



PBC connections

A Canadian PBC Society Newsletter

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IN THIS ISSUE

Learning to Live Well with PBC	1
Medical & Research News	4
PBC Society News	6
Spreading the Word	7
Regional Connections	8

LEARNING TO LIVE WELL WITH PBC

“For many of us, it is challenging to live well with PBC, and it can be difficult to explain to others what it is like to live day to day with the symptoms of a chronic illness. But that doesn’t change our desire and need to stay connected to friends, family and others, let alone meet new people.”

Kathryn Swift, Canadian PBC Society Regional Coordinator, Vancouver, B.C

“LIVING WELL WITH PBC” NATIONAL PATIENT’S CONFERENCE

Making new connections with other PBC patients ... developing new coping strategies by learning from each other’s experiences ... sharing our stories ... and gaining important insights from some of the top physicians and PBC researchers across Canada. That was the focus of this year’s National Patients Conference **“Living Well with PBC”**.

We welcomed more than 140 PBC patients, friends, and family members from across Canada and the U.S. for two days of caring, sharing, learning ... and some fun to go along with it.



Here's what some attendees had to say about their conference experience.

“Great conference. I feel less isolated as I had a chance to meet so many others with the same disease.”

“I did not think that I would learn anything new but was proved wrong. I came away on an emotional high that I still have days later. I found the doctors so open and willing to share. It was truly a learning opportunity for all of us.”

“Since my diagnosis four years ago, I have lived in isolation and had a number of unanswered questions. Being able to bring my spouse and have the opportunity to speak with the specialists directly was invaluable and I now feel so much more empowered.”

Experience the conference for yourself

If you weren't able to join us at the conference, we hope you'll take advantage of our virtual conference experience. We've posted videos of all the major presentations on the [Canadian PBC Society YouTube channel](#).

NEW! PBC WELLNESS PROGRAM

... COMING YOUR WAY IN 2020



We keep looking for new ways to help patients “live well with PBC”, and we’re excited to give you a preview of a new wellness program that’s currently being developed for PBC patients by

Dr. Puneeta Tandon, Associate Professor, Gastroenterology, Department of Medicine at the University of Alberta. Dr. Tandon gave us a sneak peak of what she and her team are working on.

Q: Dr. Tandon, can you give us a few details about this new wellness program?

A: It’s an easy-to-access way for anyone who wants to learn some new techniques to release stress, deal with negative emotions and build resilience. We’re calling it the “PBC Peace Power Pack” and we’re very excited to have this opportunity to introduce it to PBC patients!

Q: How will the program work and what will it include?

A: We’ll be rolling out the first version as a ten-week pilot program with short surveys done at the beginning and end of the ten weeks. That information will allow us to have a better understanding of the program’s impact on symptoms and stress levels. Most importantly, it will provide us with feedback on how to make the final version even better!

All PBC patients in Canada will be eligible to enroll. Each week, there will be a new theme including topics such as grounding, gratitude, forgiveness and visualization. The program will include nutrition tips designed for PBC... some

basic yoga postures that can be practiced at home... powerful breathing exercises...and unique meditations.

Participants can also tap into a vast toolbox of positive psychological practices including gratitude, visualization, affirmations, and self-compassion. And each week we’ll include some practical tips from a host of different PBC specialists.

Q: How do you think this program will help PBC patients?

A: It isn’t easy to live with the stress and symptoms of having a chronic disease. My hope is that this program will make the journey easier. By co-designing the program with the PBC Society and a patient advisory group, we’re doing our best to make sure it meets patients’ needs in very practical ways. Different parts of the program might resonate differently for everyone, but if each person can walk away with even one or two stress-release tools that can be used in their day-to-day life, that would be tremendous.

Watch for the Peace Power Pack’s introduction in early 2020!





MEDICAL & RESEARCH NEWS

TALKING WITH DR. SWAIN ... ON “WHY PBC FATIGUE IS ALL IN YOUR HEAD”



After the national patient conference, we spoke with Dr. Swain and asked him to tell us more about his research into the links between PBC and the brain, especially PBC fatigue.

Q: Your presentation about the connection between PBC and the brain got everyone’s attention. Please tell us more.

A: I’ve been interested in brain research and how the brain is impacted by chronic disease for about 25 years. When it comes to understanding PBC, one of the questions I keep asking is, “why does inflammation in the liver lead to chronic fatigue?” My research tells me that PBC fatigue isn’t really a muscle issue; it’s a brain issue, so it actually is all about what’s happening in your head.

Q: How have you reached that conclusion?

A: Much of our early research was with animals in our lab. Those studies suggest there are several ways that inflammation in the liver might be signaling the brain and changing how it functions.

