

## Celebrate Your Unbreakable Spirit at the 2010 National Conference

With the 17th Biennial National Conference on OI quickly approaching, planning is in full swing at the OI Foundation's National Office. This year's Conference adds exciting new events including a birthday party to celebrate the Foundation's 40th Anniversary, and a private screening of a new film 'Broken Dreams', featuring Nicole Gerth, an actress with OI. The screening will be followed by a Q & A session with Nicole Gerth and Director David Crabtree. National Conference favorites like the Talent Show and Awards Dinner return to the program as well. With a full conference program, and a beautiful and interesting host city to explore, the OI Foundation is confident that the 2010 National Conference on OI will be one to remember.

### How to Register for the National Conference on OI

For the first time, attendees are able to register and pay for the National Conference online. To register for the National Conference online, visit [www.oif.org](http://www.oif.org), and click on the green 'Register for Conference Now!' button. The online registration program allows users to register all members in their party, receive instant email confirmation, buy Awards Dinner only tickets, and much more. The program also allows you to e-mail the Foundation directly if you encounter problems during the registration process.

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## Thank You and Congratulations to Our 2009 Volunteer Award Recipients



**2009 Thelma Clack Lifetime Volunteer Award recipient Frank Fossati poses with OI moms Marybeth Parke (center) and Michelle Hofhine at the Southern California Petroleum Industry Charity Association (SCPICA) Golf & Tennis Tournament on Nov. 13.**

**Frank Fossati, Christine Wyman Rossi and Rebecca Lee Perritt** are the 2009 recipients of this year's OI Foundation volunteer awards.

Selected for the **Thelma Clack Lifetime Volunteer Achievement Award**, Frank Fossati has served the OI Foundation for 24 years. Motivated by his love for individuals and families with OI, Frank has been at the helm of the annual golf and tennis tournament sponsored by the Southern California Petroleum Industry Charity Association (SCPICA). Through his efforts, the SCPICA has become the longest running charity event in support of the Foundation, raising over \$1,150,000. While officially holding the title of Treasurer, Frank oversees every aspect of the tournament. It is generally understood that without him, this annual event begun in 1986 would not be realized. A past recipient of the President's Award, Frank has continued to put others before himself in support of the OI community.

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The Thelma Clack Lifetime Volunteer Achievement Award is given annually to the volunteer who best exemplifies the qualities of loyalty and dedicated service to the

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## From the Chief Executive Officer

Dear Friends:

For those of us in parts of the country where snow has been plentiful, I think I can safely say that we are ready for spring! Thinking ahead to spring makes me think of all the wonderful events and activities the OI Foundation has planned, including this year's National Conference on OI! In this edition of Breakthrough you will find detailed information about the conference and instructions on how to register. We are excited to be launching our new on-line registration this year and from those that have already used it, we're getting great feedback. We hope that registering online will make the process easier for everyone. This year's conference is shaping up to be a wonderful event filled with new information and also a look back at how far we have come as we celebrate our 40th Anniversary in 2010. If you are a first time attendee, feel free to call the office if you have any questions or concerns.

In addition to the National Conference in July, the OI Foundation will be hosting our annual scientific meeting in April. This year's meeting titled, **Improving Musculoskeletal Outcomes for Individuals with Osteogenesis Imperfecta** is chaired by Dr. Laura Tosi, a pediatric orthopaedic surgeon, and Director of the Bone Health Program at Children's National Medical Center in Washington DC. Researchers, physicians and interested parties will come together to talk about ways to expand the focus of OI research to include problems faced in adulthood and to begin to develop outcome measures that will lead to the development of evidence-based protocols for the care and treatment of people living with OI. Many thanks to Dr. Tosi and her committee for putting together such an important meeting. And of course thank you to the Buchbinder Family Foundation for continuing to support this meeting and scientific research to help improve the lives of people living with OI.

Thank you to everyone for your generous support and for continuing to do what you do for the Foundation. Remember to visit our website at [www.oif.org](http://www.oif.org) to learn about new ways to become involved – a new support group may be forming in your area or we may be launching a new fundraising event that you might like to become involved with. There is always something going on at the OI Foundation and we welcome everyone to become involved!

Think spring everyone!

All my best,



## From the President

This is a great time of year. Spring is near and our 17th Biennial National Conference is less than four months away. Portland promises to be an outstanding conference with informative sessions and many planned activities. Our OIF staff is working very hard to provide a full and substantive agenda that strives to address the broad needs of our community. We hope that you enjoy this edition of Breakthrough. There is plenty of information about conference, excellent articles that highlight individual accomplishments and a number of other informative articles that we hope you find useful.

We were all very saddened by the sudden and premature death of our dear friend Neeru Sharma in January. I was fortunate to have the opportunity to pay my final respects and meet with Neeru's family and friends. Neeru was a former OIF board member, a role model to many and an advocate for the disabled. It was wonderful to witness the outpouring of affection and deep admiration voiced by so many. From a vice president at General Motors to a multitude of colleagues, friends and family, everyone shared wonderful memories of Neeru and her zest for life. We will miss our friend Neeru but we will never forget her Unbreakable Spirit and her legacy of service that will continue through the actions of others in our community.

Warmest regards,

# 2010 National Conference on OI

## Celebrate Your Unbreakable Spirit *continued from page 1*

Hotel reservations at the Portland Hilton & Executive Tower can also be made online. To book your hotel reservation online, visit the 'Hotel Reservation' section of the OIF Website Conference Pages, located under the 'Events' tab on [www.oif.org](http://www.oif.org). Please remember that with every hotel, there are a limited number of ADA rooms available. Please be considerate to fellow attendees and only book an ADA room if a standard room cannot accommodate your needs. Contact the hotel directly to discuss specific questions or special needs regarding guestrooms. Guestroom doorway measurements are as follows:

**ADA rooms in the main hotel building:** Entrance 35", Bathroom 36"

**Standard rooms in the main hotel building:** Entrance 33", Bathroom 31"

**ADA rooms in the adjacent Tower building:** Entrance 36", Bathroom 36"

**Standard rooms in the adjacent Tower building:** Entrance 36", Bathroom 33"

## Conference Program Information

What goes into the OI Foundation's National Conference? A lot! Some of the elements include: Talent Show, Person-to-Person Sharing Sessions, Birthday Party, Teen Center, Teen Information Program, Adult Late Night Socials, Book Signing, Resource & Exhibit Center, Child Care, Medical Consultations, Motivational Speakers, Awards Dinner, Clothing Swap, and 37 information sessions covering a wide variety of topics for parents and OI adults of all ages. The theme for the 17th National Conference on OI is "**Living Well with an Unbreakable Spirit.**"

This year the Foundation is celebrating its 40th Anniversary so past, present and future perspectives will be featured in many of the sessions. A complete list of daily activities, special events and speakers is posted on the OIF Website Conference Pages. Be sure to check this often because details will change as speakers and special activities are confirmed. The conference has been shortened by one day to help contain costs for the Foundation and for families.

Here's an outline of the conference program\*

### Thursday July 8

- Medical Consultation Day 8am – 4pm
- Welcome Reception — A reception for all attendees — 6-8pm
- Evening Social and Information Activities 8-11pm
  - OI the Basics with Dr. Peter Byers
  - Gemma Geisman Book signing and reading

### Friday July 9

- Program sessions from 8:30 am -3pm
- Person-Person-Sharing sessions 3:30-4:30pm
- Talent Show 7-8:30pm
- OIF 40th Birthday Party 8:30-9:30pm
- Movie screening 'Broken Dreams' (R-rated, adults only)

### Saturday July 10

- Program sessions from 8:30am -3pm
- Awards dinner reception 6-6:30pm
- Awards dinner 6:30-8:30pm

The Conference Information Center on the 2nd floor of the hotel will be open all day July 8-10. On July 8, a special information booth will be set up to answer questions about the program and to help people who are attending the conference for the first time. Materials from the Portland Visitor Center will also be available.

There will be a Teen Center open to young people ages 13 and up. It will feature a relaxed area for playing video games, watching movies and playing games. A series of speakers and activities just for teens is being planned.

\*The National Conference program is subject to change before July 2010.

## Medical Consultation Program at Conference

On Thursday, July 8, 2010 before the National Conference officially opens, a limited number of individual appointments for a conversation with an OI specialist will be available. This special feature offers people attending the National Conference the opportunity to have a specific OI related question answered by a medical expert. This program is especially geared for those who do not have access to OI specialists at home. The consultations will be free of charge. Appointments are limited so each person will be able to reserve time with only one or two of the specialists depending on the number of people who request an appointment.

This kind of appointment is very different from visiting an OI Clinic. **No examinations will be performed.** This is only a conversation. Your appointment is an opportunity to get a second opinion or get an answer for a particular question. Each appointment is 30 minutes long. All appointments are held at the conference hotel.

Appointments will be scheduled on a first come basis. There are three ways to request an appointment:

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# 2010 National Conference on OI

**Celebrate Your Unbreakable Spirit** *continued from page 3*

- Call the OI Foundation office at 301-947-0083 or 800-981-2663. Be prepared to answer the questions on the Appointment Request form posted on the foundation web site.
- Print the Appointment Request form from the foundation web site and fax the complete document to 301-947-0456
- Copy the web site form into an e-mail and send to [mhuber@oif.org](mailto:mhuber@oif.org)

After your request has been received, a "Patient Information Form" will be sent to you by e-mail. This form must be returned to the OIF before your appointment can be confirmed. All appointments will be confirmed by April 6. Depending on which specialist you wish to see you will be asked to bring along test results, or digital x-rays. Every effort is made to fill as many requests as possible. If you have questions about this special program contact Mary Beth Huber at the OI Foundation office at telephone 800-981-2663 or by e-mail at [mhuber@oif.org](mailto:mhuber@oif.org).

