

Breakthrough

VOLUME 40 NO. 1 SPRING 2014

2014 OI Foundation National Conference

Planning is well underway for this summer's OI Foundation National Conference! In 2012, more than 800 members of the OI community gathered in Washington, DC for the 2012 OI Foundation National Conference—let's make 2014 even better! Join us for three days of informational sessions, free medical consultations, and social activities—including the first-ever National Unbreakable Spirit® Walk-n-Wheel and baseball game outing!

Here's an outline of what to expect.

The morning and early afternoon of **Friday, August 1** will be filled with three important pre-conference activities – Youth Forum (OI YEP), Women's Forum and Medical Consultations. The conference will officially open at 4 pm with the welcome session and keynote address. Evening activities will feature the Talent Show and cake party! To sign-up for the Talent Show, please contact Jessica at 800-981-2663 or jfinkel@oif.org

Women's Forum The women's forum is only open to OI women over the age of 18 and will cover health and social topics specific to women living with OI. There is an additional registration fee of \$45 to attend this event and registration is limited to 40 attendees. Attendees can register for the Women's Forum through the main conference registration form on www.oif.org/conference

OI Young, Empowered, and Proud (OI YEP) Forum
A special activity for youth and young adults at the 2014 OIF National Conference Are you young, empowered and proud? Do you want to discuss personal and professional development topics with a group of your peers? If you are between the ages of 16 and 25, sign up to participate in the OI Youth Empowered and Proud (OI YEP) Forum on Friday, August 1, 2014 in Indianapolis, IN! This is a preconference activity specifically designed for youth and young adults living with OI.

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The 5th OI Foundation Medical Consultation Day

offers the opportunity for families and adults who have OI to have a face-to-face meeting with a physician or physical therapist who has extensive experience with OI. A consultation is a conversation. No exams can be given. It is the chance to get questions answered, to have a test or diagnostic letter explained and to get a second opinion about a treatment or about how you're doing compared to others who have OI. The program runs from 8:30am until 3pm on Friday August 1. People who are registered for the conference can request one to three appointments with the specialists of their choice. Each appointment lasts 20 minutes. The following medical specialties will be represented: orthopedics, pulmonary, adult health, genetics, physical therapy, hearing, and orthotics. Additional specialists may be added if space permits.

It is easy to request an appointment.

Appointments are scheduled on a first come basis beginning at 9:30 am EDT, on Thursday, May 1, 2014. There are three ways to request an appointment.

- Print the Appointment Request form (available on www.oif.org/conference in April) and fax the completed document to 301-947-0456.
- Email the completed form to Bonelink@oif.org or
- Call the OI Foundation office at 800-981-2663. Be prepared to answer the questions on the Appointment Request form.

Who are the Doctors?

Each doctor is an expert in his or her area, and has Extensive OI experience. Many are members of the OI Foundation's Medical Advisory Council (MAC). Detailed information about each physician will be posted on www.oif.org/conference as soon as possible. Appointments will be confirmed by June 1 by email. Every effort is made to fill as many requests as possible for each family. At the 2012 National Conference, the Medical Consultation Program was able to help 83 people – children and adults – have a conversation with a specialist.



SHARE YOUR **Unbreakable Spirit[®]**!

**MAY 3 - 10 NATIONAL OSTEOGENESIS IMPERFECTA
AWARENESS WEEK 2014**

Osteogenesis imperfecta (OI), also known as brittle bone disease, is a genetic disorder that makes bones so fragile they break easily. Educate yourself and others by joining the Osteogenesis Imperfecta Foundation in celebrating **NATIONAL OI AWARENESS WEEK 2014!**

You can help! Raise awareness about OI by purchasing a wristband or making a donation to support the work of the OI Foundation at www.oif.org.



WWW.OIF.ORG/AWARENESSWEEK

Unbreakable Spirit®



Participants of the 2013 Unbreakable Spirit® Walk for OI: Buzzards Bay, MA

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

We hope you are ready to “**SHARE** Your Unbreakable Spirit®” during National Osteogenesis Imperfecta Awareness Week 2014. Since February 1st, we have already shared facts, videos and OI related information with over 13,000 people through social media posts! Thank you for your participation in “Sharing” and “Retweeting” our [SHAREforAWARENESS] posts, keep it up! [SHAREforAWARENESS] posts will continue until May 10, 2014.

National Osteogenesis Imperfecta Awareness Week is a time we encourage the OI community, Foundation, and supporters to use fundraising events, social media, and individual state proclamations to raise awareness for osteogenesis imperfecta. National OI Awareness Week, originated from and is scheduled around Wishbone Day, an international OI Awareness Day taking place on May 6th of each year.

