

# 2023 ANNUAL REPORT

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



Living Well with an  
*Unbreakable Spirit<sup>®</sup>*

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*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.*

## A Message From the Board President

### Research, Collaboration and Adult Health, Oh My!



In the 1939 classic movie, “The Wizard of Oz,” Dorothy, the Scarecrow and the Tin Man anticipate the hazards of the haunted forest as they skip down the yellow brick road chanting “Lions and tigers and bears, oh my!”. These characters had very different experiences and abilities and they banded together to confront the dangers of the forest. The past year at the OIF was also a time of banding together with teams with varied experience and skills, including the OI community, researchers and even other rare disease advocacy groups.

Events and advances occurred in the area of **research** this past year. Medicines that slow bone resorption (denosumab) and promoting bone formation (setrusumab) are in clinical trials. Encouraging results were reported out from the effectiveness phase (Phase II) clinical trial for setrusumab in children with Types I, III and IV OI.

The Brittle Bones Disorder Consortium (BBDC) Research Update Series engaged the broader OI community in research, with sessions featuring principal investigators describing their current work and answering audience questions. A Michael Geisman Fellowship was awarded to an early career researcher studying mechanisms of pain in the absence of acute fractures. And the OIF wrapped up a community involvement phase on the issue of preparing adults with OI to engage in research on access and quality of care. These sessions identified major gaps in care transitions and adult care for individuals with OI.

**Collaboration** with groups internal and external to the OI community continue to generate results. The OI Federation of Europe (OIFE) and the OIF sponsored the Pain and OI conference. In addition to bringing together an international group of professionals and patients to explore the current state of treating pain in OI, this project completed a survey to collect patient data on chronic pain for people with OI.

The survey results were reported in the June edition of the *Breakthrough* newsletter.

The OIF hosted “Somewhere to Go: Identifying the Gaps in Care that Adults with Childhood Onset Rare Diseases Confront”, a summit that gathered patient advocacy organization leaders, physicians, public policy folks and patient advocates to assess the topic and brainstorm solutions.

The OIF continues to unite with 16 rare disease organizations through the Rare Bones Disease Alliance (RBDA). The RBDA drives a number of collaborative initiatives. For example, the RBDA hosts the TeleEcho series and bootcamps, programs which spread knowledge to medical professionals across the country on rare bone disease and OI related topics.

Importantly, the OIF collaborates with members of the OI community. Examples from 2023 include support groups and fundraising events. New leaders of 5 support groups across the U.S. are being trained to hosting virtual events as well as to provide community members with information about OI, OIF programs and resources.

Addressing **Adult health** emerged both in the strategic plan as well as programming in progress at the OIF. To aid in the care transition challenges noted above, the OIF completed the Adult Health Toolkit, a comprehensive document for adults to learn more about the multidisciplinary care of OI.

Like Dorothy in the Wizard of Oz, people and families with OI often feel like they are in the Haunted Forest rather than the peaceful field of poppies. Going forward in 2024, let’s work together to build the road toward better quality of life with OI!

Sincerely,



Ted Trahan  
President, Osteogenesis Imperfecta Foundation  
Board of Directors

# 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**

- Vice President, Clinical Development and Medical Affairs at Tyra Biosciences
- Pediatrician and Medical Geneticist 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

## **Paul Esposito, MD**

- Professor Emeritus of Orthopedic Surgery and Pediatrics, University Nebraska Medical Center, Omaha, NE
- Pediatric Orthopedic Surgeon Children’s Hospital and Medical Center, Omaha, NE
- Member of the OI Clinic at Children’s Hospital and Medical Center in Omaha

## MEDICAL ADVISORY COUNCIL *(continued)*

### Jeanne Franzone, MD

- Nemours Alfred I. duPont Hospital for Children in Wilmington, DE
- Pediatric orthopaedic surgeon at the Nemours Alfred I. duPont Hospital for Children
- Co-Director of the Multidisciplinary Osteogenesis Imperfecta Program
- 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

### Francis Glorieux, OC, MD, PhD

- Canadian Shriners Hospitals for Children, Shriners Hospitals for Children, Montreal, Quebec, and McGill University in Montreal
- Principal Investigator, Brittle Bone Disorders Consortium site in Montreal, Qc, Canada
- Principal Investigator on the landmark 1998 study on using bisphosphonates to treat children with OI; author of the OI Foundation booklet, Guide to OI for Pediatricians and Primary Care Physicians, and senior editor of *Pediatric Bone: Biology & Diseases*

### 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

## 2023 Accomplishments

### Eugene Washington PCORI Engagement Award

Under the direction of OIF Medical Advisory Council member, Dr. Laura Tosi, the OI Foundation continues to administer our Eugene Washington PCORI Engagement Award, through the Patient-Centered Outcomes Research Institute (PCORI), *Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease (IDD)*. In the project's research phase, 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. These methods have helped us to identify major gaps in care transitions and adult care for individuals with OI.



## Adult Transition/ Somewhere to Go

In October 2023, the OI Foundation led a meeting of rare disease advocates from across the country focused on the issue of transitioning from pediatric to adult care. Also addressed was the issue of finding quality care for adults with rare diseases. The Osteogenesis Imperfecta Foundation is leading this effort under the leadership of Dr. Laura Tosi in response to the OI community's feedback that finding experts or providers with knowledge about OI is very difficult especially when transitioning from pediatric to adult care. The meeting developed action items and will engage those who attended in this issue over the next year.



