



# PBC connections

A **Canadian PBC Society** Newsletter

2017 • VOLUME ONE

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### PBC TREATMENT ENTERING AN EXCITING NEW PHASE

While we’re continuing to focus on finding a cure for PBC, it’s encouraging to see that the treatment of PBC has entered an exciting new phase. We’re aware of at least seven potential new treatments that are in clinical trials right now in a number of specialist centers across Canada. And with so many new studies underway, many of you have been asking:

- “What are the new treatments that are being developed?”
- “How can I access these new medications?”
- “How do specialists/hospitals decide which drug trials to run?”
- “How are PBC patients chosen to participate in a trial?”
- “If I wanted to take part in a trial – how would I do that?”

To answer your questions, we’ve invited Dr. Mark Swain, head of the gastroenterology and hepatology division at the University of Calgary, to contribute an article to this issue of PBC Connections where he answers these questions... and many more.

In his article, Dr. Swain says, “The recent release of obeticholic acid (OCA) for the treatment of PBC in those people who do not respond to UDCA therapy is an exciting advance for people whose disease continues to

progress despite UDCA treatment. However, in addition to OCA, there are numerous other medications currently in clinical trial assessment. These offer potential alternatives for therapy in PBC patients, but are all still available only through clinical trials. So the question that logically comes up is, how do I as a patient get access to these new clinical trial drugs?”

Read Dr. Swain’s comprehensive article on pages 6 & 7 where he describes how hospitals/ specialists decide what trials to run and how PBC patients are chosen to participate in these studies.

Our thanks to Dr. Swain for giving us an excellent summary of what the new drugs do, what their targets are in PBC, and the potential risks and benefits of these new drugs.





# SPREADING THE WORD

## TAKING OUR MESSAGE TO GOVERNMENT

We continue to be committed to patient advocacy, as the Canadian PBC Society takes on an expanded role as the “voice of the PBC patient” in our community, reaching out to healthcare and government policy decision-makers.

This year we were able to present a comprehensive submission to the Canadian Common Drug Review. In our submission we were able to represent the needs of PBC patients in Intercept’s OCA submission to Health Canada. We have also been meeting with members of the medical community as well as government representatives nationwide to discuss the needs of the Canadian PBC community.

To date, we have had in-person meetings with officials in Nova Scotia, New Brunswick, British Columbia and Ontario. Additional provincial meetings are currently being scheduled to take place through the balance of this year.

Our patient advocacy work has been, and continues to be, an important part of the PBC Society mandate as we continue to build awareness and a better understanding of the need for better diagnosis and treatment of PBC and the many Canadians it affects. The time for progress is now as research and new drugs come into the market, and it is our responsibility to make sure there is a good understanding of what is required to combat and eventually cure PBC.



## International PBC Day

The PBC community came together across the globe on International PBC Day to raise awareness of PBC symptoms, diagnosis and treatment with 13 countries including Austria, Denmark, Finland, Germany, Italy, Macedonia, Norway, Portugal, Sweden, The Netherlands, UK, USA and Canada participating in an international PBC awareness campaign called #PBCandMe.

On September 6th we had a wonderful gathering of Canadian and US PBC patients in Niagara Falls, NY, where we enjoyed a delicious lunch and great conversation.



Here in Canada, we took the opportunity to spend the day among Ontario government decision-makers and elected officials. PBC Awareness Day at Ontario's Queen's Park involved all the members of our Board and 10 PBC patients, friends and their family members. It included a full day of meetings with elected officials and their staff, as well as an invitation to attend the daily legislative proceedings during Question Period, personal introductions to our participants' MPPs, lunch in the legislature dining room and the group photo below – all of which helped us to raise awareness of PBC and the patient's journey.



# TELLING OUR STORIES

## IN THE SPIRIT OF SHARING

We were very fortunate this year to be included in the **National Post's "Patient Profile"** series. We know it isn't always easy to talk about our disease and what it's like to live with PBC. But we also know that one of the most powerful ways to raise awareness is by doing that very thing: to share our stories and emphasize the life-changing importance of early diagnosis and the proper treatment of PBC.

