OSTEOGENESIS IMPERFECTA
OI
FOUNDATION
Unbreakable Spirit®

Breakthrough

VOLUME 47 NO. 3 FALL 2021

New Resources for OI Community Members

As the only voluntary national health organization dedicated to supporting families living with OI, it's the goal of the OI Foundation to provide information in an easily accessible format for OI community members, medical professionals, and caregivers. The OI Foundation's online Information Center includes medically-verified information about OI, OI publications, video resources, and fact sheets.

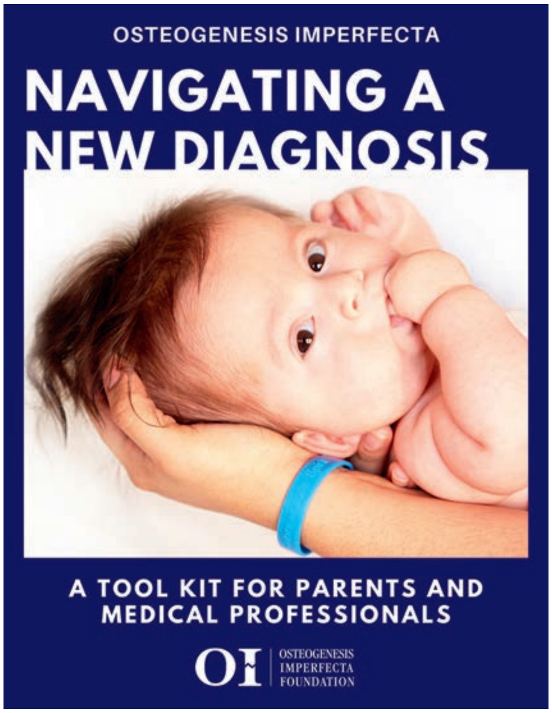
Be sure to check out some of the OIF's newest resources:

- The **OIF's COVID-19 Tool Kit** provides information and resources related to the COVID-19 pandemic for OI community members. Visit the COVID-19 Tool Kit at **www.oif.org/category/covid19**.
- **Navigating a New Diagnosis: A Tool Kit for Parents and Medical Professionals**
  This tool kit covers topics including diagnosis of OI, types of OI, caring for a newborn with OI, and information to share with your doctor. This resource is located at **www.oif.org/factsheets**.

OIF NATIONAL CONFERENCE 2022

The OIF is still evaluating the possibility of holding an in-person 2022 National Conference in Orlando, Florida and would like to hear if you would attend in-person. The safety and comfort of our community are very important to us, and your input helps us make the best planning decisions.

Please take a moment to complete the OIF's Conference Survey at **www.oif.org/confsurvey**



OSTEOGENESIS IMPERFECTA

NAVIGATING A NEW DIAGNOSIS

A TOOL KIT FOR PARENTS AND MEDICAL PROFESSIONALS

OI OSTEOGENESIS IMPERFECTA FOUNDATION

- **OI Community Virtual Mutual Support Events**
  The OIF has hosted several virtual social events throughout the pandemic to connect OI community members near and far. Events have included Friendsgiving, a New Year's Extravaganza, and the Kids Social Costume Party! Check out the OIF's online calendar (**www.oif.org/events**) for more information about upcoming events.
- **Virtual Office Hours**
  Whether you have questions for the OI Foundation, are interested in learning more about OIF programs and resources, or just want to drop in to say hello, you are welcome to call in to OIF Virtual Office Hours! Office Hours are hosted by OIF Health Educator Jessica Ransome every Tuesday and Thursday at 12:00pm ET and 6:00pm ET. To learn more or attend OIF Virtual Office Hours, please visit **www.oif.org/virtualofficehours**.

To view all of the OIF's online resources, please visit the OIF online Information Center at **www.oif.org/informationcenter**.

OIF Information Center

COVID-19 Resources for OI Community Members

Throughout the COVID-19 pandemic, the OI Foundation has hosted a series of video sessions to connect OI community members with OI experts to discuss COVID-19 related topics. These virtual sessions help members of the OI community stay up to date on the current COVID-19 pandemic and the impact it may have on those living with OI.

During the most recent COVID-19 video session, the OI Foundation was joined by Dr. Robert Sandhaus (pulmonologist and OIF Medical Advisory Council member) and Admiral Rachel Levine (Assistant Secretary of Health for the US Department of Health and Human Services) to discuss the current state of the COVID-19 pandemic within the US. This session, and all other COVID-19 sessions, are available on the OIF's YouTube channel.

