

THE BARE BONES

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

2026 National Patient Meeting

FULL STEAM AHEAD!

Choo-choo! The **2026 National Patient Meeting** is just around the corner, and we can't wait to see everyone! This annual gathering continues to bring together patients and their families, caregivers, clinicians, and industry partners from across the country. For many, this is more than just an event. **It's an opportunity to connect with people who understand the realities of living with HPP.**

We look forward to welcoming both new and returning attendees for what should be an empowering and impactful experience.

New this year is a group activity facilitated by songwriters straight from Nashville, TN! Check our **agenda** for the full lineup of events. For those registered, please check your email and respond to Cindy leading up to the event. If you have any questions or concerns, please connect with Cindy Reasor at Cindy@SoftBones.org.



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HPP Happenings



HPP United Takes Flight

Chairman of the Board and Founder of Soft Bones, Deborah Fowler, and Executive Director, Denise Goodbar, recently co-organized the **inaugural meeting of HPP United**, a newly formed global alliance of fifteen different HPP and rare disease patient organizations dedicated to advancing awareness, education, research, advocacy, and support for those affected by HPP.

The gathering highlighted both the unique challenges and shared goals of HPP communities worldwide. While access to diagnosis, treatment, specialists, and support varies greatly across countries, **participants agreed that collaboration is key to driving meaningful progress.**

Deborah and Denise left the meeting inspired by the passion and commitment of fellow advocates. Next steps are to build an action plan to strengthen the global patient voice and accelerate progress for the entire HPP community.

A special thank you to our sponsors, Alexion AstraZeneca Rare Disease, Alesta Therapeutics, and AM Pharma, whose support made this historic gathering possible.

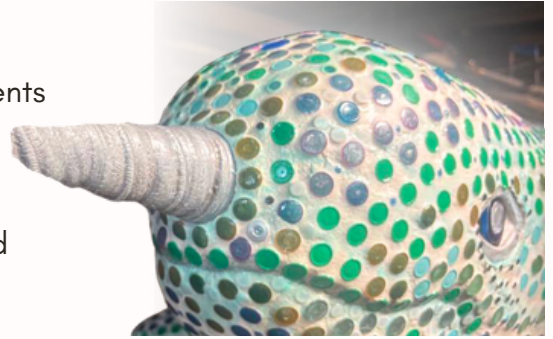
“

Despite these differences, we discovered that our challenges may be unique, but our goals are remarkably aligned.”

— Deborah F.

Turning Creativity into Awareness: An Update on the Narwhal Sculpture

Suzannah B. finished her narwhal sculpture, transforming lived experience into something meaningful and visible. Made from carved foam and covered in a mosaic of medical waste lids and recycled materials, the narwhal represents a story, and together they've become something extraordinary and beautiful. Suzannah says the creature is a symbol rich with meaning, "Narwhals are often believed to be fictional, like unicorns, but they are real. Just because they are rare and hard to spot doesn't mean they don't exist."



Research News

Back to the Bench: Touring AZ Labs & Collaborating with Others

Last month, Soft Bones Executive Director Denise Goodbar visited Washington, D.C, to attend the Alexion Pharmaceuticals' Patient Advocacy Exchange Access Focus. This important gathering brought together advocacy and industry leaders across the rare disease community to discuss the healthcare challenges patients continue to face and explore collaborative solutions to improve access to care.

During the event, Denise connected with fellow patient advocacy organizations, toured the AstraZeneca lab, and participated in conversations around funding, grants, and advancing support for rare disease communities. **The experience provided valuable insight and strengthened partnerships that can help drive future progress for individuals and families affected by HPP.**



Encouraging Data from ALXN 1850 Clinical Trials

In late March, Alexion shared **updates** from the Phase III clinical program for efzimfotase alfa (ALXN1850), known as the Mulberry, Chestnut and Hickory trials. Like STRENSIQ®, this new therapy is an injection treatment, however, with a less frequent administration regimen. We will provide updates as more information becomes available.

[Click here to view the full press release from Alexion](#)



Building Our Future Through the myHPP App

Thank you to everyone who took the time to complete Dr. Cheryl Rockman-Greenberg’s survey on the potential use of **In-Utero Enzyme Replacement Therapy (IU-ERT) for life-threatening HPP**. If you haven’t already, make sure to download the myHPP app so you can take part in future research opportunities.



