



# PBC connections

A Canadian PBC Society Newsletter

2018 • VOLUME ONE

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### MARK YOUR CALENDAR – THE NATIONAL PBC PATIENTS’ CONFERENCE IS COMING! JUNE 7-9, 2019

We’re very excited to announce our plans for a national PBC patients’ conference to be held from June 7-9 at the Toronto Airport Hilton Hotel.

This will be a fantastic opportunity to hear from internationally renowned experts in the field of PBC diagnosis, treatment, symptom management, best practices, leading-edge research and the development of new therapies.

Whether you’re newly diagnosed or a PBC veteran, join us to meet others, share experiences and get the latest PBC insights from our speaker presentations, expert panels and a special one-on-one physician meet and greet.

The conference fee will include access to all sessions, all meals and a special Saturday Recognition/Awards Dinner.

More details will follow in the New Year. But mark your calendar now and we’ll look forward to seeing you in June.

### DR. GIDEON HIRSCHFIELD – WELCOME BACK!

At the end of 2011, Dr. Gideon Hirschfield left Canada for the University of Birmingham (England). During his time there, he focused his efforts on dedicated autoimmune liver disease clinics helping a broad team to manage very large cohorts of patients with PBC, PSC and AIH. Fortunately for us (and with the significant generosity of an endowed Chair, the Lily and Terry Horner Chair in Autoimmune Liver Disease Research), he has recently returned to Canada, bringing a lot of new insights and experiences with him that will continue to influence his work here. He spoke with us recently about his plans for the Autoimmune Liver Disease programme at the Toronto Centre for Liver Disease/University Health Network. He has also caught up with the world of social media, and can equally be found occasionally on Twitter [@AutoImmuneLiver](#).



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## What has brought you back to Canada and UHN?

First, let me say how very happy I am to be back with my talented colleagues at the Toronto Centre for Liver Disease. When I went to Birmingham, I tried to stay focused! I wanted to be able to work on getting a deeper understanding of autoimmune liver disease and to drive a specialized program dedicated to PBC, PSC and Autoimmune Hepatitis patients.

In my nearly seven years there, we built a program that integrated autoimmune liver disease research, made sure that patients had access to clinical trials and the best treatment options available and, of course, I hope, excellent clinical care, including access to, and management after, liver transplantation.

But I think we've just scratched the surface in terms of the opportunities we have for going much further. The Toronto Centre for Liver Disease and our dedicated autoimmune liver disease programme is a great place for that to happen. There's no question that we have the expertise here. And we have the desire and the commitment to go much deeper and much further in understanding and treating diseases like PBC.

## What do you think your program will look like?

Well, we're just getting started. But I do have a vision for what we're working towards. And it includes our patients, working together with us, to make it happen.

Broadly speaking, I want us to be known globally as a "go-to" place for autoimmune liver disease... for excellence and innovation in patient care... and for education.

I want to make sure that PBC research and clinical care go hand in hand.

I want our patients to have access to the best treatments and clinical trials that are out there. Not just for treating PBC itself, but also for treating the many symptoms that go along with it.

I think we can improve the consistency and quality of patient care... especially for patients outside the major urban centres... by finding new and innovative ways to deliver care to them.

And I also think we can become known as a champion for the voice of rare disease and, therefore, we will be advocating actively on behalf of our patients.

## When it comes to the question of 'what causes PBC' you've had a particular focus on genetics in the past. Is that still the case?

That's correct. We're constantly in search of the answer to the question of 'what causes PBC' aren't we? And we certainly believe that genetics is one of the key factors. But as we continue to investigate, we're starting to see that genetics may account for only about 1/3 of the cause. The balance has a lot to do with something that happens in the environment around each patient.

## How do you think genetics and environmental factors are linked?

I like to try and use the analogy of a bonfire to explain it.

