

MEDICS

ON THE

MARCH

## Medics March 50 Miles for the OI Foundation's 50th Anniversary

Inspired by the Brittle Bone Society's **Medics on the March** program, ten of the OI Foundation's dedicated physicians will be taking on a 50-mile march in support and celebration of the OI Foundation's 50th anniversary coming up in 2020. The group will hike the C&O Canal Tow Path (beginning in Harper's Ferry, West Virginia and ending in Bethesda, Maryland) over the weekend of April 26-28, 2019.

Thank you to co-chairs Richard Kruse, Frank Rauch, and Reid Sutton; as well as Peter Byers, Jeanne Franzone, Eric Orwoll, Jean-Marc Retrouvey, David Rowe, Peter Smith, and Maegen Wallace for volunteering to hike 50 miles to celebrate 50 years of the OI Foundation serving the OI community!

Our Medics will be documenting their preparation for the march throughout the beginning of the year. Stay tuned to the OI Foundation's Facebook page to follow their training progress or show your support with a donation in honor of your favorite physician at [www.oif.org/MedicsontheMarch](http://www.oif.org/MedicsontheMarch).

### Meet the Medics



[www.oif.org/MedicsontheMarch](http://www.oif.org/MedicsontheMarch)

## OI Community Members Came Together at the OIF Regional Conference in Los Angeles, California

A diverse group of adults, parents, children, volunteers, and medical professionals attended the second OIF Regional Conference in Los Angeles on Saturday, November 17th 2018 at the Covell Commons Building on the campus of the University of California in Los Angeles. Physician speakers shared current medical information and multidisciplinary approaches to managing OI. Attendees participated in sessions including *Basics of OI-Inheritance Patterns and Types of OI*, *Orthopedic Treatments*, *Respiratory Health*, *Dental Concerns*, and *Beyond the Bones*. Community members had the opportunity to connect with others and share their experiences with OI at the Conference. During lunch, many participated in a variety of discussion groups around common interests and experiences. The day concluded with a panel discussion on *Advocating for Yourself* where community members shared strategies they use to support themselves in a variety of different contexts.

The OIF would like to thank Dr. Deborah Krakow and her team at UCLA for their support and generous hospitality, as well as the meeting attendees, conference speakers, and volunteers

for their participation. Physician speakers included Drs. Richard Bowen, Renna Zahr, Anthony Scaduto, Sandy Sandhaus, and Laura Tosi. Other speakers included Carolyn Tipton, Tony Jacobsen, Gunner Albitre, Stephanie Hutin, and Kam Daghighian. The OIF would like to especially thank Sam Alon and Carolyn Tipton for their help planning this successful event.



OI community member Helen Atuncar, Dr. Deborah Krakow, and Dr. Robert Sandhaus at the OIF Regional Conference in Los Angeles, CA

# SAVE THE DATE!

## 2019 OIF REGIONAL CONFERENCES

**AUG 03** ATLANTA, GA

**OCT 26** WILMINGTON, DE

For more information, visit [www.oif.org/RegionalConference](http://www.oif.org/RegionalConference)

# MARK YOUR CALENDAR!

## Attend a Fine Wines Strong Bones event near you during 2019!

**January 24, 2019** *Fine Wines Reception: Naples, FL* Join Teresa & Ken Gudek, Andrea & Jeff Stewart and Jane & Jim Early at the Naples Yacht Club for an evening of wine tasting and fundraising as they raise OI awareness in Naples, Florida.

**February 23, 2019** *Fine Wines Strong Bones Gala: Washington, DC* Returning for its 19th year, the flagship Fine Wines Strong Bones Gala in Washington, DC, will be returning to the Gaylord National Resort with a Hollywood Glamour theme. Dress to impress on the red carpet while taking a chance on casino games, raffles, auctions, and more!

**May 4, 2019** *Strong Bones Gala: Boston, MA* Kick off OI Awareness Week with the Strong Bones Boston Gala in Framingham, Massachusetts! OIF Board Member, Christine Rossi is hard at work with her committee of family and friends to make the third year of this event the best one yet!

Visit [www.oif.org/FineWinesStrongBones](http://www.oif.org/FineWinesStrongBones) for up-to-date information about upcoming receptions, to purchase tickets, or to join an event committee.

# Celebrating Our Unbreakable Spirit®!



Thank you to the 225 people who came out on Saturday, November 10th for **Boots & Bling for Better Bones** at the Armadillo Palace in Houston, TX! Together, you raised more than \$100,000 for the OI Foundation. Your support enables us to continue serving those living with OI.

Despite the cold temperature, everyone had a rocking good time thanks to the music of Weldon Henson—with a surprise guest drummer, Andersson Dyke! Guests enjoyed made-to-order guacamole, legendary Goode Company barbeque and pecan pie while hearing remarks from Dr. Brendan Lee and OI Dad, Robert Paddock.

We can't wait to see you all next year!



