

The 2022 OIF Virtual Conference is on Saturday, July 9!

This year's virtual conference program will include a full day of information sessions led by experts in their respective fields in a question-and-answer styled format, similar to the *Ask the Expert* sessions from last year.

The OI Foundation's 2022 Virtual Conference agenda will feature information sessions including Navigating a New Diagnosis, OI Research Update, Mental Health, Cardiopulmonary and OI, Women's Health, Dental Health, and (NEW!) Transition to Adult Care. Several information sessions will feature live translation to French and Spanish. Attendees will also have the opportunity to socialize with fellow participants at social sessions created for both adults and children.

The full conference agenda and registration will be available on the OIF website in May. This online program will be free of charge for all OI community members.

The 2022 Unbreakable Spirit® Walk-n-Wheel will be held on Friday, July 8, 2022. Grab your friends and family and create a walk-n-wheel team to raise awareness of OI and funds for the OI Foundation. For more information, visit www.oif.org/walknwheel2022.



OIF Regional Conferences

The OI Foundation will host several smaller, in-person Regional Conferences around the country throughout this year. By hosting smaller regional conferences, we can deliver educational resources to our community and still provide a safe environment for gathering. The first Regional Conference will be held on July 30th in Tampa, Florida. Stay tuned for more information!

We hope to see you at an OIF Conference this year!

Navigating a New Diagnosis: New Video Resources

The Osteogenesis Imperfecta Foundation's *Navigating a New Diagnosis: A Tool Kit for Parents and Medical Professionals* resource covers topics including diagnosis of OI, types of OI, caring for a newborn with OI, and information to share with your doctor.

In addition to the online tool kit, we have created a video companion piece to answer popular questions about OI and dispel common misconceptions. This video series will feature medical experts in the field of OI, pediatrics, and genetics. These videos should not be treated as telemedicine and we encourage you to discuss any questions you may have with your medical care team.

In the first video, Dr. Michael Bober (Director of the Skeletal Dysplasia Program at Nemours Children's Hospital) joined OIF Health Educator Jessica Ransome to share information for parents and medical professionals treating a new OI diagnosis.



The New Diagnosis toolkit and video resources are available on the OIF website at www.oif.org/newdiagnosis.

National Osteogenesis Imperfecta Awareness Week is April 30-May 7, 2022!

National Osteogenesis Imperfecta Awareness Week is a week dedicated to raising awareness for OI and sharing your Unbreakable Spirit®! How will you make a difference this year?

Make the most of National OI Awareness Week 2022:

RAISE OI AWARENESS ON SOCIAL MEDIA

“Like” the OI Foundation on Facebook and “Follow” the OIF on Twitter and Instagram! Help us raise OI awareness online by liking and sharing OIF Awareness Week posts on your social media pages throughout the week.

Create a Facebook Fundraiser! Invite your friends and family to show their support for the OI community by creating a Facebook fundraiser for the OI Foundation!



NEW OI AWARENESS APPAREL

The OI Foundation's online store features shirts, sweatshirts, onesies, hats, and more! With adult, youth, toddler, and infant sizes, there is something for everyone.

Each order from the online store supports the OIF's mission to improve the lives of those living with osteogenesis imperfecta.

Order Unbreakable Spirit® apparel for the whole family today at www.oif.org/shop.

DOUBLE GOOD POPCORN SHOP

We have some delicious news... the OIF's Double Good Popcorn Store is opening back up for National OI Awareness Week! Shop award winning popcorn starting at 3pm ET on May 3 until May 7. Not only will delicious popcorn be delivered to your doorstep, but 50% of the proceeds will be donated to support the OI Foundation. Don't forget to order a few extra as gifts for friends and family!

Would you like to create your own Pop-up store in support of the OIF?

1. Download the Double Good app
2. Create your own pop-up store using the OIF's code: VTNGKM
3. Invite your friends and family to purchase popcorn from your store!

Don't worry, we will POP back in on social media and email to remind you when you can start ordering popcorn! Thank you for supporting the OI Foundation!

