

Together Again: OIF National Conference 2024

Members of the OI community will come together for three days of specialized sessions on managing OI, free medical consultations, and fun social events for attendees of all ages! The entire conference will take place at the Hilton Omaha in Omaha, NE on July 19-21, 2024.

Visit www.oif.org/conference2024 to take a look at the OIF National Conference agenda, book your hotel room, apply for a Conference Scholarship, and more!

COUNTDOWN TO CONFERENCE!

It's time to start working on the Conference Countdown Checklist!

■ **REGISTER!** Don't miss Early-Bird Registration prices ending April 30th! Each conference registration type includes access to all conference sessions and conference materials. Learn more about financial assistance at the end of this article.

■ **Book Hotel and Travel:** Check out the Wheelchair Travel Guide on page 11 of this issue! The full conference will take place at the Hilton Omaha in Omaha, NE. Conference attendees MUST be registered for the OIF National Conference in order to receive the discounted hotel room rate of \$129 per night.

To request an accessible room this year, you must contact the OIF directly at bonelink@oif.org. Accessible rooms are assigned on a first come, first served basis. To ensure that you receive an ADA



room, please consider registering and submitting your request to the OIF as early as possible.

■ **Check out the Conference Program:** You won't want to miss the Unbreakable Spirit® Walk-n-Wheel, free Medical Consultations, specialized sessions, social events and more! 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 care, and an abundance of additional activities designed to address important issues for members of the OI community. Check out the full program at www.oif.org/conference2024.

(continued on page 2)



Tracy Mulroy
OIF Adult Health Initiative Community Chair

OIF Names Adult Health Initiative Community Chair

The OI Foundation is proud to announce that Tracy Mulroy has been selected to serve as the OI Foundation's first Adult Health Initiative Community Chair. This newly created role serves as a liaison between the OI community and the OIF to ensure the community voice is represented in all OIF adult health related projects. Adult health is a priority for the OIF, and the Foundation has taken the lead on several important projects, including the development of a new comprehensive *Adult Health Toolkit*. Tracy is an adult living with OI and the current chair of the Jamie Kendall Fund for Adult Health. She is a former OIF board member and has served on several steering committees for the OIF including supporting the work of the OIF's PCORI awards aimed at increasing patient engagement and exploring gaps in adult care.

Together Again: OIF National Conference 2024 *(continued from page 1)*

■ **Request a Medical Consultation:** Medical Consultation Day offers the opportunity for families and adults who have OI to have a face-to-face meeting with a physician or physical therapist who has extensive experience with OI. A consultation is a conversation. No exams can be given. This is your chance to get questions answered, to have a test or diagnostic letter explained and to get a second opinion about a treatment or about how you're doing compared to others who have OI. The program runs from 8:30am until 3:00pm on Friday, July 19. Each attendee may request up to three appointments with the specialists of their choice. Each appointment lasts 20 minutes. Medical Consultation Request Forms are available at www.oif.org/conference2024.

■ **Sign up for Childcare Services:** *To sign-up for licensed childcare services, register your child(ren) for a full 'Child Conference Registration WITH Childcare.* The deadline for advance childcare registration is June 30, 2024 or until spaces are filled. Space in the Childcare room is very limited, so sign up early to secure your child's spot.

■ **Register to take part in the Unbreakable Spirit® Walk-n-Wheel Omaha:** *For every \$1,000 raised, an individual or their team will receive one free registration!* Join fellow OI community members to raise awareness and funds that will enable the OI Foundation to continue keeping the cost of conference registration low as well as provide scholarships to help families in need attend. Read more about the Unbreakable Spirit® Walk-n-Wheel at www.oif.org/conference2024

■ **Sign Up to Perform in the OIF Conference Talent Show!** The OIF Talent Show will take place on Saturday, July 20. A Talent Show rehearsal will take place on Friday afternoon—all performers must attend. To sign up to perform in the OIF Talent Show, complete the OIF Talent Show application!

Looking for Financial Assistance to Attend National Conference?

Here at the OIF we do everything we can to keep conference fees as low as possible. Even with our fundraising efforts, we know attending the OIF National Conference can be a big expense for many people. Here are the current programs that can help with the costs:

■ **National Unbreakable Spirit® Walk-n-Wheel Omaha** Sign up to take part in the National Unbreakable Spirit® Walk-n-Wheel Omaha and for every \$1,000 your team raises, you will receive a FREE full conference registration.

■ **Kasper Kendall Conference Scholarships** Kasper Kendall Scholarships are intended for people who require financial assistance to attend the OIF National Conference. These scholarships cover registration and three nights at the conference hotel for US and Canadian residents. Applications are due March 30, 2024.

■ **The Jeanie Coleman Impact Grant Program** The Jeanie Coleman Impact Grant Program provides equipment and services that improve the quality of life for families living with OI. The program is funded by the Children's Brittle Bone Foundation (CBBF). While items that have been awarded in the past include (but are not limited to) wheelchairs, ramps, technological devices, and accessible vans, Impact Grants may also be awarded to assist in covering the cost of OIF National Conference attendance (registration, hotel, and travel costs for the whole family). The next Impact Grant cycle will open in January 2024.

