



SHOW YOUR
Unbreakable Spirit!®

MAY 6-13, 2017

NATIONAL OSTEOGENESIS IMPERFECTA AWARENESS WEEK

National Osteogenesis Imperfecta Awareness Week is May 6-13, 2017! National OI Awareness Week is a week dedicated to raising awareness for OI and sharing your Unbreakable Spirit. OI Awareness Week will kick off with **Wishbone Day**, the International OI Awareness Day, on May 6.

Here are ways you can get involved in National OI Awareness Week 2017:

1. Proclaim OI Awareness Week in Your State! Each year, our goal is to proclaim National OI Awareness Week in every state! Help us proclaim OI Awareness Week nationwide by requesting a proclamation for your state. For more information, visit www.oif.org/AwarenessWeek or contact Danielle at dcyMBER@oif.org.

2. Like, Share & Retweet! In 2016, our National OI Awareness Week posts reached over 160,000 people on Facebook! Help us raise OI awareness online by "sharing" our **#SHAREforAWARENESS** posts on your Facebook or Twitter page during OI Awareness Week. "Like" the OI Foundation on Facebook at www.facebook.com/OsteogenesisImperfectaFoundation or "Follow" the OIF on Twitter at www.twitter.com/OIFoundation.

3. Blue Jeans for Better Bones Day! Get your school, office, or community involved in National OI Awareness Week—it's as easy as throwing on a pair of blue jeans! For more information or to start planning your Blue Jeans for Better Bones Day during OI Awareness Week, visit www.oif.org/BJBB.

For more information about National OI Awareness Week 2017, visit www.oif.org/AwarenessWeek.

Paralympic Gold Medalist McKenzie Coan Will Swim for OI in May

On May 19 in New York City, three-time individual gold medalist McKenzie Coan will join OI community member 13-year-old Jaden Sacks to help raise money and awareness for OI through the OIF's 50,000 Laps – One Unbreakable Spirit® campaign. The 50,000 Laps – One Unbreakable Spirit® campaign was created in 2013 after Jaden, at the age of 9, raised more than \$125,000 through a swim event she dedicated to the OIF.

McKenzie Coan competed in the 2016 Summer Paralympics in Rio where she won three gold medals and a silver medal. To add

to her impressive swimming resume, McKenzie also set a new Paralympic Record for the 1500m Freestyle in the 2016 Summer Games. Together, Jaden and McKenzie will contribute to our goal of swimming 50,000 laps in the month of May to help raise awareness and money that helps the OIF continue to fund OI research and provide OI families with life-changing information and resources.



Paralympic Gold Medalist
McKenzie Coan

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The OIF invites all members of the OI community to join us as we set out to swim 50,000 laps during the month of May to represent the 50,000 people in the U.S. living with OI! Whether you're an experienced swimmer, a beginner, or just like to have fun in the water, join us! Pledge to swim a certain number of laps during the

month of May and create a fundraising page so your friends and family can help support you to your goal!

Stay tuned to the OIF website, E-News and social media feeds for more details! To pledge laps and create your own personal 50,000 laps – One Unbreakable Spirit® webpage, contact Samantha at stodorovich@oif.org.

Uniting Unbreakable Spirits Regional Conference Program

Are you planning to attend an OI Foundation Regional Conference this year? If you are located near the regions of Quebec, Canada or the Pacific Northwest, be sure to mark your calendar to join us for the *Uniting Unbreakable Spirits* Regional Conference Program!

Registration is now open for the OIF Regional Conference in Montreal, Quebec, Canada. The one-day meeting will be held at the Shriners Hospital for Children—Canada on Saturday, June 3, 2017. A complete registration costs \$35 and includes access to a full day of information-packed sessions, lunch, and fun activities for children and families in a supervised game room. All attendees, children and adults, must register online. Children 12 years of age and under are free, but *must be registered*. Speakers will present sessions in English, and headphones will be available for French translation. A Fine Wines Reception will follow this meeting (more information on page 3). We owe a special thank you to Dr. Francis Glorieux and his team at the Shriners Hospital for Children-Canada for their hospitality and help in organizing this fun-filled day.

We are also looking forward to the Pacific Northwest OIF Regional Conference on Saturday, November 11, 2017 at the

Oregon Health and Science University (OHSU). The one-day meeting format is similar in every regional conference meeting location. Sessions will cover a variety of topics related to understanding and living well with OI for parents and adults in the community. Special lunch time sessions will take place at lunch to focus on new parents, young adults, and individuals with mild OI and hearing loss. Details on the speakers, sessions, and registration for this meeting will be announced on the OIF website by July 1st. We send a special thank you to Dr. Eric Orwoll and his team at OHSU for their help in planning this meeting.

For more information about the *Uniting Unbreakable Spirits* Regional Conference Program or to register for the next meeting, please visit www.oif.org/regionalconference. We hope to see you this year in Montreal or Portland!



Fine Wines Strong Bones Events – Join the Fun!

