

# 2025

## ANNUAL REPORT



**OI** | OSTEOGENESIS  
IMPERFECTA  
FOUNDATION  
*Unbreakable Spirit*<sup>®</sup>

# A Message From the CEO

## Board of Directors

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Emily Voorde

Scott Walls

*The mission of the OI Foundation is to improve the quality of life for those living with osteogenesis imperfecta through research, education, awareness and mutual support.*

Dear Friends,

I'm so pleased to share this update highlighting the many exciting milestones and accomplishments of 2025 - it has truly been a remarkable and productive year! I also want to take this opportunity to thank everyone in the OI community for your continued support of the OI Foundation as we expand programs, strengthen partnerships, and advance new initiatives

In this report, you'll read about several important developments at the OIF, including programs for OI community members and medical professionals, expanded mutual support opportunities, scholarships and grants, and continued research addressing issues that impact adults with OI including transitioning to adult care and insights into cardiac health and OI.

None of this would be possible without you, our caring and generous community of supporters and donors. Thank you for investing your time and resources in the OIF.

The OI Foundation continues to lead the highly regarded Rare Bone Disease TeleECHO and OI TeleECHO programs, which educate healthcare professionals around the world on best practices for treating OI and related rare bone diseases.

This year also brought meaningful opportunities to gather and connect. Regional Conferences brought our community together to connect and learn more about OI. Our supporters also came together to support the

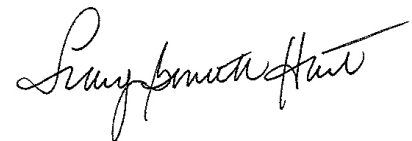
OI Foundation and OI community. Highlights from this year's fundraising efforts include the Fine Wines Strong Bones Gala in DC; Houston's Boots and Bling for Better Bones Gala; Strong Bones Boston Gala; Riley's Golf Gathering; the Abruzzi Family Golf Tournament; and the Unbreakable Spirit® Golf Tournament. We are so grateful for the commitment of our volunteers and event committees.

I would also like to extend my sincere thanks to our individual donors and corporate partners. Your generosity ensures we can continue delivering urgently needed programs and advancing research that improves lives.

We are deeply grateful for the leadership, dedication, and guidance Christine Rossi provided this year as OIF Board President. Her commitment to our mission and the time she generously gives has made a meaningful and lasting impact on our organization. Thank you, Christine!

On behalf of the OIF Board of Directors and staff, thank you for being part of such an impactful year. I look forward to all that we will accomplish together in the year ahead.

All my very best,



Tracy Hart  
Chief Executive Officer

# 2025 Accomplishments

## Support Group Program

The OIF piloted a Regional Support Group model in June 2023 and expanded to five regions with volunteer leaders and staff support. After nearly two years, attendance declined from an initial 10–25 participants per session to 1–5 participants by late 2024. To better understand community needs, the OIF conducted the Understanding Support Needs in the OI Community survey with 238 individuals with OI and family members. Based on this feedback, the Regional Support Groups will transition into an integrated OIF Support Program that builds on and incorporates the OIF’s existing Virtual Community Call program.

Recent Community Calls demonstrate a strong interest in educational engagement. In May, 95 attendees joined Dr. Eric Storch of Baylor College of Medicine for a BBDC Research Update on the OI Wellbeing Study, which highlighted findings from qualitative interviews on pain management and pediatric mental health and shared emerging data on adult psychosocial well-being. In September, 55 attendees participated in a session with Christopher Joseph, DPT, Director of Physical Therapy at Kennedy Krieger Institute, focused on exercise, physical therapy, and OI, including practical guidance for common PT scenarios. In January, 42 attendees registered for the community call on the OIF’s School-Aged Toolkit, where Dr. Michelle Fyran walked through each section of the toolkit to help families and clinicians better understand what is included in this

new resource and how it can help them navigate the school years.

The updated OIF Support Program will include:

- Quarterly Educational Sessions led by professionals and community members (building on the current Community Call series);
- Quarterly Affinity Groups with breakout rooms for women, men, young adults, parents, and individuals aging with OI
- State-Based Contacts to support local connection; and
- OI Awareness Week Events featuring social, educational, and support activities.

This revised structure reflects community feedback and is designed to offer more accessible, topic-driven opportunities for connection and support.



## Medical Advisory Council

### Cathleen Raggio, MD - Chair

- Hospital for Special Surgery, New York, NY, Orthopedic Surgeon
- Co-Director of the Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias
- Principal Investigator, Brittle Bone Disorders Consortium site in New York, NY

### Michael Bober, MD, PhD

- Pediatrician and Medical Geneticist and at Nemours Children’s Hospital, Delaware (Part-time, volunteer)

### Peter Byers, MD

- Professor of Laboratory Medicine and Pathology, and Professor of Medicine (Medical Genetics), University of Washington, Seattle, WA
- Clinical Geneticist, with specialty in heritable connective tissue disorders that include OI, Marfan syndrome, Ehlers Danlos syndrome. Founder and Director of the Collagen Diagnostic Laboratory, University of Washington
- Member of the MAC since 2004 and former MAC chair
- Recipient of the Marfan Award from the Marfan Foundation, and the inaugural Dr. John DiMasi Award from the VEDS Movement for excellence in care and research in vascular EDS.
- March of Dimes/Colonel Harland Sanders Award for lifetime achievement in the field of genetic sciences; Victor A McKusick Leadership Award from the American Society of Human Genetics