We want to know how you've raised awareness and introduced others to osteogenesis imperfecta. Did you share Facebook posts, hold a Blue Jeans Day, wear OI merchandise, host an Awareness Week event, or hang OI posters? We want to know who you educated and how! Email dcyber@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 your event today! Include your friends, family, neighbors, coworkers, local businesses and community by holding a fundraising event or leading a National Blue Jeans for Better Bones Day on May 9, 2014. Check out the events that are already planned to take place during National OI Awareness Week 2014:

- Unbreakable Spirit® Walk for OI: Buzzards Bay
- Unbreakable Spirit® Barbeque: Granger, IA
- OI Benefit Ball: Greensboro, NC
- Unbreakable Spirit® Walk-n-Wheel: Nashville, TN
- OIF Local OI Awareness Event: Gaithersburg, MD
- National OI Awareness Week Proclamation Presentation at the ABQ Biopark Zoo: Albuquerque, NM
- The Last Break: Dance for Better Bones
- MA Unbreakable Spirit® Walk for OI
- National Blue Jeans for Better Bones Day – Friday, May 9th
- Unbreakable Spirit® Walk-n-Wheel: Ohio
- 7th Annual Central TX Walk-n-Roll

No time to plan an event? There are other ways to get involved:

- Use your social media pages to share information with your circle. Share and Retweet the OIF [SHAREforAWARENESS] posts!
- Hang National OI Awareness Week 2014 posters in your community! Contact Danielle at dcyber@oif.org to order Awareness Week posters today!
- Help us proclaim May 3-10, 2014 Awareness Week 2014 in every state! Check out the Proclamation page on www.oif.org/AwarenessWeek to see if you can help! For more information about National OI Awareness Week state proclamations, please contact Jessica at jfinkel@oif.org.

Young, Empowered and Proud (OIYEP) Forum

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The OI YEP Forum will feature interactive presentations, team building activities, and discussions relating to key issues in the lives of young adults. The Forum will begin that Friday at 10 am and end at 3:30 pm, with a break for lunch on your own. Forum topics will include:

- I Am: Youth Claiming Our Own Identities
- Breaking Boundaries, Not Bones: Living and Playing in Your Community
- Friendships, Relationships, and Dating
- Skills to Pay the Bills
- OI U: College and Independent Living with OI
- Your Choices, Your Voices

There is NO FEE to attend this event; however, registration is required through the OIF National Conference registration link on www.oif.org/conference.

How to Register for the OIF National Conference

It's easy to register to attend the OIF National Conference! Register online at www.oif.org/conference or call 800-981-2663.

Registration Fees

Child Registration WITH Childcare included-

12 months to 12 years old

- \$195 Child Early Bird
- \$220 Child Regular (after early bird)
- \$245 Child on-site at conference

Child Registration-12 months to 12 years old

- \$145 Child Early Bird
- \$170 Child Regular (after early bird)
- \$195 Child on-site at conference

Teen Registration-13 years old to 17 years old

- \$180 Teen Early Bird
- \$205 Teen Regular (after early bird)
- \$230 Teen on-site at conference

Adult Registration-18 years old and older

- \$180 Adult Early Bird
- \$205 Adult Regular (after early bird)
- \$230 Adult on-site at conference

Early bird registration ends on April 30, 2014

Where to Stay

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.

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NEW!

National Unbreakable Spirit® Walk-n-Wheel

If you plan on attending the 2014 OI Foundation National Conference, we hope you will also plan on participating in the first ever, National Unbreakable Spirit® Walk-n-Wheel on Thursday, July 31st at 5:00pm. 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 or form a team with your family, friends or support group members. As the Walk-n-Wheel co-chair, Jody Cheek points out, "for the first time, we will have a chance to come together with old and new friends and raise awareness for OI as we form teams; share our stories with friends and family as we ask for support; and finally, as we walk or wheel through downtown Indianapolis to announce the start of our National Conference!"

For more information or to set up your personal team raiser page, visit www.oif.org/WalkAndWheelIndy or contact Melissa Bonardi at mbonardi@oif.org.

Baseball Game Outing

Join us for OI Night as we cheer on the Indianapolis Indians on Saturday, August 2 at 7pm! Victory Field is located directly across the street from the JW Marriott conference hotel. Tickets are \$10 each and may be purchased through the conference registration form.

Saturday, August 2 and Sunday, August 3

Saturday will focus on medical and research information and Sunday will focus on life skills. Plenary sessions will include the popular Research Update and on Sunday, a report from the OI Foundation, "Look How Far We've Come." Sessions will be "tracked" to make it easier for participants to find the sessions most useful to them. Tracks will feature a minimum of 8 workshops for People Living with Type I (Mild) OI, Parents of Children with Moderate or Severe OI, Adults over 30 and Young Adults (people who are college age and in their 20's).

Separate centers will be open on Saturday and Sunday for young people who are registered for the conference. The **Teen Center** is for youth who are in high school. The new **Pre-Teen Center** is for young people who are too old for child care but not yet in high school, ages 9-12. The chaperoned centers offer a place for fun, friendship and information.

Conference Program Outline

This program is subject to change and will be updated on www.oif.org/conference as we continue to confirm speakers and activities.

