

A Conference to Remember

“I had not anticipated how wonderful it would be for me to meet and share experiences with other families (at the OIF National Conference). I arrived home absolutely inspired. I was infused with hope, support, and a new sense of community that one could only get from attending the OIF Conference in person.”

— OIF Conference Attendee



The 2018 OIF National Conference, themed *EXPLORE*, gathered over 650 attendees and 50 speakers for a busy, fun-filled, and memorable weekend in Baltimore, Maryland! The attendees of this summer's conference represented seven countries and nearly forty US states. 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 OI Career Expo, the first-ever OIF Art Showcase, the OIF National Conference Talent Show, the Closing Dinner, and more!

National Unbreakable Spirit® Walk-n-Wheel Baltimore

On the evening of Thursday, July 12th, 300 members of the OI community took Baltimore's Inner Harbor by storm, kicking off the OIF National Conference with the National Unbreakable Spirit® Walk-n-Wheel! Participants walked and wheeled from the lobby of the Renaissance Baltimore Harborplace Hotel to the National Aquarium, where they enjoyed exclusive after-hours entry to one of the world's best aquariums. Thank you to Mereo Biopharma for sponsoring the finish line goodie bags, the Degna Spoldi Family Foundation for sponsoring the walk-n-wheel t-shirts, University of Kentucky Healthcare for cheering participants along, and Chick-fil-A for donating chicken sandwiches to all participants!

Congratulations to the Kamal & Coughlin Canucks, the top fundraising team; Sophia Kamal, the top youth fundraiser; former OIF Board President Mark Birdwhistell, the top adult fundraiser; and the Wishbone Walkabouts, the largest Walk-n-Wheel team (21 members)! Together, we raised more than \$110,000 for the OI Foundation! We cannot wait to see the turnout at the 2020 National Unbreakable Spirit® Walk-n-Wheel on Thursday, July 9, 2020, in Omaha, Nebraska!



Team Birdwhistell at the Unbreakable Spirit® Walk-n-Wheel in Baltimore, MD.

The Canadian OI Society is Back!

We are celebrating the newly revitalized Canadian Osteogenesis Imperfecta Society (COIS)! In partnership with the OI Foundation, the COIS will work to provide up-to-date OI research and resources for families affected by OI, opportunities for people with OI to connect across Canada, and COIS Clinic and Physician Directories for Canadian OI community members in search of medical experts in their area. French and English resources will be available.

For more information about the COIS, please contact COIS-SCOI@oif.org.



COIS Board member Sarah Kamal, OIF CEO Tracy Hart, Medical Advisory Council Chair Dr. Francis Glorieux, COIS Board President Jacinta Whyte, and OIF Board President Ken Gudek announced the launch of the newly revitalized Canadian OI Society (COIS) at the OIF National Conference.

Check out some of the highlights of the 2018 OIF National Conference!



OIF Conference attendees at OIF Advocacy Day on Capitol Hill.

On the morning of Thursday, July 12th, two dozen OIF Conference attendees participated in an **Advocacy Day** trip to visit lawmakers on Capitol Hill. The attendees, including OIF Board Members and advocates, met with their Senators and House members to discuss how OI has affected them and the ways in which Congress can help promote critical research. The OIF's message focused on the need for strong funding of NIH-supported OI research, particularly the Brittle Bone Disorders Rare Disease Clinical Research Consortium.

The largest OIF **Medical Consultation Day** ever began early on Friday, July 13th – the first full day of conference. Over thirty medical professionals provided 250 one-on-one meetings with Conference attendees to answer OI related questions. For many conference attendees, this opportunity was an encouraging beginning to an informative and unique weekend.



OIF staff and volunteers organizing Medical Consultation Day.

The official Conference program opened with a formal welcome from OIF CEO Tracy Hart, OIF Board of Directors President Ken Gudek, and OIF Medical Advisory Council (MAC) Chair Dr. Francis Glorieux at the **OIF National Conference Opening Session**. OIF Board Member Kara Ayers and US Paralympic Gold Medalist McKenzie Coan delivered the keynote address. Kara and McKenzie shared their experiences as Paralympic swimmers with OI, as well as the impact OIF Conferences had on their childhood and teenage years.



