



2016 OI Foundation National Conference
July 22-24, 2016 • Walt Disney Swan and Dolphin • Orlando, FL

COUNTDOWN TO CONFERENCE!

The OIF National Conference 2016 in Orlando, FL (July 22-24) is just five months away! Have you checked everything off of the Conference Checklist?

- REGISTER!** *Don't miss Early-Bird Registration Prices ending April 30th!* Each conference registration type includes: access to all conference sessions and activities (including the Talent Show with cake after-party, Youth and Women's session tracks and Teen Room), breakfast on both full days of the conference, the Closing Dinner & Dance, and conference materials.
- Book Hotel and Travel** – The full conference will take place at the Walt Disney World Swan and Dolphin Resort (in the Swan building). Conference attendees **MUST** be registered for the OIF National Conference in order to receive the discounted hotel room rate of \$149 per night.
- Request a Medical Consultation** – *Appointments may be requested starting Monday, April 25th by calling the OI Foundation at (301) 947-0083.* 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, July 22. Each attendee may request up to three appointments with the specialists of their choice. Each appointment lasts 20 minutes.
- Sign up for Childcare Services** – *To sign-up for childcare services, register your child(ren) for a full 'Child Conference Registration WITH Childcare'* The deadline for advance childcare registration is June 30, 2016 or until spaces are filled.

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OIF National Conference 2016 Sponsors

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Countdown to Conference (continued from page 1)

✔ **Check out the Conference Program** – You won't want to miss the Unbreakable Spirit Walk-n-Wheel, free medical consultations, specialized sessions, social events and more! The three-day program boasts a schedule full of information sessions on medical and practical living topics, opportunities for one-on-one medical consultations with leading experts in OI research and care, and an abundance of additional activities designed to address important issues for members of the osteogenesis imperfecta community. Check out the full program at www.oif.org/conference.

✔ **Register to take part in the Unbreakable Spirit® Walk-n-Wheel Orlando** – For every \$1,000 raised, an individual or their team will receive one free National Conference registration! Our goal for the 2016 OIF National

Unbreakable Spirit® Walk-n-Wheel in Orlando, FL – which will take place from 5-6pm on Thursday, July 21st – is to have 500 participants come together to raise awareness and funds that will enable the OI Foundation to continue keeping the cost of conference registration low as well as provide scholarships to help families in need attend. Read more about the Unbreakable Spirit® Walk-n-Wheel Orlando below, or at www.oif.org/walkandwheelorlando.

✔ **Sign Up to Perform in the OIF Conference Talent Show** taking place on Friday, July 22. A Talent Show Rehearsal will take place during the day on Friday. Sign up at www.oif.org/conference.

For more information or to register for the OIF National Conference, visit www.oif.org/conference.

Registration for the National Unbreakable Spirit® Walk-n-Wheel Orlando is now open!



The OIF's first-ever National Unbreakable Spirit® Walk-n-Wheel was a huge success at the biennial 2014 OIF National Conference in Indianapolis. Nearly 250 participants and 23 teams raised more than \$50,000 in donations and sponsorships for the OI Foundation. The fundraising efforts of our community enabled the OIF to award 17 scholarships, allowing 46 people to attend the 2014 OIF National Conference—the more money raised; the more we can do to improve lives!

Our goal for the 2016 OIF National Unbreakable Spirit® Walk-n-Wheel in Orlando, FL – which will take place from 5-6pm on Thursday, July 21st – is to have 500 participants come together to raise awareness and funds that will enable the OI Foundation to continue keeping the cost of conference registration low as well as provide scholarships to help families in need attend.

OIF National Unbreakable Spirit® Walk-n-Wheel Team Captains of the past, present and future, as well as anyone interested in leading a team or participating in the event are encouraged to register now. In early March we will be hosting a Team Captain Kick-Off call for anyone interested in, or planning to participate in the 2016 OIF National Unbreakable Spirit® Walk-n-Wheel. On the call we will review everything from “How to register as a Team Captain” to “Things you can do to help improve the lives of individuals with Osteogenesis Imperfecta.” It's a great way to hear about what others did to make their OIF National Unbreakable Spirit® Walk-n-Wheel Team's successful.

To register as an individual participant, learn more about the Team Captain Kick-Off Call or create a team for the 2016 OIF National Unbreakable Spirit® Walk-n-Wheel today, visit www.oif.org/WalkandWheelOrlando.

OIF Information Center and Monthly Podcasts for Medical Professionals

The OI Foundation has prepared a toolbox of information to assist medical professionals who are interested in osteogenesis imperfecta (OI). This new section of the OIF website contains videos, fact sheets and other resources for medical professionals. Additional resources include a quarterly newsletter for medical professionals and a monthly podcast series featuring experts on OI-related topics.

The *Leaders in the OI Field on New Advances in Research and Treatment Podcast Series* was developed by the OIF as a part of the new information center for medical professionals. Experts featured in the podcast series focus on the Basics of OI, Genetics & Diagnosis, Treatments, Non-Skeletal Issues, Pediatric Care, Adult Care and more. Listen to all podcast episodes at <http://www.blogtalkradio.com/oifoundation>.

