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BC's Hepatitis C News Bulletin

November 1998

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1997's Chicago Conference December 1997

by Professor Geoffrey Farrell.

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The American Association for Study of Liver Disease meeting is the premier international liver meeting. Of 1,400 abstracts presented in December, last year, more than 400 were on the subject of hepatitis C. The greatest interest has been on advances in treatment, on understanding the natural history and clinical outcomes, and unraveling the mechanisms whereby the immune and inflammatory response to the virus infection cause damage to the liver.

VACCINES

There seemed few advances on vaccine development—the single greatest need to halt this epidemic—but two abstracts caught my eye. One study of 40 patients clearly delineated the type of immune response required to clear the virus—mainly participation of CD4+ cells (those that are destroyed by HIV virus). Stimulating this type of lymphocyte would be a novel approach to therapy and could be the key to vaccine development.

In another study, workers from Ann Arbor, Michigan, used DNA technology to see if they could modify the HCV core protein to create a vaccine. Mice were used as an experimental model. A certain type of modification of the protein (insertion of so-called immuno-stimulatory elements—ISS) greatly enhanced the mice immune response, particularly when five individual ISS 'motifs' were designed into the experimental vaccine. This seems to be a novel and exciting step towards developing a vaccine for HCV.

NATURAL HISTORY

Understanding the natural history of hepatitis C—that is, how the disease evolves in individual persons and therefore affects their lives—is of considerable importance. A study of 160 Spanish patients who had been followed for 18 years gave further insights. The only factor that predicted which patients would develop cirrhosis and severe liver disease was the severity on the initial biopsy. This further emphasizes the importance of having an initial biopsy done to assess the severity of disease and to allow predictions about the course of the disease; the latter, I feel, is essential to guide decisions about treatment.

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Address to BC Ministry of Health

Oct 1, 1998

C.D. Mazoff, PhD

Chair, Hepatitis C Society of Canada
Victoria Chapter

On an average day between 3-5 persons newly diagnosed with hepatitis C call the office. They are frightened, confused and in need of information and treatment.

Typically they lament their own GP's self-confessed lack of knowledge about the problem. Often many of these persons have been presenting symptoms for years which finally a proper diagnosis explains.

Many, especially the elderly, became infected through transfusions, and quite a few of these in the recent past (post-1990) when the blood supply was supposed to be clean. Many more became infected a long time ago through the follies of youth or because of a broken spirit since healed. Unfortunately, the wisdom of years cannot undo the stealth of this insidious disease as it claims its revenge. And sadly, many of our youth are becoming infected today, or, already infected, are unknowingly spreading and encouraging the progression of this debilitating illness.

As my recent column in the *hepc.bull* (Oct, 98) explains, many of our members have died and are dying from this illness. Four in the recent past, and another of our members only has a few weeks to live. Although recently many of these have been elderly, quite a few are only in their late 30's to early 50's. They die from liver failure, liver cancer or variceal bleeds as the liver shuts down and the blood has nowhere to go.

What you can do:

The main thrust of the Victoria Chapter of the Hepatitis C Society of Canada is on education [editor's note: we feel that the compensation strategies are and should be orchestrated on a national level, since the travesty of tainted blood is a national issue]. This job has been made immeasurably easier by the generosity of the BCGEU. Our bulletin, which is mailed out to over 900 and is also on various websites and email lists, has received praise from the established medical community as being

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Your Mouth and HCV - Some Things You Should Know

by Darlene Morrow

A frequent side effect of interferon treatment is the lowering of the white blood cells (WBC). These cells are especially important in the fighting of bacterial infections. It is not uncommon for the release of bacteria to occur during teeth cleaning. It is also not uncommon for the mouth to bleed in which case the open wound could provide an access route for the bacteria to enter your system. In a healthy person this would not have an effect but in the case of someone with a low WBC count, it could lead to problems. For this reason it is advised that you contact both your liver specialist and your dentist in regards to any scheduled visits while you are on drug treatment.

I also forgot to mention that there is a natural product available for treating the cold sores that come up from the combo. (Thanks Ken!) It is called Zostrix and it is found in the drugstore (usually in the arthritic cream section—I have no idea why). It contains capsicum (from the hotpeppers) and is effective for both pain and the treatment of the herpes virus which causes cold sores.

For those of you who suffer from Oral Lichen Planus (OLP) there is a very effective treatment available called Topsy (you need a prescription). This is a corticosteroid that is usually used on skin only. But it is very powerful in the treatment of OLP as I myself can testify. It is a little bit of an unorthodox use of the drug but my dentist prescribed it for me and I know of specialists that also prescribe it. Heather phoned me just this week to say that she had experienced almost immediate relief from the pain after starting to use the Topsy. For best use dry the area with gauze pads and apply sparingly 3-4 times a day.

SUBSCRIPTION FORM

Please fill out include a check made out to **HeCSC - Victoria Chapter**. Send to:

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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, **Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3**, hepcbc@iforward.com or **C.D. Mazoff at squeuey@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:

Newsletter Ads:

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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.



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COMING UP:

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

Cowichan Valley Hepatitis C Support Services. Meetings: 1st Thursday 7-9 PM. 3rd Tuesday 10-12:00 noon.. 464 TCH. Duncan. NEXT MEETINGS: Nov. 5th and 17th. Contact: Debbie, 748-5450 or Leah 748-3432. vhepc@hotmail.com

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: Nov. 29th. Contact: Marjorie, 558-7488. 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: Nov. 28th. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Nanaimo HeCSC Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Nov. 12th. Contact: Helen, 245-8759.