### Hollis Chaney, MD

- The George Washington University School of Medicine and Health Sciences, Washington, DC
- Children’s National Health System, Washington, DC, as Vice Chair of the Division of Pulmonary Medicine

### Kathryn McCrystal Dahir, MD

- Professor of Medicine, Department of Endocrinology, Vanderbilt University Medical Center (Nashville, TN)
- Director of Adult Metabolic Bone Program
- Schaffner Society Liaison for the Division of Endocrinology

# 2025 Accomplishments

## MEDICAL ADVISORY COUNCIL *(continued)*

### Paul Esposito, MD

- Professor of Orthopedic Surgery and Pediatrics, University Nebraska Medical Center
- Active member of the Pediatric Orthopedic Society of North America, the American Academy of Orthopedic Surgeons and the American Academy of Pediatrics Section on Orthopedics

### Jeanne Franzone, MD

- Pediatric Orthopaedic Surgeon, Nemours Children's Health in Wilmington, DE.
- Co-Director of the Multidisciplinary Osteogenesis Imperfecta Program.
- Dr. Franzone is on the Scientific Advisory Board for the OIF's Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease PCORI project.

### Deborah Krakow, MD

- Professor and Chair, Obstetrics and Gynecology, UCLA, David Geffen School of Medicine, Los Angeles, CA
- American Board of Medical Genetics board member
- American College of Obstetrics and Gynecology policy committee on Genetics.
- Principal Investigator, Brittle Bone Disorders Consortium site in Los Angeles, CA

### Richard W. Kruse, DO, MBA

- Professor of Orthopaedic Surgery Thomas Jefferson University College of Medicine in Philadelphia, PA and the Uniformed Services University School of Medicine in Bethesda, MD.
- Vice Chair Department of Orthopedics and Chief of the Orthopedic Trauma Service at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE.
- Co-Director for the multidisciplinary OI program at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE.
- Interests: Osteogenesis Imperfecta, bone trauma, sports rehabilitation, nutrition and transition from pediatric to adult health care.

### Brendan Lee, MD, PhD

- Baylor College of Medicine, Houston, TX
- Principal Investigator, Brittle Bone Disorders Consortium
- Dr. Lee is an elected member of the National Academy of Medicine.



## OI Clinic and Bone Health Town Hall Meetings

OI Clinic and Bone Health Town Hall meetings are held twice each year and are educational meetings for medical professionals that feature multidisciplinary presentations on key topics in OI care. In 2025, the OIF hosted the first meeting in May 29, and the program included updates from the OIF, and expert sessions on basilar invagination (BI) and craniocervical issues in OI, pregnancy and OI, and fracture rates in OI from the BBDC study. The second meeting was held on November 20, and the program included updates from the OIF, an introduction to the new School-Aged Toolkit, and expert sessions on physical therapy considerations in OI, decision making in medical management, and the clinical and genetic evaluation of nonaccidental trauma versus osteogenesis imperfecta. Each presentation was followed by a facilitated discussion, allowing clinicians to share experiences, ask questions, and explore practical approaches to care. These meeting support the OIF's goal of strengthening provider education and fostering a collaborative network of professionals caring for individuals with OI.

## OIF National Information Center

This past year, OIF staff responded to around 50 direct inquiries per month regarding medically verified information. Additionally, an average of 6,000 people used the OIF website each month. Topics ranged from medical issues such as genetics, diagnosis, and treatments to daily living strategies such as school participation and employment.

The OIF is excited to introduce the School-Aged Toolkit: Caring for Children Between the Ages of Three and Eighteen to help parents, teachers, coaches, and providers care and support school-aged children with OI. The toolkit covers a variety of topics, including health and OI, daycare and aftercare programs, extracurricular activities, and navigating the school system. Additionally, it features age-appropriate language, definitions, advocacy information, and a range of resources.

Similar to the OIF's existing toolkits on Adult Health and Navigating a New Diagnosis, the School-Aged Toolkit is a comprehensive booklet available in both electronic and print formats in English with information for both patients and providers. These informational toolkits serve as effective ways for families to learn how to manage their lives at every stage and provide as an easy resource to share.

These toolkits are an easy resource to share with providers, teachers and schools and are now available in English, French and Spanish. To date, the OI Adult Health, the Navigating a New Diagnosis and School-Aged toolkits have been accessed electronically more than 6,000 times and with more than 4000 copies in print. To download our toolkits, visit [www.oif.org](http://www.oif.org).



