OSTEOGENESIS
IMPERFECTA
OI
FOUNDATION
Unbreakable Spirit®

Breakthrough

VOLUME 39 NO. 4 WINTER 2013

Expanding Our Community: National OI Awareness Week 2014 (MAY 3-10)

National OI Awareness Week is the OI Foundation's most exciting week of the year! This year, National OI Awareness Week is May 3-10th and is scheduled around Wishbone Day, the international day of OI Awareness, on May 6th. Each year during National OI Awareness Week, we encourage the OI community to use fundraising events, social media and individual state proclamations to raise awareness for osteogenesis imperfecta.

"Tell Me About Your *Unbreakable Spirit®*" the 2013 Awareness Week theme, was an exciting and inspiring way to get our community excited about raising OI awareness. WE know the OI community has an *Unbreakable Spirit®*, it's time for the world to know it! "**SHARE** Your *Unbreakable Spirit®*" is the theme for National OI Awareness Week 2014, taking place May 3-10, 2014. In 2013, we reached over 50,000 people with our social media campaign! In 2014, we can and we will educate one million people on osteogenesis imperfecta and how to get involved in the OI community's efforts. From February 1, 2014 to May 10, 2014 we will be tracking the number of people we reach through social media, word of mouth, and events. The OI Foundation will post facts on our social media sites that we encourage you to share with your friends and followers. Just think about how many people you can reach through your personal social media sites!

From March 3-7, we want you to share with us how you introduced others to osteogenesis imperfecta. Did you share Facebook posts, sport OI merchandise, hold an event, send out an email, hang educational OI posters? We want to know who you educated and how! Email **dcymber@oif.org** to share your story. Selected responses will be posted on our Awareness Week 2014 webpages and the OI Foundation's Facebook page.

Start planning! Include your friends, family, neighbors, coworkers, local businesses, and community in our one million educated on OI by holding a fundraising event or leading a National Blue Jeans for Better Bones Day.

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TAKE PART IN THE FIRST EVER NATIONAL UNBREAKABLE SPIRIT® WALK-N-WHEEL FOR OI!

To kick-off the OIF National Conference weekend, the OI community will come together to participate in the *National Unbreakable Spirit® Walk-n-Wheel for OI* on Thursday, July 31st! Beginning at the JW Marriott, participants will walk or wheel one of Indianapolis' most beautiful landmarks, the Canal Walk of White River State Park. You can choose between the 1k or 5k courses, both of which will end back at the JW Marriott for a reception to celebrate all of our participants and sponsors. You can walk or wheel individually; form a team with your family, friends or support group members; volunteer; become a supporting sponsor; or show up to cheer on the sidelines. Help us take Indianapolis by storm and make the Unbreakable Spirit® of the OI community known!

It's not too early to make your hotel reservation for the OIF National Conference! The full conference will take place at the JW Marriott in downtown Indianapolis and the hotel is offering conference attendees a discounted room rate of $149 per night. To make your reservation, visit **https://resweb.passkey.com/go/OIF2014** or call 866-704-6162 and mention that you are with the "Osteogenesis Imperfecta Foundation" National Conference.

For more information about the *National Unbreakable Spirit®* Walk-n-Wheel or to set up your personal team raiser page, visit **www.oif.org/nationalwalknwheel** or contact Melissa Bonardi at **mbonardi@oif.org.**

Letters

Dear Members:

I would like to thank the members of the Osteogenesis Imperfecta Foundation (OIF) for the honor to serve as the President of the Foundation. There are very exciting opportunities ahead for the OIF. At our recent meeting of the OIF board we welcomed our outstanding new members to the Board.

As a result of the outstanding work and leadership of our CEO Tracy Hart, and the dedicated staff, the OIF continues to gain national recognition in terms of representation on various health care and advocacy organizations. This positioning on the national stage is indeed a significant accomplishment which will be beneficial to the Foundation as we continue to advocate for more funding for our research agenda. The Board is optimistic about the prospects for future funding for research on OI.

The OIF recently held its first regional conference in Tampa, Florida. I had the privilege to attend the Tampa Conference and offer the opening remarks. This one-day conference was very successful in reaching individuals and families in the OI community. It was especially meaningful to have the OIF founder; Gemma Geisman, in attendance at the regional conference. Almost half of the 150 individuals who attended the Tampa conference had never attended an OIF conference. A very special thank you goes to OIF MAC Chair Dr. Francis Glorieux, OIF MAC Member Dr. Cathleen Raggio and Dr. Scott Beck for sharing their clinical expertise with the group. As we continue with strategic planning for future direction of the OIF, this concept of offering regional conferences and creating strategic partnerships with other organizations will be fully explored.

The OIF Board and staff are fully engaged in the planning for the 2014 OIF National Conference which is scheduled for August 1st through 3rd in Indianapolis, Indiana. There are several additions and enhancements being planned for the 2014 conference. We hope that the location and the timing of the conference will be conducive for a record number of attendees.

I look forward to working with you as we all continue to advance our priorities for service and research to benefit individuals and families impacted by osteogenesis imperfecta.

Sincerely,

Mark D. Birdwhistell

Mark D. Birdwhistell
President

Dear Friends:

It's hard to believe that 2013 is almost over – where does the time go?! Here at the OI Foundation 2013 has been a good year filled with programs, events and activities all with the goal of creating awareness about OI and funding programs and services that benefit all people living with OI. Thank you to everyone who contributed their time, talent and resources this year to helping the OI Foundation continue our mission. The OI Foundation depends on the support of a caring community and the OI community is truly a family of Unbreakable Spirits.

In this edition of ***Breakthrough*** you will read about a family that found the OI Foundation when their infant daughter was diagnosed with OI. They share their story of fear and confusion with the diagnosis that quickly turned into hope when they found out more about OI, connected with the OI Foundation and met other parents who had been on the same journey. The Sheridans represent one of many families that turn to the OI Foundation each year for support and information. With your help we can continue helping EVERY family and person with OI who needs our help.

As we enter the holiday season please know that the OI Foundation is thankful for the thousands of volunteers who support us and I look forward to seeing everyone at the 2014 OIF National Conference in Indianapolis if not before. Until then…I hope you have a safe and happy holiday.

