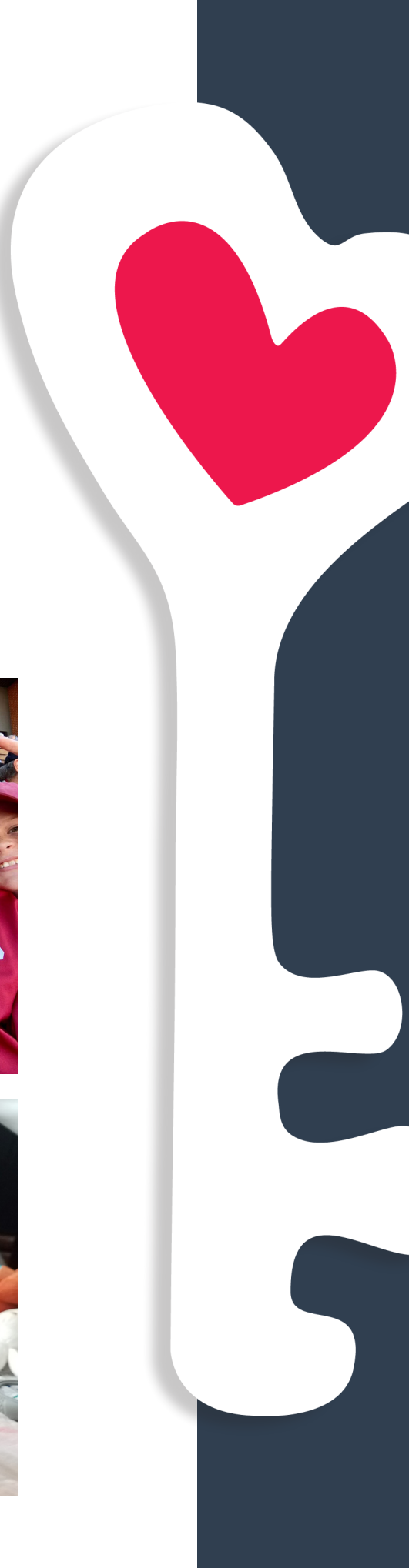


Soft Bones

2021 Annual Report



Dear HPP Friends:

I don't think any of us expected 2021 to pack such a punch. COVID-19 variants continued to impact our community and the world at large as we enter the new year. Living with a chronic disease during a pandemic brought its own set of challenges. However, our HPP community demonstrated its ability to be resilient and carry on in the face of uncertainty. Since we founded Soft Bones more than a decade ago, we also have learned the importance of collaboration, connection, and knowledge sharing for tackling difficult obstacles and identifying solutions that enable all of us to live our best lives.

Despite the challenges of the pandemic, we continued to offer our HPP families informative educational programs in virtual formats in 2021, including our virtual patient meeting and regional patient meetings. Our 2021 World HPP Day theme, "Let's All Be Heard", took on new importance as we raised our collective voices for HPP awareness, proving to ourselves that we are truly stronger together. Through our TeleECHO program, we educated healthcare professionals about HPP by offering presentations and discussions on different HPP-related topics, enabling them to amplify the knowledge for providers to deliver best-in-class care in their own communities. We exhibited virtually at the American Society for Bone and Mineral Research (ASBMR) Annual Meeting, awarded our 9th annual research grant, and announced our partnership with Aruvant Sciences making our first gene therapy research for HPP. And, our fundraising programs raised vital funds for education, advocacy, and research to benefit our organization and community.

I am grateful to everyone who contributed their time and energy to support our organization's goals, especially during these difficult times. Thank you to those who supported our foundation with a donation. And a special thank you to our Region Leads for keeping an ear to the ground at the community level to support the needs of patients and ensure their voices are being heard.

As we look ahead, we are so excited about some wonderful new initiatives we're advancing for both patients and providers that are described in this newsletter. We continue to expand our offerings to meet the needs of our community, address knowledge gaps and support HPP research and enhanced patient care.

To learn more about our 2022 plans and to see the 2021 initiatives in action, visit SoftBones.org.

Deborah Fowler
President and Founder
Soft Bones

Board of Directors



Deborah Nettune Fowler
President and Founder



Karen Carolonza
Vice President



Michelle LaBruno, CPA
Treasurer



Heidi Floyd
Secretary



Adam Grenker, Esq.
Attorney



Scott Nettune
Board Member



Brenda Ziegler, DO
Board Member



The last two years have been difficult, but our supporters have stepped up to help us reach our fundraising goals. As a result, we have become a stronger organization bolstering awareness of HPP and have a renewed focus on supporting patient access to healthcare providers who have experience with this disease and to appropriate treatments.

— *Deborah Fowler*
President and Founder

Scientific Advisory Board

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Yale School of Medicine

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Vanderbilt University Medical Center

Peter Tebben, MD
Mayo Clinic

Timothy Wright, MS, DDS
University of North Carolina Chapel Hill,
School of Dentistry

Region Leads

Chris Denune, Northeast
Blynda Kellner, Southeast
Kirsten Mitchell, Southeast
Haley Gast, Midwest I
Sharon Talkington, Midwest II
Susan Brown, Central
Jen Jansonius, Central
Nellie Sanders, Central
Kara Schweiss, Central
Cami Rush, South Central
Danielle Zibilski, South Central
Amy Britt, Southwest
Sue Krug, Southwest
Ann Haak, Northwest

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 of this rare bone disease through awareness and fundraising efforts.

