PBC connections

A Canadian PBC Society Newsletter

2016 • VOLUME TWO

IN THIS ISSUE

WITH THIS ISSUE OF PBC CONNECTIONS, we're pleased to introduce some new features to your newsletter. We hope you will find them useful and practical. Please let us know what you think about these new, regular sections of the newsletter.

'Members' Corner' in which PBC patients in Canada... and across the world... share their experiences and offer suggestions for managing the practicalities of living with PBC.

'Ask the PBC Doctor' – in each issue, we'll highlight some of the most frequent questions (and answers) about the latest developments in the diagnosis and treatment of PBC that our network of medical experts is being asked.

'Tips for Healthy Living' – our new healthy living panel has a wealth of knowledge and experience in traditional medical practice, naturopathic medicine and nutrition counselling. Their tips for healthy living will address the PBC-specific diet, exercise and overall health questions and concerns you may have.

Let's begin with Members' Corner and hear what a number of PBC patients across Canada have told us about some of the things they wished their friends and family knew about what it's like to live with PBC.

MEMBERS' CORNER

'IF ONLY YOU KNEW...'

It's difficult enough to tell your friends and family when you've been diagnosed with a rare and chronic liver disease. Sometimes it's even more difficult to help them understand how the disease affects your life... and theirs.

PBC affects everyone differently, but we all have one thing in common: it can be difficult for our friends and family to understand our daily challenges of living with a chronic illness. Kathryn S., one of our PBC Society members, recently wrote a blog on this subject on our website. As she says, "It's often a struggle for us to get our heads around not being able to do what we used to do. That doesn't change our desire and need to stay connected with friends, family and others... and also to meet new people. But we need to find ways to communicate with others and help them to better understand and empathize with our experience."

Here are a few concerns that Kathryn and other members have suggested they "wish their friends and family knew". In the spirit of better communication, we hope you will talk with your friends and families about these and other concerns that are important to you and your wellbeing. **Read Kathryn's complete blog:** **http://pbc-society.ca/blog/what-you-might-hear-from-someone-with-pbc-and-why-imho/**

1. 'Thanks, but I don't feel great'

"But you look alright (great, healthy, good)" is something many of us with PBC hear from others after letting them know we have a chronic illness. The good thing is we may not look ill. The bad thing is because we may not look ill, others have a hard time understanding that we may not feel well enough to attend their party, or accept their invitation to lunch, or head out to a movie.

Fatigue, the #1 symptom of PBC, can be chronic or intermittent, and there is no warning of when it will come on or when it will let up. This makes it hard to commit to things, as many of us can't predict how we'll feel from one day to the next or even from week to week. When we do make plans we may have to cancel them, and then feel guilty for letting others down. We also worry that friends, family and colleagues will not be open to tentative plans, for everyone prefers certainty, and all of this can lead to concern about losing friendships.

2. I'm good, thanks'

It's hard to ask for help. And it's hard to lose our sense of independence and to look after ourselves the way we once could. In an attempt to not burden others or appear needy or lazy, we pretend we are all right instead of asking for help. We forget that people can't read our minds and usually take "no, I'm good" at face value.

3. ‘I’m sorry I didn’t mean it to come out that way’

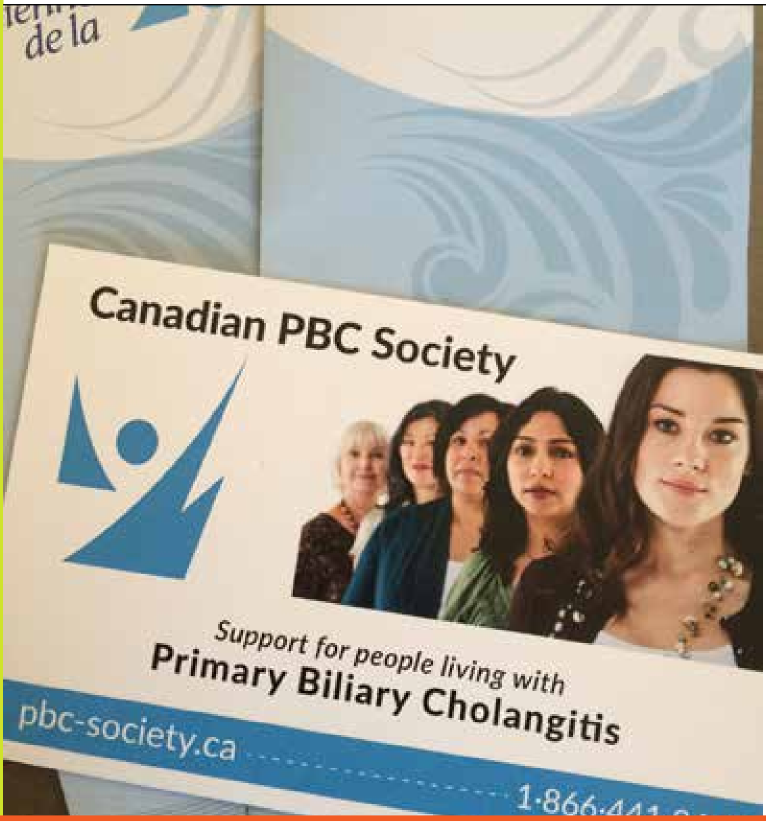
Sometimes it can be challenging to get the correct words out and sound coherent. Whether it’s the result of liver toxins backing up into our brains in late stage PBC or brain fog from fatigue or not enough energy to think before speaking, we may come across as curt or impatient at times. We really are sorry, but sometimes there just isn’t enough energy for decorum, especially if our tolerance level has been depleted by pain and insomnia.

