Soft Bones
Finding the Key to HPP

SUMMER 2025 EDITION

THE BARE BONES

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

TOGETHER WE CAN!

2025 NATIONAL PATIENT MEETING

Watch On-Demand Recordings of the Sessions & Browse the Event Gallery

IN THIS ISSUE:

Recap: 2025 National Patient Meeting

The **2025 National Patient Meeting** in Williamsburg, VA, brought together **more than 70 families** for a few days of learning, connecting, and community. Attendees heard from an exceptional roster of experts that included:

Dr. Suzanne Jan De Beur: *Hypophosphatasia Overview (University of Virginia)*

Dr. Christina Peroutka: *Hypophosphatasia: Understanding the Genetics (University of Virginia)*

Dr. Lothar Seefried: *Hypophosphatasia Beyond Bone (University of Würzburg)*

Dr. Alan Hoang *Chronic Pain and Hypophosphatasia (Vanderbilt University)*

During registration, familes browsed the Soft Bones activity tables where they could learn more about our Youth Programs, the myHPP App, and completed a community survey. We were proud to welcome exhibitors: Alexion, AstraZeneca Rare Disease, and PANTHERx Rare, with additional sponsors BeBio, PuREC, and Alesta Therapeutics.

A huge thank you to our amazing group of volunteers: Mary N., Jan. R., Amy W., Keating W., Beth G., Suzanne D., Stephanie R., Grace S., Cannon S., Clark S., Noah D., Jason S., and tech support from Rick and Cameron. An additional thank you to our Region Leads in attendance: Amy W., Laura T., Blynda K., Scott G., Cindy P., Susan B., Judith H., and Jan R.

SPECIAL THANKS TO OUR SPONSORS

Their contributions helped to make this meeting possible!

ALEXION AstraZeneca Rare Disease
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TOGETHER WE CAN! 2025 NATIONAL PATIENT MEETING

Soft Bones Finding the Key to HPP
2025 NATIONAL PATIENT MEETING

Soft Bones Exhibited at the 2025 ASBMR Meeting

Medical meetings bring together clinicians, researchers, advocates, and industry to share the latest advances in research and treatment. When you hear about a new treatment or research breakthrough, these meetings are often the first to present them.

For Soft Bones, these meetings provide opportunities to ask questions, spark new ideas, and build important professional connections. Many meetings, such as the **American Society for Bone and Mineral Research (ASBMR)**, feature expert lectures and exhibit halls where organizations can engage directly with attendees. For the past 10 years, Soft Bones, Inc. has participated in these meetings, building new relationships with physicians interested in HPP, connecting with young investigators in the field, and strengthening ties with long-standing colleagues.

In early September, the Soft Bones team traveled to Seattle to exhibit at the 2025 ASBMR Annual Meeting. The Soft Bones team was on hand to staff the booth and share key resources, including our new genetics resource and the myHPP app. This year, our booth focused on, **'Shining a Light on HPP'**, which amplified our mission to spotlight HPP that often hides behind more common bone diseases such as rickets, fibromyalgia, or osteoporosis. Visitors stopped by to take a photo at our photobooth and left with a Soft Bones-branded mini-flashlight to help spread awareness.

In addition to exhibiting at the event, on Friday, September 5th, **Deb served as a featured speaker for the Rare Bone Disease Alliance (RBDA) reception for Early and Mid-Career Investigators**, highlighting the critical role of patients as partners in research.

The following morning, **Soft Bones Scientific Advisory Board member, Dr. José Luis Millán**, delivered the keynote for the **Louis V. Avioli Lecture**. His presentation, born from our ongoing partnership, explored HPP beyond bone and was aptly titled **"Hypophosphatasia – Looking Beyond the Skeleton"**, emphasizing that research in mice shows that HPP not only impacts bones but also affects teeth, muscles, and neurological systems.

