

# THE BARE BONES

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

## COMING SOON: Your New HPP Companion, myHPP

Developed by patients and physicians, Soft Bones is excited to introduce myHPP, an app that was created to transform patient care and inform hypophosphatasia research. The Soft Bones myHPP app was designed to unite people who share the desire to better understand hypophosphatasia and who agree to share anonymous data about symptoms to alter the future of hypophosphatasia treatment.

myHPP supports, informs, and provides the tools necessary to achieve better health outcomes for HPP patients. Patients and caregivers can document their symptoms, create medication reminders, and more. The app also has a tool called "My Health Report" which summarizes patient-reported information into a myHPP report, which can be printed and handed to the doctor to better inform healthcare providers on pain,

mobility, and other symptoms. The goal is to improve discussions with doctors and ultimately lead to better patient care, while giving doctors and researchers a greater understanding of the full impact of HPP.

In addition, we at Soft Bones see our HPP community as partners in research. Our health data contains valuable information that holds the key to scientists' most pressing questions about HPP. By capturing this information, we can:

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

Patient participation is the single most critical component of the myHPP app. By using this app,



myHPP



you take an active role in research and making a difference — for yourself and others. The app is private and secure, allowing only for de-identified data to be collected.

App coming soon!



**Each of us has unique details that hold clues to the next medical advancement — sharing your health data helps uncover these new insights bringing us one step closer to the next HPP breakthrough.**

### IN THIS ISSUE:

- myHPP App Coming Soon
- Rare Disease Day 2024
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# HPP Connect: We've Moved



We are excited to announce that our professional platform for doctors and healthcare professionals, HPP Connect, has moved! Our new interface will allow healthcare professionals to engage in a more user-friendly environment. HPP Connect is an online collaborative community for ongoing, multi-specialty, peer-to-peer exchange, dialogue, and education focused on hypophosphatasia (HPP). It connects clinicians with experience evaluating and treating HPP to one another to foster knowledge-sharing and collaboration. Ultimately this will benefit patient care by improving the overall patient experience and confidence in the care team, as well as increase the number of doctors who are knowledgeable about HPP. The platform offers on-demand access to recorded TeleECHO, 2nd International Scientific Meeting sessions, and many other resources.

The platform is reserved for **clinicians and researchers** only. For more information or to register, please email [HPPConnect@softbones.org](mailto:HPPConnect@softbones.org).

## Soft Bones Community in Action

### Creating a Rare Disease Advisory Council in Mississippi

Aaron Blocker, HPP patient and advocate, participated in the ceremonial signing of Senate Bill 2156. This bill creates a Rare Disease Advisory Council (RDAC) in Mississippi. NORD's Project RDAC Initiative aims to amplify the voices of rare disease patients by identifying and addressing barriers to care and treatment. Mississippi is the 28th state to have a RDAC.

Aaron consistently posts informative content on his Instagram page, and attends

conferences throughout the country. In addition, he advocates for other diseases such as Crohn's. To learn more about the Council, click [here](#).



”

**The establishment of the Rare Disease Advisory Council in Mississippi stands as a monumental victory for patients like myself across our state. This pivotal legislation signals a profound commitment to addressing the unique needs and challenges faced by those of us battling rare diseases, offering hope and support to individuals and families.**

– Aaron Blocker, HPP Patient and Advocate



## Nellie Sanders Appointed as Oklahoma’s Secretary of Education

Congratulations to our Central Region Lead, Nellie Sanders, who recently became the Oklahoma Secretary of Education as of January 24, 2024. In this active role, Nellie communicates with educational leaders across the state to advance education on all

fronts and advises the Governor on higher education initiatives. She believes all students should have access to different tools and resources to excel.

Watch a short clip of how Nellie sees things differently, [here](#).



**As a member of the Soft Bones community, I've experienced the value of belonging to a group that understands the challenges of living with a rare disease such as hypophosphatasia. It's a privilege to use my lived experience to be a voice for those who often feel they don't have one, ensuring we all feel seen and supported.**

