hepc.bull
CANADA'S HEPATITIS C NEWS BULLETIN
June 1998 Issue No. 1

FROM HeCSC HQ

The National Office has certainly been affected by the surge in the public profile of Hepatitis C in the last few weeks. Media calls have flooded in almost on a daily basis. Our membership also continues to rise. It now stands at 1,907. We hear that the chapters are also seeing an increase in attendance at meetings. We have visited Thunder Bay, Ottawa and Kitchener recently. We look forward to seeing more people across the country in the coming months.

We are also looking forward to seeing members at the end of May at the Annual General Meeting and Conference. The theme is "Solving the Hepatitis C Puzzle." While we do not expect to do this in one weekend, we should get off to a good start. We're expecting the usual interest in treatment developments from the liver specialists, alternative treatments and the advocacy issues.

In May, we were invited to attend the meeting of the Health Ministers in Ottawa to discuss the compensation issue. Jeremy Beaty and Tracy Goegan from the board and I represented the Society. If you would like a copy of Jeremy's presentation to the Ministers, please call us at 1-(800)-652-4372 or (416) 979-5855.

We have achieved a real peak in media coverage in May, with lead stories on CBC National and Magazine, CTV News, and daily newspaper coverage—many, front pages. Our board members and chapter chairs and members have been doing a great job, either representing the society or telling their stories. Congratulations as well to members Chris Landry from Markham, Ontario, whose essay appeared in *Time* magazine Canadian Edition dated May 25, and Derek Marchand, whose interview was in the *New York Times* on May 8.

That's it for now. Keep up the good work everyone.

Tim McClemont
Executive Director

A Plea for Sanity

by Darlene Morrow

With all the issues of compensation for people with HCV, it has become very topical for the media to explore HCV. And because we must strike while the iron is hot, I find myself giving more interviews then I am used to. And in these interviews I hear myself saying: "The physicians on the front line are not equipped to deal with hepatitis C on the scale that we see today. These physicians need more education on HCV and all that that entails." The interviewers are surprised. My story began in 1994. They think that by now things must have changed. And I think—it has been four years—maybe they are right. Maybe we can relax.

But that night the telephone rings. I hear a voice that is gripped by panic and fear. Open heart surgery in 1986 lead to HCV. And now this person has been coughing up blood! He was sent home from the hospital after being told that the bleeding had stopped, and that it had nothing to do with HCV.

In the very best-case scenario this individual was not reassured. He was sent home without his fears dispelled. He was not told why the bleed did not have anything to do with HCV. And in the very worst-case scenario, could portal hypertension have reared its ugly head?

I hear this voice on the phone and I wonder, what can I do? I try to reassure him—even though I can't! I send him medical information and give him more phone numbers. I tell him what I would do. I feel ineffectual. Whatever I do—it is not enough. A failing medical system forces me to take on this ill-fitting role. It may have been four years but has anything really changed?

These people thank me profusely. I didn't do anything YOU wouldn't have done. Any of US wouldn't have done. The small act of kindness seems monumental because nothing else has been done. Or whatever has been done has been insufficient.

People are still dropped the bombshell on the telephone that they have HCV. People are still told that their symptoms have nothing to do with HCV. People are not brought into the decision-making process that governs their treatment.

We must share the blame. We have helped foster this patient-physician relationship. But it is no longer acceptable. We MUST tear it down and rebuild it. This relationship must be built

(Continued on page 5)

COMING UP:

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: June 24th.

Penticton HeCSC Meetings: Third Thursday of every month, 7-9 PM, Penticton Health Unit - Board rooms. NEXT MEETING: June 18th.

Kelowna HeCSC Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: June 27th.

Nanaimo HeCSC Meetings: Second Thursday of every month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: June 11th.

Vancouver CLF Support Group Meetings: Second Thursday of every month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). There should be signs directing you to the right room. NEXT MEETING: June 11th. Contact the CLF for more info at 681-4588 or Herb at 241-7766.

Sunshine Coast Support Group Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: June 4th. Contact Carol for more information: 886-4298 or email her at <ryker@cheerful.com>

HOW TO REACH US:

EDITORS TEL:(250) 388-4311
Joan King-Diemecke *joan_king@bc.sympatico.ca*
Darlene Morrow *hepcbc@sprint.ca*
http://www.geocities.com/HotSprings/5670
C.D. Mazoff *squeeky@pacificcoast.net*

VICTORIA HeCSC OFFICE:
hepcvic@pacificcoast.net TEL:(250) 388-4311
http://www.pacificcoast.net/~hepcvic/hepcvic~1.htm

PENTICTON HeCSC:
LESLIE GIBBENHUCK TEL:(250)490-9054 *bchepc@bc.sympatico.ca*

KELOWNA HeCSC:
ELAINE RISELY TEL:(250)768-3573 *eriseley@bcinternet.com*

CASTLEGAR/GRAND FORKS/TRAIL:
ROBIN TOMLIN TEL:(250)365-6137

NALA PAQU HeCSC:
RIA KLOMP TEL:(250)248-6072 (Parksville)

