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BC CHAPTERS NEWS BULLETIN
HEPATITIS C SOCIETY OF CANADA JUNE 97
Issue No. 2

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: July 30th (No meeting in June). Speaker(s) TBA.

Vancouver Chapter

Meetings: Second Thursday of every month, 7:30pm, 5745 Wales Street, Vancouver (between Nanaimo & Rupert on 42nd Street)

NEXT MEETING: June 12th at 7:30pm. Guest speaker: Dr. Jim Chan, ND, on the use of Oriental Medicine for HCV.

Penticton Chapter

Meetings: Third Thursday of every month, 7:00 to 9:00 PM, Penticton Health Unit - Board rooms.

Kelowna Chapter

Meetings: Last Saturday of every month, 1:00 - 3:00 PM, Rose Avenue Education Room in Kelowna General Hospital. Soon to be announced: Thursday evening meetings to return.

Vernon Chapter

Meetings: First Tuesday of every month from 2:00 - 4:00 PM, Independent Living Resource Center - housed at "The People Place."

HOW TO REACH US:

VICTORIA CHAPTER OFFICE

TEL: 388-4311

DAVID SMITH TEL: 658-4991

VANCOUVER CHAPTER

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VERNON CHAPTER:

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ROBIN TOMLIN TEL. 365 - 6137

MAY/JUNE AT THE CANADIAN LIVER FOUNDATION

The Living With Liver Disease Program continues at the Vancouver General Hospital every Monday evening from 7-9 PM. The program is free and the seminars are listed below so you can keep them on hand.

June 2: *Diet and Nutrition, Speaker: Lori Fortier, Registered Dietitian and Nutritionist*

June 9: *Wrap Up Session, Speaker: Emily Lai, Coordinator, Living With Liver Disease Program.*

If you have any questions please call Michelle Scarborough at 681-4588.

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

In Nanaimo, your contact is Cleo Vaudrin who can be reached at 753-3545. Address: 2240 Elliot Road, RR #4, Site WC-15, Nanaimo, BC, V9R 5X9.

Residents of Vancouver and surrounding areas can reach the local chapter at 681-4588. The chapter president is Jennifer Warnyca. The address: P.O. 570, 810 West Broadway, Vancouver, BC, V5Z 4C9. Call toll free (B.C. only): 1-(800)- 856-7261.

FLASH!!

On May 22, 1997 the Honourable Mr. Justice K. Smith ruled to certify the class action against the Red Cross and to appoint Anita Endean as the representative plaintiff.

The remedy sought is damages for injury, loss, and expenses caused to persons allegedly infected with hepatitis C virus through transfusions in British Columbia of whole blood or blood products during the period commencing August 1, 1986, and ending July 1, 1990.

As Ceasar would have said, let the games begin! This going to be a long and drawnout contest. Stay tuned and find out how justice will be served.

Herb

BC EXPERTS IN LIVER DISEASE

In British Columbia contacts are based in Vancouver and Surrey.

At Vancouver Hospital & Health Science Centre w10th Site, contact Dr. Frank Anderson at 876-5122.

At the UBC site, call Dr. Urs Steinbrecher at 822-7121 or Dr. Peter Kwan at 822-7727.

Dr. Robert Chan of St. Paul's Hospital can be reached at 689-7200.

In the Surrey area, please contact Dr. Henry Wong at 584-6661 at Surrey Memorial Hospital.

In Richmond you may contact Dr. Martin Fishman at 723-4447.

Dr. K. Yik can be contacted at the Royal Columbian Hospital in New Westminster at 525-0155.

At Kelowna General Hospital, you may contact Dr. Craig Render at 763-6433.

FOUNDING MEMBER ARTUR DE TORRES

A staunch member of Victoria's Portuguese community, and hard-working stone-mason, Artur passed away peacefully in Hospice on Monday, May 19th at 3:30 AM. He is survived by his wife Fernanda, and his two children. One of our founding members, he was present from the very first meeting of the group here in Victoria, and remained an active member, still attending the meeting in March, where he let us know that he was investigating possibilities of a liver transplant. Unfortunately, his liver cancer was inoperable. We will all remember his friendly smile, his bright eyes, his firm handshake, and his fighting spirit. The family is requesting that donations be made to HeCSC in his memory. Artur's well-attended funeral took place on May 22nd, at Our Lady of Fatima Church in Royal Oak.

NEWLY DIAGNOSED?

Those of us that have had Hep C for some time have to live with all that Hep C is. I get a number of calls each week from individuals who have just found out that they have Hep C and I can hear the anxiety, bewilderment and alarm in the question, "What does this mean to me?"

