hepc.bull

BC's Hepatitis C News Bulletin

October 1998 **Issue No. 5**

Background to Hepatitis C

By Natalie Rock, RN

The virus causing Hepatitis C was first identified in 1989 by Dr. Choo. The commercial test for diagnosing hepatitis C became available in 1990 and many centres began using the test in March of that year. This test was called the hepatitis C antibody test (anti-HCV). Prior to 1990, those patients who had signs or symptoms of liver disease or those who developed abnormal liver function tests following a blood transfusion and who were negative for hepatitis A and Hepatitis B, were classified as having non-A non-B hepatitis. When the anti-HCV test became available many of these patients subsequently tested positive for hepatitis C. Thus, some of the clinical information relative to hepatitis C has been gained from retrospective analysis of those non-A non-B patients who subsequently have been shown to have hepatitis C, and from following patients testing positive after 1990.

The test for diagnosing hepatitis C is an antibody test. Once exposed to hepatitis C, similar to exposure to other diseases or to a vaccination, the body produces an immune response by developing antibodies to the virus. In the case of hepatitis C, these antibodies do not indicate if the virus is still present or if the body has cleared the virus. The presence of antibodies to hepatitis C *only* indicates that the person has been exposed.

Once an individual has tested positive for hepatitis C it must then be determined whether or not the disease is active and if there is inflammation in the liver. This is done by testing for liver enzymes. The two common hepatocellular enzymes that are seen elevated in viral hepatitis are the AST and the ALT. Enzymes can be considered simplistically as “batteries.” They supply the energy for the metabolic processes of liver cells so that the liver can manufacture proteins, produce clotting factors, produce bile, and detoxify chemicals and drugs from the blood. Every metabolic process has many steps and each step is fueled by one or more enzymes. Thus, each cell has many, many enzymes. Some enzymes are specific for certain types of cells, (such as cardiac enzymes), other enzymes are

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JOEY IN VICTORIA

I have just returned home from seeing Joey and Connie off at the Victoria Airport. Joe had already left to catch a ferry. What a fine family! I know that this was Joey's project, but we mustn't forget that Joe and Connie played a major part in the success of the trip. How fortunate we are to have such nice people doing this for us!

Yesterday was a beautiful day in this area. Some of us were at Brentwood Bay and we were joined by the mayors of Central and North Saanich and members of the local media, not forgetting Gary Lunn, our Reform M.P. The ferry was 20 minutes late arriving, and that was when I started to worry. Had I got the times wrong? How will this affect the rest of our plans? Well, they arrived safely, and, due to the time element, stopped at MacDonald's for a quick bite. By the time we had finished, about 25 members of a local cycling club were ready for us. They had a long, lightweight trailer with signs on the top reading "Joey Haché's Ride of Conscience, the Hepatitis C Society of Canada." This was a lightweight trailer, towed by one of the cyclists. The sign was double-sided, so that people standing on the sidewalk could see it as well as those passing by. The Central Saanich Police department has a vintage Black and White car, and they brought this out for us. We fixed up Joey's mum with my daughter's bicycle, and Gary Lunn changed into cycling gear, and we were ready. The Black and White led the way, with Joey, Connie, Gary Lunn and the rest of the cyclists right behind, Joe with his sign-covered van, and then yours truly. I had a sign on the back of my car reading "Tainted Blood a National Scandal" and ribbons in our colours. There was another car behind me, and then a regular police car bringing up the rear.

For those of you who don't know it, the Pat Bay Highway is very busy, especially on Friday afternoons, with ferry loads of traffic, usually racing along. Not this time. I looked in my rear view mirror and the traffic was backed up for miles. I said to my wife, "If only we had a cameraman in a helicopter we could claim all these people were part of the cavalcade." On the whole, the motorists were pretty good. We got a few nasty looks, but not many.

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IBUPROFEN WARNING!

Dr. Thomas Riley III, the medical director for the liver transplant program at The Milton S. Hershey Medical Center of the Penn State Geisinger Health System says that patients with chronic hepatitis C experience a 10-fold rise in their enzymes after taking Ibuprofen, suggesting significant liver injury. He added that if too much medication is taken the patient risks speeding up the process of going from chronic hepatitis to cirrhosis of the liver.

Dr. Riley has an article in the September issue of the *American Journal of Gastroenterology.*

Donna Yeo, aged 70, of Surrey, BC, passed away on August 4th of liver cancer. She is fondly remembered by her husband Alfred, her daughters, Cheryl O'Donnell and Karen Becker and her grandchildren, Justin and Seamus O'Donnell and Harlan Hudson.

Her passing has not gone without notice.

Michael Spence, aged 75, passed away on September 6, 1998. Born in Barbados, he left behind his wife, Eileen, daughter Margot, son Jon, and their families, and many other relatives and friends. Mike worked 35 years with Shell Oil, nine of them in Trinidad. He enjoyed gardening, playing bridge and walking in the parks.

His family requests donations to HeCSC Victoria or the charity of your choice.

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

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Victoria Chapter
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Victoria, BC V8W 2L5

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

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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@sprint.ca ***or C.D. Mazoff at*** squeeky@pacificcoast.net
The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING: ***The deadline for placing advertisements in the*** **hepc.bull** ***is the 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:

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

Cowichan Valley Hepatitis C Support Services. Meetings: 1st Thursday 7-9 PM. 3rd Tuesday 10-12:00 noon,. 464 TCH. Duncan. NEXT MEETINGS: Oct. 1st and 20th. Contact: Debbie, 748-5450 or Leah 748-3432. vhepc@hotmail.com

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: Oct. 25th. 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: Oct. 31st. Contact: Michael, 860-8178 or eriseley@bcinternet.com

Nanaimo HeCSC Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Oct. 8th. Contact: Helen, 245-8759.