TED KILLOUG TEL:(250)752-1718
gjones@qb.island.net (Qualicum Beach)

HELEN HUBBARD TEL:(250) 245-8759 (Ladysmith/Nanaimo)

SUBSCRIPTION FORM

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

Hepatitis C Society of Canada
Victoria Chapter
1611 Quadra St.
Victoria, BC V8W 2L5

Name: ____________________________

Address: ____________________________

City: ____________ **Prov**. ___ **PC**______

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"I cannot afford to subscribe at this time, but I would like to receive the newsletter.
I am applying for a grant."____[]

"I would like to make a donation so that others may receive the newsletter without charge"_______[]

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

DISCLAIMER: HeCSS cannot endorse any physician, product or treatment. Any guests invited to our group to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the organization.

THANK YOU!

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. CFAX 1070 Radio, Apple Canada, Pacific Coast Net and Island Internet, Inc.

The deadline for any contributions of hepc.bull is the 22nd of each month. Please contact: Joan King-Diemecke at Tel (250) 388-4311, <joan_king@bc.sympatico.ca>, Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, < hepcbc@sprint.ca> or C.D. Mazoff at <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 15th of each month. Rates are as follows:*
Newsletter Ads:
$10 for 1/6th page, per issue
$100 for 1/6th page, 12 issues (in advance)
$20 for 1/3rd page, per issue (vertical or horizontal)
$200 for 1/6th page, 12 issues (in advance)
whole page:
$60 per issue
$600 for 12 issues
1/2 page:
$30 per issue
$300 for 12 issues

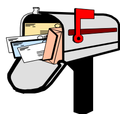
The Bulletin Grows

The *hepcBC.bull* has been very successful this year. Our subscription base has increased and now reaches Canada-wide. In order to reflect this national focus we will shift the emphasis away from BC and revert to the newsletter's original name: the *hepc.bull*.

We hope that you have enjoyed your subscription to the Bulletin and that it has provided you with up-to-date information about hepatitis C. We need your continued support, since the cost of your membership in the Hepatitis C Society of Canada does not cover the subscription/ donation to the Bulletin. If you haven't already done so, please fill out the subscription form and mail in your $10 to Victoria.

When your subscription renewal comes due, please forward us your cheque, so that we may continue to provide you with the very latest on HCV.

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



FROM THE OKANAGAN

***Editor's note:** Leslie's submission to the hepc.bull has been put on hold this month due to some controversy. You may read it on the internet at:*
<http://www.geocities.com/HotSprings/5670>

FUNDRAISER:

We are offering Tupperware to all our readers. For the next month, 15% of all orders will go to benefit the Victoria Chapter of the Hepatitis C Society of Canada. The more we order, the more we benefit.

Please call & mention Hep C
Caroline Mah
Tel: 386-9260

CANADIAN LIVER FOUNDATION UPDATE

The CLF is looking for volunteers for their Victoria Chapter to help raise awareness of liver disease.

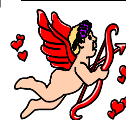
Volunteers are needed to assist in the development of support groups in Kamloops.

Please call the CLF for more info.

Phone: 604.681.4588 Fax: 604.681.6067
Toll Free in BC: 1.800.856.7266

DAVE'S COLUMN

***Editor's note:** Dave's column didn't make it into this issue. Look for it next month.*



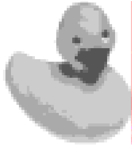
CUPID'S CORNER

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. Squeeky, 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.

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



SQUEEKY'S CORNER

MY TAKE

Like most of you I have been uplifted by the recent media response to the plight of transfused victims of hepatitis C who have clearly been denied justice and compassion. And like many of you I continue to be frustrated by the incredible indecision and evasion of responsibility on the part of our elected officials.

But while we should be encouraged by the flurry of media attention, and even by the promise of a settlement somewhere on the horizon, we should also be aware that the scope of the hepatitis C epidemic is much larger than the blood scandal and that "compensation" does not necessarily mean a "cure" or adequate monies for reasearch. And, *without a cure*, the fact remains that many of us will, in the near future, succumb to the disabling effects of the disease, and even to an untimely demise.

Despite the recent publicity, in general the public is not aware that over 85% of all people who contract the disease will have it for life; that there is no such thing as a healthy carrier state; that the current treatment with Alpha 2b Interferon has a very high relapse rate, such that in the end only from 8-15% of those treated can be considered sustained responders; that the cost of treatment is beyond the means of many persons with the disease; and that the treatment can cause irreversible thryroid, rheumatic and vascular disease as well as autoimmune disorders such as lupus. As well, and most importantly, the seriousness of the illness continues to be downplayed by many in the medical profession, and many sufferers who are seriously ill are denied treatment or access to disability benefits because their experiences (fatigue, sleep disorders, lassitude, liver pain) are discounted by doctors needed to sign approval forms for government subsidized pension benefits or treatment regimes.

