

PBC connections

A Canadian PBC Society Newsletter

2014 • VOLUME TWO



WOMEN WITH PRIMARY BILIARY CIRRHOSIS CAN SAFELY BECOME PREGNANT

Dr. Angela C. Cheung, MD, FRCP(C), Toronto Centre for Liver Disease, Toronto Western Hospital and Toronto General Hospital, University Health Network

Almost one in every four patients with primary biliary cirrhosis (PBC) is diagnosed during their child-bearing years, but there is still very little known about the effects of pregnancy on PBC and similarly, what effects PBC has on pregnancy, delivery and the baby. With the help of patients at the Toronto Centre for Liver Disease, Dr Angela Cheung and her colleagues have found that most patients with PBC can have uncomplicated pregnancies, regardless of the level of severity of their PBC, their symptoms or their history of prior miscarriages.

Seventy five percent of women with PBC who became pregnant had no changes in their liver tests during pregnancy, and ten percent of women even had an improvement in their liver tests. The opposite was true after delivery - approximately seventy five percent of women showed an increase in liver tests within 6 months of delivery. Despite this increase in liver tests, over ninety percent of these women had uncomplicated pregnancies and healthy babies, and their liver tests returned to normal within a year. This shows that a rise in liver tests may be common, particularly after delivery, but there does not seem to be any long-lasting effects.

Itch during pregnancy was the most common symptom, with nearly seven out of ten women developing either new or worsening itch. Fortunately, eighty percent of patients who developed itch either did not need medical treatment or had a complete response to medications for itch. Most importantly, none of the women had any pregnancy complications because of their itch or the medications they used for itch. Over half of the women with itch still had itch after their delivery, but a similar number of patients had itch even before becoming pregnant. It is likely that the increased estrogen during pregnancy is responsible for worsening itch during pregnancy, which explains why the symptoms improve after delivery.

While there were few women with late PBC who were pregnant, they did not seem to have a higher miscarriage rate than women with early PBC. Similarly, women with high liver tests did not appear to have a higher miscarriage rate compared to women who had normal liver tests before becoming pregnant.

It was wonderful to be able to show that women with PBC can have safe pregnancies and healthy babies, even in the face of symptoms or changes in liver tests. Dr. Cheung and her team are interested in continuing to expand our knowledge in this area to help women with PBC, their partners and their doctors understand the effects of PBC on pregnancy and vice versa, in order to optimize care during pregnancy and delivery.



ASSISTING IN RESEARCH

In September the PBC Society donated \$6000 to support this new research project by Dr. Angela Cheung of the Francis Family Liver Clinic at Toronto Western Hospital. Our donation will help Dr. Cheung and her colleagues add to the relatively scarce body of literature on the effects of PBC on pregnancy, and also to optimize patient-centred care for young women with PBC locally, nationally and around the world.

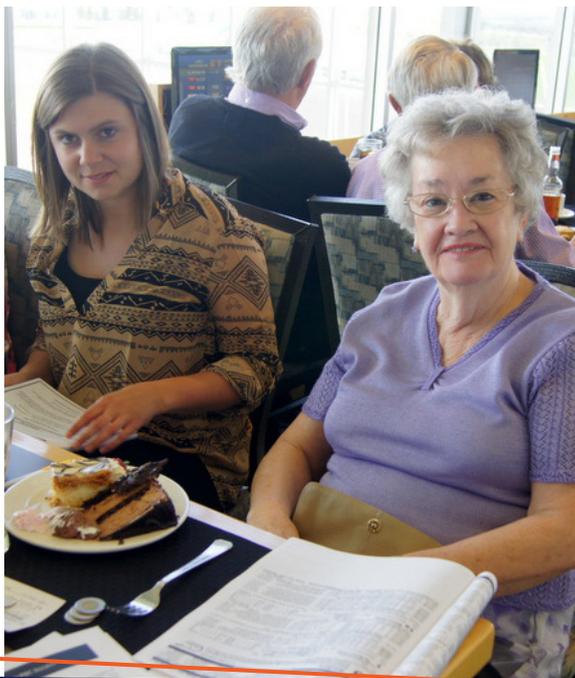
FUNDRAISING

Annual Day at the Races

Our main fundraising event, the annual Day at the Races at Woodbine Racetrack in Toronto took place on Sunday, June 1. Response was disappointing, with smaller numbers necessitating a change in venue from the private Northern Dancer Room to the public dining room. However, the 33 adults and children who attended enjoyed an excellent view of the track and delicious buffet from tables grouped together at one end of the room, allowing socializing without disturbing other customers. They also participated in a small silent auction. The smaller scale of the event inevitably led to a smaller amount raised for research: \$2,630. The executive has decided to put this event on hold in 2015.

Footnote: To have a successful event in a private setting allowing us to enjoy a speaker and silent auction we would need to double the number of this year's guests. To do so the Society needs the support of our members to organize and plan this fundraiser.

If you are interested in continuing with this event please email: info@pbc-society.ca



WHAT IS THE FUTURE OF THE CANADIAN PBC SOCIETY?