Soft Bones
Finding the Key to HPP
ASBMR®
The American Society for Bone and Mineral Research

As we reflect on ASBMR 2025, we're energized by the connections made, the awareness raised, and the continued momentum toward a better understanding and treatment of HPP.

HPP Happenings

Gear Up for World HPP Day 2025

October 30th is World HPP Day,
a time to raise awareness and push for progress.

This year, we celebrate how far we've come while recognizing how far we still need to go in understanding the impact of low alkaline phosphatase (ALP) in the body. Despite readily available blood panels, low ALP levels are often overlooked by healthcare professionals. There's an elephant in the room – or in HPP we say **a HIPPO in the room** – that is not being addressed. We need the HIPPO to be seen for timely diagnosis and care. This year's theme is to identify the HIPPO in the room and encourage everyone to check their ALP levels to confirm or rule out HPP.

Visit our World HPP Day page to learn more about HPP and how you and your family can spread awareness around the world.

> **We may have soft bones, but our spirit and our resolve to make a difference is stronger. We will not give up.**

SOFT BONES WEBSITE NOW AVAILABLE IN OVER 60 LANGUAGES!

In honor of World HPP Day, **Soft Bones is excited to announce a new website translation tool to better serve our global HPP community.** With our website and key resources now available in more than 60 languages, it's easier for patients, caregivers, and healthcare professionals around the world to access information, raise awareness, and support timely diagnosis and care.

Getting started is simple. **Just click the globe icon in the upper-right corner** of our website and choose your preferred language. Plus, you can print materials in the selected language to share with healthcare professionals and family members.

How to Use It

1. Click the **globe icon** 🌐 in the upper right corner.
2. Choose your language (60+ options).
3. View, print, or save the page in that language.

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

New Genetic Resource Released

Soft Bones is excited to announce a new educational resource developed in collaboration with Professor Wolfgang Högler, MD, FRCPCH, Johannes Kepler University, Linz, Austria. This comprehensive guide helps patients and caregivers understand frequently asked questions about the ALPL variants.

Professor Högler leads an international consortium of researchers, endocrinologists, osteologists, basic scientists, and geneticists who oversee the global ALPL Mutation Database. Many patients and families find it difficult to interpret genetic results and understand their implications. This resource provides clear, accessible answers to common questions. View the new resource: **HERE**.

Soft Bones to Travel Abroad to Co-Host an International Patient Meeting

Soft Bones and HPP Deutschland e.V. will co-host a Global Hypophosphatasia Patient Advocacy Summit on October 12th in Wurzburg, Germany. Participants can attend in person or virtually. The goal is to foster a more unified and consistent patient voice across Europe and around the world.

Research News

myHPP App Momentum

The myHPP app continues to gain momentum, with a 47% increase in new users since January. A friendly reminder to log your symptoms at least **TWICE** a month to track changes over time. Documenting your symptoms can better inform doctors' visits by giving healthcare providers a clear view of patterns and progress.

Plus, inside the app, you'll also see opportunities to participate in research surveys and quick polls. Let your voice be heard!

Haven't downloaded myHPP? Download and register today!

2025 Maher Family Research Grant: Applications Open!

Soft Bones is accepting applications for a $25,000 seed grant for research directly related to hypophosphatasia. Applications are welcome from faculty members at a university or private research institution. Proposals from junior postdoctoral trainees or research associates are acceptable, provided their mentor has a record of commitment to research concerning HPP.

- Application Deadline: **October 31, 2025**
- Winner Announcement: By December 31, 2025

LEARN MORE AND APPLY

Cannon Unbroken: Triumph Over Adversity

Soft Bones is proud to announce the launch of Cannon Unbroken, **a new podcast hosted by Cannon Sittig, who was diagnosed with hypophosphatasia (HPP) at 18 months old.** Each episode features individuals who have battled personal struggles, adversity, or rare diseases, offering raw and inspiring insights into their journeys. Tune in!

