

Countdown to the 2014 OIF National Conference!



Unbreakable Spirit®

2014 OI Foundation National Conference

August 1-3, 2014 • JW Marriott • Indianapolis, IN

The 2014 OIF National Conference is coming up fast! In less than three months, on August 1-3, the OI community will gather at the JW Marriott in Indianapolis for three days of informational sessions, social activities and awareness events!

Here is important information you should know as we get closer to the conference:

Hotel Reservations and Conference Registration

The last day to receive the discounted \$149 room rate at the JW Marriott is July 1st! Book your hotel room today at: <https://resweb.passkey.com/go/OIF2014> Be sure to register for the conference before June 30th. After June 30th, registrations must be made on-site at higher rate. Register online at www.oif.org/conference

Parking at the Conference Hotel

Conference attendees may park at the JW Marriott for \$20 per night. There are also several public parking garages located near the hotel, ranging in price from \$10-\$22 per day—the \$10 per night garage is only .1 miles away from the hotel! Please visit www.oif.org/conference for more information about parking.

Talent Show is Coming to the 2014 OIF National Conference!

The Talent Show is back for the 2014 OIF National Conference. If you have a special talent, you would like to share, please sign up! Applications will be available on the OIF conference website,

in the e-news, and shared through conference emails and Facebook. You must sign-up in order to participate, the sign-up form can be downloaded at www.oif.org/conference. There is no age limit, but is only available to conference-registered attendees. All acts should be no longer than two minutes. The Talent Show will take place Friday, August 1 at 7pm, with a rehearsal prior to the show. Please contact Susie Richard at susierichard71@gmail.com if you have any questions.

OI YEP (Young, Empowered, and Proud) Youth & Young Adult Forum – Register Now!

At this summer's National Conference, the OI Foundation will be gathering approximately 50 young adults to participate in the OI YEP (Young, Empowered, and Proud) Youth & Young Adult Forum. The Youth Forum will offer a unique experience for participants, equipping them with information, ideas, and skills to apply to life after high school. Discussions at the OI YEP Forum will be interactive and youth led, and will include topics of Claiming your Own Identity, Living Independently and Relationships.

Sign up NOW to participate in the OI YEP Forum, taking place on **Friday, August 1st** before the Opening Session of National Conference. There is no cost to attend the forum and lunch will be on your own. For more details and registration information, visit www.oif.org/conference. If you have questions, please email Bonelink@oif.org

Women's Forum at OIF National Conference

The Women's Forum, one of our pre-conference forums, will be held on Friday, August 1, from 9:30am – 3pm. Space is limited so make sure you sign up while spots are still available. The cost to attend is \$45. The Women's Forum is for women with OI, ages 18 and older, prior to the start of the OIF National Conference in Indianapolis. Dr. Emily Germain-Lee, an endocrinologist, and Dr. Deborah Krakow, an OB/GYN, will speak on the medical side of women with OI. The rest of the Forum will include panelists and speakers on a variety of topics, including women's health, pathways to parenthood, and creating a positive self-image. Visit www.oif.org/conference for additional information and how to register.

From the Information Center

Say Cheese! OIF National Conference Video and Photography

At this summer's OIF National Conference, two new features will capture the Unbreakable Spirit® of speakers, and participants! Adam Sanders, a recent college graduate who studied film, will join the OI Foundation conference team to document parts of the conference through film and photography. Several of the sessions, with permission from the speakers, will be filmed. Adding these videos to the OIF website will make this information accessible to those who are unable to attend the Indianapolis conference. Adam will also be taking posed pictures of conference attendees. The conference "Photo Booth" will be a fun way to strike a pose with old friends, new friends, family, or even by yourself! With permission, these photos will be used to illustrate OIF publications and sections of the OIF website. Your photo from the booth could be featured on the homepage of www.oif.org, or on a new brochure or fact sheet! More details will be available later this summer so keep checking the OIF website conference pages, the OIF E-News and the OIF Official Facebook Page!

Get Active! Shaping Up for Summertime

When warm weather hits, schedules can start to fill up pretty quickly. Summer camps, gardening, family cookouts, the OIF National Conference and the National Walk-N-Wheel are only a few of the possible activities. No matter what your plans, **now** is the time to get active and in shape! Remember that starting with small steps will make a difference on your journey towards a healthier lifestyle year-round. Here are a few suggestions to start planning for and living a healthier lifestyle this summer:

1. Talk to your doctor if you want to try a totally new activity.
2. Plan ahead for summer time safety, especially getting in and out of swimming pools.
3. Listen to your body. Start slow and don't rush or overdo it. If you are a wheelchair user or spend most of the time sitting, watch the Hospital for Special Surgery's video on Wheelchair Based Exercises for People with OI (http://www.hss.edu/conditions_wheelchair-based-exercises-osteogenesis-imperfecta.asp).
4. Keep fun on your agenda.

