



April, 1997

BRIAN BIRKS

Brian Birks, a regular attendee at our support group meetings, passed away on February 27th, at the age of 37. He had contracted Hepatitis C through a blood transfusion, and was involved with the class action suit. He was a member of our advocacy committee, and had just finished a 5 year course as a civil engineer/technologist.

He is survived by his son Lochlan, his parents Merle and Gilbert Birks, and his soul-mate, Norma Bryant -- also a member of our group.

He will be sorely missed.

DEATH IS NOTHING AT ALL

*Death is nothing at all.
It does not count.
I have only slipped away into the next room.
Nothing has happened.
Everything remains exactly as it was.
I am I, and you are you
And the old life that we lived so fondly together
Is untouched, unchanged.
Whatever we were to each other,
That we are still.
Call me by the old familiar name.
Speak of me in the easy way
Which you always used.
Put no difference into your tone.
Wear no forced air of solemnity or sorrow.
Laugh, as we always laughed, at the little jokes that we enjoyed together.
Play, smile, think of me, pray for me.
Let my name be ever
The household word that it always was.
Let it be spoken without an effort,
Without the ghost of a shadow upon it.
Life means all that it ever meant.
It is the same as it ever was.*

*There is an absolute unbroken continuity.
What is this death but a negligible incident?
Why should I be out of mind because I am out of sight?
I am but waiting for you,
For an interval,
Somewhere very near,
Just around the corner.
All is well.*

From a novel by Rosamond Pilcher

PATIENT ANGRY THERE ARE NO SUPPORT SERVICES FOR HEPATITIS SUFFERERS

Chris Roe, a member of our Victoria Chapter, is trying to figure out why the support services available in Nanaimo seem weaker than he is.

Diagnosed eight months ago, Roe has been trying to deal with his condition, but found community and agency support is very limited, especially from the Canadian Liver Foundation.

"They're raising money in Nanaimo but there's no services or help available here," says Roe. "I asked to have a notice put up at a doctor's office and they refused. I contacted every pharmacy in the city without any success. Only the Beaufort Centre Pharmasave has agreed to contact others using interferon, like I am."

Support groups and services are available in larger centres, like Vancouver and Victoria, and even Courtenay. But Roe prefers living in Nanaimo and can't afford to move. Since his diagnosis, Roe has received a disability pension of \$771 a month, up from the \$595 he was receiving from social assistance, and receives another \$100 a month for helping out at the Salvation Army.

"The cheaper rent here in Nanaimo is very important. And switching doctors -- it's just not feasible."

Roe says he'd like to get some training so as to provide his community with information and those with the disease an opportunity to work together. But he says the training he needs through the Liver Foundation is in Vancouver and he can't afford to attend.

"And the foundation says they don't provide expenses for people to take their training."

Roe would like to see the Canadian Liver Foundation do more than just fund research.

"Why don't they provide some services for individuals? A bus ticket to attend meetings in Victoria or Courtenay would help a lot. Maybe they could help people with the expense of the bottled water they need."

Michelle Scarborough, the regional manager for the Canadian Liver Foundation's Vancouver chapter, says CLF helps individuals by providing educational materials and directing people to self-help groups, but nothing more.

She says CLF collected \$9658 in the Nanaimo area for the first eight months of 1996. In the first nine months the organization collected \$176,164 in B.C., and that the money collected in the Nanaimo area has gone directly to medical research as chosen from grant applications selected by a CLF medical advisory committee.

Funds collected in B.C are returned to the province for regional program development, she says.

"We offer, in Vancouver, 'Living with Liver Disease,' a nine-week program designed to educate those with the disease, their families and others on how to deal with hepatitis. Doctors, nutritionists and psychologists provide the information." If you are interested in establishing a support-group in Nanaimo, call Roe at 754-3971.

BOOK REVIEW by J.P.

"The Hepatitis C Handbook" Author: *Matthew Dolan*. Publisher: *Catalyst Press, London, UK*

A portion of any profits from this book will be dedicated to Hepatitis C research

Over 200 pages of in depth and authoritative information about hepatitis C, this book is a comprehensive source of accurate information about this prevalent and serious illness. It explains clearly what hepatitis C actually is, the course of disease, associated symptoms, how it is transmitted, the process of response to a diagnosis, related issues such as 'change', what treatments are available, what they have to offer, and which lifestyle changes may help and why.

Written by Matthew Dolan, a professional systems analyst and the co-founder of the first hepatitis C support group

in the U. K., the text has been exhaustively and methodically researched. Edited for medical accuracy, it is fully up to date and includes contributions from internationally renowned specialists in the field and the experiences of patients themselves. This book will enable both patients and health professionals to address hepatitis C from an informed perspective.