4. ‘Yes, I want to be fit and healthy and I’m honestly doing the best I can’

While ideal weight, being physically fit, and eating a healthy diet is a desire for us all, it isn’t easy for many who suffer profound fatigue with or without pain. We would give anything to have enough energy to go to the gym, go for a walk, shop or cook healthy meals. Sometimes we just don’t have enough energy. We may have spent it on doctor’s appointments or taking the kids to school, or we’re in bed trying to recover from the last walk or trip to the gym. It’s challenging living with the shame and embarrassment we feel for not being able to look after these basic health needs, and we dread the judgments from others who don’t understand our challenges or assume it speaks to a flaw in our character.

5. ‘Thank you so much’

Receiving calls, emails, texts, cards or letters makes us grateful for the connection with others. We may have slowed down in reaching out ourselves (can’t commit, don’t feel well and don’t want to complain, have no energy or brain clarity left for talking or writing, spending all our energy on appointments instead of chats with friends). While we would organize more outings ourselves, and call more often if we could, when someone takes the initiative and time to reach out to us, we are eternally grateful.



NEW BROCHURES & POSTCARDS: HELP SPREAD THE WORD

We have updated our PBC brochures and we now also have a supply of postcards that are appropriate as leave-behinds in your doctors’ waiting rooms so that others can be informed and educated about this rare disease. You can help us spread the word about the symptoms and treatment of PBC and potentially encourage early diagnosis.

Call our toll free number 1-866-441-3643 to order 10 free PBC information brochures and postcards.

MEDICAL & RESEARCH NEWS

CANADIAN PBC SOCIETY WINS A GRANT

In April, the Canadian PBC Society Peer-to-Peer Support Program won a Practice to Policy Health Awards Program grant from Intercept Pharmaceuticals. The competition drew submissions from Canadian, American and European researchers, clinicians and patient groups specifically focusing on encouraging new research and improving care for people living with PBC.

The Peer-to-Peer Support Program is designed to combine educational workshops with one-to-one peer support. The project will conclude in May 2017 and publication of results will follow.

ONE STEP CLOSER TO OCA

In September, Intercept Pharmaceuticals announced the filing of a New Drug Submission to Health Canada, seeking Canadian marketing approval for obeticholic acid ('OCA'). OCA is intended to be used in combination with URSO by PBC patients who have an inadequate response to URSO – or on its own for those patients who aren't able to tolerate URSO. This is the first new treatment option for PBC in 20 years.

We are pleased to say that the submission has been granted priority review by Health Canada, recognizing the high unmet medical need for new therapies in PBC. The U.S. Food and Drug Administration (FDA) approved the marketing of OCA in May of this year.

We'll advise you immediately when Health Canada's decision has been announced.

CANADIAN PBC SOCIETY SUPPORTS ANTIRETROVIRAL THERAPY STUDY

Dr. Andrew Mason, University of Alberta, Edmonton continues his work using antiretroviral therapy for patients with PBC, with the support of the Canadian Institute for Health Research and the Canadian PBC Society.
The study continues to look into the possible viral involvement in PBC and the potential for antiretroviral therapy to have a positive impact on patients with PBC.

