

EXPLORE what the 2018 OIF National Conference has in store for you!



The OI Foundation has started gearing up for the next **OIF National Conference**, which will be held at the **Renaissance Baltimore Harborplace Hotel in Baltimore, MD, on July 13-15, 2018!** The OIF National Conference is the premier educational and social experience for families and individuals living with osteogenesis imperfecta. The three-day program boasts a schedule full of information sessions on medical and practical living topics, opportunities for one-on-one medical consultations with leading experts in OI research, and an abundance of additional activities designed to address important issues for members of the osteogenesis imperfecta community.

Schedule Overview

National Unbreakable Spirit® Walk-n-Wheel

The *National Unbreakable Spirit® Walk-n-Wheel* will kick-off the 2018 OIF National Conference on Thursday, July 12th! Beginning at the conference hotel, participants will walk-n-wheel a short route through Baltimore's scenic Inner Harbor. We invite all walk-n-wheel participants to celebrate their fundraising efforts at the *Finish Line Party* at Baltimore's famed National Aquarium. We will have the opportunity to explore four levels of exhibits, including the Black Top Reef, in a private after-hours tour exclusive to walk-n-wheel participants!

In 2016, more than 250 members of the OI Community came together for the National Unbreakable Spirit® Walk-n-Wheel in Orlando, FL, and raised nearly \$100,000 for the OI Foundation! Plan on joining your fellow OI friends and family for this fun way to spread awareness and raise money for the OI Foundation. Each individual who raises \$25 or more will receive an official National Unbreakable Spirit® Walk-n-Wheel T-shirt and for each \$1,000 raised, you will receive a complimentary registration to the OIF National Conference!

Sign up for the 2018 National Unbreakable Spirit® Walk-n-Wheel by visiting www.oif.org/WalkAndWheelBaltimore.

Register as an individual, form a new team or join an existing team. Each team member gets their own fundraising page—personalize yours with a fundraising goal, photos, and a greeting that explains how osteogenesis imperfecta

has affected you. Be sure to invite your friends and family to support you by joining your team or making a donation towards your goal.

For more information about the walk-and-wheel or assistance with registering or setting up your fundraising page, please contact Melissa Bonardi at mbonardi@oif.org or 301-947-0083.

(continued on page 2)



OI community members at OIF National Conference 2016

Conference Program

The OIF National Conference will officially begin on Friday, July 13th with medical consultations (by appointment only) throughout the morning and early afternoon. Conference participants who have a new diagnosis or need an OI refresher session are welcome to attend the hour-long introductory lecture on the *Basics of OI*. The first day of OIF National Conference also features the much-anticipated opening session, the Networking Career Fair, and the renowned *OIF Talent Show* and *Talent Show After-Party*.

Saturday, July 14th and Sunday, July 15th will begin with a general plenary session for all attendees. Participants will spend the rest of the morning in one of two large group sessions, learning about either *Issues in Managing OI Pediatric Care* or *Issues in Managing Adult OI Care*. Each conference day consists of several breakout sessions in the afternoon. Sessions cover topics such as *Aging Well with OI*, *Treatments for Hearing Loss*, *Rodding Surgeries*, *Nutrition for Bone Health*, *Raising a Resilient Family*, *Understanding OI Types*, *Respiratory Issues in OI*, *Type I: Coping with an Invisible Disorder*, and more!

At every National Conference, the OIF offers extra presentations and interactive spaces for specialized groups in the community such as youth and young adults with OI, women with OI, and parents of children with OI.

Closing Dinner & Dance

After the information sessions end on Sunday, July 15th, the 2018 OIF National Conference will conclude with the *Closing Dinner & Dance*—a chance to say goodbye to new and old friends.

Programs for Children and Youth

Camp OI Childcare will be available for children ages 12 months to 12 years old who are fully registered for conference and have preregistered for childcare. The OIF Teen Center will be available for children ages 13-18 years old to gather, make friends, and participate in a variety of informative discussions specifically designed for their age group.

Stay tuned to the OI Foundation's website as we announce further detailed information about the OIF National Conference program. A listing of sessions will be posted on the National Conference website (www.oif.org/conference) by January 1, 2018.

