

National OI Awareness Week 2017: Awareness Makes a Difference!

Each year during National Osteogenesis Imperfecta Awareness Week, the OI Foundation, OI community members and supporters come together to raise OI awareness across the nation. National OI Awareness Week is scheduled around Wishbone Day (May 6th), the international awareness day for osteogenesis imperfecta. We celebrate Wishbone Day by wearing yellow, the symbolic Wishbone Day color, and make an effort to bring attention to osteogenesis imperfecta among our friends, families and communities. Take a look at the photos of OI community members coming together to raise OI awareness on Wishbone Day 2017!

To prepare for OI Awareness Week, OI community members submitted requests to their state government to proclaim May 6-13, 2017 as National OI Awareness Week. We are so thankful for the OI community members who requested proclamations and the officials of the *17 states, 2 cities, 2 counties and 1 town* that recognized May 6-13, 2017 as National OI Awareness Week! To view all of the National OI Awareness Week proclamations, visit www.oif.org/AwarenessWeekProclamations.

(continued on page 2)



OI community members celebrating Wishbone Day 2017.

50,000 Laps – One Unbreakable Spirit® – We Blew Our Goal Out of the Water!



Jaden and her teammates swimming laps with Paralympian McKenzie Coan.

The **50,000 Laps – One Unbreakable Spirit®** program returned this year with a splash! During the month of May, OI community members were asked to contribute to our nationwide goal of swimming 50,000 laps (to represent the 50,000 people with OI in the United States) and raise \$150,000.

Thanks to dedicated community members who participated, we surpassed our lap goal of 50,000 laps with a total of 117,108 laps swam in the month of May!

OI community member Jaden, who created the 50,000 Laps, One Unbreakable Spirit® event in 2013 with her first swim which raised more than \$100,000 for OI programs and research, held her swimming event on May 20, 2017 at Asphalt Green in New York City and was joined by a very special guest – four-time Paralympic medalist McKenzie Coan! McKenzie, who was diagnosed with OI shortly after birth, participated in her second Paralympic Games in Rio de Janeiro in 2016. She went on to win four medals – three gold (50, 100 and 400 freestyle events) and one silver (400 free relay) and broke the Paralympic record in the 50 meter freestyle. Together, Jaden, McKenzie and Jaden's teammates swam 3,500 laps during their event and Jaden has raised close to another \$100,000 to support OIF programs and research!

(continued on page 2)



OI community members come together during National OI Awareness Week for the 5th Annual Wishbone Day Picnic in Washington.

Throughout National OI Awareness Week, the OI Foundation encouraged social media followers to like, share, and retweet the OI related social media posts posted by the OIF – **we reached more than 209,000 people!** Thank you so much for liking, sharing, and retweeting!

Raising OI awareness in your community is important year-round! To raise awareness by planning an event or holding a Blue Jeans for Better Bones Day in your office or school, visit www.oif.org/bjbb or contact Samantha at stodorovich@oif.org or 301-947-0083.

50,000 Laps (continued from page 1)

Seth Stubblefield, Clinical Research Coordinator at Children's National Hospital Health System, was an integral part of this year's 50,000 Laps – One Unbreakable Spirit® program. Seth swam at the University of California – Berkeley and was a part of two National Championship winning teams. He is currently on the USA Swimming National Team and was just 0.04 of a second short of going to the Rio Games. Seth and his wife Lauren, who

was also a part of two National Championship winning teams at the University of Georgia, hosted a swim event with the Nation's Capital Aquatic Club (NCAP) on May 7, 2017. NCAP raised \$1,911 and contributed 100,000 laps during their Sunday practices during the month of May! Seth also organized a swimming event with the City of Plano Swimmers (COPS) in Plano, Texas where swimmers contributed 9,000 laps. Throughout the month of May, Seth raised OI awareness by posting on social media, working with NCAP and COPS swimmers and coaches, and even getting some of his swimmer friends, like three-time Olympic gold medalist Ryan Murphy, to post about OI and 50,000 Laps on their personal social media pages!

A big shout-out and thank you to other amazing participants who each raised money and awareness for OI through the 50,000 Laps program—Don Gardner, Jr., Christopher Harkman and Lea-Rachel Kosnik swam a cumulative 1,500 laps and raised more than \$10,000 combined!

If you are interested in participating in the next swim program or are ready to get involved today, please contact Samantha Todorovich at stodorovich@oif.org.



Swimmers from the Nation's Capital Swim Club after contributing 10,000 Laps to 50,000 Laps – One Unbreakable Spirit®



OI Foundation “Uniting Unbreakable Spirits” Regional Conference Program Updates

OI Foundation Holds Successful OIF Regional Conference in Montreal, Quebec, Canada

Nearly 150 community members gathered for the OIF Regional Conference in Montreal on Saturday, June 3, 2017. The one-day meeting, led by OIF Medical Advisory Council Chairman Dr. Francis Glorieux, boasted an excellent slate of speakers including Dr. Reggie Hamdy (Shriners Hospital for Children-Canada Chief of Staff), Dr. Cathleen Raggio (OIF Medical Advisory Council Member), Dr. Laura Tosi (OIF Medical Advisory Council Member), Dr. Francois Fassier, Dr. Jean-Marc Retrouvey, Dr. Argerie Tsimicalis, Jennifer Brown, Khadidja Chougui, Natalie Cinman, Collin Laflamme, Marie-Elaine Lafrance, Corinne Mercier, Kathleen Montpetit, and Susie Wilson. Sessions covered a variety of topics related to understanding and living well with OI for parents and adults.

