

THE BARE BONES

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

HPP Happenings

Unleashing the Power of Community:

HPP Patients and Families Share their Colors on Rare Disease Day 2023

This year, Soft Bones recognized Rare Disease Day on February 28th joining the EURODIS theme **#ShareYourColors**. Members of the HPP community came out in full force, sharing pictures, videos and their experiences to raise awareness. More than 100 patients and families shared their stories on their Facebook timelines, Instagram and Twitter and some showed support by changing their profile photos to unite the HPP community.

Rare Disease Day is an international event aimed at promoting fairness in social opportunities, healthcare, and access to diagnosis and therapies for people living with rare diseases. Every year, on the rarest day of the year, February 28th (or February 29th in leap years), Rare Disease Day is observed.

Rare Disease Facts about Hypophosphatasia:

- There are six major clinical forms of HPP distinguished by the age when symptoms start and when the diagnosis is made.
- Individuals with an extremely rare form of HPP called pseudo-hypophosphatasia have normal rather than low blood levels of alkaline phosphatase in the routine clinical laboratory.



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- Exciting News
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- A Word From our Partners

ICYMI: View our Winter 2022
newsletter [HERE](#)

HPP Happenings

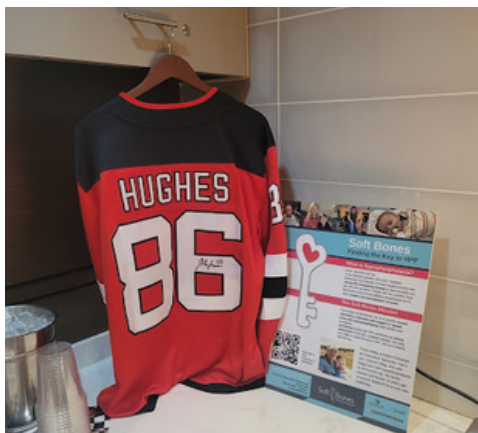
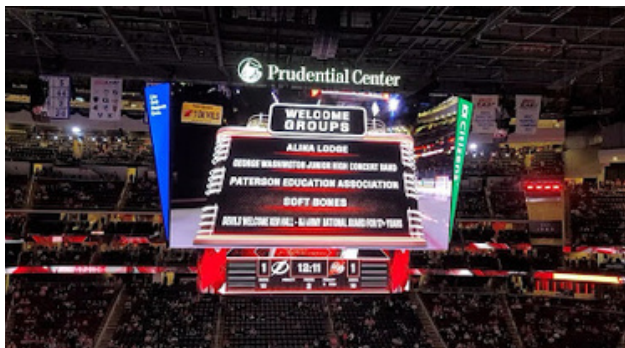
Soft Bones and HundredX Causes Team Up for a Successful Fundraiser

Thank you to all of the nearly 120 people who joined our HundredX fundraiser! From February 6th to March 7th, Soft Bones partnered with HundredX Causes to raise money in a fun and engaging way. Our supporters unlocked monetary donations to Soft Bones through completing surveys on an array of top brands and companies. Thank you to all our participants and everyone who helped spread the word to make it a successful fundraiser!



Score Big for a Good Cause: New Jersey Devils Hockey Game Fundraiser

A special thank you to Consortium Networks, Cribl and CrowdStrike for hosting a Soft Bones fundraiser at the New Jersey Devils game on March 14th! The company rented a suite at the game and sold tickets to raffle off a NJ Devils jersey signed by hockey star, Jack Hughes. The attendees were educated about HPP and were thrilled to play a part in helping support the HPP community. And it was exciting to see Soft Bones acknowledged on the Jumbotron! Thank you to everyone who donated and for caring about HPP!



HPP Happenings

Forging Connections at the Soft Bones National Patient Meeting

Over Presidents' Day weekend, February 17-18, Soft Bones held its National Patient Meeting in sunny Phoenix, Arizona. More than 40 families attended, including patients, caregivers, clinicians and friends. It was a wonderful opportunity for old friends to reconnect. For patients and caregivers who are new to the Soft Bones community, it provided an opportunity to meet others and share stories. The agenda included informative presentations by Pamela Smith, MD (Phoenix Children's Hospital), Peter Tebben, MD (Mayo Clinic), Paola Genovese, MD (Phoenix Children's Hospital), and Arie Zakaryan, PhD (Phoenix Children's Hospital). The day ended with an Art Workshop led by art instructor Anna Scanlon. Each person created an individual interpretation of a tree that began by tracing his/her/their hand in honor of Rare Disease Day and the theme [#ShareYourColors](#).



