



Soft Bones **Spring 2019 Edition** Newsletter

"Spring: A lovely reminder of how beautiful change can truly be!"

WELCOME OUR NEW REGION LEADS

**We are thrilled to welcome our newest Region Leads!
Nichole Macknight, Amanda Stoner and Nellie Sanders**

Nichole Macknight will join Sharon Talkington leading Midwest II

Nichole became a region lead to advocate and support the cause she is personally impacted by, she wants to bring others together for support and education.

Amanda Stoner will join Blynda Kellner, Jennifer Carothers and Christy Burke in the Southeast

Amanda was inspired by her daughter Emersynn, she wants to help make a difference for all individuals in the best way that she can.

Nellie Sanders joins Sue Brown, Jennifer Jansonius, Kara Schweiss and Angela Hasting leading the Central Region and supporting the Northwest Region, as needed

Nellie was inspired by the support Soft Bones gave her, she wants to give back to others who are going through a similar journey.

What Do Region Leads Do?

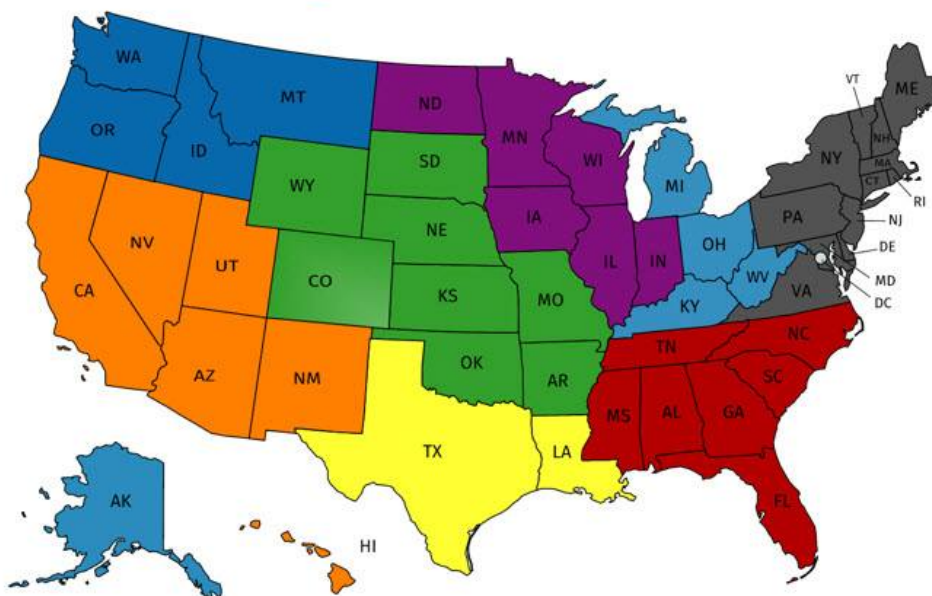
Region Leads, who commit for a two-year term, work to execute several objectives, including:

- Hosting two meetings per year
- Conducting one fundraiser per year and championing Soft Bones fundraisers
- Engaging in awareness efforts and promoting Soft Bones HPP Awareness Day
- Attending monthly conference calls
- Providing photos and region updates for the Soft Bones Newsletter and contributing a short story or update to the [BoneZone](#) blog

If you are active on Facebook, please join your region page. Region Leads will be posting about upcoming meetings and region activities and it's a great place to interact with others in your region. Don't worry -- if you aren't on Facebook, we will also be emailing those in our database details about region meetings.

If you need to update your email or need assistance joining your region Facebook page contact Adriane at adriane@softbones.org.

What Region Am I In?



REGION KEY
Northwest (WA, OR, ID, MT, Northern CA, AK)
Southwest (Southern CA, NV, UT, AZ, NM, HI)
Central (ND, SD, WY, NE, CO, KS, MO, OK, AR)
South Central (TX, LA,)
Midwest I (MN, WI, IA, IL, IN)
Midwest II (MI, OH, KY, WV)
Southeast (AL, GA, SC, NC, TN, FL, MS)
Northeast (ME, MA, NY, PA, DC, VA, NJ, CT, VT, NH, RI, MD, DE)

Who Are My Region Leads?