Visit the National OI Awareness Week website at www.oif.org/awarenessweek to learn more about how you can get involved

WISHBONE DAY

Each year on May 6, OI community members come together to celebrate Wishbone Day, the international OI awareness day. We hope you will celebrate with us by wearing yellow and sharing your OI story to raise awareness.

MAY 6, 2022

Bone China Tea

Bone China Tea is an annual fundraising campaign of the OI Foundation where participants can contribute to OI awareness, support, and research efforts by enjoying a cup of tea in the comfort of their own home. The best part is, there is no event to plan! Hosts simply invite 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 an in-person event.

Send invitations to your friends and family— we even provide the tea bag! All you pay for is the postage if you choose to send our Bone China Tea invitations to your friends and family. Many hosts use their invitations to share life updates with friends and family. Order printed invitations – complete with a tea bag – by contacting Christina Teufert at cteufert@oif.org.

National Bone China Tea Day is just around the corner on May 1, 2022! Once again, we will be kicking off National OI Awareness Week with a Virtual Bone China Tea Party hosted by Bone China Tea Chair, Susie Wilson on May 1 at 3pm ET. Log on to connect with new and old friends while enjoying a relaxing cup of tea. This event will also include a raffle and teacup contest! Help us cheers to 30 years of Bone China Tea by participating in this fundraiser. To register to attend, visit www.oif.org/virtualeatparty.



The Bone China Tea Shop is opening back up! In honor of the 30th anniversary of the OIF's Bone China Tea fundraising campaign, the OI Foundation has partnered with Driven Coffee Roasters to offer the OI Community delicious loose-leaf tea, coffee blends, honey sticks, and snacks. From **April 22 to May 1**, 30% of sales from the OIF's Bone China Tea shop will go towards supporting the work of the OI Foundation. You can also shop the NEW Bone China Tea Mug on the OIF's bonfire store by scanning the QR code or visiting www.oif.org/shop.



Share Your Story

One of the best ways to raise awareness of osteogenesis imperfecta is to share your OI story and experiences. Gemma's Corner, created in memory of OIF Founder Gemma Geisman, is a place where OI community members can share their OI story, as well as listen to others. Visit www.oif.org/gemmascorner to listen to OI community member stories in Gemma's Corner.

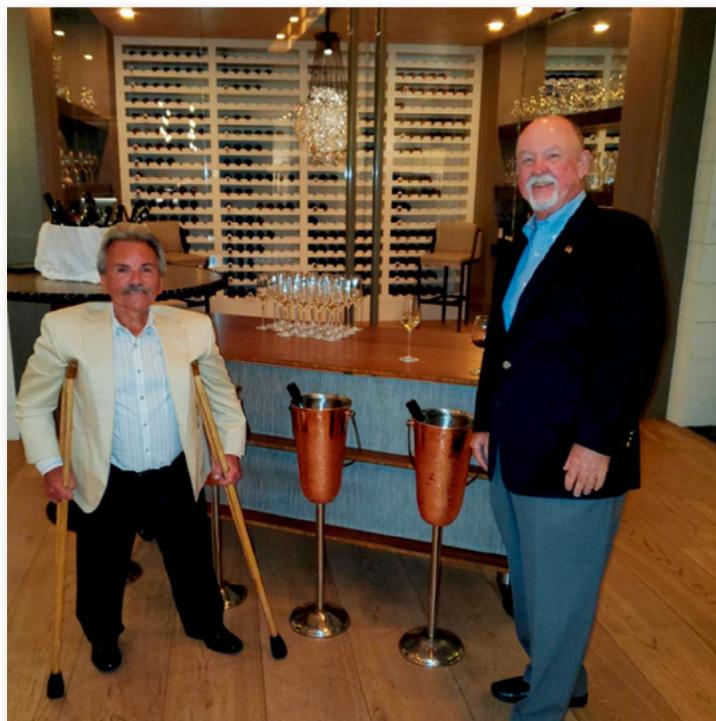
We want to hear from you! For more information or to share your story, please contact Jessica at jransome@oif.org.