US Paralympic Gold Medalist McKenzie Coan welcoming attendees to Baltimore, MD.

The President of the OI Federation of Europe (OIFE), Ingunn Westerheim, presented an update on the activities and research goals of the OIFE, and discussed how OI-related associations across the globe are working together to advance programs and research.



Former OIF Board President Mark Birdwhistell was presented the **OIF's Thelma Clack Award** for his outstanding commitment to the OI community.

Information sessions at the OIF National Conference covered a wide variety of clinical topics associated with the diagnosis, treatment, and management of OI in children and adults. Below are some of the most attended sessions:

- Dental Forum
- Physical Therapy Forum
- Women's Wellness Forum
- Men's Wellness Forum
- OI Youth Empowered and Proud Forum
- Mild OI Forum
- Physician Q&A Roundtables and Panel Sessions



Violinist, songwriter, and National Public Radio's (NPR) 2016 Tiny Desk Contest winner, **Gaelynn Lea**, performed at the OIF National Conference.



The first-ever OIF **Art Showcase**, organized by longtime volunteer Ann Marie Geiger, was open for Conference attendees to enjoy paintings, photographs, sculptures, and other artwork created by OI community members.



Tracy Mulroy was presented the **2018 President's Award** for her efforts in establishing the Jamie Kendall Fund, which is the first OI community-directed and community-funded research initiative.



The first day of OIF Conference concluded with the fantastic **OIF Talent Show**, featuring more than twenty of the OI Community's most talented youth and young adults. Thank you to Suzanne Richard for organizing and hosting this much-appreciated event.

(continued on page 4)

A Conference to Remember (continued from page 3)

On behalf of the OIF Board of Directors and Staff, we would like to thank the medical consultants, speakers, volunteers, and participants who contributed to the success of the 2018 OIF National Conference! A special thank you to Dr. Mahim Jain of Kennedy Krieger Institute, who served as the on-call/emergency first aid contact during the conference. The OIF staff and Board of Directors are overwhelmingly grateful for the many speakers, planning committees, facilitators, and volunteers who not only made careful preparations to present, but also offered their skills, knowledge, and resources to attendees beyond the weekend. This Conference certainly proved to be one to remember!

To view pictures from the OIF Conference, visit the OIF Facebook page and page 8 of this issue of Breakthrough. To read the full OIF Conference 2018 recap, please visit www.oif.org/Conference.

We hope you will be able to join us at future programs and events. Visit the OIF online calendar, website, and social media pages to stay up-to-date on events near you.

We hope to see you July 9-12, 2020 at the next OIF National Conference in Omaha, Nebraska!

Thank You to Our Sponsors!

Degna Spoldi
Family Foundation


CHILDREN'S BRITTLE BONE FOUNDATION

 Alfred I. duPont
Hospital for Children

Don't miss the OIF's 2nd Annual Boots & Bling for Better Bones event in Houston, Texas! Purchase your tickets today at www.oif.org/StrongBonesHouston



BIG AND BRIGHT

OSTEOGENESIS IMPERFECTA FOUNDATION

2ND ANNUAL BOOTS & BLING FOR BETTER BONES

SATURDAY, NOVEMBER 10, 2018

6:00 - 10:00 IN THE EVENING

THE ARMADILLO PALACE

5015 KIRBY DRIVE • HOUSTON, TEXAS 77098

COWBOY CHIC ATTIRE

Connecticut Children's Medical Center
Osteogenesis Imperfecta Center

Division of Pediatric Endocrinology
505 Farmington Avenue, 2nd Floor, Farmington, CT 06032
Clinic Coordinator: Tiffany Jack 860.837.6719, Tjack@connecticutchildrens.org



Emily Germain-Lee, MD

Chief, Division of Pediatric Endocrinology
Connecticut Children's Medical Center
Professor, Department of Pediatrics
UConn School of Medicine
Director, Center for Rare Bone Disorders
Director, Albright Center
Co-Director, Osteogenesis Imperfecta Center



Nancy Dunbar, MD

Pediatric Endocrinology
Connecticut Children's Medical Center
Assistant Professor, Department of Pediatrics
UConn School of Medicine
Director, Bone & Mineral Clinic,
Shriners Hospital for Children
Co-Director, Osteogenesis Imperfecta Center





connecticutchildrens.org

Thank you for Helping Us Spread OI Awareness Across the Nation!

