

Join Us in Orlando for the 2026 OIF National Conference!

The OI Foundation is thrilled to announce that the **2026 OIF National Conference** will take place **July 24–26, 2026, at the Rosen Centre Hotel in Orlando, Florida!**

The OIF National Conference is the largest gathering of the OI community in the United States, bringing together hundreds of individuals and families living with OI, medical professionals, and supporters from around the world. This special event offers three days of education, connection, and celebration - all designed to empower and support the OI community.

Attendees will have the opportunity to:

- **Learn** from leading OI experts through educational sessions.
- **Connect** with other families and individuals living with OI.
- **Explore** resources in the exhibit hall.
- **Enjoy** social activities and programs for children, teens, and adults.

The Rosen Centre's central location makes it easy to combine learning with family fun. Just minutes from world-famous attractions like Walt Disney World®, Universal Orlando Resort™, and ICON Park, the conference is the perfect opportunity to turn your trip into a family vacation!

Looking for Financial Assistance to Attend National Conference?

Here at the OIF we do everything we can to keep conference fees as low as possible. Even with our fundraising efforts, we know



attending the OIF National Conference can be a big expense for many people. Here are the current programs that can help with the costs:

Jeanie Coleman Impact Grant Program

The Jeanie Coleman Impact Grant Program is funded by the Children's Brittle Bone Foundation (CBBF). Impact Grants may be awarded to assist in covering the cost of OIF National Conference attendance. The next Impact Grant cycle will open in January 2026.

Kasper Kendall Conference Scholarships

Kasper Kendall Scholarships are intended for people who require financial assistance to attend the OIF National Conference. These scholarships cover registration and three nights at the conference hotel for US and Canadian residents. Applications are due March 30, 2026.

National Unbreakable Spirit® Walk-n-Wheel Orlando

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

REGISTER TODAY! For more information about registration, discounted room rates, and conference activities, please visit www.oif.org/conference2026.

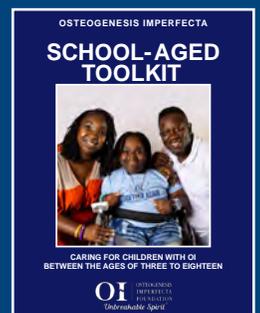
OIF School-Aged Toolkit: Caring for Children Between the Ages of Three and Eighteen

NEW RESOURCE!

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, Spanish, and French, 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.

The OI Foundation would like to thank Kara Ayers, PhD; Mike Bober, MD, PhD; Ricki Carroll, MD, MBE; Jeanne Franzone, MD; Michelle Fynan, PhD, LMHC; Sarah Gosch, OT; Jessica Hansen, APRN-NP; Katherine Harp, LCSW; Mahim Jain, MD, PhD; Joan Marini, MD, PhD; Jessica Minor, MS; Caitlyn Kubik, PA-C; Sarah Little, MSPAS, PA-C; Tina McGreal, MSN, NP-C; Nicole Needles, PT, DPT; Charlette Radik, BSN, RN, CRRN; Brianna Rezik, MS, CGC; Ameer Thekens; Danita Velasco, MD; Brandee Walton, PT; Courtney Wiese, LCSW; and the OI Foundation Medical Advisory Council for their assistance in the development of this resource.



A Message from OIF Board President, Christine Rossi

What a year 2025 has been at the OI Foundation! It is an honor to lead an organization so dedicated to its members and laser focused on progress for all living with OI. This progress can only come from support from our community and each of you! Your generosity knows no bounds, and I can speak to this firsthand after having hosted my family's 20th fundraiser for the OIF last month. Each year I am reminded of the dedication by so many to our cause and this foundation and it is truly humbling. Without that dedication from volunteers and all supporters of the OI Foundation, none of the work we do would be possible. So, allow me to start my year in review with a huge THANK YOU to whatever big or small part you played this year in supporting OIF!

Some of the highlights this year for all of us at the OI Foundation ranged from celebrating our 55th Anniversary, to supporting NEW research initiatives, to providing programs that took us abroad! Every one of these initiatives strive to improve the quality of life for individuals living with OI through research, education, awareness, and mutual support.

Since I am not a clinician or researcher myself, 21 years ago I leaned into what I could do – raise awareness and funds for the OI Foundation and to make strides in research. The OIF's Research Fund is dedicated to sustaining and advancing our critical research priorities. We continue to work diligently to close funding gaps in OI research and maintain the strong momentum toward new treatments. We are incredibly proud of the impact this fund is already making—and truly inspired by the generosity of our donors.

We are thrilled to share that Baylor College of Medicine has received renewed funding from the National Institutes of Health (NIH) for the Rare Diseases Clinical Research Network, to continue the work of the Brittle Bone Disorders Consortium (BBDC) for another five years. Since beginning in 2014, the BBDC has advanced significantly, with the OIF helping to guide the consortium's work so that patient voices inform research priorities and results.

