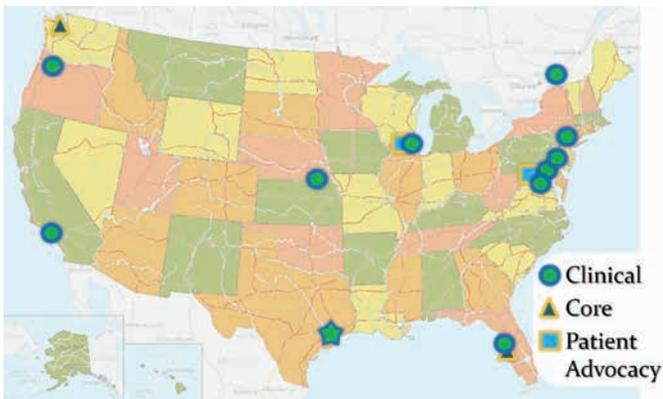


NIH Grant Funds Brittle Bone Disorders Consortium

As the lead patient advocacy organization of the Brittle Bone Disorders Consortium (BBDC), part of the NIH's Rare Diseases Clinical Research Network, the OIF is pleased to announce that the BBDC has been funded for an additional five years.

The goal of the initiative is to better understand all genetic forms of OI, expand treatment options and train the next generation of physicians and scientists to study OI. Baylor College of Medicine serves as the lead site of the 14 BBDC centers. Research sites are located across the United States and Canada.



"The formation of the consortium has been transformational in furthering OI research," said Dr. Brendan Lee, the Principal Investigator of the BBDC from Baylor College of Medicine. He added, "With this new funding we will be able to continue learning about this disorder and finding better ways to treat those who are living with it."



Dr. Brendan Lee, Principal Investigator of the BBDC

The OIF will expand on the outreach to medical professionals and constituents through the various online learning portals housed on the OIF's website as well as continue to provide opportunities for scientists and OI researchers to connect and collaborate. Visit www.oif.org and click on the Research tab to learn more about the successful work completed in the first cycle of the BBDC and information on upcoming research studies and opportunities for participation.

CELEBRATE the OIF's 50th Anniversary at the OIF National Conference in Omaha, NE!



The OI Foundation is excited for the upcoming OIF National Conference on July 9-12, 2020 in Omaha, NE! The OIF National Conference is the primary educational and social experience for families and individuals living with osteogenesis imperfecta. The three-day conference agenda is filled with information sessions on medical and practical living topics, opportunities for one-on-one medical consultations with leading OI experts, and social activities to connect OI community members from across the nation.

OIF National Conference activities will begin in Omaha, NE, on Thursday, July 9 at the Unbreakable Spirit® Walk-n-Wheel. On Day 1 of OIF National Conference (Friday, July 10) conference attendees will participate in medical consultations with OI experts, by appointment, throughout the morning and early

afternoon. Friday will also feature an hour-long introductory lecture on the Basics of OI, the much-anticipated OIF National Conference opening session, and the renowned OIF Talent Show.

Day 2 (Saturday, July 11) and Day 3 (Sunday, July 12) of OIF National Conference will consist of a plenary session for all attendees, followed by several breakout sessions in the afternoon. Topics that will be covered include Cardiopulmonary Health, Prevention and Treatments for Hearing Loss, Rodding Surgeries, Nutrition, Traveling, Independent Living Strategies, and more! On Sunday evening, the 2020 OIF National Conference will conclude with the Closing Dinner & Dance – a chance to say goodbye to new and old friends.

(continued on page 2)

CELEBRATE the OIF's 50th Anniversary (continued from page 1)

Stay tuned to the OI Foundation's website (www.oif.org/conference) for more information about the OIF National Conference program.

Programs for Children and Youth

Camp OI Childcare will be available on Saturday and Sunday for children (12 months – 12 years) who are fully registered for conference and have preregistered for childcare.

The OIF Teen Center will be available throughout the weekend for teenagers (13-18 years old) to gather, make friends, and participate in informative discussions designed for their age group.

Hotel Reservations

Conference participants must complete their OIF National Conference registration before receiving the OIF's group discounted rate of \$129 per night for one sleeping room at the Hilton Hotel.