Be sure to share our NEW Information Center for Medical Professionals website with those who are interested in learning the latest information about OI (friends, family, caregivers, doctors, nurses, physical therapists). www.oif.org/MedEd.

Medical Consultations at the OIF National Conference

On Friday July 22, 2016, the OI Foundation is offering appointments for a Consultation with an OI Specialist. This special feature provides National Conference attendees the opportunity to have a specific OI related question answered by a medical expert. This program is especially helpful for people who do not have access to OI specialists in their local community.

- Appointments are free of charge.
- Each appointment is 20 minutes long.
- All appointments are held in the conference hotel ballroom.
- Appointments are available from 8:30 am to 2:30 pm.
- No examinations are allowed; only conversation.
- Appointments are limited so each person will receive time with one or two of the specialists depending on the number of people who submit a request.
- Adults and Parents must be registered for the National Conference by June 1 to receive an appointment.

What is a Medical Consultation?

This kind of appointment is very different from visiting an OI Clinic. No examinations will be performed. This is a conversation. Your appointment is an opportunity to get a second opinion or get an answer to particular questions, to have a diagnosis explained, or to talk over test results or treatment options.

How to request an appointment

Appointments will be scheduled on a first come basis beginning at 10 am EST on Monday, April 25, 2016.

Begin by reviewing the Appointment Request Form that is posted on the National Conference page on the OIF website. Then do one of the following:

1. Call the OI Foundation office at 301-947-0083 or 844-889-7579 between 10 am and 5 pm (EST). Be prepared to answer the questions on the Request Form.
2. Print the Appointment Request Form, fill it in and fax it to the OIF office at 301-947-0456.
3. Copy the form into an email and send to Bonelink@oif.org.

You will receive confirmation by email that your request was received.

Every effort is made to fill as many requests as possible. By June 1, you will receive your personal appointment schedule. Depending on which specialist(s) you will be seeing, you may be asked to bring along test results or digital x-rays.

Who are the Doctors?

Each doctor is an expert in his or her area and has extensive experience caring for people who have OI. Many are members of the OI Foundation's Medical Advisory Council (MAC). Each doctor donates his or her services. Short biographies for each of the people on this list are on the National Conference page of the OI Foundation's website.

2016 Medical Consultants

Adult Health: Changes in OI after childhood and adolescence.

Dr. Jay Shapiro, Bethesda, MD
Dr. Sandesh Nagamani, Baylor College of Medicine, Houston, TX

Orthopedics: Bone and tendon question; rodding surgery; walking.

Dr. Cathleen Raggio, Hospital for Special Surgery, New York City
Dr. Richard Kruse, A.I. duPont Hospital for Children, Wilmington, DE
Dr. Paul Esposito, Children's Hospital and Medical Center, Omaha, NE

Genetics: Diagnosis; treatment options for children; OI Types/variability.

Dr. Michael Bober, A.I. duPont Hospital for Children, Wilmington, DE
Dr. Reid Sutton, Baylor College of Medicine & Texas Children's Hospital, Houston, TX
Dr. Joan Marini, National Institutes of Health, Bethesda, MD
Dr. Eric Rush, Children's Hospital and Medical Center/University of Nebraska Medical Center, Omaha, NE (morning only)

Pediatrics: Infant and child health care and treatment options.

Dr. Frank Rauch, McGill University & Shriners Hospital for Children, Montreal Qc, Canada
Dr. Emily Germain-Lee, Kennedy Krieger Institute, Baltimore, MD

Physical Therapy: Movement, strength, fitness and rehabilitation.

Frances Baratta-Ziska, Doctor of Physical Therapy, Hospital for Special Surgery, New York City

Hearing: Reading the audiogram; hearing aids; surgery; tinititis.

Dr. David Vernick, Beth Israel Deaconess Medical Center, Harvard, Boston, MA

Women's Health: General questions on menstruation, pregnancy, and menopause.

Dr. Deborah Krakow, David Geffen School of Medicine UCLA, Los Angeles, CA

Respiratory: Shortness of breath; risk for infection; treatments.

Dr. Hollis Chaney, Children's National Health System, Washington, DC

Vision: Changes in eye sight.

Dr. Felix Chau, University of Illinois at Chicago, Illinois Eye and Ear Infirmary, Chicago, IL

Dental: Dentinogenesis imperfecta; orthodontia; general care.

Dr. Jean-Marc Retrouvey, McGill University, Montreal Qc, Canada

Planning your Disney Adventure for your Family with OI

By Kara Ayers

The location of the 2016 OI Conference in Orlando, FL, offers families the opportunity to visit Disney Parks before or after their conference experience. As a teenager, I remember combining one of my early OI conferences with a family vacation to Disney World. Now an adult, my husband and I took our own two children to Disney World this fall. We are a mixed-ability family in that my husband and I have Osteogenesis Imperfecta. Our son, Eli (8), has achondroplasia, the most common type of dwarfism, and our daughter, Hannah (5), does not have a disability. Our family dynamics provide some interesting challenges in planning a trip to Disney but like so many other things in life, the extra time and creativity are worth the outcome of an amazing adventure.

