BONES
of Strength

Our 2024 Achievements

Fifteen years ago, Soft Bones was born from a simple but powerful idea—no one should have to face hypophosphatasia (HPP) alone. What began as a personal mission has grown into something so much greater: a global community of families, advocates, researchers, and supporters united by strength, connection, and an unwavering drive to push forward.

In 2024, we celebrated that milestone not by looking back, but by leaning into patients as the experts. Leaning into innovation, patient-centered programs, and the collective power of coming together.

From funding cutting-edge research and launching peer-led programs to expanding our reach online and in person, this year was proof that together, we can make incredible things happen.

You'll see those efforts reflected throughout this report—in the stories of people like Emily and Ray, in our growing teen and Hippo Squad programs, and in the milestones we've reached together. But our work is far from over.

Thank you for being part of our mission. Here's to what we'll accomplish next.

Deborah Fowler

Deborah Fowler, President and Founder
Soft Bones

ABOUT SOFT BONES

Soft Bones is a 501(c)(3) non-profit, US-based patient advocacy group dedicated to the community of patients, caregivers, and families living with HPP.

Soft Bones empowers the HPP community by raising awareness of this rare metabolic disease, providing hope by advocating for and funding research, and connecting patients and the medical community to advance the understanding of HPP. We provide medical information and a support system for patients and families with HPP.

A cure is possible. With the modern-day science of gene editing and gene therapy, we work closely with researchers and clinicians to champion collaboration, reduce duplication of efforts, share findings, and unite the global HPP community. We also work to position HPP as a favorable subject of research.

HPP is a serious condition. Scientists are still working to understand better the impact of low alkaline phosphatase levels on the body. While the hallmark of HPP is soft bones, as a metabolic disease, the full impact is not yet fully understood.

OUR VISION

Our vision at Soft Bones, Inc. is a world free of HPP, made possible through groundbreaking research, innovative treatments, education, awareness, and support for all, ensuring every person affected can look forward to a brighter, healthier tomorrow.

OUR MISSION

In 2024, we refined our mission statement to reflect the significant work happening at Soft Bones in supporting our HPP community and addressing their needs.

Driven by patient and caregiver insights, Soft Bones Inc. inspires and galvanizes collective action to foster greater awareness, improve diagnosis, accelerate innovative research and treatments, and ultimately, improve care for those affected by HPP.

OUR CORE VALUES

Because patients can't wait and we are passionate about making a difference:

- We are accountable
- We work with rigor
- We lead with a servant's heart
- We embrace a can-do spirit
- We show grit
- We are nimble

By the Numbers: Our 2024 Impact

In 2024, Soft Bones continued doing what we do best: supporting patients, sharing trusted information, and building connections across the HPP community. Whether through one-on-one conversations, sending out information packets, or expanding our online presence, every interaction matters. Here's a look at how our efforts impacted the HPP community over the past year.

9.6% more new patients in 2024 than 2023

With whom we've had **thousands of conversations**

275 info packets sent to newly diagnosed or suspecting HPP individuals

477 HPP mutations

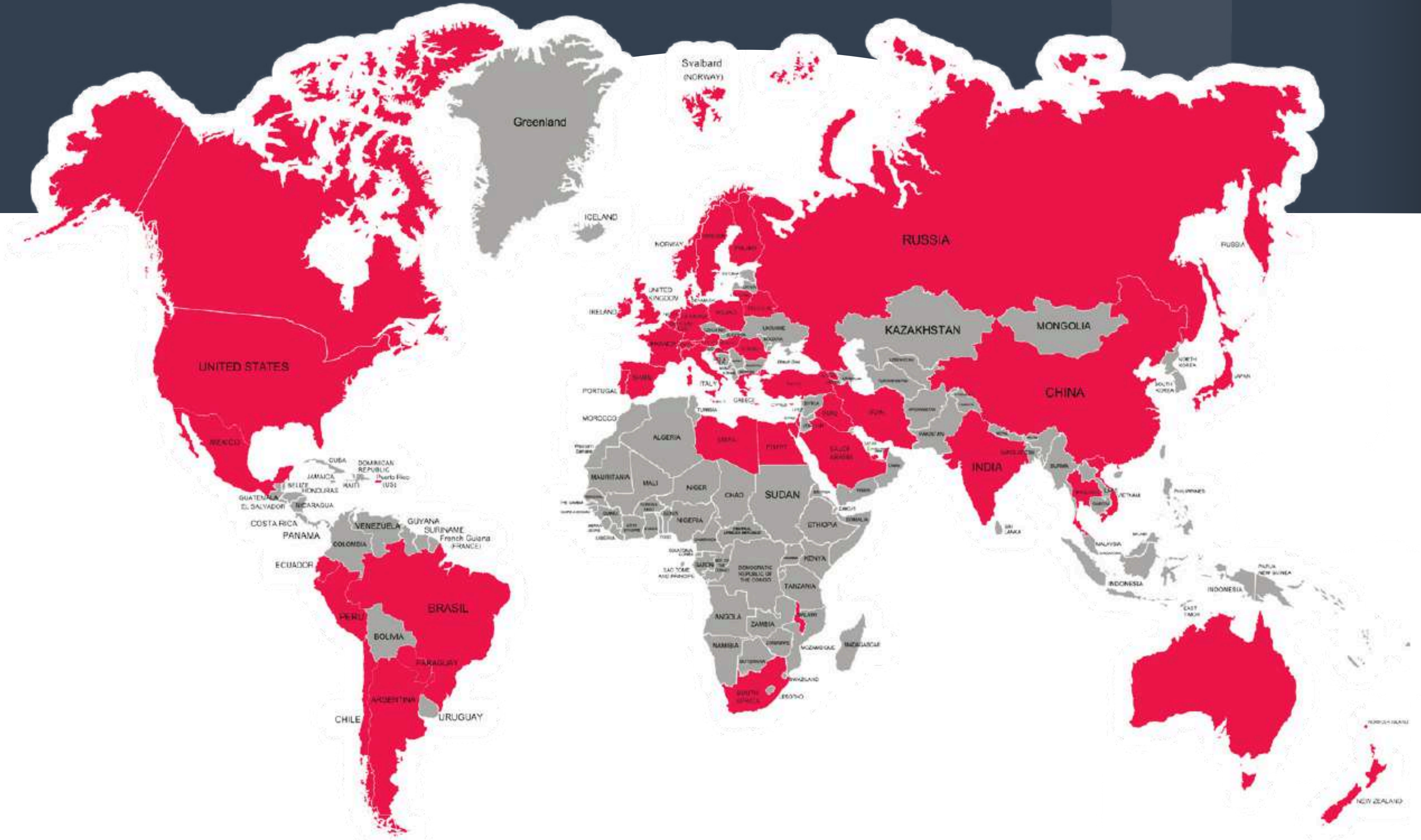
17 Travel Grants awarded

1 Research Grant Issued

71 families attended the **National Patient Meeting**

As of 2024, we have community members in 53 different countries, plus Puerto Rico.

