



Page 2

Happy New Year! continued...

Page 3

Soft Bones Kansas City Patient Meeting
– Our Biggest Yet

Page 5

2017 Soft Bones Golf outing
was A Hole In One!

Page 6-8

News and Updates

Page 9

Soft Bones Goes to 2017
International BIO Convention

Page 10-11

Medical Meetings

Page 12

Exciting Things & Creative Corner

Page 13

Spreading Awareness in the Classroom

Page 14-15

Soft Bones Around the Globe

Page 16

Have you Heard?

Page 17

Upcoming Events, Follow Us,
Important Info for Patients

HAPPY NEW YEAR!

It has been a fantastic year, full of so much progress for us here at Soft Bones.

As many of you know, we embarked on a strategic planning initiative at the beginning of this year. An independent consultant was retained to make an assessment of Soft Bones and map out a five year plan. Part of those recommendations included the formation of eight regions across the United States, to allow for better community support of HPP patients and families.

We are thrilled to announce that we have started this exercise and have identified more than two dozen Soft Bones Region Leads, who have committed to hosting more than 30 meetings across the country! Stay tuned for a regional meeting near you, or if you are interested in helping to host a meeting, please reach out to one of the Region Leads in your area.

Northwest

Megan Champagne

Southwest

Kate Fischer
Sue Krug
Amy Britt

Central

Jen Jansonious
Angela Hastings
Kara Schweiss
Lindsey Elsaesser
Susan Brown

South Central

Danielle Zibilski
Cami Rush

Midwest I

Crystal Norris
Cindy Reasor

Midwest II

Sharon Talkington
Monica Baugh
Shannon Schmitz-Cook
Dawn Gullett

Southeast

Christy Burke
Blynda Kellner
Zach McFall

Northeast

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

HAPPY NEW YEAR! (CONTINUED)



In January, the Region Leads above will travel to New Jersey for a formal training session, lead by Global Genes, to ensure they are adequately prepped for the year ahead. This is a 1-year commitment, so if you are interested in becoming a Region Lead and would like to learn more, please reach out to Denise Goodbar (denise@softbones.org) for more information.

In addition to the region support, the strategic plan also has recommendations for ramping up efforts in research in support of new treatments for HPP. Our hope is that these efforts will eventually lead to a cure. With new research in gene therapy, and even success in some diseases, we believe it is possible and want to ensure HPP is on the front lines of this research so that we can drive it forward.

We can't accomplish any of this without your support. Many of you have given generously this year – words cannot adequately express our sincere appreciation. We are committed to being good stewards of your investment and making the most of every dollar for HPP patients here and around the world!

Thank you in advance. We wish you and your loved ones a happy and healthy 2018.

Deb



SOFT BONES KANSAS CITY PATIENT MEETING – OUR BIGGEST YET!

Soft Bones held our largest patient meeting to date

July 14-15 in Kansas City, MO.

The turnout was amazing with over 150 people
in attendance – **a new record.**

The event started with an informal “Meet and Greet” on Friday evening in the lobby of the Embassy Suites. This was a wonderful time for people to connect in a relaxed and fun atmosphere. Many who have been long time Facebook friends got a chance to meet face-to-face for the first time. One attendee, who was watching the kids play, said “it’s like they just know (that they are connected by HPP)”. This captures the essence of why these meetings are so important: they give adults and kids alike the opportunity to interact with people who truly understand.

SOFT BONES KANSAS CITY PATIENT MEETING – OUR BIGGEST YET (CONTINUED)



The meeting kicked off with a registration at the state of the art Kauffman Center. The packed agenda included a welcome from our President and Founder, Deborah Fowler. Deb gave an overview of the Soft Bones Foundation and talked about the importance of advocacy. She also gave an overview of the 2017 strategic plan and some of the exciting changes on the horizon. Next up was Austin Letcher from CoRDS to talk about the importance of the International HPP Registry. He emphasized that all data entered is secure and de-identified. He also outlined how important it is to have this data available for researchers to access. If you would like more information about the Registry, contact Denise Goodbar at denise@softbones.org. Austin registered people throughout the weekend. We want to thank Austin for making the trip from South Dakota.