Many Canadians suffer from hepatitis C—many more than we may wish to acknowlege. Recent studies suggest that the LCDC statistics of 1-1.5% of the general population (i.e., not just transfused victims) are much too low and that a more accurate figure would be in the 3.5-5% range. We also know that many people continue to be infected by a blood supply that is clearly at risk, but there is unfortunately little in place in terms of a national strategy for dealing with what many medical experts are calling the next great epidemic. Hepatitis C is now referred to as "the silent epidemic" or "the silent killer," perhaps not only because of the way in which it attacks its victims, but also because of the public and political response to this looming crisis. Often the disease is portrayed as a moral issue—a "lifestyle" disease—and its sufferers as reprobates, drug users and the sexually deviant, when in fact we know that as many as 40% of those who suffer from hepatitis C have no known risk factors and others are clearly the innocent victims of a national strategy gone horribly wrong.

Hepatitis C will not go away; it is only going to get worse. As an article in *The New Yorker*, May 11, 1998 pointed out, "the study of hepatitis C is ... seriously underfunded. Last year, the National Institutes of Health spent about sixteen hundred dollars per infected person on H.I.V. research, and great advances have been made in fighting that virus; for hepatitis C, however, the N.I.H. spent only six dollars per infected person." Funding in Canada for research into HCV is proportionately less.

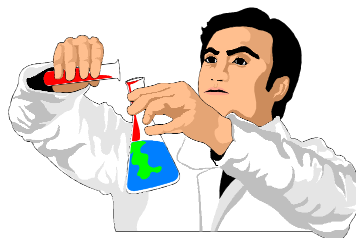
I know of many who are very worried about the cancellation of Ribavirin trials in the USA, and the possibility that the drug may be denied us here in Canada. I know of many who cannot get treatment because they earn too much, and must wait until they are bankrupted by the disease so that Medicare will cover the costs. But even then there are no guarantees, since many doctors in Canada do not favour treatment of an illness that they percieve as no more that a mosquito bite, while others are tired of fighting a government whose bottom line is profit and not people.

What Can We Do?

Many of you are probably very tired: tired from the hepatitis, tired of being ill, and tired of fighting the incredible stupidity and greed around us. But fight we must. And what we must fight for is, at bottom line, our very lives. The medical system in this country was originally designed to protect us and our health. While treatments such as lymphoblastoid interferon and thymosin, or ribavirin and other drugs are out there, they are apparently not out there for us—those who need them. This too is a travesty of justice and a wrong that should and must be righted!

So, the next time you speak to the media, or fax or email your local MP, don't forget that what we are fighting for is much larger than merely compensation. What we are and should be fighting for is **A CURE** for this insidious disease, and, to that end, vastly increased funding for research as part of a national strategy on hepatitis C.

C.D. Mazoff



Lactoferrin Markedly Inhibits Hepatitis C Virus Infection in Cultured Human Hepatocytes.

Ikeda M, Sugiyama K, Tanaka T, Tanaka K, Sekihara H, Shimotohno K, Kato N

Virology Division, National Cancer Center Research Institute, Chuo-ku, 104

[Record supplied by publisher]

We found that bovine lactoferrin (bLF), a milk protein belonging to the iron transporter family, effectively prevented hepatitis C virus (HCV) infection in cultured human hepatocytes (PH5CH8), a cell line susceptibleto HCV infection and supportive of HCV replication. Because preincubation of HCV with bLF was required to prevent the infection of HCV to the cells, and preincubation of bLF with the cells showed no inhibitory effect on HCV infection, we demonstrated that the anti-HCV activity of bLF was due to the interaction of bLF with HCV, but not due to the interaction of bLF with the cells. We further found that human lactoferrin also had anti-HCV activity, but bovine transferrin, the other member of the iron transporter family, did not have anti-HCV activity. Our findings suggest that lactoferrin is one of candidates for an anti-HCV reagent that will be well-tolerated and effective in the treatment of patients with chronic hepatitis.

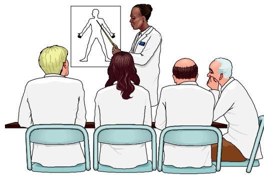
Biochem Biophys Res Commun 1998 Apr 17;245(2):549-553
Copyright1998 Academic Press.
PMID: 9571193

HeCSC VICTORIA VOLUNTEERS NEEDED

Volunteers are needed for **fundraising** for the Victoria Chapter of HeCSC. If you are interested, please contact Judith Fry at 592-0252.

Volunteers are needed to make **ribbons**. Please call Judith Fry at 592-0252.

If you would like to volunteer for the **Fun Run**, please call the office (388-4311) and leave a message for Fatima Jones. We need muffins, bought or home-made, and we need people to man the tables.



Eur J Gastroenterol Hepatol 1998 Feb;10(2):125-131

Effects of interferon therapy on fibrosis serum markers in HCV-positive chronic liver disease.