Parksville/Qualicum 163 Memorial Street, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551. dbamford@island.net

Penticton HeCSC Meetings: Third Thursday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: Nov. 19th. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca

Richmond: Meetings: Fourth Tuesday of each month from 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. NEXT MEETING: Nov. 24th. Contact: Guy, 244-1704. guy@fatherswithouthildren.com or 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: Nov. 5th. Guest Speaker for Thursday, December 3rd. will be Dr Loreen Dawson, Naturopathic Physician Contact: Karen, 885-6413. 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: Nov. 12th. Contact: the CLF, 681-4588 or Herb, 241-7766. 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: Nov. 3rd and 17th.. Contact: Marjorie, 558-7488. 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: Nov. 11th and 25th. Contact: Sharon, 542-3092. sgeegee@msn.com

Victoria HeCSC Meetings: Last Wednesday of each month, 1-3 PM, and again at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex) NEXT MEETING: Nov. 25th. (Elections will be held.) Contact: 388-4311. hepcvic@pacificcoast.net

HOW TO REACH US:

EDITORS:

TEL: (250) 388-4311

Joan King-Diemecke joan_king@bc.sympatico.ca

Darlene Morrow hepcbc@iforward.com

http://www.geocities.com/HotSprings/5670

C.D. Mazoff

squeuey@pacificcoast.net

VICTORIA HeCSC OFFICE: TEL: (250) 388-4311

hepcvic@pacificcoast.net

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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
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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

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, CFAFX 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.

Special Thanks

Our heartfelt thanks this month go to Carolyn Henderson and the team at Symantec Canada for going the extra mile and donating antivirus and utility software (including 2 copies of Winfax Pro 9, 2 copies Norton Antivirus 5 and 2 copies Norton Utilities 3) to the *hepc.bull* and the office. Too bad the antivirus only works on computers. And as for utilities?—who said I needed a tune-up!

Special thanks as well to Ed Wright and BC Rail for coming up with another redundant (to them) computer. Thanks Ed. Say hello to Tommy for me-eh? Toot-toot!

And before I forget, thanks to the nerds and tweekers (sorry Stacey & Karl) at DataImage and Computers N Stuff for making life easier for us here at hepcvic. May you never divide by zero ☺.

Last, a very special thanks to the Commercial Travellers Association, Local #434, for a very generous donation to help us publish information pamphlets.

Our continuing thanks to all of those who have helped and continue to help us can be found in the "Thank You" box above.



Elections '98

Elections for the chapter steering committee will be held at the November meetings of the Victoria Chapter. Those wishing to stand for the steering committee should come to the October meetings with a small biographical blurb that they can read to those present, stating why they wish to be elected and what they can bring to the chapter. Candidates will be invited to do the same at the November meetings just before the voting takes place. Nominations and voting will be open. The election of executive positions shall take place at a later date and be restricted to voting members of the steering committee. Some of the positions that need to be filled are: Co-Chairs, Secretary, Treasurer, and other functions yet to be determined by the steering committee.

Oh, and by the way, this is pretty serious stuff. Something you may not know about us is that we don't on the whole get anywhere near enough done. What we have are about 6 to 10 pretty committed and sick individuals running around busting their butts while the majority sit around complaining. Pretty strong stuff-eh? Well you should sit in the office sometime and try to get a handle on all the stuff that needs to be done, and how much the few do, and how many more justwell, I don't know what and I don't want to get anybody angry.

Here's my point: 2 issues ago we sent out a questionnaire to get more information TO BENE-FIT YOU. This questionnaire was the result of a new program database, and was the end result of extended efforts to procure new computers and software and then learn the bloody stuff and put it to good use so that all of us trying to fight for justice and healing would have a better chance at winning. I won't even tell you how few responses we got back.

How do we fight? With letters, and petitions, and more letters and telephone calls and emails and faxes and meetings and photocopying and running aroundand...and...and. And? Because there is a Sandy Smith and a Peggy Daisley and an Alvina Bisson and a Judith Fry and a Ron Thiel and a Vic Parsons, and Ivan Good and Joan King and others.....*SOME* stuff manages to get done, but nowhere near enough.

We need pamphlets and money to print them, so people will understand the seriousness of HCV and maybe .. just maybe think about doing something! So we need donations and fundraising. And then we need to convince people to take our pamphlets, so we need to talk to doctors and media people. And we need to answer the phones and talk to the newly diagnosed, and we need to have support lines for the ill and the depressed after hours, and we need people to do it. And we need to be accountable and keep proper records and write receipts and thank you notes

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HCV Quality of Life Survey

On Oct 9, 1998, Dr. Bob Hogg of St. Paul's Hospital Vancouver met with Joan King, Darlene Morrow, Darlene Nicolaas and me (squeeky) to go over a questionnaire being drawn up on HCV and quality of life.

Darlene Morrow, Joan and I were introduced to Dr. Hogg when, as members of the HepCTRG (Canadian Hepatitis C Clinical Trials Research Group), we were directed to St. Paul's and Dr. Martin Schechter of the HIV Clinical Trials Network.

The people at the CTN have done immeasurable service to those with HIV-AIDS and are held in extremely high regard by grassroots communities (i.e., those with HIV-AIDS). We have been hoping that the people at CTN would turn their very human attention to those with HCV.

