



hepc.bull

BC's Hepatitis C News Bulletin

January 1999

Issue No. 8

LIVING ADULT-TO-ADULT LIVER TRANSPLANT

CHAPEL HILL - Friday the 13th turned out to be a lucky November day for Mrs. Mitsuko Brown, 67, of Hubert, N.C. Her daughter, Barbra B. Howard of Asheville, and a team of University of North Carolina at Chapel Hill transplant surgeons made sure of that by providing her a healthy new liver to replace her own failing organ.

"Barbra gave me something that money can't buy, and that's my life," Brown said. "What she did and what the surgeons did was just overwhelming. Except for a sore throat, I feel good now for the first time in a long time."

At Howard's urging, UNC-CH School of Medicine physicians harvested part of the 44-year-old certified public accountant's liver and transplanted it into her mother, whose liver failed because of cancer and cirrhosis caused by hepatitis C. It was the first such operation in North Carolina and one of only a handful performed in the United States so far.

"Living-related adult-to-adult liver transplantation has just begun in this country in the past year, and that's very exciting," said Dr. Jeffrey H. Fair, assistant professor of surgery at UNC-CH.

"One of the chief reasons the new operation is so important is the shortage of organ donors," Fair said. "About 4,500 liver transplants from cadavers are done in this country each year, but that's nowhere near enough to help all the 11,000 people who are on the waiting list. About 15 percent of those people die each year because enough livers just aren't available, and the list grows by about 15 percent a year."

On the day of surgery, UNC-CH Drs. Mark Johnson and David Gerber removed the right half, or lobe, of Howard's liver. Fair, chief of the abdominal transplant service, then grafted the lobe into her mother in a six-hour operation. Both mother and daughter said they are doing well. Within about six weeks, Howard's liver will regrow to a size dictated by her body's needs, Fair said. It is the only organ that can do that. Likewise, within about the same span, Brown's new liver will grow to normal capacity.

Living adult-to-adult liver transplants have the potential of meeting up to a third of the national demand for such organs, the surgeon said. In that way, they will become comparable to living-related kidney transplants.

"This procedure affords the recipient a chance not to languish for years on the waiting list while getting sicker all the time," Fair said. "The donor

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Coping with Digestive Problems

A book review by Beatrice Trum Hunter

Good Food for Bad Stomachs by Henry D. Janowitz, MD
Oxford University Press, 198 Madison Ave., New York, New York 10016 USA
Hardcover, \$21.95, 224 pages, 1997

Good Food for Bad Stomachs is a healthy eating guide for those with digestive problems, whether it be diarrhea, constipation, intestinal gas, malabsorption, irritable bowel syndrome, ulcers, food intolerance or allergy, diverticulosis, diverticulitis, or cancer of the colon and rectum. Because the gallbladder, liver and pancreas are also involved with digestion, they are included in the discussions.

Dr. Janowitz discusses what is known about the role of eating habits in prevention, causation and treatment of the disorders that can plague the human gastrointestinal tract. He notes that frequent conflicting advice and the confusion that results as new nutritional information becomes available make it difficult to know what the "ideal diet" should be. However, we can formulate the elements of a realistic, reasonable diet. Janowitz observes that there has probably not been any evolutionary change in the human digestive tract during human history. However, the sustaining nutritional environment has changed radically, especially in the last century. He poses the question, "Can this be the source of any of our current digestive problems? We might get some insight into this question by speculating about what the human prehistory diet was or may have been that has changed so radically." Compared to the current industrialized diet, "our paleolithic ancestors ate three times as much protein and half the fat we do. They ate meat, but it was much less fatty than our current animal sources of meat, being lean game. Thus the fat they did eat was more polyunsaturated than saturated. They ate very little refined carbohydrates and no finely ground flour. They consumed twice as much calcium as we do. They consumed five to ten times more non-nutrient fiber—a substantial difference. And they didn't smoke or drink alcohol."

The author cautions about the present emphasis on raw vegetables, especially those rich in fiber, for individuals with digestive problems. Often, the nutrients are bound into a matrix of

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CLASS ACTION VERSUS COMPENSATION

Class action, in British Columbia, was first registered on September 19th, 1996. It applied only to those individuals infected between August 1st, 1986 and July 1st, 1990. This action was brought by Camp Church and Associates.

In March 1998, the Federal, Provincial and Territorial governments announced a \$1.1 billion compensation fund (\$800,000,000 to be contributed by the Federal government, \$300,000,000 to come from the Provincial and Territorial governments) to cover all those infected, by transfusion, between January 1st, 1986 and July 1st, 1990. This fund is also said to cover all haemophiliacs, all secondarily infected with HCV, as well as about 100 secondarily infected HIV claimants.¹ The government has promised this small group of HIV secondarily infected will receive a lump sum of \$240,000.00 each (approximately 24 million dollars to be paid out).

If you were transfused between January 1st, 1986 and July 31st, 1986, it is my understanding your claim must remain with Klein Lyons, and they will be negotiating compensation on your behalf.

