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Canada's Hepatitis C News Bulletin

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VERY SAD STORY: JOE STOKES August 6, 2005

Joe Stokes passed away on Saturday August 6, 2005 at VGH. His story is a very sad one and I think it needs to be told.

Joe contracted Hep C from a blood transfusion during a knee operation in 1977. He lived with the disease for 28 years. In 1996 he tried interferon from St. Paul's Hospital. It made him sick for 3 months. He was taken off it and was sort of fine for a number of years. He started seeing the BC Transplant team in 2000 because he was starting to develop symptoms. Last year (2004) Dr. Yoshida told him that the newest interferon with ribavirin was new and might eradicate the Hep C from his blood, so he should give it a try. For one year Joe couldn't make up his mind, and I told him NOT to try it because of the 1996 incident.

In February of this year, he decided to give it a try, and what a disaster that was. He developed a different symptom every week for 8 weeks. He was not managed closely enough. We were planning a trip to Las Vegas to celebrate our 20th anniversary and the transplant team said it was okay to go. We did not know that his ascites was infected, and he had sepsis.

We were gone 7 days, and the night before coming home, Joe went into confusion in a restaurant, and was hallucinating. No one told me about these side effects of liver disease. Toxicity was building up in his body and affecting his brain. We barely made it home because then next morning we had to get the pilot's permission to board the plane. What a nightmare that night was.

Anyway, that was a Thursday, and then at 4 AM Sunday morning, he woke me up and told me that we had to go to the Richmond Hospital because he probably had blood clots in his legs, because they were aching so badly and he had had these before.

(Continued on page 6)

SHARON GRANT

August 2, 2005



Sharon, of Vernon, BC, was diagnosed 1997. Her way of coping was to help others. That same year, she formed the Vernon support group, running the office from her home. Her main goal was that doctors be educated.

"Your whole personality changes with it," she said. "You enjoy the small things. You enjoy seeing someone laugh. The small things mean more." "You are angry. Sometimes, I still say, 'Why me?' I get to vent that one the group. I don't know what I'd do without them." — <http://www.hepatitisociety.com/english/HepCNewsletterSummer2000.htm>

Sharleen, from her group, says,

(Continued on page 6)

BRAD CUMMINGS

June 6, 1964—August 3, 2005

"For a number of us in the hepatitis groups, Brad may best be remembered for his excellent sign holdings at our information rallies and protests. Brad also co-presented with me at the Hep Circle meeting in Nanaimo on the nutritional supplement for those with hepatitis C.

He may perhaps be remembered for his booming laugh and infectious giggle, which could break out at the most inopportune times! Brad was so young, and a new father. I hope life will not be too hard for his partner and son. Rest in peace, Brad. You will not be forgotten!"—
Carol Romanov.

Photo: Noted troublemakers, "Los Incognitos," were spotted outside the MHR in Victoria on October 17th protesting the BC government's "liberal" application of health Reform. For those of you who are disabled and/or around the poverty line, getting the food and nutrition you need is going to be even more difficult. Stay tuned to this channel. Los Incognitos have promised to make things a "teetle hot"

<http://www.hepcbc.ca/advocacy.htm>

Brad passed away at Victoria General Hospital after a long, hard fight with Hep C. He is survived by his fiancée Kimberly Harrison, their baby son, Kilby Jordan Dean Cummings, two step-daughters, his parents Diana and Gordon Cummings, brothers Gordon and Edward and their wives, plus many more family members, friends, and grateful clients.

A service was held on August 5th. Please visit his memorial page:
<http://www.legacy.com/CAN-VICTORIA/LegacySubPage2.asp?Page=LifeStory&PersonId=14805281>

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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

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THANKS!!

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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.

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Controlling what people focus their attention on is how the shell game is played and how magicians use slight of hand to dazzle their audience. They focus our attention on the wrong thing. It is amazingly simple to execute, yet extremely effective. Don't feel guilty. We are all human, but once aware of the deception, we are wiser next time.

Sadly, governments and corporations practice this kind of deception through the news media and information sources, to influence public opinion, covering up what they don't want you to notice and run damage control. Have you ever had to tell a lie to cover up a previous one, and so on, and so on? If they start being open and truthful about HCV and all of the issues, then they would have to admit that they weren't being honest. "O what a tangled web we weave when once we practice to deceive!"

