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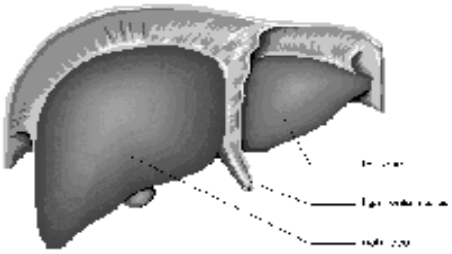
BC CHAPTERS NEWS BULLETIN
HEPATITIS C SOCIETY OF CANADA FEB 1998
Issue No. 9



From the Yale University Symposium: "Living with Hepatitis C," November 1995

THE LIVER: WHAT IT IS, WHAT IT DOES

James L. Boyer
Professor of Medicine, Chief, Section of Digestive Diseases
Director, Yale Liver Center
Department of Medicine, Yale University School of Medicine

THE LIVER: WHAT IT IS

The liver is the largest organ in the body weighing approximately 1500 grams, or 3-4 pounds. Despite its large size it is hidden beneath your rib cage on the right hand side of your body. Normally the liver remains hidden and is your silent partner. Perhaps this is why its function is so mysterious and unknown to many. It is only when it is injured by a variety of different disease processes that one becomes much more familiar with this vital organ. Functionally the liver is the most complex organ in the body carrying out a multitude of different processes which will be reviewed briefly below.

In ancient times the liver held a special place in the conscience of society. Persian armies chose their military routes after priests divined the solution by "looking into the liver." In ancient times the liver was thought to be the "seat of the soul." Still today the liver holds a much more noble position in European and Asian societies than in the United States. In France, when one does not feel well, it is always "mal de foie," rather than our customary headache or stomach ache.

THE LIVER: WHAT IT DOES

The liver both stores and releases glucose, an essential sugar and source of energy required to maintain body functions. This is particularly important during periods of fasting, for example during sleep when the liver releases glucose which is vital for brain metabolism.

(Continued on page 4)

Maxim Pharmaceuticals Announces Phase II Hepatitis C Clinical Trial Planned For Spring 1998

Stockholm: MAXIM today reported interim feasibility and safety data for the use of "Maxamine" in combination with interferon-alpha (IFN-a, Intron A®) in chronic hepatitis C (HCV) patients who have been characterized as non-responders to previous interferon treatment. Additionally, Maxim has also announced that it plans to test Maxamine in combination with interferon in a 240-patient HCV Phase II trial to commence in the United States in Spring 1998.

"Maxamine Therapy" is based on research carried out by its founding scientists from the University of Goteborg, Sweden. Research has shown that free oxygen radicals have the potential to inhibit the stimulation or activation of Natural Killer-cells (NK-cells) and T-cells by cytokines such as interferon and Interleukins. "Maxamine," a histamine type-2 receptor agonist (H2R) based on the body's natural histamine molecule, inhibits the production and release of free oxygen radicals thereby protecting NK-cells and T-cells and allowing for more effective activation by cytokines.

The Company's rationale and support for the use of "Maxamine Therapy" in the treatment of hepatitis C patients is based on a number of findings from preclinical and clinical studies:

- NK-cells, a key component of "Maxamine Therapy's" mechanism of action, have been described as the body's first line defense against viral infections. However, oxidative stress (release of reactive oxygen metabolites) caused by the inflammatory cellular response to viral infection in the liver may prevent NK-cells from performing their antiviral function.
- Specific cells that reside in the liver tissue (Kupffer cells) and act as macrophages may also inhibit NK-cells.
- Interferon-alpha, an NK-cell stimulant, is the primary treatment for HCV, yet has limited efficacy as a single agent.
- "Maxamine" has been shown to enhance or synergize with cytokines such as interferon-alpha in the treatment of cancer patients.
- "Maxamine" treatment has demonstrated efficacy in Phase II clinical trials in advanced melanoma patients having liver metastases (extending median survival to 18 months from the expected survival of 4 months).
- With respect to viral diseases, "Maxamine"

(Continued on page 5)

COMING UP:

Victoria Chapter 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**:** Feb. 25.

Penticton Chapter Meetings: Third Thursday of every month, 7-9 PM, Penticton Health Unit - Board rooms. NEXT MEETING: Feb. 19.

Kelowna Chapter Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: Feb. 28.

Nanaimo Chapter Meetings: Second Thursday of every month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Feb. 12.

Vancouver CLF Support Group: Meetings: Second Thursday of each month, 7:30 PM. NEXT MEETING: Feb. 12, Nurses' Residence, Vancouver General Hospital, 12th & Heather in the Ballroom. (Look for signs.) Contact Herb for more information: (604) 241-7766, or the CLF (604) 681-4588

Sunshine Coast Support Group- Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: Feb. 5. Contact Carol for more information: 886-4298 or email her at Carol <*ryker@cheerful.com*>

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"I would like to make a donation so that others may receive the newsletter without charge"_____[]

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

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, and Pacific Coast Net.

The deadline for any contributions of hepc.bull is the 22nd of each month. Please contact: Joan Diemecke at Tel (250) 388-4311 or FAX 479-5490 or Darlene Morrow at FAX (604) 987-7396
1203 Plateau Drive,
North Vancouver, BC, V7P 2J3
email:
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The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING: ***The deadline for placing advertisements in the hepcBC.bull is the 15th of each month. Rates are as follows:***
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$200 for 1/6th page, 12 issues (in advance)
whole page:
$60 per issue
$600 for 12 issues
1/2 page:
$30 per issue
$300 for 12 issues

FROM THE OKANAGAN

Christmas is over and the phones are once again busy.

Sorry I was not able to contribute my column last month but my 17-year-old nephew was in a single vehicle accident and sustained massive head injuries.

