

IMAGINE...Another Successful OIF National Conference!

“So when someone says ‘Can you imagine...’ my mind goes to this place in Orlando where we were surrounded by friends and knowledge and hope. Yes, I can imagine now.”

– Chris and Cheyenne McConnell, Ocala, Florida

The 2016 OIF National Conference, themed IMAGINE, celebrated what the OI community has achieved over the years and the goals we strive to reach in the future. The meeting gathered over 650 attendees and 50 speakers for three busy, fun-filled days at the end of July. New and old friends were able to participate in a full line-up of activities: one-on-one medical consultations, informational sessions, age and gender specific forums, the National Unbreakable Spirit® Walk-n-Wheel, the first time ever OI Career Expo, the OIF National Conference Talent Show and After-Party, meet-ups for parents, adults, and youth, the Closing Dinner and Dance, and more!

On Thursday, July 21st, more than 250 members of the OI Community came together for the National Unbreakable Spirit® Walk-n-Wheel! The nearly \$100,000 raised enables the OI Foundation to continue aiding members of the osteogenesis imperfecta community through research, advocacy, education and mutual support.

We would like to thank our Walk-n-Wheel sponsors: Children’s Hospital and Medical Center Omaha, Pega Medical, and Shriners Hospital for Children Tampa. Special thanks to Mickey Mouse for



taking photos with 20 of our highest fundraising teams and for helping us kick off the Walk-n-Wheel, as well as Bahia Shriners for cheering our participants on at the finish line!

The official conference program opened on Friday, July 22nd with a formal welcome from OIF CEO Tracy Hart, OIF Board of Directors Past President Mark Birdwhistell, OIF Board of Directors President Ken Gudek, Sr., OIF Medical Advisory Council Member Dr. Brendan Lee, and the Clinic Director of the conference’s Presenting Sponsor Dr. Eric Rush. A spectacular keynote address was

delivered by OI community member Anna Curry Gualano, who captured the audience with a passionate talk about her experience training for and climbing Mount Kilimanjaro with her father. After the Opening Session, conference attendees joined in the first-ever OI Career Expo, which gave OI community members the opportunity to showcase their careers. Thank you so much to community member Michael Stewart for contributing the idea of this valuable new activity. The first day ended with an outstanding Talent Show that featured some of the community’s most gifted and talented youth and adults. We are grateful to Suzanne Richard for organizing and hosting this much appreciated event. Following the Talent Show,

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Another Successful Conference (continued from page 1)

community members were then greeted across the hall by two special surprise guests, Cinderella and Belle, who celebrated in the after party festivities and took hundreds of photos with conference attendees.

The informational sessions on the second day of conference covered a wide variety of clinical topics associated with the diagnosis, treatment and management of OI in children and adults. The plenary session began with a Research Update by Dr. Brendan Lee and Dr. Francis Glorieux. Dr. Lee spoke and answered questions for nearly an hour about current and emerging OI research studies through the Brittle Bone Disorders Consortium. Dr. Glorieux discussed research trends regarding pamidronate and zoledronate treatments. The morning plenary session then divided attendees based on their interest in pediatric or adult OI health issues. The pediatric panel presented an overview of health issues that a parent of a child with OI generally should be aware of. Panel topics included managing bone health, muscle strength, gait analysis, joint health, basilar impression, pharmacological treatments, and general health topics such as immunizations, hearing loss and obesity prevention. The adult panel presented a synopsis of information on bone health, family planning, cardio-pulmonary issues, pharmacological treatments, and general health topics such as muscle health, obesity prevention, and treatment of non-OI related health issues. Both of these panels were among the most well-attended and highest-rated sessions at the conference. After a lunch break, attendees returned to learn more about clinical topics in two rounds of five afternoon breakout sessions.

The third day of conference began with a plenary session on the activities and progress of the OI Foundation, delivered by CEO Tracy Hart and Board President Ken Gudek, Sr. The remainder

of the day was formatted similar to the previous day, where attendees interested in pediatric or adult OI issues divided into two groups. The panel for parents was “Growing Up with OI: Two Perspectives,” moderated by Gail Bunker and Michelle Fynan. The panelists included four parent and child teams, who described their experiences making difficult decisions regarding participating in school and recreation activities, learning how to drive, obtaining independence, and making new friends. They shared with the audience their lessons learned and strategies to build resiliency, and also responded to tons of questions from the audience. The panel for adults was “Take Charge and Live Well,” moderated by Mary Beth Huber. The panelists discussed their perspectives of taking charge in their lives through an assortment of practical approaches. Experiences from the panelists suggested ideas on recreation and physical fitness, home adaptations, safe and stress-free traveling, self-advocacy, and mindfulness meditation. The “Take Charge of Your Health” toolkit was introduced during this session (more details printed on page 18).

Breakout sessions reconvened attendees on Sunday after lunch to discuss information about practical life skills, such as transition, independence, mental health, nutrition and physical activity. This year we were excited to welcome several new topics to the slate of afternoon breakout sessions. Among the new topics was one focused on Men’s Shared Experiences. This session provided men living with OI the space to exchange tips on living a healthy lifestyle, maintaining support systems, participating in sports and recreation, and much more! We anticipate that this session will expand at the next national conference into a large forum, similar to the OI Women’s Wellness Program. The OI Foundation would like to thank dedicated planning committees, facilitators

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Clinical Topics	Practical/Life Skill Topics
<ul style="list-style-type: none"> • The Basics of OI • Opening Session and Keynote Address • Brittle Bones Disorders Consortium (BBDC) Update • Plenary Session: Research Update Panel • Managing Pediatric Health Issues (Panel for Parents) • Managing Adult Health Issues (Panel for Adults) • Orthopedic Rodding Surgery • Aging Well with OI • OI Growth Curves and Growth Hormone Treatment • Dental Issues: Orthodontia and Malocclusions • Understanding OI Types and Inheritance Patterns • Orthopedics: Spine and Scoliosis • Prevention and Treatment of Hearing Loss • Respiratory Issues in Children and Adults • Vision and Eye Issues • Mild Type I – Medical Applications 	<ul style="list-style-type: none"> • Growing Up with OI: Two Perspectives (Panel for Parents) • Take Charge and Live Well (Panel for Adults) • Raising a Resilient Family • Preparing for Transition to Adulthood: Ready or Not! • Independence Double Session • Part I: Is a Service Dog Right for You? • Part II: Is Travel in Your Future? • Adaptive Equipment for Children • Men’s Shared Experiences • Safe Physical Activity for Children • Mental Health and OI for Adults – Managing Chronic Pain • Personal Safety: Techniques, Tools, and Technology • Nutrition for Bone Health and Obesity Prevention • Supporting Children and Adults with Mild OI • Youth Empowered and Proud Forum • Women’s Wellness Program

Another Successful Conference
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and participants of the Women's and Men's programs.

Participants of the OI Youth Empowered and Proud (OI YEP) Forum engaged in an energizing discussion on varying perspectives of interdependent living and brainstormed together ways to ease the transition process to adulthood. The OI Foundation sends a huge thank you to the facilitators of the OI Youth Empowered and Proud (OI YEP) Forum- Dr. Kara Ayers, Dr. Michelle Fynan, Cory Nourie, Dr. Richard Kruse, Michael Stewart, Lauren Brown, Adie Baez, Jessica Finkel Minor, and Collin Laflamme.