New Resource for the Accessible Housing Market

A new tool is available for those who may be entering the housing market soon. Many families face the dilemma of looking for barrier free housing. AccessibleProperties.net is a new database that lists wheelchair accessible properties in many states across the US. Their website also features a page of home renovation and equipment related links under the "Buyers Guide." Learn more by visiting www.accessibleproperties.net.

Join the Movement at the National Unbreakable Spirit® Walk-n-Wheel in Indianapolis

To kick-off our National Conference weekend, the OI community will come together for the **National Unbreakable Spirit® Walk-n-Wheel** on Thursday, July 31st! Beginning at the JW Marriott Hotel, participants will walk or wheel one of Indianapolis' most beautiful landmarks, the Canal Walk of White River State Park. You can walk or wheel individually; form a team with your family, friends or support group members; volunteer; become a supporting sponsor; or show up to cheer on the sidelines.

Signing up is as easy as 1-2-3

- 1 - Go to www.oif.org/WalkAndWheelIndy to either register as an individual, start a new team or join an existing team and follow the prompts to register yourself as a walker. Sign up as a Team Captain and recruit everyone you know, come up with a fun name, and motivate each other. Teams that raise more than \$500 collectively will be given a sign to walk under with their team name and everyone who raises \$25 or more will receive an official OIF National Walk t-shirt!
- 2 - Once you have registered, you will be taken to your personal walk page. We've written a little bit to get you started, but you should take a moment to personalize your page with a picture of yourself and a greeting that explains how osteogenesis imperfecta has affected you.
- 3 - The only thing left to do is to send out emails to all your family and friends to invite them to walk with you and/or support you with a donation. We've written a few emails to get you started, but your friends and family want to hear from you, so we encourage you to personalize your emails as well. You can even share your page on Facebook and Twitter.

Help us take Indianapolis by storm and share your Unbreakable Spirit®!



Medical Consultation Day at the National Conference

The medical consultation program offers people who are registered for the national conference the opportunity to meet one-on-one with a doctor or physical therapist who has experience with OI. This is an excellent opportunity to have a question answered. You can bring along digital x-rays or copies of reports. It is important to note that physical examinations cannot be given. Appointments are currently being accepted for Friday August 1. Requests will be taken until the end of July. If all appointment slots are filled, your name will be put on a waiting list.

It's easy to request an appointment.

1. Print the Request Form (available on www.oif.org/conference) and fax the completed form to the OIF office at 301-947-0456.
2. Copy and email the completed form to Bonlink@oif.org
3. Or, call the OI Foundation office at 301-947-0083 and be prepared to answer the questions on the Request Form.

Who are the Doctors?

Each doctor is an expert in his or her area, and has extensive OI experience. The specialists who are confirmed for this day are:

ADULT HEALTH

Dr. Jay Shapiro

Director of the Bone and Osteogenesis Imperfecta Department, Kennedy Krieger Institute, Baltimore, MD

DENTAL

Dr. James Hartsfield, Jr.

University of Kentucky College of Dentistry and Medicine, Lexington, KY

GENETICS

Dr. Michael Bober

Co-Director, Skeletal Dysplasia Program, A.I. duPont Hospital for Children, Wilmington, DE

Dr. Peter Byers

Genetic Medicine Clinic, University of Washington Medical Center, Seattle, WA

Dr. Joan Marini

Chief, Bone and Extracellular Matrix Branch, National Institute of Child Health & Human Development (NICHD), National Institutes of Health, Bethesda, MD

Dr. Eric Rush

Co-Director, OI Clinic at Children's Hospital and Medical Center, Omaha, NE

HEARING

Dr. David Vernick

Harvard Medical School & Massachusetts Eye and Ear Infirmary, Boston, MA

ORTHOPEDICS

Dr. Peter Smith

Director, OI Clinic Shriners Hospital for Children, Chicago, IL

Dr. Francois Fassier

Canadian Shriners Hospitals for Children, Montreal, Quebec

Dr. Paul Esposito

Co-Director, OI Clinic at Children's Hospital and Medical Center, Omaha, NE

Dr. Kosmas Kayes

Peyton Manning Children's Hospital at St. Vincent's, Indianapolis, IN

Dr. Richard Kruse

Co-Director Skeletal Dysplasia Program A.I. duPont Hospital for Children, Wilmington, DE

PHYSICAL THERAPY

Tim Caruso, PT

Shriners Hospital for Children, Chicago, IL

WOMEN'S HEALTH

Dr. Deborah Krakow

UCLA, David Geffen School of Medicine, Los Angeles, CA

Thank You, Congressman Ruppertsberger (D-MD)!