Both new and familiar faces, traveling from near and far, attended the OIF Regional Conference in Montreal. To accommodate French-speaking attendees, most informational sessions were translated through a professional interpreter using a wireless headset system. Immediately following the meeting was a successful Fine Wines reception, the OIF's signature fundraising event. More information on the reception can be found on page 7.

The OI Foundation would like to thank all of the meeting speakers, volunteers, and attendees for their participation and contribution to the success of this meeting. We owe a very special thank you to Dr. Francis Glorieux and the entire team at the Shriners Hospital for Children - Canada for their hospitality and help with organizing the OI Foundation's first event in Canada!



Attendees at the OIF Regional Conference Montreal

Save the Date for the OIF Regional Conference in Portland, Oregon, on Saturday, November 11, 2017!

The next OIF Regional Conference will be held in Portland, Oregon, on the Oregon Health and Science University (OHSU) campus. The general format of the one-day OIF Regional Conference will be similar to other locations. A complete registration costs \$35 per person and includes access to all sessions and lunch. Children 12 years of age and under are free to attend, but must be registered. The list of speakers, sessions, and the registration website for this regional conference will be available by July 14th at www.oif.org/regionalconference.

RESOURCE REMINDER
New Materials for Adults with OI
and Their Doctors

TAKE CHARGE OF YOUR HEALTH

*A toolkit designed to help adults
partner with their doctors to lead
healthy lives*

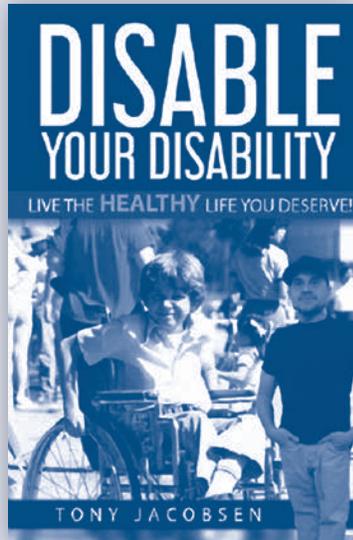
WWW.OIF.ORG/OIF_ADULTS

OSTEOGENESIS IMPERFECTA FOUNDATION

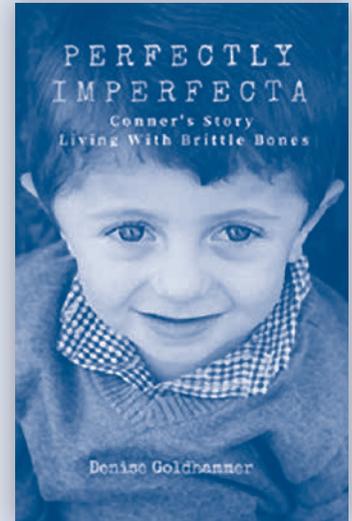
Unbreakable Spirit® Community Book Club

Living with a rare genetic disorder like osteogenesis imperfecta can present moments in life that not many are able to relate to. Often, individuals in the OI community use their talents to express their unique stories through music, painting, photography, books, and more. The OI Foundation is proud to share the hard work of two creative authors who aim to raise awareness about OI. Below are brief summaries of their books, which we hope you enjoy reading as much as we did.

Tony Jacobsen was motivated to write his first book, ***Disable Your Disability***, by his own experience as an adult living with osteogenesis imperfecta (OI). The book is divided into two parts. In the first part, Tony tells his life story and what it meant to grow up with brittle bones and live in fear of getting injured. He describes that his physical disability had always been limiting and an excuse for him to not adopt a healthy and active lifestyle. After facing a health-related and life-threatening event at the age of 42, Tony realized that something had to change. He took action to improve his health through improving his diet and exercising. Tony was able to accomplish things he never imagined he would, and he feels great about it. The second part of the book is self-guidance. In this part, Tony shares his ideas and methods that he used to help him become more physically active and stay motivated. Tony shares his tips and ideas to inspire others to better care for their health. He wants his readers to know that no matter what their physical capacity is, they should always try their best to disable their disability. The book is available on Amazon as well as from Tony's website <http://www.disableyourdisability.com>.



The book ***Perfectly Imperfecta: Conner's Story Living with Brittle Bones*** by **Denise Goldhammer** is an emotional true story of a little boy, Conner, who was born with osteogenesis imperfecta. Anticipating the arrival of a baby with a chronic and complex genetic condition completely changed the Goldhammer family dynamics. Living a classic suburban life with planned weekend activities, vacation, and social lives was long in the past for them. Now, each day brings new and often terrifying moments as Conner experiences bone fractures and other OI health-related complications. Despite many challenges, the Goldhammer family becomes stronger and inseparable as they are learning to live and appreciate their new "normal." This book is intended for anyone who is going through a similar situation. It shows that love and determination can pull you through uncertainty and tough life moments. *Perfectly Imperfecta: Conner's Story Living with Brittle Bones* is available through Amazon and Barnes and Noble. For more information about the author and the book, please visit www.perfectlyimperfecta.com



If you would like your artwork featured in an upcoming edition of *Breakthrough*, please contact Bonelink@oif.org.

Update your Contact Information!

