



PBC Connections

A Canadian PBC Society Newsletter

FALL 2007

A Big Thank You to Beverley!

When it was announced the Beverley would be stepping down as President of the Society, we all felt a collective sigh and need to say 'Thank you.' From regional coordinators, executive members, to doctors and PBC patients everywhere, there was an expressed need to thank Beverley for her huge contributions. Due to space restrictions, we could not possibly print all of the letters we received, but what follows are a few excerpts from some of these letters.

Beverley Ritcey

From Patients...

*When I first contacted Beverley she made me feel at ease and welcome. It didn't take long for me to realize that she cared deeply about the Canadian PBC Society and its members. Thanks for the dedication, hard work and most of all the inspiration – **Carol Pye***

When I first entered the Toronto health care system eight years ago, Bev spent an entire day driving me between hospitals and appointments. She stayed with me and helped me navigate corridors, paperwork, lunch menus, and an overwhelming range of emotions.

*She has continued to support, enlighten, and encourage me over the past eight years to assume control of my health, my health care, and the critical decisions that affect my well being. I am extremely grateful for her support – **Betty Gunner, Moose Factory***

From Regional Groups...

*On behalf of the Southern Alberta chapter of the PBC Society, thank you Beverley. She is a most caring and responsible worker. Under the most difficult circumstances, she was always available for advice and encouragement. Thank you and God bless you – **Beverley Monica Grainger***

*I 'met' Beverley over the phone over two years ago she was so kind and assuring; she recounted some success stories to help me look at my condition from a hopeful perspective. She has always made me feel appreciated and reminded me that my efforts are valued. Beverley – all of us in Northern Alberta wish you peace and love and thank you for all you have done for all of us. God Bless. – **Shauna Vander Well***

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Research

Fatigue in Liver Disease: Pathophysiology and Clinical Management

Dr. Mark G. Swain, MD, Queen's University; MSc, Queen's University; FRCPC Professor, Department of Medicine, Gastrointestinal Research Group

This is a summary of the article of the same name found in The Canadian Journal of Gastroenterology, March 2006, Volume 20 Issue 3: 181-188.

Published with permission from Dr. Mark Swain.

Fatigue is the most commonly encountered symptom in patients with liver disease, and it has a significant impact on their quality of life. However, although some progress has been made with regard to the understanding of the processes, which may generate fatigue in general, the underlying cause(s) of liver disease-associated fatigue remain incompletely understood. The present review describes recent advances which have been made in our ability to measure fatigue in patients with liver disease in the clinical setting, as well as in our understanding of potential pathways which are likely important in the pathogenesis of fatigue associated with liver disease. Specifically, experimental findings suggest that fatigue associated with liver disease likely occurs as a result of changes in neurotransmission within the brain. In conclusion, a reasonable approach to help guide in the management of the fatigued patient with liver disease is presented.

Fatigue is a complex symptom, which encompasses a range of complaints including lethargy, malaise, lassitude and exhaustion. Importantly, chronic fatigue commonly occurs within society, affecting up to 20% of the population. Although the exact prevalence of fatigue in patients with chronic liver disease is somewhat variable in different studies and with different specific liver diseases, it is readily apparent that fatigue constitutes the most common complaint amongst this patient group. However, because of difficulties in defining and treating fatigue, this symptom is often overlooked or minimized by physicians caring for patients with liver disease.



The prevalence of fatigue in patients with different forms of liver disease also appears to be quite variable. Specifically, cholestatic liver disease caused by primary biliary cirrhosis (PBC), primary sclerosing cholangitis (PSC) or drugs is commonly associated with fatigue.

In fact, fatigue in cholestatic patients can be the presenting symptom and occurs in 65-85% of patients. Moreover, fatigue in PBC is considered to be the worst symptom in about 50% of patients, and is disabling in about 25%. Fatigue also has a significant impact upon the health related quality of life (HRQOL) of PBC patients.

Conclusion:

Fatigue is the most common symptom reported by patients with liver disease. Although the underlying pathogenesis of fatigue in liver disease is still poorly defined, it appears to involve changes in central neurotransmission, which result from signaling between the diseased liver and the brain. A better understanding of the pathways and the neurotransmitter systems involved may provide directed, specific therapies for liver disease-associated fatigue.

Fundraising

It was exactly one year ago when we started planning a Canadian PBC Society Theatre Night in order to raise awareness of Primary Biliary Cirrhosis and to raise funds for Familial Studies in PBC directed by Dr. Jenny Heathcote of Toronto Western Hospital.

On **Wednesday Nov. 7**, forty-five patrons attended SoulPepper Theatre's production of "**Blithe Spirit**" for Canadian PBC. The 40's British comedy, written by Noel Coward, came to life on stage at the Young Centre for the Arts in the Distillery District in Toronto. We enjoyed mingling at intermission before heading back to our seats for more.

An enjoyable evening with much laughter was had by all! Thank you to all that came out to enjoy the show!



Regional Meetings

There are no meetings planned right now, but all of the regional groups will all be hosting their own holiday event. Contact the group near you for more details.



A Call for Volunteers

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.

With the recent changes on the Board, we are currently seeking a Treasurer to oversee how our money is spent; ensure that we have enough money to carry out our stated aims and objectives and report financial status to the Board. If you or someone you know can help, please contact info@pbc-society.ca or call **(416) 440-0917**.

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.

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

Welcoming New Volunteers

Welcoming a new Recording Secretary to the Executive.

This past month we welcomed Geraldine Wright, known simply as Gerri, as the newest member of the Executive.

Gerri was born in Toronto, but raised and educated the U.S., and is a widow with two married children. She was diagnosed with PBC in 2000.

She has worked as the Inventory/Imports Manager for an international Importing/Distributing company for the past 28 years, and has held various positions including acting as the Recording Secretary of the Health and Safety Committee in her office for the past 25 years.

"I am thrilled about volunteering with the Executive," Gerri says, "It's an opportunity to put my experience into action for something that is near and dear to my heart – finding a cure for PBC."



Welcoming a New Quebec Regional Coordinator

Francine Lamontagne is our new Quebec Regional representative. She is a 52 year old Montréalais, now living in Québec City. She works full time as a financial consultant and also worked several years as a Marketing Director for a large firm. She enjoys playing golf, reading and traveling.

Diagnosed with PBC in 2001 after a liver biopsy, Francine is pleased to join the Society to form a French group in Quebec. "I am looking forward to providing information to people who need it and to giving them the motivation to help me raise money for PBC research, hopefully resulting in the cure."

Francine has already made a difference as she has translated some areas of the main website to help support French-speaking patients who need our support. She wants to focus her attention on providing information on the group and the Society by approaching doctors, druggist, natural food stores, etc.

Look for Quebec-based activities and meetings coming soon.



Canadian  PBC Society

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