Soft Bones
Finding the Key to HPP

FALL 2025 EDITION

THE BARE BONES

Official Newsletter of Soft Bones, Inc., The US Hypophosphatasia Foundation

VICTORIA DEMAMBRO WINS 2025 MAHER FAMILY RESEARCH GRANT

> **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.**
>
> *– Victoria DeMambro, MS, PhD*

Soft Bones Inc. awarded its 2025 Annual Maher Family Hypophosphatasia Research Grant to Victoria DeMambro, MS, PhD, of MaineHealth Institute for Research (MHIR). This $25,000 grant will support research to better understand the underlying causes of muscle weakness and chronic fatigue symptoms that many adult HPP patients experience.

Click to Read the Full Press-Release

Each year, Soft Bones funds research to understand HPP and ultimately find a cure. The foundation has awarded over **$550,000** in research grants since 2014, supporting HPP investigators through the Maher Family Annual Hypophosphatasia Research Grant.

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

IN THIS ISSUE:

MAY THE FORCE OF GIVING BE WITH YOU

Star Wars-Themed Annual Appeal

This year, Soft Bones takes a joyful leap into the galaxy with **a playful, spirited twist on our Annual Giving Campaign**. To celebrate 16 years of connection, advocacy, and community, we are launching a Star Wars-inspired appeal — and giving is already in full Force.

From our rallying cry, "**May the Force of Giving be with you**," to surprise cameo messages from fan-favorite characters, our community is coming together in a way that feels fun-spirited, warm, and deeply meaningful. **Throughout the campaign, we are highlighting 12 incredible Patients of the Month and 4 extraordinary caregivers**, each one offering courage, insight, and hope. Their stories remind us why this mission matters and how powerful it is when people living with HPP feel seen, supported, and understood.

We are grateful for every person who engages with this campaign. **This collective involvement fuels the backbone of our work: keeping patient resources free and accessible**, supporting our national community groups, expanding our patient registry, and strengthening research awareness. At a time when healthcare grants are tightening and rare-disease funding is harder to secure, this shared commitment ensures Soft Bones can continue to meet the growing needs of the HPP community.

Because of the generosity and involvement of so many, we continue building the alliances, support systems, and educational pathways that change lives. Together, we push back against isolation with knowledge, connection, and hope.

The Soft Bones community is at the heart of this mission, and we all shine brighter because of the support and engagement of people like you.

If you'd like to participate, our Annual Giving Campaign is open for donations.

BECOME A JEDI FOR THE HPP COMMUNITY

YOUR DONATION IS YOUR LIGHTSABER

WATCH
DONATE
SHARE

HPP Happenings

World HPP Day 2025

On October 30th, our global HPP community recognized World HPP Day—an annual moment to unite, raise awareness, and push for progress. **This year's theme, "Is There a Hippo 🦛 in the Room?" highlighted the need for greater understanding of low alkaline phosphatase (ALP) and its impact on the body.** Although ALP is included in routine blood panels, many people, including healthcare professionals, are unaware of what low ALP can signify. As a result, symptoms of HPP may be overlooked or attributed to other conditions.

The HIPPO is both a symbol and a call to action–encouraging people to look at their ALP levels, ask questions, and recognize persistently low levels as a meaningful clinical indicator. HPP remains significantly underdiagnosed. By increasing awareness of low ALP, we can help ensure fewer diagnoses are missed and that more individuals receive the care they deserve.

This year, **our focus was simple: make the HIPPO visible.** Soft Bones released new awareness tools: shareable social media profile frames, a World HPP Day video, and six easily shareable fact cards designed to spread accurate information about HPP and low ALP. **Community members were invited to update their profile pictures, post the World HPP Day ribbon, and use #WorldHPPDay and #HPP to help amplify these resources online. Whether someone is living with HPP, caring for a loved one, or practicing medicine, visibility changes what's possible.**

If you would like to support ongoing resources, advocacy initiatives, and community programs, we invite you to make a meaningful contribution to Soft Bones.

