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## President's Address

by Debbie Taillefer

We have reached the end of another exciting year not only for Soft Bones Canada™ and all of our members, but for Hypophosphatasia in general. We had the privilege of representing you, our members, at ASBMR this year. The excitement amongst professionals in the area of bone and mineral research was palpable in relation to the study of our disease and the current treatment, Asfotase Alpha. The impact is rippling through the medical and scientific community and our long-held dream to see Hypophosphatasia become a house-hold name is beginning to be realized. We had many stop by our booth and congratulate all of our supporters for tirelessly holding the torch and to keep it up! It's working! We have launched a new campaign to bring more tangible support to patients and caregivers at the local level with the launch of our provincial connection support groups. And this year saw two of our own HPP medical and scientific heroes recognized and honoured – Cheryl Rockman-Greenberg, MD, CM, FRCPC, FCCMG, was inducted into the Canadian Medical Hall of Fame and José Luis Millán, Ph.D., as the 2018 Lawrence G. Raisz Award recipient. Congratulations to you both! On behalf of the entire team here at SBC, we wish everyone a very Merry Christmas and a Happy New Year!

*Thinking of each of you and wishing your family an extra measure of comfort, joy and hope this Christmas.*

*We wish you a Merry Christmas*



# New Engagement Initiative

## Connecting Patients Through Provincial Patient Groups

This year has seen the growth of three new SBC satellite patient groups in Canada. The first to formally join together as a provincial group was the **Alberta Connection**. This group met on June 25th at Alberta's Children's Hospital in Calgary. There were many familiar faces, as well as some new members to Soft Bones Canada. One of our members volunteered to help lead the Alberta connection from now on! Thanks, Jennifer!



The next group to form was the **Manitoba Connection**. The first meeting of the Manitoba/NW Ontario meeting in August was a great way for families in the area to meet and share their HPP journey. Dr. Cheryl Rockman-Greenberg was a guest. It was a casual evening that included an informal Q&A with Dr. Greenberg fielding questions and then everyone enjoyed some refreshments.



The most recent group to form was the **Ontario Connection** group, mainly attended by those from Southern Ontario. The group met at Victoria Hospital in London, ON on October 12th, 2018.



Dr. Chitra Prasad was present and opened the meeting by discussing HPP and the role that she plays in the lives of her HPP patients. We had some happy reunions with patients who had attended our national HPP conference

in Manitoba, as well as some new introductions with a family who's child was recently diagnosed.

***The goal of these meetings is to discuss new developments in research and treatments, as well as connect with other patients and families living with HPP. If you would like to start a group in your province or territory, please contact us. We would love to help!***

## Welcome Jessi Neufeld—New Office Manager of SBC!

My husband and I, along with our three children, have lived in beautiful southern Alberta since 2015. My husband teaches in a private school, and is involved in a variety of community programs in the area. I accepted the position of office manager in June of 2018, and have enjoyed being involved with such a fantastic team.

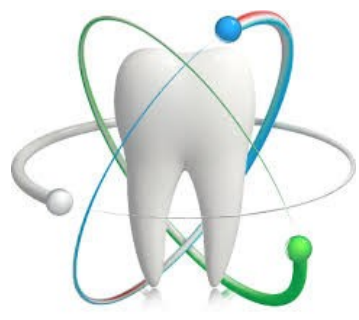
Even before his birth, my youngest brother was diagnosed with HPP. I have seen firsthand the challenges and obstacles he has faced growing up. Witnessing this has given me a special understanding and insight as to how HPP can affect families, and this continues to drive me to assist others in their fight against HPP.



## New Dental Brochures for 2019

Thanks to Dr. Bob Schroth and his colleagues for their work in creating a Canadian publication that focuses on HPP as a dental disease.

The hope is that patients will be able to bring this brochure with them to appointments to assist the dental professionals in understanding HPP and the unique challenges that this disease can present in terms of dental deformity, decay and loss of teeth.



## Canadian Medical Hall of Fame Induction Ceremony

Dr. Cheryl Rockman-Greenberg was inducted into the CMHF on April 12th, 2018 in London, ON for her contributions to the medical community and to those with rare diseases. She was honoured for bringing advanced medical knowledge and care to isolated and vulnerable populations. In addition, she developed diagnostic tests, screening programs, and treatments for disorders once untreatable and poorly understood., including HPP. In addition, she was the main investigator for the clinical trial of Asfotase Alpha, currently the only medication available to treat hypophosphatasia.

A small group of Soft Bones Canada members, as well as an HPP patient family, had the privilege of joining Dr. Greenberg to celebrate her amazing achievements.

*Dr. Rockman-Greenberg with this year's inductees.*



To read more about Dr. Rockman-Greenberg's career and the Canadian Medical Hall of Fame, please go to [www.cdnmedhall.org](http://www.cdnmedhall.org)

## SBC Annual General Meeting—April 2018

The Board of Directors met in London, ON to review policies and make plans for the upcoming year.

We are excited about the new initiatives and look forward to working with the Canadian HPP community to improve the lives of patients and caregivers.



**As always, if you have ideas, or would like get involved, please get in touch with us at [contactus@softbonescanada.ca](mailto:contactus@softbonescanada.ca)**

# The 1st International Scientific Meeting on Hypophosphatasia - Chicago June 8th-10th, 2018

Soft Bones Canada was invited to take part in the 1st Scientific Meeting hosted by the Soft Bones Foundation that took place in Chicago, Illinois June 8-10, 2018. The conference focused on the past, present and future of HPP internationally. Clinicians involved directly in HPP patient care, physician/scientists, and basic scientists traveled from three continents to take part in this exciting opportunity to share their understanding, their research and their commitment to finding ways to better understand HPP and, in doing so, help patients improve the quality of their lives.