To read their stories, please click their name!

SOUTHWEST:

[Amy Britt](#) | amy@softbones.org

[Sue Krug](#) | sue@softbones.org

CENTRAL/NORTHWEST:

[Angela Hastings](#) | angela@softbones.org

[Jen Jansonious](#) | jen@softbones.org

[Kara Schweiss](#) | kara@softbones.org

[Nellie Sanders](#) | nellie@softbones.org

[Susan Brown](#) | susan@softbones.org

[Ann Haak](#) | ann@softbones.org (NW)

SOUTH CENTRAL:

[Cami Rush](#) | cami@softbones.org [Danielle](#)

[Zibilski](#) | danielle@softbones.org

MIDWEST I:

[Crystal Norris](#) | crystal@softbones.org

MIDWEST II:

[Nichole Macknight](#) | nichole@softbones.org

[Sharon Talkington](#) | sharon@softbones.org

SOUTHEAST:

[Amanda Stoner](#) | amanda@softbones.org

[Blynda Kellner](#) | blynda@softbones.org

[Christy Burke](#) | christy@softbones.org

NORTHEAST:

[Adrianna Tuomi](#) | adrianna@softbones.org

[Chris Denune](#) | chris@softbones.org

[Lisa Danowitz](#) | lisa@softbones.org

SAVE THE DATES -- REGION MEETING DATES:

- **Central-** August 3 | Kansas City & TBD | Tulsa, OK
- **Midwest 1-** May 25 | Chicago & August 10 | Indianapolis
- **Midwest 2-** June 22 | Newark, OH & November 9 | Toledo, OH
- **Southwest-** July 13 | La Jolla & October 12 | **TB**
- **Southeast-** May 25 | Biloxi, MS & June 29 | Nashville, TN
- **South Central-** June 8 | Canyon Lake, TX

INTRODUCING
OUR NEW FUNDRAISING COMMITTEE

We've kicked off a new Fundraising Committee comprised of four different subcommittees, seen below.

- 1) **NATIONAL** - Will focus on corporate partners and grant opportunities with companies in the communities where we live. If you work at or live near a company that may be interested, we would love to have your input on this committee.
- 2) **COMMUNITY/LOCAL** - This committee will research and select the fundraising opportunities for families and people living with HPP to host in their communities.
- 3) **STORE** - Want to have a say in what merchandise we stock in our HPP online store? Then this sub-committee is for you! Be a part of the team selecting new designs and items to raise money for Soft Bones.
- 4) **PROMOTION/COMMUNITY ENGAGEMENT** - Help champion our fundraising efforts by spreading the word online, to friends and in social media. This is an important part of our fundraising efforts. Being a part of this committee, you will also learn valuable on-the-job skills like how to maximize social media exposure
- 5) **FINANCIALS** - Will focus on tracking the successfulness of each of the fundraising campaigns

If you are looking for a way to give back to Soft Bones, please consider these impactful opportunities. If you are interested in serving on any of these committees or have questions about the time commitment, please reach out to Committee Chair Nellie Sanders (nellie@softbones.org), Denise (denise@softbones.org) or Deb (deborah@softbones.org)!

We rely on your talents and support to make this committee and its initiatives a success, you can still help even if you aren't on the committee by supporting these fundraisers - we look forward to this exciting new effort to help support Soft Bones! Thank you for your support!

Webinar- The Emotional Effects of Living with a Chronic Rare Disease

On May 29, Adrianna Tuomi, a licensed clinical social worker and Soft Bones Community Member and Region Lead presented a webinar on the **psychological effects of living with hypophosphatasia**. She walked attendees through different secondary diagnoses that can come with a chronic illness, which include anxiety, depression and medical trauma.

We also discussed coping strategies for living with a diagnosis and many additional topics including, the role of caregivers, the importance of self-care, how to minimize burn-out and exhaustion from caring for a loved one.

To view past webinars and the most recent, The Emotional Effects of Living with a Chronic Rare Disease, please visit our [Youtube Channel](#), [Soft Bones HPP](#).



