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BC CHAPTERS NEWS BULLETIN

HEPATITIS C SOCIETY OF CANADA NOV 1997

Issue No. 6

Natural Strategies for Supporting Sufferers with Hepatitis C

by Blair Thomson, DN , CMT, and Mishel Rees, MH, WT, RM, B.Div. Both are Integrative Therapists using nutritional, herbal and body work therapies. They are co-owner/operators of Quantum Life Energy Natural Pharmacy & Clinic.

Part 2 Herbs & other important supplements for Hep C

One of the major discomforts which accompanies Hepatitis C is nausea. Whether it is as a result of drug therapies or merely a stage of the disease, it can be greatly reduced with the support of herbs. Ginger is the first herb of choice nausea, although not all ginger products are necessarily created equal. I have found that organic, freeze dried ground ginger to be the most potent form available. Don't be afraid to use it often, 2 or 3 capsules every few hours if needed. Ginger's powerful antioxidant action helps to protect liver cells from damage & improve liver function by promoting bile flow.

Another useful herb for nausea is Slippery Elm. Although not as powerful perhaps for Hep C related nausea as ginger, it is useful to keep in mind if you need a break from taking ginger or if the nausea is more gastrointestinal related (stomach flu, food poisoning, etc.). Slippery Elm is very nutritive, so may be useful along with ginger if food is not being tolerated well.

Essential oils may be used as an adjunct. Peppermint, ginger, lavender, marjoram or rosemary may be used externally mixed with a carrier oil, such as almond oil. Peppermint & ginger essential oils are specific for nausea, while lavender, marjoram & rosemary are analgesic & anti-inflammatory. Essential oils should be used in a 3% solution, e.g.: 3 drops of peppermint to 1 teaspoon (5mls) of almond oil, or 30 drops in 50 mls of almond oil.

Having just completed training in Biological Terrain Assessment, we would

like to add some information about this leading edge, state of the art, method of objective testing. This assessment looks at blood, saliva & urine & it is a very accurate & scientific way of tracking what is going on in the body showing effectively how your chosen therapy is working, whether it be conventional drug therapy &/or complimentary medicine - herbs, vitamins & minerals. For a complete thorough assessment call Quantum Life Energy for more details.

Of great importance in dealing with any disease, but particularly Hep C, is the importance of strengthening the immune system & taking lots of antioxidants before attempting any cleansing of the body. This is especially true with procedures such as ozone therapy. Cleansing is safe if the proper protocols are followed & Biological Terrain Assessments (BTA) are done to help monitor the therapy. If any one is interested in more information about the possibility of having safe ozone therapy, contact us for details.

We would like to stress the importance of Vitamin C with Hep C as it is one of the most important components in the production of interferon. If Vit C levels drop in the body, interferon levels also drop. Most practitioners seem to suggest rather conservative dosages, we recommend between 4 & 6 grams per day, even up to 9 gms per day for short periods of time (a few days), if you have a cold or flu. Vit C comes in many forms & from different sources. We believe both tapioca & ascorbate (buffered, especially the magnesium & potassium forms) Vit C are the preferred forms. Both come in 1gm (1,000 mg) size capsules.

Important supplements to consider when the liver is compromised are digestive enzymes, which should contain Betaine HCL & pancreatin, Co enzyme Q10, N-Acetyl Cysteine, B complex, acidophilus & essential fatty acids, such as flax seed oil, in relatively small doses. Lymphatic support is also important when the liver & digestion are impaired. Homeopaths &

herbs can also be useful here & include burdock & cleavers. Biological Terrain Assessment can be very helpful in determining individual supplementary needs. For example, we assume that everyone should take minerals. While it is probably safe to say that magnesium & potassium should be taken, there may be instances when the kidneys could be very stressed & unable to deal with mineral excretion properly disturbing the body's mineral balance. Kidney support would be a priority in this situation.

While we think it is important to take herbs to support the immune system, such as astragalus, shitake, maitake & reishi (the only one of the three mushrooms that has a major effect on the liver as well), equally as important are anti viral herbs, such as myrrh & goldenseal, barberry & garlic. Homeopaths which are viral specific can also be used.

Herbs used for liver support should only be used for 6 to 12 weeks, then give the liver a rest & focus on digestion, absorption & energy levels, before returning to liver once again. The reason for these specific times is that it takes approximately 6 weeks for the liver to replace all of its cells. Long term use of liver herbs may only place more stress on an already stressed organ. Herbs to use include, milk thistle, dandelion, burdock (important because it also supports blood & lymph) & turmeric (also very important because of its antioxidant properties).

With proper care & support a damaged liver can be encouraged to heal itself. The road to repair will depend on what you do & the proper administration of supportive therapies. The power of your body to heal itself is immense & we encourage you to take the steps necessary to awaken this innate ability.

As a side note Deepak Chopra has some interesting things to say about the mind / body connection & healing which could be considered alongside the above material.





FROM THE OKANAGAN

Well, another very busy month has come and gone.

Kelowna K.A.R.E.S. offered two seminars about HIV/AIDS in Penticton. With yet another R.C.M.P. officer being stuck with a needle, I decided it was time I took some training. Today I completed 16 wonderfully emotional hours of HIV/AIDS Core Training in Kelowna. It was an incredible experience and I hope I will be able to assist K.A.R.E.S. with disease awareness here in Penticton.

Tim McClemon (HeCSC executive director) visited the Okanagan for 3 whole days. He was able to attend our monthly meeting in Penticton, as well as the Kelowna meeting. Thank you to all who turned out to make Tim feel welcome. I believe all who got to hear his speak were impressed with him, as well as with the national commitment to listen to and to represent all members. Thank you to all who signed up as members, and welcome.

