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Canada's Hepatitis C News Bulletin

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REPORT FROM THE 1ST HEPCBC ROUNDTABLE

By Joan King & C.D. Mazoff

END OF LIFE ISSUES

Wayne Penny
BC Hospice Palliative Care Association

The British Columbia Hospice Palliative Care Association (BCHPCA) is an umbrella organization for about 100 organizations throughout BC. The care it provides encompasses several areas, blending solutions to needs such as physical, medical, political, social, emotional and spiritual, for those living with, or dying from, illness. Its goal is to improve the quality of life of these individuals.

Hospice is a philosophy, not a place. BCHPCA's major funding comes from the Sovereign Order of St. John. This organization has been around since the 800s, and began during the crusades, to give "hospice" to crusaders who needed a place to stay, food, and support. Hospice can happen in many different places: at an extended care facility, at a free-standing hospice center, at a hospital, or in the home. 80% of people would prefer to die at home, surrounded by their loved ones, but few have that opportunity.

Hospice is "prescribed" when nothing more can be done to cure the person, and efforts are turned to relieving suffering and discomfort. At the Lionsgate Hospital, where Wayne volunteers, there are more than 100 volunteers, including social workers, nurses, doctors, occupational therapists, art therapists, massage therapists, pastoral personnel, and counselors. In most centers, a home-like atmosphere is provided, and they are open 24 hours a day for visitors, who may chose to stay overnight on cots. Care is centered on the person. Curative treatments are not given. 80% of patients have terminal cancer. Only about 5% of those who would like hospice care get it. The Ministry of Health will be restructuring the hospice program now with the change of government.

Mr. Penny commented that most people die the way they have lived, with the same beliefs and the same relationship to their family members. Few change their minds, but some have end-of-life doubts. All seek a sense of comfort, and most wish a sense of an intact family. By family, the organization insists that family is what the *patient* considers to be family.

Some hospice programs are large and well-organized, while others may have barely 6 volunteers, not associated with any hospital. Others may be free-standing hospices for those who don't need pain-control. A hospital bed costs $1500-2500 daily, while home care costs about $50-100 daily. Hospice care at home costs about $400-500 a day. As of February 1st, the costs of drugs and equipment for care at home are being covered for those enrolled in the hospice program. The term "home" is open to a certain amount of loose interpretation, but doesn't include other institutions covered by MSP.

Hospice is for people with a life expectancy of 6 months or less. Wayne assured everyone that if the person lived more than 6 months, he/she wouldn't be sent away.

In the question/answer period, Wayne explained that usually the doctor refers the patient to hospice, certifying the state of health, but sometimes patients are self-referred. He also informed us that the Association offers volunteer training for those who are, for example, counseling those with End-Stage Liver Disease. Hospice is not just for cancer patients.

Wayne Penny

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INSIDE THIS ISSUE:

STATS TO GO

By Ken Thomson, ANKORS

According to Health Canada's Statistics

- Between 15 and 20 Canadians are infected with HCV every day.
- According to the BCCDC, 11 people a day test HCV positive in BC. They say the BC infection rate is four times the national average.
- Approximately 7350 young Canadian athletes are at risk from injectable steroid use.[1]
- Based upon CDC statistics for the US, Canadians are probably spending $66.6 million annually for direct and indirect health care costs as a result of Hepatitis C. Another study found that direct hospitalization costs alone were almost that high.[2]
- It has been calculated that between 2010 and 2019 these costs could rise to $9.2 billion annually in Canada ($1.1 billion – medical costs, $8.1 billion – lost productivity and disability costs)[3]
- A French study reports that hepatocellular cancer deaths will increase by 150% per year for men, 200% per year for women through to 2020, without effective treatment. Progression to cirrhosis will be 10 times greater for men. Men aged 61-70 will progress to cirrhosis 300 times faster than men aged 21-40.[4]
- The Canadian government has promised the provinces an average of $15 million per year, over 20 years, to cover the out–of–pocket medical expenses of people infected with hepatitis C. That's enough money to cover the cost of 48 weeks of treatment for 750 people, nationwide.
- Interferon/ribavirin treatment is indicated for 20% of the 40,000 HCV+ people in BC.[5] The cost for the medication alone would be $160 million.
- The Canadian government has promised to spend up to an average of $10 million dollars per year on hepatitis C community-based support and research projects. BC community-based support projects are getting approximately $307,000/year. The funding ends in 2003.

Sources:
[1] Hepatitis C Online, Health Canada [2] Hepatology (Jan.2001, Vol. 33) [3] John B. Wong, MD, 50th Annual Meeting, AASLD, Nov. 1999 (figures adjusted for population difference) [4] S. Deuffic et al, Modeling the Hepatitis Virus Epidemic in France, Hepatology, May 1999. [5] BC Hepatitis Strategy.

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Peppermint Patti's FAQ Version 4.5 is now available. The new version includes an HIV co-infection section as well as updated Canadian Links and the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only $5 each plus S&H—but if you can afford more we'll take it. Contact HepCBC.

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THANKS!!

HepCBC would like to thank the following institutions and individuals for their generosity: Lexmark, David Klein, J.J. Camp, Bruce Lemer, Elsevier Science, Blackwell Science, Massachusetts Medical Association, Health Canada, The Legal Services Society of BC, Pacific Coast Net, BC Transit, Margison Bros Printers, Carousel Computers, Island Collateral, David Lang, Alan Franciscus, Arlene & Frank Darlington and Karolyn Sweeting. Special thanks to Danielle Hanna for helping with the pamphlets and the bulletins.

CUPID'S CORNER

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APPLE CRISP

Vegetable oil spray
1 1/2 pounds (5 medium) apples, cored and sliced, unpeeled.
2 tablespoons fresh lemon juice
1/4 teaspoon ground cinnamon
2/3 cup all-purpose flour
1/2 cup firmly packed brown sugar
1/2 cup uncooked oatmeal
1/3 cup margarine

Preheat oven to 375 degrees F. Lightly spray a 2-quart casserole dish with vegetable oil spray. Arrange apples in prepared dish. Sprinkle with lemon juice and cinnamon. In a medium bowl, combine flour, brown sugar and oatmeal. Cut in margarine with a fork or pastry blender until mixture is crumbly. Spread over fruit. Bake 40 minutes or until apples are tender.

Peach Crisp: Use 1 1/2 pounds (6 medium) fresh peaches (pitted, peeled and sliced) in place of apples.

Blueberry Crisp: Use 3 cups fresh or frozen unsweetened blueberries in place of apples.

THE SQUEEKY WHEEL

YUKON'S POSITIVE LIVES SUPPORT SOCIETY

Positive Lives Support Society came into existence in March of 2000 when Yukon's existing AIDS organization's membership refused to support individuals with hepatitis C as mandated by Health Canada's Adult Program Branch. Positive Lives Support Society's initial objective was to support individuals infected with, and affected by, hepatitis C virus throughout Yukon. It was not long before Positive Lives began expanding the number of support meetings, providing education and support to other Yukon communities from their Whitehorse base. As well, Positive Lives began expanding their mandate to include HCV/HIV dual diagnosed individuals, and HIV+ persons, their family and friends.

What makes Positive Lives Support Society different from other health organizations in Yukon is that they have done all of their work to date, with little more than a $15,000 initial grant from Health Canada to help with expenses from August 1, 2000–March 31, 2001. When Health Canada was endeavouring to have the Yukon AIDS organization support individuals with Hep C, their initial agreement was to fund HCV support and education in the amount of $119,000 (start-up) and $83,000 for 3 years. When the AIDS organization refused to provide that support and Positive Lives took over the work, Health Canada reduced their offer of funding to $15,000. Even at that, Health Canada Officials of the Adult Health Programs Branch in Vancouver would only honour the funds if Positive Lives spent the majority of the monies to secure office space, building capacity, build a stronger Board of Directors (Positive Lives already had a Board in place, and still don't understand that directive), hire a staff person, secure partnerships, and the list goes on.