Next up was Dr. Eric Rush from Children's Mercy in Kansas City, who gave a fascinating and thorough HPP disease overview. He had quite a few of his very own patients in the audience and answered many audience questions. Following lunch, we took a group photo and moved onto the afternoon program, which was broken out into two tracks. One was led by Debbie Miccolis, a nutritionist, who spoke about the connection of diet, inflammation and pain. Debbie stressed that although there is no way to "eat yourself out of HPP", there are steps you can take by modifying your diet to help manage pain. The second track was led by Dr. Emily Farrow, a genetic counselor and Dr. Rush. Their presentation focused on Genetic and Inheritance Patterns of HPP. This can be quite a difficult topic to grasp, but their presentation was given in a very straightforward and easy to understand manner.

Things wrapped up around 4:00 pm. We all reconvened at 5:30 pm at the famous Jack Stack Freight House Restaurant. Dinner included a buffet of Kansas City's finest barbecue. It's safe to say nobody left hungry that night. Most importantly old and new friends alike had a chance to continue to share experiences and make memories.



2017 SOFT BONES GOLF OUTING WAS A HOLE IN ONE!

The Ninth Annual Soft Bones Golf Outing was held on Monday September 25, 2017 at the beautiful and prestigious Somerset Hills Country Club in Bernardsville, NJ. It was a steamy day, well into the 90s with high humidity. Our 92 registered golfers enjoyed the of sunshine.

Golfers started the day with a trip to the practice range followed by a delicious buffet luncheon before heading out to the links. The parade of golf carts, traveling out to the course, is a sight to see! There were contests, with prizes awarded for each, including longest drive, closest to the pin, and straightest drive. We also had a 3-hole contest where players could place a wager. For those who were feeling a little less positive about his/her abilities, we had Mulligans for sale as well. All in all a great day was had by all and the mood was incredibly positive.

Immediately following golf, the evening festivities began. There was an open bar and an impressive assortment of hors d'oeuvres and a carving station. Guests enjoyed the beautiful evening sipping cocktails on the veranda.

Our silent auction had many visitors during this portion of the event. Some of the items were hard to resist, such as honey baskets provided by our own bee keeper Cindy Patterson and custom home and pet portraits artfully sketched by Sue Krug.

The formal presentations came next. Bob Mulcahy, the event

co-chariman, made an impassioned speech about the importance of supporting Soft Bones. He also acknowledged Atlantic Health System, our Tournament Sponsor. Next, Roger Nettle, Deborah Fowler's father and Cannon Sittig's grandfather, thanked all for coming. A highpoint was when Cannon got up and read a poem he had written called "Where I'm From." It's pretty safe to say there wasn't a dry eye in the house. The Live Auction followed and things got pretty heated over the Giants vs Dallas tickets. That auctioneer had to keep on his toes during that item.

Deb was next up at bat and introduced our campaign "Fund the Mission". She talked about the opportunity to fund a research project using Mesenchymal Stem Cell (MSC) technology. She teed up (pun intended) a short video showcasing many of our patients. The footage was shot at our patient meeting in Kansas City <https://youtu.be/TSjjH1HNGrA>. With that, the auctioneer took over and began asking for pledges. He started with high values and came down as hands stopped going up a certain dollar levels. This alone raised \$69,250.00 in about a ten minute period. The generosity was incredible to behold.

Plans are already progressing for next year's 10th Golf Outing. The 2018 Golf Outing date is Monday, September 24 we are hoping to make this the best one yet. Donations for our auctions are always welcome and appreciated. If you have any ideas, contact Denise Goodbar at denise@softbones.org.

NEWS AND UPDATES

DR. KATHRYN DAHIR FROM VANDERBILT UNIVERSITY MEDICAL CENTER AWARDED 2017 SOFT BONES MAHER FAMILY RESEARCH GRANT



Dr. Kathryn Dahir, an adult endocrinologist and bone specialist at Vanderbilt University Medical Center, and colleagues were recently awarded the \$25,000.00 Soft Bones Maher Family Research Grant. The focus of this research is to study adolescents and adults with Hypophosphatasia (HPP).

