

The 2022 Virtual OIF Conference was a Success!

It was wonderful to see new and old friends at the Virtual OIF Conference on July 9, 2022. The agenda included large group sessions led by OI experts like *Navigating a New Diagnosis*, *Transition to Adult Care*, and the *OI Research Update*. These sessions featured live interpretation to French (sponsored by the Canadian Osteogenesis Imperfecta Foundation) and Spanish, as well as closed captioning.

Recordings of select sessions are available on the **OIF's YouTube channel** in English, Spanish, and French.

Check out some of the highlights from Virtual OIF Conference:

■ New Session: Transition of Care

During this new session, speakers shared advice and experience for parents and young adults as they move from pediatric to adult healthcare systems.

■ Ask the Experts

The 2022 Virtual Conference agenda featured **two** *Ask the Experts* sessions, where attendees had the opportunity to join breakout rooms with OI experts who were ready to answer questions. Topics included OIF Resources, Surgery and Recovery, Cardiopulmonary and OI, Mild OI, Genetics, Women's Health, Mental Health, and Dental Health.

■ Social Sessions

OI community members enjoyed meeting up with old friends and connecting with new friends in the OIF Virtual Lobby, the Kids Social Room, and Unbreakable Spirit® Trivia.

We are so thankful for the incredible OI community members, OI experts, and sponsors who made this event possible.

Speakers: Frances Baratta-Ziska, PT, DPT; Michael Bober, MD, PhD; Erin Carter, MS, CGC; Jeffrey Eslinger; Jeanne Franzone, MD; Michelle Fynan, LHMC; Tony Jacobsen; Mahim Jain, MD, PhD; Chaz Kellem; Deborah Krakow, MD; Brendan Lee, MD, PhD; Tracy Mulroy; Sandesh Nagamani, MD; Joseph Napoli, MD, DDS; Lindsey Nicol, MD; Michelle Potorski; Siena Potorski; Cathleen Raggio, MD; Jessica Ransome; Jean-Marc Retrouvey, DMD, MSc, FRCD; Kevin Ricker, DDS; Sandy Sandhaus, MD, PhD; Reid Sutton, MD; Laura Tosi, MD; Ted Trahan; Maegen Wallace, MD; Robin Wright.

Sponsors: Ultragenyx, Canadian Osteogenesis Imperfecta Society, Nemours Children's Health, Pega Medical



OIF Regional Conference: Tampa, FL

On Saturday, July 30, members of the OI community attended the Regional Conference: Tampa to learn more about OI and meet others in their local area. OIF Regional Conferences are one-day meetings where families and individuals impacted by OI learn from local physicians, OIF Medical Advisory Council (MAC) members, and other community members. At the first in-person Regional Conference in over 2 years, nearly 100 attendees met at the University of South Florida's (USF) Marshall Student Center.

After a welcome breakfast from the Florida OI Support Group, Dr. Danielle Reynolds, the Regional Conference Chair, welcomed attendees and framed the day. Physicians led sessions on Medical and Orthopedic Treatments, Engaging the Patient Voice in OI Research, Pain Management, Dental Health, and Pulmonary Health. Community members also heard from their peers, including a presentation on Advocating for Yourself, where

(continued on page 2)

OIF Listening Sessions – Volunteers Needed!



The OI Foundation is asking for volunteers to participate in “listening sessions” (our version of focus groups) as part of our latest project, **Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease**. Our goal is to understand barriers to and facilitators for improving access to appropriate care and raising the quality of that care for adults with OI. Most pediatric OI patients (up to ages 18-22) are cared for at one of over 60 OI clinics located around the country. Only 5 clinics, however, care for OI patients who are considered of “adult” age. The lack of adult OI care in the US poses significant problems for transition to adult care and access to quality specialty care particularly for individuals living in geographically isolated areas.

If you agree to participate, attend a single 90-minute VIRTUAL listening session with about 5-7 other members of the OI community. During the listening session you will be asked questions about issues that you think are important to transition from pediatric to adult care. You will be compensated for your time and the information you share will be used to inform and guide future programs and resources. If you are interested, or would like more information, please contact Stacie Loring at sloring@oif.org. To learn more about this project, visit www.oif.org/pcor.



Shop the OIF Online Store!

Gear up for the school year or start your holiday shopping early on the OIF's online store! Shop a collection of t-shirts, coffee mugs, tote bags, hats, and more! With adult, youth, toddler, and infant sizes, there is something for everyone. Shop now at www.bonfire.com/store/oifstore.

