

PBCConnections

A Canadian PBC Society Newsletter

SPRING 2008

The National Annual Meeting

The Canadian PBC Society Annual Meeting was held on Monday, February 11 in Toronto. The President, Barbara Badstober, presented her report on the year including updates on the previous year's events, memberships, and communications. The auditors from Starr Celeste-Falconeri LLP presented the financial reports.

A special note of thanks was given on behalf of the Society and its members nationwide to Beverly Ritcey for her amazing contributions to the Society and for her on-going dedication and guidance. Thanks were also given to Katherine Fuerst and Erica Nirenberg for helping coordinate our meetings, and to Brookfield Management and the Condo committee for their continued support in supplying a room for these meetings.

Canadian PBC Society 2008 Executive Board

Officers

President.....	Barbara Badstober
Treasurer.....	Open
Recording Secretary.....	Gerri Wright
Membership Secretary.....	Mary Jane Marley
Communications Convener.....	Doug Hohener
Corresponding Secretary.....	Lenore Bennett
Archivist.....	Esther Schwartz
Past President.....	Beverley Ritcey

Regional Coordinators

Alberta.....	Shauna Vander Well
British Columbia.....	Kathryn Swift
Greater Toronto.....	Open
Quebec.....	Francine Lamontagne
Atlantic.....	Judi Pemberton

Advisory Board

Dr. J. Heathcote.....	MB. BS. FRCP. MD. FRCPC
John I. Zeiler.....	Barrister & Solicitor
Starr Celeste-Falconeri LLP.....	Accountants



Annual Meeting 2008

President's Message

Today, as I write this message although the sun is shining and my driveway is clear, mountains of snow surround me. What a winter it has been and like most of you I am looking forward to spring!

Over the Holiday Season many of our Regional Groups hosted social events, which were enjoyed by all those in attendance. In Toronto we had a Holiday Brunch and members shared in lively conversations. The Atlantic Group held a luncheon with gift exchange, silent auction and book sale. In Alberta, members were invited to a Christmas Social held at the home of Dr. Andrew and Gina Mason, where questions and information about PBC were included in the evening's entertainment.

In February the Society held its fourth Annual meeting, I thank all those who came and contributed to the event.

In March we were hard at it – translating and posting the majority of our website and all of our forms into French as part of our out-reach program toward the new group in Quebec. The new French site can be reached from our main page by simply clicking on "Français." Congratulations to Doug Hohener [Communications] and George Boudreau [Webmaster] for their continuing volunteer work, and to Francine for her help in the translation.

Last year the Society fulfilled its financial commitment to the Familial Studies in PBC genetic research project, and we received a letter from Dr. Heathcote thanking us for our continued support of her research studies in the genetics of Primary Biliary Cirrhosis without which she and her team could not continue this research.

I am pleased to announce that we will again this year be hosting our key fundraising event our 3rd annual – "Day at the Races." The proceeds raised from this event will help the Society support future research into the possible causes and one day a cure for PBC. I encourage all who can to join us for a great day of fun and excitement and a superb buffet.

I am excited to report that I will be flying to Halifax in April to participate in the next Atlantic Group meeting. I look forward to renewing friendships and meeting members of one of our most robust regional groups.

Kind regards,



Barbara Badstober



DAY AT THE RACES

Back by popular demand – the Canadian PBC Society is proud to announce that the PBC 'Day at the Races' fundraiser event is being repeated again this year on **Sunday, June 1st** in the Northern Dancer Room at Woodbine Race Track in Toronto.

The day will kick-off at 12 noon with a meet and greet reception, followed by a mouthwatering buffet and silent auction with amazing items to bid on, and then the main event

– thoroughbred racing. There will also be a chance to be in the winner's circle photo of our sponsored race!

We encourage you to buy a ticket or two or book an entire table of 8 with your family and friends!

Tickets are available for \$85.00 per person, which includes lunch and racing. A portion of the ticket will be tax deductible.

If you'd like to volunteer on the day or donate any items for the silent auction, please contact The Canadian PBC Society.

Due to size restrictions, there are only a limited number of tickets available for this event, so sign up early! **Deadline is Friday, May 16th.**

For tickets please call 416.440.0917 or e-mail PBCsociety@yahoo.ca.



SUPPORT OUR SOCIETY WITH PBC CARDS

Writing a letter or sending a card to a friends or acquaintance? Why not use our PBC note cards? The cards were designed by our very own member Wenda Lyons of Moncton, New Brunswick.



The PBC cards are available 5 for \$15.00. Please help support our Society!

To order your cards, please contact your regional rep!

Research

New Research May Lead To Earlier Diagnosis And Treatment Of Primary Biliary Cirrhosis In Families

(Reprinted with permission from www.medicalnewstoday.com)

Article Date: September 11, 2007

Mayo Clinic researchers have found that first degree relatives (i.e., parents, siblings, children) of patients with primary biliary cirrhosis (PBC) are more likely to have the biomarker of the disease in their blood. Armed with this new information, physicians could screen and assess first-degree relatives of PBC patients with a simple blood test, enabling them to diagnose and treat more patients before the disease causes irreversible liver damage. These findings were published in this month's issue of Hepatology.

PBC is a chronic liver disease that affects nearly 50,000 people (primarily women) in North America. In individuals who have PBC, the bile ducts are slowly destroyed, causing harmful substances to build up in the liver and sometimes resulting in irreversible scarring of liver tissue and liver failure. About half of PBC patients have no symptoms and are diagnosed following abnormal results of routine liver tests.