The OI Foundation is also extremely fortunate to have the Strauch Family, who has volunteered tirelessly as chaperones in the Teen Center for many consecutive conferences. Also, the OIF sends a special thanks to the volunteers who managed the "First Timers Table," which was set up to welcome new attendees and answer questions about the program. We are so overwhelmingly grateful for the contributions of the many speakers and panelists who not only made careful preparations to present, but also offered their skills, knowledge, and resources to attendees even beyond the three days of the National Conference. This conference certainly proved to be one to remember!

Stay connected with the OI Foundation to read upcoming Breakthrough newsletter articles and listen to podcasts featuring more information on these topics!

We hope to see you at the OIF National Conference 2018 in Baltimore, Maryland!

The OIF proudly presented the following awards at the OIF National Conference in Orlando, FL:

Humanitarian Award

The OI Foundation was honored to present the 2016 Humanitarian Award to Dr. Jay R. Shapiro, MD, F.A.C.E, F.A.C.P. (pictured with Tracy Hart, OIF CEO and Dr. Francis Glorieux, OIF MAC Chair). Dr. Shapiro is a member of the OIF Medical Advisory Council. He is well known in the OI Community for his long-standing interest in the needs of adults, going the extra mile for his patients and his contributions to educating the medical community about OI.



Peter Dohm Junior Volunteer Award

Fifteen-year-old Andersson Dyke was awarded the Peter Dohm Junior Volunteer Award (pictured with Tracy Hart, OIF CEO and Ken Gudek, OIF Board President)! Andersson has written 7 books, including Missy, published in 2014. She has sold and signed hundreds of copies of her book and donated 100% of the proceeds to the OI Foundation. Way to go, Andersson!



Order your copy of Missy at www.oif.org/Missy

President's Award

The 2016 President's Award was presented to the Bennett Clayton Foundation (BCF's Paula Coomer and Brenda DeBlieck pictured with Tracy Hart, OIF CEO and Ken Gudek, OIF Board President) for their outstanding commitment to the mission of improving the lives of people living with OI. BCF has been a long time partner of the OIF, supporting many programs including this year's conference scholarships, medical consultations and the 2015 OIF Regional Conference in Minneapolis, MN.



Unbreakable Spirit® Award

The Unbreakable Spirit® Award was presented to Gail Bunker and Susie Wilson (pictured with Tracy Hart, OIF CEO and Ken Gudek, OIF Board President) on behalf of the Florida Support Group in recognition of their outstanding contributions to improving the lives of people affected by osteogenesis imperfecta. Thank you Gail and Susie for all that you do in an effort to make the Florida Support Group the largest and most active support group for the OI Foundation.



Kasper/Kendall Scholarship Program

To honor two very special women, Rosemarie Kasper and Jamie Kendall, the OI Foundation's Board of Directors has renamed the conference scholarship as the Kasper/Kendall Scholarship Program. The program is dedicated to continuing Rosemarie's and Jamie's legacies of supporting their fellow OI community members.



OI Foundation Regional Conference Program Update

The OI Foundation Regional Conference Program is back! During the 2015 series of the Uniting Unbreakable Spirits Regional Conference Program, the OIF brought new information on research and resources to over 400 families and individuals throughout Los Angeles, CA, Stamford, CT, and Minneapolis, MN. Continuing the program objectives of reaching new community members and sharing the latest information about OI with a wider audience, the OIF will gather community members in four new regions in 2016 and throughout 2017!

It's Not Too Late to Register for the OIF Regional Conference in Houston, TX, on Saturday, November 12th!

A graphic for the Houston regional conference. It features a map of Texas with the text "Uniting Unbreakable Spirits HOUSTON, TX" overlaid. The OI Foundation logo is in the top left, and the AMGEN logo is in the bottom right. Text at the bottom left reads "NOVEMBER 12, 2016 Texas Children's Hospital-Pavilion for Women". Text at the top right reads "OI Foundation Regional Conference Program". A small note says "Made possible by an educational grant from AMGEN".

The first stop in the upcoming series of regional conferences will be Houston, TX, on Saturday, November 12, 2016, at Texas Children's Hospital's Pavilion for Women. The general program format of the one-day OIF Regional Conference is similar at each location. The day begins with an opening session discussing the basics of OI and a research update. Attendees then have the choice to sit in on several parent- or adult-focused breakout sessions. Sessions cover a variety of topics related to orthopedic issues, multidisciplinary approaches to treatment, raising a resilient family, and more. The formal sessions are followed by a social reception at the end of the day, which gives attendees a chance to reconnect with old friends and meet new community members.

Registration for each regional conference costs \$35 per person and includes access to all sessions, lunch, and the closing social reception. Children 12 years of age and under are free to attend, but *must be registered* for the meeting. Space is limited, so be sure to register online (www.oif.org/regionalconferenceHouston) or by phone at (301) 947-0083 to secure your place today! Special thanks to Dr. V. Reid Sutton and the Texas Children's Hospital for chairing and sponsoring the OIF Regional Conference in Houston.

A graphic for the 2017 regional conferences. It features the text "Uniting Unbreakable Spirits 2017 REGIONAL CONFERENCES" at the top. Below this, there are three city skyline icons with their respective dates: Phoenix March, Montreal June, and Seattle November. The OI Foundation logo is in the bottom right corner.

Announcing the 2017 Locations of the OIF Regional Conference Program

If you are craving a slice of the popular and enriching OIF conference experience, the OIF Regional Conferences are dynamic educational events that you surely will not want to miss! In 2017, the OI Foundation is gearing up for regional meetings in Phoenix, AZ on March 11, 2017, Montreal, Quebec, Canada on June 3, 2017, and Seattle, WA during November 2017. We are excited to expand this program to more communities within our reach, and we hope you will be able to join us for one of these worthwhile events! More details on the 2017 meetings will be coming soon. Visit the OIF Regional Conference webpage (www.oif.org/regionalconference) for updates as they become available.

An invitation for a "Bone China Tea Party". The top text reads "You're Invited To a Bone China Tea Party". Below this is a photograph of two young girls sitting at a small table outdoors, having tea. The bottom text reads "MAKING A DIFFERENCE IS EASY WHEN YOU PARTICIPATE IN THIS PHANTOM EVENT!" and "Simply spend a quiet moment at home on **January 28, 2017** with a soothing cup of tea. Making a donation with the money you saved by not attending an event will improve lives by helping to support programs like the OIF Regional Conferences!". At the bottom, it says "Visit www.oif.org/BoneChinaTea or call Melissa Bonardi at 301-947-0083 for more information!"

Participation Matters: Opportunities to Make Your Mark in OI Research

Now is the time to make your mark in research on osteogenesis imperfecta! The Brittle Bone Disorders Consortium (BBDC) is currently coordinating several studies through the contact registry. In order to be contacted for upcoming BBDC research opportunities, you must be signed up for the contact registry.