After a very successful year of work, Vancouver's Adult Health Programs Branch office in Vancouver refused to allow Positive Lives to submit a proposal to support individuals facing HCV issues for 2001-2002. After the submission date had passed, officials of the Vancouver office said that they were awaiting the results of the Yukon Minister of Health, Don Roberts, to decide which organization would receive the Terri-

(Continued on page 8)

NEWS

METHADONE PATIENTS REJECTED FOR LIVER TRANSPLANT

One third of liver transplant programs do not accept patients on methadone maintenance therapy. Almost half (46%) of all liver transplantations are a result of people infected with hepatitis C. Nearly 6% of these people are prescribed methadone therapy to help patients overcome their opioid habit (a potentially addictive drug used to relieve pain).

Two doctors from the University of California surveyed 87 adult liver transplantation programs to identify criteria for admission to the United Network of Organ Sharing liver transplantation waiting list. It was found that 56% of these programs accept transplant patients who are receiving methadone, and if treated, one third will be required to discontinue the use of the therapy.

Requiring patients to cease the methadone treatment in order to qualify for a liver transplant can cause additional harm, and unfairly deprive them from receiving a transplant, as there is no evidence to support the practice of discontinuing methadone maintenance as a precondition for liver transplantation.

Source: Englemed Health News. JAMA 2001: 285(8): 1056-8. Feb 28, 2001

HOSPITAL WORKERS AT RISK

Despite improvements in technology and strong federal guidelines designed to prevent exposure to blood-borne diseases such as HIV, rates of exposure are still unacceptably high among hospital healthcare workers. Researchers at the University of Iowa College of Medicine studied programs designed to cut the spread of blood-borne diseases in 153 hospitals in Iowa and Virginia. What they found was that only one third of the hospitals offered new employees training on blood-borne pathogen exposure precautions twice a year or less. They also found that few physicians are receiving standard precautions training through the hospitals in which they work. Recommendations were made to hospitals to invest in protective devices and to provide standard precautions training for all healthcare personnel. The use of protective devices, such as needle-less IV systems and 24-hour access to treatment centers could reduce the risk of exposure to the disease.

SOURCE: Infection Control and Hospital Epidemiology 2001: 22:70-82

MANICURE/PEDICURE RISK

A random sample of 120 establishments was surveyed to describe infection control practices used by technicians doing manicures and pedicures in Ontario. 72 establishments were interviewed. 29 technicians indicated that they had been immunized against hepitis B. They also stated that they reused almost all their instruments, did not wear gloves while performing procedures and did not follow universal precautions when asked how they would react to incidental cuts on either the client or themselves. Infection control protocols for manicure and pedicure establishments still need development, as there is still potential for the transmission of infectious diseases.

Source: Can J Public Health 2001 Mar-Apr; 92(2):134-7 Johnson IL, Dwyer JJ, Rusen ID, Shahin R, Yaffe .

VIRUS RESEARCH BROKE SAFETY RULES

One of London's top research units, Imperial College, in West London, has admitted that it broke health and safety legislation while trying to create an artificial hybrid by combining two dangerous viruses: the hepatitis C virus and the dengue fever virus. Under regulations governing genetically modified organisms, the college has now been committed to crown court for sentencing. Imperial College has admitted to "failing to apply principles of good microbiological practice and principles of good occupational safety and hygiene." District judge Elizabeth Roscoe said that the breaches were "extremely dangerous and a matter of high public concern."

The college has also pleaded guilty to a charge of failing to ensure the safety of employees. Since the sentencing, stringent policies and procedures are now in place to regulate activities of this nature. Extra staff is now devoted to monitoring and advising on safety to ensure that such an incident cannot happen again.

Source: BBC News, May 22, 2001

TATOOING: MAJOR ROUTE OF HEP C INFECTION

Getting a tattoo could be a key infection route for hepatitis C, according to a study at the UT Southwestern Medical Center in Dallas. Participants were tested in 1991 and 1992 in an orthopedic spinal clinic, unaware that their hepatitis status was being examined. Of the 626 patients studied, 18 percent had a tattoo. Of those with a tattoo, 22 percent were infected with hepatitis C. The study found that people who had several, complex, or large tattoos or with white, yellow, orange or red pigments had an increased risk of having hepatitis C than those with only black. Hepatitis C can be passed through tattooing by reusing tattooing needles or dye, inadequate sterilization of tattooing needles between customers, or skin breaks during sterile needle testing, such as the artist pricking the back of his or her hand to test the needle's sharpness.

Source: Mindy Baxter, University of Texas Southwestern Medical Center at Dallas ,4 APRIL 2001

HEP C ED FOR GPS

Over the next 20 years, chronic Hep C is predicted to become a major burden on the health-care system. Of the 240,000 Canadians known to be infected with hepatitis C, many have not been diagnosed, and may be unaware they are infected.

Family physicians and primary care doctors now have to play a major role in discovering and managing hepatitis C in the absence of enough specialists to cope with increasing numbers of patients. Those patients tested with Hep C should see a physician with a special interest in the disease.

Further still, physicians have been cautioned not to rely on ALT levels to determine disease progression for hepatitis C patients. **Only 12% of patients with HCV and normal ALTs had normal biopsies**. It is recommended that all patients diagnosed with hepatitis C be referred for a liver biopsy to determine the severity of the infection and its rate of progression.

Source: www.medicalpost.com VOL 37, NO. 20, 5/22/01

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

CURRENT TREATMENT OF HEPATITIS C

Dr. Frank H. Anderson,
Department of Gastroenterology, Vancouver General Hospital

We were really pleased that Dr. Anderson, whom many consider BC's hepatitis C expert, was able to come and speak. Dr. Anderson's presentation was really interesting and covered everything from A-Z. Dr. Anderson gave us an overview of HCV and its natural history. He named the principal transmission routes, and explained treatment, side effects, contraindications to treatment, and what we patients can do to protect our health.

OVERVIEW

1.5% of Canada's population is infected with hepatitis, and 25% of those people are in British Columbia, which gives us a total of 40,000 people infected in BC. The virus is not new. It's been around a long time, and has been found in blood stored from World War II. Since the hepatitis A & B viruses were both discovered by 1970, and it was known that there was something else contracted through the blood system that caused hepatitis, what was known as hepatitis non-A/non-B was recognized since 1970, but not identified until 1990, when a test for the antibodies was developed. Other than humans, only chimpanzees can be infected with hepatitis C.

A virus is an amino acid sequence. There are 3000 sequences in the Hep C virus, different sequences producing different genotypes and subtypes. The genotypes have different responses to treatment, and the variety makes finding a vaccine difficult. The genotype has no relation to symptoms, viral load, biopsy results or enzyme levels.

NATURAL HISTORY

When a person is infected, there is an acute phase, which often goes unnoticed, in which the person develops antibodies. Antibodies usually help a person fight off the virus, but in the case of hepatitis C, only about 20% of those infected are able to recover spontaneously. The other 80% have chronic infections, and 25% of those people have liver damage. The risks for progression are an older age when infected, being male, using alcohol, and becoming jaundiced when first infected. 25% of chronic cases progress to cirrhosis, and 5% of chronic cases develop liver cancer, but this happens only in those who have cirrhosis. When one is cirrhotic, the liver can still function. Only 5% of cirrhotics develop decompensated liver disease (i.e., the liver cannot function without interventions). 3% of chronic sufferers will need a transplant. The average time from infection to chronic liver disease is 10 years, to cirrhosis, 20 years, and to liver cancer, 30 years, for those who do progress.

TRANSMISSION ROUTES

Hepatitis C is spread through blood-to-blood contact. Infection through blood products is now rare. It is *not* spread through the fecal/oral route, and is *rarely* spread through the blood/oral route. *Sexual transmission is uncommon*, as is mother to child. Household transmission is rare, and so is occupational transmission. 70% of all hemophiliacs, 80% of IV drug users, and 40% of the prison population are infected. Mother to child transmission is less than 8%. Breastfeeding may account for less than 5% transmission. Sexual transmission occurs in about 3% of people over a lifetime, but is more common when the person is infected with an STD. About 1.5% of health care workers are infected—about the same as the general population, and less than 1% of blood donors. Today, 1 out of 500,000 units of blood are infected with HCV. *[Editors: Many health care workers do not declare that they are infected, and many feel that the general population stats should be more at 3-5%.]*

Transmission was common from blood products before 1990. IVDU is a major route of infection, as is intranasal cocaine use. Promiscuity may be a route of transmission, especially if the person has an STD. Piercing, tattoos, and needle stick injuries are other means of transmission. Although the virus has been found in body fluids other than blood, transmission has not been proven.

