



PBC connections

A **Canadian PBC Society** Newsletter

2016 • VOLUME ONE

RUTH'S SUPPORTS HER DAUGHTER WITH PBC

Ruth contacted us because her daughter Dawn has PBC. Ruth had created very finely made, life sized Raggedy Ann and Andy dolls and she wanted to donate them to help raise money for PBC.

Dawn was diagnosed with PBC in February 2014 by her local gastroenterologist/hepatologist and was started on the Urso right away. In June 2014 she had a Fibroscan® in Toronto that indicated stage 3 liver fibrosis. A year later, the Fibroscan® indicated stage 2. Dawn is hoping to get a clearer picture of what's happening in July, when she will do another Fibroscan®. Dawn says, "I have a strong faith in what God can do, and your newsletters and information will be very helpful as I continue this journey in life."

Dawn is a Registered Nurse (shift Supervisor) in long term care and works 12 hour shifts, which can be exhausting. She prefers the nights as they are less demanding for the most part. She has a work accommodation for no more than 2 in a row so that is helpful as well. She told us, "Other than fatigue I really have no complaints :)"

Dawn is extremely grateful to Dr. Murat who has gone to great lengths to ensure Dawn receives excellent ongoing care.



Dawn with Dolls her mother made and generously donated to our fundraiser



Elsie (2 1/2 years old) got a wonderful surprise Christmas morning! Elsie's grandmother, Laurie won the raffle draw at the PBC Christmas Tradition Fundraiser, held November 25, 26 in Toronto.

president's message



DO YOU REMEMBER WHEN YOU WERE DIAGNOSED WITH PBC?

I had no symptoms, no complaints; I was at my lowest weight and feeling fit as a fiddle. My routine blood work was telling a different story though and had been for about five years: every year my liver enzymes were raising slightly over the year before. It was time to see a specialist said my family doctor. The opening round of tests confirmed that my enzyme levels were abnormal, more tests showed no AMA marker, no fatty liver, no cirrhosis. "Can it just be nothing?" I asked. "NO, it's something, let's do a biopsy" the hepatologist replied. It could be many things - none of them have a cure, one has a treatment. If the treatment doesn't work there is no other treatment." WHAT??? I was familiar with cancer patients traveling around the world to participate in unique drug trials. Welcome to the world of RARE Diseases. A biopsy showed inflamed/damaged bile duct cells consistent with PBC. I let that sink in, then felt slightly relieved that it was PBC - at least there was a treatment to try. My internet search results for "PBC" were frightening and led me to reflect deeply on my upcoming mortality. My husband and I tearfully agreed "We've had a good life". Soon after, I found the Canadian PBC Society and at once felt supported, not alone- actually optimistic that the new me would be able to carry on. I still have no symptoms and no damage, so I take the URSO, which is doing its job and I remain optimistic. However, the world around me is less kind and continues to judge

liver disease harshly. I try to face my PBC head on - I have a social cocktail now and again, at a party I will try one or two deep fried snacks (not always as good as they look), I've found the companies that will give me out of country medical insurance, I try to walk instead of drive and I'm listening carefully and learning from those who have more advanced PBC.

It's been almost four years since my diagnosis. Last year I made a decision to volunteer my time to the Canadian PBC Society in hopes of being part of a larger journey to improve the lives of those living with PBC. I want to be open and frank about my liver disease. and I tell people "I have PBC, a rare liver disease." I am not ashamed or apologetic. I have a realistic vision of the future, but most importantly I am envisioning how I want my life to be, as I age, and things stop working as well as they once did, how will I cope? who will I turn to? will I be able to ask for help when I need it?

Will liver disease loose its stigma? Will we find new treatments? Will we find a cure? The future in unknown, but I want to face PBC and my life Head On! **Wishing you all the best in your journey.**

Warmest Regards,

Gail Wright

President, Canadian PBC Society

IF YOU WANT TO TELL US YOUR PBC STORY - story should be no more than 250 words, pictures are welcome - SEND EMAIL SUBMISSION TO: info@pbc-society.ca

Canadian PBC Society would like to thank the people who support us. In coming issues look for more profiles of our support team.

OUR CREATIVE TEAM



David Groskind - our web developer. David is retired from a career in IT, but that does not stop him from keeping up to date with the latest technology developments. David is passionate about using technology to bring people together and improve their lives. He became involved with the Canadian PBC Society through his connection to our long standing Director Lenore Bennett.