## MEDICAL ADVISORY COUNCIL (continued)

### Joan Marini, MD, PhD

- Scientist Emeritus, National Institute of Child Health and Development, National Institutes of Health, Maryland
- Chief, Bone and Extracellular Matrix Branch, NICHD, National Institutes of Health, Bethesda, MD
- Geneticist, pediatrician, scientist specializing in Molecular Genetics
- Led clinical studies focused on growth in OI, pulmonary function in OI, treatment of children with pamidronate and rGH
- Her laboratory identified many of the genes causing rare forms of OI and generated mouse models to study their mechanism.
- Awarded the National Institutes of Health Director's Award three times for her research on rare bone disorders.
- Elected member of Association of American Physicians

### Sandesh C.S. Nagamani, MD

- Professor in the Departments of Molecular and Human Genetics and Internal Medicine at Baylor College of Medicine
- Vice Chair, Clinical Research Affairs, Department of Molecular and Human Genetics, Baylor College of Medicine
- Co-Director, Intellectual and Developmental Disabilities Research Center, Baylor College of Medicine
- Focused on translational research that involves evaluating new and potential therapies for various genetic disorders
- Clinical geneticist – provides clinical care for adult patients with a wide variety of heritable conditions including OI, heritable disorders of bone, and other metabolic bone diseases
- Investigator, Brittle Bone Disorders Consortium (BBDC)

### Frank Rauch, MD

- Canadian Shriner's Hospitals for Children, and McGill University Faculty of Medicine, Montreal, Quebec, Canada
- Director, Biomedical Laboratory, Shriners Hospitals for Children, Montreal, Quebec.
- Principal Investigator, Brittle Bone Disorders Consortium site in Montreal QC, Canada.

# 2025 Accomplishments

## MEDICAL ADVISORY COUNCIL *(continued)*

Eric Rush, MD

- Children's Mercy Hospital and the University of Kansas Medical Center (KUMC), Kansas City, MO.
- Clinical Geneticist at Children's Mercy Hospital and the University of Kansas Medical Center.
- Professor of Pediatrics at the University of Missouri-Kansas City.

Sandy Sandhaus, MD, PhD, FCCP

- University of Colorado School of Medicine, and National Jewish Health, Denver, CO.
- Clinical Director at the Alpha-1 Foundation, Denver, CO.
- Medical Director and Executive Vice President of AlphaNet.
- Medical Director of AlphaNet Canada.
- Dr. Sandhaus applies his experience with internal medicine, pulmonary disease, critical care medicine and the biopharmaceutical industry to the study of lung disease.

Jay Shapiro, MD

- Dr. Shapiro is Consultant to the Endocrine and Diabetes Dept. at the Walter Reed National Military Medical Center, Bethesda, MD
- Endocrinologist experienced in the treatment of genetic and metabolic bone disorders in children and adults
- Until recently, Director of the Bone and Osteogenesis Imperfecta Department, Kennedy Krieger Institute, Baltimore, MD. Professor in Dept. Physical Medicine and Rehabilitation Johns Hopkins School of Medicine
- Currently practicing in Bethesda, MD, Dr. Shapiro is Adjunct Professor, Dept. of Medicine, Uniformed Services University of Health Sciences, Bethesda, MD
- Dr. Shapiro is the Editor-in-Chief of the 2014 textbook, Osteogenesis Imperfecta: A Translational Approach to Brittle Bone Disease (Elsevier Publishers)



## Awareness Week

From May 3-10, 2025, OI community members around the world celebrated National OI Awareness Week!

Community members requested state proclamations, hosted events, created Facebook fundraisers and shared social media posts to raise OI awareness! We reached more than 282,000 users on Facebook and Instagram.





## Social Networking

The OI Foundation manages four official social networking sites: the OIF Facebook Page – followed by 15,626 Facebook users; the OI Foundation X page (@OIFoundation) – followed by 2,550 X users, the OIF Instagram page (@oifoundation) – followed by 2,723 Instagram users, and the OI Foundation TikTok page (@oifoundation) – followed by 130 TikTok users. This year the OIF YouTube channel highlighted the Rare Bone Disease TeleECHO Clinic Series, Brittle Bone Disease Consortium (BBDC) sessions, and OI community member stories in Gemma’s Corner. Be sure to follow us @oifoundation to stay updated with all the latest content and to join us in our mission to raise OI awareness.



## MEDICAL ADVISORY COUNCIL *(continued)*

### Peter Smith, MD

- Pediatric Orthopaedic Surgeon at Shriners Hospital for Children, Chicago.
- Professor, Orthopaedic Surgery, Rush University Medical Center.
- Director, Osteogenesis Imperfecta Clinic, Shriners Hospital for Children, Chicago.
- Principal Investigator, Brittle Bone Disorders Consortium site in Chicago.
- Dr. Smith has visited China, India and several countries in South America to train physicians in surgical techniques related to OI.
- Co-Editor of the 2015 textbook, *Transitional Care in Osteogenesis Imperfecta: Advances in Biology, Technology, and Clinical Practice* (Shriners Hospitals for Children-Chicago, Publishers)

### Reid Sutton, MD

- Texas Children’s Hospital Skeletal Dysplasia Clinic and Baylor College of Medicine Department of Molecular and Human Genetics, Houston, TX
- Clinical Team Liaison and Principal Investigator, Brittle Bone Disorders Consortium Rare Disease Clinical Research Center, Baylor College of Medicine and Texas Children’s Hospital, Houston, TX

### Laura Tosi, MD

- Orthopaedic Surgeon, Division of Orthopaedics & Sports Medicine, Children’s National Hospital
- Associate Professor of Orthopaedics and Pediatrics, George Washington University School of Medicine and Health Sciences, Washington, DC.
- Principal Investigator, Children’s Research Institute (CRI), Center for Genetic Medicine Research (CGMR), Children’s National Hospital, Washington, DC.
- Board of Directors, Osteogenesis Imperfecta Foundation
- Chair, Steering Committee, Rare Bone Disease Alliance
- Faculty Chair, Rare Bone Disease TeleECHO
- Principal Investigator, Brittle Bone Disorders Consortium site in Washington, DC.
- Board of Directors, US Bone & Joint Initiative
- Steering Committee, Own the Bone Program, American Orthopaedic Association
- Medical and Scientific Advisory Committee, American Bone Health

