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SOFT BONES ROLLS OUT REGIONAL SUPPORT

As a result of the strategic plan, Soft Bones has introduced a Region/Region Lead to provide localized support to a growing and geographically dispersed community. The Region Leads will be attentive to patient needs and will act as ears to the ground, in their respective areas, sending information and insights back up to the national organization to help identify programs and materials needed by the HPP community. Region Leads will also spearhead grassroots awareness, fundraising and policy efforts at the local level.

On January 20, 2018, Soft Bones hosted the first training for the newly inducted Region Leads in Morristown, NJ. Soft Bones partnered with Global Genes to develop and present the training, which was attended by 26 Soft Bones Region Leads which are geographically dispersed over 8 regions. The Region Leads and their respective Regions are as follows:

Northeast (ME, MA, NY, PA, DC, VA, NJ, CT, VT, NH, RI, MD, DE): Jennifer Carothers, Lisa Danowitz, Chris Denune, Noel Harper, Holly Kunkel, Cindy Patterson, Jennie Rinaldi, Adrianna Tuomi

Southeast (AL, GA, SC, NC, TN, FL, MS): Christy Burke, Blynda Keller, Zach McFall

Midwest I (MN, WI, IA, IL, IN): Crystal Norris, Cindy Reasor

Midwest II (MI, OH, KY, WV): Monica Baugh, Dawn Gullett, Sharon Talkington

Central (ND, SD, WY, NE, CO, KS, MO, OK, AR): Susan Brown, Lindsey Elsaesser, Angela Hastings, Jen Jansonious, Kara Schweiss

South Central (TX, LA): Cami Rush, Danielle Zibilski

Southwest (Southern CA, NV, UT, AZ, NM): Amy Britt, Kate Fisher, Sue Krug

Northwest (WA, OR, ID, MT, Northern CA): Covered temporarily by the Southwest Region Leads.



SOFT BONES ROLLS OUT REGIONAL SUPPORT

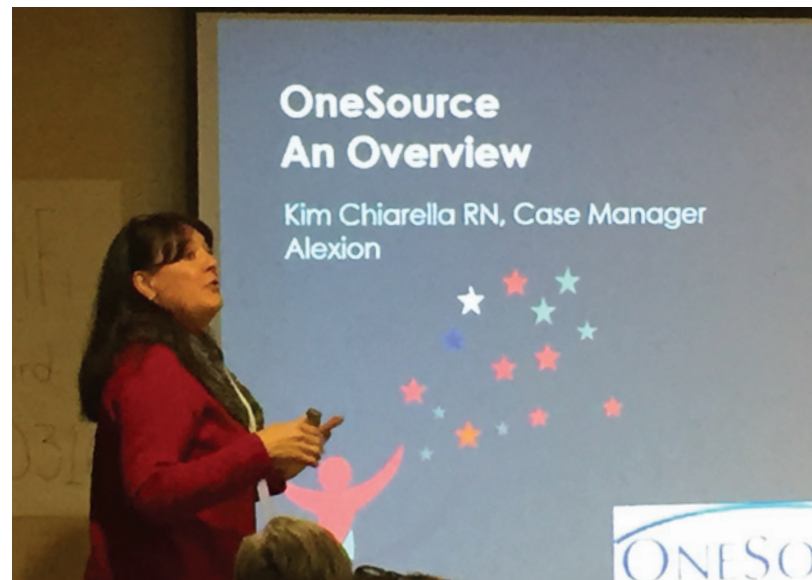
Drawing on the expertise of leaders from Soft Bones and Global Genes, this training provided Soft Bones Region Leads with information and insights they'll apply in their new role. Participants were trained on the importance of advocacy, fundraising techniques and how to conduct meetings in their local areas.

Moving forward, Region Leads will be working to execute several objectives, including hosting four meetings per year; organizing one fundraiser per year and holding one advocacy event per year. Region Leads also attend monthly conference calls, provide photos and region updates for the Soft Bones Newsletter and contribute 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 there and it's also a great place to interact with others in your region. Not to 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, contact Adriane at adriane@softbones.org.

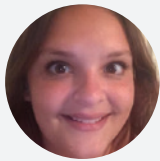
We are excited to see our Region Leads make an impact in their communities and contribute to our efforts as a national organization!

If you are interested in becoming a Region Lead, please reach out to Denise Goodbar at denise@softbones.org.



