

# THE BARE BONES

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

We're getting ready for World HPP Day on October 30th, an important day for our community when we collectively raise our voices for HPP awareness.

This year, our theme is **"Let's All Be Heard!"**

Thank you to our sponsors Alexion AstraZeneca Rare Disease, Aruvant Sciences and Delta Dental of NJ and CT for their support of our HPP Community.



WORLD HYPOPHOSPHATASIA DAY



Let's All Be Heard!

## World HPP Day is October 30th, 2021

As anyone affected by HPP knows, for some, HPP can be a very visual disease but for others, HPP can be invisible. We hope everyone will spend some time on October 30th spreading HPP awareness and bringing attention to our community.

Here are some HPP Awareness Day activities and ways you can get involved.

Check out all the activities on our website: <https://softbones.org/world-hpp-day/>

- **Participate in the HPP Photo Challenge-** Participate by sharing an image or different images that illustrate your HPP journey. These can include photos depicting challenges, emotions or inspiration from our daily lives. Get creative! Email pictures and captions to: [worldHPPday@softbones.org](mailto:worldHPPday@softbones.org).
- **Tell Your Story With the World HPP Day Media Outreach Toolkit-** Participate in media outreach to tell your HPP story and raise awareness for HPP. Find the toolkit [here](#).
- **Spread Awareness on Social Media-** Update your profile picture with a special World HPP Day photo frame and share your story and facts about HPP on social media. Images and directions for adding the photo frame to your profile can be found on the Soft Bones World HPP website. Don't forget to use our hashtags in your posts: #WorldHPPDay #SoftBonesHPP
- **Make a Donation-** Donate to Soft Bones any time during October and receive a special pin in honor of HPP awareness.
- **Shop for a Cause-** Check out our website's online store here for swag to spread awareness for HPP. As an added bonus, a portion of the proceeds will benefit Soft Bones.



"HPP has me feeling like..."

### Photo Challenge Examples



"A bad day - when my joints and bones are sharp and cutting."

### IN THIS ISSUE:

- Give Without Spending!
- TeleECHO Education For Professionals
- New HPP Podcast Launches
- Accepting Applications: SB Research Grant

# Give Without Spending For HPP Awareness Day: HundredX Causes Program

From October 4th– November 2nd, show your support for Soft Bones, simply by sharing your opinions on popular brands and companies. It's quick, easy, and free! Each review only takes 60 seconds of your time and for every opinion you share with HundredX Causes (formerly known as "Express Feedback For Good"), \$2 is earned for our organization. Complete up to 75 surveys and earn \$150 for Soft Bones, at no cost to you. **Our last campaign raised over \$11,000!** Get involved today and help us surpass this number! Please share with family & friends, too- all are welcome to participate!

Text "IMPACT" to 90412 or click the link: <https://hundredxinc.com/impactwithfeedback>.



**hundredx**<sup>®</sup>  
A mission based data & analytics company

**YOUR  
OPINIONS  
MATTER**

Support without  
spending!



Soft Bones would like to thank all of our fundraisers who generously give us their time and energy to raise funds for our organization and community. We would also like to acknowledge everyone for hosting birthday fundraisers. Thank you for all you do—we are so grateful!

**Thank you to our Facebook Birthday Fundraisers August - October:**

Dube Narley, Ed Steph Jones, Ira Hubscher Jr., King Tee, Larry Moore, Mary Prock, Melissa Barber, Melody Surginer, Shannon Schlie

**Other Fundraisers:**

Ann Haak - Norwex Online Shopping Party



**Creating a Facebook Fundraiser to commemorate a special day or honor someone is SO easy, and makes a world of impact! [Get started today!](#)**

**Interested in other fundraising opportunities like Venmo bingo, Norwex/Pampered Chef/Color Street parties, HPP restaurant nights, bake sales, and more- either in-person or online?**

Contact [bonnie@softbones.org](mailto:bonnie@softbones.org).

# 2021 Soft Bones Golf Classic Raises Vital Funds



The 13th Annual Soft Bones Golf Classic was held on September 20th at Somerset Hills Country Club in Bernardsville, NJ. This is our largest fundraiser of the year, and this year's golf classic did not disappoint. We had a beautiful early fall day and a fantastic turnout with 101 registrants. 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 loyal golfers who turn out year after year to support our mission. A special thank you to our corporate sponsors, Atlantic Health System and Aruvant Sciences.