All my best,

Tracy Smith Hart

Tracy Hart
Chief Executive Officer

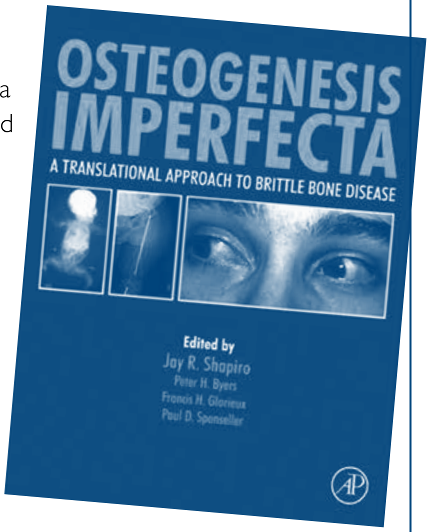
NEW Textbook about Osteogenesis Imperfecta

A monumental, nearly 600 page textbook about OI was published in September. This comprehensive reference is a collection of chapters by physicians and researchers from around the world. **Osteogenesis Imperfecta: A Translational Approach to Brittle Bone Disease** was edited by a distinguished group of OI scholars. Dr. Jay Shapiro, as the lead editor had the vision to bring together in one volume the latest information about the biochemistry, genetics, and treatments available to manage OI in children and adults. The Associate Editors included Peter Byers, MD, Francis Glorieux, MD, PhD and Paul Sponseller, MD.

The list of chapter authors reads like a "Who's Who" of people from the OI medical and scientific communities. Each chapter author is a person who is highly respected in a specialty area; highly respected as a scientist, and has extensive experience caring for children and adults who have OI. As the title indicates, the chapter authors based the information in their sections on scientific research and "translated" that information into practices for clinical care. Besides describing current practices, the authors also identified the research questions that continue to require answers and suggest promising trends that may lead to the improved treatments in the not so distant future.

The first half of the book presents information on scientific topics. Sections are included on bone biochemistry, genetics, dominant and recessive mutations, and what has been learned from animal models of OI. The rapid expansion of knowledge in these areas over the past two decades has greatly changed our understanding of how OI is inherited, how different mutations lead to the clinical signs of OI, and point the way to potential new treatments. The second half of the book takes an in-depth look at the many clinical aspects of OI. Major sections present information on orthopedics, an advanced discussion of surgical techniques applicable to OI, and on the many organ systems besides the skeleton that OI affects. Besides the sections on orthopedic treatments, separate sections are devoted to other aspects of treatment including physical medicine and rehabilitation and pharmacologic treatments including bisphosphonates. A discussion of new drugs being studied and the potential for gene and cell-based therapies close out the final section. Throughout, the material emphasizes that OI is a life-long and variable condition that requires treatment that addresses the skeletal and non-skeletal issues.

An indication of how far we have come in the work to understand OI is that the 1983 book, **The Brittle Bone Syndrome**, the only previous comprehensive textbook on OI was only 214 pages long. The new book has more than that on genetics and biochemistry alone.



Osteogenesis Imperfecta: A Translational Approach to Brittle Bone Disease is a well written and well organized textbook and general reference book. Intended for readers with a medical or science background it is a little overwhelming for the general reader, but many families will consider it worth the investment in time and money. The book is available in print or electronically, on-line through Amazon and Barnes & Noble. It can also be ordered on-line directly from the publisher, Elsevier. Cost ranges from $180-$250 depending on the source. This book definitely has a place in the reference libraries of all clinics that see people who have OI. We hope that our readers will bring this publication to the attention of the doctors, and geneticists who care for them and their children.

Expanding Our Community: National OI Awareness Week 2014 (MAY 3-10)

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No time to plan an event? Take a few minutes to hang some posters in your community and help us proclaim May 3-10th as National OI Awareness Week! As the OI Foundation is based in Maryland, we can only request the Awareness Week proclamation for our state. We need your help! Visit our Awareness Week proclamation page to get started! **www.oif.org/awarenessweek**

For more information about National OI Awareness Week events and state proclamations, please contact Danielle at **dcymber@oif.org**.

Clinical Care Conference Held in Baltimore

The 5th Clinical Care Conference on OI was held November 6-8 in Baltimore, Maryland. Titled **"Update on Managing Clinical Care Issues in OI: Standard and Emerging Treatments for Pediatric and Adult OI,"** it brought together 100 participants to hear presentations and to discuss challenges and best practices in medical care for people who have OI. The meeting was organized for the OI Foundation by Dr. Jay Shapiro, director of the OI Program at the Kennedy Krieger Institute and lead editor of the new textbook **Osteogenesis Imperfecta: A Translational Approach to Brittle Bone Disease**. Each speaker presented strategies and techniques for treating and managing OI based on a review of the scientific evidence and their personal experience as care givers.

The program included a panel discussion on orthopedic care including joint replacement and surgical interventions. Many topics related to the non-skeletal issues that are associated with OI were also covered. These included hearing loss, gastrointestinal issues, heart and lung problems and vision problems.

The concluding day featured two panel presentations. The first was on "OI and Rehabilitation," which looked at effective practices in post-surgical rehabilitation and at the role of physical therapy in managing the fatigue and muscle weakness often associated with OI. This presentation led to a robust discussion about weight management for the adult who has OI. The second panel was titled "Current Treatment of OI in Children and Adults," and looked at the use of different medicines to treat OI in children and adults.

From Left to Right: Dr. Paul Sponseller, Dr. Paul Esposito, Dr. Harpal Khanuja and Dr. Peter Smith participate in the Orthopedic Care, Joint Replacement and Surgical Interventions Panel Discussion.

In addition, each evening featured special presentations. On Wednesday evening, Dr. David Rowe from the University of Connecticut, and Dr. David Deyle from the Mayo Clinic, Rochester, MN spoke on "The Future of Stem Cell Treatment in OI." Thursday evening Leigh Bishop, Assistant DA from Queens, NY and Dr. Dina Zand from Children's National Medical Center spoke about the clinical and legal issues related to OI and the question of child abuse.

The meeting was characterized by thoughtful presentations and spirited discussions. Abstracts from the presentations will be published in the on-line in the **Journal of Musculoskeletal and Neuronal Interactions** and posted on the OIF Website. An article that summarizes the main points and conclusions from this meeting is being prepared for publication in 2014.