Click to Watch Episode 1

This Podcast is Sponsored in part by;

ALEXION®
AstraZeneca Rare Disease

Soft Bones Members in Action

Turn Medicinal Lids into Art: Strensiq® users, we need you!

Soft Bones continues to collect Strensiq® vial lids of all colors and sizes to create a meaningful art piece. Each lid represents a unique HPP journey, coming together as a symbol of strength, resilience, and community. Let your lid tell your story!

Participating is easy!

1. **Save.** Every time you or a loved one injects, make sure to store your lids in a safe place.
2. **Bundle and label.** When your ready, place lids in a small bag or envelope. Include a note with your name and, if you wish, a short message or one word that represents your HPP journey. Please do not send glass needles or packaging.
3. **Ship.** Ship your lid(s) to our office:

Soft Bones, Attn: Lid Art Project
141 Hawkins Place, #267
Boonton, NJ 07005, USA

See ideas and inspiration for vial lid crafts **HERE**.

Volunteer Spotlight

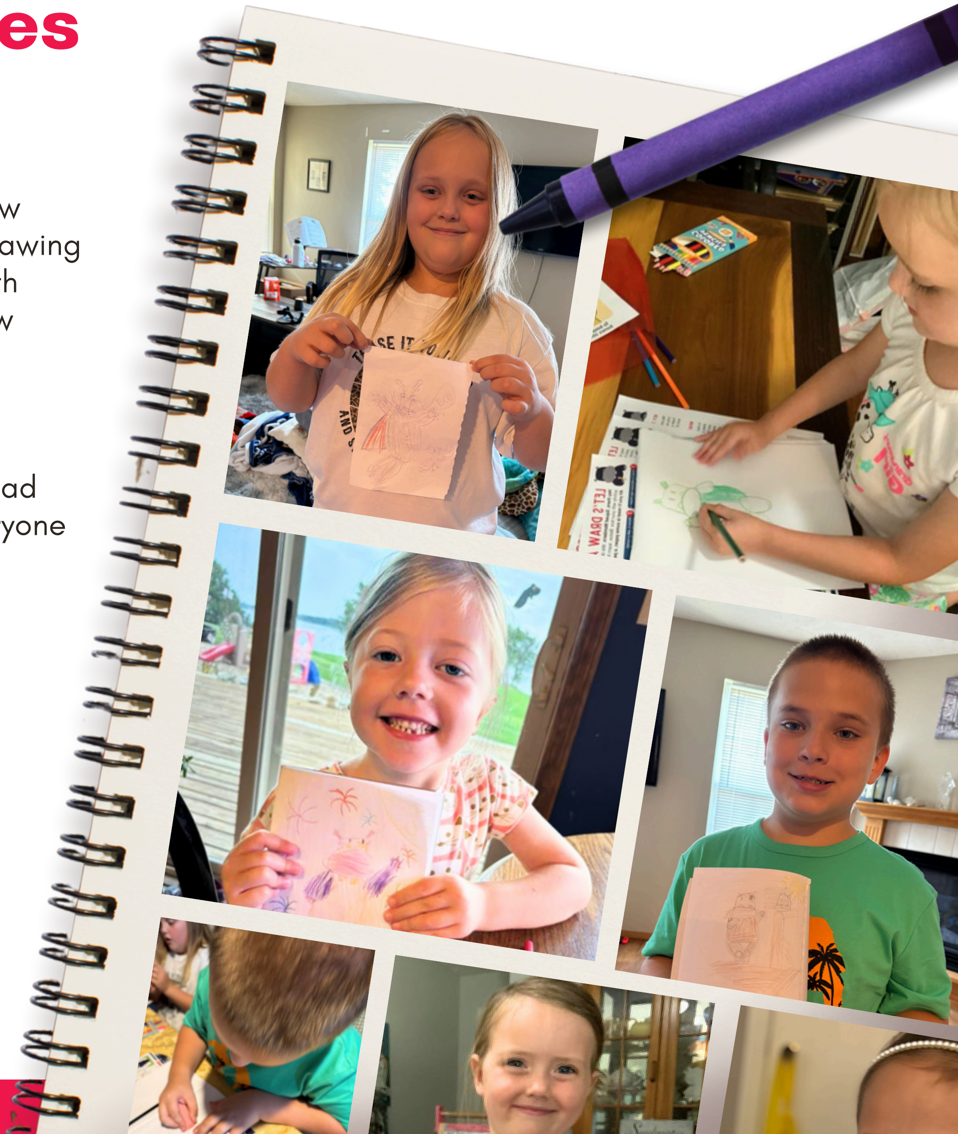
Meet your newest Central Region Lead, Nisha P.

