

## Together Again: OIF National Conference 2024

On July 19-21, 2024, hundreds of OI community members and medical professionals came together for the OIF National Conference at the Hilton Omaha in Omaha, NE. The event featured three exciting days of specialized sessions, free medical consultations, and fun social events for attendees of all ages! Stay tuned for a recap of this exciting event in the Fall issue of Breakthrough!



## OIF Hosts Meeting to Address Gaps in Adult Care

In October 2023, the OI Foundation hosted a conference titled, *Somewhere to Go for Adults with Childhood-Onset Rare Diseases: A Conversation About How We Can Fill Gaps in Care*, to bring together various stakeholders to explore the transition of care and gaps in adult care within the childhood-onset rare disease communities. Through collaboration among the patients, caregivers, clinicians, and health researchers in a wide variety of fields, we aimed to identify common themes that transcend the specifics of individual rare diseases, recognizing it is not feasible or practical to have separate strategies for each disease. These foundational elements are essential to the longer-term tasks of devising solutions, establishing the metrics necessary to evaluate their actual performance, and understanding the conditions and incentives that facilitate the adoption of adult care models that perform well for adult patients with childhood-onset rare diseases. A summary document of the meeting is available on the OIF website at [www.oif.org/stg2024](http://www.oif.org/stg2024). The summary presents our meeting findings, work products, and recommendations that resulted.



## A Message from former OIF Board President, Ted Trahan



OIF Board President, Ted Trahan

### Somewhere Over the Rainbow.

Judy Garland brought this song to popularity in the movie "The Wizard of Oz" when she sang of trouble melting like lemon drops and waking up with clouds far behind. The song speaks of belief that better days are out there. In the OI community people are looking for somewhere to go. Whether it is parents of a child with a new OI diagnosis, a young adult transitioning out of

pediatric care or an adult looking for primary care providers through the years, the need for knowledgeable, multidisciplinary care is immediate. It needs to be closer and more real than over the next rainbow.

The challenges to finding such care are significant. Is your local doctor knowledgeable on the topic of OI? Are specialists available? Do you have reliable transportation to access health care? How much of your health care is covered by insurance? Do you need care at home? How is your mental health?

What is your family or friend support system like?

The OI community and the OI Foundation are working together to make progress on these challenges. In this issue of Breakthrough, find the update on the "Somewhere To Go" initiative. Look for examples of best practices in OI care as described in the OI Clinic Spotlight. Read about the Delphi panel and the developing guidance in the specialty area of cardiovascular considerations for people with OI. In terms of spreading knowledge, a rising tide lifts all boats. Progress in one

area of bone disease benefits all areas of bone disease. Check out the activities in the rare bone disease space occurring under the auspices of the Rare Bone Disease Alliance.

Numerous works-in-progress at research sites around the U.S., Canada and the U.K. were reported at the OIF science meeting in Chicago. In one lively session, Dr. Maegen Wallace and Dr. Jeanne Franzone reached out to the research scientists with a request for molecular-level understanding of bone nonunions. This was a perfect example of patient centered outcomes meeting basic science. Check out the science meeting recap. You will also meet Marie Coussens, the newest recipient of the Michael Geisman Fellowship Grant.

Of course, all of this is made possible in part by you through fundraising events, membership and participation in OIF programming such as support groups and conferences. Wait! Are you a member?! If so, thank you! Not a member yet? Please join now! Your membership supports research, provides information, develops new resources, expands support groups and increases public and professional awareness about OI. The OI Foundation is a member supported organization!

One more note from the Wizard of Oz: although the Wizard said he hailed from Kansas, the hot air balloon that he left Oz in said "Omaha State Fair". The OIF National Conference in July took place in Omaha, Nebraska! Whether you traveled by car, plane, or hot air balloon, I was glad to see you there!

A handwritten signature in black ink that reads "Ted Trahan".

Ted Trahan





# OIF Board of Directors Updates

On July 1, 2024, we welcomed a new OIF Board President and several new Board Members. Learn more about our new members below!

## We are thrilled to introduce Christine (Wyman) Rossi as the President of the OIF Board of Directors!



**Christine (Wyman) Rossi** is a Senior Vice President at reachHIRE, an organization that puts people back to work into Fortune 500 companies after taking career breaks. She has had a 20+ professional career focused around recruiting and development of people at all ages and stages within various businesses & corporate industries.

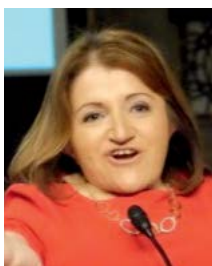
Christine has type I OI as does her father, sister, niece and son and has been volunteering within the OIF for 21 years including 2 stints on the Board of Directors (2003-2009) and (2019-present). She is the current OIF Board of Directors President. Christine started the Unbreakable Spirit® Walk OI in 2005 and took it national in 2007. After 12 years and over \$1,000,000 raised, she retired the Boston fundraising event and launched the Strong Bones Gala Boston in 2018 now in its 7th year focused on research around adult health cardiac issues of people with OI. Christine comes from a legacy of committed volunteers specifically her father Dick Wyman who has been heavily involved with OIF since the early 80s. Christine lives in Ashland, MA with her husband John and two boys, Jack & Hugo.

## New OIF Board of Directors Members:



**Dr. Kara Ayers** is an Associate Professor and the Associate Director of the University of Cincinnati Center for Excellence in Developmental Disabilities at Cincinnati Children's Hospital Medical Center. She is trained as a psychologist and leads the National Center for Disability, Equity, and Intersectionality. Dr. Ayers' research interests include health equity,

disability ethics, and parenting with a disability. She enjoys applying what she learns through research by educating policymakers about ways we can improve outcomes through better policies for all.