A couple of examples are how they make partial statements like; "60% of new hepatitis C infections occur from IV drug use", and leave out what the other 40% is from, or, "Hepatitis C is a liver disease and can lead to cirrhosis or HCC", and leave out the other, even more imperative diseases it causes. It gives the wrong impression. How can they deal with the issues and burden to public health if they won't admit they exist?

Even more amazing is how the virus HCV is a 'Master of the Art of Deception' in manipulating our immune systems. We're surrounded! I know it's no laughing matter. It is wearisome and disheartening.

The hepatitis C patient community in Canada has learned the hard way to pay more attention to what is being hidden, ignored, avoided and obscured. We have known and argued for a very long time that the popular medical depiction that HCV is a benign infection (asymptomatic), not affecting the infected person's health for 15-20 years, but eventually leading to cirrhosis in about 30% of infected people, is not accurate at all. It only gives a partial view of the overall impact or one aspect. The research that proves otherwise is not new either. I have gone back 12 years or more to verify some of the research for this article and "HCV is Lymphotropic" has been well known since the '80's.

Providing better care, saving lives and confronting the threat to public health more accurately, is a good enough reason to do this. Let's see if we can cut through some of it.

The Virus

"HCV's ability to escape from immune pressure by multiple mechanisms is further evidence that an approach involving agents with both immune stimulating and antiviral activity will be necessary if we are ever to

destroy this "clever" virus. Immune escape by viral quasispecies is the best recognized mechanism, and to this we can now add escape from cellular immunity by induction of apoptosis (natural cell death) in activated T cells. This is a very "smart" virus."— (*Immunology and Pathogenesis of Hepatitis C Virus, Nezam H. Afdhal, MD*)

"Hepatitis C virus (HCV) uses complex and unique mechanisms to prevent, evade or subvert innate and adaptive immune responses and to establish persistent infection..." - (*Hepatitis C virus infection: when silence is deception. - Trends in Immunology 2003, 24:456-464*)

"... [The] Hepatitis C virus was thought to affect only the liver. Now it is generally accepted that it also infects white blood cells (known as peripheral blood mononuclear cells), the lymphatic system and various aspects of the immune system. The effects of HCV manifest body wide. Viruses are troublesome because they may destroy cells directly or may evoke a destructive immune response that can detrimentally affect virtually any tissue. However, everyone who is infected with the Hepatitis C virus does not develop liver injury. And even those with very high viral loads do not necessarily develop liver disease, since HCV infection does not impair liver function in some individuals." —*Understanding Hepatitis C by Dr. Michael B. Wald*

"Cox's team learned that ALT levels were not closely linked with positive HCV RNA tests or in those with persistent viral infection, sex or race of an individual, or the outcome of infection." That viremia frequently precedes ALT level elevation supports the hypothesis that HCV is not a hepatotoxic virus and that factors that come into effect later, such as immune response, are responsible," the research team wrote." —*Andrea Cox, MD, PhD, Johns Hopkins University*

Hopefully we will see these changes in attitude in clinical practice and public information soon, very soon.

HCV is considered by the scientific community to be one of the most sophisticated and "highly evolved" viruses ("Smart virus") known to man, with an almost perfect strategy of survival. It is a Master virus. It is one of the top, most studied viruses in the world. There is no cure.

Apoptosis occurs naturally in the cells of our bodies. It happens at the end of the cell life cycle when the cell is "programmed" to die. In response to attack and to defend itself, HCV has the ability to "turn on" this switch in T cells that our immune systems send to attack the virus. HCV can "turn off" apoptosis to keep certain cells alive (which may be related to the development of can-

cer). This is just one of the strategies that HCV uses to ensure its own survival. HCV actually infects our immune cells that are meant to defend and protect us against infection.

HCV is an enveloped virus and has its own, unique designation of the Hepacivirus genus in the Flaviviridae family. It is not related to the hepatitis A or B viruses in any way. It is ~50 nm in diameter (huge for a virus), with a positive-stranded RNA genome of ~9600 nucleotides. The genome encodes a single polyprotein of ~3000 amino acids that is co-translationally and post-translationally cleaved into 10 structural and nonstructural proteins, and in addition, a recently described alternate open reading frame encodes a short protein of 126-162 amino acids of unknown function. The HCV envelope is derived from host membranes, into which the viral glycoproteins are inserted.