REGIONAL UPDATES

NORTHEAST



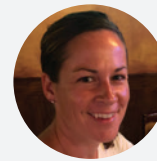
Jennifer Carothers
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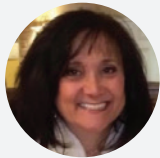
Chris Denune
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Holly Kunkel
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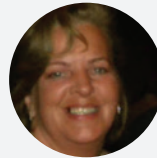
Jennie Rinaldi
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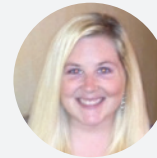
Lisa Danowitz
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Noel Harper
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Cindy Patterson
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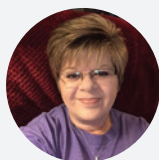


Adrianna Tuomi
adrianna@softbones.org

- We recently held a very successful patient meeting in Philadelphia, PA after the Stand with HPP meeting.
- We held our first virtual “get-together” on September 22nd.

We are excited to have an opportunity to share stories and connect people to one another across the region as well as within respective state lines! If you're in the Northeast and are interested, please reach out to one of us.

SOUTHEAST



Christy Burke
christy@softbones.org



Blynda Keller
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Zach McFall
zach@softbones.org

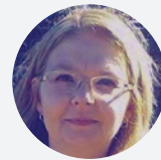
- We recently organized a Soft Bones meeting which took place after the Alexion Stand With HPP meeting in Raleigh, NC on Sunday, August 5.
- We are looking forward to hosting a Cupcake Wars in Hernando, MS sometime in the coming months – keep your eyes peeled for announcements regarding this exciting event!

REGIONAL UPDATES

MIDWEST I



Crystal Norris
crystal@softbones.org



Cindy Reasor
cindyr@softbones.org

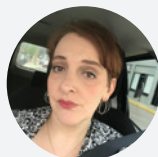


- After the Stand with HPP meeting on September 15th in Indianapolis, IN, the group stayed and chatted with Dr. Rush.

MIDWEST II



Monica Baugh
monica@softbones.org



Dawn Gullett
dawn@softbones.org



Sharon Talkington
sharon@softbones.org

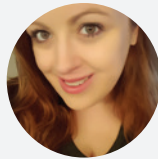
- We have enjoyed connecting with patients in our region through Facebook, over email, on the phone, and in person at the patient meeting at OSU.
- We have raised over \$215 in support of Soft Bones through a Facebook fundraiser.

REGIONAL UPDATES

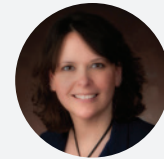
CENTRAL



Susan Brown
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Angela Hastings
angela@softbones.org



Kara Schweiss
kara@softbones.org



Lindsey Elsaesser
lindsey@softbones.org



Jen Jansonious
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- We held our first region meeting on May 5 in Omaha, NE.
- Several families from the Central region met for the first time at the Patient Meeting in Ohio.



REGIONAL UPDATES

SOUTH CENTRAL



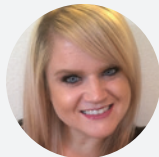
Cami Rush
cami@softbones.org



Danielle Zibilski
danielle@softbones.org

- We have a patient meet-up coming up in late Fall.
- We will be showing our support for HPP Awareness Week in late October.

SOUTH WEST



Amy Britt
amy@softbones.org



Kate Fisher
kate@softbones.org



Sue Krug
sue@softbones.org

- In the past several months, we've held a meet and lunch in Phoenix, partnered with Frys grocery store to "Care and Share" a percentage of the total cost of an order in support of Soft Bones, and gave out free lanyards, bracelets and totes at the Columbus patient meeting.
- We have several Chat and Chew events coming up in October:
 - October 13: Mesa area Chat and Chew with doctor from Phoenix Children's Hospital
 - October 27: San Diego Chat and Chew (after Stand with HPP meeting)
 - October 28: Phoenix Chat and Chew (after Stand with HPP meeting)

NORTHWEST

Covered temporarily by the Southwest region leads.

Interested in becoming a region lead?
Please contact Denise Goodbar at denise@softbones.org.



