

AUGUST 2024

SBC NEWSLETTER

SBC Dental Brochure

Greetings Soft Bones Family!

Soft Bones Canada is thrilled to announce the completion of our Dental Brochure. Much thanks to members of our Scientific Advisory Committee for their hard work on this project. Of special note, thank you to Dr. Bob Schroth, Dr. Marc McKee, and Dr. Cheryl Rockman-Greenberg.

Our new brochure contains valuable information on dental aspects of hypophosphatasia (HPP). We designed it to be educational for both patients and practitioners.

Take a look today and please contact us if you would like us to send you printed copies. We would love for our patients to be a part of distributing these new brochures to family members as well as dentists and doctors in their communities!!

Download here:
<http://bit.ly/3WLWsnI>



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Canada

Hypophosphatasia:
A Dental Disease

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Upcoming Webinar with CARDS

SBC is pleased to announce that we will be working with Dr. Leanne Ward and CARDS (Canadian Alliance for Rare Disorders of the Skeleton) to host another free educational webinar in October. Dr. Natalie Truba will be our keynote speaker and the focus will be psychological impacts on patients and families of living with rare bone disorders.

This webinar will take place on October 29 at 7 pm Eastern, the day before we celebrate World Hypophosphatasia Day.

For more information about CARDS events for patients, friends, and families and to register for the session, see: <https://www.kidsbonescanada.org/events-patients-friends-families>



Alexion 1850 Updates

Phase 3 trials for Alexion's new enzyme replacement therapy (ALXN1850) are now underway. There are six sites across Canada and three different studies are being conducted. The Hickory study includes adolescents and adults who are drug naive (have not previously been treated with asfotase alfa/Strensiq); the Mulberry Study is for drug naive pediatric patients; and the Chestnut Study is for pediatric patients who *have* been treated with asfotase alfa.

The English Hickory trial is now live and the French sites will be starting in the next few weeks. For more about the Hickory study, see: <https://hickorystudy.alexionclinicaltrials.ca/>

Chestnut and Mulberry are expected to begin at the end of August.

For more information you may contact Alexion clinical trials at clinicaltrials@alexion.com or 1-855-752-2356.





VIPeR Registry

VIPeR (Verified Interest to Participate in Research) is a new rare disease research registry in Canada. The purpose of the registry is to increase patient access to clinical trials and research by creating a Canadian national registry of rare disease patients and individuals interested in research.

No patient medical information is collected other than patient name, contact information, and the name of the rare disease. It is hoped that the registry will allow patients to have increased access to clinical trials related to their condition and improve patient care in Canada. It may also increase individual access to information about new research studies and clinical trials.

For more information, please go to Vipert. Questions may also be directed to the clinical team at M.A.G.I.C. Clinic (Metabolics and Genetics in Calgary): research@magiccalgary.ca.

CORD Fall Conference



We encourage HPP patients to stay up to date with exciting developments led by CORD (Canadian Organization for Rare Disorders). In August, CORD hosted an open dialogue webinar with Health Canada about the implementation of the new Rare Disease Strategy.

The annual fall conference will be held in Montreal this November. Funding may be available for patients or caregivers interested in attending the conference. You may contact SBC for assistance in applying for a grant.

For more information about CORD, please visit their website:
<https://www.raredisorders.ca/>



Get Involved with SBC to Support Canadian HPP Families!

At SBC, connecting patients and caregivers with the best information about the diagnosis and treatment of HPP in Canada continues to be our first priority. We welcome contact and involvement from our community members for anything HPP-related and would like to hear about the questions and concerns that are important to our patients.

Our volunteer Board of Directors continues to welcome expressions of interest from new volunteers and we are also seeking patient stories for our future newsletter. Please consider sharing your story!

Write to us today: contactus@softbonescanada.ca .

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