

We can't wait to see you in Orlando, FL, for the OIF National Conference 2016! The theme of the OIF National Conference 2016 is "IMAGINE!" We've come a long way and can only IMAGINE what the OI community can accomplish in the future.

OIF National Conference Hotel Update: The Swan and Dolphin has rooms available Friday, July 22 – Sunday, July 24th, but they are filling fast!

The OIF has secured overflow rooms at a discounted rate of \$139/night at a nearby hotel – the Caribbean Beach Resort. For registered conference attendees planning to arrive on Thursday, we encourage you book your Thursday night hotel room at the Caribbean Beach Resort.

*Be aware that reservations for accessible rooms are ONLY CONFIRMED if reserved through the OIF. If you requested an accessible room directly through the hotel, you will not be guaranteed an accessible room upon arrival.

OIF National Conference Program: The OI Foundation is looking forward to the speaker and session lineup for this summer's National Conference program! In case you are new to the world of OIF National Conferences, this event is the premier educational and social experience for families and individuals living with osteogenesis imperfecta. The three-day program always 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 care, and an abundance of additional activities designed to address important issues for members of the osteogenesis imperfecta community. This year we have activities and sessions specifically designed for first time attendees, adults living with OI, parents of children with OI, youth and young adults, women living with OI, men living with OI, and individuals living with mild OI. There is something for everyone!

(continued on page 2)

National Osteogenesis Imperfecta Awareness Week 2016

National Osteogenesis Imperfecta Awareness Week 2016 was April 30 - May 7! The OI Foundation encouraged the OI community to raise awareness for OI by sharing and retweeting **#SHAREforAWARENESS** social media posts, holding Awareness Week events, hanging posters, applying for state proclamations and holding National Blue Jeans for Better Bones Day.

Volunteers proclaimed OI Awareness Week in over 10 cities and states, as well as held multiple events nationwide. The OI community celebrated the international OI Awareness Day, Wishbone Day, on Friday, May 6, 2016 by wearing yellow to raise awareness. The OIF celebrated Wishbone Day by sharing facts and information via social media every hour for a consecutive twelve hours.



OI Community members celebrating Wishbone Day in Washington state

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Conference Program Preview – Activities and Sessions to Look Forward To

Especially For	Friday, July 22nd Opening Day	Saturday, July 23rd Medical Information Day	Sunday, July 24th Life Skills Day
EVERYONE	Medical Consultations (by appointment) Opening Session Exhibit Hall Career Expo Talent Show	Research Update Plenary Session Exhibit Hall <i>Breakout Sessions:</i> – Prevention and Treatment for Hearing Loss – Dental Issues: Orthodontia & Malocclusions – Vision and Issues: Cornea/ Glaucoma	OI Foundation Update Plenary Session Exhibit Hall <i>Breakout Sessions:</i> – Adaptive Equipment – Nutrition for Bone Health Closing Dinner and Dance
First Time Attendees	The Basics of OI Session	<i>Breakout Sessions:</i> – Understanding OI Types – OI Inheritance and Genetics	<i>Breakout Session:</i> – Is a Service Dog Right for You?
Adults with OI		Managing Adult Health Issues – Physician Panel Session <i>Breakout Sessions:</i> – Aging Well with OI – Respiratory Issues in Adults Adult Happy Hour	Tips for Being a Good Medical Consumer – Adult Health Panel Session <i>Breakout Sessions:</i> – Mental Health and OI for Adults – Personal Safety
Parents		Managing Pediatric Health Issues- Physician Panel Session <i>Breakout Sessions:</i> – Orthopedics: Rodding Surgery – Orthopedics: Spine and Scoliosis Parents Meet and Greet	What I did Right, What I would do Differently – Parent Panel Session <i>Breakout Sessions:</i> – Raising a Resilient Family – Building Bridges: Pediatric to Adult Care – Safe Physical Activity for Children
Youth and Young Adults	Career Expo Teen Center Icebreaker	Teen Center OI Youth Empowered and Proud Forum Young Adults Post-Forum Meet Up	Teen Center
Individuals with Mild OI		<i>Breakout Session:</i> – Mild/Type I Medical Application Discussion	<i>Breakout Sessions:</i> – Coping with an Invisible Disorder
Women with OI			Women's Wellness Program
Men with OI			<i>Breakout Sessions:</i> – Men's Shared Experiences Discussion

For questions about conference sessions, please email Bonelink@oif.org. See additional program details on the following pages.