There were many "celebrities" in the HPP community who presented their research and knowledge to the group over the day and a half. As an HPP patient, I was moved by the passion and excitement that was demonstrated during the meeting. While this disease can make it difficult to hope, seeing these intellectuals working together and tackling the big questions was inspiring.



*Dr. Whyte was recognized by Soft Bones US for his dedication and outstanding contributions to patients and families with HPP.*

## ASBMR—Medical Conference

Sept. 28th —Oct 1st, 2018

(American Society for Bone and Mineral Research)



Debbie Taillefer and I were able to represent Soft Bones Canada at RBDA/ASBMR in Montreal this past October. The first 2 days of the conference was a meeting of the Mechanistic Therapeutic Advances in Rare Skeletal Diseases. We were able to set up a table for participants in the conference to stop by and speak to us about HPP and Soft Bones Canada and the role of our organization in the lives of our HPP families. We also attended some of

the information workshops on Rare Skeletal Diseases. The attendees of the conference had posters describing various aspects of Rare skeletal diseases. There was over 30 posters representing HPP and the impact on lives and families and current research and drug therapies. There was a lot of interest in HPP and many researchers presented posters on the disease. SBC also met other organizations that were representing patient groups in the different rare diseases.

The next two days we shared a booth at the ASBMR conference with Soft Bones US and had many contacts with doctors from Canada, US and around the world. This was a very busy couple of days and we met many researchers, scientists and doctors, including Dr. Whyte and Dr. Milan from the US. We distributed many of our SBC thumb drives which contain our set of HPP brochures.

As the meeting was held in Canada this year, SBC thought it was very important to represent our families and increase our contacts in Canada to help our patients access medical professionals across all provinces.

- By Linda Toews

## Holiday Greetings from your SBC Scientific Advisory Board



*Members: Dr. Cheryl Rockman-Greenberg, Dr. Leanne Ward, Dr. Bob Schroth, Jessica Hartley, Dr. Marc McKee, Dr. Philippe Crine, Amy Yakimoski, Mark DeBrincat, Dr. Bob Schroth, Debbie Taillefer, Erika Bloomfield, Linda Toews*

This past year has really been a consolidation year for the SBC SAB with individual members contributing in their areas of expertise to broaden our understanding of hypophosphatasia (HPP). It would be correct to say that the more we learn about this condition and how it affects you, the individual and the family with HPP, the more it inspires us to keep searching for answers and to understand more about this complex disorder. There is an overarching theme to the work members of your SAB do, in collaboration with your membership. This is to continue to advocate overall for more research and innovation in rare disorders to allow all people living with HPP and other rare disorders to receive an accurate diagnosis, care and therapies soon after coming to medical attention. This is greatly facilitated by consortiums of Rare Disease Research, such as the International Rare Disease Research Consortium (IRDiRC) which brings together people from multiple countries, including Canada, disciplines, universities, government, industry and patient organizations from around the world. Such international consortiums greatly impact what happens in Canada within the Rare Disease arena and complements all the incredible work being done by so many in the HPP community and research community overall in Canada.

Over the past year Dr. Bob Schroth and colleagues have worked closely with SBC leadership to provide updated information and guidance on oral health in HPP and the importance of dental assessments starting early in life including assessments by and referrals to experts in the oral health of HPP patients. We remain active in the International HPP Registry and participate in publications about diverse aspects of HPP. Provincial governments are turning to the working group of metabolic and other specialists who are members of the National HPP Clinical Expert Committee for recommendations regarding starting and continuing treatment with ERT. The National HPP Clinical Expert Committee is in the final stages of refining and rolling out the clinical practice guidelines and criteria for eligibility for treatment of children with HPP with enzyme replacement therapy with asfotase alfa. Many of us along with many other stakeholders including patient organizations, have also been asked for our input on a new proposal for management of rare disease drug therapies drafted by Alberta, British Columbia, and Ontario. These 3 provinces are leading the Expensive Drugs for Rare Diseases Working Group (EDRD WG) that was formed in 2014. This process is being facilitated by CADTH (Canadian Agency for Drugs and Technology in Health), an independent organization responsible for providing our health care decision makers with the “evidence” about the use of drugs and medical devices. Stay tuned: We are hopeful there will be very positive changes in the future about how the regulatory and policy makers in Canada evaluate “evidence” and make recommendations regarding the listing of drugs on provincial formularies and their reimbursement. Wherever and whenever possible, locally, nationally and internationally, we continue to advocate for rare disorders and their impact on Canadians.

Our very best to the entire HPP community for a safe and happy holiday season.

Sincerely,

Cheryl Rockman-Greenberg

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

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

**DONATE NOW**

## De Brigj Radio Broadcasts HPP Information

De Brigj Radio in Aylmer, ON, informs, entertains and ministers to the Low German community in South-Western ON. In addition, it shares programming with stations in Paraguay, Mexico, USA, Belize and Bolivia.

As there is a disproportionate number of Mennonite Canadians with HPP, SBC felt it was important to try to reach out to this community and raise awareness.

Jennifer Boin (Soft Bones Canada Director) recorded a three part series on hypophosphatasia. Topics covered included the signs and symptoms of the disease, the impact it has on patients and caregivers and what can be done to improve the health and well being of those with HPP.

The program has aired on the station in English, but a Low German translation of the series is almost complete. These recordings will be available on our website when the project is completed.

*SBC would like to acknowledge the work of Maria Dyck and her daughter Lyli for their help recording and translating the sessions.*



**DE BRIGJ  
105.9 FM**