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: Third Thursday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: Oct. 15th. Contact: Leslie, 490-9054, bchepc@bc.sympatico.ca

Richmond: Meetings: Fourth Tuesday of each month from 7 to 9 PM, Westminster Health Unit, 7000 Westminster Hwy., main floor, room 3. NEXT MEETING: Oct. 27th. 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: Oct. 1st. 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: Oct. 8th. 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: Oct. 6th and 20th. 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: Oct. 14th and 28th. Contact: Sharon, 542-3092. sgeegee@msn.com

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: Oct. 28th. Contact: 388-4311. hepcvic@pacificcoast.net

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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

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@sprint.ca***

THANK YOU!

Victoria Chapter HeCSC acknowledges the personal donations, donations in kind and memorial donations received to date, and the following for discounts, donations of services, or equipment: Monk Office Supply. CFAX 1070 Radio, Apple Canada, Pacific Coast Net and Island Internet, Inc., Mid-Island Realty, Questar Holdings, Unity Business Machines Ltd., Microsoft of Canada, Jim Pattison Group, Society Press & Graphics, Paradon Computers, and CompuSmart. We also wish to acknowledge an anonymous agency which has generously supplied us with government surplus computer equipment.

SQUEEKY'S CORNER

In Memoriam

C.D. Mazoff, Ph.D., Dip.Th.

Yesterday, I read on the email that Daniel on the HEPV list had passed away. Only thirty-eight! We had been expecting it since he had gone into liver failure about a month ago. Last Month, Jim Thompson; a few weeks ago Annie Yeo passed away, and this week Michael Spence departed.

Yesterday as well, Mrs. Spence called me and we spoke at some length. Friends had left donations in memory of Mr. Spence to HeCSC Victoria, and she wanted to know if this money would be going to research. I told her that it could…I guess? …I mean it should…I guess?… and finally that it *would*!…(but how?…)

Where would it go? How much did we need? Where would we get it? And would it make a difference? Just thinking about how much money is needed to conduct research into a cure for HCV and then looking at our bank account seems an exercise in futility designed only to put me back to bed. How depressing!

But good things start small. They start with a question by a loving wife. They start with the concerns of specialists like Dr. Martin Schechter and Robyn Sussel of the CTN whose willingness to include HCV in their mandate for HIV research is a gesture that leaves us flabbergasted. They start with the dedication of people such as Joan King and Darlene Morrow, who despite their daily battles with the dragon find time to advocate for all of us, and to come up with strategies and ideas that will hopefully benefit us all as new treatments and even *a cure* is found. They start with the willingness of Tim McClemont and Hardeep Kaur of the national office of HeCSC to venture into new ground, to spend even more hours in an understaffed office trying to tackle an almost insurmountable problem, and with no guarantees—except frustration.

Almost insurmountable, because 10 years ago those with HIV-AIDS faced the same unwillingness of governments to deal with and respond to the very real problems posed by that deadly illness. But they persisted and fought on, pushing the government at all levels to respond with federal and provincial strategies for research, support and education.

Now it is our turn. It is our turn to remind our governments and fellow Canadians that hepatitis C is not merely a "persistent nuisance" experienced by a minority of persons of questionable character, but a chronic and progressive disease, which, if untreated, will in many cases lead to suffering, disability and death. It will also have severe fiscal repercussions as the costs from lost earnings, sick leave, unemployment insurance, welfare benefits, medical treatment for complications and treatment with ineffective and costly drugs begin to add up.

So, Mrs. Spence, I want to thank you and to tell you that we are opening a special bank account, which we shall call the Michael Spence Account (with your permission), and that all donations to the chapter for research shall be placed there. It is a beginning,

Let it grow.

Letter to the Editor: Hepatitis C and Death

When patients look for information on chronic Hep C they seek reliable sources. Patients must choose between accepted drug therapy treatment methods and the possible demise of one's health or even life itself. To make an intelligent decision, they must weigh out the best information possible from all available sources.

Statements like "5% to 20% die from Hep C" and "5% die within 3 to 5 years of contracting the disease" are quite influential to anyone's decision making. There are literally dozens of claims about imminent death. Occasionally we take higher USA numbers and apply them directly to Canada due to a lack of genuine Canadian based studies and research. This perceived epidemic threat has little basis in Canadian funded research.

Apparently some creativity is allowed in this area when seeking federal funding, as well. Medical science now claims that all reasons for liver failure collectively equal the fourth leading cause of death in Canada. This has little to do directly with Hep C, although it seems to regularly appear in discussions related to Hep C.

Canada, like many developed countries, uses a system called the International Classification of Diseases, or ICD code, to officially record its death statistics. The information, recorded at the time of death, is categorised by one or more causes locally, then sent to Ottawa to compile official national numbers.