Impact Grants Coming Soon!

CHILDREN'S BRITTLE BONE FOUNDATION

OSTEOGENESIS IMPERFECTA OI FOUNDATION *Unbreakable Spirit®*

A new Impact Grant funding cycle will become available January 6, 2014. The Children's Brittle Bone Foundation and OI Foundation administer Impact Grants to provide direct support to individuals and families with products or services that will greatly improve their quality of life. Items that have been awarded in the past include wheelchairs, orthotics, hearing aids, and modified vans, among many other amazing items. This past 2013 cycle the OI Foundation and CBBF were able to fund 19 Impact Grants! A past grant awardee states, "The funding we received for the supplies will help more than you can imagine…. Life is a struggle but the reward comes from seeing the smile on the child's face and hearing his infectious laughter. We again just wanted to say THANK YOU for being a part of our joy." Applications and a list of qualifications can be found at **www.oif.org/impactgrant**. Remember, applications will not be available until January 6 and the deadline for submitting applications is February 10. If you have any questions please email **impactgrants@oif.org**.

Is an Internship in Your Future?

A Conversation with 3 College Students

With the first semester of the school year starting to wind down, it's that time of the year when college students start to think about summer plans. The summer time provides a good opportunity to explore career options, network, gain new skills, and advance their resumes to stand out among classmates and other job seekers. For some people, a summer internship is also the opportunity to live in a different part of the country. Many talented young people come to Washington, DC each summer to work on issues like disability rights, disability awareness and hot button political topics. At the end of the summer, the OI Foundation had the opportunity to talk with three outstanding young people who all interned in Washington, DC in 2013.

Each of the students came from a different part of the US. They interned in different programs and they each had to manage their OI as well as their job responsibilities. They all had very different experiences and reasons for becoming passionate for politics and leadership, and interning in Washington, DC. The three students we spoke to are all very eager to make a difference in disability rights and excited to participate in OI Foundation Advocacy events. Emily Voorde is a Junior (class of 2015) at Notre Dame University, majoring in Political Science & Business Economics. Rosie McDonnell is also a Junior (class of 2015) at the University of California, San Diego, majoring in Sociology. James Dean is a recent Business Management graduate (class of 2012) of Pensacola Christian College in Pensacola, FL. Below are highlights of each of their experiences.

Emily Voorde Through the Notre Dame Washington Program, Emily has spent the fall semester interning in Indiana Senator Joe Donnelly's office.

"I have always had a passion for advocacy, politics and leadership, but mostly in local politics, until this internship in DC. When I was younger, I wasn't involved in a lot of advocacy because I was not around a lot of people with OI, so it never sparked a huge interest with me until recently. I am now working on developing a senior thesis on international disabilities and disability policies around the world.

I would love to get more involved, now. Listening to Rare Bone Disease Advocacy Day opened my eyes to how Senators and Representatives listen to groups and take an interest in their constituents who want to make a change. There is a way to make a change.

I am the only kid with OI in my family. My parents always taught me to not be afraid to stand up for myself. That does not mean going out and changing laws, but to be a great representation of yourself. Do not be ashamed of having a disability. Be yourself and show what you bring to the table."

Rosie McDonnell Rosie was selected to intern this past May until August in a competitive internship program through the American Association of People with Disabilities (AAPD). She interned with the Japanese American Citizen League (JACL). During her internship at JACL, she was instrumental in planning their national convention that hosted 500 people. Upon returning home to San Diego she has joined the JACL chapter in San Diego and has been able to continue her interests gained during her time in DC.

"In high school, I was a student delegate for California Youth Leadership Forum for Students with Disabilities, which focuses on empowering youth driven campaigns. We worked on Disability History and Anti-Bullying. Prior to this I hated history and politics but I found that it is easier to understand when you are passionate about it.

People believe advocacy means being in DC and wearing a suit, knowing what is going on all the time. Advocacy can be anywhere. In high school and college you can do advocacy all the time. Standing up for yourself- self-advocacy, and then expanding from there. Join advocacy groups in college. For me, I was always involved in my IEP discussion, but in high school is when I really began to voice my opinions. It is also important to network as much as you can. Do not be afraid to put yourself out there."

James Dean James currently interns at the Ameson Education & Cultural Exchange Foundation, a nonprofit organization. He had a creative method to his internship hunt. While in DC for the OIF National Conference in 2012, he visited a friend in the Ronald Reagan building and stopped by all the offices, asking companies if they were in need of interns. Ameson interviewed him and offered him an intern position.

"I really gained interest in advocacy when I went on Capitol Hill for the OIF National Conference for Advocacy Day. I have two brothers with OI and I have learned that standing up for what you believe in is very important. The President of my college also introduced me to congressional representatives and I was able to talk to them, sparking my interest in politics. I am interested in learning more and developing disability study abroad programs with my current experience at Ameson.

One tip that I want to share with young advocates is to focus on your abilities, rather than a disability. Step out there and get involved."

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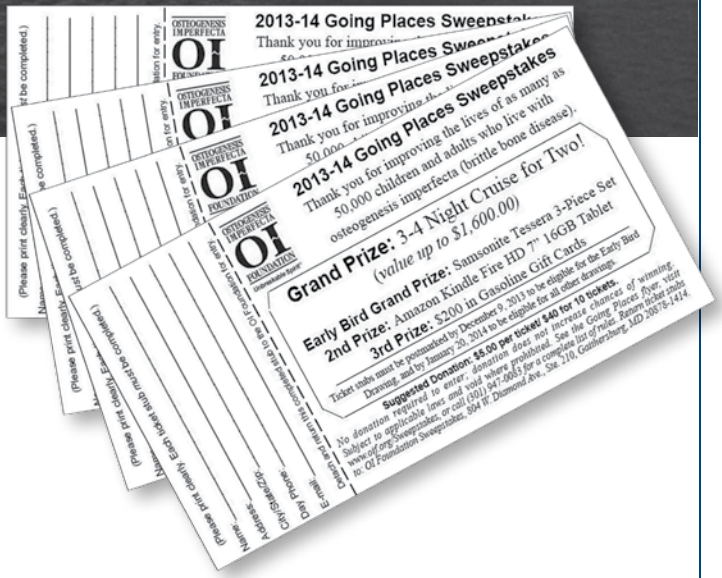
Don't Miss Out on the Chance to WIN BIG

Have you sent in your tickets for the OI Foundation's Going Places Sweepstakes? Act now before it's too late!

