



Bones of Strength

our 2023 achievements



Dear HPP Friends,

As we look back on the past year, I am so proud of the progress we've made together at Soft Bones. Our mission is to provide information, education, and support for those living with hypophosphatasia (HPP), their families, and caregivers. It continues to drive our efforts and inspire hope.

This year was one of immense progress. We sent over 400 information packets to newly diagnosed or suspected individuals, reaching 19 countries, including the USA, Italy, Portugal, the UK, Germany, Canada, and Israel. Our community now spans 41 countries, connecting families globally to share experiences and support each other.

Our commitment to advancing research and education on HPP grows each year. We awarded over \$25,000 in grants, including the 11th Maher Family Grant to Dr. Claire Stenhouse at Pennsylvania State University. Dr. Stenhouse's research focuses on respiratory complications in infants with HPP and promises significant breakthroughs. We eagerly await her findings.

We also launched significant initiatives to empower our community. The myHPP app, developed with input from patients and physicians, will be introduced in 2024 to help individuals track their health and contribute to HPP research. This innovative tool enhances patient care and aids in better treatment outcomes.

We saw amazing progress in our programs and services. Our Hippo Squad continues to grow, with 194 members and 122 families actively engaged. We awarded 35 travel grants and one research grant, and our National Patient Meeting saw 118 attendees, including over 40 families. This annual event continues to highlight the importance of community and support.

This year, our HPP Community mourned the loss of three dedicated individuals: Gerald Brandt, Dr. Philippe Crine, and Steven Bernstein. Their contributions to HPP research, patient advocacy, and community support have left an enduring legacy.

Our fundraising efforts also received remarkable support. Despite challenges, we raised significant funds through our annual initiatives, including our first-ever Denim and Diamonds event and the 15th Annual Golf Classic.

We remain dedicated to supporting and advocating for the HPP community. With advances in modern science, a cure is possible. We will continue to work closely with researchers and clinicians to unite the global HPP community and advance our understanding of HPP.

Thank you for your continued support and trust. Together, we are making a difference.



Deborah Fowler, President and Founder
Soft Bones

OUR MISSION

The mission of Soft Bones, Inc. is to provide valuable information, education, and support for people living with hypophosphatasia (HPP), their families, and caregivers. The Foundation promotes research on this rare bone disease through awareness and fundraising efforts.

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 hypophosphatasia.

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.

Hypophosphatasia 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.