TREATMENT, CONTRAINDICATIONS AND SIDE EFFECTS

Several things can cause a doctor to look for HCV, such as abnormal liver enzymes, perhaps caught during a normal checkup or for insurance purposes, a lookback notice for those who have received transfusions, a history indicating risk factors, contact with people with HCV, fatigue, autoimmune disease, or other associated conditions.

Dr. Anderson

The disease is diagnosed by testing for the antibody, and then for the virus RNA, through a PCR test. This test does not say whether the virus, if present, is dead or alive, however, but only that the structure of the virus is present. So if there is blood on a chair, for example, we may find HCV in that blood, but we don't know if that blood can infect a person. There are two types of PCR test: qualitative, which says if the virus is present or not, and quantitative, which tells the amount of virus we have in our blood. The qualitative test is more sensitive. Other tests include the AST and ALT, alkaline phosphatase, GGT, platelets, INR, etc. A biopsy can measure inflammation, fibrosis, and cirrhosis. It tells how the liver has been affected up to now. Portal inflammation is graded from 0 to 4, 0 being none, and 4 being severe. Lobular inflammation also goes from 0 to 4, 0 being no necrosis. Fibrosis is graded from 0 to 4, as well, with grade 4 indicating cirrhosis. Dr. Anderson showed slides and diagrams of the liver, explaining the artery, veins, portal veins, and the structure, comparing the cell structure to houses along a street, with the blood running along the "street." He included a comment on the back alley being where the bile is excreted. A fatty liver always begins around the portal veins, which become scarred and form fibrosis. When "bridging" starts to occur, then it is stage 2/3 fibrosis.

Some people shouldn't be treated. It is of no use to treat those who abuse alcohol or drugs because they will continue to damage their livers. Those with depression are at risk because the treatment can, itself, cause depression. The depression must be well-controlled before a patient can be treated. If there is a significant associated condition, this can make the person ineligible for treatment. Because ribavirin can cause heart problems, those with cardiac disease shouldn't be treated with that medication. Those with autoimmune disease can become sicker. Those who are anaemic can find their problem worsens with the ribavirin. Those with bleeding problems may have problems with the interferon. Others that must be treated with caution, if at all, are diabetics, those with other infections, those with low white blood counts, and those with HIV, if the CD4 count isn't high enough.

As of June of 2001, there are two approved medications for Hep C: Interferon and a combination of interferon and ribavirin, called Rebetron. For monotherapy, with IFN alone, treatment is given for 12 weeks, 3 MU/3 times a week, and if there is no response at that time, treatment may be stopped, although continuing may halt the progression of the disease. Rebetron is given the same way. The interferon is injected and the ribavirin is in the form of pills taken every day, 5 or 6, depending on the patient's weight—over or under 75 kg. Monitoring for side effects includes watching possible development of anaemia, clotting problems and changes in liver enzyme levels. A nurse does this monitoring, and a team approach is important.

Response to treatment depends on the genotype. Some are more "ornery" than others. Genotypes 1a and 1b are the most common, and also the most difficult to treat. This patient is tested after 24 weeks of treatment, and if he/she has responded, treatment is continued for another 6 months. If not, treatment is stopped. For genotype 2, 3 & 4 patients, testing is done at 24 weeks and then stopped, and the patient is monitored. Less than 20% of these patients, when they respond, relapse. The goal of treatment is normal liver enzymes, no RNA present, and no inflammation. When the patient tests negative 6 months after treatment, this is called a sustained response, and all his patients tested up to now, have remained that way. This is not yet called a "cure."

Side effects of treatment may include fever, chills, fatigue, muscle aches, nausea, diarrhea, hair loss, weight loss, rash, metallic taste, and decreased libido. No one goes bald from the treatment. Weight loss is an average of 15 pounds, but this is not advertised as a weight loss program. Neuropsychiatric symptoms may include depression, psychosis, confusion, headache, and occasionally seizures (Dr. A. has seen only one.) Epileptics should be stable for 3 years before attempting treatment. Immune symptoms may include development of diabetes, thyroid disease, autoimmune hepatitis, primary biliary cirrhosis, and lupus. Skin problems can be psoriasis, lichen planus, erythemia multiforme, and cardiac problems, lung problems cardiomiopathy, and retinopathy can occur.

The results from Dr. Anderson's trials show that out of 180 patients on Rebetron, 85 completed 24 weeks. Their ALT and PCR were tested weekly for 4 weeks, and then monthly. At 4 weeks, it is pretty certain that those who will respond have already done so. Dr. A. showed us a graph. Some patients' ALTs "spiked," and he remarked that some doctors, seeing this, think the patient is getting worse, but in fact, most of these patients respond if they continue treatment.

(ROUNDTABLE—Continued from page 4)

WHAT TO DO

When diagnosed, a patient should be vaccinated against hepatitis A & B, because a person with hepatitis C can become very sick if infected with one of these diseases as well. The patient should stop all consumption of alcohol, and it may be good to stop smoking, since this may interfere with treatment. Good nutrition and exercise are important. There is no food that stresses the liver, but some may make digestion difficult, such as fatty foods. Though these can make the patient uncomfortable, they will not hurt the liver. Protein should be 1 gram per kilo of ideal weight a day. Fasting and skipping meals strains the liver. A hepatitis C patient may need more calories because of metabolic problems. A test was done on some soldiers with hepatitis C. Half were sent to bed, and half were sent to do forced activity. There was no difference as far as the hepatitis C was concerned. It is important to keep your activity level up. Exercise will improve your energy level. Don't back off on your bad days. Discuss all medications and alternate therapies with a doctor. Some of these therapies can damage the liver or interact with other treatment. Use birth control if you are on Rebetron, or if your husband is, during treatment and for 6 months after treatment. There has been no long-term damage to the eggs of animals given ribavirin. Be careful with over-the-counter drugs. Some problems can be individual allergic reactions. Tylenol is mentioned often because it is the most common overdose in the US and Canada, and when there is an overdose, it can destroy the liver, especially when combined with alcohol. Small amounts are fine, such as 1000 mg a day (equivalent to 2 extra-strength or 3 normal strength tablets).

Future treatments are on the horizon. Pegylated interferon is now in trials. PEG stands for polyethylene glycol: the interferon is attached to anti-freeze, so it is slowly absorbed into the body, and has to be injected only once a week instead of three times. The side effects seem to be less, since there is no "bouncing" after each injection, and it seems to be more effective because the medication is there all the time, fighting the virus.

OVERVIEW OF THE BC STRATEGY ON HEPATITIS

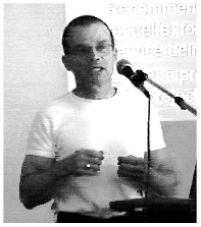
John Hamilton,
BC Centre for Disease Control

John Hamilton, was next up. John, a really personable fellow, is the Program Coordinator for the new provincial hepatitis strategy. The BC Hepatitis Strategy covers all forms of hepatitis. It has received $5 million per year of funding from Health Canada, but most of this is for vaccinations programs. It is under the auspices of the BC Centre for Disease Control and Dr. Mel Krajden, a virologist. With respect to hepatitis C, the role of the program is

- to coordinate programs and services for hepatitis C across the province, including programs for children with hepatitis C
- wade through the mass of materials on the web and screen them for medical accuracy
- provide better services in rural areas
- develop educational materials for teachers, and to try to deal with the problem of hepatitis B in Aboriginal communities.
- enhance professional education—update doctors and nurses on the latest information
- conduct needs assessment, working with Dr. Anderson, Natalie Rock and others, and develop distance learning programs for rural and regional health care providers
- collaborate with Health Canada, Regional Health Authorities, Pharmacare, and the new Canadian Viral Hepatitis Network, and so forth.
- attempt to bring the various stakeholder groups (hepatitis, HIV) together, to eliminate duplication and more wisely allocate resources.
- rely on community groups to provide input and get the message out. Acknowledge weariness and need of front line workers for peer support. Encourage formation of community networks.

