

## Gretchen and Peter Strauch Will Receive Lifetime Volunteer Award from OIF

The OI Foundation's highest volunteer award will be presented to **Gretchen and Peter Strauch** of Montville, NJ, for 20 years of dedicated service to the community. They will receive the 2010 Thelma Clack Lifetime Volunteer Award during the 20<sup>th</sup> Annual New Jersey Beefsteak Dinner on October 22.

Nine-year-old **Katie Kipperman** of Lake Zurich, IL, has been named the winner of the 2010 Peter Dohm Junior Volunteer Award, for a letter-writing campaign last summer that raised more than \$2,800 in donations to the OI Foundation. Her award will be presented during the Miracle Michael Fund Golf Outing on July 18.

**Kim and Angelo Collazo** of Rochester, NY, will be presented with the Foundation's adult volunteer of the year award for 2010, also known as the President's Award. They were recognized on May 14 during the *Alle Shea's 3rd Annual Unbreakable Spirit Walk for OI* in Rochester, which is named for and held in memory of their infant daughter.

All three honorees, along with recipients of the 2011 volunteer awards, will also be honored at the 2012 National Conference on OI outside of Washington, DC, during the Awards Dinner on July 14, 2012.

Nominations for these awards are solicited each year from the OI community. Once the nomination deadline has passed, a committee of volunteers evaluates the candidates based on a set of established criteria and recommends a winner for each award to the Foundation's Board of Directors. The Board then approves the final slate of honorees.

*"I can't even begin to explain HOW BLOWN AWAY I am for receiving such an award. I am truly at a loss of words and humbled,"* Gretchen said. *"I do what I do to give back the love, reassurance and friendship that others have given me. I'm truly blessed to be involved in such a wonderful Foundation. It's my second family."*

**Gretchen and Peter Strauch** said they became involved with the NJ Support Group shortly after their daughter was born with OI-related fractures in 1990.



**2010 Thelma Clack Lifetime Volunteer Award recipients Peter and Gretchen Strauch with daughter Shannon (center).**

*"I remember how lost I felt not knowing anything or when she was going to break something,"* Gretchen related.

They soon found the OI Foundation and attended the national conference in San Antonio. At that conference, Gretchen met many "wonderful people" who helped her. The New Jersey Support Group also formed at the Conference, providing a way for Gretchen and Peter to get involved.

"They are a vital part of the NJ Area OI Support Group," Support Group co-leader Jo Ann Berkenbush explained. "Gretchen is an excellent resource for parents and

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**From the Chief Executive Officer**

Dear Friends,

I want to take this opportunity to thank everyone for their wonderful participation in the Foundation's Awareness Week activities. It was obvious that we were showing our "Unbreakable Spirit" in communities across the country! From hanging the Awareness Week posters and participating in events to visiting legislators on Capitol Hill to educate them about OI and the work of the Foundation – you did a great job. Thank you! I know many people participated in the international Wishbone Day activities on May 6, which is terrific; it was a great way to start a week-long campaign to raise awareness about OI. The OI Foundation works collaboratively with the international OI organizations and I'm looking forward to seeing many of the OIFE delegates at the International OI Scientific Meeting in October, which will be held in Dubrovnik, Croatia. I'm sure we will be sharing stories about the wonderful OI awareness activities held around the world.

In addition to Awareness Week activities, the Foundation recently held the annual scientific meeting. Many thanks to Dr. Peter Byers and Dr. Francis Glorieux for chairing this important meeting titled, "The New Genetics of OI." An article highlighting this meeting is included in this edition of *Breakthrough* along with an announcement of our two newest Michael Geisman Fellowship recipients. It's an exciting time at the OI Foundation and in the OI field. Please check our website for information on recently released research studies that may affect you or your loved one. And, as always, please feel free to contact the Foundation if you have questions or concerns.

I hope everyone has a wonderful summer and I hope to see many of you at events and activities around the country. Thank you to everyone for continuing to support the important work of the OI Foundation.

All my best,



**From the President**

Thanks to your efforts, the number of people who are aware of OI has grown dramatically! A lot of fun and festivities took place during our Awareness Week, and I want to say "thank you" for your efforts and enthusiasm in extending awareness!

A different kind of awareness event happened in Chicago in April. A group of doctors and researchers from around the world gathered for the 11<sup>th</sup> Annual Scientific Conference. Many of you are familiar with the action items generated from the science meeting last year. The adult focus groups at the Portland conference last summer were a direct result of the 2010 Science Meeting on Adult Health Issues, and work is ongoing to improve the access of adults with OI to appropriate medical care. This year the focus was on recessively inherited OI.

One of the doctors described the balance of topics well. He said that if you look at the process of finding out more about OI, you have long term and short term investing. Last year's meeting about adult health issues was mainly about short term investing. We've already heard about tangible progress in making adult health issues more understood in the medical community. This year, the topic was focused on long term investing. The results of the studies that will be generated from this year's meeting will be years in the making. Last year was about managing OI, this year was about curing it. I think it's important to recognize that the mission of the Foundation is to do both short term and long term investing. Awareness week has increased the visibility of the Foundation to a lot of new people. The science meeting has increased awareness of a lot of ideas.

Thank you to everyone who is raising awareness of OI; from hanging a poster in your neighborhood to dedicating your professional life to working out the structure of the genetic blueprint of OI. I'm looking forward to seeing what the future holds!

Sincerely,

a wonderful baker who delights us with homemade goodies all the time. When Shannon and Sean were young children, Peter and Gretchen supplied games and crafts to keep them and the other children occupied during the meetings.”

Added Rosemarie Kasper, also a NJ Support Group co-leader, “Gretchen is very warm and caring in greeting new families and assuring that everyone feels welcome.”

For 19 years, Peter and Gretchen have served on the committee that organizes the NJ Beefsteak Dinner, often taking responsibility for setting up and raffling off the Tricky Tray items. During this time, the Beefsteak Dinner has brought in more than \$280,000 in support for the Foundation. In addition, Gretchen has served for more than a decade as a chat room monitor once or twice a month, and she has volunteered to help with the Talent Show and as a Peer Group leader during several National Conferences on OI. Both Peter and Gretchen also took on the responsibility of being Teen Room chaperones during the National Conference in 2010. For his part, Peter served on the Board of Directors from 2000-2006 and as Treasurer from 2001-2006. Since ending his Board term, Peter has continued to serve as a member of the OIF Finance Committee.

**Katie Kipperman** earned the Peter Dohm Junior Volunteer award by taking on a long-time letter-writing campaign begun ten years ago by her parents, Bonnie and Steve, shortly after Katie was born. With the help of her parents, Katie drafted the family’s annual letter to friends and family in 2010, asking them to renew their support of the OI Foundation. Her letter was well-written and even included recent photographs. Overall, since beginning the family’s efforts, the letter campaign has raised over \$57,000 toward the OI Foundation’s research programs.

Katie’s father, Steve, shared the news of her award with her. “This is a real honor and something Katie’s grandmother Pat would have been very proud of,” he said. The family’s involvement with the OI Foundation goes back to the early days through Pat’s involvement. Pat Kipperman received the Thelma Clack Lifetime Volunteer Award in 1993.

“It is very special that we have friends and family that contribute to help the OI Foundation to do research and help people with brittle bones,” Katie said.



**Nine-year-old Katie Kipperman (right), winner of the 2010 Peter Dohm Junior Volunteer Award, poses with her family – father Steve, brothers Ryan and Carson and mother Bonnie.**

Two different people nominated **Kim and Angelo Collazo** for the President’s Award. Just three months after the passing of their infant daughter Alle Shea from OI-related complications in May 2009, the Collazos held a walk for OI in her memory. In 2010, the couple held their second OI walk event and added an additional fundraiser at Pizzeria Uno, where a portion of one day’s sales were donated to the OI Foundation. During the past two years, these events have raised more than \$21,500 for the OI Foundation. The couple has also used Alle Shea’s stories and their fundraising events to reach out to local media in Rochester and raise awareness of OI, successfully scoring television, Web and print articles.