Make sure you receive the OIF monthly E-Newsletters, alerts about events in your area, and updates from the OI Foundation! Give us a call at **(301)947-0083** or email bonelink@oif.org to update your contact information (home address, email, phone number) with the OIF.

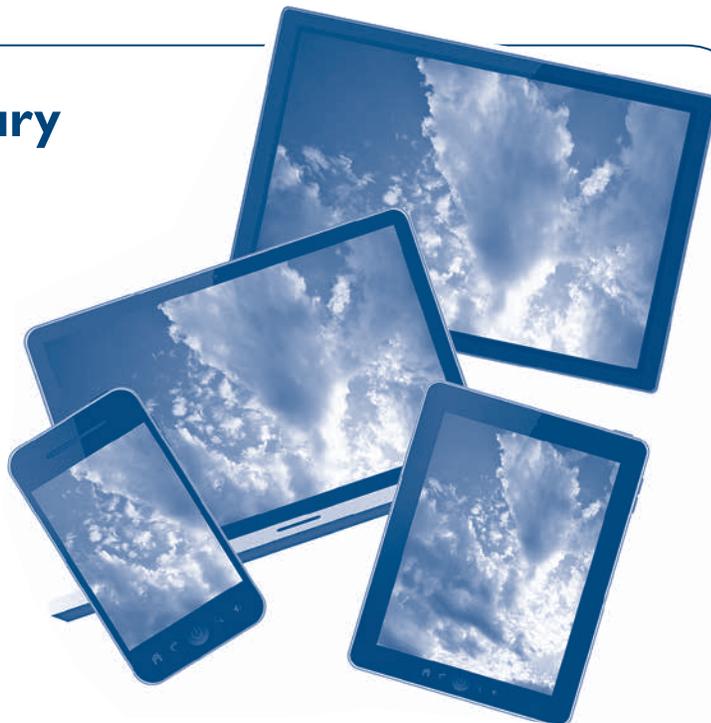
Exploring Twenty-First Century Technology Relevant to the Unbreakable Spirit® Community

How often do you see toddlers at public restaurants occupied with their tablet or cell phone? Although the child may not know how to read quite yet, they most certainly know how to turn on and off their tablet and find their favorite video games. Twenty-first century technology has indeed become a major part of everyone's lives. It may be nearly impossible to imagine life without smartphones to type as you talk, correct your spelling and navigate directions. Advances in technology have also expanded accessibility options. Below are a few examples of electronic applications that were invented to simplify the lives of individuals living with disabilities.

Amplification applications are for people with hearing impairments. Most amplification apps such as *Usound*, *Hear You Now*, and *Louder TV* work by performing a hearing test, then customizing amplification needs, making it possible to hear conversations in noisy environments, or sending increased TV sounds through the phone. *Roger Voice* is another application for people with hearing loss that uses voice recognition technology to transcribe conversations.

Pill reminder applications send smartphone reminders when medications need to be taken or prescriptions need to be refilled. These applications can be handy for people that take multiple medications at different times of the day. The most popular pill reminder apps are *Pill Reminder* and *MedCouch*.

Home automotive applications are innovative ways of controlling your home surroundings through a smartphone or tablet. Applications such as *NEST* allow users to control home temperature even from miles away. With *Easybulb* you can turn



on and off lights in your house. *SmartThings* allows you to lock your door from your phone and set the alarm. Amazon's Echo and Alexa devices can retrieve the news and weather, or play music by voice control.

Accessibility applications are designed for people with impaired physical mobility. These types of applications assist in finding public venues like bars, restaurants, hotels, and parking that are wheelchair-accessible. One of the most popular applications of this kind is called *It's Accessible*. Other applications, such as *Toilet Finder* or *Flush*, share locations of free and handicapped-accessible public toilets. These applications allow its users to rate the facilities.

Do you have a favorite electronic application that you find helpful and would like to share with the OI community? Email Kasia Krolikowska at kkrolikowska@oif.org to have your recommendations included in future newsletters.

Meet the Newest Member of the OIF Board of Directors

The OI Foundation is pleased to announce that **Sharon Mutnick** will be joining the OIF Board of Directors. Sharon is part of a multi-generational OI family (herself, her father and her daughter) and an active member of the OI community. She is currently a Finance Analyst with NCR living in Atlanta, Georgia with her husband and two children. She received her undergraduate degree from Rensselaer Polytechnic Institute with a BS in Management/Finance and double minors in Economics and Information Systems. She also earned a Masters of Business Administration from the Goizueta Business School at Emory University. She has served on the executive boards of several charitable organizations during the past 15 years. Welcome to the OIF Board of Directors, Sharon!



From the Information Center



Check Out the Abilities Expo Near You

The Abilities Expo is a commercial enterprise that hosts informative workshops and exhibit halls for people living with disabilities, their families, caregivers, seniors, and healthcare professionals. The exhibit halls are free to attend and have a wide range of products and services—from personal care items to accessible vehicles, service animals and major home renovations. The Expo travels to eight cities throughout the year- New York, Chicago, Houston, Boston, Los Angeles, Toronto, Washington, DC, and San Mateo. Visit their website (www.abilitiesexpo.com) to see if an Abilities Expo is coming to your area.