What is hepatitis C? Simply put, it is inflammation of the liver caused by the Hepatitis C Virus (HCV). Most of us know that the first part of our journey is to overcome the frustration and anger caused when we first learn we have the disease. We want to know, "Why is this happening to me?" "What does this mean to my life and the people around me on

a day to day basis?" "How do I live with and cope with HCV?"

To look for an answer to the question, "Why me?" is an exercise in futility. There is no answer, and the sooner we acknowledge that, the sooner we can begin to develop the coping skills that will help us deal with HCV and overcome some of the frustrations associated with the disease.

So, what does that mean for you? Well, for starters, you should educate yourself and learn all that you can about HCV. Make sure your doctor knows all he needs to know about the symptoms of HCV. Too often we get reports like, "My doctor is not helping me." Sometimes you have to help your doctor to help you. If you try that and you still have problems, you should get another doctor.

Stop drinking alcohol. It's a poison for your liver. Have a look at your diet and make sure it's healthy. Fatty foods are hard on your liver. Keep fit. That helps to support your immune system, the first line of defense against HCV.

On a day to day basis your life does not have to change. Pay attention to some of the things around you such as personal hygiene and NEVER share razors, toothbrushes, or nail clippers. This will minimize the risk of infecting others. Use bleach at full strength to clean and disinfect any blood spills. Remember, the virus is in your blood, so dispose of blood contaminated items safely out of the reach of others. If you are using needles, make sure you dispose of them in a proper sharps container that has a tamper-proof lid. Wear a Medic Alert bracelet. It will minimize the risk of spreading the infection if you are in an accident.

If you have one of those fatigue days where you can't get your head off the pillow, then go with what your body is telling you. Take the time out and only do what you must.

No, there is no cure -- at least not yet, but there are treatments like ribavirin and interferon which slow down the virus and minimize the damage to your liver. As research into drug treatment progresses, other drugs will become available and provide more effective treatment.

What is it like living with HepC? Well, it's manageable, after you get over the initial anger and frustration. Educate yourself and learn as much as you can. Get involved. Develop the right attitude and coping skills. The physical part of your illness is the part that can be managed. How you manage it is up to you. Be positive. A positive attitude towards your illness will improve the way you feel and boost your immune system. And remember-- you are not alone in this struggle.

Help is available to you if you ask for it.

*Herb Moeller
Chairperson of the Vancouver Chapter
Vice-chair of the National Board*

RE: HEPATITIS C

I am currently suffering from Hepatitis C. I contracted the disease after undergoing two surgeries requiring blood transfusions at Victoria General Hospital (1980, 1982) and one surgery at the Royal Jubilee Hospital (1985). I would like to know why there is no compensation for people who have contracted this disease.

In 1989, the federal government awarded HIV sufferers \$120,000 over four years. Four years later, all provinces except Nova Scotia offered \$30,000 a year for as long as the person lived. Nova Scotia offered even more. However, the health ministers slammed their doors and offered no compensation towards the victims of Hepatitis C. I feel that I am being discriminated against because Hepatitis C sufferers are in pain and there are people who are dying from this illness due to complications. We are supposed to be stress free in order to deal with a lowered immune system; however, due to lack of compensation, victims have more to deal with "alone" and with their own finances to pay for medications, vitamins, etc. These medications are extremely expensive. For example, Interferon injections cost me over \$1,000.00 -- I am alone and I must carry the burden myself to pay for this type of medication as well as other types. Hepatitis C is considered the worst public health disaster to strike Canada this century.

Having hepatitis C is not my fault. It was caused by not screening the tainted blood supply properly, therefore, I am a victim of carelessness of the Red Cross, just like HIV sufferers. I feel that members of the government and the Red Cross want to stop the inquiry into the tainted blood scandal in order to cover up this carelessness. Some people knew about the virus in the blood, but still allowed the public to be contaminated. The inquiry by Justice Horace Krever into the tainted blood scandal would produce evidence as to who is to blame, so they could resign. Victims should be compensated so that we can get on with our lives and deal with this illness without all this stress and secrecy. Whoever is

responsible for this mistake needs to pay so that this never happens again. What is the next disease going to be? The election is coming up, and all the parties should deal with this issue once and for all. I have a voting right to choose the party that is going to look after victims like myself. I encourage all Canadians to send letters and telegrams to the provincial health ministers across Canada as well as to David Dingwall, the federal health minister. You can find their addresses in the phone book or you may call me at 592-0252, and I will help you. With more voices united together, maybe someone will listen who can make a difference.

*Yours sincerely,
Judith Fry
Victoria, BC*

A PRISON STORY

I had a chat the other day with Mike G., a very articulate inmate at William Head Prison. He believes he contracted HCV through a blood transfusion at a BC hospital in 1988. Because of injuries at the time of his arrest in 1992, blood work was done, which included, unbeknownst to Mike, an HCV test. After years of not feeling "right", he asked for an HCV test in December of 1995, which came back positive.