Every British Columbia resident who meets the definition of a class member (i.e., transfused in BC, tested positive for Hepatitis C, and currently resides in BC) is automatically a member of the class action and will participate in the class action, including any settlement of the class action, unless they opt out.²

If you opt out of the class you will not likely **share in any settlement** and you will have to bring your own action against the governments and the Canadian Red Cross.²

Compensation (if successfully negotiated) will be settlement of the class action. Based on

(Continued on page 7)

ONE MORE VICTIM

Al Fortin

One of our long-time members, Al Fortin, passed away on November 29, 1998. His wife and son reported this sad news to the office of HeCSC, Victoria, and said they will get back to us soon with more details. We offer our most sincere condolences.

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**

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Address: _____

City: _____ Prov. _____ PC _____

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"I cannot afford to subscribe at this time, but I would like to receive the newsletter." _____

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"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: Neither HeCSC nor the hepc.bull can endorse any physician, product or treatment. Any guests invited to our groups 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 organisation.

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@home.com 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 12th of each month. Rates are as follows:

Newsletter Ads:

\$20 for business card size ad, per issue

There will be a maximum of 4 ads in each issue, and the ads will be published if space allows. Payments will be refunded if the ad is not published. Ads are also posted to the Web.



COMING UP IN BC:

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

Comox Valley Liver Disease Support Group Meetings: Third Thursday of each month, 7 PM, downstairs, Island Health Unit building. NEXT MEETING: Jan. 21st. Contact: Ingrid or Nicky, 335-1711, or Public Health.

Cowichan Valley Hepatitis C Support Services. Contact: Debbie, 748-5450 or Leah 748-3432. vhepc@hotmail.com

Enderby HepCURE Meetings: Will be arranged over the winter on an as need basis. 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: Jan. 30th. Contact: Michael, 860-8178, Doreen, 769-6809 or eriseley@bcinternet.com

Nanaimo HeCSC Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Jan. 14th. Contact: Helen, 245-8759.

New Westminster Support Group: Meetings: Second Monday of each month, 7:00-8:30 PM, First Nation's Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. NEXT MEETING: Jan. 11th Contact: Dianne Morrissett, 525-3790.

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: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board

rooms. NEXT MEETING: Jan. 13th. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca


Richmond: Meetings: Fourth Tuesday of each month, 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. NEXT MEETING: Jan. 26th. Contact: Guy, 244-1704. guy@fatherswithoutchildren.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: Jan. 7th. 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: Jan. 14th. 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: Jan. 5th (Cancelled) and 19th. We will make castor oil liver packs. Bring a donation to cover costs. 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: Jan. 13th and 27th. Contact: Sharon, 542-3092. sgrant@attcanada.net

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: Jan. 27th. **Afternoon speaker, JJ Camp** (Class Action). Contact:  3 8 8 - 4 3 1 1 . hepcvic@pacificcoast.net

Victoria Election Results

On November 25th, 1998, the chapter elected the following members to the Steering Committee: **Judith Fry, Ivan Good Lisa Harnois, Joan King-Diemecke, David Mazoff, and Ronald Thiel.** Ken Crews was elected an alternate. At a later meeting, Ron Thiel and David Mazoff (squeeky) were elected co-chairs, and Joan King-Diemecke as Secretary-Treasurer.

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, CFAX 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, DataImage Technologies and CompuSmart. We also wish to acknowledge an anonymous agency which has generously supplied us with government surplus computer equipment.

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

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



S Q UEEKY'S CORNER

At the recent election, I promised you all that I would do my best to represent your interests and your wishes. Many of you have called and wondered why we weren't in the press anymore, expressing your frustrations at not being heard. As a result, I have recently written a series of letters and press releases to the media and the government based on your input and suggestions, and have been invited for interviews on various radio stations, where I hope to further represent your opinions. One letter I sent this week focussed on the government's speedy agricultural bailout plan, the one below on the government's most recent slap in the face.

Wednesday, 16 December 1998

Dear Sir or Madam:

The Federal Government's proposed compensation package for hepatitis C sufferers ("Hep-C victims offered at least \$10,000: Compensation to be tied to severity of affliction") is nothing more than a slap in the face. How else can this be understood when, at the same time, the government is prepared "to pay \$240,000 to every Canadian who caught AIDS from partners infected by tainted blood" and has taken steps to squelch any ongoing legal action against the main perpetrators by the pre-86 and post-90 groups?

The compensation package being offered by the government to those who contracted hepatitis C through tainted blood compares very unfavourably with past and present compensation paid to the victims of HIV/AIDS tainted blood, and, in effect, turns the victims of hepatitis C into second-class citizens! Not only is it too little by any stretch of the imagination, but it also perpetuates the myth that the only group of HCV transfused victims deserving of any recognition is the 86-90 group. How can they offer AIDS victims \$120,000 and \$240,000, but only offer HCV victims \$10,000? Was the crime against the HCV victims somehow "LESS" than the crime against HIV victims?

The government has long promulgated the falsehood that the ALT test only became available in 1986 when, they allege, they could have done something—and didn't! It is a known fact that the ALT test was available and in use from 1959 in many countries. What the government cannot escape is the fact that their regulators and Red Cross officials decided not to buy the ALT test in July 1981. The Krever report shows clearly that the ALT test could have, and should have, been introduced into Canada many decades before 1986.

The federal government had a duty to protect the well-being of Canadian citizens under the rules governing the Pure Food and Drug Act. That they didn't, in my opinion, makes them entirely responsible for the tragedy that followed.