Hotel Reservations

Conference participants must complete their OIF National Conference registration before receiving the OIF's group discounted rate of \$159 per night for one sleeping room at the Renaissance Baltimore Harborplace Hotel. **ADA rooms are available on a first come, first served basis, and will sell out early! If you need to book an accessible (ADA) room, you will need to complete your conference**

registration and then contact the OI Foundation. Please remember that with every hotel, there are a limited number of ADA rooms available. Please be considerate to fellow attendees and only book an ADA room if a standard room cannot accommodate your needs. The hotel can provide you with certain items like hand-held shower heads and shower stools free of charge (based on availability) to help make a standard room more accessible. *To book an accessible (ADA) room, contact the OI Foundation at conference@oif.org or call the OIF at (844) 889-7579.*

OIF Conference Financial Assistance

There are two sources of funding available to OI community members interested in attending the OIF National Conference:

1. **Jeanie Coleman Impact Grant Program:** covers conference registration, hotel and travel. Applications will be available on www.oif.org on January 2, 2018. For more information, contact impactgrants@oif.org.
2. **Kasper/Kendall Conference Scholarship:** covers conference registration and three nights of hotel. Applications will be available on www.oif.org/conference or by calling the OIF office in February 2018.

Register Today and STAY TUNED for more details!

OIF National Conference 2018 registration is now open! Register at www.oif.org/Conference and start making your travel plans today. If you have any questions before the next set of conference details are announced, please contact the OIF at conference@oif.org or (844) 889-7579.

Thank you to Our Sponsors!

Nemours. Alfred I. duPont
Hospital for Children



If you are interested in supporting or locating sponsorships for the 2018 OIF National Conference or the National Unbreakable Spirit® Walk-N-Wheel, please contact Melissa Bonardi at mbonardi@oif.org.



Enter the OI Foundation's *Good Stuff Sweepstakes* Today!

Win one of three amazing prizes:



Amazon Echo and TP-Link Smart Home Starter Kit

Amazon Echo is a hands-free speaker you can control with your voice. Make your home a *smart home* by adding “works with Amazon Alexa” products around the house. Start with this TP-link Starter Kit.



\$500 Visa Gift Card

Visa is the #1 selling gift card in the United States. The Visa Gift Card can be used wherever Visa debit and credit cards are accepted.



Trip for Four to OIF's National Conference 2018

Includes four (4) full registrations to the OI Foundation's National Conference in Baltimore, MD on July 13-15, 2018 as well as one hotel room for two (2) nights at the Renaissance Baltimore Harborplace Hotel. Valued at over \$1,400.



Early Bird Prize:

\$200 American Express Gift Card

The American Express Gift Card can be used wherever American Express debit and credit cards are accepted.

To Enter: Visit www.oif.org/Sweepstakes

Suggested donation is \$5 per entry

No donation necessary to enter, donation does not increase chances of winning. See reverse side for complete rules and regulations.

Deadlines:

Early Bird Drawing: Entries must be postmarked no later than **December 1, 2017**

1st, 2nd & 3rd Prize Drawings: Entries must be postmarked no later than **January 12, 2018**



By entering the *Good Stuff Sweepstakes*, you are helping the OI Foundation produce new information resources, fund research, provide answers to more than 7,000 requests for information per year, and facilitate support groups across the country.

Thank you for your support and **GOOD LUCK!**

For more information visit www.oif.org/Sweepstakes or call **844-889-7579**

A message from CEO Tracy Hart...

During the last week of August, I had the great pleasure of attending the **OI International Scientific Meeting** in Oslo, Norway. The four-day meeting brought together experts in the field of OI scientific research and clinical care. The high level program included specialists from many different disciplines including geneticists, internists, endocrinologists, dentists, radiologists, pediatricians, physical therapists, nurses, and others who work with people with OI. Members of the OIF's Medical Advisory Council including Drs. Francis Glorieux, Joan Marini, Richard Kruse, Laura Tosi, Cathy Raggio, Reid Sutton, Hollis Chaney and David Rowe were also in attendance.

The meeting began with two dynamic keynote lectures that explored the relationship between bone and muscle and the challenge of unraveling disease pathways to establish a platform for the future development of therapeutic agents that might be beneficial in OI treatment. The rest of the meeting consisted of expert lectures on genotype-phenotype-diagnosis, collagen mutations and altered modifications, stem cell transplant possibilities for treatment, orthopedic developments, exploring the connective tissue spectrum, the current status in treatment, unmet needs in scientific research, and the relation of rehabilitation and pain to quality of life. The expert lectures concluded with an excellent overview of **What is OI in 2017** delivered by meeting scientific chair and OIF Medical Advisory Council member Dr. Joan Marini of the National Institute of Child Health and Human Development.

