

December 11, 2015

*Dear Friend,*

*As we near the end of 2015, we are pleased to present you with an update on our programs and activities and we want to thank you for your continued and generous support. This past year was very busy here at the OI Foundation and it is because of the caring and committed OI community that we are able to continue to fulfill our mission. If you haven't had the chance to remember us with a gift at this time of year, please take a minute to use the enclosed envelope or visit us on our website at [www.oif.org](http://www.oif.org). Thank you for your support; we hope 2016 is a wonderful year for you and your family!*

*The Board of Directors and Staff of the OI Foundation*

*P.S. Remember to check if your company matches charitable giving! You can find more information at [www.matchinggifts.com/oif](http://www.matchinggifts.com/oif)*

## **2015 Programs and Activities**

**Awareness**— From May 2-9, 2015, the OI Foundation held its sixth annual National OI Awareness Week, involving volunteers across the country in holding awareness and fundraising events within their communities. Volunteers proclaimed OI Awareness Week in over 10 cities and states, held multiple walks and events nationwide and displayed more than 300 official OI Awareness Week posters. Over 30 hosts participated in Bone China Tea 2015 on Monday, May 4, 2015. The OIF also participated in Wishbone Day, the international day of OI Awareness held on May 6th each year, by sharing facts and information about OI on our social media sites every hour for 12 consecutive hours. We reached over 175,000 people through our National OI Awareness Week social media campaign called [SHAREforAWARENESS]. National OI Awareness Week and Wishbone Day help raise awareness about OI all over the world.

**Regional Conferences** – In an effort to bring information and resources to more members of the OI community, the OIF held regional conferences in Los Angeles, CA, Stamford, CT, and Minneapolis, MN. Combined, the meetings reached 600 members of the OI community and more than half of the attendees had never been to an OI event before...welcome to the community! The one-day conferences featured educational sessions led by OI experts including OIF Medical Advisory Council members Dr. Jay Shapiro, Dr. Cathy Raggio, Dr. Laura Tosi, Dr. David Vernick, Dr. Deborah Krakow and Dr. Francis Glorieux.

**Scientific Meetings** – In April 2015, scientists from the United States, Canada and the United Kingdom gathered in Chicago for the 14<sup>th</sup> Annual OIF Scientific Meeting. The meeting, titled *New Directions in OI Research*, was chaired by Dr. Cathy Raggio of Hospital for Special Surgery in New York and Dr. Deborah Krakow from UCLA. Both Dr. Raggio and Dr. Krakow serve on the OI Foundation's Medical Advisory Council. The meeting reviewed progress made over the past 15 years in the study of osteogenesis imperfecta and looked ahead to the future with talks from experts on orthopedics, genetics, dental manifestations and current medical treatment available to adults and children with OI. The conference was made possible by the generous support of the Buchbinder Family Foundation.

**Research Grants** – The OI Foundation awarded a second year of funding to Dr. Brya Matthews from the University of Connecticut. Her research focuses on examining approved drugs that block TNFa. TNFa is elevated in oim mice, which may contribute to increased bone turnover. She plans to test one of the approved drugs to determine if treatment can improve bone density and strength in mice. Since these drugs are already approved for use in children and with other diseases, promising results would potentially allow rapid clinical translation of these findings, providing an alternate treatment approach for children with OI. The OI Foundation also funded the research of Dr. Kyung-Eun Lim from the Indiana University School of Medicine. Dr. Lim's research will focus on a biological target called Nuclear Protein 1 which could potentially be manipulated to improve skeletal properties in OI.

**OI Registry** - The OI Registry is a joint effort between the OI Foundation and the Kennedy Krieger Institute. Each person completes a profile of their medical characteristics, family history, fracture history, and treatment. Based on their profile, people are contacted about institution and IRB-approved clinical research study opportunities. Since the Registry opened in March 2006, more than 1,500 people from the United States and 39 other countries have joined. In 2015 the OI Registry was moved to the OI Foundation and information from the registry will be used to identify new areas of OI research.