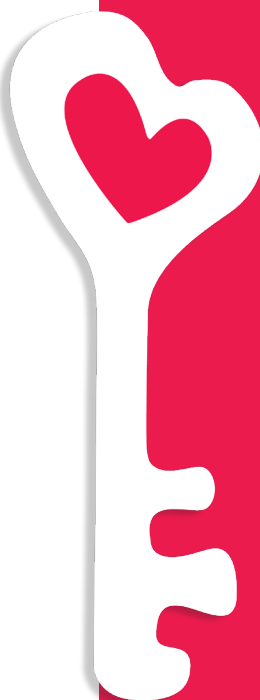
About Soft Bones

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 powers the HPP community by raising awareness of this rare, metabolic disease, providing hope by advocating for and funding research, and connecting patients with each other and with the medical community to advance the understanding of HPP. We provide medical information as well as a support system for patients and families living with HPP.

We believe a cure is possible with 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 better understand the impact of low levels of alkaline phosphatase in the body. While the hallmark of HPP is soft bones, as a metabolic disease, the full impact is not yet fully understood.



Powering Through the Pandemic: 21 % Growth from 2020!

We continue to live in unprecedented times, as the COVID-19 pandemic continues to impact the way we work and the lives of patients who live with hypophosphatasia here in the US, and around the world.

While we have experienced a drop in individual contributions due to the impact of COVID-19 on the workforce, the Soft Bones development team was able to pivot. Our team identified and applied for a variety of grants, which helped to supplement the unexpected loss. Additionally, we saw a large increase in online fundraisers through social media and private parties.

During this time, patients turned to us for healthcare advice, asking about whether HPP patients were more at risk due to an underlying condition, as well as advice on vaccines and concerns about how it could interfere with their HPP medications. The Soft Bones Scientific Advisory Board guided us and our patients by explaining how COVID could impact patients with HPP. They helped our team issue statements to our patient community to answer these questions

and let them know we were with them every step of the way. Additionally, we leveraged resources developed by fellow patient advocacy groups to provide the most relevant information to our patients and families during these uncertain times.

While the last two years were held virtually, we have big plans for 2022. Our annual national patient meetings are now in-person once again! The Soft Bones team all look forward to gathering and continuing our mission working alongside the patients that we serve.

We believe a cure is possible. With modern-day science of gene editing and gene therapy, stem cell approaches and a better understanding with HPP, we work alongside researchers and clinicians to champion collaboration, reduce duplication of efforts, share findings and patient insights, 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 better understand the impact of low levels of alkaline phosphatase in the body. While the hallmark of HPP is soft bones, as a metabolic disease, the full impact is not yet fully understood.

Staff

Deborah Fowler, President and Founder

Denise Goodbar, Executive Director

Mary Elizabeth Mulcahy, Patient Services and Program Manager

Sue Krug, Patient Liaison

Katie Trowbridge, Database/CRM and Event Coordinator

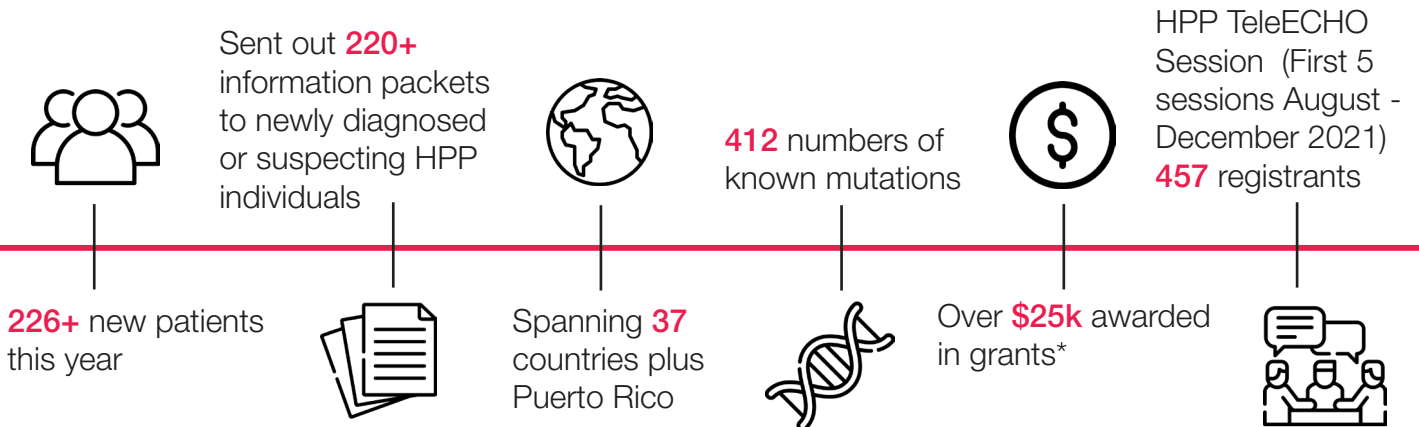
Cindy Reasor, Project Coordinator

Emma Farwell, Marketing Specialist

Liz Frawley, Administrative Assistant

Special thanks to our amazing staff who worked tirelessly throughout the last two years to keep Soft Bones running, stronger than ever before!

Our Year in Review



2021 Website Stats

38,101 Total Users
145,268 Page Views



Most Visited Page

Low ALP, Could it be HPP?