In the meantime, Dr. Hogg was approached by Camp, Church and Associates (lawyers for class action in BC for transfused victims between 86-90) to conduct an epidemiological study which would enable them to get a much better picture of the real situation and thus have a better chance of winning the case.

Dr. Hogg felt that, as with HIV-AIDS, community input and participation was needed. So we (the HepCTRG) and Darlene Nicolaas were invited to sit and pass comment on the soon to be put into action questionnaire.

We helped focus questions on symptoms, as well as questioned the relevance of certain questions, which, in our opinion, had no place in the survey. These were certain "lifestyle" questions such as, IVDU and other irrelevancies.

We are extremely pleased to have heard that Dr. Hogg and the team agreed with our comments and removed these questions and put in other more pertinent ones.

squeeky



RESEARCH NEWS

CIMM has recently developed the first *in vitro* model for replicating the human hepatitis C virus (HCV). Based on this approach, CIMM has discovered a new drug, termed compound ZSX, which has demonstrated 100% inhibition of HCV replication (as measured by the presence of viral transcripts).

Viragen initiated pre-clinical studies with Omniferon, a natural human interferon, and plans to begin human clinical studies soon.

Vertex Pharmaceuticals Incorporated has begun a Phase II clinical trial, a dose range finding study designed to measure the safety and pharmacokinetics of VX-497, a possible antiviral, as a single agent in HCV-infected patients unresponsive to prior treatment with interferon.

(Chicago Conference—Continued from page 1)

While the actual mortality from hepatitis C is relatively low, even over a life-time (perhaps 10%), we know that many people have reduced quality of life. This was recently assessed in 609 hepatitis C cases from Worcester, Massachusetts. Even though people without cirrhosis experienced markedly reduced health-related quality of life and limitation of social role (i.e., breadwinner, parent, etc.) due to physical problems, body pain, and general health perceptions, they also experienced reduced vitality, social functioning, mental health and social role limitations due to emotional problems. Such studies are very important in examining the full impact of HCV on people and populations.

LIVER DAMAGE

It is now thought that liver damage in hepatitis C is caused by the immune response and inflammation in the liver—particularly with release of host proteins called cytokines. Several abstracts at this meeting provided further evidence that oxidative processes can also contribute to scar tissue (collagen) in the liver.

Does this mean that people with hepatitis C should be taking anti-oxidants? Well, this may be the case, but proper studies are required to see whether taking antioxidants over the long-term will reduce damage to the liver. At least 'pure' antioxidants such as vitamin E do not seem to carry a risk of toxicity that comes with some herbal remedies such as some Chinese herbal medicines. On the other hand, another abstract showed that treatment with N-acetyl cysteine (Parvolex) was of no value in patients who had failed to respond to interferon.

EPIDEMIOLOGY

Even though we have been looking at hepatitis C around the world for seven years or so now, I am still staggered by the epidemiology. In a northern Italian town, more than 10% of the population aged more than 50 years has hepatitis C, whereas those aged less than 40 have a risk between 1 and 1.4% (i.e., similar to Australia). The risks for hepatitis C were blood transfusion or surgery in the past, but particularly medical use of glass syringes. These kind of figures are emerging from many parts of the world: Italy, Greece, Spain, the Middle East and Japan. Patients from these ethnic groups have had hepatitis C for 40 or 50 years and they are now comprising those at greatest risk of liver cancer or developing liver failure. More attention should be given to these ethnic groups in Australia. Another study from Los Angeles has emphasised the importance of cocaine snorting as a risk factor for hepatitis C.

SYMPTOMS

There is surprisingly little published on symptoms of hepatitis C, and an abstract from Ireland caught my eye. This addressed the issue of fatigue, the most common symptom of chronic hepatitis C, and whether it is related to the severity of liver disease or to autoimmune disorders

(Continued on page 4)



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 checks payable to **HeCSC Victoria Chapter**, and mail to **HeCSC, Attn. Squeaky, 1611 Quadra St., Victoria, BC V8W 2L5**. 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.

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(Chicago Conference—Continued from page 3)

often associated with chronic hepatitis C. Not surprisingly, people with hepatitis C did have significantly more fatigue compared with healthy controls—but what was interesting was that the perceived functional impact on quality of life was particularly high in patients with genotype 1B infection. However, fatigue was unrelated to the degree (severity) of hepatitis and could not be accounted for by the coexistence of autoimmune disease. We need to find out more about the cause of this common symptom in order to be able to ameliorate it.

INTERFERON TREATMENT

The high spot of the meeting was undoubtedly the presentation of the interferon/ribavirin re-treatment study that has been conducted internationally—including three Australian centres. The three primary types of response to interferon are non-response, response/relapse (response while on treatment followed by relapse) and sustained response (essentially a cure with permanent elimination of the virus).

The study involved 349 patients who'd already had response/relapse on interferon. Half of them were retreated with interferon plus ribavirin for six months, the other half had interferon and a ribavirin-matched placebo. The results are still preliminary but 47% of those treated with interferon/ribavirin had a sustained response compared with only 4.7% of those who received interferon plus placebo.

In patients with HCV genotype 1, the respective sustained response rates were 29% for interferon/ribavirin and 3% for interferon alone, whereas among those with other genotypes (usually type 2 or type 3), 74% had a sustained response with interferon/ribavirin versus 7% with interferon/placebo.

These are very good results for interferon/ribavirin. Readers should appreciate that there are now several studies, including two new ones pre-

sented at this meeting, which show that patients who had six months interferon and experienced response/relapse can be treated for 12 or 24 months with interferon and have at least a 40% chance of sustained response. Further studies are certainly required to see if six months interferon/ribavirin is better than 12 months (or longer) interferon for those who have had response/relapse.

