hepc.bull

Canada's Hepatitis C News Bulletin

www.hepcbc.ca

WHAT IF I SAY NO TO TREATMENT?

by Joan King

It is important to know the natural course of hepatitis C to make good choices about treatment. Two recent studies can help us make this choice.

"Nearly 80 percent of chronic hepatitis C sufferers who have the disease for several decades will develop cirrhosis or end-stage liver disease later in life." This is the conclusion of a study in London, done retrospectively in 382 Asian patients probably infected at birth and diagnosed between 1992 and 2003. They had the disease for 60 years or more. The researchers believe that disease progression occurs at the same rate for everyone, not only Asians.

This is the highest rate of HCV-associated cirrhosis ever reported. There was also a parallel Caucasian study arm, where the occurrence of cirrhosis was not quite so high, but the Asian patients were infected for 30 years longer than the Caucasian patients.

In another retrospective study, 2867 women in East Germany received Rh factor with HCV-1b between 1978 and 1979. 1980 of these women were re-examined 25 years later. Findings: 93% developed acute hepatitis C; 86% still tested positive for antibodies; 46% tested positive for HCV; 0.5% had cirrhosis; 30 women developed pre-cirrhosis; one developed HCC (liver cancer); 10 died of related complications, but half had another disease, as well; in the last 5 years, a continuous, but low progression of fibrosis was seen. The researchers conclude that healthy young women may clear HCV(1b) more than half of the time, or develop a mild disease.

Sources: Clin Gastroenterol Hepatology 2005;3:910-917. This study was funded by local investigators and an unrestricted research grant from Roche Pharmaceuticals. Journal of Hepatology Volume 43, Issue 4, October 2005, Outcome in a hepatitis C (genotype 1b) single source outbreak in Germany—a 25-year multicenter study

IS THERE A CURE?

Jules Levine, from NATAP, is questioning the reliability of the study in the Jan. 2005 issue of *Hepatology*, where HCV was found in cells of some complete responders several years later. There have been many contradictory findings, even with testing 10 years after SVR. Levine has spoken with doctors and researchers, who agree that they have not seen relapse in their patients, and some are questioning the PCR techniques involved in that study. Levine says, "I think the bottom line is--do we see relapse years after SVR is achieved? And the answer appears to be no." Levine goes on to cite the following articles:

http://www.natap.org/2004/HCV/083004_06.htm
http://www.natap.org/2004/AASLD/aasld_20.htm
http://www.natap.org/2004/AASLD/aasld_31.htm
http://www.natap.org/1999/aug/longtermhist81799.html
http://www.natap.org/2003/Jan/010803_1.htm
http://www.natap.org/2002/may/050902_2.htm
http://www.natap.org/2004/HCV/112204_02.htm

Marcellin P, et al, Ann Intern Med 1997 Nov 15;127(10):875-81.

Source: Jules Levin, NATAP - www.natap.org
Studies Showing that HCV is Not Persistent & SVR is Durable

INSIDE THIS ISSUE:

MY MIRACLE STORY

by Rebecca Young

I am writing this article because I want to share with you my experience of recovery from hepatitis C. I have suffered from hepatitis C for 22 years and chronic fatigue has been my greatest symptom. In May this year I had 11 treatments over five weeks using a combination of ultra violet blood irradiation (UVB) and hyperbaric oxygen. Comparing a baseline 2001 PCR viral load test with my post-treatment PCR test in June, I had reduced my viral load by 60%. As I can only have increased viral load since 2001, I would then estimate that I actually reduced my viral load by 60-70%. No matter what the numbers, I feel like my life has been given back to me as I no longer have to live my life in 4 hour segments with frequent exhaustion, frustration and tears. The UVB together with the hyperbaric oxygen increases the oxygen carrying capacity of the blood and stimulates the immune system. Thus the healing process continues after the treatment ends.

UVB has been around since the 30s and 40s and was used to cure polio prior to Salk's development of a vaccine. With the rise of antibiotics, UVB has been put aside. But with the increasing failure of antibiotics and the often unsuccessful treatment of many viral diseases, UVB is being researched and used again. It has been found to be effective with HIV/AIDS, Hepatitis C, and many other viruses together with bacteria and fungi. Autoimmune diseases like fibromyalgia and chronic fatigue also respond very favourably.

I have included websites for further information. These include the results of an FDA controlled study in the US using UVB

(Continued on page 6)

CORRECTION:

In the memorial notice on the first page of last month's hepc.bull, dedicated to Bradley Cummings, in the sentence, "He is survived by his fiancée Kimberly Harrison, their baby son," the name of their son should read: Kolby Jordan Dean Cummings.

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

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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.