NEW! OI Foundation Career Expo

Make plans to participate in the OIF's Networking Career Fair on the first day of conference to meet professionals living with OI who have similar career interests and backgrounds. The career fair will be open to anyone who wants to learn more about jobs in fields such as business, entertainment, healthcare, education, government, technology, public relations and more! Representatives will be available to talk about occupation-related challenges and benefits for a person living with OI, as well as training and skills required. This event will be held on Friday, July 22nd immediately following the opening session. If you are interested in participating in this event as a career representative, please send your name, field of work, and your job title to MBonardi@oif.org.

OI Youth Empowered and Proud (YEP) Forum

Youth and young adults within the age range of 16 to 30 are invited to participate in the OI Youth Empowered and Proud (YEP) Program on Saturday, July 23rd from 2pm – 5pm. The YEP Program will feature interactive presentations, team building activities, and discussions related to interdependent living issues of a young adult with OI. Program topics include:

- Exploring stages of interdependent living
- Building positivity and confidence
- Navigating the complexity of relationships and social life
- Creating an education that is beneficial for you
- Gaining a meaningful career

For more information about the program or to suggest a topic, please contact the YEP Forum facilitators at oifylc@gmail.com.

OI Women's Wellness Program

The Women's Wellness Program is returning to the National Conference program by popular demand on Sunday, July 24th from 2pm – 5pm. Women living with OI ages 18 and older are invited to join knowledgeable physicians, community professionals, and fellow women with OI in discussions about maintaining healthy life balances and taking control of our overall health. Program topics include stress management techniques, maintaining support systems, aging well through exercise and nutrition, self-esteem, and more!

Welcome, First-time Conference Attendees!

A hearty welcome awaits everyone who will be attending the OIF National Conference. Parents, children, and adults with OI of every age are all welcome. In addition, special preparations are underway to assist people who are attending for the first time. To help you make the most out of the conference

Meet the Career Fair Representatives



Jason Cance, Principal Recruiter with General Dynamics

Jason Cance has over fifteen years recruiting experience mostly in the IT field. He is currently working as a Principal IT Recruiter for General Dynamics, a government contracting company supporting US Special Operations forces, hiring IT professionals that support our troops on the ground. As Jason says, "Giving career advice, interviewing advice, resume writing techniques and just general job market knowledge is something I do every day. I am very interested in sharing my knowledge with fellow members of the OI community!"



Elizabeth Speaker, Clinic Counselor

Elizabeth Speaker, MA, LPCC, has been providing behavior therapy services to developmentally disabled adults with challenging behavioral issues and dual diagnoses for approximately 15 years. She has been working with children and adults who were facing significant medical and emotional challenges and procedures for 27 years. As a case manager, Elizabeth supports families by assisting them in developing skills, supports and knowledge to cope with the difficult decisions they need to make.

Meet Jason, Elizabeth and all the other career representatives in person on Friday, July 22nd at the OI Foundation's Career Fair immediately following the opening session of the OIF National Conference!

If you are interested in representing your career, please email Melissa Bonardi at mbonardi@oif.org

experience, be sure to stop by the Welcome Table. It will be near the Registration Desk. Volunteers will have handouts and maps to help you plan your time and find your way around the conference center. Welcome Table volunteers will:

- Explain the program and suggest sessions.
- Point out where meeting rooms and the child care center are located.
- Explain Teen Center activities.
- Describe the programs for Young Adults and Women.
- Share the schedule of social activities.
- Answer questions about meals and the closing dinner and dance.

Stop by the Welcome Table, pick up a handout and proudly add a "My First Conference" sticker to your name badge!

Medical Consultations at Conference

Once again through the generosity of its doctors, the OI Foundation will sponsor a day of Medical Consultations at the OIF National Conference. On Friday, July 22, nineteen physicians and one physical therapist will answer questions from conference attendees. A medical consultation is a free, face-to-face 20 minute meeting that provides the chance to have a conversation with an expert and get questions answered, have a test explained or get a second opinion. All of the physicians have extensive experience caring for people with OI. All of them will also be speaking during the conference.

This service is available to people who are registered for the OI Foundation's National Conference—adults with OI, parents of a child with OI and relatives.

A complete list of doctors and an appointment request form can be found on the OIF website. If you have questions about this important opportunity contact the OI Foundation office

by phone (301-947-0083 or 844-889-7579) or by email at mhuber@oif.org.

Requests for appointments are taken until every slot is full. A waiting list is also maintained in case plans change at the last minute. Don't delay. Don't be disappointed. Request an appointment today.

Just Added: Vision Study at Conference

An opportunity to participate in a research study has been added to this year's OIF National Conference. Dr. Felix Chau, from the Illinois Eye and Ear Infirmary – University of Illinois at Chicago and his colleague Dr. Victor Villegas, from the Bascom Palmer Eye Institute at Naples Florida will be collecting information about the eye health of people with OI ages 18 and older. Details about participating in this exciting study will be emailed to everyone who is registered for the conference.