## Adult Health Toolkit

The Osteogenesis Imperfecta Foundation is pleased to announce the publication of 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.

In an effort to make this information accessible to more communities, the toolkit was translated to Spanish.

## MEDICAL ADVISORY COUNCIL (continued)

### 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

### 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 Shriners' 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

## 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)

## 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 13-14, 2023, was chaired by Dr. Kenneth Kozloff (Professor of Orthopedic Surgery at the University of Michigan). The meeting featured over 30 presentations on a wide variety of topics including Energy Metabolism, Growth, OI Organizations, and Emerging Therapies. Following the meeting, OIF Medical Advisory Council member, Dr. Frank Rauch, recorded a video summarizing the key findings for members of the OI community which can be found on the OI Foundation's website.



## Michael Geisman Fellowship Grant



Giulia Montagna, PhD continues her work in 2023 as a 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. Giulia Montagna is a postdoctoral research fellow at Boston Children's Hospital, affiliated with Harvard Medical School. She holds a bachelor's degree in Biomolecular Biotechnology, a master's degree in molecular biology and Genetics, and a Doctor of Philosophy in Health Technologies, Bioengineering, and Bioinformatics from the University of Pavia in Italy. Dr. Montagna joins Ellen Busschers and Jennifer Zieba who are currently in the middle of their Geisman Fellowship funding.

## 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 American 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

- Orthopedic 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

## 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

- University of Nebraska Children's Hospital and Medical Center, Omaha, NE
- Associate Professor of Orthopaedic Surgery at the University of Nebraska Medical Center
- Wallace is the director of the Osteogenesis Imperfecta clinic at Children's hospital in Omaha and serves as a board member for the Jansen's Foundation

### 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

## 2023 OIF Regional Conferences

Since its launch in 2015, the OIF's Regional Conference program has reached more than 1,500 members of the OI community, half of whom had never attended an OI event before. OIF Regional Conferences are one day meetings that provide a more intimate educational setting for local community members to learn about OI and meet other local community members. In June 2023, the OI Foundation welcomed community members in the Mid-Atlantic region to a Regional Conference in the Washington, DC Metro Area. Chaired by OI Foundation Medical Advisory Council Member, Dr. Laura Tosi from Children's National Hospital, the meeting featured topics such as *PT & OT Options for Children and Adults; Information on Dentinogenesis Imperfecta; Bisphosphonates and Growth in Children with OI; Hearing and New Technologies; a Research Update; Upper Extremity Management;* and panels on Daily life with OI and Growing up with OI.

Upcoming OIF Regional Conferences can be found at [www.oif.org/events](http://www.oif.org/events).





## OI Clinic Outreach

In an ongoing effort to connect with medical professionals currently treating individuals with OI and to educate them on the OIF's resources for clinics and their patients, the OIF held two OI Clinic and Bone Health Town Hall meetings chaired by OIF MAC member, Dr. Laura Tosi in June and November 2023. During the November meeting, former OIF Board of Directors member, Tracy Mulroy presented the Adult Health Toolkit to those in attendance. These meetings were a unique opportunity for medical professionals who treat patients with OI and those interested in bone health to connect with each other, stay up to date on OI care topics, and learn about OIF resources. The OIF also sends a quarterly electronic newsletter specifically to this group, which includes important announcements about meetings and resources.

## OIF National Information Center

This past year, OIF staff responded to more than 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 has developed the Navigating a New Diagnosis: A Tool Kit for Parents and Medical Professionals. This tool kit provides the most up-to-date information possible on various topics including building your prenatal and pediatric care teams, navigating the neonatal intensive care unit, and looking for information on what to expect when you take your baby home. The OIF is also in the process of developing an OI Adult Health Toolkit. Educational materials are available in print and electronically through the OIF website.



# 2023 Members

Joan Ablon, Ph.D.  
Dennis & Eileen Abruzzi  
Sam & Victoria Aburto Hernandez  
Mr. Michael Ahern  
Ms. Tillie Allen  
Ms. Nancy Andrews  
Paul & Kayla Andrews  
Alan & Sherianne Angel  
Mrs. Victoria Assumma  
Ms. Michelle Backhaus  
Dee Roberts Baraw  
Jeffrey & Cynthia Barnett  
W.C. and Evelyn Barringer  
David & Marita Barth  
Ms. Dorothy Bauch-Barker  
Mr. John Becker, Jr.  
Mr. Michael Bellas  
Mrs. Ellen Benish  
Jerry & Patricia Bennett  
James & Donna Bernie  
Mr. Robert Bernstein  
Dr. Joan Berry  
Mr. Steven Biagini  
Helga Binder, M.D.  
Mr. Thomas Blecher  
Victor & Gilda Bonardi  
Ms. Darrin Booker  
Ms. Beverly Booth  
Mr. Stephen Bordenkecher  
Mrs. Linda Boryczka  
Ms. Cathy Bowen  
Karen Braitmayer & David Erskine  
Ms. Valerie Brammer  
Mr. Frederick Brooks  
Edward & Ruth Brosh  
Mrs. Faye Bross  
Nathaniel & Kim Brost  
Dan & Lynn Brown  
Michael & Tracy Bryan  
Ms. Lucille A. Buell  
Ms. Kristin Bull  
Ms. Rebecca Ann Callighan

