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Canada's Hepatitis C News Bulletin

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Members of the BC Hepatitis C Collaborative Circle, the HeCSC BC Chapter Network, and others, came together in Victoria for the "Hepatitis C: Silent No Longer" conference in Victoria, on Nov. 13-15. Many of the presentations and meeting notes are available on the www.bchepcouncil.ca web site.

In related news, the next Regional HCV Capacity-Building meeting will be held in Kamloops on December 15th. For more information, contact Ken Thomson at ksthomson@direct.ca or 250-442-1280.

—Ken Thomson

A second round of follow-up meetings to examine progress and plan next steps are planned for March 2005. The new Hepatitis C Council of BC is being formed, people are working together across the province to improve services for hepatitis C, and promising things are happening across the country, but nothing is guaranteed, and we all need to pull together and make the effort, if we want to succeed.

I was able to attend parts of the Conference in Victoria over the weekend, and was very impressed with how it was set up. Treatment was explained. Attendees were taught how to write letters advocating for improved access to treatment, and how to lobby for that access as well. Work was done on setting up the Council (which was "The Circle" and will probably have yet another name), so it can be the voice of Hep C sufferers throughout BC. Thank you, Ken, Erik and Stacey, and thanks to the sponsors for contributing to the Hep C community of B.C. Here are my notes from the Conference—
Joan King

[Please see next column over]

Treatment issues /Pharmacare Overview HEPATITIS C: SILENT NO LONGER November 13th, 14th & 15th, 2004 Victoria, British Columbia

The BC Hepatitis C Council's *Fall 2004 Skills, Education & Awareness Conference* held in partnership with the BC Network Project

Jo-Ann Ford, RN, MSN, the speaker, is with the BC Hepatitis Program, which includes Drs. Anderson, Erb, Steinbrecher, and Yoshida, among others. They do both clinical and laboratory research, and are overseen by the UBC Ethics Committee. Ms. Ford imparted her knowledge about some basics of Hep C, and the latest treatment trends, including current trials, treatment strategies, and future research trends.

The speaker pointed out firstly that a positive antibody test does not make one immune to the disease. Exposure to the dis-

ease doesn't give one lifelong immunity. 70% of HCV+ people have no symptoms.

There is an incidence rate of 2 to 3% of liver cancer per year of infection. A classic study shows progression after 20 years of infection in 20% of patients. The use of alcohol (more than 3 drinks a week) makes progression faster, as does co-infection with HIV. Most patients have "mild" disease.

The first step in treating a patient is confirming the diagnosis, which is done by testing for antibodies, and testing for the actual virus (RNA). The patient is also given ALT and AST tests, and liver function tests, such as albumin and clotting times. A patient is not always given a liver biopsy.

(Continued on page 3)



RAMONA RONDEAU Dec. 29, 1953-Oct. 15, 2004

Ramona Rondeau passed away on October 15, 2004, at age 50. Although born in Alberta, she lived most of her life here in BC, and left behind three grown children and three grandchildren to honour her memory. She is survived by her parents and her boyfriend, John Black. An artist, Ramona is remembered as a friendly, happy person who helped everyone in need. She was diagnosed with hepatitis C many years ago, and died of liver failure and pneumonia. This picture was a favorite of her family, and was taken in February of this year.

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HOW TO REACH US:

EDITORS: Joan King, Will Lawson
PHONE: TEL: (250) 595-3892
FAX: (250) 414-5102
EMAIL: iking@hepcbc.ca
WEBSITE: www.hepcbc.ca
HepCAN List <http://health.groups.yahoo.com/group/hepcan/messages>

HepCBC
306-620 View Street
Victoria BC V8W 1J6

LETTERS TO THE EDITOR:

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

NEW!!!!

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: (250) 595-3892, info@hepcbc.ca

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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, The Ocean 98.5 for their Public Service Announcements, Durhane Wong-Rieger, Bryce Brogan, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Schering Canada, Brad Kane, Chris Foster, Darlene Morrow, Will Lawson, Judith Fry, and the newsletter team: Jay P. and Diana L. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

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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.

Give us your name, tel. no., 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.

