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## Advocacy In Action at the Endocrine Society Meeting in Boston

By Tracy Doyon

Over the years I have spent many days searching online in the hopes of finding out any additional information to provide answers to some of our twins' medical problems. After a year and a half being given a completely opposite diagnosis, exome sequencing finally provided the answers as to the cause. A confirmed diagnosis should have felt like such a wonderful step forward. With an ultra-rare disease, it was instead like walking into the great unknown with only a link through media to guide me. I felt extremely fortunate to find the Soft Bones website and Facebook community page for others who have this disease. Thankfully this provides a great way to share experiences and we are all learning so much about this disease through each other and our posts.

In the middle of February, the opportunity came up to participate with Soft Bones in an Advocacy in Action

Meeting that would take place in April at the Endocrine Conference 2016 in Boston, MA. Due to how close this was to where we live, I knew I had to find a way to go. Thankfully, there were scholarships available to reimburse most of the travel costs. The hotel costs were being covered by Soft Bones which made it possible for me to plan to attend.

A Facebook group was created to keep everyone participating in the conference informed. As the days to the conference drew closer all of the information relevant to participating was provided. There was also an opportunity to have a conference call to go over some final information prior to the conference. Having not participated in anything like this before, I truly had no idea what to expect. I did know I was looking forward to meeting some of the Facebook friends I have made.

(continued on page 2)

## (Advocacy In Action at the Endocrine Society Meeting in Boston continued)

After our arrival at the beautiful hotel that evening we met with others to venture out to dinner as a group. It was so great to meet friends from online and discuss a few of the happenings the next day. Most of us were scheduled to be at the Soft Bones booth for an hour at a time, so everyone's schedule was a bit different. A shuttle was running us to the conference with a few pickup times and each person also had to go through the registration process. I decided best to head over on the first shuttle as I really wanted to have as much time there as possible.

No words can describe the overwhelming feeling I had walking in the doors of this convention. The scale of such an event is nothing I have ever experienced. The realization of being included in something much bigger, is nothing I could have ever imagined. This convention center was huge and every available space in this facility had something going on. While each person had their turn at the booth we had the opportunity to meet and reach out to so many professionals who came by and shared information about HPP and Soft Bones. Our booth was very well organized and we had so much information available to folks.

During downtime we were able to walk around and see all that the convention had to offer. There were scheduled times that doctors were speaking that patients and professionals could attend. There were so many booths, several companies with big names that we are all familiar with, and many that we have not heard of. So I did take the opportunity to visit and learn throughout the day. I also took the opportunity when meeting others at their booths to talk about HPP and Soft Bones. The most amazing booth there

(besides our Soft Bones booth of course) was the Alexion Pharmaceuticals booth displayed in bright yellow, highlighting HPP and the drug treatment Strensiq, made by Alexion. Our twins had just started on this drug a little over a month prior and it seemed so personal of a connection to be standing in this booth, next to these great folks who have found a treatment to improve our children's future health. I had no idea how much it would mean to actually meet so many of them, some who I had talked within the past.

The first day of the conference was over and we headed back to the Hotel on the shuttle. That night we were very fortunate to be treated to a special

dinner. A few of the doctors attending the conference joined us as well as a couple of folks from Alexion. Having time to sit for hours and have discussions on a more personal level was quite wonderful.

Headed back over to the conference on the morning shuttle and walking into day 2 of the conference was, thankfully, not as overwhelming. The

focus this day was to try and soak in anything I could not get to on day 1. I took advantage of any additional opportunities to share about HPP and what the Soft Bones organization is doing to raise awareness in the efforts to bring doctors and patients together. It would have been great to stay longer in the hopes of getting to meet Dr. Whyte, but that will have to wait for another time.

My sincerest of thanks to the Soft Bones organization for helping me make such important connections and providing such an incredible opportunity where I can make a difference. I look forward to any future opportunities to participate again.



# Update from Soft Bones' Founder, Deborah Nettune Fowler

Hello HPP Friends!

We have so much ground to cover since our last newsletter -- and I'm thrilled to say that in this edition much of the content is written by our patients!

We have made a lot of progress — including an International Patient Registry and a new 3D digital human body — HPP: A Journey Through The Human Body.

