

## Regional Conference – Uniting Unbreakable Spirits

Every other summer, people in the OI community use planes, trains and vans to travel thousands of miles to attend the three-day OI Foundation National Conference. The commitment of the OI Foundation's conference attendees is unwavering because the National Conference is a unique combination of opportunities – to learn the latest information about OI, to talk to leaders in medical research and to share experiences with other people living with OI. Every two years, the excitement and suspense build to reconnect with families and for some attendees, the OI Foundation National Conference is the first opportunity to meet others living with OI.

Although hundreds of people from all over the United States and many foreign countries attend each OI Foundation National Conference, that still is only a small percentage of the OI community. Time, expense and travel difficulties prevent many people from attending. In an effort to reach more of the 50,000 people in the US living with osteogenesis imperfecta, the OI Foundation's Board of Directors and a small volunteer committee joined forces to develop and re-introduce a program – a Regional Conference. Working with the volunteer committee based in South Florida, a model program for regional conferences has been developed that could make the benefits of an OI Foundation conference more accessible to more people in the United States each year.



The goal for a Regional Conference is to address the needs of adults and families in the time between OI Foundation National Conferences, and to unite adults and families in different regions all over the country. The OI Foundation's plan is to host 2-3 Regional Conferences

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## 2014 OI Foundation National Conference: 50,000 Lives, One Unbreakable Spirit®

Mark your calendars! The 2014 OI Foundation National Conference will be held August 1-3, 2014 in Indianapolis, Indiana. Last summer, 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 for Better Bones.

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

Be sure to check [www.oif.org/conference](http://www.oif.org/conference), and your next issue of *Breakthrough*, for updates about the conference program and registration information.

## Understanding Changes in the Health Insurance System

For the first time in decades, efforts are underway to update the U.S. system of health insurance and make it more accessible to people in the 21st century. Today, most people get their health insurance coverage through their employer, but the system has serious gaps. Businesses with 50 or fewer employees are not required to offer insurance; individual policies and policies offered to small businesses are extremely expensive; and insurance companies often have policies to exclude people who have an illness or a genetic condition. Under the current

system, insurance companies can have restrictive policies regarding pre-existing conditions, and limits to annual and life time coverage. Company rules often penalize people who have had a condition identified through a screening program, change jobs, move to a different state, or who can only work part time. The Affordable Care Act (ACA), sometimes referred to as Obama Care, is gradually putting into effect new rules and programs that are intended to reduce many of these inequities.

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in between each biennial National Conference. The one-day format includes national and regional speakers on a variety of topics related to understanding and living with OI, an exhibit hall featuring local clinics and resources and activities for children and families.

So the buzz you may have heard about the OI Foundation's **Regional Conference** program is true! This Fall, the OIF Regional Conference, titled "Uniting Unbreakable Spirits", will be held on Saturday, November 2, 2013 in Tampa, Florida, at the USF Embassy Suites. A complete registration will include access to a full day of information packed educational sessions and the exhibit space. The OIF Regional Conference will also provide fun activities and entertainment for children and families in a supervised game room. All attendees, children and adults, must register online. Children 12 years old and under are free.

Dr. Francis Glorieux and Dr. Cathleen Raggio of the OI Foundation's Medical Advisory Council are on the agenda, along with orthopedic surgeon Dr. Scott Beck of All Children's Hospital, Tampa, licensed Mental Health Counselor Michelle Fynan, and Tampa OIF Co-Chair Support Group Leader Susie Wilson. Conference topics include Team Approach to Managing OI in Children, Team Approach to Managing OI in Adults, Orthopedic Management in Children, Mental Health and Families, Mental Health and Adults, and Advocating for Yourself. This conference agenda also includes an opening session with research updates, a Handling Infants and Children demonstration, a closing session panel on "Life with OI", and a special exhibit session featuring a service dog demonstration by Canine Companions for Independence. To add a cherry on top (literally), we will conclude the day with an ice cream social reception!

**Register today for the OIF's Regional Conference in Tampa, Florida at [www.oif.org/regionalconference](http://www.oif.org/regionalconference).**

The full conference agenda, registration details, and hotel reservation information are available on the OIF website. Prices increase at the end of October and are subject to availability.