Each doctor is an expert in his or her area and many are members of the OI Foundation's Medical Advisory Council (MAC). Specialists include experts in Genetics, Women's Health, Hearing, Orthopedics, Adult Health and Physical Therapy. New this year, Dr. James Hartsfield, DDS, PhD, will be available to answer dental questions. All of the specialists who participate in this pre-conference special program will be speaking during the conference. For more information about each physician visit the OI Foundation web site Conference Pages.

## Conference Scholarships

The OI Foundation has obtained funding, primarily through individual contributions for a limited number of scholarships to the National Conference on OI. All those wishing to attend conference but are unable to due to financial limitations are encourage to apply.

Families and individuals are encouraged to explore all possible sources of funding. In some cases money to help people attend conferences about rare health disorders, like OI, is available from state agencies, school systems or community organizations.

- Consult with school counselors, your child's local special education department, hospital social workers, case workers and members of your network group.
- If on Medicaid, contact your case worker to see if you qualify for ongoing educational training.
- State resources (variously named, Consumer Investment Fund, Consumer Involvement Fund, etc.) as listed on the state's web site.
  - Tips for state funding search: Go to the state website ([www.statename.gov](http://www.statename.gov)). Type in DD council or disability. Look for Consumer Investment Funds or conference stipends. If that is not helpful call the state office and ask if they have funds available.
- Confer with your tax advisor. According to PUB 502 (2007), people who itemize their deductions can include paid admission and transportation to a medical conference concerning a chronic illness of a family member. The majority of time spent at the conference must be spent attending sessions on medical information. Lodging and meals are not deductible.
- Investigate web sites such as:
  - Family voices: [www.familyvoices.org](http://www.familyvoices.org)
  - Parent-to-Parent: [www.taalliance.org](http://www.taalliance.org)

Applications are due by March 15, 2010. Scholarships recipients will be notified by April 12, 2010. To download the scholarship application, please visit the OIF Website Conference Pages.

For questions about the National Conference, please call the OI Foundation at 800-981-2663 or e-mail [conference@oif.org](mailto:conference@oif.org). See you in Portland!

## OIF Creates New Product Mall

In January, the OI Foundation launched a new community feature call the Product Mall. The Product Mall allows users to sell, buy, or give away products to other members in the OI Community. Products can be anything from a used wheelchair, to clothing or other items of interest for people with OI. Visit [www.oif.org](http://www.oif.org) and click on the 'Community' tab to see what's listed or post your own items.



# 2010 National Conference on OI Talent Show Application Friday, July 9<sup>th</sup> at 7pm

The talent show is opened to registered conference attendees of all ages, and all members of the OI community, including family and friends. All acts should be limited to 2 minutes.

NAME OF ACT (be creative!) \_\_\_\_\_

NAME (S) \_\_\_\_\_ AGE\* \_\_\_\_\_

\_\_\_\_\_ AGE\* \_\_\_\_\_

\_\_\_\_\_ AGE\* \_\_\_\_\_

\_\_\_\_\_ AGE\* \_\_\_\_\_

Attach an additional sheet, if necessary. \*optional – adults may just say “adult”

CONTACT PERSON FOR THIS ACT \_\_\_\_\_

PHONE \_\_\_\_\_ E-MAIL \_\_\_\_\_

DESCRIPTION OF ACT \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

MUSIC: SONG AND ARTIST, IF APPLICABLE \_\_\_\_\_

LENGTH OF ACT \_\_\_\_\_ MINUTES

EQUIPMENT NEEDED:  TAPE PLAYER  CD PLAYER  PIANO

Accompanying music must be provided on either CD (preferred) or cassette tape and brought to rehearsals. The dates and times for rehearsals will be listed in the Conference program book. The OI Foundation cannot supply musical instruments (other than one piano) or other props; please bring your own.

OTHER COMMENTS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

STAGE CREW: I am not interested in performing, but would like to volunteer to assist.

Name \_\_\_\_\_

Name \_\_\_\_\_

**Please return form no later than June 11 to:**

OI Foundation

Talent Show

804 W. Diamond Ave, Ste 210

Gaithersburg, MD 20878

Fax: 301-947-0456 or E-mail: [conference@oif.org](mailto:conference@oif.org)

Questions? Call 800-981-2663 or E-mail: [conference@oif.org](mailto:conference@oif.org)

*Disclaimer: Space is available on a first come, first serve basis. Some acts may be modified to fit the available time.*

## Spotlight: Chaz Kellem

Teach, educate and make your life valuable. Working for the Pittsburgh Pirates as Manager of Diversity Initiatives within the Community and Public Affairs Department, 26 year old Chaz Kellem has found a forum within which to live by these words.



With a lifelong interest in sports and with a degree in Sports Administration from Edinboro University, working for the Pittsburgh Pirates offers the opportunity to be

immersed in work that is truly gratifying and of lifelong interest. It was in middle school that Chaz began to understand the sports world from a business and management perspective, crediting his gym teacher with providing the opportunity to help out with the teams he coached, and encouragement through recognition of his efforts.

When asked what he likes most about his job, Chaz responded, "I like coming to one of the best ballparks in the country to work every day. I enjoy the challenge of creating new programs and events. I love being able to impact the life of a young child through one of our initiatives. I also find it enjoyable to work in diversity which is a new field that is growing."

Experiencing the Pittsburgh Pirates as a wonderful place to work, and grateful for the opportunity to spread his wings and show what he can do, Chaz hopes to continue to influence the organization, to impact and change his region and "to make Pittsburgh a wonderful place to live in, have fun in, and work in."

Not only involved in the creation of programs, Chaz is an active participant. He coaches wheelchair basketball and plays second base for Pittsburgh's only wheelchair competitive softball team. Chaz notes that "wheelchair sports have been a blessing to have as I have seen many parts of the United States that I would not have seen."

Believing in the importance of giving one's all and just "showing up," it is no surprise that Chaz is involved in his community outside of work and sports. He serves on several non-profit boards, including the Edinboro Alumni Board, Consumer Health Coalition, UCP Pittsburgh, and the Pennsylvania Youth Leadership Network. He also serves on various state and city committees for the governor and mayor. Additionally, Chaz is group leader for the OI Foundation support group in Western Pennsylvania.

Chaz credits his parents with providing inspiration and motivation to achieve his goals. "Without them, I would not have the strength, courage and will power. They have been a true blessing!" Always motivating him to be the best, Chaz considers his mother the rock of the family. Despite also having OI she keeps pushing through with a smile and a laugh. Chaz describes his father as an energetic firecracker, always available and encouraging him to work hard and improve his skills. "He has left a true and positive impression on my life."

Joycie Kellem wanted her son to experience a more open and free environment than she did as a child. While this may have resulted in more injuries, Chaz considered his fun childhood worth the price. As he matured, Chaz became more careful and smarter about the decisions he made. "I wanted to make sure I was included and involved as a student, so being injured would not allow me to do that." Now as an adult he is careful "very careful" and tries to keep his body strong through weights, sports and "as much movement, stretching, and using my bones/muscles as much as possible."

Chaz hopes to continue making an impact. Asked what he would like to share with teens, or parents or other adults who have OI, he has this to say, "Hang in there. Live moment by moment!" "We as people have a choice in the morning when we wake up, to be happy or miserable. Which will you choose?" "People are ALWAYS watching us. When you don't think someone is watching and learning from you, they are." "Teach, educate and make your life valuable."

## *In My Own Words*

### **Short Arms? No Problem!** ***A Brief Guide for Living Independently***

*By Priscilla Carlson*

Of all the things I've had to deal with from having brittle bones, probably the one that has always made me self-conscious is my arms. Even though Type III is fairly common among people with OI, I seemed to be one of the rare ones with shorter than average arms having very minimal strength. I was unable to reach anything. This not only affected my personal care, but also my sense of self-worth. Comparing myself to others I felt at a disadvantage. I was not as independent as others and was too ashamed to talk about it. Then an amazing friend convinced me that anything was possible and that I could be more creative and stronger than I thought possible! Three years later I am living in an apartment on my own with no personal assistant needed! It just took a little creativity, a few ingenious products and adaptations, and a whole LOT of patience.

My first step to independence came in the form of two reachers. One is a short, bright green table-use type of reacher. It is made out of plastic, so it's not the best at grasping heavy or smooth objects, but it is great for wiping the table, pulling stuff close to me, elevator buttons, and for turning light switches on and off. Plus, it's small enough to fit behind me in my chair. The second is extremely long with a magnetized end. It's very durable and has the ability to pick up things as small as a quarter or as big as a notebook. Books themselves are still tricky for me, but can be done if grabbing them by the cover and a few pages. I'm not necessarily a fan of the reachers that have suction cups on the end, but some of my friends swear by them. I have since expanded my collection and now have a folding reacher that expands out to reach the floor, which I store behind my back cushion. It is excellent when I'm by myself and drop something. If no one is around, I don't feel panic-stricken anymore. I also have a reacher for personal care, and I use a hair brush to shampoo my hair.

For the creativity aspect, it became a matter of thinking outside the box. First of all, I am lucky in that I found a wheelchair that can elevate up five inches. The Invacare Pronto M61 is not as swanky as the Permobil, but it is a lot more affordable and gives me more freedom than I had with other standard motorized wheelchairs. To reach sinks, I just open up the cabinet doors underneath, pull inside, rise up, and use my reacher to turn the faucet on and off. For the kitchen, I store small cups and plates in one of the drawers

instead of a cabinet. All of my top cabinets are completely empty, save for the spare light bulbs (which I'd need help with anyway), extra rolls of paper towels or packages of napkins (things that don't hurt when I pull them down with my reacher), and the owner's manuals for all of our appliances and electronics. Before my father visited and built shelves inside with space underneath, I used a cardboard box in each of the lower cabinets to stack my pots and pans and extra dishes on so that I could reach them. I only use the most lightweight kitchen items, which means never buying a "set" of anything. I use Melamine plates & bowls and smaller glasses. My coffee cups are smaller. If guests don't feel it's enough coffee, they can have another cup! I have access to my dishwasher on both sides and use my reacher to pull the drawers out and push them back in. I do have a roommate, so if there is something too heavy or if it's put in the center, she unloads the ones I'm unable to.