Nisha was diagnosed with adolescent-onset HPP in March 2024 at age 49. After a lifetime of unresolved health issues, including difficult pregnancies, hormonal struggles, and unexplained symptoms, a Nurse Practitioner (NP) finally gave her answers. Nisha's consistently low ALP and high B6 was a strong indicator for HPP. Further testing revealed that she and her son had HPP.

Thanks to her NP, Nisha began treatment that has changed her and her family's lives. Nisha is honored to step into a leadership role to help connect others living with HPP in Colorado and beyond.

Read her full story.

Program Updates



Hippo Squad

In our latest Hippo Squad box, members followed step-by-step instructions to draw their own hippos. Careful steps help a drawing come together, and they matter for health instructions, too! Read instructions. Follow directions. Ask questions if you're unsure.

Each box included paper, crayons, and simple instructions, and the results were amazing! We loved seeing our Hippo Squad participants' creations. Thank you to everyone who shared their photos with us!

Not a member yet?
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 check eligibility **HERE**.

Teen Advisory Committee Ready to Lead

This summer, the Teen Advisory Committee (TAC), took a brief hiatus. Behind the scenes, our team has been planning a fun slate of fall activities. Here's a sneak peek at what's coming:

🍦 Virtual Ice Cream Social

🎲 Game Night

🎤 Speaker Series

✨ ...and much more!

Keep an eye out for more details soon!

Stick It To HPP

The **Stick It To HPP program** is designed to help children build **independence and confidence** with self-injections, all within a **safe and supportive environment.**

Each self-injection starter kit includes:

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

After each level, participants can snap a photo with their achievement tracker and see how far they have come. Currently, we have 14 participants.

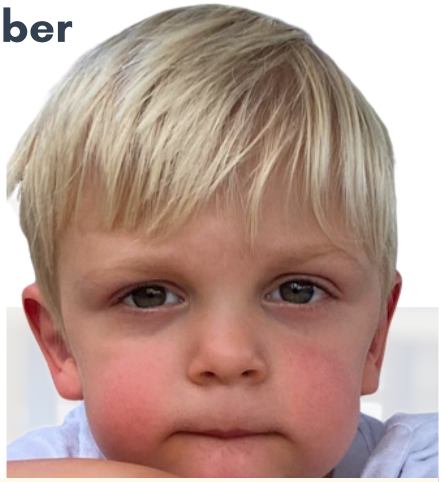
Mailings are available to U.S. residents only. **Request a kit today**!

Kirra completed Stick it to HPP and received a sweatshirt in the mail.

Curious about our programs? Learn more on the 'Programs & Services' page of our website!

Patients of the Month

for July, August, and September



July: Stephen

Meet Stephen, a hypophosphatasia (HPP) patient and advocate. Stephen brings a wealth of HPP knowledge after decades of pain, countless surgeries, and a quest to seek answers. As a retired meteorologist, he enjoys breaking down complex scientific materials and supporting others impacted by HPP.

Read his story.

August: Nikki

Meet Nikki! For years, Nikki battled a range of unexplained symptoms and acquired a list of diagnoses. But nothing added up. After consulting numerous specialists and receiving no clear answers, Nikki took action.