Here in the province of BC or in Canada, we do not have the death percentages previously stated above. In fact the actual number of hepatitis C attributed deaths are a small fraction compared to those stated above. There are many reasons for these distorted numbers; however, these numbers are the only official death statistics for Canada. The primary reason for liver failure has been, and still is, alcohol. To cross check and validate these death statistics, the next step is to verify how many livers are actually failing and require transplants to prevent imminent death. It was very surprising to learn that 99% of Canadians on the organ transplant waiting list are NOT waiting for new livers. This should be a reliable indicator of pre-imminent death, partially related to hepatitis C.

The general public does not have a desire to dwell on morbid subjects like death. However patients considering radical drug therapy should have genuine facts at hand to reach their decisions, not inflated hearsay. This is particularly true for the asymptomatic patient, who may acquire new problems with drug therapy alone. Patients in the end-stages must face grim circumstances and make tough decisions that affect both them and their families. There is no one person more qualified or willing to take on that responsibility than the patient.

The actual scientific cause of any death is not easily arrived at. This is for economic, scientific and reasons of general practicability. Blood screen tests are not reliable on the deceased. An autopsy is not performed without somebody paying the costs. Physical degradation in the liver related to hepatitis is a function that is assessed in an autopsy. Given input from the family or a doctor is the only time a cause of death would be attributed to Hep C and applied to the appropriate ICD category. A liver section analysis would solve this with more accurate data as it applies directly to Canada.

These ICD codes are not exact, but they are official to our government. If the numbers are higher, then surely people in the end stages deserve better information from the Ministry of Health, not from parties with a vested interest. Inflated numbers may have the effect of delaying any decision by the ministry to formulate a planned policy and begin effective treatments now.

If the Ministry of Health responds to a finite number of patients who want genuine life-saving treatment, it may be more manageable with our public medical system than trying to formulate one plan for a statistical mystery group. As the taxpaying financiers of the public medical system, we have some community responsibility to keep costs realistic.

Our government may not be able to afford blood screen tests for 96 viruses for the entire population of Canada under our present system. Our government may have difficulty in financing the costs of sterilising disposable medical equipment under ISO guidelines. It does have the power, however, to treat actual reported cases of chronic hepatitis patients who wish to be treated. These patients deserve facts to make an intelligent and dignified decision about their own futures.

In closing, we should all be aware that the health of the ministry is inversely proportional to the health of the medical community. Both parties must bear in mind who finances the system and who bears the human and economic cost of those decisions.

R E Milner
Port Moody, BC, Canada
Sources available on request.

Editor's response

by Darlene Morrow

We firmly believe that everyone is entitled to his or her own opinion, however, we find several key factors wrong in Mr. Milner's argument.

It is easy to play the numbers game. And while we agree that scare tactics are not good for anyone, we do not think that Mr. Milner gives us an accurate picture either.

If we accept the current two-percent of the population infected with HCV theory, then there are at least 300,000 people infected with HCV in Canada. While only 20 percent of these people will go on to develop cirrhosis (60,000), this is still a significant number. From that 60,000, five percent will go on to develop liver cancer (3,000). Liver cancer ultimately ends in death. The remaining 57,000 may go on to develop end stage liver disease, and a percentage of those people will require a

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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. 8
I read Atwood and Updike. I listen to Christine Lavin and the Wallflowers. DWM, 40ish, semi-retired, financially sound. Mentally and physically sound, so far. I'm looking for someone kind, and intelligent that I can serenade and make gourmet meals for, talk to, and have fun with. Victoria area.

Antiviral Research Programs Available at Ochsner Clinic

Antiviral research programs are sponsored by pharmaceutical companies. Research studies do not generally involve costs for the patients, except as this may apply to screening visits to determine eligibility or for the cost in travel to and from the Ochsner Clinic. Sometimes research budgets allow for partial compensation for ground travel. The research programs are conducted on an outpatient basis and patients self-administer the medication. Most studies involve a comparison of the investigational drug's performance and safety to a standard medical treatment, such as interferon. Some research trials incorporate the use of placebos (inert agents with no antiviral effects), but these studies generally allow for treatment with the investigational drug if it is shown to have proven benefit in the patients who are initially treated.

TREATMENT OF CHRONIC HEPATITIS C
Background

Until recently, conventional treatment of chronic hepatitis C has involved the use of six months of interferon therapy given alone in a dose of 3 million units three times weekly. While this regimen was generally well tolerated, only a small minority of patients (10 to 20%) was found to respond in a lasting way. Recently, it has been recommended that interferon be given for one year. This results in a somewhat higher rate of lasting response (20 to 30%), but may be less well tolerated. At the Ochsner Clinic, it is our contention that some of the unpleasant side effects as well as the limited efficacy of interferon is due to the fact that this agent has been given intermittently (i.e., three times weekly) and in too low a dose. The following research programs available at Ochsner will hopefully lead to a more effective way of treating chronic hepatitis C with equal if not better tolerability than current regimens:

1. Combination therapy with interferon and ribavirin. Ribavirin is a broad spectrum antiviral nucleoside analogue that can be taken orally. It has little activity against hepatitis C when used alone, but a number of medical reports indicate that there is a higher lasting response rate when this agent is used in combination with interferon. Currently, we are studying the use of interferon and ribavirin for the following three groups of patients:

Treatment new or naive
Relapsers after previous interferon treatment
Interferon nonresponders

Important facts to keep in mind about the combination protocols:

(1) All patients in this study are treated with the combination therapy; there is no placebo group.

(2) Patients must have insurance which enables them to cover the cost of the interferon therapy (ribavirin is provided free) and any additional costs for their care at the Clinic. This is necessary because the studies are not financially supported by the pharmaceutical industry.