He then applied, through "Freedom of Information", for his complete prison medical file. He was quite surprised and upset to read his blood work at the time of his arrest had come back positive for HCV. He has had severe symptoms of the disease, and has been unable to obtain treatment.

A bit upset about our talk, I called a nurse who works at one of the prisons. Speaking officially, she stated that some of the nurses attend our meetings so as to become more informed about the disease, and they share their newsletters with interested inmates.

Mike, admitting that the nurses do their best, estimates 30 to 60% or more of inmates, depending upon the prison, have used IV drugs, and statistics state that 70 to 90% of IV drug users have Hep C, so Mike and the nurses have good reason to be concerned. The nurse says many of the inmates with Hep C have questions about nutrition, and they have a nutritionist whom they may call for information. She believes that the inmates may receive medication, if desired, if they fulfill the criteria set by Ottawa for treatment.

Our chapter now has a couple of volunteers who are gathering information. If the inmates so request, those volunteers may possibly be allowed to visit and see how they can help.

Joan Diemecke

LIVER FIBROSIS PROGRESSION IN PATIENTS WITH HCV

Title: Natural history of liver fibrosis progression in patients with chronic hepatitis C. The OBSVIRC, METAVIR, CLINIVIR, and DOSVIRC groups

BACKGROUND: Our aim was to assess the natural history of liver fibrosis progression in hepatitis C and the factors associated with this progression.

METHODS: We recruited 2235 patients from the Observatoire de l'Hépatite C (OBSVIRC) population, the Cohorte Hépatite C Pitie-Salpetriere (DOSVIRC) population, and the original METAVIR population. All the patients had a biopsy sample compatible with chronic hepatitis C as assessed by the METAVIR scoring system (grades the stage of fibrosis on a five-point scale, F0 = no fibrosis, F4 = cirrhosis, and histological activity on a four-point scale, A0 = no activity, A3 = severe activity). No patient had received interferon treatment before the liver biopsy sample was obtained. We assessed the effect of nine factors on fibrosis progression: age at biopsy; estimated duration of infection; sex; age at infection; alcohol consumption; hepatitis C virus C (HCV) genotype; HCV viraemia; cause of infection; and histological activity grade. We defined fibrosis progression per year as the ratio between fibrosis stage in METAVIR units and the duration of infection (1 unit = one stage, 4 units = cirrhosis). **FINDINGS:** The median rate of fibrosis progression per year was 0.133 fibrosis unit (95% CI 0.125-0.143), which was similar to the estimates from previous studies (0.146 to 0.154). Three independent factors were associated with an increased rate of fibrosis progression: age at infection older than 40 years, daily alcohol consumption of 50 g or more, and male sex. There was no association between fibrosis progression and HCV genotype. The median estimated duration of infection for progression to cirrhosis was 30 years (28-32), ranging from 13 years in men infected after the age of 40 to 42 years in women who did not drink alcohol and were infected before the age of 40. Without treatment, 377 (33%) patients had an expected median time to cirrhosis of less than 20 years, and 356 (31%) will never progress to cirrhosis or will not progress for at least 50 years. **INTERPRETATION:** The host factors of ageing, alcohol consumption, and male sex have a stronger association with fibrosis progression than virological factors in HCV infection.

Author: Poynard T, Bedossa P, Opolon P, Service d'Hépatologie, URA CNRS 1484, Groupe Hospitalier Pitie Salpetriere, Paris, France.

GOOD NEWS!

Three of our members have had lab results indicating their virus is undetectable.

John Roper of Victoria had an experience similar to that of many: His family doctor sent him to a specialist who informed him that he shouldn't worry about the disease, that he wasn't sick enough yet for Interferon, and that he should just carry on with his life. As a result of contacting the support group, he got in touch with Dr. Anderson, as well as with Earl, the biochemist at Good Nature Market. Earl suggested he take alpha-lipoic acid. His enzymes, which were in the 350-range had dropped by the time he started IFN. He believes his successful response to IFN treatment may be due to the fact that his enzymes were lowered first by natural treatment, but knows he can't prove it. By getting enough exercise and sleep, he says, he was able to continue working.

Joan Diemecke, also of Victoria, has an almost identical story, except she didn't respond to the IFN alone. She probably contracted the disease 27 years ago. After 9 months of treatment as a non-responder, she entered the clinical trials combining IFN with Ribavirin being done at Dr. Anderson's office. Her enzymes were down to normal within 2 months, and her tests in February indicated the virus was undetectable. She plans to continue treatment until August. Joan was also able to continue working.