The purpose of Dr. Dahir's study is to learn more about physical impairments, abnormalities in movement, and cognitive deficits (attention and memory) in both adolescents and adults with HPP. Patients will be evaluated by a speech-language pathologist, physical therapist and occupational therapist to determine whether they have unique difficulties with learning and cognitive function, strength, or movement that might affect school or job performance, everyday living and independence. The study is a collaborative effort between adult and pediatric endocrinology and the Pi Beta Phi Rehabilitation Institute. In addition, Dr. Dahir and colleagues are partnering with the Biomechanics & Assistive Technology Laboratory at Vanderbilt University to use state-of-the-art 3-D motion analysis equipment to test for abnormalities in gait and muscle weakness in adolescents and adults with HPP.

Information from this study will be used to develop strategies for patients, families and their doctors to better identify problems and make appropriate referrals to specialists when needed.

YOU SAY HYPOPHOSPHATASIA, I SAY HYPOPHOSPHATEMIA? TIME TO EDUCATE!

This resource highlights four rare diseases of bone development including...

Hypophosphatasia (HPP)
Osteogenesis Imperfecta (OI)
Familial Hypophosphatemia (XLH)
Hereditary Hyperphosphatasia.

Patients who have HPP are often misdiagnosed, or confused, with one of these other diseases.

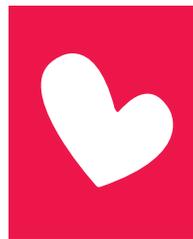
Check out our New Disease Comparison Fact sheet at...
<https://www.softbones.org/resources/fact-sheets/>

BONFIRE FUNDRAISER

Thanks to all who participated in our Bonfire Fundraiser. Shoppers had a chance to choose from products including short sleeve t-shirt, long sleeve t-shirt, and a sweatshirt available in a variety of colors and sizes. The shirt was designed by our very own talented Amy Britt. We were able to raise a total of \$1,557.73 through product sales and donations. If you didn't get a chance to purchase this time, we will be rolling out another design in the future.

SAY OLÉ TO CHIPOTLE!

Want an easy way to give back? Host a fundraiser at a local restaurant. Chipotle is a good option with 50% of the profits donated back to Soft Bones. To date we have raised over \$4000 through Chipotle fundraisers. Once the fundraiser has been approved in a local franchise, just have friends and family alert the cashier know they are supporting Soft Bones during the particular fundraiser day and time, and Chipotle donates 50% of the profits to Soft Bones. Fundraisers have been held in CT, NJ, NE, AZ, OK, KS, TX and CO. A big thank you to all who participated. This is an easy, fun and not to mention delicious fundraiser to hold. If you are interested in holding a fundraiser at Chipotle or another restaurant, in your area, contact Adriane Eoga at Adriane@softbones.org.