*Join us as we bring the OI Foundation's information resources to a greater number of the 50,000 lives affected by OI.*

*A special thank you to the planning committee for the first Regional Conference in Tampa, Florida: Susie Wilson, Jenny Wilson, Gail Bunker, and Michele Burka.*

*Stay in touch with us for upcoming announcements on the OI Foundation's new Regional Conference program.*

## Expand Our Community: National OI Awareness Week 2014

The OI Foundation is excited to announce that National Awareness Week 2014 Show Your Unbreakable Spirit® May 3-10! Last year was such a success, and we loved hearing about everyone's Unbreakable Spirit®. This year, we want to take it to the next level by sharing our Unbreakable Spirit® with everyone else! Expanding our community not only raises awareness about OI, but also creates opportunities for change and support.

If every person affected by OI reached out and shared their Unbreakable Spirit® with at least one other person, we could increase from 50,000 strong to over 100,000 strong. It's that easy! Share your Unbreakable Spirit® by hosting an event, sending out awareness materials, or even just changing your status on Facebook.

Our goal for National OI Awareness Week is to educate one million people on the issues and effects OI can have on a family. We can do it! From February 1st to May 10th we will be tracking the number of people we reach through social media,

word of mouth, and events. The OI Foundation will post facts on our social media sites that we encourage you to share with your friends and followers! Just think about how many people you can reach through your personal social media sites.

Between March 3rd and March 7th, we want you to share with us how you introduced others to osteogenesis imperfecta. Did you share Facebook posts, hold an event, send out an email, talk to a friend? We want to know who you educated and how! Post on our Facebook page or email [dcyember@oif.org](mailto:dcyember@oif.org) to share your story. These responses will be posted on our National OI Awareness Week 2014 webpage and the OI Foundation's official Facebook page!



# The Power of Competitive Swimming

Athletes living with OI have been excelling in the sport of swimming for many years. Some have been competing at the club and recreational level, and a few have gone on to compete internationally at the Paralympic Games.

Aquatic activity is advantageous for people living with OI for a number of reasons; it is an excellent form of aerobic conditioning, improving cardiovascular function and building respiratory capacity. Swimming improves muscle strength, joint stiffness, balance and endurance.

Aquatic therapy was the beginning of 10 year-old Jaden Sacks' journey to swimming on an organized team. When she was first introduced to swimming and swam only with a teacher/coach, Jaden's parents noticed that she seemed to like the sport and to challenge herself, but she was a bit lonely and there was only so long she could take lessons. Once she learned all four major strokes they tried to encourage her to be on a local swim team. According to Jaden's parents, "Even though she didn't want to join a team at first, once she met a couple girls to hang out with during practice, and most importantly on the deck of day long swim meets, she really started to enjoy herself. She also loved watching the summer Olympics and loves to watch older girls on her team and she wants to work hard to be successful like them." Swimming now plays a larger role in Jaden and her families' life and it's something she excels at, recently competing and doing well in the regional championships even with a fractured ankle. Jaden, now a competitive swimmer, trains on a team at Asphalt Green in New York City and has her goals set high—the 2020 Olympics! In addition to her competitive spirit, Jaden has used her love for swimming as a way to raise awareness for OI. Most recently, she swam 100 laps and rallied her family and friends at her Swimathon event that raised over \$125,000 to help support families and individuals living with OI.



*Jaden competes in the pool*



As Jaden knows, competing in the pool goes well beyond physical conditioning and the development of individual skills. Championship-winning swimmers are the products of long hours of practice in the pool, which requires mental toughness. Justin Zook, a three-time Paralympic Gold Medalist, a community leader, and a coach of a young swimmer living with OI, points out that competitive swimmers must learn how to intrinsically motivate themselves to grow as athletes and

**“The great thing about swimming is that it offers a safe and low-impact environment for skill-building and exploration, allowing athletes to compete on a high level with less physical risks.”**

push beyond setbacks – something familiar to many people living with OI. Justin is all too familiar with the story of “winning state championships in August, having surgery in October, and struggling to get through a practice during the recovery period.” Born with an undiagnosed growth plate disorder, Justin has now undergone 30 operations to correct the leg length discrepancy. Despite the challenges, in his twenty years of competitive swimming, Zook recognizes the swimming community to be incredibly accepting. According to Justin, “disability was noticeable on the pool deck, but swimming sets more of an equal playing field.” He adds, “The great thing about swimming is that it offers a safe and low-impact environment for skill-building and exploration, allowing athletes to compete on a high level with less physical risks.”