Jon, of Vancouver wrote: "Want to hear a similar story? I too just saw Natalie (at Dr. Anderson's office) and had my six month PCR, and it was also undetectable. I was really worried because I felt so bad from the Interferon that it was hard to tell if I was getting better or not. The whole road to recovery has been quite the experience. I was almost two years in getting a diagnosis and was tested for ulcers, gallstones, esophageal problems and one point my symptoms (pains in the side and shoulder) were suggested to be psychosomatic. Even though I am PCR undetectable, I should mention that I still get some Hep C symptoms such as pains in the abdomen and some arthritic like symptoms."

Is there anyone else who has tested "undetectable" or "negative"? Please let us know how you did it.

RIBAVIRIN TREATMENT ALONE OR IN COMBINATION WITH INTERFERON

This is a summary of a presentation by Olle Reichard, M.D., Ph.D., and Ola Weiland, M.D., Ph.D. to the NIH Consensus Development Conference on Management of Hepatitis.

Few chronic hepatitis C patients will achieve long-term benefit including viral eradication from standard interferon (IFN) treatment. Patients with autoimmune disorders, thyroid problems, cirrhosis, thrombocytopenia, and posttransplant patients, usually are not given IFN therapy due to the risk of serious reactions, so the need for other treatments for HCV infection is obvious. Ribavirin is the most extensively evaluated and promising alternative at this time. Usually well tolerated, Ribavirin has the advantage of being taken orally. How it works is poorly understood, and it is not possible to test drugs including ribavirin for antiviral effect against HCV in test tubes, since no tissue culture system is easily available for HCV replication.

Studies on ribavirin alone: Ribavirin therapy for chronic hepatitis C was first suggested in 1991, in a pilot study from Sweden. Ten HCV patients were treated, but relapsed when treatment was withdrawn. The effect on HCV replication in the blood, as measured by polymerase chain reaction (PCR), was disappointing. No patient cleared the virus during treatment even though their enzyme levels normalized. Later, several uncontrolled studies confirmed these initial results. Recently, two controlled ribavirin trials were reported, the results being consistent with previous uncontrolled studies: reduction of enzyme levels during treatment was seen in ribavirin treated patients, but the virus was not eradicated, however, a slight but significant decline of HCV virus in the blood was seen in the ribavirin group. After treatment, rebound to pretreatment levels was seen. The damage shown in the liver was significantly reduced for patients treated with ribavirin when comparing liver biopsies from before and at the end of treatment. The main adverse events noted were hemolysis (requiring a dose reduction in 13 percent of patients), fatigue, depression, insomnia, and vertigo, appetite loss and nausea, and skin problems like itching, rash, and eczema.

IFN/Ribavirin Combination Studies: Combination therapy often improves response rates and minimizes drug resistance in many infectious diseases, so the combination of IFN and ribavirin to combat chronic HCV infection seemed reasonable. Initial studies have shown that around 80 percent of relapsers and 10-25 percent of nonresponders to previous IFN therapy will have a sustained virological and biochemical response when ribavirin is combined with IFN during 24-weeks. In an Italian study, 45 chronic HCV patients who never took IFN were randomized in three groups to receive either IFN alone, ribavirin alone, or IFN combined with ribavirin, where standard doses of IFN and ribavirin were used. The sustained virological response rate was 0 percent in the ribavirin group, 13 percent in the IFN group, and 47

percent in the combination group. In an open study from Sweden, similar results were seen, where 50 percent of IFN-naive patients had a sustained response to combination treatment. Furthermore, a recent long-term followup study from Taiwan reported sustained virological response 2 years after stopping treatment in 43 percent of patients treated with IFN/ribavirin vs. only 6 percent of patients treated with IFN alone.

A randomized double-blind placebo-controlled study comprising 100 IFN-naive chronic HCV patients was performed by Dr. Reichard and Dr. Weiland in Sweden where the patients were treated with IFN alfa-2b 3 MU three times a week, combined with either ribavirin 1,000-2,000 mg/day or placebo for 24 weeks. The patients were followed for 24 weeks after treatment. With regard to age, gender, mode of transmission, liver damage, pretreatment ALT level, pretreatment HCV RNA level, and genotype, the groups were comparable. Initial results confirmed those of earlier pilot studies. The sustained virological response rate was 45 percent in the combination group vs. 23 percent in the IFN group. In the combination group, more patients either required dose reductions or withdrew from treatment due to events such as anemia, fatigue, and depression. Moreover, in order to prevent recurrent HCV in the posttransplant setting, ribavirin alone or in combination with IFN seems to offer promising results.