SOFT BONES HOSTS FIRST-EVER GLOBAL SCIENTIFIC MEETING

Michael P. Whyte, MD
Chair, Scientific Advisory Board
Soft Bones Foundation

During June 8-10, 2018 in Chicago, Illinois, USA, a multinational group of fifty clinicians, clinical investigators, and basic scientists gathered with other interested individuals to convene the First Scientific Meeting of the Soft Bones Foundation. They reviewed current understanding and uncertainties concerning hypophosphatasia (HPP) and planned work necessary to improve the lives of people with this inborn-error-of-metabolism. The importance for such a meeting was perceived by Ms. Deborah Fowler, President and Founder of the Soft Bones Foundation, and was brought to success with the help of Ms. Denise Goodbar and Ms. Charlene Waldman and support from Alexion Pharmaceuticals, PANTHERx Specialty Pharmacy, and Charles River Laboratories, Inc. Session moderators Matthew Drake MD PhD, Eric Rush MD, Frank Rauch MD, Mark Nunes MD, Kathryn Dahir MD, Craig Langman MD, and Susan Ott MD expertly kept to time the considerable enthusiasm of all attendees.

Graham Russell MD PhD gave a historical review of inorganic pyrophosphate, its action as an inhibitor of mineralization, excess in HPP, and early experiences following its modification to become the bisphosphonates. **Michael Whyte MD** described the discovery in 1923 of alkaline phosphatase (ALP), the first report in 1948 of HPP, and the many important lessons from investigation of patients, including major insight concerning the pathogenesis of the defective hard tissue mineralization leading to tooth loss and rickets during childhood and osteomalacia during adult life as well as identification of its etiology. The expanded clinical nosology of HPP was validated after using the now delineated clinical, biochemical, radiological, and histopathological features of this metabolic bone disease.

Continued on page 8.



SOFT BONES HOSTS FIRST-EVER GLOBAL SCIENTIFIC MEETING

(cont'd)

Stephen Coburn PhD discussed the derangement of vitamin B6 metabolism leading to extracellular accumulation of the deficient tissue-nonspecific ALP isoenzyme (TNSALP) substrates including pyridoxal 5'-phosphate, and the pathogenesis of the vitamin B6-dependent seizures. **Jose Luis Millan PhD** reviewed the importance of mouse models for HPP, including their role in preclinical studies of asfotase alfa (AA) enzyme-replacement therapy for HPP, and investigation of other molecules that regulate skeletal mineralization. **Larry Suva PhD** described the recent development of the first large animal model (i.e., sheep) for HPP, and the early findings concerning the clinical and biochemical phenotype. **Deborah Kraków MD** discussed the considerable uncertainties with prenatal radiological imaging of HPP, and **Deborah Wenkert MD** defined and reviewed the management of the not uncommon "benign prenatal" form. **Steven Mumm PhD** provided an overview concerning the Mendelian inheritance of HPP, and what can be said concerning genotype/phenotype correlations. Treatment for HPP now includes the benefits from enzyme replacement using AA (Strensiq™), approved multinationally in 2015 typically for pediatric-onset HPP. **Phillipe Crine PhD** reviewed the recombinant DNA structuring of AA as a TNSALP targeted to hydroxyapatite. **Jill Simmons MD** described the improvements in skeletal mineralization, respiratory and motor function, and growth observed during AA treatment studied initially for the life-threatening perinatal and infantile forms of HPP and followed to 7 years of therapy.

Nicholas Bishop MD and **Vrinda Saraff MD** reported experience with such patients in the United Kingdom. **Keiichi Ozono MD PhD** presented the Japanese experience with severe pediatric HPP. Then, **Gary Gottesman MD** provided an overview concerning AA treatment for older children debilitated by HPP, including the problems as well as the benefits. **Donna Griffin PT, PCS** reported how a modification of the Performance-Oriented Mobility Assessment-gait (mPOMA-G) could assess in real-time baseline and treatment responses of children with HPP. **Lothar Seefried MD** discussed the orthopedic complications and management of adults with HPP, including experience with AA treatment. The broad range of HPP severity encountered in this age group was reviewed by **Peter Tebben MD**, and **Frederick Singer MD** discussed the difficulties with diagnosis and treatment of these individuals.

