



# hepc.bull

## BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

May 1999

Issue No. 12

### HEP C LEAVES SUFFERERS VULNER- ABLE, STUDY FINDS

Researchers at St. Paul's Hospital say their findings show those with the disease are eight times more likely to be seriously ill.

By Lori Culbert  
Vancouver Sun

People with hepatitis C are eight times more likely to be extremely ill than those without the disease, says a study commissioned by the federal government to help it decide how to divvy up its controversial compensation package.

The study, conducted by the Centre for Health Evaluation and Outcomes Services (CHEOS) at St. Paul's Hospital, is the first one ever to measure the quality of life of hepatitis C sufferers.

It may seem self-evident that those with the disease could be sicker than those without, but one of the study's authors, Dr. Martin Schechter, said there is an erroneous perception in society that most people with hepatitis C don't suffer from any symptoms. "People will tell you it's only a small minority of people who ever suffered symptoms," said Schechter, professor of epidemiology at UBC. "What this study says to me is . . . a lot more people are more symptomatic than we think."

Last summer, when Ottawa was grappling with how to compensate tainted-blood victims, the study was commissioned to help federal and provincial governments decide how to distribute aid.

In December, following nine months of tense negotiations, a \$1.1-billion compensation deal was struck between governments to assist the thousands of victims who were infected between 1986 and 1990. It allows for a range of settlements, from \$10,000 to \$225,000, depending on the level of sickness. About 800 BC residents would qualify for the deal. But the Hepatitis C Society, which represents some victims, has panned the compensation package as too small. The Red Cross has offered to sweeten the pot by another \$60 million in exchange for victims forfeiting their right to sue, but that offer has also been criticised.

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### Why Genotype???

by Marjorie Harris  
President HepCURE  
[www.junction.net/hepcure](http://www.junction.net/hepcure)

"Why genotype?" This is a common question. And the question that goes hand in hand with this is – "Why can't I be genotyped in Canada?"

Here are some answers:

#### 1.) Availability:

In Canada, genotyping has not been readily available to the public through the medicare system. In the USA, genotyping is more available but certainly not universally available. In Canada, genotyping is usually only done when a drug study is being done, e.g., consensus interferon etc.

#### 2.) What Information is Gained from Genotyping?

Researchers have long recognised that patients will respond better to current therapies depending on their genotypes. However, other factors, such as viral load, the persons own genetics, co-infections, stage of disease and more, also determine the effectiveness of treatment.

Genotypes are geographically distributed—that is, they 'tend' to be different in different parts of the world. Sometimes you can guess when you became infected by knowing your genotype—e.g., you were travelling in South Africa and now you have genotype 5, rather than the predominant North American 1a and 1b.

Also, different risk groups 'tend' to have different genotypes. It has been noted that the majority of IV drug users have a different genotype (3a) from most of the blood transfused (1a & 1b).

#### 3.) Response to Therapy According to Genotype:

Genotype 1's tend to not respond to treatment as readily as genotypes 2 & 3. The difference in response can be quite dramatic; for instance, one study on consensus interferon reported an 80% response rate among genotypes 2 & 3 and a 16 - 20% response rate among genotype 1.

However, remember that other factors, such as viral load and disease stage, play an important part in response to treatment.

#### 4.) Should Patients have the Right to Know Their Genotype?

Yes—in my opinion, it is a very important part of the picture. The risks and side effects of current therapies definitely justify the cost of the patient being able to weigh out the "Risk-to-Benefit" ratio before embarking on treatment. For instance,

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### Diabetes Drug Rezulin Warning

From HealthCentral at: <http://www.healthcentral.com/news/newsfulltext.cfm?ID=10896> March 26, 1999

Federal officials said they have linked 38 cases of acute liver failure to the diabetes drug Rezulin and believe the danger of liver damage increases over time as patients take the drug.

Several doctors told the FDA scientific advisers that Rezulin helps many of their toughest diabetes patients, and the benefits outweigh the risk. They suggested that only perhaps 45 percent of Rezulin patients are getting the proper liver testing to detect problems in time to treat them.

The FDA called a highly unusual safety meeting because of the alarming finding that some patients who took all those precautions still died from severe liver toxicity that arose just weeks after they had passed a liver test.

Even Rezulin's harshest critics, however, don't expect the advisory group to take the drastic step of recommending that Rezulin be banned.

### Muriel Colli

By Jean Day

*Muriel Colli passed away on March 29, 1999. She was one of our first members, and attended meetings faithfully. She was at our February 24<sup>th</sup> meeting. She is survived by her son, daughter, grandchildren, and special friends. Muriel retired from Safeway after 28 years, and was a good friend to many. We will miss her..*

### Bob Cuchi

*Hello All:*

*I just wanted the group to know that we lost a friend this weekend, His name was Bob Cuchi, and he just got his paget for a transplant, but came back with an infection and passed away on Saturday. We will miss him.*

Sharon, HEPLIFE March 16, 1999

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## DONATION FORM

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(A limited number of newsletters will be available free of charge at group meetings, as well.)

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**SUBMISSIONS:** The deadline for any contributions to the hepc.bull is the 15th of each month. Please contact: Joan King-Diemecke at (250) 388-4311, [joan\\_king@bc.sympatico.ca](mailto:joan_king@bc.sympatico.ca), Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, [hepcbc@home.com](mailto:hepcbc@home.com) or C.D. Mazoff at [squeeky@pacificcoast.net](mailto:squeeky@pacificcoast.net)

The editors reserve the right to edit and cut articles in the interest of space.

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

\$20 for business card size ad, per issue  
There will be a maximum of 4 ads in each issue, and the ads will be published if space allows. Payments will be refunded if the ad is not published. Ads are also posted to the Web.



## COMING UP IN BC:

**Castlegar/Grand Forks/Trail** Contact: Robin, 365-6137.

**Chilliwack** Contact: David, 792-3467.

**Comox Valley Liver Disease Support Group**  
Meetings: Third Tuesday of each month, 7 PM, downstairs, Island Health Unit building. NEXT MEETING: May 18th. Contact: Ingrid or Nicky, 335-1711 or Jeanne Russell, [ebus96@island.net](mailto:ebus96@island.net)

**Cowichan Valley Hepatitis C Support Services** is in desperate need of a meeting place. Contact: Debbie, 748-5450, [dduncan@olink.net](mailto:dduncan@olink.net), or Leah 748-3432, [r\\_attig@bc.sympatico.ca](mailto:r_attig@bc.sympatico.ca).