Mazzoran L, Tamaro G, Mangiarotti MA, Marchi P, Baracetti S, Gerini U, Fanni-Cannelles M, Zorat F, Pozzato G

Istituto di Medicina Clinica, University School of Medicine, Trieste, Italy.

OBJECTIVE: To evaluate serum levels of prolyl-hydroxylase and helical domain of Type IV collagen, markers of hepatic fibrogenesis, in patients with HCV-positive chronic liver disease and the effects of interferon therapy on these markers.

DESIGN: Prolyl-hydroxylase and Type IV collagen were determined before therapy and each month during the treatment and follow-up.

METHODS: Fifty-seven HCV-positive patients were studied. All the subjects received alpha2a recombinant interferon, 6 MU subcutaneously three times a week for 4 weeks, followed by 3 MU thrice weekly for 5 months. After cessation of treatment, each patient was followed for 12 months. Prolyl-hydroxylase and helical domain of Type IV collagen were measured by using immunoenzymatic methods. HCV-RNA and HCV genotype were determined according to the method of Okamoto.

RESULTS: In the patients prolyl-hydroxylase (39.8+/-8.9 ng/ml) was not different from controls (39.1+/-5.9 ng/ml). On the contrary, the patients showed a mean Type IV collagen (133.6+/-93.3 ng/ml) significantly ($P < 0.01$) higher than controls (100.2+/-10.5 ng/ml). A good relationship between the degree of liver fibrosis and the Type IV collagen serum level was found ($r = 0.68$; $P < 0.005$). In both responders and non-responders the Type IV collagen levels decreased during interferon therapy. During the follow-up, in responders the Type IV collagen did not show modifications, while in non-responders/ relapsers it returned rapidly to the pretreatment levels (139.1+/-100.7 ng/ml).

CONCLUSION: In HCV-positive chronic liver disease, prolylhydroxylase is not a good marker of hepatic fibrosis, while Type IV collagen is a useful tool for evaluating fibrogenic activity. **Interferon seems to be able to reduce the liver fibrosis even without the inhibition of viral replication and independently from liver necrosis.** *[Editor: Emphasis mine]*

PMID: 9581987, UI: 98241143

A Call for Participants in an Herbal Study

by Darlene Morrow

Alta Natural Herbs and Supplements Ltd. along with the RA Co. Ltd, Tbilisi, Republic of Georgia, plan to introduce and market HEPATICO. HEPATICO is an herbal preparation (oral) made from the extracts of wildcrafted herbs (nettle, plantain and immortelle in a base of milk thistle) collected in the Mingrelian and Zemo-svanetian mountains of the Republic of Georgia.

This herbal remedy has undergone extensive preclinical and clinical investigations in the Republic of Georgia since 1992. At present, there are 17 abstracts being translated from Russian into English. This research looks at the treatment of acute and chronic forms of hepatitis and cirrhosis. The translation of these documents should be completed in the next month and copies will be sent to me. When I receive them, I will update everyone on what I find.

FROM THE COMPANY'S PRESS RELEASE:

"HEPATICO is a non-toxic, safe oral dietary supplement and herbal remedy that restores the liver and normalizes its functions. Clinical investigations with HEPATICO have shown that patients (children and adults) ill with acute Hepatitis A, or C were cured in 7 to 10 days, while patients (children and adults) suffering from chronic forms recover in 14 to 28 days. Favorable therapeutic results with HEPATICO were observed in patients with cirrhosis. Recovery from cirrhosis took place in 1 to 7 months depending on the complexity and stage of the disease."

I am strongly opposed to the use of the word "cure." The cure claim is based on the normalisation of the liver enzymes, alkaline phosphatase, bilirubin, cholesterol and bile acids. As we all know, this by no means suggests that the HCV is no longer present. What it does suggest is that there is no active liver damage going on at that particular time. Liver enzymes normally fluctuate. How long was the follow up? Neither PCR nor liver biopsies were performed to further validate their claims.

However, they further claim: "Immunological indicators have been studied. The immunological examinations were conducted one day prior to the administration of HEPATICO and two weeks after the treatment regimen ended. The following immunological indicators were determined: the content of leukocytes, lymphocytes, and the content of basis populations and subpopulations of lymphocytes by the method of flour cytometry of the T-cell (CD3), T-Helpers/ Inducers (CD4), T-suppressors/cytotoxic lymphocytes (CD8), B-lymphocytes (CD72), natural killer cells (CD16), HLA-DR lymphocytes, the ratio Tx/Tc (the immunoregulatory indicator—IRI), the level of serum immunoglobulins (lg) of the 3 classes IgA, IgM and IgG and the content of marker proteins. The researchers concluded that HEPATICO has a positive effect on patients with various forms of hepatitis as evidenced by its positive effect on the majority of the measured immunological indicators."