For more information on aquatic therapy, contact the OI Foundation's Information Center by email at **Bonelink@oif.org** or by phone at (800) 981-2663.



*Justin Zook wins gold at the 2012 Paralympic Games in London*

## Understanding Changes in the Health Insurance System *continued from page 1*

Because of the Affordable Care Act, people in the United States will have access to affordable health insurance coverage regardless of their health status or pre-existing conditions.

If you are one of the 85% of Americans who has health insurance through an employer, the ACA has made your coverage stronger than before. You may already have noticed that some health screenings such as colonoscopies no longer require you to make a copayment. If you have children under age 26, you may be able to keep them on your family plan. As of 2014, insurance rules about pre-existing conditions, annual and life-time caps on coverage will be significantly less restrictive. These rule changes will make it easier for people who are changing jobs, starting a first job or moving.

If you are part of the 15% of Americans who do not have health insurance, the next few months offers an important opportunity. Through an important new program called "The Health Insurance Marketplace," new insurance plans will be offered to people who currently do not have coverage.

### What is the Insurance Marketplace Program?

The Health Insurance Marketplace or exchange is a menu of qualified plans in each state. Online and telephone assistance is available to help people understand the plans, make a choice and enroll. The new policies are designed to fit consumers' needs and be more affordable. Here are the basics:

- Every state will have its own marketplace.
- Marketplaces will be accessible online or by phone.
- Marketplaces will make it easier to shop for health insurance. Consumers will be able to see the options in one place.
- By filling out one simple application, consumers will also be able to find out if they qualify for free or low-cost coverage through Medicaid or the Children's Health Insurance Program. In some states other subsidies are also available.
- It is estimated that 90% of people who are currently uninsured will qualify for discounted or free health insurance.
- Open enrollment starts October 1, 2013 and ends March 31, 2014.
- If you enroll by December 15, benefits begin January 1, 2014.

Each policy must cover 10 essential benefits including doctor visits, hospitalizations, emergency care, maternity care, pediatric care, prescriptions, medical tests, mental health care, substance abuse treatment, and preventive care such as vaccinations.

### Why is Health Insurance Important?

Health insurance helps pay costs when people need health care. Research indicates that people who have health insurance are

more likely to get regular care and take care of medical problems before they become a serious crisis. Families and adults living with OI need to be smart health insurance consumers. Repairing broken bones and other OI related care is expensive, but they also face the normal health issues from poison ivy to shingles that are part of everyday life.

Young people need to have health insurance to not only protect their health but also their long term financial well-being. All it takes is one major medical expense to send someone who is just starting out in adult life into a financial crisis. While we all are glad that young people are essentially healthy, car accidents, sports injuries, food poisoning and pneumonia do happen.

Health insurance is a contract between the consumer and an insurance company. The consumer buys a plan by paying premiums and the company agrees to pay part of the person's medical costs when they are sick or injured. Most plans also include coverage for preventive care such as check-ups and vaccines. Many offer coverage for prescription medicines. Besides the premium cost, it is important for consumers to understand the rules in their policy about deductibles, copayments and total out-of-pocket costs.

### Important Points to Remember

- If you have health insurance through an employer or are self-insured your coverage may not change.
- If you do not have insurance, prepare now to enroll in a plan through your state's insurance marketplace.
- Note that there is a penalty for not having insurance.

### What You Can Do Right Now

- If you have health insurance, talk to your agent to be sure you understand how changing national rules may affect your benefits.
- If you are the parent of a young adult who has OI, help them to understand health insurance and if necessary to access the new Health Insurance Marketplaces.
- If you are someone who does not have health insurance and who is not eligible for Medicaid or Medicare, now is the time to learn all you can about the Marketplace offerings in your state.

### Resources

- Kaiser Family Foundation video on Health Insurance Marketplaces posted on the OIF website
- [www.HealthCare.gov](http://www.HealthCare.gov) for information about the Marketplace Program, links to each state and additional health insurance information.
- 24/7 Consumer Call Center 1-800-318-2596

# The OI Foundation Board of Directors Welcomes Two New Members

We are pleased to welcome Kara Ayers, PhD, and Cameron Penn to the OIF Board of Directors.