The meeting ended with a lively discussion on how to encourage and define collaboration around the world including presentations on the Brittle Bone Disorders Consortium (of which the OIF is a key partner) and the European Reference Network which includes examining and improving the delivery of care for people with OI throughout

Europe. Although the initiatives are different in many ways, one objective is clearly the same: to provide updated educational materials and training opportunities for clinicians.

The next meeting of the international OI scientific community will be held in Sheffield, England in 2020 and will be chaired by Professor Nick Bishop.



OIF CEO Tracy Hart and Osteogenesis Imperfecta Federation Europe (OIFE) President Ingunn Westerheim at the 2017 OI International Scientific Meeting in Oslo, Norway

The OI Foundation is Entering a New Partnership with the Canadian Osteogenesis Imperfecta Society

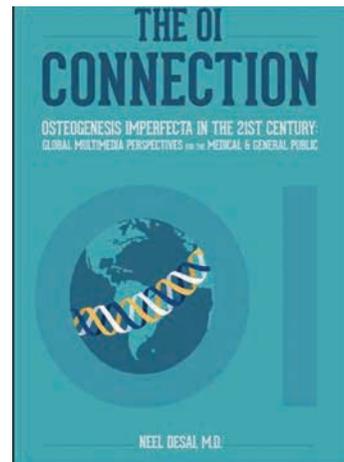
In early 2018, the OI Foundation will launch a new section of www.oif.org dedicated to serve the OI community of Canada. The Canadian Osteogenesis Imperfecta Society (COIS) page will share updated information about research, events, and resources relevant to Canadians affected by osteogenesis imperfecta. All material will be available in English and French. Stay tuned for more information about this exciting partnership!



Unbreakable Spirit® Community Book Club

After the birth of his son, Dr. Neel Desai recognized the tremendous lack of awareness about osteogenesis imperfecta (OI) not only among the general public, but among medical professionals. From learning about OI to finding the right medical team, Dr. Desai and his wife quickly learned that they would be the best advocates for their son.

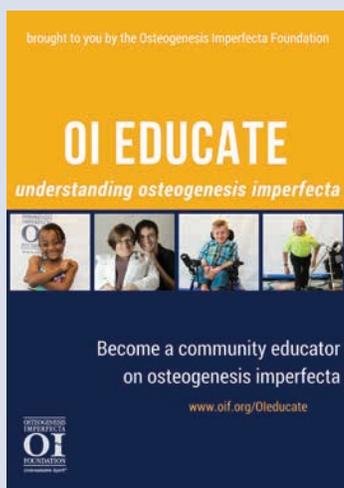
Dr. Desai, a board certified family physician, combined research, knowledge, and experience to create *The OI Connection*. *The OI Connection*, an interactive multimedia book pertinent to the OI community, raises awareness among the general public, medical professionals, parents, and members of the Unbreakable Spirit® community! *The OI Connection* is available for purchase through iTunes.



Jeanie Coleman Impact Grant Program – Applications Available January 2, 2018

Impact Grants help individuals living with OI fund projects, receive services, or purchase equipment that might not be covered by savings, other programs or insurance. Applications will be available on January 2, 2018 at www.oif.org/ImpactGrant until February 12, 2018. Please contact Impactgrants@oif.org if you have any questions.

OI Educate! Certificate Training Program



A new program supporting the OI Foundation's mission to improve the lives of those affected by OI through education, awareness, and mutual support is coming next year! As the OI community continues to grow and become more connected, the OI Foundation depends more and more on volunteers across the country to help field general questions about osteogenesis imperfecta and the OIF. The *OI Educate!*

Certificate Training Program is focused on providing medically-verified information and resources to those who request it. *OI Educators* can help spread awareness and answer common inquiries through social media, phone calls, emails, support group meetings, health fairs, medical school lectures, and other activities. This program is intended to offer OI community members the opportunity to support and provide information to others affected by OI, and not meant to provide medical advice.

The *OI Educate!* Training Program will take approximately 5 hours to complete, including the pre- and post-knowledge quiz. The first two hours of training focuses on OI-related medical information and OIF resources via webinar/conference call. The final hours of *OI Educate!* training will be offered in-person or via Skype at the 2018 OIF National Conference in Baltimore, MD.