HCV infects B cells (lymphocytes), monocytes/macrophages, dendritic cells and liver cells (hepatocytes) all equally well, where it can induce immune dysfunctions and multiple diseases

The predominant sites of replication are the liver and lymph system (lymph nodes, lymphoid tissue in GI tract, bone marrow and thymus gland), the single largest of these cell reservoirs being the liver, but it has also been found to reproduce in sweat and saliva glands, in other exocrine glands, stomach/intestines, bone marrow and blood, central nervous system and other tissues.

A Problem

This is just one of many problems caused from misinformation and misunderstanding. If people were diagnosed with a disease other than hepatitis, they would not usually be given a screening test for HCV antibodies. They are given the standard or "classic" treatment for that disease and quite often fail or even die. The persistence of the virus prevents resolution or causes recurrence of the disease. If it was known that they had HCV and they were given interferon therapy for the virus, (studies have shown this) they would respond to the classic treatment for that disease or the disease could resolve on its own, if viral clearance was successful.

HCV causes multiple diseases. I have never known of a person with HCV who did not have more than one.

These diseases can usually onset at any time during the course of HCV infection. Some of them can be fatal in 3 to 5 years, and others can present a severe danger or high risk of fatality and/or permanent damage.

To be continued....

PEGATRON TO PEGASYS SWITCH SIDE EFFECTS

by Tanya Frizzle

OK, OK. I know I said that my switch (without a break) from Pegatron to Pegasys incurred no further side effects than feeling a little more tired. My nurse has stated that the people she knows who have taken Pegatron and then switched to Pegasys (with a break in between) have reported that Pegasys is easier to tolerate. I guess I have to change my tune a little.

On the fourth week of treatment with Pegasys, I woke up with a rash—a rash from head to toe! At first I thought it might be my new body wash and cream, but after consulting with my nurse, it is not. It is a reaction to the Pegasys. Ten days later I am still itchy. I bought Reactine (It may affect the liver, according to the list of possible side effects) and the hives have subsided after three days. I had bought another brand prior to this, but it did nothing. In fact, I threw up both days that I took it. This may simply be coincidence. I also bought a huge bottle of Lubriderm to moisturize my skin. Although the hives have subsided, I am still itchy, but it is bearable. I can live with it, but I hope not for the next ten months!

I have also developed new headaches. I had one so bad the other day that I could not go to work in the morning. All I could manage to do was demand that my loving boyfriend jump and get me Tylenol. It helped, but did not take the pain fully away. I have had milder headaches steadily for the last two weeks. They seemed to plateau a few days ago. It is a different type of pain than I've ever felt before, and I hope to never have a headache like that again.

The mild headaches are bearable; it is a side effect I can live with. It's harder living with the extreme fatigue. It makes it hard to get out of bed every morning and go to work.

But I'm a trooper, and do. For me, I feel like not going to work would be like letting the HCV win. I need to feel like I am winning. I do have to keep in mind that, for people with HCV, rest is a needed part of life. If I insist that I feel I need to keep working, then I need to ensure that I get enough rest and relaxation to compensate for that. I think if I had children, I probably would not work, as there would not be enough free time to work, raise children and rest. The choice is up to the individual—what he/she can handle, and how much free time there is to rest. Sometimes it is up to the medication.

Sometimes you have no choice.

My father passed on from HCV, and he had no choice. Work was simply not an option for him when he was on treatment. Let me tell ya, he fought the choice the medication made for him tooth and nail. In the end, it was best for him to stay home and rest.

Although I've had a few more side effects, I have now completed my sixth injection. I know I am lucky, compared to what others are going through on treatment. For those thinking of switching and wondering about side effect differences, there are definitely differences, but the differences for me have not been major.

WHO IS RESPONSIBLE FOR YOUR HCV?

by Tanya Frizzle

When you first find out you have HCV, you walk around in a daze, waiting for somebody to tell you what is next—at least, I did. I saw my family doctor, and she found me a specialist. I met him, and he seemed very kind. I liked and trusted him instantly. I followed his direction, and quickly I was on Pegatron (paid for by my extended medical).

Six months after I started Pegatron, my specialist said my qualitative test showed that I was still positive for HCV and I no longer should take Pegatron. I asked about other options. His answer was to wait—that in five years or so, there might be.