PATIENT MEETINGS 2019 --- To commemorate our 10 year anniversary, we will be celebrating coast to coast! We are excited to announce there will be **TWO Soft Bones Patient Meetings in 2019** – each with a different agenda and location! HPP Patients and their families will spend the day together, share stories and listen to leading HPP professionals to present their knowledge of various aspects of living with HPP.



Saturday, July 13 at Sanford Burnham Prebys Medical Discovery Center in La Jolla, CA

Saturday, October 26, at the Sheraton Parsippany Hotel in the Parsippany, NJ

We look forward to seeing you in California and/or New Jersey!

Did you know socks are the most RARELY donated item but most needed at homeless shelters?

This year at the Soft Bones Patient Meeting in La Jolla, we are asking attendees to bring new or gently used clean adult and child socks in black, white, yellow, green and orange.

These socks will be used for a demonstration on inheritance and later donated to a local charity. We appreciate your generosity!

RESEARCH OPPORTUNITY AT THE CALIFORNIA PATIENT MEETING

Dr. Pedro Sanchez MD, MSCE, FAAP, FACMG, Director of Pediatric Genetics, David Geffen School of Medicine, UCLA Cedars-Sinai Medical Center is working with a group of university-based researchers to develop a comprehensive 3D photograph database of faces from patients with genetic conditions including hypophosphatasia.

He will be attending our Patient Meeting in La Jolla to enroll interested participants and answer any questions.

MORE DETAILS ON DR. PEDRO SANCHEZ'S PROJECT

This research will become part of the National Institutes of Health [Face Base database](#) and will be available to assist other qualified scientists who are working to better understand these conditions.

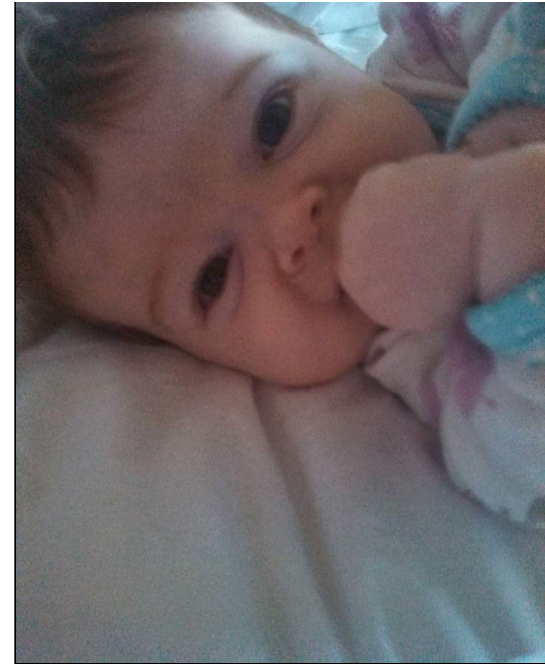


Such deep photo analyses will yield a deeper understanding of the genetic basis of facial development. Furthermore, this work will revolutionize the clinical diagnosis efforts supplementing subjective clinical impressions with objective quantitative measures and computerized assistance in facial recognition in a clinical setting, particularly in parts of the world where “clinical genetics” is not readily available.

ON DECEMBER 4, 2013 THE SOFT BONES COMMUNITY GAINED AN HPP ANGEL. IN HER HONOR, WE ARE EXCITED TO ANNOUNCE THE INTRODUCTION OF...

THE STELLA BITHER TRAVEL FUND

AN ANONYMOUS DONOR HAS COME FORWARD TO ESTABLISH A TRAVEL FUND IN MEMORY OF STELLA BITHER. THIS TRAVEL FUND WILL BE USED FOR FINANCIAL ASSISTANCE FOR FAMILIES TO ATTEND PATIENT AND REGION MEETINGS. IF YOU WOULD LIKE TO DONATE TO THE STELLA BITHER TRAVEL FUND, PLEASE CONTACT DONATION@SOFTBONES.ORG



SOFT BONES AND **NIDCR PATIENT ADVOCACY DAY**

Soft Bones is a part of the [Friends of NIDCR Patient Advocacy Council](#), part of the NIH, which is comprised of non-profit organizations who work together to support oral health research and initiatives.