New! Handle with Care Stickers Available

Have peace of mind with new informational stickers for you or your child's car seat, stroller, backpack, walker, or wheelchair to alert others of their OI diagnosis. Stickers are available at www.oif.org/shop.



OIF Regional Conference: Tampa, Florida (continued from page 1)

former OIF Board member Susie Wilson shared self-advocacy strategies for different contexts and medical scenarios.

The OIF would like to thank Dr. Danielle Reynolds and the staff at USF and Tampa General Hospital for making this meeting possible. We also want to thank Susie Wilson and Gail Bunker, co-leaders of the OI Florida Support Group, for their continued dedication to the supporting local OI community members and their valuable guidance. Other speakers included Drs. Maureen Maciel, Megan Spiewalk, Frank Sierra, Nicole Williamson, and MAC members Drs. Cathleen Raggio, Laura Tosi, and Robert Sandhaus. Upcoming OIF Regional Conferences will take place in Kansas City, MO (November 5, 2022) and Phoenix, AZ (March 2023).

Following the Regional Conference, we took a moment to honor OI Foundation founder Gemma Geisman and to celebrate the 50th Anniversary of the Osteogenesis Imperfecta Foundation. We were joined by members of Gemma's family along with current and past Board of Directors members, medical

professionals, and long time community volunteers. Remarks were given by OIF Board President, Ted Trahan; former OIF board member and co-leader of the Florida OI Support Group, Susie Wilson; Gemma's daughter, Cathy Bowen; and former OIF Treasurer and former board member, Bob Phillips. A recording of the event can be found in the Gemma's Corner playlist on the OIF's YouTube channel.



OIF Regional Conference in Tampa, FL

The Return of In-Person Fundraising Events

OI Foundation Board of Directors member Christine Wyman Rossi, former Board of Directors member Dick Wyman, and their amazing Host Committee held the first in-person *Strong Bones Gala Boston* since 2019 on June 17th in Framingham, Massachusetts. More than 150 attendees enjoyed an evening of dining, dancing, raffles and live & silent auctions to raise more than \$50,000 for the OI Foundation. Thank you to Christine Rossi and her host committee for a fabulous evening!

The next Strong Bones Gala will be the *Boots and Bling for Better Bones* event on October 15, 2022 in Houston, Texas. If you are interested in attending the event or joining the committee, please contact Melissa Bonardi at mbonardi@oif.org



Dick Wyman, Michelle Potorski, Christine Rossi, MaryEllen Wyman and Siena Potorski at the 2022 Strong Bones Gala Boston



Paddles raised during the Fund the Mission at the 2022 Strong Bones Gala Boston



Christine Rossi and Emma Minucci present Dr. Samantha Spencer with an Unbreakable Spirit® Award at the 2022 Strong Bones Gala Boston

Play Golf to Support the OI Foundation

This summer and fall, several golf tournaments are being held to support the work of the OI Foundation.

The season started with the *Miracle Michael Golf Outing* and the *Riley's Gathering Golf Outing* in Chicago, Illinois this July. Thank you to the Schultz, Benish, and Fromelt families for hosting these perennial events.

After tremendous success (and fun) over the last 15 years, the *OI Golf Classic* hosted by Teresa & Ken Gudek is relocating to the Manchester Country Club golf course with the addition of OI Foundation board member Jim Early and his wife Jane. In honor of Jim & Jane's grandson Matthew, who lost his battle with OI late last year, the OI Golf Classic has been renamed *The Matthew Smith Memorial Golf Outing*. We hope you can join us for its inaugural year on August 22, 2022 to support the mission of the OI Foundation.

We are very excited to welcome the Walls and Martin families for the inaugural year of their Unbreakable Spirit® Golf Outing being held on September 21, 2022 at the Iron Valley Golf Club in Lebanon, PA, and will include raffles, awards, contests, and an 8:00am or 1:00pm shotgun start.

We are delighted to announce the return of the *Abruzzi Golf Tournament* on Saturday, October 22nd at the Willow Hollow Golf Club in Leesport, PA. The tournament will begin with a shotgun start at 8:00am and will include lunch catered by Moyer's Catering and a 50/50 drawing! If you are interested in attending, please contact Melissa Bonardi at

mbonardi@oif.org

For details about all upcoming events, you can visit

www.oif.org/events

OIF Back to School Resources

The OIF Information Center is here to help your family transition back into the school environment. Please take a look at some of the frequently asked questions below to learn more about OIF back to school resources:

My child is starting pre-school in a few months, is there anything that we can do to prepare for this?