We are grateful to the four PBC Canada members who so openly shared their stories in the Post's **Patient Profiles** and provided important insights into the many different ways that PBC can affect us.

In that spirit of sharing, here are some excerpts from Gail, Jackie, Kate, and Carey who graciously told their stories. To read the full articles, visit our website [www.pbc-society.ca/blog](http://www.pbc-society.ca/blog)



### Gail

*"PBC is just not on the radar for most doctors and the chronic fatigue that is a common symptom can be confused with depression," Gail points out. "But my GP had been taught by a specialist in PBC. So, after seeing from routine blood tests during my annual checkup that my liver enzymes were elevated, she referred me to a liver specialist, even though I was feeling healthy and had no complaints or symptoms."*

After a year of extensive testing, Gail was diagnosed with PBC. *"I was told there was no cure and only one drug available to manage the disease. For months, my husband and I had a cloud hanging over us as we wondered what the future was going to be and how much time I had left."* It is cases like Gail's that demonstrate the need for increased awareness of rare diseases like PBC.



### Jackie

The risk of developing PBC is significantly greater for people with other autoimmune diseases. Jackie, for example, also suffers from autoimmune hepatitis. Her three sisters have autoimmune disorders, although none of them has been diagnosed with PBC. Jackie, who has three adult children, says that one daughter has been found to be clear of PBC and the second is to be tested for the disease. Her son is much less likely to be affected, as 90 per cent of sufferers are women.

Jackie's PBC, which has been categorized as advanced, forced her to give up her job in retail for health reasons. However, she is a regular volunteer with a cat rescue agency and spends as much time as possible enjoying life with her grandchildren.



### Kate

*"My journey has been a little different from that typical for other people with PBC," adds Kate. "I was 30 when I was diagnosed, which is outside the usual 40 to 60 age range. I responded immediately to the one drug for PBC, which is positive, but the biopsy that the hepatologist did showed I had signs of cirrhosis of the liver and put me at Stage 3 or 4 right away."*



