

SPRING 2025 EDITION

THE BARE BONES

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



The 3rd annual DENIM & DIAMONDS

“I can’t tell you how good it felt to have so many people come out to support our hypophosphatasia (HPP) community. I am so grateful.”

- HPP Patient

The 3rd Annual Denim and Diamonds fundraiser drew a crowd this year. We’re incredibly grateful to everyone who joined us. The energy and enthusiasm made it an unforgettable evening!

A heartfelt thank you to our sponsors, Green Room Communications, Hatfield | Schwartz Law Group, and Dr. Brenda Ziegler, who made this event possible.

An extra big shoutout to all who donated or purchased items from our Amazon Wish List for our auction. **We had over 10 gorgeous baskets!**

Everyone had a blast dancing, donning western garb, dancing to live music and having their share of BBQ, all while raising money to support our mission at Soft Bones.

**CLICK TO VIEW THE
PHOTO GALLERY**

**Stay tuned for details for our 2026
Denim and Diamonds fundraiser!**

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- Uncovering the Hidden Cost of Healthcare
- We Are Days Away From Our National Patient Meeting!
- Why YOUR Voice Matters
- Turning Vial Lids into Art

HPP Happenings

Uncovering the Hidden Cost of Healthcare

For many individuals and families affected by hypophosphatasia (HPP), **managing health isn't just about treatment, but about financial survival.** Every year, families face the challenge of securing insurance coverage, but are also hit with hidden costs that go unmentioned in policies and unaccounted for by insurers. What are the true out-of-pocket expenses for these families?

On April 15th, Soft Bones Chairman and Founder, Deborah Fowler, joined a panel hosted by No Patient Left Behind to dive into these issues. **The discussion focused on the growing out-of-pocket expenses that patients and families face, which aren't always known.** From co-pays and deductibles to uncovered therapies and travel costs, **the barriers to care are growing.**

To watch this panel on-demand, click [HERE](#).

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Navigating health insurance shouldn't feel like a full-time job—but for so many patients and caregivers, it does.

Deborah Fowler



Raising Awareness in the Rare Disease Community

In the latest edition of the Rare Revolution Magazine, HPP patient and trained scientist, Neeru B., opens up about her HPP diagnosis. After years of living with fatigue and unexplained symptoms, she finally received validation, **but sharing it with family had its challenges.**

Learn more about her diagnosis journey and why she is advocating for better resources so the burden of sharing results with family doesn't fall entirely on the patient. Click [HERE](#).



TOGETHER WE CAN! 2025 NATIONAL PATIENT MEETING

We Are Days Away From Our National Patient Meeting!

Our 2025 National Patient Meeting on **July 18-19 in Williamsburg, VA**, is fast approaching. Registration is closed, but there are still a few open spots due to cancellations. Contact PatientMeeting@SoftBones.org to inquire.

For those attending, follow the [HPP AND ME NPM forum](#) to get the latest information and connect with others before the event. Please contact Cindy@SoftBones.org if you have questions or your plans change.

ALEXION
AstraZeneca Rare Disease

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The 2025 National Patient Meeting Sponsors



Order your National Patient Meeting T-Shirts!

We are excited to announce that—back by popular demand—our **exclusive National Patient Meeting shirts are available!** This year, we are selling T-shirts to raise funds to support the cost of the meeting. Unlike many other organizations, **Soft Bones does not charge for registration and provides travel grants to those who need assistance.**

[Order yours today](#), and show your support! We can't wait to see you in Williamsburg!

Research News

Innovation in Action: New Ways of Delivering Medication Underway!

Alexion is working with a third-party to conduct future in-person usability studies at multiple locations in the U.S. and Canada. This study focuses on an auto-injector, which is a ready-to-use, pen-like device that safely gives a single dose of medication, designed for people living with HPP.

How do I get involved? If you are interested in participating in this study in the future, please contact Denise@SoftBones.org. You will be compensated for your time.

Safety During this study, you will not be injecting yourself or others with medication. This study has been approved by the International Review Board.



Maher Research Grant in Action

The 2021 Maher Research Grant Winner, Fatma F. Mohamed, PhD (pictured above), a postdoctoral researcher at The Ohio State University, **recently published an article partially funded by our research grant.** She and her team are looking at how the ALPL gene deletion can contribute to dental and skeletal abnormalities.

Read more about the study [HERE](#).

Podcasts

A Taste of Mindfulness with Alison S.

May was Mental Health Awareness Month, and we discussed stress, rare diseases, and the importance of mindset. Join guest host Cindy Reasor as she interviews certified health coach and HPP patient Alison S. as they address key topics:

- ♥ What is stress?
- ♥ How can we manage it?
- ♥ Why is it important to our health?