**2010 President Award recipients Kim and Angelo Collazo with daughter Alle Shea in 2009.**

“Alle Shea was definitely a fighter,” Kim and Angelo remembered. “Many of the doctors did not expect her to last the weekend, having type 2 OI and several healing fractures from being in utero, as well as a few “fresh” fractures from the C-section birth.

“Alle proved everyone wrong and fought for 5 weeks. ... As difficult as it was with Alle Shea’s passing, we were able to hold on to the positive memories of being able to hold her and take her outside in the sunshine. Organizing the walk in her honor helped us through the healing process, and helps us to keep her fighting spirit alive still today,” they said.

## CaringBridge: A Lifeline for Patients and Families

Families unprepared for a loved one's health diagnosis can be overwhelmed by medical terminology, treatment decisions and hospital visits. It's times like these that families need support from extended family and friends. But even trying to respond (much less reaching out) to them using the phone or personal e-mails is overwhelming and exhausting. But there is a way to receive support and provide information, while increasing time available for the individual and family.

CaringBridge was created in 1997 when Sona Mehring was devastated to learn that a close friend had delivered a premature baby and that both the baby and the mother were in critical condition. Mehring was given the task of updating family and friends about the situation. She utilized her background in web design to develop a website to communicate information to a wide circle of family and friends without disturbing the mother's need for rest or placing additional demands on hospital staff.

"I wanted to provide a space for my friend to update her support network and for her support network to provide love and encouragement," says Mehring. "The Internet was the perfect medium for that."

Sadly, after a nine-day struggle against tremendous odds, Baby Brigid died in surgery. But Mehring's revolutionary communication tool, CaringBridge, was born out of this tragedy.

A CaringBridge website saves time and energy by centralizing communication. This eases the burden of updating family and friends and keeps the focus on caring for the patient.



The websites can be an important tool to help reduce isolation and stress in a difficult time, providing a much-needed outlet for sharing feelings and receiving support. Rather than individually contacting each member of a support system, a CaringBridge site allows patients and caregivers to update everyone concerned with just one journal entry.

"On the first day I created my CaringBridge website, I received 120 hits," says CaringBridge user Sara Pallen. "I never could have communicated with 120 people in one day without this website."

A CaringBridge site also helps patients build therapeutic connections with their support networks, allowing family and friends to send messages of love and encouragement through the patient's guestbook. Many authors of CaringBridge sites say that the large volume of well-wishes and compassion they receive through the guestbook helps them experience emotional healing and improved quality of life.

In a 2010 study of people using CaringBridge to share health news, 91% of patients agreed that it helped make their health journey easier and 88% of patients agreed that it positively impacted their healing process.

CaringBridge sites can be maintained for as long as the family finds them helpful. There is no time limit, or any conditions around their ongoing use – the sites can be used when someone is facing a serious medical condition, in treatment, recovery, or on an ongoing basis.

For more information or to create your own personal website, visit [www.CaringBridge.org/oif](http://www.CaringBridge.org/oif).

## The Importance of Social Networking and Social Networking 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 consumers 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



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## *In My Own Words*

### Tips for Freshmen

By Rosie McDonnell-Horita

Below are tips from OI Community member Rosie McDonnell for new college students.

- The Department of Rehabilitation in California is a state funded program which helps people with disabilities get jobs and also pays for education. I am a consumer through them and they pay the majority of my tuition, books, etc.
- I am a part of the disabled student program services at my college, which gives students with disabilities priority registration. They give you a counselor and help figure out what classes you need to take and how many credits you'll need, etc.
- My college has some lockers available in different parts of the campus which has really helped me lighten my load of books that I carry around school.
- I highly recommend having a planner, whether it is a calendar on your phone or an actual planner. It helps me keep track of what I'm doing and when things are due.
- Best website ever [www.ratemyprofessor.com](http://www.ratemyprofessor.com)



*Andy Pilgrim, Rosie McDonnell, and Peter Smith, MD at the 2010 National Conference.*

### The Importance of Social Networking and Social Networking Safety *(continued from page 5)*

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.

## *In My Own Words*

### **Osteogenesis Imperfecta, One Size Does Not Fit All**

By *Chelsea Lush*

There are words that will be seared in your memory—as fresh and raw as the day you first heard them. When you learn your child has a disability or health problem, the words a doctor uses to share the news can build you up or tear you down.

“Your daughter has abnormal extremities. Most likely OI Type 2, her long bones are short and bowed. There is a fracture, there is a fracture, these are suspected.”

On Zoe’s birth day, I held her so close and so carefully. Being told by my nurses that we had to be careful, she had healing fractures. I held her like a priceless crystal vase. Zoe locked eyes with me and she let me admire her. We then took a nap, her cuddled in my arms. I was holding a piece of Heaven.

My child with *Osteogenesis Imperfecta* is not the same as another child with *Osteogenesis Imperfecta*; the condition isn’t one size fits all. There are various types. Even within the same type, it affects every kid (and adult) differently. My child with *Osteogenesis Imperfecta* is not defined by her disability. She is a cheerful, outgoing, affectionate, Yo Gabba Gabba-loving girl who happens to have OI. My child with OI does not have something that you can catch, although from the way I hover nervously when someone else’s child is around her, you might very well think she does.

Sleepless nights, baths, lots of bottles, diapers, bags under the eyes, pony tails, undone laundry...life’s good. I would be awoken only by a squeak or fidgeting, hardly ever a cry when it was time to eat. So...only 5 days after bringing her home, I knew something wasn’t quite right when she started screaming in pain. We knew she was going to fracture, but we didn’t expect it to happen so soon. Her left arm was double the size and we knew what had happened. The next night, we heard the sound we couldn’t have ever imagined until it actually happened. There goes the left humerus. I felt like my crystal vase had been shattered. What do we do now? Luckily, I joined an amazing support group while I was pregnant and a fellow OI mom came over (Sunday at midnight!) and showed me how to splint Zoe’s arms.

Yes, Zoe’s life will have more than her fair share of challenges. There will be periods where there is only frustration and feelings of low. But I know this, the highs will hold more joy than I think my heart can handle. Now, we might have to work harder to reach those heights. We, as parents, will do so much research for the best doctors and treatments. We will spend countless hours fighting insurance companies. Thinking late at night, “Is he the right doctor for her?” We’ll spend our days explaining why ‘giving milk won’t cure OI’ or what Pamidronate is and how it helps her to reach her milestones, even if her milestones are at her own pace. We will battle our own personal war. We will face the fear and worry with confidence and education. We just want to make it easier for our Miracle.

As an OI parent, we have the most important job of them all, to be the fiercest advocate for our child. I feel compassion for people I would have never looked twice at. I try to savor every moment instead of rushing through life. And I try to lean on God more instead of leaning on myself. Our children are young, amazing people who just so happen to have OI. But OI does not have them.

*Chelsea Lush is a new mother living in CA with her husband Curtis and their adorable daughter, Zoe. Zoe’s cord blood was tested after birth to reveal that she is OI Type 3.*



*Curtis, Zoe and Chelsea Lush*

## OI Foundation Awards Two Research Fellowships

Though they hail from opposite coasts, the two recipients of this year's Michael Geisman Fellowships have a lot in common.

First, they each were brought into OI research by mentors who have spent many years sharing their professional expertise with the OI community and the Foundation. Second, each young researcher is studying specific genetic mutations that they hope will someday lead to new treatments to strengthen bones, once they are better understood.

Each fellowship awards up to \$50,000 to post-doctoral trainees who are currently working on projects with clear relevance to OI, or who have projects that will enable them to develop expertise in OI research.

*The LRP5 Pathway: A Potential New Therapeutic Target for Osteogenesis Imperfecta*

**Christina Jacobsen, MD, PhD**  
Children's Hospital Boston

Dr. Jacobsen's study seeks to discover whether a mutation in the LRP5 gene will increase either bone strength or bone mass in mice who have OI.