### Carey

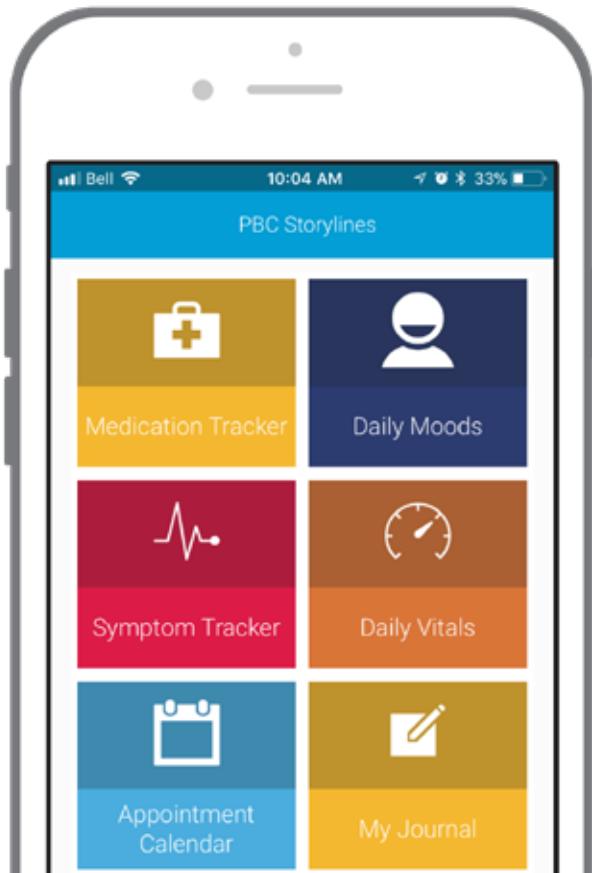
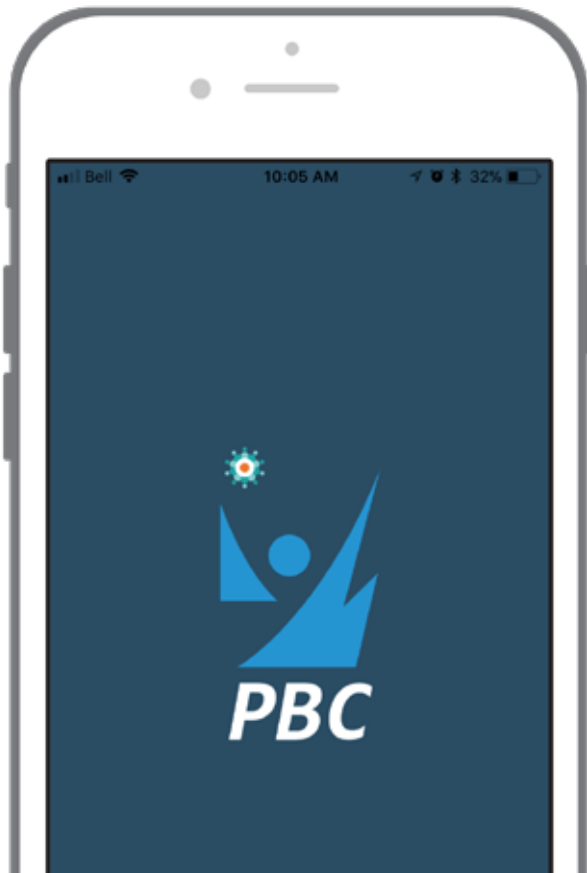
Carey is one in a million. And it is a number that the commercial bank manager would rather not claim. *"I've felt tired for most of my life without really knowing why," says Carey, whose PBC had progressed to Stage 3/4 by the time it was diagnosed. "Looking back, I know I've always needed my sleep. Even as a teen, I went to bed early. Now, there are days when I don't have the energy to sit up straight on the couch."*



## Try our FREE App: PBC Health Storylines

All the tools for managing your PBC in one place! Try it today. It's 100% FREE. Track symptoms, medications,

lab results and more on your smart phone or tablet.



# NEW MEDICATIONS FOR PBC: WHAT ARE THEY AND WILL I BE ABLE TO ACCESS THEM?

by Mark G. Swain, MD, MSc, FRCPC, FAASLD Head, Division of Gastroenterology and Hepatology, University of Calgary

Primary biliary cholangitis (PBC) is an autoimmune disease. Like all autoimmune diseases, no one knows what causes PBC and therefore treatments cannot be targeted to specific issues. Instead they are being developed to target broad processes that are associated with PBC and that damage the liver. For example, UDCA can be effective in preventing the progression of the disease in about 2/3 of patients with PBC. But how it does this is not well understood, likely targeting multiple pathways that can lead to liver damage.

Over the past few years, PBC has become the focus of drug development for a number of pharmaceutical companies, targeting different potential pathways that may contribute to liver damage in PBC patients. This research has led to the recent release of obeticholic acid (OCA) for the treatment of PBC in those people who do not respond to UDCA therapy. This is an exciting advance for people whose disease continues to progress despite UDCA treatment.

However, in addition to OCA there are numerous other medications currently in clinical trial assessment that are being developed to treat PBC. These offer potential alternatives for therapy in PBC patients, but are all still available only through clinical trials. So the question that logically comes up is, how do I as a patient get access to these new clinical trial drugs?

This article is intended to address some common questions that patients often have regarding PBC clinical trials, gaining access to new drugs, and what new drugs are out there.

## What are some of the basic ground rules about clinical trial access and involvement for PBC patients?

### 1. How do hospitals/specialists decide which trials to take on and run?

Many larger pharmaceutical companies (e.g., GSK, Gilead) have longstanding relationships with clinical sites and investigators that have carried out clinical trial research as partners in the past. This historical link provides a conduit to request interest in performing new studies in different therapeutic areas – for example going from successful trial partnerships in hepatitis C drug clinical trials to possible involvement in PBC studies.