The Going Places Sweepstakes is an annual promotion that offers you a fun and easy way to both support the OI Foundation and involve your friends and family. The more people who make a contribution and enter, the more the OI Foundation can support the 50,000 people affected by OI in the US!

Last year, 300 people participated in the Going Places Sweepstakes raising over $20,000! With those funds the OI Foundation was able to help 100 people and fund 80 hours of research. Help us to continue supporting the OI community.

Send in your tickets for a chance to win the grand prize of a 3-4 night cruise from **www.cruisesnyou.com** valued at $1,600. You could also win our early bird prize of a three piece set of Samsonite luggage valued at $165; the second prize of a 7" Kindle Fire HD with 16GB and a leather case; or third prize of $200 in gas cards.



(Please print clearly. Each ticket stub must be completed.)

Name:

Address:

City/State/Zip:

Day Phone:

E-mail:

Detach and return this completed stub to the OI Foundation for entry.

2013-14 Going Places Sweepstakes

Thank you for improving the lives of as many as 50,000 children and adults who live with osteogenesis imperfecta (brittle bone disease).

Grand Prize: 3-4 Night Cruise for Two!
(value up to $1,600.00)

Early Bird Grand Prize: Samsonite Tessera 3-Piece Set
2nd Prize: Amazon Kindle Fire HD 7" 16GB Tablet
3rd Prize: $200 in Gasoline Gift Cards

Ticket stubs must be postmarked by December 9, 2013 to be eligible for the Early Bird Drawing, and by January 20, 2014 to be eligible for all other drawings.

Suggested Donation: $5.00 per ticket/ $40 for 10 tickets.

No donation required to enter; donation does not increase chances of winning. Subject to applicable laws and void where prohibited. See the Going Places flyer, visit www.oif.org/Sweepstakes, or call (301) 947-0083 for a complete list of rules. Return ticket stubs to: OI Foundation Sweepstakes, 804 W. Diamond Ave., Ste. 210, Gaithersburg, MD 20878-1414.

To request additional tickets, visit **www.oif.org/sweepstakes**. To be entered to win the early bird prize, entries must be post marked by December 9, 2013. All other entries must be post marked by January 20, 2014 to be entered to win the grand prize, second and third prizes.

By making a gift during the Going Places Sweepstakes, you are helping the OI Foundation reach our goal to raise $10 million over the next four years to increase research, education, awareness, and support in order to improve the lives of the **50,000 Lives, One Unbreakable Spirit**® affected by OI. We can do it, but we need your help.

Recap of OIF Regional Conference

Opening Session of the Uniting Unbreakable Spirits Regional Conference.

Dr. Francis Glorieux, chair of the OI Foundation's Medical Advisory Council, talking with a parent and child.

Lauren Brown, conference attendee and representative from Canine Companions for Independence, during the Ice Cream Social Reception and service dog demonstration.

From left to right: Gemma Geisman, Tracy Hart and Rosalind James enjoying lunch.

Mother and daughter, Amber and Emme Ashley, in between sessions.

With more than 150 attendees, the OI Foundation's *Uniting Unbreakable Spirits* Regional Conference in Tampa, Florida on November 2nd was a big success. The high energy, supportive and informative day was an awesome experience for everyone who attended. The interaction between families, babies, children, adults with OI and the speakers benefited everyone! A highlight for many attendees was the 90 minute opening session with research updates from Dr. Francis Glorieux and Dr. Cathleen Raggio, two members of the OI Foundation's Medical Advisory Council. Throughout the day, conference speakers discussed and answered questions on a variety of topics, including an overview of medical approaches to managing OI in children and adults, treatment options, tips for building self-esteem and developing good mental health, and more. Attendees were inspired to take advantage of the smaller size of this conference, asking personal questions to the speakers after the sessions ended and connecting with new and old friends from across the southeast region of the United States.

A sincere thank-you goes out to everyone who attended, the conference speakers, planning committee volunteers, University of South Florida volunteers, Palm Harbor Home Depot, Doc the Magician, Shriners Hospital for Children in Tampa, and Canine Companions for Independence for your support and participation. The OI Foundation looks forward to doing more regional conferences in the future. The Foundation's next major conference for families will be the full length **2014 OI Foundation National Conference** in Indianapolis, August 1-3, 2014! We hope to see you there!!

Is an Internship in Your Future?

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If you are a student looking for a summer internship for 2014 or 2015 or if you want to gain experience in a specific field, be sure to check with your school's career services department. Some programs seek participants from all over the US, but don't forget to inquire about opportunities in your state or related to your major. Some internship programs have a lengthy application process so don't delay. The following websites are good places to start.

Idealist- Non-Profit Internships Search
www.idealist.com

Indeed – Job and Internship
www.indeed.com

DCInternships.org
www.dcinternships.org

DC-based Disability Rights Related Internships –
American Association of People with Disabilities
www.aapd.com/what-we-do/employment/internship-program/

End of Year Giving

We are so fortunate at the OI Foundation to have the continued support of the OI community. Because of your generosity, the OI Foundation is able to continue to fund important research, programs and services for families and individuals living with osteogenesis imperfecta. The following letter was recently sent out to our supporters. Please take a moment to consider giving a gift to the OI Foundation so that we can continue providing a high level of service to the OI community. You can make your gift by responding to the letter you received or by visiting **www.oif.org/50000**.

Thank you!

Dear Friends:

Maggie Shae Sheridan appeared to be very healthy when she was born on April 12, 2012. At her two week doctor's appointment she had gained so much weight and grown so much that her doctor said she didn't need to be seen again until her two month well-baby check. Maggie seemed to be the picture of health.

Less than four weeks later, Maggie's parents, Jessica and Mike, noticed that something was wrong.

Jessica remembers, *"Maggie slept six hours one night and the next day she was acting very odd, almost lethargic. I e-mailed the pediatrician to ask if this was normal, but then she started to act okay and I really didn't think too much of it until I noticed that she still wasn't moving her arm much the next day."*

Over the next two days Maggie's symptoms didn't improve. She wouldn't move her left arm and would wince and whine when touched. Jessica and Mike took Maggie to the hospital. Early the next morning, after a long night in the ER, someone mentioned osteogenesis imperfecta (OI), and at that moment they were glad that they were no longer being accused of harming their baby. Later that day a geneticist came in to talk to Jessica and Mike about OI, and that is where their journey began.

