

OI Community Celebrates 2014 OIF National Conference

The 2014 OIF National Conference took place August 1-3 at the JW Marriott in Indianapolis, IN—and what an amazing weekend it was! Throughout the weekend, over 35 experienced speakers shared information and led discussions on over 40 topics carefully selected for those interested in Type I, Adult, Young Adult and Parent information. Over 500 conference attendees took advantage of the one-on-one medical consultations, age and gender specific forums, informative sessions and enjoyable social events!

New and old friends of all ages participated in the National Unbreakable Spirit® Walk-n-Wheel, Adult Happy Hour, OIF National Conference Talent Show, Cake and Ice Cream Talent Show After-party, OI Night at the Indianapolis Indians game, Closing Dinner and Dance and more! We look forward to seeing everyone at the 2016 OIF National Conference in Orlando, Florida, at the Walt Disney Swan and Dolphin!



Check out the photos from the 2014 OIF National Conference weekend in the OI Foundation's Facebook Photo Album – Celebrate You! OIF National Conference 2014. (www.facebook.com/OsteogenesisImperfectaFoundation)



Youth Forum Brings Together Young Adults at Conference: Young Empowered and Proud [OI YEP] Forum

This year at the 2014 National Conference, the OI Foundation held its first ever Youth Forum for conference participants between the ages of 16 and 25. Ten young adults living with OI who all have various backgrounds and experiences facilitated discussions on personal and professional development. With almost 50 participants, a wide variety of discussions surfaced including social aspects of having OI, self-identity, friendships, relationships, dating, living and navigating the work place independently, and transitioning into college.

"I am hard working, independent, motivated and short. I am not short in personality or dreams, afraid to ask for help when I need it."

Each topic sparked many great conversations and questions, and formed bonds that lasted throughout the rest of conference and beyond. One of the most powerful moments during the forum was when participants were encouraged to break down stereotypes that had been used to define them as a young adult living with OI. The participants then rewrote their scripts, claiming a new

identity of how they want to be seen by others. These empowering statements are direct anonymous quotes from some of the forum participants:

"I am unique. I am not voiceless."

"I am short. I am not helpless."

"I am a woman. I am not incapable."

"I am hard working, independent, motivated and short. I am not short in personality or dreams, afraid to ask for help when I need it."

The overarching themes of the OI YEP Youth Forum were breaking boundaries and achieving independence through self-empowerment and building a strong support system. The OI Foundation sends a huge thank

you to the co-chairs who helped plan this Forum, Kara Ayers and Adrienne Baez, and many thanks to the wonderful facilitator team Sarah Della Cramer, Greg Trahan, Adam Sanders, Emily Voorde, Connor Lenahan, Desiree Forte, Kendra Michalak, Rosie McDonnell-Horita, and Jessica Finkel.



Youth Forum Committee

Bringing Women Together at the OIF National Conference

Held in conjunction with the 2014 OIF National Conference, the Women's Forum brought together women living with OI to participate in a special one-day forum focused exclusively on topics specific to women. Nine speakers presented information and led discussions about female medical issues, the path to parenthood, and building a positive self-image. Attendance was limited to only forty women, 18 years and older, to encourage a comfortable and open dialogue.

The OI Foundations thanks speakers Dr. Emily Germain-Lee, Dr. Deborah Krakow, Marie-Ann Andrews, Karen Braitmayer, Anna Curry Gualano, Jamie Kendall, Tracy Mulroy, Diane Wysocki and Jeronna Bolden, forum co-chairs Michelle Duprey and Anna Curry Gualano, and the meeting participants for taking part in this important program.

Spotlight on 2014 National Conference Award Recipients

Award recipients in three important categories were recognized at this year's National Conference: the 2013 and 2014 Thelma Clack Award (Volunteer of the Year), 2014 President's Award for Contributions to the OI Community, and the OI Foundation Humanitarian Award.

2013 Thelma Clack Award Recipient: Jamie Kendall



Jamie is currently the Director, Special Projects, at the Center for Disability and Aging Policy at the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS), a federal agency which promotes full participation of individuals with disabilities and older Americans in the community. Much of her career has focused on promoting employment opportunities for individuals with all disabilities. Previously she served as the Deputy Commissioner at the Administration on Intellectual and Developmental Disabilities (AIDD) where she provided leadership to the programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the Help America Vote Act. She has also held positions at the Social Security Administration and at the Administration for Children and Families. Jamie holds a Masters in Public Policy (MPP) from Georgetown University.