Thank You for Attending Fine Wines Strong Bones Events!

On February 26, the Osteogenesis Imperfecta Foundation hosted the 22nd annual Fine Wines Strong Bones DC – a virtual evening of wine tasting, special video presentations, live raffles, online auction, home-delivered cheese boards, and the opportunity to fund the mission of the OI Foundation. Together, attendees raised \$52,000 for the OI Foundation!

On Thursday March 3rd, Teresa & Ken Gudek and Jane & Jim Early hosted the 7th annual Fine Wines Naples reception in Naples, Florida. The reception included a wine tasting and auctions. Thank you to all who participated and raised a total of \$65,000 in support of the OI Foundation!

We hope to see you at an upcoming OI Foundation event!



Upcoming Events

June 17, 2022

Strong Bones Boston (Framingham, MA)

July 8, 2022

Unbreakable Spirit® Walk-n-Wheel (Virtual)

July 9, 2022

OIF National Conference (Virtual)

July 21, 2022

Riley's Gathering Golf at Maple Meadows Golf Course (Elmhurst, IL)

July 30, 2022

OIF Regional Conference (Tampa, FL)

August 22, 2022

The Matthew Smith Memorial Golf Outing at Manchester Country Club (Manchester, NH)

September 21, 2022

NEW! Unbreakable Spirit® Golf Tournament at Iron Valley Golf Club (Lebanon, PA)

October 15, 2022

6th Annual Boots & Bling for Better Bones (Houston, TX)

October 22, 2022

Abruzzi Family Golf Tournament

Check out upcoming OIF events on the OIF's event webpage at www.oif.org/events.

OIF Listening Sessions – Volunteers Needed!

The OI Foundation is asking for volunteers to participate in “listening sessions” (our version of focus groups) as part of our latest project, **Preparing Adults with Osteogenesis Imperfecta to Engage in Research on Access and Quality of Care for Their Rare Disease**. Our goal is to understand barriers and facilitators for improving access to appropriate care and raising the quality of that care for adults with OI. Most pediatric OI patients (up to ages 18-22) are cared for at one of over 60 OI clinics located around the country. Only 5 clinics, however, care for OI patients who are considered of “adult” age. The lack of adult OI care in the US poses significant problems for transition to adult care and access to quality specialty care particularly for individuals living in geographically isolated areas.

If you agree to participate, you will attend a VIRTUAL one-time 90-minute listening session with about 5-7 other members of the OI community. During the listening session you will be asked questions about issues that you think are important to transition from pediatric to adult care. You will be compensated for your time and the information you tell us will be used to inform and guide future programs and resources. If you are interested, or would like more information, please contact Stacie Loring at sloring@oif.org. To learn more about this project, visit www.oif.org/pcor.

OIF Medical Professional Meetings

The OI Foundation has continued to expand the collaboration and learning opportunities for medical professionals in the past few months.

On Thursday, February 17, 2022, the Rare Bone Disease Alliance (RBDA), a program of the OIF, hosted the **2nd RBDA Scientific Symposium**. This three-hour virtual meeting was chaired by Eric Rush, MD, clinical geneticist at Children's Mercy Kansas City, and focused on hypophosphatasia (HPP) and generalized arterial calcification of infancy (GACI) with over 150 attendees from 20 countries. Like the previous RBDA Scientific Symposium on Jansen's Disease and achondroplasia, this meeting highlighted two rare bone diseases at different stages of treatment innovation and understanding. Presentations included "The Neuropsychiatric Impact of HPP on Adults and Children" by Jill Simmons, MD and Rene Pierpont PhD, "Update on HPP Natural History Research" by Dr. Cheryl Rockman-Greenberg, MD, "Advances in our Understanding of GACI and Other Manifestations of ENPP1 and ABCC6-related disease" by Carlos Ferreira, MD, and "A Phase 1/2, Open-Label, Multiple Ascending Dose Study to Evaluate the Safety, Tolerability, Pharmacokinetics, and Pharmacodynamics of INZ-701 Followed by an Open-Label Long-Term Extension Period in Adults With ENPP1 Deficiency" by Gus Khursigara, PhD.