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(CONFERENCE—Continued from page 1)

The biopsy, used more in the US than in BC, is used to confirm the diagnosis and to see how severe the scarring and inflammation are. It can show the short and long term prognosis and help the doctor advise the patient about the current state of the disease. It can also evaluate other liver disease, and help decide on treatment. There are risks involved. One in 1000 has bleeding, and one in 10,000 die.

The patient at the clinic is given basic health information, including nutrition, lifestyle, keeping active, alcohol abuse, alternative medicine (discouraged during HCV treatment), smoking, and getting support. Smoking and obesity hinder treatment. Members of the patient's support system are encouraged to attend appointments. Patients are given information about the need for treatment, the nature of the side effects, and the possible outcomes. They are told about the necessity of sticking to the treatment plan.

The patient who chooses to not be treated is taught how to avoid more injury by eliminating alcohol use and obesity, and taught about the need for exercise, healthful food, stopping IV drug use, and getting Hep A and B vaccines. They get frequent ALT/AST tests, and may be given a biopsy. The risk for people with HCV of getting Hep A is significant. In one study, of 17 HCV+ people who got HAV, 7 developed liver failure, and one of those died.

To treat or not to treat is a complex issue. Points to consider are how likely the patient's disease will progress, how likely he/she is to respond (genotype, viral load), how high the risks of adverse events are in that patient, the patient's symptoms, and the patient's wishes. The goal of treatment is not just to get rid of the virus, but also to stop progression of the disease. Also, studies have shown that there is a lowered risk of liver cancer in those who have completed 6 months of treatment, with or without SVR. Treatment can improve the condition of the liver, and may lead to SVR. One year of treatment may give the patient 3 more years of life. It can normalize enzymes. To continue treatment, the patient must have a 2-log drop in viral load at 6 months for Pharmacare to approve it.

Special situations exist in treating patients with normal ALTs, which is about 30% of patients. Most of these have mild disease, but some have significant fibrosis. Treatment has been shown to be effective in these patients. Another special situation is re-treatment. Non-responders can be considered

for re-treatment, and the decision should take into consideration the type of previous therapy, the patient's tolerance to that, and whether the patient was a non-responder or a relapser.

Compliance with treatment is critical, and the patient is monitored with a PCR at week 12 and again at week 24 if the first result was positive. In the case of serious side effects, it is better to reduce the dose than to stop treatment. Adverse events cause 10 to 14% of patients to discontinue therapy.

The treatment can cause flu-like symptoms, such as headache, fever, chills, myalgia and arthralgia, and can cause bone marrow suppression, anemia, neutropenia and thrombocytopenia. It can cause depression, insomnia and irritability, and symptoms such as nausea, diarrhea, anorexia and weight loss. It can cause thyroid problems and psoriasis, as well as injection site irritation. To combat symptoms, the patient should drink lots of water, and should consider taking the injection at night. The patient is assisted with the first injection, and seen after the second. He/she is monitored for possible thyroid problems, psoriasis and injection site irritation. Side effects of ribavirin can include anemia, teratogenicity (the patient must not become pregnant or father a child within 6 months of starting or ending treatment), cough/dyspnea, rash/itchiness, insomnia, and anorexia.

There are strategies to combat side-effects. Almost all patients have complaints during the first month of treatment, and then they seem to improve. The shots should be taken at night, so the patient can sleep through the worst part. Taking Tylenol, but only as much as necessary, can help, and balancing one's life is beneficial, so as to get exercise and good nutrition. Setting priorities is a necessity.

Ribavirin makes 54% of patients anemic. Ways of dealing with it include dose reduction, withdrawal from treatment, or the use of erythropoietin, which is not often covered by Pharmacare or prescribed. It costs about \$460.00 a shot, given once a week, and is taken only as long as necessary. The doctor may ask the patient to continue only with interferon. The doctor should ensure that the patient has adequate stores of iron, vitamin B12 and folic acid, and should monitor side effects.

Neutropenia occurs in many patients because of the interferon, and is treated with dose reduction. Neupogen can raise the white blood cell count, but it isn't covered, and is expensive. Two shots a week of 300 mcg are needed.

Strategies to help the patient complete treatment include telling him/her about the management plan, and ensuring support from the family or support network and support from health care providers. The patient must attend follow-up visits and should time his/her intake of medications; for example, ribavirin should not be taken late at night.