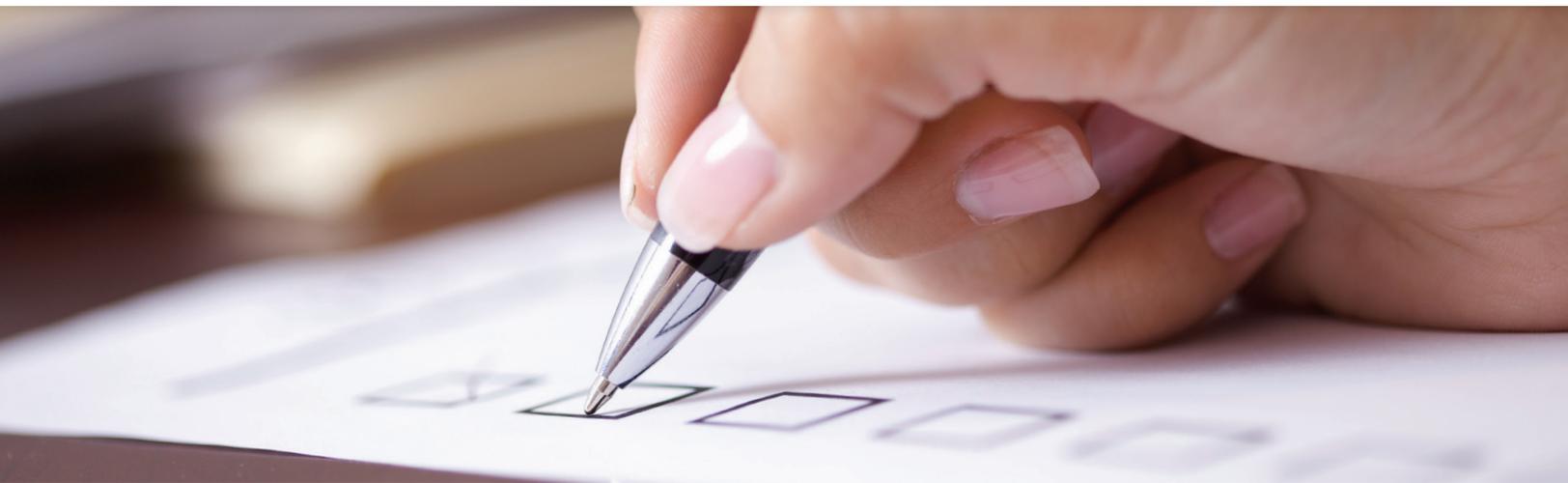


ANNUAL APPEAL – PLEASE CONSIDER GIVING

You may have received our Soft Bones annual appeal letter in the mail. Soft Bones needs your support in order to continue to provide the programs for our community, such as patient meetings, materials development, access support and so much more. In addition, with recent breakthroughs in gene therapy, the hope of a cure for this disease is actually a reality. Thanks to our fundraising efforts this year, Soft Bones is funding research that could lead to potential new treatments for HPP using stem cells.

In addition, we are planning our first-ever HPP meeting in the US, in June 2018 in Chicago inviting researchers and physicians from around the world to share their latest experiences and research with the hope of sparking new research which will ultimately lead to new treatments, and eventually a cure.

We know that there are many worthy charities out there. We ask you to remember Soft Bones as you consider charitable giving. Our traditional funding sources have been cut back, so every dollar counts. We hope you will consider making a donation to allow us to continue to support. To make a donation, go to www.softbones.org or contact Adriane Eoga at Adriane@softbones.org. All donors will receive a letter for tax credit purposes. Thank you!



REGISTRY UPDATE – OVER 150!!

Our International HPP Contact Registry currently has over 150 people fully enrolled. The three states with the highest enrollment are Ohio (12), NJ (9), and Florida (8). A total of 11 participants represent those living outside of the US (Canada, UK and Australia). We have spoken to several researchers who are interested in potentially accessing this Registry. Unless your information is contained in this Registry, you will not be contacted about research opportunities accessed through the Registry.

To enroll, visit [http:// www.sanfordresearch.org/cordsregistryform](http://www.sanfordresearch.org/cordsregistryform) fill out the form, and specify that you are interested in joining the disease specific Soft Bones International 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.



IMPORTANT MESSAGE FOR THOSE TURNING 18



Once a participant turns 18, they **will be removed from Registry** if CoRDS does not receive their updated consent.



Parents may also **need to re consent** as the participant's legally authorized representative.



CoRDS will contact all participants who have recently turned 18 to **update their information and attempt to receive consent.**

However, if they are not able to get ahold of the participant to update consent, they will be withdrawn.

SOFT BONES GOES TO 2017 INTERNATIONAL BIO CONVENTION

In early June, Soft Bones traveled to San Diego to attend the 2017 BIO International Convention. The BIO International Convention is hosted by the **Biotechnology Innovation Organization (BIO)**. BIO represents more than 1,100 biotechnology companies, academic institutions, state biotechnology centers and related organizations across the United States and in more than 30 other nations. BIO members are involved in the research and development of innovative healthcare, agricultural, industrial and environmental biotechnology products. It's a meeting where research and industry united to develop new therapies, assays, diagnostics and more.

BIO uses a "matchmaking" process as a way for organizations to request meetings with one another. Each organization creates a "profile" and messages those other organizations with whom they would like to meet. Each meeting is scheduled to last 10 minutes, resembling speed dating in many ways. We were fortunate enough to meet with some of our current partners such as Global Genes and the National Institute of Health. We also had excellent meetings with Athersys, Icagen, AM Pharma, Caregiver Action Network, National Alliance for Caregiving and Check Orphan.



Deb was also interviewed on BIO Buzz which was broadcast during the meeting.

To view this interesting interview go to...
<https://youtu.be/zguUFvORrDY>

One of the most interesting meetings was with a company called Athersys that makes a unique stem cell product called MultiStem[®] which the CEO of the company believes could have potential in treating HPP. Soft Bones connected Athersys with Luke Mortensen, the University of Georgia researcher who won the 2015 Soft Bones research grant to discuss the potential of using the MultiStem[®] product in HPP mice.