**Enderby HepCURE** Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: May 30th. Contact: Marjorie, 558-7488, [www.junction.net/hepcure/index.html](http://www.junction.net/hepcure/index.html)

**Kelowna HeCSC** Meetings: Last Saturday of each month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: May 29th. Contact: Michael, 860-8178 or [eriseley@bcinternet.com](mailto:eriseley@bcinternet.com)

**Nanaimo HeCSC** Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: May 13th. Contact: Helen, 245-8759.

**New Westminster Support Group** Meetings: Second Monday of each month, 7:00-8:30 PM, First Nation's Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. NEXT MEETING: May 10th. Contact: Dianne Morrissett, 525-3790.

**Parksville/Qualicum** 1-291 East Island Hwy, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551, [dbamford@island.net](mailto:dbamford@island.net)

**Penticton HeCSC** Meetings: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: May 12th. Contact: Leslie, 490-9054, [bchepc@bc.sympatico.ca](mailto:bchepc@bc.sympatico.ca)

**Prince Rupert** Contact: April, 627-7083.

**Quesnel** Contact: Elaine, 992-3640.

**Richmond** Meetings: Fourth Tuesday of each month, 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. NEXT MEETING: May 25th. Contact: Carmel at Richmond Health Unit, 279-4069.

**Sunshine Coast** Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: May 6th. Contact: Karen, 885-6413, [karen\\_felske@sunshine.net](mailto:karen_felske@sunshine.net)

**Vancouver CLF** Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: May 13th. Contact: the CLF, 681-4588 or Herb, 241-7766, [HMoeller@compuserve.com](mailto:HMoeller@compuserve.com)

**Vernon HepCURE** Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NEXT MEETINGS: May 4th and May 18th. Contact: Marjorie, 558-7488, [www.junction.net/hepcure/index.html](http://www.junction.net/hepcure/index.html)

**Vernon HEPLIFE** Meetings: 2nd and 4th Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. NEXT MEETINGS: May 12th and May 26th. Contact: Sharon, 542-3092, [sgrant@attcanada.net](mailto:sgrant@attcanada.net)

**Victoria HeCSC** Meetings: Last Wednesday of each month, 1-3 PM and at 7-9 PM, **STEVE ORCHERTON'S COMMUNITY OFFICE, 2736 QUADRA (at Hillside)** NEXT MEETING: May 26th. Speaker: Lynn Mori from BC Transplant Society. Contact: 388-4311. [hepcvic@pacificcoast.net](http://hepcvic@pacificcoast.net)

**White Rock Support Group:** Meeting Room #2, Peace Arch Hospital. Contact Lisa Peterson at 538-8704.



*Our condolences go to M. R. for the loss of her beloved husband.*

## HOW TO REACH US:

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Reminder: Any change of address, phone number or postal code, please let your phone contact (in Victoria) or your chapter secretary know ASAP  
HeCSC Victoria Tel. (250) 388-4311  
[hepcvic@pacificcoast.net](mailto:hepcvic@pacificcoast.net)

## REPRINTS

Past articles are available at a low cost. For a list of articles and prices, write to the hepc.bull, via Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, [hepcbc@iforward.com](mailto:hepcbc@iforward.com)

# THANKS!!

Victoria Chapter HeCSC acknowledges the personal donations, donations in kind and memorial donations received to date, and the following for discounts, donations of services, or equipment: Monk Office Supply, CFA 1070 Radio, Apple Canada, Pacific Coast Net and Island Internet, Inc., Mid-Island Realty, Questar Holdings, Unity Business Machines Ltd., Microsoft of Canada, Jim Pattison Group, Society Press & Graphics, Paradon Computers, and CompuSmart. We also wish to acknowledge an anonymous agency which has generously supplied us with government surplus computer equipment.



## SQUEEKY'S CORNER POINT COUNTER POINT

April 14, 1999

To: The Editors of the *hepc.bull*.

Your publication has become a soapbox for the Editors to attack the Society's National Office and the Board of Directors. In your April 1999 issue you failed to fulfil your responsibility and duty to provide balanced commentary on issues you find contentious.

I am certain that your readers would like to see your Editorial policy and the process you follow in presenting both sides of issues. Your commentary on the Society's unaudited 1998 Annual Statements was shameful.

We sent the statements to the Victoria Chapter to support their application for funding from the B.C. Employees Union. Without any request for explanation on their content you published your own interpretation. Annual Statements are always reviewed at the Annual General Meeting. This year it will take place at the end of May.

You published David Mazoff's letter containing seven demands to the Society but did not include the official response from the National office. It is inaccurate to say that National ignored the request.

I was shocked to see the lack of respect shown in the Emperor Cretin cartoon. We have built our excellent reputation by treating individuals with respect.

For a newsletter that is distributed using funds donated to our Society we expect that you follow suit. There is good content in your publication. Well done. With balanced commentary you can improve it further.

Yours sincerely,  
Jeremy Beaty, Chairman

*For the Record:*

**Squeeky's response:** Our publication became political only recently when we began to listen to the voices of persons with Hep C from all over Canada, who felt frustrated and betrayed by the BOD. We have tried alternate channels for almost 2 years, but we feel that you have not listened to those you were elected to represent, so we made the decision to act responsibly and inform the community.

We sent registered letters in order to ensure you received our requests, since we rarely got a reply, let alone a prompt one. And as to the 7 demands, they *were* the response of our Steering Committee to your response to our registered letter. In my opinion your response was an excuse to continue as before with what we have now come to believe is an irresponsible and uncaring policy.

As far as the financial statements—they are indeed necessary for our funding application. Thank you. But if they are inaccurate (i.e., unaudited) I hope you have a good explanation for the government auditors. We obtained the financial statements to stop HeCSC National from claiming funds to

which it is not entitled. We have been fighting this for almost 2 years, and the situation has never been settled until now, with the funding agency telling HQ clearly that this money is for BC use only. We feel that it is shameful that with an income of nearly \$300 000, HQ should be asking struggling chapters for funds instead of the other way around. We have repeatedly asked for your input both in the form of words and money to this bulletin and other educational projects, and the usual answer has been NO ANSWER, or "Wait." In our opinion, you have apparently only complied with our requests when claiming or seeking some kudo for yourselves. I have often asked HQ to contribute a regular column because many members feel abandoned. If you look at your own regulations, and your own publication record, you have certainly been weak in this respect.

