

## Countdown to the OIF National Conference 2018!

On July 13-15, 2018, the OIF National Conference will unite hundreds of attendees and dozens of professional speakers in Baltimore's historic Inner Harbor for three busy, fun-filled days. Whether you are attending conference for your twentieth time or this is your very first OIF activity—there is something informative and fun for everyone!



- ✓ **REGISTER!** Don't miss *Early-Bird Registration Prices ending April 30th!* Each conference registration includes access to all conference sessions, activities, and materials. **Register today at [www.oif.org/Conference](http://www.oif.org/Conference).**
  - ✓ **Book Hotel and Travel** – Conference participants must complete their OIF National Conference registration before receiving the OIF's group discounted rate of \$159 per night at the Renaissance Baltimore Harborplace Hotel. **ADA rooms are available on a first come, first served basis, and will sell out early!** To book an accessible (ADA) room, contact the OI Foundation at [conference@oif.org](mailto:conference@oif.org) or (844) 889-7579.
  - ✓ **Request a Medical Consultation** – Once again through the generosity of its doctors, the OI Foundation will sponsor a day of one-on-one medical consultations from 8:30am until 3pm on Friday, July 13th. Conference attendees may schedule up to three appointments to have their questions answered or get a second opinion from an OI expert. *Medical consultations will be scheduled on a first-come basis beginning at 10am EST on Monday, April 30, 2018. To request an appointment, contact the OI Foundation at (844) 889-7579 or [bonelink@oif.org](mailto:bonelink@oif.org).*
  - ✓ **Sign up for Childcare Services** – To sign-up for childcare services, register your child(ren) for a full 'Child Conference Registration WITH Childcare'. The deadline for advanced childcare registration is June 30, 2018 or until spaces are filled.
  - ✓ **Register to take part in the Unbreakable Spirit® Walk-n-Wheel Baltimore** – For every \$1,000 raised, participants will receive one free registration! Our goal for the 2018 OIF National Unbreakable Spirit® Walk-n-Wheel – which will take place from 5:30-6:30pm on Thursday, July 12th – is to have 500 participants come together to raise awareness and funds that will enable the OI Foundation to continue keeping the cost of conference registration low, as well as provide financial scholarships to help families in need attend. Read more about the Unbreakable Spirit® Walk-n-Wheel at [www.oif.org/walkandwheelBaltimore](http://www.oif.org/walkandwheelBaltimore) or on page 3 of this issue.
  - ✓ **Sign Up to Participate!** Perform in the OIF Conference Talent Show (July 13th), display your artwork in the OIF Art Showcase (July 14th), or share your professional experience with the OI community as a representative in the OIF Career Expo (July 13th). Email [conference@oif.org](mailto:conference@oif.org) for more information or to sign up today!
- Register Today and STAY TUNED for more details!** Register at [www.oif.org/Conference](http://www.oif.org/Conference) and start making your travel plans today. If you have any questions before the next set of conference details are announced, please email [conference@oif.org](mailto:conference@oif.org) or call the OIF at (844) 889-7579.

## EXPLORE the NEW Programs, Sessions, and Activities at OIF National Conference 2018

- ★ Keynote Message by Gold Medal Paralympian McKenzie Coan and OIF Medical Advisory Council Member Dr. Laura Tosi of Children's National Health System
- ★ Special Edition Plenary Session on Pain and Fatigue
- ★ Three-Hour "Living with Mild OI" Forum
- ★ Three-Hour Women's AND Men's Wellness Forums
- ★ Physician Q&A Lunchtime Roundtables
- ★ Physical Therapy Forum and Q&A
- ★ "An Evening with Gaelynn Lea" Concert Performance
- ★ Artists in the Unbreakable Spirit® Community Art Showcase and Exhibit



### There's an App for That!

We are extremely grateful to OI community member Jon Reed and OIF Board Member Joe Hall for the many hours they volunteered to create the first-ever mobile phone app for the OIF National Conference! The app will be available on Android and Apple phones, and will feature the detailed conference program, a map of the meeting space, speaker biographies, and even a chat feature to coordinate social activities with fellow conference attendees. An online tutorial and more information will be announced as it becomes available.