Argentina, Australia, Austria, Belarus, Belgium, Brazil, Canada, Chile, China, Croatia, Denmark, Ecuador, Egypt, Finland, France, Georgia, Germany, Greece, Hungary, India, Iraq, Ireland, Israel, Italy, Japan, Lebanon, Libya, Lithuania, Luxembourg, Malta, Mexico, Netherlands, New Zealand, Norfolk Island, Norway, Paraguay, Peru, Poland, Portugal, Puerto Rico, Qatar, Romania, Russian Federation, Saudi Arabia, South Africa, Spain, Sweden, Switzerland, Thailand, Turkey, United Arab Emirates, United Kingdom, Vietnam.



Celebrating 15 Years of Soft Bones!

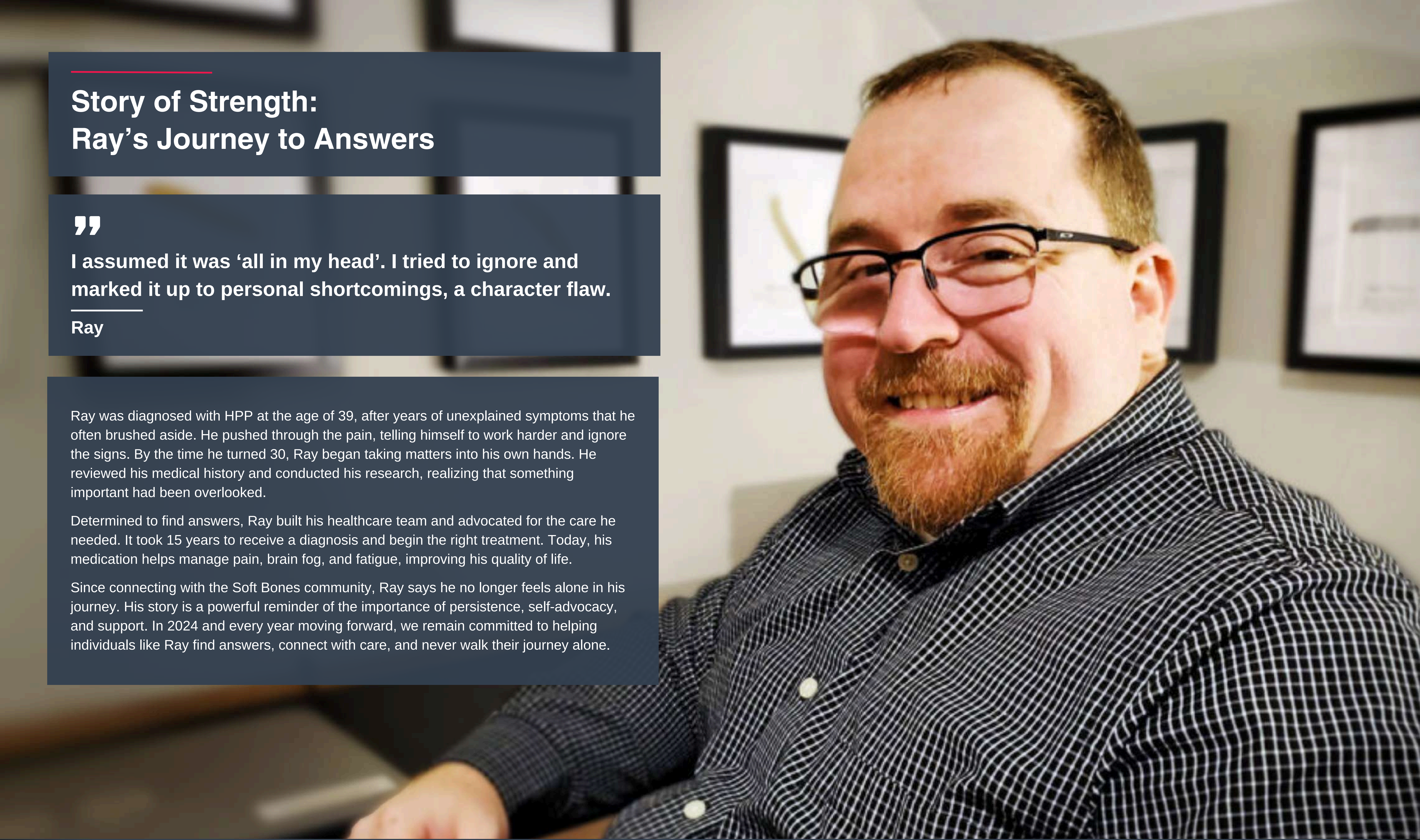
In 2024, we proudly celebrated Soft Bones' 15th anniversary. It was a powerful reminder of how far we've come together as a community. To honor the occasion, we launched the **$15 for 15 campaign**, encouraging supporters to give $15 or any multiple of it to help us reach our $3,000 goal.

Thanks to your generosity, we didn't just meet that goal — we surpassed it.

Every $15 made a real impact. Your contributions helped us:

- Provide Welcome Packets to newly diagnosed patients
- Send Hippo Squad boxes that teach kids about HPP
- Support children beginning their self-injection journey with Stick It To HPP starter kits
- Brighten someone's day with a Take Care Package
- Offset costs for regional meetings that connect our community

After 15 years, we're still growing, still learning, and still standing strong together.