**Julie Hocker** is a Director of Public Health at Guidehouse. Ms. Hocker leads advisory work for federal, state, industry, and nonprofit executives and experts who are transforming the lives of Americans with disabilities, complex medical conditions, and rare diseases. Most recently, she has been instrumental in reimagining how regulators, researchers,

pharmaceutical companies, and patient groups can transform

their partnerships and interactions to accelerate the development and approval of life-saving treatments for ultra-rare conditions and underserved populations. Prior to joining Guidehouse, Ms. Hocker served as the U.S. Commissioner on Disabilities. As Commissioner, Ms. Hocker directed the nation's leading agency, the Administration on Disabilities at the Department of Health and Human Services, charged with executing a \$375 million budget and ensuring the nation's 60 million Americans with disabilities have access to the services and supports they need to live in their communities and fully pursue the freedoms and rights we all enjoy. Ms. Hocker earned her Master of Business Administration from the University of North Carolina at Chapel Hill and resides in Arlington, Virginia.



**Tony Jacobsen** (O.I. Type I) is the author of "Disable Your Disability: Live the Healthy Life You Deserve!" and a certified personal trainer specializing in empowering individuals with disabilities. Tony is committed to helping people lead healthier, more fulfilling lives regardless of their limitations. When he's not busy coaching clients, you can catch him

energizing audiences as a motivational speaker, spreading his message of resilience and possibility. In addition to his professional pursuits, Tony actively supports the O.I. community by hosting monthly online group meetings and dreaming up creative ventures to bolster support and foster connections. Tony is all about spreading positivity, pushing boundaries, and having fun while doing it. He's ready and excited to amplify the OIF's already tremendous support for empowering, educating, and advocating for those touched by osteogenesis imperfecta.



My name is **Cindy Medina**, and I am a mother and healthcare executive in Houston, TX. In both my personal and professional life, I have a passion for improving access to quality healthcare and improving overall quality of life! Currently, I hold the role of Chief Operating Officer for Fairmont Healthcare. Throughout my career I have honed my skills in strategic planning,

budget management and community engagement. But what sets me apart is my passion for using those skills to make a positive impact in the world. I have co-chaired fundraising events, led a Girl Scout troop and even developed a scholarship program for a youth volleyball team. I also take immense pride in coordinating the best care possible for my son with special needs. All of these experiences have taught me that with passion, dedication, and commitment, parents can accomplish extraordinary things in both our personal and professional lives. Because of this and the meaningful impact the OI Foundation has made on my family, I am deeply committed to advancing the mission of the OI Foundation!

# Meet Your OIF Regional Support Group Leaders!

In April/May of 2024, the OIF launched the OIF Regional Support Group Program. This program is divided into five regional groups (Northeast, Southeast, Southwest, Midwest, and West) and offers community members in each region the opportunity to connect virtually. With the support of OIF staff, Regional Support Groups are run by OI community members. To view upcoming meetings in your region, visit [www.oif.org/supportnetworks](http://www.oif.org/supportnetworks)

## Northeast Regional Support Group Leaders



**Carol Kessler**

Carol Kessler is a child, adolescent and adult psychiatrist and a Lutheran pastor who lives in Westchester County, New York, with her husband, young adult son, two dogs, and a cat. She and her son live with Type I Osteogenesis Imperfecta. Carol enjoys singing, reading and spending time with friends. She is eager to get

to know others affected by osteogenesis imperfecta in the Northeast Region and to serve as a resource in connection with the OI Foundation.



**Dianne McNeil**

Dianne McNeil has had a lengthy career as a Paralegal in a general practice law firm outside of Boston, Massachusetts. She enjoys being part of a team that strives to provide caring and effective service to clients, and she is a strong advocate for the underserved. She is excited to help

those in the OI Community find the support they need and to help connect them with the many resources the OIF has to offer. Dianne has a strong connection with her family, friends, and community and is a big fan of live music, the local sports teams, and traveling. She is a multi-instrumentalist and the reigning and still undefeated Meatball Challenge Champion (a meatball cooking contest, not a meatball eating contest).

## Southeast Regional Support Group Leaders



**Gail Bunker**

Gail Bunker has been a member of the OIF for 40 years. She has co-chaired the Florida OI Support Group with Susie Wilson for the last 20 years. She is a past member of the Board of Directors and has participated in the Bone China Tea fundraising event since 1993. She

has attended several National and Regional Conferences in Connecticut and Florida. Gail and her husband, George, live in Valrico, Florida. Their daughter, Dr. Michelle Fynan, and granddaughters Addison and Avery, all live with OI.



**Susie Wilson**

Susie Wilson has lived in Fort Myers, FL for over 20 years, after moving from Larchmont, NY in 2003. She has been involved with the OI Foundation since 1992 and served on the OI Board of Directors for six years, co-chaired the Tampa OI Support Group for over 20 years, chaired the Bone China

Tea Fundraiser and has spoken at the National and Regional OI Conferences. Susie was in the medical billing insurance field for over 25 years before she retired in 2019. She also volunteers at JN "Ding" Darling National Wildlife Refuge on Sanibel Island. She has been a member of St. Michael All Angels Church, Sanibel, FL, for fourteen years and currently serves on the Vestry.

## Midwest Regional Support Group Leaders



**Diane Albrecht**

I've been married to Bruce for 30+ years. My work experience is in technical writing and marketing communications. Currently, I volunteer with Big Brothers Big Sisters and mentor women through our church. I enjoy baking, walking our dogs and family vacations with my husband and our two adult children. I've lived in the Midwest

my whole life and look forward to connecting with other OIF members in the region!



**Jessica Minor**

Jessica Minor lives in Fishers, IN with her husband and daughter Caroline who also has OI. Although an Indiana-native she recently moved back after spending 8.5 years in Maryland. She has worked in the disability-field her whole career and is currently the Director of Community

Engagement at accessABILITY, Center for Independent Living in Indianapolis. She is passionate about building community connections and ensuring access and inclusion for the disability community. She has a Master's in Public Policy from the University of Maryland.