For more information about OIF National Conference, Financial Assistance programs, or registration, please visit www.oif.org/conference2024.

Connect with us today!



OIF Information Center

The OI Foundation is here for you, to locate care, provide OI resources, connect you with others, and to answer questions.

The OIF offers a wide variety of services on its website, which can be found on the **Information Center** page and **Resource** page. These pages include access to many of the Foundation's services, including:

- **Medically verified factsheets.** The OIF has published many factsheets on topics related to understanding and living with OI. Topics include genetics, surgery, family planning, dental care, respiratory issues, and more.
- Medically reviewed Toolkits: **Navigating a New Diagnosis Toolkit** and the **Adult Health Toolkit.**
- Information on **Support Groups.** Organized and run by volunteers, the OI Support Group program aims to provide

a space for members of the OI community to share, educate and socialize with one another:

- **OIF Video Resources.** The OIF's YouTube page also provides videos from past conferences, community information sessions, research updates, and more.
- A publicly accessible **OI Clinic Directory.** In addition to the clinic directory, anyone looking for a specialist or doctor familiar with OI can reach out to the OIF office at **bonelink@oif.org** to locate providers in their area from a **community-generated provider list**, that is housed at the OIF.

We are here for you! Please don't hesitate to get in touch with the OI Foundation for information about OI, to connect with others, or to learn more about OIF programs.

Announcing OIF Regional Support Groups and OI Regional Support Group Leaders

The OIF Regional Support Group Program will be launching in early 2024. The Regional Support Groups are divided into five Regional Groups (Northeast, Southeast, Midwest, Southwest, and West). The groups aim to connect and foster a sense of community among OI community members in a specific region of the United States and to provide national and local resources.

The goal of the OIF Support Group Program is to provide a space for **sharing, educating, and socializing.**

- **Sharing** allows participants to talk about their experiences and feelings and offer each other mutual support and encouragement.
- **Education** occurs when group members receive new information on topics of interest.
- **Social** time provides opportunity for members to enjoy each other's company.

Each OIF Regional Support Group will be led by community members, with support from OIF staff. We are excited to announce the OI Regional Support Group Leaders below:

Northeast Regional Support Group

Carol Kessler
Dianne McNeil

Southeast Regional Support Group

Susie Wilson
Gail Bunker

Midwest Regional Support Group

Jessica Minor
Diane Albrecht

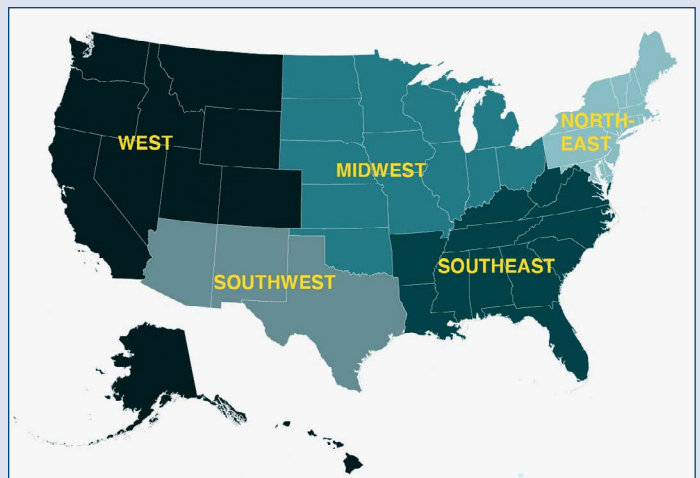
Southwest Regional Support Group

Kelli Druessel

West Regional Support Group

Diane Wysocki
Liana Teteberg

Regional Support Group Leaders serve as a contact person for families and individuals looking to connect with the OI community and OIF. One way they help bring the OI community together is through organizing and hosting regular virtual meetings. Starting early 2024, you can find more information on upcoming support group events in your region by visiting **www.oif.org/supportnetworks**!



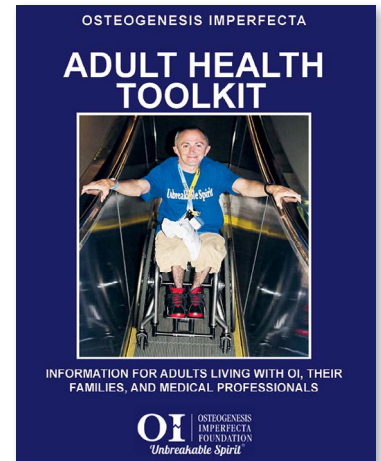
OIF Adult Health Initiatives: Introducing the Adult Health Toolkit

The Osteogenesis Imperfecta Foundation is pleased to introduce the *Adult Health Toolkit: Information for Adults Living with OI, Their Families, and Medical Professionals* to help you navigate the many aspects of managing your health as an adult living with OI. This resource seeks to provide adult OI community members with tools to use in healthcare environments and everyday life. Through this toolkit and online resources, the OI Foundation provides the most up-to-date medically reviewed information possible.