How Visitors View It



Mobile
58.4%

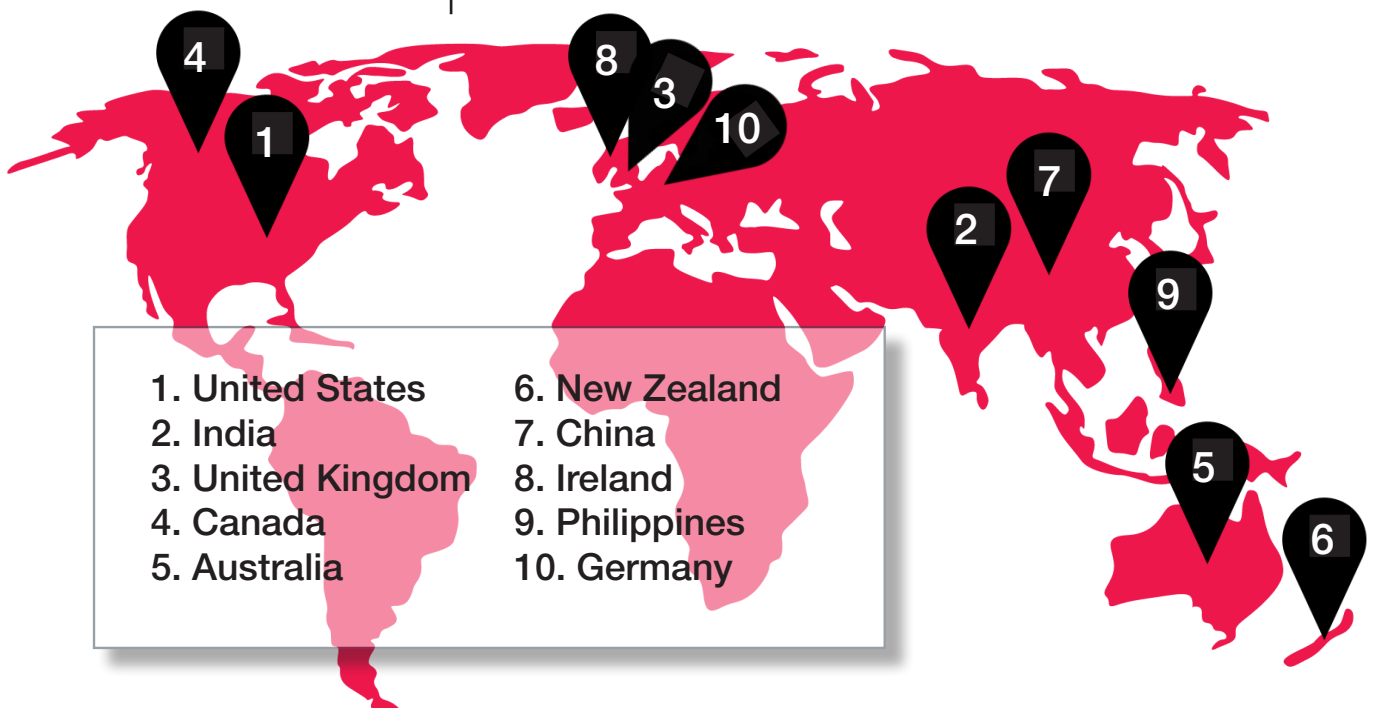


Desktop
39.6%



Tablet
2.0%

Top 10 Countries



*Soft Bones has awarded over \$450k in grants since its inception. The 2021 award was paid out in 2022.

A photograph of a young woman with long brown hair and a man with short grey hair and glasses. They are both smiling and looking at each other, holding hands. The woman is wearing a light-colored dress, and the man is wearing a dark suit. The background is blurred, showing other people in formal attire.

“

There is no single organization that has made a bigger impact on my life than Soft Bones. I would still be searching for answers and closure to health ailments that have impacted my family for six generations. From my first low ALP/high B6 reading to genetic testing to a diagnosis (after 15 years) to treatment and providing a constant ear and heartwarming support from our HPP community. Soft Bones has been with me each and every step of the way. When you are navigating a rare disease you can feel very alone but Soft Bones has been that steadfast bright light guiding me to the best quality of life I have ever had. I owe everything I have to this incredible organization and their extraordinary team.

—Nellie S.

Collectively Raising Our Voices for HPP Awareness

Celebrating World HPP Day

Each year, we celebrate World HPP Day on October 30th. Our 2021 theme “Let’s all be heard!” was a fitting one for our community. As anyone affected by HPP knows, for some, HPP can have many visual signs, but for others, HPP can be invisible. People with HPP often hear from doctors, family members and friends that they “don’t look sick.” This can make patients feel dismissed and diminish their feelings and challenges as if they don’t matter. On World HPP Day, patients and caregivers were asked to take time to share their untold stories as a way of spreading HPP awareness and bringing attention to our community. Every October, we look forward to this special day to celebrate how far we’ve come in expanding the awareness about HPP.

Rising Up for Rare Disease Day

During the weeks leading up to Rare Disease Day on February 28th, we polled our community to help bring awareness to challenges facing our HPP patients and share the results with our followers. We found the top five challenges faced among patients were how many years they spent waiting for an accurate diagnosis; limited access to physicians with knowledge of HPP; limited and highly expensive treatments; living in constant pain; and symptoms are not always visible making it difficult for friends and family members to understand. Soft Bones’ mission through research and education is to grow the understanding and spread awareness so these challenges are eradicated and HPP patients have the resources and support they need throughout life.