Priya Krishnani MD outlined the importance of functional testing of adults with HPP, and what improvements have been observed with AA treatment. **Pauline Camacho MD** discussed "off label" use of parathyroid hormone given to adults with HPP. **Mark Rallo OD** discussed occurrences of ectopic calcification on conjunctiva naturally in HPP, and perhaps increased with AA treatment but largely microscopic and asymptomatic. **Timothy Wright MS, DDS** reviewed oral and craniofacial issues of HPP, and emphasized how much more must be learned about these complications especially in adults. **Brian Foster PhD** discussed the importance of TNSALP in dentoalveolar tissue formation, and the consequences of TNSALP deficiency in HPP. **Clifford Rosen MD** reviewed early work concerning a potential role for ALP in fat metabolism, including fat accumulation at sites of AA injection in patients with HPP. **Isabel Orris PhD** provided an overview of skeletal mineralization controlled by TNSALP and pyrophosphate, and other factors. Progress reports, summarized in their abstracts were provided by the past recipients of research awards from the Soft Bones Foundation: **Steven Mumm PhD, Luke Mortensen PhD, Brian Foster PhD, Kathryn Dahir MD**. Finally, means to advance the treatment or to cure HPP, including by gene editing, ALP transfection, and mesenchymal stem cell therapy were discussed by **José Luis Millan PhD** and **Luke Mortensen PhD**.

NOTE: A meeting summary will be made available to all community members soon.

This piece will include information on key takeaways from the meeting as well as gaps in research that need to be addressed moving forward. Meeting abstracts will be published in an upcoming issue of "The Journal Bone".

2018 A BANNER YEAR FOR SOFT BONES

Phew – it has been quite a year for Soft Bones and for our hypophosphatasia community.

In June, we hosted our first Global Scientific Meeting bringing together 50 HPP experts from around the world to talk specifically about the latest findings in HPP. The purpose of the meeting was to share clinical experiences and identify research gaps to help inform treatment and research moving forward. The agenda was very robust and there was much active discussion and engagement throughout the two day meeting. We are finishing up the publication summary that captures the overall discussion. There was much interest in having another meeting, and Dr. Whyte was enthusiastic about hosting it as soon as next year.... Now we just need the funding!

We also had another successful Patient Meeting at The Ohio State University a few short weeks after the Global Scientific meeting. It was great to connect with old and new friends and listen to presentations from experts in the field, including Dr. Steven Ing, Dr. Gary Gottesman, and Donna Griffin as well as learning about how to self-advocate and navigate the educational system with Dr. Kelli Sears and finally we learned more about a new study in HPP and its impact on the brain by Dr. Rene Pierpont.

Next year, we will celebrate our 10th year anniversary as a 501c3 organization. As we reflect on how far we have come and look forward to the future, we want to be clear on where we are providing value and what we can be doing better to support patients and their families. Please keep an eye out for our 20/20 Engagement Survey which will be a short but comprehensive survey to help guide our organization and will help better assess gaps in support and materials. 20/20 will give us clarity and a foothold on where to start with an aim to reach our goals by the year 2020.



Deborah Fowler, President and Founder Soft Bones, Inc.

Please help Soft Bones by making a donation. No amount is too small!

Go to www.SoftBones.org to make a donation today. Your contribution is tax deductible.

Our 10th annual golf outing was held on September 24th, followed shortly after by HPP Awareness Day on October 30th. We look forward to the next newsletter which will be in a new format (stay tuned) and we are excited about your feedback and comments to the survey which will be published in a future newsletter addition.

Be well.

SOFT BONES SINKS TEETH INTO DENTAL EDUCATION



Since the dental manifestations of HPP can many times be an early symptom that can lead to diagnosis, Soft Bones has made it a priority to educate dentists about hypophosphatasia. To reach these dentists, Soft Bones exhibited at the Charter Oak Dental Meeting in Connecticut (May 9-11, 2018) and the Garden State Dental Conference in New Jersey (May 17-18, 2018).

The exhibits were made possible by a grant from Delta Dental of CT/NJ with the goal of developing a dental referral list of dentists in NJ and CT. Dental meetings provide an opportunity to educate dentists as well as identify those who have treated patients with HPP or are willing to treat patients going forward. Since Delta Dental is regionalized, we will have the opportunity to apply for grants in other geographic areas as well and hope to use Region Leads to staff the booths at those meeting locations. If you have a dentist who you feel should be on our referral list, please reach out to Denise at denise@softbones.org.

