Soft Bones
Finding the Key to HPP

WINTER 2026 EDITION

THE BARE BONES

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

GEAR UP FOR RARE DISEASE DAY

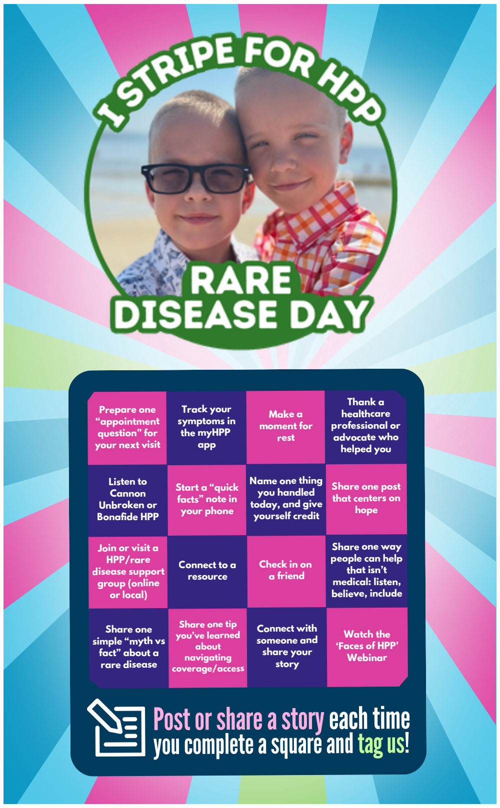
As we head into Rare Disease Day (RDD) on February 28, we're taking inspiration from 2026's "horse energy" a symbol of forward motion and breakthrough. In many Eastern traditions, the Year of the Horse is associated with action, momentum, and moving boldly ahead. Horses are known for being highly attuned to others—so it's a fitting symbol for a day rooted in empathy and awareness.

RDD reminds us that "rare" isn't small. More than 300 million people worldwide live with a rare disease! And yet, when those numbers are spread across thousands of individual conditions, it's easy for most people to miss the reality—unless they learn through someone they know, or through organizations like Soft Bones.

Behind the scenes, so many families are doing the same exhausting work: appealing denials, chasing approvals, and fighting for access to care. ***We don't have to do it alone.***

Click to check out our Rare Disease Day webpage!

IN THIS ISSUE:



Prepare one "appointment question" for your next visit	Track your symptoms in the myHPP app	Make a moment for rest	Thank a healthcare professional or advocate who helped you
Listen to Cannon Unbroken or Bonafide HPP	Start a "quick facts" note in your phone	Name one thing you handled today, and give yourself credit	Share one post that centers on hope
Join or visit a HPP/rare disease support group (online or local)	Connect to a resource	Check in on a friend	Share one way people can help that isn't medical: listen, believe, include
Share one simple "myth vs fact" about a rare disease	Share one tip you've learned about navigating coverage/access	Connect with someone and share your story	Watch the 'Faces of HPP' Webinar

Post or share a story each time you complete a square and tag us!

This year, we've made it easy to get involved with our Rare Disease Day page, featuring simple ways to take action. This includes **updating your social media profile frame, sharing your story, listening to our podcast**, and much more. We've also added a social media **bingo board** where people can do small, doable steps for a chance to win a hoodie. Plus, we will be sharing a special webinar called "**Faces of HPP**" soon.

To represent our hypophosphatasia (HPP) population, come meet some of your fellow Soft Bones patients. Learn about the various forms of HPP and how it can differ from person to person. We encourage you to share with friends and families who may not be familiar with the disease.

Let's carry that energy forward this month by connecting, sharing, and informing in ways that feel natural and meaningful.

National Patient Meeting Registration is Open!

The 2026 National Patient Meeting will be held in Chattanooga, TN from June 26-27. This is your opportunity to connect with others living with HPP and hear from leading HPP experts. View agenda **HERE**.

REGISTER TODAY FOR YOUR SPOT!

Protect Your Child's Rights in School

New Resource Alert!

Having a child in school who has HPP can bring up a set of new challenges for students and educators alike. That's why we've created this resource to break down what you need to know about your rights and how to communicate effectively to support your child with HPP at school.