Friday, August 1

8am-3pm	Medical Consults
9am-3pm	Women's Forum
10am-3:30pm	Youth Forum
2-3pm	Introduction to OI
2-3pm	How to Raise Awareness about OI
4-5:30pm	Opening Session: Welcome to Conference & Keynote Address
Evening	Talent Show followed by Cake Reception Adult Dinner College Student Gathering

Saturday, August 2

8:30-10am Research Update
Sessions have been divided into Tracks, but participants are encouraged to select sessions based on their interests.

Session I

Tracks 10:15-11:15 am

Type I	Health Issues & Treatment
Young Adult	Health Issues & Treatment
Adults	Health Issues & Treatment
Parents	Health Issues & Treatment

Session II

Tracks 11:30am-12:30pm

Type I	Hearing: Ototoxic Drugs
Young Adult	Transition to Adult Medicine
Adults	Breathing
Parents	Dental: Understanding Malocclusions
Extra #1	Orthotics
Extra #2	Parenting the Young Adult Who has OI

Lunch Demonstration

Handling Babies

Session III

Tracks 2:15-3:15pm

Type I	Vision: How OI affects the Eye
Young Adult	Genetics: Introduction to How OI is Inherited
Adults	Hearing: Cochlear Implants
Parents	Orthopedics: Spine & Scoliosis
Extra #1	Home First Aid

Session IV

Tracks 3:30-4:30pm

Type I	Orthopedics: Spine and Joint Care
Young Adult	Dental: Craniofacial surgery
Adults	Emergency Room Emergencies
Parents	Orthopedics: Rodding Surgery
Extra #1	Home First Aid
Evening	Baseball Game

Sunday, August 3

9-10am OI Foundation Update

Session V

Tracks 10:15-11:15am

Type I	Mental Health: Coping with an Invisible Disorder
Young Adult	Self-Esteem
Adults	Mental Health: Coping with a Chronic/Painful Condition
Parents	Adaptive Equipment for Children

Session VI

Tracks 11:30am-12:30pm

Type I	Exercise
Young Adult	Home Improvement: Adapting Dorms and Apartments
Adults	Exercise Panel: Fitting Activity into your Life
Parents	Mental Health: Resilient Families

Lunch

Session VII

Tracks 1:30-2:30pm

Type I	School Strategies
Young Adult	Career Building
Adults	Home Improvement: Contractors, Permits and related Adventures
Parents	Exercise: Aquatics for Kids

Session VIII

Tracks 2:45-3:45pm

Type I	Pregnancy and Family Planning Discussion
Young Adult	Exercise: Aquatics for Adults
Adults	Shop, Cook & Apps for Weight Management
Parents	School Strategies or Coping with Bullying
Evening	Closing Dinner & Dance



Patty DeLuccia with her raffle baskets at the 2013 Beefsteak Dinner

Make Your Event A Community Affair

One thing we see year after year is that the Unbreakable Spirit® that possesses members of the OI community is contagious. Creating a committee of friends, family, neighbors and co-workers enables you to share the work and the joy of organizing a fundraising or awareness event. You will be surprised and overwhelmed at how often your social network will jump at the chance to help you raise money and awareness for OI.

The New Jersey Area Beefsteak Dinner is the perfect example of a labor of love in the community. Beginning as an event led by the New Jersey Area Support Group in 1991, it has evolved into a community production with dozens of friends and family members lending a hand to sell tickets, procure hundreds of tricky tray baskets, put together raffle items and to continue making Beefsteak Dinner an event that annually demonstrates how inspiring, caring and strong the OI community truly is.

This past October, over 300 friends, neighbors, family members and co-workers attended the 22nd Annual New

Jersey Beefsteak Dinner. While Rosemarie Kasper and Jo Ann Berkenbush may be the formal volunteer event coordinators, they would not be able to hold such a successful event each year without the help of committee members like Beverly Krudys who creates many of the tricky tray baskets and Patty DeLuccia who not only creates baskets for the tricky tray but donates a super-sized basket of liquor and an extra-large board of lottery tickets for the raffles.

Proving that Beefsteak Dinner has made a lasting impression in the community, when a birthday party was held in honor of Toni Damiano last year, guests were asked to make a donation to the OI Foundation instead of giving her gifts. We are truly grateful to her for thinking of us, and we are also grateful to all the people who work so hard to make this event a keystone in the OI community calendar.

Consider gathering your friends and family to join you as a committee and hold your own fundraising or awareness event for the OI Foundation today. For more information, please contact events@oif.org.

John Benanti
 Jo Ann Berkenbush
 William Berkenbush
 Norma Botelho
 Barbara Cascio
 Douglas Cascio
 Barbara Cassella
 Elyse Constantin
 Toni & Raymond Damiano and Family
 Warren Damiano and Family
 Pat & John DeLuccia
 Ellen Haley
 Rosemarie Kasper
 Beverly Krudys
 Carol Lamendola
 Frank Petrozzino
 Marilyn Pirnat
 Irene & Ed Puzio
 Kay Rizzo
 Bill Schmidt
 Liz Schmidt
 Peter & Gretchen Strauch and Family
 Gary Tankard
 Ruth Van Houten
 Ross Webb

Bone China Tea 2014

Over the past 18 years, Bone China Tea has become a great way to ask friends, family and colleagues to support a cause you care about without asking for too much. Eliminate the hassle and expense of figuring out what to wear, who to bring and how to get there by taking part in this virtual fundraising event. Invite everyone you know to contribute to our awareness, support and research efforts by lounging on the couch and sipping a hot cup of Bone China Tea on April 9, 2014. Create your personal online Bone China Tea page and/or order your printed invitations TODAY!