## Thank you to Our OIF National Conference Sponsors!



**CHILDREN'S BRITTLE BONE FOUNDATION**

**Nemours.** Alfred I. duPont Hospital for Children



**permobil cares**



If you are interested in supporting or locating sponsorships for the 2018 OIF National Conference or the National Unbreakable Spirit® Walk-N-Wheel, please contact Melissa Bonardi at [mbonardi@oif.org](mailto:mbonardi@oif.org).

Hello!

I'm Sarah Kamal, team captain of The Kamal Canucks, and co-chair of the 2018 OIF National Unbreakable Spirit® Walk-n-Wheel. The Walk-n-Wheel will take place in Baltimore, this July 12th, as part of the 2018 OIF National Conference. The National Unbreakable Spirit® Walk-n-Wheel helps raise OI awareness and funds to support the OI Foundation and continue to keep conference costs low. NOW is the time to get started! Start planning your participation in just a few steps:

- **Register your team!** If you were a team captain last Walk-n-Wheel, you can simply re-activate your existing team. If you are new to the Walk-n-Wheel, you can form a team and invite your friends and family to join. You don't have to be attending the conference to be on a team – you can be a virtual participant and still fundraise for the OI Foundation. Get started at [www.oif.org/WalkandWheelBaltimore](http://www.oif.org/WalkandWheelBaltimore).
- **Personalize your page!** Upload a photo that represents your team and include a short write up to tell people what the OIF means to your family and why you are participating in the Walk-n-Wheel.
- **Set a fundraising goal!** You, as well as your donors, will want to track your progress. Our team was motivated by seeing the impact of each donation on the goal thermometer.
- **Get the word out!** For our fundraising, social media was a big help. I posted a link to our team page on Facebook, and sent out emails to family, friends, work colleagues, and local businesses that we had a good relationship with. Remember to always include a link to your team page in your emails.

I know that asking friends and family for donations can feel a little awkward. Make sure you express that any donation, big or small, means a lot to your family. We were overwhelmed by the generosity of our donors. I think a big part of the reason they were happy to donate was because they understand OI is such a big part of our lives, and the resources that the OIF provides are important to our family.

Good luck with all of your fundraising, and we look forward to seeing everyone in Baltimore this summer!

*Sarah*



Walk-n-Wheel Co-Chair Sarah Kamal

# OIF National Conference Program Preview

This summer's three-day conference program is packed with new and returning informational sessions and activities! Take note of the new lunch-time roundtable discussions and special topic sessions with nearly thirty OI-experienced physicians. These informal lunch-time roundtable discussions are open to everyone as the room and table capacity allows.

Conference activities that are back by popular demand include the Career Expo, the Talent Show, and the Closing Dinner and Dance. The topics and titles of the breakout sessions will be announced the last week of April. Below is an overview of the program. This schedule is subject to change.

## 2018 OIF National Conference Program

### Thursday, July 12th

5:30pm – 6:30pm National Unbreakable Spirit®  
Walk–n–Wheel

### Friday, July 13th

8:30am – 3:00pm Medical Consultations  
(by appointment)

2:00pm – 3:00pm Introductory Session –  
The Basics of OI

3:30pm – 4:30pm Welcome and Opening Session  
Keynote Message

5:00pm – 7:00pm Career Expo

7:30pm – 10:00pm Talent Show and After Party

9:30pm – 10:30pm Teen Center Icebreaker

### Saturday, July 14th

8:30am – 5:30pm Childcare

7:00am – 8:30am Breakfast

9:00am – 10:30am Plenary Session: Research Update

10:45am – 5:00pm Teen Center

10:45am – 12:30pm Pediatric and Adult Physician  
Panel Sessions

12:30pm – 2:00pm Lunch Physician Q&A Roundtable

2:00pm – 5:00pm OI Youth Empowered and Proud  
(OI YEP) Forum  
Mild OI Forum

2:00pm – 3:15pm Three Breakout Sessions  
(Medical Information Topics)

3:30pm – 4:45pm Three Breakout Sessions  
(Medical Information Topics)