Environmental factors appear to be the sparks that "ignite" the PBC 'bonfire', and how easy it is for the sparks to get things going depends on both i) the structure of the bonfire before it catches light (akin to your genetic risk) and ii) how many and how potent the sparks are that light the fire (akin to whatever it is in the environment that is the accelerant so to speak). For each of us there is therefore a different balance of genetic risk and environmental risk, but once the 'bonfire is alight' it keeps going.

Some research suggests that smoking may be a factor, as well as the impact of industrial pollution or living in an urban environment etc. But I don't think anyone really knows – yet – what environmental risks trigger PBC and other liver diseases. Even the use of nail polish and hair dye, have been mentioned, for example, but there's no consistent scientific evidence to back this up.

So yes a genetic predisposition is a critically important

factor in understanding the cause of PBC. But we need to look much more deeply into what's happening in the environment in which our patients live that might be the fuel that ignites PBC.

This is where I believe we need to focus more of our research efforts... using real patient data about their life and environment to understand how and why they have developed PBC.

## From a research point of view, then, what will your program look like?

In our unit in Birmingham, we managed some very large cohorts of patients with PBC, PSC and AIH. And the sheer size, concentration – and diversity – of our patient base made it possible for us to participate in important and relevant research. It wasn't just research in the lab. It was from the direct contribution of patient data into studies about both the cause and effects of PBC.

So here, we have similar but exciting opportunities, I believe, to help us direct our research efforts to really understanding what's behind the cause and effect of PBC.

For example, the history of a patient's blood chemistry results, which is being collected in Canada through 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. That's a huge step forward from a research point of view because it uses real patient data – not data from mice in a lab – to help us decide the right direction we might take to diagnose earlier and treat patients in a more targeted way at various stages of the disease.

This is part of 'translational research', which includes taking the evidence from our patients' history and experience and **translating** the insights from that research into targeted therapies, based on new science. It's about moving scientific studies into clinical applications for the benefit of our patients.

I'm a strong supporter of this approach and I will be a strong advocate for identifying good clinical trials that our patients can participate in and encouraging them to do so.

## What are some areas of innovation that you might be looking at?

Well, I believe we need to do more thinking about how we treat patients over the long term. I'm especially interested in looking at ways to give the patients who come to our clinics a personalized experience. In industry, you hear a lot about companies being "customer focused". We need to apply the same thinking to the patients we see in our clinics. Many of them we only see once a year. Others come to us more frequently. Regardless of how often we see them, our goal should be to be "patient focused"... to make their visit to the clinic a positive and constructive one.

In the longer term, that may mean looking at adding resources to our clinical staff so that other expert resources – such as professionals who can provide additional guidance on the management of specific symptoms – can provide information and support to our patients. That's a personal aspiration of mine that I hope we'll be able to realize one day.

I also want to look at some innovative ways to treat patients who may not live in close proximity to our incredible resources at UHN. I'm especially interested in finding new ways to support our patients in rural communities so that we can provide seamless and consistent care to all PBC patients... regardless of where they live.

## Is there a message you would like to leave with PBC patients?

Yes...actually there is.

While there isn't a cure for PBC right now, there are treatments available and plenty of research going on. So I'd invite you to adopt a way of thinking that says, "I want to own my PBC...I won't let **it** own **me**". And by that I mean, advocate on your own behalf with your PBC doctor, share your health data to help all of us understand what might be 'fueling' PBC, and be involved in research when the opportunity arises because it all helps. Fundamentally don't be shy to speak up about your PBC to navigate the best course for you.



# MEDICAL & RESEARCH NEWS

## UPDATED NEWS ON THE TREATMENT FRONT

### OCA now available to Canadian patients

In 2017, Ocaliva was approved as a treatment specifically for PBC patients who don't respond to Ursodeoxycholic Acid, and many Canadian patients are already taking this drug with good results.

In 2018, we advocated on behalf of PBC patients to make OCA available to all who need it in Canada and for it to be covered by all of the provincial health plans. We're happy to report that the cost of Ocaliva is now covered by provincial plans in Ontario, British Columbia, Manitoba, Yukon, Northwest Territories, Nunavut, Ontario and Quebec and we're hoping that the remaining provinces will follow soon.

