

THE BARE BONES

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

HPP At Your Fingertips: Download the myHPP App

Research has shown that patients struggle when discussing HPP with doctors. Therefore, we are excited to introduce the myHPP app, developed by patients, caregivers, and physicians as a platform to transform patient care and inform hypophosphatasia research.

Patient participation is the single most critical component of the Soft Bones myHPP app. Even tracking symptoms and your health a few times a month can help answer scientists' most pressing questions about HPP. By sharing information, we can:

- **Identify the needs** of patients and families
- **Develop an evidence-based approach** to meet those needs
- **Uncover new targets** for evolving therapies

With a user-friendly interface, patients can track symptoms, medication, appointments, injection schedules, and more. Before doctor's appointments, you can automatically generate and print a My Health Report that summarizes symptoms to show trends and can better help facilitate a productive dialogue with your treating physician. Learn more [HERE](#).

INVEST IN YOUR
HEALTH
WHILE SUPPORTING
RESEARCH



Love this app! I definitely think this is a game changer for us HPP peeps!!!



Join us in taking actionable steps to transform healthcare by downloading the app from the Apple Store or Google Play Store!



IN THIS ISSUE:

- **myHPP App Has Launched!**
- **Recap: 2024 National Patient Meeting**
- **Come Celebrate World HPP Day!**
- **Alexion Clinical Trials Underway**

myHPP Support



Appy Hour

Come join us every month for an Appy Hour over Zoom. See how myHPP can help you better manage your HPP journey. Learn from tech-savvy patient users and feel free to ask questions along the way. Join us in taking actionable steps to transform healthcare. If you haven't already, download the app in the Apple Store or Google Play Store today! Please visit the Soft Bones calendar for upcoming scheduled Appy Hours.

View upcoming sessions: [HERE](#)

"Genius Bar"

Come visit our "Genius Bar Forum" located on our HPP AND ME platform. We have a library of "how to" videos to help guide users. With technical support from myHPP users and the Soft Bones' team, we hope to optimize your app usage and encourage you to input your data!

Join the conversation: [HERE](#)

myHPP Brochure

Soft Bones created and distributed myHPP brochures to attendees at the 2024 National Patient Meeting. The brochure is currently available on our [Brochure Order Form](#) for healthcare professionals to display at their institutions. We will be distributing them at the upcoming 2024 Annual ASBMR Meeting in Toronto. We will also have a live demonstration of how to use the app.

Read the brochure: [HERE](#)



This app is such a gift! What an amazing thing this app is. I can't believe they made an app just for us with Hypophosphatasia. Many thanks!!!



HPP Happenings



May 18, 2024 | Harvest Hall at Alstede Farms, Chester, NJ

We appreciate the many people who came out to our Denim and Diamonds event. Thank you to our sponsors, Green Room Communications, Hatfield | Schwartz Law Group, the Koze Family, Dr. Brenda Ziegler, and Whitney Saunders & Wendy Barisonek of Turpin Real Estate, who made this event possible. In addition, thank you to those who donated and supported our Amazon Wishlist. We hope you enjoyed a night of dancing, listening to live music, and eating delicious BBQ.

Mark your calendars for our next Denim and Diamonds event on Saturday, May 17th, 2025.





2024 National Patient Meeting

July 12-13, 2024 | Mason, OH

We are still buzzing with excitement after hosting our Soft Bones National Patient Meeting in Mason, Ohio where we had record-breaking attendance! These meetings provide an important opportunity for us to reconnect with one another, strengthen our community, learn about HPP, gather valuable insights, and better understand how we can further support patients and caregivers impacted by hypophosphatasia. We also celebrated our 15th anniversary.

We had a fantastic panel of expert speakers that included:

Dr. Howard Saal (Cincinnati Children's Hospital) - HPP Overview & Genetics

Dr. Chad Deal (Cleveland Clinic) - Rheumatologic Manifestations of HPP

Dr. Sarat Thikkurissy (Cincinnati Children's Hospital) - Hypophosphatasia and Oral Health

Dr. Gary Gottesman (Washington University) - Soft Bones Scientific Meeting Recap

Dr. Stacey Feuer (Institute for Personal Development) - The Mind-Body Connection: Medical Trauma, Rare Disease, and Strategies for Resilience

During registration, we promoted our various programs which included Hippo Squad, Teen Advisory Council, Stick It To HPP, Tooth Fairy program, and the P.A.L. program. In addition, we passed out myHPP brochures to soft launch our app's debut.

Thank you to everyone who contributed to our Help Us Grow campaign! It allowed us to raise \$2,335 and welcome more families to join. We are so grateful for all of the support from our #HPPCommunity!



