



A Canadian PBC Society Newsletter

SPRING 2009

## **BREAKING NEWS!!**

**Toronto Western Hospital Liver Centre getting closer to determining the causes of Primary Biliary Cirrhosis. Details on Page 3.**

### *Annual Meeting, March 13, 2009*

We welcomed fourteen members and guests to the meeting, with a special welcome to Randall Starr and Jonathan Visva from the Society's auditors, Starr Celeste-Falconeri, Chartered Accountants LLP. This year we received a larger response to our proxy form from members across the country. Introductions of the 2009 executive were made, and thanks were proffered to members of the previous executive who chose not to stand.

#### **The 2009 Executive**

President ..... Barbara Badstober  
Recording Secretary ..... Mickie Nikoras  
Membership Secretary ..... Lenore Bennett  
Communications ..... Alwyne Graham - Editor, PBC Connections  
Corresponding Secretary ..... Carol Pye  
Archivist ..... Esther Schwartz

The financial statements were presented by Jonathan Visva who answered all questions. Members present voted for the slate of officers to be accepted with the President voting the returned proxies. A lively discussion and refreshments followed the meeting.

#### **Regional Coordinators**

Alberta ..... Shauna Vander Well  
Atlantic Group ..... Judi Pemberton  
British Columbia ..... Kathryn Swift  
Manitoba ..... Carol Seburn  
Quebec ..... Francine Lamontagne

The Society thanks the following advisors for their ongoing contributions:

Medical ..... Dr. G. Hirschfield MB.BCIR.MRCP.PhD  
Legal ..... John Zeiler B.A.,LL.B.  
Financial ..... Starr Celeste-Falconeri, LLP

## Research

# BREAKING NEWS!!

## Toronto Western Hospital Liver Centre getting closer to determining the causes of PBC

*In just the nick of time for this edition of the newsletter is exciting news from the Liver Centre at Toronto Western Hospital. In close collaboration with genetics experts at Mount Sinai Hospital, also in Toronto, as well as collaborators across Canada and the US, they have now published one of the most important breakthroughs in PBC research for at least a decade, if not longer. This work was in particular supported by the Canadian PBC Society from the outset, as well as by a major grant from the Canadian Institute for Health Research.*

*Writing in the highly influential New England Journal of Medicine, Dr. Hirschfield and his colleagues outline new genes that are associated with the development of PBC. These genes play an important role in how the immune system works and it is now clear that subtle changes in their function may be related to why patients develop this chronic disease. Commenting on the work, Gideon Hirschfield who runs the Autoimmune liver disease service in Toronto, said "We're really excited by these findings. For the first time ever we are closer to understanding why PBC begins, and how we might treat it better. We're very grateful to all the patients from across Canada and America who have given DNA samples and to the PBC society who were pivotal in providing resources to collect the Canadian samples. We're delighted that a Canadian led team is the first in the world to do this pivotal study, and hope this ushers in an era of even more collaboration as we try and work with DNA samples from many thousands of*



*patients in the future to tease apart this enigmatic disease." Jenny Heathcote and Kathy Siminovitch initiated the study about 5 years ago. Jenny, well known to patients across the world as a leading authority in PBC said "These results point to why PBC develops and where new drugs should be targeted. I'm thrilled that the patients and doctors have worked so closely together to make this breakthrough, and that a pan-Canadian network of liver centres has so successfully collaborated. This is just the start and we hope that our autoimmune liver disease clinic at the Toronto Western, as well as those across Canada, continue to be supported by patients and clinicians".*

*The paper entitled "Primary Biliary Cirrhosis Associated with HLA, IL12A, and IL12RB2 Variants" was published on-line at the New England Journal of Medicine on May 20th 2009.*

*For further information on PBC please contact Catalina Coltescu at [ccoltesc@uhnres.utoronto.ca](mailto:ccoltesc@uhnres.utoronto.ca) or visit the Toronto Western Hospital Liver Centre website at [www.torontoliver.ca](http://www.torontoliver.ca). Recruitment continues at full pace for this study, as there is still a lot more good work to do!*





## Regional Events

On April 4th the Toronto & GTA area welcomed Dr. Gideon Hirschfield, Clinician Investigator at the Liver Clinic who also runs the Autoimmune Liver Disease Clinic and research program, and Catalina Coltescu, Research Coordinator.

Twenty members, family and friends were present to listen to Dr. Hirschfield's presentation on 'Non-liver manifestations associated with PBC'. This was a very informative power point presentation, with Dr. Hirschfield answering many questions. Refreshments were served before and after the meeting when members socialized.

Barbara presented Dr. Hirschfield with a gift of appreciation; spring bulbs were presented to Catalina for her assistance in organizing the event and to Katherine Fuerst to thank her for setting up the room for the meeting.

As a component of fund-raising for the Society, craft articles donated by Mickie Nikoras were for sale, and \$55.00 was raised.

### ATLANTIC GROUP

A meeting was held on May 14, attended by 9 members and 1 guest. The meeting covered matters arising from the minutes of the previous meeting (fundraising, speakers and communications) as well as information about the spring social (Bingo bowling) on June 10 and potentially interesting events of other organizations. The group organized volunteers to obtain speakers for 2009/2010 meetings and read and summarized PBC articles from the UK. A book sale and silent auction raised \$16. Next meeting is September 17.

Social: Wednesday, June 10th, 2009 at 10:30 a.m., at the Fairlane Bowling Alley in the Halifax Shopping Centre, where we will have a Bingo Bowling session. Please bring a couple of small prizes, wrapped. We will have lunch in the mall food court after the bowling. Even if you don't bowl, come along and enjoy the fun....and bring a friend if you like.

For more information contact: Judi Pemberton at 902.798.5554 or at [atlantic@pbc-society.ca](mailto:atlantic@pbc-society.ca)

### MANITOBA

Three Liver Ladies had lunch together on May 8 at the Old Spaghetti Factory in Winnipeg. The "Liver Ladies" name came from a relative of one of the women. We shared about symptoms, fears, joys and frustrations. I will ask these women if I can share more of their stories for the newsletter.

For more information contact: Carol Seburn at 204.254.5226 or at [Manitoba@pbc-society.ca](mailto:Manitoba@pbc-society.ca)



*Dr Gideon Hirschfield speaking at the Toronto meeting*



*Manitoba Group's 1st meeting, Karen, Lori & Carol*

Canadian  PBC Society

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