Podcasts



What happens when a physical therapist becomes the patient?

Meet Adam, a physical therapist with over 27 years of experience who was diagnosed with HPP just 4.5 years ago. After a lifetime of fractures, injuries, and low ALP levels being dismissed, Adam was determined to get to the bottom of it all.

In this episode, Adam joins guest host Cindy Reasor to share **what it’s like to navigate HPP from both sides of care** and what every patient, caregiver, and provider should know.



Cannon Unbroken: Triumph Over Adversity

In the latest episode of Cannon Unbroken, Cannon sits down with legendary college football coach **Greg Schiano**, who is the current head coach of the Rutgers University Scarlet Knights. Tune in to learn how Greg’s **family-first mentality** shapes how he coaches, keeps his team accountable, and helps him rebound from fumbles on and off the field.





Volunteer Spotlight

Hi, my name is Brendan. I'm from Long Island, New York, and I go to Penn State University. Since I was young, sports have been a big part of my life. I played basketball and volleyball, and still do. When I'm not playing sports, I either go to the gym or hang out with friends & family.

My connection to Soft Bones is my friend Cannon, who has HPP. He encouraged me to join the Teen Advisory Council (TAC), and through that program, I have met people who share the same challenges as him. Hearing their stories has made me better understand what they are going through and how I can support them.

I volunteer because I want to help people live better lives and to let them know that they are not alone on this journey, and that I and others are there for them when they need it. This year, I've had the privilege of being a co-leader on the TAC with Emily and Cannon. It has been an amazing opportunity. I've enjoyed this leadership position that allows me to be more hands-on and vocal during our meetings. This is one of many ways I feel that I am making a difference.



Celebrating Our Volunteers

Our mission would not be possible without the passion, dedication, and generosity of our volunteers. They are the heart of our community and play a vital role in creating a space for individuals and families living with HPP.

Our volunteers serve in many ways: Region Leads, Facebook moderators, fundraisers, graphic designers, resource specialists, grant writers, and more. Whether working behind the scenes or directly within the community, they help connect patients, support caregivers, develop valuable resources, and raise awareness about HPP.

To every volunteer who has shared their time, expertise, and compassion this year... THANK YOU! Your commitment strengthens our community and supports our mission. We are incredibly grateful to have you as part of the Soft Bones family.



Program Updates

HIPPO SQUAD: IS IT A BIRD? IS IT A PLANE? NO, IT'S SUPERHIPPO!

Our last Hippo Squad box was a fun one. Thank you to our incredible members for sharing your amazing superhero creations and photos! Living with HPP takes courage, resilience, and heart, and those are real-life superhero powers. This box was designed to celebrate your strengths and differences, serving as a powerful reminder of how truly remarkable YOU all are.

Interested in joining the fun?

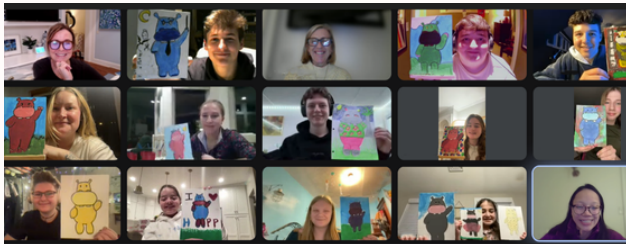
[Check eligibility & learn more!](#)



Teen Advisory Council



The Teen Advisory Council (TAC) came together for two impactful sessions, a guided art session and a conversation on how teens can take control of their health.