435 new patients
this year



400 info packets sent to newly diagnosed or suspecting HPP individuals



Over **\$25k** awarded in grants

2023 Website Stats

Soft  Bones.org

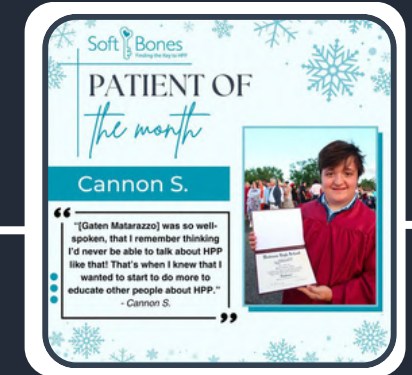
Our Best Performing Posts



Remembering Steve



Rare Bone Alliance



POM: Cannon

Connecting with Impact: Our Social Media Reach

In 2023, we had



3,889 reactions and comments across Instagram, Facebook, and Twitter



4,219 engaged Facebook users



3,248 engagements on Instagram, & 431 engagements on Twitter

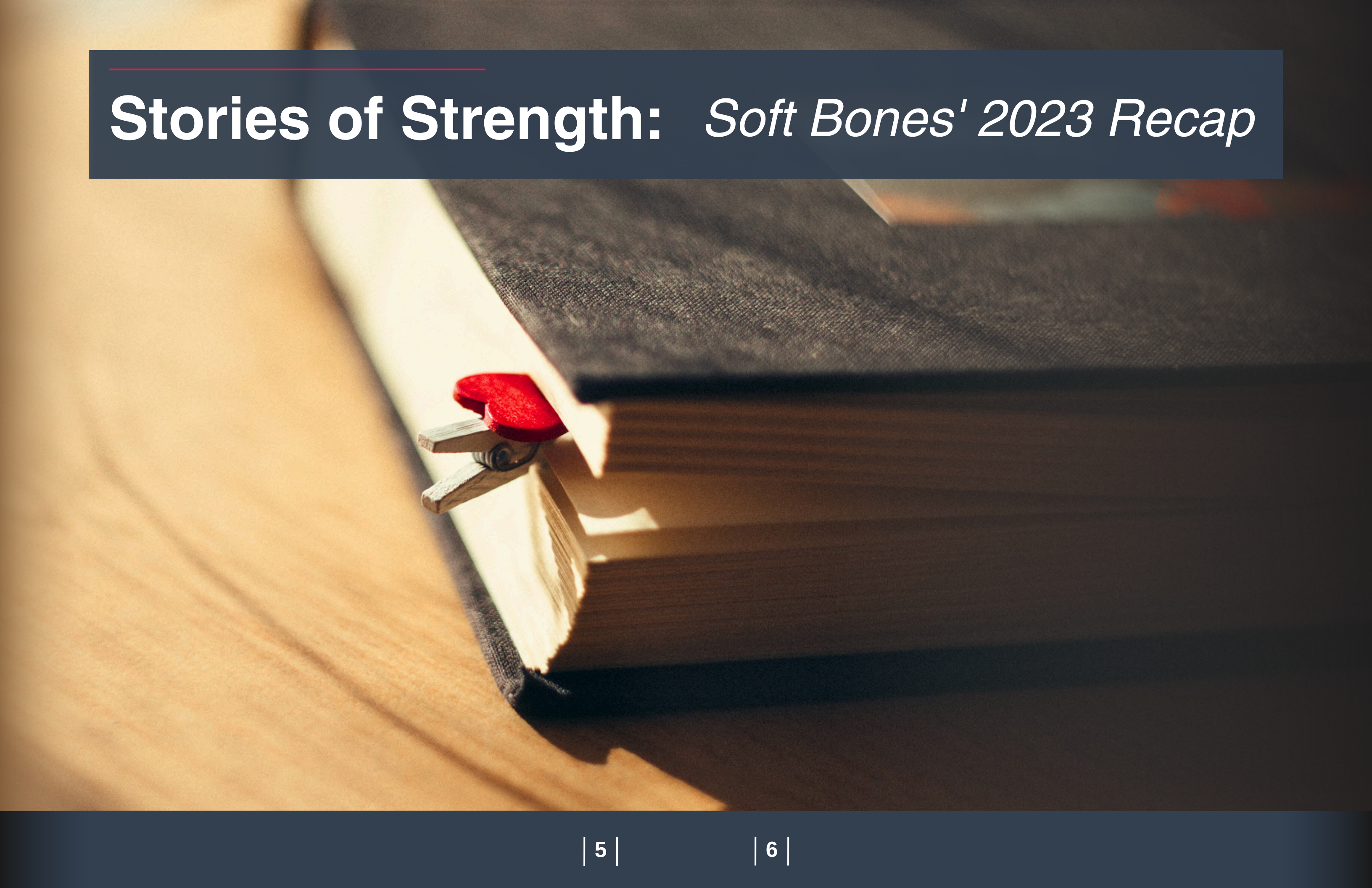


Our top Facebook post was honoring the legacy of Steven Bernstein



We hit 700 followers in 2023 on Instagram

Stories of Strength: *Soft Bones' 2023 Recap*



Awareness Days

Rare Disease Day 2023

Rare Disease Day is an annual global event to raise awareness about rare diseases as a public health concern. Held annually on February 28th, except during leap years, it serves as a platform to collectively raise our voices to promote equity, access to care, and therapies for people with rare diseases.

This year, Soft Bones embraced the EURODIS theme #ShareYourColors, and members of the HPP community united and came out in full force! More than 100 HPP patients and families created new profile photos and shared pictures, videos, and their experiences through social media to raise awareness.

World HPP Day 2023

2023 marked the 75th anniversary of Canadian pediatrician Dr. John C. Rathbun's groundbreaking discovery of HPP. Since then, significant progress has been made in research and support for the HPP community, but our journey is far from over.

On October 30th, we celebrated World HPP Day under the theme "Let's Make Noise About HPP." Soft Bones's mission is to empower and equip patients and their caregivers with the resources and knowledge to advocate for themselves. By "making noise," we aim to address the challenges of living with HPP and foster mutual support within our community. Our global HPP community gained momentum by raising awareness of HPP in many impactful ways.

HPP Community Stepped it Up on World HPP Day

In fostering communities near and far, we encouraged individuals to participate in our 2nd Annual Cannonball Run, Roll, Stroll 5k. On World HPP Day, HPP communities from Indiana, Massachusetts, New Jersey, and Florida had local meet-ups for an in-person Cannonball 5K. Together, we took 312,500 steps towards spreading awareness for HPP, embodying our theme, Bones of Strength. We extend a huge thank you to all participants, Alexion, AstraZeneca Rare Disease for supporting this event and our HPP community. Strength and support as a group make a difference!



Stories of Strength

Navigating Hypophosphatasia: August's Story of Courage and Community Support

Mercedes and Bryce Bartholomew's journey with their son August began with excitement when they learned of their pregnancy in January 2020. Despite COVID-19, they excitedly celebrated every milestone until an 18-week scan revealed that August's limbs were significantly underdeveloped.

Initially, doctors reassured Mercedes that August might just be a little person, but further tests revealed severe skeletal dysplasia, fractures, breaks, and missing bones. An amniocentesis confirmed hypophosphatasia (HPP), changing her pregnancy's course, where she was seeing doctors weekly.

With Bryce deployed overseas, Mercedes navigated frequent medical visits alone until Bryce returned early. While the family wished for short hospital stays, it was anything but that. Mercedes was moved to a specialized hospital for better care for complex pregnancies. Upon birth, August required an extended hospital stay, heavy pain medication, and suffered from pneumonia.

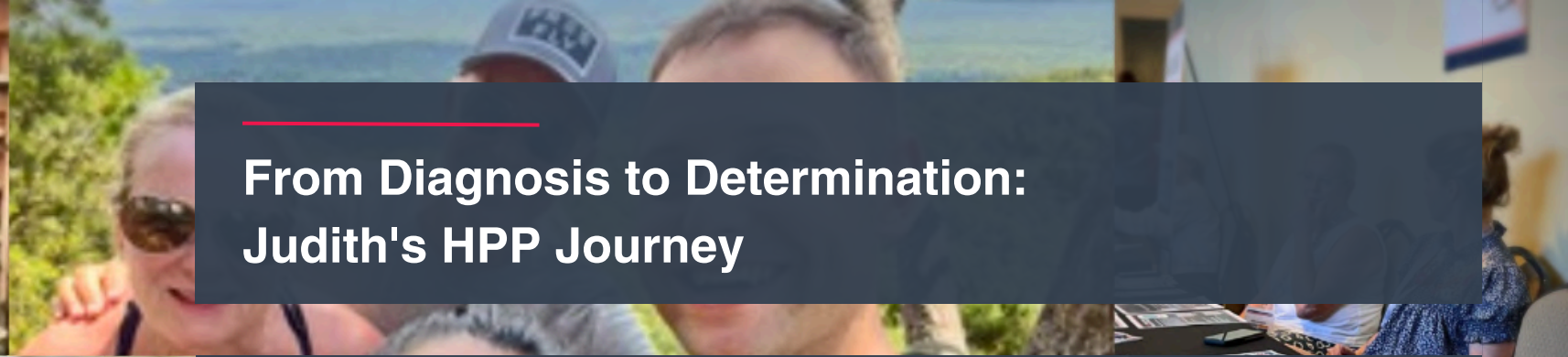
At four and a half months, August transferred to Rady Children's Hospital in San Diego. There, his care improved, and the family could spend more time together without masks. A successful tracheostomy and g-tube surgery made him more active and responsive, bringing smiles and laughter. August was a true rockstar at such a young age.

At seven months, August faced another challenge when his skull began fusing prematurely as a result of the Strensiq helping strengthen his bones, albeit just a bit too quickly for his growing head. Neurosurgeons attached steel plates to expand his skull, a successful procedure that allowed for improved brain development. August's resilience was clear as he moved from the NICU to the pulmonary floor. Bryce was now commuting for work while Mercedes stayed with their son, learning to care for him independently. The family celebrated small victories, like taking August outside for the first time in his own stroller. After nine months, August finally went home on June 17th.

Around his first birthday, the family discovered August could not hear. Despite this setback, hearing aids brought slight improvements to the family just before Christmastime. Fast-forward a few years to 2023, when August no longer needed his ventilator or G-tube. He began crawling, taking steps, eating by mouth, and communicating by using sign language! He's thriving in preschool and enjoys bath time.

