

December 11, 2017

Dear Friend,

As we near the end of 2017, we are pleased to present you with an update on our programs and activities as well as thank you for your continued support of the OI Foundation. Because of your generous support, we are able to continue providing programs and services that benefit all members of the OI community. Thank you! 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 at www.oif.org to make your gift. Thank you for your support; we hope 2018 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

2017 Programs and Activities

Awareness and Education—From May 6 – 13, 2017, the OI Foundation held its eighth annual National OI Awareness Week. Volunteers across the country held awareness and fundraising events within their communities. OI Awareness Week was proclaimed in more than 20 towns, cities, counties and states. The OIF also participated in Wishbone Day, the international day of OI awareness held on May 6 each year, by sharing facts and information about OI on our social media sites every hour for 12 consecutive hours. We reached more than 209,000 people through our National OI Awareness Week social media campaign called #SHAREforAWARENESS. National OI Awareness Week and Wishbone Day help to raise awareness about OI all around the world!

OIF Medical Advisory Council members Dr. Jay Shapiro and Dr. Cathleen Raggio hosted a clinical meeting on OI October 5-7, 2017 in Baltimore, MD. The meeting was developed as part of the Jamie Kendall Fund for OI Adult Health for clinicians and medical professionals who directly manage the care of children and adults living with OI. Sessions covered the clinical perspective of topics such as growth impairment, dental disease, pulmonary function, cardiac disease, rehabilitation and function, orthopedic treatment, pharmacologic treatment, quality of life issues, and more.



Dr. Jay Shapiro leads a session at the Clinical Meeting on OI in Baltimore, MD

Scientific Meeting — On April 19-21, 2017, the OI Foundation gathered more than 100 researchers, clinicians, and medical professionals at the 17th Annual OIF Scientific Meeting in Chicago, IL. Co-chaired by Dr. Charlotte Phillips and Dr. Sandesh Nagamani, this important meeting hosted speakers and attendees from the National Institutes of Health (NIH), the Brittle Bone Disorders Consortium (BBDC) sites, and many other OI centers and labs from across the continent. The meeting emphasized lectures and discussion surrounding novel targets and new therapeutic strategies in treating osteogenesis imperfecta. Speakers presented on topics including unmet pharmacologic therapeutic needs in OI, extraskeletal involvement, surgical treatment, and the latest data from the BBDC. The conference was made possible by the generous support of the Buchbinder Family Foundation. Prior to the scientific meeting, the principal investigators of the Brittle Bone Disorders Consortium met to evaluate progress made on the consortium led studies and activities.

Research Grants— The OIF continued funding the research of three young investigators: Dr. Ronit Marom of Baylor College of Medicine, Dr. Kyung-Eun Lim of Indiana University School of Medicine, and Dr. Ivan Duran Jimenez of UCLA David Geffen School of Medicine.

The OI Foundation continued to support, through the Jamie Kendall Fund, a pulmonary study at Hospital for Special Surgery led by Dr. Cathleen Raggio. This community directed scientific committee led study is in direct response to the growing concern in the OI community of pulmonary complications, especially in adults. It will work to determine the inherent cause of restrictive physiology (cardiopulmonary insufficiency) in people with OI so that treatments can be recommended and appropriate measurements for an accurate assessment of the restrictive physiology in OI patients can be defined by creating a standard normative reference for each OI type.



OIF Board Member, Robin Wright and Leopoldine Huyghues Despointes at the Fine Wines Reception in NYC helped to raise money for the Jamie Kendall Fund to support the OIF Pulmonary Study

Rare Bone Disease Meetings— This year’s annual meeting of the American Society for Bone and Mineral (ASBMR) featured several sessions on OI and related bone disorders. The Rare Bone Disease Working Group, chaired by Dr. Matthew Drake of the Mayo Clinic, began with an update on the Brittle Bone Disorders Consortium (BBDC) by Principal Investigator Dr. Brendan Lee of Baylor College of Medicine. Later on in the meeting, OIF Medical Advisory Council Chairman Dr. Francis Glorieux presented on the topic “30 Years of Treatment of OI: Where We Are and Where We Are Going.” Presentations throughout the meeting discussed cutting-edge research on bone pain and the biology of sclerostin and its role in bone health.