Each year during National Osteogenesis Imperfecta Awareness Week, the OI Foundation, OI community members, and supporters come together to raise OI awareness across the nation. National OI Awareness Week is scheduled around Wishbone Day (May 6th), the international awareness day for osteogenesis imperfecta. We celebrate Wishbone Day by wearing yellow, the symbolic Wishbone Day color, and by making an effort to bring attention to osteogenesis imperfecta among our friends, families and communities.

To prepare for National OI Awareness Week, OI community members submitted requests to their state government to proclaim May 5-12, 2018 as National OI Awareness Week. We are so thankful for the OI community members who requested proclamations and the officials of the 19 states, 4 cities, and 2 counties that recognized May 5-12, 2018, as National OI Awareness Week!

Throughout National OI Awareness Week, the OI Foundation encouraged social media followers to like, share, and retweet the OI related social media posts posted by the OIF. Thank you so much for helping us spread the word – **we reached over 200,000 people through social media!** More than 30 OI community members created Facebook fundraisers in support of the OI Foundation during National OI Awareness Week to raise awareness and funds for the OI Foundation.

Raising OI awareness in your community is important year-round! To raise awareness by planning an event or holding a Blue Jeans for Better Bones Day in your office or school, visit www.oif.org/bjbb or contact Jessica at jskidmore@oif.org or 844-889-7579.



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



Thank you to our partner organizations



CHILDREN'S BRITTLE BONE FOUNDATION



For their support of the 2018 Medical Consultations program



We are Pleased to Announce and Welcome Two New OIF Board Members, Ken Finkel and Christine Rossi!

Ken Finkel (pictured with his wife Ann and daughter Jessica) served on the OIF's Board of Directors from 2001-2009, including three years as OIF Board President. During his tenure, Ken oversaw the launch of the OI Linked Clinical Research Centers, which is now the centerpiece of the Brittle Bone Disorders Consortium, and advocated for the OIF to implement the OI Adult Health



Initiative. In addition, he worked with the Children's Brittle Bone Foundation to form the popular Impact Grant Program and participated in advocacy efforts at the NIH and on Capitol Hill. Under Ken's leadership, the OIF's mission and reach increased throughout the OI community.

Since 2009, Ken has stayed very active with the OIF. He continues to serve on the finance committee and previously chaired the board development committee. Ken, who owns an automotive parts supply company, and his wife Ann live in Indianapolis, IN. They have two daughters. Jessica, the oldest, has OI and lives in the DC area.

Welcome to the OIF Board of Directors, Ken and Christine!

Christine Rossi (pictured with her husband and two sons) comes from a family of five generations affected by OI. She is a person living with OI and is passionate about raising awareness and funds to find a cure for OI and improved treatments. Following in her father's footsteps, Christine served on the OIF's Board of Directors and Executive Committee from 2003-2009. Since 2009 she has remained very involved with the Foundation. After Christine launched the Unbreakable Spirit® Walk for OI and Family Fun Day in Framingham, MA, in 2005, this event continued through 2015 raising over \$650,000. Her vision was this event would be a national event held all over the country and served as mentor to get many other Walk N' Wheels launched. In 2017 she turned her efforts to addressing the link between cardiac issues and OI, hosting the first Fine Wines Strong Bones Boston Gala which raised close to \$100,000 in the first year! In total over 13 years, Christine has led these events to raise close to \$1,000,000 all of which goes directly to OIF. In addition to raising funds, Christine has served as a personal advocate for people with OI in her area and across the country raising awareness about issues that affect not only bone but issues that affect the heart and lungs of people with OI. Her Family Fun Day became an event people looked forward to as a way to connect and she continues to support other families in her area with OI.