Get Involved with the OI Foundation as a Support Group Leader

The OI Foundation helps coordinate in-person support group meetings for the Unbreakable Spirit® community throughout the year. These OI support groups provide the setting and opportunity for people to share experiences and socialize with others who can personally relate to OI stories. Even with the advancements and growing trends of social media and online networking, many people still find it beneficial to meet face-to-face. OI Support Groups include people of all ages and all types of OI, parents, grandparents, spouses, other relatives, and friends. OI Foundation Support Group Leaders host meet-and-greet socials, mixers, day trips, picnics, interactive lectures, Q&A sessions, and other fun, family-friendly activities. This spring, the long-time OI Support Group met in Tampa, FL, and two new OI Support Groups met in the DC metro area and in Atlanta, Georgia. If you feel that you have the skills and time to coordinate a support group and are interested in starting one in your area, please contact Kasia Krolikowska by emailing kkrolikowska@oif.org for more information.



Group photo of attendees at the DC, Maryland, and Virginia OI Support Group Meeting in the OIF office in Gaithersburg, Maryland

Share the OIF Medical Professionals Newsletter

This spring, the OI Foundation distributed a new issue of the OIF Medical Professionals Newsletter for clinicians and researchers who have interest and experience with OI. This newsletter promotes professional meetings, recent publications, funding announcements and other updates of interest to the medical, scientific and research communities. Please visit the OIF Medical Education website at www.oif.org/meded to subscribe and share the latest information with your medical team.

New Podcast Episode!

Dr. Suken Shah joined us on the OIF Podcast series to discuss *Spinal Issues and Basilar Invagination – Whom to Screen, How to Diagnose, and When to Treat*. Dr. Shah is the Division Chief of the Spine and Scoliosis Center at Nemours Alfred I Dupont Hospital in Wilmington, DE. Listen to the OIF Podcast Series at www.oif.org/OIFpodcast.



Dr. Karen Loechner, along with Dr. Jill Flanagan, addressing the audience at the Atlanta OI Support Group Meeting



Members of the Tampa OI Support Group listening to a presentation on self-defense delivered by Michael Johnston, and Debbie and Lauren Brown

Fine Wines Strong Bones Gala – Coming to a City Near You!

Building upon the success of the DC area gala, the OI Foundation has dedicated the past few years to growing the Fine Wines Strong Bones program into a flagship fundraising event held in multiple regions across North America. These events help the OI community share their Unbreakable Spirit® with their friends and families while raising funds to support the OIF. The OI Foundation closed out the 2016/2017 Fine Wines Strong Bones season with two new events and we're already looking forward to what the next year holds.

With a committee of local friends and family, the **Strong Bones Boston Gala** co-chairs, Christine Rossi and Dick Wyman, converted their longtime family walk-n-wheel into a very successful gala held on Saturday, May 20th in Framingham, MA. The Casino Royale themed evening included casino table games, a bag raffle, a performance dedicated to the power of the human spirit by Rob Surette (the fastest painter in the world), a live auction featuring two tickets to see Hamilton on Broadway, dugout seats to the Red Sox vs. Yankees game donated by Construction Management Builders and an opportunity to fund a new cardiac research study. More than 200 attendees helped raise \$90,000 for the OI Foundation!



Members of the Strong Bones Boston Gala Host Committee

The **Fine Wines Reception Montreal** was held immediately following the OIF Regional Conference in Montreal. The event provided OIF Regional Conference attendees a chance to unwind, relax and share their experiences of the day. It was a perfect ending to a day full of education and support at Shriners' Hospital for Children Canada.

As we look ahead to the 2017/2018 Fine Wines Strong Bones season, we are thrilled to see returning events as well as several new ones take shape. As OI Foundation Development Director, Melissa Bonardi explains, "One of my favorite things about the Fine Wines Strong Bones events is the ability to tailor them to each community we visit – whether they are a large-scale gala with more than 200 attendees, an intimate reception with 50 close friends or anything in between."



OIF MAC Chair Dr. Francis Glorieux greeting guests at the Fine Wines Reception Montreal

We hope to see many more of our members, their families and friends as these events continue to expand. Mark your calendars for these upcoming Fine Wines Strong Bones events:

- **3rd Annual Strong Bones Chicago Gala** will be held on September 30, 2017 at the Chicago Cultural Center, across from Millennium Park in downtown Chicago.
- **Beef and Brew for Better Bones** will be held at the end of October in Garfield, New Jersey and will raise money for the Kasper Kendall Conference Scholarship Program.
- **NEW! Strong Bones Houston** will be held in November 2017. With the help of OI community members Cindy Medina and Sarah Dyke, we are looking forward to building upon the excitement following the OI Regional Conference that was held in Houston during November 2016.
- **NEW! Fine Wines Las Vegas** will be hosted by an OIF Board of Directors member, Joe Hall, during a computer industry conference he attends annually at the Treasure Island Hotel.
- **3rd Annual Fine Wines Reception Naples** will be returning in January 2018. OIF Board of Directors President, Ken Gudek, his wife Teresa, former OIF Board Member Jeff Stewart and his wife Andrea will co-host this intimate wine tasting at the Le Parc Condominium in Naples, Florida.
- **18th Annual Fine Wines Strong Bones Gala** will be held at the Gaylord National Resort at Maryland's National Harbor on Saturday, February 24, 2018. We will be bringing back the Great Gatsby theme for this black tie optional event featuring casino games and a live auction that will support the Jamie Kendall Fund for OI Adult Health.
- **NEW! Strong Bones Los Angeles** is one of the newest events in the Fine Wines Strong Bones pipeline. We are looking to schedule the event for March of 2018 and we're very excited to expand to the West Coast.
- **2nd Annual Strong Bones Tampa** will be held on Saturday, April 7, 2018 at Tampa's Firefighters Museum.
- **2nd Annual Fine Wines Reception New York City** will be held in the spring of 2018 at Sotheby's Auction House in New York City.
- **2nd Annual Strong Bones Boston Gala** will be returning in May of 2018 with Christine Rossi and her committee dedicated to expanding the event to continue raising funds to support new research studies to examine how OI affects every part of the body.

