

Thank You for Joining Us at the Virtual OIF National Conference 2021!

In place of the in-person OIF National Conference this year, the OIF hosted a Virtual OIF Conference on July 10-11, 2021. The conference provided live, online versions of some of the most popular informational and social sessions at the biennial OIF National Conference. It was so wonderful to see (virtually, of course!) the familiar and new faces of close to 600 registered attendees throughout the weekend!

Recordings of select sessions are available on the OIF website and YouTube channel.

Check out some of the Highlights from Virtual OIF Conference:

■ Language Translation

For the first time ever, many of the Virtual OIF Conference sessions were translated live, allowing participants to listen to information sessions in English, Spanish, or French! Session recordings are also available in English, Spanish, and French on the OIF YouTube channel.

■ Ask the Experts

You asked, we delivered! Feedback from the 2020 OIF Virtual Conference revealed that many attendees would like more time for questions. This year, there was extra time added to information sessions to allow more time for questions, as well as the first-ever *Ask the Experts* session. During this session, attendees had the opportunity to join breakout rooms with OI experts who were ready to answer questions.

Breakout rooms included:

- ▶ **OIF's Patient Centered Outcomes Research (PCOR) Projects** Dr. Laura Tosi
- ▶ **Diversity, Equity and Inclusion** Chaz Kellem
- ▶ **Pulmonary Health and COVID-19**
Dr. Robert (Sandy) Sandhaus
- ▶ **Nutrition and OI** Deb McInerney
- ▶ **Surgery and OI** Dr. Maegen Wallace
- ▶ **Genetics** Dr. Reid Sutton
- ▶ **Mental Health** Dr. Kara Ayers

■ New Sessions

This year, the Virtual OIF Conference featured several new sessions based on feedback from the OI community. New sessions, including *Fitness and OI*, *Navigating a New Diagnosis*, and *Ask the Expert*, were well attended and a great addition to the conference schedule.

(continued on page 3)

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2021 VIRTUAL NATIONAL CONFERENCE

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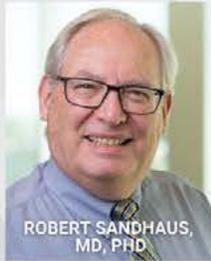
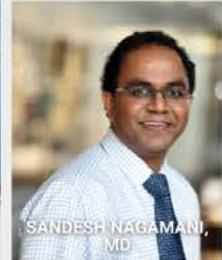
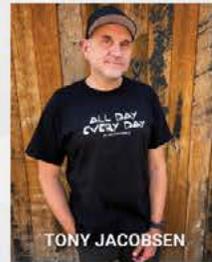

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THANK YOU TO OUR 2021 VIRTUAL OIF NATIONAL CONFERENCE SPEAKERS!



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2021 VIRTUAL NATIONAL CONFERENCE

Upcoming OIF Fundraising Events

It has been 18 months since the OI Foundation held its last in-person fundraising event. Fundraising events are a vital source of revenue for a non-profit organization who generates 70% of its annual budget from individual donations. Simply put, the OI Foundation would not be able to provide the world class programming it has become known for if we didn't have events such as Fine Wines Strong Bones galas, golf outings, walk-n-wheels, and countless individual fundraisers.

We have been so grateful for the support of our event organizers and attendees who have participated in virtual versions of their favorite fundraising events over the past year and a half.

This summer, golf outings have returned with the Riley's Gathering Golf Outing, the OI Golf Classic, and the Miracle Michael Foundation Golf Tournament. The Atkinson Family and the Abruzzi families held their OI Yard Sale and OI Carnival respectively.

The 5th annual Boots & Bling for Better Bones in Houston, Texas on October 23rd will be the OI Foundation's first official hybrid event! In person attendees will join committee members Sarah & Earl Dyke, Cindy & George Medina, Courtney & Robert Paddock, and Zarina Rasheed for an evening of award-winning BBQ, boot stomping honky tonk, and exciting auctions at Houston's outdoor venue, the Armadillo Palace. If you can't attend the event or don't feel comfortable attending in person, the event will be livestreamed for virtual attendees and auction items will be available online.

COVID-19 safety precautions and state mandates are being strictly followed at all in-person events and we do still anticipate many events being virtual or hybrid throughout the winter. Check out the OI Foundation's online event calendar at www.oif.org/events to stay connected.



Attendees enjoyed the live auction at Boots and Bling for Better Bones 2019

Virtual OIF National Conference 2021 (continued from page 1)

■ Social Sessions

OI community members enjoyed meeting up with old friends and connecting with new friends during OIF Virtual Conference social sessions! Social sessions included the *Unbreakable Spirit® Trivia Fundraiser*, the *Virtual Lobby*, *Parents Meet & Greet*, the *Kids Social Room*, and the *Adults Social Hour*.