I owe everything I have to this incredible organization and their extraordinary team.



Breaking Barriers Through Education

Virtual National Patient Meeting

While COVID may have kept many of us apart physically, technology allows us to come together virtually. On May 15th, 2021, we held our largest meeting of the year - The 2021 Soft Bones Virtual Patient Meeting. Through an online conference platform, hundreds of patients, caregivers, and medical professionals worldwide enjoyed a full morning of educational sessions. Recordings from all sessions are available on the Soft Bones YouTube Channel.

Region Program

Soft Bones has a strategic imperative to support patients in the communities where they live. We have Region Leads who work to continue to build relationships with patients in their respective geographical areas with the goal of hosting in-person, community-based meetings, to help provide patients with the care and education they need.

HPP Webinar Series

Soft Bones provides ongoing education to members about living with HPP or caring for a loved one or family member with HPP through our webinar series. Webinars feature guest experts speaking on a range of topics of interest. Curated by our Region Leads, the webinars are a helpful resource for the Soft Bones community. Topics range from mental health to easing injection anxiety to managing pain and neuropathy, and understanding the impact of HPP on the kidneys. Members can attend Soft Bones webinars live and each session is recorded and posted to our website for 24/7 access.

Bō-nə-fīde HPP Podcast

Soft Bones podcast, **Bō-nə-fīde HPP**, is designed to educate and support the families and caregivers of those affected by HPP. As a mother and caregiver, host Deborah Fowler and her guests discuss this rare genetic bone disease with people from all over the globe. **Bō-nə-fīde HPP** can be found on Spotify or in the Soft Bones Resource Library on our website.





Connecting with Our Youth and Young Adults

Hippo Squad

The Hippo Squad program is for younger HPP patients and family members between the ages of 3 and 12 who receive kid-friendly, educational activity boxes to learn more about the disease. Distribution of Hippo Squad boxes is timed with relevant HPP awareness events and activities, such as, Rare Disease Day, World HPP Day, Dental Hygiene Awareness Month, and our patient meetings. There are currently more than 70 children subscribed, but that number is on the rise! The box includes a parent guide to provide instruction, oversight and background into how the activity connects to HPP.

Teen Advisory Council (Ages 13-21)

Soft Bones' Teen Advisory Council (TAC) is made up of more than a dozen teens and young adults, ages 13 to 21, who have been diagnosed with hypophosphatasia or are friends or siblings of patients. The TAC aims to provide a platform for teenagers to educate about HPP, become more involved in advocacy and fundraising and manage content for the younger HPP community.



We don't know where we would be without the Soft Bones team.

Leia's Story

Age 3, Florida

Leia V. was diagnosed with HPP in July 2020, shortly before her second birthday. She lives in Daytona Beach, Florida with her parents, Laura and Jason, and also her brother, Jake. Leia was born premature at 31.2 weeks, weighing 3lbs 6oz. She spent nearly 2 months in the NICU to gain weight and strength. As far as her family could tell, once she returned home everything seemed pretty typical as far as growth. She was a chunky, happy girl! Around 6-7 months she started crawling. But her crawl was a bit different. Leia seemed to do more of an army crawl, dragging her legs behind her. At that point, she started to slim down, but her family thought it was typical of an active baby. Like many other babies, this seemed normal. Then as she approached 10-11 months, she was eating less and very fussy. Additionally, she started spitting up during or after feeding. Once Leia approached her first birthday, that's when things started to change. Leia was still quite thin. At her one year check up with her pediatrician, the doctor didn't like how she looked and immediately wanted bloodwork done, declared Leia "Failure to Thrive". At the time her family was unable to get the extensive blood work done because it was extremely expensive and an out-of-pocket cost. In the meantime, her condition was becoming much more severe. Leia was still vomiting, getting to the severity where it required an ER visit. The ER promptly put her on fluids and after 2 days she was transported to the children's hospital where she would be seen by many pediatric specialists. Leia eventually had to be sedated and intubated to help keep her calm. For a young baby and a beautiful family, this was very scary.

The doctors ran dozens of tests, performed in-depth scans, MRI's, bone biopsy, and more, but the doctors never found anything. Leia's doctors concluded she had mild reflux and hypertension. And, due to being intubated, she developed an oral aversion and would not eat or drink by mouth. How was she supposed to thrive? When Leia did finally eat or drink, she would gag and vomit. Gastroenterologists determined she would need a g-tube, and shortly after placement she was discharged.

After her hospital stay, she had several follow up appointments with different specialists and routine blood work two times each month. Along with all these tests and appointments, additional issues began to arise where Leia had to go to inpatient appointments and emergency room visits. Leia was becoming very weak and the doctors found spinal fluid pressure which affected her vision. She developed Nystagmus and was given IV steroids and medication to help. Upon seeing an ophthalmologist, doctors told Leia's family that she had a pale optic nerve and that they weren't sure what, or if, she could see. Leia wasn't tracking at all, some bright lights bothered her, but her family said she mostly follows sounds.

All before Leia's second birthday, she was diagnosed with stage 4 chronic kidney disease, hypercalcemia, microcephaly, optic nerve atrophy, GERD/Reflux, global developmental delay, anemia and HPP. The HPP diagnosis was finally made in July 2020 by her geneticist. While her family was relieved to finally have a diagnosis, they were upset due to it being passed down through the family. But now with the diagnosis, they were able to begin treating her accordingly. Leia's endocrinologist immediately looked into getting her started on StrensiqTM. After a few weeks, Leia received her first shipment of StrensiqTM! She started injections on August 11th, 2020 and Leia's parents noticed great changes in her energy, her mobility and overall demeanor. What a change in such a short time! Leia just recently started to sit up on her own, from laying on her stomach. She now has therapy three times per week, which has helped tremendously.