Many of our members, who are dearly ill,

have repeatedly been denied disability benefits because the reality of their illness is still not recognised by the medical community in Canada. Symptoms are dismissed as figments of the imagination—even when these persons manifest the extreme fatigue characteristic of liver disease, liver scarring, dotting problems and other related symptoms. Many have lost income, have been refused insurance, are not covered by existing health plans for the costly interferon treatments that they need, and are slowly and inevitably progressing toward insolvency. Most, if not all, of these persons, have been run ragged trying to go through the "lookback/traceback program" steps required by the Federal Government and the Red Cross to obtain proof that they did indeed receive tainted blood (a requirement waived for HIV victims). Often, hospital records have been destroyed, and these persons, now older and more ill, are exhausting themselves doing a job that is clearly the government's and the medical establishment's to undertake.

What guarantee do we have that the process proposed by the government for proving need will not be a continuation of the existing attitude, an attitude which is clearly adversarial, to say the least? We have witnessed, recently, how speedily the government came to the aid of the agricultural community, as well as to the ice and flood victims in Quebec and Ontario. We have also seen how quickly the Canadian Government can respond to the needs of disaster-stricken communities in the Third World.

What is infuriating to me and to the members of the Victoria Chapter of the Hepatitis C Society of Canada is the government's continuing refusal to recognise that hepatitis C is not only a disaster but also a national disgrace. At least 300 000 Canadians are infected with this progressive and deadly disease, 20 000 to 30 000 of whom have been infected through tainted transfusions. Current mortality statistics are between 20-30% and rising. Most sufferers will become disabled over the years by the accumulating effects of the virus—diabetes, cancer, blood disorders, dotting problems, arthritis, fibromyalgia, autoimmune disorders, and more.

We are further incensed by the fact that this government absolutely refuses to honour the findings of Justice Krever and has instead devised a scheme whereby bureaucrats and lawyers will be the primary beneficiaries of any payout that the government eventually makes. It is my understanding that of the \$1.1 billion set aside for the 86-90 group, hundreds of millions of dollars are destined for the 35 lawyers involved in the current compensation talks. We note the speed with which the lawyer-less agricultural deal was concluded, and question, seriously, this government's integrity.

Many of our members have died; many have lost parents, children and spouses to this devastating illness. Many more will die before a cure for this insidious disease is found. The promise of justice has come and gone while these Canadian citizens have gone to their graves bewildered and confused as to why, having been so mistreated in the first place, they should continue to be so maligned.

(**Transplant**—Continued from page 1)

organ is very healthy because it doesn't come from a cadaver, and it not only can be implanted immediately, it also is more likely to function well immediately.

"Surgeons can now act when recipients are at their best—before their liver disease produces serious infections or other complications that result in death or otherwise prevent the operation."

Some patients who need transplants, such as cancer victims, but who cannot get on the waiting list because they are not yet in liver failure, also will benefit almost immediately, he said.

Despite pain during recovery, Howard said she would not think twice about giving her mother part of her liver again.

"When I learned of this new operation and told my mother about it, she was afraid for me and wasn't pleased that I wanted to take what she thought was a risk," Howard said. "To me, the small risk was nothing since I love her so much. We are very grateful to all the doctors and others who helped, and I'd do it again tomorrow."

Contact: David Williamson: David.Williamson@unc.edu or 919-962-8596

Editor's Note: There are now more than 220 people across Canada on waiting lists for liver transplants, a number that is expected to increase by at least five-fold by 2008. At present, 30% of people on waiting lists for liver transplants will die while waiting for an organ because there is a shortage of donors. The BC Transplant Society has approached Allan Rock to support the creation of a national organ donor registry like the world's first organ donor registry started here in BC last year. For further information, call 1-800-663-6189.

HAPPY NEW YEAR!

CORRECTION:

It has been brought to our attention that there were several errors in "HeCSC: Twelve Months of Achievements and Progress," in the December *hepc.bull*. Ron Thiel, co-chair of the Victoria chapter, noted that there was no "rally" at Whistler, and that he saw no one there from HeCSC, other than himself. Going to the Liberal Convention was "my own idea, I paid my own way and I went there to remind Rock of the victims he is ignoring. I went there on behalf of any victim who thought I was representing them—I did not go as a representative of the Hepatitis C Society of Canada."

Ron had the opportunity to tell Mr. Rock what he thought, but we can't print that here. ☺

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We shall not let this pass without notice.

Sincerely

Dr. C.D. Mazoff

Co-Chair, Victoria Chapter



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.

Ad No. 9

Hi, my name is Shane. I have HBV, HCV. I am 31 years old, 6'3 tall, 170 lbs. If you would like to see a photo of me and read my story, you can go to <http://www.hepatitis-c.com>

Seeking SF 25-45 for laughter, friendship, sharing and intimacy.
Shane (Alberta)

Ad No. 10

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

Ad No. 11

Companion(s) for some fun in the sun this winter. Prefer Eastern Caribbean—Belize, Cozumel, Cuba or ? SWF-61-Christian, healthy lifestyle, is looking for interested support group HCV person(s) to enjoy the great outdoors. Vancouver area.