So much for what they *want* to do. Listed below is what John says they have already done:
1. They have invited 20 community groups to a meeting on June 27th in Vancouver to discuss these and other issues
2. The provincial government has already established a Provincial Hepatitis Advisory Committee (PHAC), which we are told has community representation on it, and thus provides a community voice. My take on it *(C.D. Mazoff)* is that the representation is stilted, and that our community will have no real power. HepCBC has no representation on this important, formative committee, although we have asked, and even protested. In the light of John's talk about "transparency and openness of dialogue," this does not bode well.

At the end of John Hamilton's presentation, community members asked some very good questions. Frank Darlington expressed his fear that the government was wasting a lot of money playing "Big Brother," and Carolyn Romanow reminded John that the BCCDC has a "p*ss poor record dealing with hepatitis C." She was well up on her statistics and told us that of the 40,000 plus people with hepatitis C in BC, only 1500 had been treated! John said that there are only 26,000 confirmed cases of HCV in BC (as if that makes it better!). Carol also reminded us that most people with HCV, recommended for treatment by their physicians, are denied access by Pharmacare.



John Hamilton

Marjorie Harris pointed out that the three years of Health Canada funding for the BC Hepatitis Project was not going to address the needs of the masses of people infected with HCV. John said that the money they received was only for education and that the government is beginning to acknowledge that it has a huge problem on its hands. Brad Kane told us about very dangerous hospital procedures and lack of compliance with universal precautions, and the difficulty we have in getting clinics to take our observations and recommendations seriously.

The BC Hepatitis Services can be contacted at 1-866-660-1676 or visit them on their site at www.bccdc.org/hepatitisservices.

CLINICAL TRIALS AND FUTURE RESEARCH ON HEPATITIS C

Dr. Stephen Sacks, Viridae Clinical Sciences

The next speaker, Dr. Stephen Sacks, spoke about the nature of the virus and future research. Dr. Sacks is an MD who is a specialist in internal medicine, with a sub-specialty in infectious diseases. He sees his role as "figuring out how viruses work so he can kill them."

Dr Sacks came to UBC from Stanford in 1980, where he was a professor. He is best known for his work in herpes. He says he can really sympathise with our plight and the government's unwillingness to get involved. He congratulated us on our political action, saying that it has definitely helped us get some funding, but he doesn't know if the government will follow through on its promises. He expressed a worry about the current hepatitis B situation in the province.

Dr. Sacks spoke frankly about the great amount of stress that viral diseases can cause and of their emotional and psycho-social side effects. He mentioned that perhaps the scariest part of it for people with HCV is not knowing whether they are in the 20-30% who are going to get the sickest.

He then gave us a very thorough presentation on HCV and what it looks like, what its weaknesses are, and where and why scientists are trying to disable it. I felt like I was back in graduate school at a seminar. Personally, I loved it *(squeeky)*.

According to Dr. Sacks, the single biggest factor limiting research is that nobody has been able to effectively and easily grow the virus in the lab.

The first reason he gave was that about 98% of the genomic sequence is almost entirely owned by Chiron, and the rest is owned by a Charlie Rice. Neither of the owners, according to Dr. Sacks, really feel that anyone should be able to do any research on the virus without paying them a fee. To do open research on HCV in a lab means that one has to pay a hefty fee to Chiron for the right to conduct research. The second reason he gave was that HCV is horrendously difficult to grow in the lab. The cure will come more quickly when people can easily manipulate the virus in the test tube.

When I *(squeek)* asked Dr. Sacks whether it would speed up research if Chiron dropped the licensing fee, Dr. Sacks said no, because there are many ways to do HCV research without using the genomic sequence that Chiron owns. As well, he says that a lot of research has gone underground to get around the problem of licensing. *(Please see page 7 for Chiron's response.)*

To their credit, Dr. Sacks says that Chiron does not go around suing academics for doing research, but he did say that they do sue drug companies for doing research on HCV, and this has forced some companies to stop doing research on HCV or forced them to sign a contract. In the US it is legal to own and patent genetic sequences. This is illegal in Canada, but nonetheless it affects all research done here and elsewhere.

The big problem with killing HCV is that it mutates so quickly, and that what we actually have is a multitude of viruses. What happens is that we can develop immunity to one strand, but be affected by another. He mentioned, as well, that quantitative assays are not as sensitive as qualitative. Undetectable, with quantitative, does not mean that you have no virus in your system.

(Continued on page 7)

HANDCUFFED TO A BEAR

by a fellow traveller

I am in my 27th week of Rebetron therapy to combat the Hep C virus. I am writing this to offer empathy and hope to others on the regimen, and to demystify it for those who might try.

Before I agreed to take Rebetron, I wasted a year trying alternative therapies. I had heard that Rebetron could be brutal, or it could be a walk in the park. For me it has been somewhere in between. The product literature lists 58 recognized side effects, of which I have some experience of at least 25. And the fat lady hasn't sung yet.

A few hours after my first shot found me almost comatose. Or rather, if it wasn't like the worst hangover I have ever had, it was close. A very rough night, but by next day I was recovered. This occurred each time for a week or two, although with lessening severity until I began to feel normalish.

(As I write, I no longer remember what normal feels like. Perhaps it was entirely subjective all the time, and all states of being are normal, or none.)

But then other irregularities began to arise, not all together, but in irritating little groups of several at a time—just enough to keep me basically miserable everywhere:

- Dry eyes, irritating periodically during waking hours, glued shut on waking (This is an autoimmune attack on the tear ducts; pray they don't quit altogether, forever. Buy two bottles of *Refresh Tears* or equivalent eye drops, and keep one by your bed and one in your pocket at all times. Also, TCM (Traditional Chinese Medicine) recommends the following: Infuse together, then re-infuse, green tea, 3 chrysanthemum flowers and 1 tbsp. of lycium berries. Drink both brews, then eat the berries. I think it helps me.)
- Dry mouth, felt like a corpse's mouth with which I could barely eat, then 3 dental cavities in 6 months (Brush and floss, brush and floss, and no more sweet drinks. There's a mouthwash, too, but I can't face it.)
- Disgusting taste in the mouth, made eating a chore (The TCM doctor popped a needle in under my chin and that was the end of that.)
- Dry nose, with attendant irritation, stuffiness, and bleeding (Vaseline works as well as anything, on rising and before bed.)
- Cracks at the corners of my mouth, give you a sort of oral episiotomy every time you chew or floss (Bear it; don't grin.)
- Dry skin, looks normal, but feels like *Samsonite*, and my hair straightened out and got dry and stiff (I don't care.)
- The itch, nothing visible, but the desire to tear off small pieces of my own hide was there (Take a Buddhist approach, don't touch, and it will soon fade.)
- Dry cough, periodically during the day and while trying to sleep (Cough.)
- Constipation (Keep those fruits and veggies coming, drink lots, and walk, walk, walk them on through.)
- Liver pain, probably caused by inflammation which flares up and subsides for no apparent reason (Again, be a Buddhist, assisted by acupuncture, a hot water bottle, and a diet without sin.)

TCM says that all of the above are the effects of excess "heat." Since I keep fanning the fire every time I take another shot or pill, I don't expect TCM to take the heat away, but I do think biweekly acupuncture has been helping to moderate it. I keep going back, at any rate.

Recently, I have been investigating an anti-inflammatory and immune system enhancer called *Moducare*. It is a slickly marketed cure-all by Lorna Vanderhaeghe, co-author of *The Immune System Cure*. I don't know whether it is the reason—there are too many variables right now—but I have been feeling better lately.