## 2023 MEMBERS

(continued)

Don Carolan & Madeline  
McLaughlin  
Ms. Catherine Carter  
Ms. Mary Jane Cera  
Philip & Mary Chaikin,  
Pharm.D., M.D.  
Paul & Elsa Chase  
Mrs. Yuka Chau  
Ms. Kim Chernicki  
Jim & Wendy Coleman  
Mrs. Maureen Connor  
Terence & Carmen Connors  
Ms. Elyse Constantin  
Dr. Charles Cook  
Thomas & Kristy Corkran  
Bill & Michelle Cramer  
Cliff & Terri Creek  
Mrs. Deborah Crowell  
Ms. Evelyn Culmer  
Mrs. Despina Cusulos  
Mr. & Mrs. Peter G. Dagnes  
Joe & Janice Daniel  
Ms. Angela Daniels  
Ken & Melissa Davert  
Mrs. Monica Dean  
Mr. Joshua Dean  
Mrs. Angela Dearing  
Brenda & Duane DeBlicke  
Ms. Heather DeFranco  
Mr. John Dibble  
Ken & Diane Dietterich  
Mr. Colin Donnaruma  
Earl & Sarah Dyke  
Mr. Arthur Elias  
Larry & Barbara Estrada  
Dwaine & Robin Evans  
Ms. Myrtle B. Fantroy  
Ms. Dawn Felton  
Mr. Kevin Fieldes  
Jeff & Michelle Flitcroft  
Jeanne Franzone, MD  
Ms. Rachel Fritz  
Mr. & Mrs. Robert Gaik  
Don & Renee Gardner

## Awareness Week

Each year, during National OI Awareness Week, OI community members request state proclamations, host events, tell their story, and share social media posts to raise OI awareness. This year, supporters used graphics and language from the OIF's Awareness Week Social Media Toolkit to raise OI awareness on social media. During the week of May 6-13, OIF social media posts reached nearly 100,000 people, and 25 OI community members created National OI Awareness Week Facebook Fundraisers. In addition, many individuals purchased OIF Unbreakable Spirit® apparel to support the OIF and raise awareness. The OI Foundation also hosted a "Chat with OIF" with our CEO Tracy Hart, Board of Directors President, Ted Trahan, and staff members virtually where community members were able to ask questions and learn more about OIF resources.



## OI Regional Support Groups

The OIF Regional Support Group Program will be re-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. This fall, OIF Staff interviewed interested members of the OI Community and selected Regional Support Group Leaders to serve as a contact person for families and individuals looking to connect with the OI community and OIF.



## Jeanie Coleman Impact Grants

In partnership with the Children's Brittle Bone Foundation, the Jeanie Coleman Impact Grant Program was designed to provide funding for items that will significantly improve the quality of life for a person who has OI and limited financial resources. In 2023, the OIF was able to fund \$144,550 worth of items and services for 10 families. The 2023 grants covered a range of items and services including: physical therapy assistance, med sleds, and wheelchair accessible vehicles.

## 2023 MEMBERS

*(continued)*

Mr. Timothy Gay  
Ms. Dorothy Gay  
Ms. Ann Marie Geiger  
Mr. Richard Geisman  
Mr. Chris Gitto  
Patrick & Bernadette Gleason  
John & Paula Goodrich, III  
Ms. Corinne Gottman  
Paul & Dina Granger  
Ms. Virginia Greene  
Ms. Peggy Grigg  
Mrs. Charlene Grimo  
Mrs. Juanita Gruenloh  
Mrs. Charla Gualano  
Mrs. Janice Hagan  
Mr. James Hall  
Mr. Jerry Hall  
Ms. Famida Hanif-Weddle  
Mr. Steven Hardesty  
Ms. Marilee Harrahd-Pilz  
Dr. Gerald Harris, PhD, PE  
Ms. Tracy Smith Hart  
Mrs. Brooke Hershberger  
Ms. Lenore Hill  
Mrs. Michelle Hofhine  
Ms. Eileen Hogan  
Mr. Douglas Holleman  
Jason & Emily Holub  
Ms. Helen Holubnyczyj  
Mr. David Howarter  
Larry & Pat Hufford  
Mrs. Judy Irvin  
Mr. Donald Irwin  
Ms. Noreen Islam  
Jane & Bruce Robert Charitable  
Foundation  
Eamon & Mary Jo Jennings  
Marvin & Eileen Jones  
Donald & Lynda Kehoe  
Mrs. Heidi Kelley  
Ms. Tara Keppel  
Ms. Tara Keppel  
P.J. & Jennifer Kimball  
Donna King, Ph.D.

