



VIRTUAL OIF NATIONAL CONFERENCE

JULY 10-11, 2021

Virtual OIF National Conference

Last summer, almost 900 OI community members from across the globe came together virtually to attend information sessions led by OI experts and connect with new and old friends at the first-ever OIF Virtual National Conference.

On July 10-11, 2021, the OI Foundation will host the 2021 OIF Virtual National Conference. The conference will provide live online versions of some of the most popular informational and social sessions at the biennial OIF National Conference. Please take a look at the schedule below.

Saturday, July 10, 2021

10:30-11:30am ET	Navigating a New OI Diagnosis*
12:15-1:45pm ET	Welcome & Research Update*
2:00-4:00pm ET	Pediatric Care Panel* <i>sponsored by Shriners Hospital for Children, Canada</i>
2:00-4:00pm ET	Adult Care Panel*
4:30-6:30pm ET	Parents Meet and Greet
6:30-7:30pm ET	Virtual Lobby
7:30-9:30pm ET	Adults Social Hour

Sunday, July 11, 2021

11:00-1:00pm ET	Ask the Expert
1:00-2:30pm ET	Mild OI Forum*
1:15-2:45pm ET	Surgical Panel for Children and Adults with OI*
3:00-5:00pm ET	Youth Forum
3:00-5:00pm ET	Women's Health Session
3:30-5:00pm ET	Dental Care Panel*
5:30-6:30pm ET	Closing Session*

* This session will be recorded and shared on the OIF website.

This online program will be free of charge for all OI community members. More information and registration for the Virtual OIF Conference will be available at www.oif.org/virtualconference.

**We can't wait to see you at the
2021 OIF Virtual National Conference**

OI Foundation's COVID-19 Toolkit

The OI Foundation is making every effort to provide the most up-to-date information about the COVID-19 pandemic for the OI community. The COVID-19 Toolkit, one of the OIF's newest resources, provides information and resources related to the COVID-19 pandemic specific to the OI community. To view the COVID-19 toolkit, please visit www.oif.org/category/covid19.

COVID-19 Video Resources

Throughout the COVID-19 pandemic, the OI Foundation has hosted a series of video sessions to connect OI community members with experts to discuss COVID-19 related topics. Session topics have included Medical Updates, Orthopedic Perspectives, Mental Health and Self-Care Strategies, Healthy Eating, Employment Accommodations, and COVID-19 Vaccine. To watch the recordings of these sessions, visit the OIF podcast webpage at www.oif.org/podcast.

Stay tuned for information about upcoming community calls hosted by the OI Foundation! Information will be shared on www.oif.org and on the OIF Facebook page.

COVID-19 Vaccine Resources

For those hoping to receive a COVID-19 vaccine, the OI Foundation has assembled resources and suggestions to help you advocate for priority vaccination status. To view these resources, please visit www.oif.org/vaccineresources.

**Thank you to the 649 community
members who participated in the
OIF's second COVID-19 survey!
Survey results are shared on page 4
of this newsletter.**

National Osteogenesis Imperfecta Awareness Week is May 1-8, 2021!

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. The OI community celebrates Wishbone Day by wearing yellow and sharing facts and information through social media.

Make the most of National OI Awareness Week 2021:

Proclaim OI Awareness Week in Your State

Help us raise awareness across the country by requesting an official OI Awareness Week proclamation in your state! Head to the OIF website to find a direct link to your state's government page for proclamations at

www.oif.org/awarenessweek. Just click your state and use the sample language provided to write your request! Once you submit a proclamation request, contact Christina Teufert at cteufert@oif.org.

Raise OI Awareness on Social Media

Follow the OI Foundation on Facebook, Twitter, and Instagram! Help us raise OI awareness online by liking and sharing our #SHAREforAWARENESS posts on your social media pages during OI Awareness Week.

Host A Fundraiser

Bone China Tea

Sip, Sip, Hooray! Please join the staff of the OIF and OI community member, Susie Wilson, for a virtual tea party on May 1st for Bone China Tea Day during National OI Awareness Week. To register for the event or to learn more about hosting a Bone China Tea event with your friends and family, please visit www.oif.org/campaign/bonechinatea.

Create a Facebook Fundraiser

Invite your family and friends to join you in raising OI awareness and supporting the OI Foundation by creating a fundraiser for the OIF on Facebook!

OIF Double Good Popcorn Fundraiser

Whether you are into salty or sweet, this awareness week fundraiser has something for everyone! Double Good popcorn is not only delicious, but 50% of the sales go towards supporting the mission of the OI Foundation. Purchase from the OIF's virtual popcorn store or create a store of your own! Here's how to get started:

1. Download the Double Good app
2. Create your own pop up store using the OIF's code:
TJHSBQ
3. Invite your friends and family to purchase popcorn from your pop up store in support of the OI Foundation from Monday, May 3 - Friday, May 7!

