National Osteogenesis Imperfecta Awareness Week is May 4-11, 2019!

National OI Awareness Week is a time to raise awareness for OI and share your Unbreakable Spirit®. OI Awareness Week is scheduled around Wishbone Day (May 6), the international OI Awareness Day. The OI community celebrates Wishbone Day by wearing yellow and by sharing facts and information through social media.

During OI Awareness Week, we encourage the OI community, Foundation, and supporters to use flyers, fundraising events, social media, and individual state proclamations to raise awareness for osteogenesis imperfecta. How will you raise OI awareness during National OI Awareness Week? Read more about getting involved on page 2.

(continued on page 2)

2019 Uniting Unbreakable Spirits Regional Conference Program

This year will be the biggest year yet for the Uniting Unbreakable Spirits Regional Conference program! These one day meetings bring together expert medical speakers to share information with attendees and provide people with OI and their families an opportunity to meet and connect. Past regional conferences have included presentations on genetic, orthopedic, cardiologic, and dental concerns for children and adults with OI. There have also been engaging panels on physical therapy, fitness, and self-advocacy by community members. It’s a chance to take part in informational sessions, connect with doctors, and meet new friends!

The 2019 locations include:

- **Chicago, Illinois** at Shriners Hospitals for Children: Chicago on April 13th
- **Atlanta, Georgia** in partnership with Children’s Healthcare of Atlanta on August 3rd
- **Wilmington, Delaware** at Nemours Alfred I. duPont Hospital for Children on October 26th
- **Sacramento, California** Summer 2019 - Stay tuned for more information!

Registration for each regional conference is $35 and includes access to all sessions, lunch, and a social reception after the conference. Children under the age of 13 are free to attend, but registration is required. Registration for Chicago is now open, and please check the Regional Conference Program webpage (www.oif.org/RegionalConference) on the OIF website for more details as they become available.
Make the most of National OI Awareness Week 2019:

**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](http://www.oif.org/AwarenessWeek) or contact Danielle at [dcymber@oif.org](mailto:dcymber@oif.org).

**LIKE, SHARE & RETWEET**

In 2018, our National OI Awareness Week posts reached more than 200,000 people on Facebook! Help us raise OI awareness online by liking and sharing our #SHAREforAWARENESS posts on your Facebook and Twitter pages during OI Awareness Week. “Like” the OI Foundation on Facebook at [www.facebook.com/OsteogenesisImperfectaFoundation](http://www.facebook.com/OsteogenesisImperfectaFoundation) or “Follow” the OIF on Twitter at [www.twitter.com/OIFoundation](http://www.twitter.com/OIFoundation).

**PLAN A 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](http://www.oif.org/BJBB).

**HOST A BONE CHINA TEA (May 8)**

Our favorite phantom event allows you to join your fellow OI community members for a cup of tea, no matter where you live. The best part? There’s no event to plan! Simply invite your guests to enjoy a relaxing cup of tea at home and then make a gift to the OI Foundation with the money they may have saved by not going out to a live event. For more information, visit [www.oif.org/BoneChinaTea](http://www.oif.org/BoneChinaTea).

For more information about National OI Awareness Week 2019, visit [www.oif.org/AwarenessWeek](http://www.oif.org/AwarenessWeek).

Bone China Tea is on Wednesday, May 8th!

“Your participation in Bone China Tea will help build relationships and friendships, increase awareness, and provide support among OI community members,” said Bone China Tea Chairperson Susie Wilson. “Just imagine how many more people we could reach if we meet our goal of raising $25,000 this year!”

To order printed invitations, please contact Jessica Skidmore at [jskidmore@oif.org](mailto:jskidmore@oif.org) or 301-947-0083. Share your name, home address, phone number, email address, and the number of invitations you plan to send to your family and friends and the OI Foundation will send them to you — complete with a tea bag!