In contrast, smaller pharmaceutical companies (e.g., CymaBay) may reach out broadly to investigators and specialists, often through word of mouth, to see if they would be interested in participating in a trial. Taking on a trial at a particular site is not a trivial matter,

and requires that a sound clinical and research infrastructure be in place to support doing a clinical trial. In addition, manpower must be available and time allotted to carry out the research effectively. Additionally, the investigator must have enough patients in their practice to make patient recruitment a feasible prospect. For example, doing all the necessary paper work and hiring of key personnel to enroll one or two patients would be hard to justify. Therefore, for a disease like PBC which is relatively rare, often trials can be run only through the offices or clinical sites of individuals who have large practices of liver patients containing a large cohort of PBC patients.

### 2. How do sites decide which trials to run?

Given the relatively small number of PBC patients in most clinical practices, it can be a challenge to find patients who would be eligible to participate. Given this reality, most sites need to be selective about how many trials to take on so that they are able to recruit enough patients for a given study to make all of the necessary work associated with the trial feasible. For example, let's say a specialist had 10 PBC patients in his or her practice. Six of these had responded well to UDCA therapy and of the four patients who did not, two had other illnesses that made them ineligible. That would leave only two patients to potentially enter the study, and if neither of them wanted to be included, there would be no one left to recruit. Even one study in this case would be "too many". This is the constant balance investigators and their staff deal with when deciding whether or not to take on new studies.

### 3. How are PBC patients selected to join which studies?

This decision is based on a number of things. For example, does the patient meet the eligibility criteria for the study that is being conducted (e.g., if diabetes is an exclusion criteria for study X, but not for study Y, then diabetic PBC patients would be eligible for Y but not X)? Additionally, the number of patients included in a trial is typically decided before starting a study and all sites are given a certain number of spots that they can fill. If a site is given four spaces in a trial and they have filled these, investigators often will look at other potential studies. Also, if someone has significant itch, involvement in a trial that is studying a medication not associated with itch may be a better choice for that person.

Another issue comes up with regards to potential patient access to the study medication after the clinical trial is over. Some companies provide extended access to open label medication after the end of the study, and some do not (or can not). Also,

some studies do not allow for the inclusion of patients with very advanced liver disease (e.g., cirrhosis), as they may feel that this patient population may be too far advanced for the medication to be effective.

### What new drugs are in the pipeline for PBC?

As mentioned above, PBC is an autoimmune disease that can lead to liver scarring (fibrosis) and eventually cirrhosis and liver failure. For decades, UDCA was the only medication available for treating PBC patients. However, an exciting array of drugs are currently in clinical trials for PBC, and OCA has recently received Health Canada approval for treating PBC patients. So what do the new drugs do, what are their targets in PBC, and what are the potential risks and benefits for these new drugs?

Patients with PBC can be considered to have early disease (liver damage from immune cells with associated inflammation, limited liver scarring), moderate disease (ongoing liver inflammation but now with more liver scarring), and advanced disease with extensive liver scarring possibly associated with cirrhosis and even liver failure. The new medications being developed for PBC may target one aspect of this disease spectrum (e.g., liver scarring) or multiple aspects of the disease (e.g., the overactive immune system, liver inflammation and scarring).

OCA is a bile acid (the human detergent in our bile) derivative that appears to act on a number of cell types to reduce bile acid synthesis and promote bile secretion, and to decrease inflammation and scar tissue formation. It has been shown to reduce blood liver test evidence of impaired bile flow (i.e. increased serum levels of alkaline phosphatase), the elevation of which have been linked to poorer outcomes in PBC patients. However, long-term safety and efficacy of OCA in PBC is still being assessed in post-marketing studies. OCA can induce itch and change blood cholesterol levels, side effects that can impact its use in some PBC patients. Other companies, such as Gilead and Novartis, are making drugs that are similar to OCA that are not bile acid derivatives, in the hope of avoiding the side effects seen with OCA.