A warm welcome back to Vernon. Glad to hear Sharon is starting a group.

Once again, the Krever report will be released soon. I leave for Toronto on the 19th of November, so please get your quilt squares to me as soon as possible.

Speaking of being in Toronto, would you like to join us? We have secured the services of Canadian Airlines - Conventionair. All you need to do is:

- 1) call your travel agent
- 2) tell them you'd like to travel to Toronto, to the HeCSC Horizon of Hope conference on November 21, 22, and 23, 1997
- 3) ask them to book the lowest possible airfare Canadian offers
- 4) quote Star File #MO 1881
- 5) or you can call Canadian direct at 1-800-665-5554 and give them the above information.
- 6) In addition to the lowest fare, they will also give you an additional 5% discount

Any questions or problems, call Steve in Toronto 1-800-652-4372. Steve is also working on a list of persons interested in sharing accommodation. Again if you are interested, please call him.

For anyone interested ... Last week, I contacted the BC Centre for Disease Control for the latest numbers of confirmed Hepatitis C infections in our province. I was astounded to read that there are now 22,188 positive diagnoses! If

it is to be believed that only 1 of every 10 positive persons, actually is aware he has Hepatitis C, is my math correct in estimating that 221,880 British Columbians could be infected? That figure represents 6.72% of our population! It is something to think about, until next month.

Stay positive, stay well

Leslie

SUBSCRIPTION FORM

Please fill out include a check made out to

HeCSC - Victoria Chapter, Send to:

Hepatitis C Society of Canada

Victoria Chapter

1611 Quadra St.

Victoria, BC V8W 2L5

or FAX to: (250) 479-5290

Name: _____

Address: _____

City: _____ Prov. ____ PC _____

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One Year Subscription **\$10.00**

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Vancouver Chapter

Okanagan Chapters

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

I am applying for a grant." _____

"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.)

DISCLAIMER: HeCSC cannot endorse any physician, product or treatment. Any guests invited to our group to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol. The opinions expressed in this newsletter are not necessarily those of the organization.

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. CFAV 1070 Radio, and Apple Canada.

VICTORIA RAFFLE

Victoria Chapter would like to give a great big thank you to Judith Fry for organizing the raffle, and thanks to all who bought tickets. The raffle brought in a grand total of \$654.65.

MEMBERSHIP DESK

Reminder:- Any change of address, phone number or Postal Code, please let me, your phone contact (in Victoria) or your Chapter Secretary (B.C) know at your earliest. It saves our meagre funds. Thanks.

Jim Lodge 386-8227
e-mail:- ut301@freenet.victoria.bc.ca
Vice-chairperson & Membership

Vancouver Chapter Updates

Hi Everyone

Many changes are on the horizon for the Vancouver Chapter. The next meeting will be the regularly scheduled November 13th meeting. Please attend if it is at all possible. Important issues will be discussed and your input is valued and needed.

And it is at this time that I must inform you that I will no longer be a part of the Vancouver Chapter. I will be resigning from my position as vice-chair effective immediately.

As you all know, energy is a big issue for all sufferers of HCV. And the time has come when I must choose where I will spend that energy. At present I am co-editor of this newsletter, webmaster of HepC BC, and administrator for the HEPCan, a Canadian online support group, in addition to being the vice-chair of the Vancouver Chapter and sitting on various committees for the Chapter.

My main objective has been, and will always be, to provide education and support to people with HCV. I remember how alone I felt when I was first diagnosed and would do anything to prevent that same feeling in another person.

While I am resigning from the Vancouver Chapter, I am maintaining my membership in the HeCSC and will continue as co-editor of the hepcBC.bull newsletter in addition to my other online work. I will continue to work with the Victoria Chapter and will always be available for any questions and/or help through my email address <<hepcbc@sprint.ca>>, fax: (604)987-7396, or via the Victoria Office.

The best of luck to everyone. And I'll see you in the next issue of the hepcBC.bull!

Take care.
Darlene

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 MEETINGS: Oct. 29th: Speaker Arnie Lade, TCM / herbalist. Nov. 26th: Laurie Fortier, Nutritionist.

Vancouver Chapter Meetings: Vancouver Chapter Meetings: Second Thursday of every month, 7:30pm, 5745 Wales Street, at the First Lutheran Church, Vancouver. (between Nanaimo & 42nd on Wales Street) NEXT MEETING Nov. 13th..

Penticton Chapter Meetings: Third Thursday of every month, 7-9 PM, Penticton Health Unit - Board rooms. NEXT MEETING: NOTE: **Nov. 27th.**

Kelowna Chapter Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: Nov. 29th

Nanaimo Chapter Meetings: Second Thursday of every month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: Nov. 13th

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The deadline for any contributions to the next issue of hepc.bull is November 22nd. Please contact: Joan Diemecke at Tel/FAX (250) 479-5290 or Darlene Morrow at FAX (604) 987-7396

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The editors reserve the right to edit and cut articles in the interest of space.

CANADIAN LIVER FOUNDATION

Chapters of the Canadian Liver Foundation in your area are located in Kamloops and Vancouver.

Residents of Vancouver and surrounding areas can reach the local chapter at 681-4588. Fax: 681-6067. The chapter president is Mark Quirk.