**— Nellie Sanders, Secretary of Education, Oklahoma**

## Bonafide HPP is Back with a New Episode, featuring Lindsey Willson

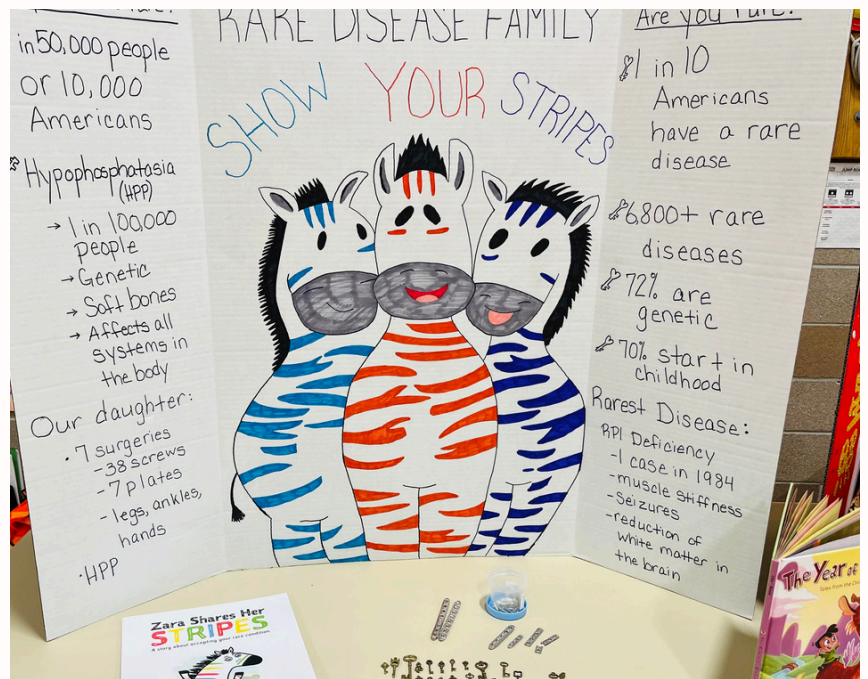
In the latest episode, guest host Cindy Reasor and Central Region Lead and patient Lindsey Willson discuss how HPP has shaped Lindsey's life. Find out why Lindsey's nickname was "I-Lean" in high school and how her athletic career led her down her HPP journey. Listen [here](#)!





## Raising Awareness on Diversity Night

On March 9th, Juliana (HPP patient) and her mom, Becky from Colorado, created a Rare Disease table for Diversity Night held at their local elementary school. They made an amazing tri-fold poster with HPP statistics and rare disease facts. In addition, they shared the “Zara Shares Her Stripes” children's book and gave out skeleton keys. Way to raise awareness for HPP and rare diseases!



## Wrestling at Regionals

Josiah and his mom from Wisconsin, created a one-of-a-kind Soft Bones singlet to be worn at his Regional Wrestling Championship on March 14th. He placed 5th at the tournament called “Go Big or Go Home” in Green Bay, Wisconsin. He is one of many HPP Warriors that doesn't let HPP stop him from doing what he loves. Way to go, Josiah!



# HPP Happenings

## Soft Bones on the Today Show Plaza...

This year, Rare Disease Day took place on February 29th. It is an international event to focus public attention on rare diseases as a public health concern. It occurs annually on February 28, unless it's a leap year like this. Through our collective voices, we strive to promote equity, access to care, and therapies for people with rare diseases. Members of our



community celebrated in different ways! Many took to social media to share or comment on their stories, while others changed their profile frames and hosted small gatherings.



### Soft Bones on the TODAY Show

This year, to mark Rare Disease Day, the Soft Bones team traveled to NYC to join forces with NORD, and other rare disease organizations on the Today Show plaza. We held up cardboard Zebra heads and connected with others from the rare disease community as we waited to see Savannah, Hoda, and Craig. We shook hands and took a selfie with Al. Did you spot us in the crowd? Watch our reel [here](#).



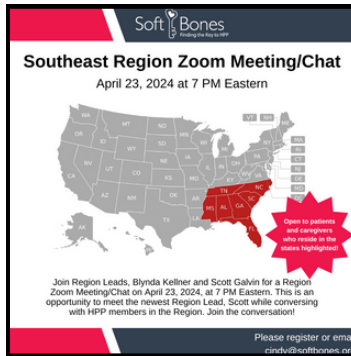
### New Designs and Resource Page for Rare Disease Day

In anticipation of Rare Disease Day, we created a brand new website landing page to raise awareness and spread shareable materials created by EURORDIS and NORD. We also launched a handful of new t-shirt designs and profile frames to show our HPP Pride. If you want to learn more about Rare Disease Day and how to get involved next year, click [here](#).

Purchase your Rare Disease Day shirt on our [store](#)!



# Upcoming Events



## Southeast Region Zoom Meeting/Chat

April 23, 2024 | 7:00 PM Eastern

Do you live in Alabama, Florida, Georgia, Mississippi, North Carolina, South Carolina, or Tennessee?

