FALL 2022 EDITION

THE BARE BONES

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

Face-to-Face In Our Regions

Scientific Advisory Board Meeting at ASBMR

During the American Society for Bone and Mineral Research (ASBMR) Annual Meeting we gathered with some of the members of our Scientific Advisory Board for the first time in person since our International Scientific Meeting in 2018. Our agenda included discussions on upcoming ECHO topics and plans for an International Scientific Meeting in 2023.

SAB members pictured: Drs. Drake, Simmons, Tebben, Seefried, Gottesman and Whyte. Deborah Fowler and Denise Goodbar are also featured.

Region Meetings - South Central, South East

By Danielle Zibilski (South Central Region Lead)

We were excited to use the opportunity of gathering at the ASBMR conference in Austin to host a luncheon for the South Central Region. It was a small but intimate group, and we gained so much from our visit over yummy tacos. Dr. Gottesman joined us and we discussed the difficulties carriers of HPP face in gaining a diagnosis and treatment plan. Dr. Gottesman was able to share a wealth of knowledge regarding tests that can be requested to pass on to doctors in order to determine if a HPP diagnosis is the right path or other treatment can be used. We look forward to our next meeting! If you're interested in meeting up, please email me at danielle@softbones.org or reach out to our Patient Services Manager, Mary Elizabeth Mulcahy at maryelizabeth@softbones.org.

IN THIS ISSUE:

- Notable Meetings
- "In Case You Missed It"
- Advocacy Updates
- Fundraising News
- And so much more!

View our Spring 2022 Newsletter **HERE**

Face-to-Face In Our Regions

ASBMR

By Danielle Zibilski (South Central Region Lead)

This year's ASBMR 2022 Annual Meeting in Austin, Texas was a huge success! With more than 2,000 attendees, 100 education sessions, 1,000+ poster presentations and an exhibit hall with many booths, we had numerous opportunities to catch up with doctors, professors, pharmaceutical companies and bright graduate students interested in exploring the latest science in the field of bone, mineral and musculoskeletal research. At the Soft Bones booth, we reunited with doctors who are world-leading experts in hypophosphatasia (HPP), and formed new connections with doctors from all over the world who are taking an interest in learning more and continuing research on HPP. We also collaborated with new researchers to help patients with rare bone disease complications. We were able to see presentations from multiple speakers, such as Dr. Whyte, who spoke about a new Vitamin B6 study, and Dr. Gaddy, the winner of the 2019 SB Research Grant, who spoke about her team's research into the effects of maternal HPP on development in sheep in utero.

The latest results were presented at a Soft Bones TeleECHO, and physicians and researchers can now request access by emailing HPPConnect@softbones.org.

National Patient Meeting

On July 9th, we held a National Patient Meeting in Orlando, Florida. Around 150 attendees, patients, caregivers and exhibitors attended this event, making it our first in-person gathering since the pandemic! Special thanks to our sponsors, Alexion Astra Zeneca, PantherRare and Aruvant Sciences. They made it possible for us to host all of our speakers and our Art Workshop, where patients were guided through a workshop to illustrate their HPP journeys on canvas with watercolor.

It was an incredible opportunity to connect with other patients and share stories. Remarkable life-long connections were made here! If you feel left out, make sure to register **HERE** to view the recordings available on our virtual platform. Keep an eye out for our next in-person National Patient Meeting!

In Case You Missed It

Annual Report

Exciting news! Soft Bones has officially released our first-ever annual report. The report gives insight into key accomplishments for the year. It includes a thorough recap of everything 2021, including an overview of growth, website statistics, HPP awareness, educational successes and more. The report also gives tribute to the donors who have generously supported our mission.

TO READ MORE ABOUT SOFT BONES AND ITS WORK, VISIT THIS **LINK**.

Patient of the Month Recap

This June, we launched our new "Patient of the Month" program! The goal of this new feature is to raise awareness about hypophosphatasia and its various manifestations, as well as to shed light on the numerous challenges patients face when living with a rare disease. Patients who are featured have the opportunity to share their personal HPP stories on our social media channels, and a link is always provided so that patients can share their stories with friends and family. So far, we've had the opportunity to highlight Amy W., Suzanne D., Chris D., Nellie S. and Denise K.

To read their stories, please visit our website **HERE**.

To nominate someone to be featured as our Patient of the Month, or to nominate yourself, email info@softbones.org.

PFDD

Reminder! On November 15th, Soft Bones will be leading a Externally-Led Patient-Focused Drug Development meeting dedicated to hypophosphatasia. These sessions are held to ensure that the FDA is actively hearing from affected patients and caregivers about their diseases and available treatments.The FDA, industry, healthcare professionals, federal partners and other key stakeholders will all be given the opportunity to hear directly from patients as well as patient advocates about living with HPP. This feedback could potentially affect future FDA decisions regarding new treatment approaches.

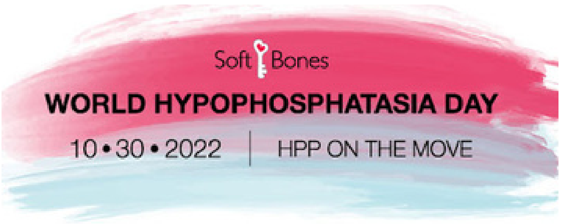
NOV 15

SAVE THE DATE!

Other News

World HPP Day

This year's theme for World HPP Day is HPP ON THE MOVE – a celebration of movement both physically and metaphorically. Whether you choose to get moving by participating in the Cannonball Run, Roll or Stroll or another form of physical activity – or you start your own movement by educating others – the goal is to create momentum for awareness of hypophosphatasia around the world.