CHARLES RIVER CHOOSES SOFT BONES FOR #EVERYPATIENT PARTNERSHIP

Earlier this year, Charles River Laboratories partnered with Soft Bones for its #EveryPatient campaign, creating a short documentary featuring Evie, an 8-year-old diagnosed with HPP. In the film, Evie's family shares their journey from diagnosis to treatment to where Evie is today. The creators of this #EveryPatient campaign hope Evie's story will provide comfort and inspiration to patients and families facing a rare disease diagnosis as well as insight into the path to market and the role patient advocates play in the development and approval of new therapies.

Darci Helbling, Associate Director of Marketing Operations, Digital Strategy & Branding at Charles River, writes, "In Evie's story, it was Soft Bones who supported her family's search for a cure. For children with rare diseases, traditional drug development timelines aren't good enough. Behind every patient stands thousands of scientists, researchers and advocates working together to develop life-saving drugs. These collaborative partnerships are imperative to accelerate therapies, especially those for rare diseases."

Charles River has pledged to donate \$1 for every social media engagement with the #EveryPatient campaign, up to \$25,000, in support of Soft Bones. Through June, there have been upwards of 7.5M impressions, 950,000 video views, and 18,000 social media engagements and the fundraising campaign continues! Please visit Charles River's Facebook, LinkedIn, Twitter, or Instagram page, share Evie's story with your network and raise money for Soft Bones.





SOFT BONES DESCENDS ON THE BUCKEYE STATE

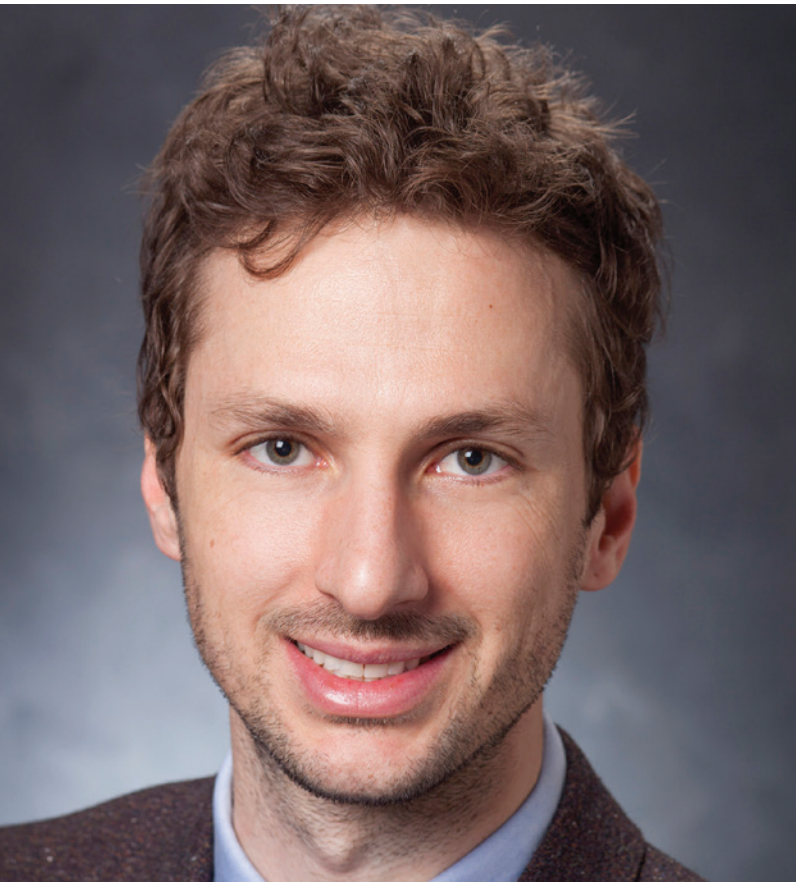
On Friday, June 29 and Saturday, June 30, 40 families convened at The Ohio State University for a Soft Bones Patient Meeting. The agenda was packed with presentations on a variety of hypophosphatasia-related topics including physical therapy, HPP and teeth, dental research, the OneSource program, improving the quality of life for HPP patients, and an overview of a study on the impact of HPP on cognitive and behavioral development.

In addition to providing attendees with information and resources, Soft Bones Patient Meetings are an opportunity for patients and families to connect with others living with the disease. For many people, attending a patient meeting is their first chance to meet someone else with HPP. These meetings have served as a catalyst for new friendships and strengthened the nationwide support network for the HPP community. A meet and greet on Friday allowed people to make some new friends and mingle with old ones in an informal setting.

