

# PBC Connections

A Canadian PBC Society Newsletter

FALL 2008

## **NEW!** Regional Group in Manitoba

Welcome to our Regional Coordinator from Winnipeg, Carol Seburn.

Carol is looking forward to hearing from PBC patients, their families or friends from Manitoba, her contact information is:

Phone: 204-254-5226

Society email: [Manitoba@pbc-society](mailto:Manitoba@pbc-society)

## **NEW!** Clinical Trials in PBC

Centers across Canada are recruiting to a study for UDCA non-responders (blood tests not normalized after therapy).

This study is called:

"Study of INT 747 in combination with URSO in patients with PBC"

Further information about the study design is on line at:

<http://clinicaltrials.gov/ct2/show/NCT00550862?term=INT+747+and+PBC&rank=1>

Catalina Coltescu at Toronto Western Hospital would be happy to provide further information, if you are interested: 416-603-5832.

## **NEW!** Canadian PBC Society Address

On October 10th 2008 we moved, if you were overlooked and failed to receive our change of address notice see below.

### **Canadian PBC Society**

4936 Yonge Street. Suite 221. Toronto Ontario M2N 6S3

Local phone: 416-440-0917

Toll Free: 1.866-441-4643



Alberta group



Dr. and Mrs. Mason, Barbara and Shauna

## President's Message

*This year I was fortunate in being able to travel to Halifax and Edmonton and meet some of our members. I would like to thank Judi and Shauna for their help and warm welcome. During my time there I took many photographs of the breathtaking scenery from the shoreline at Peggy's Cove to the Rockies.*

*It gives me great pleasure to announce that we have expanded our Regional Groups to Manitoba and a warm welcome to Carol Seburn our Regional Coordinator.*

*Carol lives in Winnipeg and I urge members in Manitoba to contact her (details on previous page) helping to establish a support network amongst PBC patients.*

*This fall we are seeing some changes to our board. Our Recording Secretary, Gerri Wright is retiring and moving away from the Toronto area. Gerri has been very conscientious, her help and support this year has been much appreciated and we wish her well in the future.*

*In late summer Lenore Bennett accepted an invitation as a Director. Lenore has been a long time member and supporter of the Society and was Corresponding Secretary, she will now help organize new memberships. Our most recent Director is Esther Schwartz who will continue with her duties as our Archivist.*

*As this year is moving to a close I would like to thank all who have supported us and contributed to the expansion and interests of the Society.*

*May I take this opportunity to wish you all the best for the coming holiday season and my best wishes for the New Year.*



Barbara Badstober



## Fundraising Success

The 2008 annual fundraising drive is underway.

You are the key to research, the PBC Society was able to fund through your donations, the blood collection for the "Family Studies in PBC", a 3-year study that will cost approx \$105,000. Last year the Society announce

that they raised these funds and finalised their commitment to covering this cost (which CIHR rarely covers).

Your continued support will enable us to move forward and find further research projects that we will be able to support for the benefit of us all.

Thank you for making a difference.



### **2009 'A DAY AT THE RACES'**

Our fundraiser at Woodbine Racetrack will be held on Sunday, May 31, 2009. Further details of this exciting annual event to be announced later in the year.

Don't delay in reserving your attendance as there are a limited number of tickets for this event. Join us for a thrilling afternoon of racing and a superb buffet.

If you would like to help or donate items for the silent auction, contact the Society.

### **PBC SOCIETY NOTE CARDS**

Our cards are available all year from the Society, or your Regional Coordinator.

Cost of a package of 5 is \$15.00 and includes postage.



## **Research**

### **PBC and Osteoporosis**

Albert Parés, M.D.

Liver Unit, Hospital Clínic

C/ Villarroel 170

08036-Barcelona, SPAIN

### **Summary**

*Osteoporosis is a complication frequently observed in patients who have PBC. The pathogenesis of osteoporosis is characterized mainly by low bone formation, although increased bone resorption also is described, especially in cholestatic women who have advanced liver disease.*

*Osteoporosis is associated with severity of liver disease, older age, and the duration of cholestasis. Patients who have osteoporosis and those who have a lumbar T score below -1.5 have a high risk for fractures, particularly at the spine.*

*For the prevention and treatment of osteoporosis, good nutrition is advisable, as are the suppression of other risk factors for osteoporosis and the administration of supplements of calcium and vitamin D.*

*There is no specific treatment for osteoporosis, although it has been demonstrated that bisphosphonates, especially alendronate, are effective in increasing bone mass.*

*The outcome in reducing the incidence of fractures has not been demonstrated adequately because of the low numbers of patients included in the therapeutic trials.*

*Hormone treatment has been suggested, although, at present, this indication is questioned, even in patients who do not have liver disease because of potential severe long-term adverse effects.*

*The potential of bisphosphonates used with only one infusion per year or the efficacy of newer agents now prescribed in patients who are at high risk for developing fractures needs further evaluation in patients who have PBC.*

## Calling on Volunteers



### Help needed in the Toronto & GTA area

A volunteer Recording Secretary is needed from December 2008. This is an executive position and entails attending ten monthly meetings of approximately 2 hours each, to record the minutes and motions of executive meetings and other recording duties when necessary.

Computer experience is essential.

We have several other areas where the Society needs help, some that can be done online. We are growing and with this expansion we require help to shoulder the workload, so that we can continue to serve our members and raise funds for research.

If you can help contact Barbara at 1-866-441-4643 or [pbc\\_society@yahoo.ca](mailto:pbc_society@yahoo.ca)

*The Canadian PBC Society would like to acknowledge Amram's Distributing Ltd. Brampton, Ontario for donating their photocopying services for this publication.*

## Regional Events

### PBC ATLANTIC FALL REPORT

Our October meeting was a planning session for the coming year and an up-date on happenings since our June meeting.

B. Ryan from the CLF gave an informative talk on the goals of the local chapter and Fatty Liver Disease, literature on diet and cholesterol was distributed.

A picture, donated by President Barbara Badstober, will be auctioned at the CLF fund raiser Masquerade Ball with proceeds being divided between our group and the local CLF. It was decided that we would join EHANS so we can distribute info on environmental pollutants to members.

Our Xmas social will be held Dec. 1 and will be a lunch followed by bowling. Hope Santa is good to everyone and we wish everyone a happy and healthy new year.

### PBC ALBERTA FALL REPORT

In September the 2nd Annual Fall BBQ was held at the home of Saule and Gary Rusel.

Gary a master at the BBQ served crab, halibut, salmon and slow roasted a piece of beef. Thanks to Saule and all who provided some delicious accompanying side dishes.

Attending were Dr. Andrew Mason, his wife Gina, Barbara Badstober and members from the Edmonton area with family and friends. Shauna welcomed everyone and Dr Mason answered questions from the group.

A wonderful time was had by all!



### COMING SOON!

#### 2ND ANNUAL CHRISTMAS WINE AND CHEESE PARTY

For further details contact Shauna Vander Well at 708-962-6217 or via email at [vwel@shaw.ca](mailto:vwel@shaw.ca) or [AlbertaN@pbc-society.ca](mailto:AlbertaN@pbc-society.ca)

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