Who is the *OI Educate!* Certificate Training Program for?

- Anyone over the age of 18
- OI Support Group Leaders and Resource Contacts
- Adults living with OI
- Parents of children living with OI
- Family members
- Friends
- Caregivers

The first cohort will be a small pilot group. The second cohort will be open to a larger number of participants. If you are interested in learning more or registering for the 2018 cohort of the ***OI Educate!* Certificate Training Program**, please visit www.oif.org/OIEducate.

The OI Foundation counts on your support to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. The following is a letter from OIF CEO, Tracy Hart, about the exciting new research and upcoming programs at the OI Foundation. Please consider helping us move forward with these valuable projects by making a gift today online at www.oif.org or by using the enclosed envelope.



804 West Diamond Avenue
Suite 210
Gaithersburg, MD 20878
(844) 889-7579 toll-free
www.oif.org

Unbreakable Spirit®

Dear Friend:

It is a very exciting time in the field of osteogenesis imperfecta research and treatment and we wanted to take a few minutes to thank you for helping make this happen! Because of your generous support, the OIF continues to be a valuable partner in the Brittle Bone Disorders Consortium (BBDC) – a network of OI clinics and professionals around the country and Canada collaborating on exciting research. All studies are focused on improving treatments for people living with OI. To date the BBDC is involved with seven studies including a pregnancy study, an early stage drug therapy study, a scoliosis study, a biomarkers study, a quality of life study, a dental study and a craniofacial study. All research is being conducted because of the outstanding support of the OI community and your willingness to be involved in ground breaking research. Thank you!

As you know, research is just one of the priorities in the OIF's mission. Our mission also includes improving the lives of people living with OI through education, advocacy and mutual support. **We hope you will consider making a gift today to help us continue this important work!**

Looking forward to July 2018, we will be gathering in Baltimore, MD, for the OIF's Biennial National Conference! The OIF's National Conference is the largest informational and social event for families and individuals living with osteogenesis imperfecta. Attendees include adults, children, and teenagers with OI; health care providers; and spouses, relatives, and friends of those who have OI. Whether an attendee is coping with a new diagnosis or just looking to expand their knowledge on OI, the National Conference has something for everyone.



Dr. Jeanne Franzone of Nemours A.I. duPont Hospital for Children in Delaware consults on x-rays for a National Conference attendee in Orlando, FL

One of the most remarkable parts of the OIF National Conference is Medical Consultation Day. We are so privileged to have members of the OI Foundation's Medical Advisory Council and OI specialists in the fields of genetics, orthopedics, pediatrics, hearing, dental, physical therapy, and more travel across the country to take part in complimentary one-on-one consultations with OI patients. These sessions are the perfect opportunity to get a second opinion on a diagnosis, ask

about new treatment options, or simply find out where to begin. On one occasion, one of the participating physicians even called doctors from the conference to advise them on what medications a new OI baby should be receiving in the NICU. His mother credits this experience as the reason her son was able to go home a mere two months later.

With your support we can continue hosting important programs like the OIF National Conference and complimentary Medical Consultations. These programs are life-changing and often have an immediate impact on members of the Unbreakable Spirit® community.

Even with all of the exciting research studies and conferences, the OI Foundation must still continue to meet the ongoing needs of the OI community for up-to-the-minute information and support. The OI Foundation answers over 7,000 inquiries annually from families, adults living with OI, students, educators, healthcare providers, employers, lawyers, and social workers seeking information and resources about living with OI. The OI Foundation's National OI Information Center is the only program in the United States dedicated to helping people understand and cope with this rare condition. Information provided by this program helps people understand the medical and genetic facts about OI, diagnosis and testing, clinical research updates, treatment options, and more. Support provided by the center is reliable, medically verified, and provided to inquirers in a timely manner.

Please consider making a gift of \$50, \$100, \$500 or more to the 50,000 Lives, One Unbreakable Spirit® campaign using the enclosed envelope or online at www.oif.org.

The OI Foundation has accomplished so much over the years. With your ongoing support, the OIF will continue our work to improve the quality of life for all people affected by OI.

Thank you, as always, for your generous support and have a wonderful holiday season!