The OIF's COVID-19 toolkit (**www.oif.org/category/covid19**) provides information and resources related to the COVID-19 pandemic for OI community members.

COVID-19 TOOLKIT

Remembering Mark Peck

On September 15th, the OI Foundation lost a former board member and dear friend, Mark Peck. Mark was a financial planner, investment broker, and motivational speaker. He traveled the world sharing his accomplishments and encouraging others. He made an impact on so many, and will be missed by the OI Foundation and OI community.

Congratulations, Dottie!

Thank you to everyone who participated in the first-ever OIF Unbreakable Spirit® T-shirt Contest! This year's winner is Dottie Ruhlig with her Unbreakable Spirit® watercolor design. To shop Dottie's design and new OIF apparel, visit **www.oif.org/shop**.

Jeanie Coleman Impact Grant Program – Applications Available January 2022

Since 2009, the Children's Brittle Bone Foundation (CBBF) and the Osteogenesis Imperfecta Foundation (OIF) have collaborated to provide OI community members with equipment or services that will improve quality of life through the Jeanie Coleman Impact Grant Program. Items that have been awarded in the past include (but are not limited to) technological devices (i.e.: laptops, tablets), hearing aids, and accessible vans.

Impact Grant applications will be available in mid-January 2022.

To learn more about the application process, please take a look at the **Impact Grants 101** video, where OIF Health Educator Jessica guides applicants through the Jeanie Coleman Impact Grant application process step by step. This video is available on the OIF's YouTube Channel.

If you have any questions about the Jeanie Coleman Impact Grant Program, please contact OIF Health Educator Jessica Ransome at **jransome@oif.org**.

Thank You for Thinking of the OI Foundation This Holiday Season!

Find the perfect gift for everyone on your list while supporting the OI Foundation!

1. Shop online using AmazonSmile for the OI Foundation! For every online purchase you make, Amazon will make a donation to the OI Foundation. Shop at **http://smile.amazon.com/ch/23-7076021**.
2. Gift *Unbreakable Spirit*® apparel to friends, family, and yourself! Shop the OIF's Online Apparel store at **www.oif.org/shop**.
3. Make a donation in honor or in memory of a loved one to the OI Foundation at **www.oif.org/donate**.

For more information about AmazonSmile, the OIF online store, or stock giving, please contact the OI Foundation at **bonelink@oif.org**.

Double Good Popcorn

Thank you for a wonderful year of popcorn sales to benefit the OI Foundation! Since November 2020, the OI Foundation has partnered with **Double Good Popcorn** to not only share delicious popcorn with the OI community, but also raise crucial funds for informational programming and resources. Together, we have raised more than $14,400 for the OI Foundation through Double Good Popcorn sales! Who knew fundraising could be so sweet!

Did you know you don't need to wait for the OIF's popcorn store campaign to hold your own popcorn fundraiser? Through **Double Good Popcorn** you can create your own store page benefiting the OI Foundation any time of the year! If you are interested in learning more about holding your own popcorn fundraiser, please contact Christina at **cteufert@oif.org**.

NEW! Seasonal Bone China Tea Shop

The Bone China Tea campaign has expanded to its own online store! The OI Foundation is excited to announce that we have partnered with **Driven Coffee co.** located in Minneapolis, MN to offer the OI Community delicious loose-leaf tea, coffee blends, and snacks to benefit the OIF.

From January 9-23, 2022, 30% of sales from the OIF's **Driven Coffee co.** online store will go towards supporting the work of the OI Foundation. Whether you are looking to stock up before National Bone China Tea Day or need last minute holiday presents, there is something for everyone!

To shop the Bone China Tea online store, visit **www.oif.org/shop** and select the Bone China Tea banner. When you get to checkout, make sure the OI Foundation is selected as your charity of choice. If you would like to host your own online Bone China Tea store, please contact Christina at **cteufert@oif.org** before January 9.

NEW OIF APPAREL!

Shop the OIF's new *Unbreakable Spirit*® apparel and items at **www.oif.org/shop**!