WE NEED YOUR HELP

by Darlene Morrow, BSc.

I'm really annoyed at the latest trend by physicians to call the combo a cure. As we all know, this virus knows how to hide. A negative PCR (which is performed on whole blood and not liver tissue) is a great thing but it doesn't mean that the virus isn't present in the liver.

Recently, someone had their physician—the chairperson of the Canadian Association for the Study of Liver Disease (CASL)—fill out a handicapped disability form with the prognosis that this PCR negative person (who is on the combo) would be CURED by February of 1999 when he finished the combo. This is criminal!

First of all the CASL recommendations were supposed to slam the brakes on this kind of thing.

And second of all, will we never learn? I'm not going to forget anytime soon that I was told in 1986 that my Hep Non-A Non-B was nothing to worry about. Surely that experience would make everyone more cautious.

So- I'm attending the Medical Research Council of Canada's HCV conference in January. I want as much research as I can get that disputes this cure nonsense before it does more harm. Lots of research is finding that you can be PCR negative in whole blood but PCR positive in liver tissue. But, I need more eyes. If anyone sees anything about this, please send it to me. And anyone that gets this kind of message on paper, I'd like a hard copy to take with me.

Thanks for your help.

Darlene

Hepatitis C: Defining a Research Agenda for Canada

by Darlene Morrow

I will be attending the "Hepatitis C: Defining a Research Agenda for Canada" conference in Ottawa on January 15 & 16, 1999. We have managed to get an invitation for the HIV-CTN who have very kindly agreed to attend. This conference is by invitation only and we are very happy to have the support of the HIV-CTN and wish to express our sincere thanks.

Please email hepcbc@iforward.com or write to me at 1203 Plateau Drive, North Vancouver, BC, V7P 2J3 if you have any input for this conference and its objectives. I would love to hear from as many people as possible. More heads thinking to the same goal is a great thing.

In preparation for this conference the HepCTRG has sent letters to the drug companies doing research into HCV, asking for any updates. I'll keep everyone posted as to our progress.

REPORT: HEALTH CANADA FOCUS GROUPS

By Darlene Morrow BSc

Hi Everyone

Here in Vancouver, the HCV focus group met with Jeff Potts from Health Canada. This is a report of that meeting.

A variety of groups were represented which included but were not limited to: Tim McClelland & Guy Thisdelle from HeCSC, Michele from the CLF, Tom Molnar and David Lesh from the Canadian Hemophiliac Society, Nina as a family member of someone who has HCV, several individuals infected with HCV and me (Darlene Morrow).

Jeff Potts of the newly founded Hepatitis C Research, Disease Prevention and Community-Based Program - the Hepatitis C Division - Research and Systems for Health Directorate, Health Promotion and Programs Branch, opened the meeting.

The Federal government will spend \$50 million over the next 5 years in the above areas (\$10 million each year). This group is only 4 weeks old and has 3 principle players- the Hepatitis C Society, the Canadian Liver Foundation and the Canadian Hemophiliac Society.

These focus group meetings (with groups & individuals infected with HCV) will be used to determine and identify the priorities of this government program. These issues include what the

(Continued on page 6)

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Website: www.vicsurf.com.natura



(GOOD FOOD—Continued from page 1)

fiber in the plants. Heating hard vegetables such as carrots or broccoli gently breaks down the fiber, and allows the human body to absorb much more of the vegetable's nutrients. Only vitamin C is found in high concentrations in raw vegetables. Its loss in cooking is offset by the gain in absorption of other nutrients. Cooking also renders starch more digestible. Only 30% of potato starch is digested if the potato is eaten raw; 98% when cooked. We benefit more from vegetables such as cauliflower, which contains large amounts of starch, when the vegetable is cooked.

Janowitz reports that we are all interested in diet's role in causing a digestive disorder, but he admits that "clear-cut and established cases" are limited to conditions such as phenylketonuria, lactose malabsorption, or gluten enteropathy. If the ileum is diseased, disordered, or removed surgically, there is difficulty in absorbing vitamin B12, some forms of fat, and results in increased oxalates in the urine, leading to kidney stones.

For those with heartburn and peptic esophagitis, the author advises the individual not to lie down or go to bed with a full stomach directly after eating. Also, carbonated beverages should be avoided because they further distend the stomach with the release of dissolved carbon dioxide. Acidic foods such as citrus fruits may need to be avoided as well.

Numerous foods increase the likelihood of reflux of stomach contents back into the esophagus, including alcohol, fats, large bulky meals, both caffeinated and decaffeinated coffee, tea, cola drinks, chocolate, peppermint, and spearmint. Certain drugs need to be avoided, including anticholinergics, theophylline, relaxants, and calcium channel blockers.

A recent estimate suggests that the majority of people over 60 years of age have gallstones. There is genetic predisposition to form stones, but dietary manipulation or change in eating habits can prevent, or treat gallbladder diseases. Commonly, high-fiber, low-fat diets are recommended, along with regular eating habits, and avoidance of crash reducing diets. Skipping meals leads to overly long bile storage in the gallbladder. Rapid weight loss can readily precipitate gallstones by mobilizing large amounts of cholesterol from the fat depots of the body.