This has been a busy year for the OI Foundation's signature fundraising events –Fine Wines Strong Bones! We hope you will join us for one of the upcoming evenings in an effort to help the OI Foundation continue our mission to serve the OI community through new information resources, funding OI research and facilitating support groups across the country.

Strong Bones TAMPA – Please join the OI Foundation on Saturday, **March 25, 2017** at the Egypt Shriners' A La Carte Event Pavilion in Tampa, FL, for the Strong **Bones Tampa**

event! We are very excited to work with members of the OI Foundation's Florida Support Group in an effort to share their passion for spreading awareness about OI and raising funds to support the mission of the OI Foundation. The evening promises to be a fun night out full of auction items, a basket of cheer raffle, cocktails and a full buffet dinner provided by Tony's restaurant in Ybor City. Tickets are available for \$50 per person or gather your friends to purchase a discounted table for ten for \$400. Visit www.oif.org/StrongBonesTampa to purchase your tickets today!

(continued on page 3)

Fine Wines Reception NEW YORK – Next up, Sotheby's Auction House is giving guests of the OI Foundation special after-hours access on **Thursday, April 6, 2017** for the first ever **Fine Wines Reception New York!** Attendees will sample Sotheby's fine wines and enjoy light fare. There will be a silent auction, a live fund-the-mission auction run by one of Sotheby's own auctioneers and even a chance to win a one-carat diamond! Visit www.oif.org/FineWinesNYC for more information or to purchase your tickets for \$75 per person.

Strong Bones Gala BOSTON – Due to the overwhelming success of their family's annual *Unbreakable Spirit® Walk-n-Wheel*, Christine Rossi and her father, Dick Wyman will be at the helm of the host committee for the first-ever **Strong Bones Gala: Boston**. The casino night themed gala will be held at the Sheraton Framingham on **Saturday, May 20, 2017** and will feature exciting casino games, a performance by Rob Surette (the fastest painter in the world) and auctions to benefit the OI Foundation. As Dick says, "We are excited about the new gala event on May 20th here in Framingham, MA! We hope that members of the OI community will attend the event, bid on silent auction items or make a donation to make the event a success. We need your help to reach our goal to raise \$100,000."

Tickets are available for \$100 each, \$180 per couple or \$850 per table of ten at www.oif.org/StrongBonesBoston.

Fine Wines MONTREAL – This intimate evening will immediately follow the OIF Regional Conference on **June 3, 2017** at the Shriner's Hospital for Children-Canada in Montreal, Quebec.

Strong Bones CHICAGO – Looking forward past the summer, the **3rd Annual Strong Bones Gala: Chicago** will be held again at the Chicago Cultural Center on **September 30, 2017!**

There are still more Fine Wines Strong Bones events being planned! If you are interested in helping with an existing event or if you would think your city would be a good location for a Strong Bones Gala or a Fine Wines Reception, please contact Melissa Bonardi at the OI Foundation at 301-947-0083. For information on all of our upcoming galas, please visit www.oif.org/FineWinesStrongBones.

Our 2017 Fine Wines Strong Bones events are off to a great start!

On **Friday, January 27, 2017**, OIF Board of Directors President Ken Gudek and his wife Teresa held the **2nd Annual Fine Wines Reception: Naples in Naples, Florida**, and on **Saturday, February 25, 2017** the OI Foundation hosted the Great Gatsby themed **17th Annual Fine Wines Strong Bones Gala** at the Gaylord National Resort at Maryland's National Harbor. These two events raised more than \$200,000 for the OI Foundation in less than a month! Thank you to everyone who attended these events and continue to support the OI Foundation's Fine Wines Strong Bones program.



OIF Board President Ken Gudek and Jamie Kendall Fund Chair Tracy Mulroy having a great time at Fine Wines Strong Bones DC



Friends Amanda Danuski and Devon Verno Having a Very Gatsby Time at the 17th Annual Fine Wines Strong Bones Gala.



Fine Wines Strong Bones Gala Committee Member Lisa Parman and her family show their Unbreakable Spirit®.



Dr. Brendan Lee, OIF CEO Tracy Hart and OIF Board President Ken Gudek at the Fine Wines Reception Naples.



BBDC PI Dr. Brendan Lee addressing the attendees of the Fine Wines Naples Reception.



How Winning the National Public Radio (NPR) Tiny Desk Contest Changed the Life of Gaelynn Lea

The OI Foundation was excited to speak with OI community member and winner of the National Public Radio's 2016 Tiny Desk Contest, Gaelynn Lea. Originally from Duluth, Minnesota, Gaelynn started playing violin in 5th grade. She participated in various musical contests through high school and college, and played in bands and solo. Her career path shifted to the next level after winning the NPR Tiny Desk Contest in March 2016. Gaelynn was happy to share with us pieces of her journey as a musician living with osteogenesis imperfecta.

Question: What was your life like as a musician before winning the contest, and how did the victory influence your career after?

Gaelynn Lea: My life as a musician before the NPR Tiny Desk contest was very average. I played in Minnesota in three or four bands over the last ten years. Teaching violin was my main job, then I started performing solo shows at least once every weekend. After I won the contest, they warned me that things would pick up. Months will be crazy, and you will get a lot of requests to play, speak, and interview. They were right, it was even more than I expected!