■ Kids Social Room

While parents attended information and social sessions, the kids had a blast in the *Kids Social Room*! The Kids Social Room featured a virtual field trip to Animal Wonders Montana, a Virtual Escape Room, games, and time to connect with other children in the OI community.

Thank you so much to all of the incredible OI community members, OI experts, and sponsors who made this event possible.

See you next year! We can't wait to see you in-person for the OIF National Conference next year! Please mark your calendar to join us in Orlando, Florida on July 7-10, 2022!

Shriners Hospitals for Children



Shriners Hospitals for Children - Honolulu staff members celebrated National OI Awareness Week

Awareness Makes a Difference!

National OI Awareness Week is a week dedicated to raising awareness for OI and sharing your Unbreakable Spirit®. OI Awareness Week is scheduled around Wishbone Day (May 6), the international OI Awareness Day. Each year, OI community members request state proclamations, hang flyers, hold events, and share social media posts to raise OI awareness. During OI Awareness Week 2021, almost 100,000 people were reached on social media, 25 states officially proclaimed National OI Awareness Week, and OI community members raised \$9,120 for the OI Foundation with Facebook fundraisers! Thank you so much for celebrating National OI Awareness Week with the OI Foundation!

Don't forget – awareness is important year-round!

Raising awareness of OI in your community, city, or state is easier than you might think! With the support of the OI Foundation, OI community members across the country hold various awareness

and fundraising events to raise awareness of OI and support the work of the OIF. The OIF offers year-round fundraising campaigns like the OIF Book Club, Bone China Tea, Blue Jeans for Better Bones, Facebook Fundraisers, and additional pop-up campaigns (like selling T-shirts or popcorn) to make fundraising and connecting with your supporters easy! Many OI community members have also created their own personal fundraisers combining their interests and passions with raising awareness of OI, for example, setting a record on the Mason-Dixon trail, hosting a charity dinner, organizing community sporting events, playing in charity video game streaming events, and so much more!

If you have an idea for a fundraising event, please reach out to Christina at cteufert@oif.org and let the OIF help you show off your Unbreakable Spirit®.

Have an IMPACT on the future of OI research, treatment & care

What

The IMPACT Survey is an **international research project** aimed at capturing and quantifying the real impact OI has on the lives of **people with OI** and their **families**

Why

Results will be used to enable **better healthcare services** for both children and adults and to support availability of potential **future treatments for OI**

Who

The IMPACT Survey is for **people with OI** and **parents/caregivers of children with OI**

When

Launching **end of June 2021** and running until **10th September 2021**

HOW DOES OI IMPACT YOUR DAILY LIFE?

WHAT IS OI BESIDES FRACTURES?

HOW MUCH DO YOU SPEND ON TREATMENT AND SUPPORT?

Get involved

and find out more at

www.impactsurveyoi.com



IMPACT is being conducted by the Osteogenesis Imperfecta Federation Europe (OIFE) and the Osteogenesis Imperfecta Foundation (OIF) with an international team of OI clinical experts from Europe and North America.

Oversight and funding: Medical support and oversight are provided by Professor Frank Rauch from the Shriners Hospital for Children and McGill University, Canada. The study is funded by Mereo BioPharma

Protecting your privacy: All information collected will be treated confidentially and remain anonymised. Survey data will be independently and safely stored by Wickenstones Ltd. according to the Data Protection Act 2018

Any questions? Please contact Samantha Prince: sam@wickenstones.com

The following is a letter from OI Foundation Chief Executive Officer, Tracy Hart. The OIF counts on your support to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. Please consider making a gift to the OI Foundation today!

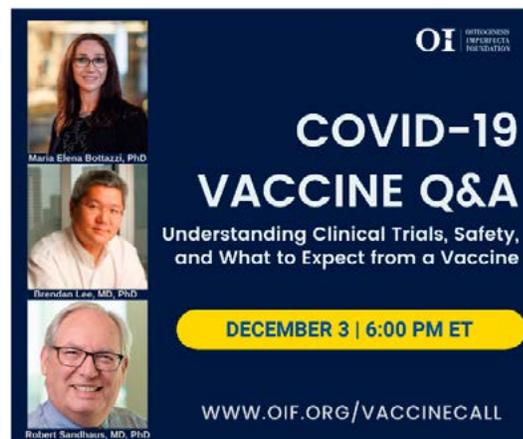


Dear Friend,

Thank you for supporting the work of the Osteogenesis Imperfecta Foundation! We are thankful for the generosity of individuals like you that has allowed us to continue providing programs and services that benefit all members of the OI community. We have worked hard over the past year to pivot and expand our programs to meet the needs of the OI community during this global crisis. We hope you will take a moment to support the many new and ongoing programs and activities of the Osteogenesis Imperfecta Foundation as we strive to improve the quality of life for individuals living with OI through research, education, awareness and mutual support.

