

December 12, 2016

Dear Friend,

As we near the end of 2016, we are pleased to present you with an update on our programs and activities and we want to 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 2017 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

2016 Programs and Activities

National Conference and Walk-n-Wheel— *“So when someone says ‘Can you imagine...’ my mind goes to this place in Orlando where we were surrounded by friends and knowledge and hope. Yes, I can imagine now.”*
— Chris and Cheyenne McConnell, OIF National Conference attendees from Ocala, Florida

The 2016 OIF National Conference, themed IMAGINE, celebrated what the OI community has achieved over the years and the goals we strive to reach in the future. The meeting gathered more than 650 attendees and 50 speakers for three busy, fun-filled days at the end of July. New and old friends were able to participate in a full line-up of activities: one-on-one medical consultations, informational sessions, age and gender specific forums, the National Unbreakable Spirit® Walk-n-Wheel, the first-time ever OI Career Expo, the OIF National Conference Talent Show and After-Party, meet-ups for parents, adults, and youth, and the Closing Dinner and Dance.



Fadi, Elijah and Jessica Mansour at the 2016 OIF National Conference

The day before the official kick-off of the conference, more than 250 members of the OI Community came together for the National Unbreakable Spirit® Walk-n-Wheel! Wearing our Unbreakable Spirit® t-shirts, our enthusiastic group made its way around the conference venue raising awareness about OI and nearly \$100,000 to support the OIF's research and education efforts.

NIH Brittle Bone Disorders Consortium (BBDC) — Now in its third year, the BBDC has made significant progress in achieving its goals. Five of the six research trials are now enrolling including; a Longitudinal Study of OI, Dental Malocclusion and Craniofacial Development in OI, Pregnancy in OI, Quality of Life, and Biomarkers of OI Pathobiology. Phase I clinical trials of a new drug, Fresolimumab, to treat severe OI is on track to begin enrollment in Spring 2017. The research being conducted through the BBDC has the potential to have a groundbreaking impact on the future of OI treatments and care. The OIF is working very hard to continue funding this project to ensure this pace of research is maintained.

Impact Grants—In partnership with the Children's Brittle Bone Foundation, the Jeanie Coleman Impact Grant program awarded more than \$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, a ramp, and water therapy. In addition, 15 families – 35 adults and 27 children—received grants to attend the OI Foundation National Conference this past summer where they were able to meet with OI medical experts and other OI families.

OIF National Information Center— Approximately 7,000 requests for information were provided during the year, and the OI Foundation website was visited 250,000 times. The Information 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. New this year, the OIF developed materials specially created for adults with OI, Take Charge of YOUR Health. This toolkit is designed to help adults become informed and pro-active health care consumers and to help them partner with their doctors to lead healthy lives. 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 11 new episodes to date.

Awareness and Education—From April 30-May 7, 2016, the OI Foundation held its seventh annual National OI Awareness Week. Volunteers across the country held awareness and fundraising events within their communities. OI Awareness Week was proclaimed in over ten cities and states, multiple walks and events were held nationwide and more than 300 official OI Awareness Week posters were displayed in communities all over the country. 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 160,000 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!

As part of the Jamie Kendall Fund Adult Health Initiative, the OIF has attended medical professional annual meetings, like the American Anesthesiology Annual Conference, hosting informational seminars and distributing materials about treating OI in adults.