5:00pm – 6:00pm Special Edition Plenary Session:  
Pain and Fatigue

6:00pm Adults Happy Hour

6:00pm Parents Meet & Greet

8:00pm – 9:30pm An Evening with Gaelynn Lea Concert

8:00pm – 10:00pm Teen Room After–Hours/  
Game Night  
Young Adults Post–Forum Meet Up

### Sunday, July 15th

7:00am – 8:30am Breakfast

8:00am – 9:00am Special Edition Physical Therapy Forum

9:00am – 10:30am Plenary Session: State of the  
OI Foundation

10:45am – 5:00pm Teen Center

10:45am – 12:30pm Parent and Adult Community  
Panel Sessions

12:30pm – 2:00pm Lunch  
Art Showcase

2:00pm – 5:00pm Women's Wellness Forum  
Men's Wellness Forum

2:00pm – 3:00pm Three Breakout Sessions  
(Daily Living Topics)

3:15pm – 4:15pm Three Breakout Sessions  
(Daily Living Topics)

6:00pm – 6:30pm Reception

6:30pm – 9:30pm Closing Dinner and Dance

### Unable to Attend This Summer's Conference?

For those who are unable to join us in Baltimore this summer, we are making plans to live-stream the morning plenary sessions on the OI Foundation's Facebook and YouTube Pages. Archived videos and handouts will also be made available in the weeks following the conference.

# National Osteogenesis Imperfecta Awareness Week is May 5-12, 2018!

National OI Awareness Week is a week dedicated to raising awareness for OI and sharing your Unbreakable Spirit®. OI Awareness Week is scheduled around **Wishbone Day** (May 6), the international OI Awareness Day. The OI community raises awareness on Wishbone Day by wearing yellow, attending awareness events, and sharing OI facts on social media pages.

## Make the most of National OI Awareness Week 2018:

### 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 [dcyember@oif.org](mailto:dcyember@oif.org).

### LIKE, SHARE & RETWEET!

In 2017, our National OI Awareness Week posts reached over 209,000 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](http://www.facebook.com/OsteogenesisImperfectaFoundation) or "Follow" the OIF on Twitter at [www.twitter.com/OIFoundation](http://www.twitter.com/OIFoundation).

### 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/bluejeansforbetterbones](http://www.oif.org/bluejeansforbetterbones).



**OSTEOGENESIS IMPERFECTA  
AWARENESS WEEK 2018**

**MAY 5 - 12**

- REQUEST AN OFFICIAL PROCLAMATION
- PLAN A BLUE JEANS FOR BETTER BONES DAY
- LIKE, SHARE, & RETWEET #SHAREforAWARENESS

[WWW.OIF.ORG/AWARENESSWEEK](http://WWW.OIF.ORG/AWARENESSWEEK)

OSTEOGENESIS IMPERFECTA  
**OI**  
FOUNDATION  
Unbreakable Spirit®

For more information about National OI Awareness Week 2018, visit [www.oif.org/AwarenessWeek](http://www.oif.org/AwarenessWeek).

# Fine Wines Strong Bones Events of 2018

Did you know that nearly a quarter of the OI Foundation's annual budget is generated from Fine Wines Strong Bones events? We are truly grateful to all committee members and attendees for supporting the OI Foundation in our mission to serve the OI community through producing new information resources, funding research, and facilitating support groups. Here is an update on the six Fine Wines Strong Bones events of 2018:

## Fine Wines Reception; Naples, FL

On January 25th, OIF Board President Ken Gudek and his wife Teresa, along with Andrea and Jeffrey Stewart, hosted the 3rd Annual Fine Wines Reception Naples. With 80 attendees and a program that included speeches from Michael Stewart and Dr. Cathleen Raggio, the evening was a great success!



Ken Gudek Jr., Michael Stewart, and Allison Stewart helped host the 3rd Annual Fine Wines Reception Naples with their parents (pictured below)

## Fine Wines Strong Bones Gala; Washington, DC

The OI Foundation's flagship Fine Wines Strong Bones Gala celebrated its 18th year on February 24th at the Gaylord National Resort. The Great Gatsby themed evening featured silent and live auctions, casino games, raffles, and a roaring good time. Founding committee members, Tim Dombro and Tracy Mulroy, gave an update on the Jamie Kendall Fund for OI Adult Health. Dr. Cathleen Raggio spoke about the new cardiopulmonary study that she is leading at Hospital for Special Surgery in New York thanks to funding generated from the fund-the-mission portion of the evening. This community directed and scientist led study is working to determine the cause of cardiopulmonary insufficiency in people with OI so that treatments can be recommended and we can determine how the restrictive physiology in people with OI may be contributing to these issues.