Thanks to our partnership with BioDigital, this virtual human shows how this metabolic disease impacts more than just bones, and takes you on a journey through the body to learn more about other complications of this condition. We are really excited about this tool, and it was a huge success as the focal point of our booth at the American Society of Bone and Mineral Research in Atlanta in September. Please visit our website to use this interactive educational tool first hand - and let us know what you think!

We are also gearing up for HPP Awareness Day on October 30. For those who are not aware, we partnered with Alexion last year on a HPP Uncommon Strength campaign where we showcased the “superhero” powers of our HPP community. We sent out superhero capes and asked people to post photos in social media to help raise visibility of HPP. We are continuing the Uncommon Strength campaign again this year -- and have a new cape design!

We look forward to seeing HPP flood the internet in the last week of October and be sure to use the hashtag [#HPPheroes](#)

Finally, we are looking to diversify our fundraising so we are not so reliant upon our golf outing. We are conducting an end of year appeal and we hope you will consider giving so we can continue the work to fulfill our mission.

Enjoy the newsletter and as always, we appreciate your support.

**Deborah**



**Please help Soft Bones by making a donation. No amount is too small!**  
Go online to [www.softbones.org](http://www.softbones.org) to make a donation today. Your contribution is tax deductible.



# Soft Bones Helps Launch International HPP Patient Registry - **Join the Movement**

By Angela Vanveldhuizen



In the rare disease space, one of the biggest challenges is overall lack of information available to patients, families, physicians, and researchers. With a disease like hypophosphatasia, the healthcare community is still learning about the spectrums of symptoms of this condition. Having a central location, such as a registry, where disease information is tracked can provide important insights to help inform research and ultimately patient care. In fact, only 20% of all rare diseases around the world are represented by a registry.

Early this year, Soft Bones and the Coordination of Rare Diseases at Sanford (CoRDS) formed a partnership to launch a patient registry to accelerate research in HPP. In order to meet this mission, CoRDS has three goals: First, to assemble contact registries; second, to generate standardized datasets through common data elements (CDEs); and third, to curate disease-specific databases on rare diseases. CoRDS

is able to collect and warehouse this information so that researchers may contact CoRDS about potential participants for research studies and clinical trials. If a researcher would like to contact CoRDS participants, CoRDS will reach out to participants on behalf of the researcher. Participants then have complete control over the decision to participate in a study or not.

CoRDS is part of Sanford Research which is part of Sanford Health, an integrated health system headquartered in the Dakotas. Sanford is one of the largest health systems in the nation with 43 hospitals and 250 clinics in 9 states and 3 countries. Sanford covers 1/8 of all U.S. land mass, serving 2.65 million people, and delivering care in more than 80 specialty areas. This gives the CoRDS team access to the expertise of world-class health professionals, researchers, and scientists to support the interests of our contracted patient advocacy groups, like Soft Bones.

One of the numerous benefits of partnering with CoRDS is that CoRDS will send representatives to attend annual patient conferences. In case you missed it, Angela Van Veldhuizen, project manager of CoRDS and Alyssa Gonzales, CoRDS intern, recently attended the annual Soft Bones Patient Meeting in Nashville. Angela presented about the CoRDS registry and the importance of participants enrolling in the registry. While at the conference, the CoRDS team was able to help participants enroll in CoRDS and answer any questions that the participants may have had about the CoRDS registry.

Prior to the conference, there were a total of 13 participants that had enrolled in the registry. As of October 23, there have been 75 participants with hypophosphatasia who have enrolled into CoRDS. There are also a total of 4 participants that are eligible to be part of the registry but have not yet gone in to complete the questionnaires. It is important to remember that in order for participants to be fully enrolled in the registry, they need to not only complete the screening form but also the questionnaires.

As exciting as it is to increase the number of participants that enroll in the CoRDS registry, it is equally as important for currently enrolled participants to go into the registry at least yearly to update their information (<https://cordsconnect.sanfordresearch.org/BayaPES/login>). The ability of CoRDS to provide accurate and up to date data is important for researchers to form a hypothesis which they can use to secure funding for research.