In reflecting on our recent trip and gleaned from true Disney experts who have crisscrossed the parks dozens of times, here are a few tips for planning your family's Disney adventures:

■ **Consider endurance when planning your day:** The Disney parks are massive. Some people have reported walking between 9-11 miles per day just visiting the park! As a manual wheelchair user, I'm thankful that most are flat but there are some occasional hills in the lines leading up to attractions. Our son walks but tires easily. We'd typically never consider a stroller for transporting him because it's not age-appropriate. Disney's strollers are different. They don't look like traditional strollers and you'll see people of all ages sitting or hanging on to catch a break. Even with this boost though, we had to factor in the LONG walks from accessible parking to the stroller rental site. Take an energy assessment of your family and consider it in every aspect of your planning.

■ **Pairing your Fast Pass with your Access Pass:** Every Disney ticket holder is allocated three Fast Passes for the day of your visit. These can be reserved online or through the Disney app up to 30 days prior to your visit. Think about it as a reservation for very popular rides or shows. Disney's Disability Access Service (DAS) is somewhat similar except you physically go to the ride the day of your visit and sign up for a time to return based on the length of the line at that time. To make the most of your time, think about which rides, character visits or shows you'd most like to do or see during the day. See which you can book via Fast Pass and prioritize the others using your DAS around the times you are already booked with your Fast Pass. Don't forget to consider the location of events. We aren't a family that can travel across the entire park in a short amount of time so we try to see all that we'd like in one part before moving on to the next. We also try to avoid traveling at opposite ends unless a break is built into our day.



■ **Advocate for yourself and your family:** Disney does its best to accommodate all of their guests. It's evident that their cast members have been trained on disability. Still, there are some common loopholes that we noticed. First, many accommodations are based on the assumption that the child will have a disability but the parent won't. We were sometimes seated at shows where it was suggested only one person who could walk could sit with us. That would mean one of our children (8 and 5) would sit unaccompanied. We encountered similar challenges in helping our children on and off rides. *Cast members frequently asked the question, "Can you transfer?" to determine which line you should go to or whether to stop the moving walkway. My definition of transfer is to move from my chair to another surface. The Disney definition usually means parking your chair a long distance from the ride and walking there unassisted. With some patience and communication, all of these issues were resolved. Let cast members know your needs and we found almost all of them very helpful.*

Our family hopes to squeeze in a quick visit to Disney before or after the conference but we are most excited about seeing old friends and meeting new ones at this year's gathering. The opportunity to see a familiar OI face while visiting Disney parks is an added bonus!

For more information about Walt Disney World's accommodations for guests with disabilities, please visit: <https://disneyworld.disney.go.com/faq/guests-with-disabilities/>.

Attention: For Young Adults Attending the OIF National Conference



If you are between the ages of 16 and 30, sign up to participate in the OI Youth Empowered and Proud Forum! The forum will feature interactive presentations, team building activities, and discussions relating to living as a young adult with OI. Topics include stages of independent living, building positivity and confidence, the complexity of relationships and social life, creating an education that is beneficial for you, and gaining a meaningful career:

Saturday, July 23rd, 2-5pm

Featured Speakers Include:

Kara Ayers, PhD
Michelle Fynan, PhD
Cory Nourie, MSS, MLSP

RSVP to YEP Forum coordinators at oifylc@gmail.com.

Join the OIF Youth Leadership Council Facebook Page!
www.facebook.org/group/oifYEP

Remembering Jamie Kendall

The Board of Directors and staff of the OI Foundation were deeply saddened by the news that former OIF Board President and long-time OIF volunteer, Jamie Kendall, passed away in November. Jamie was a talented, caring and generous person and a true advocate for persons with disabilities. During her tenure as OIF Board President, Jamie set a high standard for leadership. She increased the OIF's commitment to improving the quality of life for people living with OI and played an important role in the establishment of the OI Foundation's Linked Clinical Research Center program. Jamie was passionate about empowering the adult OI community in the areas of education,



employment and health. She continued this effort long after her board term ended and enthusiastically encouraged adults with OI to push beyond themselves and plan for a healthy future.

Jamie was awarded the OIF's Thelma Clack Lifetime Volunteer Achievement Award for her work with the OI community at the 2014 OIF National Conference. At this year's Fine Wines Strong Bones Gala, an event she and her husband Tim Dombro started 16 years ago, we will honor her memory by announcing the creation of the Jamie Kendall Fund for OI Adults Health. This initiative will raise funds for research, physician education and community awareness programs. The goal is to improve the quality of life for adults living with OI. Jamie was an accomplished professional woman (serving as the Acting Director of the Independent Living Administration), wife, mother and friend to many. She will be missed by so many and remembered with high regard for all she accomplished.