Ribavirin alone does not eradicate the virus, however ALT levels frequently normalize, and liver biopsy results improve during therapy. Ribavirin is generally well tolerated, with a mild, dose-dependent, and reversible hemolysis being the main bad reaction. For nonresponders to IFN therapy, and for patients where IFN cannot be used, maintenance therapy with ribavirin may be an option, but the long-term consequences of continuous hemolysis are not known. Hemolyzed red blood cells release iron, and significantly increased iron stores in the liver have been noted after prolonged ribavirin therapy.

Combination treatment with IFN and ribavirin for 24 weeks is clearly associated with higher sustained response rates than IFN alone, but many questions remain to be solved. Should all HCV patients receive combination treatment as a first choice, regardless of genotype, pretreatment viral load, liver histology, or other factors shown to predict sustained response to IFN alone? What are the best dose and duration of combination therapy? Should relapsers of 24 weeks of combination therapy receive longer combination treatment courses? Do patients tolerate prolonged combination therapy? What is the best treatment for nonresponders to combination therapy? Should patients with unfavorable prognostic pretreatment factors like cirrhosis, genotype 1b, and/or high pretreatment viral loads receive more aggressive and prolonged combination treatment courses? Is the risk for drug resistance diminished by combination treatment?

Ongoing studies comparing 24- and 48 week treatment with interferon alone vs. combination treatment, in naive, chronic HCV patients, will answer some of these questions in the forthcoming years. Controlled combination studies in relapsers after prior IFN treatment, and ribavirin dose-finding studies, are also in progress.

RIBAVIRIN INFO

Ribavirin, one of the first antiviral drugs discovered, is approved in the United States in an aerosol form for the treatment of a severe lung infection in infants. It is being studied in combination with ddI as an anti-HIV treatment. It has shown activity against hepatitis A and C. Ribavirin is available in many Third World countries in an oral, tablet form.

A few small, uncontrolled studies suggested that ribavirin might have activity against hepatitis C. At a conference on liver diseases last year, data was released from an NIH run study in 32 patients with hepatitis C treated with either ribavirin or placebo. The results were that patients on ribavirin had improvement in liver enzymes that show disease activity and on-going liver damage. Out of sixteen patients on drug, liver enzymes normalized in four patients and decreased by at least 50% in seven patients. The average enzyme decrease for patients on drug was 47%.

Two other phase III studies of ribavirin for hepatitis C recently ended and data should be released soon. A request has been filed for approval of Ribavirin as a treatment for hepatitis C.

There is no clear information about which dose is most appropriate. Doses of 1200-1600 MG per day appear to be toxic. The hepatitis studies used 200 mg four times a day.

Ribavirin can cause anemia and drops in T cells when given at doses of 1200-1600 mg per day. At the lower dose of 800 mg per day, ribavirin does not seem to cause anemia and appears to be well-tolerated.

Virazole, is manufactured by ICN pharmaceuticals in the Netherlands. It comes in bottles of 20 tablets containing 200 mg each. Vilona is manufactured by ICN pharmaceuticals from Mexico. It comes in boxes of 12 tablets with 200 mg each.

"Compassionate use" is a term used for a type of clinical research trial often conducted by a physician in private practice apart from licensing trials. The physician has to have an IND (individual new drug number) which has to be acquired from the FDA. There are no placebos. The person to whom the drug is given often doesn't meet the inclusion/exclusion criteria

for a phase 3 licensing trial and will have no other therapeutic alternatives. Informed consent is still given and the compassionate use has to go through an institutional review board.

ICN now has a limited compassionate use program that provides ribavirin for free to people with proof of chronic hepatitis C who can't take interferon, or who have cases that don't respond to interferon. Proof may require a liver biopsy or PCR test in people with low antibody titres. For more information your doctor should call Dr. John Gate at ICN: (714) 545-0100.

**Source: PWA Health Group 150 West 26th Street, Suite 201 New York City, NY 10001
(212) 255-0520 Fax: (212) 255-2080**

RIBAVIRIN SOURCES

Ribavirin can be obtained in other countries, often by mail. For more information, please contact your local support group. This is not intended to be legal advice or an invitation to an unlawful act. Obtain legal advice from an attorney.

Latest reports of pricing:

Mexico: Ribavirin 96 capsules (400 mg) \$300 - \$350 US. Amantadine 100 tablets (100 mg) \$30 - \$50 US
UK: Ribavirin 100 capsules (100 mg) \$68 US 400 capsules (100 mg) \$250 US
Hong Kong: 100 capsules (400 mg) \$360 US.

RIBAVIRIN [Internet] <http://www.aidsnyc.org/pwahg/info/riba.html>

Editor's note: Clinical trials patients are being randomly assigned to either a Amantadine and Interferon trial or a Ribavirin and Interferon trial. For more information, you should contact Natalie at Dr. Anderson's office at 876-5122.