Coming Together to Support the OI Foundation

This year we were very excited to announce the return of a few of the OI Foundation's outdoor fundraising events! We were thrilled to see two perennial golf events return this summer – the *Riley's Gathering Golf Outing* held in Chicago, IL, in July and the *OI Golf Classic* in Atkinson, NH, in August. In fact, the OI Golf Classic – hosted by Teresa & Ken Gudek and Jane & Jim Early – boasted its best year ever for its 15th anniversary! Thank you to the more than 200 golfers who participated and thank you to the staff at TechNeeds for all their hard work and diligent efforts. Next year, the OI Golf Classic is moving to the Manchester Country Club under the leadership of OIF Board of Directors Vice President Jim Early, and will be held on Monday, August 22, 2022.

**Our condolences go out to Jim Early and his whole family as his grandson, Matthew Smith, passed away in October 2021.*

OIF Director of Development Melissa Bonardi, former OIF Board President Ken Gudek, and OIF Board Vice President Jim Early at the 2021 OI Golf Classic.

Former OIF Board President Ken Gudek taking his traditional free putt on the 18th Green.

On October 23rd, the OI Foundation welcomed 150 guests to the *5th annual Boots & Bling for Better Bones* in Houston, TX. Attendees enjoyed legendary Goode Company barbeque and music by Hunter Perrin while bidding on fantastic items in the online auction. We want to thank Dr. Brendan Lee and Earl Dyke for their moving remarks. Together, attendees raised more than $115,000 for the OI Foundation – making it the event's best fundraising year yet! We hope anyone interested in attending next year's event will save the date of October 15, 2022 when we return to the Armadillo Palace for a big and bright good time.

Attendees enjoyed the 5th annual Boots and Bling for Better Bones.

Mark Your Calendar!

With concerns surrounding indoor gatherings, the OI Foundation has decided to continue holding winter Fine Wines Strong Bones events as virtual or hybrid gatherings.

February 26, 2022 – Fine Wines Strong Bones Gala (Virtual)
Committee members of the OIF's original Fine Wines Strong Bones Gala in Washington, DC are inviting OI community members, friends, and family to participate in the 22nd year of their event. Participants will have the option of purchasing individual packages or hosting a group based on your personal comfort level for a party pod.

March 3, 2022 – Fine Wines Naples (Hybrid)
We hope you will join Teresa & Ken Gudek and Jane & Jim Early for a virtual wine tasting.

May 2022 – Strong Bones Gala Boston (Boston, MA)
OIF Board of Directors Vice President Christine Rossi and her committee of family and friends are hoping to host an in-person, outdoor event for their 5th annual Strong Bones Gala Boston.

July 7-10, 2022 – OIF National Conference
The OIF is still evaluating the possibility of holding an in-person 2022 National Conference in Orlando, FL, and would like to hear if you would attend in-person. The safety and comfort of our community are very important to us, and your input helps us make the best planning decisions. Please take a moment to complete the OIF's Conference Survey at **www.oif.org/confsurvey**.

Details for all upcoming events will be available soon. If you have any questions, or would like to volunteer to join a committee, please contact Melissa Bonardi at **mbonardi@oif.org**. Check the OI Foundation's upcoming events page at **www.oif.org/events** for tickets and event details.

Meet Dr. Francesca Tonelli, OIF Michael Geisman Fellow

By: Gabriela Beug, OIF Science and Media Communications Intern

As osteogenesis imperfecta is a rare bone disease, research grants remain difficult to acquire worldwide. The Osteogenesis Imperfecta Foundation makes research a priority through the Michael Geisman Fellowship program (created in memory of Michael Geisman, son of OI Foundation founder Gemma Geisman), which funds post-doctoral trainees whose research aims to predict, prevent, diagnose, and treat osteogenesis imperfecta (OI).

With the support of the Michael Geisman Fellowship program, awardees work to develop new approaches for therapies targeting OI. In the developmental stages, therapies are first tested on animal models (i.e. mice, zebrafish) before passing the requirements to move on to clinical trials. Studying diseases requires organisms with the same morphological and biochemical properties as well as a similar genome to humans. Both mice and zebrafish have a high level of genetic conservation – meaning a large part of their genome is identical to humans. While in zebrafish this number is around 70%, in mice it averages around 85%. Mice and zebrafish offer an alternative to relying on human samples to test hypotheses, especially for rare bone disease where access to samples is limited.

The OI Foundation is proud to support Dr. Francesca Tonelli of the University of Pavia in Pavia, Italy.