For the window blinds in the apartment, I bought an extra tilt wand for each blind and one roll of clear, plastic tubing. My friend cut the tubing to the length I'd need to reach each window and used this to attach the two wands. The result was a tilt wand as long as I needed it, and the freedom to open and shut my blinds whenever! I removed the doors from my bedroom closet so that I could get my wheelchair inside easier. One of my closet rods was already lowered. For the one that wasn't, a trip to The Container Store found a rod that can hang on another, so that makes an extra lower rod for me. Seldom worn items, such as old bridesmaid dresses, hang on the top. Because I can't change the bedding by myself, all extra sheets and pillow cases are at the top of my closet, leaving room for what I can use without help. A canvas sweater-holder hanging from the top closet rod is used to store bath towels. Because I'm smaller, I only use hand towels, which eliminates struggling with big towels that take up too much room and are hard for me to fold anyway.

Another consequence of my arms being short with very little strength is that I am unable to lift or support my own body weight. This always required having someone around to help with transfers in and out of bed, the shower, and for toileting. Luckily, I found a bed that's the same height as my wheelchair. I flip back a

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## *In My Own Words* (continued from page 7)

corner of the bed spread and sheet, scoot in, and in the morning, there's no big deal with making the bed. I just flip the corner back. A trip to Home Depot and the purchase of a few boards, a toilet seat, and some laminate counter top took care of the bathroom issue. My friend's step-dad built a bench over the standard toilet to be the same height as my wheelchair. He cut a hole in it and put the toilet seat on top, so I can now scoot out of my wheelchair and onto the bench. The ultra-smooth laminate top makes sliding and dressing even easier, especially when I'm hurt. When purchasing a shower chair, I made sure that my chair was the same height as the shower chair. I just pull up, scoot on, and then it slides left and right, so I'm able to slide into the shower. For when I'm not at home, I recently had a transfer board attached to the underside of my leg board on my wheelchair. I raise my chair up, it pulls out, and then I can transfer onto it to use a public restroom. When I'm done, I scoot back into my chair, use my reacher to pull the board back in, and I'm on my way!

Lastly, it took patience. Putting in earrings used to take forever as I struggled with reaching the other side. Not wanting to sacrifice fashion, my friend suggested holding the back of the earring with a tweezer and that gave me the extra two inches I needed to put the back on. Whether it was putting in earrings, transferring, or even something as simple as picking an item off the

floor, there were times it would take as long as 30 minutes and a lot of frustration. Unless I was hurt, though, I kept trying. I was bound and determined not to let something as simple as movement or an inanimate object get the best of me! I can now compete internationally in the sport of picking up objects and would get the gold every time!

There are still things I am unable to do, such as laundry. However, I've turned that into fun girls' nights where I supply the drinks and dinner while my friend throws a load in. I have a cleaner that comes twice a month to do the heavier things like sheets, cleaning the bathrooms, and any extra laundry that my friends didn't get to. I guess the point is to never think that you cannot do something and to always have patience and faith in your ability to do it. Next up...driving!

It is important to note that these adaptations were customized for me. Everyone has different abilities, so what worked for me may need to be adapted differently for someone else.

I would like to give a special thanks to my Colorado family of Lisa Ferrerio, Chris Lamoreaux, Stacey Hunvald, Teresa Nguyen, Nikki Douros, Diane & Alan Holstein and of course my parents. Without their support and ideas, none of this would have been possible.

## Driving Grants

It's an unusual partnership – The OI Foundation, Shriners Hospitals for Children—Chicago and race car drivers. But this group is working together to help young people who have OI become independent and safe drivers.

Learning to drive when you have OI can be expensive and complicated. Besides learning the rules of the road like everyone else and getting insurance, the young driver with a physical disability may need to be evaluated to determine if adaptive equipment is needed, and then learn how to drive safely using the equipment. Adaptive equipment makes it possible for many people to drive, but purchasing it and installing it on a car or van is an additional expense. Often these additional expenses cause families to delay allowing their teenager who has OI learn to drive or may make it cost prohibitive all together.

During the last year, the **Driving Grant Program** offered grants of \$500 to help pay for driving evaluations, lessons or equipment. The program is open to young people between the ages of 15 and 21 with a diagnosis of OI and financial need. So far \$4,500.00 has been awarded to 9 young people across the United States.

Everyone involved in the Driving Grant Program is delighted to be able to help these deserving young people get closer to their dream of driving and looks forward to offering more grants in 2010. Application information will be available in early summer.

## Conference Connections

*By Sharon Trahan*

In 1998, I didn't want to go to conference. Greg was nearly three years old, and had sustained enough breaks that I wasn't counting anymore. We were handling living with OI just fine, thank you very much. I wasn't interested in "being supported" or in going any further than getting the newsletters from the OI foundation. I did recognize the value of the Foundation. The newsletters and information we received when Greg was born was invaluable. But spending several days with people where the focus was going to be about OI just wasn't on my to-do list.

Despite that, we went to conference. We were in Long Beach in 1998, and we've been to Orlando, Dallas, Omaha and Washington DC. What changed?? Admittedly, my husband Ted dragged me to Long Beach, but since then this has been a joint priority. Why???

I discovered that conference is really, really fun! This year, the conference conflicts with a beloved summer camp the kids have been going to for years. They didn't even blink; conference takes priority. The kids wouldn't be willing to compromise this camp experience without a serious return on the time investment. For Kaethe (12) and Greg (14), the teen room is the place to be. It's also a place to create some sneaky skill building with the creation of a teen OI council and learning about advocacy. These kids are involved in big ideas. And, of course there are the video games...

Conference is about being exposed to small ideas that grow into life changing priorities. We were introduced to adaptive yoga and strength training through conference. Greg now works with a personal trainer at our local community center. From conversations at conference, we learned about getting a medical necessity letter to take advantage of pre tax medical savings account dollars (many people have these plans at work) to pay for his workouts.

This gathering gives you the opportunity to be surrounded by people who have expertise and opinions about the treatment of OI, and are willing and eager to share. Many people take advantage of pre conference doctor consultations for individualized care suggestions. Sessions give insight into research and help increase awareness of options and ideas to bring to your medical team at home.

Between formal sessions and informal conversations, the topics are many and diverse. Some examples: What works and doesn't in school. Travel opportunities and suggestions. Home modifications to create environments where OI's challenges aren't the focus of everyday life. Rumor has it that at the last conference there was a teen discussion about being in a wheelchair on a date and how to deal with that inevitable goodnight kiss. Informally, our family is starting discussions about college and we're planning to talk with people about their search for a great education combined with the reality of needing accessibility. An adaptive skiing program (see picture) has been a fun new experience for us, and we're looking forward to sharing how it works with people. Exercise ideas. New research. Medical advice. Wonderful role models. The possibilities are limited only by what you're willing to bring up and start a conversation about.

I went into that first conference afraid to see what living with OI meant to the greater OI community. The people we talked with – many now friends – showed how the focus of conference could be on OI, but the result of that focus could help us with our priority; living a normal life that happens to include OI, but is not defined by OI.

See you in Portland!



*Board of Directors First Vice President Sharon Trahan with her husband Ted, and children Greg and Kaethe.*

## OI Registry: New Questions Have Been Added

The OI Registry connects doctors, researchers, people who have OI and their families. As of January 2010, 1,485 people with OI from the United State and 39 other countries have joined the registry. Information from each registrant helps provide a portrait of people who have OI, and is used to identify areas that need research. Registry members can easily be contacted and made aware of studies that need participants.

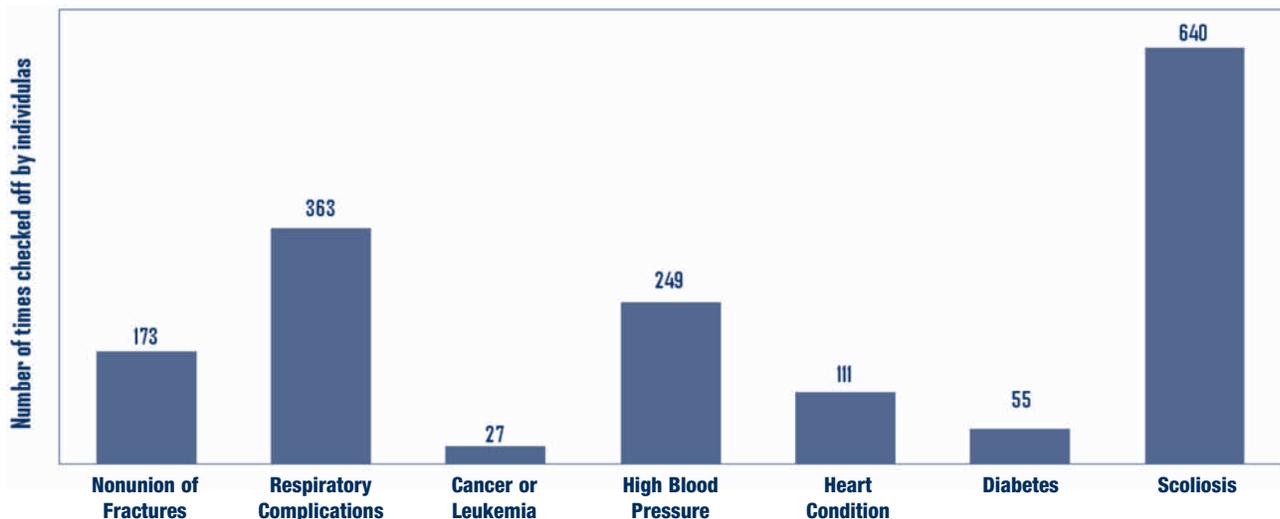
Based on suggestions from registry members and researchers, two new questions have been added. Members are urged to login and update their profile.