The down side of interferon/ribavirin is that side effects are more severe than with interferon alone—and because the treatment will be at least five times more expensive than interferon, it will not be appealing for governments to adopt it on the free list. Also, the distribution of hepatitis genotypes varies between countries. With type 3 being common in Australia, it is especially important to do interferon/ribavirin studies in our own country.

OTHER APPROACHES TO TREATMENT

To date, no new HCV antivirals have come to testing but we would hope that they may appear next year, now that so much is known about the virus enzymes.

Attempts to treat patients by other means than interferon have been disappointing. One tack has been to reduce iron levels in the liver, because a build up of iron seems to decrease response to interferon. Three separate studies showed that this was ultimately ineffective in improving response to interferon. Another approach is to add drugs of the arthritis group (NSAIDs) to interferon, but again this didn't help. A lot of people with hepatitis C have heard about amantadine from the internet. The four or five abstracts on amantadine and its first cousin, rimantadine, found minimal or no response of liver enzymes, and very little effect on the virus itself (there was one abstract which did find some effect on HCV, but this was in the minority). One small study from Italy used triple therapy (interferon plus ribavirin plus amantadine) and obtained some responses, but I have an 'open' view on this approach. In the reported study there were only 10 patients in each group, so don't rush away trying to get your amantadine until we get much better information.

Finally, many workers have tried to increase the initial dose of interferon and have often added ribavirin in complex combination programs to induce a treatment response in patients who have previously failed interferon. At least two studies showed convincingly that combination high dose interferon and ribavirin substantially and rapidly reduce the level of hepatitis C virus in blood, but to date the sustained response rates have remained disappointing. Further studies are justified for this approach to a group of patients who quite often have significant liver disease.

A CURE FOR HEPATITIS C?

Can hepatitis C be cured? Some of my patients still seem surprised when I tell them that in fact this is the case, albeit it only in a minority of cases. Six or more abstracts at this meeting

testified to the value of sustained response to interferon, particularly when the virus has been shown to be eliminated by PCR testing of blood taken 6 & 12 months after treatment.

In these patients, scarring of the liver diminishes with time and the risk of liver cancer appears to be either completely abolished or extraordinarily low compared with patients who have not had a sustained response to interferon. The issue as to whether a partial response to interferon (response/relapse) diminishes the risk of liver cancer remains somewhat contentious. I think the mounting data is that it tends to delay the onset of cancer without removing the risk.

REDUCING CANCER RISKS

The final issue as to whether treatment with interferon, without a response being evident on liver enzymes or virus levels, diminishes the risk of liver cancer is still hard to interpret, although I think the weight of evidence is stacking up against that theory. It is very difficult in the types of studies presented to look at truly controlled data because the patients who tend to have better responses to interferon are those at much lower risk of developing liver cancer anyway—their liver disease is not as bad yet as those who don't respond to interferon.

GROWING HCV

An encouraging advance during the last six months is the development of several culture systems employing modified human liver cells in which the hepatitis C virus can be grown. This will allow drugs to be tested as well as the life cycle of the virus to be understood in more detail. I'm sure that we will hear a lot more about this in the next 12 – 24 months.

In summary, this was a very stimulating and exciting meeting, reflecting the vast amount of international research into hepatitis C.

** Geoff Farrell is Robert W. Storr Professor of Hepatic Medicine at the Storr Liver Clinic, University of Sydney at Westmead Hospital, Sydney, Australia. The Hep C Review is a quarterly publication published by the Hepatitis C Council of New South Wales (NSW), Australia. The Hepatitis C Council is an independent, community-based, non-profit membership organisation, primarily funded by NSW Health.*

Liliana's Easy Banana Cake

Take 4 mashed **bananas**, 3 cups of **sugar**, 3/4 cup of **milk** plus 2 tablespoons, 1/2 cup of **walnuts** (optional), 1 and 1/2 teaspoons **baking powder**, 4 beaten **eggs**, 3 cups **flour**, 1 1/2 teaspoons of **salt**, 1/2 cup **raisins** (optional) and 1 1/2 teaspoons **vanilla extract**. Sift dry ingredients together, and then mix everything. Bake at 350 F. for 1 1/2 hours in a greased pan. Top with your favorite icing recipe, if desired.

WE'RE ALL IN THIS TOGETHER

By Marilyn Timms
Victoria, B.C.

There are approximately 300,000 Canadians now infected with HCV and 80% of these will develop chronic liver disease. This past year I have been following news reports regarding the compensations issue, and it brought me to tears hearing the comments from Brian French, whose brother passed away from HCV, and to agreeing that everyone should be included in the package no matter when they were infected. I also feel that the paltry sum offered to those infected from '86-'90 is an insult, as many of the victims are too sick to go out and steal to make ends meet. Ron Mitchell not only has HCV but also HIV and has lost his job at 38 years of age because of his poor health. And Mike McCarthy breaks my heart as he has fought so hard for all of us and dragged himself out as sick as he has been after losing his job because of being wrongfully infected with this disease. All the stress this has caused him and everyone involved only to fall upon deaf ears. Joey Haché gave up his summer to try and get help for everyone with his Cycle of Conscience from Halifax to Victoria to bring awareness and collect signatures. It's so upsetting to see sick people being treated this way when they have done nothing wrong and trusted in the System.