> *"I believe it is a unique experience to study a rare disease and I wish every scientist could have this opportunity at some point in their career. Even if I enjoy the individual aspects of lab work like creating animal models, the research in the OI field makes me feel like I will support other people and it is personally very rewarding. It's the interaction with an individual with OI and the hope of finding a cure for them that make me passionate and persistent in testing new hypotheses until we can develop a cure."* – Dr. Francesca Tonelli

Francesca Tonelli obtained her bachelor's degree in medical and pharmaceutical biotechnology from the University of Pavia in Pavia, Italy in 2012 and continued in the same field, completing her master's degree in 2014. Her journey with osteogenesis imperfecta began by characterizing the dominant OI zebrafish model *Chihuahua*, which at the time was a new model for studying osteogenesis imperfecta. During her PhD she generated several new recessive OI zebrafish models by CRISPR Cas9 gene editing technique. In 2017, Tonelli received her Ph.D. in biomedical sciences under Dr. Antonella Forlino's supervision. Continuing under her mentorship for her postdoctoral training, she is now applying her training to research in osteogenesis imperfecta. In her free time, Dr. Tonelli likes to read, kickbox, or scuba dive.

Areas of Expertise

1. Crispr-Cas9 gene editing
2. Designing, cloning, transcribing CRISPR constructs
3. Generating zebrafish models to investigate skeletal diseases
4. Drug screening: 4-PBA

It is well established that cellular stress is one of the main factors contributing to the osteogenesis imperfecta disease, which disrupts the homeostasis (the "well-being" of cells), leading to protein misfolding. The novel finding of Dr. Tonelli led to identifying chemical compounds such as 4-phenylbutyrate (4-PBA), a drug approved for urea cycle disorders whose beneficial chaperone activity also aids in ameliorating the bone phenotype of OI in the dominant and the recessive zebrafish model.

Her research now focuses on the study of bone formation, thanks to the zebrafish's ability to regenerate the caudal fin. Caudal fin regeneration essentially mimics the dermal bone formation process similarly as it would occur during the human bone growth. Caudal fin regeneration can be exploited also to test the effect of new potential drugs.

Although 4-PBA has been identified as a potential therapeutic target, steps remain to transition from the lab to the translation in patients. Dr. Tonelli's next step is to test a chemically modified version of 4-PBA, which would increase drug stability, specifically targeting bone tissue, making it more friendly for clinical trials in the future.

To learn more or view Dr. Tonelli's publications, please visit **www.oif.org/geismanfellowtonelli**.

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!

OI | OSTEOGENESIS IMPERFECTA FOUNDATION
Unbreakable Spirit

Dear Friend,

It doesn't seem possible that 2021 is almost over. While many communities and businesses begin to re-open, long overdue reunions are had, and life begins to return to normal, we at the OI Foundation want to let you know how much we have appreciated your support during this difficult time. Because of you, the OI Foundation has spent the past two years adding new programs and services to better serve the OI community and medical professionals. This was only possible because of your unwavering support – thank you!

As we welcome in 2022, we are asking for your support to help us continue moving forward!

For more than 50 years, the OIF has been proud to provide up-to-date medically verified information and offer direct support from the OIF Information Center – which answers 11,000 inquiries annually. Since March 2020, the OI Foundation has held dozens of free virtual information sessions for members of the OI community discussing topics such as COVID-19 updates, expert panels on living with OI, research updates from the Brittle Bone Disorders Consortium, etc. These video resources have joined our online information center as a resource to anyone who has questions on the OIF's website. This year, we launched OIF Virtual Office Hours. During these sessions – held bi-weekly– individuals with questions, can "drop-in" to a live zoom meeting hosted by the OIF's Health Educator, Jessica Ransome, who is available to provide live one-on-one answers to inquiries, review OIF resources and programs, or offer support.

> The Zoom presentations on COVID-19 information were extremely valuable to me. The office hours are so convenient, and I love having personal, "face-to-face" contact. I find this format easier to convey what I'm asking. These sessions have helped me in many ways including requesting a new version of the *Take Charge of Your Health Tool Kit* for adults with OI to give to my new primary care physician as an introduction to OI. I've truly appreciated all the ways the OIF has provided to keep myself informed on the latest resources and research.
>
> *Colleen Priest, OI Community Member*

In 2020 and 2021 the OIF converted the OIF National Conference to a two-day virtual event, featuring informational sessions on highly requested topics, research updates, and mutual support programming. With more than 400 virtual attendees from all over the world, the response and feedback has been overwhelmingly positive!

The OIF continues to help accelerate OI research and now more than ever, it is so important to hear the voice of the OI community to help advance research and enhance programming.