Read her story.

September: Ryan

The power of a team. ✨

Ryan was diagnosed with **#hypophosphatasia** before birth. Genetic testing revealed he had inherited two ALPL mutations. Thanks to an early diagnosis, Ryan received critical treatment right away.

Read his story.

Caregiver Corner: Beth

Meet Beth! Beth doesn't see herself as a caregiver, but a partner in this HPP journey with her husband of 37 years, Scott. Together, they support one another at doctor's appointments and through the tough days. Read how Beth practices self-care and supports Scott.

Read her story.

HPP Community: Region Roundups

South Central Region Zoom Chat

July 31, 2025 | By Cass S. and Cami R.

South Central Region Leads Amedie P., Cami R., and I hosted a Zoom meeting on July 31, 2025. Attendees shared their personal journeys and experiences, like treatment and help with symptom management. In total, we had five people on the call, with more patients to connect in the area. Amedie is planning a gathering for a meeting in Louisiana soon.

Southeast Region Meeting

August 30, 2025 | By Scott G.

The Southeast Regional meeting went well. We enjoyed connecting with both new and old friends. Our regional OneSource Case Manager, Deana, reviewed all the resources available to patients and presented scenarios on how to handle denial letters and co-pays. Before her presentation, we introduced ourselves personally and shared stories about how we were diagnosed, along with discussions on shared symptoms. I informed the group about the myHPP app, or as I call it, 'My Symptoms' app, and encouraged everyone to download it and participate. Thank you to Kirsten, a fellow HPP patient, for her efforts in promoting this event on our behalf! After lunch, we had a general discussion and then concluded the meeting.

Northwest Region In-Person Meeting

September 6, 2025

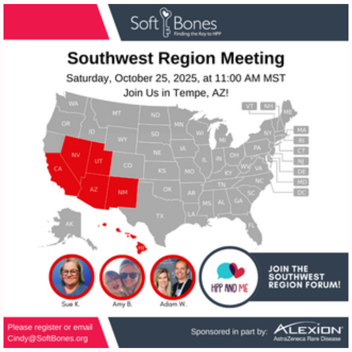
The Soft Bones' team travelled to Seattle for the 2025 ASBMR Meeting, September 5-8. On Saturday, September 6th, Northwest HPP families gathered at Bombo to meet with Deb and Denise, who stepped in for Northwest Region Leads Scarlett P. and Hayley T. It was a great turnout with lively conversations and delicious Italian food.

Northeast Region Zoom Chat

September 8, 2025 | By Judith H.

Northeast Region Leads, Chris D., Cindy P., Laura T., Amy W., and I hosted a Zoom meeting on September 8, 2025. We had a great turnout with 18 members in total. This was an informal get-together where we introduced ourselves and then opened the floor to anyone who had questions or who wanted to share their HPP experiences. Topics discussed included fatigue thought to be related to low hormone levels, even while on Strensiq®, the complexity of HPP genetics and how the same variants present differently within families, and the apparent association of Ehlers-Danlos Syndrome (EDS) with HPP. The hour went by so quickly! We all learned something new for sure!

Upcoming Events



Southwest Region Meeting

Saturday, October 25, 2025, at 11:00 AM MST

Join Us in Tempe, AZ!

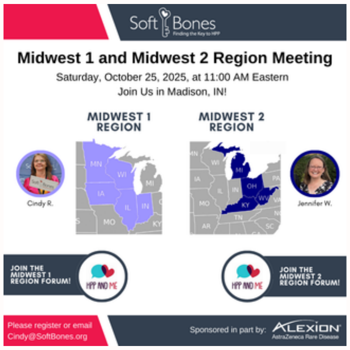
Please register or email Cindy@SoftBones.org

In-Person Southwest Region Meeting

October 25, 2025 | 11:00 AM-2:00 PM MST

Calling all members and families from the Southwest Region. Meet us in Tempe, AZ for a luncheon. Dr. Pamela Smith from Phoenix Children's Hospital will be presenting. OneSource Case Managers Joan Gustin and Angela Corso will be there to field questions. Light lunch/finger foods and soft drinks will be served. We hope to see you there!