### New Treatments in the Pipeline

COMPANY	MEDICATION NAME	CDN TRIALS	COMMENTS
generic	UDCA	N/A	Mainstay of therapy
Retrophin	Liquid UDCA		For those unable to take pills
Intercept	Ocaliva (OCA)	Yes	FXR agonist
GSK	GSK2330672	Yes	Bile acid transporter inhibitor – for itch
Genfit	Elafibranor	For NASH	PPAR $\alpha$ and $\delta$ agonist
Gilead	Selonsertib	No	ASK1 inhibitor + GS-9674
Gilead	GS-9674	Yes	FXR agonist
Genkyotex	GKT137831	Yes	NOX1/4 inhibitor
CymaBay	Seladelpar	Yes	PPAR $\delta$ agonist
Arena	Etrasimod	No	S1P1 antagonist
generic	Bezafibrate	N/A	PPAR $\alpha$ agonist; addition to UDCA

# PATIENT EDUCATION & SUPPORT

As part of our patient education and support program, our “Living Well with PBC” workshops have been held this year in Toronto, Victoria, Calgary, Halifax, Winnipeg and Ottawa. These workshops give patients, as well as their friends and family members, an opportunity to learn more about PBC in a small group setting.

The sessions are led by an experienced facilitator and participants can share their PBC experiences with each other while also learning new tools that can help them set priorities for managing the day-to-day challenges of living with PBC.

The workshop material covers a wide spectrum of topics, including: [Achieving Balance](#), [Setting Priorities](#), and [Making Personal Changes](#) specifically tailored to the challenges of those living with PBC.

**Here are a few comments that this year’s participants told us about the value of the workshops:**

*“Very informative. Learned things about myself and the disease. Nice to know what I am feeling is normal. Workshop was eye opening about setting life priorities.”*

*“Being able to talk with others with PBC put me more at ease. More confident in having to go forward with disease.”*

*“Nice to have spouses/friends in the mix.”*

In addition to the workshops, we’ve been happy to continue our PBC dinner/speaker program this year. Dinners were held in Toronto, London, Montreal, Winnipeg, Edmonton, Duncan and Vancouver with talks from Drs. Aliya Gulamhusein, Paul Marotta, Catherine Vincent, Andrew Mason, Eric Yoshida and JP Wallach.

We plan to continue our workshop and dinner/speaker programs in 2019 and sincerely hope you’ll plan to join us for those scheduled in your community.