Join Region Leads Blynda Kellner and Scott Galvin for a Region Zoom Meeting/Chat on April 23, 2024, at 7 PM Eastern. This is an opportunity to meet the newest Region Lead, Scott, while conversing with HPP members in the Region. Join in on the conversation! Registration is required. Please register [here!](#)



## HPP AND ME

May 16, 2024 | 1:00 PM EDT

You are invited to our next HPP AND ME Zoom Chat on May 16th at 1 PM EDT. Meet others within the HPP Community and connect. Come join the conversation!

Registration is required. Register [now](#).

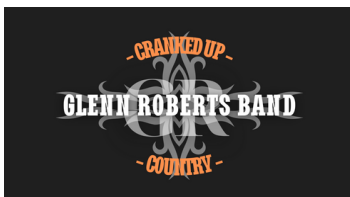


## Denim and Diamonds

May 18, 2024 | 5:30 PM - 9:30 PM

Howdy Y'all!

Join us for our 2nd Annual Soft Bones Denim and Diamonds fundraiser at Alstede Farms' Harvest Hall, in Chester, NJ on Saturday, May 18th. Dust off those cowboy boots and get ready to two-step away for a great cause. There will be live music by Glenn Roberts Cranked Up Country Band, food, drinks, dancing, and an auction. Every dollar raised will directly go towards advancing the mission of Soft Bones – to inform, educate, and support people living with HPP.



Looking to support Soft Bones, but can't come? Donate an auctionable item or event. Consider donating artwork, memorabilia, a travel package, event tickets, a spa package, etc. You can also help us create themed gift baskets for our auction by purchasing an item or two off our Amazon Wish List [here](#). Contact Lucy at Lucy@SoftBones.org to make arrangements.

Address: 100 Rte 24, Chester, NJ 07930

Register [here!](#)



## 2024 National Patient Meeting Registration is at a Soft Bones Record High!

July 12-13, 2024 | 5:30 PM

The 2024 National Patient Meeting will be held on July 12-13 in Mason, Ohio (near Cincinnati). With a record-breaking turnout of over 200 people registered, this is an opportunity for the HPP community to come together and engage with leading healthcare experts. This is free to attend.

We've reached our travel grant cap, but the waitlist and the needs of patients continue to grow. Help us clear our waitlist, so all can attend. In response to the overwhelming interest, we've created a donation page to allow our meeting to grow. Your support would be greatly appreciated. All donations are tax-deductible. Help Us Grow [here](#).

We are grateful for our sponsors who are making this event possible. Our Headline Sponsor is Alexion, our Star Sponsor is PANTHERx Rare, and our Community Sponsors are Be Biopharma and PuREC. In addition to our sponsor, Help Hope Live will be an exhibitor at this event. Please review our



agenda and look for a confirmation email in the coming months.

Please contact [cindy@softbones.org](mailto:cindy@softbones.org) for questions and more information.

Review the agenda [here](#).

**DONATE**



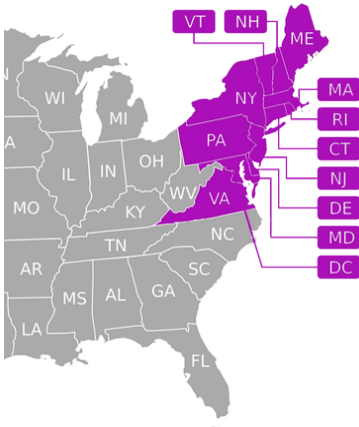
## 16th Annual Golf Classic

September 23, 2024 | 10 AM - 5:00 PM

Registration is now open for the 16th Annual Golf Classic. This is our largest and most important fundraiser. All proceeds from this event will fund our mission!

Join us for a full day of golf action, at Somerset Hills Country Club, a top-100 golf course. There will be opportunities to earn prizes for individuals and groups. Thank you to Atlantic Health System for continuing to be our tournament sponsor for this important event.

Register [now!](#)



View the agenda [here](#).

## OSAIC Grant Will Help Fund Northeast Patient Meeting

October 26, 2024 | 10 AM - 2:00 PM

Living with a rare disease can be overwhelming on many levels. There is a lot to learn about the disease and how to navigate it. Therefore, we are excited to share that we received a grant that supports volunteerism from the OSAIC Foundation. Thank you to Amy W. for being instrumental in identifying and assisting us with applying for the grant.