The company would like to continue to study the effects of HEPATICO. They would like about 100 participants for a short one month study. They expect rapid results. These results will be measured by pre and post liver function tests. HEPATICO will be supplied at no cost to participants.

The participants must have their physician's permission. Your physician would be responsible for monitoring your blood tests and providing feedback to Alta Natural.

The company would like very much to work together with the physicians. Alta Natural Herbs has 2 Russian physicians on staff: Dr. David Khoupenia and Dr. Tamar Jvania. Both received their medical training/ education at Pirogov Medical University in Moscow. At present they are not licensed to practice medicine in Canada. As Medical Directors of Alta Natural, they would like to encourage and invite other medical professionals to tour their facility and discuss the existing research.

The company is based in Richmond, BC at 1148-20800 Westminster Hwy. Please contact either Dr. David Khoupenia, or Mr. Greg Shafransky or Mr. Vernon McKay at 604/303-1131 for more information. Their email address is: <altanat@axionet.com>

(**SANITY**—*Continued from page 1)*
on mutual respect, trust, and compassion. Physicians and patients must work together to ensure that the very best choices are made in their health care.

Physicians must keep abreast of new developments in HCV. All the ramifications and complications that arise as a result of HCV are not known today. We must ALL recognise that we know very little about HCV. But WE are the patients. WE experience this disease. The lines of communication must be kept open if we are to learn anything.

This particular story has a happy ending. After receiving the information that was sent, the person took those documents to his physician. To credit his physician, he was receptive to the information. And the individual was immediately checked into the hospital and is presently undergoing tests.

But I cannot relax. And you cannot relax. We must do whatever we can to enforce education and foster an understanding of HCV. And the Canadian Liver Foundation (CLF) can help us out. If you feel that a physician might benefit from reading educational information about hepatitis C, here's what you should do:

Call the CLF (681-4588 in Vancouver or 1-800-856-7266 in BC) and request a Patient Info Package on hepatitis C. Within this package you will find a ten page document written by Dr. Jenny Heathcote for physicians about the transmission, diagnosis, and treatment of HCV. This document was prepared in late 1995/96. Even though it is slightly dated, the information contained within it is sound. An update of this version is currently underway and will hopefully be ready by fall '98.

Am J Gastroenterol 1997 Jul;92(7):1081-1091

Diagnosis and treatment of gastrointestinal bleeding secondary to portal hypertension.

American College of Gastroenterology Practice Parameters Committee.

Guidelines for clinical practice are intended to suggest preferable approaches to particular medical problems as established by interpretation and collation of scientifically valid research, derived from extensive review of published literature. When data are not available that will withstand objective scrutiny, a recommendation may be made based on a consensus of experts. Guidelines are intended to apply to the clinical situation for all physicians without regard to specialty. Guidelines are intended to be flexible, not necessarily indicating the only acceptable approach, and should be distinguished from standards of care, which are inflexible and rarely violated. Given the wide range of choices in any health care problem, the physician should select the course best suited to the individual patient and the clinical situation presented. These guidelines are developed under the auspices of the American College of Gastroenterology and its practice parameters committee. These guidelines are also approved by the governing boards of American College of Gastroenterology and Practice Parameters Committee. Expert opinion is solicited from the outset for the document. Guidelines are reviewed in depth by the committee, with participation from experienced clinicians and others in related fields. The final recommendations are based on the data available at the time of the production of the document and may be updated with pertinent scientific developments at a later time.

The following guidelines are intended for adults and not for pediatric patients.

OBJECTIVE: To develop practice guidelines for the management of gastrointestinal bleeding in adult patients with cirrhosis and portal hypertension.

METHOD: Randomized controlled trials published through October of 1993 were evaluated by members of the American College of Gastroenterology Practice Parameters Committee. Each paper was reviewed by three members of the committee and rated for quality of design by predetermined criteria. Meta-analysis of the studies for each treatment were evaluated for both outcome and quality of design and formed the basis for recommendations for treatment. Randomized controlled trials published between October of 1993 and August of 1995 have been added to update and modify the recommendations. The reader is referred to an excellent article by D'Amico et al. (The treatment of portal hypertension: A meta-analytic review. Hepatology 1995;22:332-354), which presents most of the meta-analyses reviewed by this committee.

CONCLUSIONS: Once esophageal varices have been established by endoscopy as the site of bleeding, either sclerotherapy or endoscopic variceal ligation should be performed to control the bleeding episodes. Concomitant use of vasoactive drugs lowers portal pressure, potentially offers the endoscopist a clearer field in which to work, and is the only noninvasive treatment for nonesophagogastric variceal sites of bleeding related to portal hypertension. For patients failing medical therapy, the transjugular intrahepatic portasystemic shunt procedure is a reasonable alternative to an emergency surgically created shunt. Nonselective beta-adrenergic blockers are the only proven therapy for prevention of first variceal hemorrhage. Both nonselective beta-adrenergic blockers and endoscopic variceal ligation (which has replaced sclerotherapy for this indication) are effective in reducing the risk of recurrent variceal bleeding. For patients failing these approaches, selective or total shunts or, in selected patients, liver transplantation are appropriate rescue procedures.

