

OI Foundation Approved for Engagement Award for Project on Improving Patient-Centered Outcomes

The Osteogenesis Imperfecta Foundation (OIF) has been approved for a funding award through the Eugene Washington PCORI Engagement Awards (Engagement Awards) program, an initiative of the Patient Centered Outcomes Research Institute (PCORI). PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work. The funds will support bringing together stakeholder groups on equal footing to identify and fill knowledge gaps, prioritize questions to be

addressed with research, and return discoveries to the entire OI community to support collaborative decision making and improve health outcomes.

To learn more, read the *PCOR in Action* article on page 2 of this newsletter or visit

www.oif.org/PCOR

Stay tuned for more information about this exciting project!



OIF Medical Advisory Council member and lead of the OIF's PCOR Project, Dr. Laura Tosi

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

The OI Foundation has started gearing up for the next OIF National Conference, which will be held at the Hilton Hotel in Omaha, NE, on **July 9-12, 2020!** The OIF National Conference is the premier educational and social experience for families and individuals living with osteogenesis imperfecta. More than six hundred members of the OI community come together for each

biennial National Conference. The three-day program boasts a schedule full of information sessions on medical and practical living topics, opportunities for one-on-one medical consultations with leading experts in OI research, and an abundance of additional activities designed to address important issues for members of the osteogenesis imperfecta community.

What to look forward to at OIF National Conference 2020:

- National Unbreakable Spirit® Walk-and-Wheel
- OIF Talent Show
- Programs for Children and Youth
- Meet-and-Greet Events
- Informational Sessions on Managing Pediatric and Adult OI Care
- OIF's 50th Anniversary Celebration



CELEBRATE
2020 OIF National Conference ★ Omaha, NE

We can't wait to see everyone at the 2020 OIF National Unbreakable Spirit® Walk-n-Wheel on Thursday, July 9, 2020 in Omaha, Nebraska!

Below is a note from OIF National Unbreakable Spirit® Walk-n-Wheel Co-Chair, Dr. Maegen Wallace.



My name is Maegen Wallace and I am a pediatric orthopaedic surgeon and the director of the OI clinic at Children's Hospital & Medical Center in Omaha, Nebraska. I am very excited to have the OI community coming to Omaha in July 2020 for the biennial National Conference and to be one of your co-chairs for the 2020 OIF National Unbreakable Spirit® Walk-n-Wheel!

This past spring, I had the honor of participating in the first Medics on the March where I joined 15 members of the OI medical professional community to walk 50 miles to raise funds and awareness for OI. I was unsure how responsive people would be to the fundraising campaign, but I was overwhelmed by the generosity of my families and friends.

When fundraising, people are more likely to give generously if it is a cause you are passionate about. So when you set up your team page from the templates available, make sure to include your personal story. When I participated in the Medics on the March fundraiser, friends and family were more than willing to donate to help me reach my fundraising goals once they knew how big of a role OI played in my life. I am honored to care for children with OI and excited to be a part of this event to raise awareness and funds for the OI Foundation! All funds raised go towards the OIF being able to continue doing amazing things to support the OI community. I hope you will join me!

See you in Omaha!

Dr. Maegen Wallace

We hope you plan to join Dr. Wallace for this fun kick-off to Conference! More details about the National Unbreakable Spirit® Walk-n-Wheel will be available at www.oif.org/walkandwheelomaha.

Sponsorships

If you are interested in supporting or locating sponsorships for the 2020 OIF National Conference or the National Unbreakable Spirit® Walk-N-Wheel, please contact Erika Carter at ecarter@oif.org.

STAY TUNED for more details!

Information will be shared on www.oif.org/conference as it becomes available. Mark your calendars and start making your plans now! 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.

PCOR In Action

The goal of patient-centered outcomes research (PCOR) for OI is to provide doctors and care providers with information that is relevant to the needs of the OI community. This allows clinicians to provide better care and empowers the OI community to advocate for themselves. Until recently, OI research has been focused on fractures, but the characteristics of OI go beyond bone and includes ear, lungs, eye, and heart problems. PCOR filled this gap in, addressing the needs of the OI community that have previously gone unheard.