ADA rooms are available on a first come, first served basis, and will sell out early! With every hotel, there are a limited number of ADA rooms available. Please be considerate to fellow attendees and only book an ADA room if a standard room cannot accommodate your needs. Remember, the hotel can provide you with certain items like hand-held shower heads and shower stools free of charge (but based on availability) to help make a standard room more accessible. **To book an accessible (ADA) room, contact the OI Foundation at conference@oif.org or call the OIF at (844) 889-7579.**

OIF Conference Financial Assistance

There are two sources of funding available to OI community members interested in attending the OIF National Conference:

1. *Jeanie Coleman Impact Grant Program*; covers conference registration, hotel and travel. Applications will be available on www.oif.org on January 6, 2020. For more information, contact impactgrants@oif.org.
2. *Kasper/Kendall Conference Scholarship*; covers conference registration and three nights of hotel. Applications will be available on www.oif.org/conference or by calling the OIF office in February 2020.

REGISTER TODAY! OIF National Conference 2020 registration is available at www.oif.org/Conference. If you have any questions before the next set of conference details are announced, please email conference@oif.org or call the OIF at (844) 889-7579.

Thank you to the OIF National Conference Sponsors



National Unbreakable Spirit® Walk-and-Wheel

The National Unbreakable Spirit® Walk-n-Wheel will kick-off the OIF National Conference on Thursday, July 9th! Beginning at the conference hotel, participants will walk-n-wheel a short route through Omaha to the Lewis & Clark landing on the banks of the Missouri River where we will celebrate with a finish line party.

In 2018, more than 250 members of the OI community came together for the National Unbreakable Spirit® Walk-n-Wheel in Baltimore, MD and raised nearly \$100,000 for the OI Foundation! Plan on joining your fellow OI friends and family for this fun way to spread OI awareness and raise money for the OI Foundation. Each individual who raises \$25 or more will receive an official National Unbreakable Spirit® Walk-n-Wheel T-shirt; \$50 or more will receive a complimentary ticket to Omaha's Henry Doorly Zoo to use at your convenience; and for each \$1,000 raised, you will receive a complimentary registration to the OIF National Conference!

Sign up for the 2020 National Unbreakable Spirit® Walk-and-Wheel by visiting www.oif.org/campaign/walkandwheelomaha/. Register as an individual, form a new team or join an existing team. Each team member gets their own fundraising page – personalize yours with a fundraising goal, photos, and a greeting that explains how osteogenesis imperfecta has affected you. Be sure to invite your friends and family to support you by joining your team or making a donation towards your goal.

For more information about the National Walk-n-Wheel or assistance with registering or setting up your fundraising page, please contact Melissa Bonardi at mbonardi@oif.org or (844) 889-7579.

We are Very Excited to Introduce the 2020 OIF National Unbreakable Spirit® Walk-n-Wheel Co-Chair, Stephanie Greenwood!

Stephanie led one of the top fundraising teams at the 2018 National Unbreakable Spirit® Walk-n-Wheel in Baltimore, MD. She has agreed to share her experiences and help inspire fellow members of the OI community to participate in the upcoming walk-n-wheel to help spread awareness of OI in our host city, Omaha, Nebraska, while raising money for the OI Foundation.

Hello, OI Family! My name is Stephanie Greenwood. I am mom to two amazing kids, Jude and Harper Guin, ages 12 and 9, and Co-Chair of the 2020 Walk-n-Wheel event. We live in Leawood, KS, just outside of Kansas City, MO. My daughter, Harper, was born with type IV OI, and is currently in the third grade. Some of you may have seen or met us before at conference. We have attended the past four: D.C., Indianapolis, Orlando, and Baltimore. Harper has also performed in the talent show at the last two conferences. (This is something that I NEVER dreamed she would do when our family first heard the terms, "Osteogenesis Imperfecta, Skeletal Dysplasia and Brittle Bones" before Harper was born.) We are super excited that the 2020 conference will be just a three-hour car ride away from us here in the Midwest in Omaha, Nebraska. (This is also going to allow more of Harper's family to attend for the first time, which she is excited about!) We hope to see many familiar faces again this coming summer and make lots of new friends too!

At the last conference in Baltimore, Harper, Jude and I decided to participate in the Walk-n-Wheel event for the first time. We weren't really sure what to expect from it, but we ended up raising a decent amount of money for the OIF, and just had a ball getting to parade down the street, and celebrate at the end with our OI family, medical professionals, and friends! I distinctly remember Harper and Carter Brown chanting, "We have OI, we're proud, and we're not afraid to show it!" holding up their team name posters by the Baltimore Aquarium. Jennifer Brown (Carter's mom) and I looked at each other with huge smiles on our faces when we saw that! It was just a special and proud moment to see our kiddos enjoying this effort and celebrating who they are. I encourage you and your family to take part in the next one in Omaha. You won't regret it!