*Dr. Brendan Lee welcoming guests at Boots & Bling for Better Bones in Houston, TX.*



*OI Community Member Andersson Dyke taking a turn on the drums with Weldon Henson band.*



*Courtney and Robert Paddock with their son Jim sharing their OI story*

# Fundraising Events

The OI Foundation relies on volunteer events held around the country to help raise awareness and funds to support our mission to improve the lives of people living with OI. On the next two pages, you can read about hosting your own OIF fundraiser.

For more information, email [events@oif.org](mailto:events@oif.org) or visit [www.oif.org/events](http://www.oif.org/events).

## Celebrate Rare Disease Day with the OI Foundation

*In support of Rare Disease Day, the OI Foundation has chosen February 28, 2019, for the next National Blue Jeans for Better Bones Day!*

Take advantage of this fun and easy way to celebrate Rare Disease Day while raising OI awareness in your community! A Blue Jeans for Better Bones Day is a dress-down fundraiser that is hassle-free, highly customizable, and can be held almost anywhere. Host one at your school, at your workplace, or simply among your friends and family. After donating (\$3, \$5, or more), participants are encouraged to wear jeans (or choose something different, like a theme day or a blue shirt) to raise OI awareness. The OIF will send you complimentary materials, such as stickers, wristbands, and informational brochures to distribute to participants.

Our favorite part about Blue Jeans for Better Bones? They are community-focused events that go beyond just raising money. When you host a Blue Jeans for Better Bones Day, you are also helping to raise public awareness and educate those who may not be familiar with osteogenesis imperfecta. *Are you ready to raise OI awareness in your community?*

For more information, help registering your group online, or to order free items like brochures and wristbands for your donors, please contact Development Coordinator Jessica Skidmore at 301-947-0083 or [jskidmore@oif.org](mailto:jskidmore@oif.org).



CELEBRATE RARE DISEASE DAY  
WITH THE OI FOUNDATION

**FEBRUARY 28, 2019**

**BLUE JEANS  
FOR BETTER BONES**

**Spread the word!** Invite members of your office, school, or community to celebrate Rare Disease Day!

On February 28th, participants will wear blue jeans to show support for the rare disease community.

Contact [jskidmore@oif.org](mailto:jskidmore@oif.org) to start planning your Blue Jeans Day!

FOR MORE INFORMATION, VISIT  
[WWW.OIF.ORG/BJBB](http://WWW.OIF.ORG/BJBB)

# Support the OI Foundation with an Online Event

## Bone China Tea

Another simple way to fundraise for the OI Foundation is by hosting a Bone China Tea! The best part about this event is that it isn't really an event at all. When you invite your friends, family, and co-workers to participate a Bone China Tea, you are inviting them to spend some relaxing time at home with a warm cup of tea. Afterwards, your "guests" donate money they might have saved by not attending a physical event. We provide everything, from the invite cards to the tea bag! There are two ways to participate:



1. Contact Development Coordinator Jessica Skidmore at [jskidmore@oif.org](mailto:jskidmore@oif.org) or 301-947-0083. Simply let her know your name, home address, phone number, email, and the number of invitations you are requesting. You will receive complimentary paper invites, envelopes, and tea bags!
2. Create a webpage for your Bone China Tea on the OI Foundation website ([www.oif.org/bonechinatea](http://www.oif.org/bonechinatea)). You will be able to feature your own personal OI story, send out invites via email, and share your page on social media!



## Facebook Fundraisers

Use social media for good! If you are a Facebook user, the easiest way to show support for the OI Foundation is (literally) at your fingertips. If it is your first time hosting, Facebook will even make a donation to help you get started! Create your online fundraiser at [www.facebook.com/fundraisers](http://www.facebook.com/fundraisers).

## Create Your Own Event!

Interested in changing things up a bit? From 5k runs to carnivals, OI Foundation community members all over the map have planned their own awesome fundraisers! If you have an idea of your own that you've been wanting to put into action, we welcome you to do the same. Contact Jessica Skidmore at [jskidmore@oif.org](mailto:jskidmore@oif.org) or 301-947-0083 to get started!



Angelo and Kim Collazo hosted the Alle Shee Project's Cracking Up for Better Bones comedy show to raise money for the OI Foundation.



The Abruzzi family holds an annual OI Carnival to benefit the OIF and raise OI awareness in their community.



Colin (right) organized a lemonade stand in support of the OIF.

# The Canadian Osteogenesis Imperfecta Society is Back!

At the 2018 OIF National Conference, we celebrated the return of the Canadian Osteogenesis Imperfecta Society. Partnered with the OI Foundation, the COIS aims to



- Provide emotional support on a personal level for parents and people with OI
- Fully acquaint medical personnel, hospitals, educational institutions, and social agencies with all facets of osteogenesis imperfecta
- Encourage and foster Canadian medical research into the underlying causes of OI
- Keep an up-to-date library of literature both medical and general, pertaining to OI
- Promote an understanding and awareness of brittle bones by the general public
- Establish and maintain a confidential central registry of OI patients
- Solicit and receive funds to carry out the aims of the Canadian Osteogenesis Imperfecta Society

Take a look at the new COIS webpage, [www.oif.org/COIS](http://www.oif.org/COIS), dedicated to serve the OI community of Canada. The page will feature updated information about research, events, and resources relevant to Canadians affected by osteogenesis imperfecta. All material will be available in English and French. Stay tuned for more information about this exciting partnership!