The Rare Bone Disease Alliance would like to thank the Symposium chair, the speakers, and the attendees for making this educational meeting possible. Also, we would like to thank Alexion Pharmaceuticals and Inozyme Pharma for their support of the meeting.

On Friday, April 8, the OIF held its biannual **OI Clinic and Bone Health Town Hall**. In this hybrid event with both virtual and in-person attendees, OI clinicians heard updates on a variety of topics, including pain management, pulmonary care, and OIF resources.



The **Rare Bone Disease TeleECHO Clinic Series** continues to find success in its third year. In the past few months alone, this monthly lecture and discussion series has attracted hundreds of clinicians and researchers from around the world to learn about topics related to the diagnosis and treatment of people with rare bone diseases. In each of these monthly sessions, subject-matter experts present on diagnostic and disease specific topics and are followed by case presentations from attendees. Case presentations can be given by any approved attendee and are

an excellent way to learn about the real-world complexities of diagnosing and treating people with rare bone disorders while also improving patient outcomes.

In 2022, presentations have included "Genetic Testing: Emerging Diagnostic Technologies" with Emily G. Farrow, PhD, CGC; "Hypoparathyroidism" with Rachel Gafni, MD; "Dense Bone Diseases: Too Much of a Bad or Good Thing" with Michael Whyte, MD; and "FOP and Anesthesia" with Zvi Grunwald, MD, FASA. The OI Foundation and the Rare Bone Disease Alliance would like to thank our faculty, speakers, and attendees for their continued support of this program.



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 five sessions in this series including Women's Health and Pregnancy, Dental Health, Mental Health, and New Medical Treatments. To view session recordings, visit the OIF website or YouTube channel.

The following is a letter from OIF Board of Directors President, Cameron Penn. 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
Kenneth D. Finkel
Eric Gould
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 OI community,

This will likely be my last official letter as OIF Board President. Before I depart, I want to thank my fellow board members past and present, those who came before me in this position, Gemma and her fellow founders, our tireless medical professionals, and the entire OIF staff for eight amazing years with the OI Foundation. Thanks to each of you, eight years has felt like eight minutes.

But more than anything, I want to say a heartfelt thank you to each of you. Our mission at the OIF is to provide support to members of the OI community with every resource at our disposal. But it is you who in turn support us to ensure we can be the best patient advocacy organization we can be. It is your

generosity, your Unbreakable Spirit®, and the sheer will within you to pursue a better future for those with OI that fuels everything we do.

You are the ones who helped us navigate what can only be called, uncharted territory. You supported each other from afar and helped us create a virtual OIF nation. We always knew the OI community was capable of superhuman feats and the past two years have cemented that belief. During this unprecedented time, the OI Foundation launched virtual resources such as COVID-19 community calls, virtual national conferences, mutual support programming, and additional opportunities to connect with the OIF Health Educator through virtual office hours.

As I was taking stock of what we've been able to accomplish in my eight years as a board member, this thought ran through my head: I am exactly one year older than the OIF. Then I thought about what my parents went through a half-century ago when doctors told them I probably wouldn't live six months because they had no diagnosis or understanding of what OI was. Regrettably, we know these types of conversations still occasionally happen. It's unfortunate proof that we still have a way to go, and work left to do for the OI community. However, bridging this gap takes resources and resources take financial support.

Please consider becoming a member of the OI Foundation today! Help us continue the amazing work Gemma Geisman began over 51 years ago.

It has been the highest honor serving you these past eight years and being welcomed into the OI community. I will miss it terribly and could not be prouder of what we have achieved and the legacy we are creating for future generations.

Sincerely,

Cameron R. Penn
President, OI Foundation Board of Directors



Former OIF Board President Ken Gudek, Former OIF Board of Directors members Carolyn Tipton and Robin Wright, Former OIF Board President Mark Birdwhistell and current OIF Board President Cameron Penn.