(3) Finally, the studies take advantages of several innovations in interferon therapy:

First, induction therapy is used. This means that interferon is given daily for the first month; there are data which indicate that this may lead to a higher rate of initial virologic response.

Second, therapy is continued for one year, which as mentioned above is more effective than six months of treatment.

Third, therapy is given on alternate days for 11 consecutive months rather than three times weekly to deliver more drug.

Finally, therapy is combined with ribavirin to increase the chance of a lasting response.

In these studies, the dose of interferon is based on the age of the patient. Patients less than 50 years of age, receive 5 million units for one month, followed by 5 million units on alternate days for 11 months. Patients over the age of 50 receive 3 million units. We feel that the regimens described above provide the greatest chance of lasting biochemical and virologic response.

2. Sustained release (PEG) interferon. Polyethylene glycol is an inert carrier in a number of medications. Four interferon molecules are bound to this material in a sustained release formulation of interferon (PEG interferon) which is designed to provide more steady blood levels. The medication needs to be given once weekly instead of three times weekly.

More sustained blood levels of interferon

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From the Okanagan

August 23rd to 25th, I attended the HCV Global Foundation conference in Oakland, California. It was appropriately titled "The Silent Epidemic of Hepatitis C."

I was invited by HCV Global to attend the conference and to make presentations on two panels. This was very difficult, as they had at least 6 other panels happening at the same time, and I wanted to take them all in, not attend the ones I knew the most about!

I was asked to speak on the topics of Hepatitis C and Youth, as well as the FDA Lookback. I felt privileged to be presenting with Thelma King Thiel (HFI—Hepatitis Foundation International), Dr. Norwood Hill (Texas Blood Banks), Dr. Nora Hirshler and Dr. Thomas Jackson. It was very interesting to listen to the different perspectives on what the FDA lookback study should look like when it finally gets implemented. They were very interested to hear what had been done in Canada and about any flaws in the process we had found!

My being in California on these panels brought forth opportunities I never dreamed of nor imagined. I was invited to join the Pacific HCV Support Group Coalition. This is an organisation of support group leaders from Washington, Oregon, California and B.C. who will meet regularly (via email) to discuss HCV walks, ribbons, information, media, speakers, scholarships, newsletters, organ donation awareness, clinical trials, etc. It sounds like a very committed group, with many goals to work toward!

I met some awesome individuals and left California with my wheels spinning. Roulette Smith gave an absolutely brilliant talk about research and the future of HCV. Jean Shinoda Bolen, MD, was inspiring as she described her journey to the mind, body, spirit connection. Chris Sandoval and Matthew Dolan offered other approaches to dealing with the same issues. From Alternative Approaches to Harm Reduction, Social Security & Disability Issues to Substance Abuse there really was something in it for everyone. I managed to take in a few of the panels and found them very informative and entertaining. Ron Duffy and all his helpers at HCV Global need to be applauded for a very successful conference.

Upon my return home I was called and asked to join, as an advisory board member, the team at Hepatitis C Hope Incorporated. It is an honour to have been asked and accepted as a member. This is the group based in Texas that has launched the $50 billion class action suit, on behalf of those transfused with hepatitis C. I am very excited about travelling to Texas and working alongside C. W. Henderson, Dr. C. Everett Koop and Andi Thomas. The windows of opportunity are opening in my direction.

We will be travelling to Ottawa for the opening of Parliament the week of the 21st of September. I am thrilled to be joining many others as we gather to let the Prime Minister know we have voices and are prepared to use them in seeking fair compensation for all!

Until next time....take good care of yourselves,

Leslie

1 September 1998

Dr. Martin Schechter
Canadian HIV Trials Network
608-1081 Burrard St.
Vancouver, BC V6Z 1Y6

Re: Hepatitis C Research

Dear Dr. Schechter:

It was with great pleasure that I met with you and Robyn last month. We have heard and seen wonderful things about your work at St. Paul's, and we are excited about your willingness to engage in hepatitis C research, and to apply the CTN model to HCV.

Many of our group are relapsing from Interferon treatments, and several of us are looking at the possibility of other treatments and trials, which we have heard are being done in the US and Europe, and we want to do what we can so that these trials can be brought to Canada. We have been in contact with some of the pharmaceutical companies, and have had some positive replies from companies that seem to be interested in conducting clinical trials here. It is gratifying for us to know that the infrastructure that has been used in AIDS trials may possibly be available for hepatitis research, as well.

I would appreciate it if you could expound on this matter for publication in our monthly newsletter, the *hepc.bull*, so that our members may become more informed, and thus able to lobby more effectively.

We truly appreciate your help and interest. On behalf of hepatitis C sufferers, thank you.

Sincerely,

Joan King-Diemecke
Treasurer, HeCSC Victoria Chapter

RESEARCH CAMPAIGN

If you have Hep C have, you have an incurable disease. Our government does not want to spend money on a cure. We must insist that they do, not only for ourselves, but also for those still uninfected. A package is now being developed to help you write to your MPs and Allan Rock to ask for more research and clinical trials. PLEASE PARTICIPATE!!