Many families will share resources with school staff with information about OI. The OIF's **School Emergency Instructions for OI** includes a sample procedure for fractures. This template can be edited and tailored specifically to your needs.

Is there anything that you think we should include in materials we share with our child's teachers to help them understand the social effects of OI?

The OIF's **Social and Emotional Issues fact sheet** may be helpful for this. This resource includes and explains the social effects and different issues that parents, siblings, grandparents, and individuals living with OI may experience.

This year we are visiting colleges-can you believe it? Does the OIF have any scholarships?

The OIF's **Jeanie Coleman Impact Grant Program** accepts applications every January. The grant can cover the cost of laptops or tablets for school, mobility devices – such as wheelchairs, and much more.

For more information about OIF resources, contact Jessica at jransome@oif.org.



Host a Blue Jeans for Better Bones Day at Your School

Help spread awareness of osteogenesis imperfecta by wearing the color blue or blue jeans on any day of your choosing. Once you've set a date, have everyone on your team donate \$3, \$5, or \$10 to receive an awareness sticker and wristband so they can show their support. To collect donations, you can set up a fundraising page on the OIF website by going to www.oif.org/campaign/blue-jeans/. For more information or to share your awareness photos, contact bonelink@oif.org.

Meet OIF Board President, Ted Trahan!



We are thrilled to welcome Ted Trahan as the President of the OIF Board of Directors!

Ted has been a member of the OIF Board of Directors since 2016, most recently serving as Treasurer. His son Greg was the inspiration for the family joining the OI community, which they have been members of since the San Diego national conference in 1998. Professionally, the bulk of Ted's career has been with healthcare technology company Medtronic. His roles there span development and manufacturing. Ted currently works in project management. Prior to Medtronic he worked in information management consulting for Anderson Consulting. Ted has a BS in Electrical Engineering from the University of Texas. In addition to the OI Foundation, his other community involvement has included his church, the Boy Scouts and Habitat for Humanity. Ted enjoys sailing on waters large and small. Ted and Sharon, his wife, have two grown children, Greg and Käthe.

Welcome to the OIF Medical Advisory Council!

Since the 1970's, the OI Foundation's Medical Advisory Council (MAC) has been comprised of outstanding men and women who have experience in research and the many clinical care specialties related to OI. Over the years, MAC members have made discoveries that advance our understanding of OI and improved clinical care, volunteer their time and expertise to review OI Foundation publications, advise on the implications of new research discoveries, and answer questions from the OI community and the medical community. On July 1, 2022, we welcomed four new members to the OI Foundation MAC: Michael B. Bober, MD, PhD; Jeanne M. Franzone, MD; Eric T. Rush, MD; and Maegen Wallace, MD.



Michael B. Bober, MD, is a pediatrician and geneticist who directs the Skeletal Dysplasia Program at the Alfred I. duPont Hospital for Children in Wilmington, DE. He is a Professor of Pediatrics at Thomas Jefferson University's Stanley Kimmel Medical College. Dr. Bober completed a combined M.D./Ph.D. program in

Biomedical Engineering at Tulane University. His dissertation research focused on the genetic response of bone to mechanical and hormonal stimulation. He then went on to complete a Pediatrics Residency at Tulane University and a Medical Genetics Residency and Fellowship at Johns Hopkins University. He is a board certified in Pediatrics, Clinical Genetics and Molecular Genetics. Clinically, his practice is exclusively focused on the diagnosis and management of children with skeletal dysplasia.



Jeanne M. Franzone, MD, is a pediatric orthopaedic surgeon at the Nemours Alfred. I. duPont Hospital for Children in Wilmington, DE. She is the Co-Director of the Multidisciplinary Osteogenesis Imperfecta Program. At Nemours, the multidisciplinary OI team provides comprehensive OI care from the prenatal

period through the age of 35 years. Dr. Franzone completed orthopaedic surgery residency at Columbia University Medical Center. She then completed a pediatric orthopaedic surgery fellowship at the Nemours Alfred I. duPont Hospital for children and an additional fellowship in limb deformity, lengthening and reconstruction at the International Center for Limb Lengthening in Baltimore, MD. Dr. Franzone is a member of the Limb Lengthening and Reconstruction Society and serves on the Faculty for the OIF OI TeleECHO series. Dr. Franzone is the incoming Co-Chair of the International Conference on Children's Bone Health (ICCBH) Young Investigator Networking group. Dr. Franzone is on the Scientific Advisory Board for the OIF's Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease PCORI project.