Under the leadership of OIF Board of Directors member and Medical Advisory Council member, Dr. Laura Tosi, the OI Foundation is proud to have been granted funding from the Eugene Washington PCORI Engagement Awards program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). The first two awards: *Improving Patient-Centered Outcomes: Expanding Engagement of the Osteogenesis Imperfecta Community*, and the *COVID-19 Enhancement Award*, allowed the OI Foundation to learn how to better serve and provide the resources the OI community needed over the past two years.

Currently the OIF is conducting two additional projects with PCORI. The first, titled *Leveraging Virtual Communication to Advance PCOR Adoption by the Rare Bone Disease Community*, brings together members of the Rare Bone Disease Alliance (RBDA) with stakeholders from the patient and scientific communities in a series of focus groups and 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. The newest award, *Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease*, will explore the problems that young adults with OI have as they transition from pediatric to adult care. Challenges such as difficulties individuals find when seeking primary and specialty care, difficulties pediatric OI clinics have as they seek to successfully transition their patients to adult care, and barriers and facilitators that existing adult OI clinics encounter as they seek to provide appropriate and high-quality care to adult patients.

Having medical professionals who are well-versed in OI is paramount when it comes to care for the OI community. In order to build a strong network of physicians who can provide the latest in medical advancements to their patients, the OIF has recently launched two new programs for medical professionals: OI TeleECHO and OI Clinic Town Hall meetings. Monthly OI TeleECHO sessions include a brief presentation by a an OI expert on an OI related topic followed by participant-led case presentations and group discussion on the presented cases. These grand round style virtual sessions have been growing in popularity and will be starting their second year this winter. In addition, the OIF has endeavored to link OI clinics and bone health programs with expertise in treating people with rare bone disease around the world through OI Clinic Town Hall sessions. These sessions allow for physicians to compare and contrast experiences with specific case studies in order to better serve the OI community.

Members of the Shriners Hospital for Children in Honolulu, Hawaii celebrating OI Awareness Week 2021.

The OI Foundation has not only pulled through the past two years, but we have thrived and that is all thanks to you! **We hope you will consider making a gift of $50, $100, $500 or more to help us continue this important mission.**

Thank you again for your continued and generous support.

Wishing you a happy and healthy holiday season!

Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

OIF Receives New Funding from the Patient Centered Outcomes Research Institute

The OI Foundation is thrilled to have received funding for two new projects from the Patient Centered Outcomes Research Institute (PCORI). The first project, titled *Leveraging Virtual Communication to Advance PCOR Adoption by the Rare Bone Disease Community*, will leverage the relationships among members of the Rare Bone Disease Alliance (RBDA) to achieve wider, sustained PCOR participation among patients, parents/caregivers, clinicians, researchers, as well as external groups such as industry representatives, regulators, and PROM developers who are concerned with rare bone disease.

The RBDA is a network of patient groups and professionals dedicated to improving the lives of people with various rare bone diseases. The project goal is to share the successful PCOR experience of the Osteogenesis Imperfecta Foundation with the rare bone disease community. The project will pay particular attention to reaching stakeholders from underrepresented communities and seeks to develop a roadmap to implement and sustain stakeholder engagement. The goal is to foster communication between rare bone disease clinics so that all patients and clinicians have access to the same tools and clinical trials designed to enhance patient care. To read the full project summary, please visit **www.oif.org/pcorrbda**.

The OI Foundation also received funding from the Patient Centered Outcomes Research Institute (PCORI) for a project titled *Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease.*

The focus of this project is to prepare the OI community to be able to compare different strategies for delivering high quality care for widely dispersed individuals with a complex disorder. We will accomplish this by first expanding the reach of our patient-centered outcomes research education efforts to include a diverse group of stakeholders from across the US. We will then use listening sessions, interviews and surveys to explore how patient-centered outcomes research might identify opportunities for improving adult OI care. We will explore problems that young adults with OI have as they transition from pediatric to adult care, challenges that older adults with OI encounter as they seek primary and specialty care, difficulties that pediatric OI clinics have as they seek to successfully transition their patients to adult care, and barriers and facilitators that existing adult OI clinics encounter as they seek to provide appropriate and high-quality care to adult patients.

At the completion of this project, we will have significantly expanded the knowledge, competencies, and abilities of persons with OI and other stakeholders to be meaningful partners in future PCOR and CER studies. We will have significantly strengthened the skills of researchers to be better partners with patients and other stakeholders involved in PCOR/CER. We will pursue an aggressive dissemination program, specifically including publications in both the peer-reviewed literature and OI Foundation communications.