Knowing what was wrong with Maggie was a huge relief, but the relief of the diagnosis was short-lived and Jessica felt her world had turned upside down, *"We've never had a major health concern in our family, so hearing Maggie's diagnosis was a real shock to us all."* What was this incredibly rare bone disease? Was there a cure or treatments? How would it affect their lives? What would Maggie's life look like—would she be able to go to school, make friends, live independently? Jessica had a decision to make, *"We could either stay mad, sad and upset or get involved and work to find a cure for our daughter and others like her. I think that the former just wasn't an option for us."* While searching for information and answers, Jessica heard about the OI Foundation.

The OI Foundation answers over 6,500 inquiries annually from families, adults living with OI, students, educators, health care providers, employers, lawyers and social workers. All of them are seeking information and resources about living with OI. The OI Foundation's National OI Information Center is the only information program in the United States dedicated to helping people understand and cope with this rare disorder. Information provided by the center is reliable, and medically verified, and personal support is provided to inquirers in a timely manner. This information helps people understand the medical and genetic facts about OI, diagnosis and testing, treatment options across the entire life-span, basic and clinical research, and techniques for caring for infants and young children.

For Jessica, supporting the mission of the OI Foundation was the easiest decision to make, *"The sole purpose of the OIF is to help families like us, to spread awareness and ultimately fund research to find a cure. All of these things directly benefit Maggie's quality of life."*

The OI Foundation connects scientists, medical professionals, individuals and families in an effort to improve the lives of those affected by OI. This past April, the OI Foundation gathered 100 basic and clinical scientists at the Foundation's annual science meeting. In November, the OI Foundation's clinical scientific meeting, *Important Clinical Issues in Managing Osteogenesis Imperfecta*, will bring together medical professionals to discuss translating science into improved OI treatments. The

Foundation continues to serve as a leader of the Rare Bone Patient Network and Rare Bone Disease Alliance and recently met with over 25 members of congress to advocate for increased funding for rare bone disease research. The upcoming regional conference in Florida, Uniting Unbreakable Spirits, will allow 150 members of the OI community in the southeast region to come together for a day to learn about new ways to manage OI. And as part of the Foundation's ongoing partnership with the Children's Brittle Bones Foundation, the OI Foundation continues to fund five Linked Clinical Research Centers in North America and provides over $130,000 each year in products and services to individuals living with OI through the Impact Grant Program.

With the help of generous supporters, like you, the OI Foundation has accomplished so much over the years—and with your continued support, the OIF will be available to help every one of the 50,000 people currently living with OI and will be prepared to serve those who will receive an OI diagnosis in the years to come. The Foundation's 50,000 Lives, *One Unbreakable Spirit®* campaign, with a goal of raising $10 million in four years, will ensure that these programs and services will continue and that ground-breaking research will be funded.

At the end of the four year 50,000 Lives, *One Unbreakable Spirit®* campaign, the OI Foundation will be able to report that researchers have spent over 40,000 hours working on research that will lead to advances in improved treatments and ultimately a cure for OI. And that tens of thousands of people currently living with OI will have been helped by the OIF Information Center.

Jessica and Mike have chosen to support the OI Foundation's 50,000 Lives, *One Unbreakable Spirit®* campaign. She says, *"After learning about the OIF during a visit to Shriners in Chicago soon after Maggie's diagnosis, we felt instantaneously welcomed and supported in the OI community and we knew that we would join them to work tirelessly to campaign to one day find a cure. It is completely due to our wonderful friends and family, the support of everyone at the OIF, and the warmth of the entire OI community that we have been able to continue working to achieve this goal."*

The OI Foundation needs your help to continue its work to improve the quality of life for all people affected by OI. Please consider making a gift of $50, $100 or more to the 50,000 Lives, *One Unbreakable Spirit®* campaign. If you have supported the campaign in the past, we hope that you will continue to help us reach our goal. Thank you, as always, for your generous support.

All my best,

Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

Rare Bone Disease Advocacy Alliance Day

Emily Voorde, Jessica Finkel, and Adrienne Baez preparing to meet with a Congressman's staff.

Representatives from the OI Foundation gathered outside of the US Capitol building before meetings.

The Rare Bone Disease Advocacy Alliance converged on Capitol Hill to hold its first Advocacy Day on September 18, 2013. The Rare Bone Disease Advocacy Alliance is a coalition of rare bone disease organizations that includes the Osteogenesis Imperfecta Foundation, the Fibrous Dysplasia Foundation, Lymphangiomatosis & Gorham's Disease Alliance, Lymphatic Malformation Institute, MHE Research Foundation, Soft Bones Inc., and the XLH Network. All are dedicated to promoting public policy that advances awareness, understanding and research of rare bone disorders. The Alliance was represented by a diverse group of 30 advocates that included physicians, parents and youth. Traveling in groups of four, meetings were attended with 35 congressional offices; representing ten states.

The Alliance's representatives did a fantastic job of educating lawmakers and staff about both the real-life impact of rare bone diseases and the common challenges those with rare bone diseases face. They shared statistics as well as personal stories about their experiences and challenges. The OI Foundation was represented by Tracy Hart, Dr. Richard Kruse, Justin Zook, James Dean, Emily Voorde, Adrienne Baez, Eric Gould, Suzie Richard, Jessica Finkel, Petra Harvey, Erika Carter, and Danielle Cymber.

The main goals of the advocacy event were to enhance awareness among Members of Congress and their Staff as federal public policy is considered. The Alliance informed congressional staff offices that we will submit legislative report language in early 2014 to address the need of government-sponsored research of rare bone disorders.

Kyle Mulroy, of Washington Strategic Consulting and the key leader who helped make the Rare Bone Disease Advocacy Alliance advocacy efforts possible, stated, "We laid the groundwork necessary to begin working directly with lawmakers to increase investments in medical research that will benefit the entire rare bone disease community." Thanks to all of our participants, our first Rare Bone Disease Advocacy Day was a success. We look forward to future advocacy events and further developing the Rare Bone Disease Advocacy Alliance.