Save money on postage— host your Bone China Tea event ONLINE! To set up your own personal fundraising page on the OI Foundation website, please visit [www.oif.org/bonechinatea](http://www.oif.org/bonechinatea) and select “Register as a Host.” Edit your page to tell your OI story and then send your invitations via e-mail or share it on social media.
Remembering Dan Krudys and Michael Johnston

The Board of Directors and staff of the OI Foundation were deeply saddened by the loss of two former OIF Board members this past year.

Dan Krudys joined the OI Foundation after the birth of his son, Jeffrey, in 1995. He quickly became an active member of the New Jersey Area Support Group and an active participant in their annual Beefsteak dinner. In 1996, Dan initiated an employee giving fundraiser with his company, UPS. He, along with Jeff, would visit UPS locations to spread awareness about OI and urge employees to contribute through the employee giving program. Dan was awarded the OIF’s Volunteer of the Year award in 1997 and joined the OIF Board of Directors in 2000. He served for three years, including one year as secretary. In recent years, Dan was a founding committee member for the Strong Bones Gala in Chicago, IL.

Michael Johnston was an active participant in the OI Foundation’s annual Bone China Tea fundraiser raising $100,000 since 1999. He served on the OIF Board of Directors from 2001-2007. Michael, along with his wife Bonnie and daughter Emma, were a constant presence at the OIF National Conferences and Regional Conferences both as speakers and attendees.

Both Dan and Michael were caring fathers and pillars of the OI community. They will be greatly missed.

Improving Care for Rare Bone Conditions with ECHO

Starting in the summer of 2019, the OIF, in collaboration with the Rare Bone Disease Alliance and OIF Medical Advisory Council member Dr. Laura Tosi of Children’s National Hospital, will help launch the inaugural Rare Bone Disorder ECHO Clinic. ECHO (Extension for Community Healthcare Outcomes) is a digital medical education program that increases a physician’s access to expert knowledge to help them improve their quality of care.

The Rare Bone Echo will aim to spread knowledge of rare bone conditions, like OI, to physicians and medical practitioners through monthly video tele-mentoring sessions. By increasing access to expert medical knowledge for physicians in this cutting edge and cost-effective model, the OIF aims to increase the standard of care for people with rare bone conditions.

The medical faculty will include:
- Mike Collins MD, National Institute of Dental and Craniofacial Research
- Mike Lewiecki MD, University of New Mexico School of Medicine
- Eric Rush MD, University of Kansas School of Medicine
- Jay Shapiro MD, Johns Hopkins Medicine
- Dolores Shoback MD, University of California San Francisco
- Laura Tosi MD, Children’s National Hospital
We would like to extend a special thank you to the local committee members and attendees for supporting the OI Foundation through Fine Wines Strong Bones events. You have helped support our mission to serve the OI community through creating new information resources, funding research, facilitating support groups, and raising awareness. We are proud to announce that our 2018/2019 Fine Wines Strong Bones season is off to a great start with events that have raised more than $350,000 so far! To learn more about Fine Wines Strong Bones events, please visit www.oif.org/finewinesstrongbones.

Boots & Bling for Better Bones
The Strong Bones Houston event had an amazing second year at Armadillo Palace! The event, held on November 10, 2018, featured delicious food, silent and live auctions, raffles, an open bar, and even live country music. Our host committee is very excited to announce that the 3rd Annual Boots & Bling will be held November 9, 2019!

Beef and Brew
One of the OI Foundation’s longest running fundraising events, the 2018 Beef and Brew for Better Bones, did not disappoint! Guests gathered once again at the Three Saints Cultural Center in Garfield, NJ on November 17, 2018 to enjoy a night of fun, including silent auctions, raffles, and unlimited filet mignon.

Fine Wines Reception Naples
The 4th Annual Fine Wines Reception Naples was a huge success! On January 24th, 2019, OIF Board President Ken Gudek and his wife Teresa, along with Andrea and Jeffrey Stewart and Jane and Jim Early, hosted the reception at the Naples Sailing & Yacht Club with over 100 attendees sampling fine wines, participating in live and silent auctions, and fantastic wine-themed raffles.