*COIS Board member Sarah Kamal, OIF CEO Tracy Smith Hart, Medical Advisory Council Chair Dr. Francis Glorieux, COIS Board President Jacinta Whyte, and OIF Board President Ken Gudek celebrated the return of the Canadian OI Society (COIS) at OIF National Conference.*



## Jeanie Coleman Impact Grant Program – Applications Available January 2, 2019

Impact Grants help individuals living with OI fund projects, receive services, or purchase equipment that might not be covered by savings or insurance. Applications will be available on January 2, 2019 at [www.oif.org/ImpactGrant](http://www.oif.org/ImpactGrant) until February 12, 2019. Please contact [Impactgrants@oif.org](mailto:Impactgrants@oif.org) if you have any questions.



*An OI community member getting fitted for a new wheelchair through the Jeanie Coleman CBBF/OIF Impact Grant Program.*

# My Experience Navigating School Accessibility

*As a member of the OI community, Emily Seelenfreund reflects on her experiences with educational access as a student, teacher, and lawyer*

My parents transformed into unwitting disability rights advocates the moment my local kindergarten refused to enroll me. Through a combination of back entrances, moved classrooms, and a special scooter for my many stints in a spica cast, I attended my school with my sister and neighbors for 5 years rather than become isolated from my local community. Along the way my parents instilled in me the belief that osteogenesis imperfecta should not limit my potential or choices.

However, it took until I became a teacher myself to understand just how influential inclusion can be. I initially faced obstacles toward employment, such as the high school principal who expressed doubt that I could control a classroom in which the students would be “twice my size.”

Even when I was offered a third-grade teaching position, obstacles remained. I was forced to use the student bathroom because the staff one was too small, and the back of my classroom had a large step, meaning I went the long way to get to recess. I was hesitant to ask for accommodations as I worried my principal would come to perceive me as a burden. It was my students who helped me realize meaningful inclusion is worth fighting for.

As part of my curriculum I introduced relevant disability rights heroes to teach the idea of “advocacy.” One of my students used this concept to write a journal entry advocating for a ramp toward the playground! Heartened, I decided to ask the administration and to my surprise the ramp was installed within a week. Even more surprising was how much this accommodation boosted my teaching. Not having to sprint around the building twice a day or rely on the assistance of eight-year-olds for a boost increased both my confidence and my ability to effectively supervise. Perhaps more importantly, my students received a lasting and authentic real-life lesson in the importance of accommodating and including people with disabilities.

These experiences led me to Harvard Law School and after graduating I began a two-year legal fellowship with Disability Rights Advocates, where I am investigating the physical accessibility of New York City Public schools, of which over 80% are not fully accessible.

Widespread school inaccessibility prevents many students from attending their local public schools; forcing them to travel outside of their neighborhood for education, which is both socially isolating and educationally burdensome. School inaccessibility also means that all NYC students are denied the benefits of a truly inclusive educational experience with a diverse student body that includes individuals of all abilities.

I have spoken with parents, school employees, and students who are unable to attend parent-teacher conferences and avoid using the bathroom throughout the entire school day because no stall can accommodate their wheelchair. Many of these are small fixes, akin to the ramp outside my third grade classroom, which would have an enormous impact on the affected individuals. Moreover, these accommodations are legally required under relevant disability laws, including the Americans with Disabilities Act. The ADA requires public entities to provide reasonable accommodations for individuals with disabilities, such as temporary home instruction, if needed, in the event of a broken bone. The ADA also requires that public entities provide meaningful access to their services.

If my family and I had just accepted the status inaccessibility quo, my life would look very different from the independent, fulfilling, and diverse one I have today. My experiences have led me to three pieces of advice for those facing obstacles with school access:

- *Small efforts at inclusion can have an outsized impact.* Whether it's a smaller desk chair or wider classroom aisles to accommodate a walker, there are often low-cost solutions to access barriers that can empower students and set them up for success.
- *Don't hesitate to ask for accommodations* – not only are they legally required but often public entities want to be inclusive and they just don't know how to go about doing so. If you are denied these accommodations, remember: you have legal rights.
- *Access benefits everyone.* Whether it's a grandparent attending a recital who can now use a school's ramp or the student who comes to realize that sometimes adults come in all sizes, an accessible society is a more productive and thoughtful one.

Have any follow up questions about this topic or Emily Seelenfreund's work with Disability Rights Advocates? She can be contacted directly at [eseelenfreund@dralegal.org](mailto:eseelenfreund@dralegal.org).