Read more about IEPs/504

CRITICAL FOR DEADLINES: MEDICAID, APPEALS, ETC.

IF YOU NEED A SAME-DAY POSTMARK

GO TO THE USPS COUNTER AND REQUEST A MANUAL POSTMARK!

HPP Happenings

New US Postal Service (USPS) Guidelines: Changes May Impact Postmarks on Mailed Appeals and Medicaid Information

Attention all HPPers!

Important mailing update:

Starting **December 24, 2025**, the U.S. Postal Service (USPS) will no longer automatically stamp the date on mail that is dropped in a mailbox. Instead, mail will be dated when it is processed, which may be **1–2 days later.**

This change could affect time-sensitive paperwork, such as appeals, Medicaid applications, or other medical or legal documents with deadlines.

What you should do:

If you are mailing anything with a strict deadline, please go **inside the post office and ask the clerk to hand-stamp your mail with the same-day postmark.** This helps ensure your documents are dated correctly and received on time.

If you have questions about mailing important paperwork, don't hesitate to ask your post office staff for help.

[Click to read paragraph 2 to learn more.]

Research News

New Year, New Goals.
A Stronger HPP Community.

In 2025, there was a **52.4% increase** in the number of HPP patients **downloading and using the myHPP app**. Help us continue this momentum in 2026 by tracking your symptoms at least twice a month.

As a reminder, **this app is for patients and caregivers. All information is de-identified, private, and secure.** Two researchers have already posted questions in the app, and many more are on the way. Check back often so you don't miss your chance to participate. Your data today helps shape the future of HPP research tomorrow.

Download the app and input your symptoms today!

ADHD... Anxiety, and Needle Phobia, Oh My!

In our latest episode, guest host Cindy Reasor sits down with HPP caregiver and Licensed Professional Counselor (LPC) Christine McGowan. Christine works with children and families tackling chronic illness, ADHD, anxiety, and trauma. Tune in to see how you can develop skills to cope with these issues, how to support your loved ones, and when to seek professional help.

Click to Listen Now

Soft Bones Members in Action

Turning Medical Waste Into Art

Thank you to those who have mailed in their Strensiq® lids to Soft Bones to contribute to a very special art project. Leading this effort is HPP patient Suzannah B., who is transforming lived experience into something meaningful and visible.

After conversations with her twin sister, Amy W., who also lives with HPP, Suzannah decided the sculpture would become a narwhal, an Arctic whale known for its long, spiral tusk, which is actually a specialized tooth.

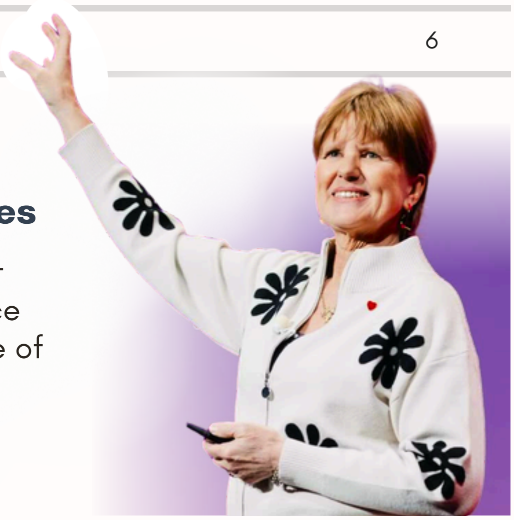
Suzannah says the creature is a symbol rich with meaning, "Narwhals are often believed to be fictional, like unicorns, but they are real. Just because they are rare and hard to spot doesn't mean they don't exist. I liked the idea that it was a water creature, because water is the place I go to ease my pain."

The outpouring of support has been moving. Suzannah recently received teal lids and a handwritten card from a young HPPer, 12 red lids representing six months of treatment from the 1850 clinical trial, and a large bag of green lids from another fellow HPPer. **Each lid represents a story, and together they're becoming something extraordinary and beautiful.**

The project is nearing completion, but Suzannah is still in need of medical cap donations. **If you have lids, please save them and send them along.** Bring them to the National Patient Meeting in Chattanooga, TN, or mail them to:

The US Hypophosphatasia Foundation
141 Hawkins Place, #267,
Boonton, NJ 07005, USA

> **"My goal is that the piece be entirely made of medical waste and adhesives, and one of my son's discarded fencing blades. It's almost complete, and I'm very nervous about the 'skin'."**
>
> — Suzannah B.