Lisa Parman and friends having a roaring good time at the 18th Annual Fine Wines Strong Bones Gala in Washington, DC



Fine Wines Reception Naples Hosts Ken Gudek, Teresa Gudek, Andrea Stewart, and Jeffrey Stewart

## Mark Your Calendars!

### Strong Bones; Tampa, Florida

As we enter the spring, the OI Foundation will be heading to Tampa, FL for the 2nd Annual Strong Bones Tampa event. We are very excited to once again work with OI community supporters: Ellen Dittman, Jason Cance, Gail Bunker, Shriners Hospital for Children® Tampa, and Oliver's Community in an effort to share their passion for spreading awareness about OI and raising funds to support the mission of the OI Foundation. A portion of the evening's proceeds will go towards funding the continued participation of Shriners Hospital for Children® Tampa in the Brittle Bone Disorders Consortium. 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 discounted tables for ten at \$400. Visit [www.oif.org/StrongBonesTampa](http://www.oif.org/StrongBonesTampa) to purchase your tickets today!

### Fine Wines Reception; New York, NY

On Wednesday, April 25th, members of the OI community will have the chance to enjoy an exclusive after-hours look at one of Sotheby's prestigious exhibits while sampling fine wines and enjoying light fare at the 2nd Annual Fine Wines Reception NYC. We will be featuring a diamond champagne game, high-end auction items, and a fund-the-mission auction led by one of Sotheby's own auctioneers! Tickets for the Fine Wines Reception NYC are now available for \$100 per person at [www.oif.org/FineWinesNYC](http://www.oif.org/FineWinesNYC).

### Strong Bones Gala; Boston, MA

After the success of the first-ever Strong Bones Gala in the Boston area, Christine Rossi, Laura Minucci, and their dedicated committee are excited to return to the Sheraton Framingham on Saturday, May 12, 2018 for the 2nd Annual Strong Bones Gala Boston! The casino night themed gala will once again feature exciting casino games, live and silent auctions, dinner, drinks and dancing to benefit the OI Foundation. Tickets are available for \$100 each, \$180 per couple or \$850 per table of ten at [www.oif.org/StrongBonesBoston](http://www.oif.org/StrongBonesBoston).

### Boots & Bling for Better Bones; Houston, TX

Save the Date! The Boots & Bling for Better Bones will be returning for a 2nd year at Houston's Armadillo Palace on Saturday, November 10, 2018! Join us for delicious food and drink, incredible auction items, and the chance to help the nearly 50,000 people in the United States affected by osteogenesis imperfecta.

If you are interested in helping with an existing event or if you think your city would be a good location for a future 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](http://www.oif.org/FineWinesStrongBones).



Longtime OIF Members, the Simmonds Family, at the 18th Annual Fine Wines Strong Bones Gala in Washington, DC



# Osteogenesis Imperfecta Foundation Membership Program

*Become a new member or renew your membership today  
by completing and returning the enclosed form*

Your membership to the OI Foundation will help:

- Accelerate the pace of OI Research through scientific and clinical meetings
- Fund new young investigator grants
- Provide medically verified information on OI to professionals, parents, caregivers and individuals living with OI
- Provide opportunities for people with OI to connect through the OIF website, social media sites and at the OIF National and Regional Conferences



*OIF Board President Ken Gudek with fellow OIF Member, Tracy Mulroy at the Fine Wines Strong Bones Gala*

## Membership Levels

### Individuals

### Businesses

All Individual members will continue to receive reduced registration fees at OIF National and Regional Conferences

#### Bronze

**\$36 per year or just \$3 a month**

#### Silver

**\$60 per year or just \$5 per month**

This membership comes with an OIF car window decal to show your OIF membership pride.



#### Gold

**\$120 per year or just \$10 a month**

This membership comes with an OIF mouse pad to let everyone know you are the definition of Unbreakable Spirit®!



