OSTEOGENESIS IMPERFECTA
OI
FOUNDATION
Unbreakable Spirit™

Unbreakable Spirit®

2013 Programs and Activities

Awareness – In May, the OI Foundation held its second national OI Awareness Week, involving volunteers across the country in holding awareness and fundraising events within their communities. Awareness Week 2013 took place May 4-11, 2013, and on May 6, 2013, the Foundation officially participated in Wishbone Day, an international awareness event that helped to raise awareness about OI all over the world! Eleven cities and states proclaimed May 4-11, 2013 National OI Awareness Week, members of the OI community hung official OI Awareness Week posters in their local schools, shops and business, over 300 people participated in the OIF's National Blue Jeans for Better Bones Day on May 10th and more than 50,000 people were reached through our National OI Awareness Week social media campaign. Over 400 people attended National OI Awareness Week events, including the OI Foundation's national annual fundraiser, Fine Wines Strong Bones and articles appeared in more than 15 newspapers around the country about OI.

National Unbreakable Spirit® Walk-n-Wheel – The OI Foundation announced the first National Unbreakable Spirit® Walk-n-Wheel for OI will be held on July 31, 2014 in Indianapolis, IN as a way to kick-off the 2014 OIF National Conference. Teams from all over the country are being recruited to participate in this event to raise awareness about osteogenesis imperfecta. OI Foundation staff is working with local Indianapolis business leaders to plan the event.

Regional Conference – In October 2013 the OI Foundation held a regional conference in Tampa, Florida. More than 150 attendees gathered for the *Uniting Unbreakable Spirits* conference that featured speakers Dr. Francis Glorieux, Shriners Hospitals for Children – Montreal and OIF Medical Advisory Chair, OIF Medical Advisory Member Dr. Cathy Raggio, Hospital for Special Surgery in New York, Dr. Scott Beck, All Children's Hospital in Florida and Michelle Bunker Fynan, clinical counselor. Throughout the day conference speakers discussed and answered questions on a variety of topics, including an overview of medical approaches to managing OI in children and adults, treatment options, tips for building self-esteem and developing good mental health. The OI Foundation looks forward to doing more regional conferences in the future.

Linked Clinical Research Centers (LCRC) – The OI Foundation, in partnership with the Children's Brittle Bone Foundation, continued funding five LCRCs and reached its enrollment goal of 500 people in the natural history study in 2011 and increased the number to 605 in 2012 and 650 in 2013 making the enrollment very strong. Dr. Reid Sutton, the LCRC's project manager, released preliminary information on findings from the study and has submitted those findings for publication in scientific journals.

Scientific Meetings – In April 2013, 100 scientists gathered in Chicago for the annual OIF Scientific Meeting. Dr. Joan Marini, Chief of the Bone and Extracellular Matrix Branch of NICHD at the National Institutes of Health provided a cutting edge update on OI bone pathology and mechanisms in murine models for OI at the molecular, cellular and tissue levels. Discussions took place on how to best move basic scientific treatment studies into new clinical avenues. The conference was made possible by the generous support of the Buchbinder Family Foundation.

In November 2013 clinicians, physicians and researchers gathered for a meeting titled, *Clinical Care Issues in OI: Standard and Emerging Treatments*. The meeting was chaired by Dr. Jay Shapiro of Kennedy Krieger Institute. The meeting discussed challenges in treating OI and presented best practices in areas of surgical intervention and physical therapy. Presenters also gave the most up to date information on pharmacological treatments and information on how OI affects other organs like the heart, lungs, kidneys, eyes and ears. The next clinical meeting will be held in October 2014 in conjunction with the International Meeting on OI which will be held in Wilmington, DE and chaired by Dr. Richard Kruse of DuPont Hospital for Children.

Research Grants – In 2013, the OI Foundation funded a new Michael Geisman Research Fellowship to a researcher at Baylor College of Medicine in Houston, TX. Dr. Ingo Grafe's research 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.

Adult Natural History Initiative (ANHI) – Work continued on the Adult Natural History Study with approximately 1100 adults with OI completing the survey for this ambitious study, led by Dr. Laura Tosi of Children's National Medical Center in Washington, DC. ANHI uses an NIH-approved, Internet-based questionnaire to collect information about participants' current health status, quality of life, and health concerns. Combining this information with the OI Registry and the Linked Clinical Research Centers will create a clearer description of the health needs of adults who have OI and identify areas needing research.

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 one's 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 $120,000 was awarded to people with OI in need of products or services that would improve the quality of their lives in 2013. 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 began on December 1, 2013.

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 in search of information. 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 and the second video, 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 four social networking sites -- Osteogenesis Imperfecta (OI) Foundation Facebook Page, NING, OI Foundation Twitter, and Sunday Night Chat. The OI Foundation continues to offer on www.oif.org links to other social networking sites as well that might be helpful or interesting to parents and young people living with OI. They continue to be managed by volunteers that the Foundation has established a working relationship with. To date over 4,000 people are members of the OIF Facebook Forum and more than 3,000 are members of the official OIF Facebook page. The official Facebook page allows the OIF to provide information in "real time" on events, activities and new information including new research updates.

Advocacy – In September 2013 the OI Foundation, in partnership with the Rare Bone Disease Advocacy Alliance, visited Capitol Hill for Advocacy Day. The Alliance members (the OI Foundation is a founding member of the Alliance) did a fantastic job of educating lawmakers and staff about both the real-life impact of rare bone disease and the common challenges those with rare bone diseases face. They shared statistics as well as personal stories about their experiences and challenges. More than 30 congressional offices received a visit from members of the Alliance.

Meetings and Conferences – The OI Foundation was represented at several large meetings including the Endocrine Society meeting and the American Society for Bone and Mineral Research (ASBMR). More than 10,000 people attended both meetings and OI Foundation staff spent quality time talking with potential new OI researchers and physicians interested in treating people with OI. Several OI Foundation Medical Advisory Council members presented posters on their OI research at the very popular ASBMR poster session.

Rare Bone Meetings/Activities – The OI Foundation continued to take a lead role in collaborating with other rare bone disease organizations at meetings and activities. The OI Foundation coordinated the Rare Bone Disease Working Group meeting at the October ASBMR annual meeting. The sold out working group meeting gathered senior scientists and industry leaders interested in working together to accelerate research in the area of rare bone disease research. Medical Advisory Council members, Dr. Brendan Lee, Dr. Matthew Warman and Dr. Michael Whyte all presented at the meeting.