Story of Strength: Ray's Journey to Answers

> I assumed it was 'all in my head'. I tried to ignore and marked it up to personal shortcomings, a character flaw.
>
> **Ray**

Ray was diagnosed with HPP at the age of 39, after years of unexplained symptoms that he often brushed aside. He pushed through the pain, telling himself to work harder and ignore the signs. By the time he turned 30, Ray began taking matters into his own hands. He reviewed his medical history and conducted his research, realizing that something important had been overlooked.

Determined to find answers, Ray built his healthcare team and advocated for the care he needed. It took 15 years to receive a diagnosis and begin the right treatment. Today, his medication helps manage pain, brain fog, and fatigue, improving his quality of life.

Since connecting with the Soft Bones community, Ray says he no longer feels alone in his journey. His story is a powerful reminder of the importance of persistence, self-advocacy, and support. In 2024 and every year moving forward, we remain committed to helping individuals like Ray find answers, connect with care, and never walk their journey alone.

Programs & Services

Teen Advisory Council

The Teen Advisory Council (TAC), a program sponsored in part by Alexion, AstraZeneca Rare Disease, is a group of teens who are living with HPP, , a family member affected by it, or are close friends of someone living with it. Through monthly virtual meetings, the TAC members work together to raise awareness, support fundraising efforts, and serve as mentors to younger members of the HPP community.

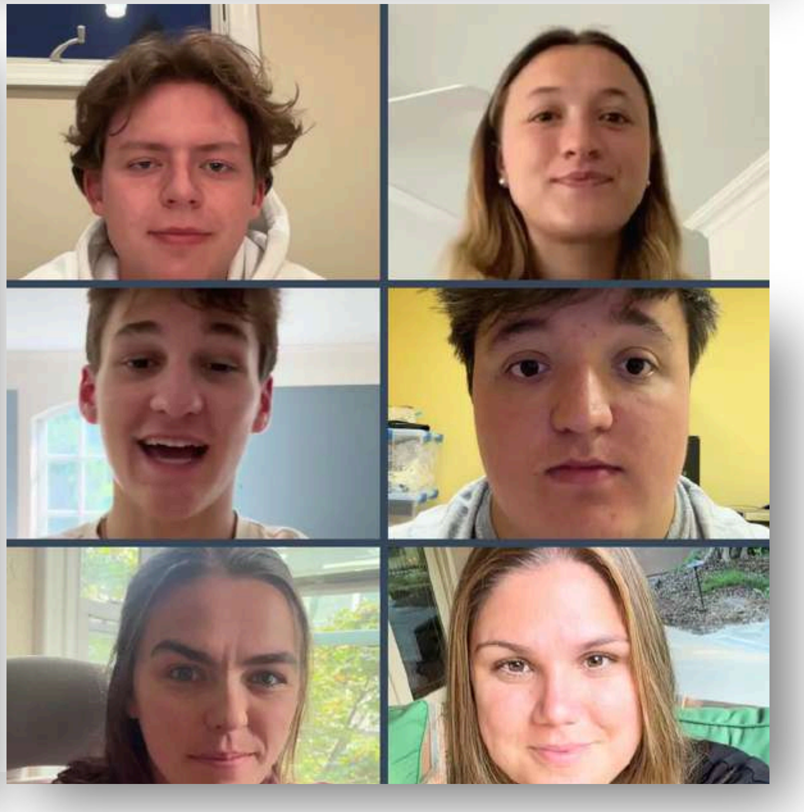
In 2024, the group included 14 members who stayed actively involved throughout the year.

Highlights included:

- Creating a recruitment video to encourage new members to join
- Learning about advocacy from Matt Hay of Alexion, AstraZeneca Rare Disease during a special guest session
- Hosting a fun virtual activity where members built snowmen from edible ingredients, which were also sent to our Hippo Squad kids

TAC members also contribute ideas and activities for our Hippo Squad boxes, helping younger patients feel seen, supported, and encouraged.

Interested in joining the TAC? Learn more and watch the full recruitment video HERE.



Soft Bones HIPPO SQUAD

The Hippo Squad, a program sponsored in part by Alexion AstraZeneca Rare Disease, is one of our most loved programs for kids in the HPP community. It's open to children living with HPP, their siblings, and the children of parents with HPP. Each quarter, kids receive fun, hands-on activity boxes at home, created with help from our Teen Advisory Council.

Here's a look at the 2024 Boxes!

Spring: Dirt Cups & Growing Strong

This spring, we had fun getting our hands (and spoons!) dirty by making dirt cups. Our bodies are like soil, full of nutrients that help us grow strong and healthy. When we give our body what it needs, it helps us thrive just like healthy soil helps grow flowers!

Summer: Butterfly Creations

Summer took flight with our colorful paper butterflies. While butterflies may look delicate, they are incredibly tough. They are capable of flying thousands of miles and navigating with precision. Our bones may be delicate, but much like a butterfly, we are strong and resilient. We have the power to soar and accomplish anything we want!

2024 was a big year for Hippo Squad! Over the course of the year...

We welcomed **30 new families** to Hippo Squad, with **48 additional children** receiving activities.

We are now up to **208 children** from **136 families** receiving Hippo Squad boxes each quarter.

Fall: How Following a Recipe Can Lead to Better Health

This fall, we mixed, baked, and decorated cupcakes all while learning how important it is to follow the recipe. Just like baking, following our doctor's orders keeps us healthy and empowered to make smart choices for the best outcome.

Winter: Snowman Snacks and Strong Bones

We had some winter fun building snowmen in the comfort of our homes. These tasty creations helped show how bone-building cells, called osteoblasts, play a dynamic role in keeping our bodies strong. Just like building a snowman piece by piece, our bones grow and stay healthy with the right support.

STICK IT TO HPP!

Stick It To HPP: Encouraging Confidence and Independence

The Stick It To HPP program was created by our Teen Advisory Council (TAC) to support children as they learn to manage self-injections. The goal is to help young patients build independence while creating a safe and supportive environment.

Participants receive a starter kit filled with helpful tips, encouragement, and fun activities designed to make the process less intimidating. As they progress through different stages of the program, they can track their achievements and celebrate each milestone with their personalized tracker.

The program is available to U.S. residents and continues to grow. In 2024, 14 children actively participated, including one who completed the full achievement tracker. For kids like Emily, Stick It to HPP offers more than guidance. It provides empowerment, encouragement, and a sense of accomplishment.