Since we're on the subject of supplements, I will confess that I take a lot. The books frequently disagree, so I've narrowed it down to B-complex, sublingual B-12, C, E, calcium & magnesium with D, selenium, NAC, iodine drops, a milk thistle complex, digestive enzymes, acidophilus & bifidus, and a TCM blood and Qi tonic (Dang Gui, Bai Shao, Korean Red and Asian White Ginsengs). And of course, green tea and lots of water. I'm doing what I think I have to to keep my blood strong, protect my eyes, heart, kidneys, and thyroid, and support healing.

This list could change. Since no one really understands Hep C, and all the different schools of medicine in this country despise one another, I reserve the right to draw my own conclusions. I figure, if the doctors knew everything, they would cure me. Meanwhile, if a supplement sounds important and the risk is low, I'll give it a try. But back to my litany of tribulations.

- Periods of nausea, never led to actual vomiting, but made eating unattractive (Flow with it, eat fruit, drink a bit of ginger ale for comfort—brush and floss—snack frequently. I would smoke pot, but I read in one book that it works by negating the effects of the drugs, so too bad.)
- Fatigue, comes and goes without warning, varies in intensity, can include shortness of breath during exercise, and sometimes stays for days. (This has to do with your hemoglobin levels, which you cannot let get too low, or the doctor will cut off your drugs. The doctor says these are beyond our control, but TCM has herbs and dietary recommendations, which may be what is helping me. I've also been forcing liver down, under salsa, every 2 or 3 days, but I'm afraid of ingesting too much iron, so when the end of treatment is in sight, I'm going to quit liver.
- Constant insomnia, from physical discomfort and general restlessness. (At this point, my waking and sleeping hours are almost reversed, and I can't control it. What with this and everything else, employment or taking courses is out of the question. Insomnia may be connected to irritability, which in me surfaces as road rage. So I simply refer all of the driving to my spouse—her dream fulfilled.)
- Flu-like discomfort from 4-10 hours after the shot, varies in intensity and can include fever, shivering, ague, joint discomfort (This feeling is not the flu, even when you have the flu; this is the feeling of interferon. Love it. It is helping you. You can make it easier to love by taking Tylenol, but that's hard on your liver, so I prefer to forego it except when I have to shine the next day, or just need a break. Purchase and use a hot water bottle.)
- Night sweats (They're icky, but harmless. Pretend you're a retired colonel paying the price for years of campaigning in the tropics.)

One side effect the manufacturers have missed is the misery of travelling—toting insulated bags of Rebetron and ice, shooting up in chilly garage washrooms, being kicked out of motel rooms shortly after you finally fell asleep, getting caught in public with the chills, living on salads without dressing (all other restaurant food in my price range is chemicals and grease). Whenever possible, stay home.

That's pretty well the list, so far. Up

(Continued on page 8)

RESEARCH

NEW STRATEGY

Scientists have discovered that the Hep C virus uses a "back door" to get into the cells. It uses what is called the internal ribosome entry site (IRES), which the cells use to synthesize proteins during stress or viral infections. This "back door" makes the cells vulnerable to attack. The researchers used cryo-electron microscopy to study the molecules involved. Jennifer Doudna, of Yale University says, "This is the first time any kind of initiation complex with the eukaryotic ribosome has been visualized."

Source: Science 2001; 291 (5510): 1959-62 12 March 2001, Scientific breakthrough on HCV infection mechanism could provide new drug targets

MAKING LIVERS

Researchers in Japan have made tissues that mimic organs like the liver, perhaps revolutionizing tissue engineering. The problems are recreating the complex arrangements of different cell types, and avoiding an immune reaction to the artificial materials.

Teruo Okano, at Tokyo Women's Medical University, creates layers of different cell types by growing each layer in a flat dish. The difficulty is that they stick to the dish. If enzymes are used to separate them, membranes are damaged, cell function is disrupted, and the cells don't stick together anymore, so he uses a non-stick surface, to which the cells stick when it's heated, and they lose their grip when it cools. He alternates sheets of liver and endothelial cells in a lasagna type of way, imitating liver structure. Liver cells only survive for about 6 days without endothelial cells. Just mixing them up doesn't work. These new cells function for 3 to 4 months. Okano is now experimenting to see if the tissues can develop a blood supply.

Source: New Scientist magazine, 07 April 2001. Liver On A Plate

WHY RIBAVIRIN WORKS

Researchers say they have discovered exactly how ribavirin works against HCV and other viruses.

In studies with poliovirus, researchers found that the drug increased the mutation rate of the virus, already very high, so much that it experiences a "genetic meltdown" and can no longer survive. This discovery may lead to new antivirals.

Reuters Health, May 21, 2001: Study could pave way for better antiviral drugs

*(**ROUNDTABLE—**Continued from page 5)*

Unlike HIV, HCV is not incorporated into the genetic structure of the host. HCV stays chronic by making many multiple copies of itself daily. But because it never becomes an actual part of the host, there is hope that it can be eventually gotten rid of.

HCV treatment is still bogged down by having to be proven to be a "therapeutic advance" and this process takes time. Treatments for HIV are able to be fast tracked and avoid the long process of approval that HCV treatments go through. But this is not necessarily good in all cases.

Dr. Sacks

Dr. Sacks was of the opinion that the decision to be treated is individual choice, and that while treatment is getting better, it is still not for everyone.

The Future for Hepatitis C

What have we accomplished so far?

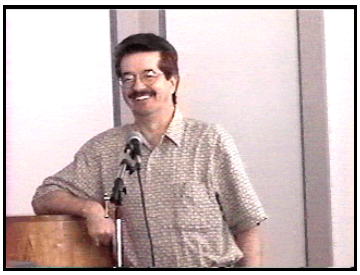
- Successful treatment of naïve patients
- Successful treatment of relapsing patients
- Limited success for treatment of nonresponders
- <50% are complete responders (this is genotype specific)
- Complete responders are essentially cured
- Fibrosis progression, inflammation reduced

Although pegylated is better, it is not a quantum leap in treatment. There is still a long way to go. Everything is still based on interferon, and Dr. Sacks would like to use something else completely, which does not have the difficult side effects of interferon.

Dr. Sacks discussed protease and helicase research and ribozymes, the future direction for HCV therapies. He talked about RNA inhibitors and internal ribozymes entry sites as interesting focal points for research. But developing a drug in a cell culture in the laboratory and delivering it to the internal site in someone's liver are two very different things.

He recommends that if you've never been treated and your ALT is elevated enough to get Pharmacare to pay for your treatment, you should take it. Unless you have a contraindication, it's worth giving it a shot. There's a chance you can get better, and you can always back off if you can't tolerate it.

Last words: "Capitalism alone will cure this virus."



Dr. Denis Petrunia opening the 1st HepCBC Provincial Roundtable

A WORD FROM CHIRON

Dear Dr. Mazoff:

Thank you for giving us the opportunity to provide some information to your members about Chiron Corporation and its contributions to the hepatitis C field.

The people of Chiron are very proud of the contributions they have made in the fight against this terrible disease. As your members probably know, Chiron scientists, led by Dr. Michael Houghton, cracked the mystery of non-A non-B hepatitis in 1987 when they found the virus responsible for this disease, now called hepatitis C. This was the first time an infectious agent was found using recombinant DNA technology. Blood tests were developed and rapidly introduced around the world, virtually eliminating the risk of contacting this disease via blood transfusions. To date, this work has saved millions of lives, as well as millions of dollars in health care costs. For this scientific achievement, Dr. Houghton was awarded the prestigious Lasker Prize (nicknamed "America's Nobel") in 2000. Dr Houghton continues to work on a vaccine that will hopefully prevent and treat this disease.

Our relevant patents are directed to man-made reagents that are tools used in the screening of possible antiviral drugs. This technology has made it possible to search for a cure to hepatitis C. In an unusual move, Chiron decided that it would not hold on to this patented technology exclusively, nor grant an exclusive license to just one multinational drug company (a common practice in biotechnology). Instead, we announced to the world that we would grant a license to any company that wishes to use our technology to find a cure for this disease. Further, to make sure licensing fees would not be a barrier, we made the licenses available for a commercially nominal fee and the opportunity to share in the profits should the use of our technology prove successful. Quite a few companies have taken a license and are trying to find an effective drug. Among the licensees are such leading companies as Pharmacia, GlaxoSmithKline and Bristol Myers Squibb.

