

# THE BARE BONES

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

## Soft Bones Awards 2020 Grant to Sanford Burnham Prebys Researcher to Promote Gene Therapy Advancements in HPP

Soft Bones is pleased to award its annual Maher Family Grant of \$25,000 to Flávia Amadeu de Oliveira, PhD, a post-doctoral associate at the Millan Lab at Sanford Burnham Prebys Medical Discovery Institute in La Jolla, California, to study the potential of gene therapy in HPP. The study objectives look to determine the efficacy of viral vector delivery of mineral-targeted tissue non-specific alkaline phosphatase (TNAP) to treat late onset or adult HPP.



Flávia Amadeu de Oliveira, PhD

"I have a long-standing interest in bone biology, especially in the molecular mechanisms that regulate bone homeostasis," said Dr. Amadeu de Oliveira. "Overall, my goal through this research proposal is to test if chronic administration of mineral-targeted TNAP in HPP mice with superimposed chronic kidney disease, which manifests vascular calcification, may have adverse consequences. In doing so, I will also attempt to validate viral vector delivery of mineral-targeted TNAP to correct the soft bones disease in late-onset HPP mice. Overall, this study will contribute to devising safe and improved therapies for HPP."

### IN THIS ISSUE:

- Patient Meeting Review
- A Successful World HPP Day Celebration
- Volunteer News
- Soft Bones Featured On CoRDS Podcast

## Update: Ensuring Last Smiles Act Moves Forward in Congress

The House Energy and Commerce Committee recently passed the Ensuring Last Smiles Act (HR 1379/S 560) on September 9, 2020. The act would require all private insurance groups and individual health care plans to cover medically necessary services resulting from congenital abnormalities. That coverage would include services and procedures for any missing or abnormal body part necessary to achieve normal body function, including teeth. This is an important advancement as many families without this coverage make significant financial sacrifices just to afford necessary dental care. Coverage would include services and procedures for any missing or abnormal body part necessary to achieve normal body function, including teeth, as determined by the treating physician (Congress.gov, Legislation, 2020). The bill needs additional review from the Education and Labor and Ways and Means Committees in the House and the HELP Committee in the Senate. Soft Bones' is committed to our HPP community members and will continue to advocate for this bill until it is seen through by the remaining Congress members.



## National Patient Meeting: A Successful Transition to a Virtual Event

The National Patient Meeting (our largest meeting of the year) was held on July 11, 2020 through an online conference platform. Staff, volunteers, patients and medical professionals quickly adapted to the new meeting format, and nearly 250 participants enjoyed a full morning of educational sessions with leading experts Dr. Priya Kishnani, Dr. Deborah Wenkert, Dr. Timothy Wright, genetic counselor Erin Huggins and mental health clinician Lauren Myler. All of the content is available to view on-demand at [www.softbones.org](http://www.softbones.org).



## 2020 Golf Classic Raises Critical Funds

The 2020 Soft Bones Golf Classic, the organization's largest fundraiser, was held on September 21, 2020 at Somerset Hills Country Club in Bernardsville, NJ. Despite the changes this year due to COVID-19, we were blessed with a beautiful fall day and were humbled by the support and positivity felt from all of the registrants, donors and sponsors. The event sold out with 90 players on the course, and brought in additional funds from donors and sponsors. Mark your calendars for next year's Golf Classic scheduled for September 20, 2021.



## Awareness and Education Efforts Pay Off During National Dental Hygiene Month

As you may know, dental hygiene plays an important role in HPP management. Through Delta Dental of New Jersey and Connecticut's SMILE Mini-Grant Program, our organization is able to connect with dental professionals in the tri-state area, as well as patients and families to provide education and outreach. During the month of October, Soft Bones launched the following dental initiatives to commemorate National Dental Hygiene Month:





- **Social Media Campaign:** Throughout the month, facts and outreach messages were posted to Twitter, Instagram and Facebook to spread awareness and direct people to our online educational resources
  - **Hippo Squad Mailer:** Each child (HPP patient or sibling ages 3-12) in the Soft Bones Hippo Squad received an activity box developed in partnership with Delta Dental staff as part of Delta's All Associates Volunteer Week program. Mailers included educational activities, themed giveaways (also provided by Delta) and a photo/video sharing opportunity. Items helped educate families on the increased oral care needs of children with HPP. The box also included learning materials for parents.
- Not part of the squad? Sign up today!**

## New AACC/LTO Partnership Will Increase Outreach and Advocate for Consistency in Lab Testing

Soft Bones recently became a Champion Partner of the American Association for Clinical Chemistry (AACC), Lab Tests Online (LTO) program. AACC is a global scientific and medical professional organization dedicated to clinical laboratory science and its application to healthcare. LTO is an award-winning AACC resource that helps patients better understand the many clinical lab tests that diagnose, monitor, and treat a broad range of conditions, including cancer, diabetes, heart disease, infectious diseases, and more. ALP levels play an integral role in an HPP diagnosis, and this partnership will aid Soft Bones in our efforts to advocate for standardization of acceptable ranges across multiple labs.