Ms. Joan King-Diemecke
Treasurer, Hepatitis C Society of Canada, Victoria Chapter
1611 Quadra Street
Victoria, BC V8W 2L5

Dear Ms. King-Diemecke

Thank you very much for your letter of September 1st. We enjoyed meeting you and your colleagues from the Victoria Chapter of the Hepatitis C Society of Canada, You were particularly interested in how the Canadian HIV Trials Network could assist with the development of an enhanced hepatitis clinical trial capacity in Canada. We were happy for the opportunity to learn more from you about the challenges of living with hepatitis C.

Like you, many others have noted the parallels between HIV and the hepatitis C virus. Both are chronic, debilitating diseases and both will continue to take a dramatic toll on the health of Canadians for decades to come. For neither disease is there anything even approaching definitive therapy, and the need for better treatments and a cure is urgent and compelling. Sadly, both these epidemics are converging in our most vulnerable populations, and the number of people who are co-infected is rising. As a result of these clear parallels, we are often asked whether the CTN model shouldn't also be applied to HCV.

We believe hepatitis C treatment remains at the stage HIV was 10 years ago with a few relatively ineffective drugs to offer patients. The need for clinical research is clear. But, our ability to attract experimental therapies at the earliest possible time for affected Canadians will depend on whether our country has a ready and able research infrastructure, and on Canada's ability to attract state-of-the-art clinical trials.

I think there are a couple of options as to how we can help you in your quest to establish an HCV trials network. One means is to expand the mandate of the CTN to include HCV. This has been suggested by a number of people in the recent past. But as I explained, this would require some important steps. We would need to consult with the HCV patient community and with those physicians and health care workers already treating people with HCV and perhaps doing research in the field to ensure that they are all an integral part of this important response. Equally, we would need to discuss this with our own advisory boards and the HIV community. There may be concerns that time and energy spent on HCV might detract from HIV research. On the other hand, it has been pointed out that efforts against HIV and HCV can be synergistic rather than competitive, and that the whole could be greater than the sum of its parts.

The second way we could help is to transfer everything we've learned from our eight years in operation to a new "trials network for HCV."

Many observers have tried to impress on us the efficiency of expanding the CTN's mandate rather than setting up a whole new infrastructure. The CTN already has a network of investigators comprising Canada's leading infectious disease specialists, many of whom are involved with the treatment of Hepatitis C, or who work closely with colleagues who do. The CTN is also experienced in working cooperatively with advocates and activists. After successfully including people living with HIV on all our committees, we've learned research can be inclusive and scientifically excellent at the same time, a reality that is sometimes lost on researchers in other fields. Because the CTN already has a data centre in place, the need for a new infrastructure to collect and process data from clinical trials need not be duplicated. This infrastructure includes computers and computer networks, academic faculty, database programmers, data analysts, biostatisticians, and data managers. Finally, we have a standing National Ethics Review Committee and a Safety and Efficacy Committee already in service. All of this together means the saving of Canadian tax dollars, and most importantly, the saving of time for people living with hepatitis C who desperately need access to new and better treatments for the disease.

I know it is difficult for you and your colleagues at the Hepatitis C Society to focus on research while the compensation issue is still outstanding. We agree with you that both issues should be pursued simultaneously. Also, we agree with your view that any funds put towards HCV research by the federal government should in no way replace or jeopardise compensation dollars.

Whether Canada chooses to build on the CTN infrastructure to support hepatitis C trials or to create a new national trials network, we will assist you in any way we can. Please feel free to contact us about this for further discussion. As you suggested, we would be happy to meet with your colleagues at the national level at their earliest convenience.

Sincerely,

Martin Schechter, National Director

NEWS FROM MATT DOLAN

About the time I was finishing the 1st edition of the *Handbook*, I was becoming increasingly aware of the shortcomings of interferon based therapies for hepatitis C, as well as their lack of suitability and efficacy for many patients. Market conditions and the structure of the pharmaceutical industry meant that alternative therapies, such as amantadine, were being edged out, or only offered with interferon. Thus the available options were settling down to interferon or nothing for most people. When I actually analysed the figures for contraindicators (both lifestyle and clinical) and incorporated the non or partial response rates, coupled with the outright patient refusal rate, it was readily apparent that the generally available solutions were not well matched to the actual needs of most patients. I was also beginning to meet apparently "cured" interferon patients, who reported that they were more debilitated after therapy than before it.

It was also crystal clear that just about all of the patients attending the Gateway clinic were saying that they were getting better, particularly in terms of day-to-day functionality, but also reporting improved clinical results. It was also noticeable that John Tindall's patients who decided to "do" interferon were finding the side effects far more tolerable than those who did not take concurrent herbal treatment; this was obvious from the greatly diminished "drop out" rates among his patients taking interferon based therapy.

I had been using Chinese herbs prescribed by John Tindall of the Gateway clinic, (an internationally respected National Health Service resource located in London), for a while, and had experienced dramatically improved levels of energy, and had noticed that my LFTs had become persistently normal. This experience was normal among his patients. Then I received the results of a recent PCR test, showing that my viral load had declined from 5 million units (2 tests before starting herbs, 1 in the early stages) to 40,000 units. In other words, my viral load was now less than 1% of the level that it had been prior to the commencement of Tindall's Chinese herb based therapy.

Although I knew that feeling better and having healthy LFTs would be of interest to many patients as therapeutic outcomes, it was the decline in the viral load that really triggered me into some action. I discovered a few other examples of diminished or disappeared virus (though usually only interferon patients have PCR measured in London, so results are hard to come by). Generally, it was obvious that this was, in many respects, a more attractive, better qualified and deeply rooted option to currently available drug therapy.