## 2023 MEMBERS (continued)

Ms. Tina Kingery  
Josh & Lindsay Klein  
Mrs. Morgan Klenda  
Mrs. Linda Koenig  
Mrs. Judith Kong  
Mrs. Gloria Kowbel  
Mrs. Sara Kreps  
Ms. Elizabeth LaFollette  
Ms. Mary Lane  
Ms. Jacqueline Lapidus  
Larry & Deborah Lapkin  
Dwayne & Dawn LaVoie  
Mr. Joseph Lawless  
Sylvia & Corey Leaf  
Brian & Kristin Lenahan  
Mrs. Elsie Leon  
Mr. David Lewallen  
Peter & Cheryl Lewis  
Mr. Lawrence Lindvig  
Michael & Caren Loguercio  
Ms. Elizabeth Lower-Basch  
Ms. Mandi Lowery  
Mrs. Jennifer Lucas  
Fred & Jean Major  
Betsy & Bob Manela  
Wallace & Deborah Mangum  
Robert & Sara Mathers  
Mrs. Charlene Maus  
Mr. Nelson Maylone  
Ms. Serena McCoy  
Ms. Rita McGrinder  
Dick & Margie McLaughlin  
Mrs. Marcia McMullen  
James & Susan Meade  
Mr. Richard T. Mehl  
Ms. Mary Merz  
Ms. Christina Mills  
Ms. Liliana Molina  
Mrs. Donna Molony  
Mrs. Shirley Moody  
Mr. Richard Morse  
Ms. Pat Morse  
Dr. Mark Papich & Marcy Murphy  
Dennis & Mary Murray

## Edward D. Cranston College Scholarship

This 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 in college to receive the funds. The OI Foundation is excited to announce the first-year recipients of the Edward D. Cranston College Scholarship: Eden Nadler and Ethan Yamashita! Eden and Ethan were selected from nearly 20 applicants by a committee of OI Foundation Board of Directors members and OI community members. We are proud to support this year's recipients as they move forward in their education!

As you can see, your support plays a vital role in what we do, and we hope we can count on your continued generosity. With your help, we hope to continue to improve the quality of life for individuals living with OI through research, education, awareness, and mutual support.

## Social Networking

The OI Foundation manages three official social networking sites: the OIF Facebook Page – followed by 14,746 Facebook users; the OI Foundation Twitter page (@OIFoundation) – followed by 2,763 Twitter users, and the OIF Instagram page (@oifoundation) – followed by 2,112 Instagram users. This year the OIF YouTube channel highlighted the Rare Bone Disease TeleECHO Clinic Series, the OIF Scientific Meeting, the RBDA Scientific Symposium and updates on the current state of OI research.



## Rare Bone Disease Alliance

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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. On March 9th, the RBDA hosted their third Virtual Scientific Symposium. In this series, intended for both researchers and clinicians, expert speakers explored the natural history and new developments in osteogenesis imperfecta. More than 100 attendees joined the live zoom presentation. The recording of the symposium can be found on the OI Foundation's YouTube channel.

## Rare Bone Disease and OI TeleECHO Sessions

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In 2023, The Rare Bone Disease TeleECHO Clinic Series continued to educate medical professionals on a variety of rare bone diseases. This virtual education program held monthly sessions for medical professionals interested in rare bone diseases beyond just OI. In each session, leading experts on diagnosing and treating rare bone diseases gave didactic presentations, followed by discussion and participant-led case presentations. These sessions, which averaged 70-100 participants from around the world, provided researchers and clinicians a professional development opportunity and gave them a forum to discuss challenging cases so that they could improve their patient's outcomes. The Rare Bone Disease TeleECHO is led by an eight-member multi-disciplinary faculty that includes five members of the OIF's Medical Advisory Council (MAC): including Dr. Laura Tosi (Chair), Dr. Frank Rauch, Dr. Eric T. Rush, Dr. Jay Shapiro, and Dr. Michael Whyte.

Sessions that took place this year include topics such as: *genetic testing, emerging therapeutics for rare bone diseases and the skeletal effects of gender-affirming medical therapy in transgender and gender-diverse youth.*

## 2023 MEMBERS (continued)

Mrs. Tammy Myers  
Allen & Kindra Nagle  
Mr. Andrew Nahass  
Mrs. Helen Nahrstedt  
Mr. Don Naifeh  
Jason & Laura Nanista  
Joseph & Charlene Nanista  
Raymond & Maureen Noeth  
Mr. Joseph Nucci  
Ms. Katharine M. O'Meara  
Mrs. Shelley Olson  
Ms. Gretchen Osborne  
Evan & Lori Perry  
Mrs. Nancy Pesce  
Mr. Raymond Phillips  
Mrs. Judy Picciallo  
Dick & Karen Pinney  
Henry & Rose Piper  
Mr. Judson Polikoff  
Mr. Frederick Pracht  
Melinda & Daniel Preston  
Dennis & Kathi Primus  
Melanie Rak, M.D.  
Mrs. Jama Rendell  
Mr. & Mrs. Roger Gray Renegar  
Miss Gail Ann Rennetty  
Mrs. Melinda Rice  
Edward & Roxanne Rios  
Conrad & Mary Rivers  
Guy & Mien Roberts  
Ms. Karla Robinson  
Mr. & Mrs. Benny Robinson  
Ms. Simone Rodriguez  
Paul & Judi Rossi  
Andrea Ives & Parke Rublee  
Archie and Jacinta Ruel  
Harvey & Lapaula Sakai  
Scott & Susan Sander  
Gerald & Sandy Scalzo  
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## Fundraising Events