Needless to say we spent both Christmas and New Year's in the Intensive Care Unit at Kelowna General Hospital. Daily trips to Kelowna have become the norm, rather than the exception. He is still in pretty bad shape and muchly in need of prayers. Any and all would be greatly appreciated by the entire family.

The 4th Annual General Meeting of the Hepatitis C Society of Canada will be held in Toronto—May 29th, 30th and 31st. We are hoping to bring in some pretty big guns—Dr. Jay Hoofnagel from the National Institutes of Health, Bethesda, Maryland, and others. We are hoping this will be our best ever, and, considering how good the last one was, we have a way to go!

Please start making plans to join us for this event. Airfare packages will be offered, so keep posted for more details.

The Health Ministers' Meeting has been postponed. It appears it will now be in mid-February. I will be there with my list of questions and recommendations.

Yesterday, January 20th, Tim and Jeremy met once again with Alan Rock in Ottawa. Rumour has it the compensation package may be a very handsome one... it appears some are hoping it will take the heat away from the criminal investigation.

Speaking of which, I was the second Canadian to be interviewed by the newly appointed Krever Task Force Inspector, Kevin Vickers, who flew in from Ottawa last Monday and spent four hours asking a lot of questions. I wish them well.

Until next month...stay positive, stay well.

Love,
Leslie

VICTORIA UPDATES

Joanne Balchin has stepped down as secretary and librarian. She is taking time off for her interferon treatment. We have all benefitted from her help,and hope she will be back with us soon. David Mazoff ("Squeeky") is taking over her duties, and is also our new Office Manager. We are asking that those of you who have overdue materials return them as soon as possible, so that others may have the benefit of them. We are desperately seeking a secretary or two, mainly to take minutes at the meetings. If you are willing to help, please let the office know (Tel. 388-4311). Also, if you have signed up for the Class Action Suit and would like to be in contact with others who have done so, please call the office.

COME ONE! COME ALL!

A fundraising dance will be held on **February 28.** Mark your calendars now. The dance will be held at the **Dorchester Hotel** in Nanaimo, and snacks will be served. All proceeds will go to HeCSC. Support your support group. Mark your calendars now! Tickets will cost **$10.00**. For more information, call Ria Klomp at (250) 248-6072. Victoria members: Call the Victoria office (388-4311) to sign up. If enough people are interested, a bus may be provided.

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

WHEN WILL IT END?

The local Parksville/Qualicum newspaper carried the following story just before Christmas that shows how dangerous Hep C can be. The headline:

HEP C CLAIMS ANOTHER LOCAL VICTIM

Hepatitis C claimed a local victim last week—43 year old Marilyn Sweet, a teachers assitant at Ballenas Secondary school—who died on December 19, a month after being hospitalized with pneumonia.

Marilyn used to walk 3 miles every day from her Martindale Road home. So last week 25 people, her family, friends and other Hep C sufferers, followed her foot steps for a walk in her memory, and decided to make it an annual event to raise public awareness of Hepatitis C.

Marilyn contacted the liver disease 13 years ago from a tranfusion of tainted blood during childbirth, said her sister. It is estimated there are around 300 people in the local area infected with Hep C. The Mid Island Chapter of the Hepatitis C Society of Canada has recently formed in Nanaimo.

Those wishing support can phone 248-6072 or 752-1718.

Gary
gjones@island.net

Squeeky's Corner

Virtual Hits Victoria: Victoria Chapter of HeCSC on the Web

http://www.pacificcoast.net/~hepcvic/hepcvic~1.htm
email: hepcvic@pacificcoast.net

Well folks, it finally happened. We iz airborne, ethereal, electric, virtual and linked. We are on the Web. Thanks to the kindness and generosity of Aaron Butters, John Woods and all the other rilly nifty people at Pacificcoast.net here in Victoria, the Victoria Chapter of the Hepatitis C Society of Canada now has its own Website and email account—donated for free for a year. Yay!!

We've been wanting to do this for some time—establish quicker links to the HepC community—but it's been difficult. Thanks to the tireless efforts of Jim Lodge (who recently stepped down), we did manage to get a computer donated to the office. And thanks to other members, in particular Dave Smith, we even managed to get an office!!

We do have our wonderful bulletin—oh yah, you already know this cuz yur reading it now—which goes online at Darlene's HepC BC page, and out to all of you subscribers by snail mail (YOU WILL REMEMBER TO RENEW YOUR SUBSCRIPTIONS----RIGHT???), but, nevertheless, for those with Web and/or email access, our presence in virtual reality will really make a difference.

Because we now have a good and widely publicised email address, we hope that many of you with questions, queries and conundrums will click us a quick post, and be able to get detailed replies very promptly. Being on the Web allows us to do database searches much more quickly and effectively, and to keep you more up-to-date than ever with regard to Hep C research, Class Action Litigation, and other issues of concern.

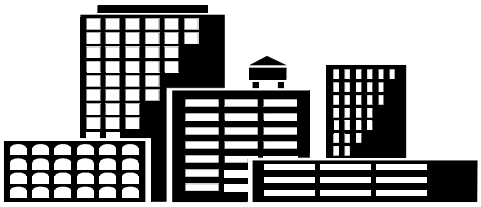
Our new site is also linked to the Hepatitis WebRing, and our stories are available to anyone anywhere on this earth with a computer and internet access.

Speaking of which: *stories*? Stories? **STORIES**??? We need stories. Your stories, to put on your own Webpage. We need input from you as to what you think would be important to share with the rest of the WorldWide Hep community. We also need to know about links that you may have found that you think should go up on our site.

Below is a list of some of the things you will find when and if you visit the site. We have links to and articles on: Hepatitis C; Who We Are; Personal Stories; Peppermint Patti's FAQs; The Liver; HEPV-L Hepatitis Support and Information Mailing List; HepC BC; Medical and Hep-related Sites of Interest; Class Action Law Suits: British Columbia; Hep C and Pregnancy; Hepatitis C and the Beauty Industry; Hep C and IV Drugs; Hep C and Sex; and lots more.