For example, researchers looked at a group of more than 200 individuals with OI, measuring their lung function. They found that individuals with severe OI had more airway impairment

than the general population. They recommended that doctors include a respiratory assessment as part of routine first visits, and also recommended vaccinations to prevent lung infections. This is a great example of how research interests that are based on the needs of the OI community can result in informed, improved care.

Tam A, Chen S, Schauer E, Grafe I, Bandi V, Shapiro JR, et al. A multicenter study to evaluate pulmonary function in osteogenesis imperfecta. Clin Genet. 2018 Dec;94(6):502-511. doi: 10.1111/cge.13440. Epub 2018 Sep 24. PubMed PMID: 30152014; PubMed Central PMCID: PMC6235719.

Thank you for Helping Us Raise OI Awareness Across the Nation!

Each year during National Osteogenesis Imperfecta Awareness Week, the OI Foundation, OI community members, and supporters come together to raise OI awareness across the nation. We are so thankful for the OI community members who requested official OI Awareness Week proclamations, held OI awareness events, and used social media to raise OI awareness!

For more information about National OI Awareness Week, www.oif.org/AwarenessWeek.



THANK YOU FOR PARTICIPATING IN NATIONAL OI AWARENESS WEEK 2019!



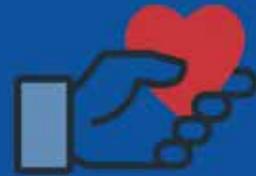
16

OI Awareness Week Proclamations



200,000

People reached via social media



61

Facebook fundraisers



Fine Wines Strong Bones Events

Ranging from intimate gatherings to large-scale ballroom affairs, Fine Wines Strong Bones are the OI Foundation's flagship fundraisers. Fine Wines Strong Bones receptions and galas are held annually in various cities across the United States, and are a perfect occasion for communities to come together to show their support, raise money, and promote OI awareness—all while enjoying a fantastic night out! In the past year, these events have collectively raised nearly \$450,000 to further the OI Foundation's mission of serving the OI community—proceeds that help us to fund research, produce new resources, facilitate support groups, and provide assistance to deserving individuals and families. We would like to extend a special thanks to our event committees, sponsors, and attendees for the all of incredible support they have shown us in 2018-2019.

Fine Wines Strong Bones Events: Spring 2019

On April 23rd, we gathered at the prestigious Sotheby's Auction House in Manhattan for the **2019 Fine Wines Reception New York City**. Guests sampled light fare and fine wines, participated in silent auctions, and took an exclusive after-hours look at an amazing exhibit—all while showing support for the OI community!

Thanks to Christine Rossi, Laura Minucci, and the rest of their hard-working host committee, the **3rd Annual Strong Bones Gala Boston** was a night to remember! Held on May 4, the Kentucky Derby-themed evening featured raffles and games, silent and live auctions, and even a contest for the best Derby hat! Everyone had a great time supporting the work of the OI Foundation at the Sheraton Framingham.

We had a great time at the **2019 Strong Bones Tampa** on June 1! Held at the historic Italian Club of Tampa in the Ybor City neighborhood, this exciting evening featured raffles, silent and live auctions, and delicious food from Tony's restaurant!



Attendees arrive at the 2019 Strong Bones Tampa



Attendees at Strong Bones Tampa browse the silent auction



The Strong Bones Boston 2019 Host Committee show off their Kentucky Derby attire



Strong Bones Tampa attendees hit the dance floor

Upcoming Fine Wines Strong Bones Events of 2019 & 2020

With summer winding down, we are very excited to announce some of our upcoming Fall 2019 and Winter 2020 Fine Wines Strong Bones events!

Beef and Brew for Better Bones will be held on October 19 in Garfield, New Jersey! Get to know fellow OI community members from the area over a delicious beefsteak dinner. As one of the OI Foundation's longest-running fundraising events, this is surely one you don't want to miss.

