

PBC connections

A Canadian PBC Society Newsletter

2011 • VOLUME TWO

regional connections

ATLANTIC CANADA

Eight members of the Atlantic Chapter of the PBC Society came to our spring social on May 17. Also, two of the husbands joined in, so we had eight people who participated in the Bingo Bowling and two score keepers. After the bowling and distribution of prizes, we had lunch together and then wished everyone a happy summer. Thanks to all who helped to make this a fun day.

Our next get-together will be held sometime in the fall, and we will combine a lunch and annual meeting at that time. I hope there will be a good turnout on that occasion.

We all wish to offer our condolences to our president, Judi Pemberton, on the loss of her father. Our thoughts and prayers are with you and your family, Judi.

For information about the group, please contact Judi Pemperton: atlantic@pbc-society.ca or 902-798-5554.

BRITISH COLUMBIA

Nine members of the Greater Vancouver/Lower Mainland Group met for an informal lunch on June 4th at The Inn at The Quay, in New Westminster. We got caught up on how everyone was doing and had a chance to share their experiences of having PBC, discuss what's new, and ask questions of each other.

Our heartfelt sympathy goes out to several BC members who have recently experienced deaths of family members and friends (not PBC-related).

It was wonderful to see everyone and we will be meeting again in the fall (date to be announced). Any new members are asked to contact Kathryn Swift if you wish to be added to the list for the next social. Have a safe and happy summer.

To find out when and where, please contact Kathryn. For information about the group, please contact Kathryn Swift: kswift@pbc-society.ca or 604-988-4030.

MANITOBA

We had a great PBC group supper on Thursday, May 26th with five of us, plus two young children and a grandmother. Our group is growing. I have handed out many of the brochures already and will take some to my Hepatologist's office on my next visit. For information about the group, please contact Carol Seburn: manitoba@pbc-society.ca or 204-254-5226.

NORTHERN ALBERTA

Dr. Andrew and Gina Mason hosted a well-attended barbecue on May 29 from 4:00 p.m. Family and friends were also invited. Dr. Mason was available to answer questions, discussion was lively and the guests included two research students, who appreciated hearing about the human side of the disease.

For information about the group, please contact Shauna Vander Well: albertaN@pbc-society.ca or 780-962-6217.





3rd photo: (Left to Right) Alberta North Coordinator, Shauna Vander Well; Gina Mason, Mark Kneteman, research student, Dr. Andrew Mason, and Mandana Rahbari, research student

QUEBEC

Un partage hors du commun et des gens très sympathiques!

Lors de cette première rencontre au restaurant l'Incrédule de Longueuil, nous avons vécu de beaux moments. Les discussions axées sur la maladie ont fait place à des échanges rassurants et bénéfiques pour chacun.

Étant donné que certaines personnes vivent déjà depuis longtemps avec la maladie, cela a contribué à donner espoir aux patients nouvellement diagnostiqués. Le groupe comptait 11 personnes, 2 autres personnes n'ont pu venir.

Malgré l'importance du sujet traité, la rencontre s'est déroulée avec beaucoup d'humour et de rires.

Les membres ont été informés du rôle de la Société canadienne de la CBP et invités à visiter le Groupe de Québec sur Facebook. Leurs commentaires sont les bienvenus.

Merci aux membres qui ont bravés les travaux routiers pour se joindre à nous.

Au plaisir d'une prochaine rencontre, d'ici là portez-vous bien.

Sharing unusual and very nice people!

At this first meeting at the restaurant L'Incrédule of Longueuil, we experienced some great moments. Discussions focused on the disease have given way to exchange reassuring and beneficial to everyone.

Since some people are already living with the disease for a long time, it helped give hope to patients newly diagnosed. The group had 11 people, two others could not come.

Despite the importance of the subject, the meeting took place with great humor and laughter.

Members were informed of the role of the Canadian PBC Society and invited to visit the Group of Quebec on Face book. Their

comments are welcome.

Thank you to members who braved the road work to join us.

Looking forward to a future meeting, in the meantime keep well.

For information about the group, please contact Francine Lamontagne: QuebecRep@pbc-society.ca



TORONTO & GTA

"Let's Get Together For Coffee"



On Sunday, June 26 a group of seven PBCers from Toronto and surrounding area met for coffee at the Starbucks in Liberty Village, Toronto. Organized by Esther Gorewicz Hayoun & Diana Ponte, they enjoyed it so much they are planning a repeat!