Thank you for helping us raise OI awareness across the nation during National OI Awareness Week!



NATIONAL OI AWARENESS WEEK
MAY 1-8, 2021 / RAISING AWARENESS OF OSTEOGENESIS IMPERFECTA
Learn how you can get involved at www.oif.org/awarenessweek

DID YOU KNOW?
Osteogenesis imperfecta is a rare and complex genetic disorder of the collagen. OI is characterized by brittle bones but can impact many other crucial body systems and is widely variable. There are an estimated **50,000** individuals living with OI in the US.

#SHAREFORAWARENESS **OI** Unbreakable Spirit

The graphic features a blue background with a white map of the United States. Three circular inset photos show individuals: a woman in a red floral top, a man in a green shirt using a walker, and a young girl. The OI logo and 'Unbreakable Spirit' tagline are at the bottom right.

Fundraising Events Continue Virtually in 2021

In the past year, we have been overwhelmed by supporters who have not let a global pandemic stop the amazing work of the OI Foundation. The *Unbreakable Spirit*® of the OI community has kept us going and we promise to continue to provide the OI community with medically verified information, opportunities for mutual support and most importantly, research to find treatments for OI. Fundraising events account for 25% of the OI Foundation's annual revenue each year – money raised at these events helps to fund research, educational resources, and the OIF Information Center. Following the great success of the *Strong Bones Boston* and *Boots & Bling for Better Bones* events going virtual this past fall, we were very excited to have two more of our yearly fundraising events move to a virtual platform this winter so that attendees could still have an opportunity to give.

The 21st annual *Fine Wines Strong Bones Gala* was held virtually on Saturday, February 20th. OI Foundation Board of Directors Vice President Christine Wyman Rossi co-hosted the event and helped highlight messages from past and current Fine Wines Strong Bones planning committee members, including Tim Dombro, Allison Schwartz, Jessica Finkel Minor, Katrina Bache, Mary McNutt, Jacqueline Bourgeois, Jeffrey Eslinger, and Dr. Laura Tosi. Following the personal OI stories, we held our first-ever virtual paddle raise to fund the mission of the OI Foundation and raised \$40,000 in support of the Jamie Kendall Fund for OI Adult Health. These funds will help move the vital research on pulmonary health being conducted by Dr. Cathleen Raggio (Hospital for Special Surgery, New York) and Dr. Robert Sandhaus (National Jewish Health in Denver, Colorado) forward to the next phase which will include study participants having bronchoscopies and eventually to establish a standard of care for individuals living with OI.



OI community members came together for the first-ever virtual Fine Wines Strong Bones DC.

On March 11th, former OIF Board President Ken Gudek and his wife Teresa were joined by OIF Board Vice President Jim Early and his wife Jane for the *Fine Wines Naples* event. For this unique event, we partnered with Benziger Family Winery out of Sonoma, California to host a virtual wine tasting. Participants were able to order bottles of Benziger wine which was shipped directly to their homes. Jill Benziger led guests on a 30-minute virtual wine tasting. During the event, guests heard from OI community members Susie Wilson and Zarina Rasheed about the importance of the programs the OI Foundation has led throughout the pandemic. Together, participants raised \$45,000 in support of the OI Foundation.

Thank you to all of our virtual attendees and we hope to see all of you at a virtual fundraiser in the near future!

Share Your Story in Gemma's Corner

Gemma Geisman, founder of the OI Foundation, was creative, passionate, and a wonderful listener. She listened to learn about you, she listened to find out how to help you, and she listened because she cared about you.

Gemma's Corner, a program created in Gemma's memory, features videos of OI community members sharing their story and encourages the OI community to keep sharing with each other, caring for each other, and providing support to one another.

A very special video highlighted in *Gemma's Corner* (titled 'Reflecting on 50 Years – A Letter From Gemma Geisman') features Gemma's daughter, Cathy Bowen. Cathy read a beautiful letter written by her mother reflecting upon the OI Foundation's 50th anniversary. We encourage you to visit the OI Foundation's YouTube channel to view this video, along with the other amazing stories shared in *Gemma's Corner*.

Your story may be just what another community member needs to hear. If you would like to share your OI story on *Gemma's Corner*, please contact OIF Health Educator Jessica Ransome at jransome@oif.org.



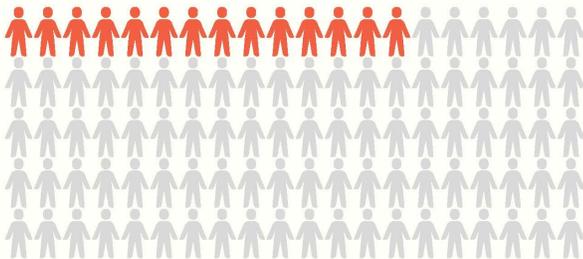
COVID-19 SURVEY II KEY FINDINGS

Tremendous thanks to everyone who completed COVID-19 Survey II. Our goal is to keep you up-to-date on the ever-changing landscape of COVID-19 and how it is impacting the OI Community.