MID: 9219775, MUID: 97363482

HOW HEP C IS TREATED IN EUROPE

by Joan King-Diemecke

According to an article appearing in the March 1998 issue of the *Journal of Viral Hepatitis,* more than three hundred European doctors filled out a questionnaire with respect to their medical practices regarding hepatitis C virus (HCV) infection. The survey found that there was general agreement concerning the necessity of screening patients for HCV in cases of a history of blood transfusion, haemodialysis, haemophilia or intravenous drug addiction (90% of positive answers), but there were differing opinions as to whether or not to test for possible cases of vertical (mother to child) and nosocomial (occupational, such as nurses) transmission of HCV.

To prevent sexual and vertical transmission, 22% of the doctors were in favour of barrier methods (condoms, etc.), and 34% were against; 49% encouraged breast-feeding for babies born to HCV-positive mothers, and 14% were against. A great majority (70%) of those surveyed were in favour of taking preventative measures in the home.

Testing practices varied, 60% using RIBA (recombinant immunoblot assay). PCR was ordered by 77% when ALTs were elevated and by 89% when ALTs were normal. Biopsies were requested by 90% of the doctors and ultrasounds were prescribed by 91% in cases of elevated ALTs. However, in cases of normal ALTs, only 40% ordered biopsies and 70% ordered ultrasound testing.

Only thirty per cent of those surveyed counseled their patients to stop drinking alcohol and 60% advised moderation.

Two-thirds of the responders did not take into account biopsy or PCR results before starting antiviral therapy (such as Interferon) . Eighty per cent of the participants reported that they gave their patients interferon (IFN) for 12 months. For most of the items studied, there was a large variation of answers.

Those who ran the survey concluded that preventive and medical practices towards HCV are not homogeneous throughout the EU and suggested the need for a European consensus conference in this regard.

Based on :
J Viral Hepat 1998 Mar;5(2):131-141
Medical practices regarding hepatitis C virus infection in Europe.
Nalpas B, Delaroques-Astagneau E, Bihan CL, Drucker J, Desenclos JC
Reseau National de Sante Publique, St Maurice, France.
PMID: 9572038, UI: 98233565

U ASK

Natalie Rock RN, BS
Hepatology Clinical Research Nurse,
Dept of Medicine UBC, Vancouver Hospital
Div. Gastroenterology

Question: When is my hair going to stop falling out?

Hair loss, although not common, does occur with interferon treatment. Often it is mild and not apparent to others, but occasionally it may be more marked. Growth of hair requires nutrients, particularly protein, but loss of hair can occur for many reasons including some immune abnormalities. It takes a while for hair to grow out from the follicle once the reason depressing hair growth has been removed. Thus, it usually takes 3 to 4 weeks after the stopping of interferon before new hair starts to grow out. From then on the hair growth generally returns to normal. There is, however, individual variation in the rate of hair growth. It will take some months before full-length hair has returned.

Question: What does it mean when you are told that you have the virus (determined through a PCR) but that it is dormant? What course of action should be taken, are there regular tests one should have, and is there anything one can do to lower the risk of the virus becoming active?

It is uncommon for viruses to cause chronic disease. Most viruses, such as measles, chickenpox etc., are eradicated from the body in a short time. Herpes, HIV, and hepatitis C are, however, chronic viruses that stay in the body and inside cells permanently. The activity of the disease caused by the virus varies, however; at times the disease is active, at times not. Herpes virus, for example, causes the so-called "cold sores." Cold sores are not always present—indeed they may only occur infrequently—but the virus is always present and if one did a biopsy at the site where the cold sore occurs the virus may be seen inside the cells but there is no inflammation or activity. The reason for this is not understood. Since the disease (inflammation, ulceration) may be the body's response rather than the activity of the virus, it may be that the disease activity is related to the "host" (or patient) rather than the virus. There may be a number of factors that influence the body's response, including immune activity, the presence of other infections, stress, and so forth. Hepatitis C is like herpes in that at times there appears to be no inflammation in the liver although the virus may be identified in the blood or in the liver. In essence, the virus is "'dormant" although it would be better to say that there is no "disease activity." This period of inactivity is extremely variable: in some people it may last many years, in others only brief periods of time, and in some people not at all.

Studies of patients whose disease is inactive have suggested that it is best not to treat, since treating may alter the state of inactivity and actually create active disease. Thus it is the present recommendation that patients be checked every 6 to 12 months and if there is evidence of disease activity (elevated enzymes) treatment should be considered at that time. It has been shown that alcohol in some way makes the hepatitis C virus more active and so alcohol use is discouraged. General good health and good nutrition is important. Patients should be vaccinated against hepatitis A since this disease combines with hepatitis C to induce a more fulminant disease.