## West Regional Support Group Leaders



### Diane Wysocki

Hello, my name is Diane Wysocki. I am honored to work with OIF as a Regional Support Group Co-Leader for the West. I am based in Seattle, WA, where I live with my 17-year-old daughter, Charlotte. Both Charlotte and I have OI type III.

Currently, I work as a Healthcare Recruiter while raising my daughter and spending a lot of time at Seattle Children's Hospital with her. I have been a part of the OI community for many years, and I am passionate about helping others who are facing similar challenges. I believe that by sharing our experiences and supporting one another, we can make a positive impact on the lives of those affected by OI.

We have a local Puget Sound Peer Support group on Facebook, and I am looking forward to expanding our local community to the West Region. I am excited to meet many of you in future Zoom calls and, hopefully, some of you at the OIF National Conference in July.



### Liana Teteberg

My daughter, Connie, and I have osteogenesis imperfecta – Type III-IV. Not until Connie was born with a fractured femur and many fractures thereafter did we become aware of the diagnosis. I have spent my career in various health-care settings, ranging from bedside

nursing, caring for patients as a nurse practitioner and physician assistant, to being part of executive management teams at several large healthcare enterprises. My final career venture was establishing and managing a hospice agency until I retired. It is my commitment to serve in the capacity of support coordinator for the West Region, bringing the skills acquired throughout my life and my experience with the challenges faced by those of us with osteogenesis imperfecta, to support families dealing with caring for loved ones with osteogenesis imperfecta.

## Southwest Regional Support Group Leader



### Kelli Druessel

Hello! My name is Kelli Druessel. I am 57 years old and have Type IV OI. Along with numerous broken fingers, toes, ribs, and spinal compression fractures, I have had around 30 broken legs, a broken wrist and most recently, a broken shoulder and yet another spinal compression fracture.

I have lived in Mesa, AZ, with Steve, my husband of eight years, since October of 2022. Prior to AZ, I lived my entire life in Bloomington, Illinois. My goal is to NEVER see snow or ice again! I retired in 2022 from Country Financial, where I worked for 39 years. I am a big sports spectator and enjoy watching baseball, golf, and tennis. I am excited for the opportunity to meet fellow folks who are impacted by OI and see what we can accomplish together and learn from one another!

## OIF Regional Conferences

OIF Regional Conferences are one-day in-person meetings held in cities around North America meant to help community members better understand and treat OI. Regional Conferences offer an intimate in-person educational experience and are a great first meeting for OI community members with less exposure to the OIF's programs and events. This year, the OI Foundation has held two Regional Conferences:

On Saturday, March 2nd, the OI Foundation hosted a Regional Conference at Children's Hospital at Vanderbilt University Medical Center in Nashville, Tennessee and welcomed 87 attendees. This meeting was chaired by Dr. Kathryn Dahir (an endocrinologist treating adults at Vanderbilt) and featured local physician speakers as well as OIF Board Secretary Dr. Michelle Fyran and OIF Medical Advisory Council members Dr. Cathleen Raggio and Dr. Laura Tosi.

Next, the OIF partnered with Shriners Hospital for Children® – Canada and the Canadian OI Society to host a Regional Conference in Montreal, Quebec on May 4th. This meeting featured presentations by many members of the medical team of Shriners Hospital for Children® – Canada as well as Canada based clinicians and OI Foundation MAC members. The child life specialists at Shriners Hospital for Children® – Canada created a wonderland of children's programming for the youngest Regional Conference attendees. All meeting materials were presented in both English and French and live French interpretation was available on the day of the meeting.

We have begun planning the Regional Conference program for 2025 and look forward to reaching more OI community members in their hometowns.



# Get Ready for Back to School!

## Preparing for Grade School

While summer is a time for relaxation, it's also an opportunity for parents to start preparing for the upcoming school year. By taking early steps, you can help make the transition back to school as smooth as possible for both you and your child. Children with OI, of all types, usually have normal to above-average intelligence and typically participate in a regular curriculum. Instructional and physical environment modification may be required for safety and to promote independence. Some children with OI benefit from assistive technology devices for energy conservation, such as lightweight writing instruments, pencil grips and adaptive scissors.

As a parent of a child with OI, it's essential to familiarize yourself with the federal and state services that offer free and appropriate education tailored to your child's needs. The Individuals with Disabilities Education Act (IDEA) sets the minimum requirements that states must meet to receive federal funding for special education and related services. By reaching out to your local public school system's central office and/or your state's Department of Education, Office of Specialist Education, you can gain insights into your state's specific laws and regulations. This knowledge will empower you to advocate effectively for your child's educational needs.

The primary concern for a child with OI is ensuring a safe learning environment that caters to their needs as a child, a student, and a person with a physical disability. If your child requires special education services, the first step is to contact the school district's office on special education and learn about the programs offered and the process for obtaining services. Public and private schools typically offer different services based on the state's laws. Each child is evaluated by school personnel and then recommended for an Individual Education Program (IEP) or a 504 plan, both of which are tailored to their unique needs. As your child progresses through school, the need for services will be reassessed yearly to ensure they continue to meet your child's specific needs.

There are a number of tips to help you as a parent ease your child's transition into the classroom. Some of these tips include:

- Start the process early. Do not wait until a few days before the first day of school.
- Well before school opens, meet with the teachers to explain OI and provide pamphlets and brochures from the OI Foundation.
- Explain that fractures may occur and when they do, no one – including the teachers and other children – should feel that they are at fault. Emphasize the benefits gained by the child's participation in regular school programs far outweigh the risk of a fracture, which could occur wherever the child may be. Provide a telephone number should an emergency arise, along with other instruction should a fracture occur.
- Decide together whether a parent, the teacher or the child with OI will explain OI to the other children.
- Explain to the teachers that it is best for your child to be treated the same as the other students, equally and without special favor or attention. It is most beneficial if the teachers understand the child's strengths and limitations and know that they have the full support of the parents.
- Arrange for an ambulatory child with OI to change classes a few minutes before the bell rings to prevent unnecessary physical contact in crowded halls.
- Keep a separate set of books at home for the student to use to avoid the need to carry heavy books for homework. Many older children use electronic textbooks.