Visit www.oif.org/bonechinatea to create your personalized Bone China Tea webpage. Invitations, provided by the OI Foundation, are complete with a specially designed tea tag, reply card and return envelope. Hosts are encouraged to personalize each invitation with a note and/or photo. Invitations are available today.

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



Order Free Printed Invitations:

To order invitation packets, contact Co-Chairs Jenny and Susie Wilson at jnwilson@aol.com or OISLW@aol.com (239) 482-0643.

Please include your:

- Complete Name and Address
- Phone number
- Email address
- Number of invitations you are planning on sending
- When you send your invitations, don't forget to include a photo or brief note explaining your OI experience. Guests will want to hear from YOU!

Bone China Tea Webpages:

The OIF website gives you the opportunity to personalize your own Bone China Tea webpage

- Display a photo, post a video or write your personal story
- Share your page on social media and via email to reach the largest number of your friends
- Track donations in real time

www.oif.org/bonechinatea

How to Register for the OIF National Conference

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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. Since the hotel has set aside a block of rooms for OIF attendees, **if you don't mention that you are part of our group, you may be told the hotel is sold out.** So remember to tell them you are attending the "Osteogenesis Imperfecta Foundation National Conference"!

If you need to book an accessible (ADA) room:

Please remember that with every hotel, there are a limited number of ADA rooms available. Please be considerate to fellow attendees and only book an ADA room if a standard room cannot accommodate your needs. ADA rooms are available on a first come, first serve basis, and will sell out early! To discuss specific questions or special needs regarding guestrooms, contact the hotel directly at 317-860-5800.

Guestroom doorway measurements are as follows:

**Standard and ADA guestroom entrance:
34.75 inches**

**Standard and ADA guestroom bathroom:
34.75 inches**

Conference Scholarships

The OI Foundation has obtained funding, primarily through individual contributions for a limited number of scholarships to the 2014 National Conference. All those wishing to attend conference but who are unable to due to financial limitations are encouraged to apply. Applications are available on www.oif.org/conference or by calling 800-981-2663 and are due by April 11th.

The location of the 2016 National Conference will be announced at the Closing Dinner and Dance on Sunday, August 3. Use the clues below to see if you can 'Guess the 2016 Conference City!' Send your guess to conference@oif.org.

1. There is no shortage of places to lay your head
2. Don't worry; they have their rodent problem under control
3. It's a Beautiful city
4. Be sure to pick the right coast
5. We may not be on Capitol Hill, but you won't have to go far to see a "Senator"
6. Enjoy the outdoors and take a stroll through one of the many parks

The OI Foundation recognizes outstanding volunteers for their service by presenting three awards to recognize significant and/or lasting contributions to the OI community — a dedicated service award, a youth award, and a volunteer of the year award.

Congratulations to our 2013 Volunteer of the Year Winners!

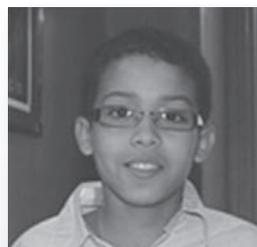


2013 Thelma Clack Lifetime Volunteer – Jamie Kendall

Jamie is currently the Director, Special Projects, at the Center for Disability and Aging Policy at the Administration for Community

Living (ACL), U.S. Department of Health and Human Services (HHS), a federal agency which promotes full participation of individuals with disabilities and older Americans in the community. Much of her career has focused on promoting employment opportunities for individuals with all disabilities. Previously she served as the Deputy Commissioner at the Administration on Intellectual and Developmental Disabilities (AIDD) where she provided leadership to the programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the Help America Vote Act. She has also held positions at the Social Security Administration and at the Administration for Children and Families. Jamie holds a Masters in Public Policy (MPP) from Georgetown University.

Jamie's involvement with the OI Foundation began as a young adult when she attended the 1996 National Conference on OI, where she met her husband, Tim Dombro. She describes the conference as a life changing experience which compelled her to volunteer with OIF in order to support the OI community. Her original volunteer job was organizing the "key pals" program, which connected teens with older adult mentors with OI. She served on the OIF Board of Directors for six years, including one term as President. Her biggest achievement during that tenure was working to establish the OI patient registry and continuing to promote the "mutual support" side of the mission of OIF. In 2001 she coalesced a critical mass of OI individuals and families to create the annual Fine Wines Strong Bones fundraising event, and still serves as an active member of the planning committee. Originally from Detroit, Michigan, Jamie and Tim live in Alexandria, Virginia and are the foster and adoptive parents of three children; Jake, Julian and Claudia.