When we think of boots on the ground and walking the walk, we have to acknowledge the amazing medical professionals who work with the OI community. Whether they are hiking more than 57 miles along the Fife Coastal Path in Scotland to raise awareness, going all the way to Hong Kong to learn about the latest in OI research and treatment, or playing a round of golf to support a local fundraiser, the clinicians and researchers who serve the OI community have spent the year truly going above and beyond and I'm sure they will continue to do so.

This year, the OIF hosted Regional Conferences in Atlanta, GA; Denver, CO; and Portland, OR. Nearly 100 OI community members and medical professionals attended each meeting to connect and discuss a range of OI related topics. We are thrilled to see this momentum continue in 2026 with the OIF National Conference taking place July 24 – 26 in Orlando, Florida! Always a favorite spot for so many of our OI families! We look forward to seeing old friends and meeting new ones and as always coming back together for our "family" reunion because after all, there is nothing like being with our OI family!

With continued efforts from both our medical professionals and OI community members, we are making great strides in improving the quality of life for those living with osteogenesis imperfecta true to our mission set forth in 1970. From bringing together support groups to expanding resources, the OI Foundation provides quality support services to more than 10,000 people each year. That is something to be incredibly proud of! Cheers to another 55 years!



Christine Rossi

A handwritten signature in black ink that reads "Christine Rossi".

Christine Rossi
OIF Board President

55 Years of the OI Foundation

This year marked the Osteogenesis Imperfecta Foundation 55th anniversary. Since its founding in 1970, the mission of the OIF has been to improve the quality of life for those living with osteogenesis imperfecta through research, education, awareness, and mutual support.

With continued efforts from both our medical professionals and OI community members, we have continued to make great strides in improving the quality of life for those living with osteogenesis imperfecta. From bringing together support groups to expanding resources, the OI Foundation provides quality support services to more than 10,000 people each year.

To help us celebrate this exciting milestone, we launched the **OIF's 55th Birthday Challenge!** The OIF's 55th Birthday Challenge invited our supporters to spread the word about the OIF & the important work we do, post a Happy Birthday message to the OIF on social media, and donate \$5, \$55, or \$555 in honor of our 55th birthday! We are so thankful to those who participated!

We are thrilled to celebrate 55 years of impact, community, and unwavering commitment to our mission—thanks to supporters like you! Here's 55 years, and many more to come.

You can still leave your birthday message & find resources to share! Visit www.oif.org/55anniversary for more information.



OIF Support Program

We Asked, You Answered!

The OIF recognizes the importance of creating spaces for members of the OI community to connect with one another and access resources. Therefore, in June of 2023, the OIF launched the first pilot of the Regional Support Group by hosting meetings for the Midwest region. Based on participant feedback and attendance numbers from these meetings, the OIF expanded the pilot program to include all five regions: Northeast, Southeast, Midwest, Southwest, and West. Each group was led by one or two volunteer OI community members, with the support of OIF staff members.

As the OIF approached the two-year mark of the initial launch and the one-year mark of the expanded Regional Support Group program, we gathered both formal and informal data, including attendance rates, community feedback surveys, and comments logged in the Zoom chats. Additionally, the OIF also distributed a survey to the entire community titled "Understanding Support Needs in the OI Community." These assessments aimed to determine whether the Regional Support Groups were meeting the needs of the OI community and to gain a better understanding of what the OI community means when they express their need for support.

The survey "Understanding Support Needs in the OI Community" received responses from 238 individuals, including those living with OI and their family members. The goal of the survey was

to assess current support preferences, usage of the Regional Support Groups, barriers to participation, and ideas for future engagement in support activities.

In response to the survey and other assessments, the OIF Regional Support Groups will transition to the OIF Support Program. The OIF Support Program includes the following components:

1. Quarterly Educational and Topic-Focused Sessions

Educational sessions and presentations on various topics of interest will be held quarterly. These meetings will feature professionals and community members leading presentations and discussions.

2. Biannual Affinity Support Group Meetings

The OIF Support Program will host virtual Affinity Support Group Meetings on Zoom, featuring breakout rooms for specific groups: women with OI, men with OI, young adults with OI, parents of children with OI, and individuals aging with OI. These meetings will be scheduled for December and May.