Hypophosphatasia is now listed under the site's ALP section, which boasts more than 2 million hits per year. We are also currently working on a scientific article for the site's "conditions" page, which is highly trafficked by patients and professionals. LTO's site overall has 2.2 to 3 million visitors each month, which will increase our visibility tremendously. Visit: [www.labtestsonline.org](http://www.labtestsonline.org) to learn more.

**Lab Tests Online®**  
Empower Your Health. Understand Your Tests.

A program of **AACC**

## SPREAD THE WORD & HELP US HELP OTHERS

Despite our recent success at the 2020 Golf Classic, COVID-19 is having a sizable impact on our fundraising targets for 2020/2021. To offset our efforts, we have taken steps to try to diversify our sources through exploration of matching gifts, employee-driven programs and other online initiatives.



### How Can You Help Soft Bones?

- If you are aware of any corporate or local grants, employee payroll deduction or employer matching gift programs (through your own employer, or through a family or friend's employer) that might be a good fit for Soft Bones, please let us know. Many are surprised to find that their employer offers these initiatives, so be sure to inquire about their availability through your employer's Human Resources Representative or Payroll Administrator.
- Shop on Amazon using the [Amazon Smile page](#) so that a portion of purchases will be donated to Soft Bones. It's free and so easy!
- [Create a Facebook fundraiser](#) online for the holidays, a birthday or other special occasion so that friends, family and colleagues can support a cause that is important to you. This is also a free and simple initiative.

Our community is strong and rapidly growing, and your support helps us to expand our services to meet the needs of the entire HPP population.

**Looking for more ideas? Contact [bonnie@softbones.org](mailto:bonnie@softbones.org).**

## RECAP: HYPOPHOSPHATASIA AWARENESS WEEK AND WORLD HYPOPHOSPHATASIA DAY 2020

This past October, communities throughout the world celebrated HPP Awareness Week and World Hypophosphatasia Day. Though a bit different from last year, we hope that everyone found a way to get involved. This year's theme was: "Together, we are stronger," which holds deep meaning for those living with a rare disease, especially during the challenges brought on by 2020.



World Hypophosphatasia Day



hpptogether

New for this year, Soft Bones coordinated a worldwide effort to recognize HPP across the globe, hence the October 30th commemoration as World Hypophosphatasia Day, and not just HPP Awareness Day. HPP Awareness Week was celebrated the week leading up to it on Oct. 24-31, and culminated with our October 30th wellness webinar, led by celebrity TV correspondent Dr. Jen Hartstein. All month long, patients, caregivers and HPP community supporters engaged in many different activities to spread awareness, promote HPP education and raise funds to support programming.

# World Hypophosphatasia Day

## Awareness Highlights

### Website Launch

This year, Soft Bones launched a brand new event-specific website and online toolkit, [www.worldhppday.org](http://www.worldhppday.org), to provide educational information, downloadable images, and activity details to describe all of the ways to participate on a global level.



### Social Media Awareness

HPP community members posted and shared educational facts and awareness messages all month long using the hashtags #HPPTogether, #SoftBones, #HPPAware, #WorldHPPDay, and #Hypophosphatasia. Nearly 200 people changed their Facebook profile picture to include the official World HPP Day frame, which is a record high for Soft Bones!

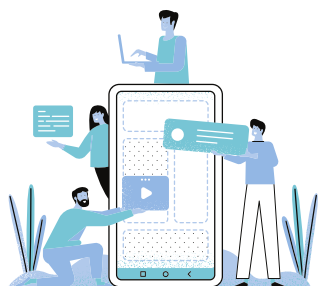
### Limited Edition T-shirts



HPP community members purchased tee shirts, long sleeve tees and even baby onesies and shared photos wearing them on World HPP Day. A portion of sales was donated to Soft Bones, helping us raise over \$600.



### Storyvine Sharing



Using the fun and easy Storyvine app, 30 individuals and families in our community recorded videos that were used to share their HPP journey and spread awareness.

### Media Highlight

Elizabeth, a fellow HPP community member, highlighted the story of 9 year-old Rowan and her parents' efforts to raise awareness about HPP this year. You can read the full article [here](#).