Adult health is a priority for the OI Foundation, and the Adult Health Toolkit is just one of several projects that the Foundation has taken the lead on over the last year. In addition to developing resources like the *Adult Health Toolkit*, the OIF has convened professional meetings to examine the landscape of adult care, gaps in adult care, and transition from pediatric to adult care. We also continue to fund and direct research to learn more about issues that impact adult health like pulmonary care, cardiovascular health, and pain.

Because these topics are of vital importance to our community, we ensure the community voice is represented in all that we do and have established a community liaison role to help guide the work of OIF Adult Health Initiative. Tracy Mulroy, former OIF Board Member and Chair of the Jamie Kendall Fund for Adult Health, is serving as the OIF's Adult Health Initiative Community Chair and has played an instrumental role in the creation of this toolkit. As an individual with OI herself, her deep understanding of the unique challenges faced by those living with OI informed not only the selection of topics, but also the tone of the toolkit, among the many other informative contributions. Her input helped the OIF recognize and address the topics most important to the adult OI community.

Tracy shared: *"I am thrilled to announce the launch of the first-ever OI Adult Health Toolkit which provides important information to OI adults, their families, and medical professionals! Because OI is a rare disease, it can be difficult to find a doctor who understands OI and, more specifically, how OI affects adults. This resource provides you and your caregivers the knowledge to help educate your healthcare providers and to effectively advocate for your health care needs. The toolkit contains medically verified information in one place with helpful worksheets that adults can use to keep track of their medical information and their healthcare team. I hope that you find this toolkit to be a helpful resource as you navigate your OI health care journey!"*



The toolkit was made possible thanks to the generous support of the Randolph D. Rouse Foundation. We are so thankful to Dr. Kara Ayers, Dr. Michelle Fynan, Dr. Mahim Jain, Dr. Deborah Krakow, Dr. Joan Marini, Dr. Sandesh Nagamani, Dr. Eric Orwoll, Dr. Alicia O'Sullivan, Dr. Cathleen Raggio, Dr. Robert (Sandy) Sandhaus, Dr. Laura Tosi, Tracy Mulroy, and the members of the OI Foundation Medical Advisory Council for their assistance in the development of the *Adult Health Toolkit: Information for Adults Living with OI, Their Families, and Medical Professionals*.

The electronic version of the toolkit can be found on the OIF website at www.oif.org/adulthealth.



Jeanie Coleman Impact Grant Program

The Jeanie Coleman Impact Grant program provides direct support to individuals and families living with OI in need of equipment or services that will improve their quality of life. Items that have been awarded in the past include (but are not limited to) wheelchairs, technological devices (laptops, tablets), hearing aids, home adaptation, and accessible vans. Applications for the 2024 cycle open on Thursday, January 4th, so stay tuned for more information. If you have any questions about the program, please feel free to reach out to Stacie Connors at sconnors@oif.org.

OIF Regional Conference Program

The OIF's Regional Conference program was created to bring information and community to families living with OI across the country. Regional Conferences are one-day educational sessions that cover topics essential to understanding OI held in cities across the country. Local families come together to hear from OI experts.

This past year, the OIF hosted two Regional Conferences in Washington, DC and Phoenix, AZ. Nearly 100 OI community members and medical professionals attended each meeting to connect and discuss a range of OI related topics. Topics at the

events included pain management, treatment options for adults and children, physical therapy, orthopedics and more.

We hope you will join us at an upcoming OIF Regional Conference!

Upcoming OIF Regional Conferences:

- March 2, 2024 – **OIF Regional Conference Nashville**
Vanderbilt Children's Hospital; Nashville, TN
- May 4, 2024 – **OIF Regional Conference Montreal**
Shriners Hospitals for Children Canada; Montreal, Canada



Edward D. Cranston College Scholarship

The OI Foundation is excited to announce the second year of the Edward D. Cranston College Scholarship. This scholarship, created in honor of OI Community Member Edward D. Cranston, is for students with osteogenesis imperfecta who are applying to or have been admitted to a college or university. Edward was born in 1962 with severe OI and challenged himself by pursuing all educational opportunities available to him to achieve his goal of working as a health care professional. He has dedicated his career to working with children with complex respiratory conditions and is currently held in high regard both by professionals in the field, as well as the families of the many children with whom he has worked.

Last cycle's recipients of the scholarship were Eden Nadler, who is attending the University of Central Florida, and Ethan Yamashita, who is attending Brigham Young University. They were selected from nearly 20 applicants by the review committee. Alongside Mr. Cranston, we are proud to support Eden and Ethan as they move forward in their educational journeys.

Applications for 2024 will be available beginning January 17th. Applicants must articulate a need for scholarship assistance to meet their academic goals, be committed to full-time college enrollment and show proof of enrollment in college to receive the funds. Preference for the scholarship is based on a combination of merit and financial need. Applicants are required to submit at least two letters of recommendation, their most recent official transcript, and a personal essay along with the application form.