A special thank you to our sponsors, Alexion AstraZeneca Rare Disease and PANTHERx Rare who helped to make this meeting possible. Another special thanks to [NORD](#) and [The Assistance Fund](#) who sent along information and swag to distribute to attendees.

Register [HERE](#) to view the recordings from this meeting on our virtual platform.

Mark your calendars for the **Soft Bones National Patient Meeting 2024** that will take place at the **Great Wolf Lodge in Mason, Ohio** (Cincinnati area) **July 12-13, 2024**.



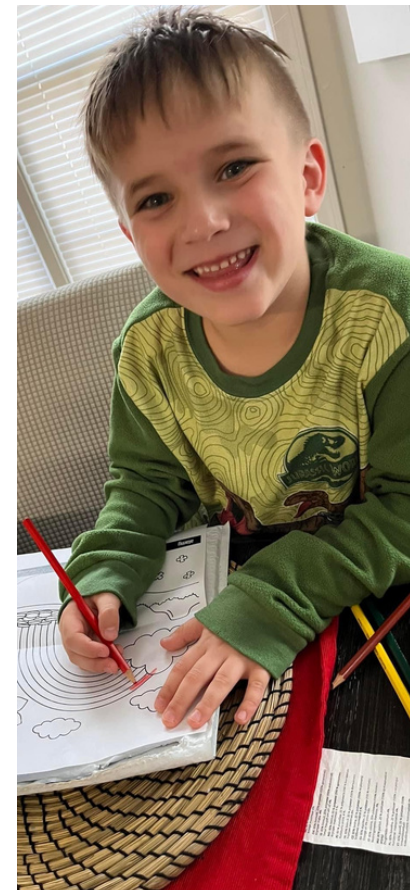
Program Highlights

Hippo Squad: Helping Children with HPP Express Their Emotions through Color

Attention all kids ages 3-12 - Have you joined the Soft Bones Hippo Squad yet? The Hippo Squad is a program that sends quarterly boxes full of educational and fun activities to kids of parents with HPP, children with HPP and their siblings. The Spring 2023 box was sent out in March, and it's been a huge hit so far! This season's box featured activities that allow children to express their emotions through color. The goal was to help kids understand their emotions through metaphors about the weather. After all, we all have bright sunny days and cloudy days, but only when we get through them do we find the pot of GOLD at the end of the rainbow.

Not only did this box use colors and weather analogies to help the children better understand and be able to speak about their feelings, but it also included several fun activities such as a rainbow coloring sheet, colored pencils, and a pot of GOLD surprise. Families were also invited to join the festivities by sharing, liking or commenting on posts about rainbows and HPP on Facebook, Instagram, Twitter, and HPP AND ME. Some even created Facebook fundraisers to raise HPP awareness and educate friends and family on what it means to live with HPP.

Don't miss out on the next Hippo Squad box! Sign up for our quarterly boxes [HERE](#).



Program Highlights

Stick It to HPP: TAC Launches New Program to Encourage Independence in Children with HPP

The Teen Advisory Council (TAC) recently launched a new initiative, called "Stick It to HPP," aimed at aiding children who are ready to start administering their own injections. Comprised of HPP patients who have successfully overcome their fear of self-injecting, along with siblings, friends, and other teens, the TAC was inspired to champion independence in others who face similar struggles on enzyme replacement therapy. By taking control of their health through self-injecting, kids gain more confidence and freedom to partake in activities like camp, traveling, and sleeping over at friends' houses.

Participants receive a starter kit with educational and motivational materials, including injection goals, achievements acknowledgment, tips for reducing needle and injection anxiety, stress ball, shot blocker, ice pack, breathing techniques, and a playlist to get excited about self-injections.

Children can also request encouraging videos or calls from other teens for support and guidance.

To learn more, please email info@softbones.org.



Will You Be Soft Bones' Next Patient of the Month?

Every month Soft Bones highlights a member of the community to share their HPP journey. Stories include their diagnostic odyssey and life after diagnosis. So far in 2023, we've featured three extraordinary hypophosphatasia patients.

