

PBC Connections

A Canadian PBC Society Newsletter

SUMMER 2008

Information and Education Presentation

An information and education presentation by Dr. Gideon Hirschfield was held on June 14 for PBC members, family and friends in the Toronto, GTA and surrounding area.

Dr. Hirschfield, Gastroenterologist and Hepatologist at Toronto Western Hospital in Toronto gave an overview of PBC. Highlights of his presentation included:

- Positive aspects of living with PBC
- What the liver does
- What the symptoms are of liver disease
- How a doctor tests for liver disease

Other highlights included giving a definition of PBC and general conclusions about this disease. These are outlined below:

What does the acronym PBC mean?

PRIMARY = UNKNOWN CAUSE (Environmental and/or genetic triggers)

BILIARY = AFFECTING THE BILE DUCTS (Small bile ducts)

CIRRHOSIS = SCARRING OF THE LIVER

This is a general term in liver disease. It doesn't mean you drink alcohol. It doesn't mean your liver doesn't work. Most people with PBC don't have cirrhosis.

How will my life be affected by PBC?

- PBC is not terminal: if treated early, many have normal survival rates
- PBC is not contagious
- PBC is not caused by alcohol or drugs
- For a few, liver replacement may eventually be needed, but that few is decreasing as treatments improve

Dr. Hirschfield also discussed various symptoms including fatigue and the biology of fatigue and then answered questions.

Many thanks to Dr. Hirschfield for his excellent and informative presentation and to Catalina Coltescu, Clinical Research Coordinator for Dr. Heathcote who helped arrange the meeting.



Dr. Gideon Hirschfield



President's Message

Hello everyone,

As we approach the halfway point of the year, I would like to welcome all new members.

We have regional coordinators based in six regions across Canada; they do a stellar job in supporting and organizing meetings.

Helping each other is what our Society is about. If at times you feel you would like to talk to someone else who shares the disease, our Coordinators and the Executive are here to assist you whether through phone calls or meetings. For a list of the Regional Coordinators and contact information see page 4 or visit our website.

I am very grateful to all those who volunteer, despite having the disease are able to give of their valuable time so freely.

I would like to take a moment to thank Debbie Gates who has volunteered to reorganize our mailing list, making the task of notifying you much easier.

There are also the doctor's and other professionals who give of their time to speak at meetings and willingly answer your PBC-related questions in person and on our website forum 'Ask the Doc, I thank you.

Raising funds to go to research is another way we help each other and the PBC community, this year's successful Day at the Races [see right column on this page] helped us in this regard.

In April I had the great pleasure of attending an Atlantic Group meeting in Halifax. I am looking forward to a vacation in Alberta this coming September where I will be able to meet members of our Edmonton and hopefully Calgary groups.

This edition of PBC Connections is the last one that Doug Hohener will be involved with. Doug has been on the Board of the Society since 2005 and has worked extremely hard to provide us with a professional newsletter.

Doug, on behalf of the Canadian PBC Society we thank you for your contribution and our best wishes to you and your family for the future.

Wishing you an enjoyable summer, and I look forward to hearing from you.

Take care,



Barbara Badstober



Fundraising Success

This year's Day at the Races fundraiser continued an annual tradition of fun and success. The weather was perfect and the Northern Dancer Room, situated above the track, presented a panoramic view of the racetrack.

The day started with a superb buffet luncheon and a guest appearance from world-renowned jockey, Sandy Hawley who circulated and spoke with several guests.

The event drew familiar faces as well as some new ones this year. We all enjoyed the silent auction and of course the thoroughbred racing! The event raised more than \$3000 for the Society.

Thank you to everyone who donated items for the auction and to those who came out to enjoy the day!

Please mark May 31, 2009 in your calendar for next year's event!



Research

Antimitochondrial Antibody⁺Negative Primary Biliary Cirrhosis

Keith D. Lindor, M.D.