# 2025 Accomplishments

## MEDICAL ADVISORY COUNCIL *(continued)*

### David Vernick, MD

- Harvard Medical School, Boston, MA
- Surgeon in Otolaryngology at Massachusetts Eye and Ear Infirmary, Beth Israel Deaconess Medical Center, Brigham and Women's Hospital, and Children's Hospital, Boston, MA

### Maegen Wallace, MD

- Pediatric Orthopedic Surgeon, Phoenix Children's Hospital
- Certified by the American Board of Orthopaedic Surgery
- Certified by the Certification Board for Professionals in Patient Safety.
- Fellow of the American Orthopaedic Association, the American Academy of Orthopaedic Surgeons, a specialty fellow of the American Academy of Pediatrics and a member of the Pediatric Orthopaedic Society of North America.

### Matthew Warman, MD

- Director of Orthopedic Research Laboratories, Department of Orthopaedic Surgery, Boston Children's Hospital, Boston, MA
- Professor, Departments of Orthopaedic Surgery and Genetics, Harvard Medical School, Boston, MA

### Michael Whyte, MD

- Emeritus Professor of Medicine, Washington University in Saint Louis
- Scientific Staff, Shriners Hospitals for Children, Saint Louis.

## Adult Transition/ Somewhere to Go

In January 2025, the OI Foundation hosted day one of our “Somewhere to Go” meeting. Rare disease patient advocates, clinicians, and other stakeholders joined us to discuss how to improve care and reduce barriers for adults with childhood-onset rare diseases across their adult lifespan. Several members of the Rare Bone Disease Alliance were in attendance.



## Scientific Meeting

Each year, leading scientists and medical professionals attend the OI Foundation Scientific Meeting, a two-day event where attendees collaborate and share research. OIF Medical Advisory Council (MAC) members, researchers in the Brittle Bone Disorders Consortium (BBDC), and other notable researchers and clinicians are invited to attend. This year's meeting, held on April 9-11, brought together more than 100 researchers, clinicians, and industry partners to learn and share the latest in OI research and treatments. The meeting was co-chaired by Dr. Roy Morello of the University of Arkansas and Dr. Ronit Marom of Baylor College of Medicine, who have provided the following summary of the conference, which was made possible with generous support from the Buchbinder Family Foundation and Ultragenyx Pharmaceuticals.

## Michael Geisman Fellowship Grant

Mahtab Toulany, MD (University of Arkansas for Medical Sciences) enters the 2026 year as the OI Foundation's newest Michael Geisman Fellow. 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. Toulany earned her Doctor of Medicine from Iran university of Medical Sciences and will study her project The Role of Osteocytes in Osteogenesis Imperfecta. Roya Bagheri, PhD (UCLA) continues her work as a Geisman fellow in 2026, as does Marie Coussens, PhD (Ghent University), who is in her second year of the fellowship.



# 2025 Members List

Joan Ablon, Ph.D.  
Mr. Michael Ahern  
Paul & Kayla Andrews  
Ms. Christina Aronhalt  
Mr. Reinhard Augustin  
Mrs. Denise Bailey  
Jeffrey & Cynthia Barnett  
Allan & Aimee Bauer  
Jerry & Patricia Bennett  
Mr. & Mrs. William Berman  
Mr. Robert Bernstein  
Mark & Martha Birdwhistell  
Mr. Thomas Blecher  
Ms. Katelyn Bobzien  
Mrs. Beverly Booth  
John & Nancy Braitmayer  
Edward & Ruth Brosh  
Mrs. Faye Bross  
Lane & Carol Brundieck  
Ms. Lucille A. Buell  
Ms. Kristin Bull  
Richard & Luisa Buntin  
Mr. Timothy Byrne  
Ms. Rebecca Ann Callighan  
Ms. Mary Jane Cera  
Mrs. Xuemei Chen  
Chris & Jennifer Chilton & Alden  
Al & Mary Cissi  
Mr. David Clark  
Ms. Breanna Coleman  
George & Pat Collett  
Mrs. Maureen Connor  
Terence & Carmen Connors  
Ms. Elyse Constantin  
Dr. Charles Cook  
Thomas & Kristy Corkran  
Bill & Michelle Cramer  
Mrs. Despina Cusulos  
Joe & Janice Daniel  
Ms. Angela Daniels  
Ken & Melissa Davert  
Mrs. Monica Dean  
Mr. Joshua Dean  
Mrs. Angela Dearing  
Brenda & Duane DeBlicke  
Ms. Heather DeFranco  
Peter & Janet Droste  
Ms. Kelli Druessel