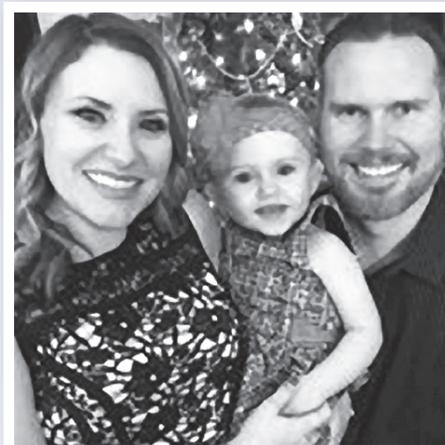
The following is a letter from lifelong OIF member, Michelle Fynan, about the OI Foundation's membership program. The OI Foundation counts on your membership to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. In addition 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 vote 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!



February 15, 2016

Hello Friends,

I'm Michelle Fynan, and I have Osteogenesis Imperfecta (OI). Because of this disorder, I have had 30+ broken bones and several major surgeries on my legs, arms, and spine. When I was first diagnosed with OI at 18 months old, my parents – Gail and George Bunker – turned to the OI Foundation for information and support. My family quickly became active members of the OI Foundation, and we began attending the National Conferences. My mother served a term as an OIF Board Member and she has been the OIF Tampa Support Group co-chair for over 10 years. We host our own Bone China Tea fundraiser faithfully each year, I've presented at the Regional Conferences in Tampa, FL, and Stamford, CT, and now we are working together with a committee of family and friends to host the first-ever Strong Bones Gala: Orlando in May this year.



The OI Foundation has always been a big part of my life. But it wasn't until I became pregnant last year, that I found myself turning to them like my mother did, when a diagnosis of OI was suspected for my daughter – Addison Layne – as we saw a probable femur fracture in her 16-week ultrasound. In spite of being a very happy and successful adult, living (and loving) life with OI, my world was shaken. Seeing our support come full circle was an amazing thing, and having them to not only reassure us but to also celebrate this experience with us was truly beautiful.

The OI Foundation counts on memberships to help fund research, provide medical information, develop new resources, and increase public and professional awareness about OI. But most of all, the OI Foundation creates a platform for support for the entire OI community. Whether you are a parent of a newly diagnosed OI baby just beginning to learn about types and treatments, or a young adult with OI who is transitioning into living on your own, or an older adult with OI who is adjusting to new complications that come with aging, the OIF will be there for you.

Regardless of if we are old friends or if we've never met, it's difficult for me to ask you for assistance. I have vivid memories of pushing my wheelchair with one hand and carrying a full tray of food in the other, refusing help from strangers and friends alike, all in the name of independence! But if I've learned anything in my old age, it's that we all need each other. The OI Foundation owes its success to its loyal, supportive members, and the organization's future strength depends on the support of new and continued members to help provide these vital resources. I would ask that each person receiving this letter consider joining the OIF in order to enable them to continue offering the varying levels of support they offer to the nearly 50,000 men, women and children living in the United States with OI. I hope you will use the enclosed envelope to renew or become a member today. Together, we truly do have an Unbreakable Spirit®.

Sincerely,



Michelle Fynan, Ph.D.

Enjoy a Cup of Tea for OI

For nearly 30 years, the OI Foundation's Bone China Tea event has invited members of the OI community to take a moment, have a cup of tea, spread awareness about osteogenesis imperfecta and raise money for the OI Foundation. Organizers Jenny and Susie Wilson would like to invite you to participate in this phantom event by hosting your own Bone China Tea on Saturday, April 9th—no matter where you live.

The best part about hosting a Bone China Tea is that there is no event to plan! You don't have to rent a space, plan entertainment or hire a caterer. Guests don't have to buy a new outfit, get their hair done or hire a baby-sitter. Simply invite your friends and family to enjoy a cup of tea at home and then make a gift to the OI Foundation with the money they may have saved by not going out to a real event. Bone China Tea participants can contribute to the OIF's awareness, support and research efforts by enjoying a cup of tea in the comfort of their own home—we even provide the tea bag! All you pay for is the postage when sending your Bone China Tea invitations to your friends and family.

There are two easy ways to invite your friends and family to participate:

1. Order printed invitations by contacting event Co-Chairs Jenny and Susie Wilson at jwilson@aol.com; OISLW@aol.com, or (239) 482-0643. Simply reach out to them with your name, home address, phone number, email address and the number of invitations you plan to send to your family and friends and they'll send them to you—complete with a tea bag.
2. You can set up your own personal webpage using by visiting www.oif.org/BoneChinaTea to register as a host and begin sending your invitations via e-mail or sharing your page on social media.



Remembering Rosemarie Kasper



On January 14th, the OI Foundation lost a long-time volunteer, former board member and dear friend. Rosemarie Kasper was a co-founder and co-leader of the NJ area support group, and helped organize the annual NJ Beefsteak Dinner event for more than 24 years. For most of her adult-life she volunteered to answer questions about aging with OI and coping with hearing loss. Roe was one of our first editors of the OI Foundation's newsletter, *Breakthrough*.

Rosemarie was born and raised in Hackensack, NJ, and fought tirelessly to push the community to be more and more accessible to people with disabilities. Many businesses in Hackensack and surrounding towns offer ramps, wheelchair seating and captioning because of Roe's efforts. When Bergen Community College was built in 1968 – with new building codes that included ramps and elevators – Rosemarie was able to fulfill a life-long dream to further her education. After receiving her Associate degree from Bergen

Community College, she continued on to Fairleigh Dickinson University where she graduated magna cum laude, followed by a master's degree in counseling. While attending school, Roe continued working full-time and retired after almost 35 years with the New Jersey Division of Vocational Rehabilitation in Hackensack.