Future research will hopefully include studies about the treatment of side-effects such as anemia and bone marrow suppression with epoetin and GSF, and less toxic drugs. There are studies being done with non-interferon-based antiviral agents, phase I and II by Vancouver doctors Steinbrecher and Yoshida. There is research in transplant recipients and the use of pegylated IFN and ribavirin, and in non-responders.



Hep C 101

Saturday December 4th 1pm - 5pm

Royal Jubilee Hospital: Woodward Room, Begbie Hall, 2101 Richmond Ave at Fort

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HOW TO START AN HCV SUPPORT PROJECT:

PART 2

Alan Franciscus, Editor-in-Chief
HCV Advocate

Part one of this series (October 2004) discussed the need for hepatitis C specific support groups. In this article I will discuss important questions potential support group leaders need to ask themselves even before starting a support group, and provide some pointers to help identify appropriate resources. There is no reason to "go it alone."

Why Do You Want to Start A Support Group?

The majority of people who start an HCV support group have very little prior experience with group facilitation or a medical background enabling them to deal with the questions about hepatitis C and psychological issues that may be needed to run a successful support group. It is important to be aware of these limitations when you start a support group. It is always easier to take on the demands of a support group if there is help available from others with a medical background and from those who have experience with running a support group. You do not need to be the expert or a person living with hepatitis C; but it is important to surround yourself with people who can aid you when you face difficult questions or situations.

Motive

If you are developing a plan of action for starting a support group it is important that you consider your motive first. It can be very difficult to be honest with yourself about the motivation for running a support group, but it is a very necessary step. Ask yourself these questions:

- Is it to get your own needs met?
- Is it to help support others?
- Is it to help yourself and others?

There is nothing wrong with starting a support group to get your own needs met, but if you are not careful it can sabotage the most important reason for a support group—to help others. Another essential purpose of a support group is to help empower other members to make important life choices, which will be difficult if you do not identify and serve the needs of the entire group, not just your own.

Are You Open-Minded and Free of Bias?

Everyone has certain points of view or biases that could potentially affect the level of support that should be available to all support group members. Ask yourself these

questions:

- Is there the possibility that I am biased?
- Would I be open to talking about any issue as it relates to hepatitis C, including:
 - o Interferon based therapies
 - o Alternative and complementary therapies
 - o Life style issues
 - o Gender
 - o Sexual orientation
 - o Substance use

-Can I accept all individual members regardless of their ethnic and cultural backgrounds?

-Am I biased concerning the mode of transmission? Will I accept others who believe they contracted hepatitis C from a blood transfusion, injection drug use, or sexual transmission, etc?

-Can I put my ego and "my issues" aside for the benefit of the entire group?

All of these questions are extremely important questions that need to be answered, and the answers will be helpful in guiding you in the process. More importantly they will help you fine tune your goals.

Identify Experts

Members of a support group look at the facilitator or support group leader as an expert in hepatitis C. This can be troublesome unless the facilitator has a medical background and is thoroughly educated about hepatitis C. However, it may be important from the beginning to emphasize that the role of a facilitator is to assist and direct the support group and is not intended to supply expert medical advice to the members. This should be left to patients' medical providers. It is not even recommended that the facilitator become the 'expert' since it could potentially derail the purpose of a support group—to support and guide others. This requires that everyone in a support group become actively involved in the process and take ownership of the group.

Having said this, it is important that a support group leader learn as much about hepatitis C as possible, as well as become knowledgeable about running or facilitating a support group. Information about hepatitis C is freely available from many sources, such as the Internet, various governmental agencies, HCV non-profits and published books on the subject.

Identify Resources

It is important to develop resources to aid you. You may want to develop a relationship with a local health provider who can serve as a consultant to the support group. It would also be useful to have as many experts as possible to consult with on a wide range of issues, and key people who could potentially present information to the group members.

Medical institutions and non-profit agencies may also provide sponsorship and free space to hold the meetings. This would also help with advertising since the agency could advertise to their clientele.

Do You Need a Co-Facilitator?

It can be very difficult when you realize that all of the group members' support falls on your shoulders. It would help to ease the pressure if you identify a person from the beginning who would be willing to step in or share in the responsibility of running a support group. The benefits of having a co-facilitator will be discussed in more detail later in this series.