July 1, 2022 – June 30, 2023

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**

Strongs Bones Gala Houston

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

Fine Wines Reception Naples

Tee Time at Fine Wines Strong Bones DC

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

A Rare Affair

Facebook Fundraisers

Matthew Smith Memorial Golf Outing

Riley's Gathering Place Golf

Unbreakable Spirit® Golf Tournament, PA

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

Abruzzi Family Golf Tournament

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

Miracle Michael Golf

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

Blue Jeans for Better Bones

Bone China Tea

Double Good Popcorn

### **\$1,000 to \$2,499**

Strong Bones Gala Boston

OI Carnival



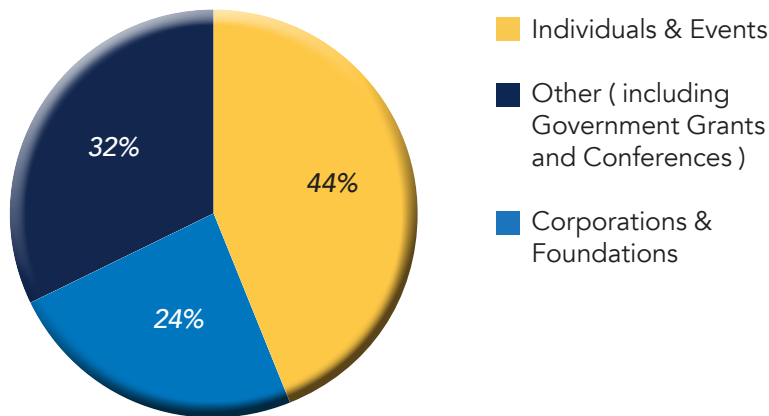
# Statement of Functional Expenses

Year Ended June 30, 2023 (with Summarized Comparative Information for year ended June 30, 2022)

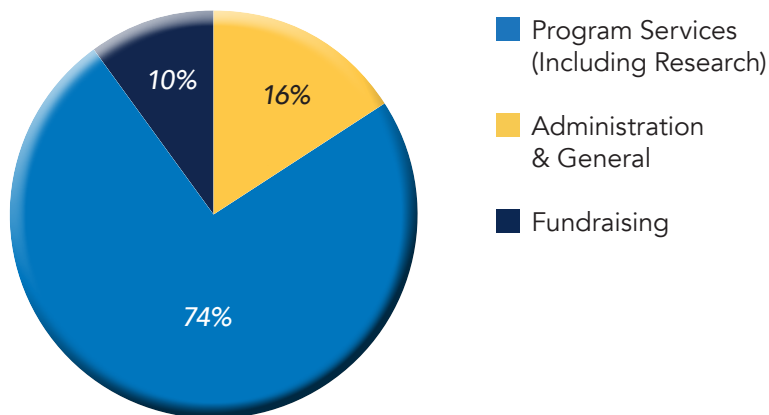
	2023				2022			
	Program Services		Support Services		Program Services		Support Services	
	Education and Support	Research	Public Awareness	Management and General	Fundraising	Total	Total	Total
Salaries and Fringe Benefits	\$ 97,116	\$ 427,505	\$ 174,494	\$ 116,791	\$ 71,724	\$ 815,906	\$ 1,131,740	\$ 1,083,803
Grants and fellowship	172	117,479	281,386	-	-	399,037	399,037	695,763
Meetings and conferences	59,133	63,390	114,134	-	-	236,657	244,182	200,146
Event expenses	-	-	-	-	117,517	-	117,517	119,543
Occupancy	4,914	22,838	8,890	6,133	-	42,775	56,522	56,784
Travel	4,116	19,128	7,446	5,137	3,702	35,827	47,341	11,286
In-kind expense	2,953	13,724	5,342	3,685	2,225	25,704	33,966	29,511
Information technology and web support	835	3,882	1,511	1,042	629	7,270	32,929	29,410
Professional fees	560	2,603	1,013	729	422	4,905	23,277	28,634
Printing and duplicating	1,922	8,933	3,477	2,399	1,448	16,731	22,108	17,617
Bank fees	-	-	-	-	18,779	-	20,196	22,268
Office supplies	1,636	7,602	2,959	2,041	1,232	14,238	19,061	17,222
Postage and delivery	1,295	6,016	2,341	1,616	975	11,268	14,892	15,161
Licenses and permits	1,125	5,229	2,035	1,404	848	9,793	12,941	21,051
Dues and subscriptions	1,035	3,757	1,872	1,291	780	7,955	12,824	9,019
Depreciation and amortization	921	4,279	1,666	1,149	694	8,015	10,590	11,002
Insurance	453	3,270	820	566	927	5,109	8,893	9,579
Telephone	744	3,457	1,346	928	560	6,475	8,556	9,035
Equipment rental and maintenance	664	3,085	1,201	828	500	5,778	7,635	7,309
Interest expense	-	-	-	-	-	-	1,714	722
Tax fees	-	-	-	-	-	-	144	-
Consulting fees	-	-	-	-	-	-	18	18,050
<b>TOTAL EXPENSES</b>	<b>\$ 179,594</b>	<b>\$ 716,177</b>	<b>\$ 611,933</b>	<b>\$ 145,739</b>	<b>\$ 210,631</b>	<b>\$ 1,653,443</b>	<b>\$ 2,226,083</b>	<b>\$ 2,412,915</b>