Up until then, I had followed my specialist's recommendations without question. That night at home, I went on the internet and started reading. I do not know why I had not done this before; maybe I was afraid of what I would discover. I was shocked to find out what I did!

My doctor had never done a liver biopsy on me. He had an ultrasound done and told me that was good enough. There was no visible damage. I read that this was not good enough, as an ultrasound may not show the damage already done.

He had also shown me the results of the tests he had done. I did not remember seeing the quantitative results. There was the qualitative test before I started treatment, showing that I was HCV positive, and the qualitative test at six months into treatment showing me I was still HCV positive. There were no tests showing me the viral load. There was no talk of any two log drop—the indicator as to whether the Pegatron was working.

I was furious. I called my dad, who also had HCV but lived on Vancouver Island, so

we did not see the same doctor. We had compared notes all through treatment, and things were different. I thought, "Hey, my doctor is a specialist, and he knows what is right for me, and my dad's doctor knows what is right for him." I voiced my concerns to my dad, and he called his health nurse, who recommended I see a new specialist. She recommended a doctor for whom she had nothing but glowing reviews, both for him and his nursing team.

I was at my family physician's office the next day, to ensure I was correct in my beliefs regarding the quantitative tests, as she got copies of every test my specialist ever did. Unfortunately I was right—no quantitative tests were ever done. My family physician agreed to keep me on Pegatron until I could see a new specialist. She did research to ensure that she was doing everything correctly. She was great.

The first thing my new specialist looked for in my file were the biopsy results. I told him I had never had one. He then looked for my quantitative results, and found out there were none. I told him I was told the medication was not going to work and there was no point in continuing it, since I was still HCV positive at six months. My new specialist advised me there simply was not sufficient evidence to support this. From what he told me and what I read on the internet, the evidence that needs to be collected in order to predict whether or not Pegatron is working is whether or not you have a two log drop in the first 12 weeks of treatment.

Next, we talked about a biopsy. Because of the medication, I was not able to have one, as my platelets are below 70 and have been that way through the entire treatment. We decided I would have one at the end of treatment instead of at the beginning, when it should have been done. How aggressively do I have to fight my HCV? Should I take risks, or should I wait the five years for a new medication? Only a biopsy will tell me this.

My boyfriend was furious when he heard that the correct tests had not been done. I think he was more angry than I. Maybe I was simply in shock.

My problems were solved, though, as my new specialist ordered quantitative tests from old frozen blood samples taken before I started treatment, at my twelve week mark, and at the twenty four week mark. It was determined that I did not have a two log drop. It was also determined that my viral load was low, though, and I was now given options. I could continue on with current

(Continued on page 6)

DIABETES + HEP C

Older people with diabetes have a 2-3 times higher risk of developing liver cancer than non-diabetics. Studying 2,061 patients with liver cancer, the Houston Veterans Affairs Medical Center in Texas found that 43% were diabetics, compared to the 19% who were not.

The WHO has adjusted its estimates of people who die yearly of diabetes to about 3.2 million people. Approximately 171 million people worldwide have the disease; this is expected to double by 2030.

Diabetes is caused by problems with insulin production. While "Type 1" diabetes most often arises in early childhood, "type 2" appears in adults over 40 and accounts for over 90% of all cases. Obesity, eating sweet and fatty foods, and sedentary lifestyles account for the rise in incidence of diabetes worldwide.

Source: http://www.dailytimes.com.pk/default.asp?page=story_14-3-2005_pg6_23

CHEMOEMBOLIZATION

For various reasons, surgery is not always an option for patients with liver cancer. Chemoembolization is a technique offering new hope for these patients. Doctors at Johns Hopkins University have found this technique is safe, can be repeated if necessary, and increases survival rates significantly enough to warrant recommendation that it be used as a standard initial treatment for inoperable liver tumours.

In chemoembolization, a catheter is in the groin, guided with x-rays through an artery to the tumour. Chemotherapy drugs are fed into the tumour to treat the cancer. Tiny sand-like particles are also injected to block blood flow to the tumour and to help contain the chemotherapy drugs to the intended site.