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- Modifications can be made in the curriculum so that a child can participate in regular programs, including gym, to the fullest extent possible.
- Many schools hire a full-time aide to assist a child using a wheelchair to get around. However, once a child has reached second grade, other classmates can sometimes be enlisted to assist the child in getting around or with other activities, when appropriate.
- If your child uses special equipment to accomplish a necessary activity, you can offer to provide the same equipment for use in school.

For more details on preparing for grade school, visit the OIF's Information Center and review the following factsheets:

**Preparing to Send a Child with OI to School** and **Education Issues**.

## OIF's Online Information Center

The OIF is here to help you locate care, provide OI resources, connect you with others, and answer questions. The **OIF Information Center** offers a variety of resources, including medically verified **factsheets**, toolkits, including the **Navigating a New Diagnosis** and the **OI Adult Health Toolkit**, an **Audio and Video Learning Center**, a **Clinic Directory**, and a **community-generated provider list** housed at the OIF.



## Preparing for College

Planning for college is an exciting and time-consuming process. When selecting a college for you and your family, it is important to balance your needs and interests. It doesn't pay to attend an accessible college that doesn't have the major you wish to pursue or attend a famous college where you cannot easily get into the labs or dorms.

When doing college site visits, you will want to evaluate the terrain, the weather, and the distance from the dorm or parking lot to dining halls and classrooms. Check out the availability of public transportation to, from or on campus, laundry facilities and health care. If you are considering residing on campus, you will need to see several dorms and evaluate the room size, furniture, closet, and restroom features. Some colleges have special accessible dorm rooms similar to ADA hotel rooms, either in a separate building or within an existing dorm. Review the OIF's **Guidelines for College Selection Process for Students Who Have OI** for a list of considerations for your selection process.

As a student with OI, you may need a great many accommodations while at college or very few, and this may vary from one semester to another. You should be thinking about your needs during a typical day. Determine what is needed to live as independently as possible, get around, study, and be a member of the community. It is also essential to talk with your family to develop a plan for handling fractures or illnesses. Review the OIF's **Checklist of Possible Accommodations to Review When Visiting Colleges** to help you prepare for college selection and entering college.

## New! The OI Adult Health Toolkit is now available in Spanish!

The OIF is excited to be able to offer the OI Adult Health Toolkit in Spanish to our Spanish-speaking OI community members, their families, and medical providers! This toolkit provides patients and providers with medically verified information on various health topics for adults with OI and contains a range of resources to help adults with OI navigate the many aspects of their health as adults living with OI.

View the Spanish-translated version of the OI Adult Health Toolkit at [www.oif.org/adulthealth](http://www.oif.org/adulthealth).





### Stay Up to Date on OI Research

Supporting research is an important part of the OI Foundation's mission. 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](http://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.

### Congratulations, Marie Coussens, PhD!

The OI Foundation is excited to introduce the latest Michael Geisman Fellowship Grant recipient, Marie Coussens, PhD.

The Michael Geisman Fellowship Grant program awards funding up to \$50,000 per year, for two years, to postdoctoral trainees who are currently working on projects with clear relevance to osteogenesis imperfecta, or who have projects that will enable them to develop expertise in OI research.

Dr. Marie Coussens, of Ghent University in Belgium, will receive funding for her project *Targeting Muscle in Adults with Osteogenesis Imperfecta: A New Exercise Approach*. This project is an interventional study to evaluate the impact of blood flow restriction training on muscle and bone health and quality of life in adults with osteogenesis imperfecta Type I.

Dr. Coussens studied physiotherapy and rehabilitation sciences with specialization in internal diseases at Ghent University (2009-2014). After this training, she worked as an independent physiotherapist at Ghent University Hospital and a private practice, which she combined with teaching physiotherapy students at the university. In 2017, she started a PhD mapping physical functioning in adults with genetic connective tissue

### 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 advance the scientific understanding of OI so that more and better treatments can be made available to the OI community. To join the OI Registry, visit [www.oif.org/oiregistry](http://www.oif.org/oiregistry)!

### Brittle Bone Disease Consortium (BBDC)

Each month, the Brittle Bone Disease Consortium (BBDC) shares summaries of recent Rare Diseases Clinical Research Network (RDCRN) grant-funded publications. Learn more and listen at <https://rb.gy/0yzjwl> and stay updated on the latest RDCRN research.



Marie Coussens, PhD

disorders. During this trajectory, she went for three months to Australia to get more experience in the world of osteogenesis imperfecta and became very passionate about working with individuals with OI. As her PhD identified significant bone and muscle impairments in adults with OI, she was eager to find a way to improve these impairments and improve their medical/physiotherapeutic care. Hence, she will follow up her PhD as a post doc

at Ghent University and will conduct the training study in adults with OI.

If you can't find Dr. Coussens in the Hospital, you can find her playing the clarinet in the royal harmony, renovating her house, having fun with her 1-year-old daughter, or going for a run in nature.

The OI Foundation looks forward to supporting Dr. Coussens and we are excited for the results of this study.