National Osteogenesis Imperfecta Awareness Week 2016 (continued from page 1)

Thank you for your social media support during National OI Awareness Week! The OI community's Facebook "Likes" and "Shares" helped us reach over 160,000 people on Facebook! Check out some of the other social media numbers:

- 560 people changed their profile pictures to show support during OI Awareness Week!
- The OIF's **#OIknowtheFacts** posts on Wishbone Day reached 60,000 people!
- The OI Foundation Facebook page gained 285 new followers!

Join the OI Contact Registry!

An important part of the OIF's awareness and education goals includes expanding the knowledge about OI among medical professionals and researchers. During OI Awareness Week, we encouraged the OI community to take the opportunity to participate in the next wave of important discoveries about OI by joining the Rare Diseases Clinical Research Network Contact Registry. During OI Awareness Week, 100 new OI community members registered!

Joining the Contact Registry is quick and easy! Sign up online at www.rarediseasesnetwork.org/cms/bbd/Get-Involved/ContactRegistry.

Thank you to the volunteers who raised awareness by holding OI Awareness Week Events!

Applebee's Dining to Donate: Scranton, PA

CT & Western MA Support Group May 2016 Meeting

Reddit AMA ("Ask Me Anything") featuring OIF Board Member Joe Hall

The Alle Shea Project Presents Cracking Up for Better Bones: Webster, NY

Unbreakable Spirit® Fashion Show and Silent Auction: Kingston, ON, Canada

Unbreakable Spirit® Walk for OI 2016: Buzzards Bay, MA

Unbreakable Spirit® Walk-n-Wheel 2016: Nashville, TN

Support the OI Foundation Anytime, Anywhere!

Bone China Tea

On April 9th, 150 members of the OI community took a moment, had a cup of tea and spread awareness about osteogenesis imperfecta all while raising money for the OI Foundation. The best part is, they didn't have to leave the house! Bone China Tea hosts across the country invited their friends and family to join them for a virtual cup of tea while donating what they would have spent on event tickets, a new outfit or a baby sitter to the OI Foundation and raised more than \$15,000 in the process!

Did you miss the April 9th Bone China Tea? That's ok! The beauty of a virtual event is that it can be held any time that is convenient for you. Volunteer coordinators, Jenny and Susie Wilson would like to invite you to participate in this phantom event by hosting your own Bone China Tea Party on a date of your choice.

There are two easy ways to invite your friends and family to participate:

1. Order printed invitations by contacting event Co-Chairs Jenny and Susie Wilson at jnwilson@aol.com; OISLW@aol.com, or (239) 482-0643. Simply reach out to them with your name, home address, phone number, email address and the number of invitations you plan to send to your family and friends and they'll send them to you – complete with a tea bag.
2. You can set up your own personal web page using by visiting www.oif.org/BoneChinaTea to register as a host and begin sending your invitations via e-mail or sharing your page on social media.

By sharing your personal story on your invitations, Bone China Tea participants can contribute to the OIF's awareness, support and research efforts. Encourage your friends and family to have a cup of tea in the comfort of their own home – we even provide the tea bag! All you pay for is the postage when sending your Bone China Tea invitations to your friends and family.



Bella Parker and Lali Scott enjoying a cup of Tea and Spreading Awareness of OI

Blue Jeans for Better Bones

For nearly a decade, members of the OI community have been spreading awareness and raising money in their communities with the Blue Jeans for Better Bones campaign. This grass roots program is a great way for kids to get their classmates involved or for whole offices to show their support. Participants are invited to make a small donation and then show their support for OI by wearing blue jeans on a certain day. You aren't limited to blue jeans – choose to have a Hawaiian Shirt Day or Crazy Hat Day or Wear Yellow Day. Simply pick a date, a donation amount and theme – then invite your friends, families or coworkers to join you!



Visit www.oif.org/BJBB to get started today! You can now download copies of Sign Up sheets, Marketing Posters and Event Leader/Materials Request Forms to make hosting a Blue Jeans for Better Bones Day as easy as possible! You can also access the Blue Jeans for Better Bones Store to order your stickers and wristbands for your next event. Our next National Blue Jeans for Better Bones day is scheduled for Friday, September 2, 2016 – the day before Labor Day weekend – but remember, you can pick any day that works for you, your office or your school!