Kara is a clinical psychologist and currently is the Advocacy Coordinator at Cincinnati Children's Hospital, University of Cincinnati UCEDD, where she directs disability advocacy activities at local,



*Kara Ayers*

regional, state and national levels. She is also a professor and teaches several psychology and child development courses in the Cincinnati area. Kara is a former Paralympian and still serves on the US Olympic Committee Ambassador Speakers' Bureau. Kara is a person living with OI and resides in Mason, Ohio, with her husband, Adam, and their daughter, Hannah.



*Cameron Penn*

Cameron is a two time Emmy Award-winning producer/director with more than 20 years of experience in the entertainment industry. He is currently the Managing Partner with Hey Guy

Media, a production/creative company based in Los Angeles, with an office in New York. He grew up in Newport Beach, CA, and attended University of California-Irvine. Cameron is a person living with OI and resides in Manhattan Beach, California, with his wife, Lauren, and their daughter, Bryn.

# The OI Foundation Program Department – Ready to Serve You!

The OI Foundation has as one of its core values, providing programs that educate, inform and provide support to the OI community. Each year the Foundation staff and volunteers work to provide programs that help fulfill the mission of the organization including providing up to date publications, holding conferences and scientific meetings, awarding research and impact grants and providing access to staff that can answer questions.

Because of improved technology people are able to access information in all kinds of ways – through websites, social media groups, webinars, informational videos etc. It is important to remember, however, that not all information is created equal! That's why the OI Foundation program staff spends a great deal of time making sure that the information that is provided is medically verified and up to date. The program staff is available every day to answer questions or to verify information you may have read about or heard from someone else. We are here to help provide you with information that will help you make informed decisions about your health or the health of a loved one.

The OI Foundation is also ready to answer questions from teachers, social workers and other professionals and can put doctors, physical therapists and other medical professionals in contact with the Foundation's Medical Advisory Council members as needed.

Over the past year the program department has expanded its resources and hopes to continue expanding to meet the needs of the OI community. If you need information please call our office at 1-800-981-2663 and ask for one of our program staff or e-mail any one of the staff below.

Mary Beth Huber, Director of Program Services. Mary Beth oversees program activities and staff, actively follows new OI research and prepares most OI publications with the support of the Medical Advisory Council. Mary Beth can be reached at [mhuber@oif.org](mailto:mhuber@oif.org).

Petra Harvey, Health Educator: Petra answers questions from the community; provides information on resources in a particular geographic area and serves as the liaison to our 36 support groups across the country. Petra can be reached at [pharvey@oif.org](mailto:pharvey@oif.org).

Jessica Finkel, Program Associate. The newest member of the program staff, Jessica works on the Foundation's scientific meetings, grant programs and other research activities. Jessica can be reached at [jfinkel@oif.org](mailto:jfinkel@oif.org).



*From left to right; Jessica Finkel, Mary Beth Huber and Petra Harvey*



## Back to School Season

Finding the perfect outfits and checking off the back-to-school supply lists may be the easy part of starting school, moving to a new school or returning to elementary school. Although frequent communication with your child's teacher is an important year-round strategy for helping your child who has OI be a happy and successful student, the start of a new school year is especially important. Autumn is a good time to meet new school staff, review information about your child's physical strengths and needs and to decide how you want OI explained to your child's classmates. It is also important to brief the school staff about any changes in your child's condition over the summer due to surgery or accident and to review plans for handling possible health concerns at school.

At the beginning of the school year meet the key people on your child's education team: your child's teacher, school counselors, principal, student aide (if applicable), and the school nurse or health aide. Review school policies about giving pain medicine at school, and have a written plan in place for how to respond to a suspected fracture at school. Everyone who interacts with the child should be knowledgeable about handling day-to-day activities and emergencies. In many elementary schools, the school nurse will be your point person for making your wishes known. Autumn is also a good time to review your child's education plan to make sure that all necessary services from physical and occupational therapists or adaptive PE teachers have been included. These specialists who are employed by the school system can provide services to help the child with OI have better access the total learning environment. This can include adapting the physical education program, providing safe activities during recess, locating adaptive sports programs, or therapy to improve basic motor skills.

Listed below are some of the important topics to talk over with the staff at your child's school:

**Fractures:** Establish a written policy in regard to handling your child and the use of his/her equipment. Establish who will be called when a fracture is suspected or your child is

in pain. Keep an emergency contact list in an established place for substitute teachers, school nurses and other school personnel.

**Physical activity:** If your child fatigues easily when performing physical activities, discuss the child's physical endurance level with the teacher.

