

Spring 2020



Message regarding COVID-19

During this challenging time, it may seem like we all have a lot to worry about. We are all experiencing uncertainty, unanswered questions, and social isolation. Whether you are concerned about your own health, the well-being of your loved ones, financial stress, childcare needs, or changes in your routine, you may find yourself feeling anxious more often than hopeful.

Although this will be challenging for all of us, we are confident in the strength of this community and know we can get through this together. Remember to keep up with your health practices and keep your social supports strong.

For more up-to-date information about COVID-19, visit the [CDC](#) or your local health department's website for evidence-based information. The [OI Foundation](#) is also a great resource for more information on how the OI community can stay healthy during this time.

This is a great time for creativity, innovation, self-care, engaging in social media, and connecting with friends and loved ones remotely. Stay strong, stay healthy, and be positive. Please take care of yourself and remember, we'll get through this!

If you are participating in a Brittle Bone Disorders Consortium study, please read the following carefully:

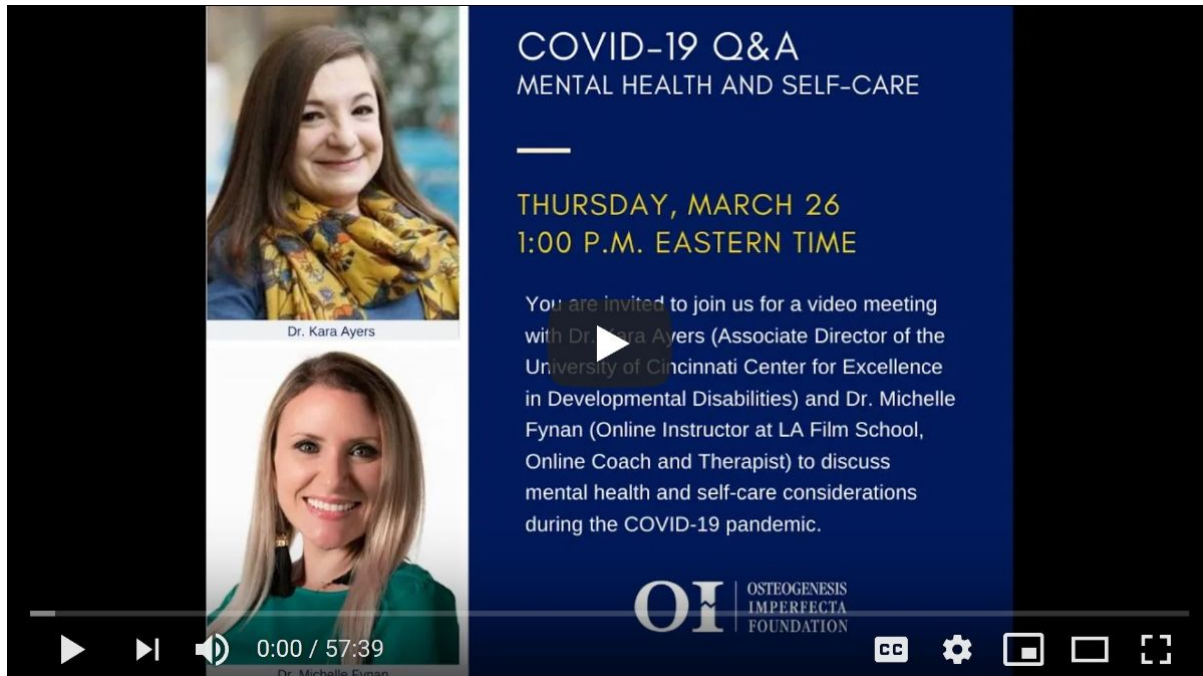
Thank you for your patience and flexibility while we navigate the ever-changing environment of the developing COVID-19 crisis. As we continue to take measures to protect the health and well-being of everyone in our community, many of our sites have made the decision to suspend nonessential operations, including research activities.

If you have a research visit scheduled, your Study Coordinator will contact you to reschedule or convert to a telehealth visit (i.e. web-based video visit or phone visit). If you are due for your annual study visit but have not scheduled it yet, your Study Coordinator will contact you once normal operations have resumed to schedule the visit.

