

SBC Newsletter

December, 2017

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## President's Address

by Debbie Taillefer

This past year has been an exciting one at SBC! We hope to have great news soon as we are told that negotiations between Pan Canadian Pharmaceutical Alliance (pCPA) and pharmaceutical company Alexion are progressing well. We welcomed Linda Toews, as our Secretary/Treasurer, who will be stepping into the role of Director of Patient Care. Lisa McGuffin, RN, has taken on the new role of Chief Nursing Officer.

Our successful planning meeting projects an action-packed 2018, with discussion spearheaded by Jennifer Boin, Director of Education and Events. On the table are proposals for a patient meeting for Ontarians in July and launch of a new initiative of local support networks. Exhibiting at two medical conferences, Peds Endo Society in Toronto in May, as well as ASBMR in September in Montreal, are also anticipated. We continue our outreach to dentists following up on the national Oasis discussion videos conducted alongside the Canadian Dental Association. A new dental brochure is currently in the works with Bob Schroth DMD, MSc, Asst. Prof. Dept. of Oral Biology and Dept. of Peds & Child Health U of M and member of our Scientific Advisory Board (SAB), with a planned mailing to dentists in 2018. We propose to be at a number of Canadian dental colleges, attending events on campuses and raising awareness with students.

We celebrate with Cheryl Rockman-Greenberg MD, CM, FRCPC, FCCMG, Dir. Metabolic Service and clinical geneticist in the Program in Genetics and Metabolism, Prof. Dept. of Peds and Child Health and Dept. of Biochemistry and Med. Genetics, U of M and Chair of our SAB, who is being inducted into the Canadian Medical Hall of Fame. We here at SBC congratulate her on this well-deserved honour and achievement!

Thank you to everyone who has donated to assist SBC endeavours! We would like to especially recognize Jennifer Boin, Linda Toews, Lisa McGuffin and Amanda Bruce for countless hours of volunteer work and our Scientific Advisory Board for their commitment to HPP patients and advocating on their behalf. I believe, based on feedback, we can safely speak for all patients that we appreciate all projects, fundraising efforts and awareness initiatives to educate, empower and connect.

*May this joyful season  
greet you with abundant  
joy, health and happiness.*



**From the team at SBC, have a Merry Christmas, a wonderful New Year and remember: keep the candle burning for HPP!**

## **Dr. Cheryl Rockman — Greenberg Being Inducted into The Canadian Medical Hall of Fame April, 2018**

Dr. Rockman-Greenberg has been selected for induction into the Canadian Medical Hall of Fame. She joins 5 other Canadian and international leaders in celebrating this important recognition at a ceremony held in association with Schulich school of Medicine and Dentistry, Western University on April 12, 2018 at the London Convention Centre in London, ON.

Canadian Medical Hall of Fame Laureates are individuals whose contributions to medicine and the health sciences have led to extraordinary improvements in human health. Their work may be a single meritorious contribution or a lifetime of superior accomplishments. Pioneers in their field, they are role models for Canadians and an inspiration to our youth to pursue careers in the health sciences.

To learn more, and to read Dr. Rockman-Greenberg's biography, please go to <http://www.cdnmedhall.org/induction-ceremony>.



# **Soft Bones Challenge 2018**

**The new year is a time for new resolutions. Why not resolve to help us spread awareness about HPP?**

We challenge **EACH OF YOU** to do **ONE THING** this year to support Soft Bones Canada™

- Give a speech in your classroom
- Organize a paid dress down day at work or school
- Share your patient story with Linda
- Present dentists in your area with our new brochure (Coming soon!)
- Donate to SBC via our [website](#) or at [www.canadahelps.org](http://www.canadahelps.org)
- Have a bake sale / car wash / pop can drive ..... (Maybe not all at once;)
- If you have website design skills, help us update our website
- Email your questions, or use the Ask The Expert button on our website

**What ever you do, take pictures, send us emails, tweets, Facebook updates, whatever works for you, so that we can feature your activities on our website as the year goes on! We want to show your fellow patients and the world that we are here!**



**TAKE THE CHALLENGE!**

## Our New Instagram Account

**@softbonescanada**

October brought the launch of our Instagram account. In order to encourage people to get involved, we asked them to like our photo and follow us. Names were entered into the draw for a \$50 Visa card and a Soft Bones Canada t-shirt. On October 30th, HPP Awareness Day, we drew a name out of the eligible entries. Madeline Friesen from Manitoba was our winner.



**Congratulations to our contest winner!**

## Chief Nursing Officer—SBC



Lisa McGuffin has stepped down from the Board of Directors of Soft Bones Canada and is taking on the role of Chief Nursing Officer.

This new position will ensure that Lisa, a registered nurse, is able to assist patients by advocating for them and helping them communicate their needs and concerns with medical professionals.

Wishing Lisa great success in her new role.

## A message from the Scientific Advisory Board of Soft Bones Canada

At the recent Scientific Advisory Board teleconference meeting held Nov. 20, 2017, Dr. Cheryl Rockman-Greenberg updated the Board on the clinical trials that ended last April 2016. With the Common Drug Review recommendation that Asfotase alfa (Strensiq) be listed on provincial formularies for patients with HPP under 18 years old, the Alberta and Manitoba governments have been negotiating on behalf of pCPA with Alexion for a funding agreement. After 19 months the pCPA and Alexion are close to an agreement. We are hoping the letter of intent will be signed shortly.