COVID-19 Response

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 pandemic may affect the OI community. Beginning in March 2020, the OI Foundation hosted more than 15 live, virtual sessions connecting OI community members with OI experts to discuss COVID-19 related topics. Sessions have included: Information on COVID-19, Mental Health and Wellness, Orthopedic Perspectives, Nutrition, Employment Accommodations, two COVID-19 Vaccine Updates, and most recently, OIF Medical Advisory Council member and pulmonologist, Dr. Robert Sandhaus answered frequently asked questions about the COVID-19 vaccine in a Q&A session. All OIF virtual sessions have been recorded and are available on the OI Foundation's website and YouTube channel.



OIF Virtual Conference

After careful consideration, the OIF's Board of Directors and OIF Staff made the difficult decision to move the 2020 biennial OIF National Conference to a virtual setting. Although we were disappointed to not gather in person, the virtual format allowed hundreds of new individuals who have not had the ability to attend an in-person OIF conference to participate in 15 of the most popular informational and social sessions from the OIF National Conference. While 2021 would not traditionally be an OIF conference year, the OIF was proud to host another two-day Virtual OIF Conference on July 10-11, 2021. We once again featured the most popular and most asked for sessions with plenty of time set aside for questions. New this year, we featured closed captioning as well as live Spanish and French interpretation during the most popular informational sessions!

Patient-Centered Outcomes Research (PCOR)

On May 31st, the OIF concluded our first Eugene Washington PCORI Engagement Award, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). A COVID-19 supplement will end on August 31st and our third project, titled *Leveraging Virtual Communication to Advance PCOR Adoption by the Rare Bone Disease Community* will begin this summer. This project will bring together the members of the Rare Bone Disease Alliance with stakeholders from the patient and scientific communities in a series of focus groups and three large group meetings to examine barriers to participation in research, barriers to access to care and patient-identified issues that need to be reflected in the development of patient-reported outcomes.

Virtual Research Updates

The OI Foundation has been very proud of our participation in the Brittle Bone Disorders Consortium for the past nine years. We are very excited to have the opportunity to share updates on the exciting research being conducted with the OI community. Beginning in May 2021, the OIF began hosting virtual sessions with researchers conducting pilot studies and research programs through the BBDC.

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.

Awareness Week

On May 1-8, 2021, the OI Foundation organized its 12th annual National OI Awareness Week. OI Awareness Week was proclaimed in 25 states across the country. Volunteers participated in virtual fundraising events such as Bone China Tea, DoubleGood Popcorn Shops, and OI Awareness Week apparel sales. Throughout the week, more than 100,000 individuals were reached on social media and 40 OI community members created Facebook fundraisers to raise nearly \$10,000 to help support the work of the OI Foundation.



OI community members in Honolulu, HI celebrate Wishbone Day on May 6th with OIF Awareness Shirts.

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 clinics 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. Nearly 100 medical professionals registered to attend the meeting, of which approximately 30 attendees represented clinics new to the OIF. We have created a new quarterly electronic newsletter specifically for this group, which will include important announcements about meetings and resources, including COVID-19 resources.

OIF National Information Center

This past year, OIF staff responded to more than 11,000 direct inquiries for medically verified information, and an average of 6,000 people used the OIF website each month. 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.

Your support plays a vital role in what we do, and we hope we can count on your continued generosity.

Please consider making a gift of \$50, \$100 or more to the OI Foundation using the enclosed envelope, or online at www.oif.org/donate.

Thank you, as always, for your continued support.