For January, Soft Bones highlighted Sharon M. Despite being active in various sports, Sharon never experienced any broken bones. However, in her early 20s, she started to break ribs without experiencing any pain. She was initially written off as a fluke of nature until multiple fractures started appearing in her feet and thighs. After a bone scan revealed multiple fractures, she was eventually diagnosed with HPP. There was no treatment at the time, but in 2015, she started receiving Strensiq.

Soft  Bones
Finding the Key to HPP



Sharon M.

It's been said there are two ways to get out of a chair, one way is to slowly rise, moaning and groaning. The other way is to just get up and go. Both ways hurt, but the first way, you are giving into the disease. The second way, you are taking control of the disease. Don't quit, don't give in."

Program Highlights

Will You Be SB's Next Patient of the Month? (cont.)



In February, Carol L. was in the spotlight. Carol's lifelong battle with HPP began at a young age. As a child, she would wake up 15-20 times a night to go to the bathroom, was thin and lanky, had no enamel on her permanent teeth, and suffered a gum infection at 11. At 45, she suffered from ischemic colitis and almost died, losing 20 pounds in one week. She's had six shoulder surgeries, including a joint replacement, meniscus rips in both knees requiring surgery, a knee replacement, and a bowel resection. She also has scoliosis, has suffered from vertigo and balance issues, and has caught MRSA twice, becoming septic the first time. At 67 years old, she developed severe ankle pain, which her family doctor dismissed, but her new rheumatologist finally diagnosed her with HPP, and she began to give herself Strensiq shots three times a week.

"Since treatment, I definitely feel better, not a lot of brain fog and my fatigue is so much better. I still have a lot of pain, especially at night, but at least I know why now...I try to educate doctors, dentists, and the general population of this progressive disease. I hope I can help someone else from going through everything that I have gone through my entire life."

For March, Soft Bones highlighted Quinn H. In the first few years of his life, Quinn experienced some gross motor delays and was unable to walk until the age of two. After losing several baby teeth, his dentist suggested that he might have a metabolic bone condition. Quinn was eventually diagnosed with HPP, and experienced physical difficulties until the arrival of Strensiq. His positive attitude and determination to live life on his own terms, regardless of his condition, has been a key factor in his success. He has participated in wheelchair basketball and softball, and as a member of the Soft Bones Teen Advisory Council (TAC), Quinn has found a supportive community of others who understand what it's like to live with HPP.

"But my main point, the reason why I have gotten through this, is because I was always myself and did not let HPP define me. I always kept a good attitude and did what I wanted to. Be yourself, always do what you want and live life the way you want. Even if you get knocked down, you can always get up. And keep going forward in life."



Nominate yourself or an **#HPP** patient who inspires you today by emailing maryelizabeth@softbones.org

Program Highlights

Meet Emma Richter: The Communications Manager on a Mission for HPP Awareness

Emma Richter joined Soft Bones as the Communications Manager in August of 2022. Emma graduated from Montclair State University in May of 2022 with her Bachelor's degree in Journalism. Emma is thrilled to be putting her classroom learnings into practical use at Soft Bones. Emma has a passion for journalism and writing and loves to inform and be informed. Emma is thrilled to be a part of such a great team that supports HPP patients daily, and she is excited to keep helping patients on their journeys. Emma is one of two children in her family, with an older brother who is studying to become a Physical Therapist. Her mother, father and brother all live in North Carolina, and she resides in Harrison, N.J. As for her work with Soft Bones, Emma has exceeded her own expectations going beyond writing copy for Soft Bones social media, Emma also manages and edits the website, creates graphics, and is taking a class on grant writing.



"I've learned to do so much since August, and I think the best part of it all is that I am working for a non-profit organization. But, not just any non-profit, Soft Bones sheds light on hypophosphatasia, and everyday I am grateful to wake up and be a part of this great organization. Thank you Soft Bones!"

Join the HPP AND ME Community: A Safe Haven for Sharing Experiences, Support, and Latest Research

With so many concerns about patient privacy online, Soft Bones created the online community **HPP AND ME** for people living with HPP. By becoming a part of the HPP AND ME community, you can inquire about concerns, receive support, exchange your experiences, and keep up with the most recent research, significant news, and announcements. Membership to the website is free and is growing everyday! The site is organized by topic and can be easily searched. A diverse range of discussions are taking place, such as seeking a diagnosis, life after diagnosis, and more. You can also find introductions and backgrounds of patients on their journeys so far.