# 2025 Accomplishments

## 2025 MEMBERS (continued)

Earl & Sarah Dyke  
Dr. Matthew Ellinwood  
Larry & Barbara Estrada  
Mr. Dwaine Evans  
Ms. Dawn Felton  
Mrs. Mary Ellen Ferguson  
Mr. Kevin Fieldes  
Ms. Renee Fill  
Mrs. Jessica Folkers  
Jeanne Franzone, MD  
Mrs. Bernice Freudensprung  
Ms. Hannah Friedman  
Ms. Rachel Fritz  
Mr. & Mrs. George Fritze  
Mrs. Laura Garcia  
Don & Renee Gardner  
Dr. Keshav Garg  
Ms. Dorothy Gay  
Ms. Ann Marie Geiger  
Mr. Richard Geisman  
Mark & Meredith Goldberg  
Ms. Sherri Goodman  
Ms. Christine Graeter  
Paul & Dina Granger  
Ms. Jennifer Grant  
Ms. Stephanie Greenwood  
Mrs. Charlene Grimo  
Mrs. Juanita Gruenloh  
Dennis & Vicki Hague  
Mr. James Hall  
Mr. Jerry Hall  
Ms. Famida Hanif-Weddle  
Jim & Kathy Harmer  
Dr. Gerald Harris, PhD, PE  
Ms. Lenore Hill  
Mrs. Michelle Hoffine  
Ms. Eileen Hogan  
Mr. Douglas Holleman  
Jason & Emily Holub  
Mrs. Pat Hufford  
Mr. Chase Huntley  
Mr. Donald Irwin  
Ms. Noreen Islam  
Dwight & Evangeline Jaggard  
Jane & Bruce Robert Charitable  
Foundation  
Mrs. Judith Jarvis  
Jean Jasinski, PhD  
Mr. Dennis Johnson



## EDWARD D. CRANSTON COLLEGE SCHOLARSHIP

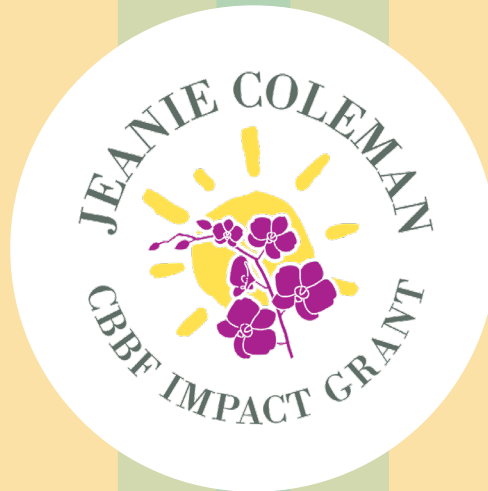


### Edward D. Cranston College Scholarship

The Edward D. Cranston College Scholarship is for students with osteogenesis imperfecta who are applying to or have been admitted to a college or university. 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 to receive the funds. Caroline Denny was the 2025 recipient of the scholarship. She attends Washington university in St. Louis. She was selected from nearly 30 applicants by a committee comprised of OI Foundation Board of Directors members and OI community members. We are proud to support Caroline as she moves forward in her education.

## Jeanie Coleman Impact Grants

In partnership with the Children's Brittle Bone Foundation, the Jeanie Coleman Impact Grant Program was established to provide funding for items and services that significantly improve the quality of life for individuals with OI and limited financial resources. In 2025 the OI Foundation and CBBF were able to fund \$144,851 for 16 families, covering a range of items and services, including (but not limited to) wheelchair-accessible vehicles, physical therapy, braces, and hearing aids. The 2026 cycle opened on January 5th and will close on February 27th.



## 2025 MEMBERS (continued)

Ms. Michelle Jones  
Donald & Lynda Kehoe  
Mr. Chaz Kellem  
Ms. Tara Keppel  
P.J. & Jennifer Kimball  
Ms. Anne Kimball  
Ms. Tina Kingery  
Mrs. Morgan Klenda  
Mrs. Linda Koenig  
Mrs. Judith Kong  
Mrs. Gloria Kowbel  
Deborah Krakow, M.D.  
Mrs. Maryann Kramer  
Dr. & Mrs. Richard Kruse  
Ms. Mary Lane  
Larry & Deborah Lapkin  
Tom and Lauren Lash  
Ms. Judith Lashman  
Mr. Joseph Lawless  
Brian & Kristin Lenahan  
Mrs. Elsie Leon  
David & Diana Lewallen  
Peter & Cheryl Lewis  
Ms. Julie Lewis  
Mr. Lawrence Lindvig  
Mrs. Ronna Linroth  
Mrs. Jennifer Lucas  
Larry & Deena Ludwig  
Fred & Jean Major  
Betsy & Bob Manela  
Robert & Louisa Matthias  
Mr. Nelson Maylone  
Mr. James McGowan  
Ms. Rita McGrinder  
Mrs. Madeline McLaughlin  
Dick & Margie McLaughlin  
Mrs. Marcia McMullen  
Mr. Richard T. Mehl  
Dr. Meenal Mehrotra  
Ms. Mary Merz  
Mr. Alex Miller  
Mr. Michael Miller  
Ms. Christina Mills  
Mrs. Shirley Moody  
Mr. Bryan Morrison  
Ms. Pat Morse  
Dennis & Michelle Moscardelli  
Mrs. Beverly Mucha

