

## OIF Celebrates Successful National Conference

The 2010 National Conference on OI was held in Portland, Oregon, on July 8-10. Over 500 people from all over the country, and world, attended this national event. The three days were filled with informative sessions, social activities, and fun!

The day before the Conference began, attendees were given the opportunity to schedule one-on-one medical consultations with an OI specialist. Over 100 appointments were made! That night, everyone gathered for a Welcome Reception, complete with a roaming magician! While the days were filled with important sessions with topics such as; "The Genetics of OI," "Splinting Workshop," and "Home Improvements & Resource Ideas," the nights were filled with social activities. The exclusive movie screening of *Broken Dreams*, featuring Nicole Gerth, an actress who has OI, was a popular event. Nicole attended the event, and answered questions about the movie and her career.

The highly anticipated Talent Show, hosted by Katee Shean from *So You Think You Can Dance*, showcased almost two dozen kids. The show was directed by Suzanne Richard, Director of the Open Circle Theater in Washington,

DC. These kids felt 10 feet tall while on the stage! After the show, approximately 500 attendees celebrated the Foundation's 40th Birthday by enjoying birthday cake with us.

One of the most notable parts of the Conference was the opportunity to present our founding mother Gemma Geisman with a Humanitarian Award for her lifetime of work; she is the mom whose article in *Redbook* magazine more than 40 years ago led to the formation of the OI Foundation. At Conference,

Gemma also read from her recently published memoir, *From the Seeds of Sadness*, along with her adult daughter Cathy and another founding mother, Renee Gardner.

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***"It finally dawned on me that lectures and presentations are secondary to the real reason for the Conference: connecting with the OI community - the folks with OI, the families, the medical and research community entrenched in finding a cure, and the organizers of the event from the OIF. The spirit of the conference is actually visible in the halls of the hotel."***

**~Laurent Beauregard,  
first time Conference attendee**

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## Breakthrough Going Green!

Starting with the 2010 Winter Edition, *Breakthrough* will be published in an electronic format three times a year, and in its standard print format once a year, for a total of four yearly issues. The electronic format will be emailed to readers.

The move to an electronic format not only helps conserve valuable resources, it allows readers to receive their copy of *Breakthrough* faster, and forward it to friends and family with just the click of a button. To ensure that you receive *Breakthrough* to your preferred email address, please make sure that you update your account with us at [www.oif.org](http://www.oif.org). If you do not have an account on our website, you can create one by clicking on the 'login' button on the top right-hand side of the page.



Questions or concerns about the new change? Please contact the OI Foundation at [eruebensaal@oif.org](mailto:eruebensaal@oif.org) or 800-981-2663.

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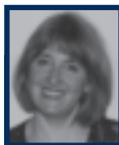
Dear Friends:

The 2010 conference is behind us now but the memories will live on...I hope everyone had a wonderful time, I know I did! It was so great connecting with old friends and meeting new ones. I enjoyed watching new relationships form and I especially enjoyed talking with people about the events and activities they wanted to become involved in when they returned to their home town. The young adults who came to me one night at conference and said, "we want to make a difference" made me especially excited. One of my goals when I came to the Foundation was to find a way to energize our young people and get them more involved...this group of young people are forming the Young Adult Advisory Council and I'm sure will do a fabulous job of moving our mission forward. Be on the look out for more information from this motivated group!

As we prepare for the 2012 conference in Washington, DC, look for information in our E-News and Breakthrough on how to become involved in advocacy activities. We will be visiting Capitol Hill again in 2012 in an effort to educate our legislators about the needs of people living with OI and the importance of supporting valuable cutting edge bone related research.

Thanks to everyone who volunteered in some capacity at this year's conference and to all those who attended and participated in the many workshops and activities. And now it's on to 2012!

All my best,



**From the President**

I love fall. The back to school time has always felt to be a time to gear up again and to "get to" things. There is a real energy in autumn.

It was hot and humid in June in Portland, but the energy level felt like fall. I personally had three different conversations with people not connected to the conference who were overwhelmed by the positive attitude, warmth and enthusiasm that our group showed (one of those conversations was with a staff person from Vice President Biden's office!).

Our 40th year anniversary conference involved sessions, events and conversations galore. Conversation resulted in a group of college age adults starting an advisory council, and a completely different group of teens that signed up to be available to do public speaking if they could be helpful. More people than I can count asked what they could do to help move the foundation into the future.

One answer to the "how can I help" question, is advocacy — talking with people about why the foundation is important to you. There are grants available to foundations like ours, and we could really use those dollars to help expand the Linked Clinical Research Centers and fund more research. Educating everyone you can is important; but there is a special role played in the political arena, and returning to Washington DC in 2012 is in recognition of that influence. If you have an opportunity to educate someone in government about OI and the foundation, please do so! And make plans to join us on the Hill as part of the conference in 2012.

Thank you for your enthusiasm, excitement and willingness to make a difference!

Sharon Trahan

# 2010 National Conference on OI

## OIF Celebrates Successful National Conference *continued from page 1*

The National Conference plays a vital role in the lives of many people with OI. In addition to the unparalleled informational sessions, and opportunities to meet with leading OI experts, the Conference provides attendees with an inviting and inclusive environment. One Mom repeated her 9-year-old daughter's happy statement that 'Everyone gets to play together here!'

The 2012 National Conference will be held in Washington, DC. at the Crystal Gateway Marriott in Crystal City, VA. A major factor in the city selection process was the opportunity Washington, DC, offers to increase advocacy and awareness efforts on Capitol Hill.



# 2010 National Conference on OI



# National Conference Sponsors and Supporters

The OI Foundation extends our sincere appreciation to the companies, organizations and individuals listed below who supported the 2010 National Conference on OI in Portland, OR. Through their gifts, these supporters helped keep registration costs down for attendees so that more adults and families could attend.

