hepc.bull

BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

January, 1997

MEMBERSHIP DESK

First I would like to wish everyone the best for the New Year and hope Santa was good to you.

The Times Colonist, on December 14th/96 carried an article which covered the HeCSC submission to the Krever Commission by Dr. Alan Powell and Jeremy Beaty, our President nationally, that persons infected through tainted blood should be treated the same as AIDS victims and urged that compensation should be given to victims.

These efforts need our backing locally so a voice is heard across the land. Writing your M.P. and M.L.A. would help a lot and I suggest that when you do, please forward a copy to me. (My address is 410-831 Dunsmuir Rd., Victoria. BC. V9A 5B9. A list of M.P.s and M.L.A.s is being compiled, and hopefully I will be able to include it in another Newsletter.) This will ultimately help in coordinating our action to the utmost effect. I have already written mine but have not received an answer as yet. Further, if anyone feels strongly enough about the issue submitted by the Toronto Office and would like to help locally, please call me. We could do with some help and suggestions. Our telephone network is working quite well and through feedback from this source I know that the feeling of some is that 'they', meaning someone else but self should do something. We need your input and support right now, so please phone me. I'm happy to report that the few members who attended the A.G.M. and gave some suggestions and attended the workshops to help HeCSC plan goals for 1997, their voice was heard and action is now underway. Thanks.

We still need you to consider becoming members as this gives us much more clout. Why not complete the Application Form (if you have mislaid it, phone for one) today and mail it to the Toronto Address.

Reminder:- Any change of address, phone number, or Postal Code please let me know at your earliest. It saves us money. Thanks.

Jim Lodge Co-chairperson 386-8227 Membership Chair.

A WORD FROM DAVE

Ideas are a dime a dozen. Executing them is the real challenge. If I learned one thing over the past year, it was this simple thing: It is easy to sit around and dream up schemes and make plans to do things to create a better working environment for our support group, to take it from a little local monthly meeting in little local burgs scattered across the country, and turn it into a national force that deals directly with governments and influences the decisions they make is a monumental task. This growth will happen only if we all work together and turn the ideas that we come up with into reality.

I suppose talking about it long and often enough is one way of making sure we don't lose sight of

what we are trying to do. Sooner or later (maybe by osmosis) the talk will turn to action and by taking a series of small tentative steps, we will achieve the goal of a funded support group, capable of reaching anybody who needs our help with anyone who needs our help being able to find us.

How far have we come in the past year? Two meetings with the Provincial Health Officer and his colleagues showed us that we are on the right track. We came away from those meetings realizing that we need to be more organized before we go back to them, cap-in-hand. That takes us back to the big ideas theory. However, they didn't dismiss us entirely, and they invited us to come back when we get our act a little more together. It's all learn as you go, gathering experience along the way. Maybe therein lies the key. Maybe there is no end result, and the journey towards that end is what counts. As long as we keep trying, it will help keep our minds from being overly preoccupied with having Hep C, and the mind/body connection being what it is, we will benefit from this. What else have we done this year? We increased our membership by 40%, which may not be a good thing. Wouldn't it be nice if we didn't have to do this at all? I mean, I'd sure like to see that day. But reality dictates something different. So, in the meantime, any increase in membership means we are heading in the right direction. You find out you have Hep C. You don't get the answers you need from the medical establishment, so you look for support elsewhere, and somehow you find out about the Hep C Society of Canada. We don't have all the answers, but we give each other the support we need to the best of our ability.

In our fight for justice we took one big step in the right direction. In September, the class action suit commenced for those transfused between '86 and '90, with other time-frames hopefully to follow. Anyone who falls in this category and is not yet hooked up, call one of the steering committee or 1-800-652-HEPC.