Spreading Fine Wines and Strong Bones Across the Country

On February 27th, the 16th annual Fine Wines Strong Bones Gala set records when Tim Dombro and Tracy Mulroy took to the stage to speak about their wife and friend Jamie Kendall. Tim and Tracy spoke of Jamie's Unbreakable Spirit® and outlined the plans for the newly created Jamie Kendall Fund for OI Adult Health. After concluding their remarks, they passed the microphone over to auctioneer Barry Cherwin who led one of the most awe inspiring fund-the-mission auctions we have ever seen. In the end, nearly every member of the 275 person audience had raised their paddle - we raised \$100,000 in under half an hour! It was a truly amazing show of generosity. As this event grows, year after year, we continue to set our sights higher. We are already planning the 17th Annual Fine Wines Strong Bones Gala for February 2017 with a Great Gatsby theme.

As part of our continuing effort to expand the Fine Wines Strong Bones program across the country, the *Strong Bones Gala: Orlando* was held on May 21st at the Orlando Science Center.

OI Foundation members Gail Bunker, Michelle Fynan, Victoria Cressman, Ellen Dittman and a committee of their friends, co-workers and family members helped launch this first-time event!

Save the date! The 2nd annual *Strong Bones Gala: Chicago* is scheduled for October 15, 2016 at the Chicago Cultural Center! We are very excited to bring this event back for a second year. If you would like to be involved in the planning of this event, please contact Melissa Bonardi at mbonardi@oif.org.

Planning has begun for additional events in New York, NY in winter 2016 and Boston, MA in spring 2017. If you would like to join an existing committee or if you think your city would be a good location for a Strong Bones Gala or a Fine Wines Reception, please contact OI Foundation at 301-947-0083 or events@oif.org. For information on all of our upcoming galas, please visit www.oif.org/FineWinesStrongBones.



Paddles raised in support of the Jamie Kendall Fund at the 16th Annual Fine Wines Strong Bones Gala



Attendees bid on silent auction items at the Fine Wines Strong Bones Gala.

Forward Thinking for Youth, Young Adults, and Parents

Youth and young adult years are a critical time for major life transitions. The complexity and confusion of the adult health care system can become overwhelming for anyone during these years, but particularly for a person living with a rare and life-long condition like osteogenesis imperfecta. Although formal “transition programs” in many health centers begin for teenagers, the process really starts before teenage years. This summer, the OIF National Conference’s Teen Center, Youth Empowered and Proud Forum, and breakout session titled *Building Bridges: Managing the Transition from Pediatric to Adult Care* will tackle the common issues that youth and their parents face during the transition process. These three opportunities will explore “life hacks” on topics such as career development, independent living, housing needs, vocational rehabilitation services, and more based on the professional experience of transition specialists and the personal experience of many community members.

The OI Foundation encourages youth and young adult conference attendees to take charge of your health and take advantage of the educational opportunities available throughout the National Conference. It is never too early to start learning and gathering resources. If you are not able to attend conference, there will be session summaries, handouts, and presentations available to use as a guide throughout your transition years and beyond. Read below for tips and resources to consider.

Take Charge of Your Health

Young adults who are working, traveling or going to school are reminded to take charge of their health. Here are a few suggestions for getting started.

- Know your own OI history including:
 - ▶ Your OI Type
 - ▶ Date and placement of rods and other medical hardware
 - ▶ Dates for beginning and stopping treatment with bone drugs such as pamidronate
- Find a primary care doctor and an orthopedist **before you need one.**
 - ▶ College students need to understand the Health Care Services provided by their school and how to access those services.
 - ▶ Students and anyone living temporarily away from home will need to find local doctors; learn about the local hospitals; and have an emergency plan.
 - ▶ If you are moving, tell your current doctors where you will be living and ask for referrals. In many cases, the OI Foundation can also help.

One Step at a Time – Advice from a Transition Specialist

“The concept of transition is such an enormous topic that many times young adults (or their families) get hung up thinking about it all and can’t move forward. I suggest people attack transition the same way they say you eat an elephant—one bite at a time. Choose one area you’re going to focus on initially, and once you concur that, move onto the next one.”

~ Cory Ellen Nourie, MSS, MLSP
Patient Transition Social Work Coordinator
Nemours Al duPont Hospital for Children

- Follow a healthy lifestyle that includes exercise, not smoking, a healthy diet, and avoiding illness.
- Seek medical care promptly for all respiratory infections.
- Have an annual physical; your basic health needs are the same as other people.
- Be sure your vaccinations are up-to-date and plan to get the annual flu shot in early autumn.
- Know your medicines.
 - ▶ Be aware that some medicines can cause bone loss or interfere with fracture healing.
 - ▶ If you are short in stature, be aware that the dose of many medicines will need to be lower than the standard adult dose.
 - ▶ Read the labels on all over-the-counter drugs especially those containing a pain reliever.
- Understand your health insurance. Know what is covered and how to make a claim.