All my best,



Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation



Attendees joined by Dr. Francis Glorieux of Shriners Hospital for Children - Canada at the 2016 OIF National Conference in Orlando, FL



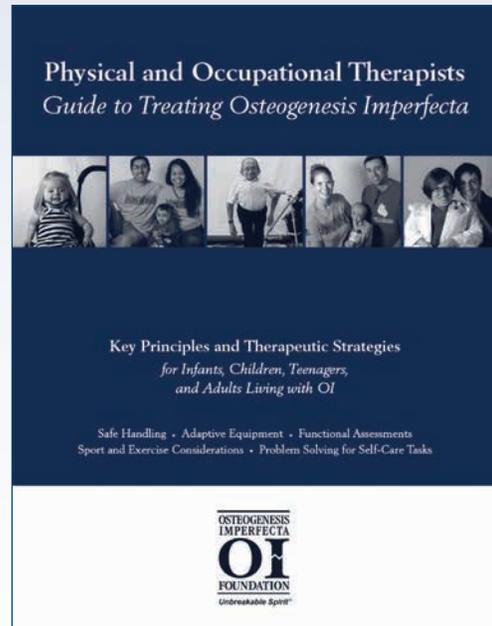
From the Information Center

Announcing a Newly Revised OIF Publication for Physical and Occupational Therapists, and More!

With constantly evolving research and strategies in OI, the OI Foundation works hard to meet the high demand for information for patients, families and medical professionals. The OI Foundation is thrilled to present the recently revised publication: **Physical and Occupational Therapists – Guide to Treating Osteogenesis Imperfecta.**

This guide, intended to serve as a tool for therapists of any level of expertise, parents, adults, educators, and more, shares strategies with a focus on safe handling, adaptive equipment, functional assessments and self-care tasks. The PDF of this document can be found in the OIF online Information Center (www.oif.org/InformationCenter) under “Books, Brochures, and Factsheets.”

If you have any questions or would like a hard copy of the guide, please contact the OI Foundation at (301) 947-0083 or bonelink@oif.org.



The OI Foundation is grateful to the physical and occupational therapists who contributed their ideas, expertise and support to this publication:

Frances Baratta-Ziska, PT, DPT, MS, PCS – *Hospital for Special Surgery, New York, NY*

Timothy Caruso, PT, MBA, MS, Cert. MDT – *Invacare Corporation, Elyria, Ohio; Community Physical Therapy, Addison, IL; the Kids Equipment Network, NFP, Itasca, IL*

Lisa Drefus, PT, DPT – *Hospital for Special Surgery, New York, NY*

Maureen Donohoe PT, DPT, PCS – *Nemours, A.I. DuPont Hospital for Children, Wilmington, DE*

Christopher Joseph, DPT – *Kennedy Krieger Institute, Baltimore, MD*

Kathleen Montpetit, OT, MSc – *Shriners Hospital for Children - Canada, Montreal, QC*

Thank You

to all the attendees of the
2017 Fine Wines Strong Bones Galas!



**We are looking forward to seeing you at a
Fine Wines Strong Bones Event in 2018!**

*Fine Wines Naples, FL
January 25, 2018*

*Fine Wines Strong Bones Washington, DC
February 24, 2018*

*Strong Bones Tampa, FL
April 7, 2018*

*Fine Wines New York City
April 26, 2018*

*Strong Bones Boston, MA
May 12, 2018*



OI Clinic Spotlights

The OI Foundation works closely with nearly 60 multidisciplinary OI Clinics across the continent to provide timely and accurate information about the range of available services. The 2017 OI Clinic Directory can be found under the "Information Center" tab on the OIF website. To give a broader overview of the background, mission, and services of these centers, the OIF spotlights new and existing OI clinics serving pediatric and adult patients. In this issue, we feature the Phoenix Children's Hospital's Skeletal Dysplasia Clinic, the National Institutes of Health Osteogenesis Imperfecta Translational Research Program, and the Osteogenesis Imperfecta Clinic at the Hospital of the University of Pennsylvania.