649 46.5

TOTAL RESPONSES

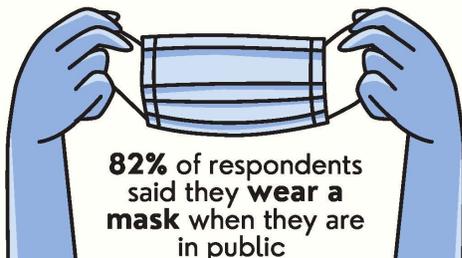
AVERAGE AGE



88 respondents (14%) believe they had COVID-19. Half of these cases were confirmed by a positive COVID-19 test or physician diagnosis.

Of the 88 individuals who report COVID-19 infection, **44 (50%) reported at least one "long COVID" symptom** lasting longer than 4 weeks.

- Ongoing fatigue
- Joint pain
- Headaches
- Brain fog
- Body aches
- Coughing
- Shortness of breath
- Loss of taste and smell
- Difficulty sleeping



82% of respondents said they **wear a mask** when they are in public



report they **have received a COVID-19 vaccine.**

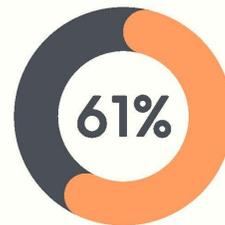


of those not yet vaccinated say they will **definitely or likely get the vaccine** once available to them

Only 13.6% said that they were hesitant about getting the vaccine, an improvement from 17% in the first survey

75% of our respondents had healthcare providers that were able to provide **telemedicine appointments**

Almost half (48%) of respondents were **able to see all of their healthcare providers**, while 21% were delaying visits.



of respondents were **less physically active now than before the pandemic started.** Exercise is essential to maintaining muscle mass and bone density, and supports mental health and mood.

70% of respondents received a flu vaccine in the past year. Vaccines are an important part of preventative health, and research demonstrates that the flu vaccine reduces the severity of symptoms if you do get the flu.



For a full report and for more COVID-19 resources, please visit www.oif.org. Stay tuned for the next survey!

OIF COVID-19 Survey 2 Results

Tremendous thanks to the 649 community members who completed the OIF's second COVID-19 survey. Our COVID-19 surveys are essential to tracking how the pandemic is impacting the OI community. Please watch out for survey number 3!

To complete future surveys about OI, we highly encourage you to sign up for the OI Registry at www.oif.org/OIregistry to be the first to hear about these opportunities.

For questions, contact the OIF via email: bonelink@oif.org or telephone: 301-947-0083.

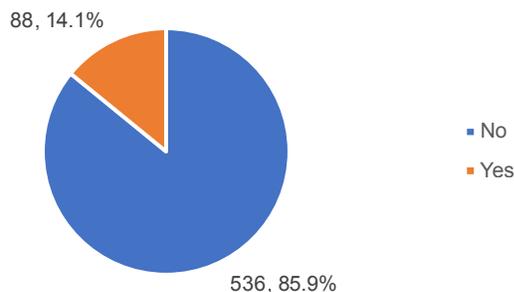
Overview

In total, **649 individuals** responded to the survey, the **average age** of respondents was **46.5**, which was higher than the average age of 39.4 for the first COVID-19 survey. For demographics, **75.3%** respondents identified as **female**, and **86.7% white**, compared to 92% previously. **6.8%** respondents identified as **Hispanic/Latino**, **4.2% Asian**, and **3.5% African American**.

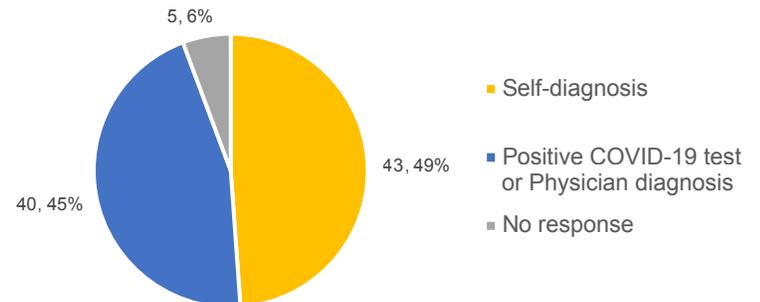
COVID-19 Impact

For questions related to COVID-19, **88 (14.1%) respondents believed they had COVID-19**, and of those, **40** reported a **positive test or physician diagnosis**, while **43** were **self-diagnosed**, and **5** did not report how they were diagnosed.

Do you believe you had COVID-19?