“

I am so glad to have found the Soft Bones page. I was able to share my daughter Leia's journey with HPP thus far and also able to read about other children's and adult's experiences as well. It has been very helpful in navigating this rare disease. Our family has been thrown this curveball and it helps to know others are going through this and are finding help or solutions to different issues they are having along the way.

—Laura V., Leia's Mother

To read more stories from those living with or caring for someone with HPP, please visit our [website](#).

HPP Education Never Stops: Supporting Our Healthcare Providers and Researchers

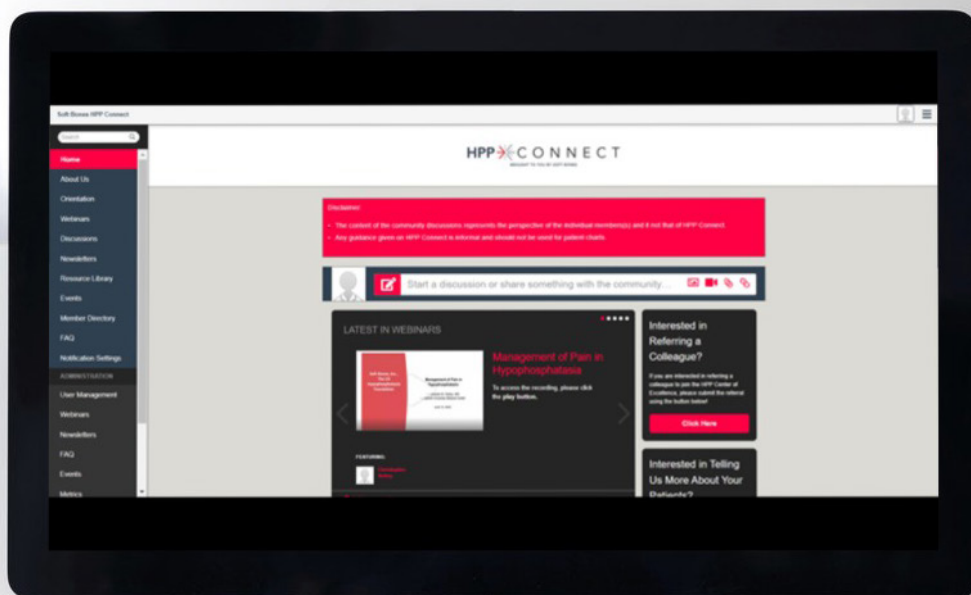
HPP Connect

Soft Bones' HPP Connect is the first and only online community dedicated to peer to peer collaboration and knowledge-sharing in hypophosphatasia. HPP Connect is an online collaborative community for ongoing, multi-specialty, peer to peer exchange, dialogue and education focused entirely on HPP. It connects clinicians with experience evaluating and treating HPP to one another, fostering knowledge-sharing and collaboration that benefits patient care. Since HPP is a rare disease that varies widely in its clinical presentation, some clinicians may have had exposure or treated only a handful of patients. HPP Connect enables access to world-leading experts in HPP, allowing the medical community to exchange information and learn from one another. Ultimately the aim is to speed up identification and appropriate treatment of patients who have HPP. The platform allows physicians to efficiently connect, collaborate

and share information in a secure, private, HIPAA-compliant online location. HPP Connect welcomes physicians involved in the direct care of HPP patients, along with residents and fellows of an accredited academic institution.

HPP TeleECHO Series

In 2021, Soft Bones launched the first-ever Soft Bones CME series for healthcare providers focused on hypophosphatasia. The Soft Bones HPP TeleECHO provides continuing medical education (CME) for eligible doctors and researchers on the HPP healthcare team. The program is designed to improve patient care through telementoring presentations and discussions on different HPP-related topics. Medical professionals from around the world have participated via Zoom and all sessions are recorded and posted on the Soft Bones HPP Connect platform.



Bridging the Gap: Bolstering HPP Access Support

ELSA

Soft Bones is extremely proud to have been involved in the advocacy and launch efforts for the Ensuring Lasting Smiles Act (ELSA). Under ELSA, it would require all private insurance groups and individual health care plans to cover medically necessary services resulting from congenital abnormalities. That coverage would include services and procedures for any missing or abnormal body part necessary to achieve normal body function, including teeth. This is an important advancement as many families without this coverage make significant financial sacrifices just to afford necessary dental care. ELSA recently passed in the US House of Representatives and now goes before the Senate for a vote.

Haystack Project

Soft Bones' and The Haystack Project's collaboration is extremely exciting. The Haystack Project is a non-profit enabling rare and ultra-rare disease patient advocacy organizations to highlight and address systemic obstacles to patient access. Their core mission is to evolve health care payment and delivery systems to make innovative quality treatments accessible to the patients they were meant to reach. This partnership offers our organization the opportunity to listen carefully to the specific concerns of the rare community- and take action on specific actions that impact the HPP community.

Standing alongside one another, Soft Bones is a supporter of the Haystack Project's goal to pass the HEART Act (Helping Experts Accelerate Rare Treatments), which will allow for rare disease experts, patients and clinicians the ability to play a role in the FDA's review process.

