

# THE BARE BONES

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

## Face-to-Face In Our Regions In Person and Online

The year kicked off with the first in-person region meeting since COVID hosted by Southwest Region Leads Sue Krug and Amy Britt at Phoenix Children's Hospital (PCH) in Arizona. The meeting format was actually a hybrid of in-person and online, and HPP experts from PCH presented on a variety of HPP topics, including orthopedics, pain management, neurology and dentistry. The meeting is available on our website and features an introduction by Sue and presentations by a variety of HPP specialists at the hospital. A special thank you to Phoenix Children's Hospital and Dr. Pamela Smith for their support with the virtual component of the meeting and to Dr. Pamela SW Smith, Ruth Bristol MD, Mohan Belthur MD, Charlie Clark DDS, Palola Genovese MD, Melissa Esparza MD, and Arie Zakaryan PhD for their excellent presentations!



### IN THIS ISSUE:

- Rare Disease Day Recap
- Staff, Program, and Advocacy Updates
- Patient Feature
- Fundraising Opportunities
- And more!

# Rare Disease Day 2022 Recap

On February 28th, we joined many other organizations to celebrate Rare Disease Day! Our campaign encouraged the HPP community to bring awareness to the wide range of symptoms and challenges patients face on a daily basis and the impact of living with a rare disease. Our Rare Disease Day activities included an RDD Webinar, a RDD coloring contest, new HPP Warrior apparel, and an RDD social media poll.

## Rare Disease Day Webinar

In partnership with Aruvant Sciences, Soft Bones hosted a webinar on gene therapy, what it is, and its promises and challenges for hypophosphatasia. Special thanks to our presenters, Dr. Jose Luis Millan from Sanford Burnham Prebys and to Matt Grol of Western University. Click [here](#) to view this webinar.



Matthew W. Grol, Ph.D.



José Luis Millán, Ph.D.

## Rare Disease Day Coloring Contest



## HPP Warrior Apparel

A new line of “HPP Warrior” apparel was launched on our website store. The apparel never goes out of style. Check out the designs [here](#).

## Rare Disease Day Poll

Our Rare Disease Day campaign also included a poll of patients to highlight some challenges of living with HPP. We encouraged the community to share these results with their network and help bring awareness to the struggles faced. The top five results were:

- Many years spent searching for an accurate diagnosis.
- Limited access to physicians with knowledge of the disease.
- Treatments are limited and very expensive.
- Living in constant pain.
- Symptoms are not always visible, making it difficult for others to understand.

## Staff Updates

Mary Elizabeth "Muffy" Mulcahy



Join us in welcoming Mary Elizabeth "Muffy" Mulcahy to Soft Bones. Mary Elizabeth is our new Patient Services and Program Manager. In her role, she will support patients and caregivers by connecting them with the various services and available resources. Her role also will include overseeing the execution of new programs as well.

Mary Elizabeth has been involved with Soft Bones since its inception, volunteering and fundraising at the annual golf outing. She has worked in healthcare for the last 14 years with her latest role working as a Patient Advocate at the local trauma center, Atlantic Health Systems in Morristown, New Jersey. Mary Elizabeth can be reached via email at [MaryElizabeth@softbones.org](mailto:MaryElizabeth@softbones.org). Please reach out and introduce yourself!

Another new face to Soft Bones is Katie Trowbridge. Katie took over a portion of Bonnie Starr's role to support marketing and communications efforts as well as events. If you have any trouble receiving **communications** from Soft Bones, she's the one you will want to contact. She currently lives with her family in a lake community in New Jersey. She has two young kids- Madeline and Benny. Katie has worked in a hospital setting for the last 8 years in a variety of roles- and loves working on creating better communication between care providers, patients, and the many teams it takes to have a positive patient experience and outcome.