3. State-Based Contacts

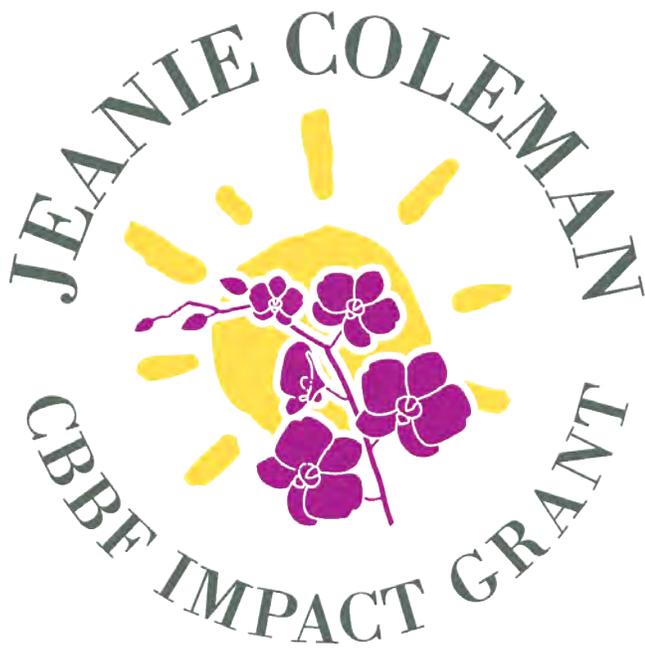
For those wishing to connect with community members in their state, the OIF maintains a list of state-based contacts. These contacts are volunteers who are willing to provide support and connect with others in their respective states. See the list of state-based contacts below. If you are interested in becoming a state-based contact, please reach out to bonelink@oif.org for more information.

4. OI Awareness Week Events

During OI Awareness Week, the OIF Support Program will host three community events. These will include social, support, and educational activities.

To learn more about upcoming OIF Support Program events, visit: www.oif.org/support-networks.





Scholarship and Grant Opportunities for OI Community Members

Jeanie Coleman Impact Grant Program

The Jeanie Coleman Impact Grant program provides direct support to individuals and families living with OI in need of equipment or services that will improve their quality of life. Items that have been awarded in the past include (but are not limited to) wheelchairs, technological devices (laptops, tablets), hearing aids, home adaptation, and accessible vans.

*Impact Grants may also be awarded to assist in covering the cost of OIF National Conference (Orlando, FL July 24-26, 2026) attendance.

Applications for the 2026 cycle open on Monday, January 5th. If you have any questions about the program, please feel free to reach out to Stacie Connors at sconnors@oif.org.

Edward D. Cranston College Scholarship

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

The 2026 cycle opens on Monday, January 12th. 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. Applicants are required to submit at least two letters of recommendation (pertaining specifically to this scholarship), their most recent official academic transcript, and a personal essay along with the application form.

2025's recipient was Caroline Denny, chosen from almost 30 applicants. She is an undergraduate student at Washington University in St. Louis, majoring in biology with a specialization in neuroscience. We remain grateful to our review committee for taking the time to learn about each of our applicants, and we are proud to support Caroline as she moves forward in her educational journey.

All applications must be submitted by April 13, 2026. For more information, please contact Stacie Connors at sconnors@oif.org.



Caroline Denny, 2025 Recipient of the Edward D. Cranston College Scholarship



MEMBER SPOTLIGHT

Sarah and Earl Dyke are parents of a young adult daughter living with OI in Houston, Texas. They are long-time OIF volunteers and members. Learn more about why Sarah and Earl renew their membership of the OI Foundation year after year!

What is your relationship with OI?

Our 24-year-old daughter, Andersson, has moderate OI.

Why is membership in the OI Foundation important to you?

The membership of the OI Foundation provided support by introducing us to families that had experience with OI and doctors who had treated patients with cutting edge procedures.

Have you attended the OIF National Conference? If so, how was your experience?

YES! Our first OIF National Conference was in Dallas, TX, when Andersson was an infant. We have gone to most of the conferences since then. Our experience has been extremely positive and very helpful.

What has been your favorite OI Foundation event?

We may be biased, but we enjoy the Boots and Bling for Better Bones fundraiser in our hometown, Houston.

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

We would say the sessions at the OIF conferences. There is always something new to learn, and the sessions cover a wide array of topics. For example, when you have an infant with OI, you might attend a session on handling your child, and when they get older, a session on how to make adaptations to your home.

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

New families should definitely try and attend the conferences. The amount and quality of information was invaluable. And making new friends... support among parents was amazing.

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

We are excited about the next conference, since we missed seeing old friends and making new ones. We are always excited by the new research updates as well.

Learn more and become a member today at [www.oif.org/membership!](http://www.oif.org/membership)

Sarah and Earl Dyke with their children



Locate Care in Your Area

Physician Directory
OI Clinic Directory



Physician Directory

The OIF Information Center maintains a community-generated list of medical professionals (ie. general physician, dentist, specialist) who have experience treating patients with osteogenesis imperfecta (OI). To locate care in your area, please email bonelink@oif.org