**Tournament Sponsor:**



**We truly value your partnership and commitment to the HPP community.**

**Birdie Sponsor:**

**The Fowler Family Charitable Foundation**

**Eagle Sponsors:**



**Additional Sponsors:**

**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

**Additional Donors:**

Amy Campbell, Andrew and Sharon Naparano, Angela Moskow, Anne and Tom Coyne, Audrey Lane, Bill and Patti Katz, Bob and Amelia Doherty, Brenda Ziegler, Brian & Sandra Maher, Cecily Harness, Charles & Betsy Miller, Chris Houston, David Kulick, Dean Richards, Edward Snowden, Gates and Mary Ellen Hawn, Gelband Family Foundation, Griffey Remodeling, James Kavanaugh, James Noonan, Jeff Brown, Joe and Eda Tato, Joe and Marie Melone, John and Judith Harris, John and Nancy Hurley, John Callendrello, John Colton, Kathy and Scott Clifford, Kelly and Dean Thompson, Kevin and Suzanne Carton, Lara and Christian Kolberg, Leslie Curran, Maffei, Masiello and Company, Margaret and Richard DePaul, Marge Waldersen, Martin Banks, Michael Caputo, Palackdharry Family, Paul Loeffler, Penny Masters Boes, Peter Keller, Peter Mitchell, Phillip Markin, Pollack Family, Priscilla Perkins, Ray Madison, Refinery Ventures, Richard E. Derrick, Richard Resnick, Cureatr, Richard Satterfield, Robert and Mary Jane Nettune, Robert and Susan Sameth, Stephanie Vuolo, Steve and Veronica Marrochello, Suzanne Spry, Thomas Sheridan, Vinay & Wendy Mehta

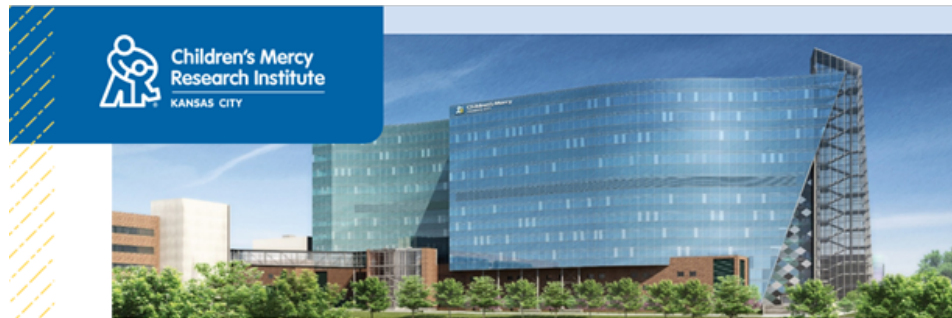
## Statement on Strensiq® and COVID-19 Vaccines



Our Foundation has received a number of inquiries about people with HPP receiving COVID-19 vaccines. We checked in with our Soft Bones Scientific Advisory Board and with Alexion AstraZeneca Rare Disease. There is no formal research indicating that HPP patients should not get the vaccine, as side effects from the vaccine of HPP patients appear to be similar to what is seen in the general patient population.

For patients on Strensiq, there are no known contraindications with vaccines. Be sure to report any reactions from the vaccine to your physician and OneSource. Patients on enzyme replacement therapy may want to avoid injecting into the same arm when receiving the vaccine. Check with your physician if you have any concerns regarding the vaccine. Read the full statement on our website [here](#).

## Hypophosphatasia US Molecular Research Center Launches Study



**The US Hypophosphatasia Molecular Research Center (HPP MRC)** at Children's Mercy Kansas City, led by Dr. Eric Rush, has officially launched. The HPP MRC is a three-year effort that seeks to take a deeper look at the genes of people who clinically appear to have the diagnosis of hypophosphatasia but do not have a pathogenic variant to prove their diagnosis. Dr. Rush and his team will study patients with variant-negative HPP using whole-genome sequencing (WGS). Individuals over 1 month of age with a clinical diagnosis of hypophosphatasia and a lack of detection of a variant on molecular analysis of the ALPL gene are eligible and there is no cost to participate.

The HPP MRC is seeking nominations from treating clinicians of patients who have a clinical diagnosis of HPP. Information and details on the study, along with the protocol for patient nomination by a physician or other provider, can be found [here](#).

## New Resources Now Available

Check out the new resources available on our website!



**Scholarship Opportunities-** A comprehensive overview of scholarship award opportunities available to HPP patients considering college. We've compiled information on 14 scholarships and where to find more information and will update these periodically. If you know of other award programs that may be of interest to the HPP community, let us know about them! Find it [here](#).