Question: What message do you try to convey through your music?

Gaelynn Lea: The songs I write just come out the way they are. I don't intentionally sit and write a song with a specific message. The inspiration comes as you start writing. I would say the overarching theme of my music in general is that "life isn't always super easy or not always super happy, but there is always something beautiful about it and reasons to be hopeful."



Everyone interprets my music in their own way. I actually have a song about OI called "The Bird Song." It's not on my solo album, but I perform this song a lot. The idea of the song is that even if your body appears to be something that might hold you back, you are still free. Many times I feel like I am limited, but I decide to try anyway- and it always surprises me what I can do.

Question: Have you ever felt like you have had a set back from fractures or surgery?

Gaelynn Lea: Yes, a couple of different experiences come to my mind. In high school, I was in a music contest, and I advanced to the finals. Of course I was really excited to compete, but I broke my arm shortly after and ended up not being able to play. That was tough, but the biggest setback was when I was 18 and my doctor told me to schedule a spinal fusion surgery whenever I was ready. I kind of waited and avoided it because I didn't want to have another surgery. So when I was finally ready, I went in and the doctors said I shouldn't have waited as long as I did because they weren't able to fix it completely. They did prevent my scoliosis from getting worse, but now I have really bad back pain. If I went earlier, the situation would have been a lot better now. When you have a medical condition like OI, it's good to stay on top of what you need to get done and be your own advocate.

Question: What do you feel has been the biggest obstacle as a musician with a disability? Have you run into accessibility issues on tour?

Gaelynn Lea: Oh for sure! Most of the time people have to carry my wheelchair because there is no ramp to the stage, only steps. I feel kind of bad, but all venues know that I use a wheelchair before I come, and they still choose not to get a ramp. I usually end up being carried on stage, and there is a dignity issue with that. I often bring up the topic, but it's also a fine line because I don't want to be perceived as difficult and not get invited back. I'm trying to get more vocal about it, but some venues choose not to prioritize it and some do- it's just trying to

figure it out which ones do. Such is life for a musician with a physical disability!

Question: What are your plans for the future? How can your fans in the OI community keep in touch with you?

Gaelynn Lea: I am really excited about what is coming up this year and the opportunity to connect with a wider audience! I'm booked through this summer, and I'm starting to fill in dates for 2018 now. I am also starting to get things together for my next album and eventually write a book. I am thrilled to meet many more OI community members, and look forward to participating in the OIF National Conference in Baltimore, Maryland, in July 2018!!

To stay connected with Gaelynn, you can visit her website at www.gaelynnlea.com, follow her on Facebook at www.facebook.com/gaelynnlea, or make plans to stop by at one of my upcoming tour locations!

“Before I toured with Gaelynn, I thought being on the road was tiring only because of driving long distances, dealing with sometimes low money, and being away from loved ones. It never occurred to me how many venues are not accessible, and how much more difficult that makes it for an artist or fan in a wheelchair to even get into the club or onto the stage. Gaelynn and I played in several venues with no ramp to the stage, meaning she had to choose between playing on the floor in front of the stage, which sometimes meant no lighting, or asking her husband Paul and three other volunteers to lift her 300 lb. wheelchair onto the stage. We also played two venues where just to get into the building, one had to go down a steep flight of stairs. Able-bodied folks need to understand that there are artists and fans who are being excluded from performing and experiencing live music because of these barriers. The fact that Gaelynn and Paul maintain a positive attitude and find a way to work around these obstacles every night is a testament to their incredible work ethic. But if these barriers were not there, musicians and fans alike would benefit immensely.”

— Jess Klein, Musician who toured and performed with Gaelynn Lea in October 2016

The OI Foundation Welcomes Kasia and Samantha!

The OI Foundation's new Health Educator, Kasia Krolikowska, is thrilled to join the OIF team. Kasia started her professional education at Montgomery College (Rockville, MD) in 2011 after immigrating to the United States from Poland. She then continued her education at the University of Maryland, where she focused her studies on Public Health and Policy. While pursuing her academic degrees, Kasia volunteered at the transplant department of Georgetown Hospital where she worked with children on a daily basis. Most recently, Kasia interned at Evolent Health in Arlington, VA, where she focused on projects that shift health systems towards implementing value-based care solutions. As the Health Educator, Kasia will be maintaining clinic and physician databases and corresponding with community members about OI-related inquiries. Kasia feels fortunate to be a part of the OI Foundation, and she is delighted to meet members of the *Unbreakable Spirit*® community!

Samantha Todorovich is excited to join the Development team here at the OI Foundation. Samantha graduated from Florida State University in 2013 with a degree in Hospitality Management. Since graduation Samantha has worked at hotels in the Baltimore Area as a Sales Coordinator and was responsible for organizing and executing small events. As Development Coordinator, Samantha will be working with our Blue Jeans for Better Bones, Bone China Tea and 50,000 Laps – One Unbreakable Spirit® programs along with assisting with our Fine Wines Strong Bones events. Samantha looks forward to working with and becoming part of the OIF family and *Unbreakable Spirit*® community!