**Christina Jacobsen,  
MD, PhD**

To accomplish this, she will mate mice who have OI with special mice—created by Matthew Warman, MD at Children's Hospital Boston—that have this mutation. Dr. Jacobsen explained that when this mutation has been found in people who do not have OI, these individuals have also had increased bone density.

Jacobsen is exploring the question: "Are there other things we can do to affect this pathway to improve outcomes with OI?"

She added that eventually, "We hope to use these mice to find new targets where medication will affect bone strength and bone mass." This would mean the medication would need to lead to less bone breakdown, more bone deposited, or both.

Jacobsen, who has a background in both genetics and endocrinology, said she was initially drawn to this type of research after attending a bone health specialty clinic focusing on low bone density with Ingrid Holm, MD, at Children's Hospital. Later, Jacobsen decided to pursue an opportunity to conduct research with Dr. Warman.

"This (research) is near and dear to my heart," she explained. "I see children with OI in my clinic, and I want to make their lives better."

\*This fellowship has been funded by Mallie's Friends Research Legacy. Please read our next issue of *Breakthrough* when Mallie and her family will talk about their decision to fund OI research.

*Molecular Mechanisms in Recessive Osteogenesis Imperfecta*

**Shawna Pyott, PhD**  
University of Washington

Dr. Pyott will work with cell cultures, focusing on three specific proteins—referred to as CRTAP, P3H1 and CYPB—that together form a complex that interacts with collagen. The goal will be to determine how a deficiency of each protein impacts the quality of collagen, and thus, bone strength and fragility.



**Shawna Pyott, PhD**

"If we figure out exactly how these proteins act on collagen, then we can help the collagen molecules fold faster, which will produce better quality collagen and ultimately, better bones," she explained.

In the long run, this research could contribute to the development of gene therapy, which would strengthen the bones of individuals with specific recessive forms of OI, and may even be applicable to the dominant forms as well.

According to Pyott, one important question about any potential gene therapy that results would be, "Would it be a lifetime treatment or one that is only necessary during a specific growth phase or period in your life?"

Dr. Pyott was first drawn into OI work as a first-year graduate student when Peter Byers, MD, gave a "chalk talk" about OI and collagen and "made it sound very interesting."

Later, she rotated in Dr. Byer's lab, where she worked on a recessive OI project. She has been a regular part of his laboratory research since the summer of 2007.

Then, in 2010, Pyott traveled to the National Conference on OI in Portland, OR.

"I went to the National Conference, and when I met all of those families, they were so happy and excited people were working on [OI research]," she said. "It was inspiring. That's what kept me in it."



# Support the OI Linked Clinical Research Centers Project This Spring, and Your Gift Will Be Matched!

When you donate to the OI Foundation's 2011 Spring Appeal, you will move forward one of the community's most exciting research programs, the OI Linked Clinical Research Centers.

Once again, the impact of your donation will be doubled by a Matching Gift Challenge! The family who issued last fall's challenge was so inspired by your enthusiastic and generous responses that they have renewed their support. This family has agreed to match any new or increased donations to this letter until June 30, up to \$5,000! **When you receive our letter, please don't wait to make your gift and encourage others to contribute!**

As you likely know, the Linked Clinical Research Centers (LCRC) are a cooperative network of research and treatment facilities for people with OI. As a group, the linked centers pursue research into osteogenesis imperfecta, offer care to adults and children who have OI, and provide training and information to researchers and health care providers.



*Debbie and Daniel meet with the physical therapist.*

Debbie from Texas wrote the following about the involvement of her son, Daniel. *"We are pleased that we have decided to be part of this study, not only to keep up with Daniel's progress, but for all of the individuals with OI yet to come."*

**Your contribution to the Linked Clinical Research Centers project will help us find answers to issues that personally affect you or your loved ones who live with OI.** For example, should parents expect their child with OI to begin talking at the same age as other children, or will this occur either earlier or later? Also, how will an adult's respiratory function change at various stages of their life, if at all, and how much is this change impacted by the type of OI that he or she has?

As Tony from Illinois explained, *"Physicians and researchers can learn from our information to help narrow down the avenues best suited for finding a cure and establishing the best treatments for OI."*

Currently, each site is conducting "The Longitudinal Study of Osteogenesis Imperfecta". For the first time ever, researchers are tracking the health of children and adults with OI over several years! This is a ground-breaking multi-year natural history study of OI that will expand knowledge about OI across the lifespan and identify areas that need more detailed research.

Currently, 379 individuals with OI are enrolled in the natural history study. Approximately half of the participants are age 19 or younger, and the group includes representatives of each recognized type of OI. The Foundation currently supports the participation of five sites—in Baltimore, Chicago, Houston, Portland and Montreal—and the LCRC oversight committee is looking at the possibility of expanding the natural history study to additional locations.

For Tony, the Linked Clinical Research Centers and the natural history study of OI represent the realization of a dream that seemed very distant not too many years ago: *"I grew up in the 60s and 70s, when very few knew what OI was, let alone if there would ever be a facility that specialized in research for children and adults with OI,"* he wrote. *"I had always hoped that there would be a place that could help coordinate treatment for adults affected by OI."*

By donating **before June 30**, you will help us finish our Fiscal Year 2011 in a strong position. If you prefer to give online to the LCRC program and the OI natural history study, simply visit [www.oif.org/donateLCRC](http://www.oif.org/donateLCRC).

If you are interested in enrolling at a Linked Clinical Research Center, please visit our Current Studies web page at [www.oif.org/RS\\_Current](http://www.oif.org/RS_Current) for more information.

Let's continue to work together to build a better future!



*Tony and son, Danny.*

# OI Researchers Attend 11th OIF Scientific Meeting in Chicago

On April 5<sup>th</sup> and 6<sup>th</sup>, members of the OI medical and research community came together in Chicago, Illinois, to attend the OI Foundation's scientific meeting. This year's meeting, titled "The New Genetics of OI: Presentation, Mechanisms, Population, and Natural History of Recessively Inherited Forms of OI" was the 11<sup>th</sup> in the series, which was initiated in 1999. Each scientific meeting brings together investigators and clinicians who are playing major roles in research relevant to understanding one aspect of OI. The goal of these meetings is to identify the pathways for clinical and basic research that will best benefit the OI community, connect with experts in related fields and facilitate creative collaborations.

Dr. Peter Byers and Dr. Francis Glorieux chaired this year's meeting and brought together 20 distinguished colleagues from the US, Canada and New Zealand. Their presentations and discussions focused on the rapidly expanding information about recessively inherited OI. They explored what this work reveals about OI and the potential for new therapies. The context for these discussions was set by Dr. Francis Glorieux. He reflected on two perplexing questions that have inspired researchers:

- Why is there such an extreme range of symptom severity in OI?
- What causes OI in people who do not have a type 1 collagen mutation?

He reviewed how understanding about OI has developed over the years from the broad categories, "Tarda" and "Congenita", to the Silence Classifications published in 1979, to the publication in 2006 of the first documented recessive mutation causing OI.

Presenters at the meeting shared information about their work on understanding and identifying genes that cause recessive forms of OI. In a few short years, we have gone from a theory that there might be a recessive cause of some forms of OI to one known recessive mutation to more than six known recessive mutations. Implications of these mutations are being assessed in several studies, but one thing is clear: understanding which mutations cause recessive forms of OI is just the first step.

The next, even more difficult, step is figuring out the mechanisms for how and why. This work is international in scope, with data being shared between labs in many countries, where small groups or even individual families are being studied. Interesting reports from the National Institute of Health and from New Zealand indicated that the spread of some recessive mutations was affected by history, cultural practices and immigration patterns.

A major theme of the presentations was complexity. These mutations affect bone and all collagen rich tissues, including lungs, kidneys, skin, muscles and tendons. The complex library of influences on bone quality and bone density was almost overwhelming. These influences—whether they are molecular mechanisms or protein interaction—point the way to potential answers for long-standing questions about the range of OI severity.

Although recessive inheritance is believed to cause only about 10% of OI cases, this research has important implications for everyone who has OI.