Recap of World HPP Day 2025!

Cannonball 5K: Swapping Swimming Goggles and Bathing Suits for Running Shoes

The Annual Cannonball 5K Run, Roll, or Stroll saw a 112% increase in participation this year, fueled by an impressive show of support from the Boerne Swimming Club. 35 swimmers from Boerne, TX, traded their goggles for running shoes after Coach Drew spotted a World HPP Day profile frame on a swimmer's parent's social media page and learned about Soft Bones and HPP.

Without telling the family in advance, Drew surprised them the morning of the race by announcing that the entire swim team would run in her honor. Turns out that swimmer was none other than Peyton W.! Currently, she is recovering from a shoulder injury, but still comes to practice to help out. Coach Drew states, "I have never seen someone so encouraging to other swimmers."

This story serves as a reminder that even a simple act, such as changing your profile picture, can have a huge impact on encouraging others to support and raise awareness.

> **"It was such an important thing for us to do to support one of our own! So we all ran in honor of her!"** ***— Drew S.***

Teeing Up and Dinking for a Cause: Golf and Pickleball Classic Recap

The 17th Annual Golf Classic and 2nd Annual Pickleball Tournament at Somerset Hills Country Club was a huge success. **Over 100 passionate golfers and pickleball players came together to play for a cause.** As our largest fundraising event of the year, every swing, every dink, and every donation brought us closer to our ultimate goal: **CURING HPP**.

A huge thank you to our Tournament Sponsor, Atlantic Health System, and our additional sponsors who made this event possible. Mark your calendars for our next **18th Annual Golf Classic and 3rd Annual Pickleball Tournament on September 28th, 2026**, at Somerset Hills Country Club.

Click **HERE** to view results and the photo gallery

SOFT BONES IS NOW SPEAKING YOUR LANGUAGE!

As our HPP community continues to expand, we recognize the growing importance of making our resources accessible to everyone, regardless of language. In October, we launched a new website translation tool to support our global HPP community.

Our website and key educational materials are now available in over **60 languages**, helping us raise awareness, improve diagnosis, and support patients, caregivers, providers, and researchers around the world.

Try it out today! Look for the globe icon in the upper right corner of our website to get started.

***Note**: This translation tool may not be 100% accurate but is intended to help international patients better understand available resources and information.*

This meeting, held in Japan is proof that HPP awareness is spreading all over the world!

Research News

Your Data Today Shapes HPP Research Tomorrow

Since January, we've seen a **52.4% increase** in the number of users downloading and using the myHPP app, and for good reason. Created by patients and physicians, this app is designed to be a tool to help patients track their symptoms and to use patient insights to drive meaningful progress in HPP research. Users' information is deidentified, private, and secure, and will only be shared with researchers and doctors.

For the best results, we ask that you aim to **track your symptoms twice a month**. Plus, app users will get first-hand access to **research questions and surveys** through the app's built-in poll feature. Two researchers have already had key questions that shaped their research answered through the app! Don't miss the opportunity to be a part of research and shape the future of HPP!

Download the app and input your symptoms today!!

myHPP

Available on the Apple App Store & Google Play Store

Cannon Unbroken: Triumph Over Adversity

In Episode 2 of Cannon Unbroken, Cannon sits down with **Martin Brodeur**, legendary hockey goalie, 3x Stanley Cup Champion, Olympic Gold Medalist, and Hall of Famer. 🏆

From battling injuries to staying mentally sharp under pressure, Brodeur shares how mental toughness, short-term goals, and a strong support system powered his career to greatness.

Click to Watch Episode 2

This podcast is sponsored in part by;

ALEXION
AstraZeneca Rare Disease

Soft Bones' Members in Action

Rare Artist Contest Finalists

Each year, the EveryLife Foundation for Rare Diseases hosts an art contest, which provides a platform for artists to share their stories and advocate for rare diseases through visual art, poetry, music, writing, and more.