Events such as these are integral to the operations of the OI Foundation and the programs and services we are able to offer to the OI community. Thank you to everyone who attended a Fine Wines Strong Bones event and to all our host committees. If you are interested in attending a local event, joining a host committee or suggesting your city for a future Strong Bones Gala or Fine Wines Reception, please contact Melissa Bonardi at mbonardi@oif.org.

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 OI Foundation's new and exciting research. Please consider helping us move forward with OI related research and programs by making a gift today online at www.oif.org or by using the enclosed envelope.



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Unbreakable Spirit®

Dear Friend,

There have been big things happening at the OI Foundation this year...and we're only getting started! The OIF has accelerated the pace of OI research and treatments for OI through new scientific studies, training for medical professionals, and medical resources for adults and families. These new and exciting efforts are only happening because of your support!

Please help us keep the momentum going by making a gift today!

Last year, you helped us secure funding for the first two years of a pulmonary study through the OIF's Jamie Kendall Fund for Adult Health. Respiratory complications are one of the leading causes of death among people with OI and we are determined to find out why. Are pulmonary problems caused by skeletal abnormalities or scoliosis? Is it an issue with the collagen in the lungs? Or is it both? This groundbreaking study – led by OI Foundation Medical Advisory Council Member Dr. Cathleen Raggio of Hospital for Special Surgery in New York – will work to answer our questions and help find a treatment that will hopefully save lives.

One of the goals of good research is to have one study open the door for the next and that is precisely what we are doing. Following the excitement and interest in the new pulmonary study, the OI Foundation is expanding research of pulmonary issues faced by the OI community to determine how the heart and vascular systems are affected by OI. Both research topics will affect the health of adults and children with OI but we need your help to make it happen!

Please help us continue all of this important work by making a gift today using the enclosed envelope or at www.oif.org/donate. Your gift of \$50, \$100, \$500 or more has lasting effects on so many individuals.



Members of the OI Foundation's Florida Support Group (from left to right) Jason Cance, Susan Wilson and Michelle Fynan



Co-Chairs of the OI Foundation's 2017 Scientific Meeting, Dr. Sandesh Nagamani and Dr. Charlotte Phillips

The OIF continues to support the research of young investigators – this investment over the years has helped keep the best and the brightest young OI investigators in the field. In fact, in 1991, the OIF funded a young investigator, Dr. Charlotte Phillips, and her study that advanced the understanding of mouse models for basic OI research. Fast forward 26 years...the most recent OIF Scientific Meeting in Chicago was co-chaired by Dr. Phillips, a leading OI scientist and a mentor to many young investigators who are now OI researchers as well! Because of your support we can continue funding these outstanding scientists who are helping to accelerate OI research.

It's important to know that more than 80% of the money the OI Foundation uses to fund groundbreaking research comes from supporters like you. Together we are changing the future for everyone affected by OI.

So, thank you for your continued and generous support of our efforts to make that next “Breakthrough” which will ultimately affect all people with OI. And while we do this we continue to update our programs and services including the newly updated online Information Center where families with a new diagnosis of OI, parents of children with OI and adults living with OI are able to access free, medically verified information on managing OI. This information is life-changing for so many families.

One of the goals of the OI Foundation is to improve the lives of people living with OI today and in the future; to share information, make treatments more effective and ultimately to find a cure. This goal cannot be achieved without your help.

All my best,

Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

P.S. Thanks to a generous donation, the impact of your donation will be DOUBLED if you contribute between now and June 30th.

P.P.S. Whether you are enrolling in the contact registry, participating in Awareness Week activities, advocating on Capitol Hill, or sharing your experiences living with OI as part of a study, YOU are shaping the future. Thank you!



Research Corner

More than 100 Clinicians and Researchers Gather at the 17th Annual OIF Scientific Meeting

On April 19-21, 2017, the OI Foundation gathered more than 100 researchers, clinicians, and medical professionals at the 17th Annual OIF Scientific Meeting in Chicago, IL. Co-chaired by Dr. Charlotte Phillips and Dr. Sandesh Nagamani, this important meeting hosted speakers and attendees from the National Institutes of Health (NIH), the Brittle Bone Disorders Consortium (BBDC) sites, and many other OI centers and labs from across the continent. The meeting emphasized lectures and discussion surrounding novel targets and new therapeutic strategies in treating osteogenesis imperfecta. Speakers presented on topics including unmet pharmacologic therapeutic needs in OI, extraskeletal involvement, surgical treatment, and the latest data from the BBDC. Twenty-seven sessions covered many major themes, including the development of OI diagnostics and genetic testing; the effects of pharmacologic therapy on fractures, pain, quality of life, and healing; and psychological approaches of pediatric and adult care.