- It provides answers for people who have OI symptoms, but do not appear to have a dominant mutation for OI.
- It allows for improved genetic counseling to help people understand their OI.
- It helps explain differences in responses to treatments.
- It opens a door to new avenues of treatment for all types of OI.

As the studies discussed at this year's scientific meeting are published and shared around the world, we look forward to the next wave of investigation and discovery.

The topic for next year's scientific meeting will be released in the summer of 2011.

## Research: Three Topics of Interest

### Research Update: New Study on Cardiovascular Issues and OI

Researchers in Norway urge all adults who have OI to include cardiovascular screenings in their routine health care.

A study of echocardiograms from 99 adults who have OI in Norway found that they had an increased risk of cardiovascular abnormalities. Types I, III and IV were represented among the 58 women and 41 men who participated. This is the first large study of heart issues of adults with OI. Few studies have been published on this topic and the majority of them have been case studies that describe the symptoms and/or treatment of one person at a time.

This study found evidence of valve dysfunction, aortic and mitral valve regurgitation, aortic root dilation and increased dimensions of the left ventricle. These abnormalities were seen in people of all types of OI, although they were more common among those with OI Type III. Heart disease includes conditions that affect the structure of the heart and its ability to function. These structural abnormalities could contribute to heart valve disease and coronary artery disease.

Because the genetic defect in type I collagen that causes OI affects not only the skeleton but all collagen-rich tissues in the human body including the heart, this team of researchers call for more studies into the types and causes of heart problems among people who have OI. They would like to find out if valve problems develop over time in a manner similar to other connective tissue disorders, whether the abnormalities seen in the heart were caused by high blood pressure,

OI or both and the prevalence of each type of heart abnormality in the OI population.

Since all of the abnormalities reported in this study have potentially serious consequences, the authors suggest that adults who have OI and their doctors should be alert to symptoms of heart disease.

The study titled “Cardiovascular Abnormalities in Adults with Osteogenesis Imperfecta,” by Zoran Radunovic, MD, Lena Wekre, MD, Lien M. Diep, and Kjetil Steine, MD, PhD, was published in the March 2011 issue of the *American Heart Journal*.

### Calcium Research to Follow

A study published in April in the online edition of the *British Medical Journal* raised some questions about the safety of taking calcium supplements. A group from the University of Auckland in New Zealand reanalyzed data from the Women’s Health Initiative Calcium/Vitamin D Supplementation Study. They found a modest increase in the risk of heart attacks and strokes among the women taking supplements. Getting calcium through diet alone was not linked to any increased risk.

This information is controversial, but will probably lead to additional studies. It is something to be aware of and to talk over with your doctor. Commentators from the Mayo Clinic and Yale University suggest that people who currently take calcium supplements should

- Talk to their doctor.
- Do not stop taking the supplements especially if they

were prescribed to go along with a bisphosphonate or one of the other osteoporosis drugs.

- Try to get adequate calcium through their diet.

These studies only include information about postmenopausal women. Children and men were not included. The Women’s Health Initiative Study was done in the United States and involved 36,282 postmenopausal women. The study published in the *British Medical Journal* is titled “Calcium Supplements with or without vitamin D and Risk of Cardiovascular Events: Reanalysis of the Women’s Health Initiative Limited Access Dataset and Meta-analysis.” The authors are Mark Bolland, Andrew Grey, Alison Avenell, Greg Gamble, and Ian R. Reid.

### Proposed Ban on Latex Gloves

People who have OI and are sensitive to products containing latex will be interested to know that the advocacy group Public Citizen recently petitioned the US Food and Drug Administration to ban natural rubber latex gloves. Increasingly, these gloves are linked to causing allergic reactions in patients and in health care workers. Serious allergic reactions are also tied to inhaling the cornstarch often used to powder the gloves. Using powdered gloves is reported to also promote infections, delay healing and cause inflammation. Public Citizen reports that safer alternatives – powder-free and non-latex gloves – are now widely available. The FDA has not yet ruled, but this is news to watch.

### OIF Welcomes New MAC Members

The OI Foundation is pleased to welcome two new members to the Medical Advisory Council (MAC). Members of the MAC are highly respected medical professionals who donate their time and expertise to the Foundation. Many MAC members speak at the National Conference on OI, and participate in the Medical Consultation program at the Conference.



**Paul Esposito, MD,**  
*Children's Hospital,*  
*Omaha, NE*

#### **Paul W. Esposito, MD**

Paul W. Esposito, MD is Professor of Orthopaedic Surgery and Professor of Pediatrics at the University of Nebraska Medical Center, Department of Orthopaedic Surgery and Rehabilitation. He received his medical degrees from Hahnemann Medical College and Hospital in Philadelphia. Dr. Esposito completed internship and residency in orthopaedic surgery at the U.S. Naval Hospital in Oakland, California and a pediatric orthopaedic fellowship at Children's Hospital Medical Center in Cincinnati, Ohio. Dr. Esposito, a board-certified orthopaedic surgeon,

is an active member of the Pediatric Orthopaedic Society of North America, the American Academy of Orthopaedic Surgeons, and the American Academy of Pediatrics. He is a member of the board of directors of the US Bone and Joint Decade, having served as the AAP delegate to the USBJD International conference, co-chairman of the Pediatric Strategic Planning Committee. He is a manuscript reviewer for *PEDIATRICS* and has had research published in peer reviewed journals. He is past president of the medical staff at Childrens Hospital and Medical Center in Omaha, and has been listed among America's Best Doctors since 1998.

Dr. Esposito's special interests are children's extremity deformities, osteogenesis imperfecta, congenital and developmental disorders, cerebral palsy, and the musculoskeletal impact of childhood obesity.



**Cathleen Raggio, MD,**  
*Hospital for Special*  
*Surgery, NY, NY*

#### **Cathleen Raggio, MD**

Dr. Raggio specializes in general pediatric orthopedics, scoliosis, and the treatment of osteogenesis imperfecta and skeletal dysplasia and is the Co-Director of the Kathryn O. and Alan C. Greenberg Center for Skeletal Dysplasias at Hospital for Special Surgery. Dr. Raggio completed her residency in orthopedic surgery at Hospital for Special Surgery and fellowship in pediatric orthopedic surgery at Alfred I. duPont Hospital for Children. Known worldwide throughout the medical community, Dr. Raggio performs basic science and clinical research on the etiology of scoliosis, osteogenesis imperfecta, osteoporosis, and skeletal dysplasias.

### OI Foundation— A Founding Member of the National Bone Health Alliance

Established in 2010, the National Bone Health Alliance is a public-private partnership that brings together the expertise and resources of various partners across a broad spectrum to promote bone health and prevent disease; improve diagnosis and treatment of bone disease; and enhance bone research, surveillance and evaluation. In addition to the OI Foundation, founding members include the American Association of Orthopedic Surgeons, the American Society for Bone and Mineral Research, the Health Monitor Network, the National Osteoporosis Foundation and the Paget Foundation for Paget's Disease of Bone and Related Disorders.

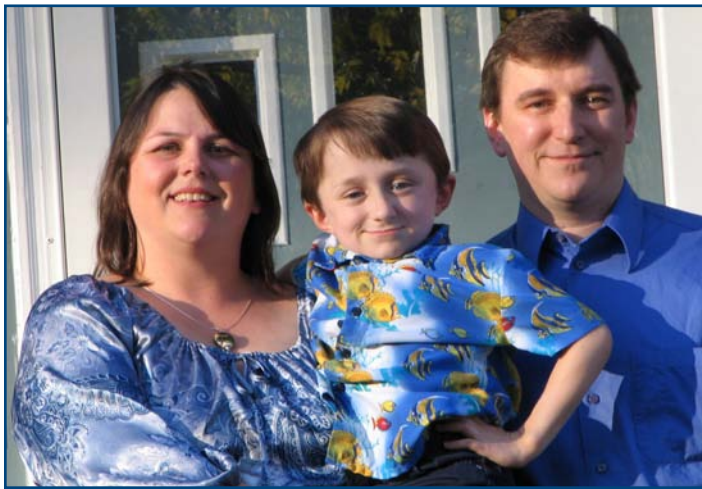
Recently, the National Bone Health Alliance announced the launch of a new website and PSA campaign. The website can be found at [www.nbha.org](http://www.nbha.org). The public awareness campaign will launch with a public service announcement running in the May 2011 issues of *Better Homes and Gardens*, *Family Circle* and *Ladies Home Journal*.