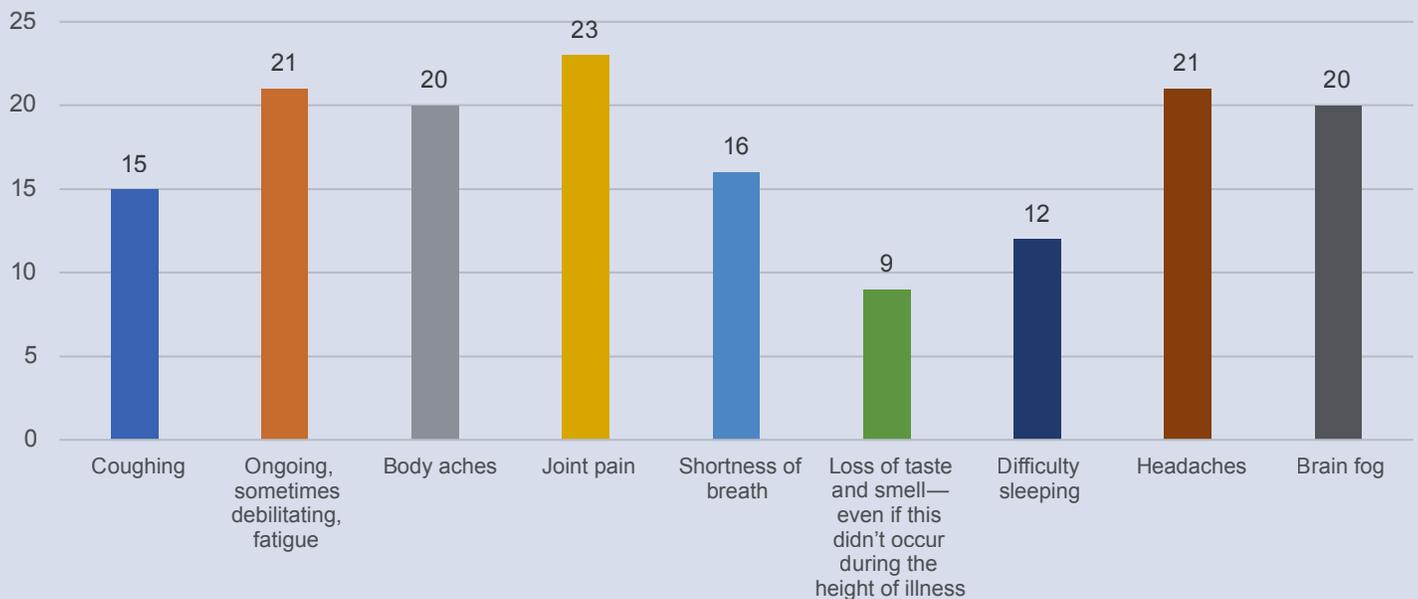


How did you receive your diagnosis?



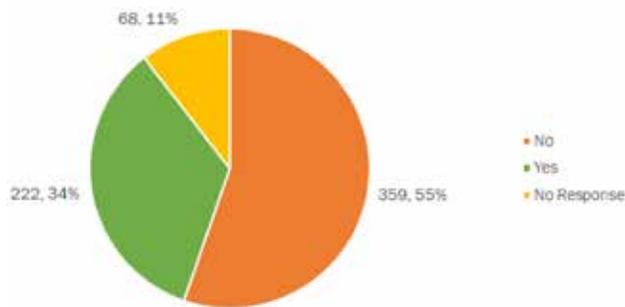
Of the **88** individuals who reported COVID-19 infection (either self-reported or clinically diagnosed), **44 (50%) reported at least one "Long COVID" symptom, lasting longer than 4 weeks after infection** (Note: respondents selected all of the Long COVID symptoms they experienced).

Long COVID Symptoms



Vaccine Update

Have you received the COVID-19 vaccine?



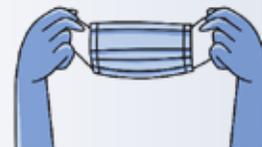
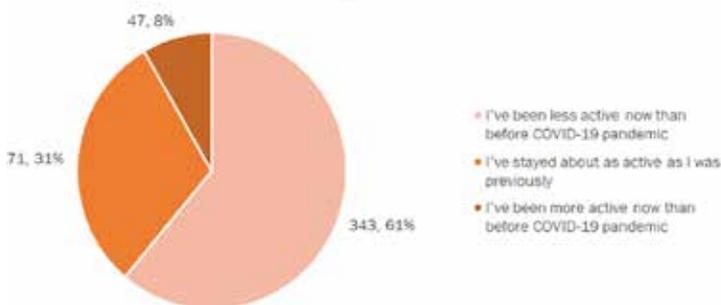
Despite challenges with vaccine rollout, **222 (34%)** respondents said they have **received the COVID-19 vaccine**. Of those who had not yet received the vaccine, **81%** report they will **definitely get or likely get the vaccine**. Only **13.6%** responded that they were hesitant about getting the vaccine.