Congressman Dutch Ruppertsberger (D-MD) has introduced a congressional resolution, H.RES.513, in the U.S. House of Representatives recognizing May 3-10 as National OI Awareness Week 2014! The OI Foundation is very excited that the House of Representatives has chosen to show support for OI awareness. We want to give a huge thank you to Congressman Ruppertsberger for all of his hard work getting this Resolution passed!

Thank you for your support and participation during National OI Awareness Week 2014: Share your Unbreakable Spirit®!

During the week of May 3-10, the OI Foundation, volunteers and supporters raised awareness for osteogenesis imperfecta by "Sharing their Unbreakable Spirit®," the theme for National OI Awareness Week 2014. Each year, National OI Awareness Week is dedicated to strengthening and expanding the OI community. As one community with one goal, we can educate others and raise awareness of osteogenesis imperfecta and our mission.

To say Awareness Week 2014 was a success feels like an understatement. We proclaimed National OI Awareness Week 2014 in 13 states, received a National OI Awareness Week Resolution from the House of Representatives, educated over 2,000 participants at OI awareness raising events, displayed over 400 Awareness Week posters and reached **OVER 300,500 people** through social media!

The week kicked off on Saturday, May 3rd with the Unbreakable Spirit® Barbeque in Granger, IA; the Unbreakable Spirit® Walk for OI in Buzzards Bay, MA; the Unbreakable Spirit® Walk-n-Wheel in Nashville, TN, which was attended by nearly 100 people; a Proclamation Presentation at the ABQ Biopark Zoo in Albuquerque, NM; and Girard Park OI Awareness Event in Lafayette, LA.

The awareness continued on Sunday, May 4th with the 10th Annual Walk for OI in Framingham, MA, where OIF CEO, Tracy Hart, presented event coordinator, Christine Rossi, with the Thelma Clack Lifetime Volunteer Award in front of the family's heroes – all those who helped year after year to make the event a success.

Wishbone day, the international day for OI Awareness was May 6th. Thousands of friends and family of OIers across the globe wore the color yellow to show their support for osteogenesis imperfecta. Many people asked their network of Facebook friends to wear yellow, change their profile pictures and tag their friends on Facebook which resulted in turning newsfeeds yellow for the day. Picnics and Wishbone Day get togethers were held from Florida to Washington bringing together the OI community for mutual support.

On May 8th, Tracy Hart, Melissa Bonardi and Jessica Finkel joined Greg Fehrbach in Indianapolis to host a kick-off luncheon for area corporate leaders to learn about the OI Foundation's upcoming National Conference and National Unbreakable Spirit® Walk-n-Wheel. They were joined by former OIF Board President, Ken Finkel along with former Indianapolis Mayor,



2nd Annual Wishbone Day Picnic in Washington State



Attendees of the Central Texas Walk-n-Roll in Round Rock TX



Attendees of the Unbreakable Spirit Walk n Wheel in Nashville TN



Attendees at the Unbreakable Spirit Walk n Wheel in Buzzards Bay



Christine and John Rossi along with their sons Jack and Hugo at the 10th Annual MA Walk for OI

Bart Peterson; members of the Indiana Pacers and Indians organizations; Dr. Linda Dimeglio from Riley's Hospital as well as representatives from Indiana's Health & Hospital Corporation, Eskenazi Health and St. Vincent's Hospital; and many more. Over three dozen people who had perhaps never heard of osteogenesis imperfecta, left the luncheon held at Harry & Izzy's in downtown Indianapolis with a new awareness of this rare disorder and the Unbreakable Spirit® that the members of the OI community who will be coming to town in 2 short months possess.

Several members of the OI community educated their offices and school about OI by asking co-workers and friends to wear blue jeans to work or school on May 9th for National Blue Jeans for Better Bones day. Also on May 9th, The Last Break Foundation hosted a Dance for Better Bones at the Olde Jailhouse Tavern in Orleans, MA. Over 150 attendees enjoyed desserts, a silent auction and night full of dancing to live music by The Grab Brothers as they raised \$3,500 for OI research.