Published with permission from Dr. Keith Lindor, Professor of Medicine and Chair of the Division of Gastroenterology and Hepatology at the Mayo Clinic College of Medicine in Rochester, Minnesota, USA.

Primary biliary cirrhosis (PBC) is a chronic liver disease of unknown cause that is characterized by elevated alkaline phosphatase levels. The liver biopsy shows damage of bile ducts and antimitochondrial antibodies (AMA) are usually present. However, a small percentage of patients who have all of the features of PBC may lack these and are termed AMA-negative PBC. AMA-negative PBC, like AMA-positive PBC, occurs predominantly in middle-aged women, and these patients are usually free of symptoms. Symptoms, when present, include tiredness, itching, and sometimes dry eyes or dry mouth.

The alkaline phosphatase, which is a blood test, is almost always elevated. Other liver enzymes, such as transaminases, are often elevated to a lesser degree. Patients with both AMA-negative PBC and AMA-positive PBC appear quite similar clinically as far as presence of symptoms and other autoimmune disease at the time of diagnosis. Complications also appear similar between the two groups.

Patients who have AMA-negative PBC usually are positive for either antinuclear and/or anti-smooth muscle antibodies which are found more often in these patients than patients who have classic AMA-positive PBC. The liver biopsy changes are indistinguishable. The treatment for both is ursodeoxycholic acid in a dose of 13-15 mg/kg/day. Patients treated this way appear to have a similar response; although the number of patients treated with AMA-negative PBC who have been studied is quite limited. Fewer patients with PBC are now requiring liver transplants. When patients with AMA-negative PBC do undergo transplantation, their results are comparable to the typical AMA-positive patients. The life expectancy for patients with AMA-negative PBC appears similar to the AMA-positive population, which is generally quite good. In general, AMA-negative PBC follows a very similar course and responds to treatment as do patients who have antimitochondrial antibodies and PBC.



Calling on Volunteers

Would you like to serve on the Executive or volunteer to help us coordinate meetings and fundraisers? We are looking for volunteers to help in many areas.

To discuss how your background and experience best fit with our volunteer openings, please contact Barbara at: pbc-society@yahoo.ca

- **Administration and Research**
- **Communications**
- **Fundraising**
- **Regional Coordinator for Toronto and surrounding areas.**
- **Treasurer**

REGIONAL COORDINATORS

Alberta North	Shauna Vander Well Phone: 780.962.6217
Alberta South	Judy Wright Phone: 403.642.3664
Atlantic Group	Judi Pemberton Phone: 902.798.5554
British Columbia	Kathryn Swift Phone: 604.988.4030
Quebec	Francine Lamontagne Phone: 418.659.6392
Toronto & Area	Contact Head Office

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

Regional Events

ATLANTIC GROUP UPDATE

Sixteen people attended the April meeting of the PBC Atlantic group. Meeting highlights included welcoming the Canadian PBC President Barbara Badstober and Blair Ryan from the Nova Scotia Canadian Liver Foundation.



Barbara gave an interesting talk and answered questions on the current activities of the PBC Society. Many thanks to Barbara who donated a beautiful framed cross-stitch picture to be used as a fundraiser for the group. A silent auction and book sale concluded the meeting.

For PBC Awareness Day they placed an ad in the paper, distributed pamphlets to doctor's offices, sent information on the Atlantic group to be included in the Liver Foundation newsletter and sent their annual newsletter to members unable to attend regional meetings. Pamphlets from their two previous guest speakers on Fraud and Environmental Illness were also distributed.

The Atlantic Group is planning an event in September with guest speaker, Dr. Peltekian who will give an update on the PBC Genetics study.

ALBERTA FALL BBQ

The Alberta Group will be holding their second Annual BBQ on the second week of September. Both Dr. Andrew Mason and Barbara Badstober will be attending.

To find out more details and how you can attend, contact Shauna Vander Well at 708.962.6217 or via email at vwell@shaw.ca or AlbertaN@pbc-society.ca

Canadian  **PBC Society**

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