The address:
#545-1130 W. Pender Street,
Vancouver, BC, V6E 4A4. Call toll free
(B.C. only): 1- (800)- 856-7266

The CLF will be the beneficiary of an event being held in both Nanaimo and Victoria on November 16 and 15 respectively. Ms S. Wrightman, a well known counselor, speaker, group facilitator and healer will be speaking on coping with the stresses in our lives and developing some simple life skills to enable us to better deal with day to day stresses and better manage illness. The event information is as follows:

Event: "The Christmas As You Like It Workshop"

Speaker: Ms. S. Wrightman, RCC, Dip. P & OT, IHP

When: November 15- Princess Mary Restaurant, 358 Harbour St., Victoria
November 16- The Dorchester Hotel, 70 Church St., Nanaimo

Cost: Before November 10- \$95.00/person or \$150.00/couple
After November 10- \$110.00/person

10% of the proceeds will benefit the Canadian Liver Foundation. These funds will be put towards further liver disease research and education.

March is "Help Fight Liver Disease Month" and that means the Spring for Daisies Campaign will once again get underway. The CLF is looking for volunteers to help with all aspects of the public and corporate campaigns and curious individuals can call Michelle at the regional office. The campaign will run in Vancouver, Victoria and Kamloops.

The Living with Liver Disease Program will commence on January 26, 1998 at Vancouver General Hospital Heather Pavillion, Lecture Hall B from 7-9pm. This seminar series is designed for patients and their families to assist them in understanding all aspects of chronic illness including coping

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NALA PAQU NOTES

Hi Everyone,

Greetings from Nala Paqu, the youngest family member (we think) of the Hepatitis C Society of Canada! Before everyone runs out for an atlas to find out where this community is to be found, however, we have a wee confession to make. Our two initial meetings held in Nanaimo (where the regional hospital is located), soon established that just as many identified Hep C'ers live in Qualicum Beach and Parksville to the north as in Ladysmith through Nanaimo in the south. Consequently, we are committed to establishing two chapters, but in the interim are referring to ourselves as NAnaimo/LAdysmith/PArksville/QUalicum Beach, or Nala Paqu for short.

Nala Paqu has come into its own thanks largely to oodles of volunteer time and effort by our very own Ria Klomp, spurred on by David Smith from Victoria Chapter. Although a number of us also began as members of Victoria Chapter, we found the travel and communications distance made it difficult to contribute to/ benefit from HeCSC objectives of support, education, research and advocacy from afar. Consequently, with Ria's careful nurturing of David's seeds of encouragement "to grow locally", we are now flowering into two additional Central Island chapters! David attended our September meeting to spread the national and provincial word about the shocking story of Hep C, as well as to motivate our organizational drive. Thereafter, Ria and I with Helen's assistance in the south and Dave's help on many occasions, have been busily promoting Nala Paqu and the Hep C cause via word of mouth, posters about town, media advertisements, three radio sessions and two newspaper interviews during an especially busy period of some three weeks!

Somehow, David also made time to further encourage us by bringing his wealth of information and positive message to our October 16th founding meeting. THANKS loads for everything, David! At this meeting, guest speaker Public Health Nurse Mary Anderson also did a super job of advising us on: the vital role of our liver in maintaining good health, blood tests which detect the Hep C virus, liver function tests, and monitoring our Hep C. Bless her, she also ended with

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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 R. Hicks, Box 263-453 Head St., Victoria, BC V9A 5S1. 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: R. Hicks and/or HeCSC cannot be held responsible for any interaction between parties brought about by this column.



Ad no. 1

Life should be an adventure. If you are female, 35/40ish, know how to sail or would like to learn, and love life, I live on a comfy sailboat with a spectacular view of Victoria Harbour. I am trim, fit, and my mom says I'm handsome. Let's talk about the possibilities!



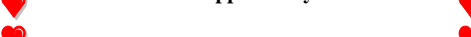
Ad no. 3

SF/S/ND 5'5", 110 lbs., Canadian, seeks Lady/Gent. 55-65, honest, with good sense of humor, needed for companionship. I am a single lady who enjoys camping, travel, nature, as well as music, cooking, garden, etc. Will answer all positive replies. Life is worth living even with Hep C.



Ad no. 4

SWM Italian, 33yrs. Life's too short to be alone. If you are a female 25/34 looking for love, understanding, and a shoulder to cry on, I'm here. I love all music, esp. country, horseback riding, walks along the lake late at night looking at the stars and dream. Once in a lifetime opportunity.



Bone Mineral Disease (BMD) and HCV

by Darlene Morrow, BSc

Background:

Many people tend to view bone as a static entity. However this is not the case. Bone is constantly being re-modelled in the body. Cells form new bone while different cells break down the old bone and recycling or re-use the components. This process is controlled by various feedback mechanisms that include hormones, alkaline phosphatase, and Vitamin D. And many of these are processed in the liver.

The initial step in bone metabolism occurs with the fat soluble Vitamin D. The body takes the inactive Vitamin D from food and supplements and converts it through a two step mechanism into its active form. The intermediary less active form is converted and stored within the liver. This is then further activated by the kidneys as needed. This final form acts as a hormone to promote intestinal absorption of calcium which causes the blood level of calcium to rise. The calcium is then used by the bone forming cells to lay down new bone. Too little Vitamin D causes a decrease in bone formation and too much causes an increase in bone breakdown.