1. **Migraine Headache:** a new checkbox on this topic has been added under the medical characteristics section. Migraine headaches have been reported by people who have OI of all ages. While migraines are common in the general population it is unknown whether people with OI have these headaches more or less often. It is possible that OI might increase a person's odds of having migraines and it is an area worthy of more study.
2. **Employment and Education Section:** a new section on this topic has been added featuring the following questions.
  - What is your highest level of education?
  - Are you currently or have you been employed?
  - What kind of job do you have/had (full-time, part-time, volunteer)?
  - What type of job do you have (field/area)?

According to a study that was conducted in Norway, adults with OI are well educated compared to the general population, and most of them are employed. Currently, there are no comparable studies about OI adults in the U.S.

Researchers are encouraged to take advantage of the invaluable information in the OI Registry. Parents and adults are encouraged to join the OI Registry. It is a quick and easy on-line process. (Paper registration forms are available on request.) Together we can all help enhance the progress of research in OI. **Reminder: if you are already in the Registry, please login and update your profile.** If you haven't joined, please visit <http://www.osteogenesisimperfecta.org/oir/>, or call the OI Registry Manager at 443-923-9180 for more information.

### Some Medical Problems 1,494 OI Registry Members Have Reported (as of Feb. 2010)



This is for information only. More information is needed before any conclusions can be drawn.

## Six Sites Included in Linked Clinical Research Center Program

The OI Foundation is pleased to announce the expansion of the Linked Clinical Research Center program and the “Longitudinal Study of Osteogenesis Imperfecta.” The addition of the new LCRC sites to those previously announced expands the network to 6 sites including one in Canada. All of the new sites have a multidisciplinary group of specialists with extensive experience caring for children who have OI. All of the sites will be participating in the natural history of OI study. The three new sites are:

National Institutes of Health – Bethesda, MD  
Shriners Hospital for Children – Chicago, IL  
Shriners Hospital for Children – Montreal, Quebec Canada

**The National Institutes of Health** — Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) through Dr. Joan Marini’s long standing, pediatric focused program will enroll children with types III and IV OI. Pediatric participants will be offered follow-up into young adulthood. Participation in NIH studies is free of charge. To learn more contact:

Contact Person: Catherine Reisenberg, FNP, PhD  
Phone Number: 301-496-0741  
Email: oiprogram@mail.nih.gov

**Shriners Hospital for Children** – Chicago  
The Chicago Linked Clinical Center site is now enrolling participants in the natural history of OI study. For the purpose of this study arrangements have been made to see adults as well as children. For more information please contact:  
Contact person: Angela Caudill, MPT  
Phone Number: 773-622-5400 EXT. 5271  
Email: acaudill@shrinenet.org

**Shriners Hospital** – Montreal, Canada will begin enrolling patients into the natural history study later this year. For the purpose of this study arrangements are being made to see adults as well as children. Contact information will be announced as soon as it is available.

### What is a Natural History of OI Study?

“The Longitudinal Study of Osteogenesis Imperfecta” is a natural history study. It will collect and analyze information about the health of people who have OI. To be successful, this study must include as many people as possible and include children and adults of all ages from infancy through senior citizen and all types of OI from the mildest to the most severe. Our goal is to enroll 500 people. Each study center will be collecting exactly the same type of health information in the same way from all participants. This information is then entered into the LCRC secure, anonymous, central database.

### Study Information

Study participants are required to visit the Linked Center once a year for 5 years. Each person will be asked for a detailed medical history and receive an extensive annual physical exam including various diagnostic studies such as a DEXA. Participating in this natural history study does not replace a person’s regular health care team and does not interfere with any other research studies he or she may already be enrolled in.

### Contact Information for all Study Sites

For detailed information about participating, please speak with a study coordinator at one of the following sites. Information is also posted on the OI Foundation website under the “Research” tab.

#### **Baylor Medical Center, Houston, TX**

Contact Person: Mary Mullins, RN  
Phone Number: 832-822-4263 or 1-800-364-5437 ext. 24263  
Email: mullins@bcm.edu  
Enrolling children and adults with OI; all ages; all types

#### **Kennedy Krieger Institute, Baltimore, MD**

Contact Person: Pamela Melvin, RN  
Phone Number: 443-923-2707  
Email: Melvin@kennedykrieger.org  
Enrolling children and adults with OI; all ages; all types

#### **Oregon Health & Science University / Portland Shriners Hospital, Portland, OR**

Contact Person: Jessica Adsit, MS  
Phone Number: 503-418-5882  
Email: Adsit@ohsu.edu  
Enrolling children and adults with OI; all ages; all types

#### **National Institutes of Health, Bethesda, MD**

Contact Person: Catherine Reisenberg, FNP, PhD  
Phone Number: 301-496-0741  
Email: oiprogram@mail.nih.gov  
Enrolling children with OI types III and IV; follow-up offered into young adulthood

#### **Shriners Hospital for Children, Chicago, IL**

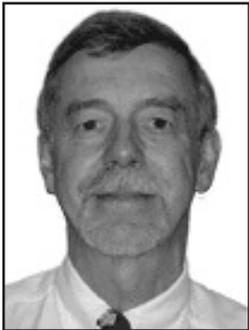
Contact person: Angela Caudill, MPT  
Phone Number: 773-622-5400 EXT. 5271  
Email: acaudill@shrinenet.org  
Enrolling children and adults with OI; all ages; all types

#### **Shriners Hospital for Children, Montreal, Quebec Canada**

Contact information will be provided as soon as possible. Children and adults with OI; all ages; all types will be eligible

## From the Medical Advisory Council

By Francis Glorieux, OC, MD, PhD



*Dr. Francis Glorieux*

For the past twenty years, I have been involved with the activities of the OI Foundation's Medical Advisory Council (MAC) and witnessed its impact within the larger scheme of the expansion of OIF activities and visibility, not only on the national scene but also internationally. As the newly appointed MAC Chair, I will do my best to continue the work initiated by my predecessors. Although a cure for OI has yet to appear on our radar screen, significant progress has been and continues to be made in medical treatment and in understanding the basic abnormalities underlying the various forms of OI. Here are, in my view, the accomplishments and challenges in these areas.

To medically influence bone mass accrual one can either stimulate osteoblast activity and bone formation, or inhibit osteoclast activity and bone resorption. In the past 15 years, medical treatment has focused on potent bisphosphonates inhibiting bone resorption. Multiple studies have shown them to be beneficial in increasing bone mass, and decreasing fracture incidence and bone pain. Although there is only one country, Italy, where the drug is an approved indication for the treatment of OI, it is used worldwide as standard care for moderate to severe OI. However, questions regarding dosage, route of administration, and duration of treatment have still to be fully answered. Continuing with well-defined protocols and clinical trials remains indispensable. OI being a disease of the osteoblast, it makes more sense conceptually to try to boost such cell activity and thus bone formation. Teriparatide is a compound that will do that, and clinical trials are currently underway in adults with OI. However, its use in children is not permitted and the duration of administration is limited to 2 years.

These compounds are only part of the treatment approach. Other important components are surgery, dentistry and OT/PT. The critical role of the latter underscores the importance of physical activity to increase bone mass. On that basis, vibration platforms are now used to promote cortical bone formation, even in subjects with reduced mobility. Such studies are currently under way in selected OI populations.

Exciting new findings on the pathophysiology of recessive forms of OI have recently been published. The initial report (Montreal, Houston, and Seattle) demonstrated that hypomorphic mutations in the CRTAP gene caused moderate OI (type VII) while its complete ablation was associated with lethal OI. With the discovery (Portland) that CRTAP forms with P3H1 and CyPB an intracellular collagen-modifying complex, mutations were also searched for and found in P3H1 (Bethesda) and CyPB (Amsterdam). They are linked to moderate to lethal forms of OI. These findings have further enhanced our understanding of the mechanisms that control collagen type I synthesis, folding and incorporation into bone matrix. It is hoped that they will ultimately allow defining new avenues of treatment.

On a more personal note, I am just back from a visit in Saudi Arabia where I was invited to talk about heritable bone diseases (including OI) at King Fahad Medical City in Riyadh. In the Department of Paediatrics of this very large hospital, I saw patients with rare recessively inherited diseases (OI among others). Such diseases have a higher incidence here due to the high degree of consanguinity in the Saudi population. Following this visit, we have established a collaboration to evaluate babies with severe OI and to incorporate them in our new treatment trial with zoledronic acid.

## Welcome Dr. Emily Germain-Lee



*Dr. Emily Germain-Lee*

Dr. Emily Germain-Lee, a pediatric endocrinologist with broad experience in the diagnosis and treatment of bone disorders has joined the OI team at the Kennedy Krieger Institute in Baltimore, MD. As Associate Director of the Bone Center and OI Program, she will work closely with Dr. Jay Shapiro and Dr. Paul Sponseller. Dr. Shapiro stated that he was delighted to welcome Dr. Germain-Lee to the OI Department at the Kennedy Krieger Institute and acknowledged her considerable expertise with bone disorders. He further explained that she will take on the duties of Director of Bone Research for the OI Department. Dr. Germain-Lee received her Bachelor's degree from Harvard University and her M.D. degree from the Johns Hopkins University School of Medicine. Her work at Johns Hopkins since then has included serving as the Principal Pediatric Endocrinologist of the Greenberg Center for Skeletal Dysplasias at the Institute of Genetic Medicine and as Director of the Johns Hopkins Pediatric Bone Center. In both capacities she was involved in the diagnosis and treatment of people with osteogenesis imperfecta as well as other skeletal disorders. Dr. Germain-Lee is known for her interest in both bone research and clinical care.