Get Connected! Resources on Transition Issues

OI Foundation Information Center and Youth Leadership Council

- ▶ Ask or send your questions to the OIF office via phone (301) 947-0083 or email Bonelink@oif.org.

Nemours Al duPont Hospital for Children YouTube Video Series

- ▶ Watch videos that cover topics such as self-advocacy, independent living, vocational rehabilitation, and other community-based resources related to transitioning health care needs. Search “Nemours Becoming an Adult” on YouTube for a list of videos.

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 program and clinical research sites. 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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www.oif.org

Unbreakable Spirit®

Dear Friend,

For nearly 50 years the OI Foundation has been committed to expanding knowledge about OI, and finding new treatments for people living with OI. Advances in OI research are happening right now and they are happening at a faster pace than ever before. This accelerated pace of research can be directly linked to the involvement of the OI community . . . you are making it happen! **Please help us to keep the momentum going by making a gift today!**

We all know that there are many faces to OI Research. There are the young investigators who have received OI Foundation Michael Geisman Fellowships who are beginning their careers in bone related research. One of those young investigators uncovered the first recessive gene for OI. That finding opened the door to discoveries of potential new drug treatments that are currently being studied. Other faces include the clinicians and researchers who care for children and adults with OI and who use their experience to improve surgical techniques, physical therapies and other treatments.

But the most important face in OI Research is yours. The OI community—the children, adults and families living with OI—is the key to every stage in the research process from raising the questions, to helping design studies, to participating in the studies themselves and helping raise the money to make everything happen as soon as possible. Every research study being conducted through the newly formed Brittle Bone Disorders Consortium relies on the participation of the OI community. This partnership between the OI community, the OI Foundation and the research community is the key to making real progress.



An excellent example of the importance of this partnership is the development of the OI Foundation's new **Jamie Kendall Fund for OI Adult Health**, named for OIF's past board president who passed away in 2015. A dangerous gap in care for and knowledge about pulmonary issues facing adults with OI was realized. Now, thanks to the generosity of members of the OI community, funding is in place for the first two years of a new pulmonary study to investigate those issues and study proposals are being accepted. This is truly the work of a committed group of people looking to improve the quality of life for people with OI.

But there is more work to be done. There are more questions to answer. There are more studies that must be done. There are many more medical professionals to train. **To do it, your help is needed!**



Dr. Brendan Lee, Principal Investigator of the Brittle Bone Disorders Consortium and OIF MAC Member



Bob Phillips, Gary Patti and Richard Wyman

More than 70% of the money the OI Foundation uses to fund groundbreaking research comes from supporters like you. **Because of our partnership**, together we are changing the future for everyone affected by OI. Please consider making a gift today by using the enclosed envelope or donating online at www.oif.org.

The goal of all research is to improve the lives of people living with OI today and in the future; to make treatments more effective and ultimately to find a cure. This goal cannot be achieved without your help.

Scientific Research + You = Breakthroughs!

Thank you for your continued generous support!

All my best,

Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

P.S. - Thanks to a generous donation from a donor, the impact of your donation will be **DOUBLED**, if you contribute between now and July 30th—just another example of how our partnerships are helping raise more money to keep OI research moving forward!

The Osteogenesis Imperfecta Foundation, Inc., has a 501(c)(3) classification from the Internal Revenue Service, and contributions are deductible for federal income tax purposes to the extent allowable by law. Financial information about the Osteogenesis Imperfecta Foundation can be obtained by writing to us at 804 West Diamond Ave., Suite 210, Gaithersburg, MD 20878, or for residents of the following states, as stated below: Colorado: Secretary of State 303-894-2680, <http://www.sos.state.co.us/> re: Registration No. 20033001101. Florida: SC No. CH2757. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATE, 1-800-HELP-FLA. Kansas: Annual financial report is on file with the Secretary of State. Maryland: For the cost of postage and copying, documents and information filed under the Maryland charitable organizations laws can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401. Michigan: MICS No. 11625. Mississippi: The official registration and financial information of the Osteogenesis Imperfecta Foundation may be obtained from the Mississippi Secretary of State's office by calling 1-888-236-6167. New Jersey: INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING 973-504-6215 AND IS AVAILABLE ON THE INTERNET AT www.njconsumeraffairs.gov/ocp.htm#charity. New York: Upon request, Attorney General Charities Bureau, 120 Broadway, New York, NY 10271. North Carolina: Financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at 1-888-830-4989. Pennsylvania: The official registration and financial information of the Osteogenesis Imperfecta Foundation may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Virginia: State Office of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218. Washington: Secretary of State, 1-800-332-4483. West Virginia: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. REGISTRATION IN A STATE DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION OF THE OSTEOGENESIS IMPERFECTA FOUNDATION BY THE STATE.