# People & Events

***The Sharrock family of Chattanooga, TN, is the 3rd OI family to be featured on the season finale of Extreme Makeover: Home Edition May 15, 2011. This is their story of how everyday life can hold the possibility of a miracle.***

*By Michael Sharrock*

Ours is an ordinary family. My wife and I both work and have barely kept the bills paid. We live with medical problems, like most families. My wife is hearing impaired and my son has O.I. type III. Like any parents, we sometimes argue. Like any child, Patrick misbehaves on occasion. Our half-century old home had been falling apart for the past 20 years or so. Walk 10 minutes from our house in any direction and you will see a home as bad or worse. My car smokes, leaks everything and half its electronics are broken. We are neither the founders of any organization nor heroes of any calamity. In short, we're common.



*Cindy, Patrick and Michael Sharrock*

So, when Ty Pennington and the gang from ABC's "Extreme Makeover Home Edition" surprised us at Patrick's homeschool science class, I was numb with shock! Sure, we recycle, help a few charities, show compassion for the strife of others and try to be good . . . But, why us? Who are we?

I struggle to understand our good fortune. Others tell me that anyone who has ever met Patrick "gets it" right away. Despite 59 fractures, multiple surgeries and countless out-of-state hospital trips, Patrick beams with happiness! He spreads joy and smiles wherever he goes. Everyone knows and loves him. And when some people talk to me about how glad they are that Cindy got a house, they cite her big heart, her belief that most people are naturally good, and her strength and endurance when times get bad. . . . Many of the reasons I married her.

We applied for a "Makeover" only a few months before it happened. A dear friend of ours pushed us to try it after Patrick shared his popcorn with her and eloquently told her all of our home's problems. When our local papers reported that "Extreme" was in town, we got excited, but we knew hundreds near us had applied. We learned that Lock and Key Productions had asked around for names in our area and "Patrick Sharrock" kept coming up.

The process was amazing! ABC needed about 2,000 volunteers. They had to stop taking names at 6,800! Northwest Georgia and Chattanooga really turned out in mass to help with food, labor, services and donations. Our wonderful neighbors gave up their lawns and privacy to onlookers, trailers and heavy equipment. Everyone we knew came to take part. They sent us on vacation to Walt Disney World Resort in Orlando, FL. Then, somehow, they built our dream house in one week!

The designers put great care into accommodating Patrick. There are wide open spaces, smooth cork floors, low sinks and counters, a customized full bath for him, a therapy pool and level outdoor sidewalks and play areas.

For my wife and me, they installed a security camera system for keeping track of Patrick. There is a special alarm system for the deaf that lets Cindy know if anything unusual happens in the house without me there. And, for our "peace of mind" the decor brings the outside inside, so we don't go stir crazy if Patrick is hurt and stuck at home.

The impressive list of benefits and features is almost as long as the list of donors and volunteers. They are too many to mention. Vision Homes and the "Big Hearts Wear Hard-Hats" team led a vast army of some of the greatest people in



*continued on page 14*

# People & Events

## Sharrock Family Extreme Home Makeover (continued from page 13)



the world! They have worked wonders here. They brought a community together in joy and kindness. Many strangers formed bonds and new friendships.

We have been humbled and are seeking ways to pay it forward. Patrick helped make a public service announcement for "Kids Like You, Kids Like Me." Cindy has gotten involved in leadership for walks for the hearing impaired and Easter Seals. I have begun contacting different groups for a fall "super hero" themed fundraiser for the Osteogenesis Imperfecta Foundation (OIF) to be called something like "Battle of Brittle Bones." This is only in its earliest stages, but I am excited about the potential.

In summary, our limits have been expanded by what was done for us. We have Don Gardner Jr., the Grys family and OIF to thank for advising the designers and our entire community to thank for rising to the challenge with amazing force.

Thank You!

Michael Sharrock

## Alle Shea's Unbreakable Spirit

In April of 2009 Alle Shea, was born with a rare genetic bone disorder, Osteogenesis Imperfecta. Many people can live a very long life having OI but within 5 weeks her parents, Kim and Angelo Collazo, were in mourning. Alle Shea's unbreakable spirit has sparked them to become advocates for this bone disorder. In August 2009, approximately 150 supporters and a variety of Rochester-area businesses helped the inaugural *Alle Shea's Walk-n-Wheel for Better Bones* to raise more than \$11,000 for OI. This walk-n-wheel event and family fun day celebrated its third year on May 14th, 2011; during OI Awareness Week. The Foundation's CEO, Tracy Hart was there to present the President's Award to Kim and Angelo Collazo for their hard work in supporting the mission of the OI Foundation.

"We wanted to honor her memory. We wanted to show her fighting spirit," said Angelo Collazo. Alle Shea's spirit is unbreakable and will continue to live on through her younger sister Ella and the unstoppable determination of her parents to spread awareness about OI.



*Tracy Hart, OIF CEO, presenting the President's Award to Kim and Angelo Collazo.*

# People & Events

## Dr. David Vernick to be Recognized for Service to OI Community

*Award will be Presented June 4 at Unbreakable Spirit walk in Framingham, MA*



*David Vernick, M.D.*

Twenty years ago, Richard (Dick) Wyman was facing OI-related hearing loss.

In 1991-1992, Dick was treated by David Vernick, MD, a hearing specialist who also was the first surgeon in New England to use a new laser procedure in middle ear surgery. Recognizing that many other individuals with OI also deal with hearing difficulties, Dick submitted Dr. Vernick as a candidate for the OI Foundation's Medical Advisory Council (MAC) and subsequently, Dr. Vernick was invited to join.

For 20 years now, Vernick has spent hours volunteering his time to the Foundation and to the OI community in a variety of ways. In addition to serving on the MAC, this well-respected specialist and surgeon has regularly answered e-mails from members of the OI community with concerns about their hearing, made presentations for families at the biennial National Conference on OI, and participated in regular scientific meetings organized by the OI Foundation, all on a volunteer basis.

**In recognition of this distinguished service to the OI community and the OIF Medical Advisory Council, Dr. Vernick will be presented with an Unbreakable Spirit Award by the OI Foundation.** The presentation will take place on Saturday, June 4, during the *7th Annual MA Unbreakable Spirit Walk for OI* at Framingham State College's Maple Street Field from Noon – 4 p.m.

Dick Wyman, who along with his daughter Christine Wyman Rossi and the rest of their family, hosts the annual Massachusetts walk event, nominated Dr. Vernick for this award.

*"This (service) speaks volumes about the person he is and his willingness to help in any way he can,"* Wyman explained. *"I have attended most of his seminars at the OIF Conferences every two years, and I have seen so many people leave his seminars with hope that their hearing problems can be addressed."*

Dr. Vernick is board certified in Otolaryngology and has received subspecialty certification in Neurotology by the American Board of Otolaryngology. He has published numerous scholarly articles, published chapters and reviews and written books and monographs on hearing, hearing loss, temporal bone malignancy, and otosclerosis. He is currently an assistant clinical professor of Otology and Laryngology at Harvard Medical School.

When asked about his volunteer work for the OI community over so many years, Vernick pointed out that as a group, individuals with OI are disproportionately represented among patients with hearing loss. Further, the laser procedure in middle ear surgery that he performs is often easier and safer for people with brittle bones than traditional forms of surgery.

*"It is a great community,"* Vernick said. *"I get lots of positive feedback in [assisting members of the OI community.]"* He stressed that the people he's worked with are interested in the information he offers about hearing loss and strategies for mitigating or correcting it.

