

Dear Friend,

As we near the end of 2018, we are pleased to present you with an update on our programs and activities. 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 have not 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 www.oif.org. Thank you for your support!

2018 Programs and Activities

National Conference and Walk-n-Wheel — *“Looking back at this past weekend, the word magical is the only way I can describe it. For four magical days, our Xavier was free. He was free to be himself, free of any judgement, questions or stares. Most importantly, he felt like he belonged.”* – Melanie Wilpon, OI parent and National Conference attendee

This past July, the OI Foundation held its 21st Biennial National Conference in Baltimore, Maryland with more than 675 members of the OI community in attendance. As the Foundation’s principal educational event, this conference provides the opportunity for attendees to have face-to-face meetings with experienced physicians, learn about the latest research, and interact with other people who are affected by OI. This year’s conference began with the OIF’s third National Unbreakable Spirit® Walk-n-Wheel event. More than 200 walkers and wheelers participated in the event and after-party at Baltimore’s National Aquarium. The next OIF National Conference and National Unbreakable Spirit® Walk-n-Wheel will be held in July 9-12, 2020 in Omaha, Nebraska, where the OI Foundation will celebrate its 50th anniversary.

Awareness and Education— On May 5 – 12, 2018, the OI Foundation held its ninth annual National OI Awareness Week. Volunteers held awareness and fundraising events, as well as requested official proclamations from their local government. OI Awareness Week was officially proclaimed in 19 states, 4 cities, and 2 counties across the United States. With the help of OI community members across the nation, the OI Foundation’s OI Awareness Week posts reached over 200,000 people on Facebook. Throughout the week, more than 30 OI community members created Facebook fundraisers to raise more than \$7,000 in support of the OI Foundation. The tenth annual National OI Awareness Week will take place May 4-11, 2019.

Scientific Meeting — The OI Foundation gathered more than one hundred scientists and researchers for the 17th Annual OIF Science Meeting on April 18-20, 2018. Dr. Christina Jacobsen and Dr. Matthew Warman of Children’s Hospital in Boston chaired the meeting, titled *Outcome Measures and Endpoints to Advance Therapeutic Options in Patients with OI*. Presentations explored topics including a patient panel to discuss patient perspectives on outcome measures, Measuring Efficacy of Physical Rehabilitation in Children and Adults, Craniofacial and Oral Health Outcome Measures and an update from Dr. Brendan Lee on the work of the BBDC. Each year, the meeting attracts scientists interested in learning more about the latest in basic and clinical OI research, and how the information could ultimately benefit people living with OI. The 17th Annual OIF Scientific Meeting was made possible by the generous support of the Buchbinder Family Foundation.



Raising awareness at the 2018 OIF National Walk-n-Wheel in Baltimore, MD.

Rare Bone Disease Meetings— The OIF successfully co-sponsored a Rare Bone Disease Working Group meeting at the American Society of Bone and Mineral Research (ASBMR) annual meeting in September 2018. The meeting drew a record 375 scientists and medical professionals. The two-day meeting, titled *Mechanistic and Therapeutic Advances in Rare Skeletal Diseases*, was chaired by Brittle Bone Disorders Consortium Principal Investigator Dr. Brendan Lee of Baylor College of Medicine and co-chaired by Dr. Maurizio Pacifici of the Children’s Hospital of Philadelphia. Presentations included topics such as Next Generation Sequencing and Multi-Omic Approaches for Diagnosing Skeletal Diseases, Therapies on the Horizon and New Disease Targets and Targeting Signaling Pathways. The meeting featured a poster session with 100 innovative research posters, and 26 young investigators were awarded travel grants to attend the meeting.

Regional Conferences—Since its launch in 2015, the OIF’s Regional Conference program, *Uniting Unbreakable Spirits*, has reached more than 800 members of the OI community, half of whom had never attended an OI event before. With more than 140 attendees, the Los Angeles regional conference held in November 2018 was one of the largest Regional Conferences in OIF history. In 2019, the OIF will host regional conferences in Atlanta, Georgia and Wilmington, Delaware.

NIH Brittle Bone Disorders Consortium (BBDC) — A key activity for the OIF continues to be the participation in the Brittle Bone Disorders Consortium (BBDC). The OIF is responsible for providing education to medical professionals through materials and meetings designed to give the most up to date information on OI care and research. This is the only rare disease network at the NIH that is studying bone and specifically OI. Under the leadership of OIF Medical Advisory Council member, Dr. Brendan Lee of Baylor College of Medicine, the BBDC has completed five studies and has several more in progress. More than 1,500 people have joined the BBD Contact Registry and the Consortium continues to work with its new partners including Tampa Shriners Hospital for Children, A.I. DuPont Hospital for Children and Cologne Hospital in Cologne, Germany.