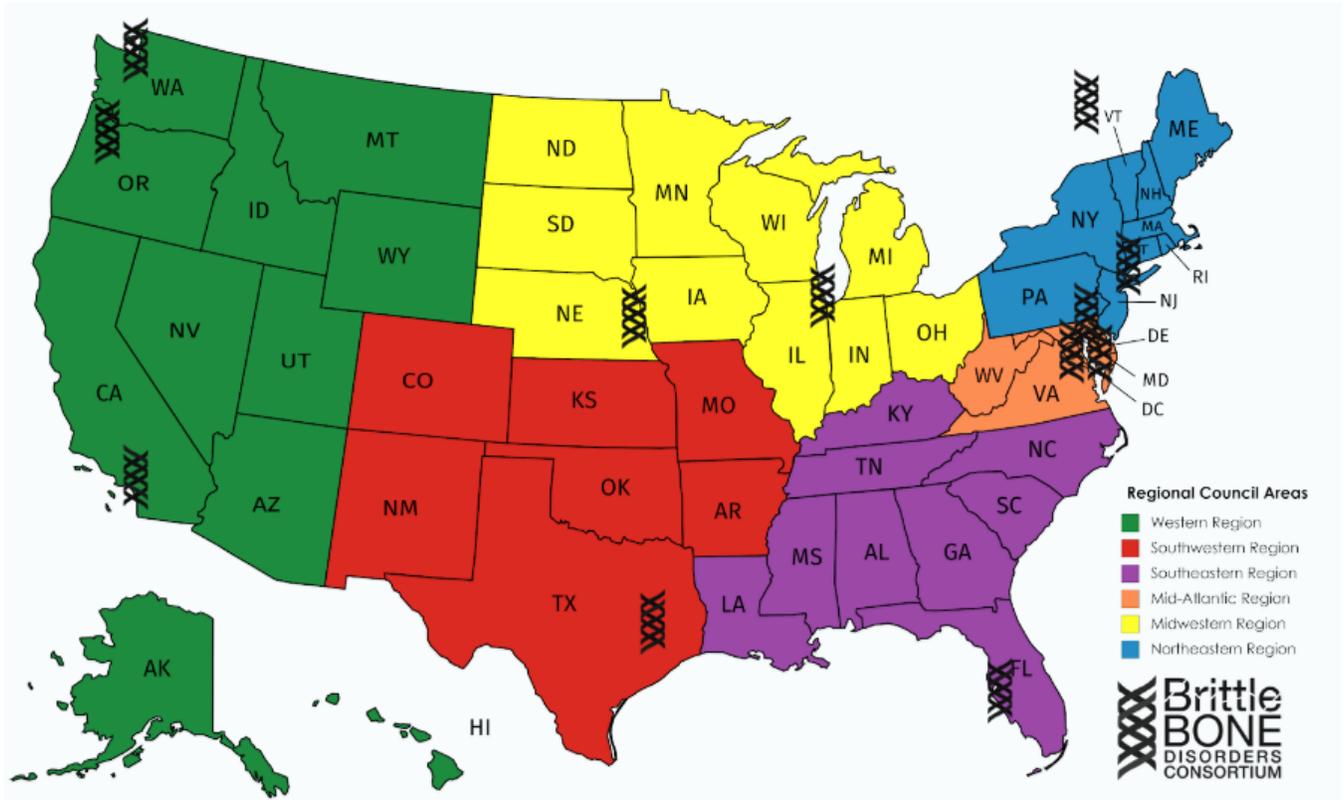
Christine and her husband live in Ashland, MA, and have two sons. Christine is a Leader of Training, Leadership & Development programs at DellEMC Technologies. She holds degrees in psychology and counseling and has spent her career focused on recruiting, career coaching, organizational design and leadership program development and management. Christine is also passionate about helping others through her practice of Reiki and work with Rodan + Fields life-changing skincare.