The grant will help support a half-day Soft Bones Northeast Region Meeting in NJ on October 26, 2024, from 10 AM to 2 PM. The meeting will be held at the Soft Bones headquarters and will be offered to families living in the tri-state area. There will be a presentation and Q&A session led by guest speaker Dr. Nickolas Tyrus. Dr. Tyrus is a rheumatologist based in Mount Laurel, NJ. Following lunch, attendees are invited to participate in the Cannonball 5K Run, Roll, or Stroll. The goal of the meeting is to educate attendees on HPP and connect patients to others living with HPP.

This meeting is also sponsor in part by Alexion, AstraZeneca Rare Disease. Registration goes live in June!

# Research News

## CoRDS International HPP Contact Registry

The CoRDS International HPP Contact Registry was designed to be an accessible database for every patient who registers to be informed about research opportunities while safeguarding patient privacy.

There are many different HPP registries and data is "owned" by different stakeholders. Soft Bones has partnered with the non-profit Coordination of Rare Diseases at Sanford (CoRDS) which allows YOU to be in charge of your data. CoRDS is the largest, free international rare disease registry for individuals diagnosed with hypophosphatasia (HPP) those who are carriers of HPP, those who are undiagnosed, or suspect they may have a rare metabolic disease. For enrollment and more information, contact CoRDS at

[cords@sanfordhealth.org](mailto:cords@sanfordhealth.org) or (877) 658-9192, or access resources and register directly through the provided link. Join now to support HPP research. You can also access the **CoRDS Participant Brochure**, **CoRDS Registration Tip Sheet**, and **CoRDS Q&A**.





# Program Updates



Congratulations to Sofiia H. for completing the Stick It To HPP program! You have taken the first steps towards gaining independence in your HPP journey.



The Stick It To HPP program was created by our own Teen Advisory Council (TAC). The goals of the program are to help children gain independence on their self-injection journey and create a safe space to do so. 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!**

## We Made Snowmen: Hippo Squad

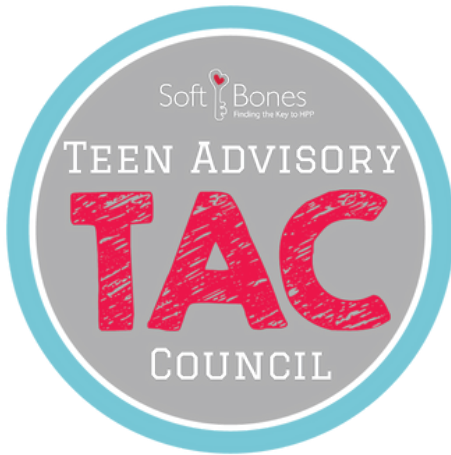
Attention, kids ages 3-12! Don't miss out on the opportunity to join the Soft Bones Hippo Squad. By joining this group, you will receive quarterly boxes filled with fun activities while learning about HPP. This program is open to kids with HPP, their siblings, and children of parent(s) with HPP. Currently, there are 121 families enrolled in the program, with 185 children receiving the Hippo Squad mailings. Currently, it is open only to US residents. Sign up [here](#).

The theme of our winter box was to vividly show the dynamic and active role our bones play in supporting our bodies. Members compared the cells in their bones to that of building a snowman and learned about the three types of bone cells: osteoblast, osteoclast, and osteocytes. Did you know that the prefix "osteo" means bone in Greek? Osteoblasts are cells that build up the bone, osteoclasts are cells that break down the bone, and osteocytes are cells that support the bones. We saw how the cells that build bones, osteoblasts, look a lot like a snowman. To make it fun, we challenge our members to build their snowmen to illustrate how our cells assemble and grow to meet the needs of our bodies.

Here are some of our creative snowmen in our winter wonderland! Thank you to our Teen Advisory Council for putting this project together!



## Teen Advisory Council (TAC)



Calling all teens 13–21 years old! Join the Soft Bones' Teen Advisory Council! TAC is a support and advocacy group made up of teens who either have HPP, are siblings or children of someone with HPP, or are friends of someone who has HPP. Members engage in several projects throughout the year, from creating and organizing fundraising events to designing Soft Bones swag and social media content.

The council aims to provide a platform for teenagers to speak up about HPP, become more involved in advocacy and fundraising, and manage content for the younger HPP community. TAC meetings take place twice a month (virtually).

Ready to lead and connect with others? Sign up [here](#).

## Patients of the Month



### Cass S.

Find out how a nurse practitioner's intuition finally led to a proper diagnosis after years of bone and nerve pain and accusations of non-compliance.