Click [HERE](#) to view the on-demand recordings of the sessions and the photo gallery.

A special thank you to our sponsors, Alexion AstraZeneca Rare Disease, PANTHERx Rare, BeBio Pharma, and PuREC who helped to make this meeting possible. Thanks to Help, Hope Live for exhibiting at the meeting and sharing information with attendees about their program.

Celebrating Soft Bones' 15th Anniversary!

From where we started to where we are today, we've come a long way. We celebrate the progress we've made in building a community of informed patients, families, and caregivers determined to advocate and support those living with HPP. We thank everyone for fueling our mission. Here's to many more years. Watch our 15th Anniversary video [HERE](#).



Calling All Doctors!

We are experiencing an unprecedented number of inquiries from new patients looking for doctors in various geographical locations. As the needs of our patients continue to grow, we need your help!

We also sent materials including our [Physician's Guide](#) and [Calling All Doctors flyer](#) to the Bone Health & Osteoporosis Foundation Meeting (June) and the Sante Fe Bone symposium (August) to be distributed to all attendees. These meetings bring together medical professionals with a special interest in bone disease. By raising awareness and supplying materials, we hope to spark an interest in attendees to learn more about HPP and potentially treat patients.

During our 2024 National Patient Meeting, we asked patients to take a survey to help us collect doctor names. After the surveys, we identified 28 new doctors! If you need a doctor or love your current healthcare provider and want them added to our list, contact us at Info@SoftBones.org.



Soft Bones Community in Action

Creating a Rare Disease Advisory Council in Arizona

We are excited to share that Sue Krug, Soft Bones staff member and patient, is actively involved in creating a Rare Disease Advisory Council in Arizona. The council will provide guidance and recommendations to educate the public, the legislature, and other government agencies and departments on the needs of individuals who have rare diseases and who are living in Arizona. They will help inform decision-makers on new laws and regulations impacting the rare disease community to improve policies and health outcomes. Learn more about Arizona’s RDAC [HERE](#).

Along with Sue, there are other HPP members such as Christine D. from New York and Aaron B. from Mississippi who are actively creating an RDAC or on the RDAC council in their state.



Invest in Others Grant

Congratulations to Amy Weinberger for receiving an honorable mention in the 2024 Invest in Others Volunteer of the Year Award. This award recognizes financial advisors who are making a difference with charities by giving their time, talent, and energy for at least 3 years. Amy has had a tremendous impact on our organization and the HPP community at large. Most notably as a Northeast Region Lead and as a moderator on our Facebook page. We are thrilled that she was recognized for her efforts through this grant. In acknowledgment of this award, Soft Bones received a \$2,000 donation. To learn more about this grant, visit the website [HERE](#).



I am drawn to RDAC legislation due to the opportunity it presents to advance the voice and rights of individuals with rare diseases and disabilities, ensuring their influence on legislative and medical decisions. I am eager to embrace these new challenges, reminiscent of my college days when I lobbied for the ADA bill in Illinois and advocated for accessible curb access. I believe that genuine improvement requires active involvement rather than mere complaint.

– Sue Krug, Soft Bones’ Patient Liaison

Thank You Osaic Foundation

This grant furthers our mission to inform, educate, and support people living with HPP.



From L to R Alex Bergquist (president of Morris Plains Rotary) Cannon Sittig, Deborah Nettune Fowler, and Steve Augenblick (Past President) at the August 2nd Weekly Rotary Meeting at Uncle Giuseppe's.

“
"It takes a special group of people to invest their time and energy into learning about a disease that they have no connection to. The Morris County Rotary Club is clearly living out its mission of advancing understanding and promoting good will in the community."
 – Deborah Fowler, Chairman of the Board and Founder of Soft Bones Inc.

Raising Awareness at the Morris Plains, NJ Rotary Club

Soft Bones Chairman of the Board and Founder Deborah Nettune Fowler along with Cannon Sittig, her son living with HPP, had the opportunity to raise awareness at the Morris Plains Rotary Club meeting on August 2, 2024.

The Rotary plays a significant role in the community by helping to address the community's needs both locally and globally. Whether they are building schools, providing clean water, or launching a health campaign, they are committed to addressing global health challenges.

A big thank you to our newest volunteer, Caroline Augenblick, and her husband Steve Augenblick for inviting us to this meeting.