We understand that someone addressing your recent roundtable suggested that Chiron now "owns" the hepatitis C virus and that our "ownership" somehow inhibits research. That is simply not true. We use our patents to share in the commercial exploitation of our technology, not to stop research. Undoubtedly there are companies who want to use our technology and keep all the profits they make. Even with those companies that refused a license and attacked our patents in court, Chiron's objective remains a reasonable royalty. We did not seek an injunction stopping their research even though the law entitles us to make such a request. It is interesting to note that those companies, Pfizer and Lilly/Vertex, have spent far in excess of our license fee on lawyers and, unlike Chiron, have not offered to make their HCV drug discovery technology available to others.

If the person addressing your group was suggesting that we were preventing academic research, again that is untrue. We have never enforced our patents against someone for engaging in academic research. Our legitimate interest is in receiving a reasonable royalty on the commercial exploitation of our inventions. Preventing basic research is not in anyone's interest, including our own, and we would never use our patents to stop research into an unmet medical need.

Sincerely,

Robert Blackburn, Vice President & Chief Patent Counsel, Chiron Corporation

TRIALS

COMBO FOR NORMAL ALT

This study was the first to examine 19 patients with normal or near-normal ALT levels on at least 3 occasions, and mild disease shown on their biopsies. In this pilot study, we treated 19 patients with induction IFN-alpha2b, 5 MU daily for 4 weeks, then standard combo treatment for 48 weeks. 47% had a sustained response. No patient had ALT flares. The authors concluded that **combo therapy may be effective** in these patients, and trials are warranted.

Source: Lee SS, et al, J Viral Hepat 2001 May;8 (3):202-5 Pilot study of interferon-alpha and ribavirin treatment in patients with chronic hepatitis C and normal transaminase values. PMID: 11380798, UI: 21275804

TEGAFUR/URACIL FOR LIVER CANCER

Researchers from Niigata University School of Medicine treated 28 patients with 400 mg doses of tegafur/uracil b.i.d. for at least 8 weeks, lasting up to patient withdrawal from the study or death. Twenty other patients, treated conservatively, were used as controls. All 48 patients had more than one tumour, in more than one lobe. 55.3% of patients treated with tegafur/uracil survived 1 year, 36.9% survived 2 years. Only 5.5% of control patients survived for one year. Median **survival times were 12.13 months among the treated patients and 6.20 months in the control group**.

Side effects were well tolerated, and included oral dryness, diarrhea and liver dysfunction.

Source: J Gastroenterol Hepatol 2001;16:452-459.

IFN AFTER LIVER CANCER OPERATION

Researchers at Osaka City University Medical School completely removed tumors in 30 patients. Half were treated with 6 MIU of IFN-alpha daily for 2 weeks, then 3 times a week for 14 weeks, then twice a week for 88 weeks. Three patients dropped out due to side effects.

Only five patients receiving IFN-alpha had recurrent tumours after an average follow-up of 1087 days, while 12 recurrences were documented after an average of 897 days in the non-IFN group.

Recurrence rates were similar in both groups for the first 2 years of follow-up. There was no more recurrence in the IFN group after this time. The researchers think that the tumours found after the operation were either metastases or were undetected at the time of operation.

Source: Ann Intern Med 2001;134:963-967.

(YUKON—*Continued from page 3)*

torial funding of $139,000 (traditionally given to HIV), before Health Canada would even enter into further discussion around funding issues. This meant that now the Yukon AIDS organization might face a funding cut if they were not going to support individuals with HCV. With the threat of a funding cut looming, the Yukon AIDS organization became suddenly in favour of supporting Yukon persons infected with and affected by HCV.

On May 11, 2001, the Territorial Minister of Health, Don Roberts, announced his decision to continue funding in the amount of $139,000 to the Yukon AIDS organization. Presently the number of HIV/AIDS cases in Yukon numbers a total of 30 persons. There are presently in excess of 406 individuals throughout Yukon who are infected with HCV. This decision was a hard blow, given the background, and given the fact those HCV+ persons and their families were not given any voice in this decision. They were not asked who they would like to have supporting their needs. They were not given their right to be heard about which organization should provide their support and educational programming as they well should have been. Letters sent to Yukon Minister of Health on behalf of the Positive Lives Support Society membership regarding the right to be heard were ignored. As well, letters received by the Minister from HCV+ persons declaring their alarm at not being part of the process fell upon deaf ears by both the Minister of Health and Premier Pat Duncan. It appears that the mandate of HCV organizations is no longer to be "grass-roots," but rather, dictated by government.

Positive Lives Support Society has made it clear that, despite the lack of funding, they will continue their important work in the Yukon through their active and dedicated volunteer base. They continue to hold support meetings, host a web site for their members, partners and interested parties, as well as provide "peer counselling" for infected and affected individuals.

Positive Lives Support Society will continue their objective to reach out to individuals infected with and affected by HCV and HCV/HIV in the Yukon. You can contact Positive Lives Support Society through their interactive Web site at www.positivelives.yk.ca. They welcome your support and encouragement at a time when their schedule is busy—and the funding is gone. Indeed, the funding may have run out, but the enthusiasm is still growing!

Anonymous Volunteer and supporter,
Positive Lives Support Society

(HANDCUFFED—*Continued from page 6)*

north, they have a saying: "Sometimes you bite the bear, and sometimes the bear bites you." Things have not happened all at once, and nothing has lasted with full intensity. I think my ability to concentrate has suffered. Also, the continued eye and mouth dryness is disturbing, and a constant feeling of being mildly poisoned is irksome—although not surprising, since that's what I am. And you must have guessed by now that I have lost weight.

But I am not depressed, not at all. This is mainly because I now have hope. My enzyme counts fell from the top 20 percent to low normal in the first two months of treatment and have stayed there. I believe that my liver is healing. My goal has been to regain enough liver function to last me until someone discovers The Cure.

Meanwhile, I have improved my approach to living. For one thing, I have found that a daily long, leisurely walk is invaluable, both physiologically and psychologically. Look up, look around, smell, feel the wind, don't think. As the TCM doctor advises, "Keep all your switches open." When I'm too fatigued, I still totter off to some pleasant spot and, there, do much the same thing. These are all ways of staying rested, which I am convinced is an essential prerequisite to healing.

I seize any excuse to laugh. I pay attention to my friends and treasure every moment with my spouse. I try not to miss the past, when I was healthy (or so I thought). It seems now like a movie I once acted in. There never were any guarantees in life. There really is only Now.

So, I had quit looking for a cure. Then last week, the doctor's office phoned. The 24-week PCR test came back negative! Can't find the virus. There are still two more tests to pass in the next year. But good grief, I might live! I don't know how long I can sustain this new-found intensity.

DID YOU GET YOUR SURVEY?

ANKORS Hep C Project needs your help to find out how people living with/affected by Hep C in West Kootenay/Boundary can best be supported. What is needed/wanted? It only takes a couple minutes and it's confidential. To get a copy or for more info, call 1-800-421-2437

GEORGE MARCELLO: SCHEDULE

Please check the 500 Day Walk schedule to see when it is coming to your community and help out the campaign by letting your City Hall know that you would like to support the awareness event in your community.

Please call George or David at (416) 540-7872 to volunteer to carry the Torch of Life.

Marjorie Harris, www.junction.net/hepcure

For more information, about organ and tissue donation and liver disease please visit the following websites:

Step by Step Organ Transplant Association
www.stepbystep.ca
BILL C-227
http://www.parl.gc.ca/36/2/parlbus/chambus/house/bills/private/c-227/c- 227_1/362032bE.html
HepCURE *(Hepatitis C United Resource Exchange) www.junction.net/hepcure/*

June 29-July 1 Port Moody
July 2 Coquitlam
July 3 Port Coquitlam
July 4 Langley
July 5 White Rock
July 6-8 New Westminster
July 9-10 Vancouver
July 11 Harrison Hot Springs
July 12 Hope
July 13-15 Chilliwack
July 16 Mission
July 17 Matsqui
July 18 Abbotsford
July 19 Campbell River
July 20-22 Courtney
July 23 Port Alberni
July 24 Parksville
July 25 Nanaimo
July 26 Duncan
July 27 Victoria

LULU NEEDS YOU!!