Fibrates (e.g., bezafibrate) are a class of medications that are PPAR agonists (agonist means that it can activate a cell, whereas an antagonist blocks an effect of an agonist on a cell). PPARs are divided into a number of types that can differentially affect metabolism and immunity. These effects can beneficially alter bile acid metabolism and can also alter how our immune system works to decrease liver damage. Bezafibrate has been available to treat increased serum lipids for many years, and can improve cholestatic liver tests in PBC patients and improve pruritus, whereas different

PPAR agonists are being actively developed to treat PBC (e.g., CymaBay, Genfit).

Reactive oxygen species (ROS) are felt to contribute to tissue damage in many diseases, and this is the reason why so many people take antioxidant supplements as part of their daily routine. In autoimmune diseases like PBC, ROS generation is controlled by specific pathways, and one of these pathways is the target of an inhibitor developed by Genkyotex for PBC patients.

PBC patients can suffer with a number of symptoms, including pruritus (itchiness). Most patients with pruritus can be effectively treated with currently available therapies. However, for some, this symptom can be devastating. Given this, GSK has developed a drug that blocks bile acid transport with the hope that it will improve PBC-related itch.

| COMPANY   | NAME                 | CND TRIALS |
|-----------|----------------------|------------|
| 29 Brands | Ursodeoxycholic Acid | N/A        |
| Retrophin | Liquid Urso          |            |
| Intercept | Ocaliva (OCA)        | Yes        |
| GSK       | GSK2330672           | Yes        |
| Genfit    | Elafibranor          |            |
| Gilead    | Selsonsertib         | Yes        |
| Genkyotex | GKT831               | Yes        |
| CymaBay   | Seladelpar           | Yes        |
| Novartis  | LJN452               | Yes        |
| Arena     | Etrasimod APD334     |            |

### Summary

The treatment of PBC has entered into an exciting new phase, with numerous potential treatments likely to be available in the coming years. Access to these new medications can be facilitated through clinical trials that are run in a number of specialist centers across Canada. If you are interested in becoming involved in one of these trials, please contact the Canadian PBC Society for potential sites in your geographical area.



## MEDICAL & RESEARCH NEWS

### 2017 OUTSTANDING PBC RESEARCHER



Earlier this year, the Canadian PBC Society recognized Dr. Andrew Mason for his contribution and dedication to PBC Research and

his ongoing commitment to his PBC patients. A world leader in PBC research and treatment, he has worked tirelessly on behalf of PBC patients. For over a decade, he has focused his research on establishing a link between the human betaretrovirus (HBRV) and PBC.

#### Dr. Mason's patients said

- "Dr. Mason was instrumental in developing treatment for PBC; he has worked extensively with fibroscan, transplant, gene research, patient care and education. His years in England, the US and ultimately in Canada at the University of Alberta have provided a wealth of new information on PBC and its treatment."
- "Dr. Mason attends our PBC support meetings and provides education about this illness to the general public."
- "Dr. Mason has always treated me with respect and I am fortunate to have him as my doctor."
- "Dr. Mason has spent his entire research career searching for the cause and treatment of PBC. His dedication to this disease is like

no other. He makes his patients a priority in his life. As one of his long term patients, for the last 17 years, he has made my battle with this disease so much easier. Even at the time of liver transplant, he was at my bedside every day to ensure my continued healthy recovery. He is so determined to put an end to PBC that he says that his life's work will not be done until the cause and cure for this disease has been found. Dr. Mason definitely deserves this grant for his commitment to PBC."

#### NEW Canadian Patient registry



In 2016, we designated the proceeds of our Day at the Races fundraiser to support PBC education, awareness and research at the Toronto Centre for Liver Disease. More than \$11,000 was raised through the event and these funds have now been committed to a special project that will help enhance and leverage the national PBC patient registry that is being established through CaNAL (Canadian Network for Autoimmune Liver Disease).

The CaNAL registry will make it possible to track and follow-up patients' medical histories and all relevant clinical events over the long term – and



on a national scale. The registry will include both existing and newly-diagnosed patients.