The OI Foundation counts on your support to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. The following is a letter from OIF CEO, Tracy Hart about the progress of the OI Foundation over the past year. Please consider helping us move forward with OI related research and programs by making a gift today online at [www.oif.org](http://www.oif.org) or by using the enclosed envelope.



804 West Diamond Avenue  
Suite 210  
Gaithersburg, MD 20878  
(844) 889-7579  
[www.oif.org](http://www.oif.org)

## Unbreakable Spirit®

Dear Friend,

With your support, the OI Foundation is able to help change the lives of thousands of individuals and families living with OI. Whether it is a family facing a new diagnosis, or an adult navigating a new health decision, the OIF is committed to providing free, medically verified information to everyone living with OI and their loved ones. We could not do any of this without your generous support. **Please consider making a gift today to help us continue this important work!**

Each year, the OI Foundation responds to more than 7,000 requests for information from individuals, families, medical professionals, teachers, and caregivers. Through physician referrals, guidebooks, in-person support group meetings, and regional and national conferences, the OIF works hard to ensure that anyone living with OI can have access to life-changing information. Melanie Wilpon, whose 8-year-old son has OI, shared her experience from the recent OIF National Conference:

*Looking back at this past weekend, the word magical is the only way I can describe it. For four magical days, our Xavier was free. He was free to be himself, free of any judgement, questions or stares. Most importantly, he felt like he belonged. For those four magical days, our boy was surrounded by hundreds of kids and adults just like him! People who know exactly how he feels and exactly what he goes through. For four days, he was part of the majority, no longer a minority! It was priceless! As a parent of a child with OI, it was such an amazing feeling to be around other parents who have shared in our struggles and heartaches. The support and love was palpable. Osteogenesis Imperfecta Foundation, I don't know where we would be without you. I am so very grateful for all you do for the OI community.*

Programs like the OIF National Conference are only possible because of help from supporters like you—**you have helped change so many lives, but there is still more work to be done!**

The OIF will be celebrating its 50th anniversary in 2020 and we are eager to continue expanding resources to reach as many families as possible. We are grateful that your support allows us to continue to work on these programs that make a difference in the quality of life for people living with OI.



Conner (L) and Xavier (R) at the OIF National Conference July 2018



*Raising awareness at the 2018 OIF National Walk-n-Wheel in Baltimore, MD*

**Training medical professionals**—The OIF’s website for medical professionals, [www.oif.org/meded](http://www.oif.org/meded), includes training documents, videos, and monthly podcast lectures from OI experts. Our goal is to continue to expand this site, adding resources and guidelines for emergency rooms professionals and in-person meetings for health care providers.

**Funding OI research**—Through the OI Foundation’s ongoing participation in the NIH’s Brittle Bone Disorders Consortium, the pace of OI research is rapidly increasing. Currently, there are fourteen OI clinical research sites across the country. Additionally, the OI Foundation is funding the Geisman Fellowship program and a new cardiopulmonary study through the Jamie Kendall Fund for OI Adult Health.

**Advocacy**—The OIF organizes Capitol Hill Days to advocate for federal funding and improved state regulations that benefit the OI community. Our goal is to continue to raise awareness of the needs of our community through visits with representatives and supporting legislature.

**Direct Services**—Programs like the Impact Grant program and Kasper/Kendall Conference Scholarship program provide direct services like free medical consultations with OI experts, mobility devices, school tuition, and financial assistance for people living with OI. Each year the OIF receives more requests than we can cover.

We hope you will **consider making a gift of \$50, \$100, \$500 or more to the 50,000 Lives, One Unbreakable Spirit® campaign using the enclosed envelope or online at [www.oif.org](http://www.oif.org).**

With your help, the OI Foundation has accomplished so much over the years; and with your continued support, we will continue our work to improve the quality of life for all people living with OI.

Thank you, as always, for your generous support!

Wishing you a happy and healthy holiday season,

A handwritten signature in black ink that reads "Tracy Hart". The signature is written in a cursive style.

*Tracy Hart*  
Chief Executive Officer



## Research Corner

### Monumental Meeting for Rare Bone Disease Alliance and Researchers

The Rare Bone Disease Alliance (RBDA) is a coalition focused on educating medical professionals, expanding research, and assisting patients and communities affected by rare skeletal diseases. The OI Foundation has been a partner and advocate of the RBDA for many years, encouraging the work and collaboration of basic science researchers involved in studying the patterning, growth, and maintenance of the skeleton. The RBDA is well-known for its annual working group scientific meeting, which is held in conjunction with the American Society for Bone and Mineral Research (ASBMR).

Each year, this meeting has steadily grown, drawing researchers from across the globe. This year's meeting built on the extremely successful efforts of previous years, which typically draw an average of 100-150 researchers. Exceeding all expectations, approximately 370 researchers, physicians, and young investigators met in Montreal, Quebec, Canada on September 26-27 to set a record for the largest rare bone meeting in history!



