



# PBCConnections

A Canadian PBC Society Newsletter

FALL 2006

## Atlantic Group

Our PBC Atlantic group held its first meeting of the new season on Monday, September 11th in a community room at Sobeys. Members came from all over Nova Scotia including Dartmouth, Halifax, Valley and Amherst. People drove two or more hours to attend this meeting!

Although the meeting was filled with lots of time to share, the group focused on planning meetings for the upcoming year. Due to weather conditions, the Atlantic group only meets in the spring, fall, and Christmas.

They are anxiously waiting to participate in the blood collection to further the PBC research. The Atlantic group volunteered in a research project on lassitude and hopes to have some feedback on that within the next year. As lassitude is a big problem for some of our members, we are interested in the results.

## Toronto and Area Region

Fifteen members of the Toronto Region met on September 9th to hear a lecture by Catalina Coltescu, Clinical Research Coordinator for Dr. Jenny Heathcote, University Health Network - Toronto Western Hospital. Catalina covered many topics including:

- What is PBC?; prevalence and incidence; predisposing factors including genetic and environmental exposures; manifestations of PBC (including fatigue and somnolence); liver failure and cirrhosis; diseases associated with PBC; diagnosis, treatment and theories re: PBC
- Ursodiol – dosage and effects

Catalina's presentation on the Genetic Study currently ongoing in Toronto, London and Halifax and more recently Edmonton and Calgary, was met with great enthusiasm. It is hoped that the enrollment in the Toronto study will double by spring 2007.

The group wishes to thank Catalina and the volunteers who helped develop this program. The group plans on inviting Catalina back when there is further updates on the Genetic Study.



*Catalina Coltescu, Research Co-ordinator, Liver Clinic, Toronto Western Hospital talking to Cathy and Erica.*



*Esther and Katherine*

## Research

### **Excellent Long-Term Survival in Patients With Primary Biliary Cirrhosis and Biochemical Response to Ursodeoxycholic Acid**

Albert Pares, LLorenc Caballeria,  
and Juan Rodes

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Excerpt from the summary of  
this article with permission from  
Albert Pares.

#### **Background and Aims:**

Because the efficacy of UDCA on long-term outcome of primary biliary cirrhosis (PBC) has not been completely elucidated, we have assessed the course of survival of patients with PBC treated with UDCA and compared with the survival predicted by the Mayo model and the estimated survival of a standardized population.

#### **Methods:**

One hundred ninety-two patients (181 women) with PBC treated with UDCA (15 mg/kg per day) for 1.5-14 years.) Response to treatment was defined by an alkaline phosphatase decrease greater than 40% of baseline values or normal levels after one year of treatment. The predicted survival was obtained by the Mayo model and the estimated survival was taken from the standardized matched Spanish population.

#### **Results:**

Seventeen patients died or fulfilled criteria for liver transplantation (8.9%). The observed survival was higher than that predicted by the Mayo model and lower than that of the control population ( $P < .001$ ). One hundred seventeen patients (61%) responded to treatment. The survival of respondents was significantly higher than that predicted by the Mayo model and similar to that estimated for the control population ( $P = .15$ ). By contrast, the survival of patients without biochemical response was lower than that estimated for the Spanish population ( $P < .001$ ) although higher than that predicted by the Mayo model.

#### **Conclusions:**

Biochemical response to UDCA after one year is associated with a similar survival to the matched control population, clearly supporting the favorable effects of this treatment in PBC. The suboptimal survival of nonresponders identifies the group for further treatments.

For a reprint of the entire article  
write to:

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## Regional Meetings

### Atlantic Group

**November 6th**, Sobey's community room, Lacewood Dr Clayton Park.

**December 4th** meeting will include a Christmas social. For more information on this group, please contact [jpemberon@pbc-society.ca](mailto:jpemberon@pbc-society.ca)

### Toronto Group

**October 24th** 7-9pm in the Meeting Room at 2 Covington Road. It will be an informal "Support Group" meeting.

**Sunday Holiday Brunch** in late November – date TBC.

For further information, please contact Bonny Kirschner at [bonkirs@sympatico.ca](mailto:bonkirs@sympatico.ca)

### British Columbia

**November meeting** – date TBD with special guest Murray Church from Axcan.

**February 2007** meeting, special guest Johane Drapeau from the Victoria group who will share her experience of the transplant process.

If you would like to get involved or further information please contact Kathryn Swift at or via e-mail at [kswift@pbc-society.ca](mailto:kswift@pbc-society.ca)

### Alberta – North

The Alberta North group is looking forward to getting a plan of upcoming events together soon.

For more information on our Alberta North group, please contact Shauna Vander Well at [vwell@shaw.ca](mailto:vwell@shaw.ca)

### Alberta – South

The Alberta South group is looking forward to getting a plan of upcoming events together soon.

For more information on our Alberta South group, please contact Monica Grainger at [grainge@shaw.ca](mailto:grainge@shaw.ca)

## Volunteering – Our Regional Coordinators

### Kathryn Swift - British Columbia

Kathryn was diagnosed with Primary Biliary Cirrhosis (PBC) in May 2005. Eager to meet others and learn more about PBC, she went to Toronto for the Canadian PBC Society conference in September 2005. Impressed by the Society's vision and enthusiasm she accepted the position of regional coordinator for BC.

Her first goal was to locate as many people with PBC in BC as possible and then to connect them. There was a preexisting group from Victoria who had been meeting monthly and Kathryn began with a few informal meetings with a handful of members in Vancouver in July 2006.

"My goal is to be as active and helpful within the PBC community as I can by bringing folks together, helping them find answers to their many questions, increasing the size of our BC membership and seeing that the BC membership plays a significant role in the future of our Canadian PBC Society."



### Bonny Kirschner - Toronto

Bonny Kirschner lives in Toronto with her husband Eddie and Westie "Keltie." She worked as a technician at the ROM in the Ethnology Department and then served as an assistant to a Vice-President of a large advertising agency. Bonny's diagnosis of PBC was confirmed after a liver biopsy in 1991.

Bonny was a founding member of the Canadian Liver Foundation's Patient Support Group; took part in a Trillium Foundation sponsored film regarding the CLF's support efforts; and was presented to the Lieutenant Governor upon the 25th anniversary of the CLF.

"It is important to realize that each member of the Society has something to contribute. We are all anxious to find a cure for this disease. Fundraising for research; support for patients, their families and friends; and education are goals of the Toronto and Area Group."



Canadian  PBC Society

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