Bridget Braun - our newsletter designer. A graduate of Ontario College of Art & Design, Bridget lives in Vancouver where she has her own part-time design business. Bridget has been designing PBC Connections since 2011. Bridget's very proud mother has PBC and lives in Ontario.



Lisa Hall - our film and media specialist. Lisa graduated from Tisch Film School in New York, 2010. She has helped us to create the face of our new website - coming soon. Lisa has contributed her creative flare in creating promotional PBC material. Our President, Gail Wright has known Lisa all of her life and is grateful for her support.

MEDICAL ADVISORS

We thank our medical advisors of recognized worldwide leaders in the field of PBC research and treatment. Their dedication is truly inspirational and give us much hope for the future.



Angela C. Cheung MD, FRCPC. Clinical Associate in Hepatology and Autoimmune Liver DiseaseMasters candidate for Health Research Methodology with specialization in Clinical Epidemiology. Toronto General Hospital, 9th Floor Eaton North, Room 224, 200 Elizabeth St., Toronto, ON, M5G 2C4



Andrew L. Mason MBBS, FRCPI, FAASLD. Professor of Medicine, Director, The Applied Genomic Core, Division of Gastroenterology and Hepatology, 7-142 Katz Group Rexall Centre, University of Alberta, Edmonton, T6G 2E1



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

STRENGTHENING THE CANADIAN PBC SOCIETY

Strategic Plan

The Canadian PBC Society began in 2003 with a dedicated group of volunteers. In the past twelve years, the group has grown to a national registered charity with members in every province. In addition to developing a Strategic Plan we are strengthening our organization by: introducing a rigorous privacy policy and code of conduct; creating job descriptions for board members; updating our society by-laws; and creating a research funding protocol, among many other things. To participate in developing our strategic plan contact us at info@pbc-society.ca.

Making PBC Voices Heard In Ottawa

We have recently attained membership in CORD - Canadian Organization of Rare Diseases and NORD - National Organization of Rare Diseases (US based). Being active members of these two groups will ensure that our voice is heard in Ottawa. We are attending the first CORD conference in Ottawa March 9-10, 2016 where we hope to meet with legislators to put a “face” on rare diseases and to invite their support in moving forth on Canada’s Rare Disease Strategy which would result in a comprehensive, coordinated and collaborative national rare disease program for Canada.



Rare Disease Day Update

On February 29, 2016 - International Rare Disease Day, the Canadian PBC Society joined a delegation from (CORD) the Organization for Rare Disorders at Queen’s Park in Toronto. Ontario Health Minister Eric Hoskins announced that he is establishing a rare disease working group to address urgent and underserved needs for Ontario families. The Ontario

working group is a first step in implementing Canada’s Rare Disease Strategy in the province. CORD has developed a rare disease strategy, the five pillars of which are: diagnosis, care, community support, access to treatment and research. For more information go to: www.raredisorders.ca/canadas-rare-disease-strategy/.

REPORT ON FUNDRAISING AND MEMBERSHIP DRIVE

The Canadian PBC Society would like to thank its members for renewing membership and making very generous donations to help us continue to do work on behalf of those living with PBC. In November we held a wonderful fundraising event The Christmas Tradition Fundraiser and we would like to thank our members and friends who supported this event and made it such a success. If you missed it this year, plan to attend the festivities next year! The Canadian PBC Society is a national registered charity, completely run by volunteers. All funds raised go to support PBC research and member education and support programs.



Our 2015 Christmas Fundraiser

Volunteers: Hal, Orpha, Jessica, Gail, Debbie, Bruce, Teddy, Henry and Matthew (absent from photo) Alwyne, Barbara, Laurie, Laurie, Alicia, Lisa, David, Jessica, Leigh, Pamela



PBC

A RARE DISEASE

PBC is a rare disease. PBC is a chronic and slowly progressing disease which results from inflammation of the small bile ducts in the liver. For some people the inflammation leads to scarring, which may after many years become extensive and lead to cirrhosis.

A RARE DISEASE is sometimes referred to as an orphan disease and may share these characteristics:

- Causes unknown - could be genetic, viral, bacterial or environmental
- Usually no cure, limited treatments
- Common underlying symptoms make rare diseases
- Hard to diagnose, misdiagnosis, delays in treatment
- Chronic, progressive and degenerative leads to poor quality of life
- People with rare diseases often have other diseases

Numbers

In Canada and Europe - a rare disease is defined as occurring in 5/10,000 population. Approximately 7,000 rare diseases have been identified by the National Organization for Rare Disorders (NORD) - PBC is one of them. In Canada there are thought to be 7,000 cases of PBC. The UK has the highest reported incidence of PBC in the world*

*At first glance this has been explained by environmental factors, however the common thinking now is that due to the awareness among the UK medical practitioners there has been more and earlier diagnosis of PBC.