The OIF's PCORI projects are led by Tracy Hart (Chief Executive Officer, OIF) Laura L. Tosi, MD (Director, Bone Health Program, Children's National Hospital), and Bryce Reeve, PhD (Professor of Population Health Sciences and Pediatrics, Duke University School of Medicine). Tracy Hart along with Drs. Tosi and Reeve co-led the OIF's two previous PCORI awards; Improving Patient-Centered Outcomes: Expanding Engagement of the Osteogenesis Imperfecta Community, and the COVID-19 Enhancement Award.

If you are interested in learning more about these projects or patient centered outcomes research, please **visit www.oif.org/pcor** or contact the OIF at **bonelink@oif.org**.

Thank You for Participating in the Impact Survey!

The Impact Survey was completed by more than 2,000 OI community members from 66 countries! The results from this survey will be used to enable better healthcare services for both children and adults and to support availability of potential future treatments for OI.

> *"We are thrilled to have collected the largest global gathering of data about the impact that osteogenesis imperfecta has on people with OI, families, and caregivers. This is a remarkable number of responses, and we eagerly await the first data publications."*
> – Tracy Hart, OI Foundation CEO

The IMPACT Survey was made possible through a close collaboration and partnership between Mereo, Ultragenyx, and the OI community, led by the Osteogenesis Imperfecta Federation Europe (OIFE) and the OI Foundation (OIF). Please take a moment to read the full press release at **www.oif.org/impactpressrelease**.

OIF Medical Professional Meetings

The OI Foundation creates and supports programs to help increase understanding of OI and other rare bone diseases and support the work of our medical experts and community members. Over the past several months, the OI Foundation has hosted virtual meetings to educate and connect medical professionals and researchers from across the globe.

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

On September 9, OIF Medical Advisory Council member Dr. Joan Marini (National Institute of Health) hosted the **IntOI 2020+1: Virtual International OI Meeting: Early Stage Investigators Symposium**. This meeting was an interim meeting for the in-person International OI Meeting, which will take place in August 2022 in Sheffield, UK. The IntOI 2020+1 Symposium highlighted the work of early-stage researchers across the globe working in the field of osteogenesis imperfecta. Professor Natalie A Sims, PhD, of St. Vincent's Institute of Medical Research in Melbourne, Australia, started off the event with her keynote talk, "Six New Technologies and What They Are Teaching Us About Bone." Early-stage investigator presentations, representing researchers from 6 countries, were organized by theme, including OI Genetics, Animal Models for OI, and Clinical Studies. The latter section was moderated by Professor Nick Bishop of the University of Sheffield, United Kingdom. More than 300 medical professionals and researchers registered for this meeting, representing thirty-seven countries, making this one of the most geographically diverse medical professional audiences ever for the OIF. The OIF would like to thank Dr. Marini, Dr. Bishop, the International OI Meeting scientific committee and all the presenters who helped make this event a success!

Rare Bone Disease Working Group Meeting

On October 7, the Rare Bone Disease Alliance (RBDA), a program of the OI Foundation, held its annual **Rare Bone Disease Working Group Meeting** as part of the American Society for Bone Mineral Research (ASBMR) 2021 Annual Meeting. The RBDA is a coalition of fourteen rare bone disease patient advocacy groups with the mission to stimulate education on and assist patients and families affected by rare bone diseases. More than 100 attendees listened to cutting edge basic-science presentations during this meeting, which was hosted by OIF Medical Advisory Council (MAC) member Dr. Matthew Warman. Presentation topics included CLOVES syndrome, Gorham-Stout, Lymphatic-mediated bone destruction from a mouse model, Multicentric Carpotarsal Osteolysis (MCTO) Syndrome, and more. The OIF would like to thank Dr. Warman for hosting this meeting and all the presenters who shared their research.

Leveraging Virtual Communication to Advance PCOR (Patient Centered Outcomes Research) Adoption by the Rare Bone Disease Community

On October 21, the OIF and the RBDA hosted its introductory meeting for a new joint initiative, **Leveraging Virtual Communication to Advance PCOR (Patient Centered Outcomes Research) Adoption by the Rare Bone Disease Community**. Attendees at this introductory meeting included a diverse group of patient representatives from various rare bone disease advocacy groups, and speakers discussed the structure of PCOR and how it can be leveraged for multiple stakeholders. Presenters also covered topics of special importance to rare disease advocates, including how to change FDA surrogate endpoints, and a discussion of diversity, equity, and inclusion in rare disease communities and its importance to patient-centered work. We would like to thank all the speakers and especially OIF Board Member and OIF Medical Advisory Council (MAC) member Dr. Laura Tosi for her tireless work to advance PCOR initiatives at the OIF!