Don't Miss Out on the Fun at the National Unbreakable Spirit® Walk-n-Wheel: Orlando

Taking place on **Thursday, July 21** at the Walt Disney World Swan and Dolphin Resort, the National Unbreakable Spirit® Walk-n-Wheel is a great way to come together and kick off the OIF National Conference. We will gather beginning at 5pm for a fun warm-up followed by walking or wheeling a short route around the Swan property and a Finish Line celebration.

There are already over 80 participants registered on 25 teams for the 2nd National Unbreakable Spirit® Walk-n-Wheel! Plan on joining your fellow OI friends and family for this fun way to spread awareness and raise money for the OI Foundation and remember, participants who raise:

- \$25 or more – receive an official National Unbreakable Spirit® Walk-n-Wheel T-shirt.
- \$500 as a team – receive an official printed team sign that you can personalize.
- \$750 or more as a team – receive an official team photo that will be printed out and given to the team captain.
- \$1,000 – receive a complimentary registration to the OIF National Conference.
- \$5,000 – recognition at the National Conference Opening Session on Friday, July 22nd.

Raising money for the OI Foundation has never been easier with the *Unbreakable Spirit®* Walk-n-Wheel! Once you register at www.oif.org/WalkandWheelOrlando, a personal walk-n-wheel page will be created for you. Just take a few moments to edit the page with your personal story and then send it to you friends and family via email or share it on social media.

If you want to do more, think about holding an event in your own community like Laura McAleer did in her hometown of Kingston, Ontario:

“Since we don't live near Orlando, I knew I wanted to have an event to raise money for my Walk-n-Wheel team. Since I'm a hair dresser and people I know love fashion, I decided to do a fun fashion show for OI awareness. I knew I wanted kids in the show and definitely OI kids. I was fortunate to have 3 OI models: my daughter Keira, Essie Reene's daughter from Ottawa (who had broken her femur the day before but rocked the red carpet anyway) and Ayeyi Justina all the way from Ghana Africa. The turnout for the event was amazing, and the response blew me away! Keira means the world to us and further awareness of OI will only help her in the future.”

In one day, Laura and her family earned four complimentary registrations to the OIF National Conference by raising more than \$4,000 for their National Walk-n-Wheel team. You can too!



Mereo is a UK-based biopharmaceutical company focussed on the rapid development of innovative medicines in **rare and specialty disease areas** that have the potential to transform patient quality of life and improve human health.
www.mereobiopharma.com

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DOING MORE.

FOR KIDS WITH OI.

ERIC RUSH, M.D.,
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Orthopaedic Surgery - Pediatric

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Orthopaedic Surgery - Pediatric



**COMPASSIONATE,
MULTIDISCIPLINARY CARE.
ADVANCED MEDICAL OPTIONS.
CONTINUED RESEARCH AIMED AT A CURE.**

The Metabolic Bone and Osteogenesis Imperfecta Clinic at Children's Hospital & Medical Center in Omaha is recognized worldwide for our expertise. Our team of health care professionals are trained and experienced in treating and managing children with OI, working together in one location to ensure the most effective, comfortable and convenient care.

Because every child deserves an active lifestyle – and hope for a bright future.


Children's
HOSPITAL & MEDICAL CENTER

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We know children.

For a pediatric OI specialist,
call **1.800.833.3100**.

Find more at ChildrensOmaha.org/OI



From the Information Center

New Book on OI!

The Shriners Hospitals for Children – Chicago has published a new book on OI titled **Transitional Care in Osteogenesis Imperfecta: Advances in Biology, Technology and Clinical Care**, edited by Dr. Peter Smith, Dr. Frank Rauch and Dr. Gerald Harris. Over 600 pages of information are divided into 4 major sections: Transitional Care, Biology, Technology and Clinical Care. The book is intended for a wide audience including families and medical professionals. The authors believe that it is important for medical staff encountering people who have OI to know the latest and most effective care methods. Transitional Care addresses the complex needs of the person with OI who is moving from childhood into adulthood. Technology discusses efforts being made to use new technologies to better understand how OI affects a person's ability to move; how to predict fracture risk; and how to prevent joint injuries across the life span. This section is based on years of collaboration between SHC-Chicago and Marquette University's Orthopaedic and Rehabilitation Engineering Center (OREC). The Clinical Care section is quite thorough and includes a number of case studies. This valuable resource is available free of charge electronically through the OREC website www.Tech4POD.org. A limited number of print copies are available by contacting the OI Foundation. Copies will also be available at the OI Foundation's National Conference this July. In the near future the book will be available through Amazon.