Jamie's involvement with the OI Foundation began as a young adult when she attended the 1996 National Conference on OI, where she met her husband, Tim Dombro. She describes the conference as a life changing experience which compelled her to volunteer with OIF in order to support the OI community. Her original volunteer job was organizing the "key pals" program, which connected teens with older adult mentors with OI. She has been a regular Bone China Tea participant. She served on the OIF Board of Directors for six years, including one term as President. Her biggest achievement during that tenure was working to establish the OI patient registry and continuing to

promote the "mutual support" side of the mission of OIF. In 2001 she coalesced a critical mass of OI individuals and families to create the annual Fine Wines Strong Bones fundraising event, and still serves as an active member of the planning committee. Originally from Detroit, Michigan, Jamie and Tim live in Alexandria, Virginia and are the foster and adoptive parents of three children; Jake, Julian and Claudia.

2014 Thelma Clack Award Recipient: Christine Rossi

Christine (Wyman) Rossi comes from a family of five generations affected by OI and she is passionate about raising awareness about OI and research to find a cure. Christine's father, Dick Wyman, became involved with the OI Foundation when Christine was born and served on the Foundation's Board of Directors and Executive Committee. Following in her father's footsteps, Christine served on the OIF's Board of Directors and Executive Committee from 2003-2009. Christine's passion for raising awareness about OI and ultimately finding a cure became non-negotiable in her mind when her son Jack was born with OI. Jack experienced two femur fractures in his first month of life and Christine vowed to do whatever she could to make a difference and impact the future for all living with OI.

With the help of her entire family, especially her brother-in-law Mike Potorksi, she created an annual Unbreakable Spirit® Walk for OI, Silent Auction & Family Fun Day in 2005 in Framingham, Massachusetts. On May 4th, they celebrated the event's 10th anniversary. Over the 10 years, the event has honored people dedicated to the cause, and in its 10th year, Christine and her family honored all of their heroes – all those who helped year after year to make the event a success – the committee, volunteers, sponsors, OI family and friends, walkers, teams, physicians, donors and all who have supported them. To date the event has raised over \$500,000 to support OIF programs and research.

When Christine started her event years ago, she had a dream that someday these OI walk-a-thons would take place across the country. And this year, when the OIF held five Unbreakable Spirit® Walks taking place in four states during National OI Awareness Week and launched the first National Unbreakable Spirit® Walk-n-Wheel at the OIF National Conference, Christine has been able to see her dream coming true!

Christine is the Finance Development PMO Program Director at EMC, an IT storage hardware solution company headquartered in Hopkinton, Massachusetts, where she has worked for eight years. Christine lives in Ashland, Massachusetts with her husband John Rossi and their two sons, Jack (9) and Hugo (6). Christine holds degrees in psychology and counseling and has spent her career focused on recruiting, career coaching, organizational design and leadership program development and management.

2014 OIF President's Award: Children's Brittle Bone Foundation



Founded in 1990, the Children's Brittle Bone Foundation has made important contributions to the OI Community. In addition to funding research and lobbying for increased government funding for OI research, the CBBF has raised a significant amount of money for two important initiatives – the Linked Clinical Research Center Program and the Impact Grant Program. The OI Foundation is proud to be a partner with the CBBF on these initiatives.

Since 2009 the Impact Grant program has provided assistance to some of the OI community's neediest people. The program pays for many things including, hearing aids, ramps, educational grants, urgent medical care and wheelchair accessible vans. In the past five years, CBBF has raised the money to award \$550,000 to over 75 Impact Grant recipients.

The Linked Clinical Research Center program grew out of an idea for a "virtual" OI center. Today the LCRC idea has become a network of hospitals and skilled health care providers. By sharing data and linking their research the Centers track how OI changes across a lifetime, and study the benefits of different treatments.

The Osteogenesis Imperfecta Foundation is honored to present the 2014 President's Award to our partner organization, the Children's Brittle Bone Foundation for their outstanding commitment to the mission of improving the lives of people living with OI.

The OIF Humanitarian Award: Dr. Francis Glorieux, OC, MD, PhD



The Osteogenesis Imperfecta Foundation Humanitarian Award is given to individuals who have devoted their own lives to improving the lives of people living with osteogenesis imperfecta. These visionaries have created scientific breakthroughs, affected public policy, improved orthopedic and rehabilitative treatments and mobilized a community to raise awareness about OI.