This past September, **the HPP community was proud to have not one, but two talented members selected as finalists for the 2025 Rare Artist Contest.**

Adeline's piece, "HPP Rainbow," was featured in the children category, while W.L. McMurphy's work, "Kin & Kith," represented the adult category. Public voting took place in late September, giving the community a chance to support these incredible artists and help raise awareness for HPP and the broader rare disease community.

Applications for the 2026 Rare Artist Contest will be available soon. **Check RareArtist.org to learn more about this year's finalists & past winners.**

A. "HPP Rainbow" by Adeline

B. "Kin & Kith" by W.L. McMurphy

A.

B.

Employee/Volunteer Spotlight

What do Broadway and Soft Bones have in common? They both have Jenn K., our latest Soft Bones' intern!

Hello! **My name is Jennifer Dunne K., and I'm so happy to have joined the Soft Bones team as an intern this past September.** Most of my career has been spent in the arts — performing on Broadway, working as a photographic editor, and producing small independent documentaries.

I'm now finishing my master's in Communications & Media at Rutgers, where my capstone explores the power of the collective through the lens of performing arts ensembles. I'm deeply interested in how we can be of service to the greater whole, which is why I'm so pleased to be assisting the Soft Bones community.

I'm also a mom to two young daughters, ages 4 and 7, who remind me daily of the wonder in small things — and the surprising motivational power of a Slurpee. When I'm not onstage or on a computer, I enjoy watching my girls make up songs or play with their soccer team. I love attending music concerts with my husband, reading, and getting my hands dirty in our garden.

I'm grateful to be here & look forward to supporting and learning from all of you.

Program Updates

Celebrating World HPP Day with Hippo Flat Stanley

In anticipation of World HPP Day (October 30th), **this quarter's Hippo Squad boxes took our friend, Hippo, on a journey around the world.** Our central theme, "Is there a HIPPO in the room?", inspired kids to bring awareness of HPP wherever they go.

In our latest box, **members were encouraged to decorate and accessorize their Hippo Flat Stanley and take it on adventures near and far.** Flat Stanley is a flat paper doll who can travel the world by mail. Our kiddos had a ton of fun bringing Hippo around and raising awareness of HPP everywhere they went.

We are whipping up something yummy for our next activity box, so keep an eye out, members. Haven't joined? Sign up before the next wave of boxes comes out!

Hippo Squad is open to kids with HPP, their siblings, and children of parent(s) with HPP, ages 3–12 years old. It is open to US residents only. Learn more and see eligibility **HERE**.

Teen Advisory Council Kicks Off the 2025-2026 Year

The Teen Advisory Council (TAC), led by **Cannon S., Brendan G., and Emily W.**, continues to make strong strides in raising awareness of HPP. TAC kicked off the 2025-2026 year in September.

In our most recent meeting, the group welcomed guest speaker **Aaron Blocker**, who shared an inspiring message about resilience. Aaron spoke about his personal experience living with HPP and Crohn's Disease and reflected on his long journey as a patient advocate since 2009. He opened the floor for TAC members to share their own challenges, culminating in a collaborative word cloud that captured different stories from our discussion.

Thank you to all our members who contribute to our conversations and consistently participate in them. We are excited to plan more speakers, events, and TAC-led fundraisers in the upcoming year.

Interested in joining the TAC? Learn more **HERE**.

Stick(ing) It To HPP!

The Stick It To HPP program **provides young HPP patients with the confidence and tips to administer their injections.**

Each self-injection starter kit includes:

- Tips and tricks on how to self-inject
- Tracker
- Merch
- and much more!

After each level, participants snap a picture with their achievement tracker and see how far they have come. Currently, we have a handful of members enrolled in the program.

Mailings are available to U.S. residents only. **Request a kit today**!

PATIENTS OF THE MONTH

October, November, December

October: Scarlett

Meet Scarlett. For most of her life, she lived in the shadows, not by choice, but because her symptoms were overlooked again and again.