#### Platinum

**\$365 per year or just \$1 per day**

Show off your Unbreakable Spirit® with both the OIF car window decal and the OIF mouse pad.

#### Professional

**\$100 per year**

This membership comes with an OIF car window decal. Healthcare professionals will also receive recognition in the OIF Annual Report; a subscription to *Breakthrough* as well as first access to the latest published scientific research and materials; invitations to local area events including scientific meetings and professional meetings.

#### Corporate

**\$1,000 per year**

This membership comes with an OIF car window decal and an OIF mouse pad. Your OI Clinic or healthcare organization will receive *Professional* benefits as well as logo placement on the OIF website and a half-page ad in *Breakthrough*; priority as an exhibitor and recognition at the OIF National Conference on conference materials as well as the opportunity to include one promotional item or flyer in the gift-bag and an invitation to Professional Series at the OIF National Conference.

**The following is a letter from OI Foundation Board President, Ken Gudek, about the OI Foundation's membership program. The OIF counts on your membership to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. In addition to supporting the work of the Foundation, membership gives you a voice in the OI Foundation's future. Please use the enclosed reply envelope to renew your current membership, or become a new member today!**

Dear Friend,

It would be the greatest understatement to say that my second year as OIF Board President was an eye-opening and rewarding experience. From the OIF Scientific Meeting in Chicago, to the Brittle Bone Disorders Consortium (BBDC) principal investigators meeting, the National Health Council Volunteer Leadership Meeting in Florida and the International OI Scientific Meeting in Oslo, Norway, you learn very quickly that OI has no borders. It's abundantly clear that there are as many dedicated people throughout the world as there are here in the U.S.

This July, OI community members will come together in Baltimore, MD for the OIF National Conference, where resources and support are provided to all individuals in need of answers. Whether you are just beginning to learn about OI types and treatment options, or you are an adult with OI adjusting to new complications, the OIF has the resources you need.

When I accepted the role of President at the OIF National Conference in 2016, my Board of Directors and I made a plea to our OI community to help in our fundraising efforts. 62% of the OI Foundation's annual budget comes from individual donations and events. Now I'm asking for your help! Your membership helps fund research, provide medical information, develop new resources, and increase public and professional awareness about OI. Things seem to be heading in the right direction, thanks to everyone that has supported us for the past 48 years. We hope that this support continues into the future.

As President of the OIF Board, my promise to each of you is that our Board and staff will continue our strong commitment and efforts toward the funding of grants, education, awareness, and research. Last year I was very proud to say that 78 cents out of every dollar raised by the OIF goes back to our community! As a matter of fact, Charity Navigator has rated the OI Foundation a 91.36 out of 100 (with four out of four stars).



*The Gudek family at the 2016 OIF National Conference*

**The OI Foundation owes its success to its loyal, supportive members; the organization's future depends on you!** I hope that you will consider joining the OIF or renewing your membership. Your membership enables us to continue offering the exemplary services we provide to all individuals affected by OI. Together, we truly do have an Unbreakable Spirit®.

Thank you for your support and I hope to see all of you in Baltimore this July!

Sincerely,

Ken W. Gudek, Sr.  
OI Foundation Board President

# Support the OIF Regional Conference Program with Bone China Tea

My first OIF National Conference was an amazing experience. Not only did I meet hundreds of OI community members, but I felt accepted and didn't have to explain myself to anyone. These were the exact reasons why my mother Jenny and I wanted to give back to the OI Foundation. After attending conference, we realized that there are other individuals and families who needed to experience that same situation—to not feel alone.

Through my years of involvement with the OI Foundation, I realized not everyone can afford to go to one of the OI Foundation's Biennial National Conferences. For this reason, in 2013, we brought back the Regional Conference program! These events are designed to accommodate families who couldn't travel to an OIF National Conference by bringing a one-day conference to a location closer to where they live. The first of these new OIF Regional Conferences was held in Tampa, FL, November 2, 2013. Since then, the OI Foundation has had seven Regional Conferences. The OI Foundation would like to be able to continue these Regional Conferences, but like everything else, this program requires funding.