Read [here](#)!



### Aubrey B.

Discover how Aubrey, an energetic 11-year-old, has surpassed all odds while learning to advocate for herself and pursuing her dreams despite the challenges she faces.

Read [here](#)!



### Lindsey W.

Lindsey is one of our Central Region Leads. Read how Lindsey learns to be gentler with herself following an HPP diagnosis after years of unexplained medical problems, pain, and self-blame.

Read [here](#)!



### Emily H.

Emily is an active 11-year-old who isn't letting HPP stop her from doing what she loves, gymnastics! Learn how she manages her diagnosis and takes things into her own hands.

Read [here](#)!

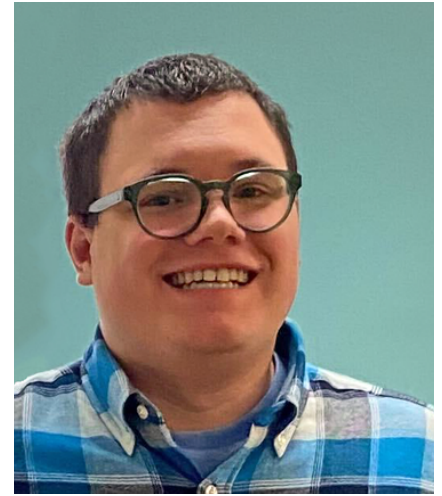
**Interested in being our next patient of the month? Contact [info@softbones.org](mailto:info@softbones.org).**

# Employee Spotlight

Hello! My name is Alex Lupo. I am Soft Bone’s Junior Graphic Designer and recently graduated from Stockton University. I love animals and spend a lot of time taking photos of local wildlife. As a result, it wasn’t until the latter half of high school that I realized Graphic Design was what I wanted to do in life. In hindsight, however, the signs were always there. I’d always been a kid who was more of a visual learner and doodled a lot. Even now I dabble in many art forms, including traditional

sketches, digital art and printmaking.

My job at Soft Bones began while I was still in college. At that point, I’d applied to dozens of design positions and hadn’t gotten anywhere. That all changed when my Dad suggested I reach out to Soft Bones. So I did, and before long I had an internship there. That was almost a year and a half ago. Now I’m properly part of the Soft Bones team and happy as a clam to be there. To have



a job in my field so soon after college is fantastic- but to play a role in helping Soft Bones do what they do? That’s something else entirely. It’s special to know that my work plays a role in helping to educate people about HPP.



# Meet Me Monday

Meet Me Monday is our newest initiative to highlight the many people who support and make Soft Bones' mission a reality. Whether they are a moderator, Region Lead, volunteer, or employee, they are integral part of the HPP Community. Get to know them on our social media platforms and in our community forums.



## Denise Goodbar

Denise is the Executive Director at Soft Bones. She oversees the strategic planning and the day-to-day operations. She is passionate about her work and is inspired by the patients and families she meets.

Did you know she was once featured on a national TV show? Learn more about Denise using the link [here](#).



## Nicole Belting

Nicole is one of our Region Leads for Midwest 1, which includes Iowa, Illinois, Indiana, Minnesota, and Wisconsin. Learn more about Nicole and find out why she likes meeting new people by using the link [here](#).



## Judith Harris

Judith is one of our Northeast Region leads. This region encompasses Connecticut, DC, Delaware, Maine, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, and Virginia. Learn more about Judith's career in clinical research and how she brings a new perspective to the Soft Bones community using the link [here](#).

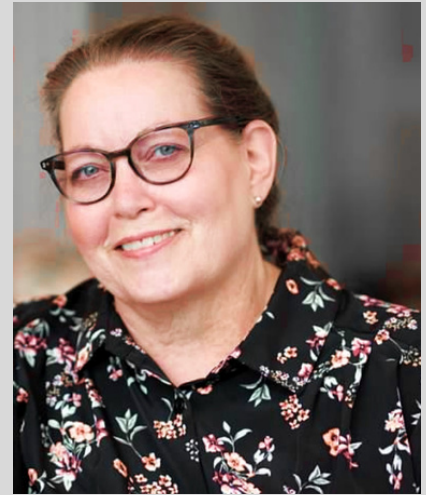
# Caregiver Corner

Soft Bones is excited to showcase the many caregivers who selflessly help others living with HPP. Read about Ellen who is a caregiver to her sister (Sue Krug) and her mom, while experiencing bone and joint degeneration herself.



**The most rewarding aspect of being a caregiver is seeing everyone lead as normal of a life as they can.**

— Ellen K



Read her story [here](#).