The Osteogenesis Imperfecta Foundation recognizes Dr. Francis Glorieux with the 2014 Humanitarian Award for his outstanding commitment to people with osteogenesis imperfecta.

Dr. Glorieux is currently an Emeritus Professor at McGill University and Chairman of the OIF Medical Advisory Council. From 1972 to 2011, he was the Director of Research at the Shriners Hospital for Children in Montreal.

Among many accomplishments, Dr. Glorieux developed a model center using a multidisciplinary approach to treating OI; trained physicians from all around the world; and built a career that combined patient care and research. His research has focused on OI and other bone disorders and includes the landmark 1998 study, on the response of children with OI to bisphosphonate therapy. More recently he has worked on identifying new forms of OI; expanding understanding of how bisphosphonates may benefit children with OI; and uncovering how different bisphosphonate molecules work in different age groups. He is the author or editor of many publications including the OIF's Guide to OI for Pediatricians and a contributor to the latest text book on OI. He is a Principal Investigator for the OIF's Linked Clinical Research Center program and continues to consult with doctors and researchers all around the world. Dr. Glorieux's sincere interest in patients and exceptional investigative skills make him a role model for the modern clinician-researcher.

The Osteogenesis Imperfecta Foundation thanks Dr. Glorieux for his leadership and his never ending commitment to children and adults living with OI.

First National Unbreakable Spirit® Walk-n-Wheel Brings OI Community Together in Indianapolis

On Thursday, July 31st, over 250 members of the OI community came together to kick-off our National Conference weekend with the National Unbreakable Spirit® Walk-n-Wheel for OI! Beginning at the JW Marriott, participants walked or wheeled one of Indianapolis' most beautiful landmarks, the Canal Walk of White River State Park. A local DJ and a clown from Shriners Hospitals for Children got the festivities started before handing the microphone over to OIF Board of Director's President Mark Birdwhistell and Indianapolis Attorney Greg Fehrbach who welcomed participants and – with the help of over a dozen children – cut the ribbon to start the group off on the mile long route. We would like to thank our sponsors: Health & Hospital Corporation of Marion County; Firestone; Eskenazi Health; Streetscape Co; BSA Life Structures; Shriner's Hospital for Children Chicago; the Indianapolis Pacers; CSO Architects; the Indianapolis Indians; and John Klipsch Consulting along with the 28 teams that were formed for helping us take Indianapolis by storm and making the Unbreakable Spirit® of the OI community known!

If you would like to hold your own Unbreakable Spirit® Walk-n-Wheel or you are interested in helping us plan our 2016 National Unbreakable Spirit® Walk-n-Wheel in Orlando, please contact Melissa Bonardi at mbonardi@oif.org.



VOLUNTEER OF THE YEAR NOMINATIONS

Do you know a volunteer from the OI community who deserves to be recognized? Nominate them for the OI Foundation's Volunteer of the Year award! Entries must be postmarked by October 17, 2014. Nomination forms are available at www.oif.org/hh_volunteers.





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National OI Awareness Week 2015

National Osteogenesis Imperfecta Awareness Week 2015 will take place May 2 - May 9, 2015!

Wishbone Day, the international OI Awareness day, is on Wednesday, May 6, 2015.

During National OI Awareness Week 2014, the OI community proclaimed OI Awareness Week in 13 states, received a National OI Awareness Week Resolution from the House of Representatives, held nationwide events with over 2,000 participants, displayed over 400 OI Awareness Week posters and reached **over 300,500** people through social media! Keep an eye out for our #SHAREforAWARENESS and #OIAwarenessWeek2015 posts!

We challenge the OI community to raise even more awareness during National OI Awareness Week 2015 – we can do it! To start planning an Awareness Week event or to take part in National OI Awareness Week Blue Jeans Day on Friday, May 8, 2015, contact Danielle at dcyember@oif.org.

Stay in the loop! For more information about National OI Awareness Week and the OIF, “Like” the OI Foundation Facebook page (www.facebook.com/osteogenesisimperfectafoundation) and follow [@OIFoundation](https://twitter.com/OIFoundation) on Twitter (www.twitter.com/oifoundation)!