2013 Peter Dohm Junior Volunteer – Marcus Davis

Marcus is currently an 8th grade student at West Seneca West Middle School, located in Western New York. Marcus became interested in

raising awareness for OI during the summer of 2012.

On March 21st, 2012 his baby cousin was born with Type 3 OI. Marcus had never heard of it, so he did his research and decided that he wanted other people to hear about it.

He raised money and awareness with bake sales, Pajama days and bracelet sales at school. Also, he spoke with several local sport organizations and asked for donations for the OI Foundation. To this day Marcus still tries in any way possible to raise awareness for OI.

2013 President's Award – Jessica Sheridan



Jessica is a former Special Education teacher and current full-time mom. Working with children with and without special needs in various facets since 2003, she received a Masters degree in Education and an endorsement in Special Education in 2009. Anticipating a life-long career

working to inspire a love of learning in children, and dedicating herself to helping those in need, she took a position working as a 1st Grade Special Education Teacher in the fall of 2009.

In 2011, Jessica and her husband Mike found out that they were expecting, and on April 12, 2012 their daughter Maggie Shae was born.

When Maggie was 6 weeks old it was realized that she had osteogenesis imperfecta, a disease that neither Jessica nor Mike had known about. It is through this traumatic, yet pivotal event that Jessica became involved with The OIF when searching for support and information. Inspired to continue helping

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The following is a letter from past OIF Board President, Roger Bache, about the OI Foundation's membership program. The OI Foundation counts on your membership to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. In addition to supporting the work of the Foundation, membership gives you a voice in the OI Foundation's future. As a member of the OIF you are invited to our Annual Meeting, where the leadership of the OI Foundation updates members on the organization's accomplishments and future directions, and you will have voting privileges in our annual elections for our Board of Directors. Please use the enclosed reply envelope to renew your current membership, or become a new member today!

Dear Friends,

As most of you know too well, a diagnosis of OI has a profound impact on the entire family. While our daughter Katrina has dealt with very painful fractures, multiple surgeries, and often long and difficult recoveries, my wife Gayle and I have dealt with many sleepless nights, long and stressful hospital stays, and continuous worries about the future. Although we have been consistently challenged as a family, the OI Foundation has been there as a trusted resource that we could always turn to for support. We will always remember how the OIF provided us a wealth of information and connected us to other OI families when Katrina was first born. I cannot imagine how difficult it was for parents in earlier years when the OIF did not exist.



We are extremely fortunate to have an OIF staff that is so talented and committed to improving the lives of people with OI. As a former OIF board member who has been active in the OI community for the past twenty years, I have personally witnessed the dedication and accomplishments of the staff and volunteers who continue to make a difference in the lives of so many. Many of us have watched as the OIF established a web portal, coordinated national conferences, funded important research, answered thousands of requests for information, reassured new parents and spearheaded the establishment of the Linked Clinical Research Centers.

The OI Foundation counts on your support to help fund research and provide medical information, develop new resources, and increase public awareness about OI. The OI Foundation owes much of its success to its loyal and supportive members, and the organization's future strength depends greatly on the support of new and old members alike to provide these vital resources. We are a very strong community with an Unbreakable Spirit® and it is so very important that we continue to support the OIF. I humbly ask that you consider joining the OIF to ensure that this great organization continues to provide a high level of support to the OI community. Thank you in advance for your support.

Sincerely,

Roger Bache

Congratulations to our 2013 Volunteer of the Year Winners! *continued from page 8*

others, and encouraged by The OIF's sense of community and compassion, she has made it her mission to work to raise money to one day find a cure for OI, improve Maggie's quality of life and help other families affected by OI.

In June of 2012 Jessica began a blog chronicling the adventures of a new mama and a baby with special needs in order to communicate Maggie's progress with family and friends, help others and to simply find humor and solace in their everyday 'adventures'. That same year she organized a Blue Jeans for Better Bones Day, and in 2013 the 1st Annual Grandpa's Gift Golf Tournament and Silent Auction was held in southeastern Michigan. Jessica hopes to continue to be an advocate for the OI community, spreading awareness and raising funds for research for as long as possible.

Originally from South Lyon, Michigan, Jessica now lives in Downers Grove, Illinois with Mike and Maggie Shae.

Nominations for the 2014 Volunteer of the Year Awards!

Know a volunteer from the OI community that deserves to be recognized for all of his or her hard work? Nominate them for the OI Foundation's 2014 Volunteer of the Year award. We are so thankful for all of our volunteers and participants who provide support in helping improve the lives of those living with OI. The Foundation recognizes these great volunteers by presenting three awards to acknowledge their outstanding contributions to the community - a dedicated service award, a youth award, and a volunteer of the year award. The person named volunteer of the year will be recognized at the 2014 National Conference. Please submit your entries to Jessica Finkel at jfinkel@oif.org by April 30.

