! Things are looking good for Mr. A!

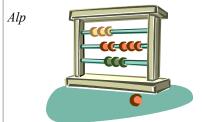
- •A 1 log drop represents 90 percent elimination of the virus.
- •A 2 log drop is 99 percent elimination.
- •A 3 log drop is 99.9%. Mr. A's viral load drop is slightly below a 3 log drop.
- A 4 log drop is 99.99%.... Guess how many 9's are in a 5 log drop. Isn't math fun?

Now there are some things to remember with viral load tests. There are currently at least 5 different ways to measure HCV viral loads and they measure slightly different things in slightly different ways. When doing viral load tests for comparison it would be wisest (and should be MANDITORY) to have both tests done at the same lab using the same technique and perhaps even by the same technician. There will be variation from lab to lab. There has been a big push to get everyone reporting viral load in IU. IU means International Units. Not everyone is reporting viral loads as IU/mL yet. Also, 1 IU/mL doesn't necessarily mean 1 viral particle/mL. There may be a conversion factor. Some viral loads give the results in eq/mL or equivalents per mL. IU and eq are not the same and again a conversion factor will have to be applied. Finally, the actual test is performed on serum. This is derived from blood by spinning blood in a centrifuge. After spinning, one obtains a clear vellow liquid which sits above a red mass. The red mass is

made up of everything dense enough to settle out during the centrifugation and includes blood cells. About one half of the volume of blood is serum so it takes 2 mL of blood to The long way: Use your calculator and get roughly 1 mL of serum. I would have to assume that when results are given they are given as so many IU per mL of SERUM. An vert this to units of blood. If one lab reports per mL of blood and the other reports per mL of serum there may be problems in comparing the two values.

One would also have to consider whether or serum. Is there a concentration of virus in a portion of the sample, inside blood cells for example, that is greater than what is re-What percentage of the virus has been ported by counting the virus in serum? I wonder if it is correct at all to specify so much virus per mL of blood or is it more accurate to use mL of serum?

> I do not do this sort of thing very often at hope I have not made any horrendous errors. It is my wish that this article will help remove some mystery behind the use of logarithms in lab test results and I hope that some of the points I have raised are considered when 2 viral load tests are to be compared.



### **COMPENSATION LINKS**

Many thanks to Wendy, who sent these links (http://www.wendyswellness.ca/links.htm)!

1 - Pre-86 Hep C Compensation Update: An update page regarding compensation for people infected through the Canadian blood system before 1986 or after 1990.

http://hepccc.blogspot.com/

2 - The Hepatitis C Compensation Coalition was formed to promote fair and equal compensation for Canadians infected with hepatitis C through the blood supply.

http://www.hepccc.ca/

3 - Yahoo group: Tainted Blood Trials and Proceedings related to the tainted blood tragedy in Canada

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

### 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/hepc/intro.html

David Harvey Toronto, ON

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

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

Roy Elliot

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

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

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:

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/tran5e.pdf

#### Pre-86/Post-90

http://www.kpmg.ca

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

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

Armstrong Hepatitis C United Resource Exchange Contact: 1-888-HepCURE rose@sunwave.net www.hepcure.ca

**AIDS Vancouver Island HCV support**  Campbell River: Drop in, harm reduc-• Comport River: Drop in, narm reduction, support, education. Contact: 250-830-0787, jeanette.reinhardt@avi.org leanne.cunningham@avi.org
• Comox Valley 355 6th St. Courtenay; Contact Phyllis 250-338-7400 phyllis.wood@avi.org Drop in, harm

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

anita.mcleod@avi.org,
•Port Hardy (Sayward, Port McNeil,
Alert Bay, Sointula and Woss) 7070 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

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

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

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

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

Kootenay Boundary: Individual support & info Contact Brian Reinhard 250-364-1112 reiny57@yahoo.ca

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

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

**Nelson Hepatitis C Support Group** 1<sup>st</sup> 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, <u>info@ankors.bc.ca</u> alex@ankors.bc.ca www.ankors.bc.ca/

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

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

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

Powell River Hep C Support Group Powell River Community Health, 3rd Floor–5000 Joyce Ave. Contact: 250-485-3310

Prince George Hep C Support Group 2<sup>nd</sup> Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 421. Contact Gina 250,263,2756 lies 250,565,7297 250-963-9756, Ilse 250-565-7387 ilse.kuepper@northernhealth.ca

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

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

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

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

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

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

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

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

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

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

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

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

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

If you have a Canadian HCV support group to list here, please send details to info@hepcbc.ca Please inform us of any changes by the 15th of the month —Joan

### **OTHER PROVINCES:**

#### **ONTARIO:**

Barrie Henatitis Support Contact: Jeanie for information/ appointment

hepcsupportbarrie@rogers.com

**Durham** Hepatitis C Support Group 2<sup>nd</sup> Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 St. Mark's United Church, 201
Centre St. South, Whitby. Oct. 12:
Factor 8: The Arkansas Prison
Blood Scandal. Nov. 9: Stephanie
Ruiter, RN (EC), UHN, Liver
Transplant Program. Contacts:
Smilin' Sandi http:// creativeintensity.com/smking/ 800-841-2729

**Hamilton Hepatitis C Network** Support Group 4<sup>th</sup> Thur. monthly 6:-7:45 PM. **NOTE: Sept. meet**ing is on Tues., Sept. 26th. Hamilton Urban Core Community Health Centre-Ask reception for the room. Contact Shannon Lane 905-522-1148 ext 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., Kitch-ener. Contact: Bob 519-886-5706 bc.cats-sens@rogers.com or Mavis (519) 743-1922 elroym222@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.

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

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

Sudbury Circle C Support Group 1st & 3rd Thurs. Contact Nancy 705-983-4396, Cathy 705-522-3352 or Ernie hepc.support@persona.ca 705-522-5156

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

Unified Networkers of Drug Nationally Users undun@sympatico.ca

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

info@hepcyorkregion.org www.hepcyorkregion.org

#### **OUEBEC:**

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

#### ATLANTIC PROVINCES:

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

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

#### PRAIRIE PROVINCES:

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

HeCSC Edmonton Contact Jackie Neufeld 780-939-3379.

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

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

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

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



Victoria & Area S.O.L.I.D. Society of Living Intravenous Drug Users, Consumers Support Group

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

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