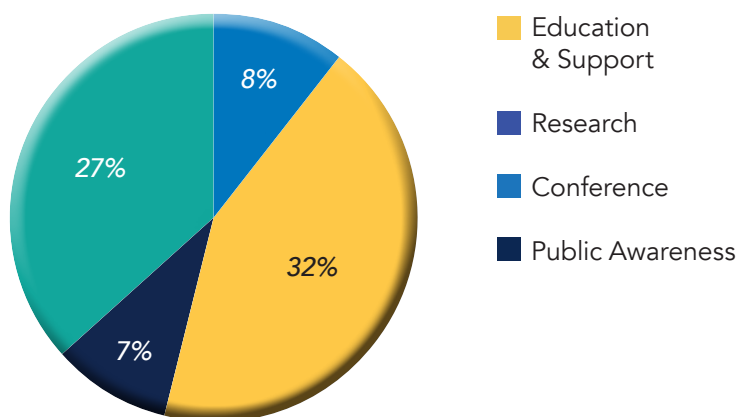
## Sources of Revenue FY 2023



## Distribution of Expenses FY 2023



## Program Expenses FY 2023



## REVENUES FY2023

CONTRIBUTIONS AND GRANTS	1,652,044
EVENT REVENUE	416,193
DIRECT MAIL REVENUE	187,840
INVESTMENT INCOME	47,333
IN-KIND CONTRIBUTIONS	33,966
CONFERENCE REVENUE	4,427
PRODUCT SALES, LESS COST OF GOODS SOLD	549
<b>TOTAL SUPPORT AND REVENUE</b>	<b>\$2,342,351</b>

## EXPENSES DISTRIBUTION FY2023

<b>PROGRAM SERVICES (INCLUDING RESEARCH)</b>	
PERCENTAGE	74%
AMOUNT	\$1,653,443
<b>FUNDRAISING</b>	
PERCENTAGE	9%
AMOUNT	210,631
<b>ADMINISTRATION &amp; GENERAL</b>	
PERCENTAGE	16%
AMOUNT	362,009
<b>TOTAL EXPENSES</b>	
PERCENTAGE	100%
AMOUNT	\$2,226,083

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July 1, 2022 to June 30, 2023

The OI Foundation gratefully acknowledges the generous individuals, foundations and corporations whose support helps us respond to thousands of inquiries each year, produce new information resources, fund research, organize National and Regional Conferences and facilitate the operation of support groups across the country. This list represents donations made from July 1, 2022 to June 30, 2023. We regret any error or omission and ask that corrections be brought to our attention.

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January 1, 2023 – December 31, 2023

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Ms. Cynthia Vaughn

### **Lawrence Vito**

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Buffalo Octagon Association  
Mrs. Frances Menno  
Ms. Natalie Santarsiero

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Ms. Teri Adams  
Ms. Kimberly Basye  
Ms. Darlene Baumlein  
Ms. Susan Best  
Mr. Matt Bryan  
Ms. Kim Clymer  
Marvin & Eileen Cook  
Mr. Ray Crane  
Nancy Dysinger, DDS

Mrs. Janet Franz  
Mrs. Marsha Frey  
Dennis & Irene Jones  
Jeffrey & Janice Jones  
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Allan & Kathleen Latta  
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### **Will Wiggers**

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### **Rebecca Wingo-Wasson**

Ms. Joan Brown  
Mrs. Lori Hurlburt  
Mrs. Patricia Junko  
Ms. Lisa Kurtz

### **Jeannie Wirscham**

Mrs. Mary Encinias



# Honorariums

January 1, 2023 – December 31, 2023

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**Janice Agranoff & Family**