National OI Awareness Week 2014 came to an end on Saturday, May 10th with a bang – including the Unbreakable Spirit Walk for OI in Uhrichsville, OH, the Wishbone 5K, Fun Run and Tot Trot in Martin, TN; and the Central Texas Walk-n-Roll where close to 50 members of the OI community gathered at the Play for All Abilities Park in Round Rock, TX. Event coordinator, Debbie Wiederhold was delighted at how many new families came out to attend her walk in its 7th year.

We set a goal to reach 100,000 people through social media from February 1st to May 10th and we certainly succeeded! By mid-April the OI Community had reached over 105,000 people with our [SHAREforAWARENESS] Facebook posts and tweets. With the help of the OI community's Facebook "shares" and Twitter "retweets", the [SHAREforAWARENESS] posts reached over triple our original goal! In addition, representatives from Colorado, Connecticut, Indiana, Lawrence County, OH, Maryland, Missouri, Nevada, New Mexico, Pennsylvania, Rochester, NY, and Washington, DC, proclaimed May 3-10, 2014 as National OI Awareness Week in their state. We also received an OI Awareness Week resolution from the House of Representatives. It is an honor to be recognized by so many people nationwide.

Please help us continue to raise awareness for osteogenesis imperfecta year-round! Holding an event, posting on social media and educating others can be done at any time!

2014 OIF Scientific Meeting



Dr. Richard Kruse and Dr. Paul Esposito connect at the 2014 OIF Science Meeting

The Osteogenesis Imperfecta Foundation held the 14th OIF Scientific Meeting in Chicago, Illinois. The meeting titled, "New Treatments for Osteogenesis Imperfecta," was chaired by Dr. Frank Rauch of Shriners

Hospitals for Children, Montreal. Dr. Rauch serves on the OI Foundation's Medical Advisory Council. Dr. Rauch began the meeting by reminding attendees that treatment of OI lies in many domains including providing the right medication, using surgical interventions and providing the person with OI with the most appropriate rehabilitation. He noted that, from a clinical perspective, scientists and physicians need to convert new basic information into improved therapeutic approaches.

The meeting included presentations by leading scientists from the United States, Canada and the United Kingdom. Presenters provided an update on bone drugs currently used to treat OI drugs that are emerging and potential drugs on the horizon. Another section of the meeting examined existing and new surgical treatments for both children and adults with OI. Techniques for minimizing complications and for solving difficult surgical questions such as severely bowed arms, scoliosis and elbow or shoulder fractures were discussed. The last section presented information on the new technologies that are being applied to rehabilitation. These technologies have great potential for increasing mobility in people with OI of all ages. An interesting theme arising across the presentations was the increased awareness that many factors can affect how a person will respond to a specific drug or rehabilitation treatment. These include age, sex and OI Type. Learning more about these variables will be important for future research.

The OI Foundation's website links to the abstracts of each presentation. The abstracts of the Young Investigator Poster Session are also included. This year five young investigators were invited to the meeting. Their presentations covered research on pain in OI; vibration and resistive exercises in Type I OI; and a mouse model that examines the sclerostin antibody. The OI Foundation continues to be committed to finding new scientists passionate about finding new treatments for people living with OI. The OI Foundation thanks the Buchbinder Family Foundation for their continued and generous support of this important meeting.

Highlights from the Baltimore Clinical Care Conference

The 5th Clinical Care Meeting on osteogenesis imperfecta was held November 6-8, 2013 in Baltimore, MD. Chaired by Dr. Jay Shapiro from the Kennedy Krieger Institute and sponsored by the OI Foundation and the Charitable Research Foundation, the meeting brought together a group of physicians who are experienced in caring for people who have OI. The meeting had three major goals – to identify useful information that is emerging from basic and clinical research, to make that information easily available to medical practitioners and to identify areas in clinical care that need to be studied.

Abstracts that summarize each speaker's presentation have been published in the March 2014 on-line medical journal, **Journal of Musculoskeletal and Neuronal Interactions**. A link to this document can be found on the OI Foundation website on the Research Update page under the Research Page.

The presentations covered a wide variety of clinical topics connected to the diagnosis, treatment and management of OI in children and adults. The large number of topics reflects the growing awareness that OI is a complex disorder that affects many parts of the body besides the skeleton. A summary of main ideas follows.

Gene Therapy – Stem cell therapy is a potential treatment for OI. While progress has been made in the technology in the lab, data is lacking on how to effectively deliver the new cells into the person who has OI.

Dental Care – The effect of OI on teeth goes beyond dentinogenesis imperfecta and includes problems with growth of the face, head, and jaw. People with moderate and severe OI tend to have more serious issues in this area. In some cases both orthodontia and orthognathic surgery may be necessary.