The OI Foundation Exhibits at ASBMR Meeting

OIF CEO Tracy Hart and OIF MAC Chair Dr. Francis Glorieux at the Foundation's exhibit booth.

The Association for Bone and Mineral Research annual meeting attracted more than 5,000 scientists, physicians and researchers all interested in bone research to the Baltimore Convention Center October 4-8, 2013. The OI Foundation participated in the meeting in several ways including displaying information about OI and the OI Foundation's research program in the exhibit hall. The OI Foundation also partnered with the Rare Bone Disease Patient Network to host the Rare Bone Disease Working Group. More than 70 researchers gathered for a dinner meeting to talk about the state of rare bone disease research and where collaboration could occur to accelerate research. Dr. Michael Whyte, a member of the OI Foundation's Medical Advisory Council chaired the meeting and Dr. Brendan Lee, also a member of the MAC presented his latest scientific information on OI research.

In addition to exhibiting and holding meetings there were several posters on display from young investigators and senior researchers highlighting their OI research. Guided tours of the posters led attendees to specific posters where the authors were stationed to talk about their research. Dr. Laura Tosi presented her information on the ANHI Study – Adult Natural History study in OI.

The meeting was an excellent way to introduce OI and the OI Foundation to scientists and newcomers to the field of rare bone disease research.

From the Information Center

Angel Bus – A Growing Service

We would like to make you aware of a very special transportation program called Angel Bus that is administered by the same people who run Mercy Medical Airlift. This is a wonderful counterpart to the air transportation program and offers free, non-emergency long-distance ground transportation to people needed medical care. For general information about this program visit their website at **www.angel-bus.org**. To inquire about help with a medical trip call 1-800-768-0238 or send an email to **info@angel-bus.org**.

Stay Healthy – Get a Flu Shot

Although the flu season is off to a slow start it's not too early or too late to get a flu shot. Protection from the flu needs to be upgraded with the new shot every year. Flu is a respiratory disease and can lead to serious illness in people who have a chronic health condition like OI. People who have OI and have asthma, who are short in stature, or who have any difficulty breathing for any reason are especially at risk. So don't delay! If you have an allergy to eggs or if you have any questions, be sure to talk to your doctor.

Are you Allergic to Latex?

Some children and adults are sensitive to latex. Here are some suggestions from the American Latex Allergy Association for how to protect yourself.

- Wear medic alert identification.
- Carry any prescribed allergy medication, non-latex gloves, non-latex bandages and a letter of explanation from your doctor.
- Make sure that all of your health-care providers know about your allergy.
- Make sure that your family, friends and co-workers are aware of your allergy.
- Avoid items typically made with latex such as balloons, condoms, and rubber gloves.
- Talk with your allergist about how to avoid hidden sources of latex such as foods prepared by people wearing latex gloves.

Reminder to Students and Travelers: Locate an Orthopedist Before You Need One

Part of planning to live away from home, or to study or travel abroad should include thinking ahead about your medical needs. Here are some suggestions from the OI Community on how to take a little bit of the worry out of emergency situations.

- Prepare a summary of your medical history including the location of any rods or other metal implants. Keep an up to date list of all medicines. Include the names and contact information for your primary care doctor and your orthopedist.
- Look for referrals to an orthopedist before you move. You can begin by talking with your home-town orthopedist. Many are aware of colleagues in other cities. Students should review how their institution's health system works and decide ahead of time if they will need to go outside their college or university's list of doctors.
- Contact the OI Foundation's Information Center.
- International travelers who are in an unfamiliar place can contact the International Association for Medical Assistance to Travelers (IAMAT). This organization can supply a list of English-speaking physicians overseas. Contact IAMAT at **716-754-4883** or **www.iamat.org**.
- Before leaving home, it is wise to check if your health insurance policy covers overseas travel. Medical assistance overseas can be very expensive. If you are not covered, your travel agent should be able to help you purchase travel health insurance.
- The OI Federation of Europe has helpful information on their website. Go to **www.oife.org** and click on "Projects." Look for the link to the **OI-Pass**. This contains a useful list of contact people in each European country. You can contact them before your leave home to get them names of doctors who are familiar with OI on your itinerary.

International OI Organizations List

The OI Foundation maintains a list of international organizations that have resources for people living with osteogenesis imperfecta. Find the current list of international OI organizations on the OIF's website under "Information and Support." If you are in contact with an international OI organization that wants to be listed, please email their contact information to **Bonelink@oif.org**.

Research to be aware of: Living with Severe OI

Any gathering of people in the OI community – adults, children, teens, their parents, siblings and other family members – includes sharing their stories. It's clear that living with a complex condition like OI is complicated. Besides managing the medical side of OI, parents and adults must also keep up with careers, housework, community activities, and family responsibilities. Young people who are growing up with OI must not only cope with medical appointments and treatments, but also with the same things other kids deal with – going to school, making and keeping friends, and the challenges of the teen years. Surprisingly very few research studies have explored questions about how parents and children feel about living with OI.

Maman Joyce DOGBA, (MD, Health Economist, PhD Public health) has been involved in health service research in Africa, France and in Canada. Her current research interests are health services organization for children, adolescents and young adults with rare genetic diseases and other chronic complex conditions. Dr. Dogba attended the OI Foundation's recent conference on clinical care for people with OI.

A recently published study, **"The Impact of Severe OI on the Lives of Young Patients and Their Parents: A Qualitative Analysis"**, was conducted by Maman Joyce Dogba and the team at the Shriners Hospital for Children in Montreal, Canada. For the study 12 young people age 15-21 and 12 parents were interviewed. All of the young people had a diagnosis of Type III or severe OI.

Goals for the study included:

- To understand what living with OI means for adolescents and their families.
- To gather information about the challenges and concerns faced by teens with OI and their families and to use that information to improve support services.

Based on these interviews, it appears that parents and teens look at OI differently. Parents consider OI in terms of change; while the young people spoke in terms of challenges. At every stage, parents and their children both felt the impact of the unpredictable nature of living with OI. The findings from this study were summarized around four themes.

