Soft Bones
Finding the Key to HPP

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Soft Bones Announces Victoria DeMambro, MS, PhD of MaineHealth Institute for Research (MHIR) as the Winner of the 2025 Maher Family Research Grant for Hypophosphatasia

BOONTON, N.J.,— Soft Bones, Inc., an organization committed to advancing education and research for those affected by hypophosphatasia (HPP), announced today that Victoria DeMambro, MS, PhD, of MaineHealth Institute for Research (MHIR) has been selected as the recipient of its 2025 Maher Family Research Grant. Now in its 13th year, these grants support initiation of promising, high-impact work where limited funding often slows innovation.

“Seed grants are vital in HPP because they support early research that lays the groundwork for future advances,” said Michael P. Whyte, MD, chairman of the Soft Bones Scientific Advisory Board. “Investigators can pursue promising ideas that advance our understanding of the disease.”

The $25,000 grant to Dr. DeMambro will support research exploring the muscle weakness and chronic fatigue many adult HPP patients experience. She will examine the effect of inorganic pyrophosphate (PPi) and pyridoxine 5′-phosphate (PLP; vitamin B6) on HPP metabolism and muscle function. The findings could deepen our understanding of these complications and may reveal new therapeutic targets to improve treatment options for HPP patients.

“I am honored and ecstatic to be this year’s recipient of the Soft Bones Maher Family Research Grant,” says DeMambro. “This award is the next step in my HPP research journey, where my goal is to have a positive impact on the lives of HPP patients, many of whom struggle with muscle weakness and chronic fatigue symptoms every day.”

About the Research Grant

Soft Bones funds research to better understand HPP and find a cure. The foundation has awarded over $550,000 in research grants since 2014, supporting HPP investigators through the Maher Family Research Grant. More information about HPP, as well as existing and ongoing research, can be found at www.SoftBones.org.

About Hypophosphatasia

Hypophosphatasia is the rare, inherited metabolic bone disease caused by deactivating mutation(s) of the ALPL gene, leading to deficient activity of the enzyme called tissue-nonspecific alkaline phosphatase (TNSALP). This deficiency results in the accumulation of TNSALP substrates (such as PLP and PPi) and it is the PPi excess that disrupts mineralization of the bones and teeth, causing a spectrum of skeletal, dental, muscular, and sometimes other complications.

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About Soft Bones, Inc.
Soft Bones, the US Hypophosphatasia Foundation, is a patient advocacy group founded in 2009. Driven by patient and caregiver insights, Soft Bones Inc. inspires and galvanizes collective action to foster greater awareness, improve diagnosis, accelerate innovative research and treatments, and ultimately improve care for those affected by HPP.

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http://www.SoftBones.org