



December 20, 2020

Dear Friend,

As we near the end of 2020, we are taking a moment to reflect on what has certainly been a historic year. We are thankful for the generosity of individuals like you that allows the OI Foundation to continue providing programs and services that benefit all members of the OI community. We have worked hard to pivot and expand our programs to meet the needs of the OI community during this global crisis and want to share a few of our accomplishments this year. If you have not had the chance to remember us with a gift this time of year, please take a moment to do so by using the enclosed envelope or visiting www.oif.org/donate. Thank you again for your support!

COVID-19 Response Information Sessions

During this challenging time, the OI Foundation has made every effort to provide individuals with the most up-to-date information on how the COVID-19 crisis may affect the OI community. The OI Foundation has connected OI community members with OI experts to discuss COVID-19 related topics in virtual information sessions throughout the pandemic. Topics included: Information on COVID-19, Mental Health and Wellness, Orthopedic Perspectives, Nutrition, and Employment Accommodations. Most recently, the OI Foundation was proud to host Dr. Maria Elena Bottazzi, a leading COVID-19 vaccine researcher, along with OIF Medical Advisory Council members Dr. Brendan Lee and Dr. Robert Sandhaus, to share insights on the current state of COVID-19 vaccine development and what to expect moving into 2021. All OIF virtual sessions have been recorded and are available on the OI Foundation's website and YouTube channel.



Maria Elena Bottazzi, PhD is an Associate Dean of the National School of Tropical Medicine, Professor of Pediatrics, Co-Director of Texas Children's Center for Vaccine Development at Baylor College of Medicine, and Co-Chair of the New Vaccines and Therapeutics Taskforce of the Lancet Commission on COVID-19.

Awareness Week

During the week of May 2-9, 2020, the OI Foundation organized its 11th annual *National OI Awareness Week*. OI Awareness Week was proclaimed in 26 states across the country. Volunteers participated in virtual fundraising events such as Bone China Tea and the OIF Art Auction. Throughout the week, more than 200,000 individuals were reached on social media and 90 OI community members created Facebook fundraisers to raise nearly \$20,000 to help support the work of the OI Foundation.

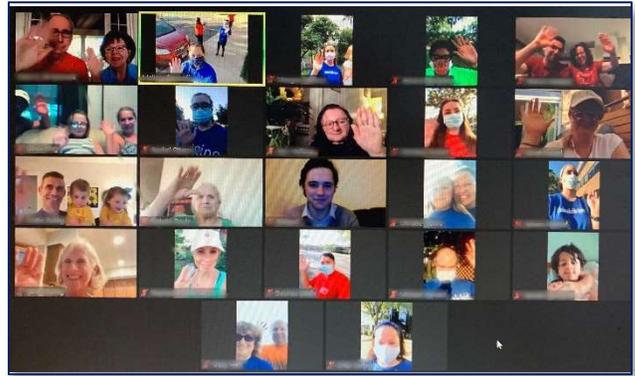
OIF Information Center

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, in addition to the more than 11,000 direct inquiries for information, the OI Foundation also began hosting virtual office hours every Tuesday for individuals who want to connect with the OI Foundation's Health Educator.

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OIF Virtual Conference

After careful consideration, the OIF's Board of Directors and OIF Staff made the difficult decision to pivot the planned *2020 OIF National Conference* to a 2-day virtual conference. Although we were disappointed to not be able to come together in person, the health and safety of the OI community comes first. The *OIF Virtual Conference* provided live online versions of 15 of the most popular informational and social sessions at the OIF National Conference to more than 900 participants from across the U.S., Canada, Europe, Africa and Australia – all free of charge. As a way to kick-off the OIF's Virtual Conference weekend, we held a *Virtual Unbreakable Spirit® Walk-n-Wheel* chaired by Mark Birdwhistell, Stephanie Greenwood and Dr. Maegen Wallace.



Participants in the *Virtual Unbreakable Spirit® Walk-n-Wheel* greet each other while walking or wheeling around their own neighborhoods.

