

December 11, 2014

This was a big year for the OI Foundation and it will be remembered for many reasons, but maybe most of all because of the exciting news received in the area of clinical research! In addition, this year the OI Foundation hosted a very successful national conference, where old friends reunited and new friendships were made. We know everyone had a wonderful time! As we near the end of 2014, we are pleased to present you with an update on our programs and activities and thank you for your support. 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. Thank you for your support; we hope 2015 is a wonderful year for you and your family!

The Board of Directors and Staff of the OI Foundation

2014 Programs and Activities

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 Research Network. This network will conduct clinical research and will incorporate the Linked Clinical Research Centers and the longitudinal study of OI. The clinical research will include a Phase I drug study, a study on scoliosis in people with severe OI, pregnancy and OI, dentogenesis 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 OI Foundation will be responsible for developing a new professional education website, as well as providing scientific meetings that will train the next generation of OI researchers and physicians. 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.

Awareness – In May, the OI Foundation held its fourth annual National OI Awareness Week, involving volunteers across the country in holding awareness and fundraising events within their communities. We proclaimed National OI Awareness Week 2014 in 13 states, received a National OI Awareness Week Resolution from the House of Representatives, educated more than 2,000 participants at 10 OI awareness raising events, displayed more than 400 official Awareness Week posters and reached 300,500+ people through our National OI Awareness Week social media campaign called [SHAREforAWARENESS]. The OIF also participated in Wishbone Day, the international day of OI Awareness held on May 6th each year, by sharing a fact about OI on our social media sites every hour for 24 hours! National OI Awareness Week and Wishbone Day help raise awareness about OI all over the world.

National Unbreakable Spirit® Walk-n-Wheel – On July 31, 2014, the OI Foundation held the first National Unbreakable Spirit® Walk-n-Wheel for OI in Indianapolis, IN, as a way to kick off the 2014 OIF National Conference. Almost 300 participants came together, from all over the country, to walk and wheel along Indianapolis' Canal Walk at White River State Park. More than \$50,000 was raised, thanks to members of the OI community and local business leaders. Planning has already begun for our next National Unbreakable Spirit® Walk-n-Wheel in Orlando, FL, in July 2016!

Regional Conferences – In an effort to bring information and resources closer to more members of the OI community, the OIF announced the implementation of a new Regional Conferences Program. Beginning in 2015, three one-day conferences will be held each year at various locations throughout the country. Each meeting will feature educational sessions led by OI experts. The first meeting in 2015 will be held on February 7th in Los Angeles, California, followed by Stamford, Connecticut, in May and Minneapolis, Minnesota, in October.

Scientific Meetings – In April 2014, scientists from the United States, Canada and the United Kingdom gathered in Chicago for the 14th Annual OIF Scientific Meeting. The meeting, titled *New Treatments for Osteogenesis Imperfecta*, was chaired by Dr. Frank Rauch of Shriners Hospitals for Children, Montreal. Dr. Rauch serves on the OI Foundation’s Medical Advisory Council. Presenters provided an update on today’s OI bone drugs, including bisphosphonates, emerging drugs, and those on the horizon. It was noted that although progress has been made in treating children with bisphosphonates, including increased bone mineral density and reduced fracture rate with some, only patients with Type I OI in the Teriparatide (FORTEO) study experienced increased bone mineral density. There was no observed benefit for those with Type III/IV OI. The OI Foundation released the FORTEO study information in the spring 2014 issue of *Breakthrough* and it is available on our website. The meeting also examined existing and new surgical treatments for both children and adults with OI, and new technologies in the rehabilitation area were discussed that have potential for increasing mobility in both children and adults. The conference was made possible by the generous support of the Buchbinder Family Foundation.

Research Grants – In 2014, the OI Foundation continued to fund Dr. Ingo Grafe’s research as a Michael Geisman Research Fellow. Dr. Grafe’s research is titled *Dysregulated matrix-cell signaling as a mechanism of osteogenesis imperfecta*. Dr. Grafe’s research will examine the bone matrix to help determine why “bad bone” is made and what can be done at this very basic level of science to correct or treat it. The OI Foundation also awarded a new SCPICA Grant for OI Research to Dr. Brya Matthews from the University of Connecticut. Her research will focus 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.

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.

Impact Grants – In partnership with the Children’s Brittle Bone Foundation, more than \$115,000 was awarded in 2014 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 5, 2015.

OI National Information Center – Approximately 6,500 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. The Foundation’s new online video center was also launched this year. The first video, a five-minute tutorial on home-splinting with Dr. Esposito and Dr. Peterson-Suri, was posted in May. The second video, an introduction to OI and the OI Foundation as told through an interview with OIF MAC Chair, Dr. Glorieux, will be posted this month.

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 4,000 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.

Advocacy – In 2014, the OI Foundation continued visiting members of Congress to update them on our work. Led by volunteers, the OI Foundation visited more than 25 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 September ASBMR annual meeting held in Houston, TX. The meeting, chaired by Dr. Laura Tosi, a member of the OI Foundation’s Medical Advisory, attracted more than 300 scientists interested in rare bone disease for a full day of presentations on current and emerging research and treatments on OI and other rare bone diseases.