Katie Trowbridge



## Hippo Squad Updates

Every quarter, kids rush to their mailboxes to see what surprise is in store thanks to the Hippo Squad. The Hippo Squad is a program for children ages 3-12 that provides HPP education through activity packages four times a year. In February, the theme centered around Valentine's Day crafts like "Hearts for Your Hero" and some fun coloring sheets. The "Hearts for Your Hero" craft was used to show appreciation for the people that experience HPP and who are affected by HPP. We also celebrated Rare Disease Day on February 28th. The February Hippo Squad was full of important facts, statistics, and helpful information about Rare Disease Day and rare diseases in general.

The May Hippo Squad mailing rocked... literally! Educational components focused on how many rocks are formed by mineralization, just as bones and teeth mineralize in the body. Rock painting was the main activity and the results were too cute!

To join the Hippo Squad: [maryelizabeth@softbones.org](mailto:maryelizabeth@softbones.org)

Not part of the squad?  
**Sign up today!**



## Tooth Fairy Program

For HPP families, every tooth lost can be a difficult reminder of the challenges of living with HPP. However, for a child, a lost tooth means one thing: the Tooth Fairy is coming! Earlier this year we launched a new Tooth Fairy Pillow Program featuring our HPP mascot, the hippo. This program is designed to comfort children and parents when they have lost a tooth, turning a potentially unsettling experience into a happy event for everyone. Request a pillow [here](#).



## Introducing The Soft Bones Patient of the Month

Soft Bones is excited to roll out our new “Patient of the Month” feature to bring awareness to hypophosphatasia, its many faces and to shed light on the different challenges patients face when living with a rare disease. Patients will have the opportunity to share their unique HPP stories throughout our social media channels and a link will be provided so that patients can share their stories with friends and family. To nominate someone to be featured as our Patient of the Month, or to nominate yourself, email [info@softbones.org](mailto:info@softbones.org).

## 2022 National Patient Meeting

We're less than one month away from the Soft Bones National Patient Meeting taking place in Orlando, Florida on July 8-9! We have a packed agenda, including a virtual escape room for teens and a special art session workshop with Alexion Pharmaceuticals. If you are unable to attend in person, presentations will be available on demand following the meeting. If you have any questions about your registration or hotel reservation please contact [patientmeeting@softbones.org](mailto:patientmeeting@softbones.org). We look forward to seeing you all at this great event!

[July 8th & 9th](#)

[More Info Here!](#)

Soft  Bones

2022 NATIONAL PATIENT MEETING

## Medscape Listing

Soft Bones has been listed as a collaborator on the Medscape website. Check it out [here](#). What is Medscape? Medscape is an online resource for physicians and healthcare professionals everywhere. They focus on the latest medical news and updates, perspectives from experts, crucial point-of-care drug and disease information, and pertinent professional education and CME courses. Overall, their goal is to advance patient care by providing healthcare professionals and physicians with access to comprehensive clinical information and resources.

## HPP In The News

In this year's Rare Disease Day issue of Rare Revolution Magazine, an interview with Soft Bones President and Founder, Deborah Fowler is featured. The issue focuses on innovation and research and celebrates some of the amazing work taking place in the RARE community. Read the article [here](#).

Hypophosphatasia patient, Melody, discusses her HPP journey in this feature article in The Daily Journal, a local publication in the Fergus Falls area of Minnesota. Read her story [here](#).

Soft Bones was featured in a local radio interview out of Windsor, Ontario and Detroit to talk about its mission and HPP. Listen to the interview [here](#). Keep an eye out on our social channels for a link to the interview, when available.

## Stay in Touch

Have you recently moved? Are you not receiving mail or emails to learn about events and updates from Soft Bones and the HPP community?

- Email [info@softbones.org](mailto:info@softbones.org) or go to <https://softbones.org/contact-us/> to add your contact information to our database. Note: Your name will never be given out or sent for solicitation.
- Also a reminder to check your spam and junk email folders and always hit "allow" for communications from any email addresses ending in @softbones.org.