Peppermint Patti's FAQ

Peppermint Patti's FAQ Version 6 is now available, and Version 5.6 is available in Spanish. The English version includes updated Canadian Links and includes the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only $6 each, plus postage. Contact HepCBC at (250) 595-3892 or info@hepcbc.ca

HepCBC Resource CD:

The CD contains back issues of the *hepc.bull* from 1997-2004; 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.

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REPRINTS

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

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, Brad Kane, Chris Foster, Judith Fry, The Four Mile Restaurant, Victoria Bridge Centre, Erik, Irene, Chateau Victoria, the Victoria Symphony, the Victoria Conservatory, the Shark Club, Recollections, Thrifty Foods, Patisserie Daniel, Preview Hair Studio, and the newsletter team: Beverly A. and Diana Ludgate. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

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

CUPID'S CORNER

This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad: Write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a $10 donation, if you can afford it. Send cheques payable to **HepCBC,** and mail to **HepCBC, Attn. Joan, #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

HepCBC gives special thanks to Lexmark for printing out our Treatment pamphlets!

PRE-PLANNING YOUR FINAL ARRANGEMENTS?

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

DIAL-A-DIETITIAN

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

FEMALE SEEKING A MALE?

by Tanya Frizzle

When I found out I had HCV, I was currently in a five year relationship. He has stood by my side and been a huge support for me. Not everybody with HCV is this fortunate.

I remember having a conversation with my sister shortly after I found out I had HCV, regarding what would happen if my boyfriend and I broke up. I felt that it would be too difficult to date. I felt that people would not give me the time of day, let alone listen to the facts about HCV. I thought this because I was not sure what my reaction would have been if I, before I found out I had HCV, had been dating a guy and he dropped that bombshell. Would I have stuck around to find out what HCV really is? I do not know. I would like to think I would have, but I am realistic enough to realize I may not have. Education about HCV to the general public is poor at best. Before I was diagnosed, I knew nothing about it and assumed it was like HIV/AIDS.

I was expressing this thought to my sister and she said, "Everyday where I work, a blind, married couple comes in. They are very happy and in-love people. I bet at some point in their lives they may have thought they would be single forever."

Before she finished, I snapped, "But what they have is not contagious!"

She looked me in the eye and said, "No, but there are other people out there like you," and she turned and walked away.

She is right. There are others out there like me. There are others who are going through what I am going through, and if I were single, who better to date than a person who completely understands my current lifestyle? That is not to say I would not date a person who did not have HCV, if they were willing to understand my HCV, but I think that it would be a great support to be with somebody who has HCV.

I did some research on the internet and came up with two dating sites for people with HCV. They are: www.hepcmatch.com and www.hepcsinglesonline.com. I am sure, with more searching, there are other sites or places that have dating services for people with HCV.

ONLINE FRIENDS

There's a land where I go when I need to share,
That's not on a map, yet exists everywhere.
A land of names without faces, a curious place,
A modern creation that's called cyberspace.

There's all sorts of people with cute little names
Like Pookie, and Sandman and Rosebud and Flames.
Some are just snobs and some are real fun,
And some of them just want to find someone.

But both good and bad they all play a role.
Still each one unique, but part of the whole.

We talk and laugh and wonder why.
We flirt and hug and sometimes cry.
We can't be heard and can't be seen.
Yet, there it is, right on our screen.

But all in all the most curious part
Is the power it has to open our heart.
To share with a stranger those things we've concealed,
Which to our closest of friends we'd never reveal.
Our deepest regrets and most troubling fears
The scars in our life which bring us to tears.

What gives them the power to reach into me
And show me the truths that I never see?
How do they manage to open my eyes
And make me confess the deceit and the lies?

I don't understand this magical spell.
But I know that without it, my life would be ... well...

This must have been planned by the Creator above,
'Cause there's no place on earth where you'll find as much love.
When I need direction, I know I can find
Those angels from heaven, just waiting online.

Anonymous
Submitted by Rick A. in Toronto

PEGETRON TO PEGASYS SWITCH—UPDATE

by Tanya Frizzle

Switching from Pegetron to Pegasys has been interesting. In the first ten weeks of the switch, there were minor differences in the side effects. When the eleventh week came, my minor differences became larger differences. My platelets dropped to 38 (apparently below 40 is not good). They were holding steady around the 70 mark when I was on Pegetron. My white blood count also dropped to a dangerous level (0.03).

It was decided that, for my eleventh week, I would take three-quarters of a shot and see if we could bring the levels up. It did not work. My white blood cells did come up a bit (to 0.04), but my platelets actually dropped lower to 35. So for week twelve, it was decided that things were getting too dangerous and my dose would be reduced to half. It worked. My platelets are now above 50.

I am going to stay at a half dose for the next two weeks. By then, the results on my viral load should be in and it will be decided whether or not to continue Pegasys, and whether or not I will raise my dose if I do continue.

I'm keeping my fingers crossed that my switch worked. On the plus side, since about my 9th week of Pegasys I've been basically feeling fine. I am still extremely tired and short of breath, but besides that, I've been doing well.