The OIF's newest employees, Samantha Todorovich and Kasia Krolikowska

Host an Event!

The OI Foundation has two long-standing programs, Blue Jeans for Better Bones and Bone China Tea. Together, the programs have raised over \$550,000 over the last 24 years.

Blue Jeans for Better Bones is a campaign that asks participants to make a donation which allows them to shed their business attire or school uniform and instead wear their favorite blue jeans. Participants can also purchase OI Foundation stickers and wristbands to wear along with their jeans. If you already wear jeans to work try making a themed day, like Hawaiian shirts or a sports team jersey. If you can't dress down, show your support by having participants wear a blue shirt, blouse or tie. The great thing about the Blue Jeans for Better Bones program is that you can tailor it to meet your specific needs. The first National Blue Jeans for Better Bones event was held on February 28th to help celebrate the 10th Annual Rare Disease Day. With seven participating schools, office and churches, the event raised more than \$2,000! Don't miss the upcoming national dates in 2017: May 12th, August 4th and November 10th. These dates don't work for you? Choose your own!



Bone China Tea is an event that takes place from the comfort of your own home. Simply choose a date and invite your guests to enjoy a cup of tea at home and make a gift to the OI Foundation with the money they saved by not going to an in-person event. The first official Bone China Tea date of 2017 was January 28th and we have added three more National Bone China Tea dates on the calendar this year: April 22nd, June 24th and October 6, 2017. If none of these national dates work for you and your community, you can host a Bone China Tea on any day you wish! You can order printed invitations from the OI Foundation or create your own Bone China Tea page online.

Blue Jeans for Better Bones and Bone China Tea participants contribute to the OI Foundation's awareness, support and research efforts and we appreciate your participation. If you wish to participate in either of these events or host your own creative event, please contact Samantha Todorovich (stodorovich@oif.org).



Best friends, Bella Parker and Lali Scott, enjoying a cup of tea

Building a Stronger BBDC Contact Registry: Calling All Men

Contact Registries play an important role in the advancement of research, especially for rare diseases. The Contact Registry is one of the projects of the Brittle Bone Disorders Consortium (BBDC) that is coordinated through a grant from the National Institutes of Health. The goals include discovering new laboratory markers that will lead to better treatments and developing improved methods to gain a deeper scientific understanding of osteogenesis imperfecta.

The contact registry continues to grow with 1215 participants and we need your help to spread the word! One demographic that we have noticed a participation difference in is **men living with OI**. Currently, only 34% of all BBDC Contact Registry participants are male, although OI occurs equally among genders. To be successful and effective, the BBDC Contact Registry needs to involve as many individuals affected by OI as possible. Proper representation of the OI population in research is critical to eventually advancing medical care.

So call your husbands, significant others, brothers, sons, and all other men in your life to make sure they are registered in the BBDC Contact Registry! Joining is easy and takes about five minutes. Besides the participant's name and contact information, they will be asked to answer a few general questions. Rest assured: all of the information in the registry is stored in a safe and secure manner. To join, visit www.rarediseasesnetwork.org/cms/bbd/Get-Involved/ContactRegistry and click on JOIN. The OI Foundation thanks you in advance for joining this registry and spreading the word.

CALLING ALL MEN

SPREAD THE WORD AND JOIN THE
BBDC CONTACT REGISTRY!

CURRENTLY only 34% of Brittle Bone Disorders Consortium (BBDC) contact registry participants are male, although OI occurs equally among males and females in all racial and ethnic groups.

SIGN UP for the **BBDC Contact Registry** to play a part in building a strong database of men and women to advance care and treatment options for osteogenesis imperfecta.

65% - FEMALE

34% - MALE

1% PREFER NOT TO ANSWER

WWW.OIF.ORG/BBDCONSORTIUM

Data Current as of January 29, 2017

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 Board Member Ted Trahan. 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 Friends,

Who do you turn to?

When our son Greg was born, we were swamped with questions and confusion. First was the unexpected medical report—a broken femur. What? *Isn't the femur a reasonably strong bone?* Then there were interviews with many health professionals; Hand surgeon *Wait, it's his leg that's broken not his hand!* Delivery doctor, pediatrician, geneticist...the list went on. And then the preliminary diagnosis: osteogenesis imperfecta. *Ok, that's one I've never heard of before.* All this was followed with more immediate tactical questions; How do you splint the leg? How do you keep an infant from shaking out of the splint? How do I care for a child with OI at home? How do the grandparents hold him safely? Are there any other local families with OI that we can talk to?

At the time it was the mid-1990s so I did a search on what was then called the *World Wide Web*. A single web page was returned for an organization called the Osteogenesis Imperfecta Foundation (OIF). *Is this group legit?* There was to be a conference in San Diego, so we signed up. So did the grandparents.

