

FALL 2024 EDITION

THE BARE BONES

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

Together We Can - Celebrating World HPP Day

In October, we came together to raise awareness about hypophosphatasia. This year's theme was **"Together We Can."** **Together We Can** is a statement in itself. But it also begs the question—what can we do together? We were overwhelmed by the participation of individuals who expressed and embodied the message in various ways.

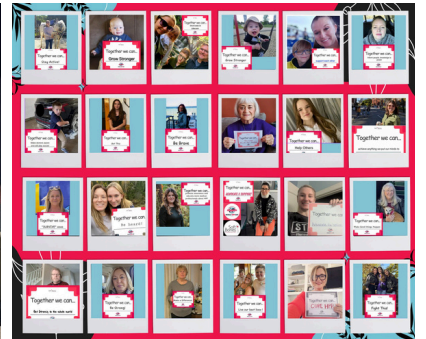
HPP advocates from around the world came out in droves. We had 11 countries represented in a powerful display of unity with an array of photos that showcased the strength and resilience of the Soft Bones community worldwide.



Participants shared what **Together We Can** meant to them, and filled their social media with personal reflections and group celebrations.

In addition, the HPP community participated in the Cannonball 5K Run, Roll, or Stroll, helping to create movement and momentum and raising important funds.

Thank you to everyone who participated this year!
View all photos [here](#).



End-Of-Year Support

Together We Can transform lives. Join us in celebrating the unwavering strength and the resilience of individuals living with HPP. In this year's **video**, we proudly showcase 12 individuals featured as our Patients of the Month. Each story is a testament to the courage, hope, and determination that defines our resilient community.



IN THIS ISSUE:

- A Successful World HPP Day Celebration
- Teeing Up for HPP
- Annual Appeal 2024!



TEERING UP FOR HPP - 16th Annual Golf Outing and 1st Annual Pickleball Tournament

On Monday, September 23rd, we hosted our 16th Annual Golf Classic and our 1st Annual Pickleball Tournament at Somerset Hills Country Club in Bernardsville, NJ. This is our largest fundraiser of the year and we are so grateful to each golfer who came out to support our cause.

A special thank you to our Tournament Sponsor, Atlantic Health System. In addition, a huge thank

you to our other sponsors.

Mark your calendars for September 29th, 2025 for our 17th Golf Classic and 2nd Annual Pickleball Tournament!



Thank You

All of our recent accomplishments would not have been possible without your generosity. Thank you for your continued support!

Tournament Sponsor: Atlantic Health System

Birdie Sponsor: The Fowler Family Charitable Foundation

Eagle Sponsors: Gates and Mary Ellen Hawn, Jack Windolf & Donnelly Construction

Beverage Station Sponsors: William F. Jones, DMD

Driving Range Sponsor: Jack Burke

Longest Drive Sponsor: Sam and Jennifer Khichi

Putting Green Sponsor: Berkshire Hathaway AZ - Harvey & Linda Salkow

Additional Tee Sponsors: Vince Bisogno, Dan Burkhardt, Carter Smiles, Richard Fowler Jr., John Kenney, Sam and Jennifer Khichi, Lara and Christian Kolberg, Daniel McNeil, Rod McRae III, McRae Capital Management, Joseph Oakes IV, M&M Perrotti's, Father Brian Sullivan, Wealthspire Advisors

19th Hole Sponsor: Joseph Micale, DMD

Soft Bones
Finding the Key to HPP



Soft Bones in Action

Behind the Mystery Premiere



Our very own Deborah Fowler and Cindy Reasor were featured on "Behind the Mystery of Hypophosphatasia". Behind the Mystery™ is a TV series, airing on Lifetime, dedicated to raising awareness about rare and genetic diseases through patient storytelling. This episode premiered on October 21st and aired again on October 29th. View the full episode [here](#).

Rampart Bioscience Award

A few months ago, Deborah Fowler and her son, Cannon, were invited as guests to present on Soft Bones and educate employees about hypophosphatasia in San Diego at Rampart's company meeting. Rampart Bioscience dedicated to advancing medicines for HPP. At the end of the event, Deborah

was awarded the inaugural Phillippe Crine Patient Impact Award for her "courageous and unwavering contributions toward improving patient lives". Dr. Phillippe Crine, who sadly passed away in 2023, is the scientist who discovered the first enzyme replacement therapy for HPP, STRENSIQ (asfotase alfa).



Two New Episodes: Bonafide HPP!

Listen now at [Bonafide HPP](#) or click an icon below to view all episodes.



myHPP Updates

Looking for a New Year's resolution that will make a difference? We can all pledge to track our symptoms in the **myHPP app**! Track your HPP data at least twice a month to help physicians and researchers understand its wide spectrum of symptoms better.