Source: http://www.hepatitisneighborhood.com/content/in_the_news/archive_2312.asp

SUPPORT GROUPS

Support groups improve health and increase overall quality of life for people with chronic hepatitis C. With its accompanying loss of control, stigmatization, isolation, and uncertainty, hepatitis C has a great impact on the lives and well-being of those living with the virus. Research supports the importance of the role of social support as an integral part of the treatment process. Gastrointestinal nurses can play an important role in ensuring patients have access to needed support that is shown to improve health outcomes and help patients enjoy higher quality of life.

Source: *Cormier M Gastroenterol Nurs. 2005 May-Jun; 28 Suppl 1: S4-9 The role of hepatitis C support groups.*

CLINICAL TRIALS *by Tanya Frizzle*

INJECTION ONCE A MONTH

Current interferon treatments involve a weekly injection that can cause flu-like symptoms. A new interferon in development, called Albuferon, is injected once a month, and does not produce as many flu-like symptoms. This new drug stays in the body longer and is more uninterrupted. Although it is not stated what the rate of success of the new interferon may be if it hits the market, it would be nice to not have to inject weekly or have as many side effects.

Source: http://hepatitis-central.com/mt/archives/2005/06/once_a_month_in.html

VX-950-- HOPE

New trials for Vertex's VX-950 were conducted over a 14 day period involving 34 people with HCV genotype 1. Seventeen, or half of the people in the trial, went below viral detection! Five of these seventeen did return to having detectable virus a month after stopping VX-950. There did not appear to be many side effects, but keep in mind that they only tested over a 14 day period. There may be long term effects. Phase 2 trials for VX-950 will involve testing over a one- to three-month period, and will involve testing the drug on its own and in combination with an interferon.

Source: http://hepatitis-central.com/mt/archives/2005/05/vertex_update.html

PEGINTRON & REBETOL ONLY 24 WEEKS?

Genotype 1 and a low viral load may allow one to be on a weight-based Peginteron and Rebetol (Pegetron) for only 24 weeks, instead of the current recommended 48, as approved by the committee for Medicinal Products for Human Use (CHMP). A study showed that the 92% of a sub-group of people with genotype 1 and low viral load who had a sustained virological response did so within 24 weeks of treatment. This sub-group formed 41% of all those on the trial.

Source: http://www.pharmaceutical-business-review.com/article_news.asp?guid=74F46834-DA25-4B06-BF1A-D4F293A3AD6D

PEG-INTERFERON MAINTENANCE THERAPY

A study was conducted by Dr. Nezam Afdhal of the Beth Israel Deaconess Medical Centre to see whether it would be better to take Colchicine (it is an anti-inflammatory and antifibrotic) or Peg-Interferon alpha-2b (interferon therapy) for maintenance therapy for HCV patients who did not respond to current medications. The study is not yet complete, but current results show there was a 50% less chance of reaching liver failure or transplantation for the patients taking the Peg-Interferon rather than the Colchicine. The dose used in the Peg-Interferon portion was one-third less than a regular full dose. Also, it did not become less effective with time and there were fewer side-effects than full dose.

Source: <http://www.hepcassoc.org/news/article99.html>

ACETAMINOPHEN SAFE?

McNeil Consumer & Specialty Pharmaceuticals (who markets Tylenol as well as Motrin and Aspirin) has released a report stating "that acetaminophen at recommended doses, when taken as directed, can be used safely in patients with liver disease and is a preferred analgesic because it lacks the gastrointestinal toxicity, renal toxicity and inhibitory actions on platelet aggregation associated with aspirin and other nonsteroidal anti-inflammatory drugs."

People with liver disease, it is claimed, are capable to metabolize acetaminophen without amplified chances of hepatotoxicity. Keep in mind not to exceed recommended doses and to use as directed by your physician.

Source: <http://www.hepcassoc.org/news/article110.html>



(VERY SAD STORY—*from page 1*)

So, this admission started a 9 week stint in two hospitals: three weeks at Richmond in ICU and 6 weeks in VGH. He was on a ventilator at Richmond for 2 weeks and was not supposed to come off, but he did. I transferred him down to VGH where he developed a reaction to the antibiotics and got Steven-Johnson Syndrome, which is 3rd degree burns all over his body. He survived this, but lost 75 pounds in the process.

Joe survived this horrific time and came home on June 9th to await a liver transplant. He went in and out of hepatic encephalopathy for 3 1/2 weeks, until July 4 at 4:50 AM, when the call came that they had found a LIVER. We were ecstatic. This could not have come at a more opportune time. Joe would have gone on life support that week.