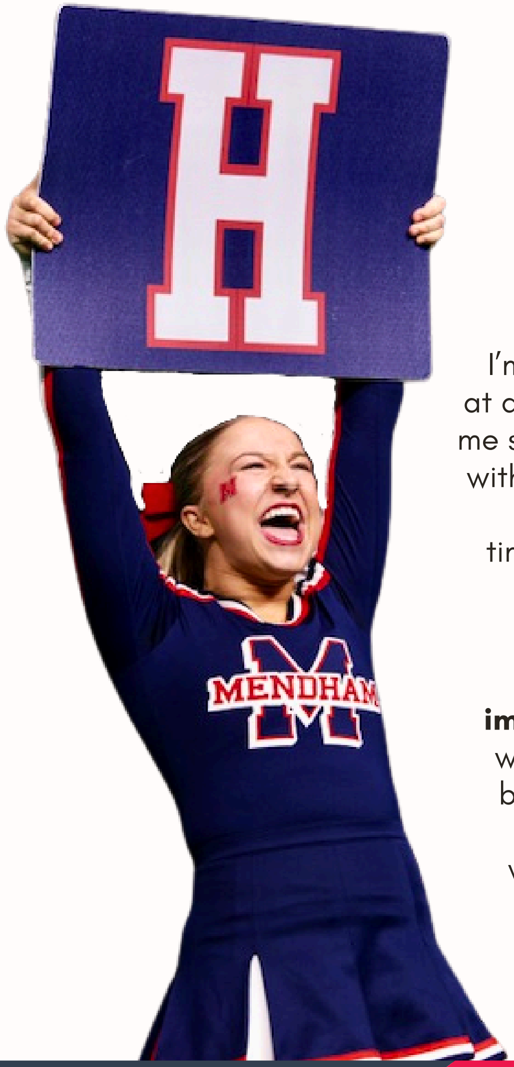
Amy W. Receives Standing Ovation for Her Osaic Speech and Accepts Grant on Behalf of Soft Bones

Recently, HPP patient Amy W. talked to over 900 other investment advisors at Osaic's Women's Forum, which is an annual conference showcasing women leaders in wealth management. Amy was one of **four Women Forward Visionaries** that was selected through a competitive application process and delivered a TED Talk-style presentation about HPP and helping her clients invest.

Through her personal journey living with HPP and serving as a caregiver, she shared how her experiences have helped her guide clients through life's uncertainties, making her a more compassionate and better investment advisor.

As a part of receiving this recognition and for presenting, Soft Bones received a generous donation. Thank you, Amy, for your hard work and dedication in raising awareness of HPP and supporting Soft Bones.

> **"By investing in others, I learned to love myself. Now I could show up authentically with my clients, and they opened up, too. I learned that clients don't want perfection. They want connection."**
>
> **— Amy W.**



Volunteer Spotlight: Meet Sidney!

Hello! My name is Sidney. Here's a little about me. I'm a Texas girl through and through. When I'm not on the sidelines or at a competition doing what I love—cheerleading—you can usually find me soaking up the sun outdoors. Cheerleading is a huge part of my life, with my team recently taking home 6th place nationally at the National High School Cheerleading Championship (NHSCC). I love spending time with my friends and family, and when I'm not in NJ, I am probably on a ranch! I love to read and to support Texas Tech football.

My connection to Soft Bones is through my mom, who works for the organization, and through her, **I've seen firsthand the incredible impact this community has on people with HPP's lives.** The reason why I volunteer is that advocacy is close to my heart—literally. Having been born with a congenital heart defect, I know what it's like to live with a "difference" that most people might not see at first glance. I volunteer because I want to be a voice for others who face medical challenges. **I believe our differences don't define us, but give us a unique kind of strength.**

Program Updates

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

In the latest box, Hippo Squad members had fun decorating superhero masks while learning how bones help their bodies move and stay strong. The lesson highlights that while people born with HPP may face different challenges and have different gifts, having courage, resilience, and compassion through it all are the real superpowers.

