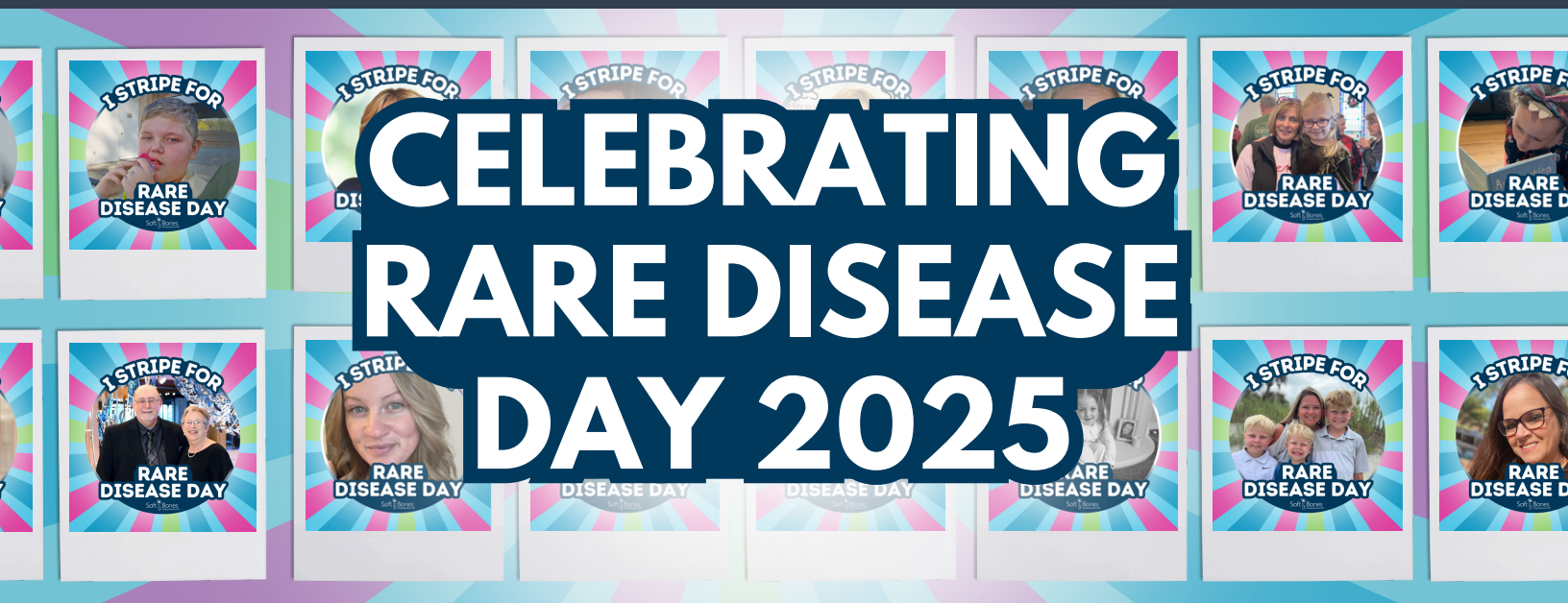


# THE BARE BONES

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



This year, Rare Disease Day fell on February 28th and the HPP community came together to shine a light on the **300+ million people** worldwide living with rare diseases. When you realize **1:10 people** have a rare disease, as a whole, rare diseases present a huge public health concern.

Rare Disease Day is about raising awareness about rare diseases and the shared challenges in the rare population, including research, access to care, and treatments, among other things. By sharing our stories and partnering with other rare organizations, we do our best to ensure that the needs of our patient community are met. On this day, we celebrated the power of the patient community in driving change—as we continue to push for earlier diagnoses, stronger support systems, and more innovation for all rare diseases.

To celebrate, we created a [Rare Disease Page](#) offering patients a variety of ways they could “show their stripes” and get involved. We hosted a Rare Disease Day chat to gather and talk about HPP and other shared rare disease experiences.

In the spirit of Rare Disease Day, we offered hats and hippos to all those who reached out. Stay tuned for a fun activity, using the hats and hippos, that we have planned for World HPP Day.