**School environment:** Walking through your child's planned routes to the playground, auditorium, or restroom can help identify areas that will be difficult for crutches, walkers or a wheelchair.

**Personal aide:** If your child has an aide, discuss the role the aide should play to ensure the child's maximum participation in classroom instruction, physical independence and peer socialization.

**Toileting:** Children with OI may require assistance for toilet transfers or may require a bathroom large enough to accommodate a walker or wheelchair. Determine a bathroom plan and discuss if the child will utilize the class bathroom, an alternate bathroom or whether his/her toileting needs will be addressed with the school nurse.

**Fire evacuation:** Parents should work with teachers and school administrators to establish a fire evacuation plan. Determine the safest way to transport the child and the wheelchair safely from the area. This should be clearly posted for all school staff to follow and should be practiced so both your child and the staff know what to do.

Understandably, there is a lot to do at the beginning of a new school year. Opening clear channels of communication now, and following up on a regular basis will help your child's learning and social growth. If the school staff has any questions about OI or how to develop plans for working with your child, give them contact information for the OI Foundation's Information and Resource Center. The OIF has informational brochures and booklets that may be useful and can answer any questions they may have.

# The OI Foundation Needs Your Help This Winter

As we wind down a summer full of extremely successful walks, golf outings and carnivals for OI, we want to remind you that fundraising and awareness events can be held year round – even when the weather forces us all indoors. With a little creative thinking, we can continue to raise money to support the **50,000 Lives, One Unbreakable Spirit®** who are affected by OI in this country.

The fall is an optimal time to get your kids involved in fundraising efforts. Holding a Blue Jeans for Better Bones day or a month long Penny War in your child's classroom would be a great way to introduce OI to a new group of classmates. Following in the footsteps of his mother and grandfather, 9 year old Jack Rossi decided to collect coins in memory of his great grandma Sophie to go along with his mother's 9th Annual MA Unbreakable Spirit Walk for OI this past June. Maybe this Halloween, while your child is trick or treating, you can have them collect coins for the OI Foundation. We can send you pamphlets for them to give your neighbors in exchange which will help raise awareness as well.

A spaghetti dinner, pancake breakfast or even more elaborate evening affairs such as The Holman Family's Beef and Beers for Better Bones or a Fine Wines Strong Bones reception are great ways to gather your community together to celebrate your Unbreakable Spirit®. You can find event space in a church hall or elks lodge, or you can ask your favorite local pizza place or bar if they will allow you to hold an event for free. Oftentimes, they will section off an area for your group and maybe even donate free appetizers and give your guests a discount on drinks.

In addition, a fundraising auction can be combined with any event or held on its own. Ask your friends to donate their time, talent or treasures which are auctioned off to the highest bidder. There are also plenty of resources in your community for acquiring auction items. Area sports teams will happily donate signed merchandise with at least 8 weeks' notice; you



*Noah's schoolmates learned about OI and raised \$4300 for OIF in the process*

could consider holding a bachelorette auction just in time for Valentine's Day; or maybe adding something as simple as a 50/50 raffle to your event. The same restaurant that is giving you space to hold your event, may also donate a gift certificate to your auction. Remember, in many cases, making a donation to your event is tax-deductible for businesses. The OI Foundation can help you by creating a gift in kind donation form along with a support letter with our tax ID for you to bring to businesses as you solicit for donations.

Another unique idea is to hold a 'phantom' or virtual event such as the OI Foundation's annual Bone China Tea. As the host of a Bone China Tea, your guests across the country will each receive an invitation to sit down for a cup of tea at home and then make a donation to the OI Foundation with the money they are able to save by not attending a live event. You can request paper invitations from co-chairs Jenny and Susie Wilson and the OI Foundation can create a website for you to email to friends and family or you could even post it on Facebook or Twitter.

Don't forget, many of our typically outdoor events can be converted to accommodate cooler temperatures. Walks can be held at local malls before hours on a Sunday or at indoor sports centers. Consider holding a mini-golf tournament at a local indoor facility, which would also be a great way to get kids or friends and family who don't have golf experience involved.

Remember, the OI Foundation is here to help. If you are interested in holding a fundraising event, please contact Melissa Bonardi at [mbonardi@oif.org](mailto:mbonardi@oif.org) or 301-947-0083.