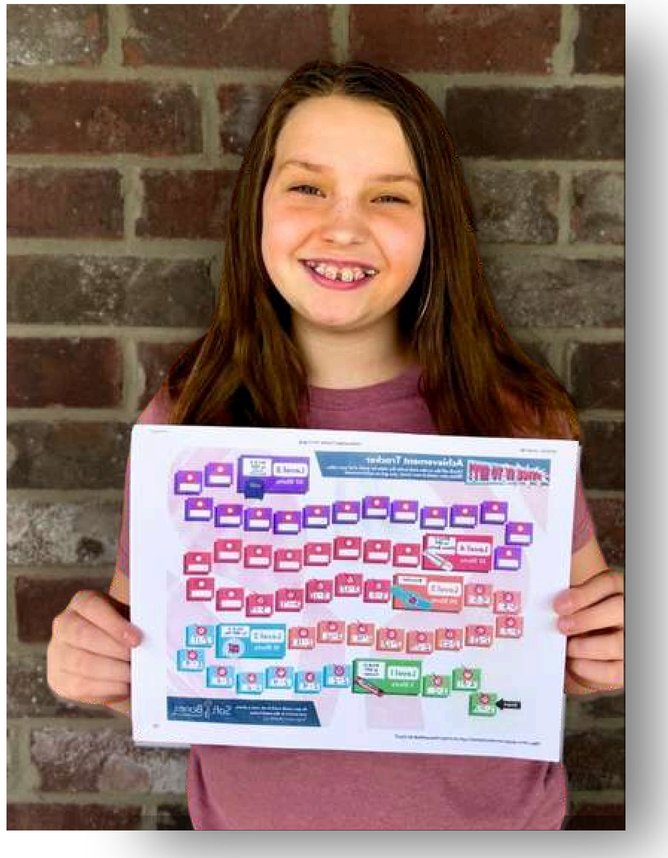
This program is sponsored in part by Alexion, AstraZeneca Rare Disease.

The Stick it To HPP Achievement Tracker allows kids to keep track of their achievements and celebrate each milestone.

If your child is interested in the Stick it To HPP program, click HERE to enroll.

Facing HPP with Strength, One Injection at a Time

Emily is an active 11-year-old. From an early age, she had frequent fractures that left her family and doctors puzzled. It wasn't until a second opinion and a genetic test confirmed a mutation for HPP that they finally had answers. She began Strensiq treatment in January. Despite the common injection site reactions and the mental toughness required for six shots a week, Emily does everything she can to push through. Determined to take control of her care, she joined our Stick it To HPP program, which helps kids gain confidence and independence on their self-injection journey. Emily and her mom hope for future treatments that are less intense and less frequent. Until then, she continues to thrive in gymnastics and meets each challenge with strength and a positive spirit. Read her story: **HERE**



HPP Connect: A New Home for Clinical Collaboration

In 2024, we transitioned HPP Connect to a new, more user-friendly platform to make it easier for clinicians and researchers to collaborate. HPP Connect is a secure online community designed for ongoing peer-to-peer exchange, dialogue, and education focused on HPP. It serves as the home for webinars, scientific meeting resources, and clinical tools that support the care and treatment of HPP. Access is reserved for clinicians and researchers, and those interested can contact Denise at **HPPConnect@SoftBones.org** to join.

The four **most searched** topics were

Strensiq®

Vitamin B6

Pregnancy, and

Pain

Zoom Chats drew familiar and new faces each month

As more people stepped away from social media, many turned to HPP AND ME. We **doubled our membership** by the end of the year.

HPP AND ME: Where We Come Together

By the end of 2024, HPP AND ME had grown by 23%. Moderated by Cindy R., this peer-led platform remains a go-to space for staying informed, sharing experiences, and connecting with others who understand life with HPP.

With 13 forums and 67 sub-forums, members dive into topics ranging from treatment options to parenting and pain management. In 2024, Cindy hosted 12 HPP AND ME Zoom chats and two Zoom Tutorial Sessions, giving members another way to get involved and feel supported without being on social media.

Whether asking questions, swapping stories, or just checking in, HPP AND ME is growing into a trusted place for connection and community.

Want to join in on the conversation? Click the link below.

HTTPS://SOFTBONES.ORG/HPP-AND-ME/

Spreading Awareness Through Education and Storytelling

In 2024, Soft Bones continued to expand awareness of HPP through education, storytelling, and community engagement. These efforts not only informed new audiences but also strengthened the voice of the HPP community.

In 2024, Soft Bones leaders and community members continued to share the HPP story in impactful ways. Deborah Fowler and her son, Cannon, were invited to Rampart Bioscience's company meeting in San Diego to present on Soft Bones and educate employees about HPP. At the close of the event, Deborah was honored with the inaugural Phillipe Crine Patient Impact Award for her "courageous and unwavering contributions toward improving patient lives". Dr. Phillipe Crine, who passed away in 2023, discovered the first enzyme replacement therapy for HPP, Strensiq® (asfotase alfa).

In addition, Deborah Fowler and Cindy Reasor were featured in a new episode of Behind the Mystery of Hypophosphatasia, part of Lifetime's Behind the Mystery™ series, which raises awareness about rare and genetic diseases through patient storytelling. The episode premiered on October 21st and aired again on October 29th, offering viewers a first-hand look into living with HPP and the mission of Soft Bones.