Remember your feedback is needed. After all this is your site, too.

squeeky



A Hepatitis Centre for Excellence Proposed

A proposal is being developed for a Hepatitis Centre for Excellence in British Columbia!

A broad-based steering committee, comprising a variety of agencies, health providers and consumer representation, has been established to develop a business proposal and implementation plan. A number of working groups complete with HCV patient representation have been meeting in January to provide input to the process.

Key components being discussed for the Centre include:

- Epidemiological analysis/forecasting, prevention and screening
- Treatment and ongoing management of hepatitis
- Outreach and education
- Research

It is expected that the business proposal and implementation plan for the Hepatitis Centre for Excellence will be completed by March for submission to the Vancouver/Richmond Health Board and the Ministry of Health.

Your ideas and suggestions for the Centre are invited. Please contact one of the following people to participate with your input:

- Herb Moeller: 604.241.7766 *email: Hmoeller@compuserve.com*
- Darlene Morrow: Fax: 604.987.7396 *email: hepcbc@iforward.com*
- HeCSC Victoria: 250.388.4311 *email*: *hepcvic@pacificcoast.net*

Stay tuned for more details.

August 23, 1997

MY LAST PRISON STORY

As I prepare to re-enter society and leave prison life behind, I have made an effort to have the Hepatitis C Peer Facilitator's position at William Head Institution classified as an employable position. This would ensure some degree of dedication and accountability for the effort required to maintain a constant amount of information gathering and distribution.

People are being diagnosed weekly with HCV. They seek me out for information and I try to give them reassurance that their lives and the hepatitis C virus can coexist.

Luckily Jim Tompson has volunteered to carry on after I leave. If it weren't for him I feel the Hepatitis C Awareness Group would slip into obscurity. The main reason, i.e., five or six dollars a day x 5 days, cannot be justified. I quote one of the feeble reasons for denying my request: "We can't have a paid position for every disease that comes along."

I was dumbfounded to hear this from a seemingly intelligent woman. It reminded me of what an institutional doctor told me 18 months ago: "You've had it for 10 years. Now you'll live another 10. Quit worrying about it."

A large initiative from Corrections Canada is geared toward HIV/AIDS, where every institution has a paid position for an HIV/AIDS facilitator. This is absolutely warranted and their coverage is commendable. With an infection rate of 10-20 HCV prisoners to 1 HIV/AIDS prisoner, I feel $5.00 per day is justifiable, if, through the spread of information about Hep C, the transmission rate is reduced from what it is now.

We'll all be released into society sooner or later, infected or not. With the proper information, hopefully not infected. From a financial standpoint the $5.00 per day Corrections Canada is saving today, at William Head, is going to cost them far more in a couple of years with the added strain on their health services from a growing population of hepatitis C infected prisoners.

Mike G.

(*Ed.: The following is a letter that Mike wrote earlier in the year)*

May 16, 1997

Dear Ladies and Gentlemen,

First off, I appreciate your taking the time to read this, and I do thank you in advance for any help or information you can provide.

I have received your address from the internet via a member of the Hepatitis C Society of Canada in Victoria, BC. I also am a member and am infected with the Hep C virus.

As briefly as possible I will relate my situation to you.

(Continued on page 6)

(Continued from page 1)

The liver is the primary source for the synthesis of proteins, particularly for proteins circulating in the blood, such as albumin and many of the clotting factors necessary to prevent bleeding into tissues. Many common drugs and potentially toxic substances are metabolised in the liver where they are excreted into the bile or through the urine. The liver both eliminates toxins as well as occasionally forms toxic substances from drugs which then paradoxically may result in liver injury. Common substances such as alcohol and sleeping medications stimulate the drug metabolising enzymes and thus may alter and affect the body levels of many medications, which may often be detrimental.

A unique function of the liver is the secretion of bile. This is an essential function of the liver, for when bile secretion is impaired, chronic liver disease may result leading in some instances to the need for transplantation. Bile is the major route of excretion for cholesterol and is important in helping to absorb fat in the diet. Thus bile performs both an excretory and a digestive function.

The liver is the major organ for detoxifying ammonia, an important by-product of protein metabolism whereby ammonia is converted into urea which is excreted by the kidney. The liver makes cholesterol which is important for cell membrane function but causes problems with arteriosclerosis and coronary heart disease when excessive amounts are produced.

THE IMPACT OF LIVER DISEASE

Liver disease in an important health problem in the United States. In 1993, 720,000 non-federal hospital admissions were caused by liver disease. The net costs exceeded $7.8 billion dollars. There are more than 100 different liver disorders which effect the lives of millions of Americans. Three and a half million people alone suffer from chronic hepatitis, the subject of today's symposium. This can be contrasted with 500,000 Americans who underwent removal of the gall bladder for gall stones annually. Thirty-four hundred people have undergone liver transplantation in 1993 and in 1992 forty-four thousand people died of liver disorders.

TYPES OF LIVER DISORDERS

There are five different types of liver injury:

1. Hepatitis, which can be both an acute and chronic inflammation of the liver produced by either a virus, drug, autoimmune or metabolic disorders. There are several forms of viral hepatitis; A, B, C, D, E, F and more recently G. Hepatitis B and hepatitis C are the most significant.

2. The second form of liver disease is cirrhosis. This term means that the liver has been damaged more severely so that its normal architecture is distorted and there is an increase in scar tissue in the liver and the liver mass is often reduced. Cirrhosis may be in consequence of long-standing injury from alcohol, certain viruses, bile duct injury or metabolic disorders including iron and copper storage diseases.

3. The liver can be affected by infiltrations from many different substances. The most common is fat which often occurs in patients who are over-weight and in diabetics. Tumours that spread from other parts of the body often invade the liver. At this stage cancer is usually widespread.