In addition to our animal-based research, more recently we’ve been using “functional MRIs” to conduct studies on people with PBC to see how different parts of the brain are working and how the brain communication networks are talking to each other. We’ve found that in PBC patients’ brains these are abnormal.

Q: In what ways are PBC patients’ brains different?

A: The brain structure is altered in PBC. Compared to non-patients, the neural activity is lower in some parts of the brain that are important for regulating our day-to-day behavior. A key portion of the PBC patient’s brain that regulates memory and emotion is smaller. That may explain why many PBC patients suffer from brain fog and mood and memory problems. That’s why I believe that when you’re told your PBC fatigue is all in your head, it probably is.

Q: Could these findings about the brain/fatigue connection lead to potential new treatments for PBC patients?

A: Yes, I believe they will one day. A better understanding of what parts of the brain are.

SURPRISING NEWS ABOUT MIRTAZAPINE FOR PBC PATIENTS

Dr. Mark Swain told us that the University of Calgary research team had access to a large database of PBC patients in England. The team looked at patients who were being treated for depression compared those who didn’t report depression. What they found was surprising: PBC patients who had depression seemed to do better clinically than those without depression.

These findings were unexpected, however the team noted that this beneficial effect was explained by an additional finding: PBC patients being treated with the anti-depressant

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Mirtazapine had improved outcomes compared to those who were treated with a different anti-depressant.

Mirtazapine appeared to significantly protect patients from liver decompensation, the need for liver transplant, and mortality. Therefore, given that it is a safe and widely used medication, Dr. Swain and his team believe that Mirtazapine may be a novel therapeutic approach to PBC and other autoimmune liver diseases in the future

TALKING WITH DR. GULAMHUSEIN ... ON THE IMPORTANCE OF THE NATIONAL PBC PATIENT REGISTRY



The purpose of the CaNAL (Canadian Network for Autoimmune Liver Disease) national registry is to track PBC and AIH patients' medical histories and all relevant clinical events over the long term. It includes existing patients and those who are newly diagnosed.

We spoke with Dr. Gulamhusein to get an update on the program and the benefits of participating.

Q: Can you give us an update on the patient registry program?

A: The data collection process began in 2018; we now have retrospective data collected from approximately 3,000 patients and about 500 prospective patients that we have recruited. All the data is now being organized in the active sites, and we're expanding the network in additional east- and west-coast centres.

Q: How many sites are currently collecting this data?

A: There are currently five active sites:

- University Health Network, Toronto, ON
- Kingston Health Sciences Centre, Kingston, ON

- Centre Hospitalier de l'Université de Montréal, Montreal, QC
- Walter C. Mackenzie Health Sciences, Edmonton, AB
- Royal University Hospital, Saskatoon, SK

Our ultimate goal is to have at least 13 active sites collecting prospective data from patients.

Q: What are the benefits of the registry?

A: It's becoming clear that if we're going to make major advances in the treatment of diseases, we have to collect clinical data on a large scale. And that includes the collection of routine data from patients' clinical records. A patient registry like CaNAL captures information on a patient's diagnosis, treatments, symptoms, and the impact of their condition. This helps us carry out further exploratory research. It also helps us improve our clinical care, facilitate large-scale clinical research on PBC, and gives patients opportunities to participate in studies to get a better understanding of all aspects of PBC.

Q: Can you give us some examples of how the data is being used?

A: A manuscript on the real-world effectiveness of Obeticholic Acid on PBC patients is currently being developed and will be submitted to a peer-reviewed journal for publication. The team will also be working on posters and abstracts to present at Canadian and European liver meetings.

Q: How can PBC patients participate in the registry?

A: Patients who attend clinics at any of the active centres can participate; they should let their doctor know if they're interested in taking part.

CANADIAN PBC SOCIETY NEWS

A MESSAGE FROM THE PRESIDENT

As I look back on everything the Canadian PBC Society has been able to achieve this year, I am truly amazed that a completely volunteer-run organization like ours has accomplished so much. We hosted a successful national patients' conference, the first in more than 10 years, and continued to deliver great programs, spread awareness, advocate for PBC patients and contribute to PBC research. This is all thanks to our extensive network of extraordinary volunteers and strong industry partnerships.

I am very proud of our entire team of PBC volunteers across the country:

- Board Members who implement our annual plan and provide oversight and direction for the Canadian PBC Society.
- Regional Coordinators who provide the foundation of our one-to-one patient support across Canada and organize local luncheons, speaker dinners, and workshops.
- Local Group Leaders who provide an opportunity for local support in distinct communities.
- Individual volunteers who help us run events, reach out to members, stuff envelopes, distribute PBC educational material and much more.
- Pro Bono Consultants who provide us with much-needed expertise in Web design, Information Technology, Legal, Accounting, and Graphic Design.
- Industry Partners who sponsor many of our special programs, provide networking opportunities, and opportunities for collaboration and research.