Thank you to the hundreds of HPP patients and caregivers who have downloaded the app. Since the launch, we've had users from all over the world. Be sure to visit the app and keep your data up to date. It can provide important insights to our physicians and research community. Important surveys and other pressing questions by researchers will continue to be pulsed out through the myHPP app.

Join our Appy Hours and visit our **Genius Bar** on the HPP AND ME forum to get app support. Find upcoming Appy Hours on our **calendar**.

Have you reported your symptoms?

Top 3 Reported Symptoms:

95%

of users
report pain

60%

of users
report brain
fog/fatigue

57%

of users report
walking and
mobility issues



Learn more about
the app below.



Soft Bones Receives PR Award for 2023 World HPP Day Campaign

Soft Bones, in collaboration with Green Room Communications, was selected as the winner of the Ragan PR Daily Award for its best PR Campaign on a Shoestring Budget. The Soft Bones 2023 World HPP Day campaign celebrated the 75th anniversary of the discovery of HPP and provided a toolkit of activities for the community to use to help raise awareness. We are grateful for this award and

also to Green Room Communications for the support in amplifying our voices around HPP.



UPCOMING EVENTS



Save the Date! Rare Disease Day 2025

Rare Disease Day is on February 28th! Details to come.



Save the Date! 3rd Annual Denim & Diamonds Fundraiser

Join us for our 3rd Annual Soft Bones Denim and Diamonds Fundraiser at Harvest Hall in Chester, New Jersey.

Date: Saturday, May 17, 2025
Location: 100 Rte 24, Chester, NJ 07930
Time: 5:30 PM - 9:30 PM

Registration link coming soon!



Save the Date! 2025 National Patient Meeting in Virginia

Join us for the 2025 National Patient Meeting in Williamsburg, Virginia.

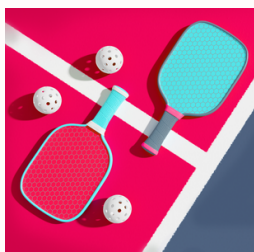
Date: Friday, July 18, 2025 - Saturday, July 19, 2025
Location: Great Wolf Lodge in Williamsburg, VA

Registration link coming soon!



Save the Date! 17th Annual Golf Classic and 2nd Annual Pickleball Tournament

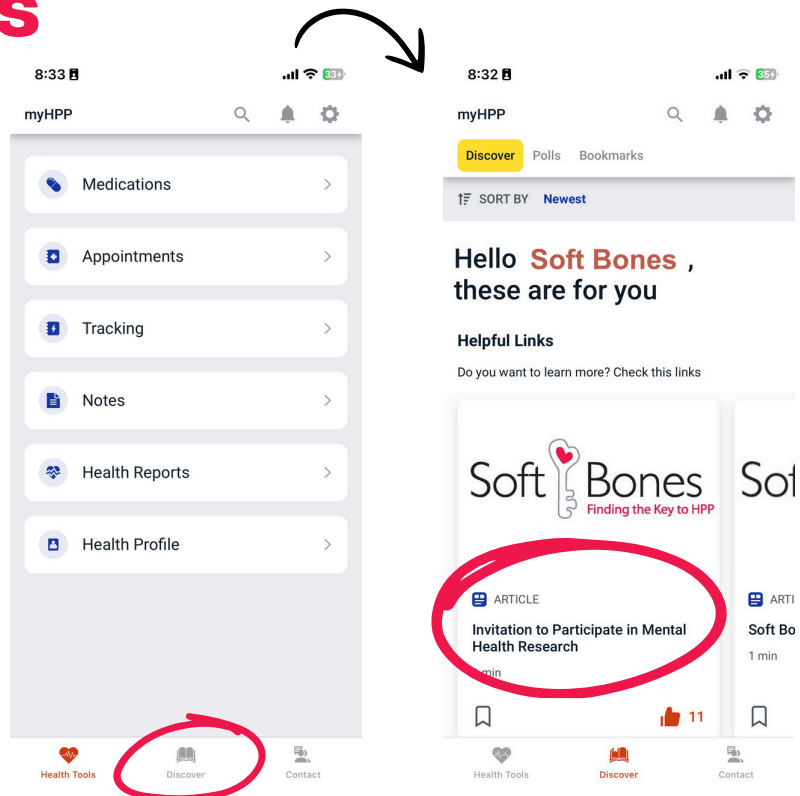
Mark your calendar! Join us for our largest fundraiser of the year on September 29th, 2025! Registration link coming soon!