He added, *"I've always enjoyed teaching, so it's a good match in that way."*

**If you would like to participate in the 7th Annual MA Unbreakable Spirit Walk for OI and join Dr. Vernick as he is honored by the OI community,** please register at [www.oif.org/MAwalk2011](http://www.oif.org/MAwalk2011). For more information, contact Christine Wyman Rossi at [c.rossi@verizon.net](mailto:c.rossi@verizon.net) or OI Foundation Development Coordinator Gretchen Schock at (800) 981-2663 or [gschock@oif.org](mailto:gschock@oif.org).

## The OI Foundation Congratulates All Graduates of the Class of 2011!



### **Richard Curtin, Afton, New York**

Graduating from Afton High School in June, with one certificate under his belt in autobody collision repair and being student of the quarter not once but twice, Richard plans to attend a vocational school in Masonville, NY for automotive repair.

**Jessica De La Rosa.** Jessica graduated from John Jay University in New York, NY, with a degree in Security Management and minor in Art. She took a year off to have surgery done and plans to go to Hunter to continue her studies so that she can become an art therapist for children with Autism.

**Lillie Christine Emmelhainz, Lake Butler, Florida.** Lillie graduated from the University of Florida Agriculture College Life Sciences on May 1 with a Bachelor's Degree with honors. She will start medical school in August. She was an ambassador, member of Golden Key International, Honor Scholar recipient (3.75 grade point average or better), scholarship and leadership awards, Florida Rural Rehab Corporation Scholarship.

**Tabitha Hope Aelee Stoffel.** Tabitha is graduating from Murray State University Murray, KY, with a Bachelor of Science in Business Administration and will be employed by Data Records Management Systems in Paducah, KY. She is planning to return to school for her MBA.

**Katherine Klimitas.** Katherine will be graduating summa cum laude from Loyola University New Orleans in May. Her degree will be in graphic design, and after school she plans to freelance. Art has always been a part of her life, and her website URL is kakartnola.com.

**Trisha Stouder.** Trisha is graduating from college with her Bachelor's Degree in social work. She is 21 years old.

**Joanne Unsworth.** Joanne is graduating from Edgehill University with a degree in Children's Nursing, BSC Honors. She has a job at Alder Hey Children's Hospital as a scrub nurse. Her special achievements include completing her degree while looking after her now 14 year old son with OI, as well as three other daughters.

**Emily Voorde, South Bend, Indiana.** Emily graduates from high school in May. She will be attending the University of Notre Dame and studying math.

## 19 New Impact Grants Awarded

This spring, the Children's Brittle Bone Foundation (CBBF) and the OIF awarded 19 new Impact Grants, for a total of \$150,000. Applications that received funding included accessible vehicles, emergency dental surgery, wheelchair ramps, hearing aids, and water therapy. Since 2009 the Grants Impacts have awarded more than \$215,000 in grants for services and products for people with osteogenesis imperfecta.

A new application cycle will open in the winter of 2011 and details will be posted on [www.oif.org](http://www.oif.org), and announced in future issues of *Breakthrough*.



CHILDREN'S BRITTLE BONE FOUNDATION



# People & Events

## Our 20th Beefsteak and Still Going Strong

By Rosemarie Kasper, NJ Support Group Co-Leader

Back in 1992, Jo Ann Berkenbush and I were exploring possible ways to raise funds for the OI Foundation. This was a dilemma because at that time we knew few people with OI in the NJ area and my own family was very small. Therefore, we needed a project not requiring extensive physical effort by a large number of people.

We had heard about “Beefsteak Dinners” whereby a caterer was hired to do all of the cooking, set up, and serving. They had become quite popular and everyone raved about the food. After making a number of contacts, we decided to give it a try. We hired Nightingale Catering, the best caterer in the area, had the help of a good friend in finding a hall, set the date and had tickets printed. We were on our way.



*Fran McLean, Ann Marie Geiger, Larry Greuninger*

Since we decided to have a tricky tray to add to the attractiveness of the event, searching for donations was a primary effort along with selling tickets. The event soon became a nightmare, as ticket sales proceeded slowly – so slowly that I became convinced there would be NO profit. Jo Ann assured me that most people purchased tickets at the last minute. She was right. By the evening of the dinner, we sold 112 tickets and we raised \$2,195!

Even better, everyone had a great time and asked when our next event would be! We had indeed picked a terrific caterer whose all-you-can-eat filet mignon was top quality, and we also had a fine selection of prizes. The next couple of years produced similar results, but gradually our attendance began to increase. In 1998 we moved to a larger, more attractive hall and our profit jumped to \$9,528. With Bev Krudys and her loyal group now on board, the following year we moved once again, to the beautiful Three Saints Cultural Center in Garfield,

where we remain. It also is now truly accessible due to their renovation of the restroom.



*Beverly Krudys with Beefsteak prizes*

Over the years, we have made several adjustments, including a silent auction and we now give away hundreds—rather than just a handful—of beautiful prizes. At our largest event, 415 people helped us to raise more than \$21,000, and our grand total of the 19 events is well over a quarter million dollars for OI! With our 20<sup>th</sup> anniversary coming up on October 22<sup>nd</sup>, our “Bone China Beefsteak” will be a celebration of our many supporters and their outstanding loyalty and generosity.



*Beefsteak silent auction table*

**WE INVITE EVERYONE TO JOIN IN THE CELEBRATION BY ATTENDING IN PERSON IF POSSIBLE, DONATING A PRIZE, OR SENDING IN A DONATION. ALL DONATIONS ARE TAX-DEDUCTIBLE AND GREATLY APPRECIATED!**

## People in the News

***People living with Osteogenesis Imperfecta are making headlines and increasing awareness about OI, showing their unbreakable spirit in their process!***

### **Bev Krudys**

A total of 11 persons from Bergen County, NJ, were honored recently for their efforts to support and advocate for people with disabilities. Sponsored by the Bergen County Division on Disability Services, this was the 12th annual event which continues to grow in prestige and popularity. It is just one of many programs developed by Director Jim Thebery, who presided over the event and presented the awards.

Osteogenesis Imperfecta (OI) supporter Beverly Krudys from Garfield has worked loyally for many years to ensure the success of the NJ OI Support Group's annual Beefsteak fundraiser. Bev's grandson

has OI, and through the efforts of Bev and her dedicated family and friends, the Beefsteak has thrived. Throughout the year, and year after year, she either purchases or solicits donated items to fill countless gift baskets which she also tirelessly decorates. Jewelry, figurines, gift cards, stuffed animals, gourmet food, appliances—the array of items is endless and fills her garage so that there is no space for her car. This labor of love is just the beginning as Bev also sells more than 100 tickets to the event, which raises funds for member services and research for a cure.

In accepting her plaque, Beverly said “Thank you very much. I am very honored to be chosen for this award.” And we are very honored to have Bev as a vital part of OIF.

### **Lea-Rachel Kosnik**

Dr. Kosnik was recently profiled in in the St. Louis, MO, *Jewish Light* online journal. She is an environmental economist who is an expert in renewable energy sources and an assistant professor at the University of Missouri in St. Louis. She advocates for clean air and water and works on practical solutions. As a scientist and a woman living with OI, Dr. Kosnik displays an unbreakable spirit.

### **Ismael Varga**

By all reports, 6-year-old Ismael Varga stole the show when he testified before members of Congress in March 2011. Escorted by his mother Patricia Varga and Dr. Daniel Green, his orthopedist, Ismael spoke about the need for research for OI and other similar problems. The youngest of the speakers at the event sponsored by the American Academy of Orthopaedic Surgeons, he impressed people with his message and his spirit.

### **Brianne Schwantes**

*Success Magazine* featured a story “Fragile Bones, Bold Ambition” about Brianne who is currently a graduate student in Milwaukee, WI. The profile emphasizes her devotion to volunteer work, her work as an advocate and her “can do” attitude. Since the age of 8, she has volunteered her time and talent in many venues including the National Institutes of Health, the Heart of American Foundation, the Red Cross and Give Kids the World. We wish Brianne every success in her next ventures.