Introducing the OI Foundation Western Regional Council

At the 2018 OIF National Conference, OIF CEO Tracy Hart announced the Western Regional Council, which will be led by former OIF Board Member Carolyn Tipton. As the first Council in the OIF Regional Council Network, council members will work to expand resources and coordinate regional conferences, fundraising events, and future programs for their region.

Over the coming months and years, the OIF will be organizing Regional Councils in the Southwest, Midwest, Southeast, Mid-Atlantic, and Northeast, totaling six areas. The draft map of the target Regional Council areas (pictured) is subject to change as the Councils develop.

If you are interested in getting involved, please contact Michael at mstewart@oif.org.



OSTEOGENESIS IMPERFECTA
OI
FOUNDATION
Unbreakable Spirit

Uniting Unbreakable Spirits
REGIONAL CONFERENCE PROGRAM

LOS ANGELES, CALIFORNIA
NOVEMBER 17, 2018

Register for the OIF Regional Conference in Los Angeles, CA

As part of the *Uniting Unbreakable Spirits* Regional Conference Program, the OIF will be hosting the next regional conference on Saturday, November 17, 2018, in Los Angeles, CA. The OIF will be partnering with the University of California in Los Angeles (UCLA) to provide a full day of programs to educate and connect the OI community in the Western region of the United States. Overall, this regional conference will give a more intimate opportunity to learn about OI and research advancements. There will also be social activities, including lunch and an afternoon reception, for attendees to connect with individuals and families affected by OI. For more information or to register today, visit www.oif.org/regionalconferenceLosAngeles2018.



explore

2018 BALTIMORE • OIF NATIONAL CONFERENCE




Dear Friends,

The Osteogenesis Imperfecta Foundation is committed to funding OI research to help improve the lives of anyone affected by OI. Over the past five years, the OIF has funded more than \$1 million to support OI research centers and promising research studies. With increased awareness and major new initiatives, like the NIH's Brittle Bone Disorders Consortium, the pace of OI research is at an all-time high. The OI Foundation is working hard to keep this momentum going and we need your help—we hope you will consider making a gift today!



Cathleen Raggio, MD, principal investigator of the OIF's new cardiopulmonary study.

Recently, through gifts made by donors like you, the OIF was able to raise enough money to fund a two-year cardiopulmonary study, currently underway at the Hospital for Special Surgery in New York City. Led by Dr. Cathleen Raggio, an orthopedic surgeon and researcher with more than 40 years of OI experience, the study is gathering important data on the effects of OI on cardiopulmonary function. The results of this study could have significant, if not life-saving, implications on how cardiopulmonary issues are treated in someone living with OI.

The OIF is continuing as a co-partner in the National Institutes of Health's Brittle Bone Disorders Consortium, which is a multi-year research project combining several clinical and basic science research

studies, including the OI Contact Registry and OI Longitudinal Study. These studies are gathering important data to help researchers learn more about the complexity of OI and potentially improve treatments.

The OI Foundation is committed to not only supporting current OI experts, but to recruiting and engaging new young investigators to the field of OI research. When the OIF is able to fund grants to support research studies like these, we are securing the future of OI medicine.



OI community members, Elijah and Zoe, at the 2018 OIF National Conference.

We hope you will consider making a gift of \$50, \$100, \$500 or more to help us reach our goal of funding new and existing research projects! Your generosity will change lives and we are grateful.

Wishing you a happy and healthy end of summer,



Tracy Hart
Chief Executive Officer



Research Corner

Upcoming Rare Bone Disease Alliance (RBDA) Meeting

The Rare Bone Disease Alliance is organizing a meeting, titled *Mechanistic and Therapeutic Advances in Rare Skeletal Diseases*, on September 26-27, 2018 in Montreal, Canada. Chaired by Dr. Brendan Lee, this program will be held in conjunction with the American Society for Bone and Mineral Research (ASBMR) immediately preceding their annual meeting. The program will cover state of the art topics in diagnosis, preclinical mechanisms of disease, clinical targeting of signaling pathways, and novel clinical endpoints for assessment of efficacy. This meeting will connect hundreds of scientists from around the world to discuss cutting-edge research in the bone, mineral, and musculoskeletal field. For more information, please visit www.oif.org/RBDAmeeeting.