OI and Bone Health Clinic Town Hall

On October 28, the OI Foundation hosted the third **OI and Bone Health Clinic Town Hall**. The OIF hosts Clinic Town Halls as an opportunity for clinicians to learn about OIF resources and to collaborate with each other. In this meeting, MAC member Dr. Sandy Sandhaus shared on his insights on treating OI during the COVID-19 pandemic, Dr. Jean-Marc Retrouvey gave a presentation on practical dental tips, and Dr. Laura Tosi announced a new PCOR project focusing on the transition from pediatric to adult care for individuals with OI.

TeleECHO Programs

The OI Foundation would like to thank everyone who participated in the **Osteogenesis Imperfecta TeleECHO Clinic Series!** This medical professional educational program completed its first year of virtual sessions on September 8, 2021. In each monthly session, medical experts gave short presentations on a topic essential to improving the diagnosis and treatment of people with OI and were followed by real-world case presentations and group discussions. By using this ECHO model for professional learning, this program helped improve patient outcomes by allow clinicians and researchers to share their expertise and best practices with over 250 medical professionals across the world. More information on this program and recordings of past presentations can be found at **www.oif.org/echo/oi/**. The OIF would especially like to thank the program's faculty members, Dr. Frank Rauch (head faculty, MAC) and Dr. Sandesh Nagamani (MAC), and Dr. Jeanne Franzone for all their hard work and dedication to this program.

The OI Foundation is also happy to announce that the **Rare Bone Disease TeleECHO Clinic Series** has begun its third year! This program was started in 2019 by head faculty member Dr. Laura Tosi. The Rare Bone Disease ECHO aims to build capacity to diagnose and treat rare bone diseases safely and effectively. To learn more about this program and sign up for future sessions, please visit **www.oif.org/echo/rbd/**.

To learn about upcoming events, please visit the OIF's new Medical Professionals Event Calendar at **www.oif.org/medprocalendar**.

The Current State of OI Research

The OI Foundation's *Current State of OI Research* video series was created to highlight and describe the work of the Brittle Bone Disorders Consortium (BBDC). The OIF has hosted four sessions in this series so far:

> *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 covered the landscape of OI research.
>
> *Current State of OI Research: Women's Health and Pregnancy*
> Deborah Krakow, MD (OIF MAC member and Professor and Chair of Obstetrics and Gynecology at UCLA) and Tracy Hart (OIF CEO) discussed current OI research regarding women's health.
>
> *Current State of OI Research: Dental Health*
> Dr. Jean-Marc Retrouvey (Professor and Chair of the Department of Orthodontics and Dentofacial Orthopedics at the University of Missouri-Kansas City) and Tracy Hart (OIF CEO) joined OI community members to discuss current research in dental health and orthodontics.
>
> *Current State of Research: Mental Health and OI*
> Dr. Reid Sutton (Geneticist at Baylor College of Medicine and OIF Medical Advisory Council member), and Dr. Eric Storch (Vice-Chair and Head of Psychology at Baylor College of Medicine) shared their experience working with the OI community and information about a new study the BBDC is undertaking around mental health.

To view session recordings, please visit the OIF website (Video Resources page) or the OI Foundation's YouTube channel.

NEW! OI Research Summaries

The Brittle Bone Disorders Consortium (BBDC), a multi-center program that focuses on understanding and providing better treatment options for all types of OI, continues to complete and share OI research.

While the research completed by the BBDC is exciting, it can be difficult to understand. The OI Foundation recently released summaries to share brief overviews of recent OI studies conducted by the BBDC. To view these summaries, please visit **www.oif.org/currentstudies**.