# 2025 Accomplishments

## 2025 MEMBERS (continued)

Gene & Beth Mulroy  
Dr. Mark Papich & Marcy Murphy  
Jonathan & Sharon Mutnick  
Mrs. Tammy Myers  
Allen & Kindra Nagle  
Joseph & Charlene Nanista  
Raymond & Maureen Noeth  
Mr. Joseph Nucci  
Mrs. Alicia O'Sullivan Adams  
Ms. Teyhana Overman  
Mr. Borden Painter  
Mr. Mark Palen  
Frank & Maureen Palestrini, Jr.  
Robert & Theresa Patten  
Mr. Stephen Patterson  
Jeffrey & Angela Paul  
Adrian & Debra Pena  
Evan & Lori Perry  
Mrs. Nancy Pesce  
Mrs. Judy Picciallo  
Dick & Karen Pinney  
Henry & Rose Piper  
Mr. Frederick Pracht  
Melinda & Daniel Preston  
Dennis & Kathi Primus  
Mrs. Lynda Pullis  
Ms. Catherine Ann Pusateri  
Melanie Rak, M.D.  
Mrs. Irene Ratto  
Mrs. Jama Rendell  
Mr. & Mrs. Roger Gray Renegar  
Jeffrey & Melinda Rice  
Linda & Johnny Rios  
Conrad & Mary Rivers  
Guy & Mien Roberts  
Mr. & Mrs. Benny Robinson  
Ms. Karla Robinson  
Ms. Simone Rodriguez  
Ms. Rachael Roth  
Mrs. Shirley Rowland  
Andrea Ives & Parke Rublee  
Harvey & Lapaula Sakai  
Scott & Susan Sander  
Ronit & Adam Sanders  
Ms. Kellie Sangwin  
Ms. Susannah Schmidt  
Mrs. Christine Schneider  
Paul & Darlene Schroeder

## Rare Bone Disease and OI TeleECHO Sessions

In 2025, the Rare Bone Disease TeleECHO Clinic Series continued to expand its global reach and clinical impact by delivering high-quality virtual education to medical professionals. This interactive program educates clinicians, researchers, and allied health professionals interested in rare skeletal diseases beyond osteogenesis imperfecta (OI), strengthening an international learning community dedicated to improving patient outcomes. With 50-80 monthly participants joining from across North and South America, Europe, and Asia, the RBD TeleECHO series serves as both a professional development platform and a collaborative forum for discussing diagnostic and management challenges in rare bone disease. The Rare Bone Disease TeleECHO is led by a multidisciplinary faculty co-chaired by Dr. Laura Tosi and Dr. Carlos Ferreira. The full faculty includes:



- **Laura Tosi, MD (Co-Chair)**  
Children's National Health System
- **Carlos Ferreira, MD (Co-Chair)**  
National Institutes of Health, NHGRI
- **Michael Collins, MD**  
National Institutes of Health, NIDCR
- **Michael Lewiecki, MD**  
University of New Mexico
- **Frank Rauch, MD**  
Shriners Hospital for Children  
- Canada
- **Eric Rush, MD**  
University of Kansas Hospital
- **Dolores Shoback, MD**  
University of California,  
San Francisco
- **Michael P. Whyte, MD**  
Washington University School  
of Medicine

The 2025–2026 sessions reflect the breadth of rare bone and mineral disorders, including Stickler's Syndrome; Pulmonary Aspects of OI; Maternal Mineral and Bone Metabolism during Pregnancy, Lactation, and Post-Weaning; and Heritable Non-OI Forms of Osteoporosis; and more.



## Rare Bone Disease Alliance

The Rare Bone Disease Alliance (RBDA), a program of the OI Foundation, brings together a coalition of seventeen (17) rare bone disease patient advocacy groups. The RBDA is committed to expanding education of rare and ultra-rare disorders and furthering research on the natural history, diagnosis, and treatment of these diseases. The RBDA unites researchers and early-stage investigators by hosting an annual Rare Bone Disease Working Group Meeting, monthly virtual TeleECHO sessions, an Early-Stage Investigator Meeting, and a Scientific Symposium.

## 2025 MEMBERS (continued)

Ulrike Schwarze, M.D.  
 Rachelle Grossman & Robert Seelenfreund  
 Mrs. Mary Ann Sergio  
 Ms. Barbara Su Sheridan  
 Mrs. Jessica Sheridan  
 Ms. Helaine Sikora  
 Ms. Carol Sirkowski  
 Mr. Eric Skolnick  
 Mr. & Mrs. James Smith  
 Ms. Pamela Smith  
 Mrs. Joyce Smyth  
 Mr. Jerome Snee, Jr.  
 Ms. Sandra Spellman  
 Ted & Marnie Starkey  
 Mark & Robin Stawasz  
 Ms. Amanda Sturgeon  
 Mrs. Pamela Sujdak  
 Dennis & Marielle Sullivan  
 David & Anne Swanson  
 Dr. Nancy Sweeney  
 Mr. Dominick Tamburri  
 Mrs. Claire (Beth) Tatman  
 Mr. Kyle Thompson  
 Ms. Alexandria Tracy  
 Edward & Sharon Trahan  
 Mrs. Judy Turner  
 Mrs. Kathy Tuttle  
 Ms. Carmen Valero  
 Ms. Adriaan Van Kempen  
 Mrs. Ashley Verinsky  
 Mr. John Wahlstrom  
 Matthew & Maegen Wallace  
 Mrs. Wendy Webb  
 Mrs. Betty Weigle  
 Mrs. Joan Weiss  
 Thomas & Susan Weller  
 Mrs. Sharon Werner  
 Mr. R. Stephan Whalen  
 Mrs. Delores Wharton  
 Mrs. Nancy White  
 Ms. Robin Wright  
 Richard & Mary Ellen Wyman  
 Ms. Diane Wysocki  
 Brandon & Angela Yamashita  
 Mr. Kenneth Young  
 Ms. Debbie Zarelli  
 Mrs. Lorraine Zelenz

# 1970 Society Members

Allan & Aimee Bauer

Mr. John Becker, Jr.