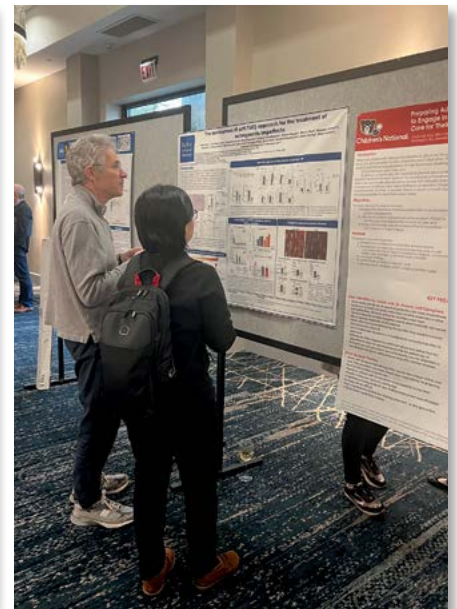


## Annual OI Foundation Scientific Meeting

The 23rd Annual OI Foundation Scientific Meeting was held in Chicago, Illinois on April 17-19, 2024. The meeting, titled *Research in Osteogenesis Imperfecta: Path to the Future*, was chaired by Dr. Charlotte Phillips of the University of Missouri and gathered more than 95 clinicians and researchers to review current research and look ahead to potential scientific advances that will improve treatment for people living with OI. Session topics include Cardiopulmonary Research, OI Mouse Models, Updates on Non-Type I OI, Partnerships to Advance Research, Clinical Needs and Challenges and Future Research Directions. The meeting included

a poster session where more than 23 participants shared findings from current research projects, and a mentor-trainee dinner for early-stage investigators to connect with senior investigators.

The annual OIF scientific meetings are an opportunity for leading researchers and clinicians from around the world to come together to share their work and collaborate to help advance the study of OI and improve treatments for individuals living with OI. This year's meeting was made possible with generous funding from the Buchbinder Family Foundation and Ultragenyx.



Above left: The 23rd Annual OI Foundation Scientific Meeting

Above right: Early Stage Investigator I-Wen Song, presenting her research to OIF Medical Advisory Council Member Dr Matthew Warman during the poster session.

Bottom left: The OIF works to engage new minds in the field of research and development of treatments of OI. Early-stage investigators, pictured above, participated and presented at the 2024 OIF Scientific Meeting.



# 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! Dr. Jeanne Franzone shares why being a 1970 society member of the OI Foundation is important to her below.

## What is your relationship with OI?

*Hello. My name is Jeanne Franzone and I am a pediatric orthopaedic surgeon at the Nemours Alfred I. duPont Hospital for Children in*



*Wilmington, DE. I am the Surgical Director of our multidisciplinary OI program and the Elizabeth W. Snyder Endowed Chair in Osteogenesis Imperfecta. Our OI program provides care for patients and families with OI from the prenatal period through the age of 35 years. We have a large multidisciplinary team and I love working with our team to provide comprehensive fracture care, medical care and surgical care. One*

*of my favorite parts of being a part of the OI community is building relationships with our OI patients and families over the years and being there for families during both the amazing victories and also the tough challenges.*

## Why is membership in the OI Foundation important to you?

*I strongly value membership in the OI Foundation as it helps support the important mission of the organization. The OIF staff is tirelessly dedicated to helping improve the quality of life of people affected by OI by advancing research, education and awareness and connecting folks to provide support. Membership in the OIF brings together a peer group interested in advancing the care options for OI patients and helps us connect with the OI community to spread this care and offer education for patients and families.*

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

*I have had the pleasure of attending many OIF meetings and conferences, all of which have been wonderful events. I particularly loved the OIF Regional Conference we hosted in Wilmington including the fun Halloween party, costumes and all! The OIF did a wonderful job carrying on the National Conferences virtually during COVID and I am very excited to re-connect in person in Omaha this coming July 2024.*

## What has been your favorite OI Foundation event?

*This is a tough question as there are so many OIF events that have been favorites! On an academic note, the OIF Scientific Meeting every April is a highlight of the year as the OIF works to connect basic science researchers and clinicians in the OI field to share ideas and help push OI care forward through meaningful research. Fundraising*



*is an important activity for the OIF and I will always cherish fond memories of hiking 50 miles along the C&O Canal with amazing members of the OIF community. Another favorite event has been the Annual Unbreakable Spirit® Golf Tournament hosted by two of our OI families in Lebanon, PA every September – our OI team travels to Iron Valley Golf Course to support the fun event and help raise funds for the OIF!*

## What OIF program are you most interested in/ benefited you most/how?

*There are so many OIF programs that are quite meaningful and push me as an OI doctor. Participating on the OIF Medical Advisory Council, Chaired by Dr. Cathleen Raggio, is an honor and a responsibility the members of the council value to help push forward the mission of the OIF and the OIF Board of Directors and provide clinical guidance and direction to the Foundation. I have also enjoyed both ongoing TeleECHO series including the OI TeleECHO series I am delighted to*

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Chair alongside Dr. Frank Rauch and Sandesh Nagamani. The OIF Clinic Town Hall series has helped incorporate more clinics into the OIF family.

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

*For new families and members of the OI community, first and foremost—welcome. I would encourage you to reach out to the OIF and take advantage of the many trusted OIF educational resources and also OIF opportunities for support. Meeting other OIF community members virtually and/or in person can be a wonderful way to gather information and seek advice. One word of caution would be to absorb clinical information within support groups with some caution as OI is*

*a condition with a large range of clinical presentation and we strive to care for each child and adult with OI as a unique individual. Two wonderful resources for new families include the recent OI Tool Kits: “Navigating a New Diagnosis: A Tool Kit for Parents and Medical Professionals” and the “Adult OI Health Toolkit.”*

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

*So very excited to see many folks in Omaha this July 2024 for the upcoming OIF National Conference – Together Again!*

**The future of the OI Foundation depends on you! Please consider becoming a member of the OI Foundation at [www.oif.org/membership](http://www.oif.org/membership).**

## Upcoming Fundraising Events!

Consider joining your fellow OI community members at an upcoming fundraising or awareness event.