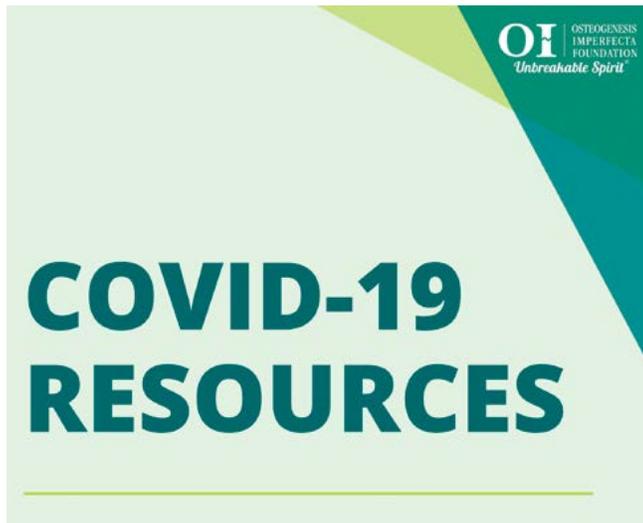
All my best,

Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

OIF Information Center

OIF Virtual Office Hours: Now Available on Tuesday AND Thursday!

We are happy to announce that OIF Virtual Office Hours are now available FOUR times each week. Office Hours are every Tuesday and Thursday at noon and 6pm EST. Log in to learn more about OI Foundation programs and resources, ask questions, or just drop in to say hello. Hosted by OIF Health Educator Jessica Ransome, this program was developed during the COVID-19 pandemic as another way to stay connected. For more information, please visit www.oif.org/virtualofficehours or email Jessica at jransome@oif.org.



OIF's COVID-19 Toolkit: An Ever-expanding Resource

The COVID-19 toolkit provides information and resources related to the COVID-19 pandemic for OI community members. The toolkit includes recordings of COVID-19 Q&A Community calls, the OIF's COVID-19 surveys and survey results, and up-to-date information for the OI community. If you have any questions, please email bonelink@oif.org.



SUBSCRIBE to the OIF's YouTube Channel!

Make sure you are subscribed to the OIF's YouTube channel to stay up to date on new OIF video resources. Our channel features more than 75 videos created for OI community members and medical professionals. Videos include podcast episodes, COVID-19 community calls, virtual conference session recordings, stories from OI community members in *Gemma's Corner*, research updates, and more!



Research Updates for the OI Community

More research into OI is being done than ever before, and the complex findings and breakthroughs can be hard to understand. On Wishbone Day (May 6), the OIF launched an educational series to highlight and explain the work of the Brittle Bone Disorders Consortium (BBDC). In the *Current State of OI Research: An Update for the OI Community*, Cameron Penn (President of the OIF Board of Directors) and Brendan Lee MD, PhD (Principal Investigator of the BBDC and OIF Medical Advisory Council Member) discussed the work of the BBDC and the landscape of OI research.

The second video in this series, *Women's Health and Pregnancy*, was held on June 24 with Deborah Krakow, MD (OIF MAC member and Professor and Chair of Obstetrics and Gynecology at UCLA) and Tracy Hart (OIF CEO). In both talks, the researchers emphasized the importance of the BBDC, how they approach researching OI, and the big questions they seek to answer. To view session recordings, please visit the OIF website (Video Resources page) or OIF YouTube channel.

Our Commitment to the OI Community

The OI Foundation has completed the initial phase of the OIF's diversity, equity, and inclusion project. This first phase was designed to assess the OIF's programs, activities, and business structures. With the help of diversity, equity and inclusion professional, Chaz Kellem, we conducted an internal review of our programs and services to determine how we can be more inclusive as a Foundation in order to support the entire OI community.

Some of the goals of the OIF's diversity, equity, and inclusion project are:

- To evolve our OI community to reflect the demographics of the locations in which we serve
- To make sure all members of the OI community are fully aware of and can access the full scope of OIF resources and services
- To ensure every OI community member, staff member, and board member feels included and fully engaged

The next phase of this project will consist of incorporating OI Foundation staff training and development, business recommendations, board development, community engagement practices, and more. Please stay tuned for updates on this important project!

Educational Meetings from the OIF: Expanding Professional and Community Learning Opportunities

This year, the OI Foundation has continued to expand its educational programs for medical professionals, researchers, and the larger OI community.

On June 23, 2021 the RBDA held the *Rare Bone Disease Alliance Scientific Symposium: Emerging Research and Clinical Applications in Rare Bone Diseases*. The Rare Bone Disease Alliance (RBDA), a program of the OIF, is a patient advocacy network with the mission to promote education on rare bone diseases for medical professionals and researchers. This inaugural meeting was co-chaired by Dr. Alison Boyce of the

National Institutes of Health and Dr. Eileen Shore of the University of Pennsylvania and highlighted two rare bone diseases beyond OI: Jansen's Disease and achondroplasia. Over 170 clinicians and researchers attended to discuss and hear the two main presentations, "How to Turn off a Mutant PTHRI: Lessons from Jansen's Disease" by Harald Jueppner, MD, and "New Developments in Achondroplasia: Natural History to Targeted Therapies" by Michael Bober, MD, PhD, and Julie Hoover-Fong, MD, PhD.