## More News

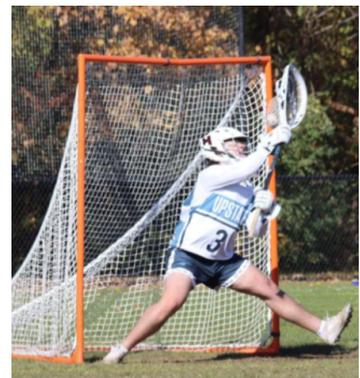


PHOTO: JOHN MUNSON | NJ ADVANCE MEDIA FOR NJ.COM

It is with heavy hearts that we share the news of the passing of Bob Mulcahy. This will be the first Soft Bones Golf Classic without Bob as Chairman of the event. As many know, Bob stepped up more than 14 years ago when Cannon Sittig was first diagnosed, and Deborah Fowler talked about the need of starting a patient advocacy group for families living with hypophosphatasia. He was committed to the cause, and through his incredible network, helped raise more than 1-million dollars for Soft Bones, making much of what has been accomplished possible. The Soft Bones Golf Classic remains the organizations #1 fundraiser and will continue in the generous spirit that Bob brought to the event. Click [here](#) to read more about Bob and the legacy he leaves behind in New Jersey. He is missed.

## #HPPSTRONG: Stories of Resilience in our Community

Meet Ryan! Ryan is a high school junior with HPP who has a passion for all things lacrosse. He wasn't able to get the chance to play lacrosse when he was younger due to the severity of his HPP, so now he likes to play every chance he can get. His quality of life has improved leaps and bounds since starting Strensiq at age 12. As he got stronger, he practiced hard to try and catch up to the other kids that had been playing for years...and he ultimately made the team as a GOALIE! Now he dreams of playing college lacrosse! He and his mom Christine would like their extended HPP family to know, "stay strong, take one day at a time, and never give up hope that we will have a cure someday!"



## More Updates

### What is a PFDD?

PFDD stands for Patient Focused Drug Development. Years ago, the Food and Drug Administration hosted these meetings to hear first-hand from patients and advocacy groups about their challenges of living with a variety of diseases. Today, these meetings continue except instead of being led by the FDA, they are led by advocacy groups themselves.

Soft Bones is proud to announce one of these PFDD meetings will be focused on hypophosphatasia later this year. The purpose of these meetings is to ensure that the FDA is actually hearing from the affected patients themselves when it comes to specific diseases and their treatment options. Patients or patient advocates can speak directly to not only the FDA, but also medical product developers, health care providers, federal partners and more. These meetings give patients and caregivers the chance to discuss symptoms, treatment options, and more. The feedback is critical as it can impact future FDA decisions when it comes to drug development and marketing applications.

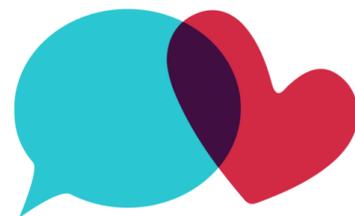
### Annual Report 2021



### HPP AND ME

We have lots of great conversations happening on HPP AND ME. Come join our online community forum that connects patients, families and caregivers. Find answers to your questions, share stories and meet others, all in a secured environment.

Click [here](#) to register.



## HPP AND ME

# Teen Advisory Council Updates

## New Group Leader

Hello! My name is Audrey Fink and I am a junior at Syracuse University studying advertising and I am also the new lead of the Soft Bones Teen Advisory Council. Prior to working with the TAC, I was unfamiliar with HPP, but have learned so much from the kids. We meet once or twice a month to discuss all things HPP such as fundraising, personal experiences, raising awareness, and more. All of our teens are so awesome and inspire me to grow alongside them, I am so excited for everything we accomplish together!

### TAC Group Leader



Learn more about the Teen Advisory Council

[HERE](#)

## New Members

Soft Bones recently welcomed six new Teen Advisory Council members! Joining the team are Charlie M., Will C., Brendan F., Quinn H., Clark S. and KC C. As TAC coordinators, they will practice how to speak about HPP and come up with new fun ways to teach others about the disease. Participants are encouraged to bring new ideas to the table to enrich the program and will have opportunities to develop their leadership skills. To connect with any of our TAC members, or inquire about the program via email, reach out to [tac@softbones.org](mailto:tac@softbones.org).

