



PBC Connections

A Canadian PBC Society Newsletter

2010 - VOLUME 1

UPDATE FROM CALIFORNIA ON RESEARCH INTO PBC DRUG, WITH INFORMATION ON CANADIAN CONTACTS.

See page 3.



Randall Starr

Starr Celeste-Falconeri LLP have been our accountants for the past several years, working without charge by returning their fee to the Society as a contribution.

Randall has been the prime contact, ably helped in the work by Jonathan Visva. Unfortunately, personal health and family factors mean that Randall has reluctantly decided that he must discontinue his association with the Society after this year's audit is completed. He has proposed a replacement and we are in the process of putting in place a new arrangement.

Our sincere thanks go to Randall for his interest in and contribution to the PBC Society, along with best wishes for the future to him and his family.

Happening in 2010

Annual Meeting

The Annual Meeting will be held in Toronto, sometime during March; the date is being finalized with the auditor. Notices will be mailed in the near future, if you can't attend, don't forget to mail back your proxies.

Post time! 5th Annual Woodbine Fundraiser

The **Day at the Races** will be held on Sunday, May 30, 2010. Details on page 2.

GTA Fall Meeting

We are planning a medical information session in the fall. Date, location and speaker will be announced later.



The British Columbia Group



Research

ADAPTED FROM THE PBC FOUNDATION (UK) LTD., NEWSLETTER, THE BEAR FACTS, NOVEMBER 2009, ISSUE NO: 48

A New Advance in the Treatment of Primary Biliary Cirrhosis?

PBC is a chronic autoimmune disease of the liver marked by the slow progressive destruction of the small bile ducts within the liver which may lead to liver failure and the need for liver transplantation. It is also a cause of important symptoms such as tiredness and itch. PBC primarily (although not exclusively) afflicts women, with up to 300,000 patients estimated worldwide. The only treatment currently available for use in all patients is ursodeoxycholic acid (UDCA or "urso") which is limited in the degree to which it is effective at treating PBC. Continued research efforts are therefore required to improve treatment in PBC.

The first results have just been announced from an important clinical trial using a drug called INT-747 to treat PBC patients who are also being treated with UDCA (the data from the study are likely to be presented at a major European liver conference in April 2010). The combination of the two drugs show a significantly greater improvement in disease markers compared to UDCA alone. This finding, if supported in larger follow-on trials, is the first real step forward in the treatment of PBC for a decade.

This is unlikely to be the whole story. Given that INT-747 is likely to have, in addition to its own specific effects, the same basic effects as UDCA it may well be that INT-747 will work as a monotherapy, having the effects of the combination on its own. It is important for us to know whether this is the case because a single treatment, if effective, as opposed to a combination of 2 medications has real advantages for patients (fewer tablets to take and potentially fewer side-effects).

*The extent to which INT-747 is effective on its own in PBC (i.e., in patients with PBC who are not taking UDCA) is currently being studied in another clinical trial ongoing in Canada at the University of Toronto by Dr. Gideon Hirschfield, the University of Alberta in Edmonton by Dr. Andrew Mason, and Hôpital Saint-Luc/CHUM in Montreal by Dr. Catherine Vincent.
(Email: catherine.vincent@umontreal.ca)*

Anyone who is interested in learning more about this trial is advised to contact the following individuals for further information.

University of Toronto:

Catalina Coltescu

Phone: (416) 603-5832 (see also, [link below](#))

University of Alberta:

Sharon Appelman-Eszcuk

Email: sharon.appelman@ualberta.ca or

Phone: (780) 492-8602

Hôpital Saint-Luc:

Christina Benjamin

Email: tinabenjamin2@gmail.com or

Phone: (514) 890-8000, Ext. 35283

Useful Links:

<http://www.torontoliver.ca>

<http://www.clinicaltrials.gov/ct2/show/NCT00570765?term=Primary+Biliary+Cirrhosis&rank=19>

<http://www.pbcfoundation.org.uk/Home.htm>

With thanks to Cathi I. Sciacca, Sr. Director, Clinical Operations, Intercept Pharmaceuticals for providing this article.

Regional Events

BRITISH COLUMBIA

We held a lunch meeting for the Greater Vancouver/Lower Mainland Group on September 26th at the New Westminster quay area, which seemed central to everyone coming from all over the lower mainland. Although some folks were not able to make it, there were seven of us, plus one grandchild at this social get together. It was a wonderful chance for four old members and three newer members to meet and catch up. We all agreed to meet twice a year, in spring and fall for lunch.

We also have some sad news to report of the passing of one of our senior members, Mary Nimmo, who passed away in December 2008 from PBC. We send our support and condolences to her husband of 52 years, Dave, and her son Scott. Mary had just celebrated her 81st birthday before she died. She will be remembered as a strong, easy going, quiet and compassionate woman who never complained.

Please contact Kathryn Swift at bc@pbc-society.ca or 604-988-4030 if you wish to be added to the list for the next social, or for any further information.

ALBERTA NORTH

Our third annual September BBQ was a success; all who came out had good weather and a great time. A BIG thank you goes out to Garry and Saule – thank you again for making this event such a success. The food was wonderful and the hospitality so welcoming.

Our silent auction was fun and raised \$330.00 for PBC research! The cheque was submitted to National Office. A couple of members also shared their experience in the current drug trial taking place at the University Hospital in Edmonton. The results look promising. A coffee date was scheduled for October, but Shauna was the only one in attendance. Plans for our next get-together are to be announced.

For further information contact Shauna Vander Well at AlbertaN@pbc-society.ca or 780-962-6217.

ALBERTA SOUTH

There are only four of us here in Southern Alberta and all seem to be doing OK. We don't get together very often. Wish there was a way to connect to more people and get something going. Don't give up on us – maybe someday. For further information contact Judy Wright at heyjude@shockware.com or 403-642-3664.

MANITOBA

We are just a tiny group but hopefully, we will grow! Two members met for lunch on Thursday, November 19 and three of us had a fun time and a lovely supper in December.

Carol attended a LIVERight seminar on liver disease at the Health Sciences Centre on September 17. The four presenters, Drs. Gerald Miniuk, Kelly Kaita, Stephen Wong and Julia Uhanova shared much information about research and other aspects of liver disease. Carol also attended a general support meeting sponsored by the Canadian Liver Foundation, which was a planning session for the future and also discussed issues of confidentiality and information sharing. This group is also very small, with attendance from 5-7.

For further information, please contact Carol Seburn at manitoba@pbc-society.ca or 204-254-5226.

ATLANTIC

The Atlantic region has not had a meeting since the last Newsletter, but is hoping to have education seminars in March and May and a social in June. Dates and speakers will be forwarded as soon as available.

For further information, please contact Judi Pemberton at atlantic@pbc-society.ca or 902-798-5554.