Soft Bones was crucial in providing resources and connecting them with a supportive community. Soft Bones' dedication to raising awareness, funding research, and supporting those with HPP has been instrumental in August's care and progress.

August's story shows how important organizations like Soft Bones are in supporting families and pursuing research for rare diseases, making a big difference for families like the Bartholomews. *You can read the [full story here](#).*



From Diagnosis to Determination: Judith's HPP Journey

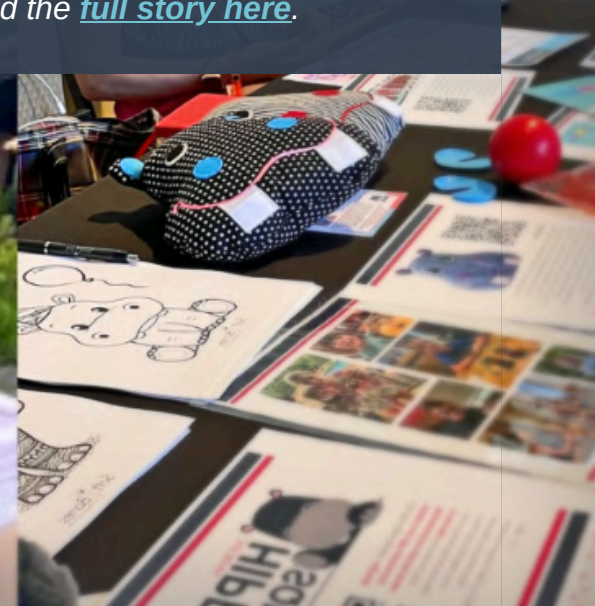
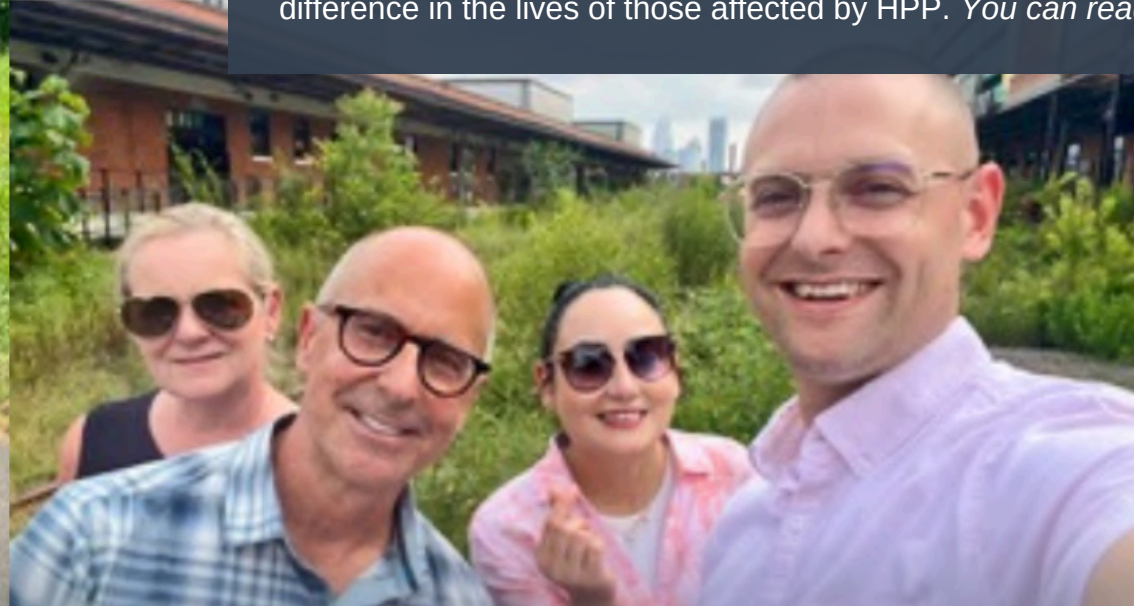


Judith is a determined woman who's faced health challenges with a positive outlook and unwavering strength. Her journey began in Northern Ireland in the early 1960s with a diagnosis of hip dysplasia, requiring her to be in a cast for the first year of her life. Little did her family know this condition was likely due to HPP.

Throughout her childhood and adulthood, Judith experienced symptoms of HPP, such as dental issues and frequent fractures. A series of fractures, the discovery of low alkaline phosphatase levels, and extensive online research led her to a self-diagnosis of HPP. Eventually, she found the right medical professional and was clinically diagnosed with juvenile-onset mild HPP.

At nearly 59, Judith began enzyme replacement therapy (Strensiq), which brought about positive changes, including improved strength, energy, and quality of life. Despite the challenges, Judith emphasizes the importance of early diagnosis and awareness within the medical community, which is a true testament to her determination.

Thanks to patient support groups like Soft Bones, patients like Judith have access to support, medical networks, a close-knit community, and ongoing research into HPP. Soft Bones provides access to valuable resources, connects patients with a network of others who understand their journey, and advocates for advancements in treatment, making a real difference in the lives of those affected by HPP. *You can read the [full story here](#).*



A New Era in HPP Management: Introducing **myHPP**

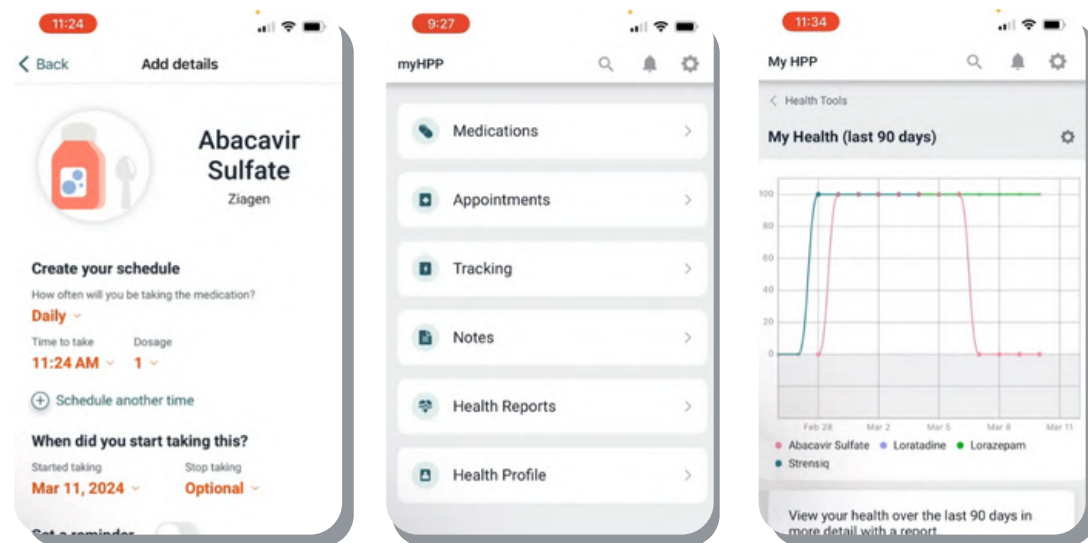
In 2023, we set out to create an all-encompassing health tracker application that would fit into our patients' lives. MyHPP app is an app developed by patients and physicians to transform patient care and inform hypophosphatasia research. It puts patients in charge of tracking their health while being a valuable partner in research for better HPP treatment and care.