- Medical Partners who volunteer their time to help us ensure that patients have timely and accurate information on PBC diagnosis, treatment and disease management - whether speaking at patient meetings, writing articles for our newsletter or reviewing content for our brochures or website.

So, my message is a BIG THANK YOU to all of you who have helped us accomplish so much. I'm looking forward to continuing our work together in the year ahead.



Gail Wright

Gail Wright

President, Canadian PBC Society



SPREADING THE WORD

PBC AWARENESS MONTH

During the September PBC Awareness Month, we once again used our online PBC Awareness Quiz as a fun and engaging way to increase awareness about our disease, its symptoms, diagnosis, and treatment. And there were prizes involved! We hope you were one of the lucky daily winners and that you shared the quiz with your friends and family so they too could learn more about PBC and how it might be affecting you. The campaign was a tremendous success, increasing PBC awareness by reaching thousands of people!



Joining PBC hands across the border

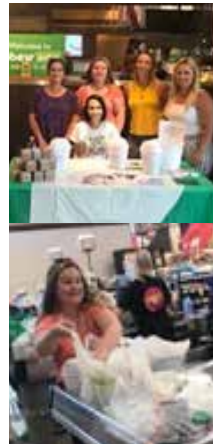
PBC Awareness Month also gave us the opportunity to come together and share our experiences at our fourth annual “PBC cross-border lunch”. The very first lunch brought one patient from Canada and one from the U.S. (and their respective spouses) together in Niagara Falls, NY. Now, three years later,



more than 20 patients travelled to Niagara Falls, NY for this annual event.

SPREADING THE WORD ... ONE BAG AT A TIME

Kailey Jackson is a young woman with a mission. Her mom is a PBC patient and Kailey says, “PBC may be a rare disease, but I’m determined to make it less rare by making more people aware of the disease and how it affects all our lives. I’m also on the look-out for new ways to raise funds for the Canadian PBC Society so we can keep



supporting patients and the research that’s needed to find a cure one day.” Kailey has come up with some unique ways to spread the word and raise some funds for PBC. This year, she got permission from her local Sobeys to bag groceries for a day, to tell customers about PBC, and share her mom’s personal story. Kailey, along with her mom and three friends spent a day spreading the word and raising \$429.20 for PBC at the same time.

RAISING AWARENESS WITH PHYSICIANS

We all recognize the importance of an early PBC diagnosis and lifelong treatment to achieve a normal life expectancy. And since early diagnosis is so important, but sometimes difficult to achieve, we’ve been testing some new ways to make the GP/family physician community more aware of PBC. In November, for example, we host an informational exhibit to bring our story to more than 1,500 physicians, nurse practitioners, researchers and other medical professionals at the Annual Scientific Assembly of Family Physicians in Ontario.

NEW! Website Portal for Physicians

To reach the broader medical community, we’ve also recently created a dedicated section of the PBC Society website with information that’s relevant and of interest to physicians and other medical professionals. Again, our goal is to increase awareness about PBC and improve the rate of early diagnosis and treatment. The site should be live early in 2020.

REGIONAL CONNECTIONS

“LIVING WELL WITH PBC” WORKSHOPS AND DINNER MEETINGS

While much of our time was focused on organizing the National Patients' Conference in the early part of this year, our members had the opportunity to take part in our special “Living Well with PBC” workshops in Victoria, Calgary and Winnipeg and dinner meetings in Vancouver and Duncan, B.C. in the autumn of 2018.



Our dinner/speaker meetings have continued throughout this autumn and we're delighted that we've had the opportunity to host first-time events in Fredericton, Hamilton, and St. John's and return visits to Vancouver, Victoria, Halifax and Edmonton.

More events are on the schedule for 2020, so check the “[Dates to Remember](#)” section on the homepage of our website to see when one may be coming your way, or make sure you are on our mailing list so that you get an email notification of events in your area. We really hope you'll join us to meet other PBC patients in your area and hear from some of our country's top PBC experts.

QUEBEC REGIONAL UPDATE

After all these years, Francine Lamontagne, our Quebec regional coordinator has decided to step aside from her role, and we sincerely appreciate all

the support she has provided over the years. We are looking for enthusiastic volunteers for this region and we hope to have a new leader for our Quebec group in place soon.

In the meantime, Brigitte Caron has graciously volunteered to help by keeping our francophone members up to date on the latest PBC news through a new Facebook page: [facebook.com/ Société Canadienne de la CBP \(Québec\)](https://facebook.com/SociétéCanadienne.de.la.CBP.(Québec)).

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