Space will not permit me to ramble on about our other positive achievements, but coming up in the new year, we have our education grant coming in, which was, in fact, one of our accomplishments from this past year. This will better enable us to help each other, and hopefully in the new year we will have an office to work from. This will make us much more accessible to each other. Let us hope that next year we accomplish what we set out to do, and inch along as steadily as we did this year. As long as we *don't give up*, and don't lose our faith and hope, we are on the right track, and let's try to support and educate the public and the medical community as well as each other. They need our help, too.
Well, that's about it for me this year. I hope everyone will have a great holiday season and a healthy and prosperous New Year. May your God be with you. See you next year. David

COORDINATING COMMITTEE -- VICTORIA CHAPTER

CO-CHAIRS:	JIM LODGE	TEL: 386-8227
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MEMBERSHIP	JIM LODGE	TEL: 386-8227
LIBRARY & BULLETIN	JOAN DIEMECKE	TEL: 479-5290 (TEL. & FAX)

NEXT MEETING: Wednesday, January 15, 1996 1 - 3 PM, and again at 7-9 PM St. John the Divine Church Lounge 1611 Quadra St. (Entrance through the rear, marked Annex)
Our guest speaker will be Phyllis Kjellander Note: Please see article in the December issue of hepc.bull.

NOTE:

HeCSS cannot endorse any physician, product or treatment. The 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

READERS' FORUM

This is a new column which will attempt to spark exchanges of information relative to Hepatitis C amongst our members. Our question for this month: **What led to your being diagnosed?**

Would you please send in your comments for next month's edition of hepc.bull? Remember, this is YOUR news bulletin. You may use a pseudomym, if you so desire. (The letters may be published individually, or certain comments may be chosen, edited, and grouped together in a single column.) Please send a SASE if you wish to have your letter returned to you.

Please send your comments to J. Diemecke, 3991 Lianne Pl., Victoria, BC V8Z 7H1, or you may FAX them to tel. 479-5290, or you may send them via email: 103125.1520@compuserve.com

The deadline for any contributions to next issue of hepc.bull is January 23rd. Please contact Joan Diemecke at Tel. 479-5290.

We reserve the right to edit items submitted for publication in hepc.bull. All manuscripts will be kept by the editor, unless you include a stamped, self-addressed envelope, or make other mutually agreeable arrangements

RECIPE CORNER: Potato Stuffed Cabbage

Categories: Vegan, Slow cooker
Yield: 8 servings

1 Head cabbage
5 lb. Potatoes peeled
2 Onions
1/2 c Rice, raw
1 t Dill, dried
1/4 t Black pepper ground
2 Egg whites
1 can Tomatoes (28 oz)
1 Apple peeled and sliced
1/4 t Ginger, dried ground

Parboil cabbage and separate the leaves. Slice off part of the heavy stalk of each leaf by slicing parallel to the leaf (do not cut into the leaf).

Grate potatoes, small inner leaves of cabbage, and one of the onions. Mix together. Add rice, dill, and black pepper. Beat egg whites until frothy and add to potato mixture.

Set aside two or three of the largest leaves. Fill each remaining cabbage leaf with approximately 2 Tbs. of the potato mixture. Fold up bottom of leaf, then fold in the sides, and roll up. Secure with toothpick if necessary.

Slice the reserved leaves and line the bottom of crock pot with them. Slice second onion and layer on top of cabbage. Add tomatoes, apple, and ginger. Place rolled stuffed cabbages into pot.

Cook at low heat for 4 to 5 hours.

What's your favorite, healthful recipe since you were diagnosed? Recipe contributions may be sent in to Joan D. (See address in READERS' FORUM.)

HCV TEST NEEDED IN THOSE WITH NEUROPATHY/MIXED CRYOGLOBULINEMIA

The journal *Hepatitis Weekly* issued August 5, states: "Patients with peripheral neuropathy [nerve damage] and essential mixed cryoglobulinemia should be tested for anti-hepatitis C virus

antibodies to determine appropriate treatment, according to a report from France."

Cryoglobulinemia is a medical problem diagnosed by the presence of certain proteins in the blood which become solid at cold temperatures. Cryoglobulinemia may be a disease by itself, or it may be caused by, or linked to, various diseases, among which Hepatitis C figures prominently.