Phoenix Children's Hospital's Skeletal Dysplasia Clinic

The Herbert J. Louis Center for Pediatric Orthopedics at Phoenix Children's Hospital launched its Skeletal Dysplasia and Bone Health Clinic earlier this year. As the only pediatric program of its kind in Arizona, the clinic treats children with all kinds of skeletal dysplasias and provides direct access to the full range of pediatric specialists required to address each child's unique needs. Patients of the clinic meet with a pediatric orthopedist and a medical geneticist. Each comprehensive visit takes about two hours and includes a complete medical history, review of any radiological imaging, and a physical examination. An endocrinologist and neurosurgeon are also available to meet with patients and families in need of their respective care. If patients have complex medical and surgical needs, the clinic has a team of pediatric physicians and care providers who are specifically qualified to treat patients with skeletal dysplasia, including: orthopedics, endocrinology, genetics, anesthesia, pulmonary, ears, nose and throat, neurosurgery and radiology.

The Clinic is co-led by Mohan Belthur, MD, and Kristin Lindstrom, MD. Dr. Belthur works as a full-time pediatric orthopedic surgeon in the Herbert J. Louis Center for Pediatric Orthopedics at Phoenix Children's. He completed his medical degree in India at Bangalore Medical College, Bangalore University. Dr. Belthur completed several Fellowships in Orthopedics and also in Limb Reconstruction at Sheffield, England; Wilmington, DE; Baltimore, MD; and Houston, TX. Dr. Belthur has spent years taking care of pediatric orthopedic patients all around the world. He is also the co-director of the neuro-orthopedic program and is Ponseti trained in treating clubfoot children. Dr. Kristin Lindstrom works as a full-time pediatric physician in the Division of Genetics and Metabolism at Phoenix Children's. Dr. Lindstrom is a clinical geneticist who has an interest in skeletal dysplasias. She trained at the Children's Hospital of Philadelphia, where she had exposure to a wide variety of different skeletal bone conditions, and continued to see patients with genetic bone disease at the University of Rochester in NY, and now at Phoenix Children's Hospital, where she's worked since December of 2014. She will be able to provide diagnostic services, as well as oversee management of the overall condition, to make sure your child is getting age-appropriate, comprehensive care.



Mohan Belthur, MD



Kristin Lindstrom, MD

Dr. Belthur and Dr. Lindstrom often work with Dr. Madia Shahid, full-time pediatric physician in the Division of Endocrinology at Phoenix Children's Hospital, and Dr. Jamal McClendon, full-time pediatric neurosurgeon at Barrow Neurological Institute at Phoenix Children's Hospital. Appointments are available on the fourth Wednesday of every month at Phoenix Children's Main Campus, 1919 E. Thomas Rd., Phoenix, AZ 85016.

Families can schedule an appointment by calling the Herbert J. Louis Center for Pediatric Orthopedics at Phoenix Children's, (602) 933-3033.

The National Institutes of Health Osteogenesis Imperfecta Translational Research Program

The Osteogenesis Imperfecta Translational Research Program is a center of excellence located at the world-renowned National Institutes of Health (NIH) in Bethesda, Maryland. This Center has been providing comprehensive care for children with OI for more than 30 years, while conducting clinical and laboratory research. Now, the program is also able to provide patients an opportunity to be seen into adulthood by some of the best clinical research professionals in the world. Since the NIH is a federal research facility, there is no cost to the patient for participation and evaluation.

Dr. Joan Marini, who has more than 30 years of experience caring for OI patients, leads the team. She has developed a unique program in which clinical and laboratory research are fully integrated. Her lab has generated mouse models for OI and organized the Consortium for OI Mutations. In the last decade, her group has been a leader in the exciting new developments about recessive OI, which have revealed new genes whose importance to normal bone formation was not previously appreciated. Her clinical research focuses on secondary symptoms (hearing loss, neurologic, heart, and dental complications) of osteogenesis imperfecta, variations in clinical severity among patients with the same mutation, and treatment with bisphosphonates and growth hormone.



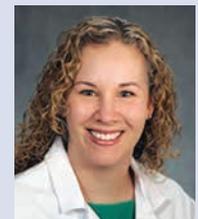
Joan Marini, MD, PhD

Patients are seen either every 4-6 months or annually, depending on their age. Visits may be 2-5 days duration based on the appointments that are needed. Patients can expect to have appointments with: audiology, dental, rehabilitation medicine, physical therapy, an orthotist; and any other specialists as needed. Testing provided to patients includes but is not limited to: genetic testing, DEXA scans, x-ray images, CAT scan for BI, and echocardiograms. Funds are available to cover travel within the United States and lodging at or near the NIH. Neither the patient nor insurance are billed for their medical evaluations.

