



June, 1996

TRANSFUSED AND ANGRY?

If you are a recipient of tainted blood, and think you are a good candidate for a Class Action Suit, please call David Smith immediately at 658-4991.

At our last meeting, on May 15th, David Butcher, a lawyer, came to talk to us about the Class Action Suit being organized by Leslie Gibbenhuck on behalf of her son, who was transfused shortly after his birth 8 years ago. Little Jarad now has Hepatitis C. Mr. Butcher was kind to leave us a transcript of his talk, which we have in our library. To borrow a copy, please call Ingrid Brundin at 920-5708 .

NEED SUPPORT?

Margaret Parry recently lost her husband, Robert, to Hepatitis C. Through her sad experience, she has gained a lot of knowledge about the disease, and a great desire to help our group. Margaret has kindly offered her support. If you need to talk, or need information, please call her at 380-1851.

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

NEXT MEETING: June 19, 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) We are hoping to have Dr. Frank Anderson to discuss treatments at both meetings. Bring your questions!

RECIPE CORNER

This recipe was given to us by Mike, a member of our local group, who has had excellent results lately, first from adapting a healthful regimen planned for him by Lynn at Good Nature Market, and second, by responding to Interferon treatment. Congratulations, Mike!

6 heaping Tbs. brown rice flakes
4 heaping Tbs. millet flakes
1/2 to 1 Cup natural soy milk
1/2 Cup boiling water
1 kiwi or strawberries or grapes
1 diced banana
1 sm. handful thawed frozen whole cranberries
1 Tbs. soy bean granular lecithin
1 Tbs. engivita yeast (or brewer's yeast)

(Any of the "stranger" ingredients can be found at most health food stores) He mixes all the ingredients together. The mixture produces about a liter, which he divides into 4 or 5 plastic containers and stores in the refrigerator to eat throughout the day. He likes to eat a 1/2 cup of yogurt first, but says you shouldn't mix yogurt with fruit.

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.

MEET PRISCILLA

I had a nice, interesting chat with Priscilla, a member of our local chapter, the other day, and found her to be a most interesting, charming person!

Did you know that she was born and in Brazil, and lived there until she was 28? She was a nurse. Now, I'm not just gos-siping about her without her permission. She kindly said I could print her story in the news bulletin. I asked, because I heard that, besides having Hep C, she was diagnosed as having cirrhosis 40 years ago! Personally, I find this very inspiring, so I proceeded to try to find out how she has succeeded so well in battling the Hep C dragon.

I asked her about her symptoms: At first, she had none. She lived a normal life. Once in a while she'd get yellow eyes and bloating -- of course, she didn't know she was sick. She says if she takes any drug or doesn't follow her dietary regimen, she gets stomach problems. She has chronic dia-rhea. She also has trouble walking- - a flu shot affected the nerves in her arms and legs a while ago-- but she says it bears no relation to Hepatitis C.

She was diagnosed with Hepatitis C in 1989 or 1990. She had been diagnosed as having Hepatitis Non A-Non B in the 80s, which was probably contracted during an operation 40 years ago, to remove her spleen. She doesn't think of herself as sick. She gets itching, usually together with liver pain once, in a while. She will occasionally take 1/2 Tylenol for pain. She's never had a biopsy. Her CAT scan doesn't show any scarring. I asked how they decided she had cirrhosis, if they haven't done a biopsy. She says they saw the cirrhosis during her operation, but they didn't say it was because of hepatitis. She rarely drank alcohol, and never drinks now. Years ago, her symptoms were worse. We discussed the possibility that perhaps she had Hepatitis A or B, and it was cured, and then got Hepatitis C.

What does she do to stay healthy? She has eaten organic produce for 2 years now. She doesn't eat red meat, nor does she drink alcohol. Her diet is low in fats, and includes lots of fruits and vegetables, especially carrots and beets. She has to take antibiotics occasionally for kidney problems. She eats low fat fish and drinks mostly fruit juices, and she takes digestive enzymes by Swiss Remedies (500 mg. a day) which contain pancreatic protein, lipase, pancrease, and alpha-amylase, amyloglucosidase, cellulase hemicellulase, and lactase, but that's been just recently. She's taking CoQ10. She drinks skim milk with Lactaid. She does eat yogurt and gelatos.

She says she takes logical pre-cautions, as well. She uses the full-serve gas, so as to not breathe the fumes. She's an artist -- so she uses a mask so as to avoid the toxic fumes from pens, etc. She doesn't spray her roses. She feels her Vitamin B complex has been helpful, and she injects it herself. She has been

having acupuncture and acupressure for about 3 years now. She has been treated with homeopathy for the last 8 months: Arsenicum, and Nux Vomica for itching, liver pain, and bloating. (Causticum for other things, as well)

So, as I said, her cirrhosis was probably not caused by Hepatitis C, but she has had cirrhosis (diagnosed 40 years ago), so I presume she still does, and she has Hepatitis C. Pretty amazing! Thank you, Priscilla, for sharing your secrets with us.

BREAKTHROUGH ON CIRRHOSIS

Citation: Pamphlet by American Liver Foundation, Sept 23, 1991 [url: <http://www.iacnet.com/health/11329974.htn>]

A major breakthrough in the treatment of cirrhosis was reported at the annual meeting of the American Association for the Study of Liver Diseases in October 1987.