CoRDS encourages everyone who has not already done so, to go in and sign up to be part of the CoRDS registry (<https://cordsconnect.sanfordresearch.org/BayaPES/sf/screeningForm?id=SFSFL>). You can contact CoRDS anytime with questions or concerns at 1-877-658-9192 Monday through Friday 8am-5pm CST or by emailing [CoRDS@sanfordhealth.org](mailto:CoRDS@sanfordhealth.org).



## JOIN THE HYPOPHOSPHATASIA MOVEMENT

Announcing the Launch of the CoRDS Soft Bones International Hypophosphatasia Registry

Soft Bones partnered with the Coordination of Rare Diseases at Sanford (CoRDS) to host a patient registry for individuals diagnosed with hypophosphatasia (HPP) and carriers of the disease.

This information provides a secure way for patients to make their basic disease information available to researchers without sacrificing privacy.

Participation is voluntary and those who enroll may withdraw at any time.

### WHO:

Anyone diagnosed with any type of HPP or those who are carriers, undiagnosed or suspect they may have the metabolic bone disease

### HOW:

To enroll in the registry, visit [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.

#### Enroll online:

1. Complete the Initial Screening Form. When filling out the diagnosis, simply enter "hypophosphatasia" and select the correct diagnosis, from the list, to the best of your ability. You can always go back in and make updates.
2. Complete the Log In Setup Page. Your username will be displayed and you will be asked to create a password. NOTE: Once your login is complete, you will receive two emails – one with your username and the other with your password. There is no need to access these emails, at this point, rather they should be saved for your records.
3. Complete the CoRDS Standard Questionnaire.
4. Complete the Soft Bones Questionnaire. Remember to select the "Share with Soft Bones Foundation" option before submitting.

#### Enroll by mail:

1. Complete the Initial Screening Form - indicate that you prefer to enroll by mail.
2. CoRDS will send the enrollment forms in the mail. Completing the forms takes approximately 20 minutes. You will not be fully enrolled in the registry until you have completed AND returned the forms. NOTE: Participants who enroll by mail but wish to switch to online, can do so by contacting CoRDS.

**NOTE:** Mobile phones and tablets are not supported for online enrollment at this time. For any technical issues, please contact CoRDS

**For more information:**

**About CoRDS**  
Visit: [www.sanfordresearch.org/cords](http://www.sanfordresearch.org/cords)  
Email: [cords@sanfordhealth.org](mailto:cords@sanfordhealth.org)  
Call: (877) 658-9192

**About Soft Bones**  
Visit: [www.SoftBones.org](http://www.SoftBones.org)  
Email: [info@softbones.org](mailto:info@softbones.org)  
Call: (866) 827-9007

Soft Bones will not have access to names or any information that allows us to identify individuals associated with the data.

CoRDS Registry  
A Coordination of Rare Diseases at Sanford

Soft Bones  
Finding the way to cure

# ASBMR 2016 Advocacy with Soft Bones

By Sharon Talkington

This past weekend my daughter Rebekah and I had the honor of traveling to the great city of Atlanta for the American Society of Bone and Mineral Research (ASBMR). During our time at ASBMR we had the opportunity to hang out and chat with other patients, doctors, and researchers. Everyone was so caring and kind. Soft Bones, our patient advocacy group, really pulls together to get things accomplished and spread the word about HPP.

While we were there I got to meet the president of Soft Bones, Deborah Fowler, whom I had befriended through the HPP community on social media several years ago. This happened to be the first time we met in person and I can't express to you the joy in connecting with her. It was also a joy to connect with the wonderful Soft Bones community of patients and caregivers that have such strong hearts despite their soft bones! It was truly incredible!

One of the main assignments of this weekend was to help support Soft Bones by talking with doctors and researchers at the Soft Bones booth. During this time of visiting and participating in staffing the booth I was able to meet and talk with some of the doctors and researchers that helped to devel-

op Strensiq™. Strensiq™ is the first treatment to ever be approved by the FDA for perinatal onset, infantile onset, and juvenile onset HPP. It's amazing to see the positive progress in the patients that are on the medication and see the hope in their eyes!

Soft Bones released a new tool HPP: A Journey Through the Body that we were able to promote in the booth to show a difference between a toddler with HPP and a toddler without HPP as well as the difference between an adult with HPP and an adult without HPP. It's an amazing tool and I loved seeing people's faces as they saw the differences in the 3D model. You can check out information about Soft Bones, Hypophosphatasia, and play with the new tool on the SoftBones website ([www.softbones.org](http://www.softbones.org)).