Whether you are living with a rare disease or supporting someone who is, **tune into this convo to break the stigma. YOU matter! Listen [HERE](#).**





Why YOUR Voice Matters

We always hear the importance of “sharing our stories” or “patient journeys”. It’s easy to think it doesn’t make a difference.

But it does!

Research and treatment options only improve when people like you get involved. A treatment is only as good as its impact on patients... and you are the expert! Join host Deborah Fowler and Dr. Anthony Yanni, SVP of Patient Centricity at Astellas Pharma, and learn how your voice can shape the future of medicine. More and more companies are looking to learn from your experience. Listen to the podcast [HERE](#).

HPP Artists Among Us

Maryanne G. Submits Stunning Artwork in the Adult Visual Art Category for the 2024 Rare Artist Annual Contest

Last year, Maryanne G., a member of the HPP community, submitted a piece titled “Beacon of Hope” to the Rare Artist Contest. Maryanne discovered art a few years ago. Art has helped her be more relaxed and present despite the challenges she faces.

Each year, the [Everylife Foundation](#) hosts the **Rare Artist Contest**. It provides a space for artists to share their stories through visual art, poetry, writing, and more, while raising awareness for the rare disease communities.

Rare Artist winners are presented with an award and invited to speak during Rare Disease Week on Capitol Hill in Washington, D.C. Their artwork is showcased throughout the year at various conferences and social media platforms.

Rare Artist 2025 is accepting entries through July 9th. Learn more [HERE](#).



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Art, for me, is a gift, a time of grace to just give myself a break. This lighthouse... is designed to keep one safe from harm, offering guidance and safety... a beacon of hope.

Maryanne G.

Trash to Treasure: Donate Your Strensiq Lids and Vials to Art Project

Calling all Strensiq users! One of our patients is getting creative and turning what would normally be pharmaceutical waste into art. Suzanne D. is asking for lids of all colors and sizes to create an art piece. Each lid will symbolize a unique HPP journey and come together in a powerful statement of strength, resilience, and unity.

**Send your lids to our office: Soft Bones, Inc.
141 Hawkins Place, #267, Boonton, NJ 07005**



HPP Member Awarded 2025 Grant from the Challenged Athletes Foundation

The Challenged Athletes Foundation (CAF) is a nonprofit organization that supports people with physical disabilities to pursue sports at any level. Every year, CAF awards around 5,000 grants worldwide across 84 different sports, with less than 50 going to Para-Equestrian/Dressage.

Last year, Gigi received a special equipment grant (available every 3 years) to purchase custom adaptive equipment, and this year she received a sports expense grant, which pays for local dressage riding lessons and clinics with visiting trainers. Grants are renewable each year, and this is her 5th CAF Grant! She has earned two medals for her dressage performances at the United States Dressage Foundation (USDF) competitions.

CAF grants are open to anyone with a doctor's note saying they have HPP and experience permanent physical disabilities! They can be spent on any sports training for para or able-bodied, and are not limited to para-specific trainers.

These grants are very important for HPP patients as **HPP is NOT an eligible disability** to train at the United States Equestrian Federation (USEF), Para-Equestrian Dressage Centers of Excellence, or compete in Para-classes or Paralympic qualifiers. Gigi encourages others with physical disabilities to apply and stay active.

Click [HERE](#) to learn more about the CAF organization.



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The support and community I've found through this program have been truly life-changing for me. It not only ensures I can keep training and going to horse shows, but it has also given me some truly amazing friendships.

Gigi K.

Employee/Volunteer Spotlight



Newest Soft Bones Employee: Cannon Sittig!

Hi. My name is Cannon Sittig. I am 19 years old with a passion for sports and a deep commitment to helping others. I was diagnosed with HPP at just 18 months old. **From a young age, I have been an advocate for individuals with rare bone diseases.** I've been a member of the Teen Advisory Council (TAC) for over 2.5 years, and most recently stepped into a bigger leadership role within the program. This year, I started work for Soft Bones as a Data Entry Specialist and Video Editor, contributing to the organization's mission of raising awareness and providing support to those affected by HPP.

In 2025, **I will be launching Cannon Unbroken, a podcast that shares powerful, real-life stories of resilience in the face of life's toughest challenges, especially those related to HPP.**

When I am not working, leading initiatives, or podcasting, I enjoy staying active through my love of sports, playing golf and basketball, and following my favorite teams in hockey, football, baseball, and golf.

Program Updates

Hippo Squad

In our last box, we challenged Hippo Squad members to build Play-Doh figures. **They learned the importance of bones and how they provide the basic structure for our body.**

We hope you had a great time molding your creations to life. Stay tuned for our next box!

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 if you are eligible to join [HERE](#).