Institute for Gene Therapies

Soft Bones is a member of the Institute for Gene Therapies (IGT) Patient Advocacy Advisory Council (PAAC). IGT's mission is to advocate for a modernized regulatory and reimbursement framework that encourages the development of transformative gene therapies and promotes patient access. The PAAC is composed of patient advocates who represent a number of diseases and contribute important perspectives that help ensure patients' interests are at the center of IGT's work.

Insurance Claim Support

Navigating health insurance is extremely complex. We continue to work hard for the Soft Bones community supporting patients' medical insurance appeals. We have a deep understanding of the disease, treatments and patient needs, which can help insurance companies better understand how patients will benefit from appropriate treatment that may not traditionally be covered without clarity. Through this process, we have worked on appeals at the state level, which triggered a new possibility for new prior authorization criteria to be put in place. These small strides make big gains for those with HPP and other rare diseases.

Beyond our Border: Growing Global Access

Soft Bones' efforts go far beyond our US border. We are frequently contacted by patients and physicians from outside the US who are in need of resources. We have translated materials into Arabic, Polish, Portuguese and Spanish. We have plans to translate into additional languages in the future.

9th Maher Family Grant awarded to Fatma F. Mohamed, PhD

Soft Bones awarded its 9th Maher Family Grant to Fatma F. Mohamed, PhD, a Postdoctoral Scholar in the laboratory of Dr. Brian Foster at The Ohio State University College of Dentistry. The \$25,000 grant will support Dr. Mohamed's studies to explore whether the nervous system adds to the disease mechanisms of bone and tooth defects encountered in HPP, a rare and sometimes life-threatening inherited (genetic) disorder.

Dr. Mohamed's research will investigate the nervous system using new mouse models of HPP to uncover the roles it might have in the formation, maintenance, and repair of dental and skeletal tissues. "This grant will open a new avenue for further investigation on HPP's influence on the nervous system and allow for evaluation of enzyme replacement efficacy in such specific contexts," said Dr. Mohamed. "With new models and a better understanding of HPP, we can generate new ideas; I am excited to get started."



Fatma F. Mohamed, PhD

Gene Therapy Update

Soft Bones has made it a priority to focus on new therapeutic approaches to treating HPP, including gene therapy. Research from Sanford Burnham Prebys highlights a new study which shows promising results for those with HPP. Published in the *Journal of Bone and Mineral Research*, this study was performed in a mouse model of the disease, further supporting the advancement of gene therapy toward human clinical trials. This preclinical lab highlights Soft Bones' Scientific Advisory Board member, Dr. José Luis Millán, along with other scientists at Sanford Burnham Prebys, established that AAV8-TNAP-D10--a gene therapy that replaces a key enzyme found in bone--may be a safe and effective single-dose treatment for hypophosphatasia (HPP). Dr. Millán was the recipient of our Soft Bones grant, and his lab was funded in part by this grant.

Centers of Expertise

Since its founding, Soft Bones has been committed to amplifying the voice and needs of the HPP community. The pandemic only aggravated the already complex situations patients face when navigating their care. From ensuring the medical team is fluent in the ever-evolving science of HPP to coordinating the myriad of specialists providing care – patients and their caregivers are exhausted, and they are asking for help.

This past year, Soft Bones began exploring the potential of “centers of HPP care” to support the needs of people living with HPP. This included interviews and discussions with disease-specific patient organizations that have established clinics dedicated to the care of people with those diseases, experts at sites with dedicated HPP resources, and people living with the disease. The purpose was to understand the issues, needs and challenges critical to ‘care’ of a person living with HPP.

While the immediate value to patients of a network of HPP care sites providing consistent and high-quality care to patients is clear, longer-term, this kind of network could establish new paradigms of care, advance health policies, and facilitate research that could lead potentially to a cure for HPP. In 2022, Soft Bones will work with our SB community – patient, caregivers and the medical and scientific experts – to begin creating the framework for these centers of HPP care – addressing patients’ needs today and bolstering the voice and impact of HPP research as it marches towards a cure.

We continue to connect with other researchers around the world to foster HPP research and look forward to new insights that could lead to curative therapies.



Laiken's Story

Hypophosphatasia. Skeletal Dysplasia. Alkaline Phosphate. Calcium. Vitamin D. Endocrinology. Nephrology. Orthopedics. Asfotase Alfa. Alexion. Panther Rare Pharmacy. Soft Bones. All phrases that I either A) had never heard of, or, B) never thought I'd need to be accustomed with. But, life has a way of introducing you to things, people, and experiences that you didn't think you'd ever need. My two babies (toddler and infant, actually), brought me to the Soft Bones Foundation. Rowan, two years old, and Rhys, five months old, both have hypophosphatasia (HPP). My husband and I share three children: Preston, Rowan, and Rhys. It was unbeknownst to us that we were both carriers of a rare genetic mutation until we conceived our second child, Rowan. Rowan's pregnancy carried with it an insurmountable amount of grief, anxiety, fear, and isolation, amongst other emotions. This theme continued across his first year of life. Despite thriving, we routinely were reminded that his health could take unexpected turns at any moment. I found the Soft Bones foundation through Facebook, shortly after receiving Rowan's official diagnosis of HPP. Feeling alone, scared, and hopeless - I mindlessly searched whatever combination of phrases I could until I found something to connect with. That is when I stumbled upon the Soft Bones Facebook Group. The foundation immediately welcomed me with open arms; I became a member of a group that I never asked to be a part of, but couldn't imagine a life without. I found and was able to connect with parents of children with HPP who shared a glimpse into their story which provided me, a pregnant mother to a child affected with a rare disease, the smallest sliver of hope. The foundation has provided my family with a family - people experiencing similar events who are always eager to help, provide insight, opinions, help navigate the technical portions (insurance, doctors), or simply listen.