Together, we are [#RareButStrong](#)

## IN THIS ISSUE:

- A Successful Rare Disease Day Celebration
- New Region Leads Onboarded!
- New Podcast Alert: Cannon Unbroken
- Fundraising Opportunities

# Soft Bones Members in Action

## New Region Leads Onboarded!

Region Leads are an integral part of Soft Bones. They are attentive to patient needs and provide multiple contact points throughout the year to connect with HPP members. **A big thank you to the Region Leads who gave their time and have stepped down for the next term: Lindsay W., Casey Ann J., Sharon T., and Nicole B.**

This year, **we welcomed 11 new Region Leads.** We are very grateful for our 14 returning Region Leads who will continue to lead grassroots awareness, local fundraisers, and policy efforts.

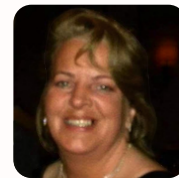
Meet the rest of the **2025 Region Leads** and learn more about our program!



Adam W.



Sadie R.



Cindy P.



Amedie P.



Gerald G.



Jan R.



Amy W.



Tess O.



Laura T.



Scarlett P.



Jennifer W.

## Introducing the PAN Foundation

**The Patient Access Network (PAN) Foundation is working towards a future where equitable, accessible healthcare is a reality for all.**

This charitable foundation provides financial, advocacy, and educational support to accelerate access to treatment and empower patients. **Here are some ways they can support you and your family:**

- **Hypophosphatasia Fund** – individuals can receive up to \$5,200 for out-of-pocket treatment costs.
- **Find financial assistance** through their FundFinder app.
- **Apply for transportation grants** to cover the cost of transportation.

Patients living with hypophosphatasia must meet eligibility requirements and apply. Learn more about their programs at [panfoundation.org](https://panfoundation.org).



## RESEARCH NEWS

### Enhancing Recognition and Treatment of Hypophosphatasia (HPP)

Soft Bones, in collaboration with Medlive and NORD, presents an expert-led program featuring Dr. Michael Lewiecki, Dr. Ruban Dhaliwal, and Dr. Allan Gibofsky. Learn about the diagnosis, management, and emerging therapies for hypophosphatasia (HPP) across all ages. Gain insights into key diagnostic clues, red flags, and a multidisciplinary approach to care.

Watch On-Demand on Medlive: [HERE](#)



**NORD**<sup>®</sup>

**medlive**  
Education that empowers



### Tune in to the Poppy Cam

Have you seen the newest Pygmy hippo? Her name is Poppy and she was born in Richmond, VA, not far from the location of our National Patient Meeting in Williamsburg. If you're traveling to the meeting, the Metro Richmond Zoo is a great place to visit.



**Check out the  
Poppy Cam!**

## EMPLOYEE SPOTLIGHT

Hello! My name is Jessica Adams and I started with Soft Bones as a Patient Engagement and Fundraising Coordinator in January. My experiences as an educator, mother, and caregiver/advocate for a family member with a rare disease prompted me to seek an opportunity to work within the nonprofit community. I could not be more excited to have landed with Soft Bones and look forward to supporting the HPP community.

Lately, my fifteen-year-old daughter occupies much of my free time with cheerleading and lacrosse. When I am not working as her personal assistant and driver, I love reading and working on projects in our circa 1860 farmhouse. My husband and I recently completed the restoration of a vintage barn on our property, turning it into a place where we enjoy entertaining our friends and watching college football. If the stars align with my schedule, you will find me back in Texas, which will always be home sweet home.



# HPP HAPPENINGS

## CANNON UNBROKEN

TRIUMPH OVER ADVERSITY

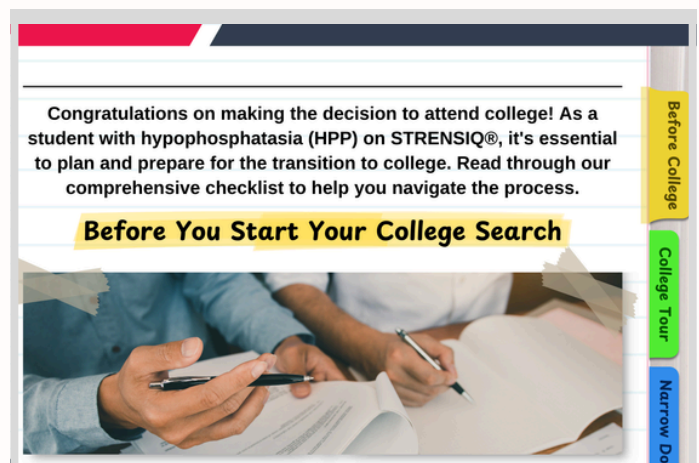


### Cannon Unbroken Podcast is now Geared for Launch

Soft Bones is proud to announce the upcoming launch of **Cannon Unbroken: Triumph Over Adversity**. Cannon Sittig, diagnosed with hypophosphatasia (HPP) at just 18 months old, has spent his life advocating for individuals with rare bone diseases. In each episode, Cannon will share powerful stories of resilience, diving deep with patients, caregivers, and experts to explore what it takes to overcome life's toughest challenges. You won't want to miss this!