On behalf of all Canadians with HCV, I ask that you reconsider your policy, and listen to your members.

**Joan's Response:** Dear Jeremy, as you know, the Victoria Chapter publishes the *hepc.bull*, therefore, anything controversial is reviewed, often not only by the editors, but also by the steering committee, and published if the majority vote to do so. I don't like to do things without consulting the others, nor do the other editors. Our steering committee, elected by our members, represents our members. We have no editorial policy, to date. We discussed one with head office a while ago, at one of the times we were discussing the newsletter. Here is the policy that was proposed by head office. I don't know if it was ever approved, since we receive no minutes of meetings, and have no representation on the Board:

- \*HeCSC supports and encourages the publishing of chapter bulletins.
- \*HeCSC publishes only one official Society Newsletter.
- \*If the chapter bulletin is published under the name of HeCSC then each issue would include a disclaimer that HeCSC is not responsible for the accuracy of the articles.
- \*If the chapter subsidises the bulletin, then each issue would include a statement that HeCSC financially supports the costs of the bulletin.
- \*The National office of HeCSC will contribute a column to each issue of the bulletin.
- \*HeCSC will have no editorial responsibility for the content.
- \*The bulletin would not be used to air any differences or criticism of the Society, The National Office, the Board, any Chapter or individual. Communication on differences would be discussed and resolved through alternate channels of communication.
- \*Any member has the freedom to publish his or her own bulletin independently of HeCSC. However it will not purport to represent the chapters or the society. The National Office will not contribute a column and the chapter

will not subsidise it.

As far as the financial statement goes, I believe that head office has the obligation to provide all of its members with these statements. If this is not the current policy, I hope you will change it at the upcoming AGM. As Treasurer of the Victoria Chapter, I always provide our members access to our records.

You will be pleased to know that as of this date, the three editors unanimously have voted to approve inclusion of your article, and no one in the steering committee has submitted comments.

I appreciate your interest in our Chapter and in the bulletin.

### Ron Thiel's Response

#### APOLOGY AND COMMENT ON LETTER TO THE EDITOR BY THE CHAIR OF THE VICTORIA STEERING COMMITTEE

First, I would like to apologise to anyone who found the "Emperor Cretin" cartoon offensive.

It seems that if anyone questions the Board they either have an "agenda" or are guilty of an "attack," something I have been accused of myself.

If one questions the possible influence of the government due to the fact that it provides funding, one is accused, in the media, of being somebody "who doesn't give a damn about anybody else but themselves." People who are living what might be the last year, month, day of their lives certainly don't give of their time and money if they don't give a damn about anybody else but themselves. Somebody has to get the information of what has been taking place out to the membership. In my opinion the Board has become nothing more than a self-perpetuating dictatorship.

I was stunned when I learned, by accident, of the Board's decision to accept the services of a lawyer who imposed such restrictive conditions on our ability to fight for justice. We looked to the Board and the Society to act in our best interests. In my opinion, those of us who were infected outside the phoney "window" period were stabbed in the back and written off by the very Society we trusted.

What about the Society's RESPONSIBILITY to inform the members of these conditions before acceptance? How many members have been informed about this decision which had such an impact on their lives? If we have such an excellent reputation why have we been treated so badly?

Lack of Respect? Respect? How much respect has been shown to us? The Prime Minister insulted us under the cover of Parliamentary Privilege. The Health Minister led us around by the nose for many months with false promises. He stated at one time that "these poor people should not be forced to go through a long legal process," yet when I spoke to him face to face regarding the plight of those outside the phoney "window" period he said "The courts may decide differently." In other words, "Sue us."



# The Hepatitis Strategy for BC, Part I

Report by Darlene Morrow

A presentation was given by Dr. Mel Krajden to the Vancouver support group Thursday March the 11<sup>th</sup>.

Dr. Krajden, from the BC LCDC, recently moved here from Toronto. His speciality is the molecular detection of viruses. He has been chosen to spearhead this third attempt at getting the Center of Excellence for Hepatitis going. The initial concerns with the original proposal were:

- not comprehensive enough
- treatment versus prevention
- was there full use of existing resources
- focus on physical structures

What we want is to improve the care of people with hepatitis. We must:

- maximise resource utilisation
- provide a correct balance between treatment and prevention
- continuously improve treatment/prevention through education and research
- develop multi-disciplinary healthcare delivery systems which build on previous experience

In BC there are between 6000-7000 cases of HCV discovered per year. This is much higher than the national average. Hepatitis B in BC is four times the rate of the rest of the country although we hope to see a decline in the number of acute cases due to the introduction of vaccine programs. BC can be at the forefront of this movement. This requires:

- a comprehensive, coordinated and integrated hepatitis program from BC
- participation of key players
- more resources for each blood borne pathogen to have its own centers of excellence hence the Center will cover all forms of hepatitis and blood-borne pathogens.

Current health care delivery is fragmented. It provides limited information for decision making for patients and populations. We need infrastructure management of resources, allocation and teaching. Policies must be set. Analysis of data must be performed. Outcomes must be observational and include clinical trials. Guidelines must include + / - services, physical, laboratory, psychology, pharmacology, inpatients and outpatients. We must have standards across the board.

The Components of a Comprehensive Program:

A. Prevention

1. education;
2. Immunisation;
3. public health;
4. survey index

THESE MUST BALANCE WITH:

B. Treatment : 1. therapeutics; 2. services

Why change?

Information technology and scientific advances have given us new knowledge in diagnostics, therapeutics and prevention. This must be driven to form a client-focused care—we must take control as consumers.

Resource Allocation

- outcome driven
- collection and tracking of data clinical problems, services, interventions, adverse effects and costs.
- definitions and measurements

-data must be transformed into information to determine the impact of interventions.

- mechanisms to alter practice and optimise care
- a seamless electronic patient record to longitudinally track individuals and populations

Near Real-time COI Model

- clinical guidelines to optimise individual care
- public health guidelines to optimise population care
- optimise services
- information technology is the glue to hold this together. We need to connect the data and transform it into usable information.

A Comprehensive Hepatitis and Blood-borne Pathogen Data Management Model

Disease: -labs;-provincial labs;-CBS

Risk Factors: -blood;-sexual transmission;-vertical transmission;-IVDU

Optimise Outcome:-individual and a population;-collect, analyse, and maintain data;-maintain specimens

Public Health Issues:-surveillance;-outbreaks

**\*\*\*\*Data Management is a key factor\*\*\*\***

We must use information technology for process improvement. We exist in silos—services are increasingly multi-disciplinary. Motivators and fundamental characteristics of people (status, appreciation, and power) will NOT change. We must potentate a solution to use information technology.