Upcoming Events



16th Annual Golf Classic and 1st Annual Pickleball Classic | Bernardsville, NJ

September 23, 2024 | 9:00 AM – 5:00 PM Eastern

Join us for our 16th Annual Soft Bones Golf Classic to be held on Monday, September 23rd, 2024. This annual fundraiser supports Roger's grandson, Cannon Sittig, who lives with HPP, along with daughter, Soft Bones Chairman of the Board and Founder, Deborah Nettune Fowler. Also this year, Somerset Hills has added pickleball courts to their facilities and we are excited to announce our 1st Pickleball Classic will take place on the same day.

Register **NOW!**

Upcoming Events (continued)



HPP AND ME Live Zoom Chat

September 24, 2024 | 3:00 PM - 4:00 PM Eastern

Join us for an HPP AND ME Zoom Chat on September 24th at 3 PM Eastern. Meet the faces behind the names, talk about HPP or life in general, and connect with others!

Registration required. Please register [HERE](#).



Cannonball 5K Run, Roll, or Stroll | Virtual and In-Person Local Region Meetups

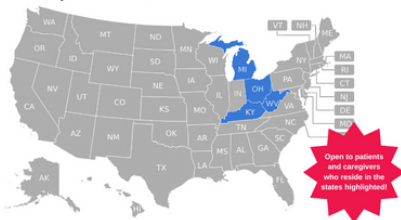
September 29, 2024 - October 31, 2024

Registration is now open for the 3rd Annual Cannonball 5K Run, Roll, or Stroll. Throughout October, leading up to World HPP Day, challenge yourself to finish a 5K! Complete the 5K in a single day or pace yourself to hit your goal over the course of the month. Gather your friends and family to participate locally or virtually. Be on the lookout for announcements about local region meetups.

Sign up [HERE!](#)

Midwest 2 Region Zoom Meeting/Chat

Thursday, October 3, 2024 at 7:30 PM Eastern



Midwest 2 Region Zoom Meeting and Chat

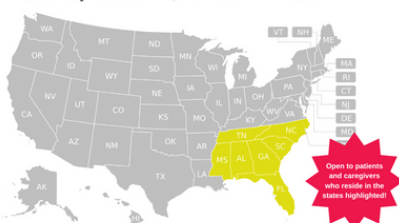
October 3, 2024 | 7:30 PM - 8:30 PM Eastern

Join Region Leads, Nichole Macknight and Sharon Talkington for a Midwest 2 Zoom Chat on Thursday, October 3rd at 7:30 PM Eastern. Connect with fellow HPP members in your region.

Registration is required. Please register [HERE](#).

Southeast Region Zoom Meeting/Chat

Saturday October 12, 2024 at 2 PM Eastern



Southeast Region Zoom Meeting and Chat

October 12, 2024 | 2:00 PM - 3:00 PM Eastern

Join Region Leads, Blynda Kellner and Scott Galvin, for a Southeast Region Zoom Chat on October 12, 2024 at 2PM Eastern. Connect with fellow HPP members from your region about HPP or life in general.

Registration is required. Please register [HERE](#).

Join Region Leads, Blynda Kellner and Scott Galvin, for a Southeast Region Zoom Chat on October 12, 2024 at 2 PM Eastern. Connect with fellow HPP members about HPP or life in general. This meeting is sponsored in part by Alexion, AstraZeneca Rare Disease.



Appy Hour

October 16, 2024 | 7:00 PM – 8:00 PM Eastern

Our next Appy Hour will be held on Wednesday, October 16, 2024 at 7 PM Eastern, which happens to coincide with our Wellness Wednesday. During the Zoom call, we will discuss and input our data together. If you haven't already downloaded the myHPP app, we encourage you to do so. Connect with current users to learn how to use the app. There will be opportunities to ask questions.

Registration is required. Please register [HERE](#).

Southwest Region Meeting

Saturday, October 19, 2024 from 12-2 PM MST
 Buca di Beppo Mesa
 1730 South Val Vista Drive, Mesa, AZ 85204



Do you live in Arizona, Hawaii, Nevada, New Mexico, Southern California or Utah?

Join Region Leads, Sue Krug and Amy Britt for a Southwest Region Luncheon on Saturday, October 19, 2024 from 12-2PM Mountain Standard Time. OneSource Case Manager, Joan Gustin, will be there to join the conversation. Dr. Pamela Smith from Phoenix, Arizona, will be attending and on hand to answer general questions about HPP. This is open to all Southwest Region members. This meeting is sponsored in part by Alexion, AstraZeneca Rare Disease. We hope to see you there!



Southwest Region Meeting | Mesa, AZ

October 19, 2024 | 12:00 PM – 2:00 PM MST

Do you live in Arizona, Hawaii, Nevada, New Mexico, Southern California or Utah?