Roe loved to travel and accompanied by her dear friend, Jo Ann Berkenbush, she had traveled to 39 states as well as Canada, the British Isles, and Bermuda. Rosemarie attended nearly every OIF National Conference since 1986 (missing only one in 2002 when her mother was in the hospital.) She especially valued her interactions at the conferences with the new generation of OI kids who were always excited to see someone like them who was living well into adulthood and inspired them to further their educations and not be limited by their diagnosis. Her presence at this year's conference in July will be greatly missed.

Fine Wines Strong Bones Events Expanding Across the Country

For nearly two decades, the OI Foundation has hosted a Fine Wines Strong Bones event in the Washington, DC metro area. This event – started by a small group of OIF supporters that included Jamie Kendall, Tim Dombro, Roger Bache, Tracy and Kyle Mulroy and Jeffrey Eslinger – began as a small wine tasting and has grown into a large casino and auction gala that will celebrate its 16th anniversary at the Gaylord National Resort on Saturday, February 27th.

Inspired by this past success, the OI Foundation has endeavored to expand the Fine Wines Strong Bones event and share it in new cities across the country. The first of these new events was the Strong Bones Gala held in Chicago on Saturday, November 14th. Nearly 175 attendees came together to raise over \$40,000 for the OI Foundation by bidding on sports collectibles, wine baskets and raising their paddles for the Fund the Mission Auction. We owe a huge thanks to Jessica and Mike Sheridan who spearheaded the formation of this event along with fellow OI community members Alma and Gil Cabacungan, Jen and Tony Benish, Sharon and Pat Fromelt, Beth and John Shultz and Dan and Jeff Krudys who all helped with the planning, acquiring of auction items, ticket sales and sponsorship. Planning has already begun for the 2nd Annual Strong Bones Gala: Chicago, so stay tuned!

On Friday, January 29th, OIF Board of Directors Treasurer Ken Gudek and his wife Teresa gathered more than 50 of their friends, neighbors and family members together for an evening of wine tasting in an effort to spread the word about OI. Ken and Teresa have held a very successful fundraising golf tournament in New Hampshire for the past eight years but recently decided they wanted to reach out to the friends and

family near their vacation home in Naples, FL. The first ever Fine Wines Reception was an intimate business casual affair that was held in their condominium's social room. Light fare was served while a local sommelier led a wine tasting with wines provided by Total Wine & More. Guests were invited to sample the wines while exploring six mission moments of the OI Foundation on display boards around the room. Attendees learned about the OIF's missions to help families with a new diagnosis, the OI Adult Health Initiative, the OI Foundation's Free Medical Consultation Program, National and Regional Conferences, Impact Grants and Research. Attendees were asked to fund the missions that resonated with them. By the end of the evening, \$25,000 had been raised for the OI Foundation! Thank you Ken and Teresa!

Up next is the Strong Bones Gala: Orlando. Gail Bunker, Michelle Fynan, and a committee of their friends, co-workers and family members are in the process of gathering auction items, finding sponsors and selling tickets to this gala event which will be held at the Orlando Science Center in the Dino Digs exhibit space on Saturday, May 21st. Tickets are currently available at www.oif.org/StrongBonesOrlando. Whether you live locally or are looking for a reason to visit Orlando in May, we hope to see many members of the OI community come together to make this event a success.

Are you interested in getting involved? If you would like to join an existing committee or if you think your city would be a good location for a Strong Bones Gala or a Fine Wines Reception, please contact Melissa Bonardi at the OI Foundation at 301-947-0083. For information on all of our upcoming galas, please visit www.oif.org/FineWinesStrongBones.



The Live Auction at the Strong Bones Gala Chicago



Attendees at the 15th Annual Fine Wines Strong Bones DC event bid on silent auction items



Ken Gudek with some of his guests at Fine Wines Reception in Naples, FL

Longitudinal Study of OI: Eight Sites in the US and Canada are Open

An important part of the Brittle Bone Disorders Consortium's work is the Longitudinal Study of OI. This study seeks to accurately describe the different types of OI and how they change as people grow up and get older. Six sites are now recruiting participants and they need to hear from as many children and adult members of the OI community as possible.

Over the years hundreds of studies about osteogenesis imperfecta (OI) have been published, but most of them only look at small pieces of the puzzle. Many studies were limited because only a few people participated, or only children or only one type of OI could be included. This leads to gaps in knowledge and gaps in treatment options. A Longitudinal Study is one way to clear up those gaps.

The Longitudinal Study of OI is a natural history study. It collects and analyzes information about the health of people of all ages and all types of OI over an extended period of time. This phase of the study builds on the information from the first phase that started in the OI Foundation's Linked Clinical Research Center program. In fact, based on what was learned from the first phase, additional questions about pregnancy, spine curves, and dental health were added to the questions about general health and bone health. The information will help answer questions about OI's variability and about the long term effects of different treatments.