## Transitioning to College with Hypophosphatasia

A Guide for Teens on Strensiq®



### A New Resource for Students: The College Transition Guide

Soft Bones has developed a comprehensive guide to help high school seniors on Strensiq navigate the transition to college. Students who have already been through this experience share tips on choosing the right college, coordinating the best support, and managing your HPP in a new environment.

Check it out: ["Transitioning to College with Hypophosphatasia: A Guide for Teens on Strensiq"](#)

# PROGRAM UPDATES



## Hippo Squad

Hippo Squad members made a splash in the kitchen. They baked delicious cupcakes while learning the importance of following directions. Like following a recipe while baking, following your doctor's instructions is crucial for effectively managing HPP. The great news is that you can be part of the conversation and take charge of your health too! We hope you had a great time baking and decorating your cupcakes. Stay tuned for our next box!

**Hippo Squad is open to kids with HPP, their siblings, and children of parent(s) with HPP ages 3-12 years old.** It is only open to US residents. Learn more and see if you are eligible to join [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. Currently, we have 20 participants ranging from 8-17 years old.

Mailings are available to U.S. residents only.  
**[Request a kit today!](#)**



## TAC: First Speaker of 2025! February 3, 2025

The Teen Advisory Council kicked off the 2025 year with a new speaker series. The first speaker was communications guru, advocate, and public speaker, Jen Zoller of Green Room Communications who led an engaging discussion on how to confidently respond to questions like, "What is HPP?" Or "What is the Teen Advisory Council?". Teens were encouraged to craft clear and confident answers tailored to different audiences. This session helped members to build their public speaking skills and to communicate with purpose.



Soft Bones  
TEEN ADVISORY  
**TAC**  
COUNCIL

**HELP US  
CREATE A  
NEW T-SHIRT!**

**February 24th  
8 PM EST**

## Designing a New T-Shirt February 24, 2025

Piggybacking from our first session, the next meeting focused on creating a word cloud to be put on our next T-shirt design for our Soft Bones store. Reflecting on the messages we developed from the last meeting, members identified words that represented what it is like to live with HPP.

Three designs were created to select the final one for launch in the Soft Bones store. The design decision will be finalized at our upcoming TAC Meeting on March 18th.

# PATIENTS OF THE MONTH

for January, February, and March



## January: Cassi K.

Imagine living with unexplained medical challenges for years, only to find the answers hiding in plain sight. Discover how Cassi navigates the challenges of #hypophosphatasia while embracing new passions.

[Read her story.](#)



## February: Evie M.

When Evie was four months old she underwent open-heart surgery for a congenital heart defect. Years later, her unexplained injuries, loose teeth, and chronic struggles led to a life-changing diagnosis of HPP. With treatment, Evie is growing stronger and chasing her dream of dancing.

[Read her story.](#)



## March: Rebecca

Rebecca had a relatively normal childhood. However, as she got older a slew of medical issues began to be more prominent. Learn how she gives herself grace as she navigates HPP knowing that it affects people differently and how this validates her struggles.

[Read her story.](#)


## Caregiver Corner: Kara S.

Kara S. may be a familiar face to many because she's a Central Region Lead. She is a caregiver to her son, Quinn, who was diagnosed with HPP at the age of 3. While his future may look uncertain, she is grateful he is becoming more independent and advocating for himself.


[Read her story.](#)



# UPCOMING EVENT



**Southeast Region Zoom Meeting/Chat**  
Saturday April 26, 2025 at 3 PM Eastern



Open to patients and caregivers who reside in the above highlighted area.

Join Region Leads Blynda K., Scott G., and Tess O., for a Southeast Region Zoom Meeting on Saturday, April 26th at 3 PM Eastern. Meet your newest Region Lead, Tess O., and connect with others in your region. Don't miss out!