CALLING ALL SWIMMERS!

Join members of the OI community in our new 50,000 Laps – One Unbreakable Spirit® Challenge! Commit to swimming any number of laps to help us reach our goal of collectively swimming 50,000 laps – to represent the 50,000 people with OI in the United States – during the month of May 2015. You can swim all of your laps in one day, or spread it out throughout the entire month. Complete your goal by yourself or swim with a team! However you do it, we ask each swimmer to register and log laps swam so you can watch the members of our community work together to reach our goal of swimming 50,000 laps and raising \$100,000 for the OI Foundation! For more information or to sign up, email Danielle at dcyember@oif.org or visit www.oif.org/50000Laps.

Back to School Season: Making a Plan for the Academic Year

For many students and parents, September means the end of summer vacation and time to shift gears to return to more rigid schedules, homework and school activities. When OI is in the picture, students and parents alike may have some anxiety in the beginning of the school year about new classmates, new school staff, and different academic expectations. The transition back to school can be stressful for the entire family; however, the start of the school year can be a good time to open clear communication channels in meeting new teachers, reviewing information about your child's physical strengths and needs, and to deciding how you want OI explained to your child's classmates. It is also important to brief the school staff about any changes in your child's condition over the summer due to surgery or accident and to review plans for handling possible health concerns at school.



If your child has an IEP or other education plan, September is a good time to review it. Parents need to monitor that the IEP is being correctly implemented. If school personnel- counselors, physical education teachers, or administrators have changed since the IEP was written, it is important for parents to introduce themselves and their child early in the school year.

In many elementary schools, your child's teachers and the school nurse will be your contacts for handling day-to-day activities and emergencies. They will be the first in line to discuss accommodations and to make any requirements known. It may also be important to you that you connect with everyone who interacts with the child, including the school counselor; principal, student aid (if applicable), and a physical/occupational therapist. Listed below are some of the important topics to talk over with the staff at your child's school:

Fractures: Establish a written policy in regard to handling your child and the use of his/her equipment. Establish who will be called when a fracture is suspected or your child is in pain. Keep an emergency contact list in an established place for substitute teachers, school nurses and other school personnel.



Time out of school: Understand the school's policies when your child has to be out of class for an extended period of time- planned or unplanned.

Physical activity: If your child fatigues easily when performing physical activities, discuss the child's physical endurance level with the teacher.

School environment: Walking through your child's planned routes to the playground, auditorium, or restroom can help identify areas that will be difficult for crutches, walkers or a wheelchair.

Personal aide: If your child has an aide, discuss the role the aide should play to ensure the child's maximum participation in classroom instruction, physical independence and peer socialization.

Toileting: Children with OI may require assistance for toilet transfers or may require a bathroom large enough to accommodate a walker or wheelchair. Determine a bathroom plan and discuss if the child will utilize the class bathroom, an alternate bathroom or whether his/her toileting needs will be addressed with the school nurse.

Fire evacuation: Parents should work with teachers and school administrators to establish a fire evacuation plan. Determine the safest way to transport the child and the wheelchair safely from the area. This should be clearly posted for all school staff to follow and should be practiced so both your child and the staff know what to do.

Balancing school with life's other demands can bring a long list of new things for parents, teachers, and students to do at the beginning of a school year. Effective parent-teacher communication year-round is essential to a healthy and successful academic year, and necessary for your child's learning and social growth. If the school staff has any questions about OI or how to develop plans for working with your child, give them contact information for the OI Foundation's Information and Resource Center. The OIF has informational brochures and booklets that may be useful and can answer any questions they may have.

The OI Foundation Welcomes Four New Board Members

In July, the OI Foundation was pleased to welcome four new board members to the Board of Directors. We look forward to these four outstanding individuals' contributions to the OI Foundation.



Michele Burka is the previous Director of Finance and Contracts for a Tampa, FL, non-profit organization. She is currently working as an adjunct professor teaching Healthcare Economics and Healthcare Finance online. She holds a Masters in Business Administration and has years of experience with finance, accounting and grant writing.

She is an avid fundraiser; OIF support group leader and has a passion for making an impact in the OI Community. Michele is an active Florida support group volunteer and helped to plan the recent regional meeting in Tampa. She lives in south Florida with her husband James, her 22 year old daughter Justine (no OI) and their daughter Olivia who is living with OI Type V.