Independent and combined action of hepatitis C virus infection and alcohol consumption on the risk of symptomatic liver cirrhosis.

By Howard J. Worman, M. D.
Corrao, G., and Arico, S. .
Hepatology 1998. 27:914-919.

Alcohol abuse and hepatitis C virus (HCV) infection are the two major risk factors for the development of cirrhosis in the Western Hemisphere. This report examined these two risk factors in two case-control studies from Italy. The cases were 285 patients with cirrhosis admitted for the first time to a hospital for worsening liver disease. The controls were 417 patients admitted during the same time period for acute diseases not related to alcohol. The odds ratio of developing symptomatic cirrhosis was 9.2 in subjects who drank no alcohol and had HCV infection compared to subjects who had zero lifetime daily alcohol consumption and no evidence of HCV infection. For heavy lifetime alcohol users (greater than 175 g/day), the odds ratio for developing symptomatic cirrhosis was 15 in those without HCV infection and 147 in those with HCV infection.

An additive relative risk for developing symptomatic cirrhosis was also seen with lower levels of daily alcohol consumption in individuals with chronic HCV infection. These results show that alcohol abuse and chronic HCV infection are independent risk factors for developing cirrhosis. These two risk factors together greatly compound the odds of developing cirrhosis, especially at high levels of alcohol use.

Stuffed Cabbage

2 cups cooked wild rice
1 cup diced onion
4 cloves of garlic, thinly sliced
raisins
apple cider (for sautéing)
one small head cabbage
tangy tomato sauce (recipe below)

In apple cider, sauté onion and garlic until onion is soft. Add rice, raisins and some more cider. Heat gently for a few minutes to let flavours meld.

Take cabbage and core and plunge into hot water for a few (5?) minutes to loosen leaves. Peel off a dozen or so leaves.

Put a layer of sauce in the bottom of the pan. Roll the cabbage leaves around the rice mixture by putting a tablespoon or so of the mixture in the middle of the cabbage leaf, fold up the sides and roll. Put the rolled cabbage on the sauce; layer as needed by putting sauce on top of the cabbage, adding more rolls, and end with sauce. Cover and bake 30 minutes in a 350 degree oven.

Tangy Tomato Sauce

1 28-oz can crushed tomatoes
1 cup diced onion
4 or more cloves minced garlic
1 tbs. apple cider
1 tbs. lemon juice

Sauté onion and garlic. Add crushed tomatoes. Simmer 5 minutes. Add apple cider and lemon juice. Simmer 5 more minutes. It's done!

KUDOS

by Darlene Morrow

I would like to thank Dr. Anderson and all the office staff for their continued help and collaboration on some of the articles that appear in the *hepcBC.bull*.

Natalie Rock is extremely busy and dedicated to helping those with HCV, among others. She patiently answers endless questions and encourages phone calls for any items that require clarification. Many a time she has sent me her column for the newsletter at 11 p.m. Other times she will submit them on a Saturday.

We all owe them a tremendous debt of gratitude for their untiring efforts to promote education about HCV.

Thank you!

AN OPEN LETTER TO THE HONOURABLE ALLAN ROCK AND ALL MEMBERS OF THE FEDERAL GOVERNMENT RE: THE TAINTED BLOOD TRAGEDY!

Dear Mr. Rock,

As a victim of tainted blood I have watched the shenanigans in Ottawa with a mixture of disbelief, disgust, contempt and as much anger as I can muster given the precarious state of my health.

In my opinion, you, the Prime Minister and members of the Liberal government, have become past masters at the art of obfuscation. You are right when you state that there is risk in any medical procedure. I accepted that risk when I had my heart valve replaced in 1983 and re-replaced in 1996. What I cannot, and will not, accept is the fact that my life is in jeopardy due to money-saving decisions made by faceless bureaucrats who are now deemed not to be responsible or accountable.

To suggest that compensating all the victims of tainted blood will bankrupt the health system and lead to a flood of claims is obfuscation and arrant nonsense. Does it bankrupt the system when we give billions of dollars to countries like Indonesia? Does it bankrupt the system when we aid our fellow Canadians affected by floods, ice storms, and so forth? I think not. About the only thing bankrupt in this whole sorry mess is, in my opinion, the morality of the federal and many provincial governments.

All decent people must feel for those who suffer from "medical misfortune," but to refer to the tainted blood tragedy as a "medical misfortune" is another example of obfuscation. The list of dates when our government could have acted goes back to the 1960's but I refer only to the decision made on July 13, 1981, by so-called "regulators" and officials of the Red Cross, not to buy a readily available surrogate test. In my opinion this decision alone condemned hundreds, perhaps even thousands, of Canadians, including me, to death. And I thought the death penalty had been abolished in Canada.

"Window of Opportunity"? My how you Liberals love that phrase. To use it in the context of the tainted blood tragedy is another example of obfuscation. I put it to you, Sir, that there is no "window," but a bloody great chasm as wide as the Grand Canyon, and you and your lackeys are teetering on the brink, and, in my opinion, unless you listen to the wishes of the vast majority of the Candian people who are your employers, you will all be pushed over the edge in the next election.