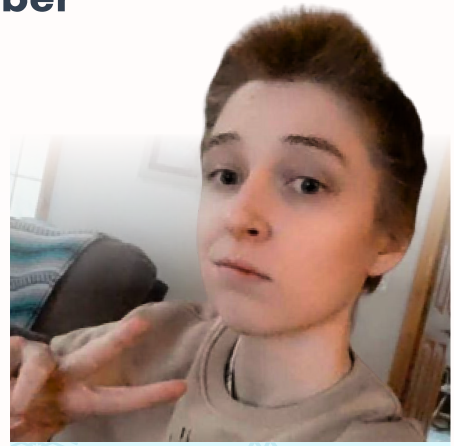
Discover how Scarlett overcame an early misdiagnosis and how she eventually found the light.

Read her story

November: James

From preemie to a powerhouse, James is a resilient 12-year-old. Early signs of growth delays, birth defects, and missed milestones prompted his family to dig deeper. After three years of chasing answers, he finally had a diagnosis.

Read his story



December: Frey

Frey is a 30-year-old artist living with three rare diseases. Frey didn't get their first correct diagnosis until their mid-20s, after years of unexplained chronic pain and feeling lost. Frey took up fiber art to help stay grounded while navigating their health journey. Luckily, Frey found an immunologist interested in learning more about HPP and helping them manage their diseases.

Read their story

Caregiver Corner: Cindy P.

Meet Cindy P. Cindy is a familiar name in our HPP community, serving as a Region Lead for our Northeast Region. HPP didn't just affect one person in her family; it affected her husband, two adult children, and three grandchildren. However, with knowledge, treatment, & support from her community, she has been a strong advocate & caregiver.

Learn more about how she navigates the unknown of HPP with her family **HERE**.

HPP Community: Region Roundups

Combined Midwest 1 and Midwest 2 Region Meeting

October 25, 2025 | Indiana

By Cindy R.

The Midwest 1 and Midwest 2 Regions came together for a joint luncheon in historic Madison, Indiana, on Saturday, October 25, 2025. Hosted by Region Leads **Jennifer W. and Cindy R.**, families from Indiana and Kentucky gathered for an afternoon of meaningful conversation, great food, and connection.

OneSource Case Manager Peter Lessard joined us and shared valuable insights about OneSource and the support it provides to individuals with HPP. Additionally, several children and teens were also present, building friendships and reminding us why community moments like this are so important.

Southwest Region Meeting

Oct. 25, 2025 | Arizona

by Sue K.

The Southwest Region meeting took place on October 25, 2025, at Dave & Buster's bringing together a roomful of HPP members, OneSource Case Managers, guest speaker Dr. Pamela Smith, and Region Leads **Amy B. and Sue K.** Throughout the afternoon, there were fun giveaways, meaningful conversations among families, and a presentation by Dr. Smith titled, "**From Childhood to Adult Onset: What We Know About HPP as We Age**".

Read the **full recap** by Sue K.

Central Region Meeting

November 16, 2025 | Colorado

By Nisha P.

The Central Region meeting was held in Denver, Colorado, at Dave and Buster's. We had a handful of patients, caregivers, and family members in attendance. I opened the meeting by introducing myself, sharing my background, and explaining why I chose to volunteer as Region Lead. I reminded them of the **HPP AND ME Forum** and the **myHPP app**.

I provided Soft Bones resources for everyone to take home, and encouraged attendees to mingle and get to know one another. One Source Case Manager, Angela Corso, presented and shared her role and resources as well. This was a great opportunity for the families to get to know one another.

Midwest 1 Region Meeting

October 25, 2025 | Wisconsin

By Jan R.

Our recent HPP regional meeting in Madison, Wisconsin brought together **many attendees, making it one of our largest gatherings yet**. I'm incredibly grateful to be part of Soft Bones and to help create spaces where our community can connect and support one another. As someone living with HPP myself, I understand the uncertainty and challenges many of us face, and these meetings remind me how important it is that we walk this journey together.