Gail Wright, Nancy Stewart & Josh Lai

CANADIAN PBC SOCIETY SUPPORTS PBC EDUCATION & AWARENESS

The Canadian PBC Society was privileged to present the proceeds from this year's 'A Day at the Races' to the Toronto General and Western Hospital Foundation. The funds will be used to initiate, develop and implement programs focused on promoting education and awareness of PBC and ensure early detection and treatment for people across Canada.

INTRODUCING THE NEW TORONTO CENTRE FOR LIVER DISEASE – One of the largest liver units in North America

The latest expansion of our network of PBC specialists came with the official opening of the **Toronto Centre for Liver Disease** (TCLD) in September. With a dozen hepatologists on board, the TCLD is one of the largest liver units in North America. The Centre is made up of three sites: the Toronto Western Hospital Francis Family Liver Clinic, the Toronto General Hospital Liver Unit and the Toronto General Hospital Liver Transplantation Unit.

We are also fortunate in welcoming two important additions to the PBC medical and research team in the TCLD:

Dr. Aliya Gulamhusein, a gastroenterology specialist who joins us from the Mayo Clinic in Rochester, Minnesota as the new PBC doctor in the liver clinic.

Dr. Bettina Hansen, biostatistician, has also joined the TCLD team. Dr. Hansen was formerly Associate Professor in the department of Gastroenterology and Hepatology, Erasmus MC University Medical Center, Rotterdam, the Netherlands. She also is a key member of the Global PBC Study Group, which was founded in 2012 as an international collaboration between medical centres performing research in PBC.

Nancy Stewart, Canadian PBC Society with
Dr. Harry Janssen, Program Director, TCLD

CANADIAN PBC SOCIETY NEWS

A MESSAGE FROM THE PRESIDENT

As we approach the end of the year, I want to say "thank you" to the many members and volunteers who have supported and helped the Canadian PBC Society increase its impact this year. Your efforts and commitment have truly paid off as you'll see from my update on all the things we have accomplished together.

Let me start by introducing our team. We are a totally volunteer, non-profit organization managed by a small executive committee:

- **Gail Wright**, *President*
- **Barbara Badstober**, *Past President*
- **Debbie Deinhart**, *Treasurer*
- **Nancy Stewart**, *Member Communications*
- **Katherine Fuerst**, *Advisor*

We continue to have ongoing relationships with a network of recognized world leaders in the field of PBC research who provide us with up-to-date information about the latest developments in diagnosis and treatment. They include:

- **Angela Cheung**, *MD, FRCPC — Research Fellow, Mayo Clinic, Rochester, Minnesota*
- **Andrew L. Mason**, *MBBS, FRCPI, FAASLD — Professor of Medicine, Director, The Applied Genomic Core, Division of Gastroenterology and Hepatology, University of Alberta, Edmonton*
- **Mark G. Swain**, *MD, MSc, FRCPC, FAASLD — Professor of Medicine, Cal Wenzel Family Foundation Chair in Hepatology; Head, Division of Gastroenterology and Hepatology, University of Calgary; Head, Section of Gastroenterology and Hepatology, Alberta Health Services, Calgary Zone*

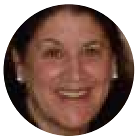
Representing the Patient's Perspective

In late September, I was invited to participant in a day-long roundtable discussion, facilitated by Intercept Pharma. Participants included a number of PBC doctors and researchers from across Canada, the Canadian Liver Foundation and representatives from government agencies. My role was to present the patient's perspective on PBC. It was an excellent opportunity for us to make our voices heard and to help the others understand the specific issues, concerns and needs that PBC patients have.

Participation in this worthwhile session has opened the door for much more dialogue and better understanding of PBC patients' needs among the medical community as well as policymakers.

The Canadian PBC Society is a small organization, but with the support and contribution of our worldwide network, we have mighty ambitions. Together with our partners we are helping to make a difference in the lives of PBC patients and their families and also helping to fund research in the search for a cure.

2016 has been a busy year – no doubt about that. We have even more exciting plans and opportunities ahead of us in 2017 and I'm looking forward to sharing more details and updates with you over the next few months. In the meantime, thank you again for your support, for your commitment to raising awareness of PBC and encouraging early diagnosis.



Warmest Regards,
Gail Wright
President, Canadian PBC Society

HERE'S WHAT THE PBC SOCIETY HAS BEEN UP TO THIS YEAR (SO FAR!)