SAVE THE DATE Birdies And Bogies 2014

For the 8th year, the OI Foundation's **Birdies and Bogies for Better Bones** charity golf outing will be held at the Arnold Palmer Signature Golf Course at Belmont Country Club in Ashburn, VA. The Captain's choice style event will also feature hole-in-one, longest drive and closest to the pin contests, as well as a silent auction of sports-related and dining items at the 19th Hole Reception immediately following the morning's golf. Mark your calendars for **June 30, 2014** and plan on joining us for a memorable day of golf that will help the OI Foundation continue its mission of funding research, providing medical information and support, developing new resources, and increasing public and professional awareness about OI.

Sponsorship opportunities start as low as \$1,000 so take this opportunity to get your company's name out to the community. Also, new this year, we will have a Social Registration available for anyone who may not be able to afford the full foursome registration of \$750. Golfers who sign up for the \$125 Social Registration will not be eligible to win the top foursome prize but will still get to enjoy a day of golf on a private

course, food and beverage for the day, and be in the running for the hole-in-one, longest drive and closest to pin contests. Registration is now open so act quickly before we sell out!

Visit www.oif.org/BirdiesAndBogies for more information or to register.



A Look Back at the OI Awareness Unbreakable Spirit® Wristband

Do you remember 2005? Charity awareness wristbands were the hot new trend. Celebrities wore them and students of all ages collected them. Like other small organizations, the OI Foundation was trying to figure out whether it was a good idea to get into the wristband business. Was the fad going to last? Were enough people interested in OI to make the up-front costs worthwhile? Was there a way to make an OI Foundation wristband stand out from the rest?

In 2005, Scott Clifford was a high school student in New Jersey. He wanted to spread awareness about OI in his local community. He wanted to do something that would catch the attention of his peers. He was convinced that an OI Awareness Wristband was an initiative with a lot of potential. So Scott and his mother, Susan Clifford, contacted the OI Foundation, and offered to test the idea in their community. Scott is credited with coming up with the magical slogan, “Unbreakable Spirit®” to be embossed on each blue band. Now the wristbands not only stood out from others but they would help spread the message that people with OI are much, much more than their fragile skeletons. The Cliffords ordered 250 wristbands, which sold out in 10 days.

Based on the enthusiasm this test batch generated, the OI Foundation began a national promotion.

During the launch of OI Awareness Wristbands back in 2005, the OI Foundation's staff and volunteers processed and shipped out thousands of blue non-allergenic silicone OI Awareness



Scott and Susan Clifford assembling the first batch of OI Awareness Unbreakable Spirit® Wristbands in 2005.



Scott Clifford, the creative mind behind the “Unbreakable Spirit®” phrase and OI awareness wristbands, in 2014

Wristbands. More than 6,000 bands, an unbelievable number, were sold in the first week alone.

Almost a decade later, OI Awareness Wristbands continue to be featured in the OIF online store and at walks and other events. Scott and Susan Clifford's idea for increasing awareness in their community has helped inform countless individuals about osteogenesis imperfecta all across the United States. So far the OI Foundation has sold more than 54,000 OI awareness wristbands. The “Unbreakable Spirit®” slogan has become a theme that is expressed in OI communities worldwide. One idea that started small, and was test-marketed by a student has had an incredible impact in spreading awareness. Each wristband opens up a conversation that helps to educate others about OI and the Unbreakable Spirit® community.

So what is Scott Clifford doing today? The creative mind behind the “Unbreakable Spirit®” phrase and OI awareness wristbands didn't rest on his laurels. Now 25 years old, Scot is a graduate of the University of the Arts in Philadelphia, Pennsylvania. He continues to be interested in marketing and communications. He is a freelance writer and a videographer, who is passionate about writing, marketing, and producing. In addition to writing for NewsWorks, Scott will soon add a new web series titled “Music & Coffee” to his portfolio.

As we near the 10th anniversary of the OI Awareness Unbreakable Spirit® Wristband the OI Foundation gratefully recognizes and thanks Scott Clifford and his family.

Thank you to our outgoing members of the Board...

Serving on the OI Foundation's Board of Directors is a commitment of time, talent and resources and the OI Foundation is truly grateful to those who serve. Each member of the Board of Directors serves a three year term and may serve two consecutive terms. In 2014 two members of the board will step down fulfilling their six year term of service. They are:

Sharon Trahan – Sharon is the OI Foundation's past President of the Board of Directors and served on the executive committee for four of her six years on the board. She led the OI Foundation to successful years of growth in the program and research area. Under her leadership the OI Foundation increased its social media presence, developed new and innovative ways to communicate with donors and constituents and funded new programs for both children and adults with OI.

Gil Cabacungan – Gil is currently the OI Foundation's 1st Vice President and has served on the executive committee for four years. His business savvy and understanding of the corporate community has made Gil a valuable member of the Finance Committee and the Audit Committee over the past four years. Gil has been instrumental in making the Impact Grant Program successful and has served on that funding committee since its inception.

The OI Foundation thanks them for their dedicated service and looks forward to their continued involvement with the OI Foundation.