Boots and Bling for Better Bones is returning to the Armadillo Palace in Houston on November 9! Come join us again for award-winning BBQ, fun-filled entertainment, silent and live auctions, raffles, an open bar, and a chance to show your support for the OI Foundation!

The **Fine Wines Reception Naples** will be celebrating its fifth anniversary in January. This Naples, FL event is an intimate reception, where guests can socialize, sample light fare and fine wines, and participate in silent and live auctions for the OI Foundation.

Our Washington, D.C. **Fine Wines Strong Bones Gala** is coming back to the beautiful Gaylord National Resort in February for its 20th anniversary, and will kick off the OI

Foundation's 50th anniversary celebrations! We hope you'll join us for a night of casino games, silent and live auctions, raffles, dinner, an open bar, and an amazing program in support of the Jamie Kendall Fund for OI Adult Health.

Strong Bones Tampa will be held again in Spring 2020! Gather with members of the OI Support Group of Florida for a night of fun, including raffles, silent and live auctions, and dinner from Tony's Restaurant in Ybor City. We can't wait to see you again soon, Tampa!

The next **Strong Bones Gala Boston** is also coming up in Spring 2020! Don't miss out on this amazing evening out in Framingham—there will be casino games, silent and live auctions, raffles, dancing, dinner, an open bar, and a photo booth! We hope we see you there.

More details and tickets for all upcoming events will be available soon! For up-to-date information, please visit www.oif.org/FineWinesStrongBones.

Interested in attending an event in your city, but don't see any listed? If you are interested in hosting an event or suggesting a new Fine Wines Strong Bones location, please contact Melissa Bonardi at mbonardi@oif.org or 301-947-0083.

OIF Regional Conferences; Uniting Unbreakable Spirits

This August, the OI Foundation was proud to host Regional Conferences in Atlanta, Georgia and Sacramento, California! At each event, speakers covered topics on understanding, treating, and managing osteogenesis imperfecta. These events also provide community members opportunities to meet new members of the OI community and connect with old friends.

Regional Conferences are impossible without all of the dedicated volunteers, physicians, attendees, and families that support them. Thank you for your support, and we look forward to serving you

in the future! The OI Foundation would also like to thank Dr. Jill Flanagan and her team at Children's Healthcare of Atlanta for their support in Atlanta and to all of the doctors and organizers involved with the Regional Conference in Sacramento, CA.

Interested in attending a future OIF Regional Conference? The OI Foundation will be hosting a Regional Conference with Nemours/Alfred I. DuPont Hospital for Children in Wilmington, Delaware on October 25-26. More information can be found at www.OIF.org/regionalconferencewilmington2019.



OIF Regional Conference in Atlanta, GA

Medics on the March Raises Awareness for OI

Many of the OI community's most dedicated supporters are the OI expert physicians and medical professionals who serve on the OIF medical advisory council and lead OI clinics across the U.S. and Canada. On Friday, April 26, 2019, a group of these medical professionals gathered in Harpers Ferry, West Virginia, to start an extraordinary journey. Over the next three days, they travelled 50 miles and spent two nights camping in an effort to raise awareness and funds for the OI Foundation.

Following in the footsteps of the Brittle Bone Society in Scotland, the OIF was honored to have Dr. Peter Byers and Dr. Virginia Sybert of University of Washington; Dr. Jill Flanagan of Children's Healthcare of Atlanta; Dr. Jeanne Franzone of Nemours/Alfred I. duPont Hospital; Dr. Richard Kruse of Nemours/Alfred I. duPont Hospital; Dr. Eric Orwoll of Oregon Health & Science University and Shelia Orwoll; Dr. Frank Rauch of Shriners Hospitals for Children - Canada; Dr. Jean-Marc Retrouvey and Suzanne Lacombe of Shriners Hospital for Children - Canada; Dr. David Rowe of University of Connecticut Health Center; Dr. Peter

Smith of Shriners Hospitals for Children - Chicago; Dr. V. Reid Sutton of Baylor College of Medicine; Dr. Maegen Wallace of Children's Hospital and Medical Center - Omaha; current OIF Board of Directors member Ted Trahan and former OIF Board of Directors president Sharon Trahan come together for this momentous event.