At this summer's OIF National Conference, more than 100 community members joined the contact registry at the BBDC booth. This demonstration of enthusiasm increased the number of participants up to 1134, as of October !! Thank you for your commitment to expanding OI research! **Without the support of individuals with OI who are willing to participate in research, new treatments and discoveries in the understanding of OI are not possible.**

Joining is easy and takes approximately 5-10 minutes. Besides your name and contact information, you will be asked to answer a few general questions about your health. The process is done online at this site: <http://www.rarediseasesnetwork.org/cms/bbd/Get-Involved/ContactRegistry>. A paper form is available from the OI Foundation if needed. Call (301) 947-0083 or send an email to bonelink@oif.org to request one.



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Thank you to our partner organizations



CHILDREN'S BRITTLE BONE FOUNDATION

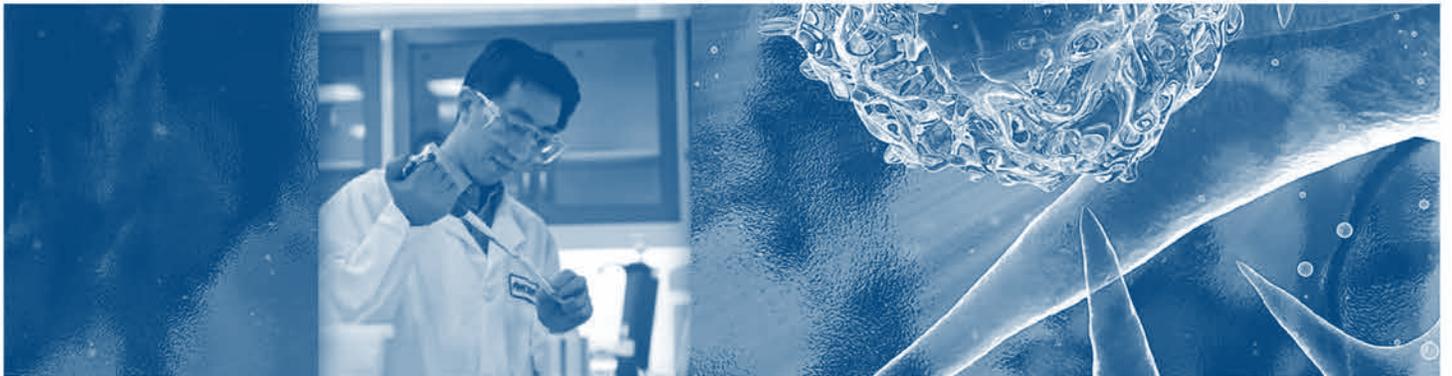


*for their support of the 2016
Medical Consultation program!*



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At Amgen, we believe that the answers to medicine's most pressing questions are written in the language of our DNA. As pioneers in biotechnology, we use our deep understanding of that language to create vital medicines that address the unmet needs of patients fighting serious illness – to dramatically improve their lives.

For more information about Amgen, our pioneering science and our vital medicines, visit www.amgen.com

Amgen is a proud sponsor of The Osteogenesis Imperfecta Foundation

Free Monthly Podcasts from the OI Foundation

The OIF provides free access to monthly podcasts featuring OI medical experts on a variety of topics related to the diagnosis and treatment of OI. The eleven uploaded podcasts have received great feedback, receiving over 2,000 downloads so far. Topics include General Clinical Research Updates, Pulmonary Issues in OI, Multidisciplinary Care for the Pediatric Patient with OI, Gaps in Care and Information on Treating Adults with OI and more. Listen to the podcasts on the OIF's Podcast webpage at www.oif.org/OIFpodcast.

OIF Podcast Series

Leaders in the OI Field on New Advances in Research and Treatment

The OIF's monthly 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.



Dr. Eric Rush, MD, FAAP, FACMG

Clinical Geneticist
Munroe-Mayer Institute for Genetics and Rehabilitation
Assistant Professor of Pediatrics, Internal Medicine, and Orthopedic Surgery
University of Nebraska Medical Center



Multidisciplinary Care for the Pediatric Patient with OI

Dr. Cathleen Raggio, MD

- Dr. Raggio specializes in general pediatric orthopedics, with a focus on the treatment of congenital musculoskeletal and skeletal dysplasias.
- Co-Director of the Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias at Hospital for Special Surgery.
- Completed her residency in orthopedic surgery at Hospital for Special Surgery and her fellowship in pediatric orthopedic surgery at Stanford.
- Adult Hospitalist at Children's Hospital of Philadelphia.
- Recent work includes research on the medical necessity of Raggio performs bone density and clinical research on the utility of systemic bisphosphonates in the treatment of osteoporosis in OI, skeletal dysplasias and the different drug treatment options using the case studies of OI.
- She has served as Co-Chair of the International Research Conference on Osteogenesis Imperfecta and has served on the International Osteoporosis Foundation.
- Consults on the OI Foundation's Advisory Advisory Council and has worked on the OI Foundation's Advisory Advisory Council and has worked on the OI Foundation's Advisory Advisory Council.



Dr. Brendan Lee, M.D., Ph.D., of Baylor College of Medicine, discussing **Clinical Research in the area of OI.**

[Click here to listen!](#)

Dr. Eric Rush, M.D. of University of Nebraska Medical Center, discusses **Identifying New OI Genes and what they mean to Understanding OI.**

[Click here to listen!](#)

Dr. Cathleen Raggio, Co-Director of the Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias at Hospital for Special Surgery, discusses **Multidisciplinary Care for the Pediatric Patient with OI.**

[Click here to listen!](#)

Gaps in Care/ Information in Treating Adults with OI



Dr. Laura Tosi, MD

Interviewed by Petra Harvey, OIF Health Educator

- Orthopedic surgeon at Children's National Medical Center in Washington, DC
- OI Foundation representative on the National Bone Health Alliance's Board of Directors
- Principal Investigator of the OI Foundation's Adult Natural History Initiative
- Member of the OI Foundation's Medical Advisory Council and Board of Directors

In addition to Dr. Tosi's professional accomplishments and experience on behalf of the OI community, she is a dedicated participant and supporter of many OIF events and activities.



Dr. Laura Tosi, orthopedic surgeon at Children's National Medical Center in Washington, DC, joined OIF Health Educator Petra Harvey to discuss **Gaps in Care and Information in Treating Adults with OI.**

[Click here to listen!](#)

Surgical Updates on Treating Children with OI



Richard W. Kruse, DO, MBA

Interviewed by Tracy Hart, OIF CEO

- Vice Chair Department of Orthopedics and Chief of the Orthopedic Trauma Service at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE
- Co-Director for the multidisciplinary OI program at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE
- Professor of Orthopedic Surgery Thomas Jefferson University College of Medicine in Philadelphia, PA and the Jefferson Science University School of Medicine in Delaware, MD
- Member of the OI Foundation's Medical Advisory Council and Board of Directors



Dr. Richard Kruse, Vice Chair Department of Orthopedics, Chief of the Orthopedic Trauma Service, and Co-Director for the multidisciplinary OI program at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE, joined OIF CEO Tracy Hart to discuss **Surgical Updates on Treating Children with OI.**

[Click here to listen!](#)