On February 26, 2019 Soft Bones attended **Advocacy Day on Capitol Hill** which is the time for organizations to communicate with federal policymakers about the important role dental, oral and craniofacial research play in our society. From contributing to the health and well-being of Americans to providing the evidence we need to reduce the economic burden of oral conditions, this research is positively shaping health and healthcare in this country!



Deb Fowler, Denise Goodbar and Cannon Sittig specifically asked that they will support the NIDCR's

request of at least \$41.6 billion for NIH and at least \$492 million for NIDCR. To ensure research agencies and programs continue to have room to receive much-needed funding increases, we are also asking that Congress work together to research a bipartisan budget deal that raises the budget caps and supports non-defense discretionary programs, which will be cut by \$55 billion if a deal is not reached. We requested sufficient funding to the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee.

Soft Bones and [CCD Smiles](#) met with the NIDCR (National Institute of Dental and Craniofacial Research) and a legislative correspondent for Senator Bob Menendez to advocate for increased NIH funding on Capitol Hill.



Soft Bones had the opportunity to meet “**Stranger Things**” star **Gaten Matarazzo** who has the rare genetic disorder, cleidocranial dysplasia (CCD), which caused him to be born without a collarbone and has affected the growth of his teeth.



Gaten Matarazzo and Deborah’s son, Cannon-- Rare boys storming Capitol Hill to raise awareness about the importance of research for their diseases -- CCD and HPP.

RARE DISEASE DAY AT THE NIH

On Feb. 28, 2019, Rare Disease Day was held at the **National Institutes of Health** (NIH) which aims to raise awareness about rare diseases, the people they affect and NIH research collaborations underway to address scientific challenges and to advance new treatments.

Deborah, Denise and Cannon had the opportunity to attend to distribute Soft Bones materials and spread awareness They also met people from the NIH industry other advocacy groups and rare disease patients

and spoke to people from Global Genes, and NORD as well as other rare disease organizations.

For more information on this event:

https://events-support.com/events/Rare_Disease_Day

What's the NIH, NIDCR and NIAMS?



The [National Institutes of Health \(NIH\)](#), a part of the U.S. Department of Health and Human Services, is the nation's medical research agency – making important discoveries that improve health and save lives. The NIDCR and NIAMS are institutes focused around areas of research.



The mission of the [National Institute of Dental and Craniofacial Research \(NIDCR\)](#) is to improve oral, dental, and craniofacial health through research, research training, and the dissemination of health information.

The mission of the [National Institute of Arthritis and Musculoskeletal and Skin Diseases](#) is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases.

SOFT BONES ENGAGEMENT SURVEY

Thank you to everyone who took the End of Year Engagement Survey. You will see many exciting changes coming soon to Soft Bones thanks to your responses!

What is the CoRDS International Registry?



In the 2019 Engagement Survey, many people shared they did not know what the CoRDS International Registry was. In rare diseases, one of the biggest challenges is having a cohort of patients to access to better inform researchers. In July of 2016, Soft Bones partnered with the Coordination of Rare Diseases at Sanford (CoRDS) to host a patient registry for individuals diagnosed with (HPP) and carriers of the disease.

The hope is that the [CoRDS HPP Registry](#) will provide information in a secure way for patients to make basic disease information available to researchers without sacrificing privacy. Anyone diagnosed with any type of HPP or those who are carriers, diagnosed or suspect they may have the metabolic bone disease may participate in the registry.

To enroll, visit [Cords Connect](#) to fill out the form, and specify that you are interested in joining the disease-specific Soft Bones Hypophosphatasia Registry. Participation is voluntary and those who enroll may withdraw any time. Soft Bones will not have any access to the names or any information that allows individuals associated with the data to be identified.

For more information, contact [Denise Goodbar](#) at denise@softbones.org.

About Soft Bones: The US Hypophosphatasia Foundation, and the Research Grant

Part of the Soft Bones mission is to promote the development of innovative research of hypophosphatasia

by new and established investigators.