Lulu Island AIDS/Hepatitis Network
Richmond, BC,
Volunteers needed desperately
Please contact Phil or Joe,
(604) 276-9273.

PRE AND POST CLAIM INCOME INFORMATION

If you are in the 86-90 window and you need pre-1980 tax forms to support your claim for your three best years of earnings and Revenue Canada does not have your records, then call CPP. When Revenue Canada went to computers, they didn't put the pre-80 info on them, and none of it, or very little of it, is available. CPP has records going all the way back. Call 1-800-277-9914 and ask for a detailed copy of your records. This will include both the amount you paid CPP on and the total gross salary for the year. It will take 3-4 weeks to get them, but they are there.

--Bruce Devenne

LASSITUDE

Within humanity's limited ability to pinpoint a health problem, we, the people with hepatitis C, have used the term "tired" to describe the most common symptom of the problem. The medical profession, however, was quick to drag out the ever-convenient catch all, "depression." I was at the conference in Montreal and heard a doctor there promote this view. He claimed that it was depression, rather than a chronic health problem, which causes the tiredness of hepatitis C. He couldn't, however, explain how or why we suffered this symptom before we knew we had a chronic health problem.

Many other members of the medical profession agree with the doctor from the Montreal Hep C conference, including Dr. Jagdeep Obhari, of the Digestive Diseases section of Baylor College of Medicine, Houston, Texas, United States, who conducted his own study and agreed that emotional problems rather than physical ones were the main reason for the fatigue. He stated that "the fatigue of chronic hepatitis C virus infection is more severe and difficult to treat, and is associated with greater feelings of anger and hostility than fatigue associated with other chronic non-liver diseases." Perhaps this is why the catch all, "depression," is so convenient.

Now, thanks to a current comprehensive study done by Dr. Michael Valis, a behavioural scientist at the QEll Health Sciences Centre in Halifax, who also presented at the Montreal conference, there is a word to describe this symptom.

The word is "lassitude." The description of lassitude fits what I, and others with hepatitis C, feel much better than does the label "fatigue."

According to his studies, there exists a general attitude toward fatigue almost as if the person with it is lazy or goofing off. "Fatigue? Go take a nap." Or, "You just got up how can you be tired?" etc. Also the fact that this symptom is difficult to measure in terms of impact or severity makes it difficult for others to understand and accept. . Lassitude, on the other hand, is more specific in terminology and well defined.

It consists of:

1. Weariness without exertion.
2. Lack of recovery with rest or nourishment
3. Rapid and dramatic weariness
4. Interference with vocational and social roles

Dr. Valis conducted a clinical study of HCV patients under excellent conditions, using several widely accepted measurement guidelines and procedures. He came up with some sound and provable, yet a little startling, results: that people with HCV suffer from the same level of lassitude as those with Multiple Sclerosis, was one that he mentioned. He will be doing further studies, the results of which could have a big impact on disability issues.

What I can't understand is why MS patients were studied and this condition was so well defined, diagnosed and named, while Hep C sufferers were quick to be labelled "depressed." Maybe the numbers involved and, therefore, the cost of proper treatment, would make it easier and cheaper to simply dole out Prozac.

Thanks to Brad Kane for his input on this subject.

Bruce DeVenne

COMPENSATION

BRITISH COLUMBIA

1986-1990
Bruce Lemer/Grant Kovacs Norell
Vancouver, BC
Phone: (604) 609-6699 Fax: (604) 609-6688

Before August 1, 1986 or 1990-1991
David A Klein/ Klein Lyons
Legal Assistants: Carol Anton or Jeanette Cheung
Vancouver, BC (604) 874-7171, 1-(800) 468-4466, Fax (604) 874-7180

also:

William Dermody/Dempster, Dermody, Riley and Buntain
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
Toronto, Ontario
Phone: (416) 595-2300, Fax: (416) 595-0527

TRACEBACK PROCEDURES:

INQUIRIES-CONTACT:

The Canadian Blood Services
Vancouver, BC
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.

RCMP Task Force TIPS Hotline
(Toll free) 1-(888) 530-1111 or 1 (905) 953-7388
Mon-Fri 7 AM-10 PM EST

CLASS ACTION/COMPENSATION

THIS SERVICE, USUALLY PROVIDED 24 HOURS A DAY FREE OF CHARGE BY LESLIE GIBBENHUCK, HAS BEEN SUSPENDED DUE TO NON-RENEWAL OF HEALTH CANADA-FUNDING.

National Compensation Hotline: 1-(888) 726- 2656

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1(888) 726-2656 or 1 (877) 434-0944.
www.hepc8690.com info@hepc8690.com

***Should you have any questions about the status of your claim (86-90), please contact the administrator. They should answer all of your questions. If, however, they do not, then please contact Bruce Lemer who has promised me that he would answer your questions at no charge.—C.D. Mazoff*

COMING UP IN BC/YUKON:

Armstrong HepCure Office and library, by appointment. Contact: Marjorie, 546-2953, amberose@sunwave.net, www.junction.net/hepcure

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

Chilliwack BC HepTalk Meetings: 2nd & 4th Wed. monthly, 7-9 PM, Chilliwack. Next meetings: July 11th & 25th. Contact: 856-6880.

Comox Valley HeCSC Meetings: 3rd Tues. monthly, 7-9 PM, St. George's United Church on Fitzgerald. Next meeting July 17th. Contact: Jayne, 336-2485 or Dan, 338-0913, Rhagen@mars.ark.com

Cowichan Valley Hepatitis C Support Contact: Leah, 748-3432.

Cranbrook HeCSC : Meetings: 1st & 3rd Tues. monthly, 2-4 PM, #39 13th Ave South, Lower Level. Next meetings July 3rd & 17th. Contact: 426-5277, hepc@cyberlink.bc.ca

Creston/Golden/Invermere Educational presentation and appointments: Contact Katerina 426-5277

Grand Forks Hep C Support Centre Each Mon, 3:30-5:30 PM, & 1st Mon. monthly, 6:30 PM, 7215 2nd St. (Boundary Women's Resource Centre) Contact Ken, 1-800-421-2437

HepCBC INFO Line. Free medical articles or other info. Contact: David, (250) 361-4808, info@hepcbc.org, www.hepcbc.org

Kelowna HeCSC Meetings: 1st Sat. monthly, 2-4 PM, Rose Avenue Education Room, Kelowna General Hospital. **NO MEETINGS JULY/AUG**. Contact Doreen, 769-6809 or Barbara-J., 862-2437

Kimberley Support Group Meetings: 1st Mon. monthly, 1-3 PM. Next meeting July 2nd. Contact Katerina 426-5277

Kootenay Boundary Meetings: 2nd & 4th Tues. monthly, 7 PM, 1159 Pine Ave, Trail. **No Summer meetings.** For individual support, info & materials, contact: Brian, 368-1141, k-9@direct.ca.

Mid Island Hepatitis C Society Meetings: 2nd Thurs. monthly, 7 PM, Central VI Health Centre 1665 Grant St, Nanaimo **Contacts—Ladysmith:** Sue 245-7635 mihepc@home.com **Nanaimo:** Barb 756-9631 bwreggitt@home.com

Mission Hepatitis C and Liver Disease Support Group Meetings: 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting July 18th. Contact Gina, 826-6582 or Patrick, 820-5576. missionsupport@eudoramail.com

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Next meeting: July 17th. Contact: Ken, 1-800-421-2437

Nelson Hepatitis C Support Group Meetings: 1st Thurs. monthly. ANKORS Offices, 101 Baker St., Next meeting: July 5th. Contact: Ken Thomson, 1-800-421-2437, 505-5506, info@ankors.bc.ca, or Ken Forsythe 355-2732, keen@netidea.com

New Westminster Support Group Meetings: 2nd Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, Suite 301-668 Carnarvon Street, New Westminster. Next meeting July 9th. Contact: Dianne Morrissettie, 525-3790.