4. Certain disorders affect the circulation in the liver such as heart failure, or vascular shock.

5. Finally many liver disorders result from abnormalities in the bile ducts both within and outside the liver that drain bile into the intestine. These disorders may occur secondary to gall stone or pancreatic disorders, from autoimmune damage to the bile duct tissue (Primary Biliary Cirrhosis, Sclerosing Cholangitis) or to tumours of the biliary ducts.

Many of the blood tests physicians order help define the type of liver disorder. Often a liver biopsy may be necessary to more firmly establish the diagnosis.

This article can also be found at our new Website: http:// www.pacificcoast.net/~hepcvic/hepcvic~1.htm

Methionine and Liver Disease - A Word of Caution

by Darlene Morrow, BSc

Methionine or SAM has been recommended to people with HCV as a liver protectant particularly in conjunction with tylenol (500mg twice a day). While it is generally accepted that methionine is a liver protectant, the evidence is not conclusive as to the recommended dosage and possible side effects. Extreme caution is necessary in individuals with severe liver disease because drugs/substances are processed in the liver. The effects of hepatitis C and liver disease vary from individual to individual. The extent of damage and your particular condition (fibrosis, cirrhosis, etc.) will all have a bearing on your body's ability to deal with outside substances. The following excerpt demonstrates the possible dangers of self-medicating. *We strongly recommend that all supplements be approved for your use by your physician.* Please keep in mind when reading the following article that the suggested dosage of methionine was 2 x 500mg which is equal to 1g.

"Should Methionine Be Added to Paracetamol (Tylenol) Formulations? - Caution in Patients with Liver Disease!" (Reprinted with permission from [Drugs & Ther Perspect 10(11): 11-13, 1997. (c) 1997 Adis International Limited] source: http://www.medscape.com/adis/DTP/1997/v10.n11/dtp1011.04/dtp1011.04.html)

Adverse effects associated with methionine include nausea, vomiting, drowsiness and irritability. [8] Moreover, methionine should be used with caution in patients with severe liver disease as this agent may aggravate hepatic damage and this drug should not be used in patients with acidosis. [8] Although methionine (an amino acid) is an essential dietary constituent, studies have shown that methionine may cause reduced serum folate levels, leucocytosis, changes in serum pH and potassium and increased urinary calcium excretion when given at dosages of 8 to 13.9 g/ day for 4 to 5 days. Moreover, functional psychoses have been seen in schizophrenic patients receiving higher dosages of 10 to 20 g/ day for 2 weeks, and single doses of 8g have precipitated hepatic encephalopathy in patients with cirrhosis. [3] Although there is no evidence in humans, animal studies indicate that methionine may have adverse effects on the cardiovascular and coagulation systems. [3,4]

References:
3.Jones AL, Hayes PC, Proudfoot AT, et al. "Should methionine be added to every paracetamol tablet? No: the risks are not well enough known." *BMJ* 1997 Aug 2; 315: 301-4
4.Krenzelok EP. "Should methionine be added to every paracetamol tablet? Yes: but perhaps only in developing countries." *BMJ* 1997 Aug 2; 315: 303-4
8.Martindale. *The Extra Pharmacopoeia*, 31st ed. London: Pharmaceutical Press, 1996: 683-4.

Thymosin Alpha-1

by Darlene Morrow, BSc

The thymus is a gland located just beneath your breastbone. Immune system cells (such as T cells) are processed in the thymus into either CD4 cells or CD8 cells. CD4 cells (helper cells) are lymphocytes which are part of the white blood cell group. They help to turn on certain immune functions and stimulate the production of antibodies. CD8 cells (killer cells) are guided by the CD4 cells to destroy invading cells such as viruses.

The CD4 cells are extremely important because of their ability to control the functions of the immune system. They do this by secretion of certain substances (for example alpha and gamma interferons), which act as messengers to tell specific cells to attack and destroy invaders. They also instruct the bone marrow to manufacture more T cells and have a role in the production of white blood cells, red blood cells and specific natural killer cells which attack and destroy cancer cells.

The programming of these T cells is mediated by a substance called thymosin (Thymosin Alpha-1). Current studies are looking into the effect of thymosin on HCV. The drug company SciClone has manufactured this hormone under the name Zadaxin. Clinical trials by SciClone are looking at thymosin alone or in combination with interferon for the treatment of HCV. Further studies are looking at various combination therapies for HIV, and there are extensive trials into the effects of thymosin on HBV.

In September '97 SciClone Pharmaceuticals announced that the European Patent Office granted a use patent for the use of thymosin

(Continued on page 7)

(Continued from page 1)

was effective in protecting animals from a lethal injection of herpes simplex virus type II (Hellstrand et al., Clin. and Diag. Lab. Immunology, 2:3, 277-280, 1995) and Maxim's scientists have shown a statistically significant difference in blood histamine levels between patients that respond to interferon treatment versus those that do not respond (publication in press).

- Lastly, the interim results of the Phase I study suggest that "Maxamine Therapy" is safe in high-risk HCV patients.

Maxim Pharmaceuticals is developing novel therapeutics and vaccines for the prevention and treatment of cancer and infectious diseases. Maxim's focus is to develop novel products that include pharmacoeconomic and disease management benefits such as out-patient therapy, improved clinical efficacy, higher level of safety, lower treatment cost and improved patient compliance. The Company's lead product "Maxamine" is in Phase III trials in the U.S., Europe and Australia for malignant melanoma and other Phase II and III Trials are ongoing or planned for other cancer indications including acute myelogenous leukemia, renal cell carcinoma, multiple myeloma and prostate adenocarcinoma. The Company's secondary platform technology, "MaxVax," now in preclinical development, utilizes a mucosal vaccine carrier/ adjuvant system for a broad range of infectious disease. The Company expects to commercialize its technologies through a combination of in-house development and collaborative agreements with pharmaceutical companies.