1. Starting at the time of diagnosis, a series of stages shaped life and the return to every day "normal."
2. Living with OI was full of "ups and downs" throughout life.
3. Every day "normal" life with OI consisted of significant changes for parents and challenges for the whole family.
4. Living with OI generated some positive experiences.

Parents reported that they keenly felt the emotional impact of OI as life altering at the time their child was diagnosed; often referring to this as an "earthquake." As time went on, a "new normal" of life with OI became the reality for each family. But this reality was characterized by a roller coaster of times with and without a crisis. Serious fractures were identified as crisis situations.

It was interesting to note that for children and youth with severe OI, normal life is life with OI. They had never experienced anything else. It was noted that some of the older participants reported that they did not feel significantly different from their peers until late elementary school or the beginning of middle school. The transition from pediatric care to adult care as the children move into their teens is often difficult.

Parents indicated that living with severe OI meant coping with constant safety concerns and with the consequences of caring for a child with a serious medical condition. These consequences often affected their marriages, social lives, careers and finances. The interviewed parents also indicated that family activities, interactions with relatives, and time with spent with their children who did not have OI were often negatively affected.

But for all the work and worry, both parents and young people reported some positive outcomes from their experience with OI. They valued the positive interactions with other OI families and with caring physicians. They also reported that they put value on solving each problem as it came up, cherishing the good days and living with compassion for others.

This study points to the importance of listening to parents and young people who have OI. Their opinions need to be heard and respected.

Based on this work several ideas surfaced for developing effective support systems to foster living well with OI.

- Physicians, communities and organizations need to be more supportive to parents at the time of diagnosis.

- Parents need to keep informed about OI and help their children learn about OI.
- Planning for transitional care from pediatric care to the adult system need to begin before the young person with OI is age 18. Children's hospitals, medical centers and individual doctors who care for children with OI need to locate and if necessary train physicians in different specialties who will be ready to care for the young adult with OI.
- A positive attitude that focuses on achievements is beneficial to parent and child.
- Care givers and the young adult with OI need to create support networks to help share the burden of care when there's a crisis and to provide emotion support at every stage of life.

Dr. Dogba and the team at the Shriners Hospital for Children in Montreal are following up on this work with additional studies on the challenges faced by young adults who move from pediatric to adult care. Through partnership with the OIF, the Montreal team is working towards expanding this health service research on OI across Canada and the US. The long-term goal of this research program is to make research available to families over the continuum of their life course starting from the diagnosis through puberty to adulthood.

Citation: Maman Joyce Dogba, Christophe Bedos, Michaela Durigova, Kathleen Montpetit, Trudy Wong, Francis H. Glorieux and Frank Rauch. The Impact of Severe Osteogenesis Imperfecta on the Lives of Young Patients and Their Parents – A Qualitative Analysis. Published in BMC Pediatrics in September 2013.

OIF MAC Member Elected to the Institute of Medicine

We are proud to announce that OIF Medical Advisory Council Member Brendan Lee, M.D., Ph.D. has been elected to the Institute of Medicine. Dr. Lee, elected by current members of the IOM, was recognized for his significant contributions to the medical sciences, health care and public health. Dr. Lee is an Investigator for the Howard Hughes Medical Institute; a Robert and Janice McNair Endowed Chair in Molecular and Human Genetics; professor in the Department of Molecular and Human Genetics at Baylor College of Medicine in Houston, Texas; AND one of our very own OIF Medical Advisory Council members.

Congratulations from the OI community, Dr. Lee!

It's Tea Time 2014

It's that time of year again! Time to start planning your Bone China Tea (BCT) 2014 event! Bone China Tea, an OIF tradition started 18 years ago, has become a great way to ask friends, family and colleagues to support a cause you care about without asking for too much. If you are unfamiliar, Bone China Tea is a fun and easy fundraising event without the hassle and expenses of figuring out what to wear, who to bring, how to get there, who to sit with, etc.

Instead of spending your hard earned time and money on a one-night outfit, event tickets, transportation, and babysitters, relax at home with a hot cup of Bone China Tea. BCT participants save the costs of attending a live event and donate the money saved to the OI Foundation. That's right; you can contribute to our awareness, support and research efforts by lounging on the couch and sipping tea in your pajamas. If this sounds easy enough, mark your calendars for April 9, 2014!

Even the planning is easy! The hardest part of leading a Bone China Tea is deciding between printed or emailed invitations.

Printed Invitations:

Invitations are provided by the OI Foundation complete with a specially designed tea tag, reply card and return envelope. Hosts are encouraged to personalize each invitation by sending a note and a photo. You may order as many invitations as you think you will need; however, we ask that you not order any more than you will actually mail. Printed invitations will be available the first week of February.

E-mail:

Send e-mails to your friends and family to announce that you are hosting a Bone China Tea and to share your personal webpage where your "guests" can make donations online. You will be able to personalize your BCT webpage as well as track gifts as they come in. The Bone China Tea website will be ready to use by December 13, 2013.

Remember, personalization is the key to succeeding in a Bone China Tea event. Your "guests" want to be invited by YOU. A personal note and photo make all the difference!

To order invitations, please contact:

Jenny Wilson **JNWilson@aol.com**
Susie Wilson at **OISLW@aol.com**
(239) 482-0643
Co-Chairs OI Bone China Tea

Don't miss your chance to participate in the easiest fundraiser of the year!

Mark Your Calendars For These Upcoming Events From The OI Foundation!

Beth Shultz gets the auction underway at the 15th Miracle Michael Foundation golf tournament.

Golfers getting ready to tee off at the Rileys Gathering Golf Outing.

March

The 14th annual Fine Wines Strong Bones benefit will be held on March 1, 2014 at the Gaylord National Resort. This year will feature a Mardi Gras theme complete with casino gaming tables. For more information, visit **www.oif.org/FineWines**.

April

Join Jenny and Susie Wilson, as they host the 21st year of their virtual Bone China Tea. Visit **www.oif.org/HH_BoneChina** to sign up as a host and invite all your friends and family to make a donation to the OIF with the money they save by not attending a live event. Since 1993, dozens of hosts have helped raise almost half a million dollars to fund OI research and OIF programs. Make 2014 the year you join them.