This national research initiative is intended to achieve the following results for patients who are living with PBC:

- Early and accurate diagnosis of disease
- Personalized investigations, treatments and

monitoring to help prevent disease progression and the need for liver transplantation

- Accurate assessment of a patient's risk for developing liver-related complications
- Identification of potential new therapies
- Improved quality of life and long-term health for PBC patients



It has been a busy year, and these are a just a few highlights of our most recent patient support, outreach and awareness building events.

### SELF-MANAGEMENT WORKSHOPS

Last year we held self-management workshops in Edmonton, Vancouver and Toronto. In 2017, we added workshops in Toronto and Duncan, British Columbia. Our members in each of these locations were able to share ideas and techniques with each other for “living better” with PBC. As a bonus, members were able to meet new PBC patients in their community and begin to build relationships with each other.

We would like to thank Anne Hartford for her work in facilitating the workshops, and to Fairlie Mendoza for her help in organizing the workshop in Duncan, BC. A special thank you goes to Dr. Andrew Mason who traveled to Duncan to present an excellent talk, clearly explaining PBC, the disease, symptoms and treatment.

We plan to offer self-management workshops in more cities across Canada, so please watch for your opportunity to take part.

Here are some comments about the workshops from previous participants:

*“After living with PBC for so many years I wondered how much I would take away from the experience. I found it very worthwhile and an enjoyable day.”*

*“Thank you for your energy and positivity.”*

*“Thank you for a fabulous day! I really enjoyed the programme and the whole concept of peer support.”*



## DINNER SPEAKER SERIES

This year, with the help of some of the top PBC experts in Canada, we've had the opportunity to bring our members together at a series of educational dinner/speaker meetings in Halifax, Victoria, Toronto, Ottawa and Calgary.



We were honoured to hear about the latest developments in PBC research, diagnosis, treatment and support from our distinguished guest speakers:

- Dr. Aliya Gulamhusein and Dr. Bettina Hansen in Toronto
- Dr. Magnus McLeod and Nurse practitioner Geri Hirsch in Halifax, where we were also pleased to present Geri with an award and special recognition for her dedication and ongoing support to PBC patients
- Dr. Andrew Mason in Victoria where we also presented him with our award for Outstanding PBC Researcher of the year
- Dr. Thomas Shaw-Stiffel, Dr. Linda Scully, Dr. Erin Kelly and Dr Cynthia Tsien in Ottawa
- Dr. Mark Swain in Calgary

These popular events have been very well attended, allowing members to get together and to speak directly with medical and research leaders who are doing critical work on our behalf in Canada.

We're looking forward to hosting more of these events in cities across the country. Check our website for future dates and locations.

## TS'EWULHTUN HEALTH CENTRE HOSTS PBC COMMUNITY DINNER IN DUNCAN, BC.

On Tuesday, September 20, 2017 the Ts'ewulhtun Health Centre hosted a PBC Community Dinner in Duncan, BC. The event was very well attended with 2/3 of the people coming from the community and the other 1/3 being PBC medical experts and members of the local health community.

The dinner began with a traditional welcome to the Cowichan Tribes Territories by Charlie George followed by a prayer before dinner by Doreen Peter.

The first guest to speak at the meeting was Beverly Williams, a PBC patient and liver transplant recipient, who shared her very moving story. Beverly was followed by Dr. Eric Yoshida who spoke about his experience in recognizing PBC in First Nations of BC. Dr. Laura Arbour then spoke about the lack of support for a major genetic factor causing PBC in First Nations in BC. Finally, Dr. J.P. Wallach, Internal Medicine specialist in Nanaimo, introduced himself and answered questions.

The evening was a great success with a lot of patient/doctor discussions at the tables throughout the evening.