## Tribute to Neeru Sharma

By Jamie Kendall

The OIF is deeply saddened by the sudden loss of our friend, and former OIF Board of Director member, Neeru Sharma. Neeru had type II/III OI and was an active member of the OIF community. What is there to say other than that Neeru had a bright light that shined on this world and made it a better place for all of us. Neeru, originally born in India, relocated as an infant with her family to Detroit, Michigan. As a high school student Neeru studied abroad in Denmark as an exchange student. She earned a bachelors degree from Kettering University and a master's degree from Oakland University. An accomplished professional, Neeru worked for General Motors (GM) and Saturn for 17 years. Additionally, she was an accomplished writer and blogger on disability issues for the **Detroit News** and traveled extensively in the United States and abroad. Neeru served on the OIF Board of Directors 2002 to 2008. In addition to this national leadership position she provided leadership at the local level by starting a support group for OI individuals and their families in Michigan. She was involved in fundraising activities including chairing her own event in Michigan for OIF, and working on corporate sponsorships with General Motors.

Neeru had a "presence" that made people around her smile and feel good. She had a way of making each of us feel special just by being around her. Neeru summed up her philosophy in an article she wrote a few years ago. "People with OI can do anything and be anything, despite our special challenges. Many people have accomplished well beyond anyone's expectations. Some of us are doctors, lawyers, teachers, business people, engineers, athletes and parents and have traveled around the world. You name it, a person with OI with the right attitude can do anything. We have Breakable bones: Strong spirits. Our bones are fragile but our spirits are undaunted. We all have faced huge challenges in life and have adapted to our circumstances but we have all developed ourselves as full human beings. Our disability is not what will define us, but our collective abilities will make us together an unbreakable and unstoppable positive force of humanity."

We are so appreciative and grateful for Neeru's leadership and the positive energy she infused into our community. She will be greatly missed, but her legacy will live on in our memories and in the actions that each of us volunteers and community members in OIF do in working together to make the world a better place. Neeru made the world a better place not just for people with OI, but for everyone. Neeru is survived by her loving parents Gurdev and Vimal Sharma, brother Naveen and sister in law Pooja.

## Are you a Member of the OI Foundation?

We want everyone in the OI community to become a member!

Becoming a member of the OI Foundation will allow you and your family to stay connected to the OI community. The funds raised through the 2010 Membership Campaign allow the OI Foundation to provide vital services and support to families who contact us for answers, such as how to handle their newborn child with OI, where to find a doctor, how to work with the school system, and what to expect as an adult with OI.

The OI Foundation owes much of its success to its loyal, supportive members, and the organization's strength depends on continued member support to provide vital services.

Membership levels range from \$30 for individuals to \$60 for families and \$120 for Supporting Members. All members receive:

- A membership card (valid for one year)
- Voting privileges in our annual elections, where members choose the board members who will lead the Foundation as we continue to grow.
- A magnet with OI Foundation contact information
- Recognition in the Annual Report

To sign up as a member, watch your mail for our invitation, or visit [www.oif.org/HH\\_Membership](http://www.oif.org/HH_Membership) and then click on the link "Become a member or renew your membership."

## UK Actress Battles More Than Fragile Bones

If Julie Fernandez could change two things in this world, it would be to impact positively how people with disabilities are portrayed in the media and help people wrongly accused of child abuse in the UK.

Julie is best known for her role as 'Brenda' in the BBC's multi-award winning show 'The Office'. She is an actress, presenter, journalist and tireless campaigner for disability rights. She is also something of a minor miracle. Born 10 weeks prematurely with osteogenesis imperfecta she was given just 2 years to live by doctors. Thirty-five years later she has starred in an award winning BBC series as well as written, presented and co-produced her own documentary.

Never one to give in to adversity Julie sees her disability as a positive thing as it allows her to 'think outside of the box'. She attributes her positive attitude, despite nearly 70 operations, to the encouragement and support of her family who instilled a "can do" attitude.

Away from acting Julie has been a passionate campaigner for parents who have been wrongfully accused of child abuse. She wrote, presented and co-produced 'Brittle Justice' a 30-minute documentary for the BBC's 'First Sight' strand. She formed 'The Disability Foundation', a national pan-disability charity offering some of the best affordable complementary therapies available to disabled people and their families.



*Julie Fernandez*

Julie has also formed a television production company called 'The Wheelie Good Company' and is currently working on program ideas. The Company's employment ethic is to have a balance of disabled and able bodied staff both in front and behind camera.

Julie has attended OI conferences in the past and looking forward to the possibility of attending the 2010 conference in Portland!

## The OI Foundation has a New Lockbox Address for Donations

Since November, you may have seen a new post office box address on many OI Foundation materials. This is because the OI Foundation has updated to a new, more efficient online lockbox system offered by PNC Bank.

In order to streamline our check-processing system, all donations accompanied by a check or money order should be sent directly to a post office box at our new bank, PNC Bank. Please discard any envelopes bearing the old P.O. Box address in Baltimore.

### **Please mail any donations to our new lockbox address:**

Osteogenesis Imperfecta Foundation  
P.O. Box 824061  
Philadelphia, PA 19182-4061

Correspondence to staff members should still be sent to the Foundation's office address in Gaithersburg, MD. When in doubt, community members should use the Gaithersburg address and staff members will route the mail appropriately.

### **Office Address:**

Osteogenesis Imperfecta Foundation  
804 West Diamond Avenue, Ste. 210  
Gaithersburg, MD 20878-1414

## People in the News

*Mesa, AZ* – Participating in a two year radio broadcasting program, 18 year old **Jacob Driscoll**, aka DJ Hot Wheelz, has been honored by his school as a DJ of the year. He also appears suited up for wheelchair fencing as the February model for a disabled sports calendar created as a fundraiser for the local sports center.

*Lodi, CA* – Believing that his city has ignored mandates to make a local stadium ADA compliant, 19 year old **Jeremy Hixson** has filed a claim under the Americans with Disabilities Act.

*Alamosa, CO* – Longtime sports editor **Lloyd Engen** has been sharing with readers his recent experience of recuperating from a fractured pelvis and splintered hip socket.

*Williamsville, IL* – With a love of basketball that he's had since grade-school, senior **Dominick Moscardelli** is realizing his dream and playing for his high school team.

*Rome, GA* – With his knowledge of cars and telling of silly jokes, 4 year old **Nicholas Hight** readily entertains those he encounters. After a February rodding surgery in Omaha, he'll return home to his modified John Deere Gator four-wheeler.

*Muskegon, MI* – Designed by the U.S. First Robotics PowerSurge team of Reeths-Puffer High School, a portable ramp was built to transfer the stroller-wheelchair of 16 month old **Leah Davidson** directly into the family van.

*South Richfield, MN* – A regular at the Montreal Shriners since she was a toddler, 12 year old **Sarah Kate Stone** greeted a group of visitors with a cheerful smile despite being in halo traction placed to take pressure off her spine.

*East Grand Forks, MN* – “The Beautiful Women of North Dakota”, a project that began when a father sought to expand his three daughter's definition of beauty, honored **Rachel Bremer** for her work on behalf of the inclusion of people with disabilities.

*Concord, NH* – **Carol Nadeau** recently retired as executive director of the governor's Commission on Disability. Her work under seven governors has always been focused on empowering others. “I think the best thing is to teach people with disabilities to be their own best advocates; then they can rely on themselves to get things done.”

*Bellefonte, PA* – Retired reading specialist, former OI board member and newlywed **Sherry Frost Runco** is remembered by her students as someone who taught much more than reading. She was forthright about disability issues and showed by example the benefits of hard work and determination.

*Brookline, PA* – After two years of living with her foster family, 9 year old **Lexie Bouchard** was officially adopted on National Adoption Day. Showing her enthusiasm, she put aside her walker and, despite being a bit wobbly, walked up to the judge.

*Huntingdon Valley, PA* – Visiting a local high school, Temple University's Rolling Owl's wheelchair basketball team entertained students and gave 16 year old **Andrew Reid** the opportunity to share the following advice: “Just get out there and not be afraid of anything. Who would have known I'd be playing basketball and traveling all over the world?”

*Wilkes-Barre, PA* – After a successful cochlear implant, 52 year old **James O'Meara** is writing a blog about his experience at [www.cochlearcommunity.com/jimbolions](http://www.cochlearcommunity.com/jimbolions).

*Inman, SC* – After reading an article about **Tyler Stroud's** dedication to the Gamecocks, his favorite football team, an anonymous donor provided the opportunity for him to live the dream by providing tickets and hotel accommodations to attend the Papajohns.com bowl in Birmingham.

*Plymouth, WI* – Wheelchair bowler **Sherri Schelk**, 33 years old, will join team Wisconsin at the Special Olympics USA National Games to be held next summer in Nebraska.

*Australia* – 25 year old **Jodi De Ruvo** writes a blog for a disability employment site at [candoability.com.au](http://candoability.com.au) and was recently featured on the Today show.

*New Zealand* – Despite the clear risks, 49 year old **Hans Hilhorst** leapt from his car to assist a police officer who was struggling with a detainee and in danger of being pushed into the road.

*Blackthorn Close, UK* – In appreciation for the work he has done as an ambassador for the charity Whizz Kids, which helps disabled children be more active, 8 year old **Alec Jenkins** was honored by the House of Lords with a special award.

*UK* – When a fall resulted in hospitalization for 10 year old **Kaitlin Gault**, interfering with her induction ceremony in Girl Guides, the unit came to the hospital where she was joined by other recruits in making her Girlguiding promise.

*UK* – While participation in a clinical trial to test the drug risedronate won't result in a return to the football played at age 13, **Luke Hall** has seen benefits, one of which is increased energy levels.

# Recap of Events

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## Golf Outing in Southern California Continues to Make a Difference!

CITY OF INDUSTRY, CA — The petroleum industry in Southern California held its 35th Annual Golf and Tennis Tournament on November 13, 2009, raising an estimated \$53,000 for OI research and other goals!

