

PBCConnections

A Canadian PBC Society Newsletter

SPRING 2006

Toronto and Area Group Meeting

On April 26th, the Toronto and Area Group met at 2 Covington Road to hear Ms. Terri Pease from Osteoporosis Canada give a presentation.

The group was welcomed and asked to participate with ideas for future programs. Bonny Kirschner advised that over the summer she would be canvassing members to determine what topics, days and times would be suitable to the greater majority.

Terri Pease was introduced and gave a presentation on osteoporosis. Although the numbers were small, the presentations sparked much enthusiasm, questions and discussion. Specifically, Terri provided a very interesting discussion of osteoporosis and how it relates to PBC.

The meeting was followed by much camaraderie. A special thank-you to Barbara for her guidance, Erica for her generosity in providing the meeting room, and to Louise, Gwen and Mickie for helping to set up and clean up!

A guest speaker/education-type program is being considered for mid-September. Various speakers including a representative from Axcan and Catalina from Dr. Heathcote's office will be approached to speak to the group on the current genetic study and to answer questions. If you have any suggestions as to who you might like to have come and speak or ideas as to topics that you would like covered, please contact Bonny Kirschner, Greater Toronto and Area Group Chair at the main Toronto office.



Attendees from our Toronto and Area Group Meeting, from left to right: Louise, Gwen, Lenore and Elzia.



Riyaz and Shannon

Research

Is there a role for anti-viral therapy for patients with Primary Biliary Cirrhosis?

Dr. Andy Mason

No one really knows for sure what causes the bile duct damage in patients with primary biliary cirrhosis (PBC). There is some evidence to suggest an infection triggers the disease process in susceptible individuals. We know, for example, that PBC occurs in families and may even present in non-related family members, such as husband and wife. Also, PBC has been found to cluster in specific geographical regions, suggesting an environmental cause for disease. PBC can recur in a minority of patients following liver transplantation as well, suggesting a persistent infection.

Several theories have been put forward to explain what causes the bile duct damage. Some have suggested that bacteria or toxins may trigger an abnormal immune response to bile ducts, while our group favors the idea that a virus triggers the process. We have identified a retrovirus in PBC patients, which we have called the human betaretrovirus, and found evidence for infection in the majority of patients. We have used two different ways to determine whether this virus is associated with PBC. In the laboratory, we used a model to show that virus infection of normal bile duct cells leads to changes seen specifically in the bile ducts of patients with PBC. In clinical pilot studies, we have found that anti-viral therapy is beneficial for patients with PBC.

Ursodiol acid is currently the only approved medical therapy for PBC patients. Therefore, we enrolled patients into the anti-viral treatment studies who were stable on Ursodiol for more than 6 months. For the first pilot study, we used Lamivudine as this drug blocks the mechanism that some viruses use to

reproduce. Lamivudine was chosen as it was known to be safe and effective for treating patients with chronic liver disease secondary to hepatitis B virus infection. Initially, patients receiving Lamivudine had a positive response with their liver function tests but this did not last. However, little change was seen in the liver tests and liver biopsy findings by the end of the one-year Lamivudine study. So we decided to use an additional therapeutic agent to bolster the anti-viral effect.

In our second pilot study, we found that combination therapy with Combivir (Lamivudine and Zidovudine) resulted in significant improvement in all liver tests after 6 months and showed significant liver biopsy improvement in inflammation and bile duct damage after one year. Most exciting of all was the increased number of bile ducts seen in the liver biopsies after one-year therapy with Combivir therapy as this has not been found with any other treatment for PBC.

Now, we are finishing up a 6-month randomized, controlled trial of Combivir in PBC patients on maintenance therapy with Ursodiol in North America. We do not know who is receiving the active drug or placebo and hope to have the results from this study towards the end of next year. This study will be used to determine whether a long term, randomized, controlled trial with Combivir would be useful for patients with PBC. This study will also have the potential to help establish whether a retrovirus infection is important in causing PBC and provide new avenues for treating this progressive disease. For example, we may need to think of using other anti-viral agents if the activity of Combivir is not potent enough to treat PBC or if the side effects limit the use of the medication. We know that more powerful combinations of treatment are often required to prevent the progression of viral infections. Only time will tell.



Regional Perspectives



Shauna Vander Well

All of our groups are in the process of planning several meetings, please visit our website in the Events section for regular updates.

Atlantic Group

For more information on our Atlantic group, please contact Judi Pemberton.

Toronto Group

For more information on the Toronto group, please contact info@pbc-society.ca

British Columbia

For more information on our British Columbia group, please contact Kathryn Swift.

Alberta - North

For more information on our Alberta North group, please contact Shauna Vander Well (pictured above).

Alberta - South

For more information on our Alberta South group, please contact Monica Grainger.

Volunteering in Alberta – Our Regional Coordinators

Shauna Vander Well – Northern Alberta

Shauna is the new regional coordinator for northern Alberta. As Alberta is such a large province, Shauna will share the province with Monica Grainger who will oversee southern Alberta.

Shauna teaches English for adults at Alberta College Campus, she is a mother of six children, and two dogs and lives in Spruce Grove, Alberta with her husband Greg.

She is a member of her local TOPS group (Take Off Pounds Sensibly) and was crowned TOPS Alberta Queen in 2003 for losing 93 pounds. She represented TOPS Alberta at the international conference in Pittsburgh, Pennsylvania. Diagnosed with PBC, stage three, in November of 2006 at the age of 43, Shauna manages her condition, by relying in part on the knowledge of the impact of nutrition and exercise on wellness that she gained through her years with TOPS.

Shauna was recently appointed as the northern Alberta Regional Coordinator for the Canadian PBC Society and says, "I am delighted to offer information, education and support to PBC patients, their families and friends. This network of support provides the comfort and hope patients seek. I am proud to be a part of this society and its strong commitment to research."

Monica Grainger – Southern Alberta

Monica is the southern Alberta Regional Coordinator. She lives in Calgary with her five children and twelve grandchildren. Now retired, she was a music teacher, church music director and also worked for several years for H&R Block.

Diagnosed with PBC in 1986, she has been an active volunteer with the Canadian Liver Foundation and ran a support group for PBC patients in the Calgary area. She adds, "I have been fortunate to attend several PBC conferences both in Canada and the US over the years and have learned a great deal from them about our disease."

If you are interested in getting involved or attending any of the regional events, please contact your regional representative.

We say Goodbye...

On a sad note, I wish to recognize the passing of Margaret Haley from Nova Scotia. Marg was very active in our Atlantic Group and we wish to send our condolences to her family.

Canadian  PBC Society

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