These are some of our most recent patient support, awareness-building and fundraising activities:

A Day at the Races

On May 6th we enjoyed the company of more than 150 guests in a private tent at Toronto's Woodbine Racetrack where we honoured Dr. Jenny Heathcote with a special Lifetime Achievement Award.

**PHOTOS: Left, Dr. Jenny Heathcote, Dr. Harry Janssen, Gail Wright.
Right, special blanket presentation**

PBC Self-Management Workshops

In June, PBC members in Alberta, Ontario and B.C. participated in the first of two self-management workshops in Toronto, Edmonton and North Vancouver. Robert Mitchell-Thain, Development Officer for the PBC Foundation, UK developed this workshop to help people live well with PBC. I would like to thank Robert and our regional coordinators, Shauna Vanderwell, Alberta and Kathyrn Swift. BC for making the workshops a resounding success.

PHOTOS: Left: Vancouver Bottom: Edmonton

**Gail Wright with
Carol Roberts**

PBC Beyond Borders

Primary Biliary Cholangitis doesn't have borders… and neither do the PBC societies and foundations. This year we have made important strides in strengthening our ties and collaboration with our colleagues in the UK and USA. Our self-management workshops were developed by Robert Mitchell-Thain from the PBC Foundation in the UK who has successfully delivered this workshop around the world.

As part of our International PBC Day communication efforts in September, I met with Carol Roberts at the Canada/US border in Niagara Falls. Carol is a key leader of the PBCers organization in the United States and we used the opportunity to get together to share stories and experiences in both our organizations and discuss ways in which we may work more closely together in the future.

Dates to Remember

Sunday September 11, 2016

International PBC Day

PBC can be symptom-free for many years. Encourage your friends and family to check their liver enzymes as part of their annual health checklist. And help us

Tweets by @PBC_Canada

PBC Canada Retweeted

Stephen Lyons @Stephen83069417

Start September off by registering to be an organ donor..It's so easy & only takes minutes 💚 beadonor.ca

New Website!

We commemorated International PBC Day on the second Sunday in September with the launch of a new, refreshed website with more comprehensive information about PBC, tips on health and nutrition, and answers to your questions from PBC doctors.

New Tools

As part of the website relaunch, we also introduced a brand new tool, developed in collaboration with a specialist company called Self Care Catalysts. The tool is an app, called ***PBC Health Storylines***, which is available FREE on both iOS and Android devices. It's a simple online tool that helps you manage your symptoms, medication, doctor appointments, lab results and more. ***It's one handy tool on your phone or tablet to TRACK EVERYTHING!***

If you haven't already done so, be sure to visit pbc-society.ca to take full advantage of all the helpful information and useful tools that are there just for you.

ASK THE PBC DOCTOR

QUESTION:

I was diagnosed with PBC approximately six years ago, but have had symptoms going back 30 years. I am current 50 years of age. According to my physicians, my blood work liver function tests keep coming back perfect (normal bilirubin, Alk phos, etc.) but the fatigue and energy level that I am experiencing is almost debilitating. I am on Ritalin in order to be alert at work, though the effect seems to be waning as the fatigue increases. I really care about nothing anymore — I just want to curl up and sleep all of the time. I just want to be left alone, as nobody understands that I am sick. Does the fatigue extent increase with the stage of the disease, and even though the blood work returns normal, is the disease progressing? I don't remember what stage it was for my biopsy; either Stage 1/2 or Stage 2/3 though my understanding of this is that it is not necessarily an accurate measurement when doing needle core biopsies.

ANSWER:

Dr. Angela Cheung:

There is no clear link between the severity of liver disease in PBC and the severity of fatigue (or tiredness) that people experience. This means that even though your liver may be functioning completely normally and your PBC is under good control and not progressing, you may experience severe fatigue. Unfortunately, there are no treatments that have been well studied for fatigue, and so the long-term safety of medications such as Ritalin have not been well-studied in PBC. It is also important to remember that there are a lot of causes of fatigue. Depression, thyroid disease and many other medical diagnoses can cause fatigue. It is important for the doctor to rule out these things too, to make sure you get the right treatment for your fatigue. A liver biopsy in PBC is fairly accurate, though now liver biopsies are rarely done because blood tests and a special ultrasound scan called a "fibroscan" can check the level of scarring in the liver.

For many more Questions & Answers from our PBC Doctors, please be sure to visit the comprehensive Q&A section of our website **http://pbc-society.ca/ask-the-doctor/**

TIPS FOR HEALTHY LIVING

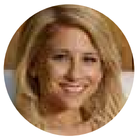
QUESTION:

I know I should be avoiding alcohol and tobacco. Are there any foods that are considered toxins or foods that will put extra stress on my liver?