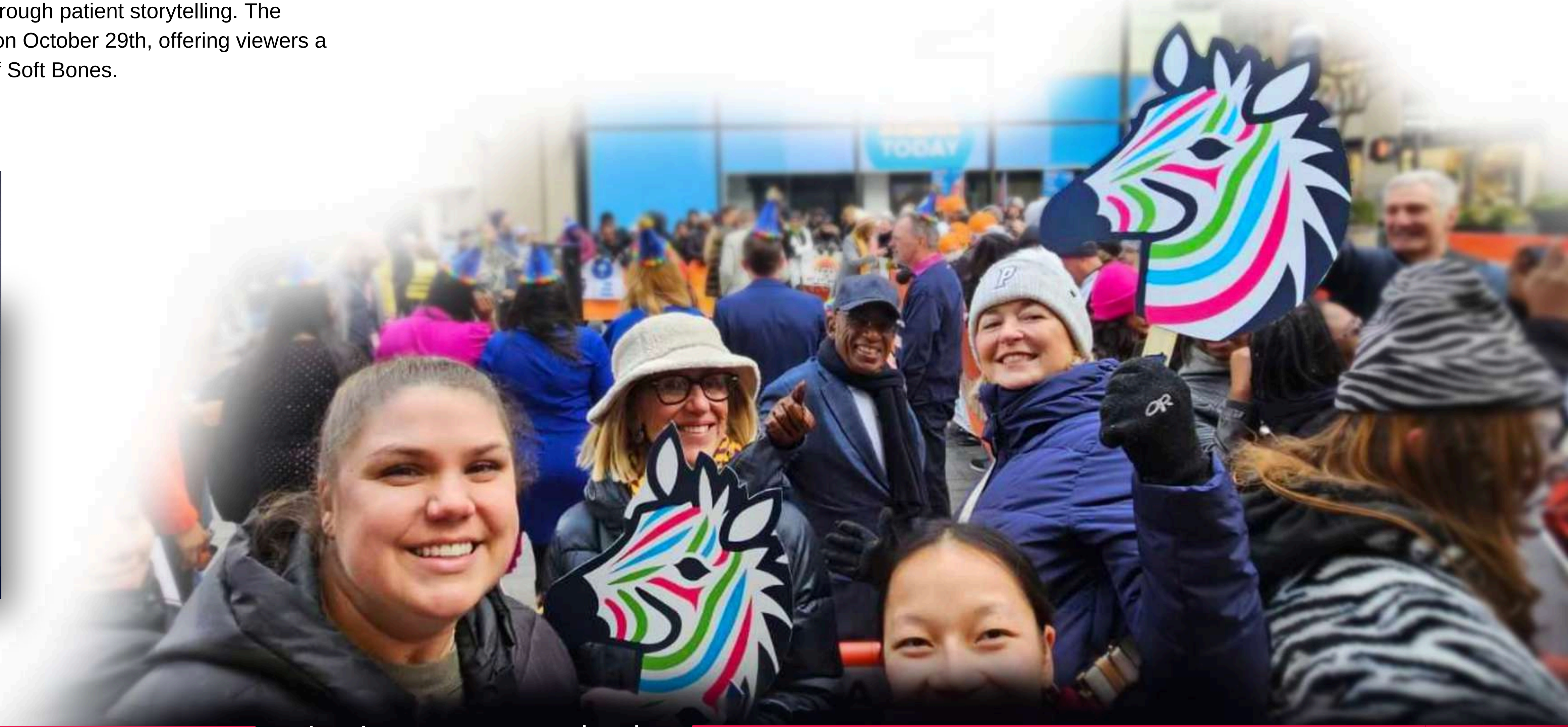
To view the episode, **click HERE**

Raising Our Voices on Rare Disease Day

Rare Disease Day was recognized globally on February 29th, a day dedicated to raising awareness of rare diseases as a public health concern. It highlights the ongoing need for equity, better access to care, and continued progress in research and treatment for the rare disease community.

Soft Bones proudly joined in the effort, with members of our community participating in different ways. Some shared their stories on social media, others updated their profile frames, and a few hosted small gatherings to help spread awareness.

To mark this special Leap Year occasion, the Soft Bones team traveled to New York City to join NORD and other advocacy groups on the Today Show plaza. Holding cardboard zebra heads—a recognized symbol of rare disease awareness—we connected with others in the rare disease space and represented the HPP community on a national stage. We even caught a glimpse of Savannah, Hoda, and Craig, and snapped a quick selfie with Al Roker. Want to see us in the crowd? **Watch the reel here.**



World HPP Day 2024 - Together We Can

In October, the global HPP community came together to raise awareness, share stories, and show what's possible when we stand united. This year's theme, *Together We Can*, was more than a message. It was a call to action that asked us to consider what we can achieve when we move forward as one community with shared strength and purpose.

We were inspired by the incredible participation from advocates around the world. With representation from 11 countries, individuals and families shared powerful images and reflections, creating a visual statement of unity and resilience. Social media filled with posts capturing what *Together We Can* meant to each person, from moments of connection to messages of hope and determination.

World HPP Day reminded us that raising awareness is not limited to a single day. It is a continuous effort to support one another, seek answers, and ensure that no one walks this path alone.

Learn more about World HPP Day and how to get involved **HERE**

Sharing Our Story, Earning Recognition: Award-Winning Awareness

Soft Bones won the Ragan PR Daily 2024 Nonprofit Communications Awards for “PR on a Shoestring Budget

Our 2023 World HPP Day campaign was celebrated for its creativity, strong impact, and ability to make a difference with limited resources. This honor reflects the dedication of our community and the power of working together to raise awareness for HPP.

Connecting Through Every Click

In 2024, the Soft Bones community showed up across all platforms. Whether it was a comment, a shared post, or a story that reached someone new, our message spread further than ever.

Over 150k users reached

1k shares

6k post likes

Facebook video views jumped by over 400%

Hundreds of comments and conversations

Thousands of impressions across all platforms

Soft Bones’ Social Media Impact

- 44.6% increase in post reactions & likes
- 392 posts

- 121% increase in post comments & replies
- 80.90% increase in post reactions & likes
- 309 posts

- 11.6% Increase in post reactions & likes
- 106 Posts

2024 Website Stats

24k total users
50k page views

Top 10 Countries

1. United States
2. Hong Kong
3. United Kingdom
4. India
5. Canada
6. Australia
7. Thailand
8. Ireland
9. Germany
10. New Zealand

Most Visited Webpage:
Low Alkaline Phosphatase

HPP MANAGEMENT GOES DIGITAL:

SIX MONTHS OF IMPACT

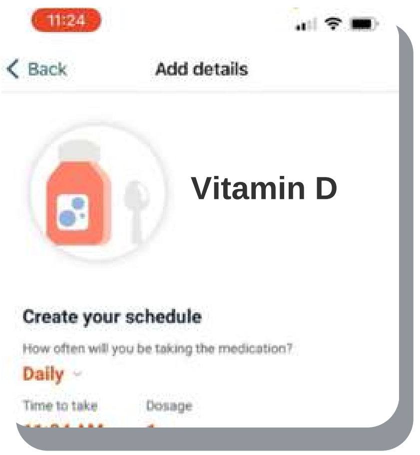
The Soft Bones ***myHPP*** app was created to connect individuals who want to understand HPP better and are willing to anonymously share their health data to help shape the future of HPP care.