Research News

Take the Mental Health Survey on the myHPP App

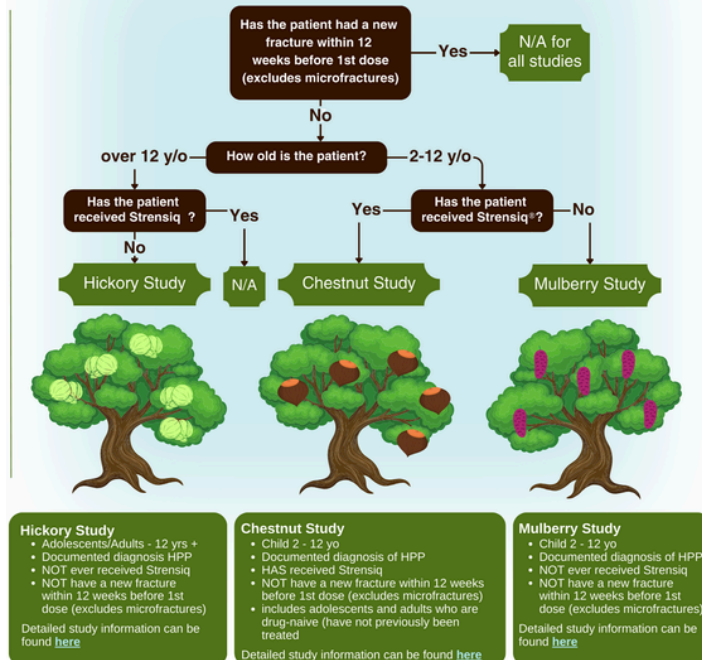
Participate in a survey to help us understand the psychological implications of HPP. The survey can be accessed on the myHPP app. Open the app and click the "Discover" icon at the bottom of your screen to get started.



ALEXION 1850 UPDATES: PHASE 3 TRIALS FOR ALEXION'S NEW ENZYME REPLACEMENT THERAPY (ALXN 1850) ARE NOW UNDERWAY

Phase 3 trials for Alexion's new enzyme replacement therapy (ALXN1850) are now underway. There are 20 sites across the United States and three different studies are being conducted.

The studies and inclusion/exclusion criteria are as follows:



For more information, you may contact Alexion Clinical Trials at 1-855-752-2356, clinicaltrials@alexion.com

Alexion 1850 Update

There are three trials underway for Alexion's new enzyme replacement therapy (ALXN1850).

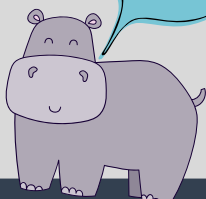
This is a global opportunity. Speak with your doctor if you think you or your child might be a candidate for the study. Click [here](#) to view each study.

Program Updates

Hippo Squad Projects of 2024!



JOIN THE
HIPPO
SQUAD



Hippo Squad

Hip, hip, hooray! We are excited to share that hundreds of participants are receiving quarterly Hippo Squad boxes filled with fun and educational materials. This past summer, we challenged our Hippo Squad members to assemble and paint paper butterflies. We had beautiful butterflies flying all around the field.

Did you know that butterflies are a lot like HPP patients? While butterflies may look fragile they are resilient. Many migrate thousands of miles each year. Individuals with HPP may have fragile bones, but that doesn't stop them from doing what they want. Our next Hippo Squad mailing is coming soon. Can you guess what it will be?

Hippo Squad is open to kids with HPP, their siblings, and children of parent(s) with HPP ages 3-12 years old. It is only open to US residents.

Sign up [here](#).



Stick It To HPP

The Stick It To HPP program offers young HPP patients different strategies to learn 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. Mailings are available to U.S. residents only. [Sign Up!](#)

Attention all Stick It To HPP participants!

Please update us on your progress at Margarete@SoftBones.org. We want to celebrate your milestones! We understand that the road to independence can be tough and the Teen Advisory Council is here to support you.



Click on the image above for full view.

Teen Advisory Council (TAC)

On November 19th, Teen Advisory Council (TAC) members had the opportunity to listen to Matt Hay, U.S. Director of Advocacy for Metabolics from Alexion present, "What is Advocacy and Why is it Important?".

In addition to being a liaison between the HPP community and Alexion, Matt has his own rare disease journey. When he was a college student, Matt was diagnosed with a rare disease called Neurofibromatosis Type 2 (NF2) that would eventually affect his hearing, balance, and facial movement. He turned his

decades of struggle into an opportunity to help others live better lives. Matt's message was that advocacy can come in many forms. Choosing to simply listen can make someone's journey a bit less lonely. A huge thank you to Matt for presenting and to all our TAC members who attended and asked questions.

TAC is composed of teens, 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 to speak up and raise awareness about HPP.



Ready to show up? If you are interested in joining the TAC and more events like these, please let us know!

Join [HERE!](#)

Patients of the Month

OCT



Kirra S.



Kirra is a resilient young girl with a big heart. Diagnosed in 2022 after 15+ fractures, Kirra and her family are grateful for their healthcare team. She expresses herself through writing poetry. Learn more about her below.

Read [here!](#)

NOV



Alana S.