In this kit, kids learn that sometimes they or their loved ones impacted by HPP may need extra care, more doctor visits, and medicine to stay strong. **Most importantly, they discover that needing support and leaning on others doesn't take away their powers, but rather it strengthens them.**

Teen Advisory Council (TAC): Trivia Night

TAC members took a short break in December and came back with new ideas and events for 2026. Co-leaders **Cannon S., Brendon F., and Emily W.** led their first meeting of the year on February 9th. Members discussed the meaning of Rare Disease Day and ways to get involved, brainstormed creative ideas for an upcoming craft-focused meeting, and wrapped up the night with a fun, fast-paced trivia game. It was a strong start to a year of connection, creativity, and leadership.

Interested in joining TAC?
Please contact us **HERE**.

New Year. New Goals.

The Stick It To HPP program is designed by teens, for kids who are ready to take charge of their enzyme replacement therapy. It helps young HPP patients with the confidence and strategies to administer their injections.

For those already in the program, please send in your achievement trackers and keep us updated on your progress. No matter where you are in your self-injecting journey, we'd love to check in and see how you are doing.

Have a child who's ready to self-inject?
Sign up today!

PATIENTS OF THE MONTH

January: Elissa

Where do you begin after years of pain, unanswered questions, self-doubts, and finally some clarity? For Elissa, an HPP diagnosis didn't end the journey, but it finally revealed a path forward.

Read her story

February: Joseph and Memphis

Meet Joseph and Memphis. What began as speech delays, low muscle tone, and failure to grow became a life-changing journey that uncovered a rare disease diagnosis affecting their entire family.

Learn more about their HPP diagnosis journey

Soft Bones
Finding the Key to HPP

PATIENT OF
the month

New Stories are Always Welcome!

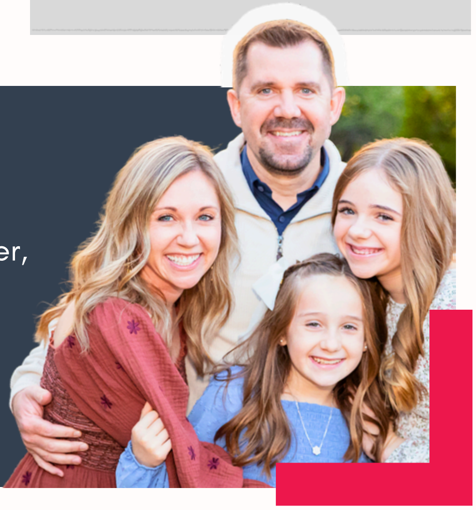
Do you or someone you know have a story to tell about living with HPP? Reach out to Soft Bones. Your story could be featured on our website, social media, and the next edition of The Bare Bones Newsletter.

Contact Us!

Caregiver Corner: Lisa W.

Meet Lisa, a devoted mom and caregiver to her oldest daughter, Peyton, who was diagnosed with HPP at the age of 9. From navigating uncertainty to finding the right resources and support, Lisa shares how she guides her family through it all.

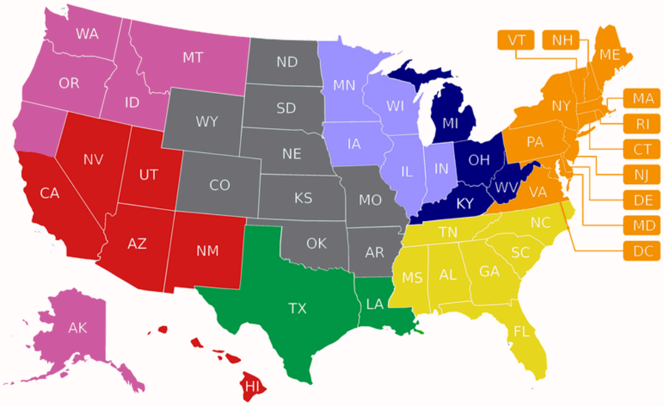
Read her story



HPP Community: Region Roundups

2025 was another stellar year led by 25 Region Leads. In total, we hosted five Region Zoom Chats and 11 in-person Region Meetings.