Fine Wines Strong Bones Gala
The Fine Wines Strong Bones Gala celebrated its 19th year on February 23rd! Guests gathered once again at the Gaylord National Resort for a masquerade-themed evening of casino games, raffles, and silent and live auctions. Founding committee member Tracy Mulroy gave an update on the Jamie Kendall Fund for OI Adult Health, and Dr. Robert Sandhaus spoke about the cardiopulmonary study he is co-leading thanks to funding generated from the fund-the-mission portion of the evening.
It’s not too late to join the fun! Consider attending one of these upcoming Fine Wines Strong Bones events:

**Fine Wines Reception New York City**
Mark your calendars for Tuesday, April 23, 2019! The 2019 New York Fine Wines Reception will be held 6-9 p.m. at the prestigious Sotheby’s Auction House. We hope you will join us for an exclusive after-hours look at the Old Master Paintings Exhibition, one of Sotheby’s premier exhibits, while enjoying light fare, sampling fine wines and raising funds for the OI Foundation.

**Strong Bones Boston**
Get your derby attire ready! The 2019 Strong Bones Gala Boston kicks off at 6pm on Saturday, May 4! Join us at the Sheraton Framingham for a fun night of games, food, an open bar, auctions and raffles, music and dancing, a photo booth, and even a contest for best Kentucky Derby hat!

**Strong Bones Tampa**
Strong Bones Tampa is coming back for another year! The 3rd annual Strong Bones Tampa will be held on Saturday, June 1, 2019 at The Italian Club of Tampa. Guests will enjoy silent and live auctions, raffles, a delicious dinner from Tony’s Restaurant, and a chance to support Shriner’s Hospital for Children Tampa’s continued participating in the Brittle Bone Disorders Consortium.

If you’d like to plan a Fine Wines Strong Bones event in your city, contact Melissa Bonardi at mbonardi@oif.org to get started.

More information about Fine Wines Strong Bones events is available at www.oif.org/finewinesstrongbones. All proceeds made from these events directly support the OI Foundation.

**Congratulations, Tom!**
Tom Costanzo, OIF Director of Finance & Administration, is retiring this summer after seventeen years of service at the OIF. While Tom will be missed by all of us at the OI Foundation, he certainly deserves his retirement. His hard work and diligence have greatly benefited the OI Foundation and OI community. Thank you, Tom!
Many individuals in the OI community use their talents to express their unique stories through music, painting, photography, books, and more. The OI Foundation is proud to share the hard work of creative OI community members who aim to raise awareness about OI.

Not Just Any Bag of Bones
Jonathan Studebaker was born with osteogenesis imperfecta (OI), and he lived a full life before his passing at age 35. Jonathan’s brother, Alden Studebaker, recently edited and published his brother’s autobiography, Not Just Any Bag of Bones, to share his story and honor his memory. Not Just Any Bag of Bones is available on Amazon.

Screenplay About OI Makes Rounds in Hollywood
The Warriors’ Concerto, written by Jamaal D. Pittman and Lila Hood, is a screenplay based on the true story of Lila’s experience taking on the legal and medical systems after being falsely accused of child abuse. Her baby had osteogenesis imperfecta. Over the course of two years, she and her family went to great lengths to seek justice and treatment for him. This screenplay has made quite an impact already, having placed in several reputable contests including semifinalist in the Austin Film Festival Screenplay Competition (top 200 out of 10,500 scripts).

Lila and Jamaal are incredibly passionate about increasing awareness for osteogenesis imperfecta and impressed with the incredible work the OI Foundation is doing. Lila is an electric violinist, an established recording artist, and a music educator. She strives to help other families who may be going through the same battles and to educate the world about this medical condition. Jamaal is a screenwriter and copy editor based out of Los Angeles and is very proud to help bring Lila’s story to the masses.

For more information about The Warriors’ Concerto, please email Lila Hood at theblueviolin@gmail.com or Jamaal D. Pittman at jp_mhouse@yahoo.com.
Since 1970, the OI Foundation has been a trusted source of information for the OI community, helping individuals stay connected and sharing up-to-date information about OI research and treatments. Help us as we prepare to celebrate the OI Foundation’s 50th Anniversary in 2020 by becoming a member today!