"The prevalence of hepatitis C virus (HCV) infection has been estimated at 43 to 84 percent in patients with essential mixed cryoglobulinemia in recent large series," researcher Emmanuelle Apartis and colleagues wrote in the *Journal of Neurology, Neuro- surgery, and Psychiatry*, June 1996. "Some of these cases have been successfully treated with interferon-alpha ."

In this study, fifteen subjects with peripheral neuropathy and essential mixed cryoglobulinemia were tested for anti-HCV antibodies. Antibodies were found in 10 of the 15 patients.

"Compared with HCV negative patients, HCV positive patients had a more pronounced and more widespread motor deficit; motor nerve conduction velocities in peroneal and median nerves were more impaired in HCV positive patients, although significance was not reached except for the mean value of the amplitude of the compound muscle action potentials of the median nerves. Necrotizing vasculitis was found in two of nine nerve biopsies from the HCV positive patients studied and in none of the three HCV negative patients," Apartis et al. wrote.

Those patients with HCV also had more frequent cryoglobulinrelated skin problems, higher cryoglobulin concentrations in their blood, and more cases of presence of rheumatoid factor.

When the 8 subjects with HCV underwent liver biopsy, damage was found ranging from chronic active to persistent hepatitis.

Two of those patients were treated with interferon over a period of six months, and seemed to have an improvement in their peripheral neuropathy.

Apartis states that peripheral neuropathy could be found in 84% of patients with cryoglobulinemia, in a study of 45 patients. Some scientists believe that there may be a relation between Hepatitis C and cryoglobulenemia, especially if there is liver damage, since there may be a cross reaction of the antibodies against both antigens.

"A high proportion of patients with peripheral neuropathy associated with essential mixed cryoglobulinemia are suspected of having serum anti-HCV antibodies, and these patients seem to have a more severe neurological condition," Apartis et al. wrote.

He also suggests that people who have both nerve damage and cryoglobulinemia should be tested for antibodies to HCV, so that the degree of liver damage can be measured and treatment decided upon, such as interferon, which he says should be looked into as a possible treatment for peripheral neuropathy.

The corresponding author for this study is Jean-Marc Leger, Service de Neurologie, Hopital de la Salpetriere, 47 bd de l'Hopital, 75651 Paris Cedex 13, France.

CRYOGLOBULINEMIA

(This article is an excerpt from the book FAQ by Patricia Johnson, better known as "Peppermint Patti". The book is available in our library.)

One-third to one-half of people with chronic hepatitis C infection have cryoglobulinemia (antibodies in the bloodstream attached to the hepatitis C RNA that happen to solidify when cold). Hepatitis C is recognized as the most common cause of mixed cryoglobulinemia. Most of the people with

cryoglobulinemia from hepatitis C have had their hepatitis for a long time or have cirrhosis. People with higher concentrations of hepatitis C RNA in their blood do not seem to have a higher risk of having cryoglobulinemia. Usually the cryoglobulins are in low concentration and cause no symptoms. About twenty-percent of people with hepatitis C and cryoglobulinemia have symptoms. Symptoms most often associated with cryoglobulinemia include mild fatigue, joint pains, or itching.

Occasionally, people with cryoglobulinemia develop vasculitis (inflammation of the blood vessels) which can cause purpura (purple skin lesions), Raynaud's phenomenon (the hands turn white, then blue, and then red from constriction and subsequent dilation of the blood vessels), or numbness in the hands and feet. The presence of cryoglobulinemia does not effect people's response to interferon. In fact, some people with vasculitis have improvement in the vasculitis as their liver tests improve on interferon

CHINESE HERBAL TREATMENT

In a report in the Chinese Journal of Integrated Traditional and Western medicine (1994), a claimed rate of cure of 56%, with most other patients showing improvements, was obtained when the following formula was administered to treat hepatitis C:

astragalus:	30 grams
salvia:	30 grams
forsythia:	30 grams
red peony:	30 grams
ho-shou-wu:	15 grams
crataegus:	15 grams
moutan:	15 grams
gardenia:	15 grams
dandelion:	15 grams
bupleurum:	10 grams