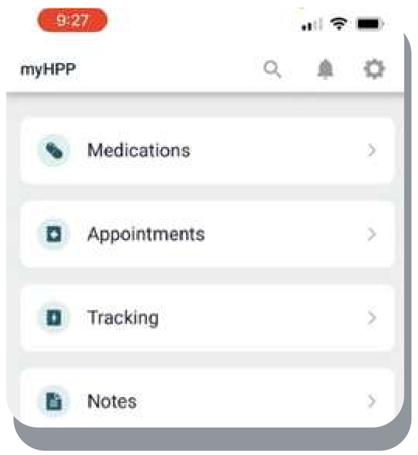
Since its launch, the purpose and impact of ***myHPP*** have grown significantly. Patient participation remains at the heart of the platform. The data being collected is already influencing research, deepening our understanding of the disease, and informing the delivery of care.

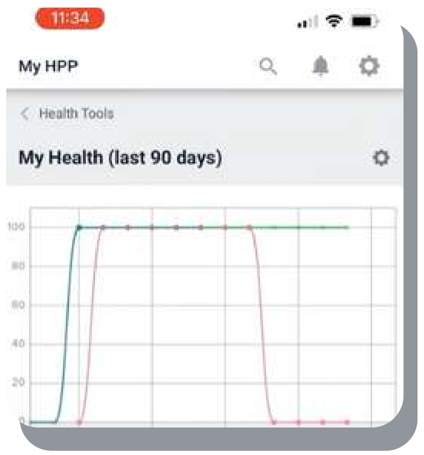
From July 2024 - December 2024, the app has seen meaningful global engagement:

- Users from 11 countries and 72 regions or states
- 10.5% of users are pending diagnosis
- New doctors have been identified through patient input
- The highest user concentrations are in Pennsylvania, California, and Texas

As adoption continues to grow, ***myHPP*** is proving to be more than a symptom tracker. It is becoming a vital tool for patient empowerment, physician engagement, and research advancement. The insight gained through the platform has the potential to directly influence clinical conversations, improve care plans, and accelerate the development of future treatments.



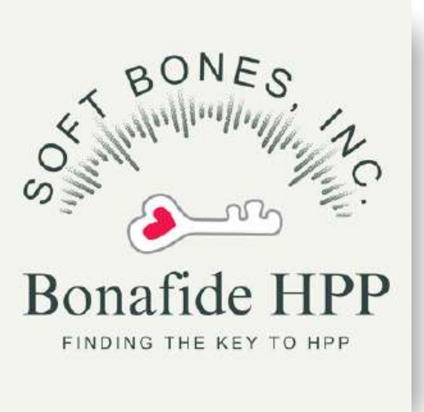




Enhancing Support: New Resources

HPP Unfiltered: Soft Bones Launches 6 New Podcasts

In 2024, we continued building meaningful connections through the *Soft Bones Podcast Series*. We released six new episodes featuring a wide range of topics for patients, families, and health professionals. From navigating HPP clinical trials and understanding ELISA testing to powerful personal stories, each episode offers insights and support for the HPP community.



Episode 6: A Conversation with Lindsay W. and How HPP Has Shaped Her Life

Episode 7: Commonly Asked Questions About ELISA Testing with Dr. Steven Petak

Episode 8: Be Involved: A Conversation with Patient, Caregiver, and Advocate, Janni K.

Episode 9: A Conversation with Guest Host Aaron Blocker and Deborah Fowler

Episode 10: Guest Host Cindy Reasor Talks with Sue Krug

Episode 11: HPP Clinical Trials: What Are They and Are They Right for Me with Deborah Fowler and Dr. Kathryn Dahir

Tune in to hear inspiring stories, helpful information, and ways to get involved in the HPP community.

5 National Patient Meeting Videos on Vimeo

285 total views

Top Videos on Vimeo:

1. HPP Overview and Genetics
2. Rheumatological Manifestations of HPP
3. HPP Pain Management

All other National Patient Meeting Videos are on Youtube

12.4K Views

124 new subscribers

Top Videos on YouTube:

1. What is Hypophosphatasia?
2. The Role of Vitamin B6: Implications
3. What is Alkaline Phosphatase and Why It Is Important

Building our Future

We raised over $240,000 in 2024

Soft Bones Support:
- 2 grants
- 32 sponsorships

Soft Bones Funded 1 Research Grant

Moving Together for A Stronger Tomorrow: Cannonball Run, Roll, or Stroll

Raising awareness takes all of us. In 2024, we continued moving forward as one. As part of our mission to build connection and community, we hosted the 3rd Annual Cannonball 5K Run, Roll, or Stroll throughout October.

Patients, families, and friends were invited to complete a 5K in their own way and at their own pace. HPP communities in Indiana, Massachusetts, New Jersey, and Florida took it a step further by hosting local gatherings, turning awareness into action and movement into momentum.

From every finish line crossed to every story shared, this event reminded us that progress happens one step at a time. The journey is stronger when we take it together.

Thank you to everyone who participated. Whether you ran, rolled, or strolled, your efforts brought us closer to a future shaped by awareness, unity, and hope.

Game on for HPP: Golf & Pickleball With Purpose

On September 23rd, Soft Bones hosted its 16th Annual Golf Classic alongside our 1st Annual Pickleball Tournament. Together, these events brought together more than 120 participants, making it our largest fundraising event to date. Golfers and pickleball players came out in full force to support the HPP community. Whether they were returning supporters or new to the cause, each participant contributed to a day filled with camaraderie, competition, and impact. Thanks to their efforts, we raised essential funds that directly support our mission to educate, empower, and advocate for those living with HPP.

We are especially grateful to our long-time golfers who continue to show up for the HPP community and to the pickleball players who served up some generous support in their debut year.