All applications must be submitted by April 17th, 2024. For more information, please contact Stacie Connors at scconnors@oif.org.





Stay Up to Date on OI Research

The OI Foundation strives to keep OI community members updated about all current and ongoing OI studies. The OIF's Current OI Studies and Publications webpage features studies that are currently recruiting participants. Visit www.oif.org/currentstudies to learn more today.

On the OIF's Current OI Studies and Publications webpage you will also find publications from recent OI research. This page includes a spreadsheet, by Riley Johnson B.S. (Research Assistant, Oregon Health and Science University), created as a resource for people interested in the medical science supporting osteogenesis imperfecta (OI) in adults. This resource includes more than 200 articles published in the last 40+ years.

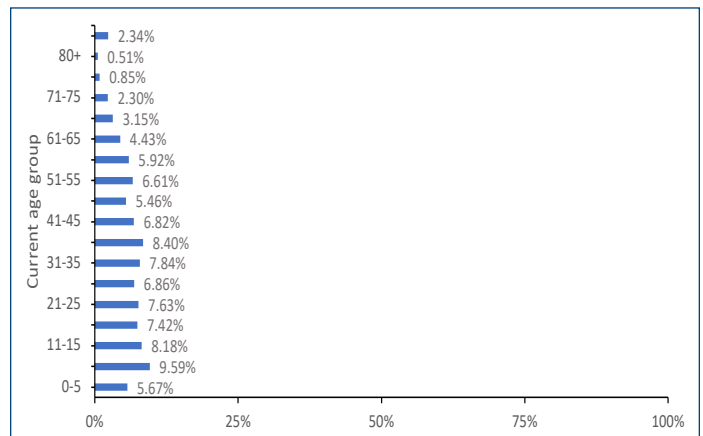
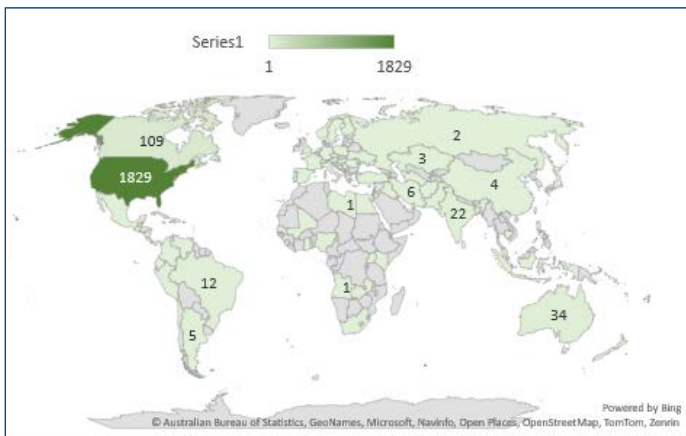
The OIF fosters relationships with pharmaceutical companies working on OI and rare bone disease research to ensure our community's needs are understood. This year, we've been able to work with industry partners on exciting clinical trials for new treatments for OI. The OI Foundation makes sure the information about these studies is distributed to the OI community in an accessible and transparent manner.

Two clinical studies, by Ultragenyx, ORBIT and COSMIC, are investigating setrusumab for the treatment of OI in pediatric and young adults. The goal of these studies is to determine whether setrusumab can safely and effectively restore bone production. Dr. Alison Skrinar (Ultragenyx) joined OIF Board Member Dr. Michelle Fynan to discuss setrusumab and the clinical trial process. Visit the **OIF website** to watch a recording of this discussion.

Participate in OI Research – Join the OI Registry!

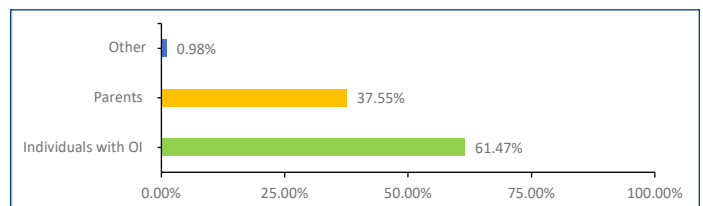
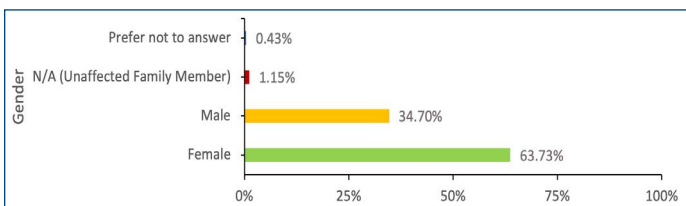
The best way to stay updated on OI research is to join the OI Registry! Individuals with OI (18 and older) and parents of children with OI are encouraged to join. Once you are enrolled, you will begin to receive information on upcoming studies and online surveys about OI. Your participation in these studies helps move OI research forward. To join the OI Registry, visit www.oif.org/oiregistry!

We are so thankful for the 2,346 individuals with OI who are helping move OI research forward by being part of the OI Registry. Learn more about this group below:



#1: The majority of participants (n=1829) are from the United States.