NIH Brittle Bone Disorders Consortium (BBDC) — Now in its fourth year, the BBDC has made significant progress in achieving its goals. There are now 14 Clinical Research Sites (doubled since 2016) working together to collaborate on exciting new research. To date, the BBDC is involved in seven studies including a pregnancy study, an early stage drug therapy study, a scoliosis study, a biomarkers study, a quality of life study, a dental study, and a craniofacial study. The OIF is working very hard to continue funding this project to ensure this pace of research is maintained.

Additionally, the OIF is funding the research participation of the Hospital for Special Surgery and the Shriners Hospital for Children- Tampa in the Brittle Bone Disorders Consortium (BBDC).

National and Regional Conferences— The *Uniting Unbreakable Spirits* Regional Conference Program, an effort to bring information and resources to more members of the OI community, hosted meetings in Houston, Texas; Montreal, Canada; and Seattle, Washington in 2017. In the New Year, the OI Foundation is excited about the 2018 OIF National Conference being held in Baltimore, Maryland in July, as well as a return to the west coast for a 2nd Regional Conference in Los Angeles, California in November 2018.

Impact Grants—In partnership with the Children’s Brittle Bone Foundation, the Jeanie Coleman Impact Grant program awarded nearly \$125,000 to people with OI in need of products or services that would improve their quality of life. Funding was provided for a wide range of items including accessible vehicles, hearing aids, eye glasses, and dental work.

OIF National Information Center— Approximately 7,000 requests for information were provided during the year and the OI Foundation website was visited more than 800,000 times. New this year, the OI Foundation has recently revised the publication: *Physical and Occupational Therapists – Guide to Treating Osteogenesis Imperfecta*. This tool for therapists, parents, adults, and educators shares strategies on safe handling, adaptive equipment, functional assessments, and self-care tasks. This new guide is available – along with a variety of resources including booklets, brochures and more than 70 newly updated fact sheets – free of charge from the OI Foundation. As a part of the Foundation's campaign to increase outreach and educate medical professionals who treat individuals with OI, the OIF continued its popular podcast series, with 17 episodes to date.

Social Networking— The OI Foundation manages two official social networking sites: the OIF Facebook Page with 9,700 likes and OI Foundation Twitter (@OIFoundation) with 2,400 followers. 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. To date, more than 8,000 people are members of the official OIF Facebook Forum page! The OIF Forum page is for OI community members to ask questions, share information and experiences, and connect with other OI community members.

International Collaborations—In August 2017, OIF CEO Tracy Hart attended the OI International Scientific Meeting in Oslo, Norway. She – along with several members of the OIF Medical Advisory Council and OIF Board President, Ken Gudek – spent four days meeting with specialists in OI care from around the world and discussing ways to encourage and define collaboration. In addition, Tracy participates in monthly calls with the OIFE president, the Executive Director of the UK Brittle Bone Society, and the Executive Director of Care for Brittle Bones located in the Netherlands. The organizations meet to discuss issues and needs that affect all OI organizations across the globe.

We are very excited to announce that in early 2018, the OI Foundation will launch a new section of www.oif.org dedicated to serving the OI community in Canada. The Canadian Osteogenesis Imperfecta Society (COIS) page will share updated information about research, events and resources relevant to Canadians affected by osteogenesis imperfecta. All materials will be available in English and French.

New Events—The Foundation continued expanding its annual Fine Wines Strong Bones Gala to host similar Fine Wines Receptions and Strong Bones Galas in new cities across the country. Nine Fine Wines Strong Bones events were held in 2017 in Naples, Florida; Washington, DC; Tampa, Florida; New York, New York; Boston, Massachusetts; Montreal, Canada; Chicago, Illinois; Garfield, New Jersey; and Houston, Texas. Money raised from these fundraising events has helped the OI Foundation provide scholarships to the OIF National Conference, create new resources, bring on new BBDC Clinical Research Sites, fund a promising pulmonary study and expand the pulmonary study to include cardiac research.



Dr. Brendan Lee addressing the crowd at the first annual Strong Bones Houston Boots and Bling event

With your help, the OI Foundation has accomplished so much over the years; and with your continued support, the OIF will continue our work to improve the quality of life for all people affected by OI. Thank you, as always, for your generous support and have a wonderful holiday season!