Alcohol is a common cause of pancreatitis, but a long list of prescription drugs, including antibiotics, diuretics, anti-tumor drugs, and others can induce pancreatitis. Fortunately, the pancreas has great regenerative power, and can recover functionally after one episode of pancreatitis.

Janowitz discusses malabsorption, with emphasis on celiac disease. A slow protein leak in the intestine from the blood can prevent the intestine from absorbing calories, especially fat calories, as well as minerals such as iron and calcium. Such malabsorption may be especially present for the fat-soluble vitamins. The author's experience with celiac patients has been that about 40% react unfavorably to millet, soy, and buckwheat, even when they avoid gluten-containing grains. He suggests that for such individuals, these foods, too, be avoided.

Malabsorption can occur when some areas of the small intestine are lost by disease, or shortened by surgical procedures. Commonly, the dietary fat is increased for such patients. Janowitz suggests the use of medium-chain triglycerides (MCTs) as the principal form of fat. MCT can be used for cooking, in salad dressing, or taken by the spoonful. Another way to increase caloric absorption is by means of a high-carbohydrate diet: 60% carbohydrate, 20% fat, and 20% protein. The colon can absorb carbohydrates more readily than fats. The carbohydrates are absorbed after being converted into short-chain fatty acids, which is the preferred food for the colon.

The most common complaint of individuals who seek help from gastroenterologists is irritable bowel syndrome (IBS). Yet, little is actually known about the fundamental nature of IBS. Irritants such as tobacco, caffeine, and alcohol are known to contribute to its discomforts and need to be avoided. Unfortunately, many IBS sufferers avoid so many foods, suspecting them as causes of discomfort, that they end up eating poorly, with unbalanced meals. Janowitz suggests that most cooked or steamed vegetables are tolerated, but some patients do better if cruciferous vegetables and legumes are eliminated. In recent years, IBS was considered a problem of altered motility or dysmotility of the intestinal tract. Now the emphasis has shifted to consider increased sensitivity of the patient's nerves, transferring the origin of the symptoms from the gut to the brain.

A chapter in the book is devoted to food intolerances and allergies, and the problems caused by some grains. For example, the carbohydrate of rice flour is absorbed completely, whereas some of the carbohydrate of all-purpose white wheat flour is not. This phenomenon is thought to be caused by an interaction between starch and wheat protein, which interferes with complete absorption of the starch, resulting in unpleasant gut reaction. Ingestion of whole oats and whole wheat results in doubling the normal fermentable material in the colon. Sugars such as sorbitol and fructose can cause discomfort; and at high levels, diarrhea.

Dr. Janowitz offers some guidelines to maintain good digestion. They bring us closer to the diet of our paleolithic ancestors.

Good Food for Bad Stomachs contains much information of interest. It is written clearly and simply, uncluttered by medicalese. Dr. Janowitz, with more than 50 years of clinical experience, is Clinical Professor of Medicine, Emeritus, at Mount Sinai School of Medicine. He had founded its gastroenterology division in 1958, and the division is now named in his honor.

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HEPATICO CONTROVERSY

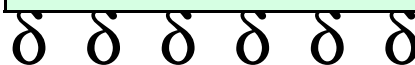
The Vancouver Sun carried an article on November 17, 1998, about a Richmond, BC, company which markets shark cartilage, and now carries a product by the name of "Hepatico," hoped to be a cure for hepatitis C. The company, Alta Natural Herbs & Supplements, is marketing the product which it says was developed in Russia over a century ago.

An official from the company, Raymond Irvine, says that Hepatico may eliminate HCV in up to 91 per cent of those who take it. Dr. Frank Anderson from UBC was quoted as saying that there is no known herbal cure for hepatitis C.

The article goes on to comment that Greg Shafransky, Alta sales vice-president, "has had prior regulatory problems," and also states, "Alta recently hired expelled accountant Piers Vanziffle."

Mixed reports about lab results have been coming in over the HepCAN list.

For more information, see <http://www.canada-stockwatch.com>



ROUTE OF INFECTION

By Natalie Rock BSN, RN
Hepatology Clinical Research Nurse
UBC Department of Medicine, Vancouver Hospital
and Health Sciences Centre

There are relatively few studies that have separated out the clinical outcome of chronic hepatitis C relative to source of infection. Many studies have determined the relative incidence from different causes but not the outcome. In a French study of 6,664 patients they found that cirrhosis was significantly higher in blood transfused patients versus intravenous drug users, the difference being 23.4% versus 7.0%. This was in spite of the fact that the occurrence of cirrhosis was also dependent on duration of disease and at point of diagnosis, previously blood transfused patients had a longer course of disease. Other studies have suggested that there are significant differences in hepatitis C genotypes dependent upon the route of infection and that intravenous drug users had a higher incidence of genotypes 1a and 3, whereas transfusion related patients had a higher incidence of genotypes 1b and 2a. Other studies have tended to concur, except in Sweden, where intravenous drug users had a high incidence of type 3a, transfusion related patients had a higher incidence of type 2b. The significance is that the clinical course and outcome might well be different in the different genotypes, type 1b generally being considered the most fulminant and least likely to respond to therapy. The development of cirrhosis has been reported as significantly higher in transfusion associated hepatitis C.

federal government can do to increase the quality of life for those people infected with HCV.