Pregnancy – Many women who have OI including those with short stature have experienced successful pregnancies, but the normal physiologic changes of pregnancy can lead to pulmonary and skeletal problems for some women who have OI. Pregnancy can pose a high degree of risk for women with any cardiac dysfunction.

Hearing Loss – OI related changes to type I collagen lead to changes in the structures of the inner ear. Hearing tests should begin during school years. Bone anchored hearing aides are not beneficial but cochlear implants with modifications are a viable option.

Eye Related Care – People with OI frequently experience common vision problems such as nearsightedness. OI also increases the fragility of the tissues of the eye; may increase the odds of developing glaucoma and retinal tears; and makes treatment for these complicated problems more difficult.

Gastrointestinal Issues – For many people, OI is accompanied by gastrointestinal symptoms that include

constipation and abdominal pain. In the absence of clear data, care is primarily supportive. Research is needed into causes, role of OI type, and response to treatments in children and adults.

The Skin – Alterations in the quantity and quality of type I collagen causes skin thinness, a tendency to form scars and other problems. Current treatment focuses on gentle skin care, and sun protection.

Pulmonary Concerns – Two elements (abnormal chest wall shape and altered lung tissue) combine to increase the risk for serious breathing problems for people who have OI. Short stature, scoliosis, and long bone deformities increase the difficulty of diagnosis and treatment of breathing problems.

Heart Disease – Cardiovascular diseases among people with OI is increasingly recognized as life-threatening and treatable. The exact prevalence is unknown, but valve diseases, aortic disease and arterial dissection have been identified, as well as related conditions such as hypertension (high blood pressure). When surgery is needed, seeking treatment at specialized centers with experience in surgery and physical rehabilitation for people with connective tissue disorders will reduce the potential for complications.

Basilar Invagination – Basilar impression, cranial settling and basilar invagination are three different problems that are seen in people who have OI. Deformity of the cervical spine and compression of the brainstem from these conditions can lead to symptoms that may become life threatening. At this time, surgical intervention is difficult.

Orthopedic Problems and Treatments – A series of presentations were given on specific orthopedic issues. There have been steady advances in the treatment of long bone deformities in children with OI. The use of medical therapies (drugs) improves the bone but does not provide normal bone density and function. Indications for surgery include frequent fractures (despite optimum medical treatment) and severe bowing. The age of the child, size of the bone and degree of bowing are factors in the selection of IM rod. Surgery to correct bowing of the humerus often improves comfort and the child's ability to use the arm. Spinal deformities are frequent in OI and the prevalence of scoliosis is much higher in OI than in the general population. Scoliosis in children with Type III and IV OI gets worse much quicker than in children with Type I OI. Joint replacement especially of the knee and hip are increasingly considered for adults who have OI. Poor bone quality, small size, the presence of rods in adjacent long bones, and fracture history are factors that complicate these surgeries. Ligament laxity has serious implications for the long-term stability of the joint replacement. Complications related to all orthopedic surgeries are common and should be discussed with the surgeon prior to deciding on a treatment.

Rehabilitation and Physical Activity – Rehabilitation plays a crucial role in promoting health and well-being for the person who has OI. At every stage of life, carefully designed programs for physical activity can help prevent obesity, improve mobility, aerobic fitness and independence as well as reduce pain. Weight-gain in teens and adults is a significant cause of mobility loss.

Bisphosphonate Treatment – A series of talks were given on this topic. Treatment with intravenous bisphosphonate has had a beneficial effect in many OI children; decreasing fractures and pain, and increasing mobility. A comparison of two bisphosphonates – pamidronate and zoledronic acid—found similar effects on fracture incidence. Oral bisphosphonate drugs do not appear to be consistently effective in children. Not all children continue to respond to bisphosphonate therapy as they enter adulthood.

OIF's Toll-Free Telephone Number

The OI Foundation's 800 Toll-Free telephone number is unavailable. If you need to contact the office, please call 301-947-0083 or email bonelink@oif.org.

Meeting Note from OIF Chief Executive Officer Tracy Hart...

On April 24 and 25 OIF Chief Executive Officer Tracy Hart attended the World Orphan Drug Congress in Washington, DC. The meeting brought together industry, government, payers and patient advocacy organizations to talk about the most pressing issues including current legislation affecting the timeline for bringing new pharmaceutical treatments to the public. Drug companies that focus primarily on rare diseases presented data on the progress of their clinical trials and industry forerunners talked about the future of rare disease research. More than 700 people attended the meeting from all over the world. According to Tracy, "Having OIF represented at these meetings and talking with pharmaceutical companies about our needs keeps OI in the conversation when companies are talking about new drug interventions for other rare diseases."