Nominations for Board of Directors

The OI Foundation is currently seeking nominations for members to be on the Board of Directors. Each member serves a three-year term, beginning July 1, 2014. The Board Development Committee looks for nominees with qualities such as a personal connection to OI and experience in various areas including accounting, finance, fundraising, organizational management, public relations, strategic planning, business, or law. If you or someone you know is committed to achieving the mission of the OI Foundation please fill out a nomination form. Nominating forms can be found at www.oif.org. Click on "Board of Directors" under "The Foundation" tab. Nominations are due by April 30.

2014 OI Clinic Directory

The 2014 OI Clinic Directory is a valuable tool in the process of locating good medical care for children and adults living with OI. Since OI is a rare disorder, it can be difficult to find local doctors who have experience with OI. An OI Clinic offers people living with OI the benefit of a medical team whose members are experienced with OI and able to coordinate care. The clinics listed in the OI Clinic Directory offer a wide range of services in interdisciplinary care. Regular appointments include time with a primary care physician, orthopedist, and members of the rehabilitation team. Additional appointments with other specialists are available as needed. It is the responsibility of parents and adults to verify whether a particular medical team



OI CLINIC DIRECTORY
FROM THE OIF INFORMATION CENTER

meets their needs. The 2014 OI Clinic Directory is organized by state, name of hospital/clinic, clinic director, contact phone number, number of OI patients seen, and services provided. For more information about the clinics listed and other physicians familiar with OI in your area, please visit the "OI Clinic Directory" tab on the OI Foundation's website or email Bonelink@oif.org.

Sunday Night Chat

Before there was Facebook, there were Chat Rooms and List Serves

Looking back over the last 40 years, it is very clear that access to the Internet made an important difference in the lives of families living with OI. Easier access to information and the opportunity to share personal experiences helped to reduce the sense of isolation associated with a rare disorder like OI. Parents facing a new diagnosis of OI for their child and adults with OI seem to have always embraced each new technology that gave them the opportunity to learn more and to share experiences. The challenges of not knowing anyone else with OI, or with your particular form of OI are easier to work through when a knowledgeable friend is available.

Before the official OI Foundation chat room was opened, there were OI List Serves on different platforms. The early push to Internet programs for the OI community was led by David Morrison and Angela Mancuso. Susie Wilson was an early leader who also helped with the move from list serves to chat rooms. David Morrison's mother, Susan Hart, remembers that David was passionate about the move to chat rooms. He saw easier access as an important step to creating a highway for exchanging information between those who had a question and those who had an answer.

After 25 years of service to the OI Community, the OI Foundation's live chat room will be closing later this spring. From its beginning, the chat room has been the work of teams of dedicated volunteers. These generous people gave up their evenings to host the chat. They kept up with new information about OI and about OIF programs. Even outside official chat room hours, the hosts welcomed new participants, saw that important questions got answered and helped keep

people connected to each other. Over the years, the chat room became an on-line support group for many people; often people who were stuck at home because of injury, bad weather, lack of transportation or lack of child care. It was a comfortable place where people from college age to retirees could share their stories, ask questions, and encourage each other.

The OI Foundation is very grateful to the current team of Chat Room Hosts – Katie Morrison, Gretchen Strauch, Cathy Fritz and Dave Norwood. They built on the original work done by early adopters like Angela Mancuso and David Morrison and Susie Wilson. And everyone is grateful to the many, many participants who really made the chat room a valuable experience.

But times and technology have changed. Access to the OIF Facebook page and multiple OI Forums now give the OI Community many ways to find the support they need in ways hardly imagined 25 years ago. Although the Chat Room is closing, the volunteer hosts leave an important legacy in the people they helped. Their important work of connecting people and providing information continues through the OIF Facebook page and the OIF Information Center.



Research to Follow

Study of Teriparatide (Forteo®) and Adults with OI is Published

Teriparatide or Forteo® is a commonly prescribed drug treatment for people with age related osteoporosis. In early February, the paper, **Evaluation of teriparatide treatment in adults with osteogenesis imperfecta** was published in The Journal of Clinical Investigation. Seventy-nine people participated in this proof-of-concept trial. They were randomly assigned to study groups, including one group that only received a placebo. This study found that Forteo® increased bone mineral density and vertebral strength in adults who have OI and that participants with Type I (Mild) OI appeared to benefit more from the treatment than those with OI Types III or IV.

Previous studies with people who have osteoporosis established that Forteo, a daily self-administered injection, increases bone mass in a manner that is different from a bisphosphonate such as Fosamax®. Forteo is not approved by the FDA for use with children. It is only approved for people who have stopped growing.

This study is important because a mainstream drug, Forteo®, which is used to treat osteoporosis, was studied specifically in adults who have OI. It showed that even though OI bone is different from bone found in other people the therapy was able to increase bone mass. This study is also important because it

suggests that people with different types of OI had different responses to the drug. This is potentially important as new drugs go into development. People who have Type I OI have less than the standard amount of type I collagen in their tissues while the type I collagen in people with the other types of OI is reduced in quality. We know that this key underlying difference affects height, and the severity of many of the symptoms of OI.