Eric T. Rush, MD, is a Clinical Geneticist at Children's Mercy Hospital and the University of Kansas Medical Center (KUMC). He is an Associate Professor of Pediatrics at the University of Missouri-Kansas City. He is Board Certified in Pediatrics, Internal Medicine and Clinical Genetics. He was previously the medical

director of the osteogenesis imperfecta and metabolic bone clinics at Children's Hospital and Medical Center in Omaha, Nebraska and currently is the co-director of the Children's Mercy Skeletal Dysplasia clinic. Dr. Rush received Bachelor of Science degrees in Biochemistry and Biology with Concentration in Genetics at the University of Kansas in 2001. He received his medical degree at University of Kansas School of Medicine, Kansas City, KS in 2005. He completed a residency in Internal Medicine and Pediatrics at the University of Nebraska Medical Center in 2009 and Chief Residency in Pediatrics at the University of Nebraska Medical Center in 2010. He finished his training with a Clinical Genetics fellowship at the University of Nebraska Medical Center in 2012. Among his clinical interests are osteogenesis Imperfecta, hypophosphatasia, X-linked hypophosphatemia (XLH), cancer genetics, cardiovascular genetics, dysmorphology, Personalized Medicine, and Genetics of Common Disease. His research interests include extraskeletal manifestations of osteogenesis Imperfecta, best practices in treatment of hypophosphatasia, skeletal pathology in peroxisomal biogenesis disorders, and molecular characterization of rare syndromes. Dr. Rush's professional affiliations include American College of Medical Genetics, American Academy of Pediatrics, the American Society for Bone and Mineral Research, the International Society for Clinical Densitometry, and Alpha Omega Alpha. He is on the Scientific Advisory Board for the Rare Bone Diseases Alliance and the Global Foundation for Peroxisomal Disease and is on the Board of Directors for RareKC.



Maegen Wallace, MD, is an Associate Professor of Orthopaedic Surgery at the University of Nebraska Medical Center and practices pediatric orthopaedic surgery at Children's Hospital and Medical Center in Omaha, Nebraska. A native of Nebraska, she graduated from Missouri State University with a BS in Sports Medicine and

Athletic Training and the University of Nebraska Medical Center with her medical degree. She completed her orthopaedic surgery residency at Saint Louis University and her pediatric orthopaedic surgery fellowship at Al duPont Hospital for Children in Wilmington, Delaware. She is the director of the Osteogenesis Imperfecta clinic at Children's hospital in Omaha and serves as a board member for the Jansen's Foundation. She has committed a significant portion of her clinical practice to OI and the majority of her academic practice to OI.



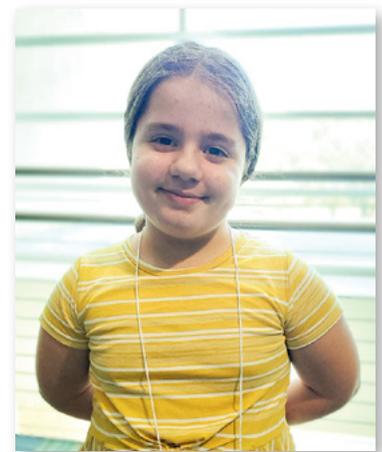
We are thankful for the generosity of community members who have supported the work of the Osteogenesis Imperfecta Foundation! We hope you will take a moment to read about the OIF's exciting accomplishments of the past year. Your support allows us to continue adding to the many new and ongoing programs and activities of the Osteogenesis Imperfecta Foundation as we strive to improve the quality of life for individuals living with OI through research, education, awareness, and mutual support.

Eugene Washington PCORI Engagement Award

Under the direction of OIF Medical Advisory Council member Dr. Laura Tosi, the OI Foundation recently completed our 3rd Eugene Washington PCORI Engagement Awards, through the Patient-Centered Outcomes Research Institute (PCORI), *Leveraging Virtual Communication to Advance PCOR Adoption by the Rare Bone Disease Community*. This award brought together members of the Rare Bone Disease Alliance (RBDA) with stakeholders from the patient and scientific communities in a series of focus groups and large group meetings to examine barriers to participation in research, barriers to access to care, and patient-identified issues that need to be reflected in the development of patient-reported outcomes. The OI Foundation is currently administering our latest award, *Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease*, which is exploring the problems that individuals with OI have as they transition from pediatric to adult care. Over the next year, we will be hosting a series of listening sessions to explore challenges such as difficulties a patient may encounter when seeking primary and specialty care, difficulties pediatric OI clinics have as they seek to successfully transition their patients to adult care, and barriers that existing adult OI clinics encounter as they seek to provide appropriate and high-quality care to adult patients.