Now, obviously this is a fun and social activity that we get to participate in—and that in and of itself is extremely rewarding—but it has a much larger purpose: to raise money for the OIF. By joining in this effort together, we can collectively raise awareness of this rare condition, and help improve the lives of our loved ones with OI. I do know fundraising can be something that some folks can be apprehensive about. Asking people for money is not always a comfortable or natural thing to do. The great thing with this cause is that we are personally connected to it and passionate about it. All you have to do is share your story and speak from the heart about why you are participating in the event. That's really it. You can do this via email, various social media platforms, text, phone call, or a combination of any or all of these options. The OIF has an extremely user-friendly platform for you to use for this. Another thing that you might find interesting is that when you ask someone to help you out, it is scientifically proven that it makes them actually like you more,

and not the other way around! So this can be a great relationship builder too.

For those of you who don't know us, I would like to share just a little bit more about Harper. Today, Harper is a thriving nine-year-old with a delightful disposition, excels at school, swims, and takes dance class. Before she was born, Harper was diagnosed with OI by

amniocentesis in the womb at 32 weeks gestation. Her genetic mutation is consistent with type IV OI. Harper's father and I were told that we most likely had a "lethal" pregnancy at twenty weeks gestation when we went to find out our baby's gender and a broken femur was visible on ultrasound. Well that ended up healing before Harper was born along with six other fractures, and she didn't break at birth. In fact, Harper has only had five major breaks in her nine years which have really all been her femurs. (She has had about twice as many micro fractures.) Harper has received bisphosphonate infusions (first Pam and now Zol) since she was eight days old, and does have Fassier-Duval rods in her femurs. She actually just had her third set placed in both femurs this past summer by Dr. Esposito in Omaha, and she was just able to start her dance classes back up again this past week. (Harper receives care at the Omaha Children's Hospital and at Children's Mercy in Kansas City.) I am thrilled to be co-chairing the Walk-n-Wheel event with Dr. Wallace, our dear friend and part of our wonderful Omaha care team!

We would be delighted if you and your family would join us this year and participate in the 2020 Walk-n-Wheel. If you have any questions or need help getting started please reach out to me. I can be reached by phone, email, or messenger. Have a great finish to your 2019, and we hope to see many of you in Omaha 2020!

Warmly,

Stephanie Greenwood
sgreenwood@entigreat.com
913.486.9080



Stephanie with her children, Jude and Harper

National Osteogenesis Imperfecta Awareness Week is May 2-9, 2020!

National OI Awareness Week is a week dedicated to raising awareness for OI and sharing your Unbreakable Spirit®. OI Awareness Week is scheduled around **Wishbone Day** (May 6), the international OI Awareness Day. The OI community celebrates Wishbone Day by wearing yellow and by sharing facts and information through social media.

Make the most of National OI Awareness Week 2020:

Proclaim OI Awareness Week in Your State

Each year, our goal is to proclaim National OI Awareness Week in every state! Help us proclaim OI Awareness Week nationwide by requesting a proclamation for your state. For more information, visit www.oif.org/AwarenessWeek or contact Danielle at dcyember@oif.org.

Like, Share & Retweet

“Like” the OI Foundation on Facebook or “Follow” the OIF on Twitter. Help us raise OI awareness online by liking and sharing our #SHAREforAWARENESS posts on your Facebook and Twitter pages during OI Awareness Week.

Host a Fundraiser

Blue Jeans for Better Bones – Get your school, office, or community involved in National OI Awareness Week – it’s as easy as throwing on a pair of blue jeans!

Bone China Tea – Our favorite phantom event allows you to join your fellow OI community members for a cup of tea, no matter where you live. Simply invite your guests to enjoy a relaxing cup of tea at home and then make a gift to the OI Foundation with the money they may have saved by not going out to a live event.

For more information about getting involved in National OI Awareness Week 2020, visit www.oif.org/AwarenessWeek.