Pricing and Ordering Information:
(Shipping materials will be marked "Confidential")

Cost:
1 Book to Canada -- Total Cost \$28.76 (\$21.99 per Book plus \$1.82 Tax and \$4.95 Shipping and Handling)
Allow two to four weeks for delivery, but most customers should receive their orders within 10 to 14 days.
To order by credit card, call Quantum Media and PJ Communications at (212) 714-6076. Credit card orders are accepted 24 hours a day 7 days a week. To order by credit card via email, send the following information:
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Be sure to include your Name/Organization Name, Address, Telephone Number and Quantity requested with your order.

For more information be sure to visit the Focus On Hepatitis C
International Website at : <http://pages.prodigy.com>



MEMBERSHIP DESK

Jim Lodge

Right off the bat, let me say thank you to the persons responding to our appeal for funds in our last newsletter. The cash donations, and donations in kind, received to date will assure the mailing of another newsletter. Excellent.

A suggestion has surfaced, in the form of a subscription being levied of, say, \$10.00 per year. Allied with this, another concern has been raised in that many look forward to the newsletter each month and cannot afford such a subscription. If that be the case, all one has to do is let me know and we'll keep sending it, funded from future sources we're looking at. When we appeal for funds, we are competing against professionals who are engaged to go after the charitable dollar. (I'm sure you have been approached in this way by phone or letter) Rest assured, we're learning fast, and together with the help of a few volunteers in this endeavour, we'll keep plugging away.

(Editor's note: Please fill out the subscription form on page 4 of this edition.)

We still need you to consider becoming members of the Society, as this gives us much more clout. Complete the Application Form today (if you have mislaid it, phone for one) and mail it off to the Toronto Address, and please don't forget to renew your membership when due. (A portion of your dues are returned to the Chapter). The expiry date is on the mailing label of the Newsletter. If it's blank, it simply means you have not made application yet for membership. If it's highlighted with an orange mark, it's a reminder it is or is about to expire.

Our Advocacy committee is getting things underway, and you will be hearing much more from them in the near future. If you are an ardent letter writer, we're looking to you to help this committee to effect an organised campaign. Come jump on the wagon. The ride could be fun, too.

David and I attended the CFA 1070 Community Awards ceremony at the Empress on March 21st/97 and received a Public Service Award of \$5000.00 worth of radio advertising and air time for HeCSC. This really makes one feel that our efforts are being noticed and appreciated, and the grant will further our cause of raising awareness of Hep. C in the community. Thank you, CFA 1070.

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
Co-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. CFAV 1070 Radio. Thank You.

The deadline for any contributions to next issue of hepc.bull is April 23rd. Please contact Joan Diemecke at Tel. 479-5290.

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.

VICTORIA CHAPTER STEERING COMMITTEE

CHAIRPERSON:	DAVID SMITH	TEL: 658-4991
VICE CHAIR:	JIM LODGE	TEL: 386-8227
SECRETARY	PRISCILLA ECKMAN	TEL: 652-6499
TREASURER & BULLETIN	JOAN DIEMECKE	TEL: 479-5290 (TEL. & FAX)
MEMBERSHIP	JIM LODGE	TEL: 386-8227
LIBRARY	JOANNE BALCHIN	TEL: 478-2356

NEXT MEETING: Wednesday APRIL 30, 1997 1 - 3 PM, and again at 7-9 PM
St. John the Divine Church Lounge
1611 Quadra St. (Entrance through the rear, marked Annex)

[MESSAGE FROM CHAIR]

This year has been shaping up to be a busy one. Our campaign to create more public awareness is starting to produce results.

Since the "Conference", formerly known as the AGM (or "TCFKATAGM" for short) in November, the steering committee, in concert with the National Board, has endeavoured to bring into the public realm a higher level of awareness of the realities of Hepatitis C. We want to make hepatitis C a household word. With your help, we can do this. Hepatitis C is not going to go away, and, in fact, it is going to get worse before it gets better. There is a perception that little is being done to educate, not only those of us who live with Hep C, but the general public, as well. Try to dispel this myth by getting more involved, talking about it, and sharing as much information as we can. Through education, we hope to dispel some of the common myths and stereotypes that surround our illness. Is there any truth to this perception? Probably so, but there is more being done than we realize, and that's where we come in, as a nationally based support group.

Locally, here's what we've done so far this year: 4 newspaper articles; discussion on Cable 11 with Dr. Erb; awareness campaigns at the University of Victoria; vigil at the Parliament Buildings.

The newspaper articles were in *The Martlett*, which is the UVIC newspaper; the *Nexus*, which is the Camosun College newspaper; *Monday Magazine*, which has a circulation big enough to reach every household in Victoria; and at this time, *The Saanich News* is doing a feature article on the Hep C issue, and this has a circulation of 38,000 households.

The Nexus and *The Martlett* were both geared to inform students of the dangers of Hep C transmission, and were

quite informative, albeit short.

Monday Magazine was a disappointment, though, as it did not have any information on our support group, or where and when it meets -- a learning experience!