**Emergency Resources-** Today, we all know too well that fires, hurricanes, flooding, and winter storms are a reality for everyone no matter where we live. For people with medical needs like HPP, it's important to have identification on hand in an emergency situation, especially when treatment or support services may be needed. For those on Strensiq, which requires refrigeration, a power outage can be catastrophic. It's not uncommon anymore for storms to cause power outages lasting days or a week or more, where access to medication could be compromised. With that need in mind, we've created the following fact sheets to help you prepare for any emergency at home or on the road. For your convenience, you can download these resources and print them out.

- **Medical ID & Hospital Preparedness-** Explains what a medical ID is, how to get one, and how to put your medical information on your smartphone; includes information on File of Life cards and emergency cards to present at the hospital. Find it [here](#).
- **Emergency Scenario Preparedness Guide and Action Plan-** A guide to emergency services and supplies to help you prepare for any emergency situation, including an Action Plan for what to do in unexpected situations such as power outages and weather events. Find it [here](#).
- **Emergency Supply Checklist-** Provides a checklist of supplies that will be needed in case of adverse weather or a short- or long-term power outage. Find it [here](#).
- **Key Emergency Contacts and Medical Information-** A sheet that allows you to fill in important emergency contacts, including your physician, hospital and pharmacy, as well as information about your medical condition, the medication you take, any allergies you may have, and your blood type. Find it [here](#).
- **Travel Preparedness Form-** Before you leave for a trip, you can fill in all of your vital information and contacts to leave with friends or family members while you're on the road. There's a section for flight and hotel information, and an infographic with tips on what to remember when traveling. Find it [here](#).

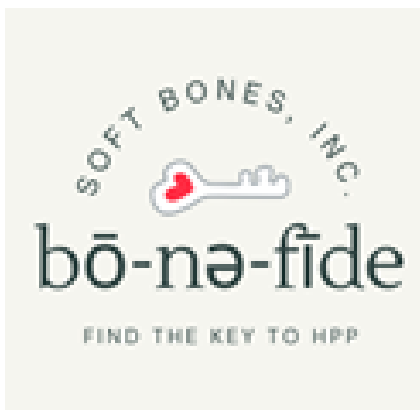
**Know Your Child's Rights for School-** Attending school for a child with a rare disease like HPP can be challenging, and parents may not be aware of what services their child is entitled to receive for in-school support, or how to navigate the system. This fact sheet provides important information for parents of school-age children with HPP about federal legislation that ensures rights for children with disabilities who attend public school. We focus on two key programs, 504 plans and Individualized Educational Programs (IEP), that provide accommodations or special education services for children in the classroom to help them succeed. It includes tips for parents with school-age children with HPP, and special considerations about how developmental and behavioral health can impact school performance or socialization with peers. Find it [here](#).

## Soft Bones Exhibits at 2021 American Society for Bone and Mineral Research (ASBMR) Annual Meeting

We had a chance to connect with bone, mineral and musculoskeletal scientists and research physicians from around the world at the American Society for Bone and Mineral Research (ASBMR) 2021 Annual Meeting, held October 1-4, in-person in San Diego, CA and real-time virtually. Soft Bones was a conference exhibitor at ASBMR, the premier scientific program dedicated to promoting excellence in bone and mineral research. We were excited to participate virtually and have the opportunity to let researchers know about our Soft Bones research grant and HPP educational programs. We also let physicians who can take HPP patients know that we maintain a referral list.



## Our New Podcast Launches



Soft Bones, Inc., is pleased to present our new podcast, bō-nə-fīde HPP. This podcast is designed to educate and support the families and caregivers of those affected with hypophosphatasia. As a mother and caregiver, host Deborah Fowler has discussions about this rare genetic bone disease with people from all over the world.

The first episode, with special guest Dr. Timothy Wright, DDS, is now live! [Click here to listen.](#)

Tune in to our next episode, featuring physical therapist Donna Griffin, Director of Rehabilitation Services Shriners Hospitals for Children in St. Louis, MO. Please be sure to post your questions on HPP and Me.

We encourage you to check out the podcast, and we welcome your questions.

## UPDATE: Teen Advisory Council (TAC)



### What is the TAC?



A support and advocacy group for teen patients with hypophosphatasia and their teenage siblings.

If you're interested, you can apply to be one of the TAC members.