OI Clinic Outreach

In an ongoing effort to connect with medical professionals who are currently treating patients with OI and educate them on the resources the OIF provides clinics and their patients, the OIF held a hybrid Town Hall Meeting for OI Clinic and Bone Health Programs in April. We were excited to gather 35 medical professionals in person with another 60 joining virtually for a half day of discussion on mental health, pain management, and pulmonary care. We have created a new quarterly electronic newsletter specifically for this group, which will include important announcements about meetings and resources.



Rare Bone Disease Alliance

The Rare Bone Disease Alliance (RBDA), a program of the OI Foundation, brings together a coalition of fifteen rare bone disease patient advocacy groups. The RBDA is committed to expanding education of rare and ultra-rare disorders and expanding research on the natural history, diagnosis, and treatment of the diseases. The RBDA unites researchers and early-stage investigators by hosting an annual Rare Bone Disease Working Group Meeting, an Early-Stage Investigator Meeting, and a Scientific Symposium. Learn more at www.rbdalliance.org.

Virtual Education Sessions

Since March 2020, the OI Foundation has hosted more than 20 live, virtual sessions connecting OI community members with OI experts to discuss COVID-19 related topics, research updates, and mutual support opportunities. Sessions have included: Information on COVID-19; Mental Health and Wellness; Nutrition and Fitness; Employment Accommodations; COVID-19 Vaccine Updates; Brittle Bone Disorders Consortium research updates; virtual holiday parties and so much more! All OIF virtual sessions have been recorded and are available on the OI Foundation's website and YouTube channel.

OIF Virtual Conference

For the past three years, the OIF has hosted a Virtual National Conference to help fill the gap between in-person OIF National Conferences. The virtual format has allowed hundreds of new individuals who have not had the ability to attend an in-person OIF National Conference to participate in the most popular informational and social sessions complete with closed captioning and live interpretation in both French and Spanish. In 2022, we utilized an “Ask the Expert” format to allow for a more informal dialogue between OI experts and virtual participants. Session recordings are available on the OI Foundation’s YouTube channel.

OIF National Information Center

This past year, OIF staff responded to more than 11,000 direct inquiries for medically verified information, and an average of 6,000 people used the OIF website each month. Topics range from medical issues such as genetics, diagnosis, and treatments to daily living strategies such as school and employment. Educational materials are available in print and electronically through the OIF website. OIF Virtual Office Hours, every Tuesday and Thursday at noon and 6pm EST, are hosted by OIF Health Educator Jessica Ransome. Individuals are invited to join office hours via Zoom to learn more about OI Foundation programs and resources, ask questions, or just say hello.

Scientific Meeting

We were very excited to resume the OIF’s annual Science Meeting in April. 70 scientists and researchers specializing in OI research and treatment came together in person – with an additional 65 attending virtually – for a two-day session to discuss *Scientific Advances in OI*. This meeting is designed for scientists interested in learning more about the latest in basic and clinical OI research, and how the information could ultimately benefit people living with OI. This year’s meeting, chaired by Dr. Deborah Krakow, featured sessions on the musculoskeletal system, quality of life, stem cell research, cardiopulmonary issues, treatment beyond bisphosphonates and a look at what’s new on the horizon.

Awareness Week

Each year during National OI Awareness Week, OI community members request state proclamations, host events, tell their story, and share social media posts to raise OI awareness. This year, during the week of April 30 – May 7, OIF social media posts reached nearly 100,000 people, we received 22 official National OI Awareness Week proclamations, and 25 OI community members created National OI Awareness Week Facebook Fundraisers. In addition, many individuals participated in Bone China Tea and DoubleGood Popcorn Fundraisers, as well as purchased OIF Unbreakable Spirit® apparel to help share their awareness.

Jeanie Coleman Impact Grants

In partnership with the Children’s Brittle Bone Foundation, the Jeanie Coleman Impact Grant Program was designed and established to provide funding for items that will significantly improve the quality of life for a person who has OI and limited financial resources. In 2022, the OIF was able to fund \$136,509 worth of items and services for 18 families. The 2022 grants covered a range of items including: mobility assistive devices, car seats and ASL class.

Your support plays a vital role in what we do, and we hope we can count on your continued generosity.

Please consider using the enclosed envelope to make a gift of \$50, \$100 or more to the OI Foundation or go online at www.oif.org/donate to donate today!



Welcome to the OIF Board of Directors!