## *Author Corner*

**Information about authors and books connected to living with OI**

### **What is it like to be stared at?**

By Judy K Johnson

This children's book is a story about Daniel, who has OI, and Andy who struggles to change his “staring” habit into a “caring” habit. The story shows how thoughtfulness is the best way to building a friendship.

Author and illustrator Judy K. Johnson creates custom children's books about real children with disabilities. Daniel is a real boy who has a severe form of OI. The book can be previewed and/or ordered through Ms. Johnson's website [www.ThoughtfulChildrensBooks.com](http://www.ThoughtfulChildrensBooks.com).

*Disclaimer: This information is provided as a service. The OI Foundation did not participate in the preparation of this book. All of the information and opinions expressed in this book is the responsibility of the author.*

Readers are encouraged to contact [Bonelink@oif.org](mailto:Bonelink@oif.org) to suggest a book or author to include in future columns.

# People & Events

## Creating Awareness Across the Country

An enormous “Thank You” goes out to our entire OI community; the first-ever OI Awareness Week would not have been possible without your support.

May 9-15, 2011 was jam packed with OI Awareness activities that included 8 Blue Jeans for Better Bones day campaigns in schools and offices around the US. Four *Unbreakable Spirit Walk for OI* walks and the *11th Annual Fine Wines Strong Bones* in Washington, DC, also were a huge success! Over 500 OI Awareness Week posters were distributed throughout the country and the Foundation’s CEO, Tracy Hart along with board and other community members had a successful advocacy day on Capitol Hill. The week concluded with the *Extreme Makeover: Home Edition* viewing party in Chattanooga, Tennessee which featured the Sharrock family.

The Foundation was also granted proclamations by the Governors of Kentucky, Maryland, Illinois and Georgia in honor of Awareness Week. Thank you again to everyone who participated in Wishbone Day and OI Awareness Week!



OIF Board Member Michelle Duprey, OIF CEO Tracy Hart, and OIF Development Coordinator Gretchen Shock at the 2011 Fine Wines Strong Bones



The McNutt Family selling raffle tickets at the 2011 Fine Wines Strong Bones



Longtime OIF volunteers Kyle Mulroy and Katrina Bache at the 2011 Fine Wines Strong Bones



MH/MH Cheerleaders at the Atchison, KS, Unbreakable Spirit Walk

# People & Events

## Countdown to Conference 2012!

The next National Conference on OI will be held July 13-15, 2012 in Washington, DC! The National Conference is a 3-day event filled with social and educational activities for all ages. Even though the Conference is a year away, it is never too early to start planning your trip! The full conference will be held at the Crystal Gateway Marriott, located at 1700 Jefferson Davis Highway in Arlington, Virginia. Arlington, VA, is situated directly across the Potomac River from downtown Washington, DC.

### Plan your Travel

With airfare at an all-time high, planning a trip early will save you money! Start shopping for travel deals by checking out discount airfare websites like [www.priceline.com](http://www.priceline.com) and [www.kayak.com](http://www.kayak.com). Many sites offer email alerts when prices drop for your destination of choice. Websites like [www.travelzoo.com](http://www.travelzoo.com) will also email you travel deals on a daily or weekly basis.

If possible, consider other modes of transportation like busses and trains. Both Greyhound and Amtrak have customer service departments designed to assist travelers with disabilities.

Greyhound Customers with Disabilities Travel Assistance Line  
Phone: 1-800-752-4841 Website: [www.greyhound.com](http://www.greyhound.com)

Amtrak Reservations  
Phone: 1-800-872-7245 Website: [www.amtrak.com](http://www.amtrak.com)

When you book your travel, be sure to discuss any special needs, such as traveling with oxygen or a power-wheelchair, with your transportation provider.

### Budget for Conference Registration and Hotel Rooms

The hotel room rate for the Conference will be \$149 per night. The hotel will begin accepting room reservations for the Conference in the Fall of 2011. Remember, if you need an ADA room, please book your hotel room early! Accessible rooms are limited and on a first come, first serve basis.

Conference registration rates have not been confirmed, but will be announced in the Enews, *Breakthrough* and on [www.oif.org](http://www.oif.org) when they are available.

### Plan your stay in Washington, DC

Whether you want to see the National Monuments, visit the Capitol Building, or spend an afternoon at the National Zoo, Washington, DC, is a great vacation destination!

The Washington, DC, Convention and Visitor Bureau's website, [www.washington.org](http://www.washington.org), is a great place to begin your search for attractions and tours.

While Washington, DC, is known as an accessible city, it can be helpful to research locations you choose to visit before your trip. <http://www.disabilityguide.org/museums.html> has a thorough review of accessibility at many popular attractions.

We look forward to seeing you in at the 2012 National Conference on OI in Washington, DC!

Are there session topics or social activities you would like to see as part of the 2012 Conference? Email [eruebensaal@oif.org](mailto:eruebensaal@oif.org) with your suggestions!



# Osteogenesis Imperfecta at Kennedy Krieger Institute

Leaders in OI Patient Care and Research

Part of an internationally recognized institute in Baltimore, Md., the Osteogenesis Imperfecta Clinic at Kennedy Krieger is dedicated to improving the lives of the children, adolescents, and adults we serve. Our comprehensive team of medical professionals takes an interdisciplinary approach to diagnosing and treating osteogenesis imperfecta (OI), ensuring that our patients receive the highest quality care available.

## The team:

Our interdisciplinary clinic includes team members from:

- Endocrinology
- Orthopedic surgery
- Radiology
- Physical therapists
- Psychiatry
- Nursing
- Nutrition
- Dentistry (in partnership with the University of Maryland)
- Social services

## Our services:

We offer the latest in OI care, including:

- State-of-the-art treatment aimed at increasing bone density and decreasing fractures
- Biochemical testing
- Genetic analysis and counseling
- Growth parameters
- Bone density evaluations through onsite DEXA scanning
- Audiology to evaluate hearing loss (common to OI)
- Dietary recommendations to improve bone strength
- Orthotic device fittings
- Social work
- Out-of-state consultation



## Leaders in OI Research:

To find out about ongoing OI research at Kennedy Krieger Institute, call 443-923-9180 or email [oiregistry-manager@kennedykrieger.org](mailto:oiregistry-manager@kennedykrieger.org).  
TTY: 443-923-2645

In addition to our high-quality clinical services, our Osteogenesis Imperfecta Registry sets us apart by helping us incorporate the latest OI research into our patients' care. As with many rare disorders, one of the obstacles to researching OI is the difficulty of finding study participants. But today, more than ever before, people with OI have opportunities to participate in research. Joining the OI Registry is one important way to help enhance the progress of OI research.

## Kennedy Krieger Institute

707 N. Broadway  
Baltimore, Md. 21205

Telephone: 443-923-2703

Visit us online at [www.osteogenesisimperfecta.org](http://www.osteogenesisimperfecta.org).

Jay R. Shapiro, M.D., Director  
Emily Germain-Lee, M.D., Associate Director



Kennedy Krieger Institute



## FROM THE INFORMATION CENTER

### Exercise Video for Adults Who Have OI

A new exercise video is now available on the website for the Hospital for Special Surgery in New York City. This program intended for adults who have OI who spend most of their time in a wheelchair or seated was created by Dr. Cathleen Raggio an orthopedist and member of the OI Foundation's Medical Advisory Council and Frances Baratta-Ziska a physical therapist in the HSS rehabilitation department. To view the video go to the Hospital for Special Surgery website [www.hss.edu](http://www.hss.edu) or try this link [http://www.hss.edu/conditions\\_wheelchair-based-exercises-osteogenesis-imperfecta.asp](http://www.hss.edu/conditions_wheelchair-based-exercises-osteogenesis-imperfecta.asp). Dr. Raggio stated, "The goal of this exercise program is to improve muscle strength, endurance, flexibility and coordination." The precautions section of the video reminds that it is important to check with your doctor or PT before starting a new exercise program and to never do a movement that is painful.

### Update: Barriers to Leisure Study

In early April adults who have OI living in the United States and the United Kingdom were given the opportunity to participate in a survey about access to leisure time recreational activities. The survey was designed as a research project by university student Ms. Gursharan Kaur. Both the OI Foundation and the Brittle Bone Society participated. Here are the results of the survey.