1. communication
  - integrated 800 help line
  - web, fax, letter, newsletter
2. connect existing databases
3. pilot seamless electronic patient records
4. streamline healthcare delivery processes

Why hepatitis and blood borne pathogen as a model?

- complex care issues
- Krever and blood system
- resources intensive testing
- model to test infrastructure
- rapidly changing technology and therapies
- active community
- limited number of health care providers
- broad learning and teaching implications

Electronic record for use in multiple healthcare environments.

- provide continuous profiles accessible to authorised personnel
- streamlining data collection and analysis
- define elements required
- broad application to other diseases states

Minimise Redundant Tasks and Increase Workflow Efficiency

- streamline test ordering and filling out forms
- allow longitudinal result viewing

Improve Healthcare Research

- longitudinal patient records for anonymous near real-time aggregate data analysis
- infrastructure for ongoing phase I-IV clinical trials
- information for biological sample bank-
- confidentiality and ownership issues

Provide Resource Allocation and Information

- incidence
- prevalence
- benefits and limitations of interventions
- current vs. projected costs
- criteria developed for healthcare intervention
- political drivers

(To be continued next month)

## IBUPROFEN FOLLOW-UP

Darlene Morrow

I have done an exhaustive (read exhaustive) search on ibuprofen and HCV. The bottom line is that there is not much evidence to support drastic action. What I have been able to find is minuscule when you look at other drugs and HCV. I was very surprised to find a lot of problems with diclofenac-induced hepatitis that looked very serious. In my article on pain management, I mentioned this anti-inflammatory. In the light of this research I think that a warning should be published.

What I did find out about ibuprofen is it is very bad for the kidneys, and it also caused some visual problems. So—we know that drugs are bad for the liver. That is a given. Some are worse than others. Certainly the case for ibuprofen should be investigated seriously. I must say that Paxil also disturbs me because it is a widely used anti-depressant that has also been associated with hepatotoxicity and death. And again, it is only isolated but ....

## THERAPEUTIC VACCINE?

Reported in the Journal of Immunology (*The Journal of Immunology*. 1999, 162: 1326-1327), Epimmune scientists and their collaborators identified nine HCV epitopes which were recognized by the immune cells of HCV infected patients but not by the immune cells of healthy blood donors. The epitopes were selected based on their conserved amino acid sequence and ability to activate CTL (Cytotoxic T Cell, or "Killer T Cell") responses in blood obtained from chronically infected HCV patients. These HCV epitopes, together with others previously identified by Epimmune, are being used to design a multi-specific, broadly applicable therapeutic vaccine that might elicit potent CTL immune responses in patients chronically infected with the hepatitis C virus. CTL cells are activated by binding to specific epitopes presented by infected cells or other antigen-presenting cells. When activated, CTLs multiply in number and attack the diseased cells like an army attacks its enemy, killing diseased cells.

## Letter to the Editors - *hepc.bull*

Dear Editors:

On April 13<sup>th</sup>, 1999, Jeremy Beaty sent out two letters to all Hepatitis C Society of Canada (HeCSC) members. One was to those who received tainted blood before January 1<sup>st</sup>, 1986, or after June 30<sup>th</sup>, 1990. This letter served as an assessment of the Canadian Red Cross' (CRC) offer to pay each pre-86 and post-90 victim approximately \$3,000 (*see page 8 in this issue*).

The other letter outlined the Society's position on the January 1<sup>st</sup>, 1986 to June 30<sup>th</sup>, 1990 proposed compensation scheme. In a preamble to the Society's assessment, Mr. Beaty said, "Since our letter of March 3, 1999, the governments agreed to pay an additional 18 million, for a total of \$1.118 billion, in exchange for the rights for the 1986 to 1990 claimants for their share of the Red Cross money."

This would lead one to believe that the HeCSC letter resulted in the addition of these funds. Not so. In a letter written to his clients, on December 18<sup>th</sup>, 1998, J.J. Camp explained, "The settlement provisions require HCV claimants to accept the risk that a fund of \$ 1.118 billion will not be sufficient in the fullness of time to satisfy all of the claims by infected HCV claimants." The additional 18 million was announced by Allan Rock, in Parliament, long before the Christmas recess.

While reading the CRC assessment, I was struck by the realisation that the Society is once again claiming to publicly state that all victims of tainted blood must be compensated on the same basis. To wit: "By accepting the CRC offer we [the Board of HeCSC] are in violation of this principle." Is this not the same Society that hired lawyer Marlys Edwardh last spring, and waived its rights to equal compensation for all?

In March 1998, a few directors of HeCSC embarked on a mission to prove the government's fault and negligence with respect to the poisoning of tens of thousands of Canadians pre-1986. We worked around the clock keeping hepatitis C the top news story for weeks! We worked tirelessly to educate Canadians about the tragedy that occurred through government negligence.

Two months later, I resigned my position of Vice President on the board of HeCSC over exactly this issue. As board members, both Jo-Anne Manser and I felt that hiring Ms Edwardh and agreeing to her "conditions" would violate the principles agreed to in February 1998 by all board members to compensate everyone equally.

Then Mr. Beaty told us it was time to abandon our "activism" efforts and return to the pacifism for which we were known. Mr. Beaty asked for Board approval to hire lawyer Marlys Edwardh and accept her list of "conditions." Mr. Beaty made his return to the board conditional on hiring Ms Edwardh.

The hiring of this lawyer, and her conditions, washed away any and all hopes of getting equal,

adequate compensation for all. Her main "condition" was that HeCSC must "not be interested in pursuing or putting forth a 'fault based analysis' of why assistance should be extended to persons beyond the periods 1986-1990," nor would we be permitted to try "to identify other time periods where the Government of Canada, provincial governments or indeed any other players in the blood system were negligent." Another point HeCSC was forced to agree with was that the board would not promote "a financial assistance package by way of a lump sum payment." (Thus not resemble HIV compensation in the least!)

These conditions directly contradicted the mandate of the HeCSC—yet the majority of directors went against the HeCSC mandate, voted to accept Jeremy back and hire a lawyer who stacked the terms and conditions for compensation against the HeCSC membership. It was a black day, as the government succeeded in dividing our group even further.