This is a multi-center study with seven centers in the United States and one in Canada. Each of the centers will see children and adults. Participants will be asked to visit the center once a year for 3 years. Each visit will be similar to a very thorough physical. For details, please contact the study coordinator for the site you wish to go to. People who were enrolled in the Longitudinal Study of OI through the OI Foundation's Linked Clinical Research Centers program are urged to re-enroll.

The ultimate goal of this study is to improve the health and quality of life for every person who has OI. The more people who enroll in this study, the better the information will be and the sooner answers will be found for many pressing questions.

Contact information for the Longitudinal Study of OI sites is listed below.

Baylor College of Medicine, Houston, TX

Principal Investigator: V. Reid Sutton, MD
Contact: Mary Mullins, RN. Phone: 832-822-4263;
Email: mullins@bcm.edu

Shriners Hospital for Children, Montreal, Canada

Principal Investigator: Frank Rauch, MD; Francis Glorieux, MD
Contact: Michaela Durigova. Phone 514-282-7158

Oregon Health and Science University, Portland, OR

Principal Investigator: Eric Orwoll, MD
Contact: Catherine Pederson. Phone: 503-494-6595;
Email: Orwoll@ohsu.edu

Hospital for Special Surgery, New York, NY

Principal Investigator: Cathleen Raggio, MD
Contact: Kate Citron. Phone: 212-774-2355;
Email: citronkj@hss.edu

Shriners Hospital for Children, Chicago, IL

Principal Investigator: Peter Smith, MD
Contact: Angela Caudill, MPT. Phone: 773-385-5868;
Email: acaudill@shrinenet.org

Children's Hospital and Medical Center/University of Nebraska Medical Center, Omaha, NE

Principal Investigator: Eric Rush, MD
Contact: Jennifer Goodwin. Phone: 402-559-0681;
Email: Jennifer.goodwin@unmc.edu

University of California Los Angeles/Orthopedic Institute for Children/Shriners Hospital for Children, Los Angeles, CA

Principal Investigator: Deborah Krakow, MD
Contact: Samantha Alon. Phone: 310-794-6420;
Email: Salon@mednet.ucla.edu

Children's National Health System, Washington, DC

Principal Investigator: Laura Tosi, MD
Contact: Marianne Floor. Phone: 210-320-2157;
Email: mfloor@gmail.com

Study Sites

Many of the sites that are participating in the Longitudinal Study of OI were also part of the OI Foundation's Linked Clinical Research Centers program. Two additions to the Brittle Bone Disorders Consortium (BBDC) and the Longitudinal Study offer new options to families in the East and Midwest to enroll in this important natural history study.

The Hospital for Special Surgery (HSS) in New York City has many decades of experience caring for children and adults who have OI. It combines cutting edge research and clinical care with an emphasis on orthopedics. HSS has been involved in studying bisphosphonates and other drugs, developing effective techniques for joint repair, and studying respiratory function of people who have OI. Their commitment to improving the quality of life for people with OI is especially evident in the series of exercise videos that is featured on the HSS website.

Dr. Cathleen Raggio, who is the principal investigator at HSS for the longitudinal study commented, "Our center's long history of working with people with OI of every age and type makes this a perfect site for the next stage of this important study."

Another addition to the BBDC is the **OI program in Omaha, NE**. The very successful OI Clinic at Children's Hospital and Medical Center cares for over 175 children each year. Building on this success, within the next few months a parallel clinic for adults with OI is expected to open in partnership with the University of Nebraska Medical Center. "One of the reasons I'm excited to be involved in the BBDC and the Longitudinal Study," said Dr. Eric Rush, principal investigator for the study, "is the shared vision of our colleagues in other OI centers and the OIF of continual improvement of care for people with OI."

Hepatitis C and Adults with OI

Hepatitis C is a common problem caused by contact with infected blood. Before 1992, blood for transfusions was not screened for the hepatitis C virus (HCV). As a result some people unknowingly became infected. There is no known association between OI and liver disorders but there is concern about exposure to the virus because of frequent childhood surgeries. OI adults may have been exposed to the virus if they **received a blood transfusion before 1992**. The medications that adults may take on a daily basis for their chronic pain also tax the liver and can increase the impact of Hepatitis C.

What is Hepatitis C?

Hepatitis C is a liver disease. It was identified in 1989. Over many years it slowly leads to serious liver damage like cirrhosis and may even result in liver cancer or the need for a liver transplant. The liver plays an important role in processing substances for use in the body. A weakened liver may affect how a person reacts to medicines and dietary supplements.

What are the symptoms?

Chronic Hepatitis C (when the virus has been present for more than 6 months) may have no obvious symptoms for decades. Initially there may have been transient flu like symptoms. Later developing symptoms may include:

- Fatigue
- Nausea
- Decreased appetite
- Stomach pain
- Fever
- Jaundice (yellow skin, eyes or dark urine).

How is it diagnosed?

Even if someone does not have symptoms, the virus can be diagnosed through a blood test. Liver function tests and/or a liver biopsy may be needed to determine how much damage has been done.

How is HCV treated?