Patients or providers interested in the OI Research Program at NIH can email: oidoc@helix.nih.gov.

The Osteogenesis Imperfecta Clinic at the Hospital of the University of Pennsylvania

The Osteogenesis Imperfecta Clinic at the Hospital of the University of Pennsylvania began in 2013 when Dr. Staci Kallish joined the Division of Translational Genetics and Medical Genetics. Dr. Kallish completed her Genetics residency at The Children's Hospital of Philadelphia and worked as a medical geneticist at Tufts Medical Center, Floating Hospital for Children prior to coming to the University of Pennsylvania. In addition to



Staci Kallish, DO

Dr. Kallish, the team includes a clinic coordinator, nurse practitioner and two genetic counselors, as well as multiple other doctors and therapists from other specialties.

The clinic at the University of Pennsylvania specializes in caring for adults with osteogenesis imperfecta, although they also work closely with the Connective Tissue Clinic at the Children's Hospital of Philadelphia to provide care across the lifetime. Their goal is to provide comprehensive

care for patients. Bisphosphonate infusions are coordinated through the University of Pennsylvania infusion center, and imaging can often be performed on the same day as clinic appointments. Dr. Kallish has also educated physical therapists to provide specialized care for patients with all types of connective tissue disorders.

For more information or to schedule an appointment, please contact Kara Welsh, clinic coordinator, at 215-662-4740.



Research Corner

Opportunities to Participate in OI Research—Sign Up for the BBDC Contact Registry

This past summer, the Brittle Bone Disorders Consortium (BBDC) launched two new studies; *Pregnancy in OI* researching maternal and fetal pregnancy outcomes in women with OI, and a *multicenter study* to evaluate safety of fresolimumab treatment in adults with moderate-to-severe osteogenesis imperfecta.

Scientists and researchers rely on the OI community to support the Brittle Bone Disorders Consortium (BBDC) by **joining the contact registry** and participating in upcoming studies, online surveys, and other research activities that will help accelerate OI clinical research. The BBDC's *longitudinal study* is also recruiting new participants to investigate how different types of OI change as individuals age. For more information on the BBDC longitudinal study or to join the contact registry, visit www.rarediseasesnetwork.org/cms/BBDC. We greatly appreciate your attention and interest in advancing the treatment of osteogenesis imperfecta.

Expanding Rare Bone Disease Collaboration to Advance Research

The Rare Bone Disease Alliance (RBDA) is a network of patient advocacy organizations founded in 2006 that works to educate physicians and accelerate research on the following rare bone disorders:

- Fibrous dysplasia
- Fibrodysplasia ossificans progressiva (FOP)
- Lymphangiomatosis
- Gorham's Disease
- Lymphatic malformation
- Melorheostosis
- Multiple hereditary exostoses (MHE)
- Osteogenesis imperfecta (OI)
- Osteopetrosis
- Hypophosphatasia (HPP)
- X-linked hypophosphatemia (XLH)

Next September, the RBDA and affiliated patient advocacy groups will host a scientific meeting as a preliminary activity of the American Society for Bone and Mineral Research (ASBMR) Annual Meeting. Co-chaired by Dr. Brendan Lee of Baylor College of Medicine and Dr. Maurizio Pacifici of the Children's Hospital of Philadelphia, the RBDA Scientific Meeting will foster scientific collaboration that the OIF is hopeful will translate into new paths of research and improved care for all individuals affected by rare bone disorders. More details about this meeting will be shared in the "Update for Medical Professionals" E-newsletter. To subscribe to this e-newsletter, visit www.oif.org/meded and click on "Sign Up."

2018 OIF Scientific Meeting—Outcome Measures and Endpoints in Osteogenesis Imperfecta

The OIF is pleased to announce that the *18th Annual OIF Scientific Meeting* scheduled for April 18-20 in Chicago will be co-chaired by Dr. Matthew Warman and Dr. Christina Jacobsen of Boston Children's Hospital. For eighteen years, the OIF Medical Advisory Council, OI Clinic Directors, and other scientific and medical consultants have used the OIF Scientific Meeting as an opportunity to discuss the present state and future directions of OI research, as well as train the next generation of researchers and clinicians.



Matthew Warman, MD



Christina Jacobsen, MD, PhD



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Gaithersburg, MD 20878

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2018

Baltimore, MD

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