In the months leading up to the March, participants shared their motivation and excitement to take part in the event. Throughout the weekend, the OI Foundation used social media to post updates on the participants' progress. In total, we were able to reach more than 100,000 people on social media and raise nearly \$40,000 to fund OIF programs.

We cannot express how thankful we are to these doctors and their families for all that they do for the OI community - whether they are leading new research, heading an OI clinic or walking 50 miles over 3 days, they are exemplifying the Unbreakable Spirit® of the OI community!



Medics on the March at the starting point in Harpers Ferry West Virginia



Dr. Richard Kruse participated on bicycle along the 50 miles



Medics on the March participants enjoy their dinner on the banks of the Potomac River



Dr. Reid Sutton and Ted Trahan enjoying the views of Great Falls



Medics on the March crossing the finish line after three days and 50 miles

OIF Board of Directors Update

The OI Foundation is pleased to introduce the new OIF Board President, Cameron Penn.

Cameron was born with Type IV OI and has served on the Board of Directors for the Osteogenesis Imperfecta Foundation since 2014. He also volunteered for FDNY's Engine 40-Ladder 35 on Manhattan's Upper West Side and the Ground Zero recovery effort from 2001-2003. During that time, he co-chaired an annual benefit for the Uniformed Firefighters Association, raising more than \$450,000 to support the 9/11 Widow's and Children's Fund.

Cameron is a two-time National Emmy Award-winner and 12-time Emmy nominee. Since 2005, Cameron has served as Managing Partner of Hey Guy Media, a branding, marketing and public relations firm with offices in Dallas-Fort Worth, Los Angeles and New England. Hey Guy's clientele includes Shell Oil, Mattel, the Walt Disney Company, KinderCare, Carl's Jr./Hardees and Chipotle Mexican Grill.

Before forming Hey Guy Media, Cameron spent 15 years in the entertainment industry, producing more than 2,000 hours of live television for ESPN, HBO, ABC and FOX. Before that, he spent four years clerking for the international litigation firm of Sedgwick, Detert, Moran & Arnold.



Cameron Penn

Cameron holds a BA in Political Science and Government from the University of California-Irvine. He currently resides in the Dallas-Fort Worth area with his wife and three daughters.

The OI Foundation would also like to welcome new OIF Board member, Jim Early.

Jim is blessed to be the grandfather of a young man who has OI. Like most people, Jim had some idea of what "brittle bone disease" was, but not until 2002 when Matthew was born did he know what it means to people with OI, and their families.

From his daughter Taryn's first exposure to the OI Foundation, Jim has seen how important the Foundation is to patients and every bit as important, their families. Jim wants to make sure that he does all he can to make sure other families know that they are not alone in their struggles with OI and that great efforts will continue to be made in medical advances and research to improve the lives of those dealing with OI.

As a retired insurance and financial planning professional with more than 40 years of experience Jim hopes to bring the experience and skills that he learned in his career to his role as a Board of Directors member. As past President of the National Structured Settlements Trade Association (NSSTA) he is active with the American Association of People with Disabilities (AAPD), an organization founded by the late Paul G. Hearne who had OI.

Jim's background in business management and financial planning for the disabled and injury victims will allow him to contribute to the success of the OI Foundation.



Jim Early with his wife (Jane) and his grandson (Matthew)

Rare Bone Disease TeleECHO Clinic Series: Increasing Access to Expert Care for Rare Bone Diseases

The OI Foundation, in partnership with the Rare Bone Disease Alliance, launched the inaugural Rare Bone Disease TeleECHO Clinic Series on August 1st, 2019. This virtual medical education initiative provides a digital platform to help physicians and medical professionals interested in treating patients with rare bone diseases. In each monthly video conference, or *clinic session*, an expert in rare bone disease leads a brief presentation and discussion, followed by participant-led case presentations. While not exclusively focused on osteogenesis imperfecta, this program will increase access to expert knowledge and improve patient outcomes for medical professionals across different fields, credentials, and countries.