## **Bone China Tea will help make future Regional Conferences possible.**

Bone China Tea is one of the easiest fundraisers you can participate in to help raise money for the OI Foundation and the OIF Regional Conference program. This phantom event will be held on April 11, 2018 (or choose your own date!). Instead of getting dressed up, finding a babysitter, and going out to an event, you are asked to have a cup of tea in the comfort of your own home. Use the money you saved by not attending a live event to donate to the OI Foundation.

*There are two ways to participate as a host:*

- 1. Send Bone China Tea Invitations** to your family and friends. To request invitations, contact the OI Foundation at [mbonardi@oif.org](mailto:mbonardi@oif.org). In my invitations, I include a personal update on how OI has affected me that past year.
- 2. Create an online Bone China Tea webpage.** Share the link with your friends, family, and co-workers via email and social media.

This is a great way to promote OI Awareness and have friends, family and co-workers learn about OI.

The OI community has an Unbreakable Spirit®—none of us want to give up on helping others with OI. Your participation in Bone China Tea will help build relationships and friendships, increase awareness, and provide support among OI community members. Just imagine how many more people we could reach if we meet our goal of raising \$25,000.

We need YOU to help us expand the Regional Conference program—participate in Bone China Tea this year!

Thank you,

*Susie Wilson*

Bone China Tea Chairperson



*Susie Wilson with her mother Jenny*



## OI Foundation Program Services Survey— The Results Are In!

Thank you so much to all of the Unbreakable Spirit® community members who participated in the OI Foundation Program Services Survey! We are excited to see the overwhelming response from over **400** adults, parents, spouses, siblings, grandparents, other family members and friends, and even health professionals!

To check out the results from the survey, visit [www.oif.org/SurveyResults](http://www.oif.org/SurveyResults). You will find that much of your feedback has already been incorporated into the 2018 OIF National Conference program. You may see your other ideas and suggestions put into action in the near future through the OIF's monthly e-newsletters, website, factsheets, podcasts, regional conferences, support networks, and more.

Stay tuned as we continue expanding the reach of the OI Foundation's mission with the help of dedicated volunteers, support group leaders, and medical advisers! Again, THANK YOU for providing such valuable feedback.



*Uniting Unbreakable Spirits*

REGIONAL CONFERENCE PROGRAM

**LOS ANGELES, CALIFORNIA**

**NOVEMBER 17, 2018**

### **Save the Date for the 2018 OIF Regional Conference in Los Angeles, CA!**

This one-day meeting is scheduled to be held on Saturday, November 17th on the campus of the University of California-Los Angeles (UCLA). Thank you to Dr. Deborah Krakow and the team at UCLA for their help in coordinating this event. More details will be shared as they become available.



## OI Clinic Spotlight

The OI Foundation works closely with nearly 60 multidisciplinary OI Clinics across the continent to provide timely and accurate information about the range of available services. The OI Clinic Directory can be found under the “Information Center” tab on the OIF website.

To give a broader overview of the background, mission, and services of these centers, the OIF spotlights new and existing OI clinics serving pediatric and adult patients. In each issue of *Breakthrough*, we will introduce at least one new clinic. In this issue, we are excited to introduce the Children’s National Bone Health Clinic in Washington, D.C.

### The Children’s National Bone Health Clinic

Osteogenesis Imperfecta care at Children’s National Health System in Washington, D.C., is coordinated by the Pediatric Bone Health Program led by Laura Tosi, M.D. This clinic includes nationally recognized experts in pediatric orthopaedics working in partnership with geneticists, endocrinologists, and social workers. Weekly clinics with the combined expertise of multiple specialists ensure rapid responses to urgent problems as well as comprehensive evaluation of issues related to growth and development. Other clinical partners also include dentists, pulmonologists, and audiologists, who are essential to provide comprehensive OI care. The clinic offers on-site X-rays as well as new, state-of-the-art EOS® imaging technology which takes better quality, full body images more quickly and with less radiation than traditional X-rays. Children’s National is one of the few pediatric programs in the country offering on-site technology for measuring bone quality, including dual-energy X-ray absorptiometry (DEXA) scans performed only by Certified Bone Densitometry Technologists (CBDT®). These professionals have been specially trained to work with children with disabilities.