STAY TUNED FOR UPDATES ON THIS BUDDING PARTNERSHIP.

To learn more about Athersys, visit www.Athersys.com

MEDICAL MEETINGS

ENDOCRINE SOCIETY MEETING

APRIL 2017 - ORLANDO, FLORIDA

Soft Bones hosted a booth at the Endocrine Society Meeting in Orlando, Florida. We had patients on hand to staff the booth and share their knowledge of HPP with doctors and medical professionals. We educated over 100 doctors and medical professionals at our booth. Our eye-catching BioDigital Human application served as an excellent tool to illustrate the effects of HPP on various parts of the body. On Saturday, we held a dinner for patients, doctors and several representatives from Alexion. The unstructured format of this dinner led to many important and meaningful discussions. A good time was had by all.

On Sunday, Deborah Fowler presented a poster entitled Patient Reported Symptomatology in Hypophosphatasia. The data for this poster was gathered at a focus group held with HPP patients at ASBMR 2016 in Atlanta where a group of US patients and caregivers were surveyed to explore the perceptions of signs and symptoms of HPP. The preliminary findings were as follows:



- These results expand on the current understanding of the spectrum of signs and symptoms experienced by patients with HPP during different life stages, particularly adulthood, which is not extensively characterized in the literature, and suggest that previous descriptions of the natural history of HPP are inadequate
- A more inclusive description of the signs and symptoms of HPP may allow for a more robust understanding of the disease by patients and caregivers, help to inform the medical management of patients with HPP, and help to define outcome measures in future clinical studies evaluating HPP therapies
- Many signs and symptoms known to be associated with the natural history of HPP (e.g. fracture, bone deformity, gait issues, tooth loss) were reported
- More than 70% of the patients/caregivers reported fatigue, a symptom not frequently reported in the HPP literature
- The 'most urgent/difficult/problematic' signs and symptoms reported were fractures, bone pain, early tooth loss, fatigue, and muscle pain
- Multiple signs and symptoms were also reported that previously have not been associated with the disease (e.g. migraine, attention deficit, brain foggiess/cognition, paresthesia, asthma)
 - It is not clear whether these are signs and symptoms of HPP or comorbidities
 - Many of the signs and symptoms 'questioned regarding relatedness to HPP' by patients/caregivers were also indicated as the 'most urgent/difficult/problematic', suggesting a high burden imposed by these signs and symptoms

AMERICAN ACADEMY OF PEDIATRIC DENTISTS ANNUAL MEETING

MAY 2017 - WASHINGTON DC



Soft Bones exhibited for the first time at a dental meeting. This was a great opportunity to spread awareness to a group who oftentimes is the first to see the tell-tale sign of early tooth loss in HPP patients. Dr. Timothy Wright, a member of our Scientific Advisory Board and renowned Pediatric Dentist with an expertise in rare bone conditions, gave a keynote address and was honored with the Paul P. Taylor Award for his dedication and commitment to the dental profession and patient community. Congratulations again, Dr. Wright!

ASBMR

SEPTEMBER 2017 - DENVER, COLORADO

BY JEN JANSONIUS

ASBMR's annual meeting was held in Denver, Colorado this year. Every fall, the American Society for Bone and Mineral Research gathers doctors, researchers, pharmaceutical companies, and medical students from around the world over to discuss and share what gains have been made in this field. Over just the last few years we have gone from seeing HPP remain a disease that few have heard from in their work, to a condition that is now being represented regularly in medical abstracts, lectures, and drug innovation. This is of course would not be possible without the involvement of Soft Bones and its patients.

Soft Bones is one of the few patient advocacy organizations regularly present at these medical meeting of the minds, and it has been vital in the increased awareness regarding HPP and diseases like it in the medical world. Every year, patients are able to meet and speak those who attend regarding topics such as the urgent need for ongoing research, possible new treatment methods for this condition, the various ages and severities in which this disease presents itself, and basic education within the medical community relating to what living with HPP truly entails. In addition, at the conclusion of the conference Soft Bones holds a dinner where patients, doctors, and researchers are able to learn from one another in a one on one setting. For someone like myself who desperately still seeks treatment and research for not only myself but the generations that will follow, these encounters are imperative in ensuring that our children may one day live in world without HPP.



EXCITING THINGS & CREATIVE CORNER

HPP AWARENESS DAY

October 30th marked our 6th official HPP Awareness Day.