The 2018 RBDA Scientific Meeting, chaired by Brittle Bone Disorders Consortium Principal Investigator Dr. Brendan Lee of Baylor College of Medicine and co-chaired by Dr. Maurizio Pacifici of the Children's Hospital of Philadelphia, was titled *Mechanistic and Therapeutic Advances in Rare Skeletal Diseases*. The two-day program was held in conjunction with the American Society for Bone and Mineral Research (ASBMR) Annual Meeting, and involved the coordination of the following patient advocacy groups:

- Fibrous Dysplasia Foundation
- International Fibrodysplasia Ossificans Progressiva (FOP) Association
- Lymphangiomatosis & Gorham's Disease Alliance
- Lymphatic Malformation Institute
- Melorheostosis Association
- The Multiple Hereditary Exostoses (MHE) Research Foundation
- Osteogenesis Imperfecta (OI) Foundation
- The Osteopetrosis Society
- Soft Bones: The U.S. Hypophosphatasia (HPP) Foundation
- X-Linked Hypophosphatemia (XLH) Network

Over 30 speakers presented information on topics such as Next Generation Sequencing and Multi-Omic Approaches for Diagnosing Skeletal Diseases, Therapies on the Horizon and New Disease Targets, Targeting Signaling Pathways, and more. Approximately 100 innovative research posters were presented, and 26 young investigators were awarded travel grants to attend the meeting.

Thank you again to the program co-chairs, planning committee, meeting organizers, sponsors, and other patient advocacy organizations that made this meeting a record-breaking success! For additional information on this program and future activities of the Rare Bone Disease Alliance, please visit [www.oif.org/RBDAmeeeting](http://www.oif.org/RBDAmeeeting) or [rbdalliance.org](http://rbdalliance.org).

## New Publication on Physical Rehabilitation in Children and Adolescents Living with OI

In September 2018, an international group of physiotherapists, occupational therapists, and physicians published seventeen consensus statements regarding physical rehabilitation in children and adolescents living with osteogenesis imperfecta. The statements are directed toward "improving muscle performance, mobility and self-care," and were written based on a collection of personal experiences and the results of a literature review. The recommendations cover a range of topics and body systems, including musculoskeletal, spine, self-care and the role of upper extremities, infant and development, mobility, and therapies after surgeries. This article was published in the *Orphanet Journal of Rare Diseases*, and is available on open access at this link: <https://doi.org/10.1186/s13023-018-0905-4>. Please share this information with your physical and occupational therapy team.

## Request for Photos and/or Videos of Children with OI for Educational Project

Frances Baratta-Ziska, DPT, MS, of the Hospital for Special Surgery in New York, is working with a group of physical therapists from England and Australia to develop educational videos about optimizing mobility and physical activity for children living with OI. They are looking for photos and/or videos of children living with OI in different environments, with and without mobility aides, undertaking different physical activities and getting around in their daily tasks. The final educational videos will be available on the Care4Brittle Bones, OI Society of Australia, and OI Foundation websites. Please contact Dr. Frances Baratta-Ziska at [barattaziskaf@hss.edu](mailto:barattaziskaf@hss.edu) if you are interested in providing videos or photos to be included in this project.

## Hospital for Special Surgery Research Study on Cardiopulmonary Outcomes in OI

Hospital for Special Surgery (HSS) is sponsoring a pilot study in which researchers are exploring respiratory function and its relation to quality of life, type of OI, presence of scoliosis/chest wall deformity, and other factors such as age or co-existing comorbidities. We hope that you will take the time to complete the St. George's Respiratory Questionnaire and Additional Questions so that we can learn more about the relationship between respiratory function and quality of life in adults with OI. Individuals 18 years of age or older who have a diagnosis of OI are eligible for this single-visit research study, which aims to enroll 50 participants. If you have any questions about the study or your eligibility, please reach out to Elizabeth Yonko. Your completion of the questionnaires will not impact your participation in the pilot study.

HSS is committed to protecting the privacy of your information, and wants you to understand how information you provide will be used and protected. All the information you provide in the questionnaires will be shared only with others who are participating in or sponsoring this study, or who have administrative or regulatory oversight of this study. Everyone who sees your information has agreed to protect it. Published study results will not contain information that could identify you. Whenever possible, all information that identifies you will be removed before your information is shared. If you do not agree to participate in this study, it will not affect the health care you receive. You may revoke your permission to use your information in this study by writing to the study contact. If you have any questions about how your information will be used and protected, please contact Elizabeth Yonko (see below). For more information or to complete the questionnaire, visit [www.oif.org/RS\\_current](http://www.oif.org/RS_current).

If you have any interest in enrolling in the pilot research study, Hospital for Special Surgery in New York City is actively recruiting study participants. Contact information for the study site is listed below.

Elizabeth Yonko  
Research Technician  
Hospital for Special Surgery  
535 East 70th Street  
Research Institute, 4th Floor  
New York, NY 10021  
(212) 774-2355

## New Study About Pain in OI

The Spanish OI Research Foundation (Fundación Ahuce) has launched a new research project in collaboration with the University of Valencia. People from all countries can participate as long as they can read and understand English or Spanish. The OIF encourages as many people with OI as possible to take part – whether chronic pain is an issue for you or not.