Join Region Leads, Sue Krug and Amy Britt for a Southwest Region Luncheon on Saturday, October 19, 2024, from 12-2 PM Mountain Standard Time. OneSource Case Manager, Joan Gustin, will be in attendance. This is open to all Southwest Region members. Lunch will be served. We hope to see you there!

Address: Buca di Beppo Mesa
 1730 South Val Vista Drive, Mesa, AZ 85204

Registration is required and will close on October 5th, 2024. Please register [HERE](#).

Northeast Region Meeting

Saturday, October 26, 2024 at 10:00 AM Eastern
 Soft Bones, Inc. Office
 1719 NJ-10, Suite 315, Parsippany, NJ 07054



Join Region Leads, Judith Harris & Chris Denune for a Northeast Region meeting from 10 AM-2 PM. Our guest speaker is Dr. Nickolas Tyrus from NJ. A OneSource Case Manager will be in attendance. Lunch will be provided. We hope to see you there! Attendees will have the option to participate in the Cannonball 5K following this meeting. Come celebrate World HPP Day with us!

Northeast Region Meeting | Parsippany, NJ

October 26, 2024 | 10:00 AM – 2:00 PM Eastern

Do you live in Connecticut, DC, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, or Virginia?

Join Region Leads, Judith Harris & Chris Denune for a Northeast Region meeting from 10-2 PM Eastern. Our guest speaker is Dr. Nickolas Tyrus, a Rheumatologist from NJ. A OneSource Case Manager will be in attendance. Lunch will be provided. We hope to see you there!

Open to all who reside in the highlighted states!



Thank you to our sponsors for supporting this meeting!

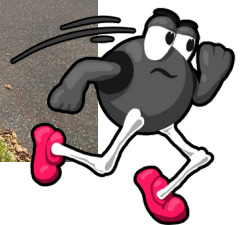


The deadline to register is October 12, 2024. Please register [HERE](#).

This meeting is sponsored in part by Alexion, AstraZeneca Rare Disease, and the Osaic Foundation. We hope to see you there!

Location: 1719 NJ-10, Parsippany, NJ 07054
Review our agenda: [HERE](#)

Following the meeting, attendees will have the option to participate in the Cannonball 5K Run, Roll, or Stroll. View pictures below from last years 5K. Please register [HERE](#).



Come Celebrate World HPP Day!

October 30, 2024 | Global Event

This year's World HPP Day theme is **"Together We Can!"**

"Together We Can" embodies the power of collective effort and unity. It suggests that by joining forces, we can achieve greater things than we could alone. It's a call to collaboration, emphasizing that shared goals and mutual support lead to stronger outcomes and positive change. Whether in a community project, a team effort, or a personal relationship, this phrase highlights the strength found in togetherness and the limitless possibilities that come when people work in harmony.

World HPP Day materials and T-shirt will be available on our website soon.



Podcast Release



ELISA Test Podcast with Dr. Steven Petak, former Head of Endocrinology at Houston Methodist Hospital, Associate Clinical professor at Weill Cornell Medical College and Texas A&M

ELISA stands for Enzyme-Linked Immunoassay. These tests are commonly used to detect and count certain antibodies, antigens, proteins, and hormones in bodily fluid samples, helping doctors diagnose and treat certain conditions.

Because they rely on an alkaline phosphatase conjugate, ELISA tests have been the topic of much discussion among patients and caregivers. Join Deborah Fowler and Dr. Stephen Petak, former Head of Endocrinology at Houston Methodist Hospital, Associate Clinical professor at Weill Cornell Medical College and Texas A&M, as he answers commonly asked questions about this test and how it can impact patient care. Listen to this episode [HERE](#).

Guest host Cindy Reasor and patient Janni K. talk about Janni's journey with HPP.

Diagnosed later in life, Janni has had to overcome the "mommy guilt", even though she didn't know she had HPP, she struggled with feelings of guilt for having passed on this disease to her children. She is learning to manage HPP while being patient with herself. Learn how Janni advocates for herself and spreads awareness by sporting Soft Bones merchandise from our store. Janni was recently highlighted as Patient of the Month in May. You can find more of her story and a picture of her HPP Hippo tattoo in the Bone Zone on our website. Listen [HERE](#).