- 504 people responded, 360 women and 144 men
- 58% reported participating in a leisure activity outside the home at least once a week
- Barriers to participating in order of significance included: Inadequate accessibility, Cost, Need to be accompanied, Fear of injury, Concern over lack of understanding about OI and Concern about lack of welcome for a person with a disability
- 52% reported that they had not lodged complaints or made suggestions to improve access or service
- 69.5% indicated that they were not aware of programs for inclusive leisure activities in their area.

Based on her survey Ms. Kaur reported that people who have OI were making a significant effort to participate in leisure activities. She also concluded that people with OI could help improve access to leisure activities by making suggestions for improvements to the activities they care about, making an effort to learn about activities that already exist in their communities, but which may be poorly advertised, and by participating in OI awareness activities in their local communities.

### Adoption

The OI Foundation has an Adoption Page on its website. Go to [www.oif.org](http://www.oif.org), click on the Resource tab and then on Adoption. This page has information about the adoption process as well as contact information for children who have OI who are available to be adopted. All information is provided by registered adoption agencies and is updated with the help of volunteers Jean Grys and Sandy Roberts. If you or someone you know is interested in giving a child who has OI a home, please visit this page.

### Medication Safety

The Food and Drug Administration and the American Pain Foundation are encouraging people to safely dispose of medicines that are expired or are no longer needed.

- Check with your pharmacist before flushing a prescription medicine; many should not be flushed.
- Medicines that can be put in the trash should be mixed with used coffee grounds or kitty litter and sealed in a plastic bag.
- Always remove and destroy all personal information on the prescription label before discarding or recycling the container.

To find additional information on the safe use of pain medications and proper disposal visit [www.painsafe.org](http://www.painsafe.org).

### Sunday Night Chat

The OI Foundation sponsors an OI Chat Room on Sunday evenings from 8:00pm to 10:00pm EDT. The chat can be accessed from the OIF web-site under the "**Support Networks**" tab, then click on "**Chat Room**" and sign in. The Sunday evening chat is hosted by a volunteer and chatters bring up the topics they would like to talk about. It's usually an open chat and a lot of different things about OI and about living with OI are discussed. What's great about The OI Chat Room is that it's **real time** so you don't have to wait for responses. We know that there are a lot of different groups on Facebook these days but you should give the OIF Chat a try. Become one of our old friends who joins us every week. Let's get the conversation started, you never know who you might be able to help or who can help you.

*continued on page 24*

## Q&A

### Radiation Safety

Exposure to medical imaging that involves radiation is a fact of life for children and adults who have OI. Radiation is used for diagnostic testing including X-rays, CT Scans (computed tomography), and DXA tests for bone density. Other medical imaging tests are used for treating different illnesses, including cancer.

#### What is an X-ray?

Most people are familiar with X-rays. They are often needed to confirm that a bone is broken. In this test, a beam of ionizing radiation passes through the body and creates a two-dimensional picture.

#### What is a CT scan?

This scan requires a large machine that the patient passes through. The radiation beams are rotated around the body creating a three-dimensional picture. A CT scan gives more information about the inside of the body, but causes significantly more radiation exposure than the X-ray.

#### What is a DXA scan?

The dual-energy X-ray absorptiometry test or bone density scan is used to measure the amount of bone in a person's skeleton. Tracking bone mineral density is one way to measure how the skeleton changes with reduced physical activity, age or after treatment with a medicine such as a bisphosphonate

or one of the other osteoporosis drugs.

#### Special Precautions When OI is Involved

- X-ray technicians must not try to straighten bent arms and legs; parents will often need to help position their child for the test so there is no additional injury.
- Ask if the technique being used has been adjusted to the size of the child or adult.
- Appropriate sized shields will be needed – children may need infant size and small adults may need shields from the pediatric department.
- Adults will need to be self-advocates regarding positioning and shielding.
- If intravenous (IV) contrast medications are needed, they must be dosed by the size of the patient and not by age.
- If the child or adult has a history of needing multiple X-rays before the fracture shows up, talk with your doctor about immobilizing the bone when a fracture is suspected and taking an X-ray later.
- Body size needs to be taken into account when interpreting medical imaging tests, especially with the DXA.
- Talk with your doctor about the best strategies to ensure that hospital emergency room staff are well informed about the special needs of a child or adult who has OI.

#### What are the risks from medical radiation?

At this time, no one knows exactly how much radiation exposure from medical imaging might cause cancer. It is assumed that very low radiation doses are not a problem. Safety

experts report that the effects of radiation are cumulative, so they recommend reducing the dose to the lowest amount necessary to get the job done and to always take safety precautions. Because they are still developing, children and infants are more at risk from radiation exposure than adults.

#### How great is the risk?

We are all exposed to small amounts of radiation from natural causes every day. This is called background radiation. One way to understand the amount of radiation exposure in different exams is to compare radiation dose estimates using millisievert units (mSv). Using this scale, an airline passenger on a cross country trip receives 0.04 mSv of radiation exposure, a chest X-ray causes 0.01 mSv, natural background radiation averages 0.01 mSv, a foot X-ray 0.5 mSv, lumbar spine X-ray 1.3 mSv and a chest CT exposes the patient to 3 mSv of radiation. Despite the limitations of estimating radiation doses, the evidence suggests that the risk of developing cancer from a single exam is very small. But since a person who has OI will typically require more medical imaging tests than average, taking precautions to minimize risk is especially important.

#### How can risk be minimized?

- Image only when there is a clear medical benefit
- Use the lowest amount of radiation based on the person's size
- Image only the indicated area
- Avoid multiple scans
- Use lead shields to protect reproductive organs, including breasts, in children as well as adults
- Use alternative diagnostic studies such as ultrasound or MRI when possible

*continued on page 24*

# Health & Wellness

## Radiation Safety *(continued from page 23)*

- Keep track of your medical images. Cards available from the Pediatric Radiology Association [www.pedrad.org/associations/5364/ig/index.cfm?page=618](http://www.pedrad.org/associations/5364/ig/index.cfm?page=618) or [www.radiologyinfo.org](http://www.radiologyinfo.org) help track date, type of exam, and imaging center.
- Is the equipment checked yearly by a qualified medical physicist?
- Is the hospital or imaging center accredited by the American College of Radiology?
- The International Atomic Energy Agency has information for all patients <http://rpop.iaea.org/RPOP/RPoP/Content/InformationFor/Patients/index.htm>
- Radiology Information at [www.radiologyinfo.org](http://www.radiologyinfo.org)

## Good Questions to Ask

- Does the imaging center use appropriate low dose techniques? Does the center participate in ALARA “as low as reasonably achievable”?
- Will a board-certified radiologist and/or an orthopedist familiar with OI interpret the images?

## Where Can I get more information?

- The Alliance for Radiation Safety in Pediatric Imaging sponsors a program called “Image Gently” that promotes safe practices. Their booklet, “What Parents Should Know about Medical Radiation Safety” is available at [www.pedrad.org/associations/5364/ig](http://www.pedrad.org/associations/5364/ig)

Thank you to Dr. Paul Esposito and Dr. Terri Love, Children’s Hospital Omaha, NE, and Dr. Priscilla Wacaster, Cicopee, MO, for their assistance with this article.

## From the Information Center *(continued from page 22)*



## IEP Checklist App for your iPhone!

The Parent Educational Advocacy Training Center (PEATC) recently announced Version 2 of the IEP Checklist iPhone app. The IEP (Individualized Education Program) allows parents and schools to work together to support the educational needs of students with disabilities. The new iPhone app gives parents a quick reference checklist and information about completing an IEP. The app is free for iPhone subscribers.



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February 1, 2011 – April 30, 2011

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February 1, 2011 – April 30, 2011

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The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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The Annual Report is a yearly recap of the Foundation's activities, including financial, program, and research accomplishments. For more information, email [bonelink@oif.org](mailto:bonelink@oif.org).