REMEMBER 1970

In 1970 a group of parents came together to form the first patient advocacy organization in the United States for people with osteogenesis imperfecta named the **Osteogenesis Imperfecta Foundation**. Since then, the OI Foundation has become the primary support organization for individuals and families with osteogenesis imperfecta in the United States.



Former OIF Board Member, Mark Peck

SHARING WITH OTHERS LESSENS OUR GRIEF AND DOUBLES OUR JOY!
TODAY IS THE FIRST DAY OF THE REST OF YOUR LIFE

— "Breakthrough" (Feb. 1970)

Our members are a network of families, friends, and medical professionals that make up the heart of the OI Foundation. Without members like you, we would be telling a very different story today. This year we dedicate our annual membership campaign to remembering where we started in 1970.

Membership Levels

THERE'S STILL
TIME TO JOIN THE
1970 SOCIETY!

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.



\$1,000^{ONE TIME GIFT}

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

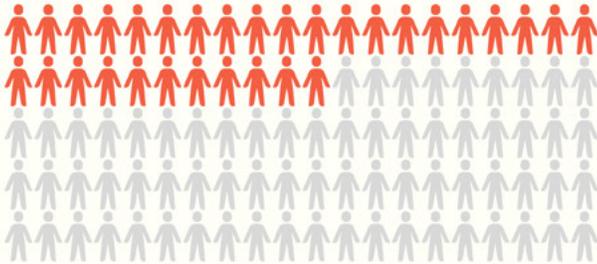


Please consider becoming a member of the OI Foundation to continue the legacy of families and individuals living with OI determined to find answers.

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

COVID-19 SURVEY III KEY FINDINGS

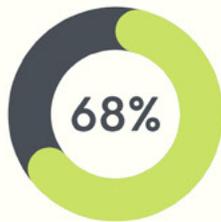
Tremendous thanks to everyone who completed our third COVID-19 Survey. Our goal is to keep you up-to-date on the ever-changing landscape of COVID-19 and how it is impacting the OI Community.



31% of respondents report they have had COVID-19 at least once.



84% report they are fully vaccinated against COVID-19.



68% report that they have received a booster shot.

Unvaccinated individuals reported higher rates of severe COVID-19 infections requiring hospitalization.

vaccinated

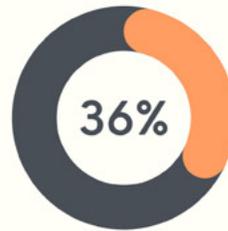


unvaccinated



- hospitalized
- moderate symptoms
- none or minor symptoms

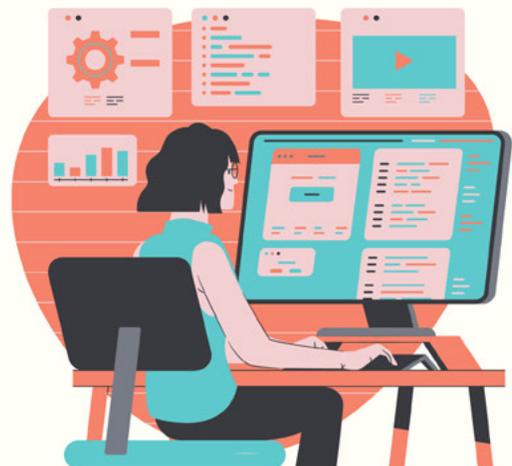
The OIF continues to recommend COVID-19 vaccines and boosters as safe and effective methods of lowering your risk for serious illness or death from COVID-19.



36% 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.

Many respondents reported positive outcomes from the pandemic including:

- more time spent with family
- working from home
- new and different social interactions
- ability to exercise and meditate
- new hobbies



For a full report and for more COVID-19 resources, please visit www.oif.org

OIF COVID-19 Survey 3 Results

Thanks to all of the 577 community members who took the time to fill out the survey, we were pleased to see such a wide response in a short amount of time. Our goal in gathering the community's input is that we can provide feedback during the changing landscape of COVID-19 and direct the OIF's resources where most needed.