This foundation allowed me the confidence as a parent to advocate for my children. Furthermore, it provided me with the confidence to conceive another child, despite the risks of being affected, once again, with a rare metabolic bone disease. Therein lies Rhys. Rhys was conceived naturally, despite knowing the genetic risks. But again, Soft Bones was there every step of the way: to join in our celebration, hesitancy, and whatever else it was that we needed. This time around, I felt more equipped to advocate for a child with a perinatal diagnosis. Members within the foundation helped me to acquire literature that would later help me win my case regarding a fair trial of labor following a cesarean that allowed me a successful VBAC and first ever immediate bonding experience with my newborn. Rhys was my first child I was able to immediately hold and he was also my first child that did not have to stay in the NICU. I've said it a million times before, and I'll say it a million more; the Soft Bones foundation gave me the strength as a mom to fight for what was right and what was needed. For that, I am forever grateful.

“

This foundation allowed me the confidence as a parent to advocate for my children... I've said it a million times before, and I'll say it a million more; the Soft Bones foundation gave me the strength as a mom to fight for what was right and what was needed. For that, I am forever grateful.



“

I never donated to charities before because I always felt like it was huge corporations/foundations that were asking for donations that already had such huge funding. But now that we have Rowan and Rhys, it has changed my perspective. Soft Bones provided me with a community of family, a community for all people affected by HPP. We started on this journey feeling so alone and Soft Bones lifted some of that burden.

—Laiken L.

Community Impact Through Fundraising

In 2021, fundraising efforts for many non-profit organizations continued to be adversely affected by the COVID-19 pandemic due. While there may have been a pause on in-person fundraising events, that didn't stop Soft Bones' supporters from coming together to raise critical funds through new fundraising initiatives.

Both longtime supporters and new friends found a way to give, some in person, and some through creative online fundraisers. We cannot thank everyone enough for their kindness and willingness to help us maintain our level of service to the HPP community, especially during times of uncertainty.



Swinging for a Cause: The 2021 Soft Bones Golf Classic

In September, the 13th Annual Soft Bones Golf Classic was held at Somerset Hills Country Club in Bernardsville, NJ. This is our largest fundraiser of the year, and this turnout did not disappoint. We had a beautiful early fall day and a fantastic group with 111 golfers!

All of our sponsors, donors, and participants had a great time playing the course and raising critical funding for our organization. We are grateful for the planning committee members, golfers and event sponsors who turn out year after year to support our mission.

Tournament Sponsor:
Atlantic Health System

Birdie Sponsor:
The Fowler Family Charitable Foundation

Eagle Sponsors:
Aruvant Sciences, Inc. and
Donnelly Industries, Inc.

Longest Drive Sponsor:
Patrick Mucci & Family

Putting Green Sponsor:
Warren Oral Surgery, Dr. Daniel Sullivan

Beverage Station Sponsors:
William F. Jones, DMD, Palackdharry Strong and
The Thompson Family

Additional Tee Sponsors:
Acorn Financial Services, Vince Bisogno, Esq.,
Dan Burkart, Jack Burke & Ted Walsh & Families,
Berkshire Hathaway AZ - Harvey & Linda Salkow,
Cannon's Golfing Friends from Canada, Christ
the King - New Vernon, NJ, The Fowler Family,
M&M Perrotti's, John Kenney, Dan & Dani McNeil,
McRae Capital Management, Neuberger Berman,
The Palackdharry Family, The Richardson Family
and Ten Four

19th Hole Sponsors:
Charles and Karen Ann Baracco, Stephanie
Gaines, Joe Micale, DMD, Stephen Verdesca and
Patricia Durner