On July 1, 2022, we welcomed Karen L. Braitmayer, Dr. Michelle Fynan, James (Jamie) Sharples, and Dr. V. Reid Sutton to the OIF Board of Directors.



Karen Braitmayer is the founder and managing principal of Studio Pacifica, an architectural consulting firm located in Seattle, Washington. The firm is committed to creating beautifully designed, barrier-free civic, commercial, education, hospitality, medical and multi-family residential projects since 1993. In addition to her role as

managing principal, she has recently served on the US Access Board, an independent Federal agency that provides leadership in accessible design public policy. According to her company's bio, "early in her career; it occurred to Karen that as an architect and a wheelchair user, it was possible for her to make a unique contribution to the field. Her professional focus on accessibility and her advocacy efforts for inclusion certainly did just that." As a member of the OI community and a person with OI, Karen is a regular and popular speaker at the OIF National Conference and is extremely helpful to community members who are undertaking renovations to make their homes more accessible. She has been a participant at various international OI meetings. In her private life she is an avid knitter, sailor and traveler and enjoys spending time with her husband and daughter.



Dr. Michelle Fynan is a Licensed Mental Health Counselor with a PhD in Clinical Sexology. She is a Board Certified Clinical Sexologist, Sex Therapist, and Relationship/Intimacy Coach. She has specialized training from Harvard Medical School in Treating Couples, and she holds a Masters of Science in Counseling with a dual

specialization in Mental Health Counseling and Marriage, Couples, & Family Therapy. She offers virtual coaching for singles, couples, and groups on the topics of dating, relationships, sex, and intimacy, with a specialization in chronic illness and disability. Michelle has Type 1 OI and grew up as an active member of the OI community, regularly attending conferences and support group meetings with her parents. Now as a mental health professional, she has presented at a number of national and regional conferences for the OI Foundation as well as scientific and town hall meetings. She is currently serving on OIF's PCORI Patient Advisory Board and was on the PCORI Education Committee for improving patient centered outcomes at the start of the COVID-19 pandemic. She was also a Masters Thesis Committee Chair for a Baylor College of Medicine Genetic

Counseling Program student who successfully defended their thesis on parental experiences and satisfaction with genetic counseling for a prenatal diagnosis of OI. Michelle lives in Florida with her husband and her two daughters (who also have OI), and she looks forward to continuing to support the mission of the OIF together with her family.



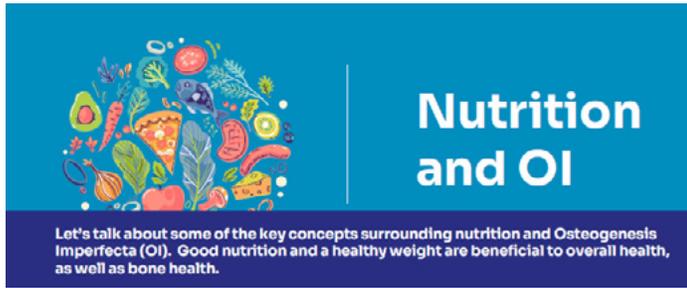
James (Jamie) Sharples lives in Downingtown, Pennsylvania, with his 13-year old daughter. He was born with Type III OI and is the only member of his family with OI. Jamie manages the private equity firm he founded in 2012 which focuses on investments in commercial real estate in the Southeast U.S. He frequently spends time in North Carolina and South Carolina for work.

Jamie previously served on the OIF Board of Directors (2003 – 2009) and has acted as the Chair of the Finance Committee for the past decade. His interest in the Foundation is deep and he said, "I've found my work with the Finance Committee very rewarding over the past many years, but I am eager to take a more active role in helping the Foundation develop the best course forward to meet the rapidly evolving challenges it and its constituents face."



Dr. Reid Sutton is Professor of Molecular & Human Genetics at Baylor College of Medicine in Houston, Texas. He is attending physician in the Skeletal Dysplasia Clinic at Texas Children's Hospital where he provides care to children and adults with OI and other skeletal disorders. He is a member of the OIF medical advisory council and

was a Principal Investigator for the OIF Linked Clinical Research Centers, a five-year longitudinal study of OI sponsored by the OIF. He is currently the co-Principal Investigator for the Longitudinal Study of the Brittle Bone Diseases Consortium of the Rare Disease Clinical Research Network (BBDC-RDCRN) and the Clinical Team Liaison for the BBDC-RDCRN. The BBDC is an NIH-sponsored, collaborative initiative with 13 participating sites across North America that aims to advance research and clinical care for individuals with OI.



