

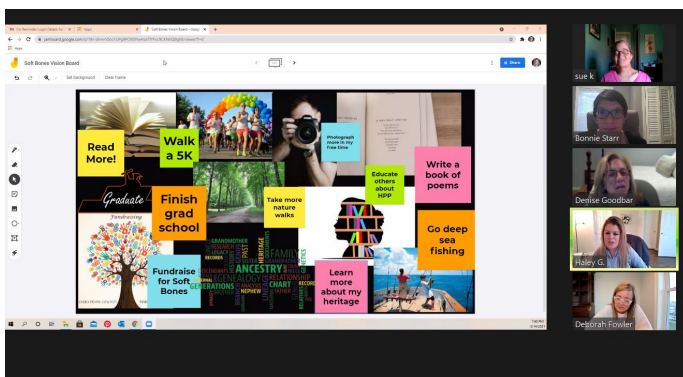
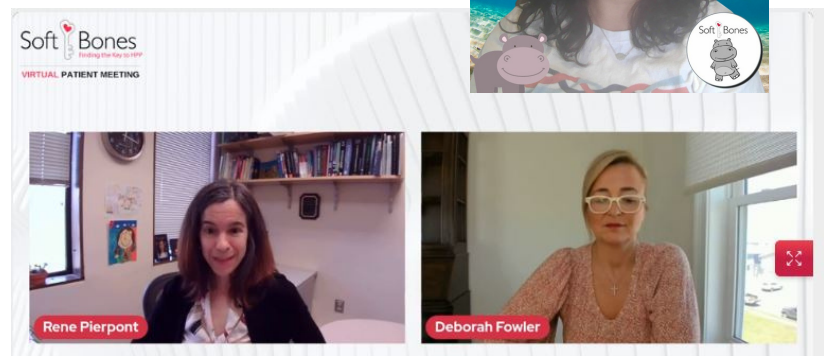
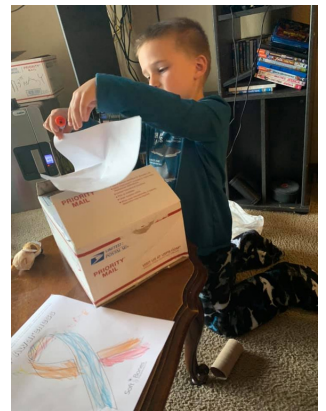
THE BARE BONES

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

Record Number of Viewers Tune In To 2021 Virtual Patient Meeting

The 2021 Soft Bones Virtual Patient Meeting, our largest meeting of the year, was held on May 15, 2021, through an online conference platform. Hundreds of patients, caregivers, and medical professionals worldwide enjoyed a full morning of educational sessions, including:

- **Keynote Address: HPP Overview and Genetics, Dr. Eric Rush, of Children's Mercy, Kansas City, MO.** During his presentation, Rush provides an important overview, including his theory on HPP as a multisystemic inborn error of metabolism.
- **Concepts of Pain Management in HPP, Dr. Christopher Sobey, Vanderbilt University Medical Center, Nashville, TN.** Here, Dr. Sobey discusses treatment-based disease modification as the goal of treating patients with HPP.
- **Neuropathy Overview, Dr. Maike Dohrn, RWTH Aachen University and University of Miami, FL.** Dr. Dohrn's presentation takes a deep dive into this topic, including symptoms of neuropathy, and how we investigate the presence of neuropathy in patients with hypophosphatasia.
- **Impact of Pediatric Hypophosphatasia on Behavioral Health and Quality of Life, Rene Pierpont, Ph.D., University of Minnesota Medical School, Minneapolis, MN.** During her session, Pierpont discusses the findings of her research, which included several members of the Soft Bones community.



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- Kidney Health Fact Sheet Now Available!
- Haystack Project Overview
- Call For Blogs and more

- **Chair Meditation/Mindfulness Workshop, Diana Schlobohm, RYT.** This session offered a 30-minute guided meditation to decompress and feel grounded after all the learning and sharing throughout the virtual patient meetings.

To provide an experience that was as close to a live meeting as possible, attendees were also able to visit exhibitor booths, download materials, chat inside networking lounges, purchase newly launched HPP Awareness swag and snap pics using a virtual photo booth. Children in the Soft Bones Hippo Squad each received a kit filled with activities and lessons about HPP for use during the meeting, and both children and adults participated in a networking event involving a virtual vision board activity on the evening before the main meeting.