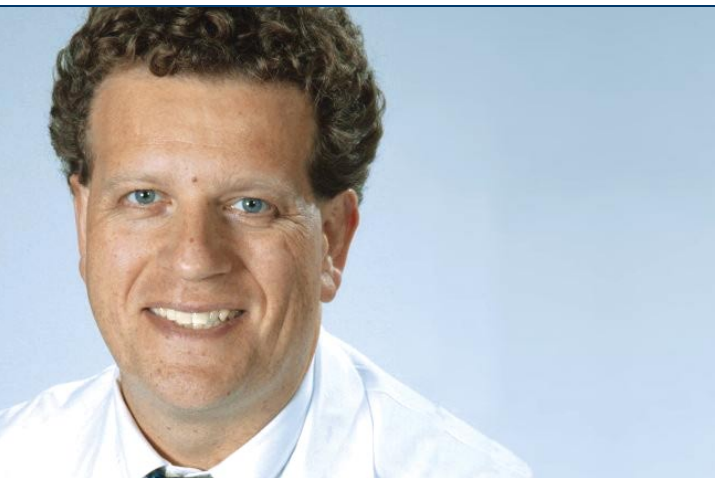
Anti mitochondrial antibodies are the biomarker, or the substance that correlates with the risk or presence of a disease, for PBC. This study, the largest of its kind, tested for anti mitochondrial antibodies in 306 first degree relatives of adult PBC patients and 196 healthy adults.

The prevalence in first degree relatives was 13.1 percent, compared to 1 percent in the control group of healthy adults. Even greater prevalence was found in female relatives, with 20.7 percent of sisters, 15.1 percent of mothers and 9.8 percent of daughters having anti mitochondrial antibodies in their blood. While testing positive for anti mitochondrial antibodies does not always lead to a diagnosis of PBC, the presence of these antibodies indicates a predisposition to develop the illness, particularly in the context of family history of the disease.

"Most PBC patients have no symptoms, but early detection is important because timely treatment can slow the progression of the disease before liver failure occurs," says Konstantinos Lazaridis, M.D., the study's lead author and a hepatologist at Mayo Clinic. "Because collectively one in five sisters of a PBC patient has anti mitochondrial antibodies in their blood, we think it is worthwhile to screen first degree relatives, particularly those older than 40 years, for this biomarker. It is a simple, inexpensive blood test that could lead to earlier diagnosis and treatment – and ultimately, better outcomes for PBC patients."

According to Dr. Lazaridis, the study's findings regarding anti-mitochondrial antibodies in PBC relatives could also be important to better understanding the known genetic predisposition to PBC. His research team plans to continue screening and monitoring first-degree relatives of PBC patients over many years to further examine these findings and to shed light on the cause of this disease.

Congratulations



Dr. Mason wins Research Award

The Canadian PBC Society would like to congratulate Dr. Andrew Mason, for winning an Alberta Heritage Foundation for Medical Research (AHFMR) 2007 Independent Investigator award for his research project on Retroviral Induction of Autoimmune Liver Disease.

AHFMR now offers the richest and longest health and medical research awards in Canada. The awards, offered to 54 internationally competitive researchers based in Alberta or in recruitment to the province, total more than \$59 million. The majority of the awards are in excess of \$1 million each.

PBC Volunteers WHERE WOULD WE BE WITHOUT YOU?

Our Society is run 100% by volunteers. From the National President to Regional Coordinators to Executive Board Members and Committee Members – we are all volunteers!

Volunteers do it all! You don't just provide desperately needed human resources to our organization you also bring special skills, new ideas and the energy needed to continue our successes.

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. Volunteers have played a vital role for the Canadian PBC Society.

Historically volunteers have played a key role enriching Canadian life immeasurably in establishing the earliest hospitals, homes for the aged and such organizations as the Y.M.C.A., St. John's Ambulance the Canadian Red Cross and others.

You are making a difference! You are keeping our Society running and therefore supporting our mission – "Reaching for the Cure."

REMEMBER:

- 1. Volunteers help others and in doing so help themselves.**
- 2. Small opportunities for volunteers produce great results.**
- 3. Volunteers come from all age groups.**
- 4. Volunteers live longer.**

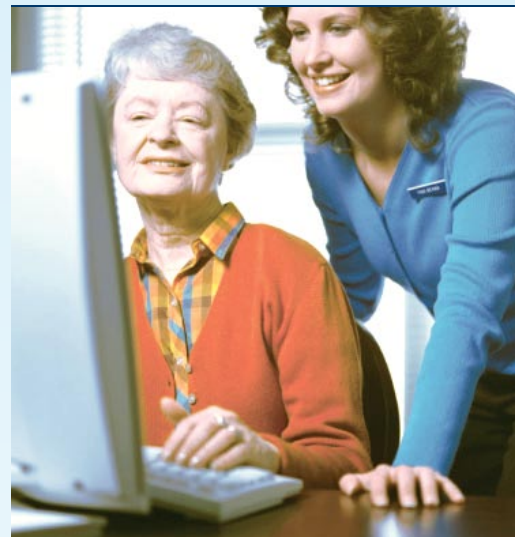
Thank you to the numerous volunteers that give up your time to help support our Society. We would be nothing without your help!

We need your help!

LOOKING FOR A SPECIAL VOLUNTEER

As a charitable, volunteer organization, the Canadian PBC society is currently seeking a Treasurer to be part of our volunteer team. The Treasurer will monitor all financial matters of the Society. We seek a dynamic and active individual who would like to volunteer in this capacity for our organization.

If you or any one you know could volunteer a few hours a month in this role, please contact Barbara for further details at pbc-society@yahoo.ca or call 416.440.0917.



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