# CANADIAN PBC SOCIETY NEWS



## A Canadian PBC Patient Charter

### A MESSAGE FROM THE PRESIDENT

What a truly exciting year this has been for our worldwide PBC community! On September 10, 2017, we recognized International PBC Day together with our partners in Europe, UK, and the USA. This year we were most encouraged by the increased interest in developing new PBC drug therapies and a growing awareness of PBC. As we anxiously await a cure, we continue to work for early diagnosis, more treatment options, and better patient education and support programs. Toward these ends, I believe that we have an influential role to play in representing the **“voice of the PBC patient”** and over the past year we have worked diligently to bring awareness of the impact of PBC to government policymakers, the medical community and the general public.

I am very proud that as an organization we have both sponsored and participated in important PBC research. By participating in clinical trials, surveys, focus groups, and PBC research studies, our members have contributed to a greater understanding of PBC symptoms and treatments.

This summer, with input from more than 100 PBC patients, we created the first Canadian PBC Patient Charter. The Charter outlines a number of elements of care to which PBC patients have rights. The Charter reflects the most important issues to PBC patients, families and caregivers. Advocating for the patient community, the PBC Society is seeking to improve the consistency and quality of care across Canada. The Patient Charter is a tool that we are using to engage with governments, institutions, and the healthcare community to help make that happen.

As we look ahead to the future, we have developed an operational plan that is focused on advocacy, and patient support and education as we expand our existing programs across the country. None of this could happen without the support of our members, the compassionate, personal support provided by our Regional Coordinators, the financial contributions of our members and their families, and the tireless work of our volunteers across the country.

I am extremely optimistic about the future of the Canadian PBC Society and what we can achieve together as the **“voice of the PBC patient”** and the progress being made by the researchers who are working on our behalf to identify the causes of PBC, to develop better treatments and ultimately find a cure.

I'm looking forward to continuing our work together in the year ahead.



Warmest Regards,

**Gail Wright**

President, Canadian PBC Society

# FUN & FUNDRAISING - A DAY AT THE RACES

On June 4th we held our annual 'A Day at the Races' fundraiser at Woodbine Racetrack in Toronto. We were fortunate to have a wonderful turnout and enjoy the company of our amazing members and their families and friends. We celebrated the progress that the PBC community has made this year, and the goals ahead of us as we continue to spread awareness, provide support and education to our members and advocate as the "voice of the PBC patient" among the medical and healthcare communities and government policy decision-makers.



## REGIONAL COORDINATORS MEETING



April 28-30, 2017 we held our first Regional Coordinators meeting in Toronto. It was great to see representatives from across the country gather together to discuss how to better support our growing membership. We discussed how we can better: communicate news; support newly diagnosed; use technology; create awareness within the medical community and many more important topics.

We're very pleased to announce that Shauna Vander Well has agreed to act as the Canadian PBC Society Regional Coordinator for all of Alberta. Shauna has been the coordinator for Alberta North for longer than many of us have been involved!

She has done an excellent job, providing personal support to PBC patients in the northern part of the province and keeping patients and their families connected through many different educational and information-sharing programs. She has also built many important relationships with the clinical community, including with Dr. Andy Mason. Many PBC patients in what we have historically called "Alberta South" have travelled to the Edmonton area to attend some of the patient meetings and workshops that Shauna has organized. By expanding her role, Shauna will now offer the same personal support, information-sharing and education events to all PBC patients and their families in Alberta. She has our personal thanks for taking on this important and expanded role.

## CANADIAN PBC SOCIETY GOVERNANCE

On April 30, 2017 we held our Annual General Meeting, where we adopted an updated and more comprehensive set of by-laws. We are happy to report that we have new legal representation with the firm of Loopstra, Nixon LLP and we will continue our relationship with the accounting firm of Wiseman and Wolanski. In this year of substantial growth we identified the need for a Research Grant Policy, and as such we developed a policy and formal guidelines for awarding research grants to important projects that contribute to better diagnoses, treatments and management of PBC. As part of the larger rare disease community, we continue to be active members of CORD, NORD and Global Gene groups.

# REGIONAL CONNECTIONS

## 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 volunteers enjoy being involved: helping to organize information sessions in their local regions, planning fundraising events, sharing life stories from our communication programs, and helping with outreach efforts to increase our membership.