■ **August 10<sup>th</sup> – Bath, PA - Abruzzi Golf**

The Abruzzi and Koch families will be hosting their 3rd annual golf tournament at the Southmoore Golf Course in Bath, Pennsylvania.

■ **September 18<sup>th</sup> – Lebanon, PA - Unbreakable Spirit® Golf**

Tara Zilling and Scott Walls will be hosting the 3rd Unbreakable Spirit® Golf outing at Iron Valley Golf Club in Lebanon, Pennsylvania.

■ **October 19<sup>th</sup> – Houston, TX - Strong Bones Houston**

The 8th annual Boots & Bling for Better Bones in Houston, Texas will be held on Saturday, October 19, 2024 at Armadillo

Palace. Join host committee members Sarah Dyke, Cindy Medina, Courtney & Robert Paddock and Zarina Rasheed for a boot stomping good time full of award-winning BBQ and Honky Tonk.

■ **November 2<sup>nd</sup> – Boston, MA - Strong Bones Boston**

Christine Rossi and her committee will be returning to the Sheraton Framingham for the 7th Strong Bones Boston Gala on Saturday, November 2, 2024.

*For details on all upcoming events including tickets and registration, visit [www.oif.org/events](http://www.oif.org/events). If you are interested in hosting your own event to support the OI Foundation, contact Irene Smith at [ismith@oif.org](mailto:ismith@oif.org).*





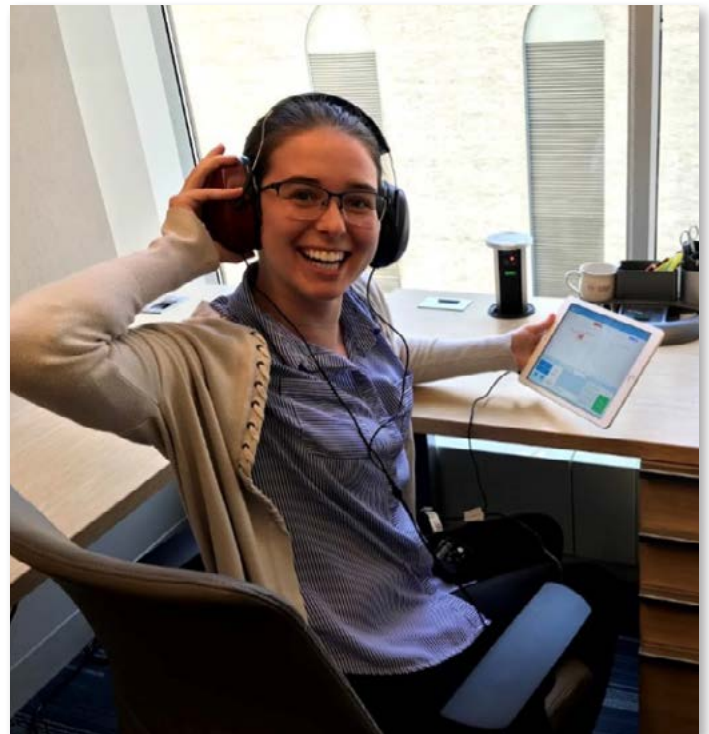
## Findings from Hospital for Special Surgery's Hearing Loss in OI Study

OIF Medical Advisory Council Chair Dr. Cathleen Raggio and her research team at the Hospital for Special Surgery (HSS) have sponsored an ongoing research study to explore hearing loss in the OI population and investigate self-reported factors that may influence how frequently members of the OI community see a professional audiologist. To date, the study has recruited 97 participants through the OI Clinic at HSS as well as at OIF regional and national conferences. Preliminary results suggest that the majority of individuals with OI in the study reported going to a professional audiologist for hearing testing less frequently than once every two years and just over half of people expressed that this was because they felt they had no issues with their hearing. Importantly, however, **the same people who reported feeling that they had normal hearing often still exhibited some degree of hearing loss during their hearing screening.** Overall, 71% of the participants in the study had at least one abnormal hearing threshold, while 43.4% of individuals had hearing loss considered to be "socially-significant" (a criterion which uses a cutoff based on words as opposed to a tone played in the ear).

Overall, information gained from this study suggests that people with OI may show signs of early hearing loss at certain frequencies even before their hearing loss becomes noticeable or begins to affect their daily living. Because of these findings, the study team would like to emphasize and add onto the OIF's Adult Health Toolkit's guidelines surrounding hearing testing. Specifically, ENT collaborators advise that individuals with OI should have **hearing testing done at least once every two years and continue to follow with an**

**audiologist once a year if hearing loss is detected.**

Furthermore, it is important to make sure you have full speech testing done during an audiology visit, because speech testing can help your audiologist or ENT provider determine whether your hearing loss may impact you in conversations or other social situations.



*A research coordinator with the SHOEBOX audiometer (headphones and tablet) used for mobile hearing testing.*

## Clinicians and Researchers Gathered to Explore the Implications of Cardiovascular Disease in OI

This past January, the OIF successfully hosted a meeting bringing together 15 leading experts from around the world for a three-day meeting to better understand the impact of OI on cardiovascular health. While there are compelling data that suggest some cardiovascular problems are more prominent in OI, the information is scattered across multiple different sources and studies, and there have been no complete evaluations of the literature concerning pathophysiology, epidemiology, and clinical characteristics. The meeting was held

using a formal Delphi process (which uses a panel of experts to work towards a consensus opinion) to accomplish the following goals: comprehensively review the available literature concerning cardiovascular disease in adults with OI, develop recommendations for clinical care, and identify compelling research needs. The group is now working together to produce a manuscript of their findings, which will be published in a peer-reviewed journal.



## OI Clinic Spotlight: Nemours Children's Health, Delaware

Nemours Children's Hospital, DE, located in Wilmington, Delaware is named one of the nation's best children's hospitals, year after year, with world-class physicians and staff in a wide variety of pediatric specialties. It is a part of one of the nation's largest multistate pediatric health systems, which includes a network of more than 70 primary and specialty care practices.