Eric Gould is a Partner of TG&C Group, a boutique federal government affairs consulting firm in Washington, DC. Eric has combined a career of law, public policy, business development and politics. He has extensive experience in working with clients in the private sector and focuses his practice on federal

government affairs, regulatory affairs, and strategic planning for businesses, trade associations and organizations.

Before developing a private practice, Eric served at the White House as a Domestic Policy Advisor to President Clinton, where he developed and managed a broad portfolio of domestic policy affairs. Eric also worked on Capitol Hill for Ways and Means Chairman Sander Levin and Representative Karen Thurman.

He earned his undergraduate degree from the University of Michigan and his law degree from the University Of Florida College Of Law.

Eric began volunteering for the OI Foundation in 2011 and helped secure congressional language in the HHS budget for OI specific research. He has helped organize the OIF's lobby day and is very active in the Rare Bone Disease Patient Network's advocacy activities.

Eric splits his time between Florida and Washington, D.C. He and his wife Laura have also been active participants in various OIF fundraising events. The Gould's nine-year-old daughter is living with OI.



Joe Hall is a web developer, and digital marketing professional who has worked on both the national and local levels around a variety of diverse topics and technologies. Most of his work has been focused on developing the tools needed for small businesses and nonprofits to become empowered on the

internet. Describing himself as "web-head", Joe engages the internet with a passion and desire to bring change and new opportunities to his clients and users. During college Joe was the co-director of the National Disabled Student's Union. Joe has type 3 OI and lives in Columbia, South Carolina.



Laura L. Tosi, MD, is a pediatric orthopaedic surgeon at Children's National Health System in Washington, D.C., where she has been on staff for over 25 years. Her clinical practice focuses on the orthopedic care of children with physical disabilities, bone health, and the medical and orthopaedic

challenges faced by adults with childhood onset conditions. Dr. Tosi is the founder and director of the Children's National Pediatric Bone Health Program. She has served on the Board of Directors of the American Academy of Orthopaedic Surgeons (AAOS), the Pediatric Orthopaedic Society of North America, the Orthopaedic Research and Education Foundation, the Academic Orthopaedic Society and the Society for Women's Health Research. Dr. Tosi is a past President of the Ruth Jackson Orthopaedic Society, the professional association for women in orthopaedics. She received their Presidential Special Merit Award in Year 2000 for her outreach on topics on women's musculoskeletal health. She received the AAOS Diversity Award in 2005. Dr. Tosi currently serves on the Medical Advisory Council of the Osteogenesis Imperfecta Foundation and is the Chair of the OI Adult Natural History Initiative.

From the Information Center



National Conference Photo Booth

The OIF is grateful to volunteer photographer Stephanie Dowell and the many people who participated in the Conference Photo Booth. Watch for these beautiful pictures on the OIF website and in upcoming publications. They really capture the OI community's unbreakable spirit.



by OI indicates that respiratory health is important for everyone who has OI. This information makes it even more important that children and adults who have OI seek treatment for respiratory infections, protect themselves from illness such as the flu, and consult with a pulmonologist if they are short of breath or have signs of sleep apnea.

Parenting Guide on Sale

Questions related to parenting the child who has OI and their siblings are frequent topics of conversation at the OIF National Conference. An excellent book by Kay Kriegsman, PhD and Sara Palmer, PhD not only offers practical suggestions, but many of the examples come directly from OI families. Dr. Kriegsman, a psychologist, has worked with OI families for decades and has spoken at several OIF National Conferences. She is very aware of the special circumstances faced by OI families. The book, **Just One of the Kids: Raising a Resilient Family When One of Your Children has a Physical Disability**, was published by Johns Hopkins Press. Each section features the stories of real families including many from the OI community. The book has received excellent reviews for being encouraging, practical and helpful. It is available for purchase through Amazon, Barnes & Noble and other on-line book stores.

Shopping Bonus in September

Through the Amazon Smile program, Amazon.com will make a donation to the OI Foundation each time you make an online purchase. Thousands of products are eligible including technology, books, clothing, toys, jewelry, shoes and movies. There is no cost to the consumer. All you have to do is go to <https://smile.amazon.com/ch/23-7076021> and follow the simple steps to sign in or set up an Amazon account. What could be easier? Please share this information with your friends, neighbors and relatives. The greater the number of shoppers who designate OIF as their charity and participate in this on-line shopping program the better!