There were 406/584 (**70%**) respondents who **received a flu vaccine in the past year**. The OIF continues to encourage flu vaccination coverage for all people with OI.

Health and Wellbeing

343/561 (**61%**) said they were **less active than before the pandemic started**, while only 171/561 (**30%**) were **just as active** and 47/561 (**8%**) said they were **more active**. Exercise is essential to maintain muscle mass and bone density, as well as support mental health and mood. Please visit www.oif.org for resources on how to stay active during the COVID-19 pandemic, applicable for all ages and levels of ability.

Have you been able to stay as physically active as you did before the COVID-19 pandemic?



82% of respondents said they wear a mask or facial covering all the time when they are in public or indoors and unable to socially distance. While some states begin to lift restrictions and mask mandates, the OIF continues to encourage people with OI to follow CDC guidelines regarding masking.

Mental Health

The COVID-19 pandemic and related consequences have been a major cause of worry for the OI community. When asked if stay-at-home orders and isolation have affected mood and behavior, **18% said most of the time, 32% said some of the time, 39% said occasionally, and 11% said not at all**. On a positive note, when asked about general health and quality of life, **80%** reported **good, very good, or excellent overall health**, while **86%** reported **good, very good, or excellent quality of life**, demonstrating the resilience of our community.

Important Findings and Topics for Future Investigation

- We seek to improve the diversity of our survey respondents in regards to age, sex, and race. Please encourage all OI community members to support future surveys.
- While COVID-19 cases among respondents were higher than in the US population, our big concern is that 50% of respondents reported COVID-19 symptoms lasting longer than 4 weeks. Watch for survey 3 as we explore this further.
- The OI community vaccination rate (34%) is higher than the overall US rate, but we still have a long way to go. We urge you to visit www.oif.org/category/covid19 for more information about vaccines and how to receive one.
- A large portion of the OI community has become less active. Health advocates believe that "movement is life." Therefore, the OIF will provide new opportunities to encourage exercises and activities.

Next Steps: Please enroll in the [OI Registry](#) and plan to participate in future surveys!

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 becoming a member of the OI Foundation today!



656 Quince Orchard Road
Suite 650
Gaithersburg, Maryland 20878
(301) 947-0083
Fax: (301) 947-0456
bonelink@oif.org
www.oif.org

Board of Directors

President

Cameron R. Penn

Vice President

Christine Wyman Rossi

Vice President

James M. Early

Treasurer

Ted Trahan

Secretary

Sharon Mutnick, MBA

Michele Burka, MBA

Brett L. Eisenberg

Kenneth D. Finkel

Eric Gould

Joe Hall

Tracy L. Mulroy, JD

Wendy E. Sacks

Michael Sheridan

Laura Tosi, MD

S. Jacinta Whyte

Chief Executive Officer

Tracy Smith Hart

Medical Advisory

Council Chair

Francis Glorieux, OC, MD, PhD

The Osteogenesis Imperfecta
Foundation, Inc., is a 501(c)3
non-profit organization.



Dear Friend,

We can't thank you enough for being an active member of the OI community! As one of our dedicated supporters, we hope you will consider becoming a member of the OI Foundation. Our continued success is only possible with your generosity and commitment.

This past year, the OI Foundation, along with the rest of the world, has experienced unprecedented challenges. But thanks to your support, we have risen above and continued to provide our members and the OI community with invaluable up-to-date information, access to ground-breaking research, educational resources for individuals and families, and opportunities for mutual support.

Over this past year, the OI Foundation has worked hard to reach as many members of the OI community as possible. Through our Virtual OIF National Conference this past July and the COVID-19 Community Calls, we have met hundreds of new individuals living with OI who were not previously connected to the OI Foundation. We have been honored to provide them with important information and services.

So far, 2021 is shaping up to be another year of change and transition for so many OI community members and our hope is to provide everyone with the information and support needed to adjust. We are looking forward to another Virtual OIF National Conference on July 10-11, 2021, several virtual community calls, virtual and hybrid events, new research from the Brittle Bone Disorders Consortium and young investigators, and a return to the in-person National Conference in 2022. We are incredibly proud of the progress we have made together, but there is still so much work to be done.

Help us as we continue to expand our reach – please use the enclosed envelope to become a member of the OI Foundation today!

Because 2020 was such a unique year, we have extended the opportunity to celebrate the OI Foundation's 50th anniversary by becoming a member of the **1970 Society** in recognition of the OI Foundation's inaugural year. Members who give at least \$1,000 will become part of this special circle. You can make your donation in a single pledge or in installments over ten months. You can also dedicate your \$1,000 gift in honor or in memory of a loved one. As a **1970 Society** member, you will receive a limited edition OIF 50th anniversary lapel pin and special acknowledgment in the OIF annual report and on the OI Foundation's website www.oif.org.

We are truly grateful for your continued support and look forward to seeing you at upcoming OIF events!