Treatment for Hepatitis C has changed a lot since 2013 as new drugs have been approved by the US Food and Drug Administration. The new treatments regimens are described as being shorter, easier and more effective than previous options. The newer medicines include Hervoni® and Viekira Pak®. Some of the newer medicines are expensive. If your insurance does not cover the new treatments it may be possible to apply directly to the drug company for assistance.

A few adults with OI have reported receiving a chronic Hepatitis C diagnosis and that they were successfully treated.

Adults who had surgery before 1992 are encouraged to ask their doctor to specifically order the test for Hepatitis C. Additionally, adults who have been living with the diagnosis but who have not received treatment may want to ask their doctor about the new treatments. See the American Liver Foundation for more information and a description of available drugs at

www.liverfoundation.org

SAVE THE DATE!

**Uniting Unbreakable Spirits
OIF Regional Conference:
HOUSTON, TX**

NOVEMBER 12, 2016



**Texas Children's Hospital-
Pavilion for Women**

AMGEN

The OI Foundation thanks Amgen for the support of our family conferences program.



From the Information Center

In Memory: Dr. Leon Root

Former Medical Advisor to the OI Foundation, Dr. Leon Root, died in September, at age 86. Dr. Root spent his long career at the Hospital for Special Surgery where he established New York City's first clinic for children with osteogenesis imperfecta. A skilled orthopedic surgeon and teacher, he cared for many children and adults with OI and trained many young surgeons. Dr. Root was well known as a skilled surgeon and for his dedication to his patients. The OI Foundation is grateful for his service and for the legacy of excellent care for people with OI that he started at the Hospital for Special Surgery.

Respiratory Issues and Surgery

Breathing problems after surgery are often reported in adults and children who have OI. Being proactive before a planned surgery can prevent potentially serious post-surgical complications. People who have OI and asthma, recurrent pneumonia, scoliosis, chronic cough or difficulties with shortness of breath should include this information and a list of their pulmonary medicines when they talk to their surgeon and anesthesiologist. When possible, surgery should be deferred until at least 2 weeks after a cold or other respiratory flare-up. If a CPAP or BiPAP is used at home, it should be used in the recovery room. Information from their latest Pulmonary Function Test should also be made available to the anesthesiologist before surgery. Some pulmonologists suggest that when the patient is prone to pneumonia that it is helpful to start antibiotics before the procedure and continue for a while afterwards. Thank you to Dr. Hollis Chaney, Children's National Health System, Washington, DC, for this information.

Smart Hearing Aids

The September/October 2015 issue of the Hearing Loss Association of America's magazine contains an excellent article on the newest generation of hearing aids. Just like smartphones changed how people view telephones, the new smart hearing aids can make an enormous difference in the quality of life for people who need help hearing. To read the article go to www.hearingloss.org and click on the "Hearing Loss Magazine" tab.

Research Update: Recently Published Articles

The **"Initial Report of the Osteogenesis Imperfecta Adult Natural History Initiative"** has been published in *Orphanet Journal of Rare Diseases*. This article reports the results of the 2010-2011 survey of 900 adults. Many health concerns besides fractures were indicated. As expected, general physical health status was lower for adults with OI than the US adult average. Unexpectedly, a few things such as the occurrence of diabetes among adults with OI was reported to be similar to the occurrence seen in the general public. This study is already being used to guide new research studies, and as part of the Information for Medical Professionals on the OIF website. To read a summary of the study, go to the OI Foundation website www.oif.org, and click the "Research and Studies" tab.

Analysis of the data collected in the OI Linked Clinical Research Centers program has led to a recently published article on pregnancy. The article **"Cesarean Delivery is Not Associated with Decreased At-Birth Fracture Rates in Osteogenesis Imperfecta"** was published in October 2015 in the medical journal *Genetics in Medicine*. Based on information provided by 540 people with OI, the study found that at-birth fracture rates were similar whether delivery was by vaginal route or by cesarean delivery. The study results suggest that cesarean delivery should be performed for maternal or fetal indications and not for the sole purpose of fracture prevention. The indications that a cesarean section might be called for include in utero fracture, the mother's history of OI and a baby in the breech position.

Managing GERD

GERD (gastroesophageal reflux disease) is a common disorder in the general population and is also frequently reported in the OI community. GERD occurs when the lower esophageal sphincter is weak or relaxing inappropriately. This allows stomach contents to come back up into the esophagus. Heartburn and reflux are common GERD symptoms. Painful swallowing and hoarseness are also seen. The Centers for Disease Control and Prevention (CDC) suggests some life style changes to help manage the condition.

- Avoid Trigger Foods – fatty, spicy, or acidic foods, chocolate, and coffee.
- Eat Smaller Meals
- Don't Lie Down – stay upright for 3 hours after eating.
- Lose Weight if overweight or obese
- Don't Smoke
- Avoid Alcohol

Drug Label Warning

The US Food and Drug Administration (FDA) held hearings on adding stronger warnings to the labels on a group of drugs called fluoroquinolones. These drugs are used to treat serious bacterial infections. The FDA's concern is that these drugs may be over prescribed and that serious side effects including tendinitis, tendon rupture and peripheral neuropathy occur more often than previously believed. These side effects may be a problem for people who have OI because they have a higher risk for tendon injury and neuropathy. The fluoroquinolones currently available in the United States include ciprofloxacin (Cipro[®], Proquin[®]), gemifloxacin (Factive[®]), levofloxacin (Levaquin[®]). The FDA suggests that at this time, whenever these drugs are suggested, that patients talk to their doctor so that potential side effects are taken under consideration in prescribing one of the medications. Thank you to Dr. Jay Shapiro for assistance with this information.

