

PBC Connections

A Canadian PBC Society Newsletter

SUMMER 2007

Regional Meetings

Toronto and Area Group Meeting

The Toronto group has been extremely busy over the past few months with meetings and special guests.

On March 10th, the Toronto and Area Group met at 2 Covington Road to hear **Dr. Heathcote** give a presentation on the latest research into the causes of PBC. Dr. Heathcote outlined the new research being done with PBC. The talk and slide presentation were followed by a question and answer period (see some of the questions and answers on Page 3). The presentation sparked much enthusiasm, questions and discussion.

The Toronto Group also held a meeting on Saturday June 9, 2007 to hear guest speaker **Sara MacHin** from the **Village Healing Centre**. Sara is a Holistic Lifestyle Consultant with 20 years of professional experience educating individuals and groups. She is a Certified Yoga Instructor, Reiki Master, Chi-Kung Instructor, Meditation Guide, Electro-Magnetic Practitioner, Lomi-Lomi Practitioner and Professional Organizer. Sara spoke to us about the need to live in a mindful way with our choices of nurturing foods and the manner in which we eat, walk, talk and meditate. She advised us on the benefits of meditation and also of yoga and other therapies including Reiki treatments. Her talk was greatly appreciated by all. Special thanks to **Katherine Fuerst** and **Erica Nirenberg** for their help with coffee and tea. Refreshments provided by **Shannon MacInnis**. The next meeting will be in September.

British Columbia

The groups in British Columbia held a couple of meetings and luncheons to support each other and to discuss future plans for the groups.

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Members at the Victoria, BC meeting



Members at the Vancouver, BC meeting

COMING SOON

The next fundraiser is a theatre night "Blithe Spirit by Noel Coward" planned for November 7th. Tickets are \$80.00 per person including premium seating and complimentary glass of wine. Tickets are limited – so don't delay book your seats today! Please visit our website or call **416-440-0917** for more information.

NEW PBC NOTES

We are pleased to announce that the PBC cards have now been printed and packaged and are now available 5 for \$15.00.

Although there were several artists considered for this card, we chose the artwork by **Wenda Lyons** of Moncton, New Brunswick. Wenda is a talented artist and a member of the Canadian PBC Society.

To order your cards, please contact your regional rep.



Research

Below you will find questions and answers to some of the questions raised at the March 10th meeting with Dr. Heathcote in Toronto.

1. How does HRT affect PBC and is there any reason pertaining to the liver, that women should not take HRT?

Can cause the bilirubin count to rise and may promote itching – all resolves off HRT.

2. Is a Fibroscan available in Canada and if so can staging be determined accurately with it?

Not approved yet and we don't know if it is a reliable test of scar tissue in the liver in PBC.

3. How to cope with fatigue – stop and rest?

No. No activity does not help. I wish we knew what might help – modafinil??

4. How do we effectively take URSO + other VitD and Calcium?

UDCA – all with supper

Ca + Vit D – spread throughout the day

5. Does steroid nasal spray or throat spray have any negative effect on liver?

No.

6. Do you treat patients who are diagnosed with both PBC and PSC differently than those who have just PBC?

Combination is very very very rare! Both treated with UDCA (higher dose for PSC).

7. Can you not canvass Gastroenterologists & Hepatologists for patients for your genetic study?

I'm not sure it would help us. Outside an academic center physicians do not generally keep a record of who has what!

Another issue that was raised at the March 10th meeting with Dr. Heathcote was the use of herbal remedies. Please find a list below of herbal remedies that can be toxic to those with PBC.

Artemisia

Atractylis

Black Cohosh

Callipsis

Camellia sinensis

(concentrated extracts of Chinese green tea)

Camphor

Cascara sagrada

Chaparrel Leaf

Chaso

Chrysanthemum

Comfrey

Crotalaria

Dai-saiko-to

Gardenia

Gerrnander

Greater Celandine

Hare's Ear

Heliotropium

Hydroxycut

Impila

Isabgol

Jim Bu Huang

Kava Kava

LIV.52

Ma Huang

Margosa oil

Mistletoe

Noni

(Morinda citrifolia)

Oil of Cloves

Onshido

Paeonia

Pennyroyal

Plantango

Red Peony root

Sassafras

Saw Palmetto

Senecio

Sho-saiko-to

Shou-wu-pian

Skullcap

Symphytum

officinale

Teucrium

chamaedrys

Teucrium polium

Valerian root



Regional Meetings cont'd

Northern Alberta

The June 6th meeting of the Alberta-North Chapter of the Canadian PBC Society was a huge success. They had a really great turn out for their guest speaker, **Dr. Andrew L. Mason**, who provided an education and information session regarding all aspects of PBC.

Dr. Mason explained his viral theory and invited patients and family to participate in a study. Dr. Mason is working with Dr. Jenny Heathcote and collecting answers to survey questions and blood samples. This was an opportunity to contribute to ongoing research into this disease.

Dr. Mason is associate professor for the department of medicine at the University of Alberta. He is also a medical research scholar for the Alberta Heritage Foundation. He is director of research for the division of gastroenterology and director of liver transplant research.

Southern Alberta

They held a meeting on April 24 for a few hours of discussion and will meet again in the fall.

Atlantic Group

They have been busy with a couple of meetings including a well attended meeting in February with guest speaker **Dr. Peltekian**, Catalina (research coordinator for Dr. Heathcote) and **Kerry Mallett** (Nova Scotia Coordinator for the project) who spoke on the familial studies in PBC research project.

They also got involved distributing PBC pamphlets for PBC Awareness Day on May 30.

A Special Volunteer

We are sorry to report **Louise King** passed away in May. Louise was an energetic, caring elementary school teacher for 36 years. She coached many sports teams both inside and outside of school. Known as "**Umpie 1**," Louise umpired for Softball Ontario and for Slo-Pitch National. Even in her senior years, she played slo-pitch, lawn bowling and 5-pin bowling. She played Bridge with two Bridge clubs and Euchre every Tuesday evening. Louise was an outgoing, helpful, generous, optimistic person who placed a high value on all her friendships. Her friend **Pat Cook** will duly miss her, but it is little wonder as she touched every person with whom she came in contact.



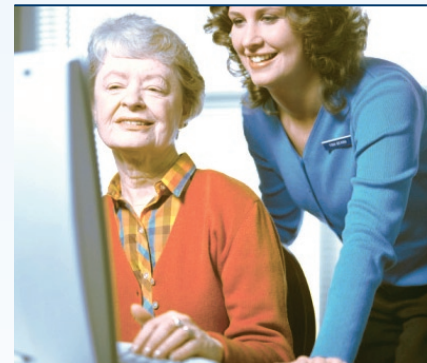
Volunteers have played a vital role for the Canadian PBC Society. We are grateful for the support of volunteers nationwide. Volunteers provide assistance both locally and nationally.

A Call for Volunteers

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 support.

We are currently seeking regular volunteers for our committees; specifically we have need for a bookkeeper to help us at the Board level. If you are interested in volunteering, please contact info@pbc-society.ca or call 416-440-0917.

Thank you to the numerous volunteers that give up your time to help support our Society. It is truly appreciated.



Canadian  PBC Society

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