The OIF Scientific Meeting presented opportunities for the three current OIF Geisman Fellows, Dr. Ivan Duran Jimenez of UCLA David Geffen School of Medicine, Dr. Kyung-Eun Lim of Indiana University School of Medicine, and Dr. Ronit Marom of Baylor College of Medicine, to report updates on their projects. This program session was moderated by Dr. Charlotte Phillips, who was the recipient of an OIF Geisman Fellowship Award herself in 1990. A poster session of twelve presenters, including the OIF Geisman Fellows, young investigators, and experienced researchers, generated productive discussion for meeting participants across every discipline.

The OI Foundation thanks Dr. Phillips and Dr. Nagamani for their superb work as meeting co-chairs, and the speakers and participants for making this once again a productive gathering. The OI Foundation especially thanks the Buchbinder Family Foundation who makes the Annual OIF Scientific Meeting possible every year.



OIF Scientific Meeting 2017 poster session



Members of the OI Foundation Medical Advisory Council



A candid group photo of Scientific Meeting sessions in progress

Make Your Physician Aware of the Clinical Meeting on Osteogenesis Imperfecta this October

OIF Medical Advisory Council members Dr. Jay Shapiro and Dr. Cathleen Raggio will be hosting a clinical meeting on October 5-7, 2017 at the Embassy Suites by Hilton Baltimore at BWI Airport. This meeting is designed for clinicians and medical professionals who directly manage the care of children and adults living with OI. Lectures and discussion will cover the *clinical perspective* of topics such as growth impairment, dental disease, pulmonary function, cardiac disease, rehabilitation and function, orthopedic treatment, pharmacologic treatment, quality of life issues and more! There is no charge for clinicians to attend this meeting; however, travel accommodations must be made individually. Please share this information with members of your medical team who have expressed interest in learning more about clinical strategies to improve the care and treatment of individuals living with OI. Email bonelink@oif.org or call (301) 947-0083 by September 1, 2017 to learn more and register for this meeting.



CLINICAL MEETING ON OSTEOGENESIS IMPERFECTA

OCT 5-7, 2017

Embassy Suites by Hilton
Baltimore at BWI Airport

A meeting designed to bring together clinicians and medical professionals who directly manage the care of children and adults living with OI.



Chaired by Jay Shapiro, MD and Cathleen Raggio, MD

FOR MORE INFORMATION, CALL THE OI FOUNDATION AT (301) 947-0083 OR EMAIL [BONELINK@OIF.ORG](mailto:bonelink@oif.org).

Make Your Mark in OI Research: Join the BBDC Contact Registry

Now is the perfect time to make your mark in osteogenesis imperfecta research! The Brittle Bone Disorders Consortium (BBDC) is currently coordinating several studies through the contact registry. In order to be contacted for upcoming BBDC research opportunities, you must be signed up for the contact registry. Joining is easy and takes approximately 5-10 minutes. Besides your name and contact information, you will be asked to answer a few general questions about your health. The process can be done online at this site: <http://www.rarediseasesnetwork.org/cms/bbd/Get-Involved/ContactRegistry>. It is also available on a paper form if you call the OI Foundation at (301) 947-0083 or email Bonelink@oif.org to request one.



OI Clinic Spotlights

The OI Foundation works closely with nearly 60 multidisciplinary OI Clinics across North America 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 will feature spotlight summaries of new and existing OI clinics serving pediatric and adult patients. In this issue, we are focusing on three of the clinics listed in the OIF Clinic Directory: the OI Center at Connecticut Children’s Medical Center, the Michigan Osteogenesis Imperfecta Multidisciplinary Clinic, and the OI Clinic at Akron Children’s Hospital.

Osteogenesis Imperfecta Center at Connecticut Children’s Medical Center

We are pleased to announce the creation of a new multidisciplinary OI Center in New England – Connecticut Children’s Medical Center’s OI Center. The Center was created upon the arrival of Dr. Emily Germain-Lee, originally from Johns Hopkins School of Medicine and Kennedy Krieger Institute, where she led the OI program prior to her move to Connecticut. She is now the Division Head of Pediatric Endocrinology at Connecticut Children’s with her laboratory in the Center for Regenerative Medicine and Skeletal Development at the University of Connecticut Health Center. Her clinical and research interests focus on rare bone disorders and skeletal dysplasias, especially OI.

Dr. Germain-Lee is joining forces with Dr. Nancy Dunbar, who has focused her career on the treatment of pediatric bone disorders. Dr. Dunbar has run the Bone and Mineral Clinic at Shriners Hospital in Springfield, Massachusetts since 2008 and has run the Bone Clinic at Connecticut Children’s since 2013. Both Dr. Dunbar and Dr. Germain-Lee have extensive experience in treating children and adults with OI.

The Center offers bisphosphonate infusions, has broad participation of multiple disciplines and is proud to offer state-of-the-art bone densitometry that can accommodate a range of ages from infancy through adulthood. Referrals are welcome! Tiffany Canino, the Administrative Assistant for the OI Center, can be reached at (860) 837-6719.

Michigan Osteogenesis Imperfecta Multidisciplinary Clinic

The Michigan Osteogenesis Imperfecta Multidisciplinary Clinic at C.S. Mott Children’s Hospital was formed in 2015 with the goal of providing the best comprehensive care for patients as well as a network for families to rely on. Read what the Michigan Osteogenesis Imperfecta Multidisciplinary Clinic has to say about their center:

There are three main aspects that distinguish the clinic at Mott: 1. Geography, our location in Ann Arbor, MI affords us the opportunity to serve our state and surrounding populations, 2. Innovation, we have a team who is committed to research on all aspects of OI, 3. Dedication, the clinic at Mott brings together health care professionals from across 13 different disciplines to provide the highest level of care possible.

