

Dear Friend,

We talk a great deal about the mission of the OI Foundation: to improve the quality of life for all individuals living with osteogenesis imperfecta through research, education, awareness, and mutual support. But what does that mean? I'd like to give you a few examples of ways in which the OIF is there, not just for adults with OI and parents of children with OI, but also for spouses, extended family members, caregivers, medical professionals, and anyone who loves or cares for individuals with OI.

Please keep in mind, **we cannot do any of this without you!** The OIF relies on donations from individuals like yourself to make up 80% of the operating budget. Every little bit helps, and we are truly grateful for all support.

Research

The OIF continues to help accelerate OI research with industry partners and research organizations like the National Institutes of Health and the Rare Disease 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 web site. 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, cardiopulmonary outcomes in OI, developing a non-invasive test to determine OI type and many more!

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 *Nutrition and OI* (prepared by OI community member Mia Gould with Deborah McInerney, MS, RD, CDN). Coming in 2023, the OIF will publish an Adult Tool Kit which is planned as an extended resource similar to the New Diagnosis Tool Kit, but will provide information for adults living with OI. Since March 2020, the OI Foundation has held dozens of virtual information sessions for members of the OI community, discussing topics such as COVID-19 updates, expert panels on living with OI, and research updates from the Brittle Bone Disorders Consortium. These video resources have joined the online information center as a resource to anyone who has questions – all available for free on the OIF's website.



Bond Varela and two-year old Lily at the 2022 Tampa Regional Conference

Awareness

Having medical professionals who are well-versed in OI is paramount when it comes to 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. 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 15 other rare bone disease patient advocacy groups to create the Rare Bone Disease Alliance. This partnership enables them to bring awareness of OI and other skeletal dysplasias to physicians and researchers around the world. In February 2023, the Rare Bone Disease Alliance will be hosting a virtual scientific symposium focused solely on OI.

Mutual Support

Sharing information and experiences with others offers a sense of community between spouses, extended family members, caregivers, and medical professionals as well as those living with OI. Coming together to greet friends while learning about the newest treatments and research is invaluable when living with a rare disorder. To that end, I am very excited to announce the return of in-person OI Foundation meetings and events! I had the pleasure of joining OI community members at the Regional Conference in Tampa this summer as well as at fundraising events such as the Boots & Bling for Better Bones in Houston this fall. Looking forward, the OIF will be hosting a Regional Conference in June 2023 in Washington, DC and another in Phoenix, AZ in September 2023. And of course, we're all eagerly looking forward to the return of the OIF National Conference in Omaha in 2024. In addition to the OI Foundation's social media pages, which link tens of thousands of OI community members across the globe, we are planning on bringing back OIF Support Groups to help create even more avenues for mutual support.



Attendees at the 2022 Tampa Regional Conference taking a break from education sessions to get to know each other

As I mentioned above, the OI Foundation cannot do what they do without you! 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.

Wishing you a happy and healthy holiday season!

A handwritten signature in black ink that reads "Ted Trahan". The signature is fluid and cursive.

Ted Trahan
President, Osteogenesis Imperfecta Foundation Board of Directors