MEDICAL CONFERENCES IN GASTROENTEROLOGY & HEPATITIS C

Sept. 20-22, 1997, La Sapiniere, Val David, Quebec, International Symposium on "Hepatocerebral Disorders: Pathophysiology of Brain Dysfunction and New Approaches to Diagnosis and Therapy" For further information Dr. Roger F. Butterworth, Neuroscience Research Unit, Hopital Saint-Luc, 1058 St-Denis St., Montreal, Quebec H2X 3J4 Canada. Telephone: (514) 281-2444 ext. 4759; Fax: (514) 281-2492; email: butterwr@ere.UMontreal.ca

March 1998, Banff, Alberta, The 3rd Canadian Digestive Disease Week 1998. There will be a symposium on liver transplantation and a lecture on the inborn errors of bile acid metabolism

July 12-17, 1998, Montreal, Canada, XVII World Congress of the Transplantation Society. Abstract Deadline: January 19, 1998. For further information: Lucy Felicissimo & Associates, Inc., 12,449 rue Cousineau, Montreal, Quebec, Canada H4K 1P9; Fax: (514) 334-5200.

[VICTORIA CHAPTER UPDATE]

On Friday, May 3rd, the Victoria Chapter of HeCSC realized a 10 month long dream of opening an office.

Our collective work load was becoming onerous, to say the least, and in view of the Health Ministry's Recipient Notification Program (RNP) we expected that this condition would only increase.

To give you an idea of how far we've come in the last 2 1/2 years, let me take you back to my first meeting. Back then, our meetings were held wherever we could find space, and only occasionally were they held in St. John's Church lounge. The date was Jan. 18, 1995, and Dr. Allison Bell, head of epidemiology in Vancouver, was the guest speaker, and almost 60 people were in attendance. Prior to this event, there had only been 3 meetings with just a handful of people. June Shane was the acting chairperson. It's hard to imagine now the brick wall we felt we were up against in our fight for support and recognition.

Now, looking back on 23, soon to be 24, meetings, it is much easier to see that a small but significant portion of that brick wall has come down. We are chipping away, brick by brick, and now we are beginning to see just what lies on the other side.

The general public is becoming more aware of the scope of the effects of Hep C, prompting many people to get tested. This is due, in large part, to the Ministry's RNP, but, I think, above and beyond that, it is a general accumulation of the facts and figures surrounding the whole Hep C issue. The Hepatitis C Society of Canada across the country has

worked very hard to bring public awareness to the fore.

As with the AIDS issue, when public knowledge and education reach critical mass, things start getting done.

The Health Ministry's recognition of the problem is the first major step beyond the behind-the-scenes work that our group has been trying to do. The Hep C Working Group was a precursor to the RNP, and there have been other committees and working groups involved in education, as well.

Getting back to the brick wall idea, though, what I see happening now are four things:

- A Hep C conference (doctors, government, and patients?)
- A clinic, with counselors and doctors who can deal specifically and knowledgeably with Hep C patients.
- A high school education program; continuing post-secondary education.
- A prison education and awareness program along the same lines as the high school education program.

There has been some talk of all of these things, but as with most mega-problems, they take time to sort themselves out.

We have come a long way in 3 years. The bricks are falling and we can see the other side. The momentum we have all created is accelerating exponentially.

If there's one thing I've come to realize since I've had my transplant, it's that all things are possible. If you work at something long enough, it will come to fruition.

In closing, I would like to wish everyone a happy and safe summer. Hep C does not take a holiday, and neither will we.

VICTORIA MEMBERSHIP DESK

As there is no issue of the newsletter in July, it is timely for me to just say thank you to all the volunteers who have helped get so many events up and running. We have made a start, but in hindsight, if we intend to better our efforts, we need many more volunteers. The Ribbon Day, for example, was a success in many ways, but next time, we have to apply for spots in higher traffic areas at more locations, needing more people.

The office is up and running, but again needs a few more hands for it to be most effective in the community. The tel. number is 388-4311. The great raffle is launched, tickets are ready for sale and Judith at 592-0251 can supply you with books of tickets priced so everyone can afford them!

Reminder:- Any change of address, phone number, postal code or if you no longer wish to receive the Newsletter, please let me, or your phone contact, know at your earliest. It saves our meagre funds. Thanks.

386-8227

Jim Lodge

e-mail:- ut301@freenet.victoria.bc.ca

Vice-chairperson & Membership

Victoria Chapter HeCSC acknowledges the personal donations, donations in kind and memorial donations received to date and the following for discounts and donations of services: Monk Office Supply. CFX 1070 Radio.