For information, please contact the Society: info@pbc-society.ca

ALL OTHER REGIONS

For information, please contact the Society: info@pbc-society.ca

People in South Alberta can contact Judy Wright at: heyjude@telusplanet.net



EXA:	5 &	PLACE POOL	15 MTR 10
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5/2	121	755	
3	124	857	
30	363	111	
11	-	367	
13	278	274	
10	204	258	
7	178	442	
3	178	663	
20	386	90	

POST: 5:41 PM
 POLYTRACK
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 TIME: 5:26 PM
 POOL TOTALS
 WIN: 11826
 PLC: 4176
 SHW: 2346
 EXA: 9508
 TRI: 11188
 SFC: 8348



FUNDRAISING

Our annual **Day at the Races** fundraising event at Woodbine Racetrack just keeps getting better. This year more people attended, with children a record 159, we had more donated items for silent auction (40!), a new feature in Mickie Nikoras's craft table, and raised more money. Dr. Gideon Hirschfield spoke about PBC and how patients live with the disease and gave a brief update of his ongoing research. As always, the buffet lunch was excellent, and the dessert table enhanced with the addition of beautifully decorated cupcakes by Diana Ponte much loved by the children – young & old!

We have outgrown the inside room, so the venue was a well-appointed track-side tent, which allowed the children to play freely and the adults to get a close-up view of the races. It was

a scene of great animation as people mixed and cheered on their chosen horses. The PBC Society sponsored race was particularly exciting with a photo-finish that kept people on edge waiting for the official result.

Sincere thanks go to Schonberg Farms for their ongoing support and sponsorship of the PBC Society race, to all those who donated items for the silent auction (and to those who bought them), to Mickie Nikoras for supplying and running the craft table, to the Woodbine staff for their helpful service and especially to Pina & Peter Aceto for their expertise for selling tickets & to Barbara Badstober for making the whole thing possible.



The Canadian PBC Society is not responsible and cannot be held liable for the accuracy of any medical or treatment information printed here, which is not necessarily representative of the views and opinions of the Society. Please consult your own health care provider before making any changes in your daily living or treatment plan.



2008 UPDATE ON OCA (FORMERLY INT-747) DRUG TRIALS

Progress toward Phase 3 of the drug trials is slow but sure, reports Cathi Sciacca, Senior Director, Clinical Operations, Intercept Pharmaceuticals. The positive results from the Phase 2 study of OCA (obeticholic acid, previously known as INT-747) as a monotherapy for primary biliary cirrhosis were presented by Dr. Kowdley of Seattle in March 2011 at the annual conference in Berlin of the European Association for the Study of the Liver. Intercept Pharmaceuticals has signed an agreement with a Japanese company, Dainippon Sumitomo Pharma, licensing them to develop OCA in Japan and China. This provides Intercept with the additional funding needed for the current Phase 3 program.



ANNUAL MEETING

The annual meeting was held on Thursday, 28th April, 2011. Difficulties in obtaining a final financial statement because of the change in accountants led to members receiving somewhat shorter notice of the annual meeting than usual. This, together with the mid-week timing, meant that only six members were in attendance, but a quorum was achieved with the 19 proxy votes received by the President.

The meeting was opened by the President at 10:30 a.m. She relayed greetings from John Zeiler, the Society's lawyer, and regrets from Mark Wolanski, the new accountant, Esther Schwartz, Treasurer, and Carol Pye, Corresponding Secretary. The Society thanked Katherine Fuerst for her help in organizing the room.

Business proceeded briskly, with approval of the minutes of the previous meeting, financial statements, and the appointment of Mark Wolanski of Wiseman and Wolanski as the Society's accountant. The meeting approved the slate of officers and regional coordinators for 2011, which is unchanged from 2010, by a show of hands. The positions of Fundraising Secretary and Regional Coordinator for Greater Toronto are open and volunteers will be welcome.

President	Barbara Badstober
Treasurer	Esther Schwarz
Recording Secretary	Mickie Nikoras
Membership Secretary	Lenore Bennett
Communications	Alwyne Graham (Editor, PBC Connections)
Corresponding Secretary	Carol Pye

Regional Coordinators:

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

The President's Report noted a measured increase in members and successful fundraising efforts in 2010, which allowed us to offer grants to aid liver research. Website traffic also increased. She acknowledged the help of various volunteers in specific areas of Society activities. In response to a question about research grants, the President informed the meeting that letters had been sent to Drs. Peltekian in Halifax, Mason in Edmonton and Swain in Calgary. No responses have been received as yet.



Please write, phone or email us at:

Canadian PBC Society

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