Laura Tosi, M.D.

The Bone Health Program also offers a bisphosphonate infusion program for the treatment of bone fragility. Advanced treatments include pamidronate or zoledronate infusions under a carefully monitored dosing regimen. A dedicated Bone Health nurse practitioner and physician assistant coordinate outpatient infusions at the infusion clinic and admissions to the neonatal ICU for children under the age of one. In addition, they closely monitor pre- and post-infusion labs, perform exams at all outpatient infusions, and provide education for patients and families. They work particularly closely with the endocrinologists who support the metabolic bone disease portion of the Children’s National/National Institutes of Health (NIH) Pediatric

Endocrinology Fellowship program to ensure personal attention and care to patients with OI.

The Bone Health Program at Children’s National has a long history, starting with a Multidisciplinary Skeletal Dysplasia Clinic that began in the 1970s. When Dr. Tosi joined the Skeletal Dysplasia team, she grew concerned about the expanding bone health needs of the growing population of survivors of childhood diseases and the need to provide more coordinated fracture and medical care for her many patients with OI. She founded the Children’s National Bone Health Program over 15 years ago in order to provide more comprehensive care and easier access for urgent problems when children with brittle bones are injured.

Dr. Tosi has dedicated her career to improving bone health across the lifespan. Her clinical care, advocacy, research, and education efforts focus on improving bone health and maximizing independence in her patients. She currently serves on the Board of Directors and Medical Advisory Board of the Osteogenesis Imperfecta Foundation and many other prominent national and international societies focused on musculoskeletal health.

The Children’s National Bone Health Program is proud to be a research/recruitment site for the Osteogenesis Imperfecta Foundation’s Brittle Bone Disease Consortium. The program is enrolling both children and adults. While the Bone Health Program cannot assume day-to-day care for adults, they are working to develop a roster of physicians willing to care for adult patients and learn about OI. The Bone Health Program research coordinators strive to coordinate all testing as well as routine clinical care into a single day to minimize time away from school and work.

For more information regarding specialized care for OI at Children’s National, please visit [www.childrensnational.org/bonehealth](http://www.childrensnational.org/bonehealth). In addition, you can make an appointment by calling 202-476-2112.

## Share with the Unbreakable Spirit® Community Book Club!

Living with a rare genetic disorder like osteogenesis imperfecta can present moments in life that few others are able to relate to. Individuals in the OI community often express themselves and share their stories through different forms of art, like writing. If you have recently published a book, or if you have a favorite OI related book, let us know! We would love to share your books with the OI community. Please send your suggestions to the OI Foundation at [Bonelink@oif.org](mailto:Bonelink@oif.org).



### Pain Management and Fatigue in OI

Pain is the body's way of responding to damaged tissue. How a person responds to pain is determined by many factors, including emotional outlook. For example, depression seems to increase a person's perception of pain and to decrease his or her ability to cope with it. Pain is classified as acute (short duration due to an injury) or chronic (longer lasting, or recurring).

People living with OI can experience both acute and chronic pain. Pain management for OI, in both adults and children, requires adequate assessment and development of an individualized plan that provides a variety of strategies for coping with and managing pain. Pain management for individuals with OI often requires a multidisciplinary approach involving specialists in medicine, psychology, and rehabilitation or a referral to a pain specialist or to a pain clinic for adequate treatment. The goal for treatment is effective therapy that will not only reduce or remove the pain but will also achieve mental well-being and an improvement in physiological function.

The Nursing Research Team at the Shriners Hospital for Children –Montreal published a literature review in January titled "Pain Experiences of Adults with Osteogenesis Imperfecta: An Integrative Review." It is an open access publication, available online. Email [Bonelink@oif.org](mailto:Bonelink@oif.org) for a link to this paper, or if you have any follow-up questions.

With this topic being of such high interest in the OI population and the general population, the 2018 OIF National Conference will host a Special Edition Plenary Session on Pain Management and Fatigue on Saturday, July 14th. More details on this session will be posted in the months leading up to conference.

# Introducing the Thomas Acquafredda Emergency Medicine Education Initiative

The OI Foundation is proud to introduce the Thomas Acquafredda Emergency Medicine Education Initiative. This initiative will provide resources to improve emergency medical care for individuals living with OI and increase awareness about OI in emergency room settings.