Here at Nemours, osteogenesis imperfecta does not feel like a rare diagnosis. Families from around the world come to our program for life-changing OI care. Our experienced team strives to provide children and young adults up to the age of 35 the best care possible, in hopes of helping them reach their fullest potential.

Our multidisciplinary OI team includes specialists in genetics and complex care, orthopedic surgery, anesthesia, neurosurgery, and physical therapy. We offer a team-based approach to bisphosphonate therapy, fracture management, extremity and spine surgery, rehabilitation therapy, pain management and more.

Additionally, the OI team at Nemours regularly collaborates with specialists in departments across the hospital including MFM and OB through our Advanced Delivery Program, neonatology, ENT/audiology, pulmonology, nutrition, ophthalmology, cardiology, radiology, and social work, to ensure the needs of each individual are met. At Nemours Children's Hospital, Delaware, we understand the importance of staying at the forefront of OI care. Our team actively participates in clinical research with the goal of improving care for individuals with OI.

Families traveling from a distance often choose to stay in the Ronald McDonald House right across the street, offering a safe and affordable home away from home, with assistance in transportation to and from our hospital. It is also a great place to meet other OI families who may be here for bisphosphonate therapy, inpatient, or outpatient care.

We hope to see you soon! Please call 302.651.4880 to speak with our nurse navigator to schedule coordinated appointments with our OI team.





Attendees at the 24th Annual Fine Wines Strong Bones Gala cheer on the auction winner in Washington, DC.

Winners of a Taylor Swift signed guitar at the 24th Annual Fine Wines Strong Bones Gala in Boston, MA.



Event host Jim Early at the Fine Wines Naples Reception.



A Wine Tasting Demonstration at the Fine Wines Naples Reception

## Thank you for Attending an OIF Event!

We are so grateful to members of the OI community who go out of their way to host, attend or volunteer at fundraising events in their area. Here are just a few of the events that have been held on behalf of the OI Foundation this year:

- Members of the Fine Wines Strong Bones Gala host committee including Tracy Mulroy, The Bache Family, Vivianne Coutts, The DeBlois Family, The McNutt Family, Lilly Molina, Lisa Parman, and The Schwartz Family held their 24th annual event at the Gaylord National Resort and raised more than \$175,000!
- Angelo and Kim Collazo from Rochester, NY recently held their annual Doughraiser at Pizzeria Uno in memory of their daughter Alle Shea raising \$800!
- Jim and Jane Early hosted the Fine Wines Naples Reception at Cedar Hammock Golf and Country Club.

Over 90 guests were in attendance to enjoy a wine tasting, silent auction, and fund the mission that raised \$30,000!

- Severance High School in Severance, Colorado hosted a community service project during OI Awareness Week in honor of teacher Rebecca Barger's daughter, who is living with Type III OI. Students were encouraged to wear yellow on Wishbone Day and by making a donation received an OI awareness wristband and were able to wear a fun hat to school.
- Tony Jacobsen hosted an OI Wanna Dance online dance party and fundraiser to kick-off Awareness Week 2024. He hosted a 5-hour virtual dance marathon and raised \$140!



## Donor Advised Funds Support the OIF Throughout the Year!

The Osteogenesis Imperfecta Foundation would like to thank those that are making donations through their donor advised funds. Your gifts made through donor advised fund providers like Fidelity Charitable, Schwab Charitable, Vanguard Charitable and T. Rowe Price Charitable are truly appreciated. We continue to update our Guidestar profile to ensure that you are provided with the most up to date information on the OIF but please also continue to visit our website at [www.oif.org](http://www.oif.org) for information.

For those not familiar with a donor advised fund, here is some information that might be helpful. This information is taken from the Fidelity Charitable's website as well as from articles written that compare donor advised fund providers.

A donor advised fund, or DAF, is like a charitable investment account for the sole purpose of supporting charitable organizations you care about...like the OIF! A DAF is an investment account that lets you take a tax deduction now and give the money to charity later. When you give money to a DAF, you can deduct that money just as you would deduct a charitable contribution. The DAF invests the money tax-free. At any time, you can direct the DAF to donate some or all of its holdings to the charity of your choice.

You can open a DAF through a donor-advised fund provider. A provider charges an administrative fee to invest your DAF and make donations in accordance with your recommendations. Donor advised funds are the fastest growing charitable giving vehicle in the United States because they are one of the easiest and most tax-advantageous ways to give to charity.

Roger Bache, an OIF donor through his donor advised fund says, "I have found donor advised accounts to be the easiest and most tax-advantageous way to give to charities. Among their many advantages, DAFs allow you to donate appreciated assets, which allows you to avoid long-term capital gains while taking the full tax deduction for your donation".

How do I set up a donor advised fund and how do I direct my donations to the OIF?

- If you have a brokerage account at Fidelity, Schwab, Vanguard or T. Rowe Price, the easiest thing to do is to open a DAF with your brokerage account. That way, you can manage all your investments in one place. Your advisor at your brokerage firm can assist you with setting up your charitable account.
- Once you set up your account you can donate cash, stocks, or non-publicly traded assets into the account to be eligible for an immediate tax deduction to that account.
- From that account you can then make a gift to the OIF at any time!

If you already have a DAF you can choose the Osteogenesis Imperfecta Foundation as your charity of choice...thank you!

If you have additional questions on donor advised funds you can call our office at 301-947-0083 or you can email us at [bonelink@oif.org](mailto:bonelink@oif.org). Thank you again for supporting the OIF.