#2: There is a broad age range of Registry participants.



#3: Females are represented almost twice as much (64%) as males (35%).

#4: While 62% of Registry participants are individuals with OI, 38% are parents of children with OI.



Findings from OIF's Research Engagement Award

The OI Foundation's two-year project, **Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease**, which received an award from the Patient-Centered Outcomes Research Institute (PCORI), has now come to an end. As previously reported, surveys were sent out to both patient advocacy group leaders and pediatric clinic leaders, interviews were done with leaders of patient advocacy organizations and various medical professionals, and listening sessions were held with members of the OI community including patients, parents, and caregivers. Topics explored in the ventures of this phase included the healthcare needs of young adults with OI transitioning from pediatric to adult care, as well as identification of barriers and opportunities for accessing quality health care across the age span.

In the last issue of Breakthrough (June 2023), we reported the findings from our listening sessions with members of the OI community. To recap, our methods helped us to identify major gaps in care transition and adult care for individuals with OI, including the following:

- Patients with osteogenesis imperfecta are not given instructions on what doctors and/or medical specialties they need to see after they have reached adulthood and were dropped by their pediatric care team; many participants were not given referrals.
- Patients are often dropped by adult care physicians before their new patient appointments once those physicians learn they have OI.
- Emergency rooms are often avoided by patients with OI when they experience fractures, as the expense is high, while the knowledge around OI is lacking.
- Patients often feel overwhelmed when it comes to consistently having to educate the physicians they see in their adult years on OI.
- Lack of adequate insurance becomes a huge roadblock for patients transitioning to adult care.
- Finding access to general providers that take disabilities and rare diseases into account when dealing with more "common" illnesses is a problem. Patients feel as though they need to see an expert, even for basic viruses.
- Adults with OI should see multiple care providers in various specialties including audiology, cardiology, endocrinology,

and pulmonology. Patients were not advised to put together these care teams as pediatric patients.

In addition to concerns found during the listening sessions done with members of the OI community, several additional concerns were identified during the interviews with clinicians:

- There are few experts trained in the care of adults with OI, or even physicians who are not experts who are willing to care for such patients. Several of the recognized adult OI experts are nearing or past retirement age and are leaving the field. Many OI experts are only/mainly knowledgeable in the care of children and some young adults and do not specialize in adult care. Some adults with OI continue to be seen in children's hospitals by pediatric specialists, due to the inability to transfer care to adult providers. While the adults with OI are still receiving care, this is a suboptimal scenario given pediatric clinicians' lack of knowledge about the aging skeleton and their limited adult care resources.
- Clinicians frequently avoid care of adults with OI due to inadequate insurance or Medicaid/Medicare reimbursement for the care of complex patients, fear of liability if health outcomes are poor (as they so often are in this challenging population), lack of a cohort of internists or family medicine colleagues caring for OI patients with which to discuss cases, and perceived lack of effectiveness of management techniques or treatments.
- The adoption of a standard OI clinic medical note template might help clinicians better track the wide range of clinical needs of this complex community and smooth information transfer as patients transition to adult care.

The OI Foundation continues to make adult health a priority, including identifying gaps in adult care, providing resources for transition to adult care, and funding research for better treatments for issues faced by adults living with OI. On the cover of this issue, we announced that Tracy Mulroy has been selected to serve as the OI Foundation's first Adult Health Initiative Community Chair. This role serves as a liaison between the OI community and the OIF to ensure the community voice is represented in all OIF adult health related projects.

We want to hear from you!

Do you believe any major gaps in care transition were missed? If you have anything to add, please reach out to Stacie Connors at sconnors@oif.org.

A Message from OIF Board President, Ted Trahan



OIF Board President, Ted Trahan

Name tags will be oh-so-important. I mean, how long has it been since you saw your best OI buddy? If it was at the last OIF National Conference, that was back in 2018—six years ago! A person can change over the course of 6 years. You might have changed jobs, changed living conditions, changed geography, gained new colleagues, lost former colleagues, or colored your hair purple. How refreshing it will be to see everyone again.

Because... the OIF National Conference returns! It returns July 19-21, 2024 in Omaha, Nebraska to be specific. And those especially valuable elements of conference will be on display and in action. Like physician consultations. Research updates. Sessions on adult health care. Parent support groups. Youth meet-ups. Information on dental care. Meeting new people, like Marnie Starkey who appears in the Member Spotlight. And much more.

What's happening between now and the conference? Clinics participating in the Brittle Bones Disorder Consortium (BBDC) continue to evaluate important questions in clinical trials. Read about the importance of clinical trials in these newsletter pages. To engage directly with the clinical trials, consider adding your name to the contact registry. While you're at it, read the update on OI focused projects sponsored by the Patient Centered Outcomes Reporting Institute (PCORI).

We often hear about the challenges of visiting a doctor, only to find out that you know more about OI than the doctor. As we move into 2024, the OI Foundation is continuing to sponsor and support programs that expand OI expertise throughout the medical community and other rare bone disease organizations. How? Check out the articles describing OI Echo and the Rare Bone Disease Alliance.