Some other highlights, of the meeting, included a Q&A with Dr. Ing from OSU and Dr. Gottesman from Shriners Hospital for Children, who were able to help answer questions about HPP in adults and children respectively. Dr. Kelli Sears, a nationally certified school psychologist, provided valuable insight into school and community support services. Several eligible families met with Dr. Rene Pierpont and participated in her study on behavioral health in children with HPP. At Region Breakout Sessions, members gathered with other patients and families, from their area, and met their Region Leads in person.

Keep an eye out for upcoming meetings in your region! Meeting information will be posted on Facebook and sent out via email.





SOFT BONES FUNDS
DR. LUKE MORTENSEN'S
RESEARCH ON
**MESENCHYMAL
STEM CELL
THERAPY** FOR
HYPOPHOSPHATASIA

Dr. Luke Mortensen, an Assistant Professor at the University of Georgia, was awarded \$140,000.00 in funding from Soft Bones to study specifically administered bone-forming mesenchymal stem cells (MSCs) as a therapeutic approach to prevent or ameliorate hypophosphatasia (HPP).

There has been considerable interest in MSCs for the treatment of systemic metabolic bone disorders, but MSC potency varies a great deal depending on culture conditions and donor properties. For MSC cells to perform their therapeutic function, the alkaline-phosphatase containing matrix vesicles produced must reach the active bone surface after infusion and achieve sufficient quantities of active alkaline phosphatase to improve patient bone mineralization. Dr. Mortensen and his team aim to identify MSC donors and production strategies capable of producing high levels of osteogenic mineralization and alkaline phosphatase activity for the treatment of HPP. The accomplishment of this aim may overcome current limitations in MSC therapy.

When attending BIO – The Biotechnology Innovation Organization's annual meeting in 2017, Soft Bones met with Athersys, a company that manufactures MultiStem®, a patented, adult-derived "off-the-shelf" stem cell product platform, for multiple disease indications in the areas of neurological, cardiovascular, and inflammatory and immune disease areas, as well as other indications where there is unmet medical need. Dr. Mortensen and Athersys researchers agreed that HPP could benefit from this type of stem cell research. The generous supporters of Soft Bones funded this grant.

Regarding the significance of this research for HPP patients, Dr. Mortensen writes, "MSCs could be a great treatment alternative with long lasting benefits—whether through the direct contribution to bone formation and healing or through indirect support of the bone environment. This could have significant benefits for those with milder forms of HPP or those who begin to have symptoms as adults."

Dr. Mortensen has a background in MSC research, and he was prompted to pursue research in MSC therapy for HPP because he saw potential to make a difference for patients. When asked what it means to receive funding from Soft Bones, Dr. Mortensen writes, "The funding provides me with a direct link to the patient community—getting to know the patients has probably been the most rewarding and meaningful experience I have had as a young scientist. I am so grateful to Soft Bones for this opportunity!"

DR. BRIAN L. FOSTER **AWARDED 2018 RESEARCH GRANT** FROM SOFT BONES

Dr. Brian L. Foster, an Assistant Professor within the Biosciences Division at the College of Dentistry at Ohio State University, and colleagues were recently awarded the 5th annual Soft Bones research grant for \$25,000. This is the second Soft Bones grant awarded to Dr. Foster.

As the recipient of a 2018 research grant from Soft Bones, Dr. Foster, in collaboration with Dr. Michael Whyte, an Endocrinologist at Shriners Hospital for Children and Washington University in St. Louis, proposes to analyze primary teeth (deciduous or baby teeth) from individuals with hypophosphatasia (HPP). This study is the first of its kind to quantitatively analyze teeth from a large group of HPP subjects. Dr. Foster hopes to gain a better understanding of how dental problems correlate to skeletal, biochemical and genetic changes in individuals with HPP. In the future, this may help medical professionals predict the severity of HPP-associated dental disease, better treat dental disorders arising from HPP, or even estimate the overall course of disease.

With this project, Dr. Foster and his team will continue building upon years of achievement in the field of HPP research, with a specific focus on the relationship between HPP and dental disorders. For several years, Dr. Foster has been studying mouse models of HPP to understand how the disorder affects the different hard tissues of teeth and supporting jaws, including enamel, dentin, cementum and bone. Dr. Foster won the 2016 Soft Bones research grant for his mouse model research, and the 2016 grant supported development of a new mouse model of HPP that was featured in the *Journal of Dental Research*.