## WHAT IT'S LIKE TO LIVE WITH PBC

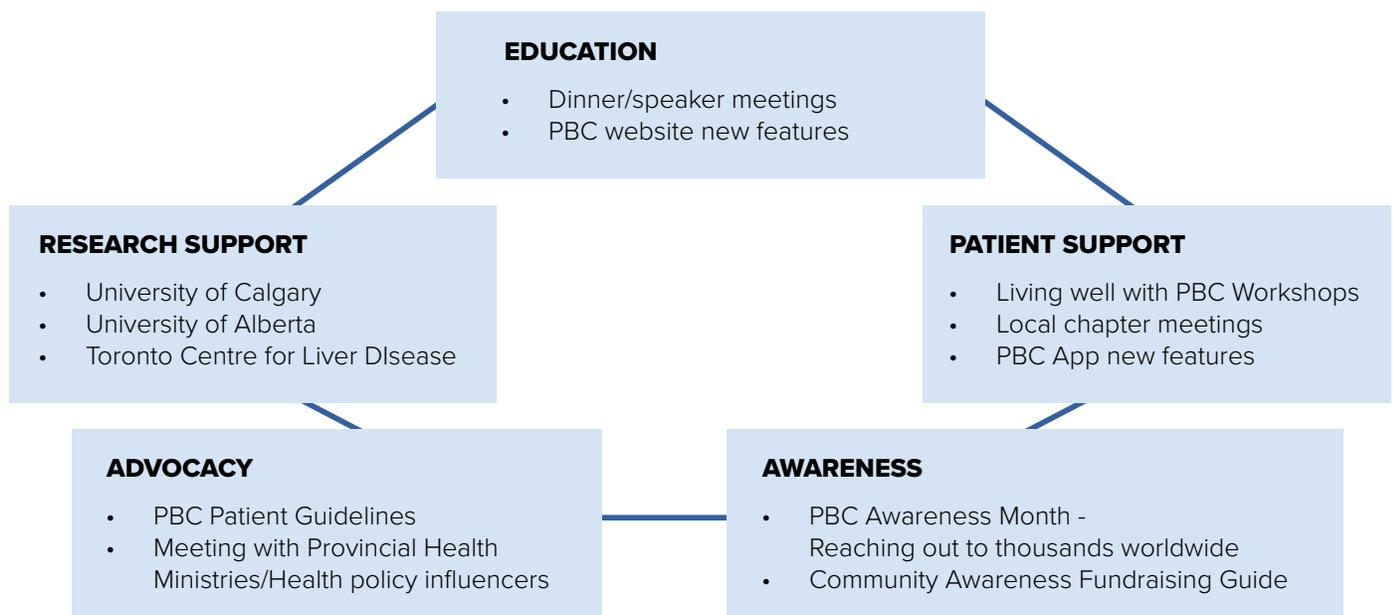
The Canadian PBC Society conducted a survey in late 2016 that asked people to describe what it's like to live with PBC. The survey focused on everyday experiences of living with PBC and was completed by 150 PBC patients across Canada. In collaboration with Dr. Andrew Mason, from the University of Alberta, an article summarizing our findings will be published in an upcoming issue of the Canadian Association for the Study of the Liver (CASL) journal.

Not surprisingly, the survey findings were consistent with other studies... that patients with PBC experience high levels of disease-related symptoms even though they may be receiving ongoing treatment.

### Here is an excerpt from the study conclusion:

*"[There is] a clear therapeutic dissonance whereby available and new therapies in the pipeline to improve hepatic biochemistry and life expectancy do so without addressing symptomatic needs. Additional emphasis is required to tackle the root cause of the disease to have an impact on symptoms and make PBC patients' lives worth living"*

## How the Canadian PBC Society helps to improve the lives of patients



# CANADIAN PBC SOCIETY NEWS

## A MESSAGE FROM THE PRESIDENT

As 2018 comes to its end, I can't help but look back on everything the Canadian PBC Society has achieved. And I'm amazed and thankful every day that a small organization like ours – run completely by dedicated volunteers – has accomplished so much.

This year alone, we've delivered great patient support programs, created new educational material, increased PBC awareness, advocated on behalf of PBC patients and participated in and sponsored important PBC research. And how has this small, but mighty, organization done all of this? It's all thanks to our extensive network of extraordinary volunteers and strong industry partnerships.

### **I am very proud of our PBC Team across the country:**

*Board Members* – volunteers who implement our annual plan and provide oversight and direction for the Canadian PBC Society.

*Regional Coordinators* – volunteers who provide the foundation for our personal 1:1 patient support in six regions across the country.

*Local Group Leaders* – volunteers who provide local patient 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 specialist expertise in Web design, Information Technology, Legal, Graphic Design and Videography.

*Industry Partners* who support us with sponsorships, networking opportunities, new platforms to help patients, 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 brochures and our website.

So my message this year is a BIG THANK YOU to everyone who has made this such a productive year!

I'm looking forward to continuing our work together and achieving more great things in the year ahead.