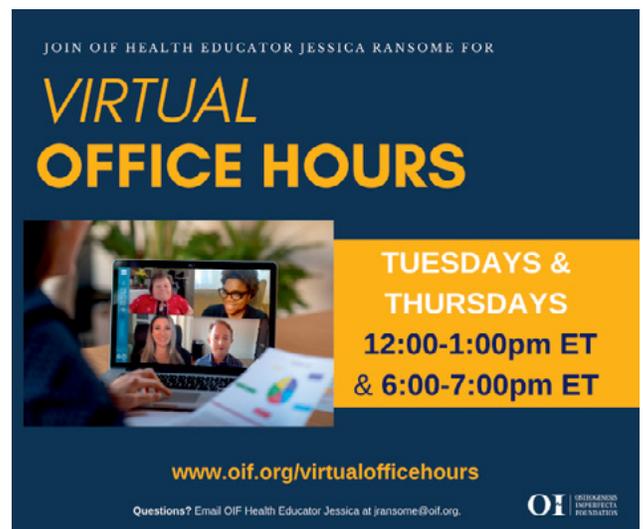
New Resource: Nutrition Factsheet

The OIF is pleased to introduce an updated factsheet on Nutrition and OI, written by OI community member Mia Gould. This factsheet was prepared in collaboration with Deborah McInerney, MS, RD, CDN (Assistant Director, Food & Nutrition Services, Kathryn O. & Alan C. Greenberg Center for Skeletal Dysplasias, Hospital for Special Surgery). Visit www.oif.org/factsheets to view the full factsheet, which highlights various factors important to overall health, and serves as a great introduction on how nutrition can contribute to improved bone health.

OIF Weekly Office Hours

One-on-One with OIF Health Educator, Jessica Ransome

OIF Virtual Office Hours are hosted by OIF Health Educator Jessica Ransome every Tuesday and Thursday at noon and 6pm ET. These sessions are completely dedicated to the need of community members. Whether you are in search of a medical professional in your area, interested in learning more about OIF resources, or have a specific question for the OIF, we encourage you to log on to OIF Virtual Office Hours. For more information, please contact Jessica at jransome@oif.org.



Michael Geisman Fellowship Grant Awardees

The Osteogenesis Imperfecta Foundation makes research a priority through the Michael Geisman Fellowship program (created in memory of Michael Geisman, son of OI Foundation founder Gemma Geisman). The Michael Geisman Fellowship program funds post-doctoral trainees whose research aims to predict, prevent, diagnose, and treat osteogenesis imperfecta (OI).

The OI Foundation is pleased to announce the most recent awardees of the Michael Geisman Fellowship Grant: Jennifer Zieba, PhD, of the University of California, Los Angeles, and Ellen Busschers, PhD, of the Baylor College of Medicine. Dr. Zieba's research project, *Collagen I mutations and ER stress in cartilage progenitors: identifying a treatment for short stature in OI*, will focus on understanding how endoplasmic reticulum (ER) stress in osteogenesis imperfecta (OI) impacts the pathogenesis of disease specifically in skeletal progenitor cells. Dr. Busscher's research project, *The role of inflammation in joint dysfunction caused by FKBP10 mutations*, proposes to determine the role of activity induced inflammation on the development of joint dysfunction in mice deficient for Fkbp10 in tendons and ligaments. We look forward to seeing the results of each project.



Jennifer Zieba, PhD



Ellen Busschers, PhD

OI Research Announcement: ORBIT Study

The OI Foundation would like to bring your attention to a research study being conducted by Ultragenyx Pharmaceutical Inc. The ORBIT Study is investigating a new treatment in children and young adults with OI. If you are interested in learning more or have any questions, go to www.patient.rarediseasetrialrecruitment.com/OI or email TrialRecruitment@ultragenyx.com.

Disclaimer: The OI Foundation is not involved in the design or management of this research, and as such, is neither endorsing nor supporting this study. The mission of the OIF is to keep the OI community informed of all relevant studies. This information is made available as a service to the OI community. We are available to answer questions on this or any other research announcement.



Clinical Study for Patients With Osteogenesis Imperfecta



Participate in OI Research and Help Make an Impact.

Why are we doing this study?

Setrusumab is a monoclonal antibody being developed for the treatment of osteogenesis imperfecta (OI). The purpose of this study is to investigate the efficacy and safety of setrusumab in pediatric and young adult patients with OI Types I, III, or IV.