PREGNANCY AND OI



Deborah Krakow, MD

Interviewed by Tracy Hart, OIF CEO

- Professor of Human Genetics and OB/GYN at David Geffen School of Medicine at UCLA
- Co-Director of the International Skeletal Dysplasia Registry
- Member of the OI Foundation's Medical Advisory Council



Dr. Deborah Krakow, Professor of Human Genetics and OB/GYN at David Geffen School of Medicine at UCLA and Co-Director of the International Skeletal Dysplasia Registry, joined OIF CEO Tracy Hart to discuss **Pregnancy in Women with OI.**

[Click here to listen!](#)

A Year of Fine Wines Strong Bones

We would like to thank everyone who came out to the Chicago Cultural Center on October 15th for the 2nd annual Strong Bones Gala: Chicago! Thanks to our new mobile bidding feature, people from across the country were able to bid along with the nearly 100 people in attendance on amazing auction items such as sports collectibles, spirits baskets and more. We were honored to have speakers, OI dad Mike Sheridan and Dr. Peter Smith, of Shriners Hospitals for Children in Chicago, share their OI stories. Fine Wines Strong Bones events offer a unique opportunity for members of the OI community to share their personal experience with people who may not be familiar with OI. As attendee, Chris Chulos shared, "We're fortunate that our daughter can walk' said a father of an OI child. Reflect on that." Thanks to funds raised during this event, the OI Foundation will be able to continue helping to advance OI research through programs like the Brittle Bones Disorders Consortium (BBDC) and research sites like Shriners Hospital for Children, Chicago! We look forward to seeing this event continue to grow with the **3rd annual Strong Bones Gala: Chicago on September 30, 2017**, at the Chicago Cultural Center!

What began 17 years ago with a group of OI community members in the Washington, DC metro area coming together to host a single fundraising event began expanding last year. Original committee member, Tracy Mulroy states, "I've always felt so passionately about being involved with the foundation and raising money. It is amazing to see what our event has grown into." As



Tracy and Kyle Mulroy at the 2016 Fine Wines Strong Bones DC Gala

we move into 2017, the dream shared by members of original Fine Wines Strong Bones planning committee is finally being realized as that growth continues with five upcoming events in the next six months.

On **Friday, January 27, 2017**, OIF Board of Directors President Ken Gudek and his wife Teresa will host the **2nd annual Fine Wines Reception: Naples** in Naples, FL. This reception will be an intimate, business casual event featuring light fare to compliment a sommelier led tasting of an assortment of Italian wines carefully selected by Ken.



Teresa and Ken Gudek with guests at the 2016 Fine Wines Reception Naples

Next, we invite ladies to find their pearls and feathers and gentlemen to dust of their dinner jackets for the *Great Gatsby*-themed **17th annual Fine Wines Strong Bones Gala on Saturday, February 25, 2017**, at the Gaylord National Hotel, just outside of Washington, DC. The evening expects to be a roaring good time, while attendees bid on more than a hundred auction items, try their hand at casino games and help continue the funding of the Jamie Kendall Fund for OI Adult Health during the Fund the Mission portion of the live auction. Last year, more than \$100,000 was raised in 15 minutes that enabled the OI Foundation to begin funding a promising pulmonary study as well as increase resources for expanding OI knowledge amongst medical professionals and new Take Charge of YOUR Health guides for adults with OI.

The **2nd annual Strong Bones Gala: Florida** will be moving to Tampa, FL, this year on **March 25, 2017**. 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 addition of Shriner's Hospital for Children-Tampa and Dr. Danielle Gomez as one of our Brittle Bones Disorder Consortium members.

Due to the overwhelming success of their family's annual Unbreakable Spirit® Walk-n-Wheel, Christine Rossi and her father, Dick Wyman will be hosting the first ever **Strong Bones Gala: Boston** at the Sheraton Framingham on **Saturday, May 20, 2017**. Christine is very excited to convert the support she received for her walk-n-wheel into a formal evening of fine wines, exciting casino games and auctions to benefit the OI Foundation.

Finally, for the first time ever, the OI Foundation will host a **Fine Wines Reception in Canada**. 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. We are very excited by this expansion as we cannot accomplish our goals to be the primary resource for information and mutual support for the nearly 50,000 individuals living with OI in North America without the support of members of the OI community in Canada.

There are still more Fine Wines Strong Bones events being planned! If you are interested in helping with an existing event or if you 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.



Live auction at the Strong Bones Gala Florida

OIF Announces Co-Chairs for 17th Annual Scientific Conference

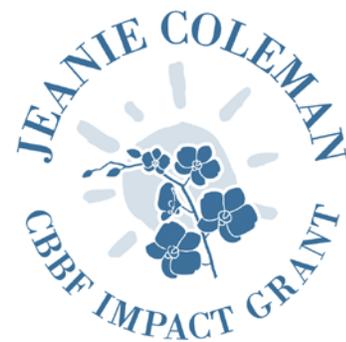
The OIF is pleased to announce that the 17th annual OIF scientific conference, scheduled for April 19-21 in Chicago, will be co- chaired by **Dr. Sandesh Nagamani** of Baylor College of Medicine and **Dr. Charlotte Phillips** of the University of Missouri. The annual OIF Scientific Conference brings together more than 100 OI researchers and clinicians to discuss the present state and future of OI research and treatments, ongoing clinical research and therapeutic trials, outline the best practices for management of OI, and train the next-generation of researchers and clinicians.



Sandesh Nagamani, MD



Charlotte Phillips, PhD

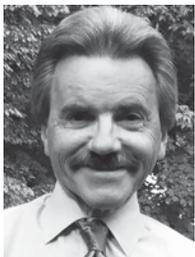


Jeanie Coleman Impact Grant – Applications Available January 2, 2017

Impact Grants help individuals living with OI fund projects, receive services or purchase equipment that might not be covered by savings, other programs or insurance. Applications will be available on January 2, 2017 at www.oif.org/ImpactGrant until February 6, 2017. Please contact Impactgrants@oif.org if you have any questions.

An Update from the OIF Board of Directors

The OI Foundation Named Ken Gudek as the New President of the Board of Directors!



Ken Gudek

As a person living with OI, Ken is committed to helping the OI Foundation meet its goals. Ken and his family have hosted the Annual New Hampshire Golf Classic to benefit the OI Foundation since 2007, and they have raised approximately \$370,000 for the Foundation's programs and services. Ken and his wife of 30 years also hold a Fine Wines for Strong Bones event in Naples, FL, to benefit the Foundation.

"The OI Foundation is so excited to have Ken lead us as we continue to implement new programs and activities for adults and children with OI," said OIF Chief Executive Officer Tracy Hart. She added, "Ken brings a level of passion and personal commitment to the OIF that we all admire."

Congratulations, Ken!

The OI Foundation Also Welcomed Two New OIF Board Members, Brett Eisenberg and Ted Trahan!

Brett Eisenberg, a person living with OI, currently serves as the Executive Director of the Bronx Independent Living Services. The mission of the BILS is to empower all people with disabilities to understand and exercise their civil and human rights in order to live fully integrated lives in mainstream society. Brett is also responsible for developing and implanting a strategic plan for the organization and creation of new programs such as "Young and Employed."