What about Fractures?

It is important to note that while this was the largest controlled trial of a drug with adults who have OI, it was not large enough to prove that Forteo® reduces the number or frequency of fractures. In fact, many people in the study did not see a decrease in fractures. A much larger and longer study is needed to determine if this drug therapy will reduce fractures.

Researchers from the three participating centers — Baylor College of Medicine, Houston, TX, Oregon Health & Science University, Portland, OR and the Kennedy Krieger Institute, Baltimore, MD – look to future studies to clarify the different responses between OI Types and to answer the fracture question. The OI Foundation is grateful to the 79 people who participated in the multi-year study. A link to the publication can be found on the OIF Website.

The OIF Medical Advisory Council – Experts Sharing Their Knowledge with the OI Community



Dr. Francis Glorieux, OIF Medical Advisory Chair

Beginning even before it was officially incorporated, the OI Foundation has benefited from the volunteer service of a team of medical advisors. Since its inception, the Medical Advisory Council (MAC) has been comprised of outstanding men and women who have experience in research and the many clinical care specialties related to OI. Over the years MAC members have made discoveries that advanced our understanding of the genetics of OI and improved

clinical care. Each MAC member must not only have extensive experience in OI, but must also be a leader in his/her special area of medical practice. All

current MAC members have published in peer-reviewed medical journals.

The MAC currently is chaired by Dr. Francis Glorieux of Shriners Hospital for Children, Montreal. All MAC members volunteer their time and expertise to review OI Foundation publications, and to advise the OI Foundation's CEO, staff and Board of Directors on the implications of new research discoveries and new medicines or treatments related to OI. They speak at OI Foundation national and regional conferences, participate in the OI Foundation's scientific meeting and represent the OI Foundation at other meetings around the world.

The OI Foundation thanks the 19 members of the MAC for their outstanding service to the OI community. To meet all the members of the MAC and to learn more about the chair of the MAC please visit the OI Foundation website at www.oif.org and click on the "The Foundation" tab.



From the Information Center

Introduction to Osteogenesis Imperfecta:

*A Guide for
Medical
Professionals,
Individuals
and Families
Affected by OI*



Revised Brochure: Introduction to Osteogenesis Imperfecta

The OI Foundation is pleased to announce that its most popular brochure has recently been revised. *Introduction to Osteogenesis Imperfecta: A Guide for Medical Professionals, Individuals and Families Affected by OI* provides a summary of up-to-date information on OI. The brochure answers basic questions, including how OI is inherited, diagnosed, and treated. It also outlines precautions to take when caring for people with OI.

The brochure was edited and reviewed by Dr. Michael Bober, of Thomas Jefferson Medical College and A.I. DuPont Hospital for

(TSA) website, www.tsa.gov, provides information about Federal regulations governing the use of oxygen and mobility aides at airports. Information about services is under the TRAVELER INFORMATION tab. While you're on the TSA site and your airline site, be sure to look into the pre-check program.

Hearing Loss and Employment

Hearing loss can complicate the business of finding and keeping a good job. The Hearing Loss Association of America (HLAA) has developed a toolkit for people with hearing loss to help them be successful in the workplace. Their free materials cover a wide range of useful topics including interview strategies, and hearing loss and the law in the workplace. To download the kit, you can go to www.hearingloss.org/content/workplace.

Health Tax Credit Tool

The Robert Wood Johnson Foundation and Consumer Reports have developed a web tool to help people figure out if they qualify for the new Health Premium Tax Credit. This new tax credit is a form of financial help that is available to people who buy their own health insurance plans. To access this website go to www.healthtaxcredittool.org.

Putting Patients First® Website

The National Health Council (NHC) has created a website to help families and individuals find a health insurance plan and understand the out-of-pocket costs of the different plans. The "Answer My Questions" page provides useful, consumer-focused materials to help people make good decisions. The NHC also invites people with rare disorders to share their stories (see "Share My Story") about buying health insurance. They will use this information to write recommendations to improve the insurance marketplace in the future. The site can be found at www.PuttingPatientsFirst.net.

New Resource for Care Givers

The Caregiver Action Network recently opened a new website for people who are caring for family members who have a rare disorder. The website has information on finding resources in local communities, practical suggestions for self-care and other related topics. The site can be found at www.RareCaregivers.org.

Children and by the OI Foundation's Medical Advisory Council. The brochure is available in print by request in the OIF's online store or by phone or email and as a PDF on the OIF website under the Information and Resource tab.

Planning for Travel

Whether you are planning to attend the OIF National Conference in Indianapolis this summer, or you have other travel plans, here are two resources that can help make your trips a little easier. If you're traveling by train, Amtrak has a helpful website including a section on services for people with special needs. Go to www.amtrak.com and click on "Accessible Travel Services" under the PLAN tab. For air travelers, there are two sources of information. Each airline has a website that includes information about their services for families and for people with special needs. The Transportation Safety Authority



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