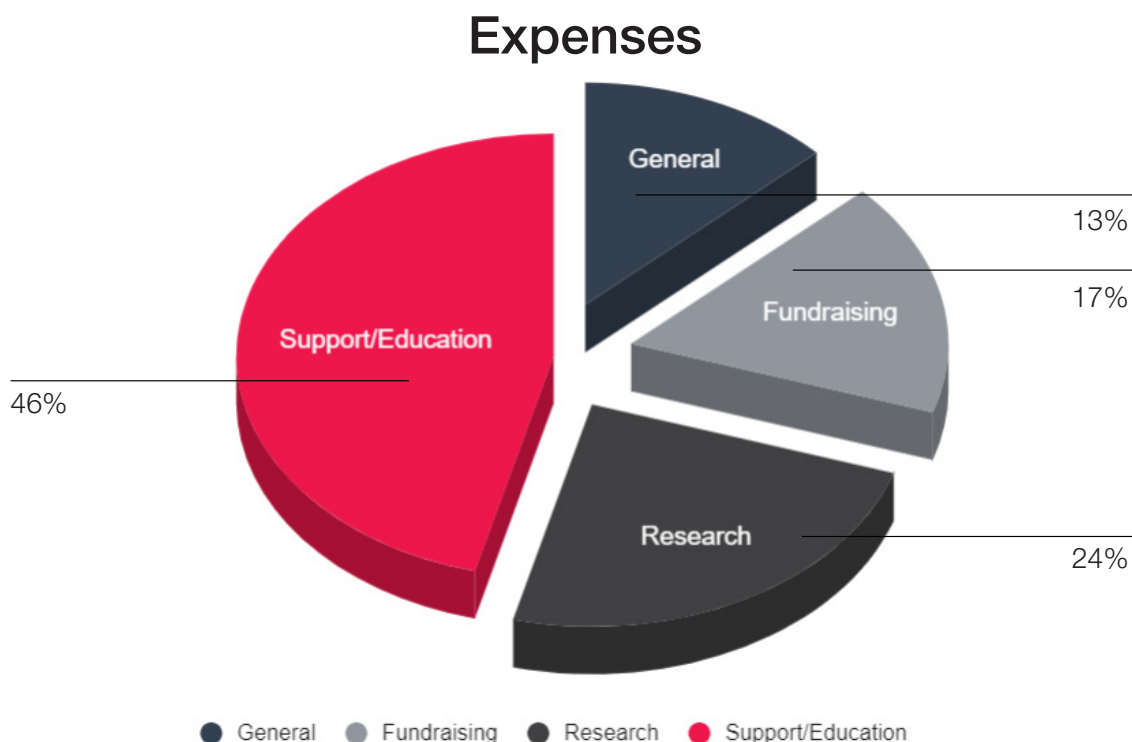
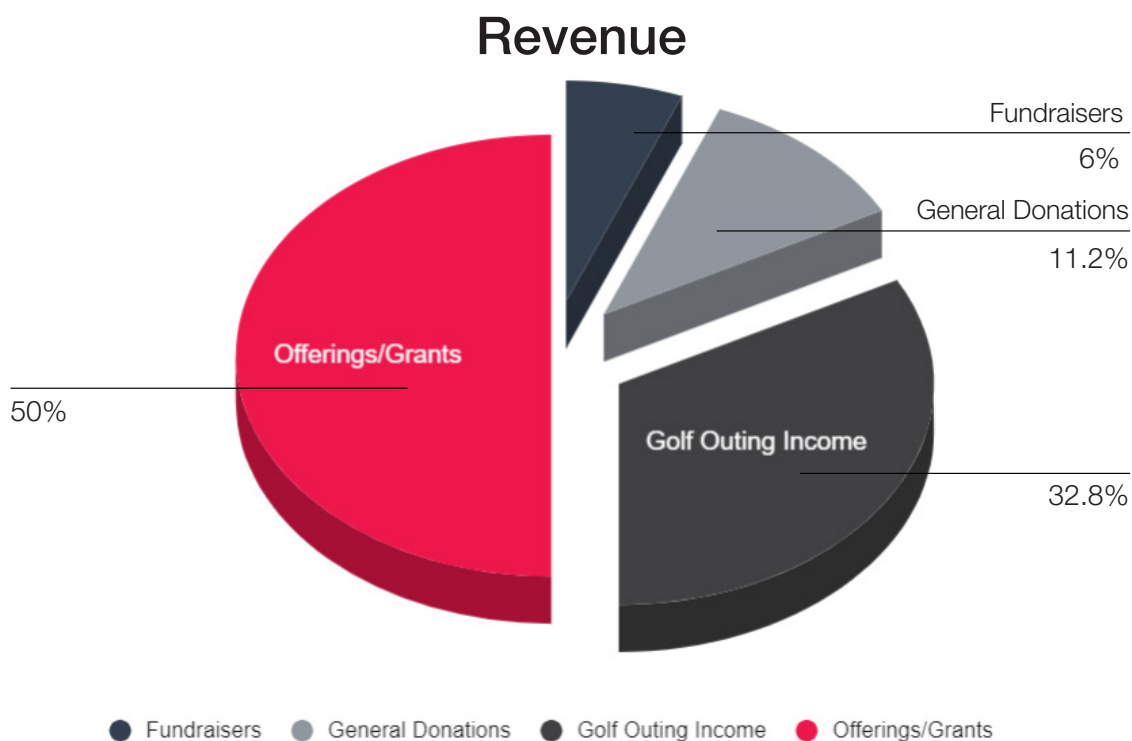
Online Fundraisers



Additional Fundraising Highlights

- ♥ The **HundredX** Causes fundraising program allows our community to support **Soft Bones** by sharing opinions on popular brands and companies. Each survey completed earns \$2 for our organization. We raised over \$5,500 during this year's campaign, and will repeat this program annually each October during Hypophosphatasia Awareness Month.
 - ♥ The **Soft Bones Teen Advisory Council (TAC)**, a support and advocacy group for teen patients with hypophosphatasia and their teenage siblings, created an Instagram bingo board fundraiser for World HPP Day, raising over \$400.
 - ♥ **SpreadShop** is an online logo shop linked to our website where a percentage of proceeds benefit **Soft Bones**. Specialty items are added during important campaigns and events such as, Official World HPP Day, where a portion of proceeds from item sales were donated back to our organization. Additionally, the **Soft Bones Teen Advisory Council (TAC)** created their own t-shirt design to help generate sales and raise funds.
- Each year, a shirt design is created for our largest patient meeting of the year, the Annual National Patient Meeting which also raises funds through a portion of sales.
- ♥ **Bonfire** is a T-shirt fundraiser that is organized by individuals where a portion of proceeds benefit Soft Bones. Bonfire is a site used for **Soft Bones** patients and caregivers, as well as supporters, to create their own shirts and raise funds to benefit our organization using unique designs.

Key Financial Information



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