After returning home from the conference, I realized this weekend helped to fulfill a promise that I made to my husband 26 years ago when he had his first symptoms of HPP during our marriage. I told him that someone, somewhere, knew something and that I was going to do whatever I could to find them and to find something that would help him. This weekend was the end and the beginning of that adventure...



We are grateful as a family for all who have contributed to the process of research, development, and treatment. From the smallest infants, to the families who have lost a loved one to HPP whether they were able to try a treatment or not you helped pave the way for those who need HPP help today. For all who have helped with Soft Bones such as President, Deborah Fowler, boards, doctors, staff, our generous contributors, and all those who have prayed and thought positive thoughts and kept the hope alive of the dream, a treatment for HPP which we now see as a reality! Here is to more breakthroughs in HPP as we join together as one for a common purpose to help all those around the world who live with the challenges daily of HPP."

— Sharon Talkington

# Advocacy in Action

## Victory in Tennessee



Nashville, Tennessee

In February, Soft Bones was made aware of a situation regarding a proposal by TennCare, a coverage plan in Tennessee, and its proposed authorization criteria for Strensiq™. This proposal stated that in order to obtain prior authorization, an individual would need to have a diagnosis of perinatal, infantile or juvenile-onset HPP and be 16 years of age or younger. Under this criteria, only children below the age of 16 would be allowed to have access to Strensiq, with no provisions for these patients once they turned 17 years old! The decision

would potentially impact patients and their access to this important therapeutic option for patients with HPP.

In response to this proposal, Soft Bones drafted a letter on behalf of our community arguing that the age limit should be consistent with the age stated in the label approved by the FDA (18 years). The Pharmacy Advisory Committee (PAC) held a public meeting to hear from experts and stakeholders including patient advocacy organizations. The letter from Soft Bones was read as part of this meeting. As a result of advocacy efforts led by physicians and the patient community, the PAC revised their draft criteria regarding Strensiq™ and removed the age restriction.

Under the final TennCare criteria for Strensiq™ that is now in effect, therapy is available to all patients with a diagnosis of perinatal, infantile or juvenile-onset HPP, which is consistent with the FDA approved indication.



## Spreading Awareness

# On the High Seas

By Kate Fischer

A funny thing happened recently...Our family was on our sailboat on the 4th of July waiting for friends to go sailing. I had purchased one of the Soft Bones shirts for my husband Mike – 1) to see how they looked and 2) because I liked the ribbon design. He happened to be wearing his Soft Bones shirt on that day. We have new neighbors on a boat next to us and the lady saw Mike in his new shirt and she said, “Do you know about Soft Bones?” She continued, saying she knew of the organization because her husband’s nephew from Utah has HPP. It absolutely made my jaw drop! Proof that the shirts really are a great way to spread the word about HPP! It was just a small thing, but really made me smile all day.



# An Eye Inside the FDA

By Sue Krug



As some of you may know, our own Sue Krug participated in a workshop sponsored by the FDA as a FDA Patient Representative for Hypophosphatasia, Scoliosis/degenerative disc disease, Diabetes, and intramedullary (IM) rod.

## What is an FDA Patient Representative and what does that mean for our HPP community?

The FDA Patient Representative Program is managed by the Office of Health and Constituent Affairs within the Office of the Commissioner. The Patient Representatives program has over 150 representatives who must have a personal experience with the disease either as a patient, or primary caregiver such as a family member or friend. Patient Reps participate on 47 FDA Advisory Committees and Panels, and in Review Division Meetings. These Patient Representatives provide direct input used to guide decision-making associated with medical products for drugs, biologics, and medical devices for the diseases they represent.

Unlike other Advisory Committee members, the FDA's selection of patients serving, involves identifying those with direct disease experience. This means that a FDA Patient Representative is assigned to an Advisory Committee meeting topic that they are well acquainted with. FDA Patient Representatives also serve in Review Division Meetings and FDA Workshops. These workshops can range from a forum of medical specialists to a panel or researcher wanting to understand the patient's perspective on living with a specific disease/disorder. The job of a Patient Representative is to provide the FDA with the unique perspective of patients and family members affected by a serious or life-threatening disease.