Book Review

Author Barbara Taylor: Raising Awareness and Donating Book Proceeds

The OI Foundation is grateful to author Barbara J. Taylor for her efforts to raise awareness about OI and support the work of the OIF. She has not only posted information about OI on her website but also is donating 5% of her proceeds from the book to the OI Foundation. As the aunt of a young man who has OI she is part of a family that experienced the physical, emotional and financial challenges that come with fragile bones. On her website, Ms. Taylor reports that 30 years after his diagnosis, her nephew is a college graduate who has a career repairing radar systems for the US military. She states "I look at the man he has become, and I marvel at how he faces life with such courage, compassion and joy."

Ms. Taylor's new book, **Sing in the Morning, Cry at Night**, has been identified as one of the best summer books of 2014 by Publishers Weekly. The OI Foundation is delighted to bring this book to your attention.

Review: *Sing in the Morning, Cry at Night*

Inspired by a real life incident, author Barbara Taylor combines fact and fiction to tell a touching story of a family facing the

aftermath of a tragic accident. The novel is set place in Scranton, PA in the early 1900's. The main story revolves around the Morgan family and their response to the unexpected death of 9 year old Daisy. Each parent and the surviving sister, Violet, must face their grief and guilt. This well written book is peopled with characters the reader can really care about and captures the feeling of a gritty 20th century coal mining community. Here are people of different nationalities and backgrounds who live in a time of social change, economic hardship and dangerous working conditions. There are people who are genuinely helpful, others who are mean spirited gossips, and still others who struggle to find their place. How the Morgan family and others in their community cope with the uncertainties and trials of life; how they help each other; and where they look for love and hope touches on timeless issues.

Sing in the Morning, Cry at Night will be released on July 1, 2014 and available online through Barnes & Noble, Amazon, Akashic Books and Indie Bound. For more information please see the author's website, www.barbarajtaylor.com.

Research to Follow

Behavior of Scoliosis during Growth in Children with OI

Scoliosis is a common spinal deformity seen in children who have OI. It causes the person's spine to become curved from side to side. Curves tend to increase over time. Progressive curves that endanger the child's function and health often require surgery. In February of this year, the **Journal of Bone and Joint Surgery** published an interesting study about scoliosis and the growing OI child. The study was conducted by Dr. Peter Smith, Dr. Kim Hammerberg and their team at the Shriners Hospital for Children in Chicago. The goal of the study was to establish the relationship on the progression of scoliosis between OI severity, the child's age and the child's history of treatment with bisphosphonate.



The research team reviewed the records of 316 children with an OI diagnosis who were seen during multiple clinic visits throughout growth over a thirty year period. OI severity was listed using the modified Sillence classification and there were sufficient numbers to evaluate Type I (Mild) Type IV (Moderate) and Type III (Severe) as distinct subgroups.

They found that over-all 50% of the children were diagnosed with scoliosis, a curvature of the spine greater than ten degrees. This is much higher than the prevalence seen in the general population. In this study, the type of OI significantly affected how many children had scoliosis and how rapidly the curve got worse. The high rates of progression seen in children with OI Type III and Type IV contrasted with the milder course seen in children with OI Type I.

- 68% of those with OI Type III developed scoliosis with a progression rate of 6 degrees per year.
- 54% of those with OI Type IV developed scoliosis with a progression rate of 4 degrees per year.
- 39% of those with OI Type I developed scoliosis with a progression rate of 1 degree per year.

Early treatment with bisphosphonates, beginning before age 6, slowed down the rate of curve progression by 3.8% but only for children with OI Type III. This is considered a significant change. No evidence was found that bisphosphonate treatment changed curve behavior in other types of OI or when the treatment started at an older age.

This study did not look at three other factors that are known to affect the development and progression of scoliosis – ligament laxity, muscle weakness and vertebral fractures. Since ligament laxity and muscle weakness are not affected by bisphosphonate treatment understanding their role in curve progression will further clarify the behavior of scoliosis in the growing child.

Reference: Behavior of Scoliosis during Growth in Children with Osteogenesis Imperfecta. *Journal of Bone and Joint Surgery*. February 5, 2014.

Osteogenesis Imperfecta Foundation Membership Program

Become a new member, or renew your membership today!

Members are the lifeline of the Osteogenesis Imperfecta Foundation. We count on your support to help fund research, provide information and support, develop new resources, expand support groups and increase public and professional awareness about this disorder that affects 50,000 people



In 2012 the OI Foundation set a goal to raise \$10 million through our **50,000 Lives, One Unbreakable Spirit®** campaign to improve the lives of people living with OI. We can do it, but we need your help!