The herbs are decocted and the amount indicated here is taken in two divided doses each day, for three months. The formula can be modified to address specific symptoms by adding additional herbs (e.g. for pain in the liver area, loss of appetite, or abdominal distention). As with treatments for hepatitis B, the formula contains herbs for treating damp-heat (forsythia, gardenia, dandelion, and bupleurum), blood stagnation (salvia, red peony, crataegus, moutan), and deficiency of qi and blood (astragalus and ho-shou-wu).

Due to the long course of therapy, one may wish to substitute dried extracts: a dose of three teaspoons (9 grams), three times daily of this formulation should produce similar response [about 27 grams per day of dried extracts is roughly equivalent to a decoction of 160 grams of crude herbs, somewhat less than is recommended in the above clinical trial; the patient cost of this treatment is about $500 per three month course]. some patients may experience loose stool or diarrhea in response to this therapy (e.g. ho shou wu, gardenia, and dandelion can act as laxatives), thus one may need to adjust the formulation somewhat if this reaction occurs and persists. It is not known if good results can be obtained by substituting powdered herbs for the extracts. If one wished to substitute tablets (which are comprised mainly of powdered crude herbs), Salvia Shgou Wu contains the salvia (extract), astragalus, crataegus, ho-shou-wu and red peony, while Nuphar 14 contains the moutan, bupleurum, and gardenia, as well as additional salvia, and Red Peony Tablets contains the dandelion and forsythia, as well as some additional red peony (extract). The use of these tablets will result in less relative dosage of the herbs than in the decoction formula, but there are additional herbs that would be expected to support their actions. One might consume three tablets of each formula each time, three times daily [total: 27 tablets per day; patient cost is about $300 per three month course]. Using the tablets, one would expect to need a somewhat longer therapy than the higher dose decoctions or granules. The dose of one or more of the formulas could be increased (e.g. to four tablets each time), if desired.

Until clinical work with hepatitis C and Chinese herbs is carried out in the United States with available materials that are in a form suitable for administration, it may be difficult to convince medical practitioners and patients to try this method. Because the herbs are non-toxic, some patients may wish to utilize this therapy in place of, or in addition to, treatment by interferon. It is reasonable to begin collecting information from such patients to provide case histories in an effort to eventually develop a clinical trial.

LIST OF HAZARDOUS HERBS

Here is a list of nine herbs that the FDA says are related to serious adverse reactions or possible dangers:

-- Chaparral. Can cause liver inflammation. Has been promoted as a``blood purifier,'' cancer cure and acne treatment..

-- Comfrey. At least seven cases of liver complications have been reported in users. Comfrey stimulates cell growth and is used for wound healing when taken externally. Toxic to the liver when taken internally.

-- Yohimbe. Produces adverse reactions when consumed with certain foods -- liver, cheese and red wine. Is valued as an aphrodisiac.

-- Lobelia. High doses can suppress breathing, cause sweating, speed the heart, lower blood pressure and even lead to coma or death. The source of lobeline, an ingredient in some over-the-counter smoking deterrents

-- Germander. Linked to liver inflammation, including one death. Used as a weight-loss aid.

-- Willow bark. Contains salicylates, like aspirin, which could cause stomach irritation or Reye syndrome Is promoted as an ``aspirin-free'' pain reliever, but no adverse effects have been reported.

-- Jin Bu Huan. An overdose can result in severe sedation requiring medical treatment, and liver inflammation. Is marketed as a sedative and pain reliever.

-- Stephania and Magnolia. Have been implicated in severe kidney injury to at least 48 women. .

-- Ma huang. Associated with high blood pressure, rapid heart rate, nerve damage, muscle injury, psychosis, stroke and memory loss; Used for weight control and enhanced energy and to treat asthma and hay fever. Contains pseudoephedrine, the active ingredient in decongestants such as Sudafed.