Ms Manser and I believed that HeCSC should continue to pressure and shame the liberal government into equal compensation. We knew we were very close to winning the battle for all and were afraid if we were to stop the pressure now—everyone would loose. More importantly, HeCSC would lose. There was a lot at stake in early May: credibility with the politicians, media and supporters, but also, more importantly, with the members we represented. We worked so hard at educating the Canadian public that even people not affected by the tainted blood scandal had an opinion. Canadians understood the hepatitis C issue and a resounding 89% of Ontario residents surveyed believed all transfused, regardless of when they were infected, should be compensated equally.

Over the past year, people familiar with our cause cannot believe that this battle was lost for pre-1986/post-1990 victims of tainted blood. Politicians, police investigators, media and even lawyers have asked, "what happened?" "Why did you back down?" "You had the government up against the wall." Hindsight is always 20/20, but in this case it is sad to see how much we truly lost. A few times throughout this year we have tried to resurrect the issue, but it appears the effort is futile.

Now Mr. Beaty asks members to "support for HeCSC's position" and says that a "YES" vote will "take the pressure off the federal government to compensate pre-86/post-90 victims." It is our belief that we lost this battle last May, when we backed down and accepted Ms. Edwardh. We lost a lot that day in May, but most of all, members lost faith in Mr. Beaty and the Board of the Hepatitis C Society of Canada.

It is time for you to stand up and be counted. The Hepatitis C Society of Canada will be holding its Annual General Meeting (AGM) and Election of Officers in Toronto, Ontario on Saturday May 29<sup>th</sup>, 1999. If you are a member of the Society you have a say in the future of the Society.

If you are a member of the Society, you will be receiving your proxy in the mail. Your proxy is your vote! It is an opportunity to make a difference. Do not let this opportunity pass you by! Ask the Society

for a complete list of who is running for election, and ask for information about these individuals. You need to know as much as possible about those being elected to represent you.

The purpose of an AGM is to set the goals and direction for the coming year. It is time for you to be listened to. Tell the Society in which direction you wish them to proceed.

When you receive your proxy in the mail, understand that if you leave it blank—the current board will cast your vote, for you. If you fill in the blank with a name - the person named **must be a member of the Society, and must be present at the AGM.** If these two criteria are not met, your proxy will be considered spoiled, and your vote will not count!

The bylaws of the Society are vague and do not clearly define some serious flaws that may have occurred in this past year. First, it is my understanding that 3 ex officio (past) directors were returned to director status, filling positions vacated by directors who left the Society. The bylaws read that an ex officio holds the position for three years. Does that mean the ex officio directors can return to director status in order to fill vacated positions? What of the three-year term of the ex officio, returned to director status? Does it start again when a new director fills the vacated position?

More importantly, the Board has not met face to face at all this year. Some business has been conducted by conference call, but unfortunately, conference calls are no substitute for face to face meetings. Regularly scheduled board meetings allow the members of the board to get to know one another and allows for strengths (and weaknesses) of the individuals to show. These meetings serve as a sounding board for the members, as represented by the directors. A telephone conference call cannot replace a board meeting, which brings together directors from across the country. It cannot replace the 16 to 24 hours spent sharing stories, ideas, and dreams.

Your Society needs hard working volunteers to fill positions on the new Board. If you have extra energy and would like to put in lots of rewarding hours, or know of someone just right for the job, please consider getting resumes in to the HeCSC National office as soon as possible. Let's send a strong message to the Hepatitis C Society of Canada—that we are willing to move ahead into the new millennium, together!

*Leslie Gibbenhuck*





## CUPID'S CORNER

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

To place an ad: Write it up! Max. 50 words. Deadline is the 15<sup>th</sup> of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send checks payable to **HeCSC Victoria Chapter**, and mail to **HeCSC, Attn. Squeeky, 926 View Street Victoria, BC V8V 3L5**. 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 check for a donation of \$2, if you can afford it. Mail to the same address as above.

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

### Ad No. 10

Respectful, respectable man (49) but looks younger who is very active and loves life. I'm 6' tall, 210 lbs. and considered nice looking, emotionally and financially secure and non-symptomatic. I won't let Hep C rule my life and am looking for a positive female to share a long-term happy life together. Vancouver area.

### Ad No. 11

Would like very much to begin a new friendship via letters, or in person, with an HCV positive man. I am an upbeat, kind-hearted, enthusiastic female, late 40's who delights in seaside walks and derives great pleasure in nature's endless array of offerings! A good sense of humour a definite plus. BC please.

### Ad No. 12

Male, artist, musician, age 48, Hep-C pos., seeking woman who is open to the future and believes it still holds the seeds of mystery. Preference given to fringe dwellers and musicians. Working with kids has been my chosen profession. I'm great with kids, but poison to the parental ego.

### (GENOTYPING—*Continued from page 1*)

my family has a history of diabetes; I have already been a gestational diabetic, with two pregnancies putting me in a 50% range for developing diabetes naturally. Interferon therapy carries with it a significant risk of triggering irreversible diabetes, even without the burden of a genetic predisposition. In weighing my treatment options I would want to know that I had a 50 - 80% chance of clearing the virus before deciding on treatment. Otherwise, if I ended up with diabetes and I still had HCV, then my quality of life would be further degraded with the additional probability of an even shorter life expectancy.

### 5.) What are the Downsides to Genotyping?

One downside is an additional 'one time' cost added to our Medicare system (estimated to be around \$300-\$350). However, the biggest downside is that eventually (if not already done by some medical insurers in the USA) government Medicare and private HMO's will use your genotype to deny you medication coverage based on the low response rates of certain genotypes. Now this is a very serious issue because 72% of North Americans are infected with a 'low' response genotype, i.e., types 1a & 1b (only a 16-20% response rate in some clinical trials). The *real* issue here is that all patients should have the undeniable right to choose for themselves the option to try to eradicate this virus from their bodies. But with government cutbacks in health care, it seems inevitable that being denied treatment based on genotype alone is a very real prospect.

### 6.) Stand Together Now Before it is Too Late—Plan Ahead!

British Columbia is rumoured to be instituting genotyping in the near future. We must stand together and make sure that genotyping is only used for our benefit and not our detriment. There have already been major cutbacks in coverage for interferon and ribavirin.

Let Us Unite to Protect Our Health!