The **Southern California Petroleum Industry Charity Association's** (SCPICA) annual charity event is organized each year by a committee of industry executives, retirees, and families in the OI community. The OI Foundation became the beneficiary of this annual golf and tennis tournament in 1986, which has contributed an impressive \$1.37 million for research and the Foundation's information services to families!

The SCPICA Golf and Tennis Tournament provided a full day of activities for participants. Under the leadership of **2009 Chairman John Pings**, the day began early with pre-tournament closest to the pin, longest drive and putting contests. Then, after a full day of golf or tennis, participants enjoyed a cocktail party and silent auction, followed by the awards dinner and live auction.

Each year, the SCPICA committee makes a special effort to invite people with OI and their families in Southern California to the dinner, offering our families a discounted dinner ticket price.

**SCPICA Treasurer Frank Fossati**, reported that the event was not immune to the current economic climate. With a turnout of 242 golfers, the tournament had fewer participants and sponsors this year than in 2008.

However, **committee member and OI mom, Michelle Hofhine**, was

definitely not disappointed. She added, "Even though numbers were down we had a great day and educated a lot of people about OI," she reported. "We had a lot of new attendees who had a great time and said they would come back again next year."

General Chairman John Pings said, "It is simply an honor to serve with the dedicated and committed SCPICA committee, OI families and volunteers and to work together on this fun event for the benefit of the Osteogenesis Imperfecta Foundation. Our 2009 Event was a wonderful day with a great crowd, and we can't wait to tee it up again for OI in 2010."

The OI Foundation is appreciative and proud to be the beneficiary of this quality event and to be actively supported by Chairman Pings, Treasurer Fossati, and the other hard-working, committed members of the SCPICA Tournament Organizing Committee!

If you are interested in seeing some photos from this event, just log onto: <http://picasaweb.google.com/scpicharityforoi>.

For those of you in the Southern California area that can attend this event, please save the date for SCPICA's next golf and tennis tournament, Friday, November 12, 2010, again at the Pacific Palms Resort, in the City of Industry, CA.

## High School Seniors in Indiana Raise More than \$2,000

FORT WAYNE, IN — The 2010 senior class of R. Nelson Snider High School in Fort Wayne, IN, raised and donated more than \$2,000 to the OI Foundation in December.

After her graduating class was given the challenge to raise funds for a worthwhile nonprofit organization,

**Olivia Henry** suggested the Osteogenesis Imperfecta Foundation. She was inspired by her cousin's one-year-old son, **Steven Parker, Jr.**, who was born with OI.

"He has overcome many of the challenges so far, but still has a long road ahead," Olivia wrote.

During October and November 2009, Olivia and her classmates designed and sold T-shirts to students, held a bake sale and raised donations at football games. Altogether, these efforts raised an impressive \$2,090.16, in Steven's honor!

We are grateful to Olivia and the Senior Class of R. Nelson Snider High School for taking the time to make a difference for children and adults with OI!

## Eighth Grader inspires Classmates to Walk for OI and Raise \$2,200

*By Teresa Kutsch*

SAN ANTONIO, TX — After listening to eighth grader **Josh Kutsch** speak about his brittle bone disease, the English class students wanted to do something to show their appreciation and compassion for their classmate and friend of eight years. After all, he was a person who inspired each of them on a daily basis; whether, through his physical differences, his positive attitude, his determination, etc.

This time, Josh had inspired them to raise money for the OI Foundation to support the foundation's search for a cure. Once the campaign "Jogging for Josh" was created, the motivation to honor Josh quickly spread throughout the entire middle school.

And so, on November 13, 2009, the middle school students of **St. Matthew Catholic School** in San Antonio, Texas eagerly exchanged their



*On November 13, eighth grader Josh Kutsch (seated) and his classmates went jogging for OI and raised more than \$2,200 in donations at St. Matthew Catholic School in San Antonio, TX.*

monetary donations for the opportunity to wear pajama bottoms at school and participate in the “Jogging for Josh” fundraiser.

From start to finish, these pre-teens raised \$2,211.34 and proudly donated it to the OI Foundation in honor of Josh Kutsch, an inspirational classmate and friend.

## **Tampa-area Companies host special birthday party for girl; Five-year-old requests donations to charity, in lieu of gifts**

*By Jamie Billig & Laurie Cushing  
Confetti Events*

TAMPA, FL — **Confetti Events, Stone House Events, and Occasions** joined forces to host “Isabella’s Ball: A Winter Wonderland” benefitting the Osteogenesis Imperfecta Foundation and Tampa’s Shriners Hospital on December 6,

2009 at the Shriner’s Temple in Tampa. The event was a GRAND success!

The Winter Wonderland-themed birthday party featured an over-the-top birthday cake, delicious gourmet food, face painters, magicians, a caricaturist & clown, three different dance school performances, hair & makeup artistry, raffle prizes, a photobooth, great music, a silent auction with amazing prizes, and outrageous decorations... it was truly a FUN party!

**Isabella Hernandez** is a five-year-old girl with OI. She is unable to walk but thankful she has received her first power chair to enable some sense of mobility. She weighs 17 pounds and is only 25 inches in height and she spent large periods during her first year and a half in and out of Shriners and All Children’s Hospitals. At Tampa Shriners Hospital, Isabella receives an IV treatment every 4 months for 3 days that cost \$850 just for the medication, which is all covered by Shriners Hospital.

It was Isabella’s wish that instead of gifts, people make a donation to OI Foundation and Tampa Shriners Hospital. We are pleased to report that Isabella did take home some birthday presents from the event.

Isabella arrived with her family in a stretch limo and had a beaming smile for the entire 2-hour event! Isabella’s mother, **Lorraine Hernandez**, said, “This was the best birthday party ever for Isabella; she had the time of her life! Words cannot express our gratitude for Isabella’s excitement for this party... she just loved it!”

Admission was free, and we sold OI bracelets at the door. With the help of donations from supporters we were able to raise more than \$1,500 for the two organizations.

Thank you to the local sponsors who helped put this event together, including **K & K Photography** for donating time and expertise to take wonderful pictures chronicling the event. This was a remarkable party for a remarkable young girl!



*Five-year-old Isabella Hernandez blows out her birthday candle at a special birthday celebration for her on December 6 at the Shriners Temple in Tampa. More than \$1,500 in donations for this event benefitted the OI Foundation and Tampa’s Shriners Hospital.*

## Check Out These Spring Events For OI in Your Community

These upcoming OI community events are not only fund raisers, but they also are opportunities to get together with other adults living with OI, families from the local support group, and their friends, neighbors, co-workers and other supporters. More details are available on the OI Foundation website calendar at <http://www.oif.org/site/Calendar?view=MonthGrid>.

We encourage you to find the OI activity closest to you, and make plans to attend!

\* \* \*

### **March 24, 2010 – Nationwide** *Bone China Tea*

Bone China Tea is a phantom tea party, and you can send out invitations from your own home! Either order free printed invitations or set up a personal web page at [www.oif.org/BoneChinaTea10](http://www.oif.org/BoneChinaTea10) to send your request by e-mail. The invitations invite your friends and loved ones to stay at home, enjoy a cup of their favorite tea, and make a donation in honor of their friend or family member who has OI.

**To order your printed invitations, contact:** Jenny Wilson ([jnwilson@aol.com](mailto:jnwilson@aol.com)) or Susie Wilson ([OISLW@aol.com](mailto:OISLW@aol.com)) by e-mail or at (239) 482-0643.

\* \* \*

### **April 24, 2010 – Atlanta, GA** *Unbreakable Spirit Walk-n-Wheel for Better Bones: Atlanta*

Come out to Piedmont Park in downtown Atlanta (site of the 1996 Summer Olympics) for a fun day celebrating the OI community! This event is being organized by a teenager who was inspired by Jodi Picoult's novel, *Handle with Care*. Registration begins at Noon. Please sign up in advance at [www.oif.org/atlantawalk10](http://www.oif.org/atlantawalk10).

**Contact:** Jordan Cumbey at (770) 906-4345 or [jlcumbey@gmail.com](mailto:jlcumbey@gmail.com).

\* \* \*

### **April 24, 2010 – Round Rock, TX** *3rd Annual Central TX Walk-n-Roll*

Bring your family to Cedar Creek Park at 9 a.m. and enjoy raffles, food and drink, and good company while you walk for a good cause. By raising a few pledges and then walking (or rolling) with us, you will help both the OI Foundation and Texas Parent to Parent to provide

information, resources, and answers to parents whose children live with disabilities, including OI. Please sign up in advance at [www.oif.org/centraltxwalk10](http://www.oif.org/centraltxwalk10).

**Contact:** Debbie Wiederhold at [Debbie@txp2p.org](mailto:Debbie@txp2p.org) or (512) 458-8600.

\* \* \*

### **April 24, 2010 – Washington, DC** *10th Annual Fine Wines Strong Bones*

Celebrate this gala event's 10th year while you enjoy a fun-filled evening that features silent and live auctions, good food, a variety of red and white wines, and a pre-event online auction. This is a great opportunity to mingle with friends and supporters of the OI community!

Order your tickets at: [www.oif.org/HH\\_FineWines](http://www.oif.org/HH_FineWines) or phone the OI Foundation at 1-800-981-2663.

\* \* \*

### **May 22, 2010 – Rochester, NY** *Alle Shea's Second Walk-n-Wheel for Better Bones*

Enjoy a variety of family activities while joining with others to walk or roll their wheelchairs for OI at West Irondequoit High School. This *Unbreakable Spirit Walk-n-Wheel for Better Bones* event is organized by Kim & Angelo Collazo, in memory of their infant daughter who was born with the most severe form of OI. Please sign up in advance at [www.oif.org/rochesterwalk10](http://www.oif.org/rochesterwalk10).