On October 7th, the TAC held a meeting to plan and complete an HPP photo challenge. The group is also launching a Venmo bingo board fundraiser, which concludes on World HPP Day on October 30th. To participate, download [this board](#) and share it via your Instagram page or stories so followers can choose a square and donate. They are also working on a new T-shirt design, which is soon to be finalized.

The TAC is a great platform to become involved in the broader HPP community, with advocacy, awareness activities, and fundraising. You will also have the opportunity to compete in challenges to win prizes and a scholarship, and participate in Soft Bones social media activities. Stay tuned for more information about how you can be a part of the 2022 TAC!

## Join The Conversation Today!



HPP AND ME is our online forum community for patients, parents, and caregivers to connect safely and privately. Here you will find robust, searchable, permanent conversations about HPP. Additionally, as a member of this community you will be given exclusive early access to new podcast episodes, research, publications, and Soft Bones resources. We hope you join us!

[Register Here](#)



The Bone Zone is our community blog for HPP patients and their families to share their stories and insights. If you are not yet featured in a Bone Zone blog, please contact us at [info@softbones.org](mailto:info@softbones.org) to share your story.

[Read The Bone Zone](#)

SOFT BONES INC, THE US HYPOPHOSPHATASIA FOUNDATION PRESENTS

# HYPOPHOSPHATASIA (HPP)

## TeleECHO PROGRAM

FOR HEALTHCARE PROFESSIONALS



Join us for monthly telementoring presentations and discussions concerning HPP. The series begins with six general HPP topics.

**Held on the 2nd Friday of each month, 12 PM EST\*.**

**Submissions of brief case presentations for discussion post-lecture are welcome.**

**There is no cost to participate.**

## HPP TeleECHO Program Offers Continuing Education To Health Professionals

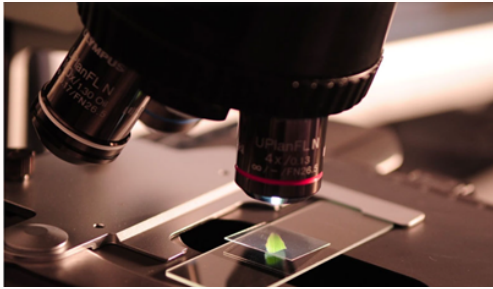
The Soft Bones TeleECHO program for healthcare professionals, which provides continuing education for the HPP healthcare team, is up and running. This six-part series, provided monthly at no cost for physicians, is designed to improve patient care through “telementoring” presentations and discussions on different HPP-related topics. The first six sessions are foundational, and more in-depth presentations will be explored once we receive feedback on the initial sessions. We had more than 100 people register for the first webinar, which was a great indicator of the level of interest in the topic.

Physicians can receive continuing medical education (CME) credit for participating in the teleECHO sessions. They are designed based on a knowledge-sharing model, where experts lead virtual clinics and amplify the knowledge for providers to deliver best-in-class care in their own communities. Brief case presentations can be submitted for discussion post-lecture.

Along with Soft Bones staff, a carefully selected faculty of experts plan and oversee the program and curriculum. Faculty members are Dr. Michael Whyte, Shriners Hospitals for Children, St. Louis, MO; Dr. Matthew Drake, Mayo Clinic, Rochester, MN; and Dr. Kathryn Dahir, Vanderbilt University Medical Center, Nashville, TN, who each bring a unique specialty to the program.

Sessions are held the second Friday of each month. Medical professionals can participate via Zoom and all sessions will be recorded and posted on the Soft Bones YouTube channel after each session. A program flyer with the schedule of upcoming programs can be found [here](#). For physicians who would like to register, email us at [echo@softbones.org](mailto:echo@softbones.org).





## Now Accepting Applications: 2021 Soft Bones Research Grant

We are **accepting applications for our annual Soft Bones Research Grant** for research in 2021-2022. As part of our mission to foster innovative research by new and established investigators, the Soft Bones Foundation offers a “seed grant” of \$25,000 for research that is directly related to hypophosphatasia.

Proposals are welcome from faculty members at a university or private research institution. Applications from senior postdoctoral trainees or research associates are acceptable provided that the mentor has a record of commitment to research relevant to HPP. This grant cannot be used for investigator salary support or indirect costs. Proposal reviews are conducted by the Soft Bones Scientific Advisory Board.

The deadline for applying is November 1, 2021. Click [here](#) for a flyer or [here](#) for an application.