Colchicine, a drug used for centuries to treat gout, has been found to significantly improve survival of patients with cirrhosis after 30 months of treatment.

Dr. David Kershenobich of the National Institute of Nutrition in Mexico City and Dr. Marcos Rojkind of the Center of Advanced Studies of the National Poly-technical Institute in Mexico have been working for several years on the basic mechanisms leading to cirrhosis, the progressive formation of scar tissue that results in impaired liver function and is among the leading causes of death world-wide. Cirrhosis results from various liver diseases.

An experimental model indicated that colchicine was effective in preventing scar formation and improving liver cell function. The results were published in 1973 and led to a randomized controlled trial. A partial account of this study was published in 1979. After 10 years of followup, Drs. Kershenobich, Rojkind and their associates in Mexico City reported to the AASLD that colchicine treatment effectively improved patients' survival. The cumulative 5-year survival in the colchicine group was 75 per cent, as compared to 34 per cent in the untreated group. At 10 years, the survival rates were 56 per cent and 20 percent, respectively.

Improvement of the liver biopsy was seen in 9 of 51 patients on colchicine, while none was seen in untreated patients. All the surviving patients remained stable and some even showed slight improvement of their clinical and laboratory status. No significant side effects were reported.

Dr. Rojkind has recently joined the faculty at Albert Einstein College of Medicine in New York City, where he is continuing work directed towards the better understanding and treatment of this chronic liver disease that affects people of all ages. It has been estimated that 20-40 people per 10,000 die each year from cirrhosis. Most are between the ages of 30 and 60. In the Western world, 60 percent of the deaths are due to alcoholic liver disease. The other 40 per-cent have various causes, including viral hepatitis and some metabolic abnormalities.

The authors concluded that colchicine significantly extended the life of patients with cirrhosis. Although it is not a miracle drug providing an instant cure, its beneficial effect represents a major breakthrough.

Until now, treatment aimed at relieving symptoms, rather than modifying the course of the disease.

CANADIAN LIVER FOUNDATION LOCAL CHAPTER

The Canadian Liver Foundation's (CLF) mandate is "to reduce the incidence and impact of all liver diseases." To ensure we can meet this mandate in the Victoria community, the CLF will be establishing a local volunteer chapter board. Your

local chapter will implement health promotion, patient education and fundraising programs within the Greater Victoria community. If you are interested in becoming a volunteer, please call Kevin Webster in Vancouver at 1-800-856-7266.

MEMBERSHIP DESK

by Jim Lodge

Again, I would like to say thank you to the many volunteers who have responded to our appeal for help, but we still need to have a back up in the areas listed below:

Fund-raising	Ryta Tracy	475-1860	
Publicity	David Smith	658-4991	
Afternoon meeting minute taker	Rae Supeene	478-1974	
Tea and Cookie helpers at both meetings-	Joy Hull	6564938	
Info Packet Project	Rae Supeene	478-1974	

Please contact the coordinator listed or phone me at 386-8227.

A note again about Membership in Hepatitis C Survivor's Society:

On becoming a member, the expiry date has now changed from the end of November each year, to a year from the date one made application for membership. A reminder that your membership has expired, or is about to, will be highlighted on your Victoria Chapter Newsletter label each month. Please renew promptly. Thank you.

To become a member of HeCSS, a membership application form has to be completed, and, with the minimum dues of \$15.00 per year, is forwarded to the National Office in Toronto. (This can be done through the Victoria Chapter. Also the dues can be paid at the rate of \$1.50 per month for the ten months the Victoria Chapter holds meetings in the year). Application forms are available at each meeting or on request. Benefits through the National Office are an Income Tax Receipt, a membership card (good for twelve months), plus receiving the National News Letter. Your Victoria Chapter benefits, too, by a portion of the dues being returned, to help with our Chapter operating expenses.

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

Jim Lodge 386-8227

Co-chairperson. Membership Chair.

AMANTADINE MORE EFFECTIVE THAN INTERFERON FOR PATIENTS WITH HEPATITIS C

SAN FRANCISCO, May 1, 1996 (Reuters) - With a program and abstract book the size of a large phone book, Digestive Disease Week and the 96th annual meeting of the American Gastro-enterological Association meeting is officially underway. On opening day, researchers at Penn State reported results of a pilot study that showed that amantadine is more effective, less toxic and much less expensive in the treatment of patients with hepatitis C than interferon, the conventional treatment for the disease.

Response Rate To Amantadine Around 70% In Patients With Hepatitis C:

Of twenty patients with interferon-resistant hepatitis C who were treated with amantadine in a pilot study led by Dr. Jill P. Smith, six responded and another eight had partial responses during the four-year study. In addition to its efficacy, Dr. Smith noted that amantadine had fewer, milder side effects than interferon, patients who received the experimental treatment reporting difficulty concentrating, constipation and, among elderly patients in the study, several cardiac complications. The cost of amantadine treatment was roughly \$20 per month. Dr. Smith cited the cost of interferon at about \$500 per month, with at least six months of interferon therapy necessary. "There was no drug company to support this study," Dr. Smith noted. "Most patients paid, and luckily it was inexpensive." She pointed out that the optimal dose of amantadine is unknown. Patients in this study received 100 milligrams twice a day. "We know this is a safe dose," Dr. Smith

noted. "If we had used a higher dose, or treated longer, it's possible that the partial responders would have responded completely." Response rates may also be higher, she said, in patients who had not already developed interferon resistance.