Each individual person with HCV was invited to speak on what they thought the priorities should be.

The primary areas of concern were the following (not necessarily listed in order of importance):

1. Research into paediatrics, vaccination and a cure. More clinical trials brought to Canada and a central agency in charge of that research so that anyone that wants to be in a trial can find the one in which they meet the criteria or the study that is researching an area of importance to that individual.
2. Support for families and people with HCV. This support should include government funded paid positions so that we can get some healthy people addressing our concerns. It should include support that will go into the individual or family's home if necessary. A comprehensive care team should include but not be limited to the psycho-social issues, home care, & education. A central place for people to meet is important, but so is support in outlying areas.
3. Equal access to treatment—everyone who wants to be treated should be treated. Money should not be a consideration.
- 4 Eligibility for CPP, social assistance and other areas should be easier and not begin with an automatic refusal.
5. Funding for alternative therapies. While alternatives may not hold the promise of a cure, they certainly do improve the quality of life (QOL) in some individuals. Also, adjunct therapies such as massage therapy should not be limited to its current number of visits.
6. And last, but far from least in everyone's eyes—physician education in HCV. Patients are receiving too many mixed messages. As everyone knows, this area is fraught with problems.

In addition to this info, I also found out that:

1. The Canadian Association for the Study of Liver Disease (CASL) which met in October, has really come to questions about this so called cure of interferon and ribavirin. The issue is far from settled. It is recognised that the PCR for HCV RNA is performed on whole blood, and that recent research has found that it is possible to be negative in whole blood, while a PCR performed on liver tissue can be positive. And the lower limits of the test are not zero, so what does it really mean to be PCR negative? It does NOT mean to be cured.
2. There will be a GP conference here in Vancouver on Hepatitis A-G. The focus will be on B & C. It is funded by the drug companies Schering and Smith-Klein Beechum. The CLF has been asked to facilitate the event. We are trying to get an invitation. ∅
At the end of the meeting I asked what was

FOCUS GROUPS: A REPORT FROM JEFF POTTS

Jeff Potts has been attending the cross-country meetings held by Health Canada, has kindly been collecting feedback from Hep C sufferers via the HepCAN list, and in person. He was on the road with Tim McClelland and visited a number of people living with Hep C and affected by it, in several places (see below). He reports back to us as follows:

Hepatitis C was very new to me when I started my work on this file, and I don't want to be one of those people that don't know what the heck you're going through. The focus groups were a real eye-opener for me. I wanted to make sure that I was continually educated and aware. The HepCAN list seemed like a good place for that.

The first phase of our outreach to people living with and affected by Hep C is complete, and I am back in Ottawa now. While we have started to sit down as a group here to discuss the outcome of each focus group session we conducted, our work pulling together the feedback and writing the summary reports is just beginning. We will be meeting in Toronto on December 16 with representatives of the three national stakeholders to discuss and validate the messages that we received on the tour. I will tell you, however, that much of the validation will be obvious when I report how consistent the messages were across the country.

We have been providing brief progress reports to the upper management all along, so they are very aware of the concerns raised by the Hep C community, as indicated to me while I was away. We are not yet in the recommendation stage of this process, only because we haven't had an opportunity to synthesize the information yet. However, all of the recommendations made during the cross-country tour, and any subsequent ones, will be included in the final summary documents, and will be considered carefully while we are drafting the Treasury Board submission.

I will make a summary report available to you all as soon as I can.

Having said that, I would encourage you to offer me continued comments and suggestions with regard to the government's position with the \$50 million. I will only use those pieces with your express permission.

The messages we received from everyone were, for the most part, consistent across the country, and those messages will be reflected in the work we do leading up to the Treasury Board submission, and the initial program plan. It is our goal to have all of the information synthesized, the Treasury Board submission filed, and the program plan in place by April 1, 1999. Officials in government have been kept informed of our activities, and are aware of the concerns expressed by the community during our focus group sessions.

The cities we visited were: Vancouver (2 meetings, one with IDUs specifically), Whitehorse, Vernon, Calgary (2 meetings), Edmonton, Regina, Winnipeg, Thunder Bay, Sault Ste. Marie, Ottawa, Toronto (2 meetings, one with Children and Families, and one with Hemophiliacs), Hamilton, Kitchener, Montreal, Moncton, Halifax, and St. John's. Some participants did, however, identify places that we should consider visiting on a second tour (Victoria, Lethbridge, Saskatoon, Thompson, Brandon, Quebec City, Trois-Rivières, Sydney, and Charlottetown). I have shared that suggestion with my colleagues, and we will investigate the feasibility of conducting further focus groups in those areas.

Thanks a bunch. I'll be in touch.

Jeff R. Potts

Program Officer
Hepatitis C Research, Disease Prevention and Community-Based Program
Hepatitis C Division - Research and Systems for Health Directorate
Health Promotion and Programs Branch
P.L. 3104D, 1600 Scott Street, Holland Cross, Tower B, Suite 410
Ottawa, ON K1A 0K9
Phone:(613)946-5678 Fax: 946-2062 e-mail: Jeff_Potts@hc-sc.gc.ca

next on the government's agenda. The details of this meeting will be presented in a report in Ottawa and they will outline the next step which will include further meetings with the HCV community. I have the email address of Jeff Potts and I'm going to ask him for his permission to post it. I think everyone can give him their feedback, not just those people that attended the meeting. In addition I asked for him to submit his report to us, so that we could prevent any misinformation. He said he would do that. As he is on the road quite a bit we will either get it next Monday or the week after. I'll post an update when that happens.