Learn More about Support Groups

There are many resources to help you learn more about running and facilitating an effective support group:

Attend other support groups in your area specific to hepatitis C. This will help you learn how others run a support group and will help you find out if the needs of the HCV population in your area are being served. If the need is being filled by another group, perhaps the best use of your time and energy would be to help an existing group. You may also find that certain people are not being served. The potential for HCV support groups is unlimited and many more specific groups can be started to help support the HCV community. These may be groups that serve Veterans, family members, substance users, or any other group with specific needs.

Visit and attend other types of support groups. There may be 12 step meetings or other disease specific support groups that would help you understand the support group process and how to support people with different needs. It is important, if you do attend other groups for research, that you let them know why you are attending. There is a certain level of trust that needs to be honored at all times.

Publications on support groups will help guide you through the process of starting a support group.

Local agencies may offer services or seminars on running a support group.

Recommended reading:

The Support Group Sourcebook, by Linda L. Klein

Self-help and Support Groups: A Handbook for Practitioners, by Linda Farris Kurtz
They are both available at Amazon.com.

Part 3 of this series will discuss the importance of establishing the type of group and factors such as group size, length of the meetings as well as the physical space needed to run an effective support group.



TREATMENT

By Jay P.

EPOETIN ALFA

Interferon epoetin alfa /ribavirin treatment causes acute anemia in some HCV patients. The onset of acute anemia in turn has traditionally called for the reduction or even discontinuation of ribavirin dosing, and, ultimately, poorer responses to treatment.

Several important studies come to the conclusion that these obstacles to successful treatment are alleviated by once-weekly administration of epoetin alfa to the combination therapy.

Well tolerated, epoetin alfa causes only mild side effects (headache and nausea). Adding 40,000 IU once a week of epoetin alfa increases hemoglobin, effectively removing the need to reduce or discontinue ribavirin as a result of treatment-induced anemia. These findings are significant enough to encourage all medical professionals to consider the addition of epoetin alfa to all recipients of combination interferon/ribavirin treatment.

The alleviation of anemia improves quality of life for patients, and the ability to maintain ribavirin dosing increases the likelihood of successful outcomes to treatment.

Sources:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=14638354

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15131791

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15117320

G-CSF

Hope for those with advanced liver disease, which has been considered to be a predictor of poor response or a contraindication to treatment altogether, is offered by a study conducted by the Oklahoma Transplant Institute.

It has been found that adding G-CSF during interferon therapy increases white blood count levels, promising successful treatment and prolonged remission, but not disease clearance, to those previously excluded.

Source:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=8847044

WARNINGS

By Jay P.

DIALYSIS MACHINES

A study in Iran proves that the risk for contracting HCV from hemodialysis machines increases up to nearly five times when those machines are shared with HCV patients.

The study randomly selected dialysis patients, some of whom had HCV and some of whom did not. Each group was given dialysis on machines either dedicated to HCV patients or machines that were used by everyone.

Using dedicated machines decreased new infection of HCV in dialysis patients, from 5.7% to 1.3% in the second follow-up.

This study demonstrates the importance of machine dedication in globally-applied measures to reduce the spread of HCV.

Source: *Abdollah S., et al BMC Nephrol. 2004 Oct 7;5(1):13 The role of hemodialysis machines dedication in reducing Hepatitis C transmission: A multicenter prospective interventional study.*



ATTENTION: ARTISTS

We at HepCBC are 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. The deadline is extended to December 15, 2004.



LETTERS TO THE EDITOR

Hi: I would like my voice to be heard on the tainted blood scandal. I had multiple transfusions in 1994, so I was outside the 1986-1990 window frame, but to hear there is a surplus of funds left over, I feel I should be entitled to some compensation, and not have the money wasted on courts and lawyers. I do not blame anyone, for it was my choice, which was against my wife's and daughter's beliefs; at the time, they were practicing the Jehovah Witness doctrine of receiving no blood.

Besides being tired and having stiff joints and lack of stamina, do we have to watch the government use the surplus of funds available go through the courts and lawyers, when we are the ones in need? I don't blame anyone but myself, but if there are funds left over, I would like to see them used wisely so we can get on with our lives in a decent manner and not be poverty-stricken individuals. Keep up the fight.