### What is the purpose of the study?

The project aims to assess the presence of chronic pain in adults affected by osteogenesis imperfecta, as well as its relationship with sociodemographic, clinical, and psychological variables.

### Who can participate in the study?

People with osteogenesis imperfecta from all countries, older than 18 years, with or without chronic pain.

### The survey is available in the following languages:

– English: [goo.gl/beSZLo](http://goo.gl/beSZLo)

– Spanish: <https://goo.gl/cDGHKr>

If you have any questions about this research project, you can consult the main researcher Rubén Muñoz at any time by emailing [psicologia.fundacion@ahuce.org](mailto:psicologia.fundacion@ahuce.org).



## OI Clinic Spotlight

The OI Foundation works closely with nearly 60 multidisciplinary OI Clinics across the continent to provide timely and accurate information about the range of available services to OI community members. The complete OI Clinic Directory can be found under the "Information Center" tab on the OIF website.

To provide an overview of the background, mission, and services of these centers, the OIF spotlights new and existing OI clinics serving pediatric and adult patients in each issue of Breakthrough. In this issue, we are excited to introduce the Musculoskeletal Genetics Program at the University of California, Los Angeles.

### Musculoskeletal Genetics Program at the University of California, Los Angeles

With its outstanding physicians and world-renowned facilities, UCLA consistently ranks as number one in the West in *U.S. News & World Report's* America's Best Hospital survey. UCLA's clinical and training programs have flourished from collaborations with clinicians, scientists, community partners, and public health officials. UCLA's mission is to deliver leading-edge patient care, research, and education. We achieve the highest possible patient satisfaction scores and provide excellent clinical outcomes for our patients.

Osteogenesis Imperfecta care at UCLA is coordinated by the Musculoskeletal Genetics Program led by Deborah Krakow, M.D. This clinic is a state-of-the-art teaching program which is held twice a month and provides diagnostic evaluations, comprehensive genetic counseling, and follow-up for individuals and families. The UCLA Musculoskeletal Genetics Clinic is one of the few programs in the country offering clinical care for patients with all kinds of skeletal dysplasias of all ages, including adults. Pediatric, adult, and prenatal diagnostic evaluations are carried out by a team of genetic counselors, nurses, and medical geneticists.

#### Diagnosis and Evaluation

The initial visit will consist of a medical evaluation including a thorough intake of medical history, family history, and a physical examination by Dr. Krakow. All aspects of medical and surgical care are addressed including bisphosphonate treatment and scoliosis management. Diagnostic testing may be a part of the evaluation. The clinic also offers on-site x-rays as well as on-site technology for measuring bone quality including dual-energy x-ray absorptiometry (DEXA) scans. These comprehensive visits can take one to two hours to complete. Follow-up reports and letters are sent to referring physicians.

Additional subspecialty care, including nephrology, dentistry, orthopaedic surgery, neurosurgery, plastic surgery, pulmonology, cardiology, neonatal care, rheumatology, endocrinology, ophthalmology, psychology, physical and occupational therapy, pain management, otolaryngology, and audiology, are involved when necessary.

#### Pediatric Infusion Center

UCLA offers a bisphosphonate infusion program for the treatment of bone fragility. Advanced treatments include pamidronate or zoledronate infusions under a carefully monitored regimen.

#### Oral & Maxillofacial Dentistry Clinic

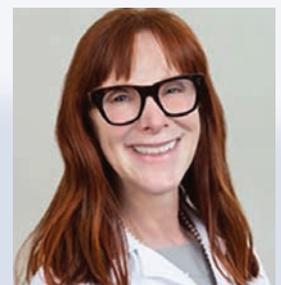
Our dental clinic is within the UCLA Dental School that has extensive programs in clinic and basic science research. The Dental Clinic is state-of-the-art with access to 3D cone beams, intraoral scans, and all the equipment and expertise necessary for dental care of patients with OI.

#### Orthopaedic Institute for Children

In 1998, Orthopaedic Institute for Children (OIC) and UCLA forged a far-reaching alliance to broaden the scope of both organizations – bringing new and expanded programs for patient care, research, and education in musculoskeletal disorders and orthopaedic surgery to Los Angeles and beyond. For more than a century, the OIC has provided unparalleled care for patients regardless of their family's ability to pay. Specialties include fracture care, clubfoot, scoliosis, spina bifida, and congenital limb disorders among many others.

As a multidisciplinary team, UCLA providers share their findings with each other so that treatment is collaborative and all in one place, making it more convenient for families.

**Dr. Deborah Krakow** is Professor and Chair of the Department of Obstetrics and Gynecology at UCLA. She is also Professor of Orthopaedic Surgery and Human Genetics at UCLA. She has extensive experience in human genetics, particularly in the area of skeletal disorders including OI. She is the Co-Director of the International Skeletal Dysplasia Registry (ISDR) and has seen hundreds of cases of OI through her work on the ISDR. She has been actively involved with gene discovery in various forms of OI, as well as elucidating the underlying biology associated with the disease through biochemical analyses. She currently serves on the



Deborah Krakow, M.D.