Research News

Soft Bones is Poised for the Next Phase of Research

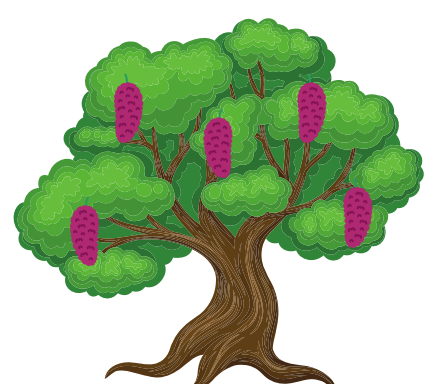
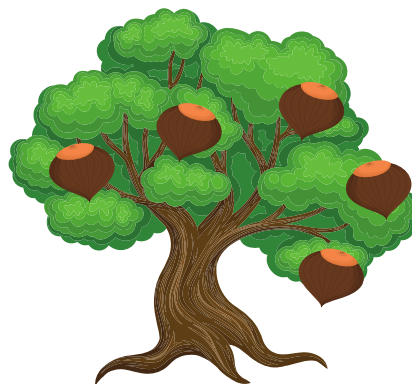
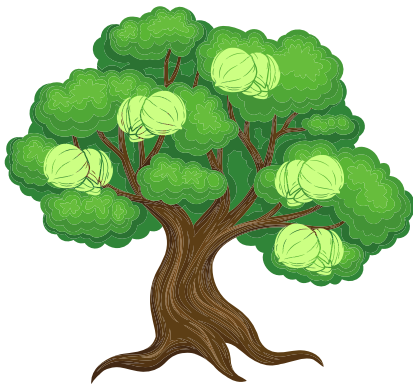
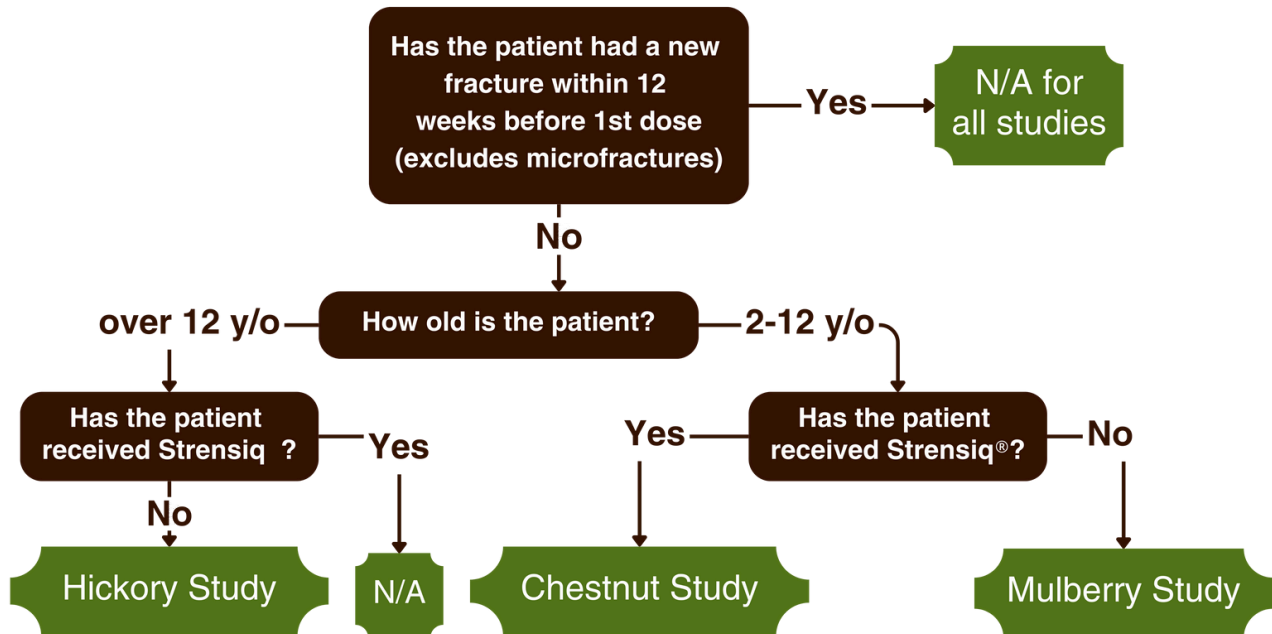
We have made exciting progress as an organization in assessing our research readiness, which would open the door for Soft Bones to apply for larger grants to fund research driven by patient insights. We have been working with a grant writer with a track record of successful applications to organizations like PCORI (Patient-Centered Outcomes Research Institute) that fund this type of research. She conducted an assessment and has concluded that we as an organization are ready to take the next step. The assessment was based on a workshop with 14 patients and caregivers in attendance at our National Patient Meeting in August. The objectives of the meeting were to educate participants on patient-centered research and to formulate a primary research question for HPP as a patient advocacy organization. The group settled on a research question focused on a greater understanding the full range of systemic symptoms of HPP. The next step is to engage with the Scientific Advisory Board to create and write a grant application to build capacity to research the full range of systemic symptoms, including how they vary/fluctuate within and among patients, with the potential to also explore how symptoms intersect with wellness and psychosocial factors.