Terry MacArthur

Dear Editor:

If you really want to get things done, try this: Write your story down and email it to all MPs, the same story, over and over again. Be direct, and ask them questions as I did. Get as many people as you can to do the same. Show them how tainted blood has affected the lives of those outside the range of adequate compensation.

Here is the website of all the MPS for Canada:

<http://www.parl.gc.ca/information/about/people/house/mpscur.asp?lang=E> Click on the name. It will pull up his or her picture. Click on contact information. Scroll down and there is an email address. Do this for every MP. If you get a couple thousand people doing this, it will have an impact. Here is my letter:

I was born with glycogen storage disease, a genetic liver illness. In my family, 2 out of 6 siblings have it, including me. I had a blood transfusion in April 1984. At that time, my father asked about having his blood saved for me, and was told that the blood went into a general blood bank, going to whom needed it. We were assured the blood was safe.

That other brother never had a blood transfusion. Today, he's normal, and healthy. In September, 2002, I was tested and told I

(Continued on page 6)

(LETTERS TO THE EDITOR—Continued from p. 5)
had hepatitis C. Odd, eh?

In the late 80's early 90's I complained of stomach pains and severe joint points. My heart would race. I would get dizzy, and did not feel well. My red blood count dropped as low as 6.8, which means I could have dropped dead.

Meanwhile, I had several specialists. One, whom I saw since I was little, said to me that they knew all the problems with me were linked to my blood. He said that I would not want to be tested--that if I knew I had tainted blood, it would ruin my whole life.

When I complained, he told me I was too young to be having those types of problems. Again, it was blamed on my liver illness.

Try to get a job when you look white as a ghost. I was asked by interviewers if I was okay. If you don't tell them about the illness, they will find out. If you do tell them, they say goodbye. Yes, they can find out!

I will never get a full time job. I have damage to my liver, which is being blamed on the liver illness with which I was born. I am anemic. I sleep a lot. Literally, I get pains in my liver, and there are times I get up in the middle of the night with my knees, ankles or liver hurting.

I will never have a pension. At age 41, I live at home with my parents. What woman wants a relationship with a guy that has illnesses? I have been called lazy and told I don't want to work by friends and family, and mocked by others.

I took the Ontario payment of \$25,000 dollars. I owe my parents a fortune. I probably will be on the street at sometime in my life, thanks to the government and the Red Cross.

In 1991 they had a test. I was at high risk, since I was born with a bad liver, had blood transfusions, and it took 11 or 12 years before it would be known that all the pain was not in my head, and that I was not lying about it!

When I found out in September 2002 that I had gotten tainted blood, I called KPMG. They said the first payment went out in April 2002. They opened a file for me, gave me a number and told me to go to the website, print the papers, and have them signed, but I never sent them. My lawyer said if I took the KPMG settlement, I would lose my right to sue.

After several months, he said he had to pass on the case, due to time constraints. I got another lawyer. I got all my files, and did much of the calling. I made an agreement in front of my parents that he would take 20 % percent of what I get. If didn't get anything, he got nothing, but I would have to pay dis-

bursements.

Last month, October 2004, I got a letter from KPMG. The envelope had my name and address typed on it, with my lawyer's name hand written above mine. Inside it had my name, and it is addressed to him, as well. He said he did not get a copy of it. Odd.

The doctors have been served, and legal action was filed with the Ontario Supreme Court prior to this. In the doctors' lawyers' opinion, I do not have a case. Basically, I am eligible for the KPMG monies. That statement is mentioned several times in the letters.

After contacting two other lawyers to no avail, I contacted KPMG, and asked them if taking the monies bar us from suing. Their reply, in one word: YES. I told them to put that in a formal response, email it to me, and email it to my lawyer. I got a reply from my lawyer, telling me to do nothing. I was asked how much the KPMG settlement is worth, and if I got any other monies. I told the lawyer I received funds from the Ontario government. He already knew this. Before I took the money, back in December 2003, he was contacted and informed about the Ontario payment. He was told to make sure that I would not lose the right to sue by accepting it.

I contacted KPMG, and they told me the first payment was \$6500, the next will be half of that, in 2004, and the last in 2011 will be half of the 2004 payment, if there is any money left.

That was about October 26. I called the lawyer, talked to his secretary, just to talk, instead of email, because things can get confusing. On October 29th, the lawyer said to take the money. Basically he is dropping me as a client, but he's not that direct. He was more direct on November 1st, when the package was supposed to be sent to KPMG.