IntOI 2020+1: Virtual International OI Meeting Early-Stage Investigator Symposium

September 9, 2021
11:00am-4:00pm EST

The *IntOI 2020+1: Virtual International OI Meeting Early-Stage Investigator Symposium* will be held on September 9. Chaired by Dr. Joan Marini of the National Institutes of Health, this is an interim International OI meeting pending the return of in-person meetings, with the postponement of the International OI meeting to 2022. The presentation focus is on engaging early-stage investigators working in the field of osteogenesis imperfecta. Meeting registration is free and open to scientific and medical professionals interested in OI research. More information and a link to registration can be found at www.oif.org/intoi.

Upcoming Events for Medical Professionals

The OIF is proud to announce that the *Rare Bone Disease TeleECHO Clinic Series* will be starting its 3rd year in August, 2021! This monthly series has grown rapidly and now includes hundreds of participants at each session representing dozens of countries. In each session, a renowned rare bone disease expert delivers a presentation and is then followed by participant-led case presentations and discussion. Dr. Laura Tosi, MD, serves as the Medical Director for this series. Learn more about this program at www.oif.org/echo/rbd.

Don't miss out on the last few sessions of the *OI TeleECHO Clinic Series*! Following the same format of the Rare Bone Disease ECHO, this program instead focuses exclusively on building capacity to diagnose and treat osteogenesis imperfecta. This program is chaired by Dr. Frank Rauch and includes Dr. Jeanne M. Franzone and Dr. Sandesh C.S. Nagamani on the faculty. Learn more about this program at www.oif.org/echo/oi.

NEW! OIF Medical Professionals Event Calendar



The OI Foundation is creating new programs to help increase understanding of OI and other rare bone diseases and support the work of our medical experts and community members. To learn about upcoming events, please visit the OIF's new *Medical Professionals Event Calendar*, located under the "Research" drop-down menu on the OIF website, or at www.oif.org/medprocalendar.

OIF Monitors 2021 Federal Policy Activity as Summer Break for Congress Looms

By Kyle Mulroy

Founder of Washington Strategic Consulting (WSC) and OI Community Member

Congress is in the midst of its annual “summer sprint” as it works to consider and pass a flurry of legislative priorities before the August recess.

At the top of the priority list for Congress is approving spending bills, or appropriations, to fund all federal departments and programs for 2022.

The House is poised to pass all of its spending bills by the end of July. This includes \$30 billion more than last year for the U.S. Department of Health & Human Services. The National Institutes of Health would receive a \$6.5 billion increase, including a \$29 million increase for Clinical and Translational Science Awards.

While the House is making quick progress on its spending bills, the Senate has yet to act at all. The Federal fiscal year ends on September 30th, which means that temporary spending measures are likely.

In addition to the federal budget, the OIF is closely monitoring other legislative activity of interest to the OI community.

In March, U.S. Representatives Anna G. Eshoo (D-CA) and Drew Ferguson (R-GA) and U.S. Senators Tammy Baldwin (D-WI) and Joni Ernst (R-IA) introduced the “Ensuring Lasting Smiles Act” (**S. 754/H.R. 1916**).

The legislation would ensure health insurance coverage for needed treatment and procedures for individuals born with congenital anomalies or birth defects. The Ensuring Lasting

Smiles Act would close a coverage gap to ensure that health plans cover medically necessary services related to a patient’s anomaly or birth defect, including any serious dental and oral-related procedures that are necessary to maintaining health and overall function.

Incredibly, more than 300 U.S. House and Senate members from both political parties have sign on as co-sponsors of the legislation.

Also, in June, Reps. Diana DeGette (D-Colo.) and Fred Upton (R-Mich.) released a **draft bill**, dubbed Cures 2.0—the follow-up to the landmark **21st Century Cures Act** biomedical innovation law. Cures 2.0 would touch on almost every part of the health-care system—from the authorization of medical research, to the Food and Drug Administration’s regulation of medical products and Medicare’s payments for cutting-edge treatments.

Importantly of the OIF community, the legislation would prioritize organizations that represent rare diseases to receive federal grants for preparing for future pandemics.

DeGette and Upton plan to hold roundtables about their proposal in June and July with the aim of releasing a final bill after Congress returns from its August break.





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THANK YOU!

We are so grateful to the OI community for supporting the OI Foundation over the past year. Our incredible community attended virtual events, shared OIF resources, hosted online fundraisers, participated in focus groups, raised OI awareness virtually, attended OIF community calls, and so much more.