The Guided Art Session, led by Miranda, an art teacher based in Wisconsin, was a huge creative success. Teens learned how to draw and paint a hippo and tested their hippo and HPP knowledge along the way. From realistic designs to bold, colorful styles, every hippo creation reflected something different, just like our HPP community. Similar to how no two drawings look the same, HPP shows up differently in each person. [View the video recap from the meeting.](#)



In our latest meeting, the teens came together and discussed how they can become better prepared to advocate for themselves as they transition from pediatric to adult doctors. They brainstormed different things to develop positive health habits in the long run. From that meeting, we created a new resource called "Take Charge of Your Health", which includes tips teens can use to make the most of each appointment- from making an appointment, jotting down questions before the visit, making eye contact, following up, and much more. [View the resource.](#)



We appreciate every teen who joins us to share their HPP insights, engage in meaningful conversations, and more. If you have a teen who is ready to join TAC and bring their voice to the table, [learn more HERE.](#)

PATIENTS OF THE MONTH



March: Tamra

Meet Tamra. For most of her life, she felt she didn't quite fit in. For a long time, she knew something wasn't right. Eventually, a doctor listened to her, which led to a proper diagnosis and supportive community.

[Read her story.](#)

April: Emma

At just one year old, Emma lost a tooth, root and all. This moment led to a life-changing diagnosis of hypophosphatasia. Now 8.5 years old and 1,000 injections later, Emma is showing the world what resilience looks like.

[Read her story.](#)



May: Ashleigh F.

What happens when you have all the little pieces, but not the full picture? Meet Ashleigh. For most of her life, she lived with unexplained fatigue, dental problems, bone pains, and uncertainty. Several doctors noted low alkaline phosphatase levels in her lab but dismissed them quickly as just being "normal" or as a "trend". It wasn't until a mystery flare that persisted for over two years prompted her to dig deeper. Learn what happened and how Ashleigh's life has changed.

[Read her story.](#)



June: Iris

At just 10 years old, Iris has already faced more challenges than most. But through it all, she continues to shine with courage, kindness, and determination. Learn more about Iris's journey to diagnosis and the many activities she excels at.

[Read her story.](#)



Caregiver Corner: Scott K.

Meet Scott! He is a caregiver to his wife and best friend, Diana. After a long and difficult journey, she was officially diagnosed with HPP last October. Balancing life as a full-time mechanic while supporting Diana hasn't been easy. The demands of work and caregiving often collide, but Scott continues to show up with strength and dedication.

[Discover what helps Scott navigate tough moments.](#)



HPP Community: Region Roundups

Northeast Region Meeting

April 25, 2026 | In-Person | By Amy W.

The Northeast Region In-Person meeting was hosted on April 25th near Times Square. We had a wonderful turnout of about 20 attendees at our meeting. Our OneSource representative, Diana Miller, introduced herself and joined us with some great swag and plenty of support. I shared an overview of the myHPP app, highlighting both its personal value for tracking our health and its powerful role in advancing HPP research.

We also had time to connect, meet new members, and welcome the family members who came to support them. Overall, it was a warm, friendly gathering and a great opportunity to strengthen our community. I was especially delighted to see how our members supported each other with their lived experiences navigating a life with HPP.



South Central Meeting

April 30, 2026 | In-Person | By Cassandra S.

On April 30th, we hosted a South Central In-Person Region Meeting in Azle, Texas, bringing together a small and engaged group connected by firsthand experience with hypophosphatasia (HPP), including both adult and pediatric patients. The intimate setting created meaningful opportunities for conversation, education, and support.

A local physical therapist currently treating a family member with HPP attended the meeting and gained valuable insight into the many complexities and day-to-day challenges of living with HPP. The discussion also highlighted the wide range of resources and support available. OneSource Case Managers Sandi Tefft and Kayla Wehrend joined the meeting, helping strengthen connections within the HPP community. During the event, attendees also learned about the myHPP app, a free tool designed to help patients and caregivers track symptoms, medications, appointments, & overall health experiences.



Northwest Region Meeting

May 17, 2026 | In-Person

Northwest Region Lead Scarlett P. hosted an in-person gathering in Penn Valley, California, bringing HPP community members together for lunch, conversation, and connection. The afternoon provided a welcoming space for attendees to share experiences and learn from one another. Thank you to Scarlett for organizing this gathering.

"As someone who's been recently diagnosed, this meeting was helpful for me to take a breath and know that I'm not alone."

— Donna M.

Zoom Calls - Virtual Meet Ups

Our Region Zoom Meetings continue to be a great way to connect with others across the country and even across the pond with our UK community. Thank you to Southeast Region Lead Blynda K. for hosting one on March 5th, and Northwest Region Leads Scarlett P. and Haley T. for bringing members together in their region on March 2nd. This year, we also expanded our virtual opportunities with monthly UK meet-ups hosted by Ash F. and Meryl C.