# HPP Community: Region Roundups

## Central Region Meeting | January 13, 2024

On January 13th, Region Leads, Nellie Sanders and Casey Anne Johnson hosted a Central Region meet-up in Piedmont, OK. They enjoyed bagels, coffee, and intimate conversations. Connections were made, and friendships formed. It was just what the doctor ordered.



## South Central Region Meeting | March 2, 2024

South Central Region Leads Cami Rush and Cassandra Self hosted a patient meeting at Texas A&M on March 2nd. Members were warmly greeted by Dr. Gaddy and Dr. Suva from Texas A&M to learn more about their research in HPP. Dr. Gaddy explained why they switched their HPP research from mice to sheep. Following that, Dr. J. Carl Pallais, from Brigham Women’s Hospital, took questions from the audience. At the farm, the group learned about the painstaking work and analysis being done on teeth, gait, and lungs. Overall, it was a great meeting and lots and lots of individuals were interested in the research they’re doing. Thank you to Cami and Cass for making this a successful opportunity for all. Interested in purchasing a “Baad to the Bone” T-shirt? Get yours **today!**

“ We are very lucky to have Dr. Gaddy and Dr. Suva as part of the HPP family working to find a cure. — Cami Rush ”



# Fundraising Corner

## Past Fundraisers



### Company Match Program

Thank you to the companies that supported Soft Bones through their matching gift programs and fundraisers throughout 2023. Special shout out to Sargento Cheese, Gallagher, Merrill Lynch, and Consortium Networks. Impactful donations like these support our mission. Does your company offer a matching program or an opportunity to fundraise? If so, let us know! We will be happy to do the leg work and submit a request on your behalf. Contact Margaret at [MargareteSoftBones.org](mailto:MargareteSoftBones.org) for more information.



### Facebook and Instagram Fundraisers - Thank You!

We are tremendously grateful for the many individuals who started their own Facebook and Instagram fundraisers for Soft Bones. Not only are you raising funds for Soft Bones, but you are also amplifying your voice and spreading awareness. Thank you for your support. If you are interested in starting a fundraiser, click [here](#) to learn more.



### Sarris Candy Fundraiser | January 31 - March 22

Thanks a Choco-lot for participating in our Sarris Candy Fundraiser and supporting our National Patient Meeting. We raised \$238.92. We hope you enjoyed your sweet treats and had fun sharing them with friends and family.



### Mary Kay Fundraiser | February 25 - March 11

We are happy to announce that the Mary Kay Fundraiser running from February 25 - March 11 was a success. With over 26 individuals joining the Facebook party and many more shopping at the online store, we raised \$75. A special thank you to Mary Kay representative, Sandra Felberg, for hosting this fundraiser and donating a portion of her proceeds to Soft Bones!

## Current Fundraisers



### Mama Alana’s Pantry | March 30 - April 30

Soft Bones is excited to partner with Mama Alana’s Pantry on this fundraiser. They specialize in providing gluten-free and vegan staples. From homemade biscuits and cake mixes to muffins and pie crusts, there is something for everyone. For the month of April, 15% of the profits will be donated to Soft Bones. Use code **SoftBones** at [MamaAlanasPantry.com](http://MamaAlanasPantry.com) and 15% of the profits will be donated to Soft Bones.



### Help Us Grow

The 2024 National Patient Meeting is set to be the largest one yet. This may be the only chance for many families to meet others living with HPP in person.

We’ve reached our travel grant cap, but the waitlist and the needs of patients continue to grow. Help us clear our waitlist so all can attend. All donations are tax-deductible.

[Donate Today](#)



### Denim and Diamonds Amazon Wish List

Soft Bones will host its 2nd Denim and Diamonds fundraiser on May 18th, 2024 and we need your help! Help us create themed gift baskets for our auction by purchasing an item or two off our Amazon Wish List. All proceeds from the auction will go directly to Soft Bones. Shop [here](#).

Already have an item ready to donate for our auction? Contact Lucy at [Lucy@SoftBones.org](mailto:Lucy@SoftBones.org) to make arrangements.



### Stop and Shop Community Bag Program

Soft Bones has been selected as a May 2024 Community Bag Program Nonprofit Partner. Our organization will receive a \$1 donation for every \$2.50 reusable bag sold at **245 Littleton Road, Morris Plains NJ**. Get your shopping bags starting May 1st!

**Visit our Shop for a Cause page [here](#), to get the full list of fundraisers happening now!**