THE HEPATITIS C SOCIETY, VANCOUVER CHAPTER, UPDATES

Column by Darlene Morrow. For info and contributions- fax: 604-987-7396,

email: darmorr@uniserve.com, snail mail: 1203 Plateau Drive, North Vancouver, BC, V7P 2J3

Hi Everyone,

I'd like to start off with thanking Laura for her wonderful cookies at the last meeting. They were delicious! Also thanks to the phone committee for phoning everyone on the list to make sure they knew about the guest speaker and the correct day of the meeting. It's really nice to see everyone getting involved.

Herb's had a busy month, as usual. He has appeared on TV and radio 3 times in the past month promoting awareness of Hepatitis C and the Society. He also continues to travel back and forth to Ottawa in his work with the formation of the New Blood Agency. Herb is also busy trying to organize some fundraisers for the HeCSC and we'll keep you posted. Anyone with experience in fundraising out there??? We could use some help.

Kenn Quayle just got back from his trip to Australia and Paris where he attended HCV conferences. Congratulations are in order for Kenn- he's been offered a job funded by the New South Wales government with the New South Wales Users and Aids Association or NUAA. He'll be working with the Injecting Drug Users community to promote education about HCV and provide support. He's leaving in August so make sure you congratulate him and wish him well.

Subscriptions are still coming in and I'd like to thank everyone who filled one out. We've just tried to cover the cost of stamps and material (\$10), so if you haven't filled out your subscription, please do so. This is an organization run entirely by volunteers and we need your contributions to continue the newsletter.

Dr. Ehmann's discussion about depression was very interesting. I'll cover the highlights for those of you who were unable to attend.

Dr. Ehmann's special area of interest is in coping strategies associated with chronic illness. Dr. Ehmann uses cognitive theory based therapy which works to re-program the individual's thinking in an effort to improve their coping strategies.

Contrary to popular misconception Dr. Ehmann stated that there are no scientific studies supporting the belief that interferon causes depression and that interferon *probably* does not cause depression.. Rather, the depression is associated with the chronic illness. In fact, it is not necessary for an individual to be excluded from interferon therapy because of an existing problem with depression. Furthermore, Dr. Ehmann cited that there are studies that show that counseling can have the same effect as drug therapy for depression. Now that's good news for HCV sufferers who don't want to burden the liver with detoxifying drugs.

Dr. Ehmann works with Dr. Anderson, who will set up an appointment for you. He works 1 1/2 days per week seeing referred outpatients at VGH.

RIBBONS: Ribbons (red and yellow) are available at the meetings by donation. Spread the word. Kenn said that they are using a purple ribbon for HCV IVDU in Australia.

INFO DAY: June 16 Kenn will be in the downtown area promoting HCV education with respect to IVDU. If you'd like to help, you may call him at tel. (604) 215-0351 or email Kenn at brian_mackenzie@mindlink.bc.ca

SUMMER BBQ: We're putting together a list for people that are interested in attending a BBQ social this summer. If you're interested please call Audrey at 940-8148 or email me. This is a great opportunity to get to know each other better, so I hope to see lots of names on that list. Other chapters' members are most welcome!

REFRESHMENT COMMITTEE:

Special thanks to Audrey for all her support in this area. She'd like a little break so if you're interested in helping out please give her a call (940-8148) or sign the sheet at the meeting. We just need cookies or squares to munch on while we enjoy our tea and chat. We also appreciate your help in cleaning up after the meetings.

INTERNET: I've been working hard expanding my website and you should stop in for a browse. The newsletter is available in full form, and meeting times and guest speakers are also posted. **The address for HepC BC is <http://www.geocities.com/HotSprings/5670>**

In addition you'll find lots of HCV info, and BC specific sites. I've also joined the HepWeb webmasters, an international group dedicated to keeping HCV info up to date, the MedWeb webmasters, a group of medical webmasters for keeping medical standards on the internet and am current administrator for the activist group called Hep-C Alert! If you'd like any info on this please let me know at darmorr@uniserve.com I hope everyone enjoys the sunshine and we'll see you next month.

FROM THE OKANAGAN

Dear Members,

LOGO CONTEST: Please join us in a "create a logo" contest. We are inviting all of our talented (and not so talented) members to help us design a distinct recognition symbol. Something as familiar as the "AIDS red ribbon"??

Do we want a ribbon? Do we want a fresh start? This symbol will be incorporated into our letterhead, and will be found on any printed matter relating to hepatitis C. Help us on the road to distinct identity. The contest prize is to be named at a later date. A dragon has been one suggestion.