What ensued is a story of the OIF growing in depth and breadth of support for the OI community, including support groups, national conferences, researchers and clinics. Over the years the Foundation has increased its scope of medically verified information and resources. The OIF's web presence has grown as well, with webinars and podcasts. Most recently, the OIF has amped up its national presence with the Brittle Bones Disorders Consortium (BBDC), a multi-center program that focuses on understanding and providing better treatment options for all types of OI.



OIF Board Member Ted Trahan and his family

I cannot place a value on how much the OI Foundation has supported us through the years.

We've come a long way since the early days. Greg is an adult, finishing up college and pursuing his dreams. Of course, the OI is still there—part of his life and ours. Along with adulthood comes new questions about health, independent living and social life. *Whom do you turn to now?*

The OI Foundation recently acted on feedback from the community and initiated regional conferences, thereby increasing access to OI resources. The BBDC sponsors studies that address issues that concern adults: pregnancy, spine issues and drug therapies for severe OI, for example. **The most up-to-date and accurate information about OI continues to be available through the OIF.**

The OI Foundation is able to provide this support because of the generosity of the OI community. Almost half of the Foundation's revenue comes from individuals and fund-raising events. New and continuing membership in the Foundation not only gives you visibility to the Foundation's resources, it is vital to help the OIF continue to provide resources and support to the OI community, as well as furthering research. So I ask you: Would you consider starting or renewing your membership with the OI Foundation right now? **You can be a part of the OI Foundation being there for the next family with OI to turn to.**

Thank you!



Ted Trahan
Member, OIF Board of Directors

Tl:dr—The OI Foundation needs your support. Become a member today!

From the Information Center



Newly Designed Online OIF Information Center

The OI Foundation is proud to share a new look for the online Information Center! As you may have noticed, our newly redesigned Information Center page includes factsheets about OI, community resources, links for support networks, the audio and video learning center, and more! The buttons are easy to navigate, which we hope will improve the usability of the site and bring more first time visitors!

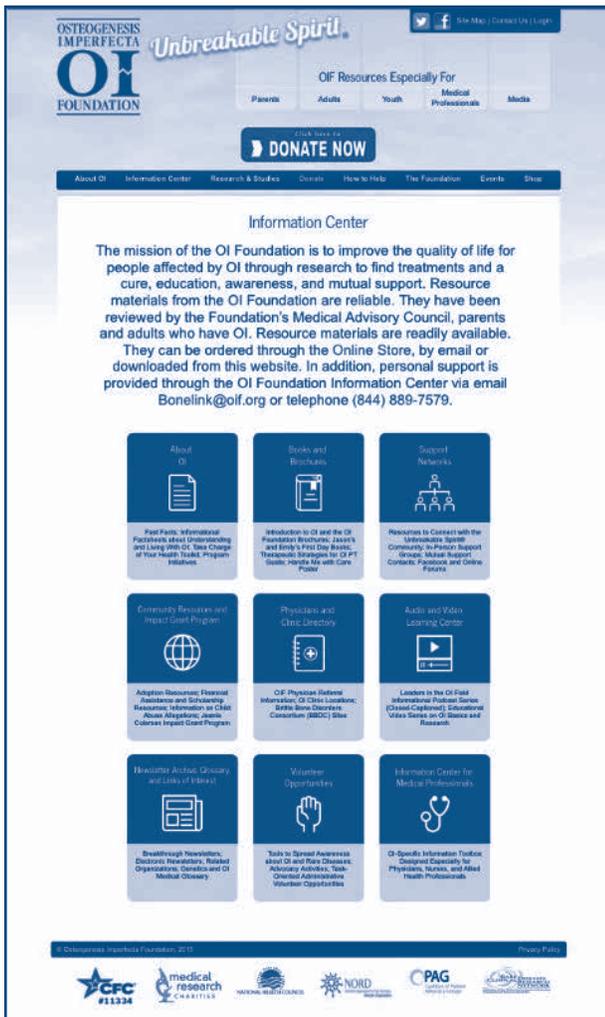
We hope that you will visit the new page at www.oif.org/InformationCenter and enjoy using it to learn more about OI and stay connected with the OIF and the Unbreakable Spirit® community!

2017 OIF Clinic Directory Available Online

The OI Foundation maintains a list of hospitals and clinics that offer coordinated treatment for people living with OI and other bone disorders. Some clinics see only children, while others see children and adults. Individuals who must travel to an OI Clinic also need a local primary care provider who will handle their routine and emergency needs. The OIF can help locate a doctor in your area who has experience treating OI. Email Bonelink@oif.org for specific physician referrals. Visit the 2017 OIF Clinic Directory at www.oif.org/ClinicDirectory to find a list of the clinics, name of clinic directors, the number of individuals with OI seen last year, and the services that each clinic offers.

Take Charge of Your Breathing

Respiratory health is a concern for children and adults with all types of OI. Lung connective tissue is altered in every OI type, but the severity of symptoms and risk for pulmonary problems are increased in people with short stature, abnormal chest shape, spine curves, and vertebral or rib fractures. Incorporating changes to *take charge of your breathing* does not have to be time consuming. Lifestyle changes as simple as avoiding smoking, getting regular exercise and talking about pulmonary health with your provider can significantly improve respiratory and overall health. If respiratory issues are ignored, the effects can dramatically diminish a person's quality of life and lead to serious health consequences. For more information on respiratory recommendations, please visit the **Take Charge of Your Breathing Factsheet** under the tab "Especially for Adults" on the OI website, or email Bonelink@oif.org.