Sincerely,

Tracy Hart
CEO, OI Foundation

**BECOME A
MEMBER
TODAY!**



The Osteogenesis Imperfecta Foundation owes its continued success to its members. The organization's future depends on you! Show your support of the OI Foundation by becoming a member today.

Bronze \$36/PER YEAR

All members will receive an annual subscription to the OI Foundation's printed newsletter, Breakthrough.



Silver \$100/PER YEAR

This membership comes with an Unbreakable Spirit® lapel pin to show off your OIF pride.



Gold \$365/PER YEAR

This membership comes with an Unbreakable Spirit® lapel pin and 50th anniversary Goldie bear.



New! This year all members will be invited to attend a special virtual Q&A on all things OI Foundation led by CEO, Tracy Hart.



OIF founders, Becky Keller, Midge Peck, Renee Gardner and Gemma Geisman at the OIF organizational meeting on April 22, 1970 at Shriners Hospital in Chicago.

THERE'S STILL TIME TO JOIN THE 1970 SOCIETY!



For only one more year you can join the OI Foundation's 1970 Society by making a special gift in honor of the **OI Foundation's 50th anniversary.**

By making a \$1,000 gift (or ten monthly installments of \$100), you will become part of the OIF's 1970 Society

commemorating 50 years of the OIF's service to the OI community. You can also dedicate your gift in honor or in memory of a loved one with OI.

Members who join the 1970 Society will receive a limited edition gold plated OI 50th anniversary lapel pin, be acknowledged in the OIF annual report and on the OIF website.

RETURN THE ENCLOSED ENVELOPE OR GO TO WWW.OIF.ORG/MEMBER



OIF Northeast Virtual Regional Conference

On Saturday, February 27th, the OIF held the first *Virtual Northeast Regional Conference*. This one-day meeting was hosted by Medical Advisory

Council (MAC) member Dr. Cathleen Raggio and included presentations that addressed OI concerns from infancy through adulthood. OIF Regional Conferences provide attendees with a more local opportunity to learn about OI and network with other OI community members that live in their area. As the first-ever Virtual Regional Conference, this event was able to include even more medical professionals and highlighted a broad array of topics. Over 50 attendees represented the states of Massachusetts, Maine, New York, New Hampshire, New Jersey, Rhode Island, Connecticut, and more.

The event featured speakers and panelists based in the Northeast, including Hospital for Special Surgery, Boston Children's Hospital, Shriners Hospital for Children — Springfield, Connecticut Children's Medical Center, Harvard Medical School, and more. The OI Foundation wants to thank everyone involved in the planning of this event, including all the speakers and panelists, and especially to our chair, Dr. Cathleen Raggio, whose leadership and vision made this event possible.

Speakers included:

- **Cathleen Raggio, MD**, OIF Medical Advisory Council member, Principal Investigator for the Brittle Bone Disorders Consortium site in New York City, Co-Director of the Kathryn O. and Alan C. Greenberg Center for

Skeletal Dysplasias, and Orthopedic Surgeon at Hospital For Special Surgery in New York City

- **Erin M. Carter, MS, CGC**, Clinical Coordinator and Genetic Counselor at Hospital for Special Surgery
- **Samantha Spencer, MD**, Orthopedic Surgeon at Boston Children's Hospital & Assistant Professor of Orthopedic Surgery at Harvard Medical School
- **Frances Baratta-Ziska, PT, DPT, MS, PCS, C/NDT**, Clinical Supervisor of Pediatric Rehabilitation at Hospital for Special Surgery
- **David Vernick, MD**, OIF Medical Advisory Council Member, Assistant Clinical Professor of Otolaryngology and Laryngology at Harvard Medical School, Surgeon in Otolaryngology at Massachusetts Eye and Ear Infirmary, Beth Israel Deaconess Medical Center, Brigham and Women's Hospital, and Boston Children's Hospital
- **Deborah McInerney, MS, RD, CDN**, Nutritionist at Hospital for Special Surgery
- **Meghan Burnett, LCSW**, Case Manager at Hospital for Special Surgery
- **Laura Tosi, MD**, OIF Medical Advisory Council member, OIF Board of Directors member, Orthopedic Surgeon at Children's National Hospital in Washington DC, and Principal Investigator of the Brittle Bone Disorders Consortium site in Washington, DC

In addition to the speakers, panelists joined the various Q&A sessions to provide further insights. The panelists included:

- Nancy S. Dunbar, MD, MPH, FAAP; Daniel W. Green, MD, MS, FAAP, FACS**, and **Christina Jacobsen, MD, PhD**.



Host a Bone China Tea!

Invite your friends and family to enjoy a cup of tea with you by hosting a Bone China Tea event to support the work of the OI Foundation. From the comfort of your own home, you can help make a difference in the lives of those living with osteogenesis imperfecta. Simply invite your guests to enjoy a relaxing cup of tea at home and then make a gift to the OI Foundation with the money they may have saved by not going out to a real event. All you pay for is the postage when sending your Bone China Tea invitations! Order printed invitations – complete with a tea bag – by contacting Christina Teufert at cteufert@oif.org or 301-947-0083.