Warmest Regards,

**Gail Wright**

President, Canadian PBC Society

## WELCOME NEW BOARD & COMMITTEE MEMBERS

### **Mary Ehle**

Board Member (*Victoria, BC*)

### **Laura Henderson**

Regional Co-ordinator (*Atlantic Region*)

### **Kailey Jackson**

Director, Community Fundraising (*Windsor, Ontario*)



## HELP US RAISE AWARENESS

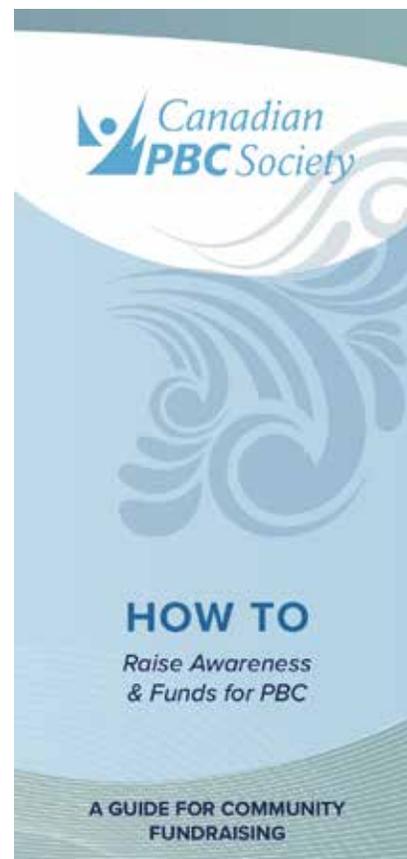
One of the most important things we do as a Society, and that you can do as a PBC patient (or a friend or family member), is to help raise awareness about PBC. As Kailey Jackson, our Director of Community Fundraising, says, “PBC is a rare disease, but we can make the awareness of it less rare. We can all help to spread the word about the symptoms and treatment of PBC and maybe even help other people to get an early diagnosis.”

That’s exactly what Kailey set out to do when she decided to organize an information meeting in her community. “I started by asking myself one key question,” she says. “What do I really want to accomplish at this event? PBC is rare and I have a personal mission to make it less rare in terms of people’s awareness and understanding of the disease. I also want to make sure that the Canadian PBC Society has the funding it needs to continue its educational and personal support programs for patients and their families.

“So when I thought about the kind of event I wanted to organize, I decided that if I was going to bring people together to learn more about PBC, I might as well raise some funds to support the PBC Society at the same time.”

That’s exactly what Kailey did and she organized an event that brought out more than 150 people

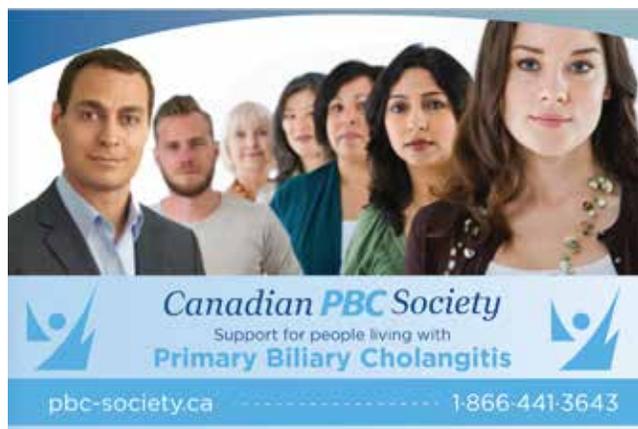
who learned about PBC for the first time and raised some important new dollars for PBC patient support. There were a lot of lessons learned along the way about how to plan an event like this, and Kailey has put together a step-by-step guide “*How to raise awareness and funds for PBC*”. If you’re thinking about organizing an awareness-building/fundraising event in your community, have a look at Kailey’s guide. You’ll find it on our website at: [pbc-society.ca/images/pdf/fundraisingguide.pdf](https://pbc-society.ca/images/pdf/fundraisingguide.pdf)



## Ask your doctor to help spread the word too

Your own doctor can help other patients to learn more about PBC and the support that's available to patients. Help your doctor to spread the word, by ordering our free PBC information brochures, postcards and posters for the doctor's office. Take them to your next appointment and ask for them to be given to patients or left in the waiting room so that others can be informed and educated about this rare disease.

