



# PBCConnections

A Canadian PBC Society Newsletter

FALL 2005

## Season Highlights

**This past season we were involved in a couple of leading educational events that were informative and brought hope to many attendees. Here are a few highlights from both our Canadian PBC Conference, held in Toronto and the World Congress of Gastroenterologists, held in Montreal.**

### Canadian PBC Society 2005 Conference

The opening registration and welcoming reception on Friday evening most certainly heralded in a very successful Scientific and Social event on Saturday, September 24, 2005.

The speakers provided a superb review of topics, all at the forefront of research activity in PBC. Drs. Jenny Heathcote, Keith Lindor, Andrew Mason, Kelly Burak, Patrick Colin, Katherine Siminovitch, Kevork Peltekian and Dominic Ng represented the Scientific flavour. Their presentations were outstanding. Attendees could not help but be impressed and encouraged. Certainly progress in the goals of prevention, treatment and cure was evident.

Appropriate excerpts may appear in future newsletters.

### World Congress of Gastroenterologists – Montreal, September, 2005

The Canadian PBC Society attended and provided active participation with our sister groups from France and the USA. We shared a booth at the Congress, aimed at promoting our patient support groups and group activities to the many attendees who passed by our table. We emphasized that our functions have a special focus on education, support and research.

It was impressive to meet physicians from around the world and hear their interest as it might pertain to their home situation. It was a most satisfying and gratifying adventure.

With our focus on education, we hope to participate in more of these preeminent conferences.



Cathy Charny and Sylvia Profit



From left: Angela Leburgue (France), Beverley Ritcey (Canada), Carol Roberts (USA) and Tina Verpoorten (Spain)

## Research

*From the desk of Dr. Jenny Heathcote, etc.*

*Primary Biliary Cirrhosis (PBC) is a chronic, but variably progressive chronic liver disease caused by ongoing inflammation of the small bile ducts within the liver. The result is cholestasis (failure of bile flow), which causes damage to the cells of the liver and promotes scarring of the liver, and this may lead to cirrhosis (nodular liver with loss of normal architecture).*

*The disease generally affects middle-aged women (40-60 years), but it has been described in a 15 year old. It may affect males too. For every 9 women with PBC there is one man affected.*

*PBC is a presumed autoimmune disease the cause of which is unknown. Genetic predisposition appears to play an important role in its pathogenesis (cause).*

*Our PBC group at the Liver Clinic, Toronto Western Hospital has had a long-standing interest in the pathogenesis, epidemiology, therapy and, more recently, genetics in PBC. Throughout the years we have conducted many national and international collaborative studies.*

*In February 2005 the Canadian Institutes of Health Research (CIHR) approved our application entitled 'Family studies in PBC.' The study will be funded for 3 years.*

*The goal of our research study is to identify susceptibility genes for PBC by testing DNA in samples of blood and correlating the results with clinical information on both patients with PBC as well as unaffected and affected parents and siblings. We will study these individuals and a cohort of healthy controls (spouses and friends will also be asked to act as the local 'control' population) with genetic markers to screen for a select set of candidate genes as well as the full genome for variants associated with PBC. There are three sites currently involved in this study: Toronto, London and Halifax that follow over 600 patients.*



*We will recruit patients with PBC (primarily from Ontario and Nova Scotia) and – 1800 of their first-degree relatives. Detailed clinical and demographic data will be obtained on all study participants and blood for DNA analysis and storage of a mononuclear cell preparation will be collected. All data will be stored in an Oracle-based relational database. Patient recruitment will involve obtaining written informed consent. Once received, documentation of the clinical (including demographic), serologic and histologic data on all patients as well as collection of blood samples for DNA analysis will be obtained. All study patients will be initially approached by their physician with follow up by the study coordinator and, if willing to participate, these individuals and their first degree relatives will be asked to provide contact addresses. They will be mailed explanatory consent forms and, once these have been returned signed, patients and their first-degree relatives will be sent questionnaires to complete and be asked to provide a blood sample (either at the study site, local hospital or private laboratory). The Canadian PBC Society will facilitate the correspondence with some patients via e-mail to minimize our mailing costs.*

*The blood collection for this 3-year study will cost approx \$105,000. The PBC Society kindly offered to cover this cost (which CIHR rarely covers) and have already generously donated a total amount of \$45,000 in 2003 and 2004. Their enthusiasm, effort and commitment to raise and donate the money to cover the entire amount are really much appreciated.*

*We hope that the study will provide opportunities for predicting disease risk, prognosis and drug responsiveness and will also provide the framework for elucidating molecular targets for use in therapeutic intervention.*

*Dr. Jenny Heathcote*

## Volunteers



Volunteers have played a vital role for the Canadian PBC Society. We are grateful for the support of volunteers nationwide. Volunteers provide assistance both locally and nationally.

Every day, volunteers for the Canadian PBC Society help support others suffering from PBC through regular chapter meetings, educational programs and events and raising funds for research efforts. We also have many volunteers who are involved in the administrative aspects including everything from gathering and counting Dominion tapes and organizing meetings to stuffing envelopes.

If you are interested in volunteering, please contact [info@pbc-society.ca](mailto:info@pbc-society.ca) or call (416) 440-0917. Thank you to the numerous volunteers that gave us their time at the annual conference. It was truly appreciated.

On another note, we want to send our apologies to Joyce Field for errors that were made in her article in the last issue of our newsletter.

 Canadian PBC Society

## Regional Perspectives

### Atlantic Group

Seventeen people attended our first meeting since our summer break. Vicky the Research Assistant for the PBC and Fatigue Study, being conducted in Nova Scotia, gave an informative presentation on the parameters of the research. Most members present signed up to participate in the study. Shayla from the CLF reported on upcoming fund raising events. She will bring organ donation forms and other info to our next meeting.

Education: Our transplant video FROM ONE TO ANOTHER was shown and found to be informative for those at the transplant stage. Three members who have had transplants generously share info on their experiences.

We received many questions to take with us to the conference and Judi and Karen will be sharing the answers to those and a huge amount of information learned at the conference at the next meeting on November 14. For more information on our Atlantic group, please contact Judi Pemberton at [kenjudi.pemberton@ns.sympatico.ca](mailto:kenjudi.pemberton@ns.sympatico.ca)

### Toronto Group

The next Toronto Group meeting is on Friday, October 21st and I look forward to seeing everyone after the summer break. We welcome all members for the meeting with a view to discussing future topics and potential speakers. We'd also like your input on our support group, how we can help each other, get more members to our meetings, and improve communication between members.

If you haven't received an invitation and would like further information please contact either the Society or Barbara Badstober at 705-456-2551 or via e-mail at [sarum@csolve.net](mailto:sarum@csolve.net). This year's Holiday Social will be a Sunday Brunch on Sunday, November 27th. Invitations will be mailed shortly.

### British Columbia

Please welcome our new representative from our British Columbia group – Kathryn Swift. For more information on this group, please contact her at [kswift@shaw.ca](mailto:kswift@shaw.ca)

### Alberta

For more information on this group contact Monica Grainger at [grainge@shaw.ca](mailto:grainge@shaw.ca)