May

The OI Foundation's 4th National OI Awareness Week will be from May 3-10, 2014. We have a week full of events planned including Jerome Hawco's 2nd annual OI BBQ in Iowa, Cheryl Manduca's *Unbreakable Spirit*® Walk-n-Wheel in Buzzards Bay, MA and Lavinia Jackson's rescheduled OI Benefit Ball in Greensboro, NC. Keep an eye on the Awareness Week page on oif.org for details as new and returning events confirm their dates and locations.

Christine Rossi will celebrate the 10th year of the MA *Unbreakable Spirit*® Walk in Framingham, MA. Join the Rossi, Potorski and Wyman families at this fun-filled event for the entire family! There will be food, live music, games, raffles, and activities for all ages throughout the afternoon.

June

The 8th Annual Birdies and Bogies for Better Bones golf outing will be held Monday, June 30, 2014 at Belmont Golf Club in Ashburn, VA. Don't miss this opportunity to play 18 holes on an Arnold Palmer Signature Golf Course.

July

Riley's Gathering Golf Tournament in Elmhurst, IL organized by Patrick Fromelt and former OIF board member Anthony Benish will be hitting its ten year anniversary this year on July 17th. Pat and Tony promise that it'll be the biggest year yet!

The Miracle Michael Foundation's annual golf outing and banquet will be Monday, July 21, 2014 at the White Eagle Golf Club in Naperville, IL. Join the Shultzes for this star-studded event, whether you attend for the golf or the evening banquet and auction.

The *National Unbreakable Spirit*® *Walk-n-Wheel for OI* will be held on July 31, 2014 in Indianapolis, IN. We hope to have teams from all over the country join us on a walk around the Canal Walk at White River State Park in Indianapolis to kick off our National Conference. To sign up as a walker or to form a team, visit **www.oif.org/nationalwalknwheel**.

August

The OI Foundation's biennial National Conference is hitting Indianapolis on August 1-3, 2014. We hope that you will join us for three days of informational sessions, free medical consultations, and social activities at the JW Marriott, Indianapolis. By popular demand, we will be bringing back the special, all day, Women's Forum as well as adding a Youth Forum and a Tween Room. For up to the minute program information, visit **www.oif.org/conference**.

We have many more events still in the preliminary planning stages. Be sure to check our events calendar on **www.oif.org** to make sure you don't miss an event in your area!

Are you interested in throwing your own fundraising event for the OI Foundation? Contact Melissa Bonardi at **mbonardi@oif.org** or **301-947-0083** to discuss your ideas.

Another Banner Year for the OIF's Beefsteak Dinner in Garfield, NJ

Between the hundreds of guests, decorated dining hall, auction items, raffle prizes and *unlimited* perfectly cooked beef, The OI Foundation's annual Beefsteak Dinner is certainly an experience to be had! Beefsteak is not your typical fundraising event, but a community built production. The repeating success of this New Jersey event is a direct result of the hard work and dedication of Jo Ann Berkenbush and Rosemarie Casper. Jo and Roe have been hosting Beefsteak, a family friendly dinner event, annually since 1992.

The crowd at Beefsteak is a reason to attend in itself. After meeting Jo Ann, Rosemarie, and their hundreds of fans, you'll be ready to buy your ticket for next year. Jo and Roe have built a 300+ person family, each excited to be involved in the event and the efforts of the OIF.

Family, friends, coworkers, and neighbors of every age rush to volunteer to help with this great experience year after year. The event annually demonstrates how inspiring, caring and strong the OI community truly is. A portion of the evening was dedicated as memorials for the recently departed Tom Acquafredda and Larry Grueninger. In addition, Toni Diamiano celebrated his birthday during a break from calling the winners of over 150 tricky tray baskets compiled by Beverly Krudys.

The Beefsteak legacy has raised an unbelievable $400,000.00 in support of the OI Foundation! Those involved have helped over 1,600 people AND funded over 1,400 hours of OI related research. We can't thank you enough for your hard work and support!

The continuous success makes it obvious that Jo Ann and Rosemarie have put endless time and effort into this event for the past 22 years. The Beefsteak family left another year behind them with full stomachs and big smiles. We look forward to Beefsteak 2014!

SAVE THE DATE

For Fine Wines Strong Bones 2014

We are very excited to announce the OI Foundation's *14th Annual Fine Wines Strong Bones* will be held on **Saturday, March 1st from 6:00 pm to 9:00 pm at the Gaylord National at Washington DC's National Harbor in Oxen Hill, MD – just across the Potomac River from Alexandria, VA**. Building on the success of the last few years, we are continuing to expand our flagship fundraising event with a new Mardi Gras theme that will feature beads; masks; international fine wines that have been hand selected to pair with our New Orleans delicacies; hundreds of high valued, unique auction items; and casino gaming tables.

We hope that you will join us for an evening that promises to be fun, entertaining and a benefit to the OI community. Proceeds from the event will help the OI Foundation respond to more than 7,000 inquiries each year, produce new information resources, fund research, and facilitate the operation of support groups across the country.

Tickets and sponsorship opportunities are now available. If you would like more details on sponsorship or the event, please visit **www.oif.org/FineWines** or contact Melissa Bonardi at **mbonardi@oif.org** or **301-947-0083**.

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Health Insurance Marketplace – Get Covered

If you are planning to use the Health Insurance Marketplace to purchase health insurance coverage for 2014, you still have time to explore your options. Unfortunately, the opening of the Health Insurance Exchanges has not gone smoothly. Technical problems have plagued the main on-line resource center, **Healthcare.gov**. Until the website is working properly, the Department of Health and Human Services is redirecting people to other ways to obtain health insurance information and to apply for insurance through this program. If you cannot get the information you need from the official website you can:

Get information by phone at (800) 318-2596 /
TTY: (855) 889-4325

Talk with a trained counselor or application assister. Find in-person help in your local area at **LocalHelp.Healthcare.gov** or by calling the 800 number.

The four basic ways to apply for health insurance through the marketplace are listed below:

- Apply online at **Healthcare.gov**
- Apply by phone at (800) 318-2596 / TTY: (855) 889-4325
- Apply in person with a trained counselor or application assister. Find in-person help in your local area at **LocalHelp.Healthcare.gov**.
- Apply by mail. Download the paper application and instructions from **Healthcare.gov**.

Open enrollment ends on March 31, 2014; however, to begin receiving benefits by January 1, 2014, you must enroll by December 15th.