### Wellness and Self-Care Webinar

To commemorate World HPP Day, Today Show and Yahoo mental health correspondent Dr. Jennifer Hartstein led a wellness and self-care webinar which was well-attended by patients, caregivers and medical professionals from all over the world. Following the webinar, patients and caregivers were whisked into video breakout sessions where they could debrief from the meeting and chat amongst peers. [View the webinar.](#)





## Volunteering In The Time Of COVID-19



A great deal of Soft Bones' success relies on the selfless work of our volunteers. Stephen Bernstein is one of many who has dedicated his time and effort to our organization. He has been with Soft Bones since March of 2020 and since that time, works on database and data entry projects. He has volunteered regularly for 4 to 5 years at other organizations since retiring, but is thankful to have found a remote way to help during these uncertain times.

The retiree found Soft Bones through a local volunteer site and felt the skillset needed for the specific position listed was a "perfect match" to his background in database administration and budget management. It was a quick decision to volunteer, and within a few weeks, Stephen was a part of the team. Although Stephen's experience was unique with only being trained in-person once before the COVID-19 pandemic forced volunteers and staff to work remotely, it was far from challenging. He praised the work of all the Soft Bones staff members who made it possible to volunteer remotely even through chaos. "The people I have contacted have been great," said Stephen. "Everyone really wants to do the work."

As Stephen has been able to assist Soft Bones, his volunteer work has also had benefits for him. One of the best parts of volunteering, especially during a pandemic, is the ability to connect with others. Along with his wife, Stephen stays home as much as possible in order to stay safe, but his work with Soft Bones has given him a daily dose of social interaction. Stephen also mentioned the self-satisfaction he feels when being able to fill a specific need for an organization that does the type of work Soft Bones does. "Everyone is looking out for themselves during these times, but Soft Bones is looking out for everyone else right now," said the volunteer. "I'm happy to be able to fit a need and help [Soft Bones] especially financially during these times."

Volunteering has also helped Stephen become more educated. With no connections to HPP, Stephen began volunteering with no information about the rare disease but observing the "clear passion of everyone," has motivated him to research HPP.

We would like to thank Stephen Bernstein for sharing not only his time with Soft Bones but also his story.

## Join The Soft Bones Volunteer Team

Every nonprofit organization, including Soft Bones, simply cannot fulfill its mission and accomplish change without the tremendous support of volunteers. To understand the impact volunteers have, let's look at some remarkable statistics. In July of 2020, the national average that a volunteer was valued at was \$27.20 an hour (Independent Sector). Therefore, the savings nonprofits gain by working with volunteers can be exponential, and these funds can then be utilized more directly to support HPP patients and their families. Every dollar counts when you are searching for a cure. Volunteers also spread awareness to others about the mission and accomplishments of Soft Bones.

Networking acts as a crucial factor in funding a nonprofit's mission and provides more opportunities for donations, grants and sponsorships. Soft Bones values its volunteers immensely and recognizes the vital work done by all of them.

Volunteering does not just benefit the nonprofit, but also offers many rewards for individuals. Volunteering has been shown to strengthen the body, improve overall mood, and relieve stress in participants (HelpGuide.org). Becoming a volunteer also boosts social interactions in one's life and provides opportunities for new friendships, bonds, and meaningful connections. Volunteer work improves one's professional life as well. Forbes reports that 60% of hiring managers admitted that volunteering makes an individual more marketable. Also, many studies have shown that volunteer work leads to enhanced leadership and teamwork skills.

Please consider making a difference in the hypophosphatasia community by volunteering with Soft Bones. **If you, or someone you know, is interested in becoming a volunteer or intern for Soft Bones, please contact Bonnie Starr at [bonnie@softbones.org](mailto:bonnie@softbones.org).**



### Opportunities To Volunteer:

- Be a Region Lead (HPP Ambassador) or HPP PAL (buddy program)
- Assist with local advocacy
- Host local fundraisers or events
- Assist with marketing and outreach
- Perform grant-related and corporate research

## Tune In To Our Podcast Episode

Soft Bones partner Sanford Research, who hosts the Hypophosphatasia International HPP Contact Registry, recently featured our organization in an episode of the CoRDSCast podcast. This was a wonderful opportunity for us to raise awareness and increase our enrollment in our registry. Listen [here](#).



## Thank You Summer 2020 Interns

Soft Bones recently worked with 4 wonderful interns who supported us remotely while gaining experience in a busy non-profit setting. **Sarah Wisniewski** from Villanova University and **Caroline Schmitt** from the University of Michigan worked on programming and public health initiatives, as well as communications and graphics for our Virtual Patient Meeting and Golf Classic.