The OI Foundation exists to support all in the OI community, whether adult, youth, person with OI or family and friends of a person with OI. The means of community support are multifaceted, and you can read about several of them in the following pages, including the OI Information Center, Support Group Program, Adult Health Toolkit and scholarships.

Speaking of scholarships, they are available for the National Conference! If you would attend conference but for the cost, please reach out to the OI Foundation by phone at (301) 947-0083 or email, bonelink@oif.org. Your scholarship request will be handled confidentially. The OIF thrives because of you, and we want to meet you in Omaha! We'll be gathering with members of the OI community from across the country, and I'm excited to greet you whether this will be your first conference or you have attended conferences previously. As it's been 6 years, names could be iffy for those of us who are name-memory challenged. I'll help out by wearing a name tag!

A handwritten signature in black ink that reads "Ted Trahan". The signature is fluid and cursive.

Ted Trahan

Members are the Heart of the OI Foundation

Without our members, we could not be the resource the OI community has come to rely on. From funding deserving research projects, to creating support groups, establishing regional and national conferences, and hosting fundraisers, we need your help! Marnie Starkey shares why being a member of the OI Foundation is important to her and her family below.

What is your relationship with OI?

My daughter, Tearrianna, has type 3 OI.

Why is membership in the OI Foundation important to you?

We have met so many new friends through OIF events like the National Conference and Regional Support Group meetings. Being a part of the OIF allows us to not only benefit from programs and resources, but also allows us to help others with OI.



Have you ever attended an OIF meeting/conference/event?

We attended the last in-person Conference in Baltimore and plan to attend the next one in Omaha. We have also participated in regional meetings held at Children's National Medical Center. We are excited to attend the next National Conference. Both Tearrianna and I have friends that we met at the last conference. It was also nice to have Tearrianna see other kids her age with OI. It made her feel less alone and isolated. I also learned so much from the different seminars that I attended.

Is there any advice you would give to a new family/member of the OI Community?

Absolutely visit www.oif.org and become a member. The knowledge and resources that are available through the foundation are invaluable. Attend every event that you are able to. Meeting others in similar situations helps so much. The OIF is a great source of support, and the events connect us all together. Listen to every podcast, read every newsletter, and reach out with any questions you may have.

What upcoming OIF program are you most looking forward to and why?

We cannot wait for Omaha 2024! We have so many friends from social media that are also planning to attend. We can finally meet in person!

The future of the OI Foundation depends on you! Please consider becoming a member of the OI Foundation at www.oif.org/membership.

Connect with the OI Foundation on Social Media!

Social media is a great tool to connect with and stay up to date on all things OI. The OI Foundation manages several social media pages.

Social media serves as a tool for communication, community building, and fundraising for the OI Foundation. Through platforms like Facebook, X (formerly Twitter), Instagram, and LinkedIn, we can raise awareness about OI, share stories from

the OI community, and communicate updates on OI research and OIF programs.

Platforms like Instagram and Facebook offer dedicated features for fundraising campaigns, making it easy for supporters to contribute to the cause directly through the platform. Facebook users can donate, share, and become advocates for the OI Foundation's mission.

Connect with us today!



Clinic Spotlight: Metabolic Bone Disorders Program at Vanderbilt University Medical Center (VUMC)

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 highlight the **Metabolic Bone Disorders Program at Vanderbilt Clinic**.



Program for Metabolic Bone Disorders at Vanderbilt

Vanderbilt University Medical Center (VUMC) in Nashville, Tennessee, is the largest comprehensive research, teaching and patient care health system in the Mid-South region. VUMC is honored to be a resource for patients and clinicians throughout Tennessee and beyond to provide advanced care for complex and rare conditions, including osteogenesis imperfecta. The Program for Metabolic Bone Disorders at Vanderbilt provides exceptional medical care and world-class discovery opportunities for individuals and families with hereditary bone disorders across the lifespan.

The Metabolic Bone Disorders at Vanderbilt clinic understands that finding out that you or a loved one has a rare bone disease can be overwhelming, and they have a cohesive and dedicated care team to help you and your loved one manage their chronic bone disorder. The clinic focuses on providing care across the lifespan, from infants to adults. This clinic is unique in that it treats

entire families with lifelong conditions. The clinic also has two case managers, Christy and George, who can help families and patients as they transition from the pediatric to adult care teams at Vanderbilt.

The clinic offers multidisciplinary care teams for pediatric and adult patients with OI. Their team is led by knowledgeable physicians and staff who are developing innovative research in order to develop guidelines to treat rare and chronic diseases. The multidisciplinary care teams have pediatric and adult providers on staff with various specialties, including endocrinology, orthopedics, anesthesiology, physical therapy, radiology, audiology, research and more.

The Metabolic Bone Disorders at Vanderbilt also recognizes that improving health care for patients with rare bone disorders requires scientific and clinical research. The unique environment at the clinic provides them with the latest technologies, collaborative expertise in diagnosis, and access to cutting-edge therapies. The staff is passionate about what they do and are engaged in several research and clinical active programs, including four OI studies for pediatric and adults that are currently open for enrollment.