## From the editors:

We apologise to our readers for the amount of political content in this and the last issue. We hope to return to "normal" next month, after the Annual General Meeting. Speaking with many persons with HCV across Canada, we felt it our duty to let you know that you are not alone. Many are isolated, and need financial support and up-to-date information. We have all assumed that the National Office of HeCSC would take care of this. Well, it hasn't. The budget we released last month reveals a shocking waste of resources, and our own investigation showed that most of you did not know about this, and that most of you were in need. We had hoped that National Office would provide these services, but they haven't. They have refused. We hope to change that at the next AGM. Until then, the only way this bulletin can continue is with your DIRECT SUPPORT. Please, if you can, subscribe to the bulletin. The cost is only \$10 a year. Thank you very much.



## HEPTAZYME

HEPTAZYME, a compound, which attacks the genetic material of the virus, is still in the development stages, but the response from the health community has been so overwhelming, Eli Lilly and Company, and Ribozyme Pharmaceuticals Inc. have joined forces to further its research and development.

<http://www.newstream.com/r99-77.html>

## Vertex's VX-497

*From March 25, 1999/PRNewswire/ via NewsEdge Corporation*

The drug VX-497's activity against viruses in cell culture was compared to that of ribavirin, both alone and with IFN-alpha. VX-497 is being studied in two Phase II clinical trials for HCV infection. VX-497 is an inhibitor of IMPDH, a human enzyme essential for one of the building blocks of RNA and DNA. It may block the growth of certain cells as well as blocking viral replication. In one of the studies of the activity of VX-497 versus ribavirin against selected viruses in vitro, VX-497 was found to be 15- to 186-times more potent against HBV and several other viruses. Preliminary data suggests VX-497 may be more potent against bovine viral diarrhoea virus (BVDV), a flavivirus, similar to HCV. Scientists have not yet created an in vitro culture system that measures the replication of HCV.

A Phase II blinded, dose range-finding study of VX-497 alone in HCV-infected IFN non-responders began last September, and will also assess VX-497's safety and efficacy in reducing ALT and RNA, key endpoints in assessing anti-HCV activity.

CONTACT: Michele Karpf, Manager, Product Communications, 617-577-6259, <http://www.prnewswire.com/comp/938395.html> or fax, 800-758-5804, ext. 938395/ (VRTX)



# Hepatitis Foundation International (HFI) Walk on Washington 1999

There were over 40 states represented, as well as one province. Russell Fleischer, FDA, spoke about the bundling problem with Rebetrone. The experts' panel discussed social security, disability and EEOC issues. Our next group of speakers included me. All were from the hepatitis C community and spoke on the issue of community outreach and advocacy. Les Wheeler, of Amgen, spoke on coping with illness.

At lunch our keynote speaker was Dr. Nora Terrault from the University of California. Her topic was "Research Update on Sexual Transmission of HCV." Dr. Leslye Johnson talked about NIH funding. Major areas of research in hepatitis C now include transmission - modes and co-factors; progression: how much, whom and when; the impact of genotypes; genetics and co-factors; and the mechanisms of recovery, persistence, pathogens, disease progression and viral replication. She went on to talk of the major research needs including tissue culture and small animal models, access to chimpanzee models and specimens, access to characteristic human population and specimens and application of sophisticated new technologies.

Dr. Joanna Buffington from the CDCP spoke about the Government lookback program. Dr. Scott Friedman spoke about anti fibrotic therapy, which should be available (at least in the US) within the next 5 years. Early studies show this therapy is very effective at reversing fibrosis but he also added cirrhosis is irreversible. Factors relating to disease progression definitely show the male gender shows faster progression. It does appear the viral load and genotype have a bearing on the likeliness of response but not of disease progression. He added the early results are promising for Interleukin 10. Dr. Maria Sjogren from Walter Reed Medical Center spoke about the Management of Hepatitis C. She explained that the disease can be further prevented by exercise, nutrition, alcohol avoidance, immunisation for Hepatitis A and B, avoidance of excess iron, and seeking early advice. Dr. Sjogren brought up a warning that I have never heard of - **DO NOT** get Hep A & B vaccinations while on interferon therapy. Latest information reports interferon can and does react with the vaccines.

Dr. Leonard Seeff, Senior Scientist NIH, reported that there will be a conference to access alternative and complimentary medicine and Hepatitis C, held in Washington DC, August 22, 23 and 24<sup>th</sup>, 1999.

The final speaker was Dr. Lynt Johnson. His topic was Liver Transplantation. The Conference ended with delegates converging on Capitol Hill to take the messages for increased funding for education, awareness and research.

I would like to thank HFI for sponsoring my trip to Washington and for their continuing support for Hepatitis C around the world. I would also

like to thank Amgen for giving HFI a non-restrictive educational grant that allowed the Congress to happen.

HFI has masterminded a brilliant video geared at teens and young people called "Respect Yourself, Protect Yourself -Teens Talk to Teens About Liver Wellness." It is a nine minute educational must, that teaches the risks associated with the spread of hepatitis B & C.

We were also told that HCV Global Foundation will be hosting the Third Annual Conference - "The World and HCV," August 21<sup>st</sup> - 23<sup>rd</sup>, 1999 at Mills College in Oakland, California.

Co-infection is becoming a major issue for many. Check out a new web site [www.HIVandHepatitis.com](http://www.HIVandHepatitis.com)

I hope you find this information helpful, should you want more information, please do not hesitate to call me at: (250) 490-9054

Leslie Gibbenhuck

(VULNERABLE—Continued from page 1)

Class action lawsuits by some victims are still outstanding in BC, Ontario and Quebec.

Dr. Robert Hogg, who also worked on the study, said the federal government hasn't responded to it yet, noting it is part of on-going negotiations. He said the BC government and lawyers representing the victims were also involved in the year-long study, and said the doctors working on the report remained neutral to all sides.

The study was based on interviews with 241 people who received hepatitis C through blood transfusions between 1986 and 1990, and who are seeking compensation from the government. The results were compared to a control group of 222 people, who were hepatitis C negative despite having at least one blood transfusion during the same period.

The study, entitled "Through the Looking Glass," found:

- 68 per cent of those infected had a long-term disability or handicap, and 45 per cent of those said it was a result of hepatitis C. In the control group, 43 per cent reported a long-term disability or handicap.
- Seven per cent of those infected reported being in excellent or very good health, versus 38 per cent of the control group.
- Those infected reported more nausea, diarrhoea, fatigue, insomnia, memory loss, depression, migraines, and weight loss. The control group had more high blood pressure and heart disease.
- Those infected say they spent an average of \$1,039 a month on medical-related services, versus \$485 per month in the control group.
- 62 per cent of those infected don't work, and 64 per cent of those said it was because they're disabled or ill. There was 35 per cent unemployment in the control group, and 38 per cent of those attributed it to illness.