Navigating a New Diagnosis: A Toolkit for Parents and Medical Professionals

This tool kit, sponsored in part by a donation from Minnesota Neonatal Physicians in memory of Michael Johnston – a long time OIF volunteer and past board member – covers topics including diagnosis of OI, types of OI, caring for a newborn with OI, and information to share with your doctor. The *Navigating a New Diagnosis Toolkit* is available online and in print for OI community members, medical professionals, OI clinics, and bone health programs.

Social Networking

The OI Foundation manages three official social networking sites: the OIF Facebook Page – followed by 13,274 Facebook users; the OI Foundation Twitter page (@OIFoundation) - followed by 2,577 Twitter users, and the OIF Instagram page (@oifoundation) - followed by 1,215 Instagram users. This year the OI Foundation also launched the OIF YouTube channel highlighting virtual information sessions, COVID-19 community calls, and fundraising event recordings. A new playlist was created in honor of OI Foundation founder, Gemma Geisman, to share stories from OI community members. *Gemma's Corner* encourages the OI community to keep sharing with each other, caring for each other, and providing support to one another.

Focus Groups

In August, the OIF held its first focus group to hear directly from OI community members about what topics were most important to them at this point in their quarantine. For this session, we engaged members of the OI community directly for a productive hour-long discussion. The overwhelming theme expressed by participants was fear of exposure to COVID-19—for themselves and their loved ones. This fear led to feelings of isolation and depression, compounded by difficult decisions about going back to work and school as states across the country began to open after quarantine. The OIF responded with a community call on Mental Health and Self-Care, specifically focused on the concerns raised during the focus group, led by Dr. Kara Ayers and Dr. Michelle Fynan, both psychologists and adults living with OI. Dr. Robert Sandhaus, OI expert and pulmonologist, was available on the call to help address questions specific to medical concerns of COVID-19 exposure. A second focus group was held in early October; topics of importance to the group were questions about a COVID-19 vaccine, thoughts on in-person meetings and connecting socially with peers safely. We continue to work on increasing the diversity of the group to include participants from different racial, social-economic and geographic groups, as well as diversity in type and relationship to OI.

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 limited financial resources. In 2020, the OIF was able to fund more than \$90,000 worth of items and services for 25 families. The 2020 grants covered a range of items including: hearing aids, a wheelchair, computers, and physical therapy.

Michael Geisman Fellowship

The 2020 Geisman Fellowship award was presented to Dr. Francesca Tonelli of the University of Pavia, Italy for her study titled, *Bone specific delivery of the chemical chaperone 4-phenylbutyrate for osteogenesis imperfecta treatment*. Funding for the project will begin in January 2021.

OI TeleECHO Sessions

The OI Foundation and Rare Bone Disease Alliance's monthly TeleECHO Clinics have been gaining popularity in the medical community both in the U.S. and internationally. In October 2020, the OIF launched the first OI focused TeleECHO series with a presentation by Dr. Eric Rush speaking about OI Diagnosis and Genetic Testing. Each TeleECHO session follows the same format of a brief didactic presentation by a faculty member or guest speaker followed by participant-led case presentations and group discussion on the presented cases. This virtual continuing medical education platform will increase access to expert medical knowledge for participating physicians and medical professionals and improve the ability of medical professionals to treat patients with OI.



Dr. Jeanne Franzone from Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE celebrates a young patient.

OIF Young Investigator Symposium

Chaired by Dr. Roy Morello (University of Arkansas and former OIF Geisman Fellowship recipient), the *OIF Young Investigator Symposium* was held in November. This virtual meeting was offered as a pre-meeting event to the 2020 International Conference on Children's Bone Health's Virtual Forum (chaired by OIF MAC member Dr. Frank Rauch). The session featured 13 abstract presentations from a selection of U.S. and international participants, who study OI and other related rare bone diseases.