Here are some upcoming events hosted by Region Leads this year.



Northwest Region Zoom Chat

March 2, 2026 | Online

By Haley T. & Scarlett P.

Calling all HPP members from Alaska, Idaho, Montana, Northern California, Oregon, or Washington?

Join Region Leads, Haley T. & Scarlett P., for a Zoom Chat on March 2, 2026, at 7 PM Pacific Time. All Northwest Region patients and caregivers are welcome to connect and chat.

Registration is required. Please register **HERE**. Once you register, you will receive the Zoom join link directly via email from Zoom. We'd love to see you there!

Remember to join the HPP AND ME Northwest Forum: **HERE**

Southeast Region Zoom Chat

March 5, 2026 | Online

Blynda K. and Tess O

Calling all HPP members from Alabama, Florida, Georgia, Mississippi, North Carolina, South Carolina, or Tennessee?

Join Region Leads, Blynda K. and Tess O., for a Zoom Chat on March 5, 2026, at 7 PM Central/ 8 PM Eastern. All Southeast Region members and families are welcome to learn more about your local HPP support system and connect with fellow members!

Registration is required. Please register: **HERE**

HPP AND ME Southeast Forum: **HERE**

After registering, you will receive the Zoom join link directly via email from Zoom. We'd love to see you there!

Upcoming Events

18th Annual Golf Classic
3RD ANNUAL PICKLEBALL CLASSIC

A Legacy that Continues to Bring Hope

Our Annual Soft Bones Golf Classic has been an important event in raising money to support the HPP community. **As our largest fundraising event of the year, we invite golf enthusiasts and their families and friends to enjoy a full day of play** at Somerset Hills Country Club in best ball or scramble formats. It's consistently ranked as one of the top 100 greatest golf courses in America.

Join us for an unforgettable day at Somerset Hills Country Club featuring our 18th Annual Soft Bones Golf Classic and 3rd Annual Pickleball Event. Whether you're driving it down the fairway or batting it out on the pickleball courts, there's something for everyone. Support the HPP community and share this event with friends and family who want to play for a purpose! There are also many levels of sponsorships available – we appreciate your support!

Support the HPP community and share this event with friends and family. Registration link coming soon.

Denim and Diamonds

Save the Date! Our Annual Denim and Diamonds event will be held later this year to soak up the late summer rays and harvest season. Join us on **September 12, 2026**, as we bask in the crisp air and the peak harvest-season vibes. **It's the perfect time to dust off your denim, add a little sparkle, and Two Step for a great cause.**

Date: September 12, 2026
Location: 100 Rte 24, Chester, NJ 07930
Time: 5:30 PM – 9:30 PM

Registration link coming soon! Mark your calendars and get ready to celebrate the changing of the season.

Fundraising Corner

New Designs, New You!

2026 has already been a busy year with the release of three new, one-of-a-kind designs to raise awareness of HPP. Two were inspired directly by messages from our community, capturing the humor, frustration, and real experiences of living with HPP. We've also released our 2026 National Patient Meeting shirt designs, just in time for our meeting in Chattanooga, TN, on June 26-27. Grab yourself and your loved ones' new swag to raise awareness of HPP, spark conversation, and stand with a community that deserves to be seen and understood.

Order yours today!

Sarris CANDIES

Friendly reminder that our Sarris Candies Fundraiser is still going strong. Treat your loved ones to rich, delicious chocolates and treats that are sure to bring a big smile. From classic favorites to irresistible treats, every order helps support the Soft Bones mission.

From now through March 22nd, let the ones you love know how sweet they are. **Order yours now!**

Past Fundraisers

Soft Bones wrapped up 2025 with several exciting fundraisers, including Pampered Chef, Lynch Creek, and Sarris Candies, perfectly timed for the holiday season! **Thanks to your incredible support, every purchase helped advance our mission.** We hope you loved your sweet treats, festive wreaths, and kitchen gadgets. Thank you for shopping with purpose and making a meaningful difference. Stay tuned for upcoming fundraisers throughout the year.