OI community members celebrating Wishbone Day during National OI Awareness Week 2019

Four Regional Conferences, One Unbreakable Spirit®

In 2019, the OI Foundation met hundreds of new and long-time community members at Regional Conferences across the country. In Chicago, IL; Atlanta, GA; Sacramento, CA; and Wilmington, DE, we collaborated with physicians and institutions to bring expert medical knowledge and care to OI community members across the United States. In sessions on understanding, managing, and treating osteogenesis imperfecta, attendees and medical professionals discussed the latest breakthroughs, broke down misconceptions, and learned how to improve their quality of life.

2019 Regional Conferences by the numbers:

- ▶ 4 Regional Conferences
- ▶ 39 Sessions, Panels, and Roundtables
- ▶ 44 Speakers
- ▶ 340 Attendees from over 30 States
- ▶ 11 Hospitals and Medical Systems Represented
- ▶ 1 United *Unbreakable Spirit*®

Thank you to all who attended an OIF Regional Conference during 2019!



OIF Regional Conference in Chicago, IL



OI community members at the Halloween Social in Wilmington, DE



OIF Regional Conference speakers and members of the Nemours OI Team at the OIF Regional Conference in Wilmington, DE



Attendees at the OIF Regional Conference in Sacramento, CA

Celebrating Our Unbreakable Spirit®!

The 2019/2020 Fine Wines Strong Bones calendar kicked-off with a great start at the annual Beef & Brew for Better Bones in Garfield, NJ. Thank you to committee members Jo Ann Berkenbush and Gretchen Strauch for bringing together members of the OI community in New Jersey for this event. With nearly 80 raffle items, the event raised more than \$12,000 for the OI Foundation and \$3,000 towards the Kasper Kendall Scholarship Fund to help families attend the OIF National Conference.



Committee member Gretchen Strauch at Beef and Brew 2019



New Jersey Support Group members at Beef and Brew 2019

Next, we came together in Houston, TX, for the 3rd Annual Boots & Bling for Better Bones at the Armadillo Palace. The nearly 200 attendees had a rocking good time thanks to the music of Weldon Henson. Guests enjoyed made-to-order guacamole, legendary Goode Company barbeque, and pecan pie while hearing remarks from OI mom Zarina Rasheed. Thank you to those who attended and helped raise nearly \$100,000 for the OI Foundation!

We hope to see you at an upcoming OIF event!



OI community members at Strong Bones Houston



Strong Bones Houston attendees enjoyed live music by the Weldon Henson Band

Save the Date – Fine Wines Strong Bones are coming up around the country!

Fine Wines Naples, FL

January 30, 2020

Join Teresa & Ken Gudek, Andrea & Jeff Stewart, and Jane & Jim Early at the Naples Yacht Club for an evening of wines from around the world, light fare, silent auctions, raffles, and great company as we raise OI awareness in Naples, Florida. Tickets are available now at www.oif.org/FineWinesNaples.

Fine Wines Strong Bones DC

February 22, 2020

Celebrate the OI Foundation's 50th anniversary with an evening of glitter and gold at the 20th annual Fine Wines Strong Bones Gala at the Gaylord National Resort. Enjoy an evening of cocktails, casino games, raffles, auctions, and more! Buy a table for ten and bring your friends to celebrate 50 years of the OI Foundation. Tables and individual tickets are available at www.oif.org/FineWinesDC.

Visit the upcoming event page at www.oif.org/events to get up to the date information on upcoming receptions, purchase tickets and volunteer to join a committee.

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FOUNDATION

NOVEMBER 9TH 2019

WWW.ECHOPARK.COM

The poster features a green-tinted background image of a group of people smiling and holding up a white t-shirt. The text is overlaid in white.

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FOUNDATION

NOVEMBER 9TH 2019

WWW.SONICAUTOMOTIVE.COM

The poster features a red-tinted background image of a car driving on a road with people in the back seat. The text is overlaid in white.

Support the Work of the OIF as We Celebrate 50 Years

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 OIF recently sent out a letter from OIF CEO Tracy Hart about the progress of the OI Foundation over the past year.

For five decades the Osteogenesis Imperfecta Foundation has been providing the OI community with information and resources. And, on the eve of the OIF's 50th Anniversary we are asking for your support to help us continue this important work.

This summer, the OIF will celebrate its 50th anniversary. In 1970, a group of OI parents led by Gemma Geisman came together to share their experiences with OI and their vision to create an organization where families and individuals could come together to learn, drive research, and form a community that would change lives. Fifty years later, the OI Foundation is responding to more than 11,000 requests for information each year, funding more OI research than ever before, and serving as the voice of the OI community with researchers and medical professionals. The OIF has come so far in fifty years, but there is still so much work left to be done and we need your help!