Take care.
Darlene

IN SEARCH OF A CURE

By Joan King-Diemecke

3M Pharmaceuticals and Vanguard Medica, Guildford, U.K, are working together to develop an analogue of the drug imiquimod, used to treat genital warts, as a potential oral treatment for liver infection caused by hepatitis C virus (HCV). Clinical studies to determine the efficacy and safety of the compound will begin soon. Early studies using oral administration of the compound have shown an increase in the levels of interferons and other cytokines.

Hemispherx Biopharma, Inc., Philadelphia, PA, is a pharmaceutical company engaged in the manufacture and development of new drug entities in the nucleic acid (NA) class for chronic viral diseases and disorders of the immune system, including hepatitis C. Interleukin 12 Phase II and Peg Interferon/Ribavirin Clinical Trials are being conducted in the US at the VA Medical Center, Long Beach, CA. If you would like information about that trial or about the other sites which are available, please contact Carol at GLITTERS12@AOL.COM or call (562)-494-5933.



A new clinical trial will be starting early in the new year. The trial will be open to treatment naive patients—that is those patients who have not been previously treated with Interferon. This trial will consist of pegylated interferon combined with ribavirin. The cost of the drugs will be covered by Schering. Pegylated interferon is a type of sustained release interferon that is injected on a once a week basis. For more info please call Susan at (604) 876-5122.



VOLUNTEERS NEEDED

Do you have a bit of extra time? Would you like to help your local chapter? HeCSC Victoria desperately needs **volunteers for the phone list**. The work involves making an average of one or two calls a month to 10 or more members. If you're interested, please call the office at 388-4311 and leave a message with your name and phone number.



HEP C VICTIM PLEASED WITH COMPENSATION

"I'm not counting my \$10,000 until I have a cheque"

By CHRISTY CHASE

Staff writer *Whitby This Week*

Friday Edition, November 27, 1998

OSHAWA-

Cathie Norwick is pleased the Province is going to compensate others who've contracted hepatitis C through contaminated blood **beyond a five-year period**. "Whoever's going to get the money, I'm happy for them," Ms. Norwick said of the plan announced Monday by Health Minister Elizabeth Witmer. Ms. Norwick contracted the disease of the liver from contaminated blood transfusions in the 1990's, treatments for a rare blood disease that caused a heart attack and several strokes. The Province will give \$10,000 to each person who got hepatitis C through the blood system **before** January 1986 and **after** July 1, 1990. The estimated 5,000 Ontario residents infected between those dates are being compensated under a \$1.1 billion federal, provincial and territorial package. "We are committed to doing what is fair, equitable and compassionate to provide this much-needed support to victims as quickly as possible," Ms. Witmer said. "The time for action is now." "It's a start," Ms. Norwick said. "I'm pleased that they're moving on it so quickly." But she added the \$10,000 won't go very far for someone whose hepatitis C is active, unlike hers which is dormant. "It's like a temporary, bandage fix," she said. "I'm lucky mine's not active but that could change." Ms. Norwick, in her mid-40's, is still waiting to determine just which compensation plan she comes under. She received 200 units of blood within the five-year period and more than 200 units outside the time frame. "I'm not counting my \$10,000 until I have a cheque in my hands," she added. While she's waiting for information on where she fits, she'll also be waiting for information on whether Ontario residents who accept the \$10,000 will be required to give up their right to sue. "If anybody wants to sue, I don't see how anybody else can say 'No, you can't,'" she said. The \$10,000 being provided by the Province is based on the same share Ontario is providing for the 1986 to 1990 program and will be reviewed when the 1986-1990 people receive their assistance. Ontario, Quebec and British Columbia, unhappy with compensation limited to that period, urged the deal be reopened but were not successful. Ontario is now going ahead with compensating its residents who fall outside that time period. "Hopefully the other provinces will follow suit," Ms. Norwick said. Hepatitis C is an infection of the liver that can, in its most severe form, lead to liver cancer or death.

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(CLASS ACTION—Continued from page 1)
the above statement, in BC you may not receive compensation if you have opted out of the class action.

The opt out date is **February 28th, 1999**. All requests to opt out must be post marked no later than this date.²

Should you wish to opt out prior to February 28th, 1999, the fee agreement you **signed will be void and is of no effect**.³ It is my understanding that you will **not** be responsible for any disbursements or contingency fees incurred to date.

On the other hand, you should seek legal advice before making any decision to opt out. This includes both the Camp Church and Associates or the Klein Lyons class action.

If you have not heard from either of the law firms, please call them to see if they have you registered. There is **no list** held by the Hepatitis C Society of Canada, any other agency or any individuals that will automatically entitle you (or your estate) to compensation or to class action settlement.

