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Christmas is a season of great joy: a time for remembering the past and hoping for the future. May the glorious message of peace and love fill you with joy during this wonderful season.

All the best to you and your families from Soft Bones Canada.

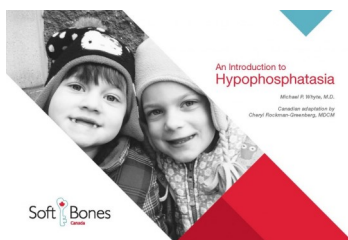
President's Report

This past year we had exceptional opportunities to be involved in a variety of activities and achievements on behalf of patients and their families suffering from HPP in Canada. We formally completed our charitable status which was a huge step for SBC. We hope this opens doors for anyone seeking to support the mission of SBC, who maybe doesn't have time to give in other ways. We also set about expanding our patient reach and interest by inducting our Patient Advisory Board. Engaging stakeholders to be a voice in health care, national and international rare disease groups, government and industry rounds out some of our momentous goals accomplished in a very short period of time!

A big part of our mandate is to inform not only patients in regards to issues affecting them, but also educate health care professionals (HCP). This mission led to attending conferences such as the American Society of Bone and Mineral Research and Endocrine Society. There, we successfully engaged Canadian HCP's, scientists, researchers and students, endeavoring to raise awareness. Our goal was to educate medical professionals in an attempt to shorten the time to diagnosis and encourage the pursuit of research and development of new therapies. It was interesting to see the transformation with HCP's after listening to our presentation. As they started to ask questions, the realization would often set in that they not only needed the information we had but that they would pull patient files to re-evaluate. This was very rewarding for us not only in disseminating as much information as we could to those who are on the frontlines of diagnosis, testing and advocate for access to support and therapy, but to consider the impact we would have on all of those patients who are currently suffering undiagnosed or misdiagnosed.

As a national organization, we determined the need to be taken seriously with all stakeholders including policymakers. With patient consent, information and images, we were able to develop and craft beautiful, professional, Canadian tri-fold, genetics, patient information and physician awareness brochures. The brochures were placed in clinics and hospitals, sent out to patients for education about HPP and taken to appointments to shorten the wait time for appropriate diagnostics and to bring everyone up to speed on treatment. We also crafted our inaugural newsletter and designed a modern website, enabling us to reach out beyond our own walls and communities, keeping everyone up to date with HPP news and innovations and in order to reach new patients and families across the nation.

Following this was the highly successful contest to design and launch our new T-shirts, courtesy of our



Patient Advisory Board. They did a fantastic job and people even as far-flung as Australia and the United Kingdom were very impressed with the design.

During the late spring, a partnership was formed between McGill University, RSBO, and members of SBC's Scientific Advisory Board. These groups joined to take part in a Café Scientific in Montreal, PQ which highlighted all aspects of HPP as a soft tooth and bone disease. In addition, they presented information about the drug discovery and the challenges of bringing a drug to market, especially for an ultra-rare disease. SBC was able to fund camera men, cameras and production to bring this presentation to TV on Canal Savoir and provide for sub-titles to help reach Francophone Canadian patients and HCP's.

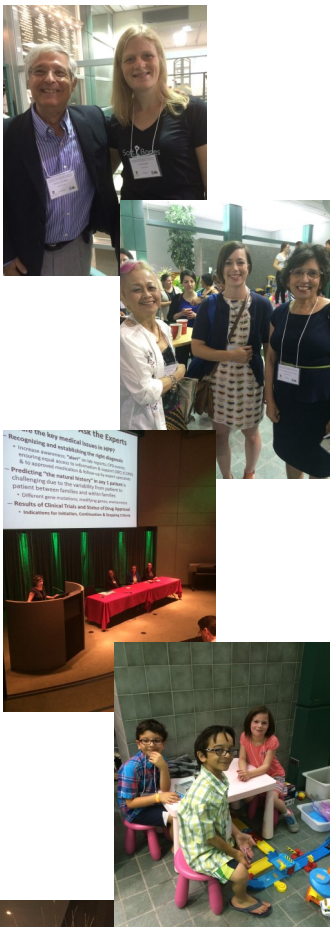
Definitely the highlight of our year had to be our Family and Professional Medical Conference held in July in Winnipeg, Manitoba. It was our desire to plan a very special occasion as well as ensure a well-rounded educational experience. We sought to have a variety of topics that provided a holistic perspective on how to manage and understand the disease, as well as hear about cutting edge research. Topics included an introduction to the science, as well as an extensive talk about the impact of the disease on the teeth. There was also exposition about how asfotase alfa operates in the body. A great deal of discussion was also generated about how the disease impacts individuals and families, both physically and psychologically.