I had some doubts about getting involved in the production of medicines for HCV, largely because I was a respected writer on the subject, and I knew it might raise questions of impartiality. However I also thought that it would be ethically questionable not to do something that might benefit other patients, particularly when I knew that the balance of evidence strongly suggested that this was a great source of potentially beneficial treatments and that I was very well placed to take this initiative.

I therefore approached John and asked him if he thought it would be possible to produce some broad range herbal formulations for general use, with a view to letting a wider percentage of the patient population benefit from his expertise.

He decided that he could design some broad range formulations which could deliver a good probability of benefits in particular subgroups of patients. Above all it was possible to design formulations which would be safe, so that the worst outcome would be that they would not work. (This remains the qualification to these products). We approached East West Herbs and were able to negotiate the production of heavily quality controlled tableted versions of our first 2 formulations.

John, I, and around 15 other patients, some of whom are extremely able and well-qualified, are now involved in setting up a national charity which will aim to create a centre of excellence for the multidisciplinary treatment of HCV, and will also serve as a centre for research. This will be called The Yuan Centre. (Or clinic?) (Yuan means "source"). It is hoped that the herbs will become sources of income for the Yuan Centre thus benefiting everyone, and removing the hassle from John and me.

In the UK these products are available from East West Herbs Shop, 3 Neals Yard, Covent Garden, London WC2H 9DP phone: +44 (0)171 379 1312 or their office in Oxfordshire, Tel +44 (0)1608 658862.

In the USA they are distributed by East West Herbs USA to practitioners only; their number is (510) 652-2807.

These companies employ rigorous, extensive quality control procedures, comply with statutory regulations in the USA and EC, and are subject to regular inspection by government agencies. Price for one month's standard supply will be around £17 or $25 (US).

Cure????????

by Darlene Morrow

On August 7th I finished my last day on the combination treatment of ribavirin/interferon. I had been on ribavirin for 12 months and interferon for a total of 21 months. I found the time on the combination to be very difficult. However, I have gone from a PCR of >750,000 to PCR undetectable. In addition my ALT is around 20. I am very pleased with these results and will undergo a second biopsy in November to see if there has been a reversal of the scarring.

But the hard part of this treatment is *remaining* PCR negative because the odds do not necessarily favour me. I did not respond initially and my PCR was very high. Both of these parameters have been shown to negatively affect a sustained response.

I have heard some people refer to the combination as a possible cure. As hopeful as I am, a word of caution is necessary. We need to remember several things. First of all, the criteria for measuring a cure has been remaining PCR negative for six months. This is far too short time. We all know how successful this virus is at hiding. If someone were to remain undetectable for five years, I might consider using the term cure.

The second item of concern is the fact that the PCR is still performed using blood. We all know that the virus resides in the liver. But performing a PCR on liver tissue is beyond our current resources. This test is very specialised and requires expensive equipment that isn't readily available. But a person could be PCR negative using blood and PCR positive using liver tissue. This is very frustrating for all of us.

So we must use great caution when we use the word *cure*. It can have the effect of placating the public and removing HCV as a cause for concern. We must have research dollars from the government going into hepatitis C. We must have funding for clinical trials for HCV. Every single person that has HCV should be receiving some kind of treatment, or be in a clinical trial. What happens to the people that fail to respond to combination therapy? At this point there is nowhere for them to go. We sit and wait. Waiting for another treatment option. Waiting for the virus to continue its damage. Pushing the envelope of time closer and closer to the edge. This is not an acceptable alternative.

I implore those of you that are not symptomatic to get involved. We need to lobby the government for funds. We must have a clinical registry set up for HCV trials. We dare to hope for a cure, but only YOU can make this objective our reality. Do not become passive victims. Get involved. Collectively we CAN make a difference.

*(**Ochsner**—Continued from page 4)*

could be a more effective way of giving interferon, since it could result in a lower rate of interferon resistant viral variants. Equally important, sustained release interferon appears to be better tolerated, avoiding the "highs" and "lows" of interferon therapy given three times weekly. A study is underway at Ochsner Clinic comparing one year of PEG IFN given once weekly in one of three different doses to 12 months of conventional interferon given three times weekly (randomization is 1:1:1:1).

There are no medical costs associated with this research protocol since both the PEG interferon and study visits are supported by the manufacturer of the drug (Schering Plough).

FOR MORE INFORMATION about these protocols and other options for patients, you can contact Dr. Perrillo's office at (504) 842-4893 or E-mail address: RPerrillo@Ochsner.org

*(**BACKGROUND**—Continued from page 1)*
common to many different types of cells. Since the liver is so metabolically active it has many, many different enzymes that are classified according to which cells are releasing them. In a healthy liver, enzymes do not normally "leak" out of the liver cells, therefore there is usually only a low level of enzymes in the blood. If the liver cell is irritated and inflamed, there may be a "leaking" of the enzymes into the bloodstream and a constant low level of enzymes in the blood. If the liver cell dies there may be a sudden release of the enzymes and thus a transient high level in the blood.

Liver enzymes may be elevated in the blood for many, many reasons, including alcohol, prescription and non-prescription drugs, fat in the liver (caused from diabetes, high cholesterol, obesity etc.), viruses (hepatitis A, B, C, D, and G), and metabolic diseases (Hemochromatosis, Wilson's Disease, Alpha-one antitrypsin deficiency). Therefore, if the liver enzymes are elevated a number of other blood tests need to be performed to rule out other causes of elevated liver enzymes. Keep in mind that the normal enzyme range in one lab may be quite different than the normal ranges for another lab.