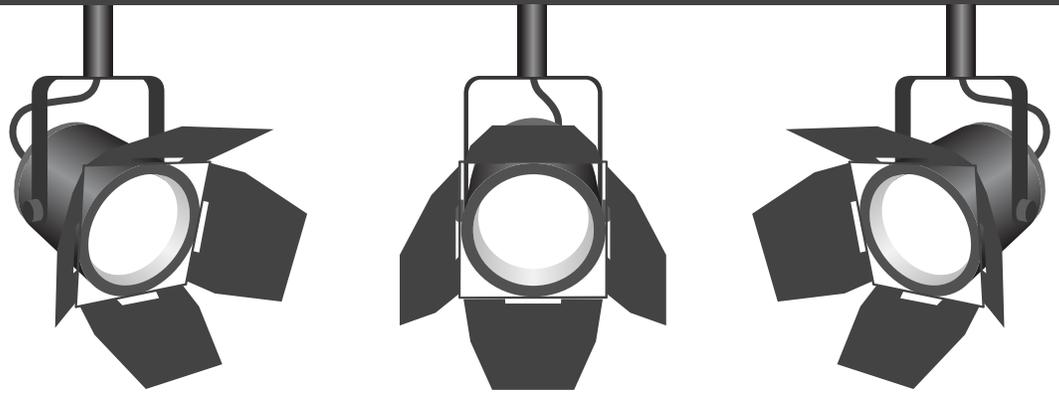
Clinic Directory

The **OI Clinic Directory** provides you and your family with accurate, verified, and easily accessible information to assist you in locating dependable multidisciplinary medical care.

OSTEOGENESIS IMPERFECTA

OI FOUNDATION

Unbreakable Spirit®



CLINIC SPOTLIGHT: Skeletal Dysplasia Clinic at UCLA Health

The OI Foundation works closely with nearly 60 multidisciplinary OI Clinics across the continent to provide timely and accurate information about the range of available services to OI community members. The complete OI Clinic Directory can be found at www.oif.org/ClinicDirectory

To provide an overview of the background, mission, and services of these centers, the OIF spotlights new and existing OI clinics serving pediatric and adult patients in each issue of Breakthrough. In this issue, we are excited to highlight the **Skeletal Dysplasia Clinic at UCLA Health**.

Skeletal Dysplasia Clinic at UCLA Health

With its outstanding physicians and world-renowned facilities, UCLA consistently ranks as number one in the West in U.S. News & World Report's America's Best Hospital survey. UCLA's clinical and training programs have flourished from collaborations with clinicians, scientists, community partners, and public health officials. UCLA's mission is to deliver leading-edge patient care, research, and education. We achieve the highest possible patient satisfaction scores and provide excellent clinical outcomes for our patients.

Care for Osteogenesis Imperfecta (OI) at UCLA is managed by the Skeletal Dysplasia Clinic. This clinic offers full-spectrum care across the lifespan, from prenatal management to adult treatment, for skeletal dysplasia conditions, including OI. It is one of the few programs in the country that provides clinical care for patients of all ages affected by various types of skeletal dysplasia. The clinic offers dedicated support for children and young adults under 21 at the **UCLA Health-affiliated Luskin Orthopaedic Institute**. While patients of all ages can seek evaluations and treatment at the **UCLA Santa Monica Medical Center**. This ensures comprehensive care from a dedicated team of experts for both pediatric and adult patients.

The Skeletal Dysplasia Clinic features a multidisciplinary team of experts, including geneticists, orthopedic surgeons, and endocrinologists, all with extensive experience in diagnosing and managing different skeletal dysplasia conditions. Due to UCLA's vast resources, the clinic can work closely with various specialty areas, including nephrology, dentistry, orthopaedic surgery, neurosurgery, plastic surgery, pulmonology, cardiology, neonatal care, rheumatology, endocrinology, ophthalmology, psychology, physical and occupational therapy, pain management, otolaryngology, and audiology. This collaboration ensures patients receive the care they need. For families receiving a diagnosis of skeletal dysplasia before the baby is born, the clinic collaborates with UCLA's

maternal-fetal medicine team to ensure a seamless transition of care after delivery.

Treatments for OI are tailored to individual needs. The core team of experts at the Skeletal Dysplasia Clinic closely monitors each patient to determine the most appropriate treatment at the right time. They provide comprehensive care plans aimed at helping patients achieve the highest quality of life.

As leaders in skeletal dysplasia care and research, UCLA Health is the home of the International Skeletal Dysplasia Registry,

co-directed by Dr. Deborah Krakow. The team at the Skeletal Dysplasia Clinic engages in research to study new advancements in the treatment of skeletal dysplasia conditions, including OI, ensuring patients have access to the latest and most effective treatment options. To highlight the high standard and dedication to researching OI occurring at UCLA, the OIF Scientific Review Committee selected Roya Bagheri, PhD, as the OI Foundation's Michael Geisman Fellow with her project, *Investigating the Biomechanics and Pathways Underlying Pulmonary Vulnerability in Osteogenesis Imperfecta*.



Deborah Krakow, MD, is Professor and Chair of the Department of Obstetrics and Gynecology at UCLA. She is also Professor of Orthopaedic Surgery and Human Genetics at UCLA. She has extensive experience in human genetics, particularly in the area of skeletal disorders, including OI. She is the Co-Director of the International Skeletal Dysplasia Registry (ISDR) and has seen

hundreds of cases of OI through her work on the ISDR. She has been actively involved with gene discovery in various forms of OI, as well as elucidating the underlying biology associated with the disease through biochemical analyses. She currently serves on the Medical Advisory Board of the OI Foundation and many other prominent national and international societies focused on musculoskeletal health.