The interdisciplinary medical faculty is led by Dr. Laura Tosi, orthopedic surgeon and member of the OIF Board of Directors and Medical Advisory Council, and includes:

- Michael Collins, MD, *National Institutes of Health, NIDCR*
- Michael Lewiecki, MD, *University of New Mexico*
- Eric Rush, MD, *University of Kansas Hospital*
- Jay Shapiro, MD, *Uniformed Services University of Health Sciences*
- Dolores Shoback, MD, *University of California San Francisco*



The graphic is a calendar-style poster for the Rare Bone Disease TeleECHO Clinic Series. It features a blue and yellow diagonal background. At the top right, there are logos for the OI Foundation (with the tagline 'Osteogenesis Imperfecta Foundation - Understanding Sport') and Project ECHO. The main title 'Rare Bone Disease TeleECHO Clinic Series' is in large blue font. A yellow banner with the text 'MARK YOUR CALENDAR!' is slanted across the top. Below this, a list of dates and topics is provided, each followed by the speaker's name and affiliation. At the bottom, there is a registration link and contact information.

Rare Bone Disease TeleECHO Clinic Series

MARK YOUR CALENDAR!

08/01/19 Genetic Testing in the Diagnosis of Rare Bone Disease
Eric T. Rush, MD, FAAP, FACMG - University of Kansas Medical Center

09/05/19 OI Dominant vs Recessive: Impact on Treatment
Reid Sutton, MD - Baylor College of Medicine

10/03/19 Hypocalcemia
Dolores Shoback, MD - University of California, San Francisco

11/07/19 Fibrous Dysplasia - McCune Albright
Michael Collins, MD - National Institutes of Health, NIDCR

12/05/19 Non-Accidental Trauma
Peter Byers, MD - University of Washington Medicine

01/02/20 XLH Disorders
Thomas Carpenter, MD - Yale Medicine

02/06/20 Diagnostic Approach to the Child with a Skeletal Dysplasia
Julie Hoover-Fong, MD, PhD - Johns Hopkins Medicine

03/05/20 Hypophosphatasia
Michael Whyte, MD - Shriners Hospitals for Children — St. Louis

04/02/20 Management of Pregnancy & Delivery in the Patient with a Skeletal Disorder
Deborah Krakow, MD - University of California, Los Angeles

05/07/20 Osteopetrosis
Michael Econs, MD - Indiana University School of Medicine

06/04/20 Evaluation of the Child with Rickets
Erik Imel, MD - Indiana University School of Medicine

07/02/20 Fibrodysplasia Ossificans Progressiva
Edward Hsiao, MD, PhD - University of California, San Francisco

Register at www.oif.org/ECHO

If you have questions about this program, please contact Mstewart@oif.org.

Presented by the OI Foundation in partnership with the Rare Bone Disease Alliance.



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 Comprehensive Limb Difference Program at Children's Healthcare of Atlanta (CHOA) and the Osteogenesis Imperfecta program at Children's Hospital & Medical Center in Omaha, Nebraska.

Comprehensive Limb Difference Program Osteogenesis Imperfecta Program at Children's Healthcare of Atlanta

The Comprehensive Limb Difference Program at Children's Healthcare of Atlanta (CHOA), is a multidisciplinary program serving the greater Atlanta area as well as the Southeast.



Physician champions of the program include Dr. Jill Flanagan, from pediatric orthopaedic surgery, Dr. Karen Loechner, from pediatric endocrinology, and Dr. William Wilcox from genetics. In addition to this core group of physicians, there are expert dentists in the Atlanta area, pulmonologists, ophthalmologists, as well as ENT physicians. PTs and OTs are well versed in OI, and Scottish Rite recently opened its new therapy pool in 2019 at the Scottish Rite campus.