OI Clinic Directory

The OI Foundation recognizes that one of the difficulties that many OI community members face is finding a team of medical professionals who are familiar with working with OI. Since 2005, we have tried to make locating medical care easier by providing the community with a directory of over 50 U.S. based OI clinics listed by state. The OI Clinic Directory is featured on our website (www.oif.org/clinicdirectory), and aims to provide you and your family with accurate, verified, and easily accessible information to assist you in locating dependable and multidisciplinary medical care. The directory provides information including the hospital and clinic names, contact information, and the services each clinic offers. Please use the QR code below to visit the OI Clinic Directory! If you are looking for a specific type of physician, the OIF also maintains a Physician Referral List that can be accessed by calling or e-mailing the OIF office at bonelink@oif.org or (301) 947-0083.



Do you know of a clinic or a physician that works with people with OI that you don't see on our lists? Help us provide the most up-to-date information to the community by letting us know! Please email or call us with the name of the physician or clinic at bonelink@oif.org or (301) 947-0083.



Give the Gift of an Unbreakable Spirit®

Does your friend or family member have a birthday, anniversary, or special day coming up? Give the gift of an *Unbreakable Spirit*® when you make a gift in honor of a special someone to support the important work of the OI Foundation.

Mother's Day is just around the corner! Let the women who mean everything to you know how much you appreciate them by making a Mother's Day Honor Gift during the month of May and we will send them a special Mother's Day card. To make an honor gift today, visit www.oif.org/donate and select 'Memorial or Honor Gift' from the dropdown.

Our Commitment to the OI Community

In July 2020, the OI Foundation released a statement confirming our commitment to diversity, equity, and inclusion initiatives at the OI Foundation.

We realize change starts with us and we are conducting 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.

We are proud to partner with diversity, equity and inclusion professional (and OI community member!), **Chaz Kellem.**



Chaz Kellem

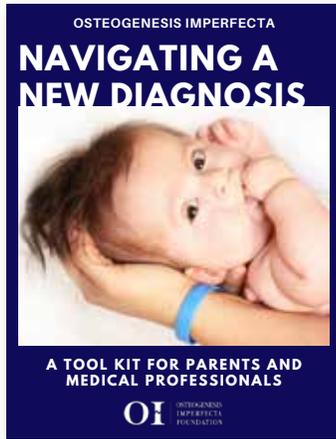
"In the past year, the OIF board of directors and staff took a long, hard look at our programs and how we're engaging all members of the OI community. That exploration led us to Chaz Kellem. As an OI community member, Chaz not only has an intimate understanding of the OIF's mission, but he's also an expert in developing and sustaining engagement efforts at the local, regional and national levels, across diverse constituencies. We know Chaz's people-first approach will identify and address opportunities within the OIF, so we can better drive transparency, understanding and accountability." – CAMERON PENN, OIF Board President

Chaz has ten years of experience as a diversity, equity, and inclusion professional. He currently serves as the Director of PittServes, a program that provides University of Pittsburgh students the opportunity to engage in ethical and sustainable service to the community on a local, national and international scale. Chaz is active and committed to the community, as he serves on several non-profit boards including ACHIEVA, Best Buddies PA and Miracle League of Moon.

"It is such an honor to work with the Osteogenesis Imperfecta Foundation as we explore diversity, equity, and inclusion initiatives within the organization. The team is putting in hard work to assure our programs and services are accessible and available for the entire OI community." – CHAZ KELLEM

The OI Foundation is thrilled to have Chaz on our team as we continue our work to support the entire OI community!

OIF Information Center



Navigating a New Diagnosis: A Tool Kit for Parents and Medical Professionals

The *Navigating a New Diagnosis* tool kit, sponsored in part by Minnesota Neonatal Physicians in memory of Michael Johnston, provides guidance for parents and medical professionals caring for a child with a recent osteogenesis imperfecta diagnosis. Readers will find information and resources on topics including prenatal care, diagnosis of OI, types of OI, caring for a newborn with OI, and fracture care. The tool kit also highlights related OIF resources and provides information to share with your doctor.

To download your copy of the *Navigating a New Diagnosis* tool kit, please visit www.oif.org/factsheets or contact the OI Foundation at bonelink@oif.org.

Virtual Office Hours

Join OIF Health Educator Jessica Ransome every Tuesday at noon & 6:00PM EST to learn more about Foundation resources, ask questions, or just drop in to say hello during the OIF's Virtual Office Hours. Questions? Email Jessica at jransome@oif.org.

To log on to Virtual Office Hours, visit www.oif.org/virtualofficehours.