If you missed the meeting or would like to re-watch any of the sessions, you can still access them on-demand via the Soft Bones YouTube channel. [Watch Now](#)

[Thank you again to our generous supporters who helped make this event possible:](#)

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Virtual Patient Meeting Will Return To An In-Person Event in 2022

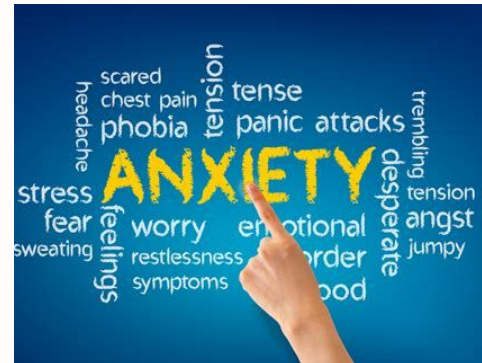
We are so pleased to announce that the 2022 Soft Bones National Patient Meeting will be held in person (as long as it remains safe to travel) in sunny Orlando, Florida!

More details to follow!



Managing Anxiety and Chronic Disease in the "New Normal"

Immediately following Mental Health Awareness Month this past May, Today Show and Yahoo mental health correspondent Dr. Jennifer Hartstein led a wellness and self-care webinar for our community, offering tips to manage anxiety. Emotional wellness is so important in the rare disease community, and Hartstein focused on a topic that affects patients and caregivers while managing a chronic disease such as HPP and has heightened during the recent pandemic period of uncertainty. Following the webinar, attendees were given the opportunity to ask questions of the expert. Hartstein also provided a handout with mindfulness exercises such as Square Breathing and easy-to-use apps like Headspace that provide relaxation for stressful days. You can watch the webinar [here](#) and further read tips for managing anxiety [here](#).



HPP and the Kidneys: What You Need to Know

HPP is not just about Soft Bones. Did you know that kidney health is a concern for many patients in the community? In fact, those who have HPP can be at a greater-than-typical risk for kidney damage— both because of the effect of insufficient ALP on the kidneys and as a result of high doses of certain pain medications. A new fact sheet authored by pediatric nephrology specialists Dr. John Mahan of Nationwide Children's Hospital and The Ohio State University College of Medicine and Dr. Rose Mary Ayooob of Marshall University Health System, Huntington, WV, on the "The Impact of HPP on Kidney Health" for patients is available on our website.



The information is based on their recent webinar mentioned in our prior newsletter, which can be found on the website [here](#). It also includes tips for maintaining kidney health like having regular DEXA imaging and bone-lab monitoring procedures, which should include parathyroid hormone and vitamin D status. Read the new fact sheet [here](#).

Travel Resources and Fact Sheets

Don't Forget: The Soft Bones website offers a comprehensive [online library](#) of fact sheets and other resources that can be easily downloaded by patients and caregivers, as well as printed or shared via email with physicians and healthcare specialists. Educational materials are helpful tools to bring to doctor's visits, too! Featured fact sheets include the following summer-safety practices to keep in mind now that traveling has become safer:

- [Traveling with Strensiq™ \(Asfotase Alfa\)](#)
- [Traveling with Hypophosphatasia - Airline Travel](#)
- [Traveling with a Wheelchair - Airline Travel](#)



Soft Bones Advocates For HEART Act

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.

The goal of the Haystack project is to support the passing of the HEART Act. The HEART Act (Helping Experts Accelerate Rare Treatments) will allow for rare disease experts, patients and clinicians the ability to play a role in the FDA's review process. Having these individuals in an active role within the FDA's review process, will allow them to express important perspectives they have, as well as offer their expertise with those already working hard for our patient community.

As a supporter of the HEART Act, Soft Bones is proud to be a member of the Haystack Project. This partnership offers our organization the opportunity to listen carefully to the specific concerns of our community- and take action. To learn more about the Haystack Project, [visit their website](#).



Call For Blogs:

BONE ZONE

Did you know that the Bone Zone is our community blog for HPP patients and their families? This can be a great resource to learn tips and tricks from others in the HPP community! [Visit the blog](#) today to read their stories. Not listed on the blog yet? Contact Logan@softbones.org to add your story today.

Here Are Some Examples...



Living with HPP: Larry M.