Note: "Maxamine," "Maxamine Therapy," "MaxVax" and the Maxim logo are trademarks of the company.This release is also available on the Internet at: http://www.noonanrusso.com.
SOURCE Maxim Pharmaceuticals

Alternative Treatment Made a Difference for Me

By Herb Moeller

Following a course of Interferon treatment in 1995, during which I came close to normal AST and ALT levels, my AST and ALT levels returned to levels experienced prior to the Interferon treatment within weeks after treatment stopped. A second course of combination Interferon - Ribavirin treatment had some unexpected side effects and I had to discontinue treatment.

This prompted me to look for alternative treatment. During my search I came across the *Hepatitis C Handbook*, by Matthew Dolan (London: Catalyst Press) ISBN No. 0952950901. This book can be ordered through your local bookstore.

In the book a number of treatment options are discussed; one option I found interesting dealt with Traditional Chinese Medicine or TCM. The symptoms described in the book very much described my symptoms and suggested a treatment.

I was experiencing symptoms such as night sweats; thirst; dry mouth; liver pains; vertigo; dry skin; fatigue; dry cough; and mood swings. It was time to do something about this—so I contacted the author in London and discussed with him the possibility of obtaining the TCM herbal treatment discussed in the book. Since I was going to be in London, he invited me to meet with him and John Tindall (a TCM practitioner) at the Gateway Clinic in London, to discuss a possible course of treatment.

I started the treatment 'Cool Water' in August 97 and have seen a slow but continued alleviation of symptoms. My night sweats have almost disappeared and so have my joint pain-discomfort, and fatigue-tiredness, and, best of all, I am starting to feel more like myself again. While this herbal medication is not a cure—my AST and ALT levels have remained in their usual range—it is certainly a treatment that has made a difference in the way I feel physically and emotionally.

I recommend the *Hepatitis C Handbook*. It's comprehensive, well-written and describes what hepatitis C is all about. It is filled with helpful hints, helping the reader to develop a better understanding of hepatitis C and thereby deal with its attendant complications.

The *Handbook* covers background, facts, figures and theories of hepatitis C including treatment options, such as conventional medicine, traditional Chinese medicine, Western herbal medicine, vitamins, minerals, and homeopathic treatments, as well as lifestyle issues, such as diet, alcohol, drugs, exercise, yoga, Qi Qong and stress.

Anyone wishing to contact me may do so at 604-241-7766 or by email *HMoeller@compuserve.com*

DAVE'S COLUMN

In my last column I talked about the benefits of being an optimist and how it translates into positive physiological responses. Well I must say at this time that in the last three weeks I have experienced the most depressing interlude since I had my liver transplant nearly two and a half years ago.

It seemed as though everything I had learned about myself and how to stay positive had just flown out the window. I felt like I was flying in uncharted territory. I was unanchored, unhinged. I felt like I was freefalling, spiralling. I couldn't eat or sleep. I have to say that I felt pretty awful. It looked like I was going to have to take those damned anti-depressant drugs after all! It was all that I could do to get up in the morning and come to the office.

How did I deal with this new development in my post-transplant journey? Well, fortunately a part of me knew what was going on. I think that something as serious as a liver transplant leaves lasting psychic scars—a kind of post-traumatic stress syndrome, if you will. The invasiveness of the procedure alone is enough to inexplicably scramble your wiring. Layer on top of that the cumulative effects of end stage liver disease, which in my case lasted two years, and how could I not have crashed at some point? I have talked to numerous other recipients over time and I've heard it said that a crash occurs around the two year mark. Perhaps two other reasons for this sort of crash happening are the effects of the drugs on your moods—most notably prednisone. I had stopped taking it in Feb. of '97. Since then I have lost close to 25 lbs. It certainly had its effect on MY appetite and its effects on mood are quite well-documented. The absence of prednisone after taking it in megadoses (at the beginning anyway) for 18 months would undoubtedly have an incredible effect on the psyche. Factor in what life deals you under "normal" conditions and you have a recipe for major upheaval.

There's one more thing that I would like to suggest is an important factor—perhaps THE most important—and that is the effect of the donor organ with its own DNA, hormones and enzymes, on the host body. We've all heard the stories about the recipient who upon re-entry to post-transplant life suddenly craved foods that he'd never eaten before only to discover that they had been well-liked by the donor while still alive. Draw your own conclusions! I have personally experienced dreams that seemed not to be my own and I have noticed changes in my personality, albeit subtle, over the last two and a half years also. A new liver would have an undeniably profound effect on someone who was at end stage. I can only conclude from all this theorising that no one really knows the full extent of the effects of transplantation on the psyche of the recipient. Let's go way out there for a minute and suppose that every instant of a person's life is locked up in their DNA. In transplantation then, could it be possible that we hardwire a complete set of memories from donor to recipient? If there is any truth to this then I could say that I am harbouring a complete set of memories somewhere deep inside of me and somehow they are influencing my behaviour in a subtle yet profound way. With all due respect, I have no idea who my donor might have been, and not a day goes by that I don't think about that person and give thanks for the life I've been given.

So to get to my original question on how I'm dealing with all this stuff. First of all, I started a course of accupressure and I've had two treatments so far; and secondly, I started meditating again. The accupressure has shown immediate results in my level of stress. Waves of anxiety would wash over me in an uncontrollable fashion and they had all but disappeared by my second treatment. Meditation, on the other hand, is something that doesn't start working immediately but its long term benefits are quite profound. So, I must stick with it. I think there are two important things to consider here and they are: recognising that, hey, there's something wrong here. Why do I feel the way I do? and then

(Continued on page 8)

This is an open letter *to all that have received tainted blood and then been caught in the circle of continuing to pass it on. I have experienced many bouts of depression since hearing the news that I tested positive for HepC. In writing this open letter maybe I can rid my mind of some negative thoughts.*

My short story

In 1978 I received multiple transfusions during surgery. I was so grateful for the gift of blood that saved my life that day. I was a 27-year-old mother of two children. I had emergency surgery that was far worse than the doctors expected.