To be continued...

CONTRAINDICATIONS TO PEGINTERFERON AND RIBAVIRIN COMBINATION THERAPY

- Severe or uncontrolled psychiatric disease
- Poorly controlled epilepsy
- Active serious infection
- Pregnancy or inadequate contraception
- Severe heart disease
- Advanced renal failure
- Documented poor compliance
- Hemoglobinopathy
- Uncontrolled serious medical illness
- Relative contraindications
- Hepatic decompensation
- Solid organ transplantation (except liver)
- Autoimmune diseases
- Neutrophils <.75 × 109/L
- Platelet count <50 × 109/L
- Severe anemia
- Ongoing alcohol or substance abuse

http://www.hivandhepatitis.com/hep_c/news/2005/ad/070805_c.html

MANIPULATION BY FOCUS OF ATTENTION Part II

by Bradley Kane

The Diseases and Menace to Public health

What are a few of the primary diseases that HCV causes?

Cancer Patients infected with the hepatitis C virus (HCV) are six times as likely to develop non-Hodgkin's lymphoma (NHL) than individuals who are virus free, and HCV infected patients have a seventeen-fold higher risk for developing diffuse large B-Cell lymphoma, researchers from British Columbia documented, confirming the viral-cancer link suspected. *(Agnes Lai, John Spinelli, Randy Gascoyne, Joseph Connors, Pat Lee, Rozmin Janoo-Galani, and Richard Gallagher, BC Cancer Agency; Anton Andonov, Health Canada National Microbiology Laboratories, Winnipeg, Manitoba, and Darrel Cook, British Columbia Centre for Disease Control.)*

A number of other cancers including leukemia, multiple melanomas and HCC (hepatocellular carcinoma or liver cancer) have also been associated with HCV infection.

Cryoglobulinaemia Severe cryoglobulinaemia can be very dangerous and an “attack” can be fatal. It can cause weakness and lesions of blood vessels resulting in an increased risk of embolism and thrombosis. Low body temperature (hypothermia) can cause cryoglobulins to solidify (precipitate) in the blood stream as gel. Warming redissolves the gel. Cryoglobulinaemia is present with the majority of auto-immune and extrahepatic disorders that are common to people with HCV. Cryoglobulins can wreak havoc throughout the body and can cause damage to many organs and systems. HCV is the leading cause of cryoglobulinaemia.

70.7% of HCV positive people were positive for cryoglobulinaemia. (High prevalence of cryoglobulinemia in persistent hepatitis C virus infection. - *Hepatology Research Volume 27, Issue 1, September 2003, Pages 18-22*)

Diabetes The crude percentage of diabetes in a cross-sectional study was 14.5% for patients with HCV, different from the crude rate of 7.8% for the general population (p= 0.0008) and from the rate of 7.3% observed in a matched control group with non-HCV liver disease. The presence of advanced histological disease in genetically predisposed HCV-patients is associated with a higher prevalence of DM/IFG. DM and IFG were not associated with anthropomorphic markers of obesity in HCV patients, suggesting a unique multifactorial pathogenesis of DM in HCV. *(Am J Gastroenterol. 2005 Jan;100 (1):48-55.)*

Liver diseases Liver disease occurs in around 30% of people with HCV infection. HCV can cause low grade hepatitis (inflammation of the liver). Over 15-20 years, this chronic inflammation can lead to scarring (fibrosis), and altered structure (cirrhosis). Hepatocellular carcinoma (HCC) or liver cancer and steatosis (fatty liver disease) can also occur.

Kidney disease Hepatitis C is both a cause and a complication of chronic renal disease and can lead to membranoproliferative glomerulonephritis (MPGN). - *(American Journal of Kidney Diseases. OCT 2003; 42 (4) : 631-657)*

Neuropathy/psychiatry The risk of depressive disorders in people with HCV infection (even without interferon/ribavirin [IFN/RBV] treatment) has been reported as high as 37% *(Dieperink et al., 2000; Yovtcheva et al., 2001).*

Mood disorders were present in 38% of (HCV) patients; personality disorders in 30%; PTSD in 19%; other anxiety disorders in 9%; and psychotic disorders in 17%. Psychosomatics 2001; 42:411415

Choline/creatine ratios were significantly higher in the white matter and basal ganglia of people with HCV. *(Lancet 2001; 358: 38-9)*

Cytopenias The following cytopenias were identified in people with HCV: autoimmune hemolytic anemia (AHA), thrombocytopenia, aplastic anemia, neutropenia, refractory sideroblastic anemia, and pure red cell aplasia. *(Medicine (Baltimore). 2003 Mar;82 (2):87-96.)*

Thyroid disorders People chronically infected with hepatitis C virus (HCV) have a significantly increased rate of thyroid abnormalities and are positive for anti-thyroid auto-antibodies. 13% have hypothyroidism. *(Thyroid disorders common with hepatitis C_2004-07-08 [Reuters Health] - By Will Boggs, MD, New York [Reuters Health])*

Arthritis Joint pain is probably the most common symptom reported by HCV patients. Polyarthritis (involving more than one pair of joints, bilaterally), high circulating Rheumatoid factors, bone density loss, have all been associated with HCV infection.