Join us for a HPP AND ME Community Chat on April 12th at 8:00pm EDT. This will be a time to get to know one another, meet the people behind the screen names, ask questions and just talk with others who get it. I hope you will join us! If you need assistance, please email Cindy@SoftBones.org.

Soft Bones
Finding the Key to HPP

HPP AND ME

Join In A HPP AND ME Live Chat
Via Zoom!

Wednesday April 12th at 8:00 p.m. EDT
Click the link to register!

Register for the meeting [HERE](#).

Exciting News

HPP Network (Centers of Expertise) – Taking Our Concepts Into Actions

Starting the year full speed ahead with building our HPP Network! Soft Bones has conducted two additional meetings with our working group focusing on increasing HPP knowledge and building physician-peer connections to foster greater HPP education. We are excited by the opportunity to launch a couple of concrete initiatives resulting from the input of our champions (working group and steering committee members) in the upcoming months. Some of the concepts we are now discussing include how to: 1) establish a HPP consensus statement series, 2) encourage greater information exchange between physicians/peers, and 3) increase usage and credibility of our numerous educational resources. We are also very excited to be moving forward with the creation of the MyHPP Tracker. Our goal is to review a draft of version 1.0 with our champions by the third quarter. Stay tuned for more on all these initiatives in the upcoming newsletters.

Meet Rob Moskow: Soft Bones Newest Board Member



Rob Moskow, Esq

Soft Bones is excited to announce that Rob Moskow, Esq. has joined our Board of Directors. Mr. Moskow runs his own consulting firm, Equity Wine Ventures, which focuses on utilizing his extensive legal background to add value to the wine industry and assist clients with business strategy and implementation. He works to help individuals, insurance companies and other interested parties avoid acquiring counterfeit wines and seek recompense for counterfeit wines already in inventory. He also advises wine collectors with curation of cellars, cellar management, and procurement of wine at auction.

Mr. Moskow started his career in the legal field with the Nassau County, New York District Attorney's office and then practiced for twenty years with firms in New York, Kansas, Missouri, and New Jersey. His areas of specialty include corporate law, construction law, insurance defense litigation, and complex commercial litigation. He has multiple federal and state court admissions including the Supreme Court of the United States.

In addition to serving on the Soft Bones Board, Mr. Moskow currently serves as the Secretary of the Hamilton Farm Homeowners' Association Board and is a member of its Architectural Subcommittee. He is the head baseball coach for the Bernards Township Middle School and an assistant coach for the Ridge High School freshman baseball team. Previously, he served as President of the Board of Directors for the Basking Ridge Little League. Mr. Moskow holds a degree in Finance from the Robins School of Business at the University of Richmond and a Juris Doctor from St. John's University. He and his wife have two children, a German Shepherd, and reside in New Jersey. He also enjoys endurance racing, having completed two full Ironmans and the X-Terra World Championships, as well as golf, travel and wine collecting.

Exciting News

Revolutionize Your Giving: Explore Several Ways You Can Make a Difference

As you may be aware, Amazon recently canceled its AmazonSmile program and therefore, we are no longer able to receive donations through this platform. However, we have some exciting news to share with you!

iGive: Shop online and contribute to Soft Bones! Register for iGive, a unique online shopping platform that allows users to donate a portion of their purchases to their favorite charities. With over 1,700 partner stores like Amazon, Target, BestBuy, and more, users can shop for everyday items while also supporting their chosen cause. Sign up for iGive (remember to select 'New Jersey' as your state) today and help raise money for Soft Bones when you shop - click [HERE](#) to get started!



Walmart Spark Good Program: Walmart recently launched the Spark Good Round Up program where customers can round up their online purchases to the nearest dollar and donate the change to their favorite charity of choice. Remember to select Soft Bones for your next purchase at Walmart - click [HERE](#) to learn more!