## What does a Patient Representative do?

Some of the ways a Patient Representative may serve are:

- On FDA Advisory Committees, where you will offer the patient perspective, ask questions, and give comments to assist the committee in making recommendations
- As a consultant for the review divisions (doctors and scientists who review data to determine whether the medical product's benefits outweigh the potential risks)
- As presenters at FDA meetings and workshops on disease-specific or regulatory and health policy issues

## How are Patient Representatives selected?

The FDA selects Patient Representatives based on a number of different criteria. First, each prospective Patient Representative must be nominated by either a medical professional, researcher, or pharmaceutical company. The FDA then does a background check of the applicant which includes:

- Personal experience with the disease either as a patient, or primary caregiver such as a family member or friend

- Ability to be objective while representing the concerns of other patients; while putting their needs and opinions aside from their views.
- Willingness to communicate their views openly to high official without emotional reactions while expressing their views
- Knowledge about treatment options for the disease and research in that area
- No financial or ethical conflicts of interest for self or close family member (for example, financial interest, such as stock, in companies that may be affected by FDA decisions).

Following the background check, each person has to submit to an in-depth security background check. This includes disclosing all Financial interests. Assuming all the screening is passed, he/she is classified as a Special Government Employees (SGE).

The next step is a swearing in with a Federal judge. This includes placing a hand on the bible and taking the same oath as a military commissioned officer pledging to uphold the Constitution of the United States of America, and defend this country from foreign and domestic harm – solemn stuff for sure! A notary is present and waivers are signed which allow a fingerprints search to be conducted by the CIA. The individual is now officially a Patient Representative. However, the title of Special Government Employees (SGE) is only activated while actively serving on a committee or advisory board.

### Is there any training involved?

Training is the next step in the process. This includes online classes, webinars and of course tests (which are timed). Some of the webinar topics included: “Basic Regulatory Overview”, “Learning How to Read Statistics in Medical Submissions of New Treatments and Devices”, and “How to Rationalize the Balance Between Risk and Benefits of a New Treatment”. When coursework is complete and tests passed, you are finally activated to hear and participate in teleconferences about new treatments and devices seeking approval by the FDA.

The FDA holds a Workshop yearly for all new and some long time serving Patient Representatives. The workshop is two days (12 hours each) and involves more training, testing, and meeting your fellow Patient Representatives and Federal Officials (my bosses – also in the military). At the end, you are asked to answer one question. The question is posed directly by the Commissioner of the FDA; this question can be anything from what was in your box lunch to explain the difference between mean, median, and mode. Representations have to answer and then explain how they derived the answer. The reason for this on-the-spot Q&A is to test Representatives using information presented during the workshop versus making a decision based on a previously conceived notion.

### In closing

The most amazing part of the workshop was meeting the other Patient Representatives and learning about their conditions and their personal journeys. This experience made me realize how lucky I am to only have HPP. It was an amazing time and I’m honored to represent our HPP community and its needs.



# Sonora Jewel's Shoes

By Tracy Williams



We often hear from patients who like to express their creativity in living with a rare disease. If you would like to share your creative ideas and express your creativity, please email [info@softbones.org](mailto:info@softbones.org).

Many thanks to **Tracy Williams** for “**Sonora Jewel's Shoes**”

On the way to the mall to shop for grade school clothes mom Marian explains to her daughter Sonora Jewel why she can't buy the shiny red shoes. Her bowed legs, crooked pelvis with a leg length difference, severe scoliosis, fragile foot bones, weak muscles and wobbly gait gives this family no flexibility in footwear options. Facing the truth about Sonora's HPP special needs means wearing corrective shoes and orthotics is essential to balance her muscles and bones. Mobility compensation comes natural to Sonora, however, the pain of not being able to dress-up in high heels runs deep within this young girl's heart.

Years later, arts & crafts becomes a fun way to redirect long held uncomfortable feelings into a collection of fancy miniature shoes decorated with sparkly sequins, rhinestones, feathers, stickers and beads. Instead of regrets, Sonora learns to move forward one step at a time to make the most of every situation.