I wish I'd been a JW on May 5th, 1987. That's the day I was rushed to the hospital and received eleven blood transfusions because of a GI bleed and I always said I never felt the same since. Not long afterwards I seemed to tire easily and never really felt well. By 1989 I started my numerous doctors' visits only to be told it's that new flu going around. So as time marched on, I started to feel like a hypochondriac and just hated it when people asked how I was. I noticed my "flu" was lasting longer and getting worse as each year went by. I had now developed chronic fatigue and was too tired to even put one foot in front of the other. I also had nausea for months on end, itchy skin and dehydration for days on end and stiff achy bones getting worse each year, along with loss of muscle strength. I felt so spaced out, shaky and dizzy, I thought many times this was the end. So many years wasted on poor health. I had gone from a social butterfly to a waterbed potato. I finally found out last October I had contracted hepatitis C from one of the transfusions I had received ten years earlier. So now I knew I wasn't a hypochondriac after all. And I don't have to tell you the emotional roller-coaster you are on after finding out you have this disease. Especially since there is no cure and the only treatment, Interferon, doesn't seem to help many. I found out about an herb they have been testing in Russia that seems to have helped up to 85% so I was interested in giving it a try. It's called Hepatico and I have been taking it for two months and have felt better than I have in years. Although my liver function tests are still up and down, my symptoms

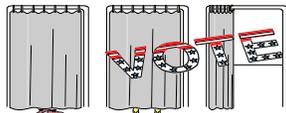
have lessened. My bones are no longer stiff and achy, my liver pain is gone, I haven't had the nausea back and although I'm still tired, I no longer have the chronic fatigue and I actually have bursts of energy throughout the day. It should be on the market before Christmas and I would suggest that anyone who has symptoms give this a try. You have nothing to lose. It's only an herb, and I know you won't be disappointed. We all have to stick together, no matter how we were infected, and I hope soon we'll all receive the help we deserve. For those of us involved in the scandal, having David Smith here in Victoria and Jeremy Beaty and Dr. Durhane Wong-Reiger in our lives has made a difference. Their ongoing compassion and endless hours they have put in for us is greatly appreciated.

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Website: www.vicsurf.com.natura



(Squeeky—Continued from page 3)

that actually get mailed out on time. And we need to have paper to photocopy on and toner for the photocopier and then have it all ready for the next Rally whenever that is. And we need to strategize to convince the government to **DO SOMETHING**, and we don't have enough volunteers and....that's where you come in!

So: **PLEASE** come to the October meetings and the November meetings and stand up and either nominate yourself or a friend and then carry on through with what you have promised to do. Because without you, not without Alan Rock, or Penny Priddy, or Toronto....but without YOU, this whole darn thing is going to fall apart.

We need you.

Please don't let yourself down.

squeeky

(Speech—Continued from page 1)

excellent. William Head Prison has expressed an interest in having our FAQ document available for the inmates, the majority of whom carry this deadly disease. More and more doctor's clinics are interested in carrying our bulletin, the FAQ and various pamphlets which we are in the process of developing. As well, our website has also received praise from local and other press.

But, despite the praise, we get little support for our endeavours apart from the generosity of the BCGEU, and sadly it is not enough. It is not enough because the demand increases daily and the costs rise accordingly. It is not enough because our office and equipment are not suitable to the task. It is not enough because we need more than just money to keep going. We need volunteers—healthy non-infected volunteers to help ease the burden on our present volunteers, including me, who are all infected with this disease.

We have recently begun an outreach campaign into the community at large, seeking corporate funding and formal links with the medical community, especially with regard to clinical trials and development of a vaccine. We are extremely excited about our recent meeting with Dr. Martin Schechter of the HIV CTN in Vancouver who is doing his best to help us.

Ten years ago those with HIV-AIDS faced the same kinds of problems those with hepatitis C face today. But they persisted and fought on, pushing the government at all levels to respond with federal and provincial strategies for research, support and education.

Now it is our turn. It is our turn to remind our governments and fellow Canadians that hepatitis C is not merely a "persistent nuisance" experienced by a minority of persons of questionable character, but a chronic and progressive disease, which, if untreated, will in many cases lead to suffering, disability and death. It will also have severe fiscal repercussions as the costs in lost earnings, sick leave, unemployment insurance, welfare benefits, medical treatment for complications and treatment with ineffective and costly drugs begin to add up.

So, on behalf of all those infected with hepatitis C, I wish to thank you from the bottom of my heart for your past, present and continued support, and hope that you will be able to continue to help us not only financially but also with your wisdom.

Thank you very much.



Janice's Story

This is a forward from my wife Janice with the intention of showing what a support person of a hepatitis C sufferer feels.

Raymond Boudreau

My hubby has Hep C and we found out while I was carrying our first child. He decided at the time not to have treatment for various reasons. Now, however, it has gotten to the point that he has a tough time functioning. Our family has grown to include me, my husband and our two children, a boy and a girl. Because he did not have the treatment right away, he developed an antibody that attacks his platelets. Now that he is on the treatment, he has two things attacking his platelets, the anti-body and the drug(s). He is a hardworking man, but with this disease getting the best of him at times, he has been forced not to work, and we have had to depend a lot on our government to help us, which can be, at times, degrading to any healthy lifestyle. Yes, that depression mode can be devastating, and the trouble with it is that you can get dragged in by it too with him. That is the tough part for me and I have to be on my guard. I can be there for him, but I can't let him drag me down too. No it's not always easy, but I didn't expect it to be either. I don't know if you are religious or anything, but the one thing that I lean on lots is God. He and the help of people that I can talk to and just vent without having to vent on him and get him more depressed helps me get through months, weeks and at times just one day. Realistically, I can't do anything, I can't help him, and I won't baby him. Yes he is going through probably the toughest thing in his life, but babying him won't help him, me or our family. He is not that fragile; yes, he's weak, exhausted, sore, frustrated, and, like any man, probably has in his mind that he can't do his "manly" job and support his family. But I haven't given up on him nor will I ever. He might at times in his mind just figure what the use, and there goes the depression stage ever so much more.