It is our goal to keep the OI community informed about how COVID-19 impacts individuals with OI. If you missed the first three surveys, keep an eye out for the next one! 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.

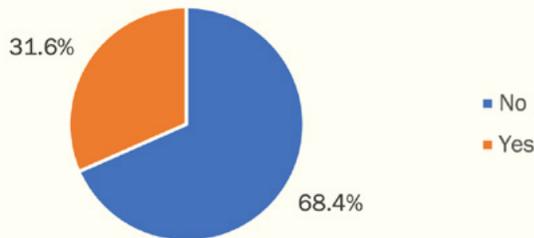
Overview

In total, **577 individuals** responded to the survey, the average **age** of respondents was **40.4** [Survey 1 **39.4**, Survey 2 **46.5**]. For demographics, **70.7%** respondents identified as **female** [compared to 75% in Survey 2], and **85.1% white**, compared to 87% and 92% previously. **8.8%** respondents identified as **Hispanic/Latino**, **3.8% Asian**, and **4.5% African American**, which represented a more diverse group of respondents than the first two surveys.

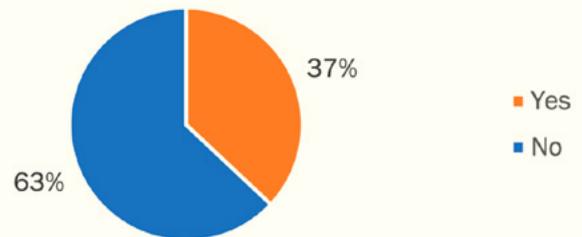
COVID-19

The number of respondents reporting that they had COVID increased significantly from **14.1%** to **31.6%**, but this remains less than the CDC estimate of 43% nationwide (CDC link). Of these, **120 (68%)** reported a **positive test** while **38 (22%)** were **self-diagnosis** and **18 (10%)** were **physician diagnosis**.

Do you believe you have had COVID-19?

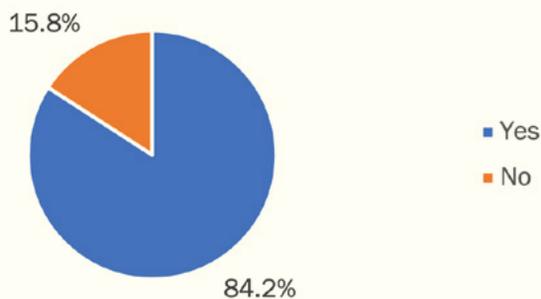


Did you still experience symptoms 4 weeks after your initial infection?

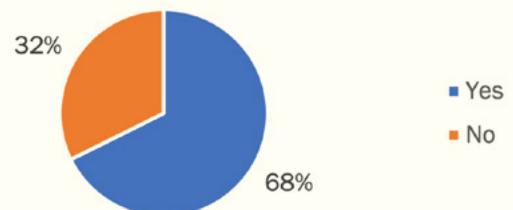


The percentage of individuals who reported symptoms 4 weeks after initial infection **fell from 50% to 37%**. After over a year of vaccine availability, **462 (84.2%)** respondents **had received the COVID-19 vaccine**, which is **significantly up** from **222 (34%)** a year ago. This is also better than US data where only 76.4% of eligible people have gotten at least one dose (per CDC data https://covid.cdc.gov/covid-data-tracker/#vaccinations_vacc-total-admin-rate-total). Similar results were seen regarding **COVID-19 Booster** doses: **68% of respondents** had received a booster. To date, only **44% of those eligible in the US** have received a booster:

Have you received the COVID-19 vaccine?