*Irving Elementary School showing their OI support during Maggie Shae's Blue Jeans for Better Bones Day*

## Rare Bone Disease Advocacy Alliance to Hold Advocacy Day

The newly created Rare Bone Disease Advocacy Alliance held its first Advocacy Day on Wednesday September 18, 2013. The Osteogenesis Imperfecta Foundation is a founding member of the Alliance and will join advocates from six other rare bone disease organizations to meet in person with elected officials and congressional staff. These meetings are intended to inform our elected officials about the formation of the Alliance and its mission, the personal experiences of rare bone disease on the lives of Alliance members and the need for additional federal funding to support rare bone disease research.

The Rare Bone Disease Advocacy Alliance is a coalition of rare bone disease organizations dedicated to promoting public policy that advances awareness, understanding and research of rare bone disorders including osteogenesis imperfecta. The Alliance will serve as a voice on behalf of its member organizations by facilitating and sustaining on open dialogue with Congress and the Executive Branch about the need to increase federal funding of research, and other priorities, that will lead to a better understanding of the commonalities among the disorders and advance the state of science for each disease.

Washington Strategic Consulting Group, [www.wscdc.com](http://www.wscdc.com), led by managing partner Kyle Mulroy led the lobby day activity and is helping the Alliance develop a strong public policy agenda.

The public policy goals of the Alliance align with the goals of the OI Foundation and include:

1. Accelerated research
2. Better understanding of the prevalence of rare bone diseases
3. Improved diagnostic techniques
4. Development of effective treatments
5. Development of novel drug therapies that treat the underlying causes of rare bone disease

The OI Foundation will be represented on Capitol Hill by OIF CEO Tracy Hart; Dr. Richard Kruse, Orthopedic Surgeon with A.i. DuPont Hospital and chair of the 2014 OI International Scientific Meeting to be held in Wilmington, DE; Justin Zook, gold medal paralympian swimmer and other OIF community members.

## Dr. Frank Rauch to Chair OIF Scientific Meeting



*Dr. Frank Rauch, Chair of the 2014 OIF Scientific Meeting*

Dr. Frank Rauch, pediatrician and clinical scientist with the Shriners Hospitals for Children, Montreal and Associate Professor, Department of Pediatrics at McGill University has been named chair of the OIF's annual scientific meeting titled "New Treatments for Osteogenesis

Imperfecta". The meeting will focus on various forms of treatments including pharmacological and rehabilitation that will ultimately improve the lives of people living with OI. "Treatments are all about improvement," said Dr. Rauch, he added "looking at new treatments that are within our reach as scientists and clinicians will be the focus of this important meeting." The meeting will take place April 9-11, 2014 in Chicago, IL, and is generously supported by the Buchbinder Family Foundation.

Dr. Rauch has published 140 peer-reviewed publications since 2009 and has been Editor of the Journal of Musculoskeletal and Neuronal Interaction. His main research areas are muscle-bone interaction and heritable bone disorders in children. He oversees the OI Clinic at the Shriners Hospital for Children, Montreal and is a member of the OIF's Medical Advisory Council. A detailed meeting summary will be available shortly after the April 2014 meeting.

## Backpack Safety

Backpack safety is an important back to school issue for students of all ages. A good resource for parents and teens is the “OrthoInfo” section of the American Academy of Orthopaedic Surgeons website <http://orthoinfo.aaos.org>. The article on Backpack Safety offers tips for choosing and using backpacks.

Students who have OI should never carry a heavy backpack. The risk of a serious spine injury is too great. It is important to work out alternative strategies to get the most out each class while preventing injuries. Students suggest the following:

- Keeping a set of textbooks at home.
- Storing the necessary text books in each classroom the student uses.
- Carrying only lightweight notebooks.
- Using e-books if appropriate.

## Hepatitis C and Baby Boomers

Were you born between 1945 and 1965? Did you receive a blood transfusion before 1985? According to a recent report from the U.S. Preventative Services Task Force you might be at risk for hepatitis C, a serious blood infection. In most people, hepatitis C is a silent disease that when left untreated, can cause a variety of serious liver problems including cancer as a person ages. Public health officials urge everyone age 48-68 to use the “better safe than sorry” approach and ask about screening for hepatitis C at their next doctor appointment. This information is important for adults who have OI because the blood transfusions they may have received during surgery when they were children might have been tainted.

