



Dear Friend,

At the end of each year, most of us take some time to reflect...we think about all the good things that happened to us and the challenges we encountered. When we, at the Osteogenesis Imperfecta Foundation, think about the past year we are overwhelmed with such wonderful memories of being together with so many OI community members and we are so grateful for those moments.

From OIF Regional Conferences, to the annual Scientific Meeting, to exciting community events, the OIF worked hard to move forward in our mission to improve the lives of every person with OI through research, education, awareness and mutual support. Please keep in mind, **we cannot do any of this without you!** So, let's reflect a bit on a very exciting year!

Research

The OIF continues to help accelerate OI research with industry partners and research organizations like the National Institutes of Health and the Rare Diseases Clinical Research Network. More and more we are seeing how important it is to hear the voice of the OI community to help advance research and enhance programming. Through awards from the Patient Centered Outcomes Research Institute, the OI Foundation has been conducting a series of research studies to determine what issues are most impactful to the OI community. The results of these studies appear in the Research section of the OIF website. Through the Brittle Bone Disorder Consortium, studies are being conducted on topics including new medical treatments for OI, the effects of aging with OI, quality of life with OI, pregnancy in OI, craniofacial development in OI and cardiopulmonary outcomes in OI. The OIF also fosters relationships with pharmaceutical companies working on OI and rare bone disease research to ensure our community's needs are understood. This year, we've been able to work with these industry partners on exciting clinical trials for new treatments for OI. The OI Foundation makes sure the information about these studies is distributed to the OI community in an accessible and transparent manner.



Attendees at the OIF Regional Conference in Washington, DC

Education

For more than 50 years, the OIF has been proud to provide up-to-date, medically verified information and offer direct support from the OIF Information Center which answers more than 11,000 inquiries annually. The OIF's online information center features OIF publications and informational fact sheets including *Navigating a New Diagnosis: A Tool Kit for Parents and Medical Professionals*; *What You Need to Know About Clinical Trials*; and by the end of this year, the OIF will publish the *Adult Health Tool Kit* which provides information for adults living with OI and medical professionals providing care for adults with OI. Visit the OIF website to view these resources as well as the growing number of video resources available on our YouTube channel.

Awareness

Having medical professionals who are well-versed in OI is so important when it comes to providing care for the OI community. To build a strong network of physicians who can provide the latest in medical advancements to their patients, the OIF has been bringing directors of bone health programs across the country together for biannual OI Clinic Town Hall meetings. The most recent of these meetings was held virtually in November. These sessions allow for physicians to compare experiences with specific case studies to better serve the OI community. The OI Foundation has also partnered with 17 other rare bone disease patient advocacy groups that make up the Rare Bone Disease Alliance.



Attendees at the Strong Bones Houston event

Mutual Support

Sharing information and experiences with others provides a sense of community. Coming together with old and new friends while learning about the newest treatments and research is invaluable when living with a rare disorder. The OIF is so excited that the OIF National Conference is back in person and will be held July 19-21, 2024 in Omaha, Nebraska. We hope you will visit the OIF website to find out more information and register to attend. Scholarships and financial support are available.

We would also like to share the OIF's enhanced national OI Support Group program, giving people with OI the opportunity to connect with other OI community members in their area. Look for more information in Breakthrough and OIF E-news to find virtual meetings and in-person gatherings in your area.

This was a wonderful year! We cannot do what we do without you and are so grateful for your continued support. We hope you will consider making a gift of \$50, \$100, \$500 or more to help us continue this vital mission. Use the enclosed envelope or go online to www.oif.org/donate to show your support today!

Thank you again for your continued and generous support.

All my best for a safe and happy holiday season,

Tracy Hart
Chief Executive Officer