Sincerely,
The BBDC Team

On March 26, 2020, the OI Foundation hosted a video meeting to connect OI community members with Dr. Kara Ayers (Associate Director of the University of Cincinnati Center for Excellence in Developmental

Disabilities) and Dr. Michelle Fynan (Online Instructor at LA Film School, Online Coach and Therapist) to discuss mental health and self-care considerations during the COVID-19 pandemic. You can view the video below.



PARTICIPATE IN OUR STUDIES



- Longitudinal Study
- Pregnancy Study
- Invisalign Trial

We are currently enrolling participants for our **Longitudinal Study**! If you or someone you know may be interested in participating, please contact us => The participating sites are

listed below.

We are also conducting a **Pregnancy Study** and **Invisalign Trial** later this year. Please contact us to see if you are eligible to participate.

RECRUITING SITES



OI PUBLICATIONS NOW AVAILABLE ONLINE

Our study has published 15 research articles in scientific and medical journals. Our research team has been presenting findings at meetings and seminars over the past several years. Thanks to our study participants for their ongoing participation, which allows us to make significant contributions to OI research!

[Hearing loss in individuals with OI](#)

This group of researchers collected and analyzed hearing loss using audiology data from 312 individuals with OI who were enrolled in the Linked Clinical Research Centers and the BBDC. The prevalence, type, and severity of hearing loss in COL1A1/COL1A2-related OI were reported. The paper shows that the prevalence of hearing loss in OI is 28% and increased with age in Type I OI but not in Types III and IV. Individuals with OI Types III and IV are at a higher risk to develop hearing loss in the first decade of life when compared to OI Type I. The data supports the need in early routine hearing evaluation in all types of OI that can be adjusted to the severity of OI.



[Incorporating the patient perspective in the study of rare bone disease: insights from the OI community](#)

In order to explore and prioritize health concerns that adults with OI feel have been inadequately addressed in health care and research, investigators held discussions with leaders from the global adult OI community at a conference on OI in Oslo, Norway as part of the preconference seminar "Patient Participation in OI Research." Investigators were part of the BBDC.



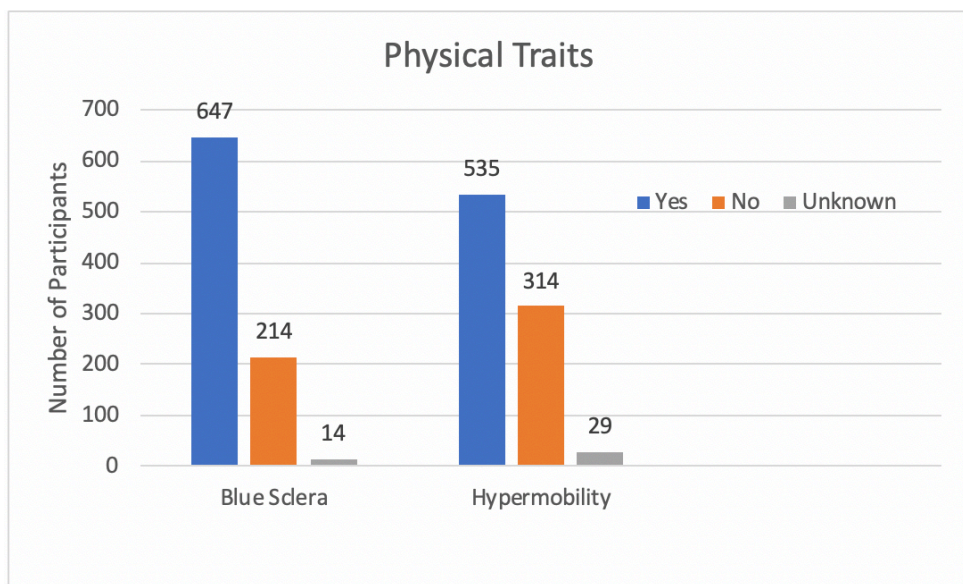
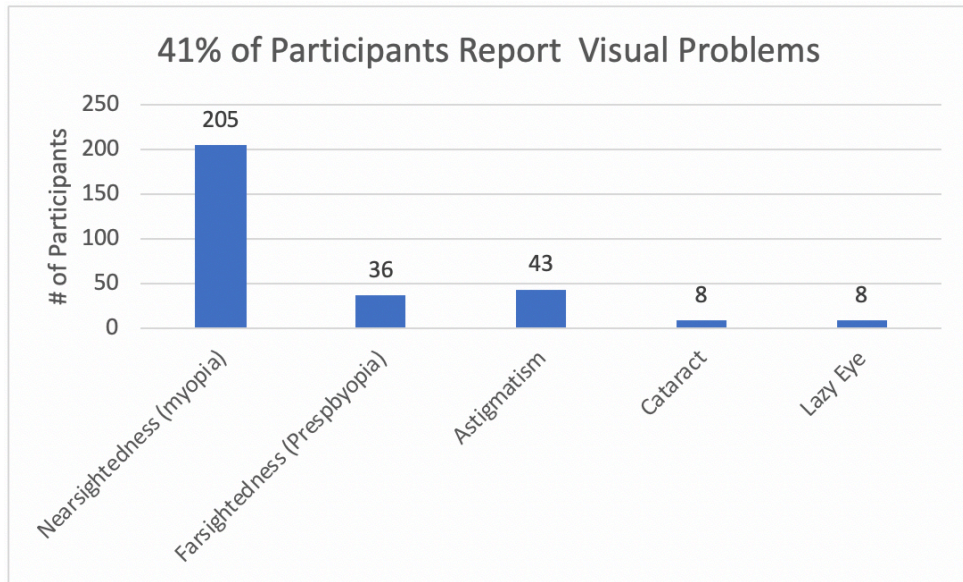
Participants noted that while fractures and brittle bones are the most common feature of OI, a number of body systems are under-studied in this disorder. They particularly emphasized breathing, hearing, and the effects of aging as primary concerns that researchers and physicians may not fully understand or address. Other areas included pain, gastrointestinal problems, mental health, nutrition, menopause/pregnancy, and basilar invagination. Participants also emphasized that they must be informed of study results. They underscored that outcome measures incorporated into future drug trials must look beyond fractures and consider the whole patient.