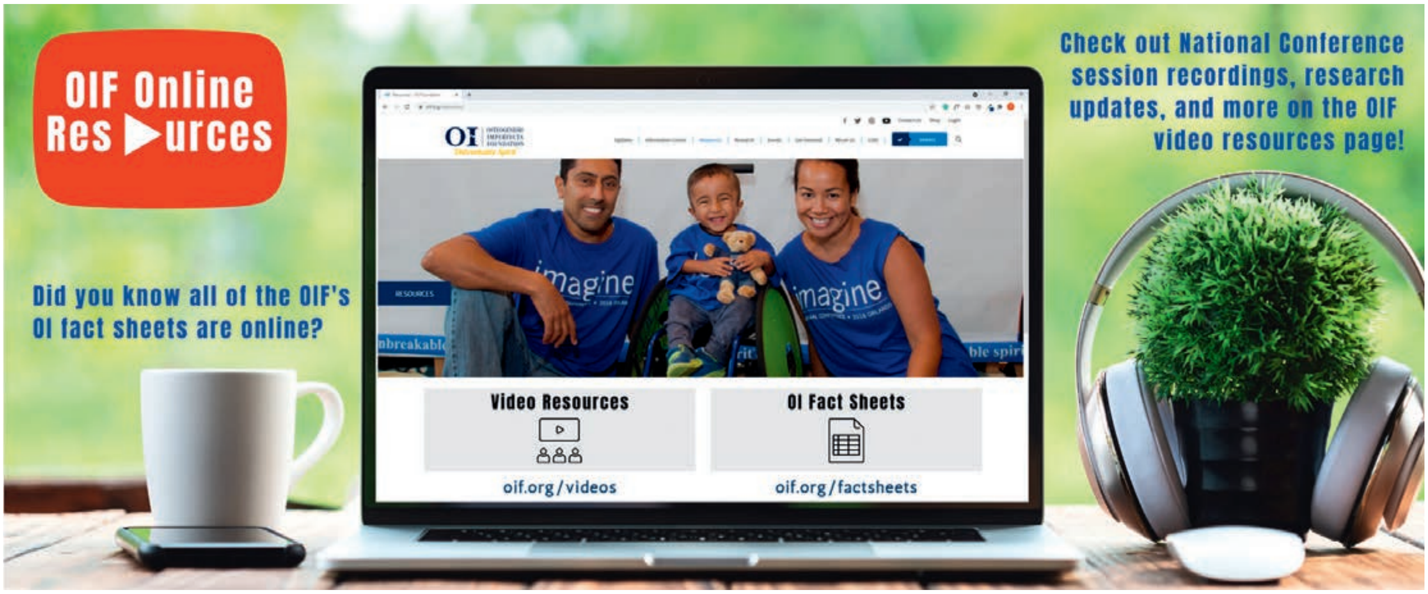
SHAPE FUTURE OI RESEARCH

JOIN THE OI REGISTRY

WWW.OIF.ORG/CURRENTSTUDIES

Participate in Current OI Studies

Supporting research is an important part of the OI Foundation's mission. Often, the success of clinical studies of a rare disorder like osteogenesis imperfecta (OI) depends on getting enough people to participate in the study so the results are meaningful. If you are interested in learning more about current OI studies or would like to join the OI Registry, please visit **www.oif.org/currentstudies**.



Enter the OIF Good Stuff Sweepstakes!

Don't miss out on your opportunity to win one of the amazing prizes! Each entry into the Good Stuff Sweepstakes has a suggested donation of $5 but donation is not required for entry. To submit one free entry please contact Christina at **cteufert@oif.org**. Enter today at **www.oif.org/Sweepstakes**!

RETURN THE ENCLOSED FORM OR GO TO WWW.OIF.ORG/SWEEPSTAKES TO ENTER!

OI FOUNDATION *Good Stuff* SWEEPSTAKES

WIN ONE OF THESE AMAZING PRIZES WHILE SUPPORTING THE OI FOUNDATION!

Lenovo Laptop

Working from home or taking classes online? Upgrade your technology with a brand new Lenovo IdeaPad 5 laptop with a 15.6" display and 16GB of storage. Valued at $1,000.

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1ST, 2ND, 3RD PRIZE DRAWINGS: ENTRIES MUST BE POSTMARKED NO LATER THAN JANUARY 7, 2022

BY ENTERING THE GOOD STUFF SWEEPSTAKES, YOU ARE HELPING THE OI FOUNDATION PRODUCE NEW INFORMATION RESOURCES, FUND RESEARCH, PROVIDE ANSWERS TO MORE THAN 11,000 REQUESTS FOR INFORMATION PER YEAR, AND FACILITATE SUPPORT GROUPS ACROSS THE COUNTRY.

THANK YOU FOR YOUR SUPPORT AND GOOD LUCK!

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HAPPY NEW YEAR!