Skin diseases, opportunistic bacterial or fungal infections Due to their impaired and altered immune systems, people with HCV are very susceptible to a wide range of bacterial and fungal infections to which they normally would not be, which is why most health authorities have approved pneumonia and flu vaccines for HCV patients. Skin diseases are very common.

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

Chronic hepatitis C virus (HCV) infection is associated with several extrahepatic disorders. Although the exact pathogenesis of these conditions is not fully understood, several studies have provided insight into the role of HCV in their development. This review discusses the different conditions that have been associated with HCV infection. Among the most commonly reported are cryoglobulinaemia, membranoproliferative glomerulonephritis, leukocytoclastic vasculitis, Sjogren's syndrome, lichen planus and porphyria cutanea tarda. In some patients, these disorders are the first sign of HCV infection. *(Department of Medicine, Division of Gastroenterology-Hepatology, University of Connecticut Health Center, Farmington, CT, USA)*

As you can see, the effect of HCV infection on peoples health and, consequently, the burden on the health care system is enormous. It is an unprecedented health threat, currently affecting around 300,000 diagnosed Canadians. Most people with HCV are not aware they have it and have not been tested yet.

Providing better care, saving lives and confronting the threat to public health more accurately, is a good enough reason to change attitudes about HCV. Because this virus is spread by re-using contaminated equipment, it was/is preventable, whether used in a hospital or back alley makes no difference. Tainted blood/blood products were also preventable. Mankind allowed this epidemic by doing nothing about it and not stopping the practices and procedures. I hope for change.

HEPATITIS C COUNCIL OF BC

News: September 2005

Conference web poll

We're planning for the next Hepatitis C Council of BC conference, to be held October 28-30 at the Airport Marriot in Richmond, BC. Please take a minute to let us know what you think should be on the agenda by responding to the survey at *www.bchepcouncil.ca*

One lucky person will win a $25 gift certificate to Chapters or Overwaitea. The winner will be announced on September 30, 2005.

Other Council Activity

On June 25 in Victoria, Karen Dennis from HepCBC and Carol Romanow from SOLID attended the "Inner City Health and Hepatitis C" conference, where they provided participants with information and resources such as the "Renewed Focus" document, backgrounder and fact sheet.

Carol will be doing the same at the "Where's the Patient's Voice in Health Professional Education?" November 3-5.

A presentation was made to the Interior Health Board of Directors on July 20. Meeting minutes and a copy of that presentation are available at *www.interiorhealth.ca/Information/About+Interior+Health/Board+of+Directors/Board+Minutes+Agendas.htm*

Robin Tomlin and Ken Thomson met with Katrine Conroy (NDP Caucus Whip and Seniors Health critic) to present information on the need for HCV services. We are currently working to arrange presentations for the NDP and Liberal Health Caucus. Representatives from both parties are being invited to attend and speak at the Council conference. They later met with the editor of the *Castlegar News*. An excellent article resulted.

On a Bright Note

Tom Kelman, who has done remarkable and innovative work on the Sunshine Coast, disappeared from view a couple of years ago, due to the ravages of HCV. I was extremely pleased to run into him at the BC Transplant Society offices. He's alive and kicking and wearing the pager that will let him know when a transplant is available. Here's hoping that call comes soon.

Have you and everyone in your family registered as organ donors?

Grab your Care Card number and head on over to *www.transplant.bc.ca*

Canadian Liver Foundation- Living with Liver Disease Workshops

Nelson- October 17, 24, 31, November 07. Nelson Municipal Library, 602 Stanley St., 7-9pm. For info and to register, call 1-800-856-7266.

RESEARCH *by Tanya Frizzle*

HCV AND CIRRHOSIS

A study was preformed by the Queen Mary's School of Medicine and Dentistry in London regarding the frequency of cirrhosis in people with chronic HCV. They studied Asian patients who were born with HCV. They found that 80% of patients who had HCV for 60 plus years developed cirrhosis. "This study suggests that prolonged infection with hepatitis C leads to cirrhosis in the majority of those who are infected," said Graham R. Foster, PhD.

Source: http://www.innovations-report.com/print/print_en01.php3?id=48634&ctyp=1

COFFEE POSSIBLY GOOD FOR ME?

A study has been done by the Division of Epidemiology at the Tohoku University Graduate School of Medicine in Sendai, Japan. It was found that consumption of coffee reduced the risk of liver cancer. Another study done by the National Cancer Center in Tokyo found that five cups of coffee a day or more cut the chance of liver cancer in half. However, it was noted that these studies were not performed on patients with HCV and it is not known if they will receive the same benefits from coffee.