The Comprehensive Limb Difference team at CHOA is dedicated to providing innovative and compassionate care to all of their OI patients and families. The physicians are all active in research and clinical trials to help learn more about OI and improve treatments in years to come. Dr. Jill Flanagan has extensive experience in managing the OI patient from birth through college. She is well versed at treating the simplest fractures to the most complex of upper or lower limb deformities. After evaluation with Dr. Flanagan, she will typically seek genetic confirmation from Dr. Wilcox and his team, and then refers to Dr. Loechner, from pediatric endocrinology, for medical treatment of OI. Dr. Loechner has a keen interest in pediatric bone disorders and manages the bisphosphonate infusion program. Dr. Wilcox is nationally known for his expertise in the genetics of skeletal dysplasias. With this virtual program, the physicians at CHOA treat greater than 100 OI patients annually, making this program one of the busiest in the country.

For more information about the Comprehensive Limb Difference program at Children's Healthcare of Atlanta, please go to www.choa.org/orthopedics or directly contact Dr. Flanagan's patient care coordinator, Dana Joyner, at 678-686-6821. Genetics can be reached at 404-785-0702.

Osteogenesis Imperfecta Program at Children's Hospital & Medical Center

The Osteogenesis Imperfecta Program at Children's Hospital & Medical Center in Omaha, Nebraska, has been providing the highest quality of multidisciplinary care for patients and families from around the world for decades. Learn what makes this program unique directly from the team:

Our multidisciplinary team represents nearly 10 pediatric specialties—from genetic specialists to dentists. The team works together in one centralized location to ensure a personalized approach to patient care. With a strong history of advocating for patients and providing high-quality surgical and post-operative care, our program's expertise in OI treatment and aggressive pain management techniques ensure greater comfort for children.

Beyond multi-specialty care, our clinical research efforts and mission are rooted in education. We are part of The Brittle Bone Disorders Consortium, part of the NIH's Rare Diseases Clinical Research Network. The consortium is a multi-centered program that focuses on understanding and providing better treatment options for all types of OI. With proficiency in pediatric bone disorders, our clinic developed a low-dose regimen of treatment known as the "Omaha Protocol" in the mid-'90s that is frequently requested by physicians worldwide who treat pediatric bone disorders. Surgeons, pediatric physicians and advanced practice providers trust us as a source of ongoing education, raising the standard of care for all children with OI.

Dr. Maegen Wallace serves as Medical Director of our program, contributing to the clinical expertise that is



Children's Hospital and Medical Center

consistently recognized as one of the top in the nation. Led in collaboration with Dr. Paul Esposito, who received personal training from the co-inventor of the Fassier-Duval lengthening surgical rods used in rodding surgery, our program is often consulted by pediatric orthopedic surgeons nationwide. Although a challenging surgical procedure, this specialized treatment is easier on patients, less invasive and requires shorter recovery time. Since the rods are designed to lengthen as a child grows, they are effective in preventing fewer surgical procedures and allow for treating multiple fractured bones at once.

In 2018, our program attracted nearly 200 patients nationwide. Families from outside the Omaha metropolitan area who come here for treatment enjoy staying at our 56-room Carolyn Scott Rainbow House, a hospitality house offering complimentary lodging just blocks away from the hospital. Another family-first

aspect of our program is its focus on early preventative care; our team makes a concerted, coordinated, effort to safely and collaboratively administer medications and other therapies, working with primary care providers in patients' hometowns.

Another incredibly impactful member of our OI team was Rose Kreikemeier, APRN, who passed away earlier this year. Rose was instrumental in growing our community infusion program, building inroads with providers nationwide. She guided local providers and counseled countless parents through this rare disease's initial diagnosis. We are grateful for her contributions to our profession, reassuring countless families of the quality of life possible for their child and building a legacy of hope.

To schedule a patient consult or referral, please call Ameer Thedens or Jessica Hansen, APRN, at 402-955-4199, option 5.