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 Burkhart, 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

2ND ANNUAL

DENIM & DIAMONDS

On May 18th, 2024, Soft Bones hosted its 2nd Denim & Diamonds event. We're grateful to everyone who attended and supported our efforts to raise awareness and funds for the HPP community. Guests enjoyed an evening of live music, delicious food, and the excitement of a lively auction

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, for helping make the night possible. We also appreciate those who contributed to our Amazon Wishlist and auction. Your generosity helped make this event a success.

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THE HEART OF GIVING: COMMUNITY FUNDRAISERS

Power in Every Post: Community Fundraising on Facebook and Instagram

We are incredibly grateful to everyone who chose to support Soft Bones through personal fundraisers in 2024, whether in honor of a birthday, to mark a rare disease awareness day, during year-end giving, or to show continued support for our mission. Thanks to your generosity and advocacy, here's a look at the impact made through Facebook and Instagram fundraising efforts this year:

13 Fundraisers Created Through Facebook

109 People Who donated

SOFT BONES HOSTED 16 ONLINE FUNDRAISERS AND RAISED OVER $6,000

spreadshop: Funding Our Future through Fashion

We Added 12 New Designs

Top 3 popular products:

- Men's Premium T-Shirt
- Women's Premium T-Shirt
- Women's Hoodie

Popular Designs:

Baad to the Bone

Soft Bones Logo

World HPP Day

143 Items Sold and Raised $900+

Engaging Our Community to Make an Impact

In 2024, the Soft Bones community found creative and effective ways to support our mission.

Denim & Diamonds Amazon List

To help make our Denim and Diamonds auction a success, families and friends donated directly from our Amazon Wishlist, helping us secure fun and useful items for the event.

Help us Grow Campaign

Leading up to the 2024 National Patient Meeting, we launched our "Help Us Grow" campaign. Thanks to the support we received, more families than ever before received $500 travel grants to attend.

Throughout the year, we participated in four ongoing online fundraisers where everyday purchases helped raise funds for Soft Bones. These included RaiseRight, Walmart SparkGood, Kroger Rewards, and iGive.

RaiseRight. sparkgood

kroger community rewards iGive.com Change online shopping for good.

Shopping for a Cause, Our 2024 Fundraisers

Seasonal product-based fundraisers gave our supporters more ways to give back. From popcorn to home goods, each purchase sent a portion of proceeds to support our work. We also ran several successful online campaigns with partners like Pampered Chef, Lynch Creek, Mama Alana's Pantry, Mary Kay, Sarris Candies, Charleston Wrap, and Poppin' Popcorn.

Together, *these efforts raised over $6,000*. A true testament to the power of community and collective giving.

To learn more about our fundraising efforts and current fundraisers, visit our Shop for a Cause page, **HERE**.

From Local to National: Soft Bones Conferences, Seminars & Meetings.

In 2024, our mission to educate, connect, and support the HPP community took us across the country. From online meetups to in-person gatherings, these events played a vital role in strengthening connections and expanding awareness.

2024 National Patient Meeting

Held July 12–13 in Mason, Ohio, the 2024 National Patient Meeting brought together patients and caregivers and gave them the chance to connect in person, share their experiences, and learn from leaders in the field.

We welcomed an outstanding panel of expert speakers, including:

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)
Rare Disease, & Strategies for Resilience

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After a day of education and discussion, attendees participated in a creative, hands-on art workshop that allowed for reflection and connection.

Missed the event? On-demand recordings of the 2024 National Patient Meeting are available on our **website** or our **YouTube channel**.

Regional Round Ups

Throughout the year, our Region Leads hosted 8 in-person and 7 virtual Region Meetings. These gatherings give patients and families a place to share their stories, ask questions, and access helpful information. Region Leads play an essential role in driving local awareness, leading fundraising initiatives, and offering support close to home.

Building Research Readiness

At the 2024 National Patient Meeting, we introduced a new initiative focused on assessing our research readiness. This effort is an important step toward positioning Soft Bones to apply for larger-scale research grants that center on patient perspectives and priorities.

Recruiting for Clinical Trials

Soft Bones plays a critical role in educating and recruiting patients for research. This year, we supported Alexion's 1850 clinical trials, helping connect patients to the next-generation of enzyme replacement therapy. By actively supporting researchers and industry partners, we help ensure that patients have a voice in advancing scientific progress, while improving treatment options.

View the flyer we promoted, HERE.

Research in Focus: Sara M. Survey on HPP and Mental Health

With the launch of the myHPP app, we were proud to help promote a research survey led by Sara M., an HPP patient and doctoral student in Clinical Psychology at Fielding Graduate University.

Sara's study explores how living with HPP affects mental health and the different coping strategies people use to manage day-to-day challenges. The survey was open to registered members of the CoRDS HPP Registry and users of the myHPP app who were 18 or older and either diagnosed with HPP or carriers of associated gene mutations.

By participating, our community supported research that brings valuable insight into the emotional side of living with HPP. We're committed to uplifting patient-led research and advancing understanding from every perspective.

Collective Action for Change: CoRDS International HPP Contact Registry

The CoRDS International HPP Contact Registry continues to be a cornerstone of patient-driven research. This accessible database connects every registered individual with opportunities to participate in studies while safeguarding patient privacy. Through our partnership with the Coordination of Rare Diseases at Sanford (CoRDS), patients maintain control of their data while contributing to a global effort to advance HPP research.

CoRDS is the largest free international rare disease registry available to those diagnosed with HPP, carriers of HPP, and individuals who are undiagnosed but suspect they may have a rare metabolic condition.

By the end of 2024, the CoRDS registry grew by 12%:

Representation from 48 states, with the largest groups from Florida, Texas, and Ohio

Participation from 13 countries worldwide

The continued growth of CoRDS demonstrates the collective power of the HPP community. Each registration adds to a stronger foundation for research, policy advocacy, and ultimately, improved care for people living with HPP.

Advancing Research: 2024 Maher Family Grant Winner

In 2024, Soft Bones awarded its annual Maher Family Hypophosphatasia Research Grant to Valeria Guglielmi, Ph.D., a postdoctoral associate at the Sanford Burnham Prebys Medical Discovery Institute in La Jolla, California.