Thank you to everyone who attended and shared their stories. Your openness and strength are what make this community so meaningful. I look forward to continuing this important work together.

Save the Date: Upcoming Events!

Golf Outing & Pickleball Classic

Get ready to tee it up or dink for a great cause! The 18th Annual Soft Bones Golf Classic and 3rd Annual Pickleball Classic will take place on **Monday, September 28, 2026, at Somerset Hills Country Club.**

Join us for a day of friendly competition and community, all while supporting people living with HPP. Contact us to be added to our email list, and you'll be the first to know when registration opens!

Registration link coming soon!

National Patient Meeting

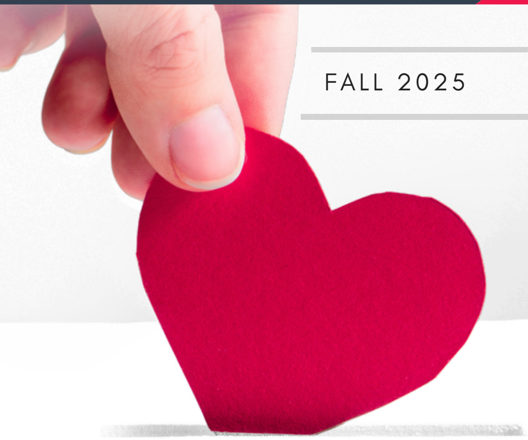
We're thrilled to announce the 2026 National Patient Meeting is in 🥁🥁🥁

Chattanooga, TN!

Date: June 26-27, 2026
Location: Chattanoogan Hotel

This important event brings together HPP community members, health experts, and companies to gain valuable knowledge on HPP while connecting with others. Join us!

The registration link will be open after the first week of the new year. Keep on eye out!



Fundraising Corner

pampered chef Now Through December 31st

There's still time to buy your last-minute gifts or to ring in the new year with new kitchen gadgets. Give the cooks in your life stocking stuffers and gifts they'll love and use all year round!

Check out our **Pampered Chef Holiday Pop Up Shop** now until December 31st!

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sparkgood

Do you shop at Walmart? Learn how you can make an impact!

'Tis the season to give (and shop)!

As you check off your gift list and holiday must-haves, make every purchase count with Walmart's Spark Good program.

Through this program, you can make a difference by rounding up your online Walmart purchases to the nearest dollar. Every cent adds up to support those living with HPP. Make this season a little brighter for someone else!

You must use zip code **07005** and type in "Soft Bones" to set up and select our charity. Click **HERE** to get started.

Sarris Candies: Now Until December 15th

There's still time to support Soft Bones through the Sarris Candies fundraiser. Stock up on the many chocolate delights in time for the holidays! **25% of every purchase supports Soft Bones** and helps us continue supporting those living with HPP. Support our cause and express gratitude to your loved ones with these one-of-a-kind treats.

Chocolates are shipped within 72 hours of ordering. Orders over $100 ship free; all others are $7 flat rate. The custom link to place an order is **HERE**.

iGive, You Give, We all Give!

Elevate your holiday and everyday shopping experience while supporting Soft Bones.

iGive automatically donates a portion of your online purchase to a charity of your choice. The best part? It's FREE!

Fill out a form on **iGive.com**, designate **Soft Bones** as your chosen charity, and install the **iGive button** onto your browser when prompted or download the app on your phone. Your actions will go above and beyond in supporting us and making a difference.

Thanks to iGive's recent $15 New Shopper Bonus, Soft Bones received an additional boost when supporters made their first purchase between Black Friday and Cyber Monday, even if they registered years ago. Moments like this show how small actions from our community can turn into meaningful funding for our programs. Happy Shopping!

Register **HERE**.

For more information, please contact the Soft Bones Foundation
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