Roya Bagheri, PhD, is a postdoctoral research fellow at UCLA and is the current OI Foundation's Michael Geisman Fellow recipient for her project titled *Investigating the Biomechanics and Pathways Underlying Pulmonary Vulnerability in Osteogenesis Imperfecta*. The study aims to understand the reasons behind lung weakness in OI to discover new treatment options. She holds

a Bachelor of Science in Material Science and Engineering from Iran University, a Master of Science in Biomedical Engineering from the University of Tehran, and a Doctor of Philosophy in Mechanical Engineering from Michigan Technological University.

2025 YEAR END AC

As we near the end of another incredibly special year - this one even more so as it marked our 55th anniversary - we are taking a moment to look back on all that the OIF has been able to accomplish since our founding in 1970, and looking ahead at all the future milestones that lay before us.

We hope you will take a moment to read about some of our most exciting accomplishments in 2025 as we strive to improve the quality of life for individuals living with OI through research, education, awareness, and mutual support. Please consider helping the OI Foundation continue our efforts to improve the quality of life for individuals with OI by making an end of year contribution using the enclosed envelope or visiting www.oif.org/donate. Thank you in advance for your support!



Medics on the March

This summer, the OI Foundation joined physicians from the United Kingdom & Europe on a more than 57-mile hike along Scotland's Fife Coastal Path in honor of the Brittle Bone Society's 57th anniversary.

Dr. Jeanne Franzone from *Nemours Health*, Dr. Reid Sutton from *Texas Children's Hospital*, Dr. Maegen Wallace from *Phoenix Children's Hospital*, and Dr. Peter Smith from *Shriner's Hospital Chicago*, all represented the OI Foundation during the 3-day journey and worked tirelessly to help us pass our fundraising goal of \$50,000.

All four doctors participated in this event back in 2019 in honor of the OI Foundation's 50th anniversary, so they were excited to tackle a new terrain this time around. This campaign was unique as people could "join a team" to support their favorite doctor during our fundraising efforts and get team merchandise to help spread the word. This exciting community endeavor helped raise over \$61,000 for OI research.

Thank you to everyone who made the Medics on the March event such a success.

Research Fund

Our Research Fund was launched as a focused effort to raise new funds to ensure the continued support of our essential research priorities. The Foundation's mission is to improve the quality of life for people affected by OI through research, education, awareness, and mutual support, and while programming makes up 80% of our total spending at the OIF, the OI Foundation is working to fill funding gaps in OI research to continue the current aggressive pace of research that is helping to find new treatments.

Since its launch earlier this year, the fund has focused on priorities such as the Michael Geisman Fellowship Grant, Expert Consensus Meetings, Adult Care Initiative, The Annual OIF Scientific Meeting, and Clinical Research Sites of the Brittle Bone Disorders Consortium, among several others.

If you'd like to make a gift to support these efforts, donors may designate gifts towards a particular research priority or make their gift an unrestricted research donation. The OIF also accepts gifts

of stock and is available to work with your financial advisor on making a gift from your donor advised fund.

Thank you for your support!



ACCOMPLISHMENTS

New OIF and RBDA Website

While our brand new OIF website launched earlier this year, providing an easier way to access our information and resource center, among other things, we've also been hard at work at building a new Rare Bone Disease Alliance website!

We were able to completely redesign the outdated website and bring in new functions that will serve as a hub for the Rare Bone Disease Alliance organizations. We hope both websites will be able to serve the community better for years to come.

Regional Conferences 2025 (Atlanta, Denver, and Portland)

This year, our Regional Conference program took us to Atlanta, Denver, and Portland, where we had close to 75 attendees at each conference! These exciting one-day events include sessions and discussions on understanding and living with osteogenesis imperfecta.

These events serve as great opportunities for new and long-time OI community members to learn from expert speakers and meet other individuals and families in the area. OIF Regional Conferences have included sessions on medical and orthopedic treatments, pulmonary health, dental health, pain management, and more.



Thank you to our host locations in each city. This valuable program helps us to connect with different members throughout the country.

The Washington, DC Metabolic & Rare Bone Disease Club

This exciting new venture features a series of quarterly dinners focused on new developments in research, diagnosis, and treatment of metabolic and rare bone disorders.

The goal of the Washington, DC Metabolic & Rare Bone Disease Club is to bring together endocrinologists, rheumatologists, geneticists and orthopedic surgeons with easy access to innovative and robust data as well as to help them expand their professional relationships across the varied disciplines.

These quarterly dinners have hosted over 150 people so far and continue to grow in popularity. This program strives to bring medical professionals together in this rapidly changing field, as we seek to grow the community of clinicians focused on improving care for these thought-provoking disorders. Thank you to all the professionals who have joined this quarterly outing; we are excited to see this club grow in the years to come!