# Eighth Annual Soft Bones Golf Outing

September 12, 2016

Our eighth annual Soft Bones Golf Outing took place on September 12th and was a great success. A big thank you to our Tournament Sponsor Atlantic Health System and to our Program Sponsors The Fowler Family Charitable Foundation Inc. and Gates and Mary Ellen Hawn. This popular event, our biggest fundraiser, was held once again at Somerset Hills Country Club in Bernardsville, New Jersey. Somerset Hills is rated one of the top 100 courses in the country! We had 115 golfers registered golfers who enjoyed lunch, golf and a cocktail and hors d'oeuvres reception. A highlight of the event is our Live and Silent Auction. Thank you so much to all who donated items for our auction and to those who provided video clips for our "thank you" video. We really appreciate your generosity! If you didn't have the opportunity to donate this year, there is always next year!



# Soft Bones Nashville Meeting: A Patient's Perspective

By Cami Rush



Hello! My name is Cami Rush. Brett is my husband and we have 3 fantastic kids, 2 of whom have hypophosphatasia. We had the amazing opportunity to attend the patient meeting in Nashville this July. It was a fabulous experience for our family!

We have been members of the HPP online community since it's infancy as just a Yahoo! group. Over the last 15 years, since our oldest son's diagnosis, we have met lots of inspiring, caring, helpful people along the way. I had opened up my worrisome heart to many

of these people. They were strangers in every sense of the word; we had never met before. But true strangers, they were not. I grew to know these people and their kids through our online interactions over the course of all those years. I grew to admire these people for sharing their stories, their successes, their failures, their worries, and their fears. I admired them for their involvement in the HPP community (both locally and on the internet) and their willingness to answer questions, give advice, and share their opinions. In my eyes, these people were superstars! Through 15 years of



online friendship, the interaction really helped me feel like I “knew” these people, even though we had never met in real life. My dream was to one day meet these people. To look into their eyes with my own eyes and tell them thank you. To physically hug them and thank them for their willingness to be a part of my family’s life and a part of our HPP journey.

For one reason or another, we hadn’t ever been able to attend a patient meeting and meet these wonderful people until this year. I was so excited to meet these people who had blessed my life in a way that nobody else (even my own family members) really could.

With that introduction, I can honestly say that going to the patient meeting in Nashville felt like a family reunion. People that I had “known” for so long only through the internet were there with smiles and hugs, waiting to formally introduce themselves to me and my family. It was such a satisfying feeling to set my own eyes on them and to be able to physically embrace them and thank them for all they’ve done for my family.

I particularly liked hearing about the beginnings of Soft Bones and how much we have grown, and what we, as patients and families, can do to help us grow even more! It was also great to meet the recipient of the research grant last year, Dr. Mortensen. He was very attentive and kind, and genuinely interested in our story. Also in attendance were executives from Alexion who were also very interested in hearing about our success with Strensiq™. It was very cool to be able to tell them “thank you” in person. Strensiq™ has really made a difference in our sons’ lives.

The classes and seminars offered with the staff at Vanderbilt were very informative. The doctors were eager to hear our stories and answer any questions we had. I was excited that they were so willing to share their experience treating their patients with HPP.

As for the kids, they had a great time! Meeting other teens and kids with HPP was so rewarding for them. They made friendships that will last a lifetime and they can’t wait for the next meeting.

The trip to Nashville was one that we will always remember. Being able to meet our HPP family was the highlight and we are grateful to all those involved with Soft Bones and for the travel grant made possible by Alexion.



# Upcoming events



**October 30th** |  
HPP AWARENESS DAY -  
LET'S FLOOD SOCIAL MEDIA  
WITH PICS AND HASHTAGS  
[#HPPHEROES](#)



**November 4** |  
HPP EXCHANGE  
AT THE OHIO STATE  
UNIVERSITY

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**Keep an eye out for our two  
publications for the HPP Community!**



To order these publications  
please visit our website at  
[www.softbones.org](http://www.softbones.org) or  
e-mail [denise@softbones.org](mailto:denise@softbones.org).

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## 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 copy of the Soft Bones Referral Network via mail or email, contact Denise at [denise@softbones.org](mailto:denise@softbones.org) or call 973-453-3093.

**For more information, please contact  
the Soft Bones Foundation.**

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