In 1980 I was able to start donating blood. I thought it only fitting to give back to such a worthwhile cause. After all I had received such a precious gift, and I was more than willing to respond in kind. The Red Cross was very happy to have me on board as a donor. My "O" negative blood is always in high demand, especially for new-born babies. My mother had known the tragedy of losing a baby to Rh factors. I myself was extra cautious when I was pregnant. I was only too glad to give some helpless child and parent a chance at life, although I am sure some went to adults too.

I was called many times over the years to come in for donation. In 1988, I was even called one day at my place of work: would I come in and donate for an emergency involving a baby? They would even pay my cab fare to the Oak street clinic from Burnaby.

It is that very day that haunted me the most in 1993 when I got the news that I was Hep C positive. I had donated blood after a four year rest. I had been travelling and experiencing ill health occasionally, probably HepC related. I received a letter in the mail on a Friday from the Red Cross informing me that I had tested positive for Hep C. I was dumbstruck. I was thinking it was AIDS related and I was about to die anytime real soon. Of course my doctor was not available until Monday.

It was then that my thoughts were with the many babies that had received blood from my donations. How were they? How could this be happening—how horrific? My mind went into meltdown; as a human being I felt somehow responsible. I know that I had no control or knowledge of such actions, but I found it difficult to cope with almost anything. I internalised the idea that I was tainted.

I gave myself over to my own terror of what was next for me. I had in my mind that this HepC was like AIDS, and I suppose it is in a way. I had questions about what effect this would have on me and how was I going to die, thinking that it was surely a death sentence that was being handed to me. I became furious with the Red Cross. How could they—this trusted agency—make such a horrendous set of events come to be.

My doctor explained that the "test" wasn't available until recently and that the best was now being done. It was not until much later that I began finding out the truth about the testing and how it wasn't being done. I am very angry most days still. I not only received tainted blood but also was included in the continued use of tainted blood.

I still cringe when I see the advertising for the Gift of Life. What other unknown blood virus is going to surface next?

Yet all in all I am very glad that I received the transfusions. I have seen my children grow into beautiful women and one has become a mother herself. Now I look at my grandchildren.

Maybe it is this very event that brings me to tears every time I think of a helpless baby and others so fragile receiving tainted blood. Not just for me but for the thousands of other donors as well and how they could have been brought into the circle of continuance. Now I tend to get mad rather than sad about these events.

I have learned so much about Hep C from this group. I have researched every possible source of information. I am learning more and living better for it. I sought out the advice and care of a Naturopath in January 1997. This has made a big difference in my care and understanding of Hep C. I still have tired days and still need to watch my health.

I am starting to work on the willingness to forgive the Red Cross. They do (did) have a Gift of Life: many people have enjoyed extra years in their lives because of blood transfusions. Not everyone has suffered. Not everyone knew not all was done. Not all is lost.

But, I still go into a kind of shock every time I get a nick or cut my hands. I just stop; it's like I can't touch anything, and especially anyone. I want to hide. I have thrown out whole pots full of potatoes because I nicked myself while peeling. I don't think there is a Band-Aid big enough or strong enough to keep the virus inside me. This may seem a little farfetched but I am realising that I am human and can have anxious moments about something so insidious.

My bouts of depression are lessening. The research and knowledge of others has helped. For that I am very grateful. Thank you, one and all, especially fellow HepCer's. I will get to a meeting eventually and make visual contact with some of you.

Sincerely,
Louise Schmidt
Hepatitis C Society of Canada # 1015

(Continued from page 3)

I am currently incarcerated and am serving a ten year term for manslaughter. I should be paroled sometime in the next six months. My first day of incarceration was Dec. 5th, 1992. I was hospitalised with wounds and unbeknown to me at that time, blood was taken. After a couple of days, I was taken to Vancouver pre-trial to await a court appearance. After three days I was transferred to another Pre-Trial closer to the courthouse. This one was Surrey Pre-Trial Centre. I remained at Surrey Pre-Trial for twelve months. My health at that time seemed to be abnormal. I experienced pains in my right side, nausea, depression and fatigue. Also at this time I was insulin dependent and handling my own blood two or three times a day for testing and injecting insulin.

For the year I was there, no solution, remedy or reasons for my deteriorating health were offered.

In November '93, I was sentenced to ten years. In December '93 I was transferred to a federal institution. All transfer papers said "No Contagious Diseases." At the Matsqui Reception Centre my health was still in question. I couldn't understand why I always felt ill. No answers or explanations were given to me.

In February '93 I was transferred to my permanent institution, William Head in Victoria, BC (on Vancouver Island). Again, all transfer papers said "No Contagious Diseases." All the time I have been at William Head I have been ill. Nobody knows why!

In December '95 I requested a Hep C blood test. January '96 the results came back "Positive". Health care officials, i.e., the nurses and the doctor seemed surprised. So after four years of illness, I now have a name for it: "Hepatitis C."

Today, May 16th 1997, I have chronic viral hepatitis. My liver has piecemeal necrosis with bridging fibrosis. My enzymes are 4 to 8 times above normal.

In June '96 a specialist recommended interferon treatments and nothing has been done to this day.

I was transfused with two litres of blood in 1988 at Prince George Regional Hospital. I believe I am one of the twelve thousand people who received tainted blood from the government and the Red Cross between 1985 and 1990.

Out of curiosity I applied through the Freedom of Information Act to receive my provincial medical file. Upon receiving it last year, I was very surprised to read a blood test from a lab dated December 19, 1992, and that my blood was positive for the Hep C virus. There were four individual papers stating I was positive for Hep C. Needless to say, I was very upset. For four years I have gone unnotified and untreated.