Source: http://janis7hepc.com/hepatitis_c_research52.htm#l

RIBAVIRIN + AMANTADINE + UDCA

Egyptian researchers, looking for an effective and inexpensive treatment for HCV patients, enrolled 170 naive patients with elevated ALT in a study.

Group I were given a daily combination of ribavirin (600-800 mg) plus amantadine (200 mg) and ursodeoxycholic acid (UDCA) (500 mg) for 24 weeks. Group II were given milk thistle 450 mg/day for 24 weeks.

Results based on the remaining patients after 16 dropped out: ALT was normal in 58.5% and 15.3%, respectively, and end of treatment virologic response (ETVR) was achieved in 2.4% and 0% of Groups I and II, respectively.

Twenty-four weeks after the end of therapy, sustained biochemical response (SBR) was retained in 28% and 2.8%, and SVR was maintained in 2.4% and 0%. Biopsies showed improvement in group I patients.

Source: Liver Int. 2005 Aug;25(4):746-51. Non-interferon-based therapy: an option for amelioration of necro-inflammation in hepatitis C patients who cannot afford interferon therapy.

NEWS

miR-122

Researchers at Stanford University discovered that microRNA-122 (miR-122), found only in the liver, interacts with the 5' noncoding region of HCV mRNA to help it reproduce. This is the first time a molecule like this has been discovered to regulate gene expression. miR-122 makes up 70% of microRNAs found in the liver, and when that molecule was inactivated, HCV RNA dropped by around 80%. The scientists concluded that miR-122 is necessary so that HCV can multiply. Of course, HCV can spread in other body parts than the liver, and it doesn't need miR-122 to replicate in the other cells.

Alnylam and Isis Pharmaceuticals have signed an agreement, and together will have exclusive access to miR-122. Alnylam is collaborating with Novartis to develop RNAi therapies which can treat disease by silencing genes that cause disease.

Sourcse: D. Steinberg, "MicroRNA target practice," The Scientist, June 20, 2005. http://www.the-scientist.com/2005/6/20/14/1
Silicon Valley/San Jose Business Journal – Sept 13, 2005, Stanford licenses gene for hepatitis C treatment

UNIFIED DATABASE

More and more, we need international standardized names for the different genotypes of HCV. Discoveries about the differences that exist between the genotypes are coming about because of the genetic sequence databases being developed in Japan, France and the US. Some of these databases are using different names, so this paper was written to attempt to resolve conflicts and decide on the assignment of newly discovered genotypes in the future.

The classification proposal takes into account new discoveries of genetic differences and epidemiology, and uses 6 genotypes defined by phylogenetic analysis, and provides the structure for the HCV databases. The subtypes may be provisional (or even remain unassigned, if there are fewer than 3 samples) according to whether the sequence data is complete or not.

Source: Simmonds P, et al, Hepatology. 2005 Sep 7; Consensus proposals for a unified system of nomenclature of hepatitis C virus genotypes. PMID: 16149085 [PubMed - as supplied by publisher]

FOR THE FAMILIES OF HCV PATIENTS

by Tanya Frizzle

My father was diagnosed with HCV around February of 2004. He had become ill with a virus, and while undergoing testing it was discovered he had more than one virus. He also had HCV. A few months later I decided, on a whim, to get tested for HCV, and I found out I also have it. But we had different genotypes, so we did not get it from each other.

Since we both found out we had HCV around the same time, we started treatment a few months apart. It was such a great support, doing this together with my father. We called each other almost every day to "compare notes" on new side effects and our most current doctors' results. I had mild side effects, but my father was not that fortunate. He had to leave work and basically could not move from the couch. He was very uncomfortable and in a lot of pain. The doctors were evasive with us. We knew his liver was severely damaged, and they were not sure the medication would do anything, but they thought it was worth a shot.

In February of 2005 he was extremely bloated. His stomach was twice its size, and he could barely move because he could barely breathe. Not only was the medication making it hard to breathe, but the fluid in his stomach was pressing on his lungs. The fluid was dangerous because if it became infected, there was nothing that could be done. On the other hand the doctors did not want to drain the fluid because they were afraid the surgery would cause an infection. It was decided though that the surgery would have to be performed. The fluid was drained, and he felt a little better, a little more comfortable.

Unfortunately, by March 2005 he became markedly worse. His speech became slurred, his thought patterns and memory were impaired, his breathing extremely labored, and he shook all the time. There were days you would swear he had been drinking, but it was not possible, as he could not leave the house to get any alcohol. The doctors kept checking for infection but not finding anything.