OI community members celebrated Wishbone Day at Children's Hospital and Medical Center in Omaha, NE



OIF Medical Advisory Council Member Spotlight: Dr. Reid Sutton

Dr. Reid Sutton is professor and vice-chair for education in the Department of Molecular and Human Genetics at Baylor College of Medicine. He sees patients in the skeletal dysplasia and inborn errors of metabolism clinics at Texas Children's Hospital. He serves as the Administrative Principal Investigator for the Brittle Bone Disorders Consortium Rare Disease Clinical Research Center, which is funded by the National Institutes of Health with eleven sites across North America. This study has over 850 individuals with OI enrolled in a natural history study, as well as important components looking at quality of life, dental health, scoliosis, biomarkers for disease and investigating new medications to treat OI.



Dr. Reid Sutton

We're thankful that Dr. Sutton also finds the time to be involved with the OI Foundation! Dr. Sutton not only sits

on our Medical Advisory Council, but he also participates in OI Foundation events. Most recently, over the weekend of April 26-28, 2019, he served as co-chair of the OIF Medics on the March event and walked 50 miles from Harpers Ferry, WV to Bethesda, MD to raise awareness and funds for the OI Foundation! Dr. Sutton also attended events such as Boots & Bling for Better Bones in Houston, hosted the OIF Regional Conference in Houston, TX, and has been a popular speaker at the OI Foundation's National Conferences.

When asked about his involvement with the OI Foundation, he said: "It is a pleasure to be able to work with the OI Foundation to improve the lives of people with OI. The staff and volunteers for the OIF are dedicated, hardworking, and well-organized. It is truly an honor to be able to assist the OIF in its mission and to serve the OI community."

Thank you, Dr. Sutton, for all the work you do for the OI community!



New OIF Podcast Episode: Rodding Surgery and OI

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. The most recent episode focused on Rodding Surgery and OI featuring Dr. Maegen Wallace, a pediatric orthopedic surgeon at Children's Hospital and Medical Center in Omaha, NE.

To listen to all available OIF Podcast episodes, visit www.oif.org/OIFpodcast.

Rodding Surgery and OI



Maegen Wallace, MD

Pediatric Orthopedic Surgeon
Children's Hospital and Medical Center
Omaha, Nebraska



From the Information Center

OIF Annual Science Meeting

On April 10-12, 2019, the OI Foundation gathered over 77 researchers, clinicians, and medical professionals at the 19th Annual OIF Science Meeting in Chicago, IL. Co-chaired by Dr. Joan Marini and Dr. Cathleen Raggio, this important meeting hosted speakers and attendees from the National Institutes of Health (NIH), the Brittle Bone Disorders Consortium (BBDC) sites, and many other centers and labs from across the continent. Speakers presented data on topics ranging from the Effect of Rapamycin on Bone Mass and Strength in Amish Mice to an Update on treatment of adults with OI. The OI Foundation thanks Dr. Marini and Dr. Raggio for their outstanding work as meeting co-chairs, and the speakers and participants for making this a productive meeting. The OI Foundation especially thanks the Buchbinder Family Foundation who makes the Annual OIF Science Meeting possible every year.



Medical Advisory Council Chairman Dr. Francis Glorieux with OIF Scientific Meeting Co-Chairs Joan Marini, MD, PhD and Cathleen Raggio, MD

Blue Jeans for Better Bones Day

The next National Blue Jeans for Better Bones Day will be Friday, September 13th! Join your fellow members of the OI community on the 13th or pick your own date. With a Blue Jeans for Better Bones Day, you can raise funds for the Foundation and educate your classmates and teachers about OI, all while

wearing your favorite pair of jeans or a fun themed outfit. More information can be found at www.oif.org/bjbb. Contact Melissa Bonardi at mbonardi@oif.org or 301-947-0083 for help getting started with your own fundraiser!



Prepare to go



Finding the perfect outfits and checking off the back-to-school supply lists may be the easy part of starting school, moving to a new school, or returning to elementary school. Although frequent communication with your child's teacher is an important year-round strategy for helping your child who has OI be a happy and successful student, the start of a new school year is especially important. Autumn is a good time to meet new school staff, review information about your child's physical strengths and needs and to decide how you want OI explained to your child's classmates. It is also important to brief the school staff about any changes in your child's condition over the summer due to surgery or accident and to review plans for handling possible health concerns at school.