Kroger Community Giving Program: Kroger's Community Rewards program is designed to support local nonprofit organizations in the communities where Kroger operates. It also works for Frys stores, which are a part of the Kroger brand. The program allows Kroger shoppers to select a nonprofit organization to support, and Kroger then donates a portion of the shopper's purchases to the chosen organization. Click [HERE](#) to search for Soft Bones and support our organization with your next Kroger purchase!



Stock Donations: Stocks are not only a smart way to donate to a charity, but can provide potential tax benefits for the person donating the stock. By donating stocks that have appreciated for over a year, your contributions could be higher (up to 20% more) than if you sold the stocks and made a cash donation, because you avoid capital gains taxes. Additionally, it can serve as a useful tool for balancing stock portfolios. Donating stock to Soft Bones can be a mutually beneficial option!

If you are interested in creating your own fundraiser to share on social media or with your friends and family, we can create a customized fundraiser page for you. Please reach out to maryelizabethsoftbones.org to get started.

We are grateful for your continued support. Please visit the [Ways to Donate](#) tab on our website for more information. Thank you for your generosity!

Upcoming Events

Announcing Soft Bones 2nd International Scientific Meeting

Plans are well underway for the 2nd Soft Bones International Scientific Meeting. The gathering will be held June 3-4 in Bethesda, Maryland and will bring together researchers and clinicians from around the world with an interest in HPP. The first meeting was held in 2018 and brought together 70+ attendees. The 2023 planning committee, chaired by Michael Whyte, MD (Washington University–St. Louis, MO) includes Kathryn Dahir, MD (Vanderbilt University Medical Center, Nashville, TN), Jose Luis Millan, PhD (Sanford Burnham Prebys, La Jolla, CA), Cheryl Rockman Greenberg, MD, CM, FRCPC, FCCMG (University of Manitoba, Canada), and Peter Tebben, MD (Mayo Clinic, Rochester, MN). This year's meeting will bring together experts in clinical care and basic research with the goal of sharing advances in research and treatment as well as to gain a better understanding of gaps to better inform future care. The agenda includes both opportunities for presentation and discussion. A summary of abstracts is planned for publication after the meeting.

Opportunities for sponsorship are available. This meeting is by invitation only.



Get ready to don your finest denim & diamonds and dance the night away at Soft Bones' upcoming fundraiser. With live music from Catz 'n Dawgz, delicious food and drinks, and an exciting auction featuring unique items, this event promises to be a fun-filled night for a great cause. This event will run from 5:30pm – 9:30 pm ET on Saturday, May 20th, at Harvest Hall in Chester, NJ. All proceeds will go towards supporting Soft Bones, so put on your dancing shoes and join us for an evening of fun and philanthropy!

Find out more about the Denim & Diamonds Fundraiser [HERE](#).

Connect with Your Local HPP Community Through the SB Region Lead Program

The Region Lead Program was established to strengthen the HPP community by fostering patient relationships and offering a secure and comfortable environment for patients and caregivers to connect and learn from each other. The program includes eight regions within the U.S., each of which is served by a Region Lead. These Leads are highly attuned to patient requirements and act as local ears to the ground, communicating their observations and insights to the national organization in order to help necessary identify programs and materials. Additionally, Region Leads spearhead grassroots awareness, fundraising, and policy efforts in their respective regions. Two meetings are held per year in each region, which may entail in-person gatherings featuring speakers or social events for networking. On occasion, virtual meetings may be scheduled. For those who wish to become a Region Lead or to be connected with their Region Lead, please direct inquiries to maryelizabeth@softbones.org.

A Word From Our Partners

PANTHERx Rare

Traveling with Strensiq – With Spring Break traveling coming up, please make sure to give PANTHERx a call to walk you through how to keep your medication cold and stable for use during your travels.

View the Soft Bones' Traveling with Strensiq Fact Sheet [HERE](#).

Storing and traveling with Strensiq™

In general, Strensiq™ should be kept refrigerated between 36°F and 46°F, or 2°C and 8°C, (which is the standard temperature for most refrigerators) at all times.



Weather Delays – As we move out of the winter season, we are hoping to see less weather delays reported across the US. As always, PANTHERx Rare will notify you of any issues with your shipment and work with you to update shipping addresses and dates as needed.



ALEXION



Helping the Hypophosphatasia (HPP) Community

Always Here to Help



To Learn More, Call **1.888.765.4747**

Enroll Today at:

www.AlexionOneSource.com



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