He's not glass he won't break

What have I done? Well not much really, as I said there is not much I can do for him, but just be there when he needs it, let him rant, rave, scream, yell, get down right angry. That's all he has the energy to do, that is all he feels he can do. Why should I deny him the last thing that he feels he can do, even though it might not be the only thing? I can't find that out for him though, he has to find his limits and go to them, not wait for them to crash around him. I love him dearly, and I will forever love him. I keep in my mind that this too is a phase and it will pass. I do what I can for him, love him when he wants or needs it, and keep away from him when he wants or needs it. He pushes away at times, but he always comes back. It's very tough to be strong for two

(Continued on page 7)

Karen's Story

Hello from the Sunshine Coast!

I guess my story goes back to the 70's. I was so tired of being exhausted and out of sorts that I finally went to the doctor. After many months, and a liver biopsy, it was decided that I had "chronic active hepatitis." By the time they figured out what was wrong with me, I was 3 months pregnant, so I had to decide whether or not I wanted to go on "prednisone" and "Imuran." After learning that the most harm the drugs could do to my unborn child would be a cleft palate, or a cleft lip, and it was better for me to take the drugs, that was the decision I had made. Fortunately when my daughter was born 5 months later, she was healthy and normal, one month early. Shortly afterwards I had another liver biopsy, and it revealed "chronic persistent hepatitis" so I had to have another course of the same drugs. I remember having one more biopsy, and I was really quite sick.

Oh, I really should explain how they did biopsies back then—nothing like today! First I was on my back on a table in the specialist's office. There was no one else in the building! He felt where my liver was, and then took his ball point pen and marked a big X right on my abdomen, in between my ribs where he was going to plunge the needle, which by the way was almost big enough to be a turkey baster! Well, he plunged this big needle into me, and sucked up part of my liver, and do you know that to this day I can still feel it! I ended up having three biopsies in total, the final one revealing "chronic persistent hepatitis." I remember every Friday I had to go to the lab at the hospital and give them 8 very large vials of blood for at least 6 months. Over the years I would meet with specialists and would have routine blood tests done. At least every 6 months my liver enzymes were tested.

So you see, for the past 22 years I have been having doctors poke at my liver and take my blood. That is a long time to be living with liver problems.

20 years later, and 2 more children, I was feeling ok. When I first was diagnosed in the 70's I was told to quit drinking alcohol and did for 7 years, until we moved from Winnipeg to Calgary where I met a hepatologist who told me that I didn't have to quit drinking! So by this time I felt pretty confident that I must be back to my old self.

We moved to the Sunshine Coast in '92 and I found a doctor here that took interest in my liver condition. She did some tests and decided that it must have been hepatitis B that I had back in the 70's because I have the antigen to it. Funny, my specialist now thinks that I must have had "autoimmune hepatitis" because of the drugs that I was given! In 1995 and my husband and I had applied for life insurance. A month or so later I got a letter in the mail telling me that I had been

(Continued on page 7)

Shane's Story

Hi. My name is Shane. I was born in New Zealand and moved to Canada in 1976. I have lived in Calgary for the last 21 years and moved to Red Deer in 1997.

In October 1990 I was told I had Hep B and something called Non B. In 1995 the Doctor said I had hepatitis B and hepatitis C.

The route of infection was probably from that pound of cocaine I did (IVD) between Jan 1989 and July 1990. I have not consumed any cocaine or alcohol since 1990.

I do partake of a "medicinal herb" which my hepatologist said is not processed through the liver. It helps stimulate my appetite and reduces my nausea. I have 11 hours of tattoos on my chest and shoulders but suspect it (HBV, HCV) was from my past drug use.

Tests done: Liver Biopsy early 1996. Scarring ¾. Fibrosis 2/4. ALT's Before interferon 150-250

On Interferon Alfa 2b for 8 months in 1996, ALT levels 30-48. My interferon treatment was stopped (4 months short) because of depression (Suicidal Ideation which I NEVER HAD BEFORE INTERFERON).

According to my hepatologist in Calgary there have been 7 reported cases of suicidal ideation associated with interferon use (that is 7 people actually committed suicide while on interferon) It is a side effect that affects < 1 % of interferon patients.

After 5 months off interferon in April 1996, my ALT was 63.

July 97, ALT	978
Aug 97, ALT	753
Sep 97, ALT	459
Dec 97, ALT	109
Jan 98, ALT	44
July 98, ALT	858AST 457
Aug 98, ALT	459AST 149
Sep 98, ALT	250AST 112

I am HCV RNA positive and a chronic active carrier of both HBV and HCV. I don't know my genotype or my viral load. I suspect I might have multiple genotype strains of HCV.

My specialists are refusing to put me back on interferon or the Combo because of my severe reaction the first time around. I'm now waiting for the next new round of protease inhibitors or a liver transplant—whichever comes first.