Dr. Michelle Caird, a pediatric orthopaedic surgeon, is the founder and co-director, along with Dr. Inas Thomas, of pediatric endocrinology, of the Michigan Osteogenesis Imperfecta Multidisciplinary Clinic. Dr. Caird’s areas of special expertise include treating fractures and spinal deformity in children with OI, and in the laboratory she investigates bone healing in this disorder. Dr. Caird is an Associate Professor of Orthopaedic Surgery at the University of Michigan in the Division of Pediatric Orthopaedics. She is a past member of the Board of Directors of the Pediatric Orthopaedic Society of North America (POSNA) and represented POSNA in Northern Europe as one of the 2012 POSNA Traveling Fellows where she studied and taught at major European centers.

The clinics we offer are two days in length and each family comes once a year. We offer two to three clinics each year, depending on scheduling. Typically, we have a range from 10 -15 families present at each clinic we host. While attending a clinic, patients and their families can expect to have appointments with: audiology, orthopaedic surgery, rehabilitation medicine with representatives from physical and occupational therapy, genetics, endocrinology, and social work on the first day, and we provide lunch that gives families the chance to network with each other. On the second day patients will see pediatric dentistry, ophthalmology, and otolaryngology, as needed.

The Mott Clinic is very passionate about their work at the University of Michigan and are always enthusiastic to work with many more wonderful families. For any questions about the clinic Richana Gaskin, administrative assistant to Dr. Caird, can be reached via phone at (734) 615-3599.

The Osteogenesis Imperfecta Clinic of Akron Children's Hospital

The Osteogenesis Imperfecta Clinic of Akron Children's Hospital was established in 2015 in order to better meet the needs of families identified through both Department of Orthopedics & the Skeletal Dysplasia Clinic. Akron Children's Skeletal Dysplasia Clinic, formed in the 1990s, served as the model for the comprehensive, multispecialty and patient-centered care offered in the OI Clinic.

Dr. William Schrader, founder and co-director of the OI Clinic, has been a practicing pediatric orthopedic surgeon for the past three decades. Throughout his distinguished career, Dr. Schrader has served as the director of pediatric orthopedic education, associate professor of orthopedic surgery for Northeast Ohio Medical University and assistant director of pediatric orthopedics and surgical training at Akron Children's. Along with co-authoring numerous research publications, Dr. Schrader has served as a reviewer for the Journal of the American Academy of Orthopaedic Surgeons. After caring for generations of families affected by osteogenesis imperfecta, Dr. Schrader was the leading force that catalyzed the formation of Akron's OI Clinic.

Dr. Frank Artinian, co-director, arrived at Akron Children's Hospital in 2015 after functioning as medical director and Chief of Maternal Child Medicine in his past employment. Dr. Artinian is a pediatrician, Fellow of the American Academy of Pediatrics and has over a decade of experience managing complex pediatric patients in both the clinic and hospital setting. As an individual affected by skeletal dysplasia, Dr. Artinian is particularly passionate about providing outstanding care to his patients in the OI Clinic. This includes clear and age-appropriate explanation of therapy plans, coordination between all specialists involved, timely communication with primary care providers and accessibility to families between clinic visits.

At a typical appointment in the OI Clinic of Akron Children's Hospital, families can expect to work with Drs. Schrader & Artinian along with a genetic counselor, physical & occupational therapists, diet & nutritional services and social workers. All aspects of medical and surgical care are addressed including bisphosphonate treatment, Fassier-Duval telescoping rod placement, scoliosis management, etc. Involvement of additional subspecialists including neurosurgical, endocrine, cardiology, pulmonary & dental are involved when necessary. Best of all, this occurs in a warm and friendly environment where a true sense of community is encountered. Clinic coordinator Shannon Leslie RN is available via phone at (330) 543-0735 for families and referring providers. Shannon serves as the OI Clinic's first point of contact and care coordinator.



Countdown to the 2018 OI Foundation National Conference in Baltimore, Maryland!

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. More than six hundred members of the OI community come together for each biennial National Conference. The three-day program boasts a schedule full of informational 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.

What to look forward to at OIF National Conference 2018:

- National Unbreakable Spirit® Walk-and-Wheel
- OIF Talent Show
- Programs for Children and Youth
- Meet-and-Greet Events
- Informational Sessions on Managing Pediatric and Adult OI Care
- Dinner & Dance Reception

Sponsorships

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 Erika Carter at ecarter@oif.org.

STAY TUNED for more details!

Information will be shared on www.oif.org/conference as it becomes available. Mark your calendars and start making your plans now! If you have any questions before the next set of conference details are announced, please email conference@oif.org or call the OIF at (844) 889-7579.

Meet the 2018 OIF National Unbreakable Spirit® Walk-n-Wheel Co-Chairs – Erin Nicholson Ortiz and Sarah Kamal

Erin and Sarah both led their family teams at the 2016 National Unbreakable Spirit® Walk-n-Wheel to be the two top fundraising teams. They have agreed to share their experiences and help inspire fellow members of the OI community to participate in the upcoming walk-n-wheel to help spread awareness of OI to our host city, Baltimore, Maryland, while raising money for the OI Foundation.