My HPP journey started after attending a conference in Phoenix, Arizona in 2017. I brought my son, Zane, who was diagnosed with HPP 19 years ago. While being educated at this conference, I was asked from staff what my history was. I quickly explained that I was just a caretaker. They said, "but we want [...]"

[Read more](#)



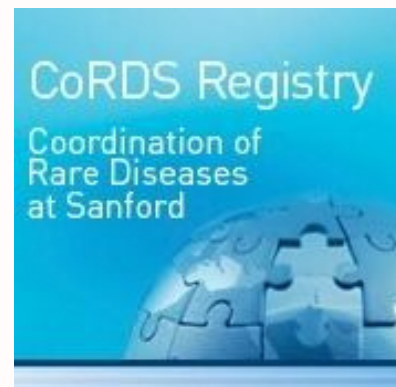
Mei Mei's Story

Not long ago, Becky R. and her husband adopted a little baby girl, Mei Mei, from China. When she was first adopted, doctors were worried that Mei Mei had a syndrome because of her club hands, club feet, and short stature. However, after extensive blood work, full body x-rays, ruling out heart issues, and visiting [...]"

[Read more](#)

Help Move The Needle On Important HPP Research By Enrolling in the CoRDS Patient Registry

Soft Bones has partnered with Coordination of Rare Diseases at Sanford (CoRDS) to create an International HPP Contact Registry. The registry provides patients and caregivers with a secure means of making their basic disease information available to researchers without sacrificing privacy. By joining the registry, you can help researchers see the whole picture and gain valuable information for a disease that they know too little about.



Information learned through the registry plays a vital role in improving treatments and finding a potential cure. Patients and family members are encouraged to learn more and register. Download the brochure to learn more or enroll in the study [here](#).

Breaking News: Gene Therapy

As you are aware, Soft Bones has made it a priority to focus on new therapeutic approaches to treating HPP, including gene therapy. Click [here](#) to read the press release from Sanford Burnham Prebys highlighting a new study, published in the Journal of Bone and Mineral Research and performed in a mouse model of the disease, further supporting the advancement of gene therapy toward human clinical trials. The study spotlights research by Dr. José Luis Millán (a member of our Soft Bones Scientific Advisory Board) and his lab, which was funded in part by our Soft Bones grant.

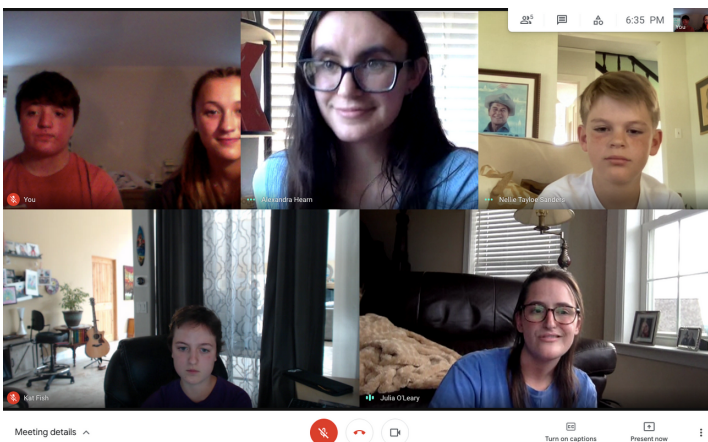
We would be remiss if we didn't express our sincere gratitude to Dr. Millán and the Scientific Advisory Board for their continued commitment to advancing understanding of and research in HPP.



Jose Luis Millan



TAC Talk: Teen Advisory Council Update



"The Teen Advisory Council (TAC) is in full swing with a phenomenal group of kids! We have had two meetings thus far and are setting the foundation for a strong group of advocates. These teens are passionate, dedicated, and ready to share their unique connections to HPP with the world. As coordinators, we feel so lucky to be able to work with such special individuals.

Over the next couple of meetings, we will continue to build strong relationships among the teens, as well as, dive deeper into what it means to be an advocate. We will be creating a fundraising plan and finalizing t-shirt designs too! The TAC is lots of fun and will continue to serve as a safe space for the needs of our teens. We can't wait to see how our teens continue to grow! - **Julia and Alex, Co-Coordinator**