Exploring a New OIF Initiative Focused on Dental Education and Research

At the 2018 OIF National Conference, a group of dentists experienced in OI met to identify immediate and long-term dental needs of the OI community. Dr. Jean-Marc Retrouvey of McGill University led this team effort, which included Dr. Renna Hazboun Zahr, Dr. Kevin Ricker, and Dr. Jay Neugarten. Several topics were discussed during their first meeting including future collaborations in research protocols of the Brittle Bone Disorders Consortium (BBDC), advocacy and education of dental practitioners through professional associations, and plans to contribute virtual workshops and podcasts for community members. More information will be provided as it becomes available. The OI Foundation is excited to support these efforts to meet a critical need in the OI community.

A Place of Hope and Healing for Families Living with OI

TO REACH OUR TEAM :

Email : Mon-OI@shrinenet.org

By phone toll free in Canada :
(800) 361-7256 ext. 8314

By phone direct line : 514-282-8314
shrinershospitalsforchildren.org/Canada



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Canada

Participating in Clinical Research on OI

Are you looking for more information about ways to participate in clinical research on OI? The OI Foundation's Current Studies Page (www.oif.org/RS_Current) is home to text and video descriptions of research studies organized by the Brittle Bone Disorders Consortium (BBDC) and other research sites.

The most recent update is a new video, developed by Oregon Health & Science University (OHSU) with Mereo BioPharma, about their antisclerostin drug study. Multiple sites in the United States, Canada and several other countries are now recruiting eligible study participants. Adults age 18-75 who have a diagnosis of OI Types I, III, or IV are eligible for this 1 year clinical research study, which aims to enroll up to 140 patients. Lodging and travel for the research participant and one travel companion are provided through the study. Learn more about the study on clinicaltrials.gov or through their study website at www.asteroidstudy.com.

Make Your Mark on Osteogenesis Imperfecta Research—Sign Up for the Contact Registry!

Now is the perfect time to make your mark on osteogenesis imperfecta research! The Rare Diseases Clinical Research Network (RDCRN) hosts the Contact Registry for the Brittle Bone Disorders Consortium (BBDC), as well as twenty-two other rare disorder consortia. The BBDC Contact Registry is currently coordinating several studies, which you can learn more about by visiting their website www.rarediseasesnetwork.org/cms/bbd/Get-Involved/ContactRegistry.

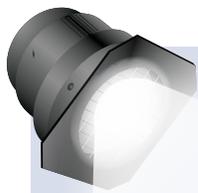


Supporting the Brittle Bone Disorders Consortium (BBDC) and other OI research is an important part of the OI Foundation's mission. Often, the success of clinical studies of a rare disorder like osteogenesis imperfecta (OI) depends on getting enough people to participate in the study so the results are meaningful. To learn about this registry and other OI-related research, visit the OI Foundation's Current Studies webpage (www.oif.org/RS_Current). Please contact the OI Foundation office if you have any questions.



Mereo is a UK-based biopharmaceutical company focussed on the rapid development of innovative medicines in **rare and specialty disease areas** that have the potential to transform patient quality of life and improve human health.

www.mereobiopharma.com



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 to OI community members. The complete OI Clinic Directory can be found under the “Information Center” tab on the OIF website.

To provide an 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*. In this issue, we are excited to introduce the Osteogenesis Imperfecta (OI) Program at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE, a sponsor of the recent 2018 OIF National Conference in Baltimore, MD.

The Osteogenesis Imperfecta (OI) Program at Nemours/Alfred I. duPont Hospital for Children in Wilmington, DE

The Osteogenesis Imperfecta (OI) Program at Nemours/Alfred I. duPont Hospital for Children in Wilmington includes world-renowned specialists in genetics, orthopedics—including complex spine care—pain management, therapy services, transition care, and more. Ranked among the best children’s hospitals in the nation for orthopedics by *U.S. News & World Report*, their goal is to tailor a care plan that best meets the needs of the patient and family. Nemours treats OI patients from newborns to the age of 35 from across the country and around the world.