Ted Trahan is a parent of a young adult with OI. Ted currently works for Medtronic PLC in the area of project management for manufacturing process development and has been a volunteer with the OIF for 15 years. Ted says "Upon attending our first OIF conference in San Diego, our OI world expanded. We met people with OI across many age ranges. We met families who could give us calm understanding of how acute and long term care was managed at home. We were introduced to leaders in OI related research. We gathered much knowledge through speakers and papers but more importantly we met a group of people who overcame obstacles with a sense of "can do" that was most inspiring. The people and resources of the OI Foundation impacted our family deeply and in positive ways. I am both sincerely grateful and excited by the opportunities the Foundation has opening up before it."

Welcome to the OIF Board of Directors, Brett and Ted!

OIF Program Director Retires After 19 Years of Service—We will miss you, Mary Beth!

Memo

To: The OI Community

From: Mary Beth Huber, Director of Program Services

Topic: Retirement

It is with mixed feelings that I have decided to turn in my keys and name badge and retire from the OI Foundation at the end of December. For the past 19 years, I've had challenging work that drew on all of my skills as a teacher, writer and researcher. I've had the opportunity to meet, work with and learn from wonderful people from all over the world. In 1997, I found the OIF through a help-wanted ad in a local paper. I thought I had found a new job. In reality I found the whole OI community—a group I came to care about very much. I'm grateful to have had the opportunity to work with talented co-workers, dozens of OIF Board members, and Medical Advisors who patiently answered so many questions. But most of all I'm grateful for the people in the OI Community who shared their personal stories and allowed me into their lives. It has been a privilege.

Wish me luck as I try this new thing called "retirement."



Mary Beth Huber

Report: Pulmonary Focus Group

A group of eight adults who have OI met with Medical Advisory Council member and pulmonologist, Dr. Sandy Sandhaus during the summer conference to discuss their experiences with respiratory issues. Research suggests that everyone, even those with the milder forms of OI have altered lung tissue. Studies also suggest that short stature and changes in chest shape can significantly contribute to a greater likelihood of breathing problems. But the question remains – What does this mean to the daily life of OI adults?

Members of the group included men and women, as well as all types of OI – mild, moderate and more severe. Some walked unassisted, some used a walker and some used a wheelchair. Discussion topics brought up by the group included comments on frequency of colds and bronchitis, length of time to recover from bronchitis, experiences with anesthesia, and with having low energy or feeling short of breath. Before leaving they took a short survey.

Results of the survey suggest that breathing problems have an effect on the lives of people with all types of OI. Almost

everyone in the focus group had experienced at least one lung infection (more serious than a mild cold) during the past 2 years. Half of the group saw a pulmonologist as part of their regular health care and a third had been diagnosed with sleep apnea.

Plans are underway to follow-up by surveying a greater number of people with OI. The goal would be to get more detailed information about their experiences with breathing problems and how that affects their daily lives.

Until more information is available, OI adults are advised

- Not to smoke and to avoid second hand smoke
- Get vaccinated for pneumonia if they haven't been already
- Keep up with the annual flu shot
- Talk to their doctor about more aggressive treatment for recurring bronchitis.
- If anesthesia is needed for surgery or a test like a colonoscopy, talk to the doctor ahead of time about the possibility of a reaction such as nausea, vomiting or gas.



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and families with
osteogenesis imperfecta*

shrinershospitalsforchildren.org/Canada
 facebook.com/ShrinersHospitalsforChildrenCanada
 twitter.com/ShrinersCanada

The OI Foundation counts on your support to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. The following is a letter from OIF CEO, Tracy Hart, about the progress of the OI Foundation over the past year. 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.



804 West Diamond Avenue
Suite 210
Gaithersburg, MD 20878
(844) 889-7579 toll-free
www.oif.org

Unbreakable Spirit®

Dear Friend:

Our mission at the Osteogenesis Imperfecta Foundation is to improve the lives of everyone affected by OI through education, advocacy, mutual support and research. Over the past year, because of generous supporters like you, we have laid the groundwork for a multi-pronged effort to address specific health concerns of adults and children living with OI.

We hope you will consider making a gift today to help us continue this important work!

This past summer at the 2016 OIF National Conference, we introduced a new set of materials—**Take Charge of YOUR Health**. This tool kit is designed to help adults become informed, proactive healthcare consumers and to help them partner with their doctors to lead healthy lives. The materials were developed under the OIF's Adult Health Initiative, a program only made possible through your help last year.

Because of your support, we were not only able to develop these new vital materials, but also secure enough funding for **the first year of a new pulmonary research study**. This new study, a direct result of advocacy from the OI community, will work to find answers to the seeming rise in adults with OI experiencing pulmonary complications after and during "routine" medical procedures; experiencing severe pulmonary complications while battling a respiratory illness; and experiencing an increased dependence on supplemental oxygen to help keep lung function at a productive level.



OIF Board Member Kara Ayers and her family at the 2016 OIF National Conference

The **Take Charge of YOUR Health materials** and the **Adult Health Initiative** were only made possible because of help from supporters like you—you have helped change so many lives—but **there is still more work to be done!**

As a companion piece to the **Take Charge of YOUR Health** for adults, we are developing a series of educational programs for children and families with a new diagnosis. The first exciting project is a series of videos on Caring for Infants and Babies who have OI. The first video will focus on safely handling the baby and the second on the encouragement of movement in older babies and toddlers.



A new attendee at the OIF National Conference.

With your support we can continue our work on important programs like funding a second year of our pulmonary study and providing Take Charge of YOUR Health materials for families faced with a new OI diagnosis. These programs are life-changing and many times have an immediate impact on a family's life.

The OI Foundation is committed to meeting the needs of the entire OI community...parents, children and adults with OI and the people that care for and love them.

Please consider making a gift of \$50, \$100, \$500 or more to the 50,000 Lives, One Unbreakable Spirit® campaign using the enclosed envelope or online at www.oif.org.

With your help, the OI Foundation has accomplished so much over the years; and with your continued support, the OIF will continue our work to improve the quality of life for all people affected by OI.

Thank you, as always, for your generous support and have a wonderful holiday season!

All my best,



Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

Enter The OI Foundation's Good Stuff Sweepstakes Today You Can Win!

Select One of Three Amazing Prizes:



GoPro Hero 4 Silver

Capture your world in an all-new way with HERO4 Silver, the first ever GoPro to feature a built-in touch display. Capture 1080p60 and 720p120 video plus 12MP photos at a staggering 30 frames per second.

Valued at \$400



Trip for Four to Any 2017 OIF Regional Conference

Includes four (4) full registrations to your choice of one (1) OIF Regional Conference in 2017 as well as one hotel room for one (1) night at the contracted hotel. Choose from Phoenix, Montreal or Seattle.

Valued at \$300



\$100 Amazon Gift Card

An Amazon.com gift card can be redeemed for millions of items including:

electronics, books, movies, tunes, toys and more.

Valued at \$100

Early Bird Prize:

\$200 Target Gift Card

A card full of possibilities!

Target Gift Cards can be used in store or online to purchase anything from groceries to furniture.