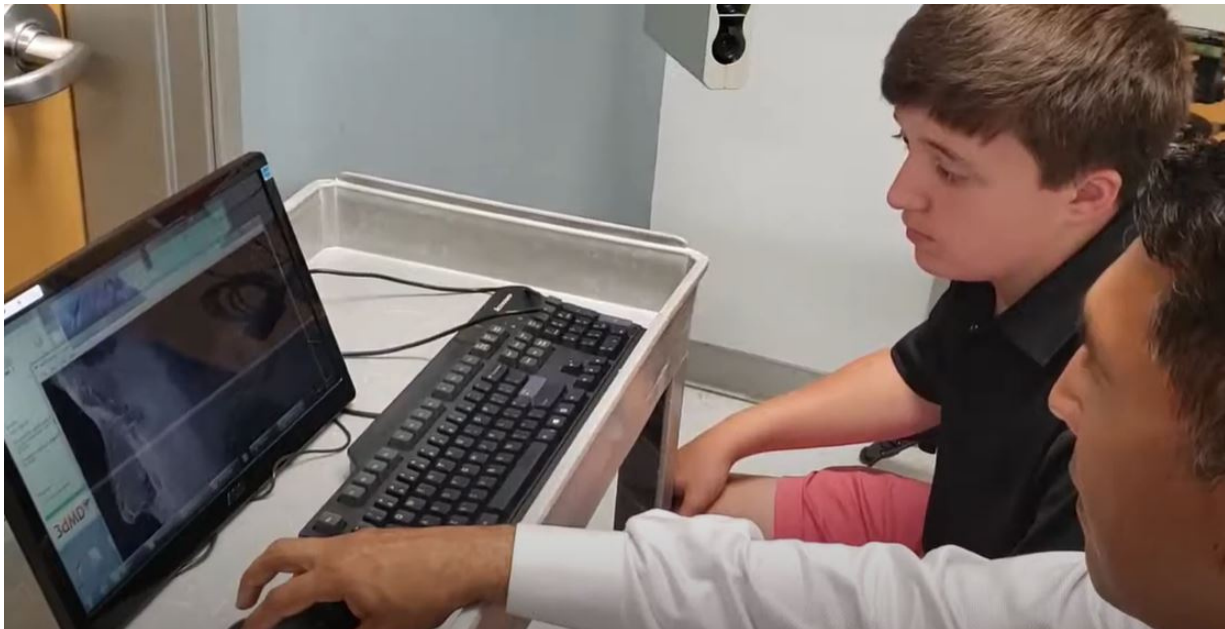
Want to learn more about the TAC? [Visit their website.](#)

Could Your Face Be Used to Diagnose HPP?

Deep phenotyping is the analysis of phenotypic abnormalities in which the components of a phenotype are observed. In about 30-40% of known genetic syndromes, the shape of the face is affected and dysmorphic craniofacial features can help in initial clinical diagnoses. In this study, 3D imaging is used to try and determine whether genetic syndromes can be diagnosed from facial images. The subjects' ages ranged from newborns to >80 years and included slightly more females. An assembled library, available through FaceBase, contains 3D images from over 5900 individuals as well as over 900 unaffected relatives.

Patterns of facial shape variation were evaluated when understanding the accuracy of classifying subjects to syndromes. The conclusion of the study indicates that deep phenotyping from 3D facial imaging has a high potential in syndrome diagnosis. Additionally, the imaging taken from "unaffected" subjects can identify unrecognized cases.

Several of our Soft Bones community members were a part of the study. Click [here](#) to view the complete study. You can also check out a [brief YouTube video](#) featuring Cannon Sittig, Soft Bones community member (and son of Founder Deb Fowler). Cannon was the first person from our community to "test" out this software. So neat!



Thank You to Our Interns!

We are excited to introduce our recent grads and new Soft Bones summer interns! We look forward to all of their contributions to the Soft Bones' community, and hope they learn as much as they can about HPP and how a non-profit organization operates throughout their tenure with us.

Karley Warden



Hi there! My name is Karley Warden, and I am an intern for Soft Bones. I recently graduated in May from Syracuse University with a B.A. in Public Relations and Political Science. This summer, I'll be joining Real Chemistry, an analytics-driven creative marketing and communications firm, as an Account Coordinator.

Since joining Soft Bones, I have learned so much more about the rare disease and HPP communities than I ever could have imagined. I was initially nervous knowing so little about HPP and the experiences of those who have it, but I am so appreciative of the opportunity to work with such a brave and passionate group. I want to give a special thanks to the Soft Bones team I have had the pleasure of working with, Bonnie, Deb, and Denise, for teaching me so much in so little time and for their constant support.