In 2019, Nemours will open a state-of-the-art Special Delivery Center that is uniquely equipped to deliver babies in need of specialized intensive care, mitigating the risks and delays involved in patient transfer.

Diagnosis and Evaluation

The initial visit includes a medical evaluation by geneticist, Michael Bober, MD, PhD, and Tina McGreal, MSN, NP-C. These visits are comprehensive and can take one to two hours to complete. Diagnostic testing may be part of the evaluation. Dr. Bober and Tina oversee the medical management of patients with OI including bisphosphonate therapy, nutrition, and care coordination.

Orthopedic Treatment

Treatment is directed toward maximizing mobility, correcting deformity, minimizing fractures, and preventing complications. Internationally revered pediatric orthopedic surgeons, Suken A. Shah, MD, spine specialist and Richard W. Kruse, DO, OI surgical and fracture care expert, along with limb deformity specialist, Jeanne M. Franzone, MD, lead the team of surgical specialists.

This highly skilled team provides:

- Daily fracture care
- Upper and lower extremity rodding procedures
- Complex upper and lower extremity deformity and joint reconstruction procedures
- Spinal fusion and growing rod procedures

With one of just 11 fully accredited Gait and Motion Analysis Labs in the country, children for whom surgery is an option may be referred for a gait analysis to examine the possible causes of their walking problems. The gait analysis guides the surgical plan and helps the team identify specific ways to improve a child’s ability to walk, step, and run.

Nemours extended team includes specialists in plastic surgery, neurosurgery, pain management, neonatal care, nephrology (kidney care), cardiology, ENT (ear, nose and throat), audiology, ophthalmology (eye care), radiology, psychology and social work, physical and occupational therapy, including aquatic therapy, mobility products and services, and transition to adult care.

As a multidisciplinary team, Nemours providers share their findings with each other so that treatment is collaborative and all in one place, making it more convenient for families.

Appointments

To schedule an appointment, call the nurse navigator, Mary Ellen Little at (302) 651-4880.

Nemours/Alfred I. duPont Hospital for Children is located in Wilmington, DE, near several international airports. Lodging is available at the Ronald McDonald House of Delaware, located across the street from the hospital. Visit rmhde.org or call (302) 656-HUGS to request a room. Learn more at Nemours.org/OI.

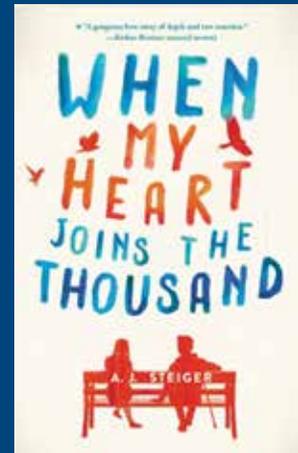


The multidisciplinary team of Nemours Alfred I. duPont Hospital

Unbreakable Spirit® Book Club!

The novel **When My Heart Joins the Thousand** by A.J. Steiger is described as “a heartbreaking debut romance featuring a neuroatypical girl with a tragic history and the chronically ill boy trying to break the vault encasing her heart.” The novel features a love story between two characters, one of which is affected by osteogenesis imperfecta, with honesty about the obstacles they face and the messy aspects of real love. The book is available on Amazon, Barnes & Noble, and Google Play Books.

If you would like your publication or favorite book to be featured in an upcoming edition of *Breakthrough*, please email bonelink@oif.org.