If you are interested in exploring volunteer opportunities, please email or phone our national office [info@pbc-society.ca](mailto:info@pbc-society.ca) or **1-866-441-3643**

Visit our website!



[www.pbc-society.ca](http://www.pbc-society.ca)

## ALBERTA

For information, please contact **Shauna Vander Well:** [alberta@pbc-society.ca](mailto:alberta@pbc-society.ca)

## ATLANTIC

For information, please contact **Judi Pemberton:** [atlantic@pbc-society.ca](mailto:atlantic@pbc-society.ca)

## BRITISH COLUMBIA

For information, please contact **Kathryn Swift:** [bc@pbc-society.ca](mailto:bc@pbc-society.ca)

## GOLDEN HORSESHOE REGION

For information, please contact **Karen Isbister:** [kisbister@cogeco.ca](mailto:kisbister@cogeco.ca) or **Jackie Gay:** [gingerjack@cogeco.ca](mailto:gingerjack@cogeco.ca)

## MANITOBA

For information, please contact **Carol Seburn:** [manitoba@pbc-society.ca](mailto:manitoba@pbc-society.ca)

## TORONTO

For information, please contact: [info@pbc-society.ca](mailto:info@pbc-society.ca)

## OTTAWA

For information, please contact **France Foucault** or **Leslie Kaufman:** [ottawarep@pbc-society.ca](mailto:ottawarep@pbc-society.ca)

## QUÉBEC

For more information, please contact **Francine Lamontagne**, représentante Québec, Société canadienne de la CBP: [quebecrep@pbc-society.ca](mailto:quebecrep@pbc-society.ca)

## MANITOBA/SASKATCHEWAN

### Update from Carol Seburn

To acknowledge International PBC Day, our Manitoba group met for a potluck supper on Friday, September 15. Six members attended, including one new member, along with four of their spouses/partners. We enjoyed a delicious dinner together and as we shared our stories throughout the evening, the lively conversation made icebreaker games unnecessary.

We discovered that one of our members is currently waiting for a compatible living donor. She has been interviewed on both television and radio and we trust that the perfect donor will be found. Another member received a transplant earlier this year, has healed and is already back at work.



The Alberta BBQ, this year honoring Dr. Andrew Mason, “PBC Researcher of the Year”

## QUEBEC REGION

### Update from Francine Lamontagne



## ALBERTA REGION

### Update from Shauna Van der Well

Patient information and support at August's coffee meeting in Alberta



Rencontre - 7e Edition Groupe de Québec les 15, 16 et 17 septembre 2017 à l'Hôtel du Lac Carling

Une autre magnifique rencontre remplie d'échanges enrichissants, de partages et de rires. Cette année, quatre nouvelles membres se joignaient au groupe. Absentes sur la photo: Micheline et Isabel. Un grand merci aux participantes.

Nous nous donnons rendez-vous l'année prochaine dans la région de Québec.

7th Meeting of the Quebec Group September 15, 16 and 17, 2017 at the Lac Carling Hotel

Another wonderful event filled with enriching exchanges, sharing and laughter. Four new members joined the group this year, and many thanks to the participants. Absent in this year's photo: Micheline and Isabel.

We will be meeting again next year in the Quebec City area.

## ATLANTIC REGION

### Update from Judi Pemberton

"We had a great turnout for our spring lunch and meeting at Cora's in Halifax, on June 14, 2017. There were 10 members present...two of whom were new to our group. It is always nice to meet family members as well, and a mother, granddaughter, and husband were also there for support. We each introduced ourselves and told a little about how long we have had PBC, and how we are coping with the disease."



The Canadian PBC Society is not responsible and cannot be held liable for the accuracy of any medical or treatment information printed here, which is not necessarily representative of the views and opinions of the Society. Please consult your own health care provider before making any changes in your daily living or treatment plan.

## 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](mailto: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](mailto:info@pbc-society.ca)

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## CONTACT US

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