My name is Taralyn Naslonski and I have been an intern with Soft Bones since the fall of 2020. Throughout my internship, I have learned so much about hypophosphatasia and the impact it has on individuals and families. Being a part of the Soft Bones organization has also provided me with insight into how non-profit organizations operate. The experiences that I have had and the mentoring from my Soft Bones colleagues has been invaluable to me. I feel very fortunate to be working with a prestigious organization such as this.

I have just graduated from Rutgers University where I also played on the D1 women's lacrosse team. My undergraduate degree is in Public Health with a minor in Human Resources.

Taralyn (T.T.) Naslonski



Due to the ongoing COVID-19 pandemic, I received an extra year of eligibility to continue my education whilst playing lacrosse. Thus, I plan on continuing my lacrosse career at Rutgers University while studying to receive a Masters degree. I'm excited about the prospective opportunities my experience and degrees will bring me in my future career aspirations.

Eleni (Ellie) Thomson



Hi all! My name is Ellie Thomson, and I'm an intern at Soft Bones this summer. I am currently a junior at Brown University studying Public Health, with a strong emphasis on Maternal and Child Health. At Brown, I am enrolled in the AB/MPH dual-degree program, where I am able to get both my Bachelor's and Master's degrees in Public Health in five years. My previous experience working at a rare disease nonprofit led me to Soft Bones- where I hope to bring my background and interest in patient advocacy, education, and problem-solving to use. So far, learning about HPP and the incredible community here has been both eye-opening and inspirational, and I am excited to learn more and engage with the community in the coming months.

Hi! My name is Logan Cox and I am a Social Media Fellow for Soft Bones. I graduated from High Point University in 2019 with a B.S in Strategic Communication. My dad and I currently have 3 retail stores on the Jersey Shore that we run full-time.

I decided to join the Soft Bones team because I believe that in the age of social media, organizations like Soft Bones are able to put their cause on a bigger platform, and are able to make a difference and spread their message to the masses. Since joining and interviewing patients with HPP, the experience has humbled me knowing what patients go through and learning that the scope of HPP is so vast. It has been great to work with such a passionate team who are so selfless and patient-centric, and it's been great to help out in any capacity that I can!

Logan Cox - Fellow



Fundraising Corner

It's always a great time to support Soft Bones and the hypophosphatasia community through fundraising initiatives. No matter what you decide to plan or participate in, every dollar raised is critical to our mission of supporting our members throughout the world.

Here's What's Happening This Summer....

In honor of community member Blynda K's special day, 10% of sales from her Ebay store **DarBly's Happy Finds** will be donated to our organization until Blynda's birthday on **July 19**.



Spread The Word: Sponsorships and Player Registration are now available for the **Soft Bones 13th Annual Golf Classic**- September 20, 2021
Bernardsville, NJ

Supporters and friends in New Jersey: Visit the **Acme Supermarket** in Boonton, NJ until **July 31** and purchase a bag to support Soft Bones through the **Give Back Where It Counts Program**.

ACME

we've been selected for the
**ACME GIVE BACK WHERE IT COUNTS
BAG PROGRAM!**

When you buy this bag, we will receive a \$1 donation this month.

Soft Bones
Leading the way to life

Donors Among Us?



Do you have a friend or family member who might be interested in making a donation to Soft Bones? If so, be sure to share their names and addresses so we can include them in our end of year giving campaign. Thank you in advance for your support in helping us reach our giving goals!

†

Special thanks to our community members and supporters that recently hosted their own fundraisers to benefit our organization:

Ann Haak- Norwex Virtual Fundraiser (Ann hosted her own fundraiser, but as a Consultant, offers to host parties for anyone interested and will donate 25% of sales to Soft Bones)

Sharon Talkington, Susan Brown, LuAnne Rutter, Alison Giesse Purdon, Michelle Hutson- Pampered Chef Online Fundraisers

And- a big thank you to all of the supporters who participated in our ongoing fundraising initiatives by:

- creating or donating to a Facebook fundraiser to honor a birthday, anniversary, graduation or other milestone
- purchasing logo items or HPP awareness items from the Soft Bones online store
- making Amazon purchases through smile.amazon.com with Soft Bones as the designated charity

Don't see anything in your area and want to start your own local event like a restaurant give-back or walk? Would you like to host an online fundraiser via Facebook or have an online party but not sure where to begin? Simply reach out to bonnie@softbones.org. We've got lots of resources to help you get started!