Medical Advisory Board of the OI Foundation and many other prominent national and international societies focused on musculoskeletal health.

**Dr. Renna Zahr** is the Residency Program Director for the Advanced Education in General Dentistry and Attending Faculty for the General Practice Residency in the Special Patient Care Clinic at UCLA School of Dentistry. Her clinical practice and research interests include patients with special needs, including patients with OI and dentinogenesis imperfecta, patients with a history of bisphosphonate medications, medication-related osteonecrosis of the jaw (MRONJ), and osteoradionecrosis.



Renna Zahr, D.M.D.

She has developed significant expertise in the area of OI and participates in regional and national conferences on the topic.

UCLA is proud to be a research/recruitment site for the OI Foundation's Brittle Bone Disease Consortium. The program is currently enrolling participants of all ages.

Referrals are welcome! To schedule an appointment, please call the UCLA Mattel Children's Health Center at (310) 825-0867. For information on research opportunities, please contact the Research Coordinator, Samantha Alon, at (310) 794-6420.

## Have You Listened to the OIF Podcast Series?

The OI Foundation's podcast series, *Leaders in the OI Field on New Advances in Research and Treatment*, is a part of the OI Foundation's campaign to increase outreach and educate medical professionals who treat individuals with osteogenesis imperfecta. To listen to the available episodes (listed below), visit [www.oif.org/OIFpodcast](http://www.oif.org/OIFpodcast) and stay tuned for future episodes!



### Clinical Research in the Area of OI

Brendan Lee, MD, PhD

### Gaps in Care and Information in Treating Adults with OI

Laura Tosi, MD

### Hearing Loss in Patients with Osteogenesis Imperfecta

David Vernick, MD

### Identifying New OI Genes and what they mean to Understanding OI

Eric Rush, MD

### Surgical Updates on Treating Children with OI

Richard W. Kruse, DO, MBA

### Linked Clinical Research Centers and their Effect on the Rare Bone Disease Research Community

Sandesh Nagamani, MD FACMG

### Multidisciplinary Care for the Pediatric Patient with OI

Cathleen Raggio, MD

### Pregnancy in Women with OI

Deborah Krakow, MD

### The Importance of Treating the "Whole" Person with OI

Michelle Fynan, PhD

### Pulmonary Issues and OI

Robert A. Sandhaus, MD, PhD, FCCP

### Craniofacial and Dental Issues in OI

Jean-Marc Retrouvey, DMD MSc, FRCD

### Physical and Occupational Therapeutic Strategies for Children with OI

Frances Baratta-Ziska PT, DPT, MS, PCS, C/NDT

### Physical and Occupational Therapeutic Strategies for Adults with OI

Frances Baratta-Ziska PT, DPT, MS, PCS, C/NDT

### Transitioning; Taking Charge of your Health as a Young Adult

Cory Nourie MSS, MSLP

### Spinal Issues and Basilar Invagination Whom to Screen, How to Diagnose, When to Treat

Suken Shah, MD

### Update on the Brittle Bone Disorders Consortium

Brendan Lee, MD, PhD

### Best Practices for Using Anesthesia in Patients with OI

Leelach Rothschild, MD

### A Reflection on the Status of OI Research and Clinical Care

Jay Shapiro, MD

### Disability Identity and OI

Kara Ayers, PhD

### Muscle Function in Mouse Models of OI

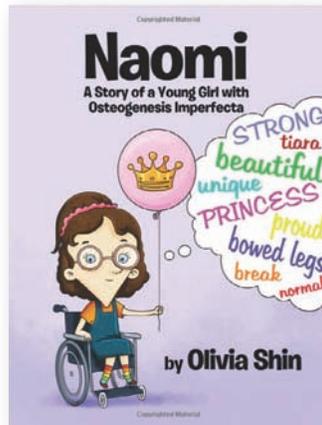
Charlotte Phillips, PhD

## Unbreakable Spirit® Community Book Club

### Naomi – A Story of a Young Girl with Osteogenesis Imperfecta

by Olivia Shin

Naomi Clark is an 8 year-old girl living with OI. Naomi, just like many other children living with OI or other limited abilities, has struggled to accept the fact that she cannot join her peers and participate in activities that could potentially be dangerous for her. Naomi's wheelchair, short stature, and blue sclera often make her feel like she just simply does not "fit-in". When she has moments of doubt, her mom, dad, and little brother Johnny come to the rescue. Through their love, support, and time together, Naomi learns very important lessons about kindness and self-compassion. This book is intended for all children, including those living OI or other disabilities, and their peers. *Naomi – A Story of a Young Girl with Osteogenesis Imperfecta* is available through Amazon.



## Patients as Teachers Project

The Patients as Teachers event was hosted by Baylor College of Medicine and Dr. Lorraine Potocki, M.D., FACMG, on September 5th in Houston, Texas. During this annual event, patients and their families take the opportunity to teach and answer questions for first-year medical students.