Please help us continue this important work by making a gift today online at www.oif.org or by using the enclosed envelope.



OI community members coming together at OIF National Conference

OI | REGISTRY

Because Your Information Matters

Join the OI Registry

Supporting OI research is an important part of the OI Foundation's mission. Often, the success of clinical studies of a rare disorder like osteogenesis imperfecta (OI) depends on getting enough people to participate in the study so the results are meaningful. Individuals with OI (18 and older) and parents of children with OI are encouraged to join the OI Registry. The OI Registry is a database of individuals with OI who are interested in participating in OI research. Once you are enrolled, you will begin to receive information on upcoming studies and online surveys about OI. Your participation in these studies helps move OI research forward.

To join the OI Registry, visit www.oif.org/currentstudies. If you have any questions, please contact the OI Foundation at bonelink@oif.org or (844)889-7579.

Resource **REMINDER** Materials for Adults with OI

The *Take Charge of Your Health* tool kit is designed to help adults partnering with their doctors to lead healthy lives. The materials include a Pocket Guide available from the OIF online store and a set of fact sheets that are posted on the OIF website at www.oif.org/factsheets.

If you would like to receive a hard copy of these materials, please email Bonelink@oif.org or call the office at (301) 947-0083.

OIF Board of Directors Nominations

The OI Foundation is currently seeking nominations for new members of the OIF Board of Directors. The Board Development Committee looks for nominees with qualities such as a personal connection to OI and experience in areas including accounting, finance, fundraising, organizational management, public relations, strategic planning, business, and/or law.

If you or someone you know is committed to achieving the mission of the OI Foundation please fill out a nomination form at www.oif.org/board by January 17, 2020.



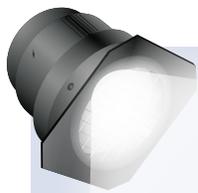
Former OIF Board President Ken Gudek and OIF Board member Jim Early at the Annual OI Golf Classic

It's Time to Get Your Flu Shot

This is the time of year to talk to your doctor about whether you or your child should receive the flu and/or pneumonia vaccine. Unlike other vaccinations, the flu vaccine must be given every year.

Viral infections like colds or the flu, and bacterial infections such as bronchitis or pneumonia are common respiratory problems. Even when lung problems are not directly caused by OI, experience tells us that these infections can be more severe in people who have OI.

Getting enough rest, hand washing, and avoiding people who are ill are other ways you can protect your health during the cold and flu season.



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 at www.oif.org/ClinicDirectory.

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 **Skeletal Dysplasia & Bone Health Clinic at Phoenix Children's Hospital**.



Phoenix Children's Hospital in Phoenix, Arizona, is a tertiary care center that features centers of excellence in every specialty. It has provided family-centered care for children and their families since its creation in 1983, and has a medical staff of nearly 250 specialists. It also was named one of the Best Children's Hospitals in all ten specialties by U.S. News since 2016 until today. It is also one of only twelve children's hospitals named in the Leapfrog Group's website for patient safety.

Phoenix Children's Hospital has a multidisciplinary team of physicians who work with people with OI in their Skeletal Dysplasia & Bone Health Clinic to bring specialized, comprehensive care that addresses each of their patients' healthcare needs. The Bone Health Clinic currently sees 87 people with OI, but many other children with OI are seen in the individual subspecialty clinics.

Their core group of highly trained medical professionals specialize in the following areas: pediatric orthopedics, neurosurgery, medical genetics, and endocrinology. They also work closely with pediatric physicians and care providers who are specifically qualified to treat patients with skeletal dysplasia. These experts come from a variety of departments within the Hospital, such as: anesthesia, pulmonary, ear, nose and throat (ENT), neurosurgery, and radiology.

At Phoenix Children's Hospital, the orthopedists and neurosurgeons work together to provide care for upper,

lower extremity and spine related issues. The physicians in the bone health clinic have received special training from institutions such as The Shriners' Hospital for Children, Montreal and the Shriners' Hospital for Children, St. Louis (Center for Metabolic Bone Disease and Molecular Research) in working with children with OI.