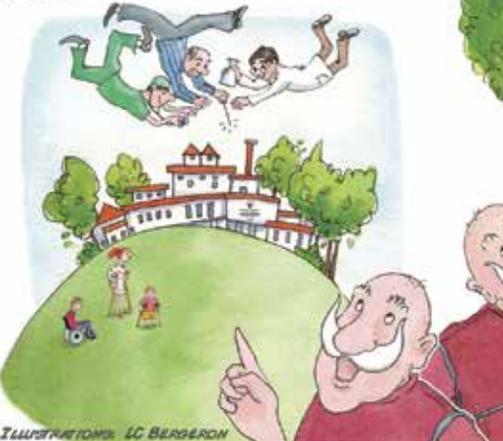
IN THE YEAR OF 3015, A LITTLE BOY LOOKING FOR ARCHEOLOGICAL TREASURES IN THE GREEN ECO-TERRITORY OF THE SAINT-JACQUES ESCARPMENT IN THE CITY OF MONTREAL FINDS A TIME-CAPSULE. THE BOY OPENS IT TO DISCOVER A STRANGE LOOKING OBJECT AND RUNS TO SHOW IT TO HIS GREAT-GREAT-GREAT-GREAT GRANDFATHER WHO, THE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



From the Information Center



New Factsheet Available! Overview of Bisphosphonate Use in Children Living with OI

A new factsheet, which provides an overview of bisphosphonate use in children, is now available on the OI Foundation's website. This document explains the difference between various types of treatment and answers common questions from community members and providers. Thank you to Dr. Francis Glorieux, the Chair of the OI Foundation's Medical Advisory Council, for his assistance in preparing this document. To view or download the new fact sheet, visit the OIF's portal for medical professionals www.oif.org/meded and click on "Treatments." The link to this factsheet is listed on the right side of the page.

OI Educate!—New Program Coming in 2019!

A new OI Foundation program supporting the mission through education, awareness, and mutual support is coming next year! As the OI community becomes more connected, the OI Foundation depends more and more on volunteers across the country to help field general questions about osteogenesis imperfecta and the OIF. The *OI Educate!* Certificate Training Program is focused on providing medically verified information and resources to community contacts, or

"OI educators," who can help spread awareness and answer common inquiries through social media, phone calls, emails, support group meetings, health fairs, medical school lectures, and other activities. This program is intended to offer community members with a first line of support and does not qualify members to provide medical advice. The OIF Board of Directors and Regional Council Members will be piloting and tweaking the program before offering this opportunity to a larger group in 2019. For more details, please visit www.oif.org/OIEducate.

Resource Reminder— Free OIF Podcasts

The OIF provides free access to podcast episodes featuring OI medical experts on a variety of topics related to the diagnosis and treatment of OI. The eighteen uploaded podcasts have received positive feedback, receiving over 4,000 downloads so far. Topics include General Clinical Research Updates, Pulmonary Issues in OI, Multidisciplinary Care for the Pediatric Patient with OI, Spine and Scoliosis Issues, Gaps in Care and Information on Treating Adults with OI, and more. Listen to the podcasts on the OIF's Audio/Video Learning Center webpage at www.oif.org/OIFpodcast.



GOING FURTHER.
DOING MORE.

**FOR KIDS
WITH OI.**



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ADVANCED MEDICAL OPTIONS.
CONTINUED RESEARCH AIMED AT A CURE.

For a pediatric OI specialist, call **1.800.833.3100**

ChildrensOmaha.org/OI

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®!

September

- September 26–27** Rare Bone Disease Alliance Meeting (preceding ASBMR Annual Meeting) – Montreal, Quebec
September 28 Blue Jeans for Better Bones Day – Anywhere

October

- October 6** Florida Support Group Meeting – Tampa, FL

November

- November 3** DC/MD/VA Support Group Meeting – Washington, DC
November 10 2nd Annual Boots & Bling for Better Bones – Houston, TX
November 17 OI Foundation Regional Conference – Los Angeles, CA
November 27 Giving Tuesday

December

- December 1** OI Awareness Night with the NHL Florida Panthers – Sunrise, FL

January

- January 24** Fine Wines Reception – Naples, FL
January 26 Florida Support Group Meeting – Tampa, FL

February

- February 23** 19th Annual Fine Wines Strong Bone Gala – National Harbor, MD
February 28 Blue Jeans for Better Bones Day in honor of Rare Disease Day – Anywhere

New events are being added all the time. Visit the events calendar at 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 for more information today!

Follow us on social media!



www.facebook.com/OsteogenesisImperfectaFoundation



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



[@OIFoundation](https://www.instagram.com/OIFoundation)

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