I have not worked since being off interferon 23 months ago. I now spend my days surfing the Web (I don't have a computer yet but I use the one at the library one hour a day).

If you would like to write me my e-mail address is shanehepc@hotmail.com

Hepster on the Frozen Tundra,

Shane



(Janice—Continued from page 6)

people, and for me, I find it harder with my children; but that's a whole different ballgame, they play a completely different part in our lives. How can you help him? I don't know if you can. I don't know how committed you both are; however, this disease is very powerful, and it can tear anybody or thing apart. We have days that all we do is yell and scream at each other, cause we are both frustrated and there is nothing else that seems that either of us can do. Some days are ok, few are great, others are just pure hell. I don't know what you expect in the end. If you want anything else, or have any other questions, or need other comments that I have not touched upon, please feel free to email me personally and I will give you additional information if need be. My email is janiseb@wave.home.com

I hope that this was sort of helpful for you and for any others that needed it.

Janice Boudreau

ICQ #7306970--my authorisation is required. Please state reason.

(Karen—Continued from page 6)

turned down. I had already explained to my broker that I had hepatitis in the past and a couple of insurance companies declined me in Calgary, but we did find one to accept me (too bad we were too broke at that time to make those payments!). It was my insurance broker who broke the news to me that I had "hepatitis C." I told him that he was wrong, I didn't have Hep C, but I had "chronic persistent hepatitis" or "hepatitis B" but I'm ok now. Well, it took what felt like a year to get re-tested by my doctor, have my husband and kids tested for Hep C, and sure enough I tested positive. My specialist today feels that I've probably had Hep C for the past 25 years!!!

After another biopsy last spring I went on interferon for three months. At that time my viral load was 350,000 copies. I stopped after three months because the side effects were too hard for me to handle. So I took a break. The interferon didn't do anything for me anyway. This past January my specialist (and everyone else) told me that I really should be on treatment, and combine the interferon with ribavirin. I told him I needed to think about it, but I wanted to try a naturopath first, and get "prepared for treatment." I went back to my specialist 6 months later, all ready to go back on treatment. He told me that there was no point! My viral load was now greater than 500,000 copies (the old reading was up to 750,000 copies, and the new reading peaks at 500,000 copies), that I was slightly older, and that it probably wouldn't work for me. Well how do you like that??? Just wonderful. He said that I should just wait for a couple of years and they may have a new treatment by then. You can imagine how all of this makes me feel!

I read about the "Hepatico Study" in July and decided that I needed to try it out. Luckily I got on the study just before the cut off. When I started the Hepatico in August my AST was 54 and ALT was 102. I had my blood work checked

every two weeks, and my enzymes were slowly going down. In total I was on the Hepatico for 40 days. My last AST-46 ALT-73. Before starting the Hepatico my enzymes were slowly going up. I am hoping that my specialist will allow for another PCR test to see if my viral load has come down. As he puts it "those AST/ALT numbers really don't mean too much."

I do have symptoms with Hep C. I feel lucky that it hasn't got the best of me—yet? I try to keep a positive outlook, but I have to admit that sometimes I do feel scared. I do have 3 children, ages 21, 12, 10 and a husband to think about. My younger kids have already seen me at my worst while I was on treatment. I know that my 12 year old daughter worries about me all the time.

I feel very frustrated with the government and their dumb policies regarding compensation. How many thousands of people are out there like me that have no idea how they contracted this deadly disease? What about us? What happens when I cannot care for my children and may need care for myself or someone to clean my house because I cannot do it anymore?? Who is going to pay for the help?? Why should it be different for me??? Maybe I got the disease from the dentist? Or when I had my routine blood work in the hospital every Friday for six months??

I know how scary and lonely it is to be told that "You have hepatitis C" and not be able to find any information or support—that's what it was like for me. Even as little as three years ago there were hardly any answers. No one could answer my questions very well. Even the two so-called specialists that I saw really couldn't tell me much or answer some of my questions. They actually admitted that they didn't know themselves! This is why I want to continue coordinating our support group on the Sunshine Coast. If I can help someone feel not so lonely and afraid, that will make my day. We are living with a very lonely, and frightening illness. We need each other.

Thanks for listening. Take Care,

Karen Felske

Glycyrrhiza Glabra & Glycyrrhizin

The root of licorice, *Glycyrrhiza glabra* L. and Chinese licorice, *G. uralensis*, is an important medicine around the world. Glycyrrhizin is one of the main components of licorice root. During the course of such clinical use, glycyrrhizin preparations were found to be effective for chronic hepatitis and have been widely used for chronic hepatitis and liver cirrhosis in Japan.

- Glycyrrhizin inhibits liver cell injury but does not reverse reduced protein synthesis. It is effective against carbon tetrachloride, benzene hexachloride, PCB and GaIN.

- Antibody production is enhanced by glycyrrhizin. When mononuclear cells from human peripheral blood were stimulated with pokeweed mitogen in the presence of glycyrrhizin, polyclonal antibody production was significantly enhanced. Glycyrrhizin may facilitate antibody formation through the production of interleukin I.

- Glycyrrhizin inhibits the growth of several DNA and RNA viruses, inactivating Herpes simplex virus particles irreversibly.

- Its effect against chronic hepatitis was demonstrated in a double-blind test with 133 patients. Elevated serum transaminase and γ -GTP levels were reduced.