*Friends reconnect at the
2016 OIF National Conference*

Scientific Meetings —In April 2016, 100 scientists from the United States and Canada gathered in Chicago for the 15th Annual OIF Scientific Meeting. The meeting, titled The Future of OI Research, was chaired by Dr. Eric Rush from University of Nebraska Medical Center and Dr. Pierre Moffatt from Shriners Hospital for Children, Montreal. The meeting focused on pathways to potential treatment, treatment implications from gene discovery, novel animal model study progress, muscle and bone interaction in OI, clinical targets for treatment and surgical and rehabilitation updates. 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 OI Foundation awarded second year funding to Dr. Kyung-Eun Lim from the Indiana University School of Medicine. Dr. Lim's research focuses on a biological target called Nuclear Protein 1 which could potentially be manipulated to improve skeletal properties in OI. The OI Foundation also funded two new research proposals – the first, Dr. Ivan Duran Jimenez from UCLA will explore new mechanisms and therapies for OI caused by mutations in type I procollagen chaperones. The other research proposal from Dr. Ronit Maron from Baylor College of Medicine will study the IFITM5 recurrent mutation and the disease causing mechanism in OI Type V. The OI Foundation continues to be interested and committed to funding young investigators – all three grant recipients receive a Michael Geisman Fellowship, the OIF's young investigator grant program named for the son of OIF Founder Gemma Geisman.

In addition to the Geisman Fellowships the OI Foundation will be awarding a research grant in 2017 that will focus on understanding why pulmonary issues affect people with OI and what types of treatments can be developed to help prevent serious illness related to respiratory infections and other pulmonary infections. Funds for this grant were raised by the hard work of volunteers who implemented the Jamie Kendall Fund in honor of former OIF board president and long-time OIF volunteer Jamie Kendall who passed away in 2015.

Social Networking— The OI Foundation manages two official social networking sites: the OIF Facebook Page and OI Foundation Twitter (@OIFoundation). 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 page! This page allows the OIF to provide information in real time on events, activities and new information, including research updates.

Regional Conferences— The *Uniting Unbreakable Spirits* Regional Conference Program, an effort to bring information and resources to more members of the OI community, hosted a meeting in Houston, Texas and has upcoming dates in Montreal, Canada and Seattle, Washington. In the New Year, the OI Foundation will share an exciting updated format to these one-day meetings based on the program's overwhelming popularity and feedback from the OI community.

International Collaborations—In 2016 the OIF was represented at international scientific meetings and participated in a number of global partnerships. OIF CEO Tracy Hart participated in the joint meeting of the Spain and Portugal OI Societies in October 2016 and met with representatives of other international organizations interested in the area of rare bone disease research to discuss possible collaborations. In addition she 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. The OIF has also entered into a close working relationship with the Canadian OI Society and looks forward to working even more closely together in the months ahead. Tracy will be attending the OI International Meeting in Oslo, Norway in August 2017.

Rare Bone Disease Meetings— The OIF continues to take a leadership role in collaborating with other rare bone disease organizations and stakeholders. In 2016 the OIF formed the Rare Bone Disease Alliance, a group dedicated to accelerating rare bone disease research and to providing information to medical professionals and constituents on the diagnosis and treatment of rare bone disease. The OIF continues to engage with stakeholders including pharmaceutical companies that are developing new treatments for rare bone disease including OI. Tracy Hart, OIF CEO, is the co-chair of the Rare Bone Disease Alliance and feels being involved with research that affects other rare bone diseases could potentially benefit the OI community. The OIF continues to take a leadership role in organizing the Rare Bone Disease Working Group meeting that takes place each year at the annual meeting of the American Society of Bone and Mineral Research.

New Events—This year, the Foundation continued expanding its annual Fine Wines Strong Bones Galas to host similar Fine Wines Receptions and Strong Bones Galas in new cities across the country. Four Fine Wines Strong Bones events were held in 2016 in Naples, Florida; Washington, DC; Orlando, Florida and Chicago, Illinois. We have seven events already scheduled for 2017 with the additions of Mt. Airy, Maryland; Boston, Massachusetts and Montreal, Quebec. Money raised from these fundraising events has helped the OI Foundation provide scholarships to the OIF National Conference, create new resources to encourage adults living with OI to Take Charge of YOUR Health and fund the first year of a promising pulmonary study. Our hopes for the 2017 events will be to continue funding the Adult Health Initiative along with bringing on new BBDC Clinical Research Sites.



OIF Health Educator, Petra Harvey, welcomes attendees to the OIF Regional Conference in Houston, TX