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. Thank you, as always, for your continued support.

Fine Wine Strong Bones Events 2025

We were excited to close out our year by holding two of our annual Fine Wines, Strong Bones events in Houston, TX and Boston, MA. Both of these exciting events are close to celebrating their 10-year anniversary and have become tradition in their communities.

The 9th annual Boots & Bling for Better Bones was held on October 25th at the Armadillo Palace in Houston, TX. This cowboy-chic themed event featured delicious food, live entertainment, an exciting online silent auction (with new online bidding capabilities) and beautiful decor. Thanks to our dedicated

event chair, Dr. Zarina Rasheed, and our kind volunteers, donors, and sponsors, the event raised \$229,000 and was attended by more than 225 people. We are so thankful to everyone who continues to make this annual event a staple in the OIF community!



The 8th Annual Strong Bones Gala Boston was held on November 8th at the Sheraton Needham Hotel. The red carpet was rolled out for this Hollywood themed event where Event Chair and Board President Christine Wyman Rossi, along with her dedicated committee, raised more than \$110,000 for the OI Foundation while bringing an exciting energy to a new theme this year. This star-studded evening boasted over 200 attendees where they enjoyed delicious food, exciting raffle bags and unique silent auction donation items through a new online auction platform, Give Butter. Thanks to the work of this tight-knit group of engaged volunteers, this annual event was bigger and better than ever!

Golf Events for OI

The Abruzzi/Koch Family Golf Tournament was held by the Abruzzi and Koch families at the South Moore Golf Course in Bath, PA on August 9th. The tournament raised more than \$9,500 during the August event, enjoying the morning playing golf and followed with a beautiful catered luncheon featuring Thiess Oyster Shucking Services. Spirits were high for this annual summer event!

The Unbreakable Spirit® Golf Tournament was held by the Walls and Zilling families at the Iron Valley Golf Club in Lebanon, PA on September 17th. The tournament raised more than \$47,000 and boasted over 112 golfers! The rain at the start of the event





didn't dampen anyone's spirits, and the large crowd encouraged everyone to cheer on one another in classic Unbreakable Spirit® fashion!

Thank you to everyone who supported, played, and donated and a huge thank you to our host families for continuing to put together such wonderful events.



What is coming next? Clinical Trials and the OI Foundation

2025 and 2026 are exciting years for OI research. In the United States and across the world, researchers are conducting many clinical trials on new types of treatments and investigating innovative ways to improve care for people with OI. While no two studies are the same, all of them need participants with OI to enroll. The OIF, as an organization dedicated to promoting research and education, continues to play an essential role in spreading awareness, assisting investigators, and educating the community about the importance of research participation.

The first way that the OIF supports research is through financial support. This includes grants such as the Michael Geisman Fellowship, which provides \$50,000 awards to early-stage researchers studying OI. The OIF also fosters professional development and collaboration by hosting in-person networking and educational events, including the annual OIF Scientific Meeting, OI and Rare Bone Disease TeleECHO Clinic Series, and OI and Bone Health Clinic Town Halls, all designed to connect clinicians and scientists to one another and to the latest developments in the field.

Another keyway the OIF contributes to research is by sharing opportunities for clinical trial enrollment. Academic researchers, partner organizations, and pharmaceutical companies frequently contact the Foundation seeking participants for a wide range of studies. When appropriate, the OIF shares these opportunities

with the OI community, with the important caveat that while the Foundation does not endorse any individual study, it provides the information as a service to help connect people with research.

As clinical research has expanded, the OIF's partnerships with pharmaceutical companies have also evolved. For studies that are still in the early phases, the OIF may help companies and researchers understand the OI experience by arranging listening sessions, interviews, or focus groups with community members. For later-stage trials that have begun recruiting, the OIF often hosts virtual Q&A sessions or public webinars, giving individuals and families the chance to ask questions directly of the scientists leading the work. These events help ensure transparency, build trust, and keep the community informed about emerging treatment options.

Looking ahead, the OIF will continue to support all aspects of OI research. Every new study brings the potential for progress, and every participant brings us closer to improving care and expanding treatment options for people with OI.

Are you interested in learning more about OI-related clinical trials? The OIF regularly shares announcements from partner organizations that are enrolling participants, offers educational resources on how trials work, and what participation involves. To stay updated, visit www.oif.org/currentstudies or contact the OIF at bonelink@oif.org.

Strengthening Connections: OIF Resources for Medical Professionals Advancing OI Care

In addition to patient education and community support, an equally vital part of the OIF's mission is to equip healthcare providers with the latest tools, research, and connections to improve care for people with OI. Through innovative programs such as the **Michael Geisman Fellowship**, the **OI and Rare Bone Disease TeleECHO Clinic Series**, Clinic Town Halls, and the DC Bone Club, the OIF fosters a robust network of clinicians, researchers, and trainees dedicated to lifelong bone health.