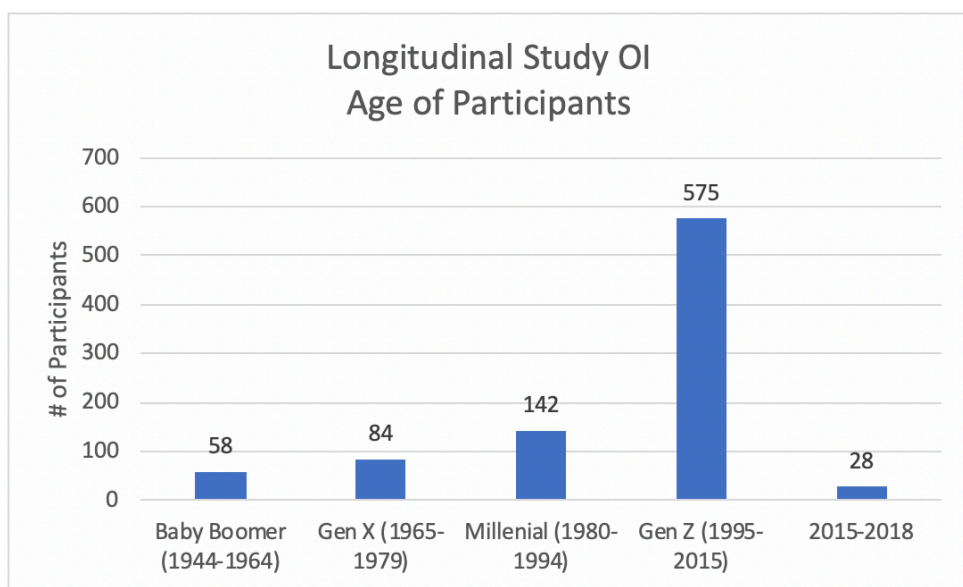
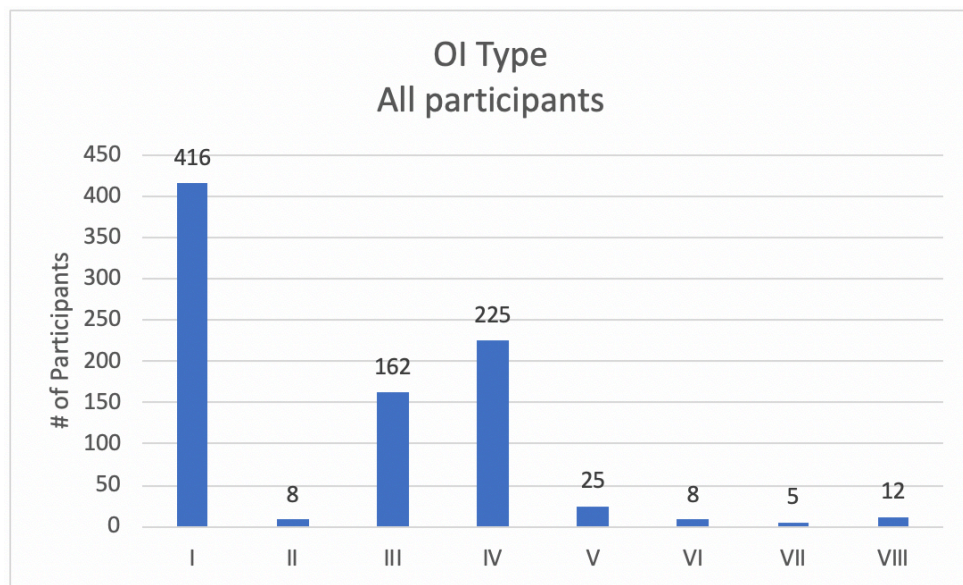
Click on the following links to read our additional published papers:

- [A cross-sectional multicenter study of OI in North America – results from the linked clinical research centers](#)
- [A multicenter observational cohort study to evaluate the effects of bisphosphonate exposure on bone mineral density and other health outcomes in OI](#)
- [A multicenter study to evaluate pulmonary function in OI](#)
- [Assessing disease experience across the life span for individuals with OI: challenges and opportunities for patient-reported outcomes \(PROs\) measurement: a pilot study](#)
- [Caries prevalence and experience in individuals with OI](#)
- [Cesarean delivery is not associated with decreased at-birth fracture rates in OI](#)
- [Cone-beam computed tomography of OI types III and IV: three-dimensional evaluation of craniofacial features and upper airways](#)
- [Dental and craniofacial characteristics caused by the p.Ser40Leu mutation in IFITM5](#)
- [Dental and facial characteristics of OI type V](#)

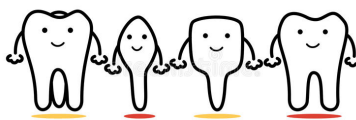
- [Growth characteristics in individuals with OI in North America](#)
- [Mobility in OI: a multicenter North America study](#)
- [Oral health-related quality of life in children and adolescents with OI: cross-sectional study](#)
- [Osteogenesis imperfecta: potential therapeutic approaches](#)

FACTS





OI DENTAL APPROACHES



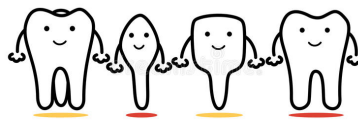
The main dental manifestation of OI is dentinogenesis imperfecta (DI), but it is not visibly present in every patient affected with OI. DI is present in 25% of the OI type I population, 60% of OI type IV, and up to 80% of OI type III. OI types V and VI do not seem to be affected by DI. DI is characterized by yellow to bluish-brown discoloration of teeth and enamel that is prone to fracture. Teeth affected by DI are not at greater risk of developing cavities.

Primary teeth are more vulnerable to breakdown by DI than permanent teeth. Treatment should

be initiated at an early stage. All OI patients should take precautions when it comes to dental work. The treatment plan for individuals with OI should depend on comprehensive examination by the dentist and should be correlated to the severity of the OI type.