Currently, there are many services that the clinic provides to people with OI, including: individual specialty evaluations, routine bone density scans, monitoring for spine changes, administration of bisphosphonate infusions, nutrition counseling, and other aspects of multi-disciplinary care.

The physicians at Phoenix Children's Hospital are proud to work at a facility that focuses on the needs of the child and of the family, and are guided by the Hospital's mission to provide hope, healing, and the best healthcare for children and their families.

In addition to their clinic, the Phoenix Children's Hospital is also excited to be hosting an Osteogenesis Imperfecta Foundation Regional Conference on March 7, 2020. For any questions about the meeting, please contact Michael Stewart, OIF Regional Program Services Manager, at mstewart@oif.org.

To contact Phoenix Children's Hospital about their services, please call 602-933-3033.



Phoenix Children's Hospital



Dr. Madhia Shahid, Dr. Kristin Lindstrom, Dr. Pamela Smith, and Dr. Mohan Belthur



INFORMATION CENTER



Check Out Our New Look!

This fall, the OI Foundation launched its newly redesigned website. As the only voluntary national health organization dedicated to supporting families living with OI, it's our goal to provide information in an easily accessible format for OI community members, medical professionals, and caregivers. Visit us at www.oif.org!

The OI Foundation's online Information Center includes introductory information about OI, OI publications, podcast, and factsheets. The OI Foundation's online Information Center is available at www.oif.org/informationcenter.

OIF Informational Fact Sheets

Educational resources on a wide-range of OI-related subjects are available on the OIF website. For example, the "Fast Facts about OI" factsheet is a useful document to share with family and friends. This factsheet covers introductory information on OI including definition, prevalence, diagnosis, clinical features, types, inheritance factors, treatments, and prognosis.

OIF Publications

The OIF Publications section of the OIF Information Center provides books and brochures for OI community members, caregivers, and medical professionals. The brochure *Introduction to Osteogenesis Imperfecta* serves as a guide for medical professionals, individuals, and families affected by OI. The brochure provides information for multiple audiences by providing an in-depth understanding of OI including a description of OI types, genetics, OI treatment options and more. This may be great resource to share with your doctors, and other people in your life who would like to learn more about OI.

OIF Podcast Series

The Audio/Video Learning Center houses the OIF Podcast series: Leaders in the OI Field on New Advances in Research and Treatment. These podcasts feature OI experts discussing an OI-centered topic in their respective fields. Topics include research, physical and occupational therapy techniques, disability identity, rodding surgery, and more.

If you are ever in need of help locating OI information or resources, please contact the OI Foundation at bonelink@oif.org.

Build Your Medical Care Team

OI Clinic Directory

The OI Foundation recognizes that one of the difficulties that many OI community members face is finding a team of medical professionals who are familiar with working with this disorder. The OI Clinic Directory provides you and your family with accurate, verified, and easily accessible information to assist you in locating dependable multidisciplinary medical care. All information included in the directory is provided by a representative of each clinic. View the OIF Clinic Directory at www.oif.org/clinicdirectory.

Our clinic directory is under constant expansion. To be listed in the 2019 OIF Clinic Directory, a program must have coordinated interdisciplinary care for children and/or adults with OI. If you are a staff member or medical professional, and are interested in having your clinic listed, contact us. For further information on the clinic directory listing process, feel free to email us at bonelink@oif.org.

OIF Physician Directory

The OI Foundation maintains a list of medical professionals of varying specialties with experience with OI. The OIF Physician Directory lists medical professionals throughout the United States and Canada. Please be mindful that availability of medical professionals varies based upon location. If you would like the contact information for medical professionals in your area, contact us via phone or email at bonelink@oif.org.

Tell us about your healthcare team! Please contact us if you feel that any members of your team would be a helpful addition to our current database of medical professionals. If you would like your doctor, orthopedic surgeon, physical therapist, endocrinologist, or any member of your healthcare team included – contact us via phone or email at bonelink@oif.org.

OIF Patient-led Listening Session at the U.S. Food and Drug Administration (FDA) 09/17/2019

Objective of Session

The objectives of the session were to discuss with the U.S. Food and Drug Administration (FDA) the impactful symptoms of osteogenesis imperfecta (OI), the experience of living with OI, as well as the impacts that current treatments have on daily life. Lastly, the group wanted to discuss the importance of including endpoints other than fracture in future research.