In 2019, unlike other years where Soft Bones only offered one \$25,000 grant, this year we are offering TWO seed grants of \$25,000 each for basic, clinical or translational research directly related to HPP.

All applications will be reviewed by our Scientific Advisory Board and the winners will be announced in June.

Soft Bones Spread Awareness



Patient Liason, Adriane Eoga and Project Manager, Nicole Williams reached out to dentists, hygienists, students and office staff to spread awareness on HPP and build the dental referral list! They tabled at the New Jersey Dental Association's Garden State Dental Conference & Expo on May 2-3 in Newark, NJ and at the Connecticut State Dental Association's Charter Oak Dental Meeting on May 9-10.



Patient Liason, Sue Krug, her sister, Ellen and patients Crystal Norris and Christin Sappington also spread awareness in Chicago at the Amer Academy of Pediatric Dentistry on May 24-26.



To help spread awareness of HPP and **Rare Disease Day**, we asked people to answer "Why I care about Rare," then take a photo of themselves holding their responses up. Soft Bones Patient Liaison, Sue Krug shared the photos through our social media channels for Rare Disease Day on February 28th, 2019.



Caregiver Corner: Recognizing Rare Caregivers for Caregiver Appreciation Day

Caregiver Appreciation Day, held on both November 13 and March 3, is intended to celebrate the people in our lives who help us maintain the health and wellbeing of our loved ones. Caregivers are especially worthy of celebration, considering the personal, high-stakes labor invested by these compassionate professionals.

Soft Bones would like to highlight the many caregivers in our HPP community with a new section of the newsletter, "Caregiver Corner."

If you are interested in being featured in "Caregiver Corner" please email Nicole Williams at nicole@softbones.org for more information!



"Being a caregiver makes you a better person. It lets you focus on the bigger picture, it makes you more caring, more of an advocate, more understanding – and this will spill over in everything you do." - Ellen

How did you feel when your loved one was first diagnosed with HPP?

I was just 4, but as I became more aware, it made me grateful for all the things that I could do. When I was with friends I did kid stuff, when I was with family we still did kid stuff, but geared to her limitations. The family never made it a “thing”.

Tell us about your caregiver journey.

I am just one of several family members that grew up in a support system, it just becomes a way of life. I never walk anywhere, even when I'm alone, that I'm not checking the floor for water or cracks (anything that one could slip on).



What is the most rewarding part of being a caregiver?

Making daily life easier for someone who had no choice in their disability.

What is the most challenging part of being a caregiver?

Being selfless and remembering no matter how bothered you may feel at times, you have to remember that they would much rather do it for themselves but can't.

What advice would you give someone who is new to caregiving? What do you wish someone had told you?

The level of care needed is individualized, so it's hard to give advice. I think it's all about your mindset. Take one day at a time and enjoy the moments.

Don't dwell on the CAN'T DOs, look at it as a new adventure and go with the CAN DOs!



UPCOMING EVENTS

- June 15th, 2019 - **Announcement of Grant Awards**
- June 28th, 2019- **Midwest 2 Region Meeting (Newark, OH)**
- July 8, 2019 - **South Central Region Meeting (Canyon Lake, TX)**
- July 29, 2019 - **Southeast Region Meeting (Nashville, TN)**
- July 12- 13, 2019 - **National Patient Meeting in La Jolla, CA**
- July 13, 2019 - **Southwest Region Meeting (La Jolla, CA)**
- August 3rd, 2019- **Central Region Meeting (Kansas City)**
- August 10, 2019 - **Midwest 1 Region Meeting (Indianapolis)**
- September 20-23, 2019 - **ASBMR 2019 Annual Meeting in Orlando, FL**
- September 23rd, 2019 - **Soft Bones 11th Annual Golf Classic**
- October 26th, 2019 - **National Patient Meeting in Parsippany, NJ**
- October 30th, 2019 – **HPP Awareness Day**
- November 9th, 2019 - **Midwest 2 Region Meeting (Nashville, TN)**



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For more information, please contact the Soft Bones Foundation.

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