Your membership to the OI Foundation will:

- Accelerate the pace of OI Research through scientific and clinical meetings, increased advocacy for funding from Capitol Hill and new young investigator grants.
- Provide medically verified information about OI to professionals, parents, caregivers and people living with OI.
- Provide opportunities for people with OI to connect through the OIF website, social networking sites and at the OIF National Conference.

Membership Levels and Benefits:

All members receive:

- A membership card
- Voting privileges in our annual board member elections
- An OI Foundation lapel pin

Membership Levels

- Friend (\$36/year, just \$3 per month)
- Family (\$60/year, just \$5 per month)

Professional Member (\$100/year)

Healthcare professionals will receive recognition in the OIF Annual Report; a subscription to Breakthrough and first access to the latest published scientific research and materials; Invitations to local area events including scientific meetings and professional meetings.

Unbreakable Spirit® Member (\$120/year, just \$10 per month)

You will receive recognition in the OIF Annual Report along with early bird pre-registration for our most popular events that sell out quickly such as Medical Consultations or Women's Forum at the OIF National Conference.

Corporate Member (\$1,000/year)

Your OI Clinic or healthcare organization will receive: recognition in the OIF Annual Report along with logo placement on the OIF website; a subscription and half-page ad in Breakthrough; invitations to local area events; Priority as an exhibitor and recognition at the OIF National Conference on all conference materials as well as the opportunity to include one promotional item or flyer in the gift bag and an invitation to Professional Series at the OIF National Conference.



**To become a new member or renew your membership,
please visit www.oif.org/membership**

50,000 Lives, One Unbreakable Spirit®

Information Sessions at the OI Foundation National Conference

The program for this summer's national conference will cover a wide range of topics. An All-Star line-up of speakers has been asked to direct their remarks to specific audiences – the Type I OI Community, Adults who have OI, Young Adults (college students and above) who have OI, and Parents of Children who have a diagnosis of moderate or severe OI. This “tracking” will not prevent anyone from attending a session on a topic of interest, but it is our hope that the system will help attendees make their selections.

Friday, August 1, the Pre-Conference Day, features several different programs. Pre-registration is required to attend the Women's Forum or the Youth Forum. The free medical consultation program is open to **everyone who is registered** for the conference. A list of the doctors is provided on the OIF website and elsewhere in this newsletter. Early Friday afternoon, two bonus sessions will be offered. One session will be on raising awareness about OI. This session will be of interest to anyone who is thinking about holding an event, giving an interview or speaking about OI in their community. The second session is titled “Introduction to OI.” This session will be particularly useful to people who have a family member with a new diagnosis, or who have not attended a national conference before. The conference officially opens at 4pm with a general session that will be of interest to all.

Sessions on Saturday, August 2 will present medical and research information, while Sunday sessions focus on life skills. The following medical professionals are confirmed speakers.

Michael Bober, MD, PhD

A.I. duPont hospital for Children, Wilmington, DE

Peter Byers, MD

University of Washington, Seattle, WA

Tim Caruso, PT

Chicago Shriners Hospitals for Children, Chicago, IL

Linda DiMeglio, MD

Riley Hospital for Children, Indianapolis, IN

Maureen Donohoe, PT

A.I. duPont Hospital for Children, Wilmington, DE

Paul Esposito, MD

Children's Hospital and Medical Center, Omaha, NE

Francois Fassier, MD

Canadian Shriners Hospitals for Children, Montreal, Quebec

Francis Glorieux, OC, MD, PhD

Canadian Shriners Hospitals for Children, Montreal, Quebec

James Hartsfield, Jr., DMD, PhD

University of Kentucky, Lexington KY

Kosmas Kayes, MD

Peyton Manning Children's Hospital/St. Vincent's, Indianapolis

Deborah Krakow, MD

UCLA, Los Angeles, CA

Richard Kruse, DO

A.I. duPont Hospital for Children, Wilmington, DE

Brendan Lee MD, PhD

Baylor College of Medicine, Houston, TX

Joan Marini MD, PhD

National Institutes of Health, Bethesda, MD

Cathleen Raggio, MD

Hospital for Special Surgery, New York City, NY

Eric Rush, MD

Children's Hospital and Medical Center, Omaha, NE

Robert Sandhaus, MD, PhD

University of CO School of Medicine, Denver, CO

Jay Shapiro, MD

Kennedy Krieger Institute, Baltimore, MD

Peter Smith, MD

Chicago Shriners Hospitals for Children, Chicago, IL

Laura Tosi, MD

Children's National Medical Center, Washington, DC

David Vernick, MD

Harvard Medical School, Boston, MA

Other speakers will include the following members of the OI Community.