MEMBERSHIP ENGAGEMENT SURVEY

Can you believe we are approaching our 10 year anniversary as an HPP Community? As part of our preparation, we will be conducting a membership engagement survey. The survey will help us understand where we are succeeding and also falling short. We hope you will all take a few minutes to take this survey and provide your honest feedback, as it will help us grow as an advocacy organization and better understand how to support you and your family moving forward. Stay tuned!

RESEARCH STUDY OPPORTUNITY: **BEHAVIORAL HEALTH IN CHILDREN** WITH **HYPOPHOSPHATASIA**

Dr. Rene Pierpont, a Pediatric Neuropsychologist and Assistant Professor of Pediatrics at the University of Minnesota, and colleagues are conducting a study on social, emotional and behavioral health in children ages 3-18 who are diagnosed with hypophosphatasia (HPP). The purpose of this study is to learn more about HPP and its manifestations in the realm of psychological and brain sciences.

Dr. Pierpont attended the recent Soft Bones patient meeting in Columbus, Ohio to learn more about HPP and connect with patients and families eligible to participate in her research. Several families participated in the study during their time at the patient meeting by completing questionnaires in which they shared their observations and experiences related to the behavioral health of their child with HPP.

THIS STUDY IS CURRENTLY RECRUITING PARTICIPANTS!

To complete the study, parents/caregivers of a child with HPP will be asked to complete a set of questionnaires regarding their children's emotional and behavioral health, including information about sleep, pain and family background. The questionnaires may take up to two hours to complete and families will receive a \$25 gift card for participating in the study.



If you are interested in participating in this study or staying informed of future opportunities to participate in HPP research, please join our international patient registry, hosted in partnership with the Coordination of Rare Diseases at Sanford. You can join the registry at www.sanfordresearch.org/SpecialPrograms/cords.

FUNDRAISING OPPORTUNITIES

Thanks to all who have held or supported our various fundraisers! Every dollar helps to fund our various programs.

Did you know that it doesn't cost anything for you to enroll in programs such as Amazon Smile, iGive, Kroeger'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. If you have any questions about any of these programs, contact Adriane at adriane@softbones.org.

We also have a great opportunity with Schwans home food delivery. You can set up your own campaign and share with all your friends. There are over 300 items to choose from and the food is delivered directly to your door.

Some "must try" items from those who have ordered already include: The chicken cordon bleu, the gluten free pizza and of course, the ice cream (the mint cookie sandwiches are to die for!)

To set up your own fundraiser go to <https://www.schwans-cares.com/signup> or contact Adriane at adriane@softboens.org for assistance.

Facebook fundraisers are another great way to raise dollars easily. Thanks to those who held birthday fundraisers to benefit Soft Bones. The tally for those fundraisers, to date, is over \$10,000! If you have questions about setting up a Facebook fundraiser, contact Adriane at adriane@softbones.org.

Upcoming Events

September 26-27

Mechanistic and Therapeutic Advances in Rare Skeletal Diseases meeting, Montreal, Canada

September 28th- October 1st

ASBMR, Montreal Canada

October 29th

Webinar: HPP Genetics Boot Camp - Learning More About ALPL Gene Changes and HPP in Families

October 30th

HPP Awareness Day

November 23rd

28th Greater NY Dental Meeting, Javits Center NYC

Follow Us

To ensure we are saturating social media channels so that patients find us no matter where they are communicating, Soft Bones has launched two additional social media channels in addition to our Facebook page. You can now find us on Twitter and Instagram by searching [@SoftBonesHPP](https://twitter.com/SoftBonesHPP). Please be sure to share with younger generations that are active on some of these other channels and see what we are up to around the world raising awareness of HPP!

Important Information For Patients The Soft Bones Physician Referral Network

The physicians in this Network have given their consent to participate based on their interests in and experience with HPP. Other physicians may be added in the future. For a copy of the Soft Bones Referral Network via mail or email, contact Denise at denise@softbones.org or call 973-453-3093.

For more information, please contact the Soft Bones Foundation.

(866) 827-9937 – Toll Free

(973) 453-3093 – Direct Line

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