Thanks to all who flooded social media with awesome pictures and HPP facts with the hashtag #HPPAware. We had over 200 people change their profile pictures to the frame created by our own Sue Krug. Thanks to all who participated and helped get the word out about HPP.

Here are some of the awesome moments captured from the week.



PLAY DATE

BY TRACY WILLIAMS



Movie character Mike Wazowski of Monsters, Inc. makes an unexpected cameo appearance with Princess Hippo in a make-believe story about an epic journey to a magical land. Mike's large eye points to the importance of cultivating a sense of humor to spice up a delicious recipe for coping with Hypophosphatasia. Before I discovered Soft Bones I had adopted a stifled, muffled and unusual way of laughing to protect a delicate skeletal core; internal vibrations caused me to feel like I might collapse. One year of enzyme replacement has helped me regain the ability to spontaneous belly laugh like when out-of-control goofiness occurs between friends. I'm lucky an active imagination believes this superstar connection encourages an appreciation of simple pleasures.

SPREADING AWARENESS IN THE CLASSROOM

RYAN DOUGLAS MAKES THE GRADE WITH HIS POWER OF ONE PROJECT

BY CHRISTINE DOUGLAS



Ryan is a fun-loving, caring 12 year old boy who was diagnosed with “childhood” HPP at Age 2. As Ryan continues to grow, we face more hurdles each year. He recently had to complete a 6th grade International Baccalaureate school project called the “Power of One”. This project was to raise awareness and demonstrate how one person can make a difference. Ryan chose Hypophosphatasia! Even though his life is impacted every day with this rare disease, there is still so much that we continue to learn. Ryan spent a few months compiling facts into a slideshow presentation, created a display poster, raised awareness through an HPP bracelet fundraiser, put together a Kahoot (which was a new techie term that I have never heard of) – this was an online survey to see what people knew about HPP, and he even got the fun task of interviewing his long-distance buddy, Cannon! Ryan

received a lot of compliments and felt very proud to raise awareness of this rare disease that makes him, and everyone else with HPP, so special. Ryan made his “Power of One” commitment to make a difference by giving back to such a wonderful organization and has made a donation from his bracelet fundraiser to Soft Bones, Inc.

Soft Bones, thank you for all you do! As we face the everyday challenges of this disease, it is reassuring to know we are never alone and have an “extended family” of those who truly care and understand.

BRYCE POSTON PRESENTS THE SCIENCE OF HPP WITH AN EGGSELLENT DEMONSTRATION

BY BRYCE POSTON



I did my science project on my condition Hypophosphatasia. I wanted to share with students and teachers what this condition causes. To say I have this condition, most people look at me like they are very confused. Some people say drink more milk or eat a vitamin but it is much more than that. I also explained the procedure of taking Strensiq™ every day. In my project, I used the soft-shell egg experiment to demonstrate bone demineralization. I used SweetTart bones to lure some kids to my table. The eggs were really cool to squeeze and both were a big hit. I used the BioDigital application from the Soft Bones website on my laptop to show the difference in a normal toddler and one with HPP. I think the presentation worked well and more people now know what I have to deal with every day.

SOFT BONES AROUND THE GLOBE

SOFT BONES CANADA UPDATE

BY DEBBIE TAILLEFER, PRESIDENT, SOFT BONES CANADA



These recent months have been exciting here at SBC! We celebrated HPP Awareness Day by launching a new Instagram account and contest. Our winner, Madeleine Friesen of Manitoba, was the recipient of an SBC t-shirt and a \$50 visa gift card. We welcomed Linda Toews, currently our Secretary/Treasurer, into the role of Director of Patient Care. Lisa McGuffin, who is a Registered Nurse, has taken on a new role as Chief Nursing Officer. This month we look forward to our Scientific Advisory Board Annual Meeting and hearing from experts across the country. We celebrate with Dr. Cheryl Rockman-Greenberg, Chair of the SAB, as she is being inducted into the Canadian Medical Hall of Fame; see www.softbonescanada.ca for details.