Recommended treatments for damaged/decayed primary teeth are full-coverage restorations, including stainless steel crowns or zirconia crowns. Full-coverage restorations are also recommended for permanent teeth. Intracoronar restorations should be avoided in more severe cases as they promote structural tooth loss. Simple extractions can also be performed but not immediately before or after intravenous bisphosphonate infusions. Dental implants and orthodontic treatments can be performed in OI type I but should be carefully approached in more severe types. Clear aligners are a promising option for orthodontic treatment but are still untested. Their efficacy will be tested in our upcoming **Invisalign trial**. In severe OI types, orthognathic surgery, also known as corrective jaw surgery, is discouraged. Given the great variations in the severity of OI and the limited quantity of information available, the best treatment option relies heavily on the practitioner's preliminary examination, judgment, and experience treating these conditions. A multidisciplinary team approach offered by dedicated centers is encouraged and favored in more severe cases in order to optimize diagnosis and treatment.



PHYSICIAN SPOTLIGHT

Jean-Marc Retrouvey, D.M.D., M.Sc. FRCD (C), is the Leo Rogers Endowed Chair of the Orthodontic Department at the University of Missouri Kansas City.

He is a RCDC (Royal College of Dentists of Canada) examiner, an NDEB advisor and member of the AAO, the American College of Dentists, The Angle East Society of Orthodontists, a Fellow in the Académie Dentaire du Quebec, and the past president of the Canadian Association of Orthodontists.

As a teacher, he has received the McGill Dental Society, the Wood, Katz, and Silverstone awards for excellence in teaching. Dr. Retrouvey also received the Bravo award for his implication at McGill in teaching and research at McGill University. Dr.



Retrouvey is also involved with HVO (Health Volunteer Overseas) in the development of a blended teaching program for emerging countries and is president of the International Foundation for Dental Education, a nonprofit organization offering orthodontic courses in Vietnam.

Between 2008 and 2014, Dr. Retrouvey was involved with the craniofacial research center at the Montreal Children's Hospital whose goal was to study the craniofacial characteristics of several syndromes. He is the principal collaborator for the dental aspect of the Longitudinal Study of Osteogenesis Imperfecta and is the Principal Investigator for the "Dental Malocclusion and Craniofacial Development in OI". These research projects are conducted by the Brittle Bone Disorders Consortium (BBDC) from the RDCRN network of the NIH.

Since joining UMKC, Dr. Retrouvey has been assisting Dr. Rush in his quest to become a BBDC center and has initiated a new NIH-supported clinical research program dedicated to the orthodontic treatment of OI subjects using the Invisalign appliance. He is also very involved with the craniofacial center at the Kansas City Children's Mercy Hospital for the development of digital technologies.

Dr. Retrouvey has collaborated to a chapter on the dental and craniofacial manifestations of OI in "*Osteogenesis Imperfecta: A Translational Approach to Brittle Bone Disease*." He has also published several articles on OI in collaboration with the Montreal Shriners staff.

MEDICS ON THE MARCH



The Brittle Bone Disorders Consortium (BBDC) works closely with the Osteogenesis Imperfecta Foundation (OIF). Last spring, several of our BBDC site investigators (listed below) joined a group of doctors to walk 50 miles in support of the OIF and OI community. The participants walked and camped along the C&O Canal Trail from Harpers Ferry, West Virginia to Bethesda, Maryland.

V. Reid Sutton, M.D. - Baylor College of Medicine

Frank Rauch, M.D. - Shriners Hospital for Children, Montreal

Eric Orwoll, M.D. - Oregon Health and Science University

Peter Smith, M.D. - Shriners Hospital for Children, Chicago / Marquette University

Richard Kruse, D.O. - Alfred I. duPont Hospital for Children

Jean-Marc Retrouvey D.M.D. - Shriners Hospital for Children - Canada

Updates from the OI Foundation



Click [HERE](#) to view upcoming events hosted by the OI Foundation.

Join the OI Registry

Supporting OI research is an important part of the OI Foundation's mission. Often, the success of clinical studies of a rare disorder like OI depends on getting enough people to participate in the study so the results are meaningful. Individuals with OI (18 and older) and parents of children with OI are encouraged to join the OI Registry. The OI Registry is a database of individuals with OI who are interested in participating in OI research. Once you are enrolled, you will begin to receive information on upcoming studies and online surveys about OI. Your participation in these studies helps move OI research forward.

[Click here to join the OI Registry.](#)

If you have any questions, please contact the OI Foundation at bonelink@oif.org or (844) 889-7579.

If you have any comments or questions, please reach out to the study team.

Contact Us



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