The Michael Geisman Fellowship Grant

Named in memory of Michael Geisman, the son of OIF Founder Gemma Geisman, the **Michael Geisman Research Fellowship Grant** provides critical funding to promising early stage investigators pursuing research about OI. Each year, the OIF awards one- or two-year fellowships that support early-career scientists—often postdoctoral researchers or new faculty—working in areas such as genetics, bone biology, orthopedics, and rehabilitation.

Geisman Fellows have investigated topics ranging from the molecular mechanisms of collagen defects to innovative imaging technologies and clinical outcome measures. The Fellowship awards up to \$50,000 per year, and it can be extended into a second year. For many early-stage investigators, the award serves as a gateway to long-term engagement with the OI field and future research.

OI and Rare Bone Disease TeleECHO Series

The OIF hosts two ECHO programs, the **OI TeleECHO Clinic Series** and the **Rare Bone Disease TeleECHO Clinic Series**. The TeleECHO model allows the OIF to reach clinicians across diverse settings—community hospitals, academic centers, and international clinics—providing ongoing professional development at no cost. In addition, continuing medical education (CME) credit is available for participants, further reinforcing the Foundation's commitment to accessible, high-quality education for all providers caring for people with OI and other rare bone diseases.

The Rare Bone Disease Alliance (RBDA), a program of the OIF, hosts the **Rare Bone Disease TeleECHO Clinic Series**, a virtual education program that brings together healthcare professionals from around the world. The monthly TeleECHO sessions connect expert faculty with community clinicians, allowing participants to present cases, share experiences, and discuss best practices in real time. Since their creation, hundreds of healthcare providers have attended both

Each session features a short didactic presentation followed by case-based discussion. Topics have included adult care, surgical

management, dental and hearing health, pain management, and emerging therapies. Participants include endocrinologists, orthopedists, rehabilitation specialists, geneticists, primary care physicians, and nurses—many of whom may have limited prior exposure to rare bone diseases in their practice. For more information on both programs, go to www.oif.org/echo/.

Clinic Town Halls: Strengthening Clinical Networks

Another cornerstone of the OIF's professional engagement are **OI And Bone Health Clinic Town Halls**, which brings together representatives from OI Clinics across the United States and beyond. These virtual meetings is for clinicians, nurses, and health professionals to share updates, discuss challenges, and coordinate strategies for improving multidisciplinary care. These meetings are held twice per year, once virtually and once in person. Attendance ranges from 50-100+ per meeting.

The Town Halls on clinical issues and research updates—standardizing outcome measures, sharing patient education materials, or providing information on research milestones that have direct impact on patient care. They also help build a sense of community among OI clinics, many of which operate within larger hospital systems but face similar challenges in managing complex, lifelong bone disorders.

Through these discussions, the OIF supports the exchange of ideas that drive clinical innovation and consistency across centers, ensuring that individuals with OI can access knowledgeable, coordinated care no matter where they live.

DC Metabolic & Rare Bone Disease Club

At the regional level, the Rare Bone Disease Alliance, a program of the OIF, sponsors the **DC Metabolic & Rare Bone Disease Club**, a quarterly dinner series for endocrinologists, orthopedists, and bone researchers to hear from speakers in the field. Each meeting features presentations from leading experts, including NIH scientists and regional clinicians, followed by open discussion.

The goal of the Washington, DC Metabolic & Rare Bone Disease Club is to bring together endocrinologists, rheumatologists, geneticists, and orthopedic surgeons with easy access to innovative and robust data as well as to help them expand their professional relationships across the varied disciplines that care for these challenging patients.

2025 Bone Club sessions:

- **An Overview of Hypophosphatasia (HPP)** with Eric Rush, MD, FAAP, CCD - Sponsored by Alexion
- **Introduction to ENPPI and ABCC6 deficiencies** with Jennie Miller, MD, CCD - Sponsored by Inozyme

- **Expert Insights: Views on the International X-Linked Hypophosphatemia (XLH) Management Guidelines** with Robin Dore, MD and Charles McKay, MD - Sponsored by Kyowa Kirin
- **An Overview of Achondroplasia** with Pedro A. Sanchez-Lara, MD - Sponsored by BioMarin

Medical professionals interested in learning more or joining these initiatives can visit the Medical Professional section of the OIF website or contact the OIF at bonelink@oif.org.

Osteogenesis Imperfecta Foundation Welcomes Renewal of NIH Funding for the Brittle Bone Disorders Consortium

The Osteogenesis Imperfecta Foundation (OIF) is proud to share that Baylor College of Medicine has received renewed funding from the National Institutes of Health (NIH) for the Rare Diseases Clinical Research Network, including \$7.4 million over five years to continue the work of the Brittle Bone Disorders Consortium (BBDC). The OIF has been deeply involved in shaping the consortium's work, ensuring that patient voices guide the research priorities and outcomes.