Victoria Assumma, Kara and Adam Ayers, Mary Alice Birdwhistell, Mark Birdwhistell, Karen Braitmayer, Jody and Vance Cheek, Michelle Duprey, Daniel Ferreira, Greg Fehribach, Ann & Ken Finkel, Jamie Kendall, Amy Lee, Cameron Penn, Christine Rossi, Sharon & Ted Trahan

Special programming has been arranged for young people age 9 and above **who are registered for the conference**. As in past years, the Teen Center will be open all day Saturday and Sunday. Teens, age 13 and above will have a space of their own. The Strauch family will be this year's lead chaperones. They are planning several days of fun and information. A list of the discussion sessions especially for Teens will be in the conference program book and posted on the OIF website in July.

New this year, will be a Pre-Teen Center for young people age 9-12. Led by chief chaperone, Suzanne Richard, this center will offer a place for this age group to meet each other, participate in crafts and other activities and hear several speakers. The Pre-Teen Center will be open on Saturday and Sunday. Parental sign-in/sign-out will be required. If you would like to volunteer to be a part-time chaperone in either of these Centers, please contact Mary Beth Huber at the OI Foundation National Office (301-947-0083 or mhuber@oif.org).

A few sessions were not confirmed by the deadline for this newsletter. To see the latest information be sure to check the complete list of sessions and speakers on the OIF website.



Ken Gudek at the 2013 OI Golf Classic in Atkinson, NH



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



Golfers heading out for a day at Belmont Country Club for the Birdies and Bogies Golf Outing

Spotlight: Tee Up For The OI Foundation This Summer

As the summer finally approaches we have so much to look forward to including the OIF National Conference on OI and the National Unbreakable Spirit® Walk-n-Wheel, but amidst all that hustle and bustle, many members of the OI community just want to get out and enjoy a relaxing game of golf. If you are one of them, you should consider attending one of the several fundraising golf outings we have scheduled this year:

May 31st – Maggie Shae's Grandpa was very devoted to finding a cure for her osteogenesis imperfecta, and hopeful and optimistic that one day a cure will be found for all who live with it. At the **2nd Annual Grandpa's Gift Golf Outing**, you can help Grandpa Tom's generous spirit and great, big heart live on to continue this mission. This family-oriented event will be taking place at The Village Links of Glen Ellyn Golf Course in Glen Ellyn, IL. The Sheridan and Gottman families' day of fun will begin with a 9-hole golf tournament featuring skills contests and prizes. The indoor/outdoor after party includes a raffle, silent auction, kids' activities, music, food/drinks & fun for all! To register to golf or just attend the post-golf reception, visit: www.oif.org/GrandpasGiftGolf.

June 30th – 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. We hope you will join us for a memorable day of golf. Visit www.oif.org/BirdiesAndBogies for more information or to register.

July 10th – Celebrating its 10th anniversary, the **Riley's Gathering Golf Tournament** promises to be bigger and better than ever this year! Enjoy 18 holes, scramble format at Maple Meadows Golf Club in Wood Dale, IL. Then, after a fun day of golf, join us for a buffet dinner with a 2 1/2-hour open bar at Riley's Gathering Place in Elmhurst, IL. During dinner, you will have the opportunity to participate in a silent auction and raffle for some great items. To register for golf or just dinner, contact Patrick Fromelt at 630-244-9982 or pplfro@aol.com.

July 14th – Come to the White Eagle Golf Club in Naperville, IL for the **Miracle Michael Foundation's 16th Annual Golf Tournament and Banquet**. Founder Beth Shultz is anticipating an even more star-studded event than in years past. Whether you attend for the golf or the evening banquet and auction, you'll be helping the Miracle Michael Foundation as they approach nearly \$500,000 in funds raised to help the OI Foundation and Chicago Area OI Families. Contact Beth Shultz at 630-922-3363 to register.

August 18th – Join OIF Board Treasurer, Ken Gudek at the top notch 18-hole championship golf course at the Atkinson Country Club in Atkinson, NH for the **2014 OI Golf Classic**. The scramble style tournament will begin at 7:30am and will be followed by a buffet lunch at noon. Visit www.oif.org/HH_oiclassicnh for more information or to register today.

If you would like to hold a golf outing in your area, contact events@oif.org and we'll help get you started.



Osteogenesis Imperfecta Foundation
804 West Diamond Avenue, Suite 210
Gaithersburg, MD 20878

NON-PROFIT
U.S. POSTAGE
PAID
SUBURBAN, MD
PERMIT #5857