Her project focuses on understanding how tissue-nonspecific alkaline phosphatase affects B-cell biology and immune system function in individuals with HPP. This research represents a new and promising direction, with the potential to improve care and deepen scientific understanding of the disease.

The $25,000 grant supports early-stage research that could lead to larger studies and future treatment strategies. Each year, the grant reflects our commitment to driving forward research that directly benefits patients and helps shape the future of care.

Patient Impact Award

Deborah Fowler and her son, Cannon, were invited as guests to present on Soft Bones and educate employees about HPP in San Diego at Rampart's company meeting. Rampart Bioscience is dedicated to advancing medicines for HPP. At the end of the event, Deborah was awarded the inaugural Phillipe Crine Patient Impact Award for her "courageous and unwavering contributions toward improving patient lives". Dr. Phillipe Crine, who sadly passed away in 2023, is the scientist who discovered the first enzyme replacement therapy for HPP, Strensiq® (asfotase alfa).

Welcoming New Leadership

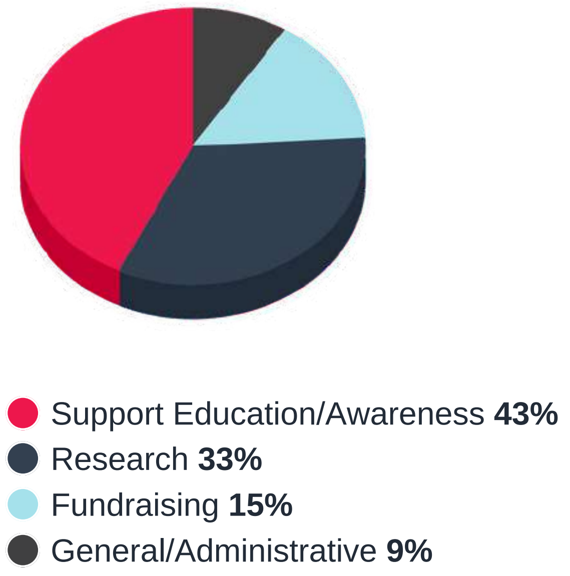
We're pleased to welcome Beverly Natale to the Soft Bones Board of Trustees. Beverly is the Director of Clinical Services at Morristown Medical Center, part of Atlantic Health System in New Jersey. She brings decades of healthcare leadership experience, having started her career as a Respiratory Care Practitioner in 1986 before becoming Director in 2015.

She now oversees a wide range of services, including therapy, endoscopy, wound care, and pain management. Beverly also lends her expertise to several advisory boards, including the MMC Community Advisory Board, Salvation Army, and local chambers of commerce.

Outside of work, Beverly enjoys time at the Jersey Shore with her husband and their dog, Sheba. We are grateful for her dedication to patient care and her commitment to the Soft Bones mission.

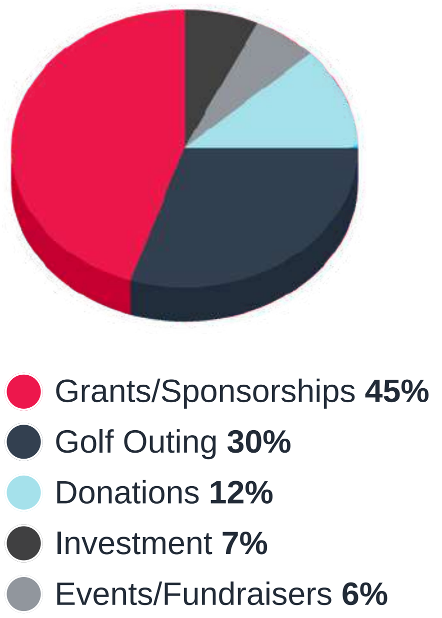
Financials

Expenses



● Support Education/Awareness **43%**
● Research **33%**
● Fundraising **15%**
● General/Administrative **9%**

Income



● Grants/Sponsorships **45%**
● Golf Outing **30%**
● Donations **12%**
● Investment **7%**
● Events/Fundraisers **6%**

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Online Fundraisers:

In 2024, Soft Bones hosted 16 online fundraisers, and it would not have been possible without you. From launching Facebook fundraisers and wearing Soft Bones gear to making purchases or simply sharing a post, every action added up. Your support helped raise awareness and essential funds for our mission. These efforts show that even small steps can create a big impact when our community works together. We are so grateful for your generosity, your commitment, and your voice.

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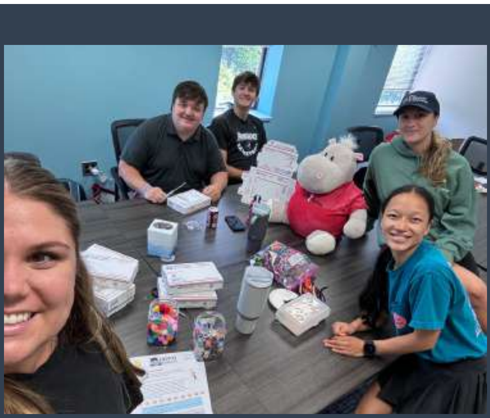

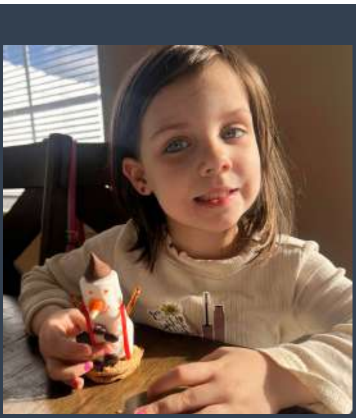

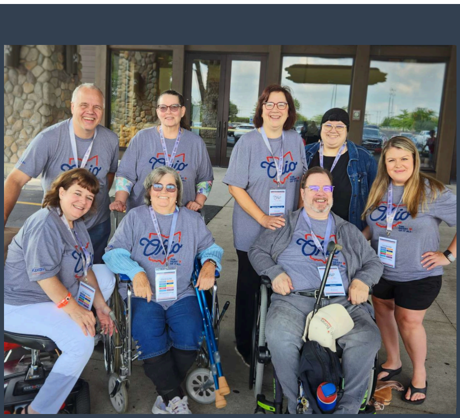
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