Designed by TAC Members

Check out the Teen Advisory Council's (TAC) new design in our Soft Bones online store!

TAC members shared the words that describe the realities of living with HPP. Then they chose to put those words in a word cloud in the shape of a Soft Bones key.

Get yours today at the **Soft Bones Store!**

A percentage of the proceeds goes directly back to Soft Bones! Shop for our cause while raising awareness of HPP and looking stylish at the same time!



Using Influence to Raise Awareness of HPP

Our recent TAC meeting featured Meghan Dillon, Vice President of Digital at Green Room Communications, who **shared tips and tricks on how to be an influencer and how to make a real impact.**

The TAC is composed of teens and young adults, 13-21 years old, who either have HPP, are siblings or children of someone with HPP, or are friends of someone who has HPP. It provides a platform for teenagers and young adults to speak up and raise awareness about HPP.



RDILA Virtual Advocacy Day

Each year, the Rare Disease Legislative Advocates (RDILA) hosts a Virtual Youth & Teen Advocacy Day, giving young advocates (ages 10-18 years old) the chance to meet with members of Congress, share their stories, and learn how laws are made. RDILA supports the advocacy of all rare disease patients and organizations. Just as the Teen Advisory Council (TAC) is a support and advocacy group for teens affected by HPP.

This year, our TAC members have excelled—designing merchandise, exploring ways they can be influencers, and refining their personal stories. We brought this opportunity to them so that they can gain the experience and confidence to advocate on an even larger scale. If you are interested in this, future opportunities, or know of ways our teens can get involved, please contact us!



Stick It To HPP

A huge shoutout to Kirra S. for completing the Stick It To HPP program. We are so proud of her!

The **Stick It To HPP** program provides young HPP patients with the confidence and strategies to administer their injections. The self-injection starter kit comes with tips and fun activities. After each level, participants can snap a picture 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!**



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

PATIENTS OF THE MONTH

for April, May, and June



April: Amedie

Meet Amedie! She was diagnosed with HPP after being misdiagnosed with fibromyalgia. Her relentless search led to answers that would change her life.

Discover how Amedie's journey has taught her the power of rest below.

[Read her story.](#)



May: Alison S.

Alison spent decades knowing something wasn't right. She was finally diagnosed with HPP—a rare, progressive, and often misunderstood disease. Now, she's using her voice to spread awareness.

[Read her story.](#)



June: Cleo H.

At just two months old, Cleo was diagnosed with HPP, a rare metabolic disease that would impact her health and overall quality of life. Despite the challenges of living with HPP, she is an active little girl who loves gymnastics. Read more about Cleo's diagnosis journey and how her family has navigated life with HPP.

[Read her story.](#)

Caregiver Corner: Cassandra

Meet Cassandra. Many might know her as she is one of our Region Leads for the South Central Region. She has HPP and is a caregiver to her son, Jackson, who also has HPP. Learn more about how she navigates the challenges of HPP while taking care of herself too.

[Read her story.](#)



HPP Community: Region Roundups



Northeast Region Connect In-Person

April 12, 2025 | Rhode Island

By Deb F.

Caffe Nero in Providence, Rhode Island was the perfect place for a Northeast Region Meeting in early April. Patients gathered over coffee and delicious pastries to share stories about living with HPP. It's always fascinating to learn about the spectrum of symptoms and how the road to diagnosis is different for each person. A special thank you to those who turned out despite the rainy weather!

Southwest Region Meets Virtually Online

April 17, 2025 | Zoom

By Sue K.

We had a great Zoom meeting with 8 people joining in for a relaxed and fun chat about HPP. The vibe was casual and upbeat—more of a fun chat fest than a formal session—but we still managed to work our way through parts of the slide deck and share some helpful HPP info along the way. Everyone contributed bits of their experience, and it was a nice mix of support, laughs, and opportunity to learn from one another.



Midwest 1 Region Connects Twice in Two Different States!

April 27, 2025 | Iowa
May 25, 2025 | Minnesota

By Jan R.

We hosted two regional support meetings for individuals and families affected by HPP. One was held in Iowa (April 27) and the other in Minnesota (May 25). Attendees shared personal experiences, discussed both physical and emotional challenges, and found comfort in connecting with others in the HPP community.

Common themes included the need for more in-person support and interest in hearing from medical professionals and pharmaceutical representatives. Please help us spread the word. The more connections we build, the stronger our support network becomes.

Northwest Region Hosts Two Events

June 7, 2025 | California
May 8, 2025 | Zoom

By Scarlett P.

Northwest Region Leads, Scarlett P. and Hayley T., hosted a Region Zoom Meeting on May 8th, followed by an in-person meeting hosted by Scarlett in California on June 7th.