The International HPP Registry Report was presented by Amy Yakimoski. The goals of the Registry are to collect data to help define the natural history of HPP and be used as a comprehensive resource. Participation is entirely voluntary. 160 patients are currently registered around the world. Children's Hospital/Health Sciences Centre in Winnipeg is the only site in Canada. Possibly a Quebec site will be added. Dr. Greenberg will attend a meeting of the Registry next month in Madrid. To date in Canada we have:

- 22 patients enrolled
- 11 patients are receiving the drug Strensiq
- 16 patients who had been in the clinical trials have not enrolled in the current Registry.

Several key articles have also been published over the past year on HPP

Many thanks to all who have contributed to this initiative.

- Dr. Cheryl-Rockman Greenberg

## Welcome Conor Colbourne as the new Secretary of SBC!

Hello, my name is Conor Colbourne and I am thrilled to be coming on board with Soft Bones Canada as Secretary. I look forward to using the skills I bring to the table to help and support those with HPP. I remember when I first realized my brother wouldn't be able play the sports and do the things that I could as a child because he has HPP. Seeing the struggles that those with HPP go through on a daily basis motivates me to do all that I can to support those with HPP.



## Linda Toews: New Director of Patient Care

As the new Director of Patient Care for Soft Bones Canada, I would like to introduce myself. My name is Linda Toews and I have a 15 year old son named Willem who has HPP. My family lives in southern Manitoba. As Director of Patient care, my goals for the next year are connecting with families, sharing information about new developments on the HPP front and helping families connect with Health Care Providers.



I am compiling a database of Health Care Providers across Canada to make available to patients and families. We hope to expand our database across this country and have resources for all Canadians with HPP. As I connect with different families, I would like to record your Health Care Providers contact information in order to put it into a database for all Canadian HPP families to access. I look forward to calling you in the new year to connect and see how Soft Bones Canada can continue to encourage and educate our families.

As I have more information and resources I will share this information with you via our various social media accounts. I look forward to representing Soft Bones Canada as Director of Patient Care.

We have created a new account on Instagram – @softbonescanada and look forward to patients submitting pictures of their family to show the strength and courage HPP patients and their caregivers have. Please check out our Instagram, Twitter and Facebook pages to see updated information and connect with patients and families.

I would love to hear from you and your stories about living with HPP. Reading about your story can be a huge encouragement to someone who has just been diagnosed with HPP or who is sharing your experience. You can contact me via email at [linda@softbonescanada.ca](mailto:linda@softbonescanada.ca). You can also call 204-202-3211.

My family wishes you a Merry Christmas and a Happy New Year.

Linda Toews

Director of Patient Care

**DONATE NOW**

**If you would like to contribute financially to Soft Bones Canada™, please visit our website at:**

**<http://softbonescanada.ca/donate-now/>**

**It makes a great Christmas gift idea!**



## The Canadian Dental Association - Increasing Dentists' Awareness of Hypophosphatasia

The CDA produced and shared a four-part video series focusing on hypophosphatasia as part of their National Oasis Discussion Videos. Three members of our Scientific Advisory Board, Dr. Cheryl Rockman-Greenberg, Dr. Marc McKee, and Dr. Bob Schroth, were featured in these videos, as was our Soft Bones Canada President, Debbie Taillefer.

You can watch the videos on our website, or by visiting  
<http://oasisdiscussions.ca/2017/06/07/hpp/>

The CDA also published an article entitled "Hypophosphatasia of Bones and Teeth" in CDA Essentials: The Canadian Dental Association Magazine.

<https://www.cda-adc.ca/en/services/essentials/2017/issue7/30/>



### Metabolic Family Workshop

A big thank you to Pat Hoffer and Jane Ungar for setting up our display and working the table at the Metabolic Family Workshop in London, ON this past spring.

Several HPP families attended this event and enjoyed learning and connecting with other patients.



Learn more - [http://www.lhsc.on.ca/About\\_Us/LHSC/Publications/Homepage/MetabolicFamilyWorkshop.htm](http://www.lhsc.on.ca/About_Us/LHSC/Publications/Homepage/MetabolicFamilyWorkshop.htm)

If there are similar events in your area, please send us an email so that we can spread the word!

### Director of Education and Events Report: by Jennifer Boin

#### *Looking Forward: Events and Educational Opportunities in 2018*

- Dr. Greenberg has generously offered to host an online talk with students in a Health and Wellness High Skills Major at St. Joseph's Catholic High School in St. Thomas, ON.
- We hope to launch smaller regional patient meetings focusing on connecting patients with one another. The goal is to begin with a patient meeting this July in Ontario. More information to come!
- SBC will be sending 2 members of our Board of Directors to the Peds Endo Society Annual Meeting in Toronto this May.
- Members of the Board of Directors will take part in the ASBMR conference (American Society for Bone and Mineral Research) in Montreal this September.
- October 30th is HPP Awareness Day. We look forward to getting all of our members both young and old(er) engaged in our campaign.

As the year unfolds, I hope to find new and exciting ways to increase awareness and education about HPP. I also want to work with SBC to engage patients and help provide a caring community of support.

All the best to you and your families in 2018.