We cannot adequately express what a privilege it was to be a part of reducing isolation and to see patients from all over Canada come together and be able to connect and spend time with each other. As difficult as it is that we share a rare disease, it is an honor to be associated with such a compassionate, courageous, resilient and inspiring group of people, as well as such a dedicated team of health professionals, scientists, advocacy and business leaders. You are definitely the reason we do what we do every single day!

Finally, we have been involved in both a Canadian and international engagement between government, payers and industry in regards to access and reimbursement for asfotase alfa. We have also been active in supporting the need for Canada to have a national disease framework, which would go a long way to prevent lengthy wait times during the negotiations for access to treatment.

It has been a challenging and exciting year! We remain hopeful that there will be some positive outcomes on all fronts for everyone ahead, and we remain committed to advocate for patients and their families to receive equitable access to healthcare and therapies as Canadians with other more commonly known diseases.

Everyone at SBC would like to wish you and yours a very Merry Christmas and a Happy New Year!



Memories From the 2016 1st National Hypophosphatasia Conference in Canada

On July 22nd and 23rd we held the ***Soft Bones Canada – 1st National Hypophosphatasia Conference: The Journey From Diagnosis to Treatment in Winnipeg, MB.*** Patients and professionals had an opportunity to listen to world renowned scientists and experts in the HPP community. In addition, there were many opportunities to engage with medical professionals during the panel discussions and, informally, throughout the weekends many events. Patients of all ages were also given a voice during a patient panel. This was created to allow those who work with HPP patients and families to better understand their needs and experiences.

The conference was a tremendous success! We received resounding praise for the quality of the speakers and panels, the venues, the food and especially for the positive atmosphere that was created for patients and medical professionals alike. We hope that this will usher in a new level of understanding and engagement for those with the disease, as well as for those who work to assist patients and families.



Annual General Meeting—Directors’ Meet in Niagara-on-the-Lake

October 28th –29th marked the first AGM for the director’s of Soft Bones Canada. The board reviewed all aspects of the organization over their two-day meeting. This was also an opportunity for the board to do some team building.

“As a team building exercise, we decided to see if we could free ourselves from an escape room in Niagara Falls. Sadly, we didn’t escape in time, but they let us out in the end. “ Jen Boin



Dental tips for parents of children with HPP:

by Dr. Schroth

We know that children with HPP often face considerable dental issues.



Early loss of baby incisors (often before 18 months of age)

Missing or lack of cementum covering roots

Enlarged dental pulp (nerve) areas – this means treating the smallest of cavities is important.

Enamel defects (pits or missing enamel). This increases the risk for tooth decay/cavities. Some defects are unattractive and may be covered up with resin fillings. That is why early and regular dental care for children with HPP is so important.

Celebrate your child’s first birthday with a trip to the dentist. The first dental visit is recommended before or by 12 months of age, which helps establish a dental home for the child.

Thereafter, ongoing dental visits should be tailored for each child based on their risk for developing cavities. This cavity-risk assessment can be performed by your child’s dentist.

What are some healthy steps to reduce my child’s risk of developing dental problems?

Brushing twice daily with fluoride toothpaste: use the size of a grain of rice if < 3 years of age. Children ≥ 3 years of age can use a green pea size. Remember: most children need assistance with brushing until age 8 years of age.