The meeting was lovely, and it was so good to meet other HPPers (this was my first meeting) and connect. Great food and great company. It was amazing to hear parts of each other's journeys and where we are all at with diagnoses and treatment. Most were also pretty recently diagnosed and either waiting for prior auth or had just started Strensiq a few weeks prior.

It was good to meet other medical unicorns like me and be in a herd for once. The decades-long journey to diagnosis can be very alienating, as we are told we are normal, and it must be anxiety. To meet strangers who suddenly become a second family is priceless, with many shared experiences, both good and bad.

Southeast Region Forge Connections at Two Key Events

May 10, 2025 | Tennessee
April 26, 2025 | Zoom



By Scott G.

During our Zoom Call on April 26th, we had a good time catching up and talking about living with HPP. We discussed the upcoming National Patient Meeting and how we are looking forward to seeing each other in person, then we started talking about site reactions and injection sites.

At our in-person meeting on May 10th, I brought two studies for us to discuss. I found an online paper about the importance of B6 and what it does in the body and another paper on Beyond Bone explaining the different comorbidities of how HPP basically affects our entire body and the additional symptoms it causes.

Upcoming Events

17th Annual Golf Classic

&

LET'S PLAY PICKLEBALL



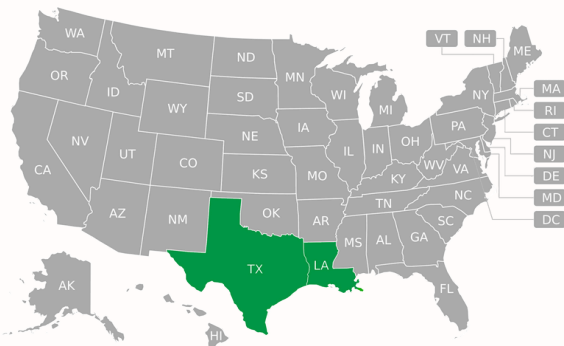
SAVE THE DATE AND REGISTER!

9/29/25

Join us for our 17th Annual Golf Classic and 2nd Annual Pickleball Tournament on Monday, **September 29, 2025, at Somerset Hills Country Club in Bernardsville, NJ**. This is our largest and most important fundraiser of the year. Please consider donating or sponsoring a golfer at our event! All proceeds from this event will fund our mission. We hope to see you there!



REGISTER HERE



South Central Region Zoom Meeting

July 31, 2025 | 7:00 PM Eastern

Do you live in Louisiana or Texas? Join South Central Region Leads Amedie P., Cami R. and Cassandra S. for a Zoom Chat on July 31, 2025 at 7 PM Central. Meet your newest Region Lead, Amedie, and connect with others.



REGISTER NOW

Fundraising Corner (past)



From January 6 - April 13, we hosted a Sarris Candies fundraiser. Families and friends were encouraged to buy chocolates just in time for Valentine's Day and Easter. Thank you to everyone who purchased chocolates to support our cause. We hope you enjoyed them and spread the word!



Our Southeast Region Leads dough-nated their time and energy to host a Little Caesars fundraiser. Thanks to the incredible generosity of friends and family, we raised funds through Pizza Kits and Meal Deal codes. Stay tuned for our next Little Caesars Fundraiser!



Midwest 2 Region Leads hosted a Pampered Chef fundraiser from April 20 - May 10. Family and friends were encouraged to shop for all their kitchen essentials while learning new recipes and kitchen tips. We appreciate all who engaged during the party and those who ordered. We hope you enjoy your new kitchen gadgets!



Soft Bones hosted a Meadow Farms Spring fundraiser from March 15 - March 29. Meadow Farms features popular brands and locally sourced products such as Kringle Candle, Stonewall Kitchen, Gertrude Hawk Chocolate, LEGO, Boston Coffee Cakes, etc. Thank you to everyone who supported this fundraiser!

Fundraising Corner (current)

Facebook Fundraisers

Looking to give back? Host fundraisers on Facebook or Instagram for your birthday, awareness days, end-of-year giving or any other time you want to show support for Soft Bones!

RaiseRight

RaiseRight is a platform where you can buy Gift Cards to over 750+ brands, and a percentage of the proceeds goes to Soft Bones. Buy gift cards to shop for groceries, gas, school & household essentials, dining out, and more. To view the enrollment code on HPP AND ME, click [HERE](#).



kroger community rewards

The Kroger's Community Rewards program allows shoppers to select a nonprofit organization to support. Kroger then donates a portion of the shopper's purchases to the chosen organization. Learn more [HERE](#).



sparkgood™

Walmart allows customers to round up purchases to the nearest dollar and donate the change to their charity of choice. Choose Soft Bones and donate every time you shop ONLINE at [Walmart.com](https://www.walmart.com).