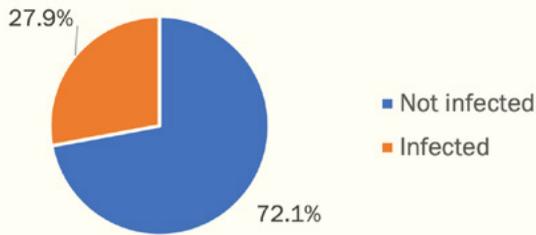


Have you received a COVID-19 vaccine booster?

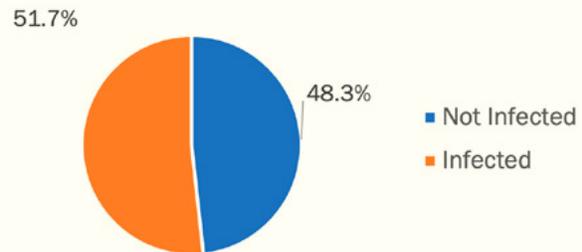


Of those surveyed, a **smaller portion (27.9%) of those vaccinated** against COVID-19 reported **having COVID** versus those who were **unvaccinated (51.7%)**. This appears to match CDC data which demonstrates a 3-fold increased risk for testing positive for COVID-19 in unvaccinated adults (<https://covid.cdc.gov/covid-data-tracker/#rates-by-vaccine-status>). Most importantly, a larger percentage of those **unvaccinated who contracted COVID had severe illness requiring hospitalization (9%), versus 1% in those who were vaccinated.**

Vaccinated Against COVID-19



Unvaccinated Against COVID-19

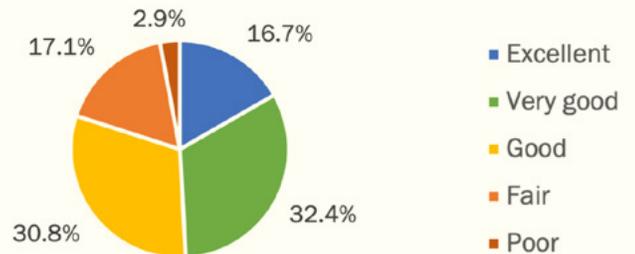


Impact of COVID-19 on OI Community (Resiliency)

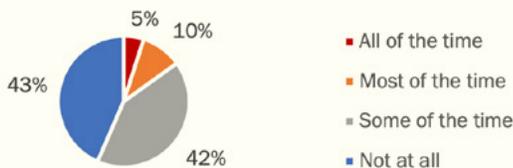
Most respondents reported having **Good, Very Good, or Excellent mental health (80%)** including mood and ability to think. In addition, only a small number of respondents felt depressed or isolated most or all of the time, demonstrating the resiliency of the OI community in the face of a prolonged global pandemic.

Healthy Habits – 50% of respondents have been **about as active as before COVID-19**, while **36% are less active** and **14% are more active** compared to 30% the same, 62% less, and 8% more active in Survey 2. For the OI community, decrease in activity is a source of concern as it can lead to muscle loss and reduced bone density. Physical activity is also a major component of 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.

In general, how would you currently rate your mental health, including your mood and your ability to think?



You feel depressed.



You feel isolated.

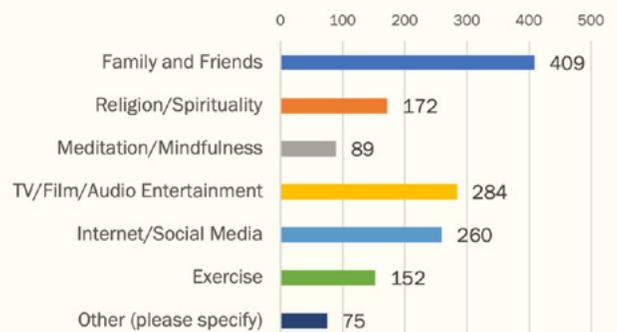


Individuals also reported a number of positive aspects of the pandemic, and listed things that helped them deal with the challenges of COVID-19. Respondents said more time with family (222), benefits of working from home (140), and picking up new hobbies (116) were common benefits, while friends and family (409), entertainment (284), and the internet (260) were commonly cited as helping people deal with the pandemic.