Patricia Gay Riggs, a 59-year-old adult with Type III OI, has participated in two class sessions. For each session, she was equipped with a packet of OIF materials designed specifically for medical professionals. Riggs said, "When introducing myself to each class, I ask, 'By show of hands, has anyone ever met or known a person with OI?' Only the moderator raised her hand. Clearly, this justifies the need for offering exposure of rare genetic conditions like OI to individuals beginning their journey in medical studies."

Medical students benefit from hearing directly from patients on topics such as pain management, historical observations for treatment, pregnancy and birth complications experienced, the best and worst experiences offered by doctors, and best communication practices with patients.

Riggs went on to say, "I deeply appreciate every opportunity to spread awareness about OI. Expanding our knowledge and building interest in solutions allows us hope for a better future. Until we connect with people directly, we will not progress."

This type of program is a great opportunity to raise OI awareness while providing future medical professionals a broader understanding about OI. Speak with your doctor or local medical school about the opportunity to participate in the 'Patients as Teachers' program.



OI community member Patricia Riggs participated in the Patients as Teachers project at Baylor College of Medicine in Houston, TX.

# Join Fellow Members of the OI Community at an Upcoming Event



With just 50,000 people affected by osteogenesis imperfecta in the United States, coming together with others in your area to support the OI Foundation is vital. The OI Foundation is very lucky to have a large number of volunteers around the country who hold fundraising events, awareness events and support group meetings. Here are some of the events being held in the upcoming months. Try to attend one near you and share our Unbreakable Spirit®!

## January

- January 24** Fine Wines Reception – Naples, FL
- January 26** Florida Support Group Meeting – Tampa, FL

## February

- February 23** 19th Annual Fine Wines Strong Bone Gala – National Harbor, MD
- February 28** Blue Jeans for Better Bones Day in honor of Rare Disease Day – Anywhere

## May

- May 4-11** National OI Awareness Week
- May 4** 3rd Annual Strong Bones Gala, Boston – Framingham, MA
- May 4** Unbreakable Spirit® Dance – Buzzards Bay, MA
- May 6** Wishbone Day – Everywhere!

Are you interested in holding awareness or fundraising events for the OI Foundation? Contact [events@oif.org](mailto:events@oif.org) for more information today!

### Follow us on social media!

-  [www.facebook.com/OsteogenesisImperfectaFoundation](http://www.facebook.com/OsteogenesisImperfectaFoundation)
-  [@OIFoundation](https://twitter.com/OIFoundation)
-  [@OIFoundation](https://www.instagram.com/OIFoundation)

New events are being added all the time. Visit the events calendar at [www.oif.org](http://www.oif.org) for up-to-date details.

## DON'T MISS OUT ON YOUR CHANCE TO



The Good Stuff Sweepstakes is an annual promotion that offers you a fun and easy way to support the OI Foundation and involve your friends and family. When you and your friends enter the sweepstakes with your suggested donation of \$5 per ticket or 25 tickets for \$100, you are making a difference!

In the past 17 years, the OI Foundation's sweepstakes campaign has raised more than \$300,000 to help the 50,000 people in the United States affected by OI. The money raised has funded vital research, scholarships to the OIF National Conference, the OI Information Center—which responds to more than 7,000 inquiries a year and generates up-to-date fact sheets, and support groups across the country.

### Return the form on the back of this page for a chance to win!

Prizes include: four park-hopper passes to the Walt Disney World Resort in Orlando, FL, with airfare for two; an all new 2nd generation Echo Show; or a \$100 Target gift card.

### All entries must be postmarked by January 11, 2019.

For more information, visit [www.oif.org/Sweepstakes](http://www.oif.org/Sweepstakes).

*No donation necessary to enter, donation does not increase chances of winning. You must be a legal resident of the United States to win.*





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**Return your entries by January 11, 2019  
or enter online at [www.OIF.org/Sweepstakes](http://www.OIF.org/Sweepstakes)**

**I WOULD LIKE**

**1 Entry (\$5)**  **5 Entries (\$25)**  **10 Entries (\$50)**  **25 Entries (\$100)** \_\_\_\_\_ **Entries (\$ \_\_\_\_\_ )**

**MY CHECK PAYABLE TO THE OI FOUNDATION FOR \$ \_\_\_\_\_ IS ENCLOSED**

**AMEX**  **DISCOVER**  **MASTERCARD**  **VISA**

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Phone Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Credit Card Number: \_\_\_\_\_

Signature: \_\_\_\_\_

Expiration Date: \_\_\_\_\_ CVV Number: \_\_\_\_\_

**Mail your entry form to:**

**The OI Foundation  
Attn: Sweepstakes  
804 W. Diamond Ave  
Suite 210  
Gaithersburg, MD 20878**

*No donation necessary to enter; donation does not increase chances of winning. To enter without a donation, please call 844-889-7579*