What got me was who at KPMG got to my lawyer? I am by no means wealthy. I need legal help. I need someone that can win, do it on contingency, and can get a hold of doctors that can or do know about my liver illness and hepatitis C.

The lawyer said the case would be costly, lengthy, and at least two more years before it was resolved. He knew all this over a year ago. He even said that he might have to get doctors from the States to testify.

KPMG monies are about the Red Cross, which was in many ways is government related. What happened in 10 or 11 days that scared my lawyer off, that made him run? What is the government up to? What kind of manipulation is going on? There is huge money involved, with the lawsuit, and

with tainted blood monies.

The simple fact is, if MPs were to live on, say, \$7000 a year, not the typical minimum of \$136,000, plus taxable and untaxable benefits, I am sure the MPs would have their own interest at heart, and correct the situation. Instead, they complain about this or that, to make it look nice to the public, but they don't give a darn about anyone else's problems unless it hurts their pocket books.

You know, \$500,000 dollars plus medical coverage for the people, for anywhere in the world they might be, plus, funeral expenses, plus educational training, would be well spent. The government could easily afford to put \$200,000,000 million in a special fund for the 10 years.

The government wastes vast sums of money on gun registries and bad military equipment. It adds an extra zero or two to a steamship line that the prime minister owns, and strangely enough, all that is okay. But allowing the Red Cross to be fair and compensate people with illness caused by their failure to control and regulate the blood supply, which the government oversaw, seems to be wrong!

You people have no idea what damage poor health, and bad blood can cause. If each one of the MPs had it, then they would change the rules. One starts to question the Canadian concept of fairness.

The politicians make the laws, the judges oversee them, and police enforce them. What's the average Canadian to do?

If all the politicians had to give up an arm to be a politician, would they? Would they work to change the law so that it would be to their benefit? Of course they would.

How many of you politicians were affected by tainted blood? How many were born with a rare liver illness? How many still live with mom and dad, who are seniors? How many borrow money off mom and dad, because of their circumstances in life? How many are in their 40s now, and say, hell, I might even end up on the street in years to come? If the politicians looked out for the interest of those who are wronged, instead of their huge pay raises, maybe this country might be great again!

Remember you are elected, you are there to serve the people, and if the government is responsible for problems it caused that hurt anyone, such as tainted blood, you have a responsibility to act, to set things straight, to correct what was messed up in the past.

Sincerely
J. S.



FROM SILENCE TO VOICE:

A QUALITATIVE GLIMPSE INTO THE LIVES OF PEOPLE LIVING WITH HEPATITIS C

Every day we learn more about hepatitis C, yet few academic studies exist into the experience of living with it. To address this, the Canadian Institutes of Health is funding a national study of people living with hepatitis C. Two professors of political science, Michael Orsini, University of Ottawa, and Francesca Scala, Concordia University, are the principal investigators for *From Silence to Voice: a qualitative glimpse into the lives of people living with Hepatitis C*. By interviewing people with hepatitis C, researchers hope to better our understanding of the Canadian situation. Findings could inform future health policy directions, better reflecting the needs of those living with it. Put simply, *From Silence to Voice* wants to hear your story.

Wherever possible, face-to-face interviews will be held. If this proves impractical, interviews can be done by phone, at no cost to participants. The interview ranges from a discussion of your experience of hepatitis C to considering efforts to address it. While attending the recent "Silent No Longer Conference", Victoria, research assistant Michael Graydon was able to interview six people. Interviews take about 90 minutes, and Mr. Graydon is planning to be in the Greater Toronto area for several days in early December. Early in 2005 we hope to have scheduled interviews on the east coast, in Quebec and on the Prairies.

The stories of those living with hepatitis C are multifaceted. Researchers are acutely aware of the need to respect—and take measures to protect—your privacy. Participants may allow us to: a) quote from the interview and identify the speaker; b) quote from the interview but conceal speaker identity; or c) neither quote directly nor identify the speaker. You may withdraw from the interview at any time or decline any question. As an academic study, the rigour and presentation of findings is held to the highest ethical standards. The research is intended for scholarly publication only, and any information you agree to provide will not be shared with others.