On April 9, 2005 he called 911 to go to the hospital, as he could not breathe. I met him at the hospital. The nurse said to me "I'm sorry, but he is not going home. His liver is failing and there is nothing we can do besides comfort measures." Three hours after he checked into the hospital, he passed away, surrounded by family and friends. It was a shock. I was not prepared for that to happen. I was very close to my father, and five months later I am still in shock. I miss him deeply.

In the hospital I heard the words "end-stage liver disease" and looked it up on the internet when I got home. He had been exhibiting symptoms for the last month, at least. I was angry at the doctors. Why had they not told us he had end-stage liver disease? Why had they not told us he was going to die? I talked to his family doctor. He said they themselves did not know he was going to die like that. They theorize that he had an infection that they could not detect that shut down his liver. Maybe this is true. But they knew in the last month he was dying, and nobody told us. I felt cheated.

Then I started thinking about it. What if I had known he was going to pass on that quickly? How would that have been? It would have been terrible. I would have spent every moment stuck to his side and boy, would he have been sick of me! I would have had tears in my eyes every time we spoke, and he would have hated to have been treated like he was dying. On my last day with him, we spent our time talking and laughing and playing with his granddaughter. I think the greatest gift we had is that the final days we had with him were happy. We had hope. We gave him hope. The day he passed on, I was talking to him about my sister's wedding and what food he was going to prepare for it. He had just stopped taking Pegetron (he did clear the virus), and we were talking about how much better he was going to feel soon. We were not mournful in his presence. We were happy. So would I change it? Do I want it any different, if it comes to that, for me with my HCV?

No. I want it the exact same way.

(MY MIRACLE STORY—Continued from page 1)

to treat Hep C with highly favourable results.

I am now in the process of doing a few more treatments to continue to eliminate more of the virus and to stimulate my immune system. For more information about this treatment call HOC at 995 1811 or email me: Rebecca at rmayoung2002@yahoo.ca

www.bio-immuno-development.com/ubitherapy.html
www.mnwelldir.org/docs/immune/ubi.htm
www.mnwelldir.org/
http://www.hemophilia.org/News/medicalnews/mn_04_26_05.htm

[Editor's note: It is fairly common for viral load to fluctuate with no apparent cause. http://hepatitis-central.com/hcv/hepatitis/virus/relate.html]

CONFERENCES

October 6, 2005

Living with Chronic Illness: Psychological Management & Maximize Your Nutrition: Kelowna, BC
Canadian Liver Foundations: 1-800-856-7266

October 28-30, 2005

Hepatitis C Council of BC Conference
Vancouver Airport Marriott, Richmond, BC
e-mail: stacy@bchepcouncil.ca
www.bchepcouncil.ca

November 3, 2005

Royal College of Physicians of Edinburgh - Hepatitis C, Edinburgh, Scotland
www.sign.ac.uk/events/index.html

November 11-15, 2005

56th Annual Meeting of the American Society for the Study of Liver Diseases (AASLD)
San Francisco, CA
www.aasld.org/eweb/DynamicPage.aspx?webcode=05_Annualmeeting

March 25--28, 2006

Shanghai - Hong Kong International Liver Congress 2006, Shanghai, China
www.livercongress.org/en/news/20041015.htm

CARE-LINE

CARE-Line, is available in Canada for some people receiving Pegetron. Patients can call 1-800-603-2754 extension 2121 to find out if they are eligible for help from this program. Health care providers who wish to make inquiries about their patients' access to CARE-Line may call 1-800-463-4636 extension 346.

Source: http://www.hepcyorkregion.org/docs/352,1,Slide 1

BANANABERRY SMOOTHIE

16 oz. fat-free yogurt
2 small ripe bananas
1 C strawberries
1 C berries (i.e., raspberries, blueberries, and/or blackberries)

Blend yogurt, bananas, and berries; cover and puree until nearly smooth.

Makes 4 servings. 125 calories, 1g fat

CLINICAL TRIALS

GI-5005

GlobeImmune has initiated a Phase 1b, double-blind, placebo controlled, dose-escalation, multi-center study of GI-5005, a Tarmogen, for the treatment of HCV infection (HCV). Tamogens, also used to fight cancer, are a *Saccharomyces cerevisiae* yeast, changed to express protein antigens to stimulate the immune system. "NS3 and Core are HCV protein antigens that are expressed in infected cells and are essential for virus replication." The product has shown effectiveness in pre-clinical trials, causing an immune response like the one that occurs in those with spontaneous clearance.

Source: PRNewswire, GlobeImmune Initiates Phase 1b Study of GI-5005 for Chronic Hepatitis C Infection July 26, 2005 www.globeimmune.com.