## Protect Your Health: Get a Flu Shot

Back to school season is a good time to start thinking about getting your annual flu and pneumonia vaccines. Children and adults who have OI have an increased risk for serious respiratory infections particularly if they are short in stature or have scoliosis. These vaccines can help keep you healthy.

## Physical Therapy Study Now Open

The OI Foundation would like to bring to your attention that information about a new research survey has been placed on the OIF website. Please go to [www.oif.org](http://www.oif.org) for information about a survey on OI and Physical Therapy. This study is being conducted by the OI Program and the PT Department at the Kennedy Krieger Institute in Baltimore, MD.

## International Conference on Children’s Bone Health

Dr. Laura Tosi, an orthopedist at Children’s National Medical Center, Washington DC and a member of the OI Foundation’s Medical Advisory Council, represented the OIF at the 6th International Conference on Children’s Bone Health. This prestigious meeting was held in Rotterdam, Netherlands in June of this year. Dr. Tosi presented a poster titled **Beyond Brittle Bones: A Preliminary Report from the OI Adult Natural History Initiative.**

## New Book on Parenting

Johns Hopkins Press recently published **Just One of the Kids: Raising a Resilient Family When One of Your Children has a Physical Disability.** Written by Kay Kriegsman, PhD, and Sara Palmer, PhD, the book features the stories of dozens of families including many from the OI community. Dr. Kriegsman, a psychologist, has worked with OI families for decades and has spoken at several OIF National Conferences. The book has received excellent reviews for being encouraging, practical and helpful. It is available for purchase through Amazon, Barnes & Noble and other on-line book stores.

# The Importance of Social Networking and Internet Safety

Social networking is a powerful tool that has leveraged the communications world to an unprecedented level of constant contact. With sites like Facebook, MySpace, NING and LinkedIn, users are able to keep friends, family and coworkers updated on daily life with just a few clicks on a keyboard. Communication on these sites is fast, easily accessible, and plentiful.

Businesses have harnessed the use of social networking to keep their constituents up to date on their latest activities, helping to form a closer connection between client and company. The OI Foundation uses Facebook, Twitter, chat rooms, and NING to keep community members informed, and to allow members a place to connect with other families and individuals with OI.

With the amount of information being posted and accessed on the internet, users are cautioned to be vigilant about the personal details, including medical information, they choose to share about themselves online. Deciding what information to share about yourself can be tricky, particularly on social networking sites that create a comfortable and communal environment for users.

Remember, anything you post online is public and permanent. While almost every social networking site has privacy settings available, anything you post can be printed, forwarded, or saved by members of your approved network. Even if you are posting on a private page or private group, you may not know every member of the group, or know what information is accessible to 'friends of friends' on an individual's private page. As a general rule, it is best to refrain from posting your personal information, particularly sensitive medical information, online.

The tips below were taken from the Federal Trade Commission's website, [www.ftc.gov](http://www.ftc.gov), on Facts for Consumers.

The FTC suggests these tips for socializing safely online:

- Think about how different sites work before deciding to join a site. Some sites will allow only a defined community of users to access posted content; others allow anyone and everyone to view postings.
- Think about keeping some control over the information you post. Consider restricting access to your page to a select group of people, for example, your friends from school, your club, your team, your community groups, or your family.
- Keep your information to yourself. Don't post your full name, Social Security number, address, phone number, or bank and credit card account numbers — and don't post other people's information, either. Be cautious about posting information that could be used to identify you or locate you offline. This could include the name of



your school, sports team, clubs, and where you work or hang out.

- Make sure your screen name doesn't say too much about you. Don't use your name, your age, or your hometown. Even if you think your screen name makes you anonymous, it doesn't take a genius to combine clues to figure out who you are and where you can be found.
- Post only information that you are comfortable with others seeing — and knowing — about you. Many people can see your page, including your parents, your teachers, the police, the college you might want to apply to next year, or the job you might want to apply for in five years.
- Remember that once you post information online, you can't take it back. Even if you delete the information from a site, older versions exist on other people's computers.
- Consider not posting your photo. It can be altered and broadcast in ways you may not be happy about. If you do post one, ask yourself whether it's one your mom would display in the living room.
- Flirting with strangers online could have serious consequences. Because some people lie about who they really are, you never really know who you're dealing with.
- Be wary if a new online friend wants to meet you in person. Before you decide to meet someone, do your research: Ask whether any of your friends know the person, and see what background you can dig up through online search engines. If you decide to meet them, be smart about it: Meet in a public place, during the day, with friends you trust. Tell an adult or a responsible sibling where you're going, and when you expect to be back.
- Trust your gut if you have suspicions. If you feel threatened by someone or uncomfortable because of something online, tell an adult you trust and report it to the police and the social networking site. You could end up preventing someone else from becoming a victim.