If you have any questions or require more information or are interested in participating please contact project research assistant Michael Graydon at:

cihs_hc@yahoo.ca



hepc.bull

CARE-LINE

A limited patient assistance program, called 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.Slide1>

HEPCBC INFO SESSIONS

HePCBC in Victoria, BC, is offering moderated 8-session pilot groups for those who are infected with hepatitis C. Please sign up, leaving your name and phone number at 250-595-3892, or email info@hepcbc.ca. Space will be limited.

CHICKEN CUTLETS WITH PORTOBELLO MUSHROOMS AND ASIAGO

*This recipe serves 4
Preparation time: 15 minutes
Cooking time: 15 minutes*

Source: <http://www.foodfit.com/recipe.asp?rid=2159>

Ingredients:

- 1 T. olive oil
- 4 boneless, skinless chicken breasts, cut into thin cutlets
- salt to taste
- freshly ground black pepper
- flour for dredging
- 8 oz. portobello mushrooms, sliced
- 1/3 C. dry white wine
- 2/3 C. low-sodium chicken broth
- 3/4 C. freshly grated Asiago cheese

Cooking Instructions:

1. Preheat broiler.
2. Heat olive oil in large non-stick skillet. While oil is heating, season chicken with salt and pepper and dredge in flour.
3. Cook chicken over medium-high heat until golden brown, about 2 minutes on each side. Transfer to large baking dish and set aside.
4. Add mushrooms to skillet, season with salt and pepper and cook, stirring occasionally, until mushrooms are tender.
5. Add wine, stir with wooden spoon to release any caramelized bits that may be stuck to pan and cook until wine has almost completely evaporated. Add chicken broth. Cook 1 minute more.
6. Arrange the mushroom slices on top of the chicken and pour the cooking liquid into the baking dish. Sprinkle the cheese over the mushrooms.
7. Place the baking dish under the broiler and cook until the cheese is melted.

*Nutrition Facts: Calories Per Serving: 359
Total Fat 12 g Saturated Fat 6 Protein 50 g*

COMPENSATION

LEGAL ACTION

Hepatitis C Class Action Suit Line:
1-800-229-LEAD (5323)



1986-1990

Bruce Lemer/Grant Kovacs Norell
Vancouver, BC
Phone: 1-604-609-6699 Fax: 1-604-609-6688

Pre-86/Post-90

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

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
Lookback 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

National Compensation Hotline: 1-888-726-2656
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
Toronto Compensation: 1-416-327-0539, 1-877-434-0944
Quebec Red Cross Compensation: 1-888-840-5764
1986-1990 Hepatitis C Class Actions Settlement
6/15/99 www.hepc8690.ca/

ADMINISTRATOR

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>

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 in Courtenay, Campbell River and Port Hardy. Contact Jeanette or Leanne: 830-0787, leanne.cunningham@avi.org

Castlegar Contact Robin 365-6137

Comox Valley Mon.-Thurs. drop-in support 9-4 PM. Contact AIDS Vancouver Island Hep C Community Support (250) 338-7400 355 6th St. Courtenay or Del: dggrinstad@shaw.ca

Cowichan Valley Hepatitis C Support Contact Leah 748-3432

Cranbrook HeCSC-EK Support Group Monthly meetings. Call for details: Katerina (250) 417-2010, hecsc-ek@shaw.ca or Leslie (250) 426-6078, ldlong@shaw.ca

Kamloops Call the AIDS Society of Kamloops (ASK) at (250) 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 Riseley (250) 768-3573, eriselev@shaw.ca or Lisa Mortell 766-5132 lmortell@silk.net or toll-free 1-866-766-5132.