EMZ702

Transition Therapeutics is enrolling 28 patients in a Phase I/II trial of EMZ702, one of its Interferon Enhancing Therapy (HCV-I.E.T) candidates, to test its efficacy in non-responders to standard combination therapy. EMZ702 has shown good anti-viral synergy with interferon and excellent safety. The subjects will receive EMZ702 twice weekly, along with standard pegylated interferon and ribavirin. The principal investigator is Dr. Morris Sherman, University of Toronto. Combining EMZ702 with standard treatment in surrogate models has shown 2 to 3 times more antiviral activity than standard treatment alone.

Source: Transition Therapeutics Commences Enrolment of Phase I/II Hepatitis C Clinical Trial July 27, 2005 www.transitiontherapeutics.com

GS 9132

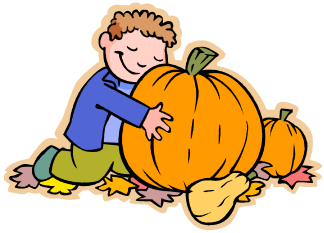
Gilead Sciences and Achillion Pharmaceuticals have begun a Phase I double-blind, randomized, placebo-controlled dose-escalation study of GS 9132, also known as ACH-806, to evaluate the pharmacokinetics, tolerability and safety in 20 healthy volunteers. GS 9132 is a small molecule inhibitor of hepatitis C virus (HCV) replication, which involves HCV protease.

Source: www.gilead.com, August 15, 2005, Gilead and Achillion Announce Initiation of Phase I Clinical Trial Evaluating GS 9132 for the Treatment of Hepatitis C

ANA245

Anadys Pharmaceuticals reported the results of a 7-day-long Phase IB dose-escalating, open-label clinical trial of isatoribine (ANA245), which concluded that treatment with ANA245 resulted in good antiviral activity with few, mild side effects. The trial treated HCV naïve or non-responder patients. Ten of the 12 patients receiving the most effective, large dose had genotype 1.

Sources: PRNewswire-FirstCall Aug. 23 2005, Peer Reviewed Report in HEPATOLOGY Details Inhibition of Hepatitis C Virus and Immune Activation by a TLR7 Agonist
Horsmans Y, et al, "Isatoribine, an Agonist of TLR7, Reduces Plasma Virus Concentration in Chronic Hepatitis C Virus Infection". Hepatology 2005; 42:724-731.
www.anadyspharma.com



COMPETITION!

HepCBC is looking for writers for the November 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 October, ***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

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.

Goodman and Carr LLP
pre86hepc@goodmancarr.com
www.goodmancarr.com

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 207)
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.

MISCELLANEOUS

Excellent Website!!: HCV Tainted Blood, Canada: http://creativeintensity.com/smking/tainted.htm

COMING UP IN BC/YUKON:

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

AIDS Vancouver Island Hep C support:
♦**Campbell River:** Mon-Thu 9AM-4 PM, 1249 Ironwood. Contact Jeanette or Leanne: 830-0787, jeanette.reinhardt@avi.org leanne.cunningham@avi.org
♦**Comox Valley** 355 6th St. Courtenay Contact:Phyllis 338-7400 phyllis.wood@avi.org
♦**Nanaimo** Drop-In **as of June 1st,** each Wed 2-4PM, #201-55 Victoria Rd. Contact Anita 753-2437 anita.mcleod@avi.org

Castlegar Contact Robin 365-6137

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Contact Katerina 417-2010, hecsc-ek@shaw.ca Leslie 426-6078, ldlong@shaw.ca

Kamloops AIDS Society of Kamloops (ASK) 372-7585 for support or referral. ask@telus.net

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Contact Elaine 768-3573, erise-ley@shaw.ca or Lisa 766-5132 ljmor-tell@cablelan.net or 1-866-766-5132.

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

Mid Island Hepatitis C Society 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Contact Sue 245-7635, mihepc@shaw.ca

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Contact Vivian 265-0073

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St. Contact Alex 1-800-421-2437, 505-5506, info@ankors.bc.ca www.ankors.bc.ca/

Boundary Hep C Support. Contact Ken 250-442-1280 ksthomson@direct.ca

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

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations Urban Community Society, 623 Agnes Street, New Westminster. Contact Dianne Morrissettie, 604-517-6120 dmorrissettie@excite.com

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

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Prince George Regional Hospital, Rm. 107. Contact Gina 963-9756, or Ilse 565-7387 ilse.kuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Contact Ted 624-7480 Ted.Rogers@northernhealth.ca

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

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy 557-2487, wmm@island.net, www.island.net/~wmm/ http://health.groups.yahoo.com/group/CANhepc/

Salmo Hep C Support Group 2nd Wed. monthly 6 PM, 311 Railway, Contact Giselle Rogers 357-9511, Carol 357-9293 or alex@ankors.bc.ca

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

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, 3862F Broadway Contact 1-866-877-0042 or Doreen 847-2132, deb@plnw.org

Sunshine Coast-Sechelt Healthy Livers Support Group 2nd Thurs. monthly, 3-5 PM, Sechelt Health Unit, 5571 Inlet. Contact Brent or Bill 604-740-9042 brent.fitzsimmons@cgh.bc.ca