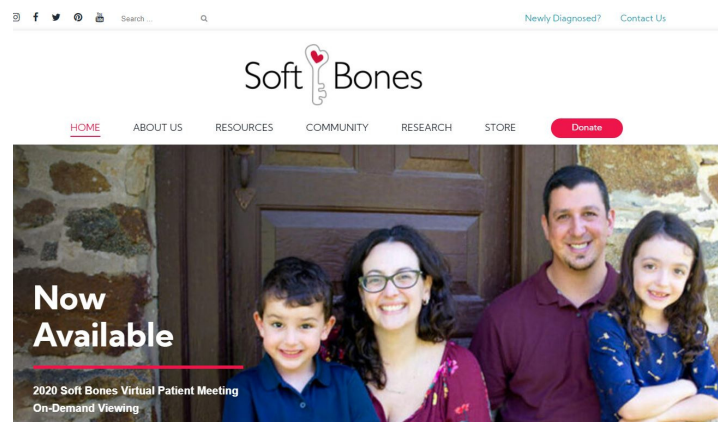
**Anjali Kapoor** from Princeton University developed a framework, materials and a website for our Teen Advisory Council (TAC), launching in 2021. **Michael Parisi** from Elon University prepared materials, messaging and a t-shirt campaign for the HPP Awareness Week and World HPP Day initiatives. Smart, creative students like these help us accomplish so much, and we are so grateful that they've chosen Soft Bones for this opportunity. We wish them much success in their future studies and professional work.





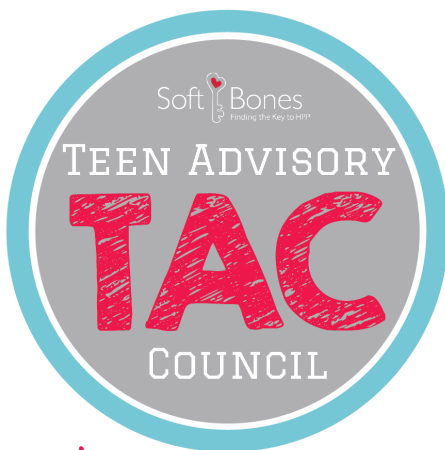
## Check Out Our Newly Redesigned Website

Soft Bones is excited to announce our newly redesigned website, created with the needs of all of our various stakeholders in mind. Be sure to visit the HPP Resource Library, where you can search Soft Bones publications, journal articles and more. It's a great place to find the latest information on HPP and learn about all of our programs and services. There's also a new Soft Bones online store with logo apparel and items for all ages!



Take a tour at [www.softbones.org](http://www.softbones.org) and let us know what you think!

## Calling All Teens: Join Our Empowering Community



### Make it YOUR platform

TAC provides a platform for teens to speak up about HPP to the broader community. Members can directly reach out to local politicians to garner federal support, or fundraise and spread awareness within their schools and communities.



### Get Involved

From writing blog posts to participating in social media challenges, there are numerous ways for you to get involved. By joining the team, you can compete in challenges to **win prizes**, be selected for **awards**, or even **win a scholarship!**



### Council Management

As part of the team you will have the opportunity to run SB's social media accounts, participate in content challenges on YouTube, Tik Tok, and Instagram, organize fundraising events such as bake-sales, walks, and raffles, and much more!

## SUBMIT YOUR APPLICATION

Apply now at [www.softbonetac.wixsite.com/website/apply](http://www.softbonetac.wixsite.com/website/apply).

## A Year-End Message From Our Founder

Dear HPP Community,

What a year it has been. One unlike any that we have seen before, 2020 gives us reason to reflect on what has mattered most these past months, while being hopeful about many brighter days ahead. Since we founded Soft Bones more than a decade ago, we have had the opportunity to connect with families like yours around the world who have been impacted by HPP. We know how important it is to be part of a community of people who understand what it's like to live with this rare disease. We recognize the value of having a place where you can collaborate to build relationships, obtain medical information and connect with knowledgeable experts as you navigate your disease journey. We are excited to share the achievements we have made this year as well as the exciting upcoming plans the organization is focused on as we head into a new year, keeping patients at the forefront of all that we do.

This year, COVID-19 has presented a set of unprecedented challenges that we all have had to address. We know it hasn't been easy for you - adapting to telemedicine appointments, facing delays in diagnosis due to the cancelation of doctors' appointments, grappling with concerns about life-saving medication being impacted by shut downs, not to mention the additional layer of anxiety on top of the existing stress of having a pre-existing underlying chronic disease.

It is people like you, resilient and determined, who remind us why we continue to do the work that we do and make us even more focused and resolute in our mission. Despite the unique challenges of 2020, we have been able to accomplish significant goals, with the intention of further advocating for and supporting the HPP community. With your help, we have accomplished so much in just one year, and we want to continue to make strides to improve the lives of those living with HPP.

I hope you will consider a donation to the Soft Bones Foundation at [www.softbones.org](http://www.softbones.org). Thank you in advance for your support. We wish you Happy Holidays and all the best in 2021.

Sincerely,



Deborah Fowler  
President and Founder