Thank you to our members who made a very special gift in 2020 and joined the 1970 Society in recognition of the OI Foundation's founding year!

Anthony & Jennifer Benish
Ellen Benish
Jo Ann Berkenbush
John & Nancy Braitmayer
Lane & Carol Brundieck
William Danner
Jeanne Franzone, MD
Francis Glorieux
Sherri Goodman
Stephanie Greenwood
Stephen Gudek, Sr.

Gerald Harris, PhD, PE
Tracy Smith Hart
Priscilla Kilman
Richard Kruse
Ben & Barbara Miller
Jonathan & Sharon Mutnick
Melanie Rak
Robert Sandhaus
Peter Smith, MD
Jack & Carol Sprawls
S. Jacinta Whyte

There is still time to join the **1970 Society!** Members who donate \$1,000 in either 2020 or 2021 will be inducted into this special group and will receive a limited edition lapel pin as well as recognition in the OI Foundation's Annual Report and website, www.oif.org.



Resources and Learning Opportunities for Medical Professionals

The OI Foundation has been providing new resources and learning opportunities for medical professionals throughout the country and around the world. These initiatives have helped increase knowledge of osteogenesis imperfecta and other rare bone diseases among the medical community and are a central part of how the OIF accomplishes its mission of improving the quality of life for those living with osteogenesis imperfecta.

In the past 3 months, the OIF's virtual events for medical professionals have included more than 400 attendees from hundreds of medical institutions and over 25 countries. We are excited to continue providing additional virtual learning opportunities and look forward to meet even more medical professionals at future events!

Rare Bone Disease TeleECHO Clinic Series

During recurring sessions on **the first Thursday of each month at 3pm ET**, a featured speaker gives a brief presentation on a specific rare bone disease or an interdisciplinary topic, followed by participant-led case presentations and group discussions. Started In 2019, the Rare Bone Disease TeleECHO Clinic Series has had thousands of medical professionals attend from over 25 countries with each monthly session averaging over 100 participants. The OIF would like to thank the program's medical director, Laura Tosi, MD, and the entire faculty: Michael Collins, MD; Michael Lewiecki, MD; Eric Rush, MD; Jay Shapiro, MD; and Dolores Shoback, MD.

Continuing Medical Education (CME) credit is available for eligible attendees. Upcoming TeleECHO sessions include:

May 6, 2021; 3:00pm EST

DXA Evaluation in the Child

Catherine Gordon, MD Adolescent Chief, Boston Children's Hospital; Robert P. Masland, Jr. Chair of Adolescent Medicine, Professor of Pediatrics, Harvard Medical School

June 3, 2021; 3:00pm EST

Adult Hypophosphatasia

Kathryn Dahir, MD Professor of Medicine, Vanderbilt University Medical Center

More information and recordings of past sessions can be found at www.oif.org/echo/rbd.

OI TeleECHO Clinic Series

The goal of the **OI TeleECHO Clinic** is to build capacity to safely and effectively diagnose and treat osteogenesis imperfecta. This series is geared towards medical professionals and takes place on the **second Wednesday of each month at 3pm ET**. In each monthly session, faculty members or guest speakers give a brief didactic presentation followed by participant-led case presentations and group discussion of the presented cases. The OIF would like to thank the program's Medical Director, Frank Rauch, MD; and the faculty members Jeanne M. Franzone, MD; and Sandesh C.S. Nagamani, MD. Continuing Medical Education (CME) credit is available for eligible attendees.

Upcoming OI TeleECHO sessions include:

May 12, 2021; 3:00pm EST

Dental and Orthodontics

Jean-Marc Retrouvey, DMD, MSc, FRCD – Professor and Chair of Department of Orthodontics and Dentofacial Orthopedics, University of Missouri-Kansas City, MO

June 9, 2021; 3:00pm EST

Pulmonary Issues

Robert A. Sandhaus, MD, PhD, FCCP – Pulmonologist, National Jewish Health in Denver, CO

More information and recordings of past sessions can be found at www.oif.org/echo/oi.





Osteogenesis Imperfecta Foundation
656 Quince Orchard Road
Suite # 650
Gaithersburg, MD 20878

NON-PROFIT
U.S. POSTAGE
PAID
SUBURBAN, MD
PERMIT #5857

Since 1970, generous support from donors like you has helped the OI Foundation provide information and resources that improve the quality of life for families living with OI.

*To commemorate the OIF's 50th anniversary we are offering a limited opportunity to become a member of the OIF's **1970 Society**, a group that recognizes donors who have given \$1,000 in 2020 or 2021 to support the work of the OI Foundation.*

Members will receive a limited edition OIF 50th anniversary lapel pin and a miniature Goldie 50th anniversary teddy bear. Your generous gift is equivalent to \$20 a year for every year the Foundation has been incorporated. Donors can make a one-time donation or pledge \$100 a month for 10 months.

Visit www.oif.org/member to sign up today!