Your OIF membership will help:
- Provide medically verified information on OI to medical professionals, parents, caregivers, and individuals living with OI.
- Provide opportunities for people with OI to connect through the OIF website, social media sites, local support groups, and the OIF National and Regional Conferences.
- Accelerate the pace of OI research through scientific and clinical meetings and by funding new young investigator grants.

The OI Foundation owes its success to its members. The organization’s future depends on you! Show your support of the OIF by becoming a member today.

**Individual Membership Levels**
All individual members will receive an annual subscription to the OI Foundation’s newsletter, *Breakthrough*.

**Bronze**
$36 per year or just $3 a month
This membership comes with a 50th anniversary car magnet to show your OIF membership pride.

**Silver**
$60 per year or just $5 per month
This membership comes with a 50th anniversary OIF mouse pad to let everyone know you have an Unbreakable Spirit®!

**Gold**
$120 per year or just $10 a month
This membership comes with a 50th anniversary OIF mouse pad to let everyone know you have an Unbreakable Spirit®!

**Platinum**
$365 per year or just $1 per day
Show off your Unbreakable Spirit® with both the 50th anniversary magnet and mouse pad.

**Business Membership Levels**
All business members will receive recognition in the OIF Annual Report, a subscription to *Breakthrough*, access to the latest published scientific research and materials through the OIF’s MedEd newsletter.

**Professional**
$100 per year
This membership comes with a 50th anniversary car magnet.

**Corporate**
$1,000 per year
This membership comes with a 50th anniversary car magnet and mouse pad, logo placement on the OIF website, a half-page ad in *Breakthrough*, priority as an exhibitor and recognition in OIF National Conference materials, and the opportunity to include one flyer in the OIF National Conference attendee gift-bag.
Founded in 1863, Hospital for Special Surgery (HSS) is the oldest orthopedic hospital in the United States. Today, HSS is a 226-bed free-standing orthopaedic and rheumatologic hospital. As a leader in treating and investigating musculoskeletal disorders, HSS is committed to addressing problems related to bone growth and development. Towards that end, the OI Clinic at HSS began in 1970 under the direction of Drs. Leon Root and Peter Bullough. Today, the OI Clinic continues to offer individuals with OI acute and ongoing surgical orthopaedic care under the direction of Dr. Daniel Green. In 2003, orthopaedic surgeon and OIF MAC member Dr. Cathleen Raggio and medical geneticist Dr. Jessica G. Davis established the Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias (CSD) at HSS. The mission of CSD is the holistic care of patients, irrespective of age. This program was developed to meet the longitudinal needs of patients with skeletal dysplasias, including individuals with OI, across the entire lifespan. These combined services at HSS address the needs of children as well as adults, who need care despite having aged out of the pediatric departments at most hospitals in our region.

Patients and families with OI are followed by a multidisciplinary team. Clinical services include genetic evaluation, diagnosis and counseling; orthopaedic screening and treatment; physical therapy evaluation; psychosocial assessment; clinical nutrition evaluation; and referrals to a dedicated group of consultants for specialty medical evaluation/services. The multidisciplinary team develops an individualized treatment and management plan designed to meet the diagnostic, therapeutic and long term health needs of each individual and their families seeking services through the Center. Following the initial evaluation, the team develops an individualized treatment and management plan in conjunction with the patient and/or family. This approach fosters continuity of care across a person’s lifespan, and bridges the pediatric-adulthood gap for individuals and families whose lives are affected by OI.

People who are followed by our Center’s team have the option to participate in clinical research studies. These studies add to the medical knowledge about OI, and help us to evaluate treatments and therapies that may work to improve the lives of people with OI and their families. The Center serves as the New York site of the Brittle Bone Disorders Consortium, which is part of the National Institutes of Health Rare Diseases Clinical Research Network.