**Contact:** Kim & Angelo Collazo at [allesheaproject@yahoo.com](mailto:allesheaproject@yahoo.com) or (585) 266-5115.

\* \* \*

### **June 5, 2010 – Framingham, MA** *6th Annual Massachusetts Unbreakable Spirit Walk-n-Wheel for OI, in honor of Ilene McBride*

This year's OI walk-n-wheel event will be held at a new location — Maple Street Field at Framingham State College. Bring the entire family for fun-filled event from Noon to 4 p.m. You can walk/wheel one lap or 100 to support the cause. There will also be food, live music, games, raffles, and activities for all ages throughout the afternoon. Please sign up in advance at [www.oif.org/massachusettswalk10](http://www.oif.org/massachusettswalk10).

**Contact:** Christine Wyman Rossi at (508) 620-0991 or [c.rossi@verizon.net](mailto:c.rossi@verizon.net).

## New Jersey Supporter Wins Cruise in “Going Places” Sweepstakes

Out of more than 5,000 entries, **Barbara Carli** of Vineland, NJ, was randomly selected as the Grand Prize winner of the OI Foundation’s “Going Places” Sweepstakes.

As a result, she will receive a 3- or 4-day cruise of her choice and Roundtrip Air Travel for Two! The air travel has been donated by **Southwest Airlines**. OI community members **Karen & Glenn Vowell** of Cruisesnyou.com will arrange the cruise.

Ms. Carli said she began supporting the OI Foundation because a classmate from college has a son with OI. She plans to give the cruise as a gift to a relative.

The “Going Places” Sweepstakes is a fun annual promotion that supports the OI Foundation’s research, support, education and awareness activities. The Sweepstakes raised more than \$23,000 this year, making it the most successful campaign of the past four years.

Three other lucky participants also won prizes this year.

**Eric Sonntag** of Somerset, NJ, was the 2nd Prize winner and received the Apple iPod touch Digital Player 16GB.

Third prize winner **Sharon Nucci** of Mesa, AZ, won a large basket full of DVDs and memorabilia from the hit television show *Survivor*, donated by **Gayle P. DePoli**.

**Ralph and Kay West** of Corpus Christi, TX, were selected in the Early Bird drawing for \$200 in gasoline gift cards, donated by past Board president Ken Finkel and his family.

### Gift Wrap Sale Raises Almost \$6,000

Sally Foster campaign chairperson Connie Kasputis and dozens of volunteers brought in almost \$6,000 for the OI Foundation simply by selling Sally Foster gift wrap and accessories.

The Sally Foster catalog offers a selection of quality holiday and all-occasion wrapping paper, gift bags, handy kitchen essentials, gourmet edibles, and unique gift items. Volunteers who buy or sell products on behalf of the OI Foundation earn back **50% of every purchase** to support our mission.

Each year, the Foundation mails Sally Foster catalogs to interested volunteers and purchases can be made online in the Fall. If you would like to receive a catalog in 2010, please let us know at [development@oif.org](mailto:development@oif.org).

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## 2009 Annual Report is Available Online

The OI Foundation’s FY 2009 Annual Report is now available on our website at [www.oif.org/AB\\_Reports](http://www.oif.org/AB_Reports).

The Annual Report is designed to report on the Foundation’s accomplishments. It also provides you with financial information that shows where we stood at the end of the fiscal year and how that compares to the previous year. The OI Foundation’s fiscal year runs from July 1 – June 30.

In our continuing efforts to use your donations wisely and to follow environmentally sound practices, we have elected not to send the Annual Report through a mass mailing this year. Instead, we encourage you to download, save or print a copy from our website.

Printed copies are available upon request.

## Support Group Update

It wasn't just the warm weather that made Florida the place to be in January. Both the Central OI Support Group and its newer counterpart in the Miami area held meetings the last weekend of the month. Dr. Jay Shapiro was present and spoke about the Kennedy Krieger Institute and the Linked Clinical Research Centers for OI patients, the latest research, and the importance of joining the OI Registry. Our CEO Tracy Hart spoke about the upcoming OI Conference, the 40th Anniversary celebration, and the behind the scenes advocacy work that has such potential to make a difference in the lives of people with OI. Advocacy and public awareness are also high on the list of priorities for the Miami support group which is fortunate to have members involved in public media.

February was a time for groups in Arizona and New Mexico to reconnect after the business of the holiday season, with the big topic being who is going to Conference.

A new group is forming on Long Island with a first meeting planned for April. If you're in the neighborhood, stop by and introduce yourself. First meetings are important as they offer the means of defining needs of the members, determining future meeting topics and frequency of meeting.

Southwest Missouri has a new support group, with information about a first meeting to follow.

Dates, times and other information about scheduled meetings can be found on the OIF online calendar at <http://www.oif.org/site/Calendar?view=MonthGrid>.



*OI Support Group leader Curtiss Wilson was selected to participate in the New Mexico Game & Fish One in a Life Time Hunt on December 19. This was a Handicapped Oryx Hunt; Curtiss successfully shot the Bull before 7:20 a.m. from 208 yards on the White Sands Missile Range, Rhodes Canyon Range.*

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## Seattle Holiday Regional Reception Brings OI'ers Together

**Dr. Peter Byers** was guest speaker at the Seattle Holiday Regional Reception in December hosted by **Parker and Carol Folsø**. Dr. Byers shared his vision of quality care for every person and family living with osteogenesis imperfecta through the network of Linked Clinical Research Centers.

**Karen Braitmayer**, one of the leaders of the Seattle-area OI Support Group said, "It was an exciting time to hear about all the recent advances in OI research from Dr Byers - and to learn about the variations in the condition that are being isolated. This can lead to better treatment options for all ages and types of OI."

"I think everyone who attended really enjoyed themselves and had the opportunity to make new friends and share stories. The Ranier Club was an excellent venue and hopefully we will have the opportunity to do this again next year," added **John O'Brien**, Director of Development.

More than 30 people attended this wonderful event.

## Paralympics Watch

Tune in from March 12-20th and watch 23 year-old Taylor Lipsett in the Sled Hockey competition. Taylor competed in the Paralympics in 2006, assisting his team in winning a bronze medal. More recently, a gold medal was won by the team at the 2009 World Championships in the Czech Republic. For coverage of the Paralympic Games go to [www.universalsports.com](http://www.universalsports.com).

A wheelchair user since third grade, Taylor first began playing street hockey with his brother, pushing himself around on a skateboard.

Sled hockey, known as sledge hockey outside of the United States, was invented in 1960 at a rehabilitation center in Sweden by a group of men who wished to continue playing hockey despite their physical disability. It was introduced as a medal sport in 1994 at the Lillehammer Games.

Like ice hockey, sled hockey is played with six players and a goalie. The rinks and goals are regulation size and the game consists of three 15 minute periods. In sled hockey, players propel themselves with two three foot-long sticks while sitting on specially designed sleds that sit on two hockey skate blades. The sticks have spikes on the ends which enable players to maneuver, shoot and pass.

In addition to playing hockey, Taylor is studying finance at the Cox Business School at Southern Methodist University. He is married and lives in Texas.

## Wells Fargo Foundation Awards OI Foundation \$1,000

For the outstanding work the OI Foundation is doing in the San Diego, CA community by responding personally to each and every inquiry regarding this rare disorder, producing new information resources, funding research, and facilitating the operation of support groups not only in the CA area, but across the country, Wells Fargo awarded the Foundation a contribution of \$1,000.

Frank Booth and his 16 year old grand daughter Taylor Carpenter who has OI, represented the OI Foundation at a reception and grant presentation ceremony held at the Old Globe Theatre in Balboa Park in San Diego, CA.

"I really appreciate Frank and his grand daughter representing the OI Foundation at this wonderful event held by Wells Fargo" said John O'Brien, Director of Development, it's great to partner with an organization like Wells Fargo that shares your values and mission of making a difference"

The OI Foundation would like to thank Lauren Tobiassen, Regional President for the opportunity to be recognized. We would also like to thank Kristin Callahan and members of the Scripps Ranch Center Store for their support and belief in our cause.



*From left to right: Kristin Callahan, Manager, Wells Fargo Bank; Frank Booth, Sr.; Marie Quintana, Assistant Manager, Wells Fargo Bank; and Taylor Carpenter*

## From the Information Center

### ***New Healthy Children Website***

The American Academy of Pediatrics (AAP) has launched a new website, [HealthyChildren.org](http://HealthyChildren.org). It is designed to provide reliable, up-to-date information on child health and parenting. The site contains information on a wide range of topics related to physical, mental, and social health and well-being for infants, children adolescents and young adults.

### ***Hearing Aid Information***

People with OI are among the 35 million Americans who have some degree of hearing loss. Two new resources are available to help people become informed consumers. In recent years, as hearing aids have become more sophisticated and more expensive selecting the right one has become more and more complex. The US Food and Drug Administration's publication "A New Online Guide to Hearing Aids" describes the different types and styles of hearing aids, answers frequently asked questions, and includes a check list of steps to take before purchasing. The guide can be found at <http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm185723.htm>.

The Hearing Loss Association of America another source of reliable information has added a "Checklist for Consumers," to their library of information about hearing aids. It is an organized list of questions consumers should ask about hearing testing, selecting aids, and consumer protections. The checklist can be found on-line at [www.hearingloss.org](http://www.hearingloss.org) under the "Learn" tab.

### ***Travel***

Today all travelers, especially those who need to travel by air, face many challenges. The Transportation Security Administration website ([www.tsa.gov](http://www.tsa.gov)) contains an excellent section for ***Travelers with Disabilities and Medical Conditions***. It covers what to expect at airport screening stations, as well as how to pack medications you need to take in your carry-on luggage.

People who must take oxygen along with them when they travel face some additional challenges. Since 2004 the Federal Aviation Administration rules allow people with chronic lung disease to bring a portable +oxygen concentrator on flights. But airline policies and procedures vary. Before booking your trip, it is a good idea to contact your airline's medical desk and check on their specific requirements. The TSA website mentioned above also contains detailed information about traveling with oxygen. Another organization, the National Home Oxygen Patients Association ([www.homeoxygen.org](http://www.homeoxygen.org)) is another reputable resource.