At the beginning of the school year, meet the key people on your child's education team: your child's teacher, school counselors, principal, student aide (if applicable), and the school nurse or health aide. Review school policies about giving pain medicine at school, and have a written plan in place for how to respond to a suspected fracture at school. Everyone who interacts with the child should be knowledgeable about handling day-to-day activities and emergencies. In many elementary schools, the school nurse will be your point person for making your wishes known. Autumn is also a good time to review your child's education plan to make sure that all necessary services from physical and occupational therapists or adaptive PE teachers have been included. These specialists who are employed by the school system can provide services to help the child with OI have better access the total learning environment. This can include adapting the physical education program, providing safe activities during recess, locating adaptive sports programs, or therapy to improve basic motor skills.

Listed below are some of the important topics to talk over with the staff at your child's school:

- **Fractures:** Establish a written policy in regard to handling your child and the use of his/her equipment. Establish who will be called when a fracture is suspected or your child is in pain. Keep an emergency contact list in an established place for substitute teachers, school nurses and other school personnel.

- **Physical activity:** If your child fatigues easily when performing physical activities, discuss the child's physical endurance level with the teacher.
- **School environment:** Walking through your child's planned routes to the playground, auditorium, or restroom can help identify areas that will be difficult for crutches, walkers or a wheelchair.
- **Personal aide:** If your child has an aide, discuss the role the aide should play to ensure the child's maximum participation in classroom instruction, physical independence and peer socialization.
- **Toileting:** Children with OI may require assistance for toilet transfers or may require a bathroom large enough to accommodate a walker or wheelchair. Determine a bathroom plan and discuss if the child will utilize the class bathroom, an alternate bathroom or whether his/her toileting needs will be addressed with the school nurse.
- **Fire evacuation:** Parents should work with teachers and school administrators to establish a fire evacuation plan. Determine the safest way to transport the child and the wheelchair safely from the area. This should be clearly posted for all school staff to follow and should be practiced so both your child and the staff know what to do.

College students should understand their prospective school's accessibility and accommodation policies before selecting a school. Considering the school's accessibility to residence halls, dining facilities, classrooms, libraries, and campus transportation are all important to know well ahead of the move-in date and the beginning of the semester.

Understandably, there is a lot for any student to do at the beginning of a new school year. Opening clear channels of communication now, and following up on a regular basis will help your or your child's learning and social growth. If the school staff has any questions about OI or how to develop plans for working with your child, give them contact information for the OI Foundation's Information and Resource Center. The OIF has informational brochures and booklets that may be useful and can answer any questions they may have.

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



One of the most valuable ways to support the mission of the OI Foundation is by uniting the Unbreakable Spirit® community! Every year, dedicated volunteers donate their time by hosting events and facilitating support group meetings across the country. Our website calendar is a great way to stay in the loop about upcoming events in your area. New events are being added all the time, and we have listed a few below:

September

- September 13th** National Blue Jeans for Better Bones Day
- September 21st** Jacaranda Summer Series Golf Tournament – Plantation, FL

October

- October 13th** Alle Shea's OI Love Dessert & Dance Fundraiser – Webster, NY
- October 19th** Beef & Brew for Better Bones – Garfield, NJ
- October 26th** OIF Regional Conference – Wilmington, DE

November

- November 9th** Boots & Bling for Better Bones – Houston, TX



Are you interested in holding awareness and/or fundraising events for the OI Foundation? Please contact Melissa Bonardi at mbonardi@oif.org or 301-947-0083 to get started!

Follow us on social media!



www.facebook.com/OsteogenesisImperfectaFoundation



[@OIFoundation](https://twitter.com/OIFoundation)

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We're celebrating

50 YEARS

OF SERVICE TO THE OI COMMUNITY

CELEBRATE!

OIF NATIONAL CONFERENCE

Omaha, NE

JULY 9-12, 2020