Ranked number one in its specialties by U.S. News & World Report, HSS takes tremendous pride in providing care to our patients, delivering specialty training to residents and fellows, and pursuing research that influences the future of musculoskeletal care. HSS is affiliated with New York-Presbyterian Hospital/Weill Cornell Medical Center, and every HSS doctor holds an appointment on the faculty of Weill Cornell Medical College. Accordingly, our team refers as needed to medical specialists at that institution. Their faculty, across various specialties, have experience caring for individuals who have OI.

For more information, please call Erin Carter, MS CGC at 212-774-7332.
Medics March 50 Miles in Support of the OI Foundation

The OI Foundation is lucky to have a group of dedicated physicians who generously donate their time to the OI Foundation and OI community. These physicians support OIF National and Regional Conferences, share information on the OIF podcast, lead OI research, and make themselves available to answer inquiries. Several members of the OI physician community are taking that dedication one step further by participating in the OIF’s first-ever Medics on the March event, where they will hike 50 miles to raise OI Awareness!

Support our incredible physicians and help them reach their collective goal of raising $100,000 – make a donation today at www.oif.org/MedicsontheMarch!

*Don’t forget to follow the OI Foundation’s Facebook page to see information about each medic and their progress on the march.

Become a Volunteer Community Educator Through OI Educate!

The OIF is proud to share more information about its newest training initiative: OI Educate. Over the past few years, the Uniting Unbreakable Spirits Regional Conference Program has grown and supported the OIF’s mission to increase awareness, education, and mutual support for those living with OI across the US. At these meetings, individuals have come together to learn new medical information and share their unique stories. The expertise in each room expands far beyond the physician speakers and medical professionals; many individuals and families have had to explain the condition and how it affects their lives to a variety of different audiences. With the new OI Educate program, the OIF aims to develop and support those who want to engage with a broader community by training them as OI Educators.

This program will provide volunteers with succinct, medically verified information so that they can better spread awareness and answer common inquiries about OI and the work of the OIF. OI Educators will serve as the “first line of support” in support group meetings, health fairs, medical school lectures, and digital fields like social media, phone calls, and emails. They will represent the OIF by helping to spread awareness of OI, its various treatment options, and by encouraging community engagement.

The program will cover basics of OI and the work of the OIF; including outreach, fundraising, volunteering. It will take approximately 5 hours to complete and include a pre-assessment and final quiz.

Interested? Contact Michael, the Regional Program Services Manager, at Mstewart@oif.org for more information.
Resource Reminders from the OIF Information Center

Brochures, Books, Factsheets, Support Group Information, Clinic Directory, Links of Interests, Audio/Video Learning and more are easy to access online at [www.oif.org/InformationCenter](http://www.oif.org/InformationCenter).

**OI Clinic Directory**

The OI Foundation recognizes that one of the difficulties that many OI community members face is finding a team of medical professionals who are familiar with OI. The OI Clinic Directory was created to provide you and your family with accurate, verified, and easily accessible information while locating multidisciplinary medical care.

The OI Foundation would like to express our gratitude to the clinic directors and their care teams for providing the information listed in the OI Clinic Directory. Please note that this list is offered as a service. Being listed does not indicate that the OI Foundation endorses services and quality of care provided by these institutions. It is the responsibility of parents and adults with OI to verify whether a particular medical team meets their needs.

The OI Clinic Directory is available at [www.oif.org/ClinicDirectory](http://www.oif.org/ClinicDirectory). For more information about the clinics listed, or to locate other physicians familiar with OI in your area, please email bonelink@oif.org.

**OIF Online Information Center**

The OI Foundation’s online Information Center provides published factsheets on many topics related to understanding and living with OI. More than 50 OI factsheets on topics including About OI, Education, Health Issues, Babies and OI, Spine, Adult Health, and more are available at [www.oif.org/RES_Information](http://www.oif.org/RES_Information).

**OIF Podcast Series**

The OI Foundation’s podcast series, Leaders in the OI Field on New Advances in Research and Treatment, is a part of the OI Foundation’s campaign to increase outreach and educate medical professionals who treat individuals with osteogenesis imperfecta. To listen to the available episodes, visit [www.oif.org/OIFpodcast](http://www.oif.org/OIFpodcast).