Research Corner

The OI Foundation would like to bring your attention to a new section of *Breakthrough* called the Research Corner. The OIF regularly monitors research in the field of osteogenesis imperfecta and other related conditions, which will be highlighted in this section to increase education, understanding, and public awareness about OI. The Research Corner will feature easy-to-follow synopses of the latest research, discoveries and meetings relevant to the OI community.

Recent Publication about Spine Issues in OI

An article titled *The Spine in Patients with Osteogenesis Imperfecta* was recently published in the December 2016 edition of the *Journal of the American Academy of Orthopaedic Surgeons (JAAOS)*. Dr. Maegen Wallace of the Children's Hospital of Omaha, Dr. Richard Kruse and Dr. Suken Shah of Nemours/A.I. Dupont Hospital for Children in Delaware reviewed the incidence and treatment recommendations for several spinal manifestations of OI. Spinal deformities discussed in their article include scoliosis, kyphosis, craniocervical abnormalities, and lumbosacral pathology. For definitions of these terms, see the box below.

Types of Spinal Manifestations in OI

Scoliosis – a condition that causes abnormal thoracic and lumbar spinal curves

Kyphosis – a condition that causes abnormal excessive outward curvature of the spine

Kyphoscoliosis – the combination of scoliosis and kyphosis (common in severe OI)

Craniocervical junction abnormalities

- **Platybasias** – abnormal flattening of the base of the skull
- **Basilar impressions** – the process where the base of the skull lowers into the uppermost part of the cervical spine
- **Basilar invaginations** – more severe form, causing a narrowing of the opening where the spinal cord passes through to the brain. Can result in headaches, sleep apnea, weakness and loss of balance.
- **Secondary hydrocephalus** – a condition of excess cerebrospinal fluid in the brain cavities, perhaps due to the above conditions

Prevalence and Causes of Spinal Deformities

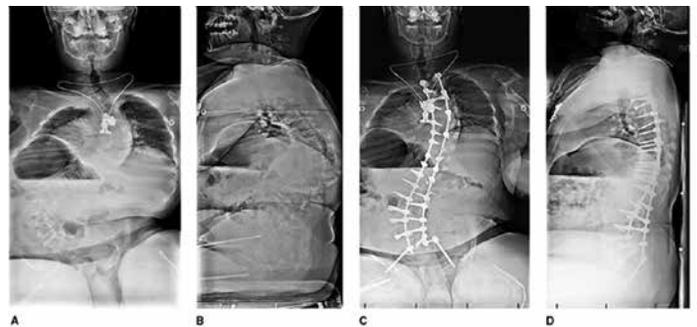
According to various studies cited in this article, the prevalence of scoliosis in OI ranges from 39% to 80%, depending on the type of OI. The exact cause of scoliosis in the OI population remains unclear and controversial. There are different theories used to explain the causes of scoliosis, including vertebral fractures, ligament laxity, muscle weakness, and unequal leg length.

Screening for Spinal Deformities

Scoliosis usually occurs after the age of 6; however, it is important to prevent rapid progression after it is diagnosed. "Kids with OI should be monitored for scoliosis; it can progress during the growth spurt and become quite severe very quickly, affecting their pulmonary function and quality of life," stated Dr. Suken Shah in the *Orthopedics This Week (OTW)* magazine.

Treatment to Correct Spinal Manifestations

Due to the high prevalence of respiratory issues in the OI population, it is important to note that progressive scoliosis can negatively affect pulmonary function, and eventually lead to restrictive lung disease. In this article, the authors noted that as thoracic scoliosis worsened by 20 degrees, vital lung capacity decreased by 37 percent. Surgical options to correct spine curves vary based on age, bone quality, curve rigidity, severity of



PA (A) and lateral (B) radiographs demonstrating severe osteogenesis imperfecta in a 16-year-old boy with an 87 degree thoracic curve, a 115 degree thoracolumbar curve, and substantial pelvic obliquity. PA (C) and lateral (D) radiographs obtained 2.5 years postoperatively demonstrate spinal fusion from T1 to the sacrum with cement-augmented pedicle screws and pelvic fixation. Image contributed by Nemours/Alfred I duPont Hospital for Children and copyright *Journal of the American Academy of Orthopaedic Surgeons*, 2017.

(continued on page 12)

OI, and other individual characteristics. Halo gravity traction and spinal fusion are two of the common treatments discussed in this article for individuals with progressive spine curves. The authors of this study agree that early bisphosphonate therapy can have positive effects on delaying scoliosis progression. Individual clinical evaluation and monitoring is necessary to determine the appropriate treatment strategy for spinal deformities in people living with osteogenesis imperfecta. For more information about this topic, please contact the OI Foundation Information Center at Bonelink@oif.org or (301) 947-0083.