Current Research Studies, Under 18 Years

- Ultragenyx Pharmaceuticals: A Randomized, Double Blind, Placebo-controlled, Phase 2/3 Study to Assess the Efficacy and Safety of Setrusumab in Subjects with Osteogenesis Imperfecta.
- Ultragenyx Pharmaceuticals: An Open-Label, Randomized, Active-controlled, Phase 3 Study of Setrusumab Compared with Bisphosphonates in Pediatric Subjects 2 to <5 Years of Age with Osteogenesis Imperfecta Types I, III, or IV.

In addition, Amgen Pharmaceuticals: A Phase 3, Open-label, Multicenter, Randomized Study to Evaluate the Efficacy and Safety of Romosozumab Compared with Bisphosphonates in Children and Adolescents with Osteogenesis Imperfecta is expected to open for enrollment late Fall 2023.

Current Research Studies, 18 Years and Older

- A Phase 2/3, Multicenter, Multinational, Double-blind, Dose-finding Study, incorporating an open label substudy, in Adult Patients ages 12 to 26 with Type I, III or IV Osteogenesis Imperfecta Treated with setrusumab (BPS804)
- A Phase 1b, single ascending dose, randomized, double-blind study to evaluate the safety, tolerability, and activity of SAR439459 in adults with osteogenesis imperfecta.

To contact the Metabolic Bone Disorders at Vanderbilt about their services or research studies, please call **615-936-8866**.



5 Key Points of Planning a Flight with a Mobility Device

This article was written by OI Community Member Aaron Busch. Aaron brings 20 years of hands-on experience in Accessible Travel to his role as a professional Travel Consultant. He is the founder of Atyzi.com, a platform that equips disabled travelers with resources for secure and inclusive experiences. With a strong track record of booking substantial travel packages, Aaron is dedicated to advocating for the unique needs of his clients. He has also contributed his expertise to notable podcasts like Accessible Media Inc. and Disability After Dark. Aaron specializes in travel solutions that prioritize comfort, accessibility, and enjoyment.

Whether you are a first-time flyer or a seasoned traveler, this Wheelchair Travel Guide aims to boost your confidence. It does so by outlining key steps and protocols that are advisable to follow consistently when you travel by plane, thereby mitigating risks. This information has been significantly truncated for the purpose of the Breakthrough newsletter, but you can read the entire article at www.oif.org/wheelchairtravelguide.

Key Point #1: Wheelchair Dimensions

Knowing your wheelchair's dimensions isn't just for your own peace of mind. You must call the Airline to advise the height, width, length, weight, and battery type of your wheelchair as it will be when transported. It is recommended to remove anything that isn't permanently secured.

Key Point #2: Advance Communication

Airlines may require prior approval in circumstances that are medically significant. This can include traveling with CPAP or Portable Oxygen Concentrators, Service Animals, or if you are recovering from surgery.

Key Point #3: Pre-Flight Maintenance

Get your mobility device inspected and maintain a copy of the report at least 72 Hours prior to your flight. While Airlines are indeed liable, they can counter a claim by contending the damage was pre-existing. It is crucial to report any wheelchair damage prior to leaving the airport; otherwise, the Airline might evade liability.



Key Point #4: Seating Assignments

The Bulkhead section is designated for travelers with disabilities, offering enhanced legroom and are located close to the lavatories. Airlines cannot impose added costs as it is your legal right under the Air Carrier Access Act (ACAA) within the United States.

Key Point #5: Aircraft Types, Boarding, and Connections

Regional Jets and Embraers may be too small to accommodate a power wheelchair, thus increasing the likelihood of physical damage or rebooking. Connections less than ninety minutes introduce significant risks of a missed flight, as individual boarding processes may introduce unforeseen delays. You should always verify this information at the time of booking.

Final Thoughts

If self-booking feels daunting, it may be prudent to consult a Travel Consultant specializing in Accessible Travel. With two decades of hands-on experience, Aaron Busch has created Atyzi.com, a free digital platform allowing travelers to securely store and share important information about their mobility device using a QR Code. Attach the QR Code to the backrest, instructing Ramp Agents to scan it and pull up all the information you have specified.

Please take a moment to read the full Wheelchair Travel Guide on the OIF website at www.oif.org/wheelchairtravelguide!

Activities of the Rare Bone Disease Alliance

The Rare Bone Disease Alliance (RBDA) is a program of the Osteogenesis Imperfecta Foundation that brings together a coalition of 17 rare bone disease patient advocacy groups and enables us to share our resources to raise awareness and improve education resources for these rare and ultra-rare disorders. In order to reach medical professionals around the world, the RBDA hosts monthly teleECHO sessions, attends specialist meetings, and hosts in-person and virtual meetings with experts.