Summary of Topics Discussed

Symptoms Important to People with OI

- **Fractures:** Fracturing bones are one of the hallmarks of OI. Although it was the goal of the group to encourage future research to include other endpoints in research, fracture is still important. Fractures cause people with OI to miss time from their lives and cause pain.
- **Pain Management:** People with OI experience both acute and chronic pain. Our group expressed the importance of finding treatments that can address both kinds of pain.
- **Mobility:** The group emphasized that people with OI can have a wide range of mobility needs day-to-day. They also identified that after a fracture, it is important to regain mobility as quickly as possible so that they can return to work, to taking care of their families, and to be able to get back to their normal routine.
- **Early Mortality:** Our group wanted to emphasize that we are losing members of our community early. We also addressed concern for lack of research and treatment options for adults that currently exist.
- **Pulmonary Issues:** The primary respiratory problem for people with OI is loss of lung capacity, but can also include problems such as sleep apnea. We emphasized the need for more research in the area of respiratory issues and OI.
- **Cardiovascular Issues:** The cardiovascular effects of OI are currently severely understudied in research, but are essential. The group emphasized that cardiovascular issues need to be studied to lower the early mortality rate.
- **Dental Issues:** Brittle teeth are seen in 50% of people who have OI. Dental care was extremely important to the group. The cost of dental care alone is a huge burden to our community, let alone trying to find research to inform dental care. The group also identified the need for increased research regarding dental implants for people with OI.
- **Hearing Loss:** Hearing loss may begin in the early 20's and by middle age in more than 50% of people with OI. Our group discussed how the anxiety of not knowing if someone will lose their hearing is important to them.

- **Anxiety and Mental Health:** Having severe fractures or not knowing when the next fracture will occur can negatively affect people with OI. Along with fracturing, healing time spent away from friends and family can have negative mental health effects.

Life Events Important to People with OI

- Having healthy pregnancies.
- Living an active life with OI.
- Having access to aids for school and sports.
- Healing time to decrease so that people may return to work and taking care of their families faster.
- Having access to clinicians with expertise in OI.
- Increasing expertise in the treatment of Dentinogenesis Imperfecta to address dental issues.

Research Endpoint Selection

- It can be difficult to make decisions clinically based on the variance of OI.
- Future research should consider a variety of endpoints, not just fracture, to fully address the multi-system needs of people with OI.
- The standard of care has evolved greatly with bisphosphonates and orthopedic rods, but there is more work to do.
- More research needs to be conducted for adults with OI. It will be critical moving forward that more longitudinal information about people with OI is collected so that the appropriate protocols can be developed.
- The OI Foundation, in partnership with the Brittle Bones Disorders Consortium, is working on collecting data on the Natural History of OI.



Participants of the OIF panel at the FDA Listening Session

Partner Organization

The Osteogenesis Imperfecta Foundation (OI Foundation) worked directly with the FDA to prepare this meeting. The OI Foundation paid for the travel and accommodation of the community members that attended the meeting.

FDA Divisions Represented

Office of the Commissioner

Patient Affairs Staff (*organizer*)
Office of Clinical Policy and Programs
Office of Orphan Products Development

Center for Drug Evaluation and Research

Office of New Drugs
Office of New Drugs/ Office of Drug Evaluation III/ Division of Bone, Reproductive and Urologic Products
Office of Translational Sciences/ Office of Biostatistics/ Division of Biometrics II
Office of Translational Sciences/ Office of Biostatistics/ Division of Biometrics III

Disclaimer

Discussions in FDA Rare Disease Listening Sessions are informal. All opinions, recommendations, and proposals are unofficial and nonbinding on FDA and all other participants. This report reflects the Osteogenesis Imperfecta Foundation's account of the perspectives of patients and caregivers who participated in the Rare Disease Listening Session with the FDA. To the extent possible, the terms used in this summary to describe specific manifestations of osteogenesis imperfecta, health effects and impacts, and treatment experiences, reflect those of the participants. This report is not meant to be representative of the views and experiences of the entire osteogenesis imperfecta patient population or any specific group of individuals or entities. There may be experiences that are not mentioned in this report.

Center for Biologics Evaluation and Research

Office of the Center Director
Office of Tissues and Advanced Therapies / Division of Clinical Evaluation & Pharmacology/Toxicology
Office of Tissues and Advanced Therapies / Division of Clinical Evaluation & Pharmacology/Toxicology/ General Medicine Branch I

Patients Represented

Out of the nine participants, seven were people with OI, three people were parents of a child with OI, two people were a spouse of someone with OI, and one who is a physician who sees children with OI.