Cirrhosis and the Bone:

Metabolic bone disease is well documented in cirrhosis.(1, 2, 5, 8, 9, 12) Osteoporosis (thinning of the bones) is commonly observed and results from decreases in bone formation and increases in bone breakdown.(4, 5) These problems can be due to a variety of problems in the feedback mechanisms that were mentioned earlier. Vitamin D metabolism (5,6,12) parathyroid hormone levels, and testosterone (6) are among those that are disturbed. Further complicating the issue is the iron overload that can also be seen in HCV. A connection between high levels of iron and osteoporosis has also been observed. (2)

It is not unreasonable to assume that these changes to the bone do not happen overnight. Studies that have looked at the various stages of cirrhosis (Child-Pugh's classifications A, B, and C) have found that the bone changes and

osteoporosis worsened as the cirrhosis became more severe. (6)

Now let's go one step further. If the bone disorders increase as the cirrhosis increases, when does the problem begin? Will osteopenia (pre-osteoporosis) or osteoporosis show up in pre-cirrhotic individuals?

Chronic Liver Disease and the Bone:

And in fact studies have found that both osteopenia and osteoporosis began in pre-cirrhotic individuals. (4, 5) So a gradual thinning of the bone appears to occur in chronic HCV. And this problem is not gender specific. BMD is observed in both men and women. (3,6,8) and many of the studies include both men and women. (5,9,11)

The next question that comes up is can the BMD caused by HCV be further complicated in special conditions?

Special Situations:

Age- As we age there is a normal loss of bone. One study comparing normal women to cirrhotic women found that there was an increased loss of bone in the cirrhotic women after the age of sixty. (8)

Women- Some menopausal women are at an increased risk of osteoporosis. As estrogen production decreases with loss of ovary function the rates of bone breakdown increase and the buildup decreases. And many women with chronic liver disease cannot take estrogen replacement therapy because the hormone is processed in the liver. This double whammy is bound to have a detrimental effect on bone integrity.

What Can We Do?

See your doctor. Bone density can be measured using dual-energy X-ray absorptiometry. This non-invasive procedure is painless. Low level gamma radiation is used to measure your lumbar spine and hip and these measurements are fed into a computer which compares your values with the normal population.

It is my personal opinion that osteopenia and osteoporosis are an under-reported complication of HCV. Women over 40 and particularly those women that have had HCV a long time and have a family history of osteoporosis should discuss the need for having this procedure with their doctors.

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SQUEEKY'S CORNER

FATIGUE

When I first started feeling sick with Hep C lots of people would say to me: "Gee, you sure look tired!" My usual response was confusion and annoyance. I didn't *feel* tired, which I translated into feeling *sleepy*. Instead I felt woozy, cloudy, foggy, dizzy, and generally exhausted. And when I explained this to the doctors I was seeing (who told me that I had HepC, but that I shouldn't worry), the general consensus was that my symptoms were the psychosomatic projections of a mentally unbalanced individual. Well, for those of you who know me: "what can I say" ☺!

Fatigue, however, is very real for many sufferers of Hepatitis C. In fact, fatigue is one of the major clinical signs of this disease, sometimes the only one, that can render an individual completely incapable of normal functioning. The problem for the medical profession is that fatigue is subjective (see above) and that there is no objective way of evaluating it based on quantifiable biochemical parameters. Increasingly, however, doctors are coming to accept that the activity of chronic viral hepatitis is enough to explain the asthenia (i.e., weakness) which effectively prevents many sufferers of HepC from engaging in steady and gainful employment.

According to the article "Chronic Viral Hepatitis," in one of the most current textbooks on hepatology, "the major and most common symptom of chronic viral hepatitis is fatigue, which can be variously described as malaise, easy fatigability, tiredness, lassitude, weakness, or lack of stamina. Patients may attribute the symptom to ageing or to stress or other factors. The fatigue may be subtle and only elicited by direct questioning. Typically the fatigue of chronic hepatitis is intermittent and is worse after prolonged activity, such as at the end of the day."¹ But, depending on the individual, "fatigue may also occur at any time of day but is most common in the morning about an hour after awakening. By 9 a.m. one may already feel the exhaustion of a full workday. Others describe weakness and a lack of energy throughout the entire day. Their usual "pep" is now gone. Even little tasks become more trying and around 4 p. m., they simply must lie down to take a nap."²

The medical profession is increasingly

coming to recognise that there is no direct relation between the severity of symptoms (i.e., fatigue) and the severity of the disease (i.e., height of enzyme levels, or even stage of liver damage), and perhaps this is one reason why doctors, who have relied upon blood tests and biopsies as the sole measures of liver disease, have been slow to acknowledge the reality of fatigue in the lives of those afflicted. The biochemical mechanism of hepatitis-related fatigue is still not clearly understood, but it is thought to be "related to production of inflammatory cytokines,"³ or to "an altered homeostatic mechanism which is deranged independent of the severity and aetiology of liver disease."⁴

What can you do? Not much. Rest when you need to, and cut down on any OTC medications you may be taking. Check with your physician about any other medications you may be currently taking, and if you smoke, STOP. Other than that, switch to sensible nutrition guidelines, such as those recommended in our very own *hepcBC.bull*, and reduce stress in your life. My own experience with stress is, frankly, that it makes me ill—and quickly too. In this respect, practising kindness, prayer and meditation can be very helpful.

Time for a nap!

¹ Bisceglie & Hoofnagle, in *Hepatology: A Textbook of Liver Disease*, by David Zakim and Thomas D. Boyer, vol. 2, 3rd. ed. (London: Saunders, 1995): 1300.

² Dr. Melissa Palmer, <http://www.livertdisease.com>.

³ Bisceglie & Hoofnagle, 1300.