It also found those infected are more often men, younger, and live in lesser housing conditions than those in the control group. Schechter says the good news with hepatitis C is that it is almost never spread through the blood stream now. But the disease is raging through injection drug users.

Schechter warns the medical system in the future will be handling those who became infected through blood transfusions and the "burgeoning epidemic" among drug users. "It means lots of suffering and incredible burdens on the health-care system," he said.

He noted hepatitis is similar to where HIV was 10 years ago—there are only a few effective drugs to treat it. But he said there are indications that Hep C is curable, while HIV is not.

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## Ribbon Day Update

I just received a letter from Allan Rock re: Ribbon Day, and May as HCV month. Mr. Rock said that the way to get these things done is to **ask your local MP to put forward "a Private Member's Bill, or a Private Member's Statement,"** to be read in the House of Commons."

### Start Phoning!

squeeky



## WE'RE MOVING!

The Victoria Chapter of HeCSC will be moving *at the end of April*. Our phone and email numbers will remain the same but our address will change.

Our new address is:

**HeCSC Victoria  
926 View Street  
Victoria, BC, V8V 3L5**

We will be sharing an office with the ACPD, the Action Committee of People with Disabilities. As well, the location of our monthly meetings will change.

**Starting May 26th**, our meetings will be held at Steve Orcheron's community office, at **2736 Quadra Street (near Hillside)**.

Meetings in April, will still be held at the St. John the Divine Church, 1611 Quadra.

**HECSC ON CRC  
COMPENSATION  
OFFER TO PRE-1986 AND  
POST-1990 VICTIMS**

HeCSC Head Office sent the following information to the HepCAN list. It has been shortened to fit in this bulletin. If this issue concerns you, you should obtain the complete information through the office of your local chapter.

If you received tainted blood before January 1, 1986 or after June 30, 1990 this information is very important to you. Your Society has prepared an assessment of the Canadian Red Cross (CRC) offer to pay each pre-86/post-90 victim approximately \$3,000. Our comments are based on the CRC press release dated March 29, 1999. Proposed Timetable—The Society believes that this timetable is impossible to achieve:

April - publish notices of guidelines on how to make claims and receive voting materials.

May 31 - deadline to register to receive information packages.

June 15 - deadline to submit claims for voting purposes.

June - creditor meetings and voting will take place.

July 16 - if sanctioned by the court, the plan will be implemented on July 16.

Within thirty days of the implementation date cheques will be issued to each transfusion victim.

Your decision may be influenced by the following:

**If you vote NO** and more than one third of the transfusion claimants vote NO:

- You will not receive approximately \$3,000.
- You will be in a position to participate in all future developments without waiving any of your rights; for example the RCMP criminal investigation and the pre-86 negligence in buying US prison blood products.
- You will show your support for HeCSC's position.

**If you vote YES** and more than two thirds of the transfusion claimants vote YES:

- You will receive a cheque for approximately \$3,000.
- You will waive your rights to sue the CRC.
- You will take the pressure off the federal government to compensate pre-86/post-90 victims.

**Unknown:**

- If the transfusion claimants vote NO and the government does not increase the compensation package and the CRC goes bankrupt, the amount of compensation for the pre-86/post-90 victims is undefined.
- If the CRC wishes to initiate compensation to each victim with a cheque for \$3000 but no waiver, we support this compassionate and humanitarian gesture. We recommend that they follow the payment without waiver approach of the Ontario Government. In December 1998 the Ontario Government began issuing cheques of \$10,000 to each pre-86/post-90 victim in Ontario. Our society has always publicly stated that all victims of tainted blood must be compensated on the same basis. By accepting the

CRC offer we are in violation of this principle.

We cannot advise you on which decision to make. However, the information will help you make the right choice for your own situation.

If you have any questions about the offer you should call the closest CRC location to you. We have asked for an '800' or collect number to call but have not received it at time of going to press.

**Vote  
Responsibly**

U.S.H.A.

**The United States  
Hepatitis Alliance**

**Wake Up America!**

**A rally at our Washington state  
capitol building**

**To increase awareness of  
HEPATITIS C**

**May 3, 1999 At 11 AM**

**Why?**

- **Because 4 MILLION Americans already suffer from this "Silent Epidemic"!**
- **Because Half a BILLION suffer world-wide!  
(10,000 per year die in America alone... Hundreds of thousands world-wide!)**
- **Because your family and friends are sick and there is "NO CURE"!**
- **Because funding to 'find a cure' for this disease is pathetic!**

**Please Join Us!**

**We will gather at Sylvester Park in Olympia at 10 AM and march to the capitol together. Information and handouts will be available.**

**2 guest speakers.**

**Call or e-mail us for more information**

**CONTACT:**

**Ane Palmo USHA Chair for  
Washington State**

[lamapalmo@w-link.net](mailto:lamapalmo@w-link.net)  
**(206) 324-0873**

**For those of you who can't go to Olympia, HeCSC Victoria will be holding a sympathy rally in Victoria, which will coincide with the HIV/HCV Conference taking place there. Contact them for details**

**CLASS ACTION SUITS:**

**BRITISH COLUMBIA**

Camp Church and Associates  
Sharon Matthews / Kim Graham  
4th Floor, Randall Building  
Vancouver, BC V6B 1Z5  
1-(888)-236-7797



Grant Kovacs Norell  
Bruce Lemer  
Grosvenor Building  
930-1040 West Georgia Street  
Vancouver, BC, V6E 4H1  
Phone: (604) 609-6699 Fax: (604) 609-6688

Before August 1, 1986  
Klein Lyons  
David A Klein  
805 West Broadway, Suite 500  
Vancouver, BC V5Z 1K1  
(604) 874-7171 or 1-(800) 468-4466  
(604) 874-7180 (FAX)

also:

Dempster, Dermody, Riley and Buntain  
William Dermody  
4 Hughson Street South, 2nd Floor  
Hamilton, Ontario L8N 3Z1  
(905) 572- 6688

The toll free number to get you in touch with the Hepatitis C Counsel is 1-(800)-229-LEAD (5323).