Regular trips to the dentist are important. Even if you think they are fine, keep on top of their dental issues.

Give your child dental friendly snacks like fruit, vegetables, and cheese. Vitamin D rich foods and supplements may also help prevent cavities.

Limit between meal snacks and drinks containing sugar and consider sugar substitutes.

Dental sealants can be placed on the tops of permanent and baby molars to prevent cavities from forming.



Some parents get concerned with the appearance of missing teeth. Talk to your child’s dentist to see if they are suited for a fixed dental appliance to replace missing teeth.

A message from the Scientific Advisory Board of Soft Bones Canada

Recently I attended a meeting in Munich sponsored by Alexion Global on pediatric- onset adult Hypophosphatasia (HPP). It was one of a series of such meetings I have attended over the past few years in my capacity as a member of Alexion’s advisory board; each time learning more about HPP and what binds us together in Soft Bones Canada. In spite of many differences globally, there is more that binds us together than keeps us apart.

We know a great deal about HPP- its symptoms, its signs, the variability in the signs and symptoms within and between families, the dental manifestations, the manifestations in the bony skeleton and skull and the manifestations beyond the skeleton. We have learnt more about the impact of this disorder on the wellbeing of the patient, the family and his or her community. We have learnt a great deal about chronic pain in bones, muscles and joints in patients with HPP, the fractures that don’t heal well or refuse to heal and the severe debility this disease can have in newborns, infants, children and adults. We, on the Soft Bones Canada Scientific Advisory Board, are committed to help in your mission to increase awareness of HPP, to lessen the isolation many families feel, to help you and your care providers in management of HPP and to continue to instill hope for the future. We hope to continue to work together with you to ensure the right care is provided for the right patient at the right time.

Asfotase alfa™ offers a great deal of hope for the management of patients with HPP. The excitement about its potential is palpable. In the world of rare and ultra-rare disorders, hearing the recommendation of the Common Drug Review in April 2016 to list (with conditions) asfotase alfa™ in our public formularies in Canada, has generated this excitement – and with every reason. There are still mountains to climb, and much we do not know about HPP. Decisions regarding reimbursement by the public payers in our country are still not finalized and this can be demoralizing. I would like to quote something I read in the National Post on an Air Canada flight on the way home from Munich recently. The reporter was commenting on Mr. Joe Biden, the outgoing vice-president of the United States who is visiting Canada. The reporter wrote that Mr. Biden will offer reassurance to us all in these challenging political times in the United States. “*It will all be ok in the end and if it’s not ok then it’s not the end.*” Indeed with respect to HPP the challenges are numerous but we will continue to work diligently with you so that all will be ok!

We, the SAB of Soft Bones Canada, wish you all a safe and happy holiday season and the best in 2017.

Cheryl Rockman- Greenberg, Chair



Congratulations to Dr. Greenberg!

This fall, the Rx&D Research Foundation at the University of Manitoba awarded Dr. Greenberg with the Medal of Honour for her many accomplishments, including her impact on medical research and the health of children, which continues to have a global impact.

To read more go to:

<http://news.umanitoba.ca/pediatric-geneticist-awarded-medal-of-honour/>

Meet Linda Toews, SBC’s new Treasurer

< New Post > Home
Write a comment...



Hi my name is Linda Toews. I am a mother blessed with 6 beautiful children. My youngest son has HPP. We have been actively involved with HPP for 21 years. I am looking forward to working with Soft Bones Canada to promote and support our HPP community in Canada.

Linda

Director of Education and Events Report: by Jennifer Boin

Looking Back: Events and Educational Opportunities from 2016

Teleconference

- In January of 2016, Soft Bones Canada organized a very successful and well attended teleconference for patients interested in learning more about HPP in Canada and more specifically about how a drug, like Strensiq, goes from research to an available drug treatment for patients in Canada.