⁴ JN Plevis, JA Cossar et al., "Chronic Fatigue in Patients With Liver Disease: A Preliminary Study" (Liver Research Laboratories University Department of Medicine and Clinical Psychology, The Royal Infirmary Edinburgh).

HAVE YOU NOTIFIED THE RED CROSS?

The traceback process can work both ways

If you have tested positive for HepC and if you have given blood, it would be of great assistance to the Red Cross if you would call in and help them with their traceback program. Many of us do not know when or where got our hep. I know that I gave blood between 1978 and 1992 (about 10 pints). I never recieved notification from the Red Cross that my blood was tainted, but it has been suggested to me that I have had HepC for about 20 years. I have repeatedly asked for PCR tests (which are not free) to help me find out the approximate date that I acquired the virus. The medical profession has not been helpful in the least.

So: by notifying the Red Cross that you have given blood, you are doing 2 things: 1) helping those who have acquired the infection through blood products pinpoint the source of their infection; and 2) helping yourself pinpoint where, when, or how you recieved the virus.

For example: in my case, should the blood I donated in 1983 come back negative then I know that I did not get my infection "20 years ago." Also, if the Red Cross is thorough they should be able to find that pint in the ten I gave which reveals the time of infection.

I called the Canadian Red Cross traceback program to notify them that I was positive and to ask them to trace my blood donations. They thought this was an excellent idea and suggested that we get more persons infected with the virus to do the same.

I told them that I would pass on the request.

Dr. C. D. Mazoff

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Sunshine- Vitamin D can be obtained by the direct action of the sun on the skin. It is particularly important to get some outdoor light during the winter.

Exercise- Weight bearing activity causes an increase in bone formation and an increase in calcium deposition (resulting in stronger bones). Energy is a limited resource for people with HCV. However you should consider 30 minutes a priority whenever possible. This exercise need not be vigorous and slow walking is perfectly acceptable. Weight training also has a positive affect.

Vitamin D and Calcium Supplementation- The studies do not agree on the correlation between Vitamin D levels and BMD. While they all found that there were lower levels of Vitamin D in chronic liver disease, some found that the low levels were associated with decreased bone density (3,10) but others did not. (5) Calcium supplementation is standard for aging women but again I urge you to see your doctor / specialist and discuss this with them.

References:

1. Idilman R, deMaria N, Uzunalimoglu O, va Thiel DH. *Hepatic Osteodystrophy: A Review*. *Hepatology* 1997 Mar;44(14):574-581.
2. Sinigaglia L, Fargion S, Fracanzani AL, Binelli L, Battafarano N, Varenna M, Pipero A, Fiorelli G. *Bone and joint involvement in genetic hemochromatosis: role of cirrhosis and iron overload*. *Rheumatol* 1997 Sep;24(9):1809-1813

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LIVER CANCER

“Joan, they found a dollar-sized lump on my liver.”

I received the long distance call from my internet pen pal a few days ago. She had just undergone a biopsy as a follow-up to her IFN/Ribavirin treatment, and the ultrasound was ominous. Six months ago, everything looked fine on her ultrasound. She had a CAT scan today, which made the doctors schedule her for another biopsy. (Strangely enough, the condition of her liver has improved—except for the lump.) In the meantime, my means of coping is to look up everything I can find—dare I say it?—about liver cancer.

My searches lead me to conclude that there are at least two types of cancer associated with hepatitis C: hepatocellular cancer (HCC), and non-Hodgkins lymphoma (NHL).

Hep C is well-known as a major risk factor for HCC, but it usually takes two or three decades of infection for the HCC to develop.¹ Hepatocellular carcinoma is strongly associated with Hep B or C and cirrhosis, although only 60 to 90% of patients with HCC actually have cirrhosis. There are reports proving that one does not have to have cirrhosis to develop HCC.²

Non-Hodgkin's lymphoma interests me because it is not usually associated with Hep C. Many specialists are not aware that NHL patients are often infected with Hep C. Studies were done in several research centers throughout northern Italy, and an article from Fukuoka, Japan, states: "Recently, cases of malignant B cell lymphoma associated with hepatitis C virus infection have been reported."³ In Trieste, researchers found that 28% of their NHL patients were suffering from Hep C,⁴ and in Pisa, the results were 34%.⁵ The Italian researchers concur with most specialists that Hep C is the principal cause of cryoglobulinemia, which can develop into more aggressive blood disorders, such as low-grade NHL. In fact, in Florence all the patients with both cryoglobulinemia and NHL had Hep C.⁶ Tests in 120 B-cell NHL patients in the US detected HCV in 23%, compared to 7% in a control group with malignant blood conditions, and 5% in a group with nonmalignant conditions.⁷

What can we do to avoid liver cancer? We can choose a healthy lifestyle. We can eliminate alcohol, one of the principal causes of HCC, other toxins, and mouldy foods. We can get yearly ultrasounds and alphafetoprotein tests done. We can request that these tests be done every six months, rather than annually. We can consider interferon treatment, which some studies suggest reduces the chance of liver cancer,

even in non-responders.

Common treatments for liver cancer include removal of localized, small tumors, radiation therapy, and chemotherapy. Liver transplantation is also used in some cases. Newer, experimental therapies, such as warming the body to kill the cancer cells, and therapies using the body's own immune system, are being studied. There are other novel methods, such as cryosurgery which attacks lethal liver tumors by freezing them with liquid nitrogen that is placed in the tumors with hollow steel probes, causing the cancer cells to freeze to death and explode.⁸ Other techniques include local ablation with ethanol, microwave therapy, hepatic artery, transarterial embolization and targeted radiotherapy. Promising experiments with polyphenolic acid are being done which could prevent additional tumors from forming.