**Impact Grants** – In partnership with the Children’s Brittle Bone Foundation, more than \$135,000 was awarded in 2015 to people with OI in need of products or services that would improve the quality of their lives. Grantees received funds to purchase adapted vehicles, new mobility devices, computers, hearing aids, dental work and other products and services. A new cycle of funding begins on January 4, 2016.

**OI National Information Center** – Approximately 7,000 requests for information were provided during the year, and the OI Foundation website was visited 205,000 times. The Center also offers a variety of resources, many of which can be downloaded free of charge, including booklets, brochures and more than 70 fact sheets. As part of the new information center for medical professionals (which was launched in October of this past year) the OIF introduced a new monthly podcast series featuring OI experts presenting on topics that advance the care of children and adults living with OI.

**Social Networking** - The OI Foundation manages three social networking sites: Osteogenesis Imperfecta (OI) Foundation Facebook Page; NING; and OI Foundation Twitter. The OI Foundation website continues to offer links to other social networking sites that might be helpful or interesting to parents and individuals living with OI. They continue to be managed by volunteers with whom the Foundation has established a working relationship. To date, more than 6,000 people are members of the official OIF Facebook page. This page allows the OIF to provide information in “real time” on events, activities and new information, including research updates.

**New Events** – This year, the Foundation expanded its annual Fine Wines Strong Bones Gala and began hosting similar Strong Bones Galas at venues across the country. On November 14, 2015, the first ever Strong Bones Gala: Chicago was held with 175 attendees at the National Italian American Sports Hall of Fame in Chicago, IL. In 2016, this program will continue to grow with a Fine Wines Reception in Naples, Florida; the return of the flagship Fine Wines Strong Bones Gala for its 16<sup>th</sup> year in the Washington, DC metro area; and Strong Bones Galas in Orlando and Boston. These events are a wonderful way for people to come together, meet new friends and reconnect with old acquaintances all while enjoying an evening of fine wines and good times with the OI Foundation.

**Advocacy** – In 2015, the OI Foundation continued visiting members of Congress to update them on our work. Led by volunteers, the OI Foundation visited more than 20 congressional offices this year.

**Rare Bone Meetings/Activities** – The OI Foundation continued to take a leading role in collaborating with other rare bone disease organizations at meetings and activities. For example, the OI Foundation coordinated the Rare Bone Disease Scientific meeting at the October 2015 ASBMR annual meeting held in Seattle, WA. The meeting, chaired by Dr. Roy Morello and Dr. Frank Rauch attracted more than 100 scientists interested in rare bone disease. Presentations on current clinical trials and a panel discussion that included representatives from the FDA made for a very successful program. The meeting specifically targeted young investigators and those new to the field of OI and rare bone research.

**NIH Rare Diseases Consortium Grant** – At the 2014 OIF National Conference it was announced that the OI Foundation is part of a team that will be receiving funds from the NIH to form the Brittle Bone Disorders Consortium as part of the NIH’s Rare Diseases Clinical Research Network. This network will conduct clinical research and will incorporate the Linked Clinical Research Centers and the longitudinal study of OI. We are pleased to report that the BBDC in 2015 has four studies up and running and the OIF has successfully launched the medical education site on the OIF website. In addition almost 1,000 people have joined the BBD Contract Registry and a new partner, the Omaha Children’s Hospital and Medical Center, has joined the consortium. As a reminder, the clinical research will include a Phase I drug study, a study on scoliosis in people with severe OI, pregnancy and OI, dentinogenesis imperfecta and other dental/craniofacial issues and OI, a biomarkers study and a quality of life and OI study. This is the only rare disease network at the NIH that is studying bone and specifically OI. The network is led by OIF Medical Advisory Council member, Dr. Brendan Lee, at Baylor College of Medicine. To learn more about the network, visit our website at [www.oif.org](http://www.oif.org).