There are also "liver function tests" that are performed to determine how well the liver is working. The liver has many specific functions and by testing them it is possible to determine whether the liver is having any difficulties. Blood tests to assess liver dysfunction are:

1 *Bilirubin* is an orange bile pigment produced by the breakdown of heme. Bilirubin normally circulates in the blood and is taken up by liver cells and processed into a water-soluble pigment which is then excreted in the bile. Failure of the liver cells to excrete bile or obstruction of bile ducts can cause an increased amount of bili in the blood and thus lead to jaundice or yellowing of the skin and eyes. Normally 99% of bilirubin is excreted in the feces and the rest in the urine but in liver disease it is excreted through the skin.

2 *Albumin* is a protein formed in the liver. Albumin is responsible for balancing the water concentration between the blood and the space between the tissues. When the albumin is low in the blood, the water in the blood vessels is forced out into the tissues. This results in an increase in fluid on the abdomen (ascites) and feet (pedal edema). Other conditions such as severe malnutrition, kidney disease, or extensive burns may cause a decrease of proteins in the blood.

3 *INR* or *Prothrombin Time* are blood tests used to assess the blood clotting factors which are proteins produced by the liver. These tests measure the time it takes for the blood to clot. Clotting factors are essential to normal clotting when a person is injured and there is a potential for bleeding. When the liver is scarred and is not functioning properly, the INR will become prolonged, meaning it takes the blood longer to clot. Patients with a prolonged bleeding time are at higher risk for bleeding.

4 *Platelets* are formed in bone marrow. Approximately one third of platelets are in the spleen and the rest circulate in the blood. Platelets aggregate to the walls of damaged blood vessels preventing blood from escaping. When the liver is scarred, the circulating blood is not able to pass through the liver as readily; this puts a back pressure on the spleen, resulting in a destruction of some of the platelets. A low level of platelets is called thrombocytopoenia. Other conditions that cause low platelets are idiopathic thrombocytopoenia purpura and pernicious anemia.

The blood test used to actually measure the presence of the virus in the blood is called a PCR test (Polymerase Chain Reaction that measures the HCV RNA found in the blood). This test was developed and became available in 1993. At present, this test is primarily only available in large centres conducting research. The PCR test is very expensive and subject to error if not properly stored and analyzed. There are two types of PCR tests: a qualitative PCR which provides a positive or negative result indicating presence or absence of the virus, and a quantitative PCR which gives the actual number of virus particles present in the blood. A PCR result is useful, prior to commencing therapy, during therapy, and post therapy, to assess the degree of response and whether the virus has been eradicated.

The replicative process of hepatitis C is not consistent or genetically uniform in its composition or structure. Due to this error in replication there are different genotypes within hepatitis C that have slight alterations in their genetic make-up. When the hepatitis C virus replicates a negative strand will first be formed as a template, from which a new virus (i.e., the positive strand) will then be produced. Like many other RNA viruses, the replication of hepatitis C is error-prone. The envelope proteins E1 and E2 are the most variable regions with the highest mutation rate at both the nucleotide and the predicted amino acid levels. The rapid mutation rate in these areas, which may allow the virus to escape from immune surveillance, indicates that these regions may be under selective pressure of the host immune system. The high occurrence of chronicity in hepatitis C infection may be primarily due to the role of immune selection of the virus (Anderson, Rock 1996).

Within each of the 9 genotypes that have been identified there are more than 30 subtypes. Often a predominate type is observed in a specific country or geographic area, indicating a geographic distribution of hepatitis C. In North America, genotype 1 is the predominate type. In British Columbia, genotype 1 is predominate (59.1%), followed by type 3 (22.7%), and type 2 (18.2%).

The genetic variability seen in hepatitis C may have an impact on the clinical course of the disease, treatment response rates, the development of a vaccine, and the prevention of hepatitis C transmission.

Is Interferon Chemotherapy?

By Marjorie Harris (mharris@junction.net)
www.junction.net/hepcure

This debate was started on the Internet recently, and Squeeky (C.D. Mazoff), asked me to make a few comments. First, I would like all of those who read my previous comments on the Internet to ignore them and start afresh with the referenced information I dug up at the local university library.

Well, without further suspense, the answer to the big question right up front I say is, "No, interferon is not considered to be a cancer chemotherapy drug, even though it is used alone or in combination with chemotherapy drugs to combat certain cancers."

Now the reasons why: a definition of chemotherapy from the *Concise Encyclopedia of Biology*[1], explains that "chemotherapy is the use of synthetic compounds to selectively kill infectious organisms, parasites and tumor cells in animals and humans, without causing damage to host cells. Chemotherapy is based on the principle of selective toxicity. . ." The key point in this statement is that chemotherapy drugs selectively 'kill' the target. "It is believed that interferon does not 'kill' the cancer cells, but inhibits their growth and/or promotes their development into cells with more normal behavior[2]." Interferons work by attaching to an infected cells surface and stimulating an immunological chain reaction which ultimately results in the production of an enzyme that "cleaves both the viral and cellular single-stranded mRNA."[2] mRNA is a strand of essential information that viruses and cells use to reproduce; by cleaving the mRNA both the virus and the host cell are inhibited from reproducing. "Interferons, therefore do not directly protect cells against viral infection, but rather render cells less suitable as an environment for viral replication, a condition known as the 'antiviral state'." [2] "Interferons, …are examples of BIOLOGICAL RESPONSE MODIFIERS.[3] "Biological Response Modifiers, which are normally produced by humans and other mammals to augment their immune response to tumors and infection, have been used alone and in combination with other agents in the experimental treatment of human cancers."