*Sylvia & Corey Leaf*

**Gunner Albitre**

*Gunner Albitre*

**Malani Rose Araujo**

*Miss Patricia Araujo*

*Mrs. Maria Araujo*

**Tina Argetsinger**

*Ron & Sally Smith*

**Nicholas Atkinson**

*James & Mary Jane Agasar*

**Gavin Baker**

*Dr. Shannon O'Donnell*

**Mr. & Mrs. Bain, Matthew & Grace**

*Sylvia & Corey Leaf*

**Gwen Claire Bateman**

*Ron & Karen Bateman*

**Dr. Joan Berry**

*Mr. George Willey*

**Mark Birdwhistell and Family**

*Ms. Virginia Fox*

*Ms. Carol Rosenthal*

**Mary Alice Birdwhistell & Evan**

**Jacoby (Wedding)**

*Ms. Vivian Bowles*

*Mrs. Paula Carter*

*Paul & Anne Cox*

*Robert & Cheryl Davis*

*Mr. & Mrs. Donald Edwards*

*Mrs. Laura Hagan*

*David & Pat Heimerdinger*

*Ms. Rosalind Heinz*

*Mr. Mike Jacoby*

*Mr. Mike Jacoby*

*Mr. Kenneth Johnson*

*Mr. Bennie League*

*Lula Reynolds & Nancy Jurgeevich*

*Ms. Arlette Tinsley*

*Mrs. Judy Turner*

**Joe & Brenda Bourque**

**(Anniversary)**

*Kevin & Kathleen Gerow*

**Mr. & Mrs. William Brown & Family**

*Sylvia & Corey Leaf*

**Alec Cabacungan**

*Mr. Chris Chulos*

**Mr. & Mrs. Jack Caya, Jerri &**

**Family**

*Sylvia & Corey Leaf*

**Mr. & Mrs. Andrew Chapkis & Family**

*Sylvia & Corey Leaf*

**Alden Chilton**

*Ms. Cindy Chessor*

*Chris & Jennifer Chilton*

*Ms. Lindsey Guill*

*Joseph & Charlene Hunt*

*Mrs. Cookie Mays*

*Ms. Kelley Newman*

*John & Kathy Scott*

**Thomas Richard Clark**

*Mr. David Clark*

**Annalisa Dimino & Family**

*Sylvia & Corey Leaf*

**Michelle Duprey**

*Ms. Victoria Eichler*

**Andersson Dyke**

*Milton & Dorothy Allen*

*Ms. Katherine Kohlmeyer*

**Kim & Audrey Eap & Family**

*Sylvia & Corey Leaf*

**Jim & Jane Early**

*Mr. Peter Sullivan*

**Emmylou**

*Ms. Prathima Gangula*

**Caroline Entsminger**

*Ms. Ann O'Herron*

**Sherry Erikson, Austin, Aidan,**

**Cathy & Family & Cat**

*Sylvia & Corey Leaf*

**Frances Ettling & Sam Clodfelter**

*Missouri Pageant Alumnae Club*

**Jacob Everett**

*Mrs. Doris Everett*

*Robert & Debra Harwell*

**My Great Granddaughter**

*Mrs. Jennifer Lucas*

**Jacob Gry**

*Ms. Elizabeth Gry*

**Anna Curry Gualano**

*Vestavia Friends of the Library*

**Greg A. Gutfleisch, Family & Staff**

*Sylvia & Corey Leaf*

**Chris Harkman**

*Mr. Derek Dees*

**Tracy Hart & Family**

*Sylvia & Corey Leaf*

**Mr. & Mrs. Neil Hattem & Family**

*Sylvia & Corey Leaf*

**Jerry & Dixie Hertel**

*Mrs. Ann Westerman*

**Dr. & Mrs. Robert Hoff**

*Sylvia & Corey Leaf*

**Emma Johnston & Family**

*William & Patricia Sharp*

**Sophia Kamal**

*Mr. Danny Sgro*

**Makari Kamau**

*Dr. Sallye Lamont*

**Makari Kamau**

*Bryan, Melanie & Zadie*

*MacHanley*

*Ms. Karla Miller*

*Ms. Michaela Neller*

**Mr. & Mrs. Alan Karp**

*Sylvia & Corey Leaf*

**Jodi Karp**

*Sylvia & Corey Leaf*

**Drew Kendall-20th Anniversary**

**with AlixPartners**

*AlixPartners*

**Bradley Koch**

*Mr. Steven Sandbrook*

**Jeffrey Krudys**

*John & Patricia DeLuccia*

**Corey Leaf**

*Sylvia Leaf*

**Jenna Leaf, Jonathan & His Family,**

**Myles**

*Sylvia & Corey Leaf*

**Kyle Leaf**

*Sylvia & Corey Leaf*

**Mr. & Mrs. Mark Leaf, Tyler &**

**Crush**

*Sylvia & Corey Leaf*

**Dr. Ted Leaf & Pets**

*Sylvia & Corey Leaf*

**Elise Ludwig (18th Birthday)**

*Larry & Deena Ludwig*

**Michelle Martin, Partners, Friends**

**& Family**

*Sylvia & Corey Leaf*

**Olga Martinez & Louis**

*Sylvia & Corey Leaf*

## HONORARIUMS JANUARY – DECEMBER 2023 *(continued)*

**Lauren Miller**  
*Philip & Bess Shockey*

**Miss Emma Minnucci**  
*Mr. Robert Baum*  
*Mrs. Jane Carlson*  
*Priscilla Claman*  
*Ms. Marianne DePamphilis*  
*Ms. Stephanie Galvani*  
*Ms. Nancy Johnson*  
*Ms. Jennifer Potter*  
*Ms. Meryl Waldman*