Soft Bones heavily invested in this app in 2023. We organized a series of focus groups to assist with deriving a solution. The group felt that a more accurate way to capture the impacts of HPP could lead to more productive discussions with their doctors and facilitate better care and management of their disease.

When speaking with physicians, many said that having patients track their ongoing symptoms, including improvements or worsening, would be extremely helpful in providing better patient care and helping patients with insurance appeals.

Users can easily track symptoms and manage their disease with a user-friendly interface. The myHPP app will also capture these entries to generate a discussion guide to facilitate a more meaningful dialogue with HPP providers.

the myHPP app was launched in the latter half of 2024. You can find [more info here](#).



Maher Family Grant Winner

CONGRATULATIONS

Soft Bones 2023
Research Grant
Winner is

Claire Stenhouse, PhD

Assistant Professor
Department of Animal Science
Center for Reproductive Biology and Health
The Huck Institutes for the Life Sciences
Pennsylvania State University

Soft Bones is dedicated to advancing research and education for those affected by HPP. The 11th Maher Family Grant was awarded to Claire Stenhouse, Ph.D., an assistant professor at the Huck Institutes for the Life Sciences at Pennsylvania State University. The grant will support Dr. Stenhouse's studies on sheep to understand the mechanisms behind respiratory complications in newborns and infants severely affected by HPP.

Read more [here](#).

Over **\$25k**
awarded
in grants



**1 Research
Grant**



**35 Travel
Grants**

Summary of the Second International Scientific Meeting

The Second International Scientific Meeting was held, and a summary was published and made available on JBMR Plus®. Video recordings from the meeting are available for researchers and clinicians through HPP Connect.

View the JBMR Plus article [here](#).



Soft Bones Presents at the OI Foundation Conference

On October 19-20, Deborah Fowler (President of Soft Bones) and Denise Goodbar (Executive Director) traveled to Arlington, VA, to participate in a meeting hosted by the OI Foundation. This gathering brought together healthcare leaders to discuss challenges faced by adult patients with rare diseases while navigating the healthcare system. The meeting evaluated how current care infrastructures and technologies address their unique needs.



Introducing Our Newest Team Members



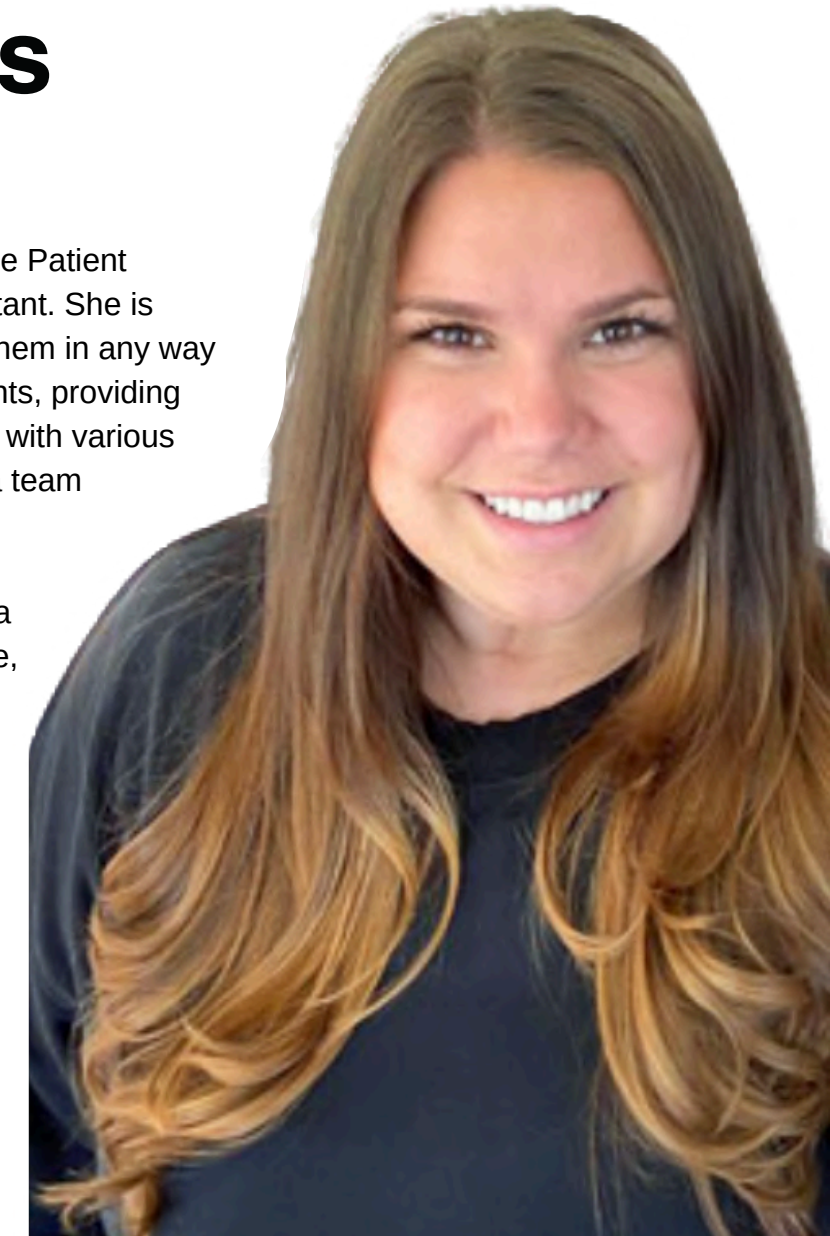
Margaret Robb

Margaret Robb is the Communications Manager and Patient/Caregiver Navigator at Soft Bones. She was drawn to our organization by the opportunity to continue advocating for patients and assisting them in navigating the healthcare system.