Stay tuned for more information about how you can get involved by following us on **Instagram**, **Facebook** and **Twitter**.

ELSA

Soft Bones is a proud sponsor of the upcoming ELSA Advocacy Day on October 19th, hosted by the National Foundation for Ectodermal Dysplasias (NFED). NFED has been working tirelessly to get the Senate to pass ELSA, or the Ensuring Lasting Smiles Act, as national law so that patients, caregivers and families everywhere can stop spending their time appealing insurance denials. Sign up to be an advocate on October 19th **HERE**.

New Resource: How to Talk to Family Members About Genetic Diseases

Soft Bones recently added a new resource to the website about how to talk to family members about genetic diseases. Patients have shared stories about how this can be a difficult and uncomfortable conversation, so based on advice from a therapist, the guide explores possible family dynamics and scenarios to help patients prepare for this discussion. The guide also provides resources and support for families. Please note however, that this is a guide, not a script, as we recognize that every conversation will look different. Find the "HPP Talking to Your Family Guide" **HERE**.

Fall Hippo Squad Box

Four times a year, children ages 3-12 get to run to the mailbox to discover what new surprise the Hippo Squad has in store for them. The Hippo Squad is a program that provides HPP education for kids by providing them fun, educational activity boxes every quarter. The upcoming Hippo Squad boxes will also include fun facts, important statistics and helpful information about World Hypophosphatasia Day and rare diseases in general.

This Fall, the box's theme will be HPP ON THE MOVE in honor of World Hypophosphatasia Day on October 30th. The purpose of this theme is to teach kids the importance of moving your body, while also acknowledging that movement may mean different things for different people. For some, movement may be less of a physical action and more about starting a movement by making a difference and advocating for yourself and others.

For more info and to sign up today, email maryelizabeth@softbones.org.

Soft Bones
HIPPO
SQUAD

Fundraising Corner

Cannonball 5k Run, Stroll or Roll

This year, in honor of World HPP Day, Soft Bones is putting on a virtual run/walk. All you need to do in order to participate is register for the race, print your bib and complete a 5k run/walk at your convenience, any time, anywhere between October 1-30, 2022.

Register for the Cannonball 5k Run, Stroll or Roll **HERE**.

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! We are stronger together, and when we move, we move as one! There is no correct form of movement, so let's see you run, stroll and roll!

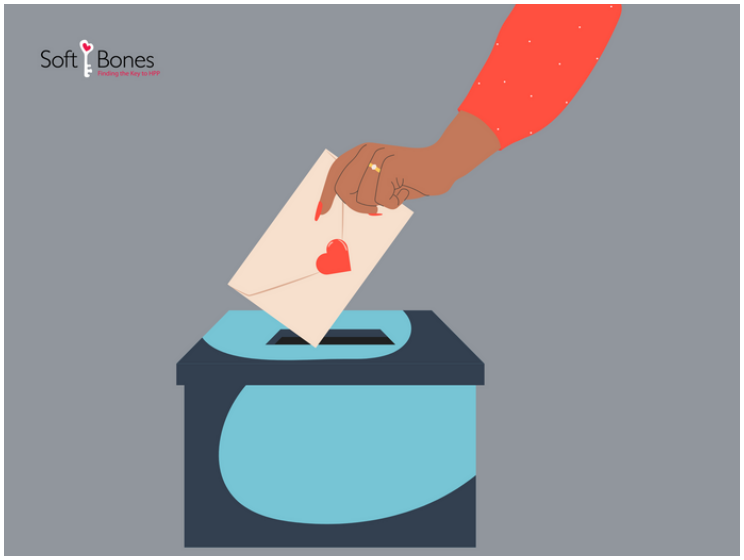
To buy Cannonball 5k and World HPP Day apparel, visit our shop **HERE**.

Thank you to our sponsors Alexion AstraZeneca Rare Disease and Aruvant Sciences for their support of our HPP Community!

Fundraising Corner

NEW: Soft Bones Now Accepting Stock Donations

Soft Bones is now able to accept stock donations. Did you know that donating appreciated stock is one of the simplest ways to contribute more to causes that are important to you? In fact, it's also a smart way to give to a charity. When stock donations have appreciated for over a year, contributions can be up to 20% more than if you sold the stock and made a cash donation by avoiding capital gains taxes. It can also be an excellent way to rebalance your stock portfolio if needed. Plus, any increase in the value of a stock can also mean significant gains for you if you sell. Donating stock to Soft Bones can be a win-win!



Please contact us at info@softbones.org for more info.

Fundraising Corner

2022 Annual Golf Classic

The 14th Annual Soft Bones Golf Classic was held on September 19th at Somerset Hills Country Club in Bernardsville, NJ. This is our largest fundraiser, and this year's golf classic was another successful event. We had 113 golfers join us for another beautiful fall day. Sponsors, donors, patients and participants had a great time playing the course while helping raise critical funds for our organization. We are grateful for the loyal golfers who turn out year after year to support our mission. A special thank you to our **Tournament Sponsor, Atlantic Health System.**

Thank you to our other sponsors: The Fowler Family Charitable Foundation, Gates & Mary Ellen Hawn, Donnelly Construction and Patrick Mucci & Family

Keep an eye out for our future events by checking our **event calendar**!

Wreath Fundraiser

It's the holiday season, and Soft Bones is here to get you ready! This year, Lynch Creek Farm has teamed up with us for an online fundraising campaign. Choose from an assortment of beautiful fall and winter decor, such as, wreaths, garlands, centerpieces, decorative signs and much more! You can join our fundraiser, and 15% of each purchase will go back to Soft Bones. Also, enjoy free shipping!

Shop fall and winter decor **HERE**