History of interferons: Interferons were first discovered in 1975. They are a large family of glycoproteins, called Cytokines. Interferons are naturally made by your body with the alpha and beta interferons appearing to be made by virtually every white blood cell in your body and gamma interferon only being produced by your T cells. Interferons are also made synthetically in the laboratory by putting interferons into bacteria and cultivating mass amounts of them for therapeutic uses.

1. Concise Encyclopedia of Biology, Thomas Scott; New York, de Gruyter, 1996.
2. The Cancer Dictionary, Roberta Altman; New York, Facts on File, 1992.
3. Scientific American Medicine, New York, Scientific American Inc., 1996.

Written Sept. 15th, 1998

*(**Death**—Continued from page 3)*
liver transplant. Twenty-five percent of those people that receive a liver transplant will die.

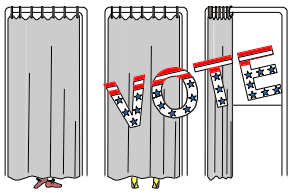
Furthermore, the above paragraph deals with percentages calculated from old data. Remember that HCV has only been actively studied since 1989. We think that 20 percent of those people will develop cirrhosis, but, in fact, that number could be higher. We also believe that only five percent will go on to develop liver cancer, and I fear that this percentage may also be much higher.

In addition, comparing liver transplant numbers with other organ transplants is futile. What difference does it make how many people need kidney transplants? The fact is that people still die waiting for a compatible liver.

Mr. Milner is correct in saying that there is no current ICD code for HCV. But rather than overstating the deaths from hepatitis C, I believe that deaths are severely under-reported. The people that die from liver cancer which they got because of the increased risk due to cirrhosis, which they got because of HCV—is only attributed to liver cancer. In fact, HCV is the cause. What other diseases associated with HCV could be responsible for death? We just don't know, but I assure you there will be others.

While I agree that our health-care system is in jeopardy, without an increase in research funding to HCV, it will only get worse. Many people who are sick with HCV are no longer able to work. These people don't pay income tax and do not have extra money to spend—so no provincial tax and no GST. Furthermore, it is not uncommon for people to use up all of their savings and end up on welfare. These sick people can no longer contribute to the system and now can only take the meagre amount that is doled out to them, and you can bet that none of these people want to be there.

So with some foresight, it is possible for the government to increase funding for research into hepatitis C and avoid the above scenario by facilitating both the discovery of a cure for HCV and a vaccine to prevent the spread of this terrible disease.



VICTORIA CHAPTER ELECTIONS

Elections for the steering committee of the Victoria Chapter of HeCSC will be held at the November meetings. Nominations may be made in person at the October and November meetings.

*(**JOEY**—Continued from page 1)*
I had been told so many times by the police that Douglas Street was under all kinds of construction and it would take time to get through, so I cut out of the cavalcade so that I could warn the people at Mile "0" that Joey would be late. I got down there very quickly and parked and was telling a photographer that they would be another 20 minutes when he pointed over my shoulder and said, "Here they come now!" I still don't know how they managed it, but it made things difficult for the Canadian Scottish Regiment piper, who was going to lead them in, as they just went speeding by. We got that sorted out, however.

There were about fifty people waiting, lots of media types, and two mounties in their scarlet, which added a nice touch to the proceedings. There are a lot of steps down to the water at "Mile 0," and Gary Lunn carried Joey's bike down for him. Then Joey was filmed dipping the wheel into the Pacific. He also filled a jar with water and laughingly asked if anyone would like to drink it. After getting his feet thoroughly wet, he returned up the cliff for the ceremonies.

All the speeches were short and were given by Gary Lunn, Murray Coell, MLA for Saanich and the Islands (my son-in-law's brother-in-law), Frank Leonard, mayor of Saanich, Alderman Young representing the City of Victoria, Steve Orcherton representing premier Clark, and a couple of our members. David Mazoff (squeeky) read a letter to Joey from Jeremy Beaty, National Chairperson of the Hepatitis C Society of Canada.

A number of presentations were made and then the piper gave us a few bars. Two notable absentees were David Anderson, the Federal Fisheries Minister, and somebody by the name of Jean Chrétien, and the only Rocks in evidence were on the beach with the driftwood and other rubbish!!

The Haché family were delighted by their reception, and although I would have liked to have seen more people there, it was Friday afternoon, a difficult time for many. All in all, I think Victoria was a success, but remember the old saying, "He who sits on his Laurels gets a sore behind!"

In conclusion, I would like to express my personal thanks to everyone from coast to coast who contributed to the success of Joey's trip.

If you'd like to send Joey a card or note of appreciation, his address is the following:

Joey Haché
434 Sujack Street
Rusel, ON K4R 1G2

Very best wishes to all of you,

Ron Thiel, Saanichton (Victoria)

PS: Pictures of Joey's arrival can be found on our website at: http://www.pacificcoast.net/~hepcvic/hepcvic~1.htm

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
E-mail: *plunket@islandnet.com*