Have you secured documents that may be required to prove your transfusion? It has been reported that having your general practitioner request them may result in swifter action. You may be required to provide the following to assist in proving your entitlement to compensation:

- (a) hospital records pertaining to all occasions on which you were transfused or may have been transfused;
- (b) any letters, communications or the like with the British Columbia Ministry of Health advising you that you were transfused and that you should have your blood tested for Hepatitis C; and
- (c) any traceback records generated by the Red Cross Society pertaining to the infectious nature of the blood you received.¹

If you have been told by the hospital that your records have been destroyed, ask for a letter confirming:

1. that all records pertaining to your hospitalisation have been destroyed since sometimes only part of those records have been destroyed;
2. the date on which the records were destroyed; and
3. the reason for the destruction of the hospital records.¹

If you have been told by the Red Cross they cannot locate all your donors, or that your donor is highly suspect because they have passed away, ask for a letter to support these statements.

It has been suggested that you may be required to prove only that you received a transfusion (through hospital records, their own evidence, the evidence of physicians and surgeons, etc.)⁴ to qualify for no fault compensation. It is important that you secure all required paper work as soon as possible.

J.J. Camp told Dennis Bueckert of the Canadian Press that he hopes to see an agreement in principle (compensation) by Christmas.

The class action, first stage, is currently scheduled to take place in early 2000. Class ac-

(Continued on page 8)

(CLASS ACTION—Continued from page 7)

tion proceedings may last up to eight years. It is very interesting to review some of what has been said over the past two months...

- October 14th, 1998 - the lawyers were reported as saying the talks could last another year
- October 15th, 1998 - Allan Rock reaffirmed to federal negotiators that they should take the position that contingency fees should not be allowed
- Lawyers added negotiations are proving more protracted and difficult than expected
- November 1st, 1998 - Lawyer Claude Lapointe said secret talks were suspended last summer. Everybody is waiting to see—will we return to the negotiating table, and if so, when?
- Allan Rock denied negotiations have been suspended. Our information is that negotiations continue and progress is being made
- Durhane Wong Reiger said they suspended discussions until Fall and they have not got back together. The group in BC has one idea, and some people have different ideas. There are 3 or 4 camps
- Lawyer Harvey Strosberg says an out of court settlement may prove unattainable
- November 2nd, 1998 - Allan Rock again denies talks are stalled. The parties are communicating, and progress is being made. There are also separate and accelerated discussions for those in urgent need
- November 23rd, 1998 Allan Rock in the House of Commons - "I want to remind you what the government of Canada has **done**."
- He says they have committed \$1.3 billion for those who have contracted hepatitis C through the blood system; \$800 million with the provinces to settle class action lawsuit; \$300 million to share the cost of medical services not covered by insurance for those who got the disease at any time; \$125 million to strengthen the regulation of the blood system following on the recommendations of Justice Krever; \$50 million for research; and \$50 million for trace back programs
- The Government position for before 1986 and after 1990 is that the sick should get care not cash, and they should get treatment not payment
- Increasingly optimistic that claims can be resolved quickly
- Thinks they are close enough to an agreement with the parties on the overall claim that it might be reached before we could get payments to those in emergency need.⁵

and finally in the December issue of *Chatelaine* magazine - this past September - 9 years and almost 2 billion after the first tainted blood victims received compensation, Health Minister Allan Rock announced the individual compensation payouts were finished.

I sincerely hope this adds clarity to this complicated issue. *Leslie Gibbenhuck* ε ε ε ε

Should you have any further questions or concerns please call:

Camp Church and Associates 1-888-236-7797
Klein Lyons 1-800-468-4466

KEY:

¹ correspondence from Camp Church and Associates - June 11th, 1998

² update from Camp Church and Associates - September

FROM JOEY



Sorry I'm so late getting back to everyone but I have been VERY busy! Since my Cycle of Conscience ended after 67 days on Aug 21, many things have happened. I presented my petition of 30,000 names to Prime Minister Chretien on Sept 21. He told me: "I'm sorry, I just don't have any more money for interest groups." He still doesn't get it: we are not an interest group, we are victims of a crime of negligence!

On Nov 23, I went down to the House of Commons to celebrate the fact that Premier Harris decided to make it official and compensate all victims of tainted blood. The night before, I faxed Health Minister Rock and asked him to meet me at 1 PM to explain to me, face to face, why he didn't want to. His office called my Dad early Monday morning and asked if we could make it at 1:45. We did. He said that "legally," the date they chose for compensation was 1986-90. He said there was "an argument" for an earlier date but 1986-90 was what the government chose and he had to stick with that. Well, that's not good enough for me; what about you?

My new website is up at: <http://home.istar.ca/~jhache> and I am going to start a new program to get this in the news ALL OVER THE WORLD!!! I'm only 15 and I believe that "any one, any age, can make a difference!" Can you imagine what we could make happen if we all worked together using the technology that we have. WE COULD ALL MAKE A HUGE DIFFERENCE!

Please go to my website (check out my pictures from the trip etc.) and log into the newsletter. We can make a big difference and TOGETHER WE CAN MAKE IT HAPPEN!!!

*Joey Hache
Cycle of Conscience
Ottawa, Canada*

11th, 1998

³ correspondence from Camp Church and Associates - May 28th, 1998

⁴ Camp Church and Associates letter to lawyers for governments and Red Cross - December 17th, 1997.

⁵ Question Period Hansard - November 23rd, 1998

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