Website

- At the beginning of 2016 we contracted Redding Designs in Aylmer, ON to design our Soft Bones Canada website. With the help of the design team and the SBC board of directors, the website was launched in April.



National Patient Conference

- One of the biggest undertakings of 2016 was hosting the first national HPP patient and medical professional conference in Canada, in Winnipeg, Manitoba, with the help of the CPD Medicine Program, Rady Faculty of Health Sciences at the University of Manitoba in conjunction with the Children’s Hospital Research Institute of Manitoba.

It has been my pleasure to work with such a supportive, committed and professional group of individuals, who work tirelessly – truly tirelessly – for the benefit of those with HPP and for their families. I consider it an honour to work with them.

I look forward to continuing in my role as Director of Education and Events and hope to find new and exciting ways to help the HPP community in Canada.

T-SHIRTS FOR SALE!!

Men’s crew neck and Women’s V-neck

S, M, L, XL, XXL

\$25.00

Email your order to lisa@softbonescanada.ca



From the Director of Patient Services:

Lisa McGuffin

Sometimes (most times actually) I think that I have the solution to all of my world's problems. I know where the clean clothes are, how to make paper snowflakes, and what's edible in the back of the fridge. I am so good at conveying this that I have convinced my children that I am the only one capable of running the washing machine (properly), and loading the dishwasher (properly). Because of this, I feel as though I have been running the show and doing everything, and guess what? I'm not *really* capable of doing everything. I am learning that allowing the gifts of creativity, energy, organization, and fun to develop in our family makes life more interesting. Everything may not turn out exactly as I envisioned it, but the benefit of sharing the jobs helps us to become a better team and our family runs a lot more smoothly when we work together.

So how does this relate to Soft Bones Canada? Well, this year I have learned quite a bit about the patients here in Canada – some people speak French, some are fantastic cake decorators, some are great with organization and numbers, some know a lot about managing illness with diet...the list is long! Everyone has something to bring to the table, and each strength, talent, and perspective is so valuable.

We have a place where we hope YOU feel able to share your thoughts and ideas with each other, and have the ability to make things happen here at Soft Bones Canada (SBC). *Technically* speaking, a Patient Advisory Board (PAB) is a place for patients to provide their unique and invaluable perspective to SBC and our Scientific Advisory Board, about how to make improvements, with the goal of better serving all patients and caregivers. *Creatively* speaking? A PAB is a place to brainstorm ideas about what would make life better for our Canadian patients and help make those ideas a reality. This could be information that you think would be valuable to include in patient packages, ways to raise HPP awareness in your region, fundraisers to keep the wheels turning, and doing it together. You are the voice of HPP patients and have an impact on the vision of SBC!

With this in mind, I want to say **!!THANK YOU !!** to all of those who have volunteered on our first patient advisory board in 2016. Your contribution to designing a t-shirt and swag bag for our first patient conference was wonderful! Both patients and caregivers/parents from several provinces are currently represented on this team, and it would be great to see more of Eastern Canada represented here. If you are interested in joining this group or want to help in any way, please send me an email at

It has been my privilege to hold the position of Director of Patient Support Services this year. This has given me the opportunity to speak with many of you personally and hear your stories and concerns. Parts of my job include liaising with the PAB, helping people access information through the patient packages – which contain information for patients, physicians, and families about the causes, symptoms, and treatment of HPP – or even providing the name of a physician who has experience with HPP patients.

We have several forums available to connect patients with each other on Facebook – Soft Bones Canada Hypophosphatasia, both a public and a private page, and are continuing to develop a physician referral list of knowledgeable Canadian doctors. You can get in touch with me at the email address above, or by Facebook message.

Looking forward to another year of working together!

Merry Christmas from our family to yours,

Lisa McGuffin



If you are interested in volunteering with Soft Bones Canada, please get in touch with us by contacting Lisa at lisa.softbonescanada.ca or by calling our toll-free # 1-844-255-8477.

***You can also visit our website
www.softbonescanada.ca***