Other rare diseases you might know

Raynouds Syndrome
Ulcerative Colitis
Sjogren's Syndrome
Rheumatic Fever
CREST



UPCOMING EVENTS

ONTARIO/ALBERTA - New PBC Research Study - starting June, 2016

If you have PBC and live in Alberta or Ontario and you are interested in participating in a research study on improving the quality of life for people living with PBC, please contact us at info@pbc-society.ca

Annual General Meeting

Saturday, April 30, 2016. All members are welcome. We have openings on our Board, if you are interested please submit your application. Meeting location and time as well as ballots/proxy forms will be emailed out April 15, 2016 please return your ballots/proxy forms by April 28, 2016.

A DAY AT THE RACES *TO HONOUR*



DR. JENNY HEATHCOTE *WITH A LIFETIME ACHIEVEMENT AWARD*

On **Sunday May 15, 2016** from **12:00– 4:00pm**
At Woodbine Racetrack, Toronto, Ontario

Under the lovely white tent we will enjoy:

- The presentation of a Lifetime Achievement Award to Dr. Jenny Heathcote
- The excitement of horse racing from a unique trackside vista
- A delicious racing buffet– including beef Wellington carving station
- Dedicated track betting attendants, an enticing silent auction
- A very special Woodbine Winner's Circle Blanket Presentation (donated on behalf of PBC)

TICKETS: ADULTS - \$90 | CHILDREN 5-12 - \$25 | CHILDREN UNDER 5 - FREE

ORDER TICKETS ONLINE: pbc-society.ca/races/orderform.html

All proceeds from this event will go to University Health Network Liver research team, to initiate, develop and implement programs focused on promoting education and awareness of Primary Biliary Cholangitis, to ensure early detection and treatment for individuals across Canada.



NEWS

OCA approval in the USA

The OCA (Obeticholic Acid) approval decision by the United States Food and Drug Administration (FDA) in the USA, initially scheduled for February, 2016, is now anticipated at the end of May. The drug has not been approved in Canada yet, filings suggest a one year lag behind the USA launch. Individuals in Canada who do not respond to URSO, may apply to get OCA through a US trial study. Intercept is enrolling patients in Clinical Trials in Canada in Calgary and Montreal. Intercept is currently conducting a clinical research study designed to study the effect of OCA on the overall health and quality of life of patients with PBC. This investigational study will enroll eligible patients at a number of sites across Canada. More information on this study and Canadian centers can be found at: www.pbc-study.com

NEW WAYS TO HELP

You can now donate to Canadian PBC Society by donating



AIR MILES

We are now able to receive cash donations from Air Miles redemptions. You can donate \$10 for 95 AIR MILES POINTS. To Donate: Go to <https://changeit.airmiles.ca/browse> Sign in with your AIR MILES account- Enter Charity name: CANADIAN PBC SOCIETY, click on name and get charity donation code Click on: REDEEM NOW



AEROPLAN MILES

We are registered to receive Aeroplan Miles donations. This will provide us more travel options in connecting programs and people across the country. To Donate: Go to <https://beyondmiles.aeroplan.com> Sign in with your own aeroplan account and go to Participating Charities: enter CANADIAN PBC SOCIETY (this feature will be active April, 2016)



OPTIMUM POINTS

You can now donate your OPTIMUM points to the Canadian PBC Society, which will allow us to purchase miscellaneous supplies for fundraising events and items for silent auction fundraising. To donate your Shoppers Optimum Points go to: www1.shoppersdrugmart.ca/en/optimum-new-transfer, login to your OPTIMUM account and click on DONATE/TRANSFER POINTS - select Donate Points to a Charity and find and click Canadian PBC Society- enter amount and DONATE.

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, please 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

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

CANADA HELPS

What We Do CanadaHelps is a registered charity with a goal to make giving simple. Through CanadaHelps.org, anyone can donate online to any registered Canadian charity. We have proudly facilitated over \$100 million in charitable donations through our website since it was launched in 2000. For Donors CanadaHelps is a one-stop-shop for giving. We made donating online easy and secure.

ONLINE VIA FACEBOOK

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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