- It appears to be effective on the pre-treatment of post-transfusion hepatitis. In one trial comparing glycyrrhizin and an inactive placebo in 336 patients, a significant reduction of the incidence of non-B hepatitis after transfusion was observed in the treated group. Because a remarkable reduction of the incidence of post-transfusion hepatitis was observed from 2 weeks to 6 weeks after transfusion, it suggests that the incidence of short-incubation post-transfusion hepatitis might be suppressed by using glycyrrhizin.

-It helps prevent post-transfusion hepatitis. When IV administration was continued for about 2 weeks, starting on the day of transfusion, the incidence of hepatitis was reduced from 17.6 to 12.8%. From these and other results, it was concluded that the use of this phytochemical is effective for the prevention of post-transfusion hepatitis.

The Herbalist by David Hoffman, (c) 1993 David Hoffman, Hopkins Technology

Contraindications to Treatment

By Natalie Rock, BSN, RN

There are a number of contraindications to the use of interferon. Interferon is both an immune stimulator and an anti-viral. It also depresses the platelets and the white blood cells. Thus, it may potentiate existing autoimmune disease, accentuate a prior low platelet count, and increase bacterial infection. Interferon may also potentiate neuro-psychiatric conditions. For these reasons the following are some of the main contraindications to the use of interferon:

- | | |
|---|--|
| A. Decompensated liver disease.. | F. Active bacterial infection |
| B. Depression | G. Marked thrombocytopenia (low platelet count) |
| C. Significant heart disease | H. Marked neutropenia (low white blood cell count) |
| D. Auto-immune hepatitis | I. Continued use of alcohol |
| E. Other major auto-immune disease, such as thyroid disease | J. Continued intravenous drug use |
| | K. HIV positive patients with CD4 count below 250 |

There are some relative contraindications to the use of interferon and careful clinical judgement is required to make the decision whether to treat or not. Some of these conditions are:

- A. Compensated cirrhosis
- B. Systemic diseases: 1) Diabetes mellitus 2) Coronary artery disease 3) Severe psoriasis
- C. Mild depression
- D. Mild auto-immune disease

HAAC

The Hepatitis C Action & Advocacy Coalition (HAAC) is a grassroots, all-volunteer group of individuals committed to non-violent direct action to end the Hepatitis C crisis. We work to provide access to life-extending treatments to people with hepatitis C, foster effective prevention efforts, encourage sound public health policies, and to ensure adequate funding and resources for the care, treatment, and prevention of hepatitis C. We work cooperatively with government and industry when progress is being made, and take to focused non-violent direct action when progress is stalled. We accept no money from pharmaceutical companies.

Ending the hepatitis C crisis is our highest priority. As you may know, our current major project is our protest with Schering on their outrageous business practices regarding their drug combination Rebetrone. You and your readers can help!!

Please read and copy, print and circulate the following information (see next column) and request for letters of support. It can help enormously to pressure Schering!! You folks in Canada need to demand a meeting with Schering there and your own government to demand these practices of Schering not be entrenched there!!!

Thanks for your interest, if you need further information, please contact me again. thank you!!!—*Brian Klein, HAAC, San Francisco.*



At the time of going to press, Ron the Reaper took it upon his noble self to man the protest lines at the Annual Liberal Convention at Whistler. Good luck Ron and thanks from all of us.

STOP SCHERING'S EXPLOITATION OF PEOPLE WITH HEPATITIS C VIRUS

To all concerned organizations and individuals:

The Hepatitis C Action & Advocacy Coalition, HAAC, has demanded and obtained a meeting in San Francisco with Schering-Plough Pharmaceuticals on Thursday, October 15, in San Francisco. The purpose of the meeting is to discuss with Schering their pricing, marketing and business practices regarding Rebetrone, a combination treatment for hepatitis C.

Rebetrone is a bundled product consisting of ribavirin and Intron A, Schering's interferon. The FDA has handed Schering an unprecedented monopoly. Ribavirin is not available separately in the US for research or use with any other HCV treatment, some of which may be better for some individuals. Just in the past 3 years, Schering has quadrupled the price of ribavirin.

A rapidly growing number of individuals and organizations across North America consider Schering's practices in this arena to be monopolistic, arrogant and exploitative. Consequently, HAAC announces the formation of The Coalition to Stop Schering's Exploitation of People with HCV, to fight these practices. We urge all concerned organizations and individuals to take action by joining this coalition. Send HAAC a letter of support for the coalition's demands to Schering. You may copy and use the sample letter on the next page if you wish. These letters will be presented to Schering at the meeting. Individuals and representatives from organizations sending letters of 100% support for these demands will be invited to attend the meeting with Schering, space permitting. The demands are as follows:

Unbundle ribavirin; make it available separately so patients, doctors, and researchers may choose to use or study it in combination with other treatments.

Implementation of a 75% price cut for ribavirin from the current estimated price (AWP) of \$1020/month to \$255/month, where it was three years ago, and in line with other drugs in its class.

Implementation of a comprehensive patient assistance program for individuals who cannot afford treatment; this program is to have clearly written criteria for eligibility similar to that used for the AIDS Drug Assistance Program.

Cessation of all aggressive sales tactics currently being used against patient support and advocacy groups.

Please send your letter of support as soon as possible by mail, fax or Email to:

The Coalition to Stop Schering's Exploitation of People with HCV
c/o HAAC-Hepatitis C action & Advocacy Coalition
530 Divisadero Street, #162
San Francisco, CA 94117
Fax: (415) 863-1593
Email: haac_sf@hotmail.com

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

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:
Tricia Plunkett Tel. (250) 479-5369
E-mail: plunket@islandnet.com