Learn More About Local Summer Camps for Your Family

When the word “camp” comes up, many children and adults think about traditional, outdoor living, sleep-over camps. There are actually many different types of camps, classes, tours and summer experiences that are designed for children and adults living with disabilities. An increasing number of traditional residential camps are tailored specifically for children and families affected by osteogenesis imperfecta. Popular camps in the Unbreakable Spirit® community include the Center for Courageous Kids (Scottsville, KY), Camp Korey (Mt. Vernon, WA), Camp Twin Lakes (Atlanta, GA), and the Hole in the Wall Gang Camp (Ashford, CT). Camp activities may include swimming, bowling, cooking, theater/performing arts, boating, fishing, arts and crafts, and more. Scholarships or financial assistance may be available for camps or classes.

If you are interested in learning more about summer camps, be sure to check with your local children’s hospitals or the nearest Shriners’ Hospital for information about programs that would be suitable for a child with OI. The American Camp Association, your local YMCA, or your city’s department of recreation may also have resources for children and families interested in participating in a summer experience this year.

Thank You for Your Service, Angel Flight East

Angel Flight East has experienced significant growth in the service provided to people who need air transportation to access medical care far from home. In the past 5 years, flights from throughout the Northeast, Ohio to Maine to Virginia, increased 44% — from just under 400 in 2013 to 909 at year-end 2018.

The value of this service to patients is immeasurable. No matter the number of flights, passenger families will never be charged. They are able to focus on healing, gaining relief from the stress of figuring out costly transportation on a monthly, bi-weekly and sometimes even weekly basis. At the same time, the friendships that develop between the volunteer pilots and the patients create an invaluable addition to families’ support networks.

For more information, please visit [www.angelflighteast.org](http://www.angelflighteast.org) or call 215-358-1900.
Join Fellow Members of the OI Community at an Upcoming Event

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

April

- April 13th: Chicago Regional Conference – Shriner’s Hospital for Children, Chicago, IL
- April 23rd: Fine Wines Reception NYC – Sotheby’s Auction House, New York, NY
- April 26th–28th: Medics on the March – C&O Canal Towpath, MD
- April 27th: Nicholas’ Bone China Tea Party – Yardley, PA

May

- May 4th–11th: National OI Awareness Week
- May 6th: Wishbone Day
- May 4th: 3rd annual Strong Bones Gala, Boston – Framingham, MA
- May 4th: Unbreakable Spirit® Dance – Buzzards Bay, MA
- May 8th: National Bone China Tea Day
- May 10th: National Blue Jeans for Better Bones Day – Your school or office

June

- June 1st: Strong Bones Tampa
- June 8th: OI Day at Capron Park Zoo – Attleboro, MA
- June 8th: Yard Sale for OI – Newton, PA

July

- July 7th: OI Carnival – Whitehall, PA
- July 11th: Riley’s Gathering Golf Outing – Elmhurst, IL
- July 15th: Miracle Michael Golf Outing – Naperville, IL
- Summer *TBD*: Northern California Regional Conference – Sacramento, CA

August

- August 3rd: Atlanta Regional Conference
- August 12th: OI Golf Classic – Atkinson, NH

New events are being added all the time. Visit the events calendar at [www.oif.org](http://www.oif.org) for up-to-date details.

Are you interested in holding awareness or fundraising events for the OI Foundation? Contact [events@oif.org](mailto:events@oif.org) for more information today!

Follow us on social media!

- [www.facebook.com/OsteogenesisImperfectaFoundation](http://www.facebook.com/OsteogenesisImperfectaFoundation)
- [@OIFoundation](https://twitter.com/OIFoundation)

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We're celebrating
50 YEARS
OF SERVICE TO THE OI COMMUNITY

The OIF is turning FIFTY in 2020! We're looking forward to a year of exciting events and activities to celebrate with the OI community!