## Turning Your Passion into Fundraising

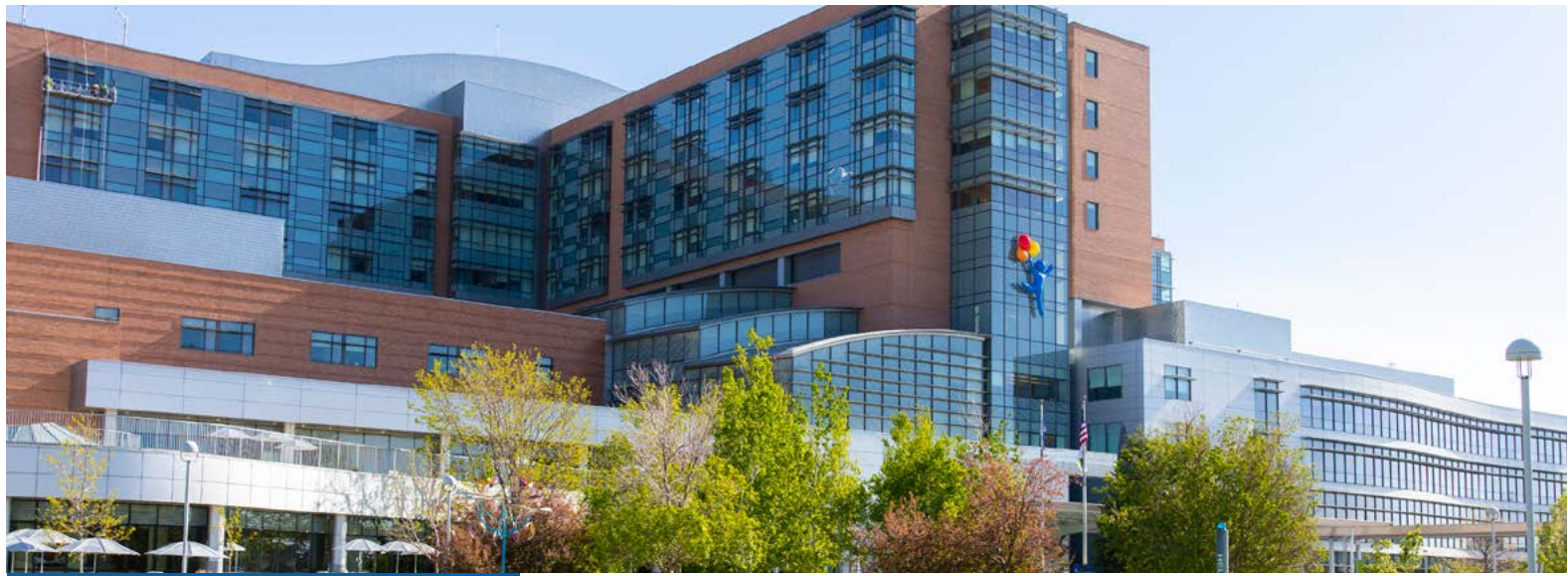
While it can be said that fundraising is at the core of any non-profit organization, the task can seem—at times—daunting. Where do I begin? Will my contribution even make a difference? How can I truly help? Yes, your contribution absolutely does make a difference! Where to begin and how you can truly help, well here's where your passion and fundraising can meet.

70% of the OI Foundation's budget comes by way of donations, directly raised through various fundraising efforts of all shapes and sizes. While larger events are important to our fundraising goals, at the heart of the foundation, our smaller events carry just as much significance. After all, the OI Foundation was originally founded by a small group of parents who wanted to enact big change. At that time, they banded together to stimulate public and professional interest, support families and encourage research. Today, many of the people who serve on the Board

of Directors and oversee the Foundation's operations and fundraising efforts have OI themselves or are parents of children with OI. This "small" group has grown to help over 50,000 community members and would be able to tell you firsthand how any fundraising effort, no matter how small, carries a big weight.

So, if you have an idea for a fundraising activity—whether it's creating a Facebook fundraiser, hosting a bake sale, holding walk-n-wheel event in your community, or a neighborhood awareness event highlighting our bracelets or other OI merchandise, or simply a social media post shedding light on the organization—it all matters. We at the OI Foundation believe that fundraising is a passion, especially when those efforts help so many that we love.

If you are interested in hosting your own event to support the OI Foundation, contact Irene Smith at [ismith@oif.org](mailto:ismith@oif.org).



# Largest

Multidisciplinary clinic of its kind

## 26

Exam rooms

## 10

Consult rooms

## 24,000

Square feet

## 60+

Participating clinics,  
providing tailored care



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Here, it's different.™

## Building a Community of Care for Your Family

*At Children's Hospital Colorado, we excel at the kind of care that puts kids first. The experts in our multidisciplinary clinic are dedicated to caring for kids with osteogenesis imperfecta. And because we see more, treat more and heal more kids than any other hospital in the region, you can trust us to offer skilled and experienced care for you and your family.*

**Schedule an appointment with our Orthopedics Institute by calling 720-777-6600.**



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## 1970 Society Members

The 1970 Society honors the inception of the Osteogenesis Imperfecta Foundation, the first patient advocacy organization in the United States for individuals with osteogenesis imperfecta (OI), established by a dedicated group of parents on August 21, 1970. For over 50 years, the OI Foundation has been the primary support system for those affected by OI, expanding research efforts, advocating for awareness, updating resources, training medical professionals, and offering support programs like National and Regional Conferences. To commemorate the Foundation's 50th anniversary, the 1970 Society recognizes individuals who contribute at least \$1,000 to membership, either in a single pledge or installments over ten months. To join the 1970 Society, visit [www.oif.org/membership](http://www.oif.org/membership).

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Ms. Angela Daniels	Mrs. Priscilla Kilman	Ms. Candice Stevens
Mr. William Danner	Dr. & Mrs. Richard Kruse	Ms. Robin Wright
Ms. Kimberly Estrada	Sylvia & Corey Leaf	

## 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!

Connect with us today!





## Thank you to our Members!

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*This member directory was compiled on May 31, 2024 and includes individuals with current memberships along with Lifetime Members.*





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