## Advocacy Updates

### ELSA Legislation

The Ensuring Lasting Smiles Act (ELSA) is an important piece of legislation that's currently under consideration by U.S. Congress that would require dental insurance companies to cover the costs of procedures that stem from a congenital anomaly. Soft Bones was a sponsor of the NFED Virtual Advocacy Day on Capitol Hill on March 30th and joined patients from around the country to speak with members of the House of Representatives to share their stories, underscore the need for this type of coverage for patients and families and urge them to vote in favor of this legislation. The good news is that the bill passed the House vote, and now goes onto the Senate for consideration. Soft Bones will continue to support this legislation as the cause is important to HPP patients who may have dental or craniofacial implications and need procedures that in the past have not been covered by insurance.

### CSDA Meeting- May 2022

On May 11-13, Soft Bones exhibited to help spread awareness about hypophosphatasia at the Connecticut State Dental Association's Charter Oak Dental Meeting at the Mohegan Sun in Connecticut. During the course of the meeting, Soft Bones was able to connect with more than 100 dentists, professors, students and dental professionals. Many visitors to the booth had never heard of HPP and were very receptive to receiving the information developed by our Scientific Advisory Board. Overall, it was a huge success!



Adriane Eoga greeted more than 100 dentists at the Soft Bones booth at the CSDA meeting, educating them about HPP and the various programs available to dentists at Soft Bones.

# Fundraising Corner

## Rutgers Men's and Women's Lacrosse Fundraiser Recap

The Rutgers Men's and Women's Lacrosse teams partnered together to raise money for Soft Bones as part of their annual charity event. The combined value raised by both teams was **\$6,691.50!!!** A big THANK YOU to all who donated!



# Thank you to our community!

We are grateful to all who hosted fundraisers in their local and online communities to benefit Soft Bones. **Together you raised \$9,577.73!** Great work! Thank you to the following individuals and companies who made these fundraisers possible!



**The Pretty Pink Rooster** - Online and in-person fundraiser in Bernardsville, NJ



**Pampered Chef** - Sharon T. for the Midwest 1 Region

**Bourbon Raffle** - Ben T.



**Facebook Fundraisers** - Jill R., Diana T., Brianna H., Olivia H., LaVonne M., Kristin CP., Jessica L., Kristen M., Kenneth R., Melinda CP., Danielle ZZ., Amanda LR., Shawn CO., Myra W., Lauren R., Deziree H.



**Little Caesar's** - Cindy R., Amy W., Blynda K., Deb F.



2022 is flying by, and it’s already time to mark your calendar for our largest fundraiser of the year, the 14th Annual Soft Bones Golf Classic! This year’s event will be held on **Monday, September 19th, 2022** at Somerset Hills Country Club in Bernardsville, NJ. As you may already know, Soft Bones and the HPP Community recently mourned the loss of longtime committee chair, friend and HPP champion Bob Mulcahy. In addition to joining us for a round of golf, there are a number of ways to support the outing. If you are interested in volunteering, donating an item for raffles or securing a sponsorship, please reach out to [info@softbones.org](mailto:info@softbones.org). Thank you to our tournament sponsor, Atlantic Health Systems.

Did you know that it doesn’t cost anything for you to enroll in programs such as [Amazon Smile](#), [iGive](#), [Kroger’s](#) or [Fry’s](#) shopping card programs? All you have to do is sign up and do your regular shopping and Soft Bones receives a % back. Sign up today!



Does your doctor or treatment team want to learn more about hypophosphatasia? Soft Bones has a variety of free resources intended to help improve medical professionals understanding and treatment of people with HPP.

Click [here](#) to forward these helpful resources to your medical team.