RIBBON CAMPAIGN: Chapter fundraiser - sell awareness ribbons!! These have proven very profitable... but it does require organization and a certain amount of effort. Bolts (can make about 200 ribbons each) can be ordered through our

Toronto head office or can be requested directly from Leslie Gibbenhuck, P.O. Box 21058, Penticton, BC V2A 8K8 Tel. (250) 490-9054. \$40.00 covers package cost (one bolt) and shipping

HEPATITIS C AWARENESS MONTH: The month of May has already been designated hepatitis awareness month in the United States. We attempted to get the same designation here, but did not receive David Dingwall's blessing. He told us to try to align ourselves with the Canadian Liver Foundation or the Red Cross. I will leave my comment out of it!

LOOKBACK/TRACEBACK: The last week of April saw British Columbians receiving notices of blood transfusions. They cover the period January 1985 to June 1990. It was reported 52,000 notices were sent out by registered mail, at a cost to taxpayers of \$5,000,000.00

Our postal unit, which covers one of the smallest sections of Penticton, received 94 notices for transfused adults and one transfused child notice. Yes, despite all of our publicity, Jarad got one, but his was totally different. Not only was his in a thicker, hand written envelope, the contents were very different too. The child's study requests all family members to be tested as well as the transfused child.

We noticed there was no place on the form to mark if you knew prior to the lookback/traceback study. Our advice ... get retested and have your results counted as part of the study.

I was sent the Information package our doctors received from provincial government. It is 4 pages of inaccurate facts, that raise more concerns about why our doctors do not treat this disease seriously. One statement says it takes 10 years for symptoms, 20 for cirrhosis and 30 for cancer. I personally know of more than one person who had accomplished all those steps, and even death from liver failure, in less than 8 years!

PCR UNDETECTABLE: For some the news is received with welcome arms, for others it is met with some skepticism. There has been some discussion about the temperamental tests, and many feel they are far from accurate. I feel we all ride a roller coaster with this disease, and would like to avoid as many hills and valleys as we can. We must demand ACCURATE screening for PCR's.

B.C. children are being denied access to PCR testing and liver biopsies because there is "no treatment available for children". The B.C. government is careful to explain that because there is no treatment, and you would not really learn much, why should taxpayers pay for the testing? Also, if there is no treatment, why would you want to know what is happening, or how bad it could be???

HEPATITIS C QUILT: Help us make our quilt complete. Send your 12 x 12 square, complete with your hand print, name, message, etc. If your group would like some squares, or require more information, please contact Leslie (250) 490-9054

A SINCERE WELCOME: To all newly diagnosed Hep C'ers, a very heartfelt welcome to our family. I am so glad that you found us so soon.

Talk to you next month, have a great one!
Love, Leslie

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!

SUBSCRIPTION FORM

Please fill out include a check made out to **HeCSC - Victoria Chapter**,

Send to:

Jim Lodge

410-831 Dunsmuir Rd.

Victoria, BC V9A 5B9

or FAX to: 479-5290

Name: _____

Address: _____

City: _____ Prov. _____ PC _____

Home(____) _____ Work(____) _____

One Year Subscription **\$10.00**

Member of:

Victoria Chapter..... o

Vancouver Chapter..... o

Okanagan Chapters..... o

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

I am applying for a grant."o

"I would like to make a donation so that others may receive the newsletter without charge".....o

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

Victoria Chapter HeCSC

1611 Quadra St.

Victoria, BC V8W 2L5

IN OUR AUGUST ISSUE: ALTERNATIVE TREATMENTS

? HEPATITIS C SOCIETY - U ASK

by Natalie Rock, BScN

Natalie is vacationing in eastern Canada and will be unavailable for questions this month. Have a great time, Natalie, and we look forward to your contributions next month.

DISCLAIMER

HeCSS cannot endorse any physician, product or treatment. The 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.

[DEADLINE]

The deadline for any contributions to the next issue of hepc.bull is July 22nd. Please contact Joan Diemecke at Tel. (250) 479-5290.

email: pdiemecke@compuserve.com

HEPATITIS C HANDBOOK

Herb will be going to England the week of June 9th. He's going to pick up the *Hepatitis C Handbook* by Matthew Dolan. If you wish to order a copy, email Herb: HMoeller@compuserve.com or phone at (604) 271-7766. We're not sure of the cost at this time, but it will be approximately \$22 US.

The Hepatitis C Handbook by Matthew Dolan: The book contains research into all aspects of this medical condition, and focuses on the experiences of patients, particularly with a view to the issues of alcohol and drug dependency.

INTERNATIONAL AVAILABILITY: To secure a copy please call Quantum Media Group at (802) 655-3415 daily, 12:00 noon to 10 PM EST, or call (212) 714-6076 24 hours a day, 7 days a week. Major credit cards accepted. They need your name, mailing address, card type and number, expiry date, and quantity requested. You may order by mail: Handbook, PJ Communications DBA/MBE, 511 Ave. of the Americas, New York, NY 10011, USA..Total Cost- 1 book shipped to Canada: \$26.94