Breathing – Popular Session at National Conference

Getting the most out of each breath is obviously important to all of us. Dr. Robert Sandhaus, a pulmonologist from Denver, CO and a member of the OIF's Medical Advisory Council spoke on this important topic at this year's National Conference. He reminded his audience that OI affects not only bones but the connective tissues of many organs. Lungs are rich in type I collagen and their structure is affected by the OI mutation. People who have OI can have a variety of breathing (pulmonary) problems. Until recently problems with bones such as rib or vertebral fractures, chest wall size and shape, kyphoscoliosis and short stature were seen as the causes for most breathing problems. Understanding that the lungs themselves are affected

Transition to Adult Health Care

The many challenges of moving from childhood to adulthood and in particular from care at a pediatric medical center into the adult health care system were the focus of a series of conference sessions for Young Adults who have OI. A pediatric transition team from Nemours Alfred I. duPont Hospital for Children in Delaware, who spoke at the conference, recently produced a series of videos titled "Becoming an Adult" for youth and young adults with special health care needs and their families. The video series covers topics such as self-advocacy, independent living, vocational rehabilitation, and other community-based resources related to transitioning health care needs. Titles currently available are "What Will I do After High School," "Legal and Financial Planning," "Taking More Responsibility for My Health Care," and "Where Will I Live after High School." The videos are closed captioned, and can be viewed online and on the YouTube web/mobile phone application. Go to the hospital website, www.nemours.org, and enter "Transition of Care" in the search box to find the link to the video page.

Wheelchair Exercise Video Continues to be Popular

Have you noticed that these days, the solution for everything from clothes that don't fit well, to a grumpy mood is to start exercising? The series of exercise videos on the Hospital for Special Surgery website for people who spend most of their time in a wheelchair or who prefer to be seated can be a good place to start. The program for adults was created by Dr. Cathleen Raggio, an orthopedist and member of the OI Foundation's Medical Advisory Council and Frances Baratta-Ziska PT. The goal of any exercise program is to improve your ability to do things that matter in your life. Dr. Raggio stated, "This exercise program provides opportunities to improve muscle strength, endurance, flexibility and coordination." The precautions section of the first video reminds viewers that it is important to check with your doctor or PT before starting a new exercise program and to never do a movement that is painful. To view the videos go to the Hospital for Special Surgery website www.hss.edu and click on "Conditions and Treatments" and then on the letter "O."

What You Need to Know about Lupin

Lupin is a legume that belongs to the same family as peanuts and increasingly it is being used in packaged foods. It has been brought to our attention, because lupin and lupine derived ingredients are often used in gluten-free products. Some people who have OI also have peanut allergies or are on gluten-free diets. Not everyone who is allergic to peanuts is sensitive to lupin but a peanut allergy increases the chances of developing a lupin allergy. This is another reminder of the importance of reading the labels on food packages. Symptoms of a reaction to lupin include hives, swelling of the lips, vomiting and breathing difficulties. Advice from the US Food and Drug Administration is to stop eating the product and to seek medical attention.

National Conference Session Summaries

This year, many of the conference speakers provided handouts, or wrote short summaries or "Take Home Messages" for their sessions. These have been posted on the OIF website. To view them, go to www.oif.org and click on the Events Tab. The summaries are listed on the bottom of the national conference page. Items continue to be added as they become available.

New OIF Toll-Free Telephone Number

The OI Foundation has a new toll-free number! Please update your records with our new toll-free number, 844-889-7579. You may also reach OI Foundation staff at 301-947-0083 and by email at bonelink@oif.org. The OI Foundation office is open Monday through Friday 9am-5pm EST.

Research Announcement

The OI Foundation would like to bring a study to your attention. Adrienne Baez, a Master's Degree student who has OI herself, is doing a survey about how people who have an obvious physical difference cope. It is titled "Body Image as a Moderator of Disability and Resilience." This on-line survey is estimated to take 30 minutes. You are eligible to take this survey if you meet the following criteria:

1. You have a diagnosis of osteogenesis imperfecta (OI).
2. You are age 18 or older.
3. Your first language is English.

For more information and to read the official announcement, go to the OIF website and click the Research Tab. If you would like to participate in this study go to <http://tinyurl.com/OI disability survey>.

15TH ANNUAL FINE WINES STRONG BONES

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