We can all help to make PBC a less rare disease.



## Want to get involved?

As a totally volunteer-run organization, we always welcome and appreciate your help. So if you have the time and interest, we can put your talents to good use. We have many areas where you might enjoy being involved. You can help organize one of our workshops, or a dinner meeting or a fundraising event in your local community, for example. Not only will that help us, it will also give you the opportunity to get to know other PBC patients in your area... as well as their friends and family.

If you aren't interested in helping out with events, we're always looking for patient bloggers or patients' life stories for our communication programs, and helping with outreach efforts to increase our membership.

There are lots of areas where you can get involved whether it's a few hours spent on a community event or a special kind of expertise that could contribute to the Society overall. If you're interested in exploring some volunteer opportunities, we'd love to hear from you. Please email or phone our national office [info@pbc-society.ca](mailto:info@pbc-society.ca) 1-866-441-3643

## International PBC Awareness Month

Every September, there are plenty of things to do and get involved in to raise the profile of PBC during PBC Awareness month and International PBC Day. This year was no exception, and we were in public getting patients together, raising our voices and raising funds for PBC.



# REGIONAL CONNECTIONS

## ALBERTA

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



## ATLANTIC

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



## TORONTO

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



## BRITISH COLUMBIA

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



## A DAY AT THE RACES 2018



### NEW ATLANTIC REGIONAL COORDINATOR

Judi Pemberton, Atlantic Regional Coordinator, has decided to retire from this role. However, we're pleased to say that Judi will continue to coordinate activities with members in the Halifax area. Our thanks to Judi for her leadership in the Atlantic region for so many years and for continuing to support patients in the Halifax area.

In Judi's place, we're pleased to welcome Laura Henderson as the new Atlantic Coordinator.

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.

## WHAT ARE YOU MISSING?

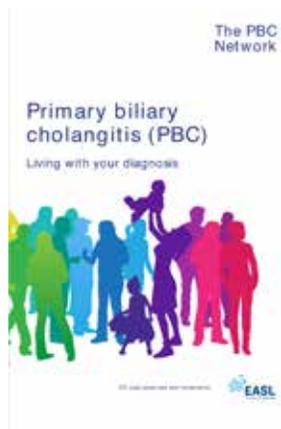
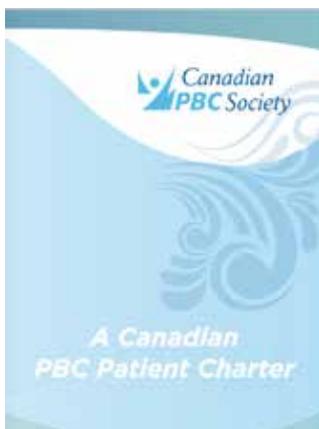
If you haven't visited the PBC website lately [www.pbc-society.ca](http://www.pbc-society.ca) you may be surprised by what you'll find.

The main page of the website is refreshed with new content every day! If you check it out frequently you'll find the latest updates on our Facebook page, Twitter feed and blog postings. From time to time, we also post new videos such as a recent one with Dr. Aliya Gulamhusein answering patients' questions at one of our dinner/speaker meetings.

You'll be able to see when and where a workshop, dinner or other PBC event may be coming your way, check for other important dates to remember as well as see the highlights of recent events. If you want to sign up for an event, all you have to do is click on a convenient link and you'll be registered immediately.

You may also find you've missed some important new tools and information that have been added to the site such as our Patient Charter or the recently published "PBC patient guidelines" or the new step-by-step guide to community fundraising "How to Raise Awareness and Funds for PBC".

Whatever your area of PBC interest, you're sure to find lots of good and up-to-date information on the site. So, please visit us soon and make sure you never miss anything important again.



## 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)

## FOLLOW US ON FACEBOOK & TWITTER!



### Alberta



## CONTACT US

### Canadian PBC Society

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