Margaret brings unique experience from her time volunteering with the Jesuit Volunteer Corps. She lived with six housemates and worked at different non-profits throughout Cleveland during her tenure. She dedicated her efforts to supporting refugees and immigrants at a federally qualified healthcare center, helping to reduce barriers to care and promote resources and community events.

This experience highlighted gaps in the healthcare system, which Margaret is now eager to address further, particularly for rare diseases like HPP. Her background in undergraduate studies fuels her passion for diving deeper into the scientific aspects of these conditions.

She enjoys listening to people's stories and understanding research that enhances care and treatment options. Margaret is excited to connect with the HPP community and contribute to the mission of Soft Bones.



Lucy George

In November, Lucy George joined Soft Bones as the Patient Engagement Coordinator and Administrative Assistant. She is passionate about talking to patients and assisting them in any way possible. Lucy's role involves interacting with patients, providing them with educational materials, and aligning them with various program offerings. She feels grateful to be part of a team that supports HPP patients.

Lucy is the youngest of six siblings. Growing up in a large family taught her valuable teamwork, patience, and effective communication skills, which have proven extremely valuable during her time at Soft Bones. These skills greatly benefit her work, as she demonstrates patience with the patients she interacts with and conveys her caring personality over the phone.

Lucy is excited to be part of the Soft Bones team and is always ready to help. She is the friendly voice on the other end of the phone and is eager to assist with any needs.

Building Our Future:



We added **3** jobs



and had **2** interns



Alex Lupo

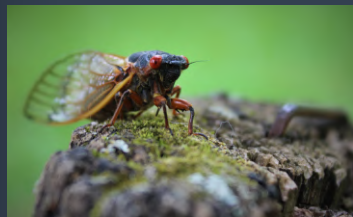
Alex Lupo joined Soft Bones in 2023 as a Junior Graphic Designer and has played a key role in creating our annual report for two years.

Alex has a passion for animals and enjoys taking photos of local wildlife. During high school, he was interested in visual arts, and his passion for photography eventually led him in a different

direction. Alex soon realized that graphic design was his true calling. Reflecting on this journey, it's clear that the signs were always there; Alex was a visual learner and loved doodling. He dabbles in various art forms, including traditional sketches, digital art, and printmaking.

Alex's career at Soft Bones began during college. After applying to numerous design positions without success, his father suggested reaching out to Soft Bones, which led him to an internship.

Now, Alex is a member of the Soft Bones team and is thrilled to be part of it. Having a job in the field so soon after college is fantastic, but playing a role in helping Soft Bones achieve its mission is truly special. Alex takes pride in knowing that his work helps educate people about HPP.



Driving Change: Soft Bones Golf Outing and 1st Annual Gala



On October 2nd, Soft Bones hosted its 15th Annual Golf Classic, **drawing a record-setting 112 golfers!** This year's event was our largest fundraiser, generating essential funds for our organization. We deeply appreciate the dedicated golfers who consistently support our mission year after year.

Tournament Sponsor: Atlantic Health System

Birdie Sponsor: The Fowler Family Charitable Foundation

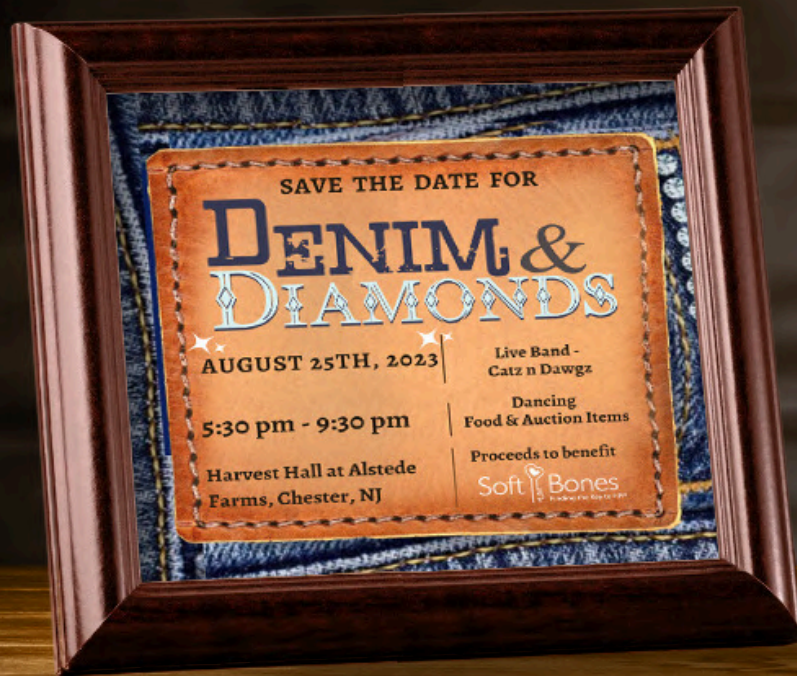
Eagle Sponsors: Gates and Mary Ellen Hawn & Donnelly Construction

Driving Range Sponsor: College Mind Counseling- Kristen Tarantola

Beverage Station Sponsors: William F. Jones, DMD, and Ted Walsh

Additional Tee Sponsors: Dan Burkhart, Berkshire Hathaway AZ - Harvey & Linda Salkow, The Pollock Firm LLC, FOMO Bar in Morristown, Vince Bisogno, Daniel McNeil, Richard Fowler Jr., Peter Dahms, McRae Capital Management, and M&M Perrotti's

19th Hole Sponsors: Joseph Micale, DMD, and Francis Kenneally



DENIM & DIAMONDS



Denim and Diamonds:

Soft Bones hosted its first-ever Denim and Diamonds event on August 25th, welcoming over 60 attendees. Guests enjoyed a lively evening with live music, delicious food, and the excitement of bidding on auction items.

**SADDLE-UP
GOLD SPONSOR**



**GUNMETAL
SILVER SPONSOR**

**EQUITY WINE
VENTURES LLC**

RANCH HAND BRONZE SPONSORS



SALOON SPONSOR



**STRUT YOUR
STUFF SPONSOR**



**TIP THE
HAT SPONSOR**



Enhancing Support: New Individual Resources

HPP AND ME Zoom | Zoom Chat & Tutorial Sessions

In 2023, we launched the HPP AND ME Zoom Chat and Tutorials sessions. HPP AND ME is an online platform that provides patients with a safe and secure space to ask questions and engage with other HPP members. Hosted monthly, the HPP AND ME Zoom Chat offers an opportunity to connect virtually. Cindy R. leads the HPP AND ME Zoom Tutorials for our newest members, helping them navigate the platform and continue the conversation.