Greetings and salutations to my OI family!

Hi everyone! I'm mom to two outstanding boys – Alci (11) and Fisher (9) – type 4, rods in femurs and tibias as well as bisphosphonate-modified. My husband, also named Alci, has served on the OIF Board of Directors for the past 6 years. We live in Potomac, MD, just outside of Washington, DC, and down the road from the OI Foundation headquarters. I am deeply honored and incredibly excited to be one of your fundraising co-chairs for the next National Conference. Yes, we're talking about the 2018 conference!! Part of me feels like we just left Disney World. The memories are still fresh in my mind. In addition to family activities, visiting with friends, and participating in sensational sessions, one of the best things about the National Conference is that we have the opportunity to FUNDRAISE!

How many of you just cringed a little bit? It's okay. Most people are uncomfortable with the idea of asking people to donate money. Even when it's for a very good cause that is personally meaningful to them. That's where we come in. "We" being your fundraising co-chairs and the superb team at the OI Foundation. We're going to help you every step of the way with tools, templates, personal advice and an infectious OI-Can enthusiasm.

I doubt any of you that participated in the last Walk-n-Wheel actually cringed because you seriously knocked it out of the park at OIF National Conference 2016 – Raising over \$100,000 for the OI Foundation!! Let's see how far we can take it in 2018.

Whether your personal goal is to raise \$200 or \$20,000, we'll be here to support and empower every member of our OI family. We're all in this together!

Fondly,

Erin



The Ortiz Family at the 2016 National Unbreakable Spirit® Walk-n-Wheel

We can't wait to see everyone at the 2018 OIF National Unbreakable Spirit® Walk-n-Wheel on Thursday, July 12, 2018 in Baltimore, Maryland! To register as a participant or form a team today, visit www.oif.org/WalkandWheelBaltimore!

Hi everyone,

I'm Sarah, from Toronto, Canada. I am a mother to 3 amazing children. Adam, Noah, and our youngest, Sophia, who is 4 years old and has type III OI. I am honored and excited to be one of your fundraising co-chairs for the 2018 OIF National Unbreakable Spirit® Walk-n-Wheel!

Last summer in Orlando was our first time participating in an OIF walk-n-wheel. We were unsure how responsive people would be to our fundraising campaign, but we were overwhelmed by the generosity of our families and friends. We were incredibly honored to be one of the top fundraising teams, and loved being able to represent Canada in doing so. The Canadian presence at the OIF conference was amazing to see and I hope it's even larger in 2018!

The thing about fundraising is, people are often more likely to give generously if it is a cause you are passionate about. With OI being such a big part of our lives, friends were more than willing to donate to help us reach our fundraising goals. No amount is too small, as it all goes towards the OIF being able to continue doing amazing things to support the OI community. So when you set up your team page from the templates available, make sure to include your personal story. The OI community is like family to us, and I believe that comradeship resonates with all of us. I can't wait to help everyone reach their fundraising goals for 2018!

Warm regards,

Sarah



The Kamal Family at the 2016 National Unbreakable Spirit® Walk-n-Wheel

Join Fellow Members of the OI Community at an Upcoming Event



With just 50,000 people affected by osteogenesis imperfecta in the United States, coming together with others in your area to support the OI Foundation is vital. The OI Foundation is very lucky to have a large number of volunteers around the country who hold fundraising events, awareness events and support group meetings. Here are some of the events being held in the upcoming months. Try to attend one near you and share our Unbreakable Spirit®!

June

June 30th Picture With Wally – Kiddie Lodge – Framingham, MA

July

July 10th 19th Annual Miracle Michael Fund Charity Golf Outing – White Eagle Golf Club – Naperville, IL
July 13th 13th Annual Riley's Gathering Place Golf Outing – Golf at Maple Meadows Golf Club, Wood Dale, IL, followed by Dinner at Riley's Gathering Place – Elmhurst, IL
July 15th Just Keep Swimming Fundraiser – Spire Institute – Geneva, OH
July 28th Bennett Clayton Foundation Golf Tournament – Shoreland Country Club – St. Peter, MN

August

August 14th 11th Annual OI Golf Classic – Atkinson Country Club – Atkinson, NH
August 15th OI Day at Dogfishhead Alehouse – Gaithersburg, MD
August 27th Miami Marlins OI Awareness Day – Marlins Park – Miami, FL

September

September 1st Bill Ludwig's Spiritual Hat Trick – Lourdes, France
September 30th 3rd Annual Strong Bones Gala Chicago – Chicago Cultural Center – Chicago, IL

October

October 7th Florida OI Support Group Meeting – Shriners Hospitals for Children, Tampa

November

November 4th Strong Bones Gala Houston – Houston, TX
November 11th OIF Regional Conference – Portland, OR

New events are being added all the time. Visit the events calendar at www.oif.org for up to the date details.

Are you interested in holding awareness or fundraising events for the OI Foundation? Contact events@oif.org for more information today!

Follow us on social media!



www.facebook.com/OsteogenesisImperfectaFoundation



[@OIFoundation](https://twitter.com/OIFoundation)

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WE CAN'T WAIT TO SEE YOU IN BALTIMORE, MD!

OIF NATIONAL CONFERENCE

July 13-15, 2018

Renaissance Baltimore
Harborplace Hotel