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## Research Grant Update

The **2019 winner of our Soft Bones Research Grant, Dobrawa Napierala, PhD**, recently finalized her data collection and submitted a final research report on her project. The data she was able to collect through this seed funding will support an NIH grant application for more comprehensive studies on the molecular mechanisms underlying bone and mineral disorders. Dr. Napierala’s research focuses on the novel function of tissue-nonspecific alkaline phosphatase (TNAP) in biomineralization. Greater understanding of the role of TNAP in the fundamental functioning of cells could have benefits for hypophosphatasia patients as well as for patients with other diseases caused by abnormal extracellular phosphate (Pi) levels. Dr. Napierala, is an Associate Professor and Co-director of the Oral and Craniofacial Sciences Graduate Program, Center for Craniofacial Regeneration, at the Pittsburgh Center for Interdisciplinary Bone and Mineral Research, McGowan Institute for Regenerative Medicine, School of Dental Medicine, University of Pittsburgh.



**Dobrawa Napierala, PhD**

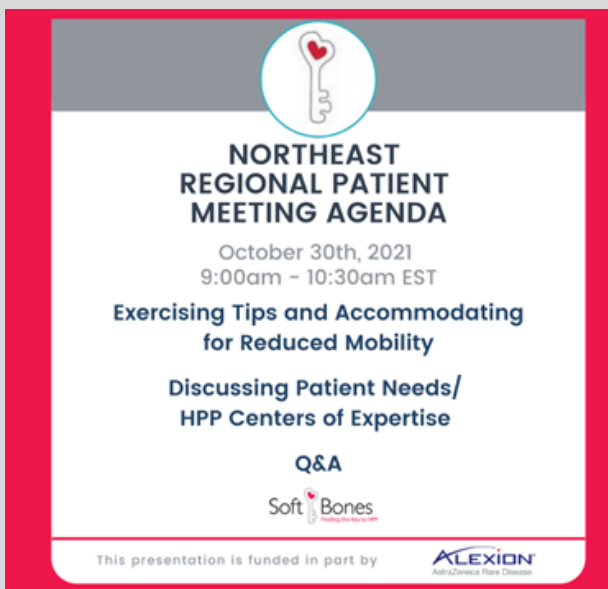
## Region Updates & Upcoming Events

**Saturday, October 23**  
**9:00-11:00 AM EDT**



A reminder to our community in Midwest Region 1 (Minnesota, Wisconsin, Iowa, Illinois, Indiana) and Midwest Region 2 (Ohio, Michigan, West Virginia, Kentucky): Please join Soft Bones Midwest 1 and Midwest 2 Region Leads for an educational program presented by HPP experts from the Midwest Region, hosted by Haley Gast, Soft Bones Region Lead Midwest 1, and Sharon Talkington, Soft Bones Region Lead Midwest 2. Open to patients, caregivers, and loved ones residing in the Midwest 1 and Midwest 2 Regions. Click [here](#) to register, or read the [full agenda](#) for information on topics and speakers.

**Saturday, October 30- World HPP Day**  
**9:00-10:30 AM EDT**



Join Region Lead Chris Denune on World HPP Day- October 30th- for our Northeast Region Virtual Regional Patient Meeting. Speakers: Donna Griffin (PT, Shriners Children's Hospital, St. Louis- Soft Bones champion and HPP expert), and Gloria Stone, a consultant working directly with Soft Bones who will explore establishing multi-disciplinary clinics across the country with the hopes of having more Centers of Expertise for HPP. Provide Gloria with feedback on what's most important to us and hear more about the initiative! Attendees will also have the opportunity to catch up with each other as we've done in the past. Open to patients, caregivers, and loved ones residing in the Northeast Region (Maine, Massachusetts, New York, Pennsylvania, District of Columbia, Virginia, New Jersey, Connecticut, Vermont, New Hampshire, Rhode Island, Maryland and Delaware). Click [here](#) to register, or read the [full agenda](#) for more information on topics and speakers.

## Region Updates & Upcoming Events (Cont'd.)

**Saturday, October 30- World HPP Day  
4:00 PM EDT**

**Soft Bones**  
Finding the Key to HPP

**Brings the BOO To YOU!**

**Come Join a Virtual Costume Party to Celebrate World HPP Day!**

**Who:**  
Newborn to 13 yrs old  
Parents Welcome

**How:**  
Zoom connection

**When:**  
Saturday October 30<sup>th</sup>  
4 pm EDT,  
3 pm CDT,  
2 pm MDT  
1 pm PDT & AZ,  
9 pm United Kingdom

Click [here](#) to register  
or email [sue@softbones.org](mailto:sue@softbones.org)