He underwent 6 hours of surgery on July 4th, and came out, no problem. Unfortunately they have a protocol that says the patient is taken off the ventilator within 24 hours. Well, my husband was very sick going into the operation, and they did not stop to think. He tried to breathe for 2 1/2 days, and then they put him back on it. He was okay for 6 days, and then slipped into a coma. The doctors at VGH ICU didn't know what was wrong. Was there an infection, or what? Joe also had MRSA, lung abscesses, kidney failure and a bit of liver rejection.

They did CT scans of his chest, EEGs, CT head, everything to save this man, but in the end, the MRI showed a bleed in his brain stem and he never woke up. He was put on palliative care on Monday, August 1st and died in my arms on Saturday, August 6th.

It has been a horrible 4 months for my son Jason and me. Joe was so sick, but somehow fought against all odds to survive, but in the end, it was too much for his brain and body to take. Everyone involved with Joe's care is devastated about this loss. They did everything possible to save him.

I blame the interferon completely, because he would have gotten a liver transplant without trying to get rid of the Hep C.

He was only 50, and left behind a life half lived.

Heidi Stokes

ERROR

In the August 2005 edition of the *hepc.bull*, the article, "DON'T INTERFERE WITH MY INTERFERON" contains a typo that was pointed out to me by Brian in Merrit via a long distance call. It reads 2 billion people worldwide. It should read 200 million people worldwide. —Brad Kane

(SHARON GRANT—*Continued from page 1*)

"We will all miss her deeply. Sharon can finally rest without pain. Missed, but not forgotten, and the group will continue to run in Remembrance of Sharon....."

Brad Kane, Princeton Support Group, sent this:

"No man is an island, entire of itself; every man is a piece of the continent, a part of the main. If a clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as if a manor of thy friend's or of thine own were: any man's death diminishes me, because I am involved in mankind, and therefore never send to know for whom the bells tolls; it tolls for thee."

—John Donne

She fought and worked hard for a long time and was dedicated to the cause of people with HCV.

We were counterparts, in the sense that she did her support work in the north Okanagan and I in the south. We always held a mutual respect for each other. We met occasionally at high profile conferences and learned that we both shared an appreciation for "common sense". She was tough, and she made me grin.

Thanks be to God for giving us Sharon Grant.

CARE-LINE

CARE-Line, is available in Canada for some people receiving Pegatron. 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>

CONFERENCES

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

(WHO IS RESPONSIBLE?—*Continued from page 4*)

treatment, switch directly to Pegasys (with no break), or stop treatment, get a biopsy, and then decide if I wanted to continue treatment for maintenance until a new medication comes along. There were more options other than to wait! It would have been an easier decision had I had the biopsy results in my hand. I chose the second option.

Whose fault was it that I did not get what I consider correct medical treatment from the beginning? A large part of me wants to blame the specialist. I know that this is not entirely correct. It is my responsibility to take care of myself. I need to read and learn about HCV. I need to keep on top of it and not wait for others to do it for me. Yes, you should have a great specialist, and he/she should know HCV inside and out, but if I had done the correct research in my first month of seeing my specialist, I would have realized that things were not being done correctly. I would have asked the right questions and realized that he was not the doctor for me, and moved on. I am happy that I did the correct research, and now I am actively in charge of my HCV.

If you are reading this in the *hepc.bull*, hopefully you are in charge of your HCV. Find out what tests need to be done, how you qualify for treatment, what needs to be monitored, what new medications are in the pipeline... Only you can ensure that you are being taken care of correctly. Do not feel bad for switching doctors. You need to do what is best for you. I felt like a betrayer, going to a new specialist, but I soon found out it was the best choice for me.