**ONTARIO AND OTHER PROVINCES**

Pre 1986/post 1990  
Mr. David Harvey  
Goodman & Carr  
200 King Street West  
Suite 2300  
Toronto, Ontario, M5H 3W5  
Phone: (416) 595-2300  
Fax: (416) 595-0527

**CLASS ACTION FOR CHILDREN**

Poyner Baxter Blaxland  
Jim Poyner or Ken Baxter  
Tel. (604) 988-6321  
Fax (604) 988-3632  
[poyner.baxter@bc.sympatico.ca](mailto:poyner.baxter@bc.sympatico.ca)

or

Siskind, Cromarty, Ivey and Dowler  
Michael Eiazenga  
Tel. (519)672- 2121 Local 332  
Tel. 1-(800) 461-6166

**TRACEBACK PROCEDURES:**

**INQUIRIES-CONTACT:**

The Canadian Red Cross Society  
4750 Oak Street  
Vancouver, BC, V6H 2N9  
1-(888) 332-5663 (local 207)

This information is for anyone who has received blood transfusions in Canada, if they wish to find out if their donors were Hep C positive.

**CLASS ACTION/COMPENSATION**

If you would like more information about class action/compensation, you can contact:  
Trisha Plunkett Tel. (250) 479-5369  
E-mail: [plunket@islandnet.com](mailto:plunket@islandnet.com)

National Compensation Hotline  
Tel. 1-(888) 780-1111



**SUPPORT GROUP MEETING LOCATION:** For the past year we have been meeting in space loaned to us by the AIDS Committee of Ottawa (who get a grant because they united and fought), but for many reasons we will not be able to use their facilities in the future. Therefore, for information about future meeting places and times, please phone (613) 233-9703. If anyone knows of a place, with reasonable parking, where space may be booked, hopefully free of charge, please let us know at the above number.

**THE SOCIETY IS FOR ALL INFECTED PEOPLE, FAMILY AND FRIENDS:** From time to time we hear that some people presume that the Hepatitis C Society is made up only of people that were infected through blood transfusions. Nothing could be farther from the truth. Perhaps this is so because the media has featured the fight for compensation and has neglected the true story of the tragedy of Hepatitis C. In fact, close to half of those affected have no idea as to how they contacted the disease. We do not ask how anyone was infected, if indeed they do know, because that is a private matter. For the record, it is estimated that less than a third of those who attend support group meetings are victims of tainted blood, so all are welcome. The purpose of the meetings is to provide support and comfort, and exchange information, with those who truly know, like no outsider can, what it is really like to have Hepatitis C.

**PUBLIC FORUM:** A Public Forum was held at Regional Government Headquarters on the evening of 12 April 1999, hosted by the Regional Government of Ottawa-Carleton, under the sponsorship of the Hepatitis C Society of Canada, Ottawa Chapter, and Hemophilia Canada. The purpose of the meeting was to gather information from those infected with Hepatitis C, their family and supporters regarding their needs in the areas of public information, treatment and care. This information will form the basis for a report to be presented to the Community Services Committee of Ottawa-Carleton. The forum was co-chaired by Alex Munter chairperson of the Community Services Committee and Jo-Anne Manser of our local Hepatitis C Society chapter. Present were representatives from Health Canada and the Regional

Government as well as health care professionals and care givers serving the Hepatitis C community. The Ontario Government chose not to be represented. Because of considerable media exposure close to 75 people attended. A pleasant surprise, especially because there were so many new faces. A local television station gave the forum very good coverage featuring the information that, to their surprise, Hepatitis C can be contracted by means other than IV drug use and blood transfusions. The TV report expressed shock that Hep C can be passed through body piercing and poorly sterilised dental and barber instruments. No new news was presented by officials from Health Canada or the Region, as this was not the purpose of the forum. Interesting, though, was that the Regional Health Department acknowledged that since 1995 they have registered close to 3000 new cases of Hep C, and that there may be in excess of 6000 people infected in the region alone. This admission is significant in that it may be a sign that awareness may be increasing in public officials of the seriousness of the situation. Many very useful suggestions were made as to the needs of Hepatitis C sufferers. As usual, the priority request was for more public information. These needs and concerns were noted and will form the basis of our report to the local Health Services Committee.

**SUPPORT OF THE OTTAWA HEPATITIS C COMMUNITY:** Considering that the Ottawa chapter has over 150 people on its mailing list, and there are an estimated 10,000 to 20,000 people in eastern Ontario suffering from Hepatitis C, support for the society from those infected has been disappointing. It is interesting that when the compensation fight was at its height attendance at meetings rose to a hundred and more people, but as that issue faded from the headlines, or was partially resolved in the minds of many, continuing support faded. Apparently money counts. The Society in the Ottawa area is kept going by less than a dozen volunteers. Where is the help and UNITY we need to continue the fight for justice, recognition, health care (for both the short and long term), and the many issues facing all those with hepatitis C? If people want the hepatitis C crisis eased, a co-ordinated approach is an absolute need. Continued, everyday pressure is essential. Granted, many are ill or are unable to make it to meetings or offer direct help for very legitimate reasons. Others pay their dues and make generous financial donations, and we are so very grateful to them. Without their help we could not operate. Nevertheless, one gets the impression that, to

many, an organisation like ours is something you take from in a self-serving way without giving much in return. Letting someone else do it is the attitude of many—and of course complain a lot later. We need help and support. Our volunteers are getting burned out. Governments are showing signs of renegeing on the slim promises made a few months ago and, at best, are moving at a snail's pace. What can you do to help?

**THE HEPATITIS C BULLETIN – SUBSCRIPTIONS:** This hepatitis C bulletin is expanding to cover national interests and include items of local events Canada-wide. It is also expected to meet the information areas identified in the recent study undertaken by the Ottawa chapter. It is without doubt one of the best and informative publications on hepatitis C in North America. Unfortunately, the Ottawa Chapter cannot afford to continue to pay the cost of mailing this bulletin to our complete mailing list each month. Our only source of revenue is our seven-dollar share of each twenty-dollar paid-up membership, gifts and donations. A single mailing costs more than \$100.00. The rest of the yearly fee is used by the national office, for advocacy work and administration. A recent request to the Regional Government for a modest grant was turned down. If you like this newsletter please take out a yearly subscription. The cost is \$10.00 per year for 12 issues. Soon, it is hoped the National Office of the Hepatitis C Society in Toronto can be persuaded to pick up this expense, but for the time being we are asking you to pay for your copies in the future. Subscription details can be found in the newsletter.

*Ron Lee*

**HepFest  
NorthWest  
Victoria  
July 16-18th**