Have you found any positive consequences of the COVID-19 pandemic? (check all that apply currently)



What is helping you currently to deal with the pandemic? (check all that apply)



Important Findings

- While COVID-19 vaccination and boosters were higher among OI respondents than in the United States overall, a significant percentage of unvaccinated OI respondents had COVID and, moreover, had severe COVID requiring hospitalization. Please visit <https://oif.org/category/covid19/> for more information about COVID vaccines, boosters and how to receive one.
- A portion of the OI community has become less active, and this negatively impacts bone and overall health. We encourage all community members to utilize the following resources to maintain active and healthy lifestyles! Click the link or type in the URLs below.
 - National Conference 2021 Fitness and OI Presentation- YouTube Recording <https://youtu.be/oJ-PeOc13pA>
 - Exercise and Activity: Key Elements in the Management of OI- OIF Factsheet https://oif.org/wp-content/uploads/2019/08/Exercise___Activity.pdf
 - Wheelchair-Based Exercises for People with Osteogenesis Imperfecta- HSS four-part video series https://www.hss.edu/conditions_wheelchair-based-exercises-osteogenesis-imperfecta.asp
 - How to Be Physically Active While Social Distancing- CDC recommendations <https://www.cdc.gov/physicalactivity/how-to-be-physically-active-while-social-distancing.html>
- Despite the many challenges of the COVID-19 pandemic, the OI community has proven itself to be incredibly resilient!!! Community members have particularly found family and friends to be critical to coping with these difficult times.

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

In Case You Missed It- The OIF COVID-19 Toolkit provides a wide range of content which is all available for free on the OIF website, which can be found here: www.oif.org/category/covid19/

COVID-19 Community Calls (recordings)

- [COVID-19 Q&A - Dr. Sandhaus, Dr. Glorieux](#)
- [Mental Health and Self-Care](#)
- [Orthopedic Perspectives on COVID-19](#)
- [Eating Healthy during the COVID-19 Pandemic](#)
- [COVID-19 Q&A - Dr. Sandhaus, Dr. Nagamani](#)
- [Preparing for Your TeleHealth Appointment](#)
- [Mental Health during COVID-19](#)
- [Employment Accommodations and COVID-19](#)

COVID-19 Surveys

- [COVID-19 Survey I Results](#)
- [COVID-19 Survey II Results](#)

COVID-19 Vaccine Resources

- [COVID-19 Vaccine Q&A - Dr. Bottazzi, Dr. Sandhaus, Dr. Lee](#)
- [COVID-19 Vaccine State Distribution Information](#)
- [Resources on COVID-19 Vaccinations](#)
- [COVID-19 Vaccine Statement from the OIF Medical Advisory Council](#)
- [CDC Vaccine Finder](#)
- [COVID-19 Vaccine Q&A - Dr. Sandhaus](#)
- [COVID-19 Vaccine Update](#)

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.

MOVE OI RESEARCH FORWARD

Participate in OI Studies!

www.oif.org/currentstudies

OI OSTEOGENESIS IMPERFECTA FOUNDATION



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

Pre-Sorted
First Class
U.S. Postage
PAID
Permit #5857
Suburban, MD

Through funding from the Patient-Centered Outcomes Research Institute (PCORI), the OI Foundation is trying to connect with those who lack internet access or may feel challenged by virtual technology. We believe we can develop solutions to ensure everyone is able to receive the information and resources they need from the OI Foundation. If you are experiencing technology challenges, we want to hear from you!

THE OIF WANTS TO CONNECT WITH YOU!

Patient advocacy organizations put **YOU** first when creating initiatives, designing programs, and developing research studies.

Please take a moment to complete a brief survey at www.oif.org/contactsurvey or give us a call at 844-889-7579.

We are currently evaluating individuals with rare bone disorders' access to the internet to better understand community needs and benefit future research studies.

Please take a moment to give us a call at 844-889-7579 or visit www.oif.org/contactsurvey to take a brief survey so your voice can be heard!