"Precedent"? This is a word you Liberals appear to hate as much as you love "Window of Opportunity." Again I put it to you, Sir, that by using the dates 1986 to 1990 you have created two dangerous precedents that could have an enormous impact on Canada. You have made the United States not only arbiter of the Canadian health system but also of Canadian law. We are sick and tired of hearing about the United States. A country where the number of citizens who cannot afford health insurance exceeds the population of Canada is no example by which to judge our health care system. You did not wait for the United States to act when you brought in gun control against the wishes of vast numbers of law-abiding citizens.

Now you are faced with an issue where the vast majority of Canadians believe the victims of tainted blood should be compensated and those responsible be brought to account. And what is your response? To go against the wishes of the people and continue defending the indefensible. If one of our ships is in a collision the captain has to answer to a court martial and is held responsible for his actions. Yet in the civil arm of government, individuals or groups of individuals can cause untold harm to their fellow citizens by their actions or lack of action, yet walk away scot free. Why is there this double standard? Why are those who fail to carry out their duties in a responsible manner never held accountable?

In my opinion those who are responsible for the blood tragedy should be made to answer for their actions or lack thereof as has happened in other countries.

Ron Thiel
Victoria

ROCK HARD IN OTTAWA - ODE TO A ROCK HEAD

Like the Rock of Gibraltar
He stands firm and square
Allan Rock will not alter
So try if you dare

He's made his stand
And stuck to his guns
By treating Hep-C'ers
Like miserable bums

And if you don't like it
Well, that's just sour grapes
But remember ----- Gibraltar
Is crawling with apes.

Ron.T.

CLASS ACTION SUITS:

BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, B.C. V6B 1Z5
1-(800) 689-2322

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, B.C. 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:

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.

TRACEBACK INQUIRIES

Contact:
Dr. Lisa Jeppesen, Dr. P Doyle, or Glenda
The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-(888) 332-5663 (local 207)

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
Meetings will be set up so that we can share our experiences dealing with lawyers, the results of our own investigations, and so that we can decide what is in our own best interest as far as legal steps to take.

RUN FOR LIFE!

Hepatitis C Society

5K FUN RUN

– June 28, 1998 at 9:00am –

LOCATION: Cordova Bay – Lochside Park – Lochside Trail, Dooley Road, Hunt Road back to Lochside Park via Lochside Trail -- Victoria BC

COURSE: Flat trail, country roads.

CATEGORIES: Men's and Women's winners.

AWARDS: Trophies for overall Male and Female winners.

PRIZES: Draw prizes after the race.

T-SHIRTS: First 200 get t-shirts before race. Later registration get shirts after race.

ENTRY FEE: $15.00 up to June 14th
$20.00 late registration up to June 28th deadline.

REGISTRATION: Drop off at Victoria Running Room, 1008 Douglas Street.

RACE KIT PICK-UP: 10:00am to 5:00pm on June 27th.

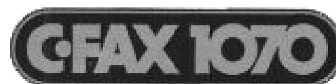
FOR MORE INFORMATION:

Call Victoria Running Room at 383-4224

OR

Hepatitis C Society at 388-4311

Proceeds go to the Hepatitis C Society of Canada



RUN FOR LIFE Hepatitis C Society 5K Fun Run — Race # 1145

Name: .... Address: ....

City: .... Postal Code: .... Phone Number: ....

Age: .... Sex: M ☐ F ☐ T-shirt Size: M ☐ L ☐ XL ☐

Entry Fees: Before June 14th: $15.00 Late Registration up to June 28th: $20.00 Cheque payable to the Hepatitis C Society

Waiver: I know that running / walking a road race is a potentially hazardous activity. I should not enter and run/walk unless I am medically able and properly trained. I also know, although police protection will be provided, there will be traffic on the course route. I assume any and all other risks associated with running / walking the event including but not limited to falls, contact with other participants, the effects of the weather including high heat and/or humidity, the conditions of the roads, all such risks being known and appreciated by me. Knowing these facts, in consideration of the Running Room Sports Inc., Event Sponsors, Volunteers and Organizers accepting this entry, I hereby for myself, my heirs, executors and administrators, waive and release any and all rights and claims for damages sustained by me as a result of this walk/run event, for any cause whatsoever, including negligence. It is expressly understood by the undersigned that this run/walk event is entered into at the sole risk of the undersigned & that the organizers and sponsors of the run are exempt from liability for any and all damages sustained & any and all injury & loss, including personal & property loss arising from any cause whatsoever, including negligence. Applications for minors will be accepted only with a parent's signature and should be signed by the minor also. I hereby acknowledge having read this Release and Waiver and I understand and accept its terms.

Signature (Parent or Guardian if under 19): .... Date: ....

April 21,1998