Rolling Out Our Patient of the Month Series

In 2023, we launched the Soft Bones Patient of the Month series to give more visibility to personal stories. Each month, we highlight the journey of an adult or child with HPP. This initiative raises the voices of our HPP members and fosters greater connections, as shared experiences help us feel less alone. It provides a platform for patients to shed light on their daily lives, challenges, victories, hopes for the future, and more. We featured our 12 Patients of the Month during our Annual Appeal campaign. Read more about their journeys [here](#).



PATIENT OF
the month

VOICE OF THE PATIENT

A summary of the Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD) on Hypophosphatasia

Public meeting: November 15, 2022 - Report submitted: April 21, 2023
Hosted by: Soft Bones, Inc., The U.S. Hypophosphatasia Foundation



This report is dedicated to the courageous patients, caregivers and families impacted by HPP.



Voice of the Patient Report

In 2023, we published the official summary of the Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD) held in November 2022. This meeting was designed to communicate to the FDA the impacts of HPP on individuals' daily lives, the treatments that have the most significant impact and benefits, and the perspectives of patients and caregivers on the effectiveness of available therapies.

This landmark report includes written statements and transcripts, summarized in the main body and fully provided in the appendices. It is dedicated to the courageous patients, caregivers, and families impacted by HPP. The Report can be read [here](#).



Second International Scientific Meeting | Bethesda, Maryland

The Second International Scientific Meeting, held on June 2-4 in Bethesda, Maryland, brought together over 70 clinicians, physician-scientists, basic science researchers, and industry representatives from four continents to advance the understanding and treatment of hypophosphatasia (HPP). This diverse group shared their knowledge and experiences to improve patient care and support families with HPP. The group discussed the latest advances and ongoing research on this rare and complex metabolic disorder.

The meeting included experts from various clinical disciplines, such as pediatrics, internal medicine, genetics, dentistry, orthopedics, rehabilitation medicine, optometry, and rheumatology. Basic scientists, including enzymologists and bone biologists, also participated. Translational research focused on enzyme replacement, marrow cell transplantation, and genetic approaches for HPP.

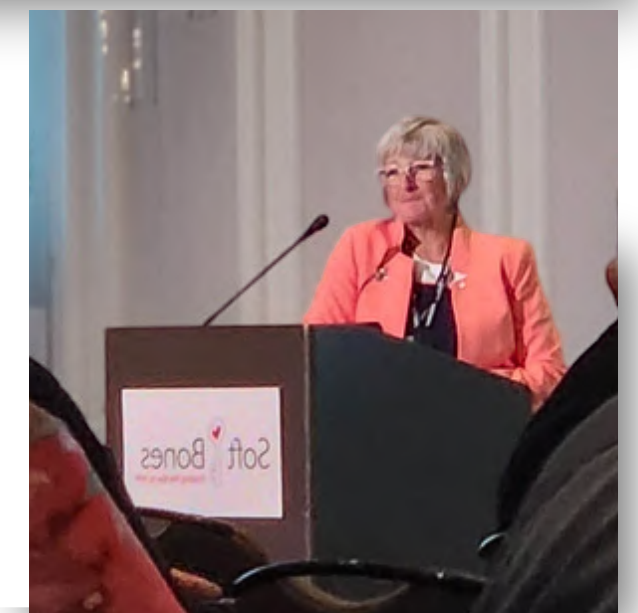
The meeting underscored the collaborative effort required to tackle HPP, which displays the broadest range of severity among skeletal diseases. By bringing together such a wide range of expertise, the event highlighted the importance of interdisciplinary collaboration and cutting-edge research in advancing the care and treatment of patients with HPP. Special thanks to the sponsors: Alexion AstraZeneca Rare Disease, AM Pharma, Charles River, PuREC, Rallybio, RampartBio, Be Biopharma, and 1cBio.

Regional Round Ups

In 2023, we hosted five regional meet-ups across five states (CA, IN, MA, MN and OH) and one virtual meet-up. Our dedicated Region Leads went above and beyond to create welcoming spaces for patients to connect and share their HPP journeys. They were crucial in spearheading grassroots awareness, driving fundraising efforts, and bringing valuable resources to the local level.

HPP Network | Virtual

Soft Bones started the year with strong momentum, building our HPP Network! We conducted two additional meetings with our working group, focusing on enhancing HPP knowledge and fostering physician-peer connections to promote greater HPP education. We are excited by the opportunity to launch several concrete initiatives resulting from the input of our champions, including the working group and steering committee members. On the 2024 horizon, Soft Bones is working to establish an HPP consensus statement or clinical guidelines series, encourage greater information exchange between physicians and peers, and increase the usage and credibility of our extensive educational resources. These efforts reflect our commitment to strengthening the HPP community and improving education and collaboration.



Programs & Services



The Hippo Squad consists of kids in our HPP community who receive fun-filled educational activity boxes in the mail every quarter. Each box is filled with HPP educational activities along with a sprinkle of fun! Members will receive their boxes four times a year to get involved in engagement activities while developing important connections with peers. Mailings are available to U.S. residents only.

This program is open to kids with HPP, their siblings, and children of parents with HPP. Each season, the Teen Advisory Council (TAC) creates fun and educational activities.

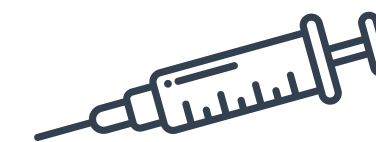
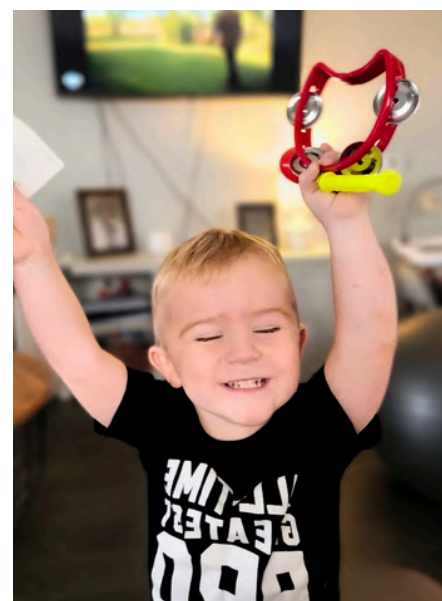
In the spring box, kids explored expressing emotions through colors. They received rainbow coloring sheets, colored pencils, and a pot of GOLD to symbolize that even after the stormiest weather, there's always a rainbow and a pot of gold at the end!