Mrs. Ellen Benish

Anthony & Jennifer Benish

Ms. Jo Ann Berkenbush

John & Nancy Braitmayer

Lane & Carol Brundieck

Chris & Jennifer Chilton & Alden

Mr. David Clark

George & Pat Collett

Dr. Charles Cook

Ms. Angela Daniels

Mr. William Danner

Ms. Kimberly Estrada

Jeanne Franzone, MD

Ms. Sherri Goodman

Ms. Stephanie Greenwood

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# Fundraising Events



## July 1, 2024 – June 30, 2025

As a small organization for a rare disorder, the OI Foundation relies on volunteer events held around the country to help raise awareness and funds to support the OI Foundation's mission to improve the lives of people living with osteogenesis imperfecta. Thank you to all the hosts and attendees!

### **\$100,000 and greater**

Fine Wines Strong Bone DC  
Strong Bones Gala Boston  
Strong Bones Gala Houston

### **\$25,000 to \$49,999**

Fine Wines Reception Naples  
Medics on the March  
Riley's Gathering Place Golf  
Unbreakable Spirit®  
Golf Tournament, PA

### **\$50,000 to \$99,999**

National Unbreakable Spirit®  
Walk-n-Wheel

### **\$10,000 to \$24,999**

Facebook Fundraisers

### **\$5,000 to \$9,999**

Abruzzi Family Golf Tournament  
Miracle Michael Golf

### **\$2,500 to \$4,999**

Christmas Tea  
Double Good Popcorn

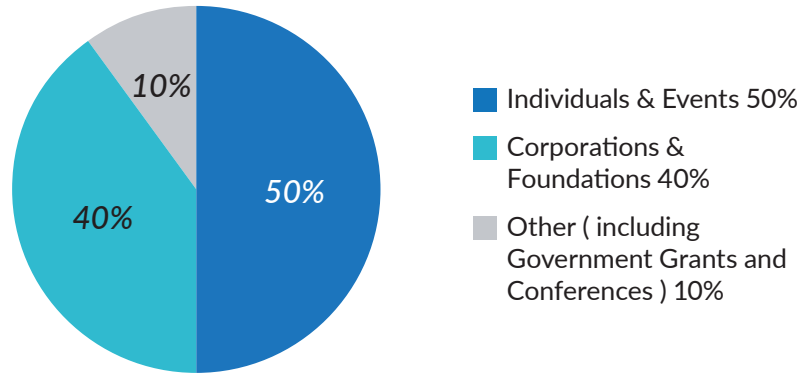
## REVENUE FY2025

CONTRIBUTIONS AND GRANTS	1,529,274
EVENT REVENUE	599,413
INVESTMENT INCOME	309,216
DIRECT MAIL REVENUE	169,778
CONFERENCE REVENUE	215,927
PRODUCT SALES, LESS COST OF GOODS SOLD	643
IN-KIND CONTRIBUTIONS	77,908
<b>TOTAL SUPPORT AND REVENUE</b>	<b>2,902,159</b>

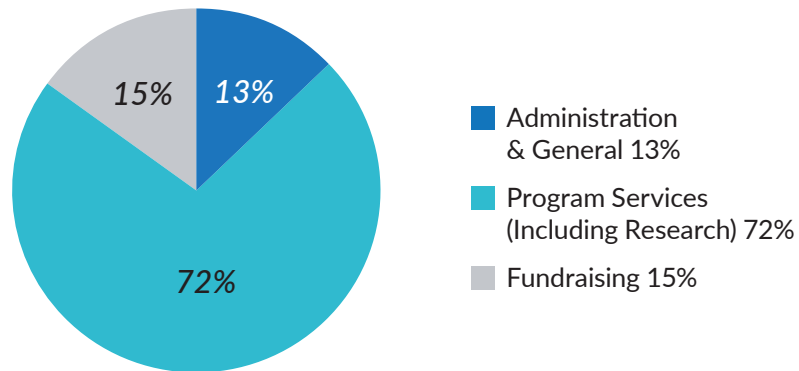
## EXPENSES DISTRIBUTION FY2025

PROGRAM SERVICES (INCLUDING RESEARCH)	
PERCENTAGE	72%
AMOUNT	2,037,443
FUNDRAISING	
PERCENTAGE	15%
AMOUNT	206,071
ADMINISTRATION & GENERAL	
PERCENTAGE	13%
AMOUNT	383,791
<b>TOTAL EXPENSES</b>	
PERCENTAGE	100%
AMOUNT	2,909,899