Our successful planning meeting had us contemplating an action-packed 2018 with discussion spearheaded by Jennifer Boin, Director of Education and Events. On the table are proposals for a patient meeting in Ontario in July, as well as two medical conferences, one for Pediatric Endocrinology as well as Bone and Mineral Research. We continue our outreach to Dentists in Canada following up on the Oasis discussion videos, with a new dental brochure currently in production with Dr. Bob Schroth, and a planned mail out once completed. We propose to be at four dental colleges in different provinces next year attending events on campuses and raising awareness with students. We welcome Nicky Dobrin of British Columbia, as a new moderator for engagement/support on Facebook, and Amanda Bruce of Alberta, on Instagram.

We have started a monthly MailChimp newsletter with more detail of patient stories, upcoming educational offerings and events, special announcements and other news and opportunities. Register today and stay on top of happenings in your province and to contribute if you have something to say! Look for your December e-zine crafted by Jen, in your inbox. We want to welcome our new patient contacts these past months and thank everyone who has donated their time and finances to keep SBC doing what we are doing for Canadian patients and their families. From the team at Soft Bones Canada, keep the candle burning, have a Merry Christmas and warm wishes for a wonderful New Year!



SOFT BONES UK – BONDED BY SOFT BONES

BY MERYL CHAMBERS, PRESIDENT SOFT BONES UK

This year has been so busy and full of many wonderful achievements. NICE made their final recommendations and Strensiq™ has been approved for childhood Hypophosphatasia (HPP). Whilst this is an incredible achievement and it will make a difference to so many, we were disappointed with the outcome that not all people living with HPP can gain access to Strensiq™. It is also still uncertain as to how the Managed Access Agreement (MAA), which NICE have proposed will work and we are awaiting a meeting with NHS England to find out more. Regular updates will be posted on the Facebook group.

We were lucky enough to have been invited by CLIMB to hold our first Soft Bones UK patient afternoon at the CLIMB conference in Birmingham this year. We feel very privileged to have had some real inspirational speakers take part and interesting talks from leading health care professionals on a variety of relevant paediatric and adult topics.

The afternoon started with Professor Eastell, who gave us all an insight into adult Hypophosphatasia and the developments in care and management of such patients. He stressed the importance of people and families affected by HPP to sign up to the RUDY study. Currently there is some research taking place in Sheffield for adult HPP. Melanie Williams also spoke about RUDY and the importance of signing up, with HPP being such a rare disease, we are still learning of the affect it has on people, and also the potential implications of family members who may have milder symptoms.

We had talks from Dr Vrinda Saraff, Dr Sarah Mckaig and Claire Sweeney, discussing paediatric HPP, HPP and teeth and therapy

and the allied health professional role for children with HPP.

Lyndsay Weaver the CEO of CLIMB gave an update on access to Strensiq™. She has been heavily involved in the NICE process to gain access to Strensiq™ and working with health professionals in putting together the Managed Access Agreement (MAA).

We were extremely privileged to have Deborah Fowler, her daughter Grace and Denise Goodbar from Soft Bones US be part of the conference. Deborah gave a talk on Advocacy, awareness of HPP and the ability to impact access across the world.

The conference allowed the opportunity for us all to meet and for people to share experiences. It was truly wonderful to have a room full of people affected with HPP.

So whats next for Soft Bones UK.....

Whilst Deborah and Denise were over they very kindly set up a meeting with Find-A-Cure who are going to help mentor us in gaining our charity registration, this will be a great support for us in moving forward with Soft Bones UK.

We have also have started working on the content for a website, we have a couple of local fundraisers in the pipeline and we are hoping with all your support we can really grow. Thank you to all who attending, we welcome any feedback on the conference and just in general what you would like to see from Soft Bones UK.

HAVE YOU HEARD?



INTERNATIONAL HPP MEETING

We are excited to announce that we are hosting our first-ever hypophosphatasia focused meeting in the United States...

**on June 9-10 in Rosemont, Illinois,
which is the Chicago area**

The invitation-only meeting will be for physicians and researchers and the Soft Bones Scientific Advisory Board is organizing the agenda and will determine all the invitees.

SOFTBONES HAS A NEW ADDRESS!

141 Hawkins Place, #267
Boonton, New Jersey 07005

Upcoming Events

JANUARY

Region Lead Training

FEBRUARY

Rare Disease Day

JUNE

International HPP Meeting

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](#). 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 interest in and experience with HPP. Other physicians may be added in the future. For a list of physicians in your area, 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
141 Hawkins Place, #267
Boonton, New Jersey 07005
www.softbones.org