Consider participating if you:

- Are at least 5 but not yet 26 years of age
- Have a confirmed diagnosis of OI Types I, III, or IV
- Had at least one fracture in the past year or at least two fractures in the past 2 years
- Are willing to not receive bisphosphonate therapy during the study

Why is it important to be willing to not receive bisphosphonate therapy during the study?

This study is designed to see the effect of setrusumab on the effects of OI. That effect can be more clear if all participants are not receiving bisphosphonates during the study. All participants will be closely monitored throughout the study. If you do experience frequent fractures during the study (while potentially receiving placebo), then you would be eligible to receive active drug after as little as 12 months.

What is involved?

Study duration:

- **Screening Period:** Up to 1 month
- **Study Treatment Period:** 1 to 2 years (depending on when you enroll)
- **Treatment Extension Period:** Receive setrusumab until commercial drug is available



Study treatment:

- Setrusumab (2 in 3 chance) or placebo (1 in 3 chance), given by intravenous (IV) infusion once a month



Study visits:

- You will receive study treatment and have lab tests and assessments at monthly study visits. The number of visits you will have will depend on when you enroll in the study and when commercial drug is available.

What to expect:

						
Infusion of study medication into your arm	Blood and urine tests	Physical exams and vital signs	X-rays and bone density tests	Heart tests	Dental health and hearing assessments	Electronic diary and questionnaires

 For additional OI study information, please contact TrialRecruitment@Ultragenyx.com

At Ultragenyx, we are committed to bringing patients new treatments for rare and ultra-rare diseases.

MRCM-LX143-00010 2/1/21

Check Out the OIF Website's New Accessibility Features

The OI Foundation is committed to making OI Foundation resources and programs accessible to all who may need them. The OIF website provides accessibility accommodations for users with visual impairment, those who use keyboard navigation or a screen reader, and more. To use these tools, simply press on the yellow icon at the bottom left corner of the website, www.oif.org.



GET IN TOUCH WITH THE OIF

 301-947-0083
 bonelink@oif.org
 656 Quince Orchard Rd., Suite 650
 Gaithersburg, MD 20878

www.oif.org

Resources for Your Doctor



Does your doctor or treatment team want to learn more about osteogenesis imperfecta? The OI Foundation has a variety of free resources intended to help improve medical professional understanding and treatment of people with OI. All of the OIF's resources are created in close collaboration with our Medical Advisory Council members and other leading experts.

Medical Professional Emails

The OIF sends out periodic emails to medical professionals about upcoming events, programs, and resources to help them better understand and treat patients with osteogenesis imperfecta. To sign up, they can go to www.oif.org/medprocalendar.

Professional Consultations

Finding knowledgeable colleagues to consult on patients with osteogenesis imperfecta can be challenging. The OIF is happy to connect any medical professional with members of our Medical Advisory Council (MAC) or other clinicians with expertise in treating patients with OI.

Medical Professional Database

The OIF maintains a list of medical professionals who have experience treating patients with osteogenesis imperfecta. Please contact the OIF's Health Educator, Jessica Ransome, at jransome@oif.org if you would like to be added to this database or if you want to request information on other local clinicians.

Medical Professional Calendar

The OIF maintains a calendar for medical professionals to keep track of upcoming medical professional events and meetings. To see this regularly updated list of public meetings, go to www.oif.org/medprocalendar

OIF Information Center

The OIF has a library of resources to help explain various topics about understanding, treating, and living with OI. The OIF Information Center at www.oif.org/informationcenter includes factsheets and publications on genetics, respiratory issues, dental care, pregnancy, and much more.

TeleECHO Sessions and Recordings

The OI Foundation holds monthly TeleECHO Clinic sessions on rare bone disease and OI topics for medical professionals. In each session, an expert speaker delivers the main presentation on a rare bone disease topic, followed by discussion and participant-led case presentations. Medical professionals of all levels are welcome to attend and present cases, and we especially encourage early-stage clinicians to present cases. Free CME is available for all attendees. A full schedule of upcoming Rare Bone Disease TeleECHO sessions is available at www.rbdalliance.org, and recordings of all past presentations can be found on the OIF's YouTube channel.

Educational Videos and Recorded Professional Meetings

The OIF has multiple videos of past professional meetings available on the OIF Youtube channel. This includes Rare Bone Disease and OI TeleECHO presentations, Rare Bone Disease Alliance Scientific Symposiums, and OI Research Updates. Also, we have a wide variety of patient-facing recordings, including sessions of past OIF National Conferences in English, Spanish, and French.



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OIF

Check out the OIF
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current OIF resources,
programs, and events!

