

OCTOBER 2023

SBC NEWSLETTER

World Hypophosphatasia Day

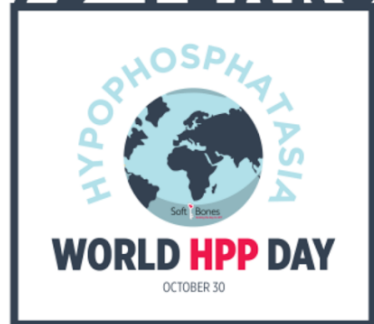
Happy World Hypophosphatasia Day: October 30, 2023

Did you know that it has been 75 years since HPP was first named? In 1948, a Canadian pediatrician named Dr. John Rathbun reported on low levels of ALP in an infant, thereby discovering and naming hypophosphatasia. To find out more, please visit the American Soft Bones website. <https://softbones.org/world-hpp-day-2023/>

Thank you to Soft Bones for posting this information for our communities!

Here in Canada, SBC Board members have been creating and hosting events in their communities to raise awareness about HPP. Watch for more info on our social media and let us know how you are celebrating and spreading the word about HPP!

75 YEARS



75TH ANNIVERSARY OF HYPOPHOSPHATASIA

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Passing of Philippe Crine

As many of you have heard, HPP lost a beloved community member since our last newsletter was issued. Dr. Philippe Crine was a professor of biochemistry at Université de Montreal and founder of Enobia Pharma in 1997. His research was critical to the discovery of the molecule that has become the primary treatment for HPP in Canada and around the world: the bone-targeted enzyme replacement therapy known as asfotase alfa. He has served as a dedicated member of SBC's Scientific Advisory Board since the founding of our charity. He was a man of great passion, kindness, and humility. Dr. Philippe Crine passed away on June 13, 2023.



Webinar with CARDS

SBC was delighted to collaborate again with Dr. Leanne Ward and CARDS (Canadian Alliance for Rare Disorders of the Skeleton) for a free educational webinar focussed on the psychological effects of living with rare bone disease. A keynote address was made by Dr. Natalie Truba, clinical assistant professor of psychology at Ohio State University, and SBC's own Jeremy Harany also shared his story of living with HPP with a focus on the psychological impact the disease has had on him and his family. The webinar's "open mic" format allowed for these presentations to be followed by informal discussion open to all participants. To watch the full video, click [here](https://www.kidsbonescanada.org/)

For more information about CARDS, visit:
<https://www.kidsbonescanada.org/>





New ERT Drug Trial in Canada: Alexion Study 1850

Alexion is progressing the next generation alkaline phosphatase enzyme replacement therapy (ERT) in clinical trials for adults and children with HPP. The intention is to uncover new ways to improve the patient experience and provide additional treatment options to help more people living with this devastating disease.

A Phase 1 study of ALXN1850 (“next-generation asfotase alfa”) in adults with HPP was successfully completed in 2022. Information on the study can be found on [here at clinicaltrials.gov](https://clinicaltrials.gov). More information will be available in coming months.

CORD Conference in Calgary

The Canadian Organization for Rare Disorders (CORD) is holding its fall conference in Calgary this year, November 29-30. SBC Board members are planning to attend to gather more information about the incredible work CORD has been doing to advance Canada’s Rare Disease Strategy and to connect with other members of the rare disease community in Canada. Any HPP community members attending this gathering are encouraged to let us know that you will be there and we can arrange to say “Hi!” We are always so happy to meet with members of the HPP community. Email: contactus@softbonescanada.ca

A Call for Volunteers

At SBC, we are always keen to grow our family of active supporters. If you are interested in becoming involved, please contact jennifer.paulson@softbonescanada.ca.



How to Help!

- Join our community! It's as easy as sharing your experiences with others from the SBC by joining our Facebook page or following us on Instagram.
- Let us know if you'd like to submit a patient story!
- Thank you to our regular donors - your generous contributions make our work possible!
- Seeking new volunteers - you can directly assist us in our work to spread awareness. Please email us at jennifer.paulson@softbonescanada.ca if you are interested in joining our team.

Soft Bones Canada

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