Throughout her life, Alana has struggled with various health challenges that were dismissed and overlooked. Finally, at age 45, she was diagnosed with HPP. Despite numerous misdiagnoses and chronic pain, Alana maintains a positive outlook on life. Learn what keeps her grounded below.

Read [here!](#)

DEC



Adeline H.



Adeline is 6 years old and doesn't let HPP stop her. Despite a list of medical conditions on top of her HPP diagnosis, her family is hopeful. Discover more about Adeline's hobbies and experiences as she learns to advocate for herself below.

Read [here!](#)



Watch Our Video Featuring Our 2024 Patients of the Month!



Volunteer Spotlight

Amy W.

Hi, my name is Amy W. and I've been living with mild infantile hypophosphatasia. My twin sister, Suzanne, and I have fought through its symptoms all our lives, but for years, doctors dismissed our pain and struggles. It wasn't until 2021, after enduring bone pain, joint pain, muscle pain, and more that I finally got some answers. A genetic test revealed I had a defective ALPL gene, which led me to Soft Bones.

Since joining this HPP community, I felt supported in so many ways. My experience made me want to give back. I helped out at this year's National Patient Meeting by educating others about the myHPP app, helping with setup and greeting attendees. I also serve as a moderator on the Soft Bones Facebook page. Additionally, this year I secured funding for the Soft Bones Northeast Region Meeting

through my company, an experience that allowed me to connect with others in the community. I look forward to making an even greater impact in the coming year.



Caregiver Corner

Darrell K.

Soft Bones is excited to showcase the many caregivers who selflessly help others living with HPP. Today, we feature Darrell K. husband and caregiver to Blynda K.

Read his story [here](#).

HPP Community: Region Round Ups

Northeast Region Meeting | October 26, 2024 By Chris D.

On October 26th, the Northeast Region hosted a patient meeting at Soft Bones headquarters in Parsippany, NJ with approximately 24 patients and caregivers in attendance, ranging as far south as Washington DC and as north as Boston. The meeting kicked off with Chris D. and Judith H. giving an overview of Soft Bones' mission and resources. Amy W. then presented the myHPP app and the value it can bring to patients and their doctors, using her own direct experience with the app as an example. The feature presentation came from Dr. Tyris, a NJ-based

rheumatologist familiar with treating HPP. Dr Tyris covered HPP basics including ALP and B6 impacts on the body as well as (rheumatologic) manifestations in HPP children and adults, and the variability of outcomes. The presentation was followed by an engaging Q&A with Dr Tyris and group lunch. The afternoon ended with a 5K fundraising walk around Soft Bones headquarters. Thank you to everyone who participated, to Lucy, Margaret, Denise and Cindy for the planning and setup, and to our very own Deb for the space.



Southwest Region Hosts a Memorable HPP Lunch Gathering | October 19, 2024

On October 19th, the Southwest Region hosted a luncheon at Bucca di Beppo in Mesa, AZ, organized by Region Leads, Amy B. and Sue K. There were 19 attendees, including 9 families. Dr. Pamela Smith, her service dog, Fleetwood, and OneSource Case Manager, Joan Gustin, were also in attendance. Participants shared their HPP experiences, enjoyed a Q&A session with Dr. Pamela Smith, and learned more about the myHPP app.

Northwest Region Meeting | November 2, 2024



On November 2nd, Northwest Region Lead, Haley T., hosted her first-ever in-person Region meeting at Starbucks in Roseville, CA.



We were small but mighty and in great company. We listened to each other and drank coffee.

– Haley T.

zoom

Region Zoom Meeting/Chat

Region Zoom Meetings are a great way to connect with others. Thank you to Midwest 2 Region Leads, Sharon T. and Nichole M., for hosting one on October 3rd and Southeast Region Leads, Blynda K. and Scott G., for hosting one on October 12th. Region Leads 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.

Fundraising

Can't imagine a world without Soft Bones? We need your help!

Fundraisers are an important part of making our programs and services possible. We rely on generous donations and supporters like you. Your support can have a significant impact, whether through donating appreciated stocks, contributing to Charitable Gift Funds, or making direct contributions from your IRA. Every gesture helps drive meaningful change.

Plus, your every day shopping can help support Soft Bones! Click [here](#) to find out how.

There are also ways to participate without spending a dime. Sharing your story within your friends and family could inspire someone to donate on your behalf since they know you! Help us expand our donor reach by being local advocates for Soft Bones.

Get involved [here](#).

Annual Appeal

Did you know that Soft Bones is celebrating its 15th Anniversary? Help commemorate this milestone by donating \$15 or in increments of 15.

Here are 5 ways \$15 can help to fund:

- A welcome packet for a newly diagnosed patient.
- A Hippo Squad box to educate a child about HPP.
- A Stick It To HPP starter kit for children starting their self-injection journey.
- Send a Take Care package to brighten someone's day.
- Underwrite expenses for a Region Meeting.

[Donate Now!](#)