OI Podcast Series is Going Strong

As part of its commitment to providing up-to-date information for medical professionals, the OI Foundation has started a monthly podcast series featuring experts on OI. **All of the podcasts are available to anyone in the OI Community and to the general public.** Dr. Eric Rush spoke on Discovering New Genes. Dr. Deborah Krakow's February talk on Pregnancy and Women who have OI provided information about having a healthy pregnancy for the woman who is pregnant or who is thinking about pregnancy. The March talk, by Dr. David Vernick, covered issues related to hearing loss. In April, Dr. Nagamani from Baylor Medical College in Houston spoke on the Effect of the Linked Clinical Research Centers. Captioning will soon be added to all of the episodes. To see a complete list of topics and speakers and to listen to the podcasts go to the OIF website www.oif.org and click on the tab "For Medical Professionals" or go to www.oif.org/oifpodcast.

Travel Tips: Preparing for Summer Vacation

Summer 2016 may mean traveling to the OI Foundation National Conference in Orlando, FL, visiting friends and relatives, or maybe an international travel adventure. Whether you're going across your state or across the ocean, there are things you can do now to ensure a happy, healthy trip.

- Carry a letter from your doctor stating the OI diagnosis.
- If you are flying, check the US Transportation Security Administration (TSA) website for the latest information about airport screening www.tsa.gov. Under "Traveler Information" there is a section for people with medical conditions/disabilities.
- Check your airline's website if you need assistance boarding the plane or will be traveling with a scooter or wheelchair.
- If you are taking a train, check the Amtrak website www.amtrak.com for travel tips and a list of services.
- Check the website for all of the hotels and sights you wish to visit to see if they meet your personal accessibility needs.
- Add fracture first aid materials to your first aid kit. Include latex free wraps and bandages if needed.
- Carry a list of your doctors and their phone numbers or pager numbers.

Anyone who travels alone, especially children, teens or young adults may wish to consider enrolling in one of the medical alert programs that provide bracelets or necklaces and 24/7 monitoring.

Update: 2016 Impact Grant Program

We are pleased to report that this year's Impact Grant Program was able to fund 30 of the 53 requests submitted last January. Funding was provided for a wide range of items including hearing aids, a ramp, and water therapy. In addition, 15 families – 35 adults and 27 children—received grants to attend the OI Foundation National Conference this summer. The OI Foundation is grateful to the Children's Brittle Bone Foundation, our partner in this important project, and to the hard-working volunteer committee who helped evaluate the applications. Applications for the 2017 Impact Grant Program will be available next January.

Opportunity to Enroll in an OI Longitudinal Study Near You!

A central piece of the research being conducted through the Brittle Bone Disorders Consortium is the longitudinal study of osteogenesis imperfecta. This study, also referred to as a natural history study, seeks to accurately describe the different types of OI and how they may change as across the lifespan. Principal investigators are seeking to match up features of OI with the genetic causes and track the long-term effects of different treatments. As a multicenter study, there are seven centers in the United States and one center in Canada that are now open for enrollment.

Many of the exams and activities related to this study are considered standard of care for a person with OI and will likely be covered by your insurance. If your insurance does not cover the cost of exams, it may be able to be covered by a research grant. Should you choose to participate, study measures will include:

- A review of your medical history
- A physical exam
- Hearing and dental exam
- Pulmonary Function Testing
- Blood and urine collection
- X-rays (including spine, hand, dental)
- Bone density testing
- Strength, coordination, and mobility measures

The ultimate goal of this study is to improve the health and quality of life for every person who has OI. The more people who enroll in this study, the better the information will be and the sooner answers will be found for many puzzling questions. If you are interested in learning more about this study or enrolling at a site near you, please contact one of the site coordinators listed below:

Site Information:

Baylor College of Medicine, Houston, TX
Principal Investigator: V. Reid Sutton, MD
Contact: Mary Mullins, RN. Phone: 832-822-4263;
Email: mullins@bcm.edu

Shriners Hospital for Children, Montreal, Canada
Principal Investigator: Frank Rauch, MD; Francis Glorieux, MD
Contact: Michaela Durigova. Phone 514-282-7158;
Email: mdurigova@shriners.mcgill.ca

Oregon Health and Science University, Portland, OR
Principal Investigator: Eric Orwoll, MD
Contact: Catherine Pederson. Phone: 503-494-6595;
Email: Orwoll@ohsu.edu