The Saanich News article should be out by the time you read this, and promises to be much more informative than the *Monday* article.

Our efforts to reach the post-secondary students does not end here, though. On the 25th and 27th of March, Jim and I will be at the student union building at UVIC, handing out pamphlets and answering questions. In the second week of April, we will be doing the same at Camosun, hopefully at both campuses. This will cover the post-secondary students to a significant extent for this year. We'll go back perhaps in the Fall. Hopefully we will do a high school campaign, too. Incidentally, we will be doing radio spots at both UVIC and Camosun, as well. All ten newspaper articles are available through our library.

Dr. Siegfried Erb, liver transplant medical director at Vancouver General, was our special guest on a Shaw Cable 11 program on the 19th. He talked about the 5 main reasons why Hep C is such an important disease to raise awareness of and educate about. (To be included in next month's *hepc.bull*) He even praised our efforts. I asked him if the word "epidemic" was a word we could use in describing the present Hep C condition. "Yes," was his answer. He is definitely "on our side". This will be aired first week in April.

Last, but not least, we have the Vigil on Wed. the 26th - the same day as the meeting. It will have happened by the time you read this, and I can't say enough about the importance of this event. We are not only paying our respects to those who have died (4 locally in the last year) but we are also raising the profile of the Hepatitis C Society of Canada, Victoria Chapter, in our community. A great deal of work has gone into all these projects. It requires a lot of leg work and creative thinking to bring projects such as these to fruition with dignity and respect for those we are attempting to educate. My thanks to all of you who are going the extra mile, and you know who you are.

In closing, I would like to add that the Hepatitis C Society, Victoria Chapter, was the recipient of a \$5000.00 PSA grant for air time from CFX 1070, and Jim Lodge and myself humbly accepted this award at the CFX Community Service Awards on the 21st at the Empress Crystal Ballroom. We look forward to working with CFX to create more awareness in the future. See ya next month.

Dave Smith

DETECTION AND SIGNIFICANCE OF HCV RNA IN SALIVA, SEMINAL FLUID AND VAGINAL DISCHARGE IN PATIENTS WITH HEPATITIS C

J Tongji Med Univ

Author: Tang Z; Yang D; Hao L; Tang Z; Huang Y; Wang S;

Date of Pub: 1996 Issue: 1 Volume: 16 Pagation: 11-3, 24

Abstract: To investigate the transmission of HCV infection through family contact, we detected HCV RNA in body fluids (saliva, seminal and vaginal discharge) of 16 serum HCV RNA positive patients (including 7 men and 9 women) and in sera of their family members. The positive rates of HCV RNA in the body fluids were 31.25% (5/16) in saliva, 57.14% (4/7) in seminal fluid and 22.22% (2/9) in vaginal discharge, respectively. Among the family members in our series, all were negative for both anti-HCV and HCV RNA, despite two spouses positive for HCV RNA. This result strongly suggested the potential possibility of the transmission of HCV infection through the family contact.

Abstract By: Author

Address: *Abteilung fur klinische Immunologie.*

Transliterated/Vernacular Title: *Nachweis und Bedeutung von HCV RNA im Speichel, Sperma und Vaginalsekret von Patienten mit Hepatitis C.*

RECIPE CORNER

Milk Thistle Oatmeal Cookies

This is the original BACafe Milk Thistle Oatmeal, famous the world over, first sent to fellow heppers around the globe from the Alaska B. A. Cafe in the summer of 1995.

Ingredients:

1 cup soft butter (not melted)
1/2 tsp. Baking Soda
Sea Salt (to taste)
1 cup flour
2 Dark brown sugar
3-4 cups old fashioned oats
2 tbs. Vanilla Extract.
Water (about 1/3 cup)
1 tsp. Milk Thistle Extract

Putting it all together:

Pre-heat oven to 325

In a large mixing bowl combine butter, sugar, vanilla, milk thistle, and water. Hand 'till creamy. Lumps are a sign of creativity. Add flour and baking powder and salt. Sift if you must.

Stir smooth, add water as necessary.

Stir in the oatmeal. Then bake 'em on a cookie sheet for about 10 minutes or till they are done.

Better round up some cold milk!

Minutes of past meetings are available through the Lending Library. Contact Joanne Balchin at **478-2356**

INTERNET ADDRESSES

HEPCan: A small, informal mailing list for Canadian residents with Hepatitis c.

Contact: Joan Diemecke at pdiemecke@compuserve.com

HeCSC: HeCSS@idirect.com

HEPV-L List: An international support group with over 1000 members. Contact: Peppermint Patti at clotho@alaska.net

HCV-Activist List: Over 200 members. Contact Terry Bass at HCVACT@AOL.COM

SUBSCRIPTION / MEMBERSHIP FORM, VICTORIA HeCSC CHAPTER

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

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