Rare Bone Disease Alliance Working Group Meeting

As a member of the Rare Bone Disease Alliance, the OIF helped organize and lead a *Working Group Meeting* focused on rare bone diseases during the American Society for Bone and Mineral Research's virtual annual meeting. The *Working Group Meeting*, held on September 11, was chaired by Dr. Eric Rush of Children's Mercy Kansas City and attracted almost 400 attendees.

Eugene Washington PCORI Engagement Award

This year, the OI Foundation received supplemental funding for our current PCORI award through the Eugene Washington PCORI Engagement Awards program. The supplemental funding is being used to examine the impact the COVID-19 pandemic has had on the OI community. A task force comprised of medical experts and OI community leaders helps guide the work of the supplemental funding award. Patient-Centered Outcomes Research Institute (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 is to develop a coalition of community and medical professionals who will direct and encourage new OI research. The project uses the OI Registry as one of several platforms for gathering insights from the community, allowing you to really tell us your story.

OI Clinic Outreach

In September, the OIF held its first *Town Hall Meeting for OI Clinic and Bone Health Programs*. The goal of the meeting was to connect with medical professionals who are currently treating patients with OI and educate them on the resources the OIF has for them and their patients, including the most recent COVID-19 materials. We also wanted to hear from medical professionals about which resources would be most helpful to them and their patients. Nearly 100 medical professionals registered to attend the meeting, of which approximately 30 were from clinics new to the OIF. The feedback was overwhelmingly positive and there are plans to hold another Town Hall Meeting in the spring of 2021. We have created a new quarterly electronic newsletter specifically for this group, which will include important announcements about meetings and resources, including the COVID-19 resources.

Fundraising Events

In January and February, the OI Foundation was able to celebrate its 50th anniversary at the *Fine Wines Naples* reception and the 20th *annual Fine Wines Strong Bones Gala*. Because of the nationwide shutdowns, in-person fundraising events could not be held for the majority of 2020. But that didn't stop our dedicated group of volunteer event leaders! Events such as the *National Unbreakable Spirit® Walk-n-Wheel*, the *Strong Bones Gala Boston*, and the *Boots and Bling for Better Bones* event in Houston were hosted virtually this year. Fundraising events such as these are critical for funding the programs and resources of the OI Foundation.



Matthew Casper, a young-adult living with OI, at the Fine Wines Strong Bones Gala in February 2020.

With your help, the OI Foundation has accomplished so much over the years. With your 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 2021 is a wonderful year for you and your family!

The Board of Directors and Staff of the OI Foundation

The Osteogenesis Imperfecta Foundation, Inc., has a 501(c)(3) classification from the Internal Revenue Service, and contributions are deductible for federal income tax purposes to the extent allowable by law. Financial information about the Osteogenesis Imperfecta Foundation can be obtained by writing to us at 804 West Diamond Ave., Suite 210, Gaithersburg, MD 20878, or for residents of the following states, as stated below: **Colorado:** Secretary of State 303-894-2680, <http://www.sos.state.co.us/> re: Registration No. 20033001101. **Florida:** SC No. CH2757. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATE, 1-800-HELP-FLA. **Kansas:** Annual financial report is on file with the Secretary of State. **Maryland:** For the cost of postage and copying, documents and information filed under the Maryland charitable organizations laws can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401. **Michigan:** MICS No. 11625. **Mississippi:** The official registration and financial information of the Osteogenesis Imperfecta Foundation may be obtained from the Mississippi Secretary of State's office by calling 1-888-236-6167. **New Jersey:** INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215 AND IS AVAILABLE ON THE INTERNET AT www.njconsumeraffairs.gov/ocp.htm#charity. **New York:** Upon request, Attorney General Charities Bureau, 120 Broadway, New York, NY 10271. **North Carolina:** Financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at 1-888-830-4989. **Pennsylvania:** The official registration and financial information of the Osteogenesis Imperfecta Foundation may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. **Virginia:** State Office of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218. **Washington:** Secretary of State, 1-800-332-4483. **West Virginia:** West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. REGISTRATION IN A STATE DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION OF THE OSTEOGENESIS IMPERFECTA FOUNDATION BY THE STATE.