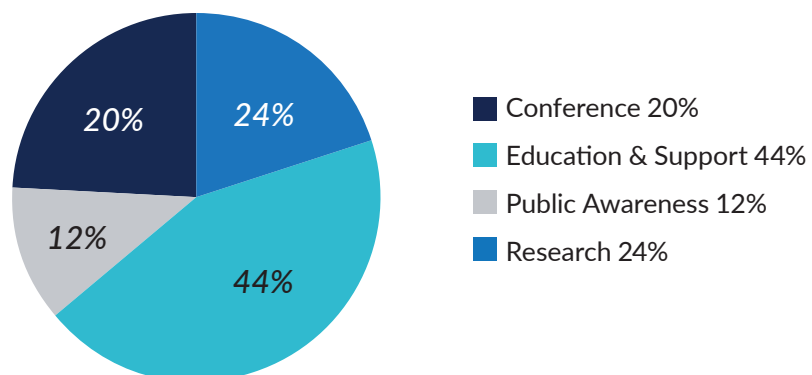
## Sources of Revenue FY 2025



## Distribution of Expenses FY 2025



## Program Services FY 2025



# Statement of Functional Expenses

Year Ended June 30, 2025 (with Summarized Comparative Information for year ended June 30, 2024)

	2025					2024			
	Program Services			Support Services		Total	Management and General		Total
	Education and Support	Research	Public Awareness	General	Fundraising		Management and General	Fundraising	
Salaries, taxes and fringe benefits	\$ 127,178	\$ 476,589	\$ 125,338	\$ 188,523	\$ 917,628	\$ 251,407	\$ 172,718	\$ 1,341,753	\$ 1,170,290
Meetings and conferences	257,760	104,187	128,316	-	490,263	1,782	-	492,045	216,646
Grants and fellowship	-	173,681	215,021	-	388,702	-	-	388,702	663,333
Event expenses	-	-	-	-	-	-	221,658	221,658	209,313
In-kind expense	7,292	27,587	7,188	10,887	52,954	14,866	10,088	77,908	64,800
Consulting fees	-	47,790	17,050	-	64,840	-	-	64,840	10,000
Occupancy	5,771	21,835	5,689	8,617	41,912	11,767	7,985	61,664	60,262
Travel	3,416	12,924	3,367	5,100	24,807	6,965	4,725	36,497	53,446
Information technology and web support	1,048	3,964	1,033	1,564	7,609	26,008	1,450	35,067	32,650
Professional fees	922	3,487	909	1,376	6,694	21,932	1,275	29,901	27,204
Bank fees	-	2,081	-	-	2,081	22,922	-	25,003	22,908
Dues and subscriptions	2,157	8,162	2,127	3,221	15,667	4,400	2,985	23,052	15,250
Office supplies	1,820	6,887	1,794	2,718	13,219	3,712	2,518	19,449	19,916
Postage and delivery	1,816	6,872	1,791	2,712	13,191	3,704	2,513	19,408	17,658
Printing and duplicating	1,707	6,459	1,683	2,549	12,398	3,481	2,362	18,241	6,672
Licenses and permits	973	3,680	959	1,452	7,064	1,984	1,346	10,394	11,112
Telephone	841	3,182	829	1,255	6,107	1,715	1,164	8,986	10,156
Insurance	393	3,529	387	586	4,895	801	2,943	8,639	8,578
Depreciation and amortization	787	2,980	776	1,176	5,719	1,605	1,089	8,413	9,504
Equipment rental and maintenance	721	2,728	711	1,076	5,236	1,470	998	7,704	9,177
Bad debt expense	-	4,153	-	-	4,153	-	-	4,153	2,500
Interest expense	-	-	-	-	-	3,491	-	3,491	2,933
Other Expenses	-	-	-	-	-	2,931	-	2,931	69,065
<b>TOTAL EXPENSES</b>	<b>\$ 414,602</b>	<b>\$ 922,757</b>	<b>\$ 514,968</b>	<b>\$ 232,812</b>	<b>\$ 2,085,139</b>	<b>\$ 386,943</b>	<b>\$ 437,817</b>	<b>\$ 2,909,899</b>	<b>\$ 2,713,373</b>

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- \$292,551** Children's Brittle Bone Foundation to support the Jeanie Coleman Impact Grant Program and the OIF National Conference
- \$155,000** Baylor College of Medicine in support of the Brittle Bone Disorders Consortium
- \$105,000** Ultragenyx Pharmaceuticals to support the OIF Science Meeting, OIF Regional Conferences, and Somewhere to Go meeting
- \$30,000** Amgen to support the OIF Regional Conferences
- \$20,100** Ipsen Biopharmaceuticals to support the Rare Bone Disease Alliance Metabolic and Rare Bone Disease Club
- \$20,000** Alexion Pharmaceuticals to support the Rare Bone Disease Alliance Metabolic and Rare Bone Disease Club
- \$20,000** Angitia Biopharmaceuticals to support Research
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- \$17,500** Inozyme Pharma, Inc to support the Rare Bone Disease Alliance Metabolic and Rare Bone Disease Club
- \$10,000** Bennett Clayton Foundation to support research, and general funding
- \$10,000** Children's Hospital Nebraska to support the OIF National Conference
- \$10,000** Kyowa Kirin, Inc to support the Rare Bone Disease Alliance Metabolic and Rare Bone Disease Club
- \$5,000** AstraZeneca Pharmaceuticals LP to support Somewhere to Go Meeting
- \$5,000** Everylife Foundation to support Somewhere to Go Meeting
- \$5,000** Phoenix Children's Hospital to support the Medics on the March
- \$2,500** Children's Healthcare of Atlanta to support the OIF Regional Conferences



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