Book Review

OI Community member Christinah Curtis has written a memoir entitled **“Twisted Physician’s Assistant in Spaceship Earth: Rescue Mission in the Space-Time Continuum.”** She refers to herself throughout the book by the name Jobah and describes herself as a modern-day, female Job. This book is elegantly written, and presents an interesting window on her life, philosophy, and spirituality. The book abounds in Judeo-Christian references and quotes from writers such as Buckminster Fuller, Werner Von Braun, Victor Frankl and James Madison. Christinah (Jobah) never let OI define her. Rather she presents it as one facet of her being; one that gives her a unique perspective on life and history. As she writes, “We come into this earth naked; we go out that way. Over a lifetime, learning how to negotiate time and space, we can experience every detail of our life either as miracle events or believe we are just worm food!” The book was published by Westbow Press a division of Zondervan Publishing Company. You can read a review at: <http://authorwebservices-gem.net/WestBowPress/700151/> or purchase it in hardback, softback or e-book also at Amazon.com, or Barnes and Noble.



Organize a Blue Jeans for Better Bones during OI Awareness Week!

National OI Awareness Week 2016 begins on Saturday, April 30th and will conclude on Saturday, May 7th! As part of Awareness Week, the OI Foundation is asking you—members and supporters of the OI Community—to join us in raising awareness about osteogenesis imperfecta by hosting a Blue Jeans for Better Bones with your personal network.

Choose one day (or more) during OI Awareness week to show your support for the OI community with your family, friends or colleagues by wearing jeans and some OI Foundation “Flair”. Yes, we have “flair” and we’re not afraid to share! Through the OIF Online Store you can order Blue Jeans for Better Bones Stickers, OI Awareness Wristband or even OI Foundation shades for your Blue Jeans for Better Bones participants to sport during OI Awareness Week. For more information visit the Blue Jeans for Better Bones page on the OI Foundation Website at www.oif.org/BJBB and click “Host a Blue Jeans for Better Bones Day.”



National OI Awareness Week 2016 is April 30th – May 7th!

Scheduled around Wishbone Day, an international OI Awareness Day, National Osteogenesis Imperfecta Awareness Week 2016 will take place April 30 – May 7. Wishbone Day, represented by the color yellow, invites all communities to contribute to this worldwide community awareness effort on May 6th each year. Each year during OI Awareness Week, we encourage the OI community, Foundation and constituents to use fundraising events, social media and individual state proclamations to raise awareness for osteogenesis imperfecta.

Proclaim OI Awareness Week in your state. It'll only take a minute! Help us proclaim National OI Awareness Week in every state! Contact Danielle at dcyber@oif.org for more information about requesting a proclamation in your state.

Lead a Blue Jeans for Better Bones Day. Blue Jeans for Better Bones is a fun and easy way to raise awareness for OI in your community. Hold your BJBB Day on Wishbone Day (a National Blue Jeans for Better Bones Day) – Friday, May 6, 2016. For more information, visit www.oif.org/bjbb.

#SHAREforAWARENESS Keep an eye out for #SHAREforAWARENESS posts on the OI Foundation's social media pages leading up to and during National OI Awareness Week. Help us raise awareness online by "sharing" or "retweeting"!

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

Join Fellow Members of the OI Community at an Upcoming Event

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

March

Renew your OIF membership at www.oif.org/membership

March 12th Tampa OI Support Group Meeting – Tampa, FL

April

April 9th Bone China Tea – Anywhere!

May

April 30th-May 7th National OI Awareness Week

May 6th Wishbone Day and National Blue Jeans for Better Bones Day

May 7th Connecticut and Western Massachusetts OI Support Group Meeting – Hamden, CT

May 7th 5th Annual Unbreakable Spirit Walk-n-Wheel – Buzzards Bay, MA

May 21st Strong Bones Gala: Orlando – Orlando, FL
Beaumont OI Support Group Meeting – Beaumont, TX

June

June 18th South Shore OI Support Group Meeting – Weymouth, MA

June 19th 5th Annual Carnival for OI – Coplay, PA

July

July 21st National Unbreakable Spirit® Walk-n-Wheel – Orlando, FL

July 22nd – 24th OIF National Conference – Orlando, FL

August

August 15th OI Golf Classic – Atkinson, NH

New events are being added all the time. Visit the events calendar at www.oif.org for up to the date details.



Participants in the 2015 Unbreakable Spirit® Walk-n-Wheel in Buzzards Bay, MA, are looking forward to the 2016 event.

Are you interested in holding awareness or fundraising events for the OI Foundation?
Contact events@oif.org for more information today!



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