OSTEOGENESIS IMPERFECTA
OI
FOUNDATION
50TH ANNIVERSARY

December 20, 2019

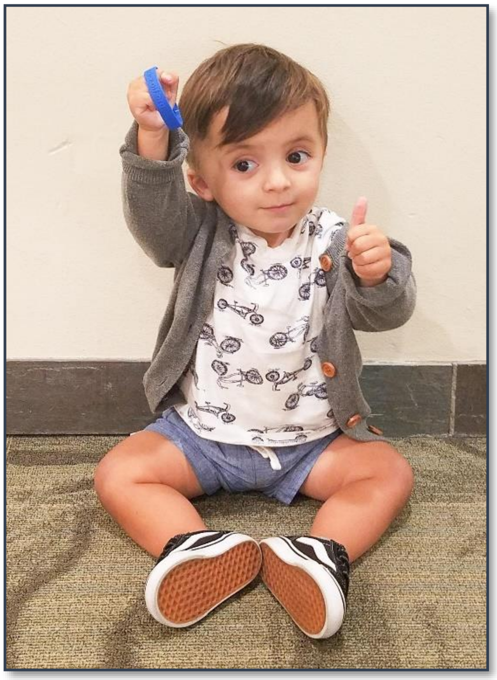
Dear Friend,

As we near the end of 2019, 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 again for your support!

Awareness and Education

In October 2019, the OI Foundation launched its newly redesigned website which allows users to more easily access and share information. As the only voluntary national health organization dedicated to supporting families living with OI, it is our goal to provide information in an easily accessible format for OI community members, medical professionals, and caregivers. The OIF website receives an average of 27,000 unique visitors each month.

With the help of OI community members across the nation, National OI Awareness Week 2019 was officially proclaimed in 16 states across the country and the OI Foundation's #SHAREforAWARENESS posts reached over 200,000 people on Facebook. Throughout the week, more than 60 OI community members created Facebook fundraisers to raise more than $9,000 in support of the OI Foundation. The next annual National OI Awareness Week will take place May 2-9, 2020. National OI Awareness Week is scheduled around the international OI awareness day, Wishbone Day (May 6th).



A thumbs up for Unbreakable Spirit®

OIF Annual Scientific Meeting

On April 10-12, 2019, the OI Foundation gathered over 77 researchers, clinicians, and medical professionals at the 19th Annual OIF Scientific Meeting in Chicago, IL. Co-chaired by Dr. Joan Marini and Dr. Cathleen Raggio, this important meeting hosted speakers and attendees from the National Institutes of Health (NIH), the Brittle Bone Disorders Consortium (BBDC) sites, and many other centers and labs from across the continent. Speakers presented data on topics ranging from the "Effect of Rapamycin on Bone Mass" and "Strength in Amish Mice" to an "Update on Treatment of Adults with OI". The OI Foundation thanks Dr. Marini and Dr. Raggio for their outstanding work as meeting co-chairs, and the speakers and participants for making this a productive meeting. The OI Foundation especially thanks the Buchbinder Family Foundation who makes the Annual OIF Scientific Meeting possible every year.

(Continued on back)

Attendees at the Sacramento, California Regional Conference on August 10, 2019.

Regional Conferences

Since its launch in 2015, the OIF's Regional Conference program, *Uniting Unbreakable Spirits*, has reached more than 1,100 members of the OI community, half of whom had never attended an OI event before. In 2019, the OIF hosted a record four regional conferences in Chicago, Illinois; Atlanta, Georgia; Sacramento, California; and Wilmington, Delaware.

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 2019. The meeting gathered more than 200 scientists and medical professionals. The meeting was chaired by Dr. Laura Tosi, a member of the OIF's Medical Advisory Council, and included topics such as "Management Pearls to Enhance the Care of Patients with Rare Bone Diseases", "New Disease Models" and "Clinic Trial Updates".

NIH Brittle Bone Disorders Consortium (BBDC)

The OIF is pleased to announce that the BBDC has been funded as part of the National Institutes of Health's Rare Diseases Clinical Research Network for an additional five years. The goal of the initiative is to better understand all genetic forms of OI, expand treatment options and train the next generation of physicians and scientists to study OI. As the lead patient advocacy organization partner, the OIF will expand on the outreach to medical professionals and constituents through the various online learning portals housed on the OIF's website, as well as continue to provide opportunities for scientists and OI researchers to connect and collaborate.

Eugene Washington PCORI Engagement Award

In the Spring of 2019, the OIF was approved for a two-year funding award through the Eugene Washington PCORI Engagement Awards program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). PCORI is an independent, nonprofit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. The goal of patient-centered outcomes research (PCOR) for OI is to provide doctors and care providers with information that is relevant to the needs of the OI community. This allows clinicians to provide better care and empowers the OI community to advocate for themselves. Until recently, OI research has been focused on fractures, but the characteristics of OI go beyond bone and includes ear, lungs, eye, and, heart problems. PCOR filled this gap in addressing the needs of the OI community that have previously gone unheard.

Rare Bone Disorder TeleECHO Program

Starting in the summer of 2019, the OIF, in collaboration with the Rare Bone Disease Alliance and OIF Medical Advisory Council member Dr. Laura Tosi of Children's National Hospital, helped launch the inaugural Rare Bone Disorder TeleECHO Program. ECHO (Extension for Community Healthcare Outcomes) is a digital medical education program that increases a physician's access to expert knowledge to help them improve their quality of care.