To Enter Today: Go to www.oif.org/Sweepstakes

Suggested donation is \$5 per entry

No donation necessary to enter; donation does not increase chances of winning. See reverse side for complete rules and regulations.

Deadlines:

Early Bird drawing -- Entries must be postmarked no later than **December 2, 2016.**

1st, 2nd, & 3rd Prize drawings -- Entries must be postmarked by **January 13, 2017.**

Uniting Unbreakable Spirits



By entering the Good Stuff Sweepstakes, you are helping the OI Foundation produce new information resources; fund research; provide answers to more than 7,000 requests for information a year; and facilitate support groups across the country.

In addition, the OI Foundation is constantly adding new programs like the OIF Regional Conference Series, which brings medical information, world-class experts and an opportunity for mutual support to OI community members across the continent. This year, the OIF Regional Conferences will span from Houston, Texas to Phoenix, Arizona to Montreal, Quebec to Seattle, Washington. Help us to continue reaching members of the OI community today!

Thank you for your support and Good Luck!

For more information, visit www.oif.org/sweepstakes or call **844-889-7579.**



From the Information Center

Time to Protect Yourself from Flu

Back-to-school time means it is not too early to prepare for the flu season by getting the annual flu shot. The flu is a respiratory illness. It can make people seriously ill, short of breath and it can lead to even more serious lung infections including pneumonia. Children and adults who have OI have a higher risk than other people for lung infections due to alterations in rib cage shape and weaknesses in their lung tissue. While no flu vaccine provides complete protection, it will reduce the chance of getting the flu and it typically makes any case of the flu much milder. The American Academy of Pediatrics (AAP) recommends that all children age 6 months and older and their caregivers receive the seasonal flu vaccine. They recommend getting the injection (shot). The AAP and other medical organizations are warning people NOT to use the nasal spray vaccine since it is ineffective and does not provide adequate protection.

Adaptive Equipment Resource on Pinterest

For her presentation at the OI Foundation National Conference this summer, physical therapist Dr. Reenee Donohoe from Nemours A.I. duPont Hospital for Children organized a Pinterest page for sharing examples of adaptive equipment for children who have OI. Some of the equipment showcased is from commercial vendors; others are homemade or homemade modifications of a commercial product. Visit the Nemours Pinterest page on OI at this link: <https://www.pinterest.com/nemours/osteogenesis-imperfecta/>.

Finding and Evaluating Online Health Information

The National Center for Complementary and Integrative Health has published an excellent guide to finding information online that is trustworthy. Go to <http://l.usa.gov/ISRhufH> to see the whole article. It offers 5 questions to help you evaluate a new website.

Who? Who runs the website? Can you trust them?

What? What does the site say? Do its claims seem too good to be true?

When? When was the information posted or reviewed? Is it up-to-date?

Where? Where did the information come from? Is it based on scientific research?

Why? Why does the site exist? Is it selling something?

Recent Journal Article Looks at Causes of Death for People with OI

A recent journal article provides new information about causes of death that may be associated with OI. Dr. Lars Folkestad and his colleagues examined records contained in the National Danish Patient Registry. They compared 687 entries for people with an OI diagnosis to people representing the general Danish population. They found that the risk of death from cancer or heart disease was similar in both groups. On the other hand, people with OI had a higher risk of death from respiratory illness, gastrointestinal illnesses and trauma (accidents) than other people living in Denmark. This study is an improvement over earlier studies but it is limited, as disclosed in the article's discussion section, by the design of the Danish Patient Registry: OI Types or levels of severity are not identified; Age at death is not mentioned but babies who died at birth are included; and the specific gastrointestinal problems are not identified. Articles like this are important because they point to questions that need to be examined in more detail. This article has already drawn attention to the need for significantly more research into the gastrointestinal issues faced by people of all ages and types of OI. (Mortality and Causes of Death in Patients with OI: A Register-Based Nationwide Cohort Study by Lars Folkestad and others in the Journal of Bone and Mineral Research, 2016. A link to the abstract for this article is on the OIF website.)

Tool Kit for Parents

Preparations have begun for a new section for the OIF website – a Tool Kit for Parents of Children who have OI. Materials will cover the information parents need immediately when their child is diagnosed and at different developmental stages from birth through school age.

In addition, thanks to an anonymous donor's recognition of Mary Beth Huber's retirement, funds are available to produce a video on handling infants and children. The goal is to have the new materials ready by summer 2017.

Celebrate Rare Disease Day by Holding a Blue Jeans for Better Bones Day!

Research is the key to identifying and understanding diseases and enables doctors to develop new treatments. This is precisely why *Research* is the theme for the 10th annual Rare Disease Day, being celebrated globally on February 28, 2017.

To show support for Rare Disease Day and raise awareness for osteogenesis imperfecta, the OI Foundation has chosen February 28, 2017 for the next **National Blue Jeans for Better Bones Day**.

Blue Jeans for Better Bones participants make a donation to allow 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. Tailor your Blue Jeans for Better Bones program to meet your specific needs. February 28th doesn't work for you? Choose your own date to host your Blue Jeans for Better Bones Day!

Contact Samantha Todorovich (stodorovich@oif.org) to register your team for the National Blue Jeans for Better Bones campaign or to schedule your own day.



Take Charge of YOUR Health: New Materials for Adults with OI and Their Doctors

At the OIF National Conference a new set of materials was introduced—**Take Charge of YOUR Health**. This toolkit is designed to help adults become informed and proactive healthcare consumers and to help them partner with their doctors to lead healthy lives. Many people—adults with OI, parents of young adults and doctors—contributed to the materials to make sure that everything is useful and valid.

The materials include a **Pocket Guide** which is a quick wallet sized summary of important things for adults with OI to be aware of. The rest of the materials are organized in three sets of documents posted on the OIF website under the tab “Especially for Adults.” The first group is for all adults. This includes a one-page set of suggestions for managing OI and staying well. The **Handle Adults with Care poster** can be used in a hospital or outpatient surgery center.

The second set is especially for teens and young adults. It includes information for youth and their parents about the transition from pediatric to adult healthcare. The two page worksheet, **Know Your OI**, is especially useful for preparing young people who are moving out on their own. In addition, it will help any adult put together their basic OI health history or prioritize a large group of health records.

The third set of materials is meant to be shared with doctors. The cornerstone document is **Care for the Adult with OI**. It is based on interviews with doctors who regularly see OI adults. It describes what should be covered in the annual physical and health issues that need to be watched. This document can help introduce OI when changing primary care doctors.

Another document that is useful for all adults and for their doctors is the **Chart of Common Procedures**. This document covers many of the common tests and medical procedures that adults might encounter. If OI is a factor, the issues, precautions, or special practices are described.

The **Take Charge of YOUR Health** materials are on the OI Foundation website under the tab, “Especially for Adults.” The Pocket Guide and single sets of the fact sheets can be ordered, through the online store or by contacting the OIF Office. Over the next several months new features will be added including additional documents and links to podcasts. If you have an idea for additional documents, please call the OIF office or email Bonelink@oif.org.