Alexion 1850 Updates: Phase 3 trials for Alexion’s new enzyme replacement therapy (ALXN1850) 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:



Hickory Study

- Adolescents/Adults - 12 yrs +
- Documented diagnosis HPP
- NOT ever received Strensiq
- NOT have a new fracture within 12 weeks before 1st dose (excludes microfractures)

Detailed study information can be found [HERE](#).

Chestnut Study

- Child 2 - 12 yo
- Documented diagnosis of HPP
- HAS received Strensiq
- NOT have a new fracture within 12 weeks before 1st dose (excludes microfractures)
- includes adolescents and adults who are drug-naive (have not previously been treated)

Detailed study information can be found [HERE](#).

Mulberry Study

- Child 2 - 12 yo
- Documented diagnosis of HPP
- NOT ever receive Strensiq
- NOT have a new fracture within 12 weeks before 1st dose (excludes microfractures)

Detailed study information can be found [HERE](#).

Employee/Volunteer Spotlight

Liesl K. | Design

I'm Liesl Kopp, a mom of three amazing kids—Adeline (5), Sadie (3), and Charlie (6 months). My journey with hypophosphatasia (HPP) began during my pregnancy with Adeline. It was a challenging time as we learned about her condition, and I discovered that I also have HPP, as well as my dad and brother. Finding the Soft Bones organization was a comforting experience; it provided a sense of community and support where I could connect with others who understood our situation.

Five years since our diagnosis, I've been dedicated to learning more about HPP and am eager to give back to the Soft Bones organization. My husband is in the army, so our family moves around quite a bit, but no matter where we are, Soft Bones feels like home. Originally from Maryland, I'm currently pursuing a marketing degree with a minor in web and digital design. I'm excited to contribute my skills and collaborate with like-minded people.



Caroline A. | Fundraising and Grant Research

Hello, my name is Caroline Augenblick. I met Deborah Nettune Fowler in 1st grade when she and I were Girl Scouts looking to get good deeds done. We are both still very much interested in doing good deeds for others.

I was inspired by Cannon Sittig's journey and the Soft Bones community and what the organization does to expand outreach and funding for research to help HPP patients.

My experience is in raising money for various causes like a Newark-based private school that runs on the generosity of scholarships, a downtown improvement organization to put up a bronze sculpture of Millicent Fenwick in Bernardsville, and a public policy center in the Somerset and Morris Counties.

I have been married for 28 years and live in Morris County where I raised two daughters who are grown up and fulfilling their own goals and dreams in healthcare. I have two dogs and I work in a nursery school supporting the teaching staff. I love learning about the HPP community and I am hoping I can add and enhance the already established programs and grow new opportunities for Soft Bones.



Caroline A. helping Lucy and Margaret at the Soft Bones' office. We stuffed 500+ envelopes to mail to golfers for our 16th Annual Golf Classic and 1st Annual Pickleball Classic.

Soft Bones Expands Board of Directors with the Addition of Beverly Natale



We are excited to share that Soft Bones has added a new board member. Part of her role on this board will be in community health, which will be integral for Soft Bones.

Beverly Natale is the Director of Clinical Services at Morristown Medical Center, part of Atlantic Health System, in Morristown, New Jersey. Beverly received her Bachelor of Science degree from Wheeling College, West Virginia, and her Master of Administrative Science degree from Fairleigh Dickinson University, New Jersey. She began her career with Morristown Medical Center (MMC) in 1986 as a Respiratory Care Practitioner. In 2015, she became Director of Clinical Services leading hospital-wide initiatives to improve access, clinical outcomes, and efficiency. She is on several advisory boards throughout Morris County. We are excited to have her join our board.

Program Updates

Stick it to HPP



We currently have 19 kids enrolled in our Stick it to HPP program!

The Stick It To HPP program was created by members of the Teen Advisory Council (TAC) who worked together alongside HPP patients who had to use different strategies to learn to administer their own 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.

Request a kit today!

Teen Advisory Council - Currently Accepting Applications

Hear directly from our Teen Advisory Council (TAC) members on why YOU should join! TAC is comprised 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 about HPP. This

year, there are several committees to get involved in, including fundraising, social media, and raising HPP awareness. TAC meetings take place twice a month (virtually). We can't wait to see some new faces to continue this important work. **Join the TAC today!**





Hippo Squad

Spring Box

In our Spring box, Squad members made edible flower pots out of pudding, Oreos, gummy worms, and edible flowers. They learned that the many layers in the soil help flowers grow. Just like soil, humans are full of nutrients! For HPP patients, having the right amount and type of nutrients can help them grow and thrive. Our Hippo Squad members did not disappoint. It was wonderful to see our Soft Bones gardeners planting away and many sent photo submissions to fill our garden. We hope all involved had a blast assembling and eating their dirt cups.