The Canadian PBC Society has been in existence for 11 years now. In that time, membership has grown and we have made a substantial financial contribution to research into primary biliary cirrhosis, but the Society has reached a stage when change is necessary. Activities and fundraising have begun to stagnate.

The current Board has served since 2009 (some members even longer) and although its members feel that they have accomplished a great deal, it is time to move forward to meet the new challenges. A fresh board will bring the innovative ideas and new energy needed to keep the Society vital and dynamic. It is time for a change in leadership.

It would seem from the response to the recent need to re-register the Society under the new Not for Profit Act that its members value the Society and want its work to continue. For that to happen, we need people to step forward and form a new slate of officers to stand for election at the Annual General Meeting in May next year. The continuation of the Society depends on finding willing new volunteers.

Please let us know your thoughts and ideas on this important issue. We are looking for the next generation of board members. You can reach us by mail and e-mail.



CANADA HELPS

What We Do CanadaHelps is a registered charity with a goal to make giving simple. Through CanadaHelps.org, anyone can donate online to any registered Canadian charity. We have proudly facilitated over \$100 million in charitable donations through our website since it was launched in 2000. **For Donors** CanadaHelps is a one-stop-shop for giving. We made donating online easy and secure.

CONTACT US

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DEAR FRIENDS OF THE CANADIAN PBC SOCIETY:

2014 Fundraising Drive

The Society's mission is to aid research into the causes and treatment of primary biliary cirrhosis and to provide information and support to those diagnosed with the disease. We provide grants to researchers in various locations across the country, researchers who are advancing our understanding of the causes and effects of PBC and exploring new treatments. Our latest grant is to a project involving researchers in multiple centres to explore the impact of PBC in pregnancy. We maintain contact with a wide network of researchers, hepatologists and gastroenterologists so that we can support and supply information to members through our Newsletter, web site, and informational and social meetings in regional centres.

The Society's work is carried out by hard-working and dedicated volunteers like our regional coordinators and board members. However, it would not be possible without generous donors such as you to enable us to continue. The PBC Society is an entirely volunteer-run organization, so that all of the money you donate is used to further our aims or to pay for operating expenses, which are kept to a minimum.

Thank you for your help and support. Your contribution is very much appreciated.

CANADIAN PBC SOCIETY DONATION & MEMBERSHIP FOR 2014

NAME (PRINT) _____

ADDRESS _____

CITY _____

PROVINCE _____

PC _____

Enclosed is my gift: \$ _____

Membership \$15: \$ _____ *Includes mailed copy of PBC Connections for 2015*

TOTAL: \$ _____

Choose a payment method:

Enclosed is my cheque VISA MasterCard

NAME ON CARD (PRINT) _____

CARD # _____

EXPIRY _____

MONTH / YEAR

SIGNATURE _____

regional connections

ALBERTA NORTH

For more information, please contact **Shauna Vander Well:** AlbertaN@pbc-society.ca or 780-962-6217.

ATLANTIC

Spring Lunch: Five of us had a lovely lunch and a little meeting on Wednesday, June 4, at Resto Urban Dining. It was so nice to get together.



Fall Social/Meeting: The PBC Atlantic Group held our Fall social/meeting in October with rather poor attendance due to it being cold and flu season. It ended up that three of us got together: Judi Pemberton, Karen Beehan and Patricia Berrigan. We wondered if people were not interested in group activities anymore and discussed the continuation of the PBC Atlantic Region get-togethers. Input from members regarding their preferred types of activities and interest in participating is requested.

Judi announced that we have \$220.35 and we decided to send \$100 to the research fund. We decided to discontinue the personal care packages that we were doing up for the transplant unit, since these no longer seem to be required.

For more information, please contact **Judi Pemberton:** atlantic@pbc-society.ca or 902-798-5554.

BRITISH COLUMBIA

For more information, please contact **Kathryn Swift:** bc@pbc-society.ca

GOLDEN HORSESHOE REGION

For more information, please contact: **Karen Isbister:** kisbister@cogeco.ca or 905-336-3502 and **Jackie Gay:** gingerjack@cogeco.ca or 905-937-1081.

MANITOBA



Six of us had lunch together on Friday, Oct. 24 at The Olive Garden. We discussed getting together for a Christmas Party, possibly in a church building. This is still in the early planning stages. We could rent the facility for a meal and a time of fellowship. The sanctuary is an all purpose room; we just move the chairs and roll in the tables. Will notify you if this takes place. On November 8 there will be a Talent Show/Fund Raising evening for Karen F. who is preparing for a transplant. A number of us plan to attend.

For more information, please contact **Carol Seburn:** Manitoba@pbc-society.ca or 204-254-5226.

OTTAWA

For more information, please contact **France Foucalt:** ffoucalt@hotmail.com

QUÉBEC

For more information, please contact **Francine Lamontagne,** Représentante Québec, Société canadienne de la PBC: quebecrep@pbc-society.ca

SOUTHWESTERN ONTARIO

For more information, please contact **Betty Van Luven:** bvanluven@rogers.com

TORONTO

Please contact: info@pbc-society.ca or 416-440-0917 or toll-free 1-886-441-3643