Take Charge of YOUR Health Materials

For All Adults

- ♦ Take Charge of Your Health
- ♦ Take Charge of Your Breathing
- ♦ Take Charge of Planning for Surgery
- ♦ Pneumonia Vaccine Update
- ♦ Know Your OI: A Basic Health History
- ♦ Poster: Handle with Care- Adults

For Teens and Young Adults

- ♦ Moving from Pediatric to Adult Care
- ♦ Know Your OI: A Basic Health History

To Share with Your Doctors

- ♦ Care for the Adult Patient with OI
- ♦ Chart: OI and Common Medical Tests and Procedures
- ♦ Resource for Medical Professionals

THANK YOU TO
THE NJ AREA OI SUPPORT GROUP FOR
HOSTING THE 25TH BEEFSTEAK DINNER!



293 Attendees
136 Tricky Tray Baskets
25 Bottles in the Basket of Cheer
Countless Slices of Beef
More than \$20,000 raised in support of the OIF!



OI and the Eye Study Update

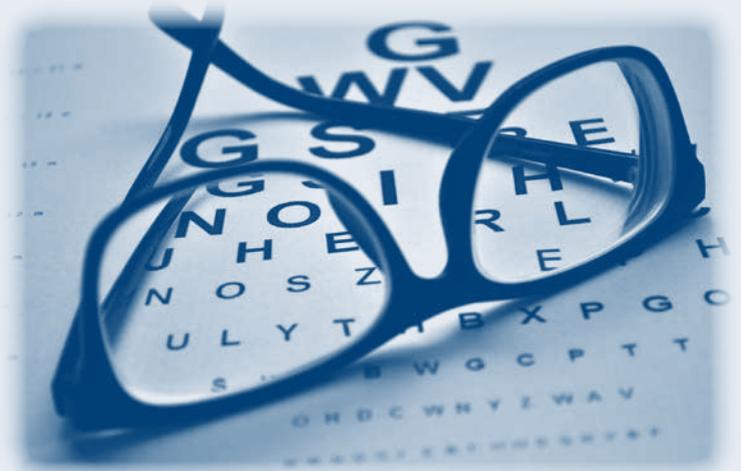
The “Vision Study/OI and the Eye Study” at the Osteogenesis Imperfecta Foundation National Meeting in Orlando, FL, in July 2016 was very successful. The study was conducted by Dr. Felix Chau, University of Illinois at Chicago, Illinois Eye and Ear Infirmary, with assistance from Dr. Victor Villegas, Bascom Palmer Eye Institute at Naples and Connor Larkin from Forus Health. Information was collected from 38 people and the groundwork was laid for a larger study. The overall study goal is to understand more clearly how different OI types affect the eyes and vision. This will help families, OI adults and eye doctors take actions to keep eyes healthy and respond correctly if a problem emerges.

There are two steps in this study:

1. Collecting data from local ophthalmologist—eye exam records of people age 18 and older who have OI. A form was made available online before the conference and people were asked to have their local eye doctor fill it out. All documents were de-identified to protect participant privacy.
2. Gathering additional eye data from study participants. This included taking a brief medical and eye history, checking visual acuities, recording eye pressures with an iCare ic100 tonometer, and digitally photographing corneas, sclerae, optic nerves and central retinas with a 3nethra portable camera.

Next Steps — Some people who received eye exams at the conference still need to ask their local ophthalmologist (Eye MD) to fill out the “OI Eye Exam Form.” Once completed, these forms can be sent to Dr. Chau.

It’s Not Too Late to Participate — Anyone with OI age 18 and older who is interested in participating in the next phase of this study may see their local ophthalmologist (Eye MD) and submit an “OI Eye Exam Form.” The form can be printed from the OIF website www.oif.org/RS_Current. Participants are reminded to answer the question about OI Type, but NOT to include your name or other personal information to protect privacy. Once complete, these forms can be sent to Dr. Chau.



In the near future all of the data collected will be compiled and an article will be published describing the findings. This information will be shared with other researchers in the Brittle Bone Disease Consortium in an effort to improve the accuracy of eye health information that is collected in the Longitudinal Study of OI and encourage further research. In the long term future, Dr. Chau hopes to repeat the eye data collection program at other OIF meetings. People who have OI are encouraged to work with local ophthalmologists for routine eye care.

Dr. Felix Y. Chau, MD

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My Experience with Surgery and Recovery

By Tracy Mulroy

Recently the need for elective surgery reminded me that surgery for an adult who has OI can be complicated and emotionally difficult. To be a good healthcare consumer a person with OI needs to:

1. Do a lot of advanced planning
2. Learn about the surgical procedure
3. Plan for the recovery period
4. Have a support network

Here's what my husband Kyle and I learned from my elective surgery.

During the Planning Process

Talk to your doctor until all of your questions have been answered. If the doctor is new to you be sure that he/she is fully aware of your form of OI and consults with your primary OI doctor.

Be sure you fully understand what will happen during the surgery, during your hospital stay and during your recovery period at home. Surprisingly many surgeons offer little or no information about what to expect after you leave the operating room.

Because of OI, you will need a consultation with a pulmonologist. Get your pulmonary function testing done right away. Your respiratory status determines if you are eligible for an elective procedure, affects the type of anesthesia and suggests the odds you will need to be put on a ventilator during or after the surgery. Tests you typically need include: Forced Vital Capacity (FVC), Maximum Voluntary Ventilation (MVV), and Arterial Blood Gas or a similar test to measure oxygenation and ventilation.

Get an anesthesiology consultation. If at all possible, have your pulmonary function testing done prior to meeting with your anesthesiologist. Without the results of your pulmonary function tests the anesthesiologist, especially one with little OI experience, may describe all of the worst case possibilities whether or not they really apply to you. This can be frightening.

If questions or concerns come up during the time you're planning for surgery, never hesitate to consult with your primary OI doctor. The doctor who knows you best can help you sort through the information and conflicts.

Talk to your surgeon to get definite assurance that nursing, operating room and recovery room personnel will be fully informed about your needs as a person with OI, especially how to safely move you.

Talk with your surgeon to make sure that a plan is in writing for pain management and for handling the gastrointestinal issues that accompany most pain medicines associated with surgery.

Be proactive and insist that your doctor anticipate potential constipation issues. It is an unglamorous fact that patients cannot leave the hospital until they have had a "normal bowel movement." This can be difficult not only due to the constipation often associated with pain medicines, but it can become even more difficult if the person with OI is small in stature or unable to walk. Once home, make sure that a good plan for constipation is in place and is being followed. If constipation issues persist, contact your primary OI doctor for advice on how to proceed.

Special OI Related Considerations

A standard part of recovering from anesthesia usually involves getting the patient up, and taking deep breaths. This can be more difficult for the person who has OI. Be sure that the recovery room personnel have been briefed on how to safely help you turn and sit up.

People who cannot walk or stand face additional challenges, since walking is a standard part of helping a person recover from surgery. Sitting at the side of the bed, moving the legs either while sitting or while lying down, taking deep breaths and coughing while hugging a pillow can help.

Staying well hydrated is important, but make sure that the hospital staff take your smaller size into consideration when they calculate how much water you drink.