I then perused my federal medical files by the

(Continued on page 7)

Ayurvedic Medicine
Part One: An Introduction

Ayurveda, Yoga and Trantra are the three ancient life disciplines that have been practised in India for thousands of years. They are mentioned in the scriptures of the Vedas and Upanishads. Yoga is the science of the union with spirit, the Divine, with Truth; Trantra is the most direct method of controlling the energy that creates the ultimate union with Truth; and Ayurveda is 'The Science of Life." One of its basic tenets is that it is the "Mother of all healing systems." Ayurveda encompasses not only science but also religion (beliefs and disciplines) and philosophy (the love of and search for truth) as well. It is a science of truth as it is expressed in all life, and the whole of life's journey is considered sacred [1.2.]. The practice of Ayurveda is the Science of everyday living (preventative medicine) to maintain optimal health and balance, and its records date back some 5,000 years.

Ayurveda is concerned with eight principle branches of medicine: pediatrics, gynecology, obstetrics, geriatrics, opthamology, otolaryngology (ear, nose and throat), general medicine and surgery. Each of these medical specialties is addressed according the theories of the five elements (Ether, Air, Fire, Water, Earth); the tridosha, or constitution: vata, pitta, kapha the seven dhatus, or body tissues; three ma/at; (urine, stool, sweat): Ned! or pulse diagnosis; Jihva or tongue diagnosis and the trinity of life: body, mind and spiritual awareness.

There are seven types of constitutions: (1) vata, (2) pitta, (3) kapha, (4) vata-pitta, (5) pitta-kapha, (6) vata-kapha, and (7) vata-pitta-kapha. Among these seven general constitutions there are innumerable subtle variations that depend upon the percentage of vata-pitta-kapha elements in the constitution [1].

The constitution is called *prakruti* in Sanskrit, a term which means "nature," "creativity" or "first creation." The doshas are determined at birth, by the environment of the womb and genetics, influenced more by the mother than the father. The basic constitution of a person remains unaltered during the lifetime. The combination of elements present at birth remains constant. However, the combination of elements that governs the continuous physiopathological changes in the body alters its response to changes in the environment.

Throughout life, there is an endless interaction between the external (macrocosm) and internal (microcosm) environment, the internal environment being governed by the tri dosha. A basic principal of healing in Ayurveda is that a balance may be created in the internal forces working in the body by altering diet and habits of living to counteract changes in the external environment.

There are aspects of all the five elements in everything. At birth we are the most Earth and least Ether that we will ever be in our lives. The reverse is true when we get older. With respect to the tridoshas: Earth (predominate)/Water; pitta = Water/ fire (predominate); vata = Air (predominate)/Ether. According to Ayurveda, the first requirement for healing oneself and others is to have a clear understanding of the tridoshas.

Disease Process

Health can be defined as balance or order; disease is imbalance or disorder. The body is always moving between balance and imbalance. When we are sensitive or in tune with our bodies we are aware of any subtle differences and are able to make the necessary changes to enhance and support the body towards a balanced state. *Dis* means "do the opposite of," "deprived of," and *ease* means "the state of being comfortable."

In Ayurveda, the concept of health is fundamental to the understanding of disease. What is health in Ayurveda? A state of health exists when: the digestive fire (agni) is in equilibrium; the tridosha are in equilibrium; the three waste products (urine, feces and sweat) are produced at normal levels and are in balance; the senses are functioning normally, and the body, mind and consciousness are harmoniously working as one. When the balance of any of these systems is disturbed, the disease process begins [1]. If all of the above elements are in balance and the body is in a state of health, even coming in contact with contagious diseases will not effect a person.

The mind/body connection is often underestimated or even overlooked. It is important to consider a person's emotional and mental state when considering the disease process. The mind often cannot deal with every disturbance or issue it has and will store these issues somewhere in the body to be later dealt with. Hence, an important daily practice in Ayurveda is meditation and spiritual practices.

Suggestions for a Daily Health Routine

- Arise before sunrise, excrete
- Brush teeth, clean tongue-including the back of the tongue,
- Massage gums with finger and Sesame oil, daily.
- Spiritual practice, meditation.
- Wash eyes—remove kapha (sleep) using Oregon grape tea.
- Clean out nose, sniff salt water (very effective for sinus headaches), or ginger in water.
- Clear throat, gargle with astringent or Sesame oil.
- Clear chest, breathing exercises (twelve pranayamas, creates clearness & clarity in the body & mind), inhalation with 3-5 eucalyptus (helps to stimulate the immune system) essential oil.
- Bathe daily.
- Eat breakfast before 8am.
- Wash hands before and after eating.
- Eat in silence with an awareness of the food that is nourishing your body. Eat slowly.
- Exercise daily, this could be as little as a 15 minute walk after meals,
- Have a massage weekly.
- Rub feet with almond oil before bed.
- Sleep before 10:00pm

NOTE: The largest meal of the day should be in the middle of the day. Do not eat before bed. Dinner should be between 4 & 6 PM. Kapha's are encouraged to go without breakfast. Vata's should eat regularly and often —5 small meals per day.

Part 2 will cover healing, herbs and various formulas useful for heppers.

Mishel Rees, MH, WT, RM, Bdiv is a Healing Guide and Master Herbalist, using many different healing modalities to support her clients. She is co-owner and the operator of Quantum Life Energy Natural Dispensary & Clinic, 1050 Marine Drive, North Vancouver, BC Ph: 604.986.7908, Fax: 604.986.7925, Email: <blairt@wimsey.com>

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(Continued from page 6)

same method. There were the blood tests from 1992. Very easy to read, I might add.

In keeping this brief I have everything I have said here documented, including my medical files from the hospital where I was transfused in which I was given two litres of blood.