ANSWER:

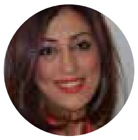
Dr. Angela Cheung, MD:

Previously, it was felt that people with liver disease should be put on a low protein diet, especially those with advanced cirrhosis. We now know that this is not true, and in fact often patients with cirrhosis will need to increase the protein in their diet, as cirrhosis causes “muscle-wasting” or an increase in the breakdown of the muscles in your body. The extra protein can be taken through food, or through supplemental protein powders or dietary supplements like Ensure or Boost, which will increase the amount of calories you take in, some of which will be converted to protein. People with PBC with no cirrhosis or very early cirrhosis may take normal amounts of protein in their diet (i.e., 10-15% of your total intake or 2 servings a day for women and 3 servings a day for men).



Dr. Regan Tessis, ND:

You should also try to eat a diet that is rich in whole, unprocessed foods to limit your exposure to liver toxic additives and preservatives. Shop the outside aisles of the grocery store to fill up on fresh produce, fish, poultry, and whole grains and only choose packaged foods with recognizable ingredients. Limit your intake of added sugar as this can lead to fat buildup in the liver which can result in liver inflammation. You may also need to limit your fat intake (other than MCTs) as indicated above if you are experiencing diarrhea and abdominal pain. Dietary sodium can cause tissue swelling and the buildup of fluid in the abdomen and so it is also a good idea to reduce your sodium intake. Purchase unsalted or low sodium products only. Use seasonings other than salt to flavour your foods.



Kathy Oghalai, RD:

Try to eat as much fresh, unprocessed food as possible. Avoid soft drinks, cold cuts and all processed meats.

For many more diet, nutrition and exercise questions and answers, please be sure to visit the comprehensive Healthy Living section of our website http://pbc-society.ca/healthy-living/

WANT TO GET INVOLVED?

As a totally volunteer-run organization, we are always happy to welcome new members to our team. So if you have the time and interest, we can put your talents to good use. We have many areas where our volunteers enjoy being involved: helping to organize information sessions in their local regions, planning fundraising events, providing life stories for our communication programs, and helping with outreach efforts to increase our membership.

Current Volunteer Opportunities

You can make a difference! The Canadian PBC Society is looking for volunteers in the following areas:

- **Board of Directors** — Director at Large
- **Community Coordinator** — Local support for newly diagnosed
- **PBC Blogger** — Submit monthly blog of 250 words plus pictures

If you are interested in exploring some current volunteer opportunities, please email or phone our national office info@pbc-society.ca or 1-866-441-3643

TELL US WHAT YOU THINK

Please let us know what you think about the PBC Connections newsletter:

- What you like
- What you find most useful/helpful
- What you don't like
- What you think we should remove
- What new content/subject areas would be helpful to you

Please email our national office: **info@pbc-society.ca** with the subject line "CONNECTIONS" or phone 1-866-441-3643.

IF YOU WANT TO TELL US YOUR PBC STORY

Your story should be no more than 250 words, pictures are welcome. Please send email submission to: **info@pbc-society.ca**

FOLLOW US ON FACEBOOK & TWITTER!

twitter.com/PBC_Canada

facebook.com/CanadianPBCSociety

Alberta North
www.facebook.com/pages/Canadian-PBC-Society-Alberta-North-Region

Ontario
www.facebook.com/pages/Canadian-PBC-Society-Ontario-Region

Quebec
www.facebook.com/pages/Société-canadienne-de-la-CBP

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REGIONAL
CONNECTIONS

ALBERTA NORTH

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

ATLANTIC

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

BRITISH COLUMBIA

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

GOLDEN HORSESHOE REGION

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

MANITOBA

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

TORONTO

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

SOUTHWESTERN ONTARIO

For more information, please contact **Betty Van Luven**: bvanluven@rogers.com or 226-339-3173

OTTAWA

For information, please contact **France Foucault**: ffoucault@hotmail.com

QUÉBEC

En septembre 2016, notre rencontre s'est tenue dans la belle région de Charlevoix. Ces deux journées ont permis de fraterniser, d'échanger sur plusieurs points de vue de la CBP, de visiter certains attraits de la région et de passer du réel bon temps ensemble. Nous nous donnons rendez-vous l'an prochain dans l'Outaouais.

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