Global and Local Involvement in Scientific Research Community

Over the past several years, the OI Foundation has become more involved globally, participating in international meetings and developing partnerships with other OI organizations and associations around the world. Over the past year, OIF CEO Tracy Hart and her counterparts at the Brittle Bone Society in the United Kingdom, Care for Brittle Bones in the Netherlands and the Osteogenesis Imperfecta Federation Europe have been meeting monthly via Skype to share information that potentially will benefit all organizations. They communicate about upcoming scientific and clinical meetings, awareness activities and challenges that they all face in providing programs and services for all members of the OI communities they serve. In August 2017 the OI International Scientific Meeting will be held in Oslo, Norway and will be attended by scientists and clinicians from all over the world interested in learning more about OI research. Several members of the OIF's Medical Advisory Council will be featured speakers and participants. Tracy Hart and OIF Board President Ken Gudek will be representing the OIF as well. "It's important to stay current with global research that focuses on OI", said OIF CEO Tracy Hart. She added "Organizations like the OIF can play an important role in facilitating and accelerating research by making sure we have an informed and knowledgeable community ready to participate in upcoming studies and trials."

While the OIF continues to collaborate internationally, specifically with other OI organizations, the OIF has also become a leader in the rare bone disease community which includes other disorders that affect bone including but not limited to OI. The newly formed Rare Bone Disease Alliance, a program of the OIF, will strive to expand awareness and accelerate research of rare bone disease and other disorders where bone is involved. Alliance partners will include industry, medical/scientific representation

Primary Source: Wallace, Maegen J., Richard W. Kruse, and Suken A. Shah. "The Spine in Patients with Osteogenesis Imperfecta." *Journal of the American Academy of Orthopaedic Surgeons* (2016).

Secondary Source: Hofheinz, Elizabeth. "Osteogenesis Imperfecta: What's Happening in the Spine?" *Orthopedics This Week*. RRY Publications. (2017). <https://ryortho.com/breaking/osteogenesis-imperfecta-whats-happening-in-the-spine/>



From left to right; Inger-Margrethe Stavdal Paulsen (President of the Norwegian Osteogenesis Imperfecta Foundation), Silje Marie Hebnes, Tracy Hart (CEO of the OIF) and Rebecca Skarberg (front)

and patient organizations committed to finding treatments that will improve the quality of life for people living with a rare bone disease. The goals of the Alliance include educating physicians by participating in professional society meetings, encourage legislators to increase research dollars to the NIH to study rare bone disease and help patient organizations to increase programs and activities that directly benefit people living with a rare bone disease. The OIF has witnessed an increase in interest from industry and scientists in studying rare bone disease and is committed to being a resource to all involved to ensure that OI research is at top of mind for those developing treatments and therapies. For more information the Rare Bone Disease Alliance, visit www.rbdalliance.org.

Unbreakable Spirit® Community Service Dog Owners: Insights on Finding Companionship, Independence, and Security

Commonly referred to as “man’s best friend,” dogs are known for their loyalty and companionship with humans. Many Unbreakable Spirit® community members can relate to this sentiment, especially with personal experiences of owning a skilled companion or service dog. According to the Americans with Disabilities Act (ADA), a service animal is defined as a dog that is individually trained to do work or perform tasks for people with disabilities. The service dog screening, selection, and training process varies between dog centers and sponsoring agencies. The functions and types of service dogs include wheelchair assistance dogs, medical alert dogs, hearing dogs, mobility support dogs, visual assistance dogs, psychiatric service dogs, and more.

Many individuals living with OI and other physical disabilities are able to reach new levels of independence with a service dog. It is common for people with OI to use service dogs to assist with mobility, retrieve dropped items, open doors, turn on and off light switches, press elevator buttons, push or pull wheelchairs, and help with other personal tasks. Below are a couple of quotes and stories from Unbreakable Spirit® community service dog owners:

“Chloe has absolutely changed my life! She is such a blessing. It’s the simple things like being able to pick up something off of the floor, or open a door that many people take for granted. Chloe allows me to be so much more independent, and my life has improved immensely since she has come into my life.”

– Michaela Davert, Bay City, Michigan



Michaela Davert with her service dog, Chloe.

“Three years ago, I broke my left tibial/fibula and had to have surgery. During this time, I also suffered tendon/ligament damage and was in great pain. In the hospital, I was not able to relax well until I put my hand on Lloyd’s head. Lloyd has been such a blessing because he has performed tasks for me, such as getting my medical bag. This is a new command I taught Lloyd. The medical bag has different items I might need in an immediate emergency if I were to fall and break. He also helped me by picking up my phone and other items that I would not have been able to reach from my wheelchair. Lloyd has been a blessing beyond words. Lloyd is very special to me and I can’t see my life without him. Canine Companions for Independence (CCI) has given me the ability to have independence that I would not be able to have otherwise. Because CCI provides their dogs at no cost to the recipient this allows more individuals to receive assistance dogs that really need them. Having an assistance dog has been the best thing that has happened to me because he has helped me recover from surgeries, breaks and through stressful times.”