Please register or email [cindy@softbones.org](mailto:cindy@softbones.org)

## Southeast Region Zoom/Chat Meeting


April 26, 2025 | 3:00 PM-4:00 PM Eastern

Do you live in Alabama, Florida, Georgia, Mississippi, North Carolina, South Carolina, or Tennessee? Join Region Leads Blynda K., Scott G., and Tess O., for a Southeast Region Zoom Meeting on Saturday, April 26th at 3 PM Eastern. Meet your newest Region Lead, Tess O., and connect with others in your region. Don't miss out!

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



**Midwest 1 Region Meeting**  
Sunday, April 27, 2025, from 10 AM-1 PM Central  
Join Us in Coralville, IA!



Join Midwest 1 Region Lead, Jan R. for a luncheon on Sunday, April 27, 2025, from 10 AM-1 PM Central in Coralville, IA. All Midwest 1 Region members and families are welcome. Connect and chat with others from your region. Lunch will be served.


Please register or email [Cindy@SoftBones.org](mailto:Cindy@SoftBones.org)

## Midwest 1 Region In-Person Meeting


April 27, 2025 | 10:00 AM-1:00 PM Eastern

Do you live in Illinois, Indiana, Iowa, Minnesota, or Wisconsin? Join Midwest 1 Region Lead, Jan R. for a luncheon on Sunday, April 27, 2025, from 10 AM - 1 PM Central in Coralville, IA. All Midwest 1 Region members and families are welcome. Connect and chat with others from your region. Lunch will be served.

Registration is required and will close on April 12th. Register [HERE](#).



**Southeast Region Meeting**  
Saturday, May 10th at 10:30 AM-1:30 PM Central  
Join Us in Nashville, TN!



Southeast Region Leads, Blynda K., Scott G., and Tess O., have planned a lunch get-together on May 10, 2025, 10:30 AM-1:30 PM Central. All Southeast Region members and families are welcome to learn more about your local HPP support system and connect with fellow HPP families! Lunch will be provided.

Please register or email [Cindy@SoftBones.org](mailto:Cindy@SoftBones.org)

## Southeast Region In-Person Meeting

May 10, 2025 | 10:30 AM-1:30 PM Central

Southeast Region Leads, Blynda K., Scott G., and Tess O., have planned a lunch get-together. All Southeast Region members and families are welcome to learn more about your local HPP support system and connect with fellow HPP families!

Registration is required and will close on April 26th, 2025. Please register [HERE](#).



## 3rd Annual Denim and Diamonds Fundraising Event

Saturday, May 17, 2025 | 5:30 PM - 9:30 PM

Registration is now open for the 3rd Annual Denim and Diamonds fundraiser at Alstede Farms. Get ready to Two-Step for a great cause. Do you know anyone local to the North New Jersey area? We encourage you to invite them to this event to raise vital funds for Soft Bones. Help us spread the word!

Details and registration link, [HERE](#).



# UPCOMING EVENTS (Cont.)



## National Patient Meeting

Friday & Saturday, July 18th - 19th, 2025

Just one week after opening registration, we were at capacity for the 2025 Soft Bones National Patient Meeting on July 18th - 19th in Williamsburg, VA. This is a great opportunity for HPP families to connect and learn from leading HPP experts. Did you miss the registration window, but are interested in attending?

Please contact [PatientMeeting@SoftBones.org](mailto:PatientMeeting@SoftBones.org) to join our waiting list.



## Golf & Pickleball Outing

Join us for our 17th Annual Golf Classics and 2nd Annual Pickleball Tournament on Monday, September 29, 2025, at Somerset Hills Country Club in Bernardsville, NJ.

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



# FUNDRAISING CORNER




## Sarris Candies Fundraiser

Want to satisfy your sweet tooth and help Soft Bones earn 25% of all proceeds?

Now through April 13th, order your chocolates and goodies to be included in your baskets just in time for Easter. Hop, hop to it!

Order [HERE!](#)

## Spring Fundraiser Flowers, Keychains and Candles

*Meadow Farms Fundraising*  
"helping our youth in fundraising"

Flowers, keychains, candles - oh my!

Spring into warmer weather with one-of-a-kind New England-based items. Meadow Farms feature popular brands and locally sourced products such as **Kringle Candle**, **Stonewall Kitchen**, **Gertrude Hawk Chocolate**, **LEGO**, **Boston Coffee Cakes**, & much more. Plus, a percentage of all proceeds will support **Soft Bones**.

Learn more and order [HERE!](#)