My quality of life has deteriorated greatly in the past five years. I would appreciate some answers from these people. I'd like to know why I wasn't told and offered some treatment. I feel the doctors and nurses at the Surrey and Vancouver Pre-Trials were careless and very negligent in their duties in not informing me (Who else could I have infected?). I am upset over this situation and I hope you can help me or point me in an appropriate direction. To date I have received no treatment, although it was recommended by a specialist. I fear my ability to earn a moderate living upon my release is diminishing along with my health.

Thank you for your time and consideration.

Mike G.

PS: I've wondered lately if I am the only case, or is there a conspiracy to cover up the Hep C cases in provincial jails to avoid treatments?

(Continued from page 4)

alpha-1 as a treatment for hepatitis C as a monotherapy or in combination with interferon. The exclusive use patent covers 15 countries on the European continent as well as the United Kingdom.

ZADAXIN, which is given by injection, has been shown to be an extremely safe and well tolerated agent. There has been no evidence of toxicity and virtually no reports of drug-related side effects in over 2,000 patients studied to date.

An article in the *Hepatology Journal*, September '97 by Herbert L. Bonkovsky, M.D., of the University of Massachusetts Medical Centre reviews and summarises the literature discussed at the recent National Institutes of Health Consensus Development Conference on the management of hepatitis C. The conference examined approaches to the treatment of the disease other than the current standard therapy, alpha interferon.

Dr. Bonkovsky writes: "Because current standard therapy of chronic hepatitis C with alpha interferon is less than ideal, numerous other approaches have been studied....Several cytokines and immunomodulators have undergone limited study; perhaps the most promising of these is thymosin alpha-1."

The review article refers to clinical data presented by researchers at the Fourth International Meeting on Hepatitis and Related Viruses held in March in Kyoto, Japan. The data showed that histological improvement was most evident in those patients who received both thymosin alpha-1 and alpha interferon.

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Variceal Pressure Is a Factor Predicting the Risk of a First Variceal Bleeding: A Prospective Cohort Study in Cirrhotic Patients

FREDERIK NEVENS,1 RAMI BUSTAMI,2 ILSE SCHEYS,2 EMMANUEL LESAFFRE,2 AND JOHAN FEVERY1

Predictive criteria for a first variceal hemorrhage lack substantial accuracy. Cross-sectional studies suggest a close relationship between variceal pressure (VP) and the occurrence of variceal bleeding.

In the present prospective cohort study, the significance of VP measurement for prediction of a first variceal bleed was assessed. Eighty-seven patients with cirrhosis and large esophageal varices who had never developed variceal bleeding were followed for 12 months. The endpoint of the study was the presentation or not of a variceal hemorrhage. Thirty-four patients (39%) were in Child's class A, 37 in class B (43%), and 16 in class C (18%). The median interval between endoscopic diagnosis of varices and the beginning of the study was 15 months. Twenty-eight patients (32%) developed a variceal hemorrhage with a bleeding-related mortality of 18% (n=5). The 1-year mortality overall was 16% (n=14). Variables predictive of a first bleed identified by Cox proportional hazards regression model were: the level of VP, the North Italian Endoscopic Club (NIEC) score, and the interval between the diagnosis of varices and the start of the study. By adding VP to NIEC, a significant gain in prognostic accuracy was obtained (P = .003). In conclusion, the present study provides evidence that the level of VP is a major predictive factor for variceal hemorrhage, and that it provides further prognostic information in addition to the NIEC index.

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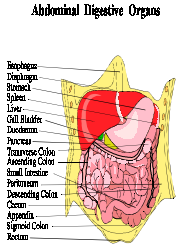

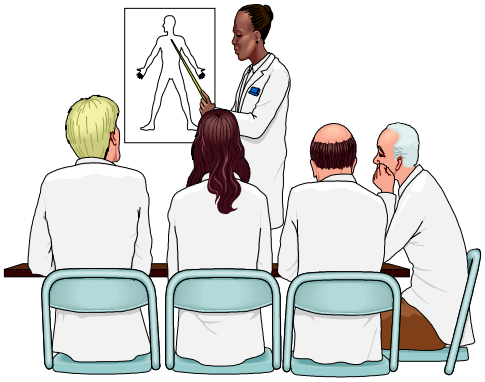

Chronic Hepatitis C Virus Infection Causes a Significant Reduction in Quality of Life in the Absence of Cirrhosis

G. R. FOSTER, R. D. GOLDIN, AND H. C. THOMAS

The effects of chronic hepatitis C virus (HCV) infection, in the absence of cirrhosis, on patients' quality of life was assessed using the short form 36 (SF36) symptomatology questionnaire. Patients with chronic hepatitis C were polysymptomatic and had significant reductions in their SF36 scores for all of the modalities tested. Patients with chronic hepatitis B virus (HBV) infection showed a reduction in the SF36 scores that assessed mental functions, but they had no decrease in the scores that measured physical symptoms, indicating that the symptoms associated with chronic HCV infection are qualitatively different from those associated with chronic HBV infection. Patients with chronic HCV infection who had used intravenous drugs in the past had the greatest impairment in quality-of-life scores, but the reduction in quality-of-life scores was still found in patients who had never used drugs. The reduction in quality of life could not be attributed to the degree of liver inflammation or to the mode of acquisition of the infection. Hence, chronic infection with HCV per se gives rise to physical symptoms that reduce the quality of life of infected patients.

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(Continued from page 5)

resolving to do something about it. Meditation and accupressure (along with other potential solutions) will give you insight into what's causing the depression and provide the tools for dealing with it. There is no quick fix and it requires constant attention if you're to see positive results. Sometimes, though, you can't see the forest for the trees and at this point you've just got to drag yourself into the doctor's and ask for help.

David Smith

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The toll free number to get you in touch with the Hepatitis C Counsel is 1-(800)-229-LEAD (5323).

TRACEBACK PROCEDURES:

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.
TRACEBACK INQUIRIES

Contact:
Dr. Lisa Jeppesen, Dr. P Doyle,or Glenda
The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-888-332-5663 (local 207)