The summer box focused on storytelling with puppets. It emphasized educating others about HPP. Kids received materials to create their puppets and a script to help them learn how to talk about HPP.

For the fall box, members received musical instruments to make some noise for World HPP Day! It highlighted the power of community and how coming together can achieve incredible things.

The winter box featured snowmen crafts, demonstrating how bone-building cells, or osteoblasts, resemble snowmen. It also included lessons on the dynamic and active role bones play in supporting our bodies.

122 families are enrolled in the program, with 194 children receiving the Hippo Squad mailings.



14 Stick It To HPP members



194 Hippo Squad members, **122** Families

Podcast Statistics



- Viewed in four different countries: the U.S, the UK, Japan, and Belgium
- Over 60 downloads from five different episodes
- The top episode downloaded was: **Pain Management**



Teen Advisory Program

The 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 with HPP. Through monthly meetings, teens discuss ways to raise funds and awareness.

This year, the TAC had 14 members. In May 2023, the TAC hosted its first-ever trivia night to raise money for Soft Bones, with over 20 in attendance and raising \$600. The TAC plays an important role in creating activities for the Hippo Squad and serving as mentors to the younger HPP community.

TAC Trivia Night

The Soft Bones Teen Advisory Council (TAC) hosted its first-ever Trivia Night on May 23rd. Friends, family, and members of the HPP community came together to test their knowledge and compete for prizes. Although participation was free, the event raised nearly \$600 in donations.



Stick It To HPP

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. In 2023, we had 14 active Stick It To HPP members and one successful individual who completed the achievement tracker.

Fundraising Efforts within the Community



New Jersey Devils Hockey Game Fundraiser

On March 14th, Consortium Networks, Cribl, and CrowdStrike hosted a Soft Bones fundraiser at the New Jersey Devils game. They rented a suite and sold tickets to raffle off a NJ Devils jersey signed by hockey star Jack Hughes.

Attendees learned about HPP and were excited to support the HPP community. It was thrilling to see Soft Bones acknowledged on the Jumbotron! Thank you to everyone who donated and showed their support for HPP!



Facebook and Instagram Fundraiser 2023

In 2023, six individuals created Facebook fundraising pages for Soft Bones. Despite our platform being down for most of the year, we collectively raised \$425. We deeply appreciate everyone who raised money for Soft Bones, whether for birthdays, awareness days, end-of-year giving, or other occasions.






The Spreadshop store added **5 new designs**

We sold **100 items**

Our Top 3 Designs

 Soft Bones Logo

 HPP Hippo

 Cannonball Run, Roll or Stroll 5k

Our Most Popular Products

 Women's T-Shirt

 Sticker

 Unisex Crew Sweatshirt



Kroger's Community Rewards program allows shoppers to select a nonprofit organization to support. Kroger then donates a portion of the shopper's purchases to the chosen organization. In 2023, we raised \$38.84.



Shop online and contribute to Soft Bones. Register for iGive – a unique online shopping platform that allows shoppers to donate a portion of their purchases to their favorite charities! \$1,064

Bonfire T-Shirt

To raise awareness on World HPP Day, we created a special design to commemorate this year's 75th anniversary of the discovery of HPP by Canadian pediatrician Dr. John C. Rathbun. We sold 89 shirts!



Lynch Creek Wreath

This holiday season, we partnered with Lynch Creek Farm for a wreath fundraiser where 15% of the proceeds went to Soft Bones. Lynch Creek Farm handcrafts traditional and decorated Christmas wreaths, centerpieces, and other holiday gifts. We raised \$128.91



Bundt Cake Fundraiser

Cassandra Self, a Southwest Region Lead, hosted a local fundraiser in Texas with Nothing Bundt Cakes in October to coincide with World HPP Day. Thank you, Cassandra, for all your efforts!



RaiseRight is our newest fundraiser. It is a platform where you can buy gift cards to over 750+ brands, and a percentage of the proceeds goes to Soft Bones. Use our enrollment code LCHS1ABAFERN to join and support us through every gift card purchased!



Round up your change for good! Walmart allows customers to round up purchases to the nearest dollar and donate the change to their charity of choice. Choose Soft Bones and donate every time you shop ONLINE at Walmart.com.

Legislative & Community Action Collective Action for Change

CoRDS International Contact Registry

The CoRDS International HPP Contact Registry is an accessible database that informs every registered patient about research opportunities while safeguarding patient privacy. Soft Bones has partnered with the non-profit Coordination of Rare Diseases at Sanford (CoRDS), allowing individuals to control their data. CoRDS is the largest free international rare disease registry for individuals diagnosed with hypophosphatasia (HPP), carriers of HPP, undiagnosed, or those who suspect they may have a rare metabolic disease. As of 2023, 405 individuals were registered.

Demonstrating Our Commitment to Data Security and Privacy

At Soft Bones, we prioritize the security and privacy of sensitive information. Recognizing the importance of safeguarding our community's data and the complexities of cybersecurity, we have taken proactive measures to ensure that our data management practices meet the highest standards.

We have engaged top-tier third-party experts to manage our databases and patient information for a more secure network. By partnering with companies for their expertise and strict security protocols, we can offer enhanced protection for all data. In addition to SSL encryptions, we've employed a variety of tools to increase security:

- Invision for HPP AND Me: Ensuring secure and user-friendly interactions.
- Security for our website: Providing comprehensive website security solutions.
- Google for email: Delivering reliable and secure email communication.
- Within3 for HPP Connect: Facilitating safe and confidential community engagement.
- Box.com for archiving materials: Offering secure and accessible storage solutions.

Soft Bones's new app platform applies stringent privacy procedures and protocols, which was a key factor in our vendor selection process. Each of our partners has established policies to promptly alert stakeholders in the event of any data breaches, underscoring our collective commitment to transparency and accountability.

While no organization can guarantee absolute security, we are dedicated to maintaining data safety and privacy. By continuously investing in advanced security measures and collaborating with industry leaders, we strive to protect everyone affiliated with Soft Bones and maintain their trust in our commitment to their well-being.