Joan Diemecke

Postscript: I just received a call from my friend. The biopsy of the lump proved that it is a hemoangioma. It's not cancer, thank goodness!

¹ Di Bisceglie AM, "Hepatitis C and hepatocellular carcinoma," Department of Internal Medicine, St. Louis University School of Medicine. PMID: 9305661, MUID: 97449192.

² Nzeako U, Goodman ZD, Ishak KG, "Hepatocellular carcinoma in cirrhotic and noncirrhotic livers," *Am J Clin Pathol* 105 (1996): 65-75.

³ K Hiroshige, "Primary splenic non-Hodgkins B-cell lymphoma in a patient with chronic hepatitis C - case report," *Journal of Gastroenterology and Hepatology* 11 (8) (1996 Aug): 724-727.

⁴ G Pozzato, "Hepatitis-C Virus and Non-Hodgkins-Lymphomas," *British Journal of Haematology* 94 (3) (1996 SEP): 544-550.

⁵ C. Ferri, F. Caracciolo, A.L. Zignego, et. al., "Hepatitis C virus infection in patients with non-Hodgkin's lymphoma," *Br. J. Haematol.* 88 (1994): 392-4.

⁶ Zignego AL, "HCV Infection in Cryoglobulinemia and B Cell Non-Hodgkins Lymphoma," *Archives of Virology* 142 (3) (1997): 545-555.

⁷ Zuckerman E, "Hepatitis C virus infection in patients with B-cell non-Hodgkin lymphoma," *Annals of Internal Medicine* 127 (6) (1997 Sep 15): 423-428.

⁸ SOURCE: Doctor's Guide to Medical News - September 9, 1997

WHAT THE HECK?

Have you read something in the hepcBC.bull that you don't understand? Or have you read something that appears to contradict another article? Then this is the place for you! If you have any questions that you would like to ask the staff at the hepcBC.bull, you can phone: (250)388-4311, fax: (250)479-5290 (Victoria) OR (604)987-7396 (Vancouver) or email: <<pdiemecke@compuserve.com> OR <<hepcbc@sprint.ca>, and mail your questions to "What the Heck?" 1611 Quadra Street, Victoria, BC, V8W 2L5.

Question: The articles on transmission of HCV in the October 1997 Issue of the

hepcBC.bull appear to disagree on the transmissibility of the hepatitis c virus and on the method that works best to kill the virus. Why is this so?

Answer: You have to remember that until very recently there was no animal model to infect with the hepatitis C virus and therefore no way to directly study the virus transmissibility. I say until very recently because they have now been able to infect a chimpanzee with HCV and that chimpanzee became ill with the disease. This is a very good move forward for all of us. And many of these apparent controversies may be resolved in the future.

So, until now, the researchers have in fact disagreed with one another. More studies must be done and these studies must be with larger numbers of participants. It is one thing to look at a small group of participants and make conclusions based on this group. But it is quite another thing to reproduce that study with a larger number of participants and also reproduce the conclusion and findings. What may have looked like a cause and effect relationship with a group of twenty becomes a unimportant blip in a larger group.

It is our opinion however, that based on both the small and large studies, that we must err on the side of caution.

Remember—HCV is not well understood. If it is even remotely possible that chemical agents alone will not kill the hepatitis C virus, then when it is possible, other methods should be used (heat). It is not possible to do this in the home. So bleach used to clean up blood spills becomes our next best agent.

FROM THE VICTORIA LIBRARY

If you missed the Oct. 2nd airing of Tyabji's news presentation on Hepatitis C, you may want to borrow a taped copy of the program from the HepC library of the Hepatitis C Society - Victoria Chapter at our next monthly meeting.

The program which can be viewed daily at 1 o'clock on Channel 6 started with Tyabji informing viewers that Hepatitis C was an illness she knew very little about but along with viewers would be learning about during the forthcoming hour. The first 20

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minutes of the show focused on a current description of the disease, and provided some background information about the Krevier Commission. Events (from 1981 to the present) were outlined. Events that now implicate the Red Cross in what has become known and referred to as "Canada's Tainted Blood Scandal". The program also addressed concerns about transmission and prevention.

The highlight of the show for me was how reassuring and reaffirming it was to see familiar faces. Dave Smith and Joan Diemecke, guests of the program, were the first people I had talked to when I received my diagnosis about one and a half years ago. After having been told by my family doctor that she knew nothing about this new disease, it was Dave Smith and Joan Diemecke that listened to my concerns and tried to answer my questions or direct me to appropriate information sources. As guests of the program, Joan and Dave responded to Tyabji's comments and helped with the numerous questions coming in from viewers.

Family members and I personally felt that the information the program provided was thorough and comprehensive. Because of this disease my life has truly been turned upside-down. Being one of the 15,000 diagnosed transfused victims (I was infected through a transfusion in 1984), the challenge of this disease has, on more than one occasion, made me feel isolated, invisible and extremely vulnerable. Thank you Tyabji, Joan and Dave, for giving the dreaded disease, and the plight of those caught in its snares, some visibility. Currently on a medical leave, I find myself frequently tuning into channel 6 at 1:00 p.m. to see what is being covered. I now enjoy watching Tyabji. It is a very interesting and informative current affairs news show.

Joanne Balchin

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some very positive, practical advice on how we can deal with this chronic illness by helping ourselves to get healthy!