– Lauren Brown, Cape Coral, Florida



Lauren, her parents Brent and Debbie, and service dog Lloyd at the 2016 OIF National Conference.

If you are considering adding a service dog to your family, there are resources available to help you decide and develop a plan. Organizations that the OI Foundation is familiar with include Canine Companions for Independence, Paws with a Cause, Assistance Dogs International, Service Dogs for America, and NEADS. For more information or to connect with a service dog owner in the Unbreakable Spirit® community, contact Bonelink@oif.org.

Give Thanks with a Grateful Heart

Dick Wyman



Former OIF Board Member
Dick Wyman

Since the early 90s, I have written a number of articles in *Breakthrough* to inform readers of personal OI related matters involving surgeries for hearing loss and heart valve replacement as well as financial articles and even the first OI Planned Giving Booklet. Now I am once again sharing my personal experience in hope that I help answer questions for my fellow members of the OI community.

As I reach 70-and-a-half this month, I knew that I faced having to take qualified distributions from the funds I had put into my IRA and 401k plans over the past 40+ years and I knew I would be taxed on these distributions. You must take a minimum distribution based upon both the amount(s) accumulated and

mortality factors, every year after reaching 70½. Now, the Pension Protection Act (PPA) permits individuals to roll over up to \$100,000 from IRAs directly to a qualified charity without recognizing the assets transferred as income. There is also no requirement that the entire amount be made in one transfer or that the entire amount go to a single qualified charitable organization. Thus in a given year, you can choose to support the OI Foundation, OIF events in your area and other charities you support with funds that must be withdrawn from your IRA or 401k annually and will be treated as taxable income if you do not elect to make a qualified charitable distribution.

The first step to see if the PPA makes sense for you and your family is to contact the funds administration of the retirement fund(s). It is important you contact all fund administrators directly because the minimum distribution amount required must be calculated on a case by case basis based on the total funds you have in all accounts. Once the minimum distribution amount is calculated, you can choose which charities you would like to assign for your minimum charitable distribution(s). As my 70½ birthday approaches, I spoke with my fund administrator and was able to determine my personal minimum distribution requirements. I will be detailing my intentions in writing to my IRA account administrator for 2017 of my plans for my first minimum distribution to go towards our new Strong Bones Gala Boston event on May 20, 2017 as well as other charities I currently support. It is very important that any distributions go directly from your fund administrator to the charities you have selected in order to satisfy the requirements of PPA and so that you will receive full tax benefits.

The OI Foundation, under Tracy Hart's leadership, with her professional staff has brought our Foundation to unprecedented levels. My family is thankful for how far our Foundation has come over the past 45 years, but we know we need to do whatever we can to help the OIF continue to grow.

According to retirement plan industry expert, Jessica Espinoza, CFA, Vice President of Meltzer Retirement Plan Services "Charitable contributions from an IRA can provide enhanced tax advantages to those accountholders over the age of 70.5 that face Required Minimum Distributions (RMDs). RMD rules require that a certain level of distributions be made from IRA's annually, and that those distributions be taxed. This can force an accountholder to take out more in personal assets than they would have originally needed and increase their tax liability and potentially even their tax bracket. By directing an IRA distribution directly to a charity, an accountholder can avoid paying taxes on those dollars, and avoid having those dollars count towards their overall taxable income for the year. The charitable contribution satisfies the RMD requirement and keeps the accountholder tax neutral. We encourage all IRA accountholders in this situation to consult their tax advisor for more details."



Jessica Espinoza
Vice President
Meltzer Retirement Plan Services

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.

Join Fellow Members of the OI Community at an Upcoming Event



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®!

March

March 11th Florida Support Group Meeting – Shriner's Hospital for Children Tampa
March 25th Strong Bones Tampa – A La Carte Event Pavilion, Tampa, FL

April

April 6th Fine Wines New York City – Sotheby's Auction House, NY
April 22nd Bone China Tea

May

May 6th –13th National OI Awareness Week
May 6th Unbreakable Spirit Event – Buzzards Bay, MA
May 13th Atlanta Support Group Meeting – Children's Healthcare of Atlanta – Egleston Hospital, Atlanta, GA
May 19th 50,000 Laps, One Unbreakable Spirit
May 20th Strong Bones Gala Boston – Sheraton, Framingham, MA

June

June 3rd OIF Regional Conference: Montreal – Shriner's Hospital for Children: Canada
June 3rd Fine Wines Montreal – Shriner's Hospital for Children: Canada
June 10th 2nd Annual Sweat for Sammy 5k – Ridley Creek State Park, PA
June 17th Tri-for-OI – Callaway Gardens, GA

July

July 10th Miracle Michael Golf Outing – White Eagle Golf Club, Naperville, IL
July 13th Riley's Gathering Golf Outing – Maple Meadows Golf Club, Wood Dale, IL

August

August 14th OI Golf Classic – Atkinson, NH
August 15th Dogfish Head Alehouse OI Day – Gaithersburg, MD

September

September 30th 3rd Annual Strong Bones Gala Chicago – Chicago Cultural Center, Chicago, IL

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