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

Mid Island Hepatitis C Society Friendship and support group, 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 Sherstobitoff, 1-800-421-2437, 505-5506, info@ankors.bc.ca <http://www.ankors.bc.ca/>

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

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations Urban Community Society, 623 Agnes Street, New Westminster. Contact Dianne Morrissett, 604-517-6120 dmorrissett@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, room 107. Contact Gina 963-9756, gina1444@yahoo.ca or Ilse 565-7387 ilse.kuepper@northernhealth.ca

Prince Rupert Hepatitis C Support Contact Ted Rogers (250) 624-7480, Ted.Rogers@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Contact Brad 295-6510, kane@nethop.net

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, 926 Davies. Contact Giselle Rogers 357-9511, Alex 304-3448 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, **3862 Broadway (behind Panago).** Contact Deb 877-0042 or Doreen 847-2132, deb@plnw.org

Sunshine Coast-Sechelt Healthy Livers Support Group 2nd Monday monthly, 6:30 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, waterspider@telus.net

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: H.A.R.M. Each Mon., 10 AM, 50 East Hasting St. Bus fare & snack. Contact 604-683-8595 (ask for VANDU) Space limited. **Satellite Hep-C group,** each Mon. 2 PM, HCC, 166 E. Hastings, 604-658-1224. 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. For info, contact Caitlin Padgett caitlinp@youthco.org For support, contact Matt Lovick 604-688-1441 or 1-877-YOUTHCO www.youthco.org Brandy.Svendson@youthco.org

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

Victoria Support & Info Contact the Needle Exchange 384-2366

Victoria HepCBC & INFO line—Contact (250) 595-3892 info@hepcbc.ca, www.hepcbc.ca Library open M-F 306-620 View St. Phone support or private interviews.

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 705-735-8153 hepcsupportbarrie@rogers.com

Durham Hepatitis C Support Group 2nd Thurs. mthly, 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

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, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact: Bob bc.cats-sens@rogers.com

Niagara Falls Hep C Support Group Last Thurs. monthly, 7 PM excluding July and Dec., Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact Rhonda (905) 295-4260, hepcnfi@becon.org

Peel Region Hep C Support Group Third Mon. monthly, 11AM-1PM Mississauga Office, 3038 Hurontario St. (Classroom C) Contact (905) 799-7700

healthlinepeel@peelregion.ca

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

Hepatitis C Network of Windsor & Essex County Contact Andrea 250-5399 or Michelle 256-1878, hepcnetwork@mailcan.com <http://hepcnetwork.cjb.net>

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

QUEBEC:

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

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

We would love to announce our Hepatitis C Peer Educators Training at YouthCO AIDS Society, **Dec 10-12**. The training is open to youth aged 15-29 who are interested in educating their peers and other youth about hepatitis C and related issues. For more information, please contact Brandy Svendson at 604-688-1441 or brandys@youthco.org

ATLANTIC PROVINCES:

Fredericton, NB Contact: Bob, 453-1340

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 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 call 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, 7 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 Meetings each Wed. 7 PM Turning Point Agencies 4611-50th Ave., Red Deer. **December 15: "Hepatitis C Capacity Building" workshop in Red Deer.** For info, 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, hrc@smd.mb.ca

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



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



HEPATITIS C: THE SILENT KILLER. HAVE YOU BEEN TESTED?

Dear concerned friend,

You or someone you know has hepatitis C. Sadly, you will know get to know more people with the disease. There are an estimated 170 million cases, worldwide. Hepatitis C is now a major epidemic.

We at HepCBC are doing everything in our power to provide educational materials (the *hepc.bull* --a monthly 8-page newsletter, the FAQ, our pamphlet series), to provide support via our info phone line, and to further research and better treatment with letter campaigns. We have limited funding, and depend entirely on friends like you.

We desperately need your support. Please give what you can. Money and volunteers are in short supply. It takes many dollars to print and mail out the newsletter each month, and many volunteers to continue vital work on these projects, provided at little or no cost. It is no longer feasible to work from our homes. Thanks to your donations last year, we now have an office that provides working and meeting space--a centralized space to store files, counsel people, and house our extensive library. We have started a support group. We are organizing Hep C conferences. Your donation will help to ensure our continued work. We have no Government funding for these initiatives, and depend entirely on friends like you. Your money goes directly to fighting hepatitis C through education.

Please respond to this **urgent** request!

Yes, I want to help HepCBC!

*HepCBC Hepatitis C Education and Prevention Society is a
Registered Canadian Charity 86800-4979-RR0001*

As a volunteer. Name _____
Tel. No. and/or email: _____

Here is my tax-deductible donation of \$20 _____ \$50 _____ \$100 _____ Other _____
(Any amount is welcome!) **“This includes my SUBSCRIPTION/MEMBERSHIP”**
(Please circle one or both, if applicable)

Name: _____
Address: _____

Phone: _____