Hospital for Special Surgery, New York, NY
Principal Investigator: Cathleen Raggio, MD
Contact: Kate Citron. Phone 212-774-2355;
Email: citronk@hss.edu

Shriners Hospital for Children, Chicago, IL
Principal Investigator: Peter Smith, MD
Contact: Angela Caudill, MPT. Phone: 773-385-5868;
Email: acaudill@shrinenet.org

Children's Hospital and Medical Center/University of Nebraska Medical Center, Omaha, NE
Principal Investigator: Eric Rush, MD
Contact: Jennifer Goodwin. Phone: 402-559-0681;
Email: Jennifer.goodwin@unmc.edu

University of California Los Angeles/Orthopedic Institute for Children/Shriners Hospital for Children, Los Angeles, CA
Principal Investigator: Deborah Krakow, MD
Contact: Samantha Alon. Phone: 310-794-6420;
Email: Salon@mednet.ucla.edu

Children's National Health System, Washington, DC
Principal Investigator: Laura Tosi, MD
Contact: Marianne Floor. Phone 210-320-2157;
Email: mfloor@childrensnational.org

Participate in the next wave of important discoveries about OI—
JOIN THE OI CONTACT REGISTRY!

Please encourage your friends and family to join- every person who has OI, child or adult, is eligible join this registry!

Joining is quick and easy! Sign up online at
www.oif.org/BBDConsortium

16th Annual OIF Science Meeting

The OI Foundation gathered more than ninety scientists and researchers for the 16th Annual OIF Science Meeting on April 13-15, 2016. The two-day meeting, titled "The Future of OI Research," featured a slate of presentations on topics ranging from basic biology and animal studies to treatment implications and discussions on care delivery models. The meeting was chaired by Dr. Eric Rush of the University of Nebraska Medical Center and Dr. Pierre Moffatt of Shriners Hospital for Children – Montreal. The sessions included Pathways to Potential Treatments; Gene Discovery and Treatment Implications; Animal Model Progress; Muscle and Bone Interaction and OI; Clinical Targets for Treatment; Technology and Treatment and Surgical Interventions. Updates from the Brittle Bone Disorders Consortium stimulated productive and innovative conversations surrounding clinical targets and potential treatment options. Clinicians collaborated in several supplementary focus groups regarding the launch of a new pulmonary study, and advancements in surgical techniques and rehabilitation medicine for osteogenesis imperfecta. The meeting each year attracts scientists interested in learning more about the latest OI research, both basic and clinical, and how that research will ultimately benefit people living with OI.

The OI Foundation thanks the co-chairs of this meeting, Dr. Rush and Dr. Moffatt, and a very special thank you to the Buchbinder Family Foundation that makes this event possible every year.

SAVE THE DATE!

**Uniting Unbreakable Spirits
OIF Regional Conference:
HOUSTON, TX**

NOVEMBER 12, 2016



**Texas Children's Hospital-
Pavilion for Women**

AMGEN

The OI Foundation thanks Amgen for the support of our family conferences program.



Have you signed up to perform in the **OIF National Conference Talent Show**?

Visit www.oif.org/Conference for an application.

We can't wait to see what you've got!

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 is a vital level of support for our community. 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 your Unbreakable Spirit®!

June

- June 4th** Sweat for Sammy and Strong Bones – Media, PA
- June 5th** Unbreakable Spirit® Walk-n-Wheel for Cheyenne – Melrose, MN
- June 18th** Tri for OI – Columbus, GA
- June 19th** 5th Annual Carnival for OI – Coplay, PA

July

- July 11th** Miracle Michael Golf Tournament – Naperville, IL
- July 14th** Riley's Gather Golf Outing – Elmhurst, IL
- July 21st** National Unbreakable Spirit Walk-n-Wheel – Orlando, FL
- July 22-24th** OIF National Conference – Orlando, FL
- July 30th** Katie Petro's Swim for OI – Lake Eerie

August

- August 15th** OI Golf Classic – Atkinson, NH

September

- September 2nd** National Blue Jeans for Better Bones Day

October

- October 15th** 2nd Annual Strong Bones Gala: Chicago – Chicago, IL
- October 22nd** 25th Annual NJ Area Support Group's Beefsteak Dinner – Garfield, NJ

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!

OI Foundation
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Gaithersburg, MD 20878
(301) 947-0083
(844) 889-7579
www.oif.org
Bonelink@oif.org



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Unbreakable Spirit®

Register Today!

We hope to see everyone at the
2016 OIF National Conference
at the Walt Disney World Swan and
Dolphin Resort in Orlando, Florida,
on July 22-24, 2016!

www.OIF.org/Conference