During the Hospital Stay

- You will need a strong-willed and well-informed advocate. This should be someone who knows you well, knows your OI and who knows what to expect in the hospital. Your advocate should have written permission to speak for you and to hear all medical information.
- Ideally an advocate should stay with you day and night during the first few days after your surgery.
- Post notices that you are a person with OI in your room, on your chart and at the nursing station. The new poster, **Handle Adults with Care**, from the OI Foundation is handy. If you have hearing loss and typically use hearing aids, be sure your hospital caregivers know.
- Request a physical therapy/occupational therapy consultation for before you leave the hospital. You will need a plan for regaining your strength and mobility.

Before You Go Home

- Get written instructions about prescription and over-the-counter medicines
- Be sure all of your questions are answered about wound care, diet, and when to immediately call the doctor.
- Get specific instructions about exercise, doing various daily living tasks, transferring into and out of wheelchairs, using a walker and returning to your regular activities such as swimming.

The new OIF fact sheet – **Take Charge of Your Surgery** offers some useful suggestions. You can find it on the OIF website along with the Handle Adults with Care Poster.

While at Home

- Rest! Overdoing it will slow down your full recovery.
- Allow people to help with childcare, housework, errands, cooking etc.
- Follow instructions for wound care, diet and exercise. Depending on what kind of surgery you've had, physical therapy may be needed to keep unaffected muscles strong, or to re-learn how to safely transfer or return to walking.
- Follow the hydration and diet plan to prevent constipation. If constipation returns contact your primary OI doctor without delay.
- Celebrate the day you feel fully recovered!

Note: *Tracy Mulroy is an adult living with OI who uses a scooter for mobility. She recently had elective surgery at Johns Hopkins Medical Center in Baltimore, MD. Tracy gives much of the credit for her recovery to her husband Kyle who was her tireless advocate. Mary Beth Huber, OIF Program Director assisted with this article.*

Resources: The fact sheet and poster mentioned in this article can be found under the tab "Especially for Adults" on the OI Foundation website www.oif.org.

Book Review: *All Waiting is Long*

All Waiting is Long is a powerful sequel to Barbara Taylor's earlier book, *Sing in the Morning Cry at Night*.

The story picks up in 1930 and follows the Morgan sisters, Violet and her younger sister Lily, as they become young women, make difficult choices and struggle to find and understand love and forgiveness. This thought-provoking story is driven by the repercussions of Lily's teen pregnancy and Violet's devotion to her family. The early depression years, a Pennsylvania coal industry in crisis and labor unrest provide the gritty setting. As in her earlier book, the history of the era has been carefully researched and then brought to life with memorable multidimensional characters. Each character in his or her own way faces the most vulnerable part of themselves; where they can easily be broken.

The OI Foundation is grateful to author Barbara J. Taylor for her efforts to raise awareness about OI and support the work of the OI Foundation. She has not only posted information about OI on her website but is also donating a part of her proceeds from the book to the OIF. As the aunt of a young man who has OI she is part of a family that experienced the many challenges that come with fragile bones.

All Waiting is Long is available online through Akashic Books, Barnes & Noble, Amazon and Indie Bound. For more information please see the author's website, www.barbarajtaylor.com.

IN THE YEAR OF 3015, A LITTLE BOY LOOKING FOR ARCHEOLOGICAL TREASURES IN THE GREEN ECO-TERRITORY OF THE SAINT-JACQUES ESCARPMENT IN THE CITY OF MONTREAL FINDS A TIME-CAPSULE. THE BOY OPENS IT TO DISCOVER A STRANGE LOOKING OBJECT AND RUNS TO SHOW IT TO HIS GREAT-GREAT-GREAT-GREAT GRANDFATHER WHO, THE BOY WAS SURE, KNEW WHAT IT WAS AS THE OLD MAN KNEW EVERYTHING.

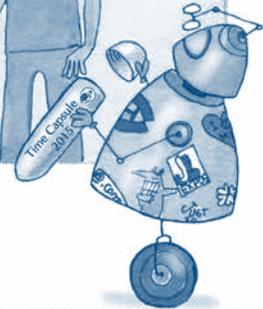


HE TOOK THE OBJECT IN HIS OLD, OLD HANDS AND SAID: OF COURSE I KNOW! I REMEMBER HEARING ABOUT IT IN



NEWSPAPERS, TV EVEN BOOKS! THE FD ROD, THAT IS WHAT YOU CALL THIS LITTLE DEVICE.

LISTEN TO MY STORY NOW:



A THOUSAND YEARS AGO, THERE WAS A LITTLE RED ROOFED ORTHOPEDIC HOSPITAL ON TOP OF THE MOUNTAIN WHERE A GROUP OF MAGICAL DOCTORS AND INGENUOUS BIOENGINEERS HELPED KIDS FROM ALL OVER THE WORLD WITH RARE BONE DISEASES.



WHILE SEARCHING FOR A CURE, THEY HELPED KIDS WITH BONES AS FRAGILE AS GLASS, TO WALK, PLAY, AND EVEN RUN, BY MAKING THEIR BONES STRONGER WITH MEDICINE AND STRAIGHTEN THEIR LEGS AND ARMS WITH THIS LITTLE DEVICE THAT GREW AND GREW AS THE KIDS GOT TALLER AND TALLER.

LIKE THE CHILDREN, THE LITTLE HOSPITAL ALSO GREW, AND UNDER THE NEW BUILDING THEY BURIED THE FD ROD INSIDE THIS TIME-CAPSULE TO MAKE SURE THE HOSPITAL ALSO GREW STRONG!

THE LITTLE HOSPITAL WAS THE MONTREAL SHRINERS HOSPITAL, AND THE ENGINEERS WERE FROM PEGA MEDICAL.

ILLUSTRATIONS: LC BERGERON



20 years working together to bring innovative treatments to children around the world.



Join Fellow Members of the OI Community at an Upcoming Event



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

November

November 12th OIF Regional Conference: Houston, TX – Texas Children's Hospital, Pavilion for Women

November 12th Connecticut and Western Massachusetts OI Support Group Meeting – Hamden, CT

December

December 3rd Florida Support Group Meeting – Shriners' Hospital for Children Tampa

January

January 27th 2nd Annual Fine Wines Reception: Naples – Naples, FL

January 28th Bone China Tea – Anywhere

February

February 25th 17th Annual Fine Wines Strong Bones Gala: DC – Gaylord National Resort

February 28th Celebrate Rare Disease Day by holding a Blue Jeans for Better Bones Day. Go to www.oif.org/BJBB for more information.

March

March 11th OIF Regional Conference: Phoenix, AZ

March 25th 2nd Annual Strong Bones Gala: Florida – Tampa, FL

May

May 6th - 13th National OI Awareness Week

May 12th National Blue Jeans for Better Bones Day

May 20th Strong Bones Gala: Boston – Framingham, MA

June

June 3rd OIF Regional Conference: Montreal – Shriners' Hospital for Children: Canada

June 3rd Fine Wines Reception: Montreal – Shriners' Hospital for Children: Canada

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!



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[@OIFoundation](https://twitter.com/OIFoundation)

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WE CAN'T WAIT TO SEE YOU IN BALTIMORE, MD!

OIF NATIONAL CONFERENCE 2018