Pender Harbour Hep C Support & Info Contact Myrtle Winchester 604-883-9911 or 604-883-0010

Vancouver Native Health Three levels of training on HIV, Hepatitis STD's, drug use and harm reduction using a peer support model. Next intake: January. Contact Ken: 604-816-0192

VANDU Vancouver Area Network of Drug Users: Satelite Hep-C group, each Thurs. 2 PM, HCC, 166 E. Hastings,. Bus fare & snack. 604-658-1224. **H.A.R.M. group e**ach Mon., 10 AM, 50 East Hasting St. Bus fare & snack. Contact 604-683-8595 vandu@vandu.org www.vandu.org

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

Vancouver Hepatitis C Support Group Meetings: 3rd Tues monthly, 7-9 PM, Lauener Room JPP 2809, Sassafras Cafeteria, Jim Pattison Pavilion, South Level 2, Vancouver General Hospital, and 1st Tues monthly, 5-8 PM, Java Express, 3420 Cambie St. Contact Robert, CLF: 1-800-856-7266

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

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

Victoria Support & Info Contact the Needle Exchange 384-2366

Victoria HepCBC Library open M-F 306-620 View St. Phone support or private interviews. Contact 595-3892 info@hepcbc.ca, www.hepcbc.ca

Works Without Words Yukon Hep C Support Group Every Thurs. at 7 PM., Grace Community Church, 8th & Wheeler St. Contacts: Harry & Debbie 867-667-2402 harry.mckenzie@klondiker.com. Brian: 867-668-4483 P.O Box 31216, Whitehorse,YK.

OTHER PROVINCES:

ONTARIO:

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

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7-9 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Oct. 13: Dr. Peter Campbell, Gastroenterologist will speak on the Head to Head Pegylated interferon drug trials. A drug representative will speak on financial issues for conventional treatment. Contacts: Smilin' Sandi smking@rogers.com Sandi's Crusade Against Hepatitis C http://creativeintensity.com/smking/ http://health.groups.yahoo.com/group/hepc-info/ 1-800-841-2729.

Hepatitis C Network of Windsor & Essex County, Last Thurs. monthly, 7-9 PM. Contact (519) 562-1741 Fax (519) 256-1383 hepc@hepcnetwork.net, http://hepcnetwork.net

Kingston Hep C Support Group 1st Wed. monthly, 5:30-9 PM St. George's Cathedral, King and Johnson St. (Wellington St. entrance) Contact: HIV/AIDS Regional Service 613-545-3698

Unified Networkers of Drug Users Nationally undun@sympatico.ca

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

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

North Bay HCV Support Group 2nd Monday monthly 7 PM, 269 Main St. West, Suite 201, North Bay. Contact: Gabe Giroux, Hep C Education and Support Coordinator 705-497-3560 ggiroux@vianet.ca

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

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

York Chapter HeCSC 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

If you have a Canadian HCV support group to list on this page, please send the name of the group, day, time, place, contact name/phone, and email address to info@hepcbc.ca Please inform us of any changes by the 15th of the month —*Joan King*

QUEBEC:

Arundel Contact Andy Aitken chcn.alexander@sympatico.ca
Canadian Hepatitis C Network http://www.canhepc.net/

Quebec City Region Contact Renée Daurio 418-836-2467 reneedaurio@hotmail.com

ATLANTIC PROVINCES:

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

Cape Breton Island, N.S. The Hepatitis Outreach Society Support Group 2nd Tues. monthly 150 Bentinck Street, Sydney, N.S. 7-9 PM. Call Cindy Coles 1-800-521-0572, (902) 539-2871 FAX (902) 539-2657 hoscb@ns.aliantzinc.ca

PRAIRIE PROVINCES:

Regina, Saskatchewan Contact Doug 306-565-8593 hep-c.regina@accesscomm.ca http://nonprofits.accesscomm.ca/hep-c.regina/

HeCSC Edmonton Contact Jackie Neufeld 939-3379.

Hep C Edmonton HCV, pre/post liver transplant support Contact Fox 473-7600, or cell 690-4076, fox@kihewcarvings.com

Fort McMurray, Alberta Hepatitis C Support Network—Info and support. #205, 10012A Franklin Ave. Contact Lyn, (780) 743-9200 Fax (780) 943-9254 wbhas@telus.net

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

The Life with Hepatitis Society of Central Alberta Support group meets each Wed. 7 PM Turning Point Agencies 4611-50th Ave., Red Deer. Contact: Chris (403) 341-6026 crthomas@shaw.ca

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

BE PART OF THE TEAM!

We need people to summarize articles. HepCBC needs office staff and 6 people to help with our website. The HepCAN list needs a moderator trainee. Please contact Joan at 250-595-3892 or info@hepcbc.ca