### ***Education Scholarship Available to Students with OI***

An education scholarship is being offered by the Patient Advocate Foundation (PAF), an organization that provides mediation and arbitration services to people with chronic, debilitating and life-threatening illnesses. The scholarship is open to students under the age of 25 living with any chronic disorder including OI. The award amount is \$3,000 which would be paid directly to the college, university or vocational-technical school for the purpose of defraying tuition and other fee costs. Books are not included. The deadline to return a complete application packet is April 12, 2010. The application is available at [www.patientadvocate.org](http://www.patientadvocate.org) under the program section.

### ***Paralympics***

The 2010 Winter Paralympics, officially known as the X Paralympic Winter Games, will be held in Vancouver and Whistler, British Columbia, Canada between March 12 to March 21, 2010. Five sports will be on the program: Alpine Skiing, Nordic Skiing, Cross-Country Skiing, Wheelchair Curling, and Sledge Hockey. Information about these sports and the US Paralympic Team is posted on the United States Team website, [www.usparalympics.org](http://www.usparalympics.org).



## OI and Your Heart

### What is “Heart Disease”?

Although recent statistics indicate a decrease in the incidence of coronary heart disease in the United States, heart disease remains the leading cause of death for men and women in the United States. It includes conditions affecting the structure of the heart and/or its ability to function. These include coronary artery disease, abnormal rhythms, heart valve disease, and congestive heart failure.

### Is heart disease a part of having OI?

It is not known if people who have OI develop heart disease more often than people who do not. Having OI could increase a person’s chance of developing heart disease for several reasons. The underlying problem that causes most types of OI is a defect in Type 1 collagen. Besides being an important part of bones, this type of collagen is also found in many parts of the body including the lungs, tendons, and heart valves. It also provides strength and elasticity to the blood vessels. Weakness in these important connective tissues can lead to different kinds of heart and respiratory problems. Many people who have OI develop breathing problems related to having low oxygen levels in their blood

and weak lungs. Respiratory problems also put stress on the heart. It has been suggested that people with the more severe forms of OI might experience more heart disease, but this has not been thoroughly studied. It has also been suggested that as more people with OI live longer, more cases of heart disease will be seen. Whether heart diseases experience by people with OI are simply related to aging and life-style or if weak heart valve tissue is the cause also needs to be studied.

### What is the most common heart problem faced by people with OI?

Heart valve problems including mitral valve prolapse and aortic root dilation are reported most often in the medical literature. Heart valves and blood vessels contain collagen and can be affected by connective tissue disorders.

### What is mitral valve prolapse?

The mitral valve controls blood flow on the left side of the heart. The valve opens and closes with each heartbeat. It works like a one-way gate, letting blood flow from the upper heart chamber to the lower chamber. When you have mitral valve prolapse (MVP), the valve closes after blood flows through, but bulges backward a little. It looks like a tiny balloon as it bulges. Over time this bulge can stretch and weaken the valve so it no longer closes completely. MVP can lead to irregular heart rhythm, dizziness and infection.

### What is aortic root dilation?

Blood from the left side of the heart goes out to the body through the aortic valve and into the aorta, the main blood vessel leaving the heart. The section of the aorta that is connected to the heart is called the aortic root. If it becomes enlarged or dilated, it pulls the aortic valve out of

shape, causing it to leak. This weakens the heart’s ability to beat.

### Are people who have OI more at risk for a heart attack than other people?

People with OI have the same life-style risks for a heart attack as everyone else. These include smoking, high blood pressure, high blood cholesterol, obesity, diabetes, emotional stress and physical inactivity. OI can add to these risks because of the stress of living with a life long health problem, and because maintaining a healthy weight and being physically active can be difficult when trying to avoid fractures or there is limited access to recreation facilities.

### Can people who have OI have heart surgery?

Yes. A number of articles, usually case studies (a report about one doctor’s experience with one or two patients) have been published about heart surgery for people who have OI. In articles about heart valve replacement the most frequent problems mentioned are excessive bleeding, and getting a good fit from a replacement valve. Being in good health before the surgery and having a surgeon who is experienced with the procedure and who understands OI are other important factors.

### Can CPR be done on people who have OI?

Yes. The first issue is to save a life. Children with OI require less force to achieve the proper compression depth. When treating adults with OI, age determines the ratio of chest compressions to breaths. Size determines the force needed to achieve proper compression depth and as in children less force may be needed. Rib fractures do not always occur.

*continued on page 24*

# Health & Wellness

*continued from page 23*

## **Should all children and adults who have OI be screened by a cardiologist?**

As far as we know, there is no need for most children to see a cardiologist. Studies from the past indicated that children have about the same incidence of mitral valve prolapse as children in the general population. Young adults should be screened for general heart health and followed up as necessary. Both children and adults should be referred to a cardiologist if their primary care physician has a concern, hears a “murmur” or if there is a family history of heart disease.

## **What can people do to lower their risks and keep their hearts healthy?**

The guidelines suggested by the American Heart Association apply to everyone including children and adults with OI. These include eating a healthy diet that is low in fat, maintaining a healthy weight, being physically active, keeping cholesterol levels low, learning to manage stress, controlling high blood pressure and not smoking or exposing children to second hand smoke. Good communication with your primary care physician can catch problems when

they are minor so report all troubling symptoms including increased fatigue or the sensation of your heart skipping a beat and be sure to discuss your family’s heart health history. There is a lot that is not known about OI and the heart. The OI Foundation’s Natural History of OI study includes questions about heart health and is an important step in getting reliable information on this important topic.

*This report was prepared by OI Foundation staff with the assistance of Jay Shapiro, MD, Director of the Bone Center and the OI Program at the Kennedy Krieger Institute in Baltimore, MD.*

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## **2009 Volunteer Award Recipients** *continued from page 1*

Foundation and its members. Recipients demonstrate a willingness to put others before themselves as demonstrated by the late Thelma Clack.

This year’s recipient of the **President’s (Volunteer of the Year) Award** is Christine Wyman Rossi. The President’s Award is given to the outstanding volunteer of the past year. The award is given to an individual who best exemplifies the qualities of volunteer service to the OI Foundation and the OI community.

Following in the family tradition, Christine has served the OI community in many capacities. She recently completed six years serving on the Board of Directors, a position she began before the birth of her son Jack who, like Christine and her father Dick Wyman, also has OI. The arrival of Jack, or more specifically the arrival of his first femur fracture, inspired a desire to raise funds for research to find a cure and treatment for OI. So began an annual walk-n-wheel event in Massachusetts, now in its 6th year. As chairperson, Christine is involved in all aspects of what has become a very successful event. In addition, through her role as a local support group leader, the Massachusetts OI community has benefited from Christine’s availability in sharing information and support as well as from efforts to coordinate presentations of OI related issues by experts in the field. Most recently, Christine’s work on behalf of the OI community were rewarded by her company, EMC Corporation, with a \$10,000 award to the OI Foundation. Christine lives in Framingham with her husband John and sons Jack and 2 year old Hugo.

A volunteer from the age of 2 years old, Rebecca Perritt leads by example. Rebecca is this year’s recipient of the **Peter Dohm Junior Volunteer Award**. The award is given to an outstanding youth volunteer of the past year. Peter Dohm began volunteering for the OI Foundation as a young man when his parents helped organize an OI conference. He continued to volunteer throughout his lifetime.

A strong advocate for people with disabilities, Rebecca lends her support to local endeavors such as Junior Civitan, Special Olympics and as a student board member of Parents of Children with Special Needs, Inc. Rebecca is a strong OI advocate, and from the age of 5, she has spoken about her disability to teachers at Eastern Kentucky University, encouraging them to advocate for their students. She has also addressed Senators and Representatives about healthcare, helping them understand the needs of those with disabilities. Rebecca has done fundraising for the OI Foundation as well as participated in an OI walk-n-wheel event in Kentucky. With a perseverance that moves others, her spirit in participation has encouraged many youth in the community to join or participate in activities. Some are amazed to see her going and doing what she does in a wheelchair. Rebecca responds, “I’m not handicapped...I just use a wheelchair”. If someone needs help, Rebecca is there.

Frank, Christine and Rebecca will receive their awards at the 2010 Biennial National Conference in Portland, Oregon.

# *In Honor Of*

November 1, 2009 – January 31, 2010

Donations to the OIF were made in Honor of the people whose names are printed in bold. Donors are listed below each honoree.

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# Breakthrough

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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**General Correspondence:** The OI Foundation welcomes submissions of news articles, photos, personal stories, and information of interest to the OI community for inclusion in *Breakthrough*.

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## *Happy 40th Anniversary*

The 1980's the OI Foundation's second decade was a time of change. Game Boy and Rubik's cube were invented. The most popular video game was PAC-MAN. Mt. St. Helens a volcano near Seattle, Washington erupted and the Berlin Wall came down. Change was occurring in the world of OI research as well. The now familiar system of classifying OI by type – Type I, II, III and IV – that had been developed in the late 1970's in Australia by Dr. David Sillence gained world-wide acceptance leading to greater insight about OI's variability. (A grant from the OIF helped pay for Dr. Sillence's study.) In 1981, the Michael Geisman Fellowship Fund was established. It continues to be an important and respected part of the OIF research grant program and a way to encourage young researchers to study OI. In the early 1980's the two genes involved in the most common forms of OI were identified giving researchers and families new tools for recognizing and understanding OI. Over this decade the OI Foundation was growing, changing and starting important traditions. In 1982, the OIF held its first national family conference in Little Rock, AR. Two international conferences for medical researchers were held in this decade with the help of the OIF. Then, in 1987 after years of working out of people's homes, a National Office was opened in Tampa, FL.

Help celebrate 40 years of discoveries about understanding and living well with OI. Come to the OI Foundation's 2010 National Conference in Portland, OR. July 8-10.