HepCBC

ANNUAL GENERAL MEETING Part II

Wednesday, Sept 7, 2005
7 PM

Woodward Room
Begbie Bldg
Royal Jubilee Hospital
Victoria, BC

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

AGENDA:

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

LETTER TO THE EDITOR: MANNATECH

Have you ever heard of Mannatech and/or "glyconutrients"? They are nutrients which, it is alleged, we do not get enough of because of soil depletion, poor diet, and so on. I believe they're harmless; just a sort of concentrated food. The stuff is extremely expensive and the company makes a big profit through a multilevel marketing arrangement in which individuals who sell enough can get free product for their own use. Maybe there's money in it for them, too; I don't know. Anyway, I had been aware of it for a long time, but was never in a position to get into it. Sick people I know don't have the money, and nobody I know is into marketing things to each other. But a well-meaning cousin talked me into trying it for three months, and even somehow managed to foot most of the bill. The result was negligible. No change in my enzyme levels, energy level, or any other aspect of my health. So if you or anyone you know is wondering about trying this product to cope with the effects of Hep C, I think they would be wasting their time. This is not to say that it is useless in treating every disease. I have heard several testimonies that it has helped a lot with asthma. And originally, it was a homecare nurse who advised me to try it, so perhaps she had seen it work in other cases. But not, I think, for Hep C.

—Will Lawson

Editor: I can only speak on a personal level. I had the same experience. A friend was selling it, and I had a hard time saying "No." I have my LFTs done monthly and have had for years. The Mannatech did nothing to reduce them. It didn't make them worse, either.

PEGASYS APPROVED FOR HBV

On July 28, 2005 PEGASYS became the first pegylated interferon to be approved for the treatment of chronic hepatitis B by Health Canada.

About 288,000 Canadians are infected with hepatitis B. Those who are chronically infected are at risk for cirrhosis and liver cancer. (Hep B is especially dangerous for the many who are co-infected with Hep C.) PEGASYS, already approved in Canada for hepatitis C, gives hope of a treatment-free life for those with Hep B. Results of clinical trials published in the *New England Journal of Medicine*, showed that PEGASYS produced more sustained responses in patients with chronic Hep B, compared to lamivudine, which only attacks the virus. PEGASYS attacks the virus, and stimulates the immune system, as well.

Source: Press Release August 8, 2005—Health Canada Approval Makes PEGASYS® the First and Only Pegylated Interferon Indicated for the Treatment of Chronic Hepatitis B

THE RIGHT TRACK

The face in the mirror, staring back at me
Is not the person I used to be
Shattered and hollow, where did I go
I want to return, I want to be whole
My life is not my own anymore

I did not ask to be so ill
This will not go away simply by taking a pill
I will come back, and be better than before
My blood is diseased, but that is all
I still have a body, mind and soul
Look into that hollow shell I have become
I can return, filled up by your love

What's happened to me can happen to you
No reason, No clues, No fault of my own
People hear "Hep C" and think the worst
We need to learn to see the 'person' first
A disease is just that, a virus or more
It enters unwanted, we do not open the door
We must heal ourselves with love and respect
It starts today.....

I'M ON THE RIGHT TRACK.

I wrote this poem 8 days after my diagnosis, and am still trying to come to terms with this disease and how to live with it. I found out I have had it for 4 years, just 4 days after my husband passed away, on the day that would have been his birthday—not the best of time of year for me to find out this kind of news! (Not that there is any good time.)

I am one of those people for whom there is no known reason for contracting this, other than I have worked in health care for 20 yrs, before they used universal precautions. Gloves were at that time too expensive for us to use on a regular basis. Now how much am I going to cost health care system????

*"Puff"
Aug 13 2005
Day 8 post-diagnosis*

COMPETITION!

HepCBC is looking for writers for the October 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 August, **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 ambrorse@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, eriseley@shaw.ca or Lisa 766-5132 ljmorte@telus.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 Morrisette, 604-517-6120 dmorrisette@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 lise 565-7387 lise.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: Healing Our Spirit—HCV and HIV education, support for Aboriginal People in BC. 100 - 2425 Quebec St. Contact 1-800 336-9726, info@healingourspirit.org www.healingourspirit.org

VANDU Vancouver Area Network of Drug Users: Satellite Hep-C group, each Thurs. 2 PM, HCC, 166 E. Hastings. Bus fare & snack. 604-658-1224. **H.A.R.M. group** each 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 Svendsen 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. 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 ext. 2919

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

HepCBC is looking for a new, bold logo. We are prepared to offer \$100.00 for any logo that is used on our website or bulletin as a result of this contest. To enter, please send your logo design to info@hepcbc.ca

QUEBEC:

Arundel Contact Andy Aitken chn.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@nbnnet.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 hosc@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 wahas@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 orthomas@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, hcr@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