Region Leads and UK Zoom hosts are valuable members who help guide the conversation and create a welcoming environment. Stay tuned for upcoming meetings on our social media platforms and our website calendar.

Upcoming Events



Registration link coming soon for the **4th Annual Denim and Diamonds**. Each year, this special evening brings together longtime supporters, donors, and friends of Soft Bones to celebrate our community while raising critical funds for individuals and families living with HPP.

This year, we invite you to join us at Alstede Farms to soak up the late summer rays and the start of the harvest season. **This is the perfect time to dust off your denim, add a little sparkle, and Two Step for a great cause.** Please share this with friends and family in the NJ region too!

 September 12, 2026

 **Alstede Farms**
100 Rte 24, Chester, NJ 07930

 **Time:** 5:30 PM - 9:30 PM

Interested in donating a Silent Auction item or being a sponsor? Please contact Jessica at Jessica@SoftBones.org for more information.





18th Annual Golf Classic

3RD ANNUAL PICKLEBALL CLASSIC

Hit the greens or the pickleball courts and make a difference!

The Soft Bones 18th Annual Golf Classic and 3rd Annual Pickleball Tournament brings together supporters and community members for a day of golf or pickleball, connection, and impact. Every swing and volley helps raise awareness and support for individuals living with hypophosphatasia (HPP).

Whether you're playing, sponsoring, or cheering from the sidelines, your involvement helps strengthen resources and advance research for the HPP community. Don't live in the area? Share with family and friends who live nearby to come out and support us for a great cause. [Register HERE.](#)



September 28, 2026



Somerset Hills Country Club


Fundraising Corner

We depend on fundraisers and donations to deliver on our mission.

Living with HPP comes with real challenges, from medical expenses and delayed diagnoses to mobility issues, isolation, and the need for ongoing support and education. That's why fundraising matters. Every dollar raised helps create resources, connections, advocacy efforts, and programs that directly support individuals and families affected by HPP.

We recently released a fundraising guide filled with tools, templates, and ideas to help make your fundraising simple and successful. Plus, we are actively raising money for **Soft Bones Third International Scientific Meeting** in New York City this November. Every fundraiser makes a difference. Donate [HERE](#) or create a Facebook or Instagram fundraiser and help us reach our **\$25,000 goal!**

How to Fundraise on Facebook & Instagram



New!

Looking for a simple way to make a meaningful impact on the community? Creating a Facebook or Instagram fundraiser is one way to raise awareness, inspire support, and help provide critical resources for families affected by HPP.

Start by sharing your story or personalizing one of our ready-to-use fundraiser posts. Then, [follow this guide for steps](#) to quickly set up your fundraising post and start making a difference.

Sample Posts to Copy & Paste

Sample Post 1: Rare Disease Awareness Starts With Us!
 I'm raising money for [Soft Bones](#), the U.S. Hypophosphatasia Foundation, to support individuals and families affected by hypophosphatasia (HPP).
 HPP is a rare genetic condition that affects bones and teeth, but many people have never heard of it. Raising awareness can help patients get diagnosed sooner and connect families to support. Your donation helps fund education, advocacy, patient programs, and community support for people living with HPP.
 Please donate if you can and share this fundraiser to help spread awareness. Every share matters! ❤️

Sample Post 2: My Birthday Wish This Year
 Instead of gifts, I'm asking friends and family to support [Soft Bones](#) and the hypophosphatasia (HPP) community. HPP is a rare metabolic bone disease that can cause chronic pain, fractures, fatigue, dental issues, mobility challenges, and more. Many families face years of misdiagnosis and uncertainty before finally getting answers.
 Every dollar raised helps provide:
 ❤️ Patient support, advocacy, and awareness efforts
 ❤️ Community programs and educational resources
 ❤️ Hope for people living with HPP
 If you're able, please consider donating or sharing my fundraiser. Thank you for helping me make a difference for the HPP community!
[#SoftBonesHPP](#) [#HPPCommunity](#) [#hypophosphatasia](#) [#RareDisease](#) [#BirthdayFundraiser](#)



[Click to read our Fundraising Guide](#)