Since its launch in 2014, the BBDC has made tremendous progress. Researchers, working in close collaboration with the OI community, have:

- Built the world's largest longitudinal cohort of OI patients.
- Collected critical data on skeletal features, quality of life, and psychosocial impacts.
- Launched two interventional clinical trials addressing bone and dental health, including one that led to an industry-sponsored trial of anti-TGF treatment.
- Initiated 10 pilot studies to respond to community-identified needs.
- Published nearly 50 scientific papers using data collected directly from people with OI.

Looking Ahead

As the BBDC enters its third and final five-year funding cycle, researchers and the OIF will continue to work together on three major projects:

1. **Long-term follow-up of more than 1,000 participants** – including whole genome sequencing, return of results, and imaging analysis to better understand disease progression.
2. **A randomized controlled trial on pain management** – addressing a top priority identified by the OI community.
3. **Advanced imaging studies** – using high-resolution CT scans to identify measurable endpoints for future clinical trials.

In addition, the consortium will continue its focus on training the next generation of researchers and partnering with the OIF to provide education and advocacy for the OI community.

"The OI community has been clear about the importance of advancing research that improves health and quality of life. We are grateful to continue our partnership with the BBDC investigators and to see the NIH's strong commitment to OI research," said Tracy Hart, CEO of the OI Foundation.

About the Funding

The BBDC is funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (U54AR068069), with additional support from the National Center for Advancing Translational Sciences, the National Human Genome Research Institute, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Office of Research on Women's Health, and the National Institute of Dental & Craniofacial Research.

BBDC Clinic Sites

Alfred I. duPont Hospital for Children/Nemours
Wilmington, DE

Baltimore, MD

Marquette University
Milwaukee, WI

Baylor College of Medicine - Administrative Core
Houston, TX

McGill University
Montreal, Quebec QC

Children's Mercy Hospital
Kansas City, MO

National Institutes of Dental Craniofacial Research
Bethesda, MD

Children's National Medical Center
Washington, DC

Oregon Health & Science University
Portland, OR

Hospital for Special Surgery
New York, NY

Phoenix Children's Hospital
Phoenix, AZ

Kennedy Krieger Institute



Shriners Hospital for Children Montreal
Montreal, Quebec

University of Missouri Kansas City
Kansas City, MO

University of California at Los Angeles
Los Angeles, CA

University of South Florida
Tampa, FL

NEW! OIF Factsheet & Toolkit Chatbox

The OIF Factsheet & Toolkit Chatbox is an easy-to-use tool, that was created by the OIF using ChatGPT. It gives quick, reliable answers based on trusted OIF resources like the OI factsheets and toolkits. You can ask about OI types, diagnosis, treatment options, and more. Just remember: this chatbox is for general information only and isn't a replacement for medical advice. Users are encouraged to consult qualified healthcare providers for personalized care. Visit www.oif.org/oif-information-library to use the OIF Chatbox.



Stay Up to Date on OI Research

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

To view OI Publications, visit www.oif.org/oi-publications. On this page you will find a list of publications from recent OI research.

Participate in OI Research – Join the OI Registry!

As someone living with OI, your experiences and insights are invaluable to advancing OI research. 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!

A dark green banner with a white envelope icon at the top center. On the left, there is a photo of a young girl with blonde hair, wearing sunglasses and a pink hoodie, holding a sign that says "OI Can". To the right of the photo is a white rounded rectangle containing the text "Join the OIF Email List!" followed by "Sign up to receive updates from the OI Foundation including our monthly e-newsletter, research updates, and upcoming event information." and "Sign up today at www.oif.org/email". At the bottom center is the OI logo and "OSTEOGENESIS IMPERFECTA FOUNDATION". At the bottom right is a QR code.

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.

50,000

An estimated 50,000 people in the US are affected by OI.



The OIF has consistently received Charity Navigator's highest rating of 4 stars.

10,000



Each month, over 10,000 people use the OIF website and OIF staff respond to more than 50 direct inquiries regarding medically verified information.

80%

Programming & other Priority Programs make up 80% of total spending at the OIF.



RESEARCH



The OIF Research Fund follows a focused effort to raise new funds to ensure the continued support of essential research related to OI.



EDUCATION

The OIF provides resources and information for OI community members and medical professionals including the online OIF Information Library, educational events, and updates through the OIF newsletters.

AWARENESS



The Foundation strives to build public awareness and generate additional support among individuals, community organizations, and medical professionals.



MUTUAL SUPPORT

The OIF manages the OI Support Group program as well as hosts Regional Conferences (100+ attendees) and National Conferences (500+ attendees) to bring together OI community members and families.

TAKE ACTION!

Support the mission of The OI Foundation by raising OI awareness or hosting a fundraiser.

**RAISE
AWARENESS**

DONATE

**BECOME A
MEMBER**

SUPPORT THE OIF!

We are deeply grateful for your continued support in helping to expand and strengthen the resources available to those living with OI.



VISIT WWW.OIF.ORG FOR MORE INFORMATION



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