Registration is required and will close on October 11, 2025. Register **HERE**.



Midwest 1 and Midwest 2 Region Meeting

Saturday, October 25, 2025, at 11:00 AM Eastern

Join Us in Madison, IN!

Please register or email Cindy@SoftBones.org

Combined Midwest 1 and Midwest 2 Region Meeting

October 25, 2025 | 11:00 AM-1:00 PM Eastern

Calling all Midwest 1 and Midwest 2 families. Join us in Madison, IN! Join Midwest 1 Region Lead, Cindy R., and Midwest 2 Region Lead, Jennifer W., for a luncheon. OneSource Case Manager, Peter Lessard, will be there to answer questions. Connect with patients from your region and neighboring states as well! Lunch will be provided.

Registration is required and will close on October 19th. Please register **HERE**. If you have any questions, reach out to Cindy@SoftBones.org.

Following the meeting, attendees can participate in our Annual Cannonball 5K Run, Roll, or Stroll. Learn how you can participate **HERE**.

Northeast Region In-Person Meeting

Saturday, October 25, 2025, at 10:00 AM Eastern

Join Us in Parsippany, NJ!

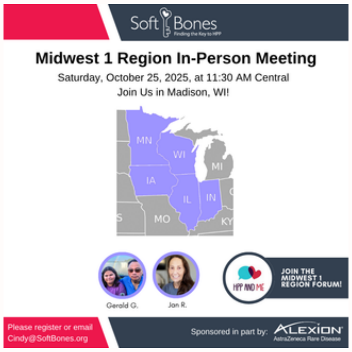
Please register or email Cindy@SoftBones.org

Northeast Region Meeting

October 25, 2025 | 10:00 AM-2:00 PM Eastern

Calling all Northeast Region HPP patients. Meet us in Parsippany, NJ!

Our guest speaker is Dr. Matthew Drake, who is a board-certified Endocrinologist at the Hospital for Special Surgery (HSS). Attendees will have the opportunity to connect with others and ask questions. Lunch will be provided. After lunch, we will participate in the Cannonball 5K Run, Roll, or Stroll event. We hope to see you there. Register **HERE**.



Midwest 1 Region In-Person Meeting

Saturday, October 25, 2025, at 11:30 AM Central

Join Us in Madison, WI!

Please register or email Cindy@SoftBones.org

Midwest 1 Region Meeting

October 25, 2025 | 11:30 AM-2:00 PM Central

Join us in Madison, WI! Region Leads Gerald G. and Jan R. will be hosting a luncheon. All Midwest 1 Region members and families are welcome to learn and connect. Lunch will be provided. Registration is required and will close on October 19th.

Register **HERE**.

Fundraising Corner

pampered chef

August Fundraiser (past)

Soft Bones had a Pampered Chef Fundraiser during August. Cindy R. hosted an online party showcasing the different products and perks, and Region Lead, Amy W., posted about her favorite buys from Pampered Chef. Thank you to everyone who participated and who spread the word!

LYNCH CREEK FARM®

We are hosting a Lynch Creek Farm fundraiser for the holiday season! They handcraft traditional and decorated wreaths, centerpieces, home decor, and more. Now until December 5th, Soft Bones will earn a percentage of the proceeds. Shop **HERE**.

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pampered chef

Now Through December 31st

It’s never too early to buy your holiday entertaining and baking needs for family and friends. Soft Bones is hosting a Pop Up Shop this fall and winter. View the catalog **HERE**.

Sarris CANDIES

We are back with another Sarris Candies Fundraiser leading up to the holidays. Now until December 14, indulge in delicious treats and make a real impact. Order **HERE**.