On October 12th, OI Foundation staff and Rare Bone Disease Alliance leaders attended the American Society for Bone and Mineral Research (ASBMR) Pre-Meeting on rare bone disease in Vancouver, BC. RBDA Steering Committee chair, Dr. Eric Rush, worked closely with ASBMR and a steering committee which include OIF Medical Advisory Council member, Dr. Maegen Wallace. The meeting was attended by about 350 physicians and researchers in rare bone disease. We look forward to continuing our partnership with ASBMR to host similar Rare Bone Disease Pre-Meetings with the RBDA.

In November, OIF Staff hosted a Rare Bone Disease Alliance booth at the American Society of Human Genetics Annual Meeting in Washington, DC. This meeting exposes OI and the other rare bone diseases in our coalition to a host of early-stage investigators and post-doctoral fellows who are early in their career and looking to find a medical area of focus.

In the next year, we are excited to launch a Rare Bone Disease Bootcamp program that will help bring valuable education about rare bone diseases to a wider population. Dr. Kathryn Dahir and Dr. Danielle Reynolds will co-chair the program which will feature presentations on each of the disorders represented by the RBDA. Each patient advocacy group will provide a printable/linkable one-pager about their disorder. This program will be a powerful tool for educating medical professionals and will live as a reference on the OI Foundation's YouTube channel.

RBDA Patient Network Organizations



carolina@bornahero.org
www.bornahero.org



amcbride@fibrousdysplasia.org
www.fdmassAlliance.org



info@gaciglobal.org
www.gaciglobal.org



mrayes@hypopara.org
www.hypopara.org



michelle.davis@ifopa.org
www.ifopa.org



neenan@thejansensfoundation.org
www.thejansensfoundation.org



deb.himsel@lpaonline.org
www.lpaonline.org



iklepper@lgdalliance.org
www.lgdalliance.org



mdellinger@lmiresearch.org
www.lmiresearch.org



Kathleen@melorheostosis.org
www.melorheostosis.org



sziegler@paleyinstitute.org
www.mherf.org



bonelink@oif.org
www.oif.org



patrick@osteopetrosis.org
www.osteopetrosis.org



deborah@softbones.org
www.SoftBones.org



hello@sophiesneighborhood.org
www.sophiesneighborhood.org



odette@tinsoldiers.org
www.tinsoldiers.org



executivedirector@xlhnetwork.org
www.XLHNetwork.org



Tracy Mulroy, Tim Dombro and members of the Dombro family at Tee Time for Fine Wines Strong Bones in May 2023.



The Walls family with members of the Nemours OI Clinic team at the 2nd annual Unbreakable Spirit® Golf Tournament.



Sarah, Andersson and Earl Dyke at the 7th annual Boots and Bling for Better Bones.



Bidding at the 7th annual Boots and Bling for Better Bones.

Thank you for Attending an OIF Event!

We want to thank all the OI community members who held or attended a fundraising event this year. More than 20% of the OI Foundation's annual operating budget comes from volunteer fundraising events and we would not be able to provide the beneficial programs and services we are known for without the support of events such as the Fine Wines Strong Bones galas, golf outings, walk-n-wheels, and countless personal fundraisers!

In May, we held the **23rd annual Fine Wines Strong Bones DC** at Top Golf National Harbor! We welcomed more than 100 attendees for a full bbq menu, open bar, signature cocktails, silent auction, raffles and fund the mission auction. OIF Board of Directors members, Tracy Mulroy and Michelle Fynan, made remarks to update guests on the Jamie Kendall Fund for OI Adult Health.

Over the summer, several golf tournaments were held in honor of the OI Foundation including: the 19th annual **Rileys Gathering Golf Outing** in Elmhurst, Illinois; the 2nd annual **Matthew Smith Golf Outing** in Manchester, New Hampshire; the 2nd annual **Unbreakable Spirit® Golf** in Lebanon, Pennsylvania; and **Abruzzi Family Golf** in Bath, Pennsylvania.

We closed out the year with two Strong Bones Galas! The **7th annual Boots & Bling for Better Bones** in Houston, Texas was held on October 28th and welcomed 150 attendees who enjoyed world-famous barbeque, live honky-tonk from Weldon Henson Band, and raised more than \$100,000 for the OI Foundation. On November 4th, OIF Board Vice President, Christine Rossi, hosted her annual **Strong Bones Gala Boston** in Framingham, Massachusetts. Her committee secured amazing auction items – including signed, framed jerseys and a signed Taylor Swift guitar that helped them raise more than \$65,000!

Your support helps fund OI research and expands our reach to ensure the OIF's programs and services are accessible to every person with OI! Consider joining fellow OI community members in supporting the OI Foundation at an OIF fundraiser. Whether you want to donate the money raised at a yard sale, run a marathon, hold a family fun day, attend a gala or participate in the upcoming **OIF National Unbreakable Spirit® Walk-n-Wheel**, the OIF fundraising staff is here to help!

Please contact Irene at ISmith@oif.org if you are thinking about holding an event to raise money for the OI Foundation, or if you would like to be on a committee that plans a fundraiser. Thank you!

Thank you to our Members!

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This member directory was compiled on November 13, 2023 and includes individuals with current memberships along with Lifetime Members.



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