Research Grants— To support late-stage postdoctoral fellows and new faculty of the BBDC, the OI Foundation awarded second year funding to Dr. Ivan Duran Jimenez from UCLA and his work on new mechanisms and therapies for OI caused by mutations in type I procollagen chaperones. In addition to the two main goals of his project, Dr. Duran Jimenez’s study yielded an unexpected result of lethality due to respiratory insufficiency, which his team confirmed were due to detected abnormalities in the brochi wall. Dr. Duran Jimenez is a recipient of an OIF Michael Geisman Fellowship, the OIF’s young investigator grant program named for the son of OIF Founder, Gemma Geisman.

OI Adult Health Initiative –The OIF funded the first year of a new cardiopulmonary grant. 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. The study 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.

Impact Grants—In partnership with the Children’s Brittle Bone Foundation, the Jeanie Coleman Impact Grant program was designed and established to provide funding for items that will significantly improve the quality of life for a person who has OI and who has limited financial resources. This past year, the OIF was able to fund 31 families (72 individuals) to attend the OIF National Conference. In addition to funding conference scholarships, funding was provided to nine families for a range of items including hearing aids, a wheelchair, and physical therapy.



OI community member Helen Atuncar, Dr. Deborah Krakow, and Dr. Robert Sandhaus at the OIF Regional Conference in Los Angeles, CA.



An OI community member getting fitted for a new wheelchair through the CBBF/OIF Jeanie Coleman Impact Grant program.

OIF National Information Center— The Foundation provides medically verified information related to OI. Topics range from medical issues such as genetics, diagnosis, and, treatments to daily living strategies such as school and employment. Educational materials are available in print and electronically through the OIF website. This past year, OIF staff responded to more than 7,500 direct inquiries for information, and an average of 40,000 people used the OIF website each month. The OIF also sponsors a network of support groups across the United States. Support group activities provide opportunities for mutual support and increased community awareness. Currently, there are 38 active groups in 32 states.

The OIF continues to improve its web-based “tool kit” called the Information Center for Medical Professionals. The information center, located at www.oif.org/meded, covers information about OI, issues that affect children and adults, and provides online resources for providers who see few OI patients. The site is also host to the OIF podcasts (20 to date) on a variety of topics including; spine issues and basilar invagination in OI; dental; surgical interventions; pregnancy and OI; hearing loss and OI; mental health and the OI patient; treatment options for adults and children; and an overview of the diagnosis and treatment of OI. The podcasts have been downloaded 2,300 times and are a very popular feature of our medical professional education outreach.

Social Networking—The OI Foundation manages two official social networking sites: the OIF Facebook Page – liked by 10,948 Facebook users; and the OI Foundation Twitter page (@OIFoundation) - followed by 2,441 Twitter users. The OIF Forum page, a Facebook group with 9,405 members, is for OI community members to ask questions, share information and experiences, and connect with other OI community members.

International Collaborations—Several international partnerships were created, celebrated, and strengthened throughout the OI community in 2018. This summer, OIF CEO Tracy Hart, OIF Board President Ken Gudek, OIF Medical Advisory Council Chair Dr. Francis Glorieux and OIF Board Member Jacinta Whyte traveled to Dundee, Scotland to represent the Foundation at the Annual General Meeting and 50th Anniversary Celebration of the Brittle Bone Society (BBS- UK). The OIF team presented updates regarding new activities of the OI Foundation and the latest research updates from the Brittle Bone Disorders Consortium. Also this year, the OIF began promoting the multi-language OIFE Passport, which serves as a handy communication support for individuals affected by OI who are traveling internationally or living abroad. This pamphlet contains the statement that the bearer has OI, a brief explanation of what that means and how a person with OI should be treated in emergency situations- in 22 languages! The OIFE Passport was debuted by OIFE President Ingunn Westerheim at this summer’s national conference and is available to download online or request in print.



In 2018 the OIF successfully helped the Canadian OI Society relaunch their organization. The OIF will continue to partner with COIS to help provide services to members of the OI community living in Canada.

New Events— This past year, the OI Foundation held seven Fine Wines Strong Bones galas or receptions. These volunteer led events are critical to enhancing the operating budget of the Foundation. 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, and fund the first patient directed research project - a promising cardio pulmonary study. As we look to the New Year, we are excited to add a new Fine Wines Reception in Indianapolis, Indiana as well as a new Medics on the March program! Based off the Brittle Bone Society’s event in Scotland, ten of the OI Foundation’s dedicated physicians will be hiking 50 miles along the C&O Canal Trail and endeavoring to raise \$100,000 for the OI Foundation.

With your help, the OI Foundation has accomplished so much over the years. 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! We hope 2019 is a wonderful year for you and your family!

The Board of Directors and Staff of the OI Foundation