Summer Box

We recently sent our summer Hippo Squad boxes out. In the box, kids had all the materials they needed to make a papered butterfly.

We were blown away by the colorful butterflies that flew into our Soft Bones 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. We have many HPP patients working or attending college, playing sports, serving our community, and more!

Since our last Hippo Squad mailing, we've had 10 new families sign up! Don't miss out on the fun. Sign up today to receive quarterly boxes filled with fun activities, while learning about HPP.

This program is open to kids with HPP, their siblings, and children of parent(s) with HPP ages 3-12 years old. Currently, there are 131 families enrolled in the program, with 205 children receiving the Hippo Squad mailings. It is only open to US residents. Sign up [HERE](#).



Patients of the Month

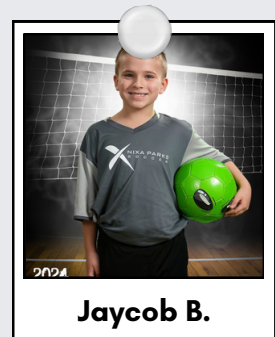


Janni K.

May

Janni is a loving person who has seven grandchildren. Diagnosed late in life, she navigates HPP alongside her son and granddaughter. She utilizes Soft Bones resources for insight and proudly wears the swag to raise awareness. See a photo of her Soft Bones purple hippo tattoo, a design made using the letters HPP below.

Read her story [HERE](#).



Jaycob B.

June

Jaycob is an active 8-year-old who loves his family and soccer. As a member of the Hippo Squad and Stick it to HPP program, he enjoys the educational activities and the opportunity to become an advocate for himself, even at a young age. Jaycob is currently learning how to administer his own enzyme replacement therapy.

Read his journey [HERE](#).



Ray T.

July

Despite experiencing symptoms throughout his life, Ray was officially diagnosed with HPP at the age of 39. He is grateful to have access to a medication that has improved his quality of life. Find out how his own research and curiosity helped address his unexplained muscle and bone pain.

Read his experience [HERE](#).



Juliana R.

August

Juliana is a resilient child adopted from China. Despite the challenges of living with HPP and having several learning disabilities, she doesn't let it get in her way. Surrounded by supportive friends and family, Juliana excels in school and loves riding horses.

Read her story [HERE](#).



Carol K.

September

Carol is an active HPP patient who loves the great outdoors. She first heard about HPP when she was 25 years old after her nephew was diagnosed. It wasn't until she slipped on some stairs years later that she remembered the HPP information and sought an HPP specialist. Learn more about her HPP journey and various hobbies, mission work, and photos of her scuba diving below.

Read her journey [HERE](#).

HPP Community: Region Roundups

Central Region Meeting | Papillon, NE

By Kara S. (Region Lead)

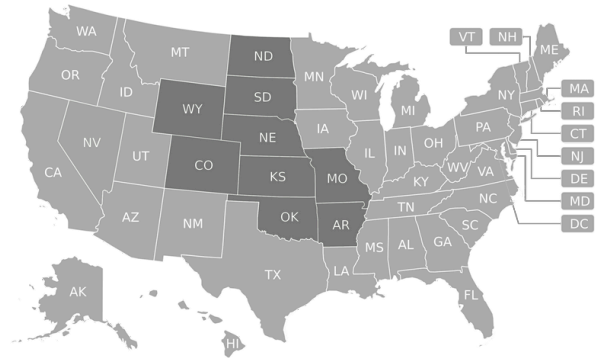
The Central Region hosted a lunch meeting on Sunday, July 20, in Papillon, Nebraska. Eighteen attendees representing five area families—including one family who is new to Soft Bones—met for a casual gathering. We were amazed to discover multiple professional and personal connections in our group with the new family, making them feel immediately welcome. Those of us who’ve met before haven’t been together in person since 2018, so it was nice to see how much our group of now-teens has grown and changed in the last six years. At our last gathering, the kids played together while the adults talked, but this time everyone participated in the conversation and shared their experiences with HPP from the perspective of a patient, caregiver, or family member.

We had so much fun that we forgot to take a photo! We look forward to the next time we can all get together...