New Board of Trustees/Staff

Introducing Rob Moskow to the Soft Bones Board in 2023

Rob Moskow joined the Soft Bones Board with a wealth of expertise from his legal background and his consulting firm, Equity Wine Ventures. He assists clients in the wine industry with business strategy, counterfeit wine issues, and cellar management.

Mr. Moskow began his legal career with the Nassau County District Attorney's office. He has over twenty years of experience in corporate law, construction law, insurance defense litigation, and complex commercial litigation across several states, including New York and New Jersey. He is admitted to multiple federal and state courts, including the United States Supreme Court.



In addition to his role on the Soft Bones Board, he serves as the Secretary of the Hamilton Farm Homeowners' Association Board and is a member of its Architectural Subcommittee. He also coached baseball at Bernards Township Middle School and Ridge High School and was formerly President of the Basking Ridge Little League Board of Directors.

Mr. Moskow holds a degree in Finance from the University of Richmond and a Juris Doctor from St. John's University. He lives in New Jersey with his wife, two children, and a German Shepherd. He enjoys endurance racing, golf, travel, and wine collecting in his free time.

In Memoriam

Tribute to Our Advocates: Their Legacy in HPP Advancements

Gerald Brandt



On May 19, 2023, Gerald Brandt, the founder of Soft Bones in Germany, passed away. He was an outspoken advocate for the hypophosphatasia community and the founder of HPP Deutschland eV, one of the first HPP patient advocacy groups ever created. He was vital in the formation of Soft Bones.

As an accomplished writer in both English and German, Gerald shared his lifelong stories of living with the disease. He learned to walk late, described himself as not very resilient as a child, endured early tooth loss, and developed strong knock knees. After several operations and numerous fractures during childhood and into adulthood, he then endured joint problems and pronounced kidney dysfunction. According to his statements, he stopped counting the number of broken bones.

In 2006, he founded HPP Deutschland eV to unite the HPP community in Germany, hosting annual patient meetings, advocating with policymakers for HPP recognition, and spending countless hours on the phone with patients and families, supporting, educating, and connecting them with appropriate care teams. He was also a sought-after speaker and published author, [hypothesizing that King Tutankhamun had hypophosphatasia](#)

Many of us will remember Gerald as a lifeline in times of need. He supported patients and families from around the world, answering questions and continually raising awareness of HPP. He is greatly missed by all of us at Soft Bones, and the impact of his work will continue for years to come. As the German HPP group shared, "You can close your eyes and wish for him to come back, or you can open them and see what he left behind."

Dr. Phillippe Crine



On June 13, 2023, Dr. Phillippe Crine, a pioneering researcher in developing asfotase alfa, passed away. He was swept away by pancreatic cancer within two months. He died peacefully at home, surrounded by his loved ones.

Dr. Crine was a Professor of Biochemistry at the Université de Montréal and founded Enobia Pharma in Montreal in 1997. Enobia Pharma was a biotechnology start-up specializing in bone-related orphan diseases. The company developed a bone-targeted enzyme replacement therapy for hypophosphatasia, a rare and often fatal inherited metabolic bone disease, for which there was no approved therapy at the time.

Phillippe will be remembered as the man who, along with a team of dedicated and passionate researchers, gave a new lease on life to children born with hypophosphatasia. The innovative therapy he helped develop allowed children with the disease to survive and lead normal lives. Forever humble, he considered himself and his team privileged to have made such a significant difference in the lives of many children and families.

Steven Bernstein



With deep sadness, we announce the passing of Steven Bernstein in 2023, one of Soft Bones' most dedicated volunteers from Rockaway, NJ. Steven supported Soft Bones in various capacities for the past five years, including our annual golf outing. His wife, Jean, was also actively involved.

Steven will be remembered for his unwavering dedication and contributions to our community. He will be missed immensely. Our thoughts and prayers are with his family during this difficult time. We are grateful to have known him and had the privilege of working with him all these years.

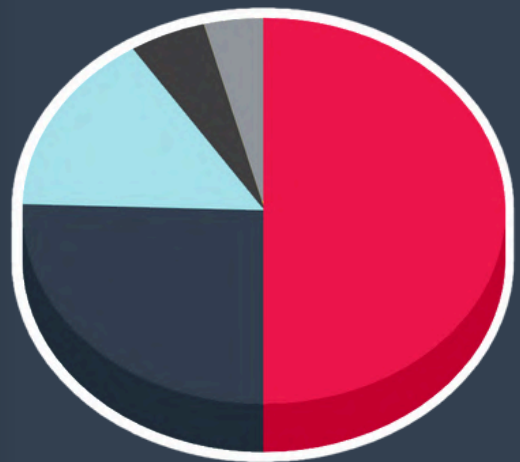
Financials

Expenses



- Support Education/Awareness 43%
- Research 39%
- General/Administrative 9%
- Fundraising 9%

Income



- Grants/Sponsorships 49.5%
- Donations 25.7%
- Golf Outing 15.8%
- Events/Fundraisers 5%
- Other 4%

Events

World HPP Day is our chance as a community to spread awareness for this rare bone disease and bring everyone together. From patients living with HPP, to caregivers, families, loved ones, researchers and doctors, we want everyone to get involved! Learn how you can participate [here](#).



3rd Annual Cannonball 5K Run, Roll, or Stroll
September 29, 2024 - October 31, 2024

Join us as we come together as an HPP community to raise global awareness of hypophosphatasia. Register now for the 3rd Annual Cannonball 5K. Complete a 5K in a single day or pace yourself over the course of the month or choose to support an active participant.



“Together We Can” is a call to action that showcases the collective power of our community. TOGETHER WE CAN is a statement in itself. But also, it begs an answer – what can we do together?

Submit a photo of yourself with this sign filled out to be featured on our social media platform!



World HPP Day Contest Alert
October 1, 2024 - October 30, 2024

Leading up to World HPP Day, we challenge you to download the myHPP app and track your symptoms. Every day you track, you can be entered for a chance to win a World HPP Day sweatshirt. Click [here](#) for full details.



World HPP Day Zoom Open House & Costume Contest
October 30, 2024

Join Cindy R. and Sue K. on October 30th from 8:30 PM - 10:30 PM Eastern for a spooktacular night of chats, costumes, and camaraderie!

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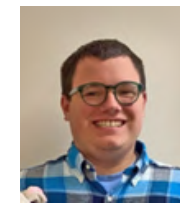


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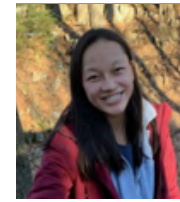
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