As I'm writing these Notes, a radio news item is announcing the Nova Scotia government will undertake to contact 20,000 transfused persons who may have received blood tainted with the hepatitis C virus. Once again the sheer magnitude of the numbers — and the shocking physical, emotional, and financial suffering and loss these represent — is numbing! But the volume of the combined voices of all who are infected and affected shall be just that much the louder!

Here's to a powerful and productive Annual General Meeting — and Krevier Report later this month. Together, let's teach the world to LISTEN — as well as to SING!

Best wishes,

TED -

a fellow member of "the Hep C Generation"

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strategies, pain management, diet and nutrition, and alternative therapies.

In Victoria the Living with Liver Disease Program will also commence in January 1998. A date and venue have yet to be confirmed.

A WORD FROM DAVE

On October 20, 1993, my life took a different path that the one I had previously been taking. Today, October 29th, 1997, I took a moment to reflect upon the path I came to find myself travelling. Actually, all my thought processes were imbued with thinking about it. It's always easier to look back than it is to look forward. Hindsight is 20/20 (far different from my own!) When I came out of intensive care, only to discover that my esophagus had burst, that I was in end stage liver disease, and that it had been caused by hepatitis C, I thought my life was over. In hindsight, I realize it was just beginning, although it took over two years and a liver transplant to get comfortable with the idea.

I realize now, in retrospect, that when one door closes, another one opens, and in my case, the one that opened did so very widely, and into a world that was vastly different from the one that slammed shut on that fateful day.

Oddly enough, one of the first things I thought about was whether or not there was a support group for people with HCV. I was not to find out for another year, and it took yet another year before I became actively involved in the Hep C Society, when Dr. Powell, our founder, asked me to.

This was 3 months after my transplant, and I was still trying to understand the grave new world I was unceremoniously tossed into. As a matter of fact, I'm still trying to figure it all out, because truth only reveals itself in small doses and occasional false starts, and sometimes when you're not expecting it.

Suffering is a by-product of this disease. We all suffer to a greater or lesser degree, depending how symptomatic we are. When I was waiting for my transplant, I didn't say, "Why me?" I said, "Why *not* me?" Why should I be exempt from suffering the slings and arrows that life hurls at anything or anyone living? In retrospect, this helped me a great deal because it reduced the sense of alienation that comes from having a chronic illness. I felt a sense of connectedness to life that I

had never experienced before. Words cannot really express the feeling I had, but after my transplant, those feelings were further validated when I saw how other transplant recipients responded to their disease. So does that mean suffering is good? I can't answer that question for anyone else, but in the context of HCV and liver transplantation, for myself, it didn't do any harm. The word "suffering" never entered my vocabulary, as in, "Boy, am I suffering," but suffer, I did, and suffer, we all do. enough on this for now.

Afterword: Last week, October 15-16, I took a trip up island to visit the Nala Paqu Chapter up there, of which Ted has already graciously written. It is being spearheaded by Ria and Ted, and the meeting I attended on Oct. 16 had 18 people. I was really inspired by this group, and I see them in approximately the same position that we were in 18 months ago. Hi, Ted, Ria, and all the great people up there.

I talked to Rae S. in Cumberland, who used to be Secretary of the Victoria Chapter, and she assures me that plans are underway to form a chapter in Courtenay-Comox area. In Campbell River, I talked to Kim C., and she is attempting to get a group going up there. Best of luck, and if there's anything we can do from down here, we'll be glad to help.

GLOSSARY

ablation- the removal of a part, especially by cutting.

aetiology- the theory of the cause of disease.

carcinoma- a malignant new growth that ends to infiltrate the surrounding tissue.

cryoglobulinemia- presence of cryoglobulins in the serum.

cryoglobulins- a serum globulin that crystallizes at low temperatures.

globulins- a class of proteins.

hepatocellular- pertaining to or affecting liver cells.

homeostatic- to keep things stable in the body.

lymphoma- a general term referring to any cancer of the lymph tissue.

monocytes- a type of white blood cell (leukocyte).

osteoporosis- bone disease in which the matrix of the bone is altered.

purpura- depending on the cause this skin condition can manifest as easy bruising, wheals or itching.

ZINC SUPPLEMENTS

Are older people more susceptible to viruses? L. Rink, from the University of Lubeck in Germany, thinks so. He says that elderly people are more apt to catch viral infections than are younger adults. When a virus strikes, our bodies' natural interferons enter the picture. Interferons are proteins that fight against invaders such as viruses, so that they won't multiply. They get our immune system into battle mode. In his article "Zinc supplementation reconstitutes the production of interferon-alpha by leukocytes from elderly persons," Rink reports that he and his colleagues studied the white blood cells of 16 people. Their average age was 72 years. Those people produced less interferon when infected with a virus than did 16 young adults with an average age of 28. The interferon produced came from monocytes. Interestingly, he found another monocyte product, interleukin-6 (IL-6) in greater amounts in the cells of the older people than in those of the younger ones. The author concludes that the elderly do not have a defect in their monocytes. There have been reports, according to the author, that a weakened immune system in older patients seems to be associated with a zinc deficiency. When they supplemented their white blood cells with zinc (15 mu M), however, they produced interferon in amounts similar to the younger adults. This seems to indicate that zinc may help older patients to fight off viruses. Be sure to check with your physician before taking any supplements.