## Research to Be Aware Of: A Recent Study of Risedronate as a Treatment for OI

The OI Foundation applauds the ongoing work of researchers to improve treatments for children with all forms of osteogenesis imperfecta. A recent study adds important information to this knowledge.

An article published August 6, 2013 in the medical journal **The Lancet** reports on a carefully designed study of the drug risedronate. Principle investigator Dr. Nicholas Bishop from Sheffield, England was joined in this study by researchers from other countries including the United States, Germany and Australia. Risedronate, which is sold under the name Actonel, is a member of the bisphosphonate family that includes well known intravenous drugs such as pamidronate and zoledronic acid. Unlike those drugs, risedronate comes as a tablet and is taken by mouth.

This study is important because it followed the most rigorous research design—randomized, double-blind and placebo-controlled. Studies of drug treatments for children are often smaller and have a simpler design. The authors found that children with mild forms of OI had over-all fewer fractures while taking the drug risedronate although the frequency of vertebral fractures (fractures in the spine) were not reduced.

Commentators in several publications including **The Lancet** have noted that:

- The study included only children with mild OI. Therefore the results cannot be applied to children with the moderate or severe forms.
- All subjects were 4 years and older: The daily dose was taken at least 30 minutes before the day's first food and drink (apart from plain water) and the child remained upright for 30 minutes afterwards. This was mandatory to avoid esophageal irritation. This means that babies and children who cannot sit upright first thing in the morning are not eligible for this treatment.

- All fractures were counted together except for spine fractures. The report does not differentiate between minor broken bones (fingers and toes) and major long bone fractures to the tibia and femur.

Commentators suggest that additional studies of a similar rigorous design are needed to:

- Evaluate whether risedronate treatment reduces major fractures including spine fractures in children with moderate and severe forms of OI.
- Explain why vertebral fractures were not decreased in this group of children and teens with mild OI.

Until there is more information:

- Based on this study alone, treatment plans for children with moderate and severe forms of OI probably will remain the same.
- For those children with mild forms of OI who experience frequent fractures, physicians may want to consider risedronate treatment instead of one of the intravenous drugs.

It is important to remember that:

- All bisphosphonates are more effective in growing children than in adults.
- All bisphosphonates are more effective when the drug therapy is combined with a guided program of physical activity and, if necessary, corrective surgery.
- Bisphosphonate treatment for children with the mild forms of OI who fracture infrequently is not universally recommended.

The abstract for the article, "**Risedronate in children with osteogenesis imperfecta: a randomized, double-blind, placebo-controlled trial,**" is posted on the OI Foundation website.



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

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## Get Connected! Join an OI Foundation Support Group

When people live with a rare and complex health condition like OI, it is easy to feel alone and isolated. A support group provides the setting and opportunity for people to share experiences and socialize with others who can personally relate to OI stories. Even with the advancements and growing trends of social media and online networking, many people still find it beneficial to meet face-to-face. More ways to connect with others have grown the Unbreakable Spirit® community in all directions.

OI Support Groups include people of all ages and all types of OI, parents, grandparents, other relatives, and friends. OI Foundation Support Group Leaders host meet-and-greet socials, mixers, day trips, picnics, and other fun, family-friendly activities. Some support groups feature speakers with medical information about OI or representatives from local disability related resources. Whether gathering to grill up hot dogs, have a play day in the local zoo, or hear a medical professional talk about managing hearing loss, support groups gather to enjoy each other's company, share information and encourage each other.

OI Foundation Support Group Leaders are friendly and easy to talk to, good at planning get-togethers, and comfortable talking about OI. If you feel that you have the skills to coordinate a support group and are interested in starting one in your area, please contact the OI Foundation to request the Support Group Leader Handbook and application form.

Many support groups are planning fall meetings. Check the Events Calendar at [www.oif.org](http://www.oif.org) to find a meeting in your area, or contact the support group leader. For more information, contact Petra Harvey at [pharvey@oif.org](mailto:pharvey@oif.org).