The Rare Bone ECHO helps to spread knowledge of rare bone conditions like OI to physicians and medical practitioners through monthly video tele-mentoring sessions. By increasing access to expert medical knowledge for physicians in this cutting edge and cost-effective model, the OIF can help increase the standard of care for people with rare bone conditions.

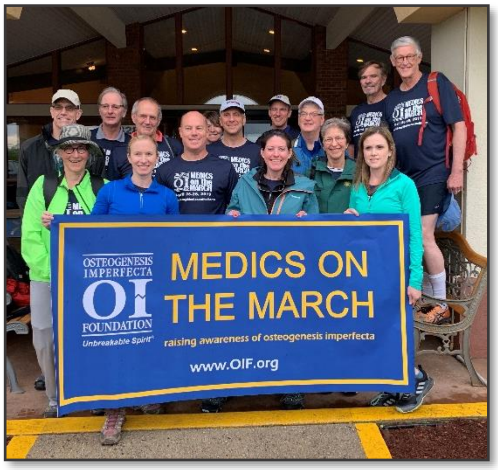
Impact Grants

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. In 2019, the OIF was able to fund more than $100,000 worth of items and services for 24 families. The 2019 grants covered a range of items including hearing aids, a wheelchair, an outdoor ramp for access to a home, and travel expenses for surgery.

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 11,000 direct inquiries for information. 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 OI Foundation's online Information Center includes medically verified information about OI in OIF publications, podcast episodes, and fact sheets. Visit the OIF online Information Center at www.oif.org/informationcenter.



Members of the OI medical community marched 50 miles to bring awareness and raise funds for OIF.

Social Networking

The OI Foundation manages three official social networking sites: the OIF Facebook Page – followed by 12,390 Facebook users; the OI Foundation Twitter page (@OIFoundation) - followed by 2,528 Twitter users, and the OIF Instagram page (@oifoundation) - followed by 656 Instagram users. The OIF Forum page, a Facebook group with 10,247 members, is for OI community members to ask questions, share information and experiences, and connect with other OI community members.

OIF Patient-led Listening Session at the U.S. Food and Drug Administration (FDA)

In September 2019, the OIF brought together a group of ten OI parents, adults, and medical professionals for a patient-led listening session at the FDA. The objectives of the session were to discuss with the FDA the symptoms of OI, the experience of living with OI, and the impact that current treatments have on daily life. The discussion also covered the importance of including endpoints other than fractures in future research. Staff members from several FDA divisions attended the meeting, including; the Office of the Commissioner, Center for Drug Evaluation and Research, and the Center for Biologics Evaluation and Research.

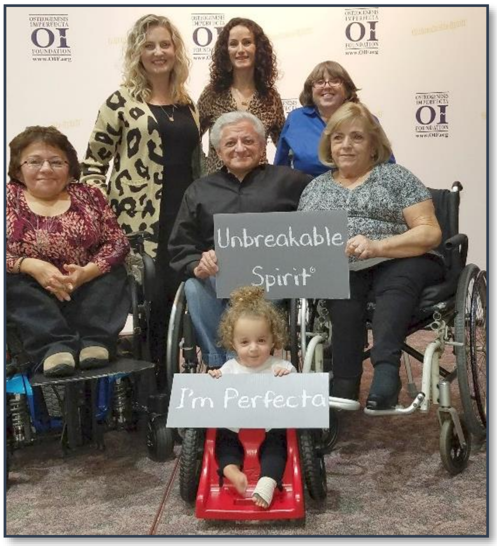
(Continued on back)

International Collaborations

The OIF had the opportunity to be a part of an international meeting on quality of life in November of 2019. The Quality of Life 4 OI Conference, held in Amsterdam and coordinated by Care4BrittleBones, was a conference designed to examine ways to measure quality of life in all areas of OI research and care and to improve outcomes for people with OI. The conference was supported by the OIF and included speakers and session leaders from our Medical Advisory Council. OI Foundation CEO, Tracy Hart, led a session with her colleagues, Patricia Osbourne, Brittle Bone Society in the UK and Ingunn Westerheim, President of the OIFE, on patient engagement and empowerment across borders. Also this year, the OIF continued 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**! Lastly, the OIF is helping to plan the OI International Meeting in Sheffield, UK in September 2020.

Fundraising Events

During 2019, the OI Foundation held seven Fine Wines Strong Bones galas, two golf tournaments, and the new Medics on the March event. These volunteer led events are critical to funding the programs and resources of the Foundation. Money raised from these fundraising events will help the OI Foundation provide scholarships to the OIF National Conference, create new resources, and fund new research. In 2020, we are looking forward to implementing a new speaker series to help fund future Michael Geisman Fellowships and of course, the return of the OIF's National Unbreakable Spirit® Walk-n-Wheel to kick-off the National Conference weekend in Omaha, NE on July 9th! In May 2020, the OIF will host its second annual Medics on the March event, where 15 of the OIF's medical advisors will walk 50 miles to raise awareness for OI. This year's walk will begin in downtown Washington, DC and follow the historic C & O Canal Towpath into Maryland. You can follow their progress on www.oif.org and the OIF's Facebook page!



Members of the New Jersey Area OI Support Group at the annual Beefsteak Dinner

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 2020 is a wonderful year for you and your family!

The Board of Directors and Staff of the OI Foundation