Funding from the Thomas Acquafredda Emergency Medicine Education Initiative allowed the OI Foundation to participate in the 2017 American College of Emergency Physicians (ACEP) Annual Meeting in Washington, DC, where a new *Emergency Room Care* pocket guide was piloted. The pocket guide is available by request through the online store or by emailing [Bonelink@oif.org](mailto:Bonelink@oif.org). New educational materials on pain management and palliative care are being developed to debut at future professional society meetings and will be distributed to the OI community.



Materials developed with the support and funding from the Thomas Acquafredda Emergency Medicine Initiative.

This emergency medicine education initiative aligns with the OI Foundation's mission to improve the quality of life for people with OI through education, awareness, mutual support, and research. We are tremendously thankful to the family of the late Thomas Acquafredda for the vision to fulfill this critical need in the osteogenesis imperfecta community. Thomas and his family were active in the New Jersey OI Support Group and the Annual New Jersey Beefsteak Fundraiser for many years. He also loved attending the OIF National Conferences. Please read a note below from the Acquafredda Family:

*The Acquafredda Family is so thrilled that this initiative has been established to help those living with OI advocate for safe and appropriate health care and to educate physicians and hospital staff on the special needs of individuals living with OI. Tom was born in 1954 when there was little known about the severity of OI and fragile bones. Tom had a severe case of OI and as a result, fractured from the slightest movement or touch.*

*This initiative is based on the experience of my brother after an accident in 2012. He was seen at a local hospital's emergency room on Christmas Eve and was admitted. The staff did little to address his pain despite the fact that he suffered multiple facial fractures and trauma to the body. He was placed in a semi-private room with an elderly confused gentleman, with only Tylenol to sustain him. In this setting, which was far away from the nurses' station, he was not able to call for help.*

*It is critical that people with OI have adequate pain medication as well as proper nursing and medical supervision to avoid their care being compromised. It is the goal of the Thomas Acquafredda Emergency Medicine Education Initiative to inform and educate physicians and hospital staff on the necessary accommodations for safety, and the need for sufficient monitoring and pain management. In addition, information and resources are available to OI patients and their support networks to help in the aspects of advocacy and care.*



Thomas Acquafredda



The Acquafredda Family

*The field of palliative care (specialized medical care for individuals with serious illness) has made strides to understand rare disorders like OI; however, it is critical that the hospital team be sensitive and astute to the special concerns that people with OI can present. Tom was an amazing man and lived life to the fullest, despite its challenges. He did not let his disability define him.*

*We are grateful to the OI Foundation for their role in helping people with OI secure a better life. Tom and the family were active members of the OIF and enjoyed all the benefits of being involved and attending conferences. The friendships have endured and the memories are priceless.*

*Take good care and advocate! We hope the information and resources available help ensure your safety and wellbeing.*

# 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 7th** Strong Bones Tampa Event – Tampa Firefighters Museum – Tampa, FL
- April 7th** Nicholas' 1st Annual Bone China Tea Party – Yardley Library – Yardley, PA
- April 11th** Bone China Tea – Anywhere!
- April 25th** Fine Wines Reception New York – Sotheby's Auction House – New York, NY

## May

- May 5th – 12th** National OI Awareness Week – Everywhere!
- May 5th** Florida OI Support Group Meeting – Shriners Hospital for Children Tampa
- May 5th** Unbreakable Spirit® Event Buzzards Bay 2018 – Buzzards Bay, MA
- May 12th** Strong Bones Gala Boston – Sheraton Framingham – Framingham, MA

## June

- June 9th** Sweat For Sammy Run/Walk-N-Wheel – Ridley Creek State Park, PA

## July

- July 12th** Riley's Gathering Golf Outing – Elmhurst, IL
- July 12th** National Unbreakable Spirit® Walk-n-Wheel – Baltimore, MD
- July 13th – 15th** OIF National Conference – Marriott Harborplace – Baltimore, MD
- July 24th** Dogfish Head Alehouse Fundraiser – Gaithersburg, MD

## August

- August 13th** OI Golf Classic – Atkinson Country Club – 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!

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