Five Region Zoom Meetings Held This Summer



Five Regions hosted a Zoom Meeting/Chat this summer. This was a great opportunity to connect virtually with other HPP members. From talking about the National Patient Meeting to promoting the myHPP app, these chats were filled with personal stories and questions. We appreciate Region Leads, Amy Britt (Southwest), Sue Krug (Southwest), Nicole Belting (Midwest 1), Cindy Reasor (Midwest 1), Sharon Talkington (Midwest 2), Nichole Macknight (Midwest 2), Ann Haak (Northwest), Haley Thornton (Northwest), Chris Denune (Northeast), and Judith Harris (Northeast) who made it happen! Stay tuned for upcoming Region Zoom Chats on our social media platforms and website calendar.



Caregiver Corner

Sharon T.

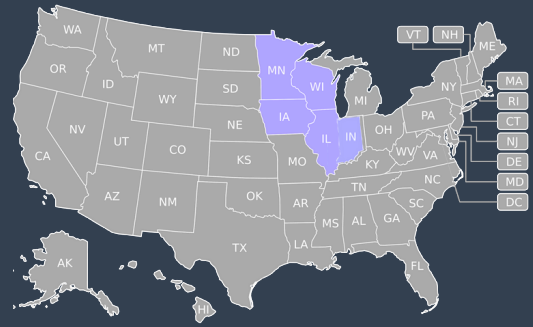
Soft Bones is excited to showcase the many caregivers who selflessly help others living with HPP. Sharon T. may be a familiar face to many because she’s a Region Lead for the Midwest 1 area. She cares for her husband Dave and has become a fierce advocate for him as well as the HPP community at large.

Read her story and nominate a caregiver [HERE](#).



Midwest 1 Region Meeting | Montgomery, IL

On August 17, 2024, Region Lead Nicole Belting hosted a meet-up in Illinois at Blackberry Trails Park for lunch. With 10 people in attendance and a OneSource Case Manager, it was great to connect with HPP members and enjoy the great outdoors.



Fundraising Corner

Past Fundraisers

Help Us Grow

Thank you to everyone who contributed to our Help Us Grow campaign! In early May, we reached our travel grant cap, but the waitlist for the National Patient Meeting continued to grow. We asked patients, families, caregivers, and donors to help us raise vital funds to expand our meeting through DonorView. We raised \$2,335 through online donations and additional support from the Sarris Candies Fundraiser, Mary Kay Fundraiser, and HundredX Campaign.

With nearly 250 people in attendance, this was our largest meeting in Soft Bones history. We are so grateful for all of the support from our #HPPCommunity!

HundredX

Many of our members ask for ways that they can help support our mission when they don't have the financial means to donate. One way is through the HundredX fundraiser, which allows people to raise money by sharing their opinions on popular brands and companies. For every quality HundredX survey completed, \$1.60 goes to Soft Bones. It's a great way to give back without spending a dime.

Thank you to everyone who completed surveys on behalf of Soft Bones! With over 125 participants, we collectively raised \$2,772.80. A special shout out to Adriane, Denise, Deborah, Judith, Sue, Ellen, Kendra, Cindy, Kevin, and Jennifer, who reached the maximum amount of 75 surveys!



Pampered Chef

Our Pampered Chef Fundraiser ran from August 6 - August 13. Cindy Reasor hosted a virtual Pampered Chef Facebook party that included kitchen tips, recipes, raffles, and games, to encourage individuals to stock up on a variety of kitchen gadgets, appliances, and basics. The fundraiser was extended to August 30, so people could continue shopping for all their kitchen essentials. In total, we raised \$786.68!

Pampered Chef donated 30% of all fundraiser sales.

Current and Upcoming Fundraisers



Sarris Candy Fundraiser

Soft Bones is excited to partner again with Sarris Candies for a chocolate fundraiser. From September 16, 2024 - December 15, 2024, 25% of the proceeds will support Soft Bones. Treat your family and friends to a variety of seasonal chocolates and treats.

Order [HERE](#).



Gift Wrap Fundraiser

Our gift wrap fundraiser is back for another holiday season. Treat yourself and your family and friends to high-quality gift wrapping paper to add a magical touch to all your gifts. The link to order will be available soon.



Lynch Creek Wreaths

We are hosting a Lynch Creek Farm wreath fundraiser! Lynch Creek Farm handcrafts traditional and decorated Christmas wreaths, centerpieces, and other holiday gifts. From now until December 15, 2024, 15% of all sales will go towards Soft Bones.

Order [HERE](#).



Popcorn Fundraiser

This December, we will be hosting our first-ever popcorn fundraiser. More details to come.

Visit our Shop for a Cause page [HERE](#), to get the full list of ongoing fundraisers!