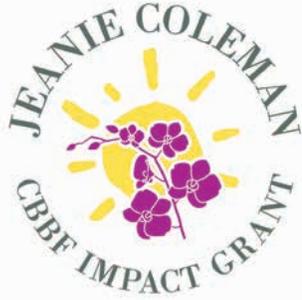
PCOR in Action: Incorporating the Community in the Study of Osteogenesis Imperfecta

For years, research in OI has been about what doctors found important and researchers rarely asked the OI community about what mattered to them. This all changed when researchers began doing “patient-centered outcomes research” – studies that are focused on what patients found important. The first step in this process was having a conversation with the OI community to understand the condition and how it affects daily living. After all, who understands OI better than people with OI?

In 2017, members of the OI community and researchers gathered in Oslo, Norway for the International Conference on OI. They had conversations about health concerns, how well

doctors understood OI, and what the OI community wanted researchers to study. Even though doctors were focused on broken bones, the OI community said that they cared more about issues with breathing, hearing, and aging (among many other concerns). They also said that doctors did not understand OI well enough to provide them with the care they needed. In terms of research, the OI community explained that although they had participated in research, nobody was sharing the results with them. They wanted researchers to keep them involved, instead of just using them for surveys.

The conversations in Oslo showed researchers that they need to give the OI community a voice in research. This was a great first step in creating a better relationship between the OI community and researchers, and will hopefully lead to information that will improve quality of life for people with OI. For more information on the Oslo discussions, you can find it on www.oif.org/pcor listed under Additional Readings about PCOR.



Jeanie Coleman Impact Grant Program – Applications Available January 6, 2020

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 6, 2020 at www.oif.org/ImpactGrant until February 12, 2020. Please contact Impactgrants@oif.org if you have any questions.

Rare Bone Disease TeleECHO Clinic Series

The OI Foundation and the Rare Bone Disease Alliance are excited to announce the Rare Bone Disease TeleECHO Clinic Series. The goal of the program is to build capacity in the medical community to safely and effectively diagnose and treat rare bone diseases and disorders. Five sessions have been held with positive feedback from the attendees. Sessions are held on the first Thursday of every month. For more information about the series, to listen to past sessions, or to register for an upcoming session, please visit www.oif.org/ECHO or contact Michael Stewart at mstewart@oif.org.



OI Foundation Good Stuff Sweepstakes

Win one of these amazing prizes while supporting the OI Foundation



Watch over your home and answer the door from your phone, tablet and PC with the Ring Video Doorbell 2. With Ring, you can see, hear and speak to visitors from anywhere. *Valued at \$200.*



Four (4) full registrations to the OI Foundation's National Conference in Omaha, NE from July 9-12, 2020 as well as one hotel room for three (3) nights at the Hilton Omaha. *Valued at \$1,500.*



Treat yourself to the good stuff of your choice. The American Express Gift Card can be used wherever American Express debit and credit cards are accepted. *Valued at \$100.*

By entering the Good Stuff Sweepstakes, you are helping the OI Foundation produce new information resources, fund research, provide answers to more than 7,000 requests for information per year, and facilitate support groups across the country. Thank you for your support and GOOD LUCK!

Go to www.oif.org/sweepstakes to enter before January 10, 2020

Join 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 30 Fine Wines Reception – Naples, FL

February

February 22 20th Annual Fine Wines Strong Bone Gala – National Harbor, MD
February 28 National Blue Jeans for Better Bones Day
February 28 Rare Disease Day

March

March 7 OIF Regional Conference – Phoenix, AZ

May

May 1–3 Medics on the March – Washington, DC
May 2–9 National OI Awareness Week
May 9 3rd Annual Unbreakable Spirit® Dance – Buzzards Bay, MA

July

July 9 National Unbreakable Spirit® Walk-n-Wheel – Omaha, NE
July 10–12 OIF National Conference – Omaha, NE

New events are being added all the time. Visit the events calendar at www.oif.org/events for up to date details.

Are you interested in holding awareness or fundraising events for the OI Foundation? Contact events@oif.org for more information today!

Follow us on social media!



Osteogenesis Imperfecta Foundation



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Omaha, NE

JULY 9-12, 2020



REGISTER TODAY AT WWW.OIF.ORG