From an article by: L RINK, UNIV LUBECK, SCH MED, INST IMMUNOL & TRANSFUS MED, RATZBURGER ALLEE160 D-23538 LUBECK, GERMANY

Source: JOURNAL OF INTERFERON AND CYTOKINE RESEARCH 1997 AUG;17(8):469-472

(Continued from page 5)

3. Monegal A, Navasa M, Guanabens N, Peris P, Pons F, Martinez de Osaba MJ, Rimola A, Rodes J, Munoz-Gomez J. Osteoporosis and Bone Mineral Metabolism in Cirrhotic Patients Referred for Orthotopic Liver Transplantation. *Calcif Tissue Int* 60 (2):148-154 (Feb 1997).
4. Nakano A, Kanda T, Abe H. Bone changes and mineral disorders in rats with experimental liver cirrhosis. *J Gastroenterol Hepatol* 1996 Dec;11(12):1143-1154.
5. Tsuneoka K, Tameda Y, Takase K, Nakano T. Osteodystrophy in patients with chronic hepatitis and liver cirrhosis. *J Gastroenterol* 1996 Oct;31(5):669-678.
6. Chen CC, Wang SS, Jeng FS, Lee SD. Metabolic bone disease of liver cirrhosis: is it parallel to the clinical severity of cirrhosis? *J Gastroenterol Hepatol* 1996 May;11(5):417-421.
7. Kalef-Ezra JA, Merkouropoulos MH, Challa A, Hatzikonstantinou J, Karantanas AH, Tsianos EV. Amount and composition of bone minerals in chronic liver disease. *Dig Dis Sci* 1996 May;41(5):1008-1013.
8. Shiomi S, Kuroki T, Masaki K, Takeda T, Nishiguchi S, Nakajima S, Seki S, Kobayashi K, Okaamura T, Ochi H. Osteopenia in primary biliary cirrhosis and cirrhosis of the liver in women, evaluated by dual-energy X-ray absorptiometry. *J Gastroenterol* 1994 Oct;29(5):605-609.
9. Nakano A, Kanda T, Miyamoto T, Ishigami Y, sato T, Shimizu Y. A study of osteopenia in liver cirrhosis by dual energy X-ray absorptiometry. *Nippon Shokakibyo Gakkai Zasshi* 1993 Aug;90(8):1689-1694.
10. Sezai S, Herano M, Iwase T. Osteodystrophy in liver cirrhosis: detection and treatment evaluation using 99Tcm methylene diphosphonate bone scintigraphy. *Clin Radiol* 1991 Jan;43(1):32-38.
11. Szalay F, Lakatos P, Nemeth J, Abonyi M, Buki B, Tarjan G, Hollo I. Decreased serum osteocalcin level in non-alcoholic and alcoholic chronic liver diseases. *Orv Hetil* 1991 Jun 16;132(24):1301-1305.
12. Pietschmann P, Resch H, Muller C, Woloszczuk W, Willvonseder R. Decreased serum osteocalcin levels in patients with liver cirrhosis. *Bone Miner* 1990 Feb;(2):103-108.

PERIPHERAL NEUROPATHY AND HCV

by Darlene Morrow, BSc

Peripheral Neuropathy (PN) is a condition in which pain or tingling is observed in the limbs. Typically the hands, legs and feet are involved. The pain is from nerve involvement and can range from mild to severe. The sensations can include shooting pain, burning, tingling and numbness. There are many different causes for this condition and they include diabetes, mixed cryoglobulinemia, HCV, Vitamin B6 or B12 deficiency, decreased thyroid function, acute porphyria and reactions to drugs.

The prevalence of hepatitis C virus (HCV) infection has been estimated at 43 to 84% in patients with essential mixed cryoglobulinemia. Cryoglobulins are proteins that form crystals at low temperatures. These crystals can damage the filtering apparatus of the kidneys and cause excessive protein leakage into the urine, plug up and inflame the small blood vessels in the skin (causing painful ulcerations), and interfere with the nerves in the hands and feet (causing tingling and numbness).

Some purpura has been successfully treated with interferon-alpha which lowers the amount of cryoglobulins. However existing nerve damage is rarely reversible. And the interferon can rarely cause a worsening of the neuropathy. Furthermore, in a small percentage of the population, interferon can also cause thyroid abnormalities which can also be a cause of PN.

Nucleoside analogs often cause a transient PN. Ribavirin is a nucleoside analog. While it has not been associated with PN I think it is important to consider all possible causes particularly when it is usually given in conjunction with interferon.

SOME THINGS TO CONSIDER IF YOU SUFFER FROM THIS PROBLEM:

1. See your doctor. Blood tests can rule out cryoglobulinemia and other auto-immune causes. Also discuss B6, B12 or alpha lipoic acid (an anti-oxidant) supplementation with either your doctor or naturopath. Alpha lipoic acid has been used in the temporary treatment of peripheral neuropathy. Long term usage is not recommended.
2. Avoid sitting or standing for long periods.
3. Don't stop exercising. While you may associate the pain with exercise, it is in fact helping to keep muscle tone and increase your body's sensitivity to insulin which is important in diabetes. Swimming is an excellent option as it reduces the pressure on the legs. Cycling exercises your legs without injuring your feet. Rowing is also easier on your feet, and because you're sitting down you don't have to worry about poor balance due to neuropathy.

ADVOCACY ANNOUNCEMENT

CLASS ACTION SUITS:

BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, B.C. V6B 1Z5
1-800-689-2322

Lemer Kambas
Bruce Lemer
Suite 1550,625 Howe Street
Vancouver, B.C. V6C 2T6
(604) 669-4004

Before 1986 and after 1990
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, B.C. V5Z 1K1
(604)874-7171
(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). It may not be working yet so please be patient.

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)