Parksville Support Group Contact Ria, 248-6072

Parksville/Qualicum 102a-156 Morison Avenue, PO Box 157, Parksville, BC V9P 2G4. Open daily from 9AM to 4 PM, M-F. Contact: 248-5551, sasg@island.net

Penticton Hep C Family Support Group SUSPENDED DUE TO NON-RENEWAL OF HEALTH CANADA-FUNDING

Powell River Hep C Support Group: No meetings over the summer, but we will hold a social evening September 12th to begin again in the fall. Contact number for the summer is Cheryl at 483-3804, or the Health Unit at 485-8850.

Prince George Hep C Support Group Meetings: 2nd Tues. monthly, 7-9 PM, Health Unit Auditorium. Next meeting July 10th. Contact: Gina, 963-9756, gwrickaby@telus.net or Ilse, ikuepper@pgrhosp.hnet.bc.ca

Princeton Meetings: 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Next meeting July 14th. Contact: Brad, 295-6510, citizenk@nethop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy: 557-9362, e-mail: wmm@island.net

Quesnel: Meetings last Mon. evening every other month. Contact Elaine Barry, 992-3640, ebarry@goldcity.net

Richmond: Lulu Island AIDS/Hepatitis Network: Meetings/drop-in dinner each Mon. 7-9 PM. Contact Phil or Joe, 276-9273.

Slocan Valley Support Group Meetings: Contact: Ken, 355-2732, keen@netidea.com

Smithers: Positive Living North West Meetings: 2nd Wed. monthly, 7-9 PM, 3731 1st Avenue, Upstairs. **No Meetings July/Aug.** Contact: Deb. 877-0042, 1-866-877-0042, or Doreen, 847-2132, plnw_hepc@bulkley.net

Sunshine Coast—Sechelt: Contact: Kathy, 886-3211, kathy_rietze@uniserve.com—**Gibsons**: Contact Bill, pager 740-9042

Vancouver HepHIVE: Contact: 254.9950 hephive@mdi.ca **Meetings:**

- **Carnegie Centre** Hep C & HIV/HCV Meetings: Each Mon., 4:30-6 PM, 3rd floor, room. 2.
- **HepHIVE and HepC VSG** Hep C & HIV/HCV Meetings: Last Wed. monthly, 10:30-12:30, BCCDC Building, 655 West 12th Tom Cox Boardroom 2nd floor. **Next meeting Aug. 29th. (None Jun/July)**
- **Positive Outlook**. 441 East Hastings Street. Hep C & HIV/HCV, 1st & 3rd Thurs. monthly, 2-3PM.

VANDU Vancouver Area Network of Drug Users Meetings each Mon., 1 PM, #350 - 163 West Hastings St., (Cambie & Hastings) Bus fare and snack. Contact: Ed or Ann, 683-8595, vandu@vandu.org, annlive@direct.ca, www.vandu.ca

Vernon HeCSC HEPLIFE Meetings: 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Next meetings July 11th & 25th. Contact: Sharon, 542-3092, sggrant@netcom.ca

Victoria HeCSC Meetings: 1st Mon. monthly, 6:30-9 PM, CHR 1947 Cook St. Multi-Purpose Room and last Wed., St. John's, 1-3 PM. Contact: 388-4311, hepcvic@coastnet.com

Victoria Support and Discussion Group Meetings: 1st Wed. monthly, 7-9 PM, Next meeting July 4th. Contact Hermione, Street Outreach Services 384-1345, hermione@avi.org

Victoria HepCBC Support Groups Small support groups for men or women. Men, contact David at 361-4808, cdm@hepcbc.org Women, contact Joan at 595-3882, or jking@hepcbc.org

Yukon Positive Lives Meetings: 3rd Wed. monthly , Whitehorse. Next meeting July 18th. Contact 456-2017, positivelives@yknet.yk.ca or Heather, fromme@marshlake.polarcom.com, www.positivelives.yk.ca

OTHER PROVINCES

ATLANTIC PROVINCES:

Atlantic Hepatitis C Coalition, QEII Health Sciences Centre, Bethune Building, Rm 223, 1278 Tower Road, Halifax, TEL: 420-1767 or 1-800-521-0572, rahcc@ns.sympatico.ca, www.ahcc.ca **Meetings:**

- **Antigonish:** 2nd Wed. monthly, 7 PM, St. Martha's Health Centre, 25 Bay St, Level 1 Conference Room
- **Bridgewater:** Last Wed. monthly, 7 PM, South Shore Regional Hospital, 90 Glen Allen Dr., Private Dining Room
- **Halifax:** 3rd Tues. monthly, 7 PM, QEII Health Sciences Centre, 1278 Tower Rd, Dickson Bldg, Rm 5110
- **Kentville:** 2nd Tues. monthly, 6:30 PM, KingsTech Campus, 236 Belcher St, Rm 214
- **Truro:** Last Tues. monthly, 7 PM, Colchester Regional Hospital, 25 Willow St, Conference Room
- **Yarmouth**: 1st Tues. monthly, 7 PM, Yarmouth Regional Hospital, 60 Vancouver St, Lecture Room 1—Main level

Fredericton, NB HeCSC Meetings: 7 PM Odell Park Lodge. Contact: Sandi, 452-1982 sandik@leamstream.com

Greater Moncton, N.B. HeCSC Contact Debi, 1-888-461-4372 or 858-8519, monchepc@nbnet.nb.ca

Saint John & Area/HeCSC: 3rd Thurs. monthly, 7 PM, Community Health Centre, 116 Coburg Street. Contact Esmonde, 653-5637, hepcsj@nb.aibn.com, www.isaintjohn.com/hepc/

ONTARIO:

Durham Hepatitis C Support Group Meetings: 2nd Thurs. monthly, 7 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Topic: Pegylated Interferon, Colina Yim, R.N. BScn, Sr Hep Nurse at Toronto Western Hospital & Pres., Can. Assoc. of Hep Nurses. Contact: Smilin' Sandi, smking@home.com http://members.home.net/smking/index.htm, Jim (905) 743-0319, Ken Ng , (905) 723-8521, or 1-800-841-2729 (Ext. 2170)

Hep C Niagara Falls Support Group Meetings: Last Thurs. monthly, 7 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thurold. Contact: Rhonda, 295-4260 or hepcnf@becon.org

HepSEE Barrie Chapter Meetings: 3rd Tues. monthly, 7-9 PM, AIDS Committee of Simcoe County, 80 Bradford Street, Suite 336 Contact: Jeanie, 735-8153 hepseebarrie@home.com

Kitchener Area Chapter Meetings: 3rd Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. **NO MEETINGS JULY/AUG.** Contact: Carolyn, 893-9136 lollipop@golden.net

Windsor Support Group Meetings: Each Thurs., 7 PM, 1100 University Ave. W. Contact 739-0301 or Ruth or Janice (Hep-C), 258-8954, truds99@hotmail.com

PRAIRIE PROVINCES:

Edmonton, AB Hepatitis C Informal Support Group Meetings: 3rd Thurs. monthly, 6 PM, 10230-111 Avenue, Conference Room "A" (basement) Contact: Jackie Neufeld, 939-3379

Edmonton, AB Meetings: 2nd Wed. monthly , #702-10242 105 St. Contact Fox, 488-5773, 473-7600, or fox@kihewcarvings.com

HepSEE WPG Winnipeg Meetings: Each Wed., 7-9 PM, Young United Church, 222 Furby St., Rm AB, Main Floor. Contact: 774-8123, bbuckels@escape.ca

QUEBEC:

Hepatitis C Foundation of Quebec Meetings: 4th Tues. monthly, 7-9 PM, Montreal General Hospital, room A1.109, 1650 Cedar Ave. 7-9 PM., and 3rd Wed. monthly, 2-4 PM, 4341 Verdun Ave. Contact Eileen to reserve (limited seating): 769-9040 or fhcq@qc.aibn.com