**Minnucci Family**  
*Ms. Jalene Buckner*

**Luca Mounts**  
*Al & Mary Cissi*

**Stephen Mucher**  
*Ronald & Kathy Ice*

**Kyle Mulroy**  
*Mrs. Margaret Buck*

**Dean Nadler**  
*Ms. Robyn Duvall*

**Walker Nickel (1st Birthday)**  
*Ms. Tiffany Baird*  
*Ms. Janey Garrison*  
*Mrs. Paige Taylor*

**Josephine Noriega**  
*Sylvia & Corey Leaf*

**Jim Paddock**  
*Judith & Henry Sauer*  
*Mr. Vaughan Scott & Memorial*  
*High School Classes of 1992*  
*& 1993*

**Paddock Family**  
*David & Mary Valentine*

**Patricia Park**  
*Mr. Thomas Park*

**Mike Potorski (Birthday)**  
*John & Judith Potorski*

**Stefanie Quintal**  
*Mrs. Catherine Headley*

**Dr. Jean-Marc Retrouvey**  
*Mrs. Xuemei Chen*

**Miss Jaden Sacks**  
*Mitchell & Geraldine Sacks*

**Mr. & Mrs. Lenny Samuels**  
*Sylvia & Corey Leaf*

**Mrs. & Mrs. Michael Samuels**  
*Sylvia & Corey Leaf*

**Quinn & Lyla Sartorius**  
*Eric & Melissa Sartorius*

**Mary Schlink (100 Birthday)**  
*Robert & Barbara Hatch*

**Tammy Fairweather Schwark**  
*Mrs. Pamela Taylor*

**Miss Maggie Sheridan**  
*Mr. Doug Barker*  
*Dean & Karen Bergquist*  
*Rob & Rosemarie Bouman*  
*Mr. Rich Doherty*  
*Bob & Stacy Fugger*  
*Mr. Joe Goodwin*  
*Mr. Michael Gordon*  
*Ms. Candace Hanley*  
*Mr. Jeffrey Singh*

**Mrs. C.Z. Sherman, Raymond, Sue,  
Caregivers & Pets**  
*Sylvia & Corey Leaf*

**Soeur Clemence St-Amour**  
*Ms. Louise LeBlanc*

**Anna Zamosc Stone**  
*Mr. Kurt Stone*

**MJ Strickland**  
*Mrs. Melinda Rice*

**Jenny Stup & Joey Reed**  
*Sylvia & Corey Leaf*

**Deanna Szabo & Family**  
*Sylvia & Corey Leaf*

**Trisha Ann Taylor**  
*Mr. Jim Hilliard*

**Carolyn Tipton**  
*Scott & Joanne Blum*

**Vivian Toporcer**  
*Mr. Carl Smith*

**Greyson Walls**  
*Ms. Virginia Robbins*

**Dr. & Mrs. Art Weiss, Family &  
Staff**  
*Sylvia & Corey Leaf*

**Kay Wilcox West**  
*Robert & Louisa Matthias*

**Sam Wice & Einav Hart**  
*Mr. Martin Wice*

**Annie & Justin Winner**  
*Sylvia & Corey Leaf*

**Mr. & Mrs. Ethan Winner, Jackson  
& Alexandria & Family**  
*Sylvia & Corey Leaf*

**Nicole Winner & Family**  
*Sylvia & Corey Leaf*

**Mr. & Mrs. Zach Winner, Max &  
Sofia**

*Sylvia & Corey Leaf*

**Wyman & Rossi Families**  
*Ms Susan Lipsitz*

**Wyman Family**  
*Mr. Joe Stanley*

## 2023 Workplace & Online Giving

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A3 Consulting LLC  
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Andersen Corporation-YourCause, LLC  
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CM-UWW  
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Cybergrants-CAFA  
Duke Energy  
Elsevier Science-Book Royalty  
Mr. Chris Erickson  
Frontstream  
Mr. Matthew Gaunt  
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Michael & Carol Goebel  
Ms. Stephanie Goode  
Google  
Mr. Addle Hamad  
Ms. Jennifer Hertha  
Highmark Health  
Intel Foundation  
Ms. Erik Johns  
Mr. Robert Johnson  
JPMorgan Chase Foundation-Matching Gift  
Mr. Joel Keith  
Mr. Chaz Kellem  
Ms. Marie Kennedy  
Kimberly-Clark Foundation  
Mr. Mark Lee  
Liberty Mutual Group, Inc.  
Douglas & Michelle Major  
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Ms. Melissa McConnell  
Mr. Justin McWilliams  
Microsoft Matching Gifts Program  
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Paypal Charitable Giving Fund  
Mr. Robert Pizza  
Pledgeling Foundation  
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Mr. Charles Rhoades  
Ms. Christina L. Schrier  
Ms. Joanna Schulte  
State Employees' Community Campaign  
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Ms. Christy Valent  
VMware Foundation  
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Mr. Jeffrey Werner  
Mr. Nicholas Whitmore  
Robin Wolfecone

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**\$145,000** Baylor College of Medicine in support of the Brittle Bone Disorders Consortium

**\$86,509** Children's Brittle Bone Foundation to support the Jeanie Coleman Impact Grant Program

**\$80,000** Ultragenyx Pharmaceuticals to support the OIF Science Meeting, OIF Regional Conferences, OIF Clinic Town Hall and the Rare Bone Disease Alliance Ancillary Meeting at ASHG

**\$62,204** Patient Centered Outcomes Research Institute in support of PCOR award

**\$20,000** Alexion Pharmaceuticals, Inc to support the Rare Bone Disease Alliance Ancillary Meeting at ASHG

**\$10,000** Angitia Biopharmaceuticals to support the Rare Bone Disease Alliance

**\$10,000** Bennett Clayton Foundation to support research and general funding

**\$10,000** Mereo BioPharma to support the research and general funding

**\$8,676** Sanofi to support the Rare Bone Disease Alliance









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