In addition, generous gifts by the Scholarship Donors below enabled the OI Foundation to award 17 scholarships, covering the registration and/or hotel costs for 47 children and adults.

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## Spotlight: Nicole Lynn Gerth



If you were in Portland this summer and attended the screening of the David Crabtree film “Broken Dreams,” you likely met Nicole Gerth, the 25 year old actress who appears in the film. If you were a teen hanging out in the designated teen room, you also may have met Nicole as she and Adam Sanders co-lead a highly successful discussion about dating and relationships.

Or maybe you attended “Parenting: What My Parents Got Right” and heard Nicole share her experience of growing up with OI. Because this was Nicole’s first time at conference we asked her to share thoughts about her experience as both a contributor and first time attendee. Nicole had this to say.

“Thank you from the bottom of my heart for including me at the Osteogenesis Imperfecta Foundation’s 17th National Conference! It was such an honor to be able to share my life story, profession and art with the OI community.

Screening “Broken Dreams” at the conference was very rewarding to me as this was my very first feature film! It is very important to me to share my art with my peers. Thank you for making this possible.

This was my very first OI conference and I am overwhelmed with the vast number of wonderful and inspiring people I have made connections with. I am so happy to know that the “What My Parents Got Right” session was a success! It was my intention to put any parental worries to rest and instill the families with as much hope and inspiration as possible.

The younger people with OI made a profound impact on me. It was such a joy to speak to the young teens about dating, relationships, pursuing a career and maintaining personal confidence as someone with OI. I was very overcome with emotion by how much the younger children and teenagers with OI looked up to me. It was an incredible feeling of responsibility and purpose to what I do as an artist and as a young adult. They have completely inspired me. As I kept telling all of the young children and teenagers at the conference – anything is possible, dream big!

Thank you again for making my journey to the OI Conference possible. I am honored to have been included in these wonderful seminars. I have every

intention to continue to be an active member inside the Foundation! Please let me know if there is anything I can do.”

### So, who is Nicole Gerth?

Nicole grew up in Simi Valley, part of the greater Los Angeles area and now lives in Hollywood. She earned a B.A. in Theatre and a Masters in Fine Arts in Theatre, Film & Television from California State University. She is a working actor and writer. Nicole shared her thoughts on various topics in a recent interview.

### Tell me about your mother and father – what were they like?

My mother and father are incredible human beings. Both of my parents, Sandra and Craig are so full of love and generosity. They have always told me to go after what I want in life and they always told me that I am to never let someone tell me that I couldn’t do something. They are the reason I am the person I am today. I owe everything to them. They have given me the confidence and support that I need to live my life.

### Who had the greatest influence on you during your childhood?

My parents and brother. Simply put, I’m the person I am today because of the incredible family I have been blessed with. This is where I get my humor, my drive, my support and my inspiration.

### What teacher had the greatest impact on you?

Richard Lawson of the Beverly Hills Playhouse and Richard Lawson Studios. He helped me to discover myself as an artist. It wasn’t until I started studying under him, that I truly realized that my physical challenge is an asset to my creative and personal life, not at all a hindrance or liability. He is a fabulous friend, acting teacher, role model, and life coach. He has helped to shape my life and my way of thinking.

### As a child, what did you want to be when you grew up?

Indiana Jones, I was a quirky little kid...

### If you could be or do anything else - what?

I’ve thought about this many times. I often think that if I go down my creative path, I probably would have studied medicine. The human body is fascinating to me. However, I love the career path that I’m on, and wouldn’t change it for the world. I’d rather just play a medical doctor on TV. . . haha!

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# Lifestyle

**Nicole Lynn Gerth** *continued from page 6*

## **If you could change one thing in your past, what might that be?**

I chose not to think this way. I don't like the concept of having regrets. I believe that everything happens for a reason. We learn from all the experiences that we encounter, good and bad. It helps to inform your next choice in life. I wouldn't change a thing.

## **What are you most proud of?**

That I completed most of my career goals that I set for myself in 2009! I wrote them out and when I was cleaning my apartment the other day, I came across my 2009 Goal List. It felt amazing that I accomplished the majority of what I set out to do, because that list is a portion of what my life's dream is. I am so proud of myself as I'm slowly making my dreams a reality. I got teary eyed when I read it!!

## **How would you like to be remembered?**

As someone honest, open-minded, trustworthy, intelligent, kind, loving, sexy, creative. Someone that went after what they wanted and got it. Someone that never let someone tell them no.

## **What's the one thing about you few people know?**

That I am a huge science geek. I love watching and studying astronomy, chemistry and biology. I love watching documentaries about the most obscure things... fire ants, the cosmos, rare plants that grow in the far corners of the earth.

## **What do you like most about your job? What do you like least?**

The thing I like most about being an actor is that on every new project that I work on, I get to portray a new person, with a new life. The constant creativity and creation is very rewarding.

The thing I like least about being an actor? .... Nothing. This is my dream job.

## **What are your special interests, and/or hobbies?**

I'm interested in acting and writing for television, film and theatre. I've come to realize that my physical challenge of having OI has completely shaped who I am as an artist. I use my size and shape to my advantage in every role I play. It is an asset, not a liability baby!

## **Have you had the opportunity to travel? If so when and where?**

Yes, I've had the wonderful opportunity to travel to Shanghai China. I was a part of an avant-garde dance

show called Houdini's Box. We were asked to come to Shanghai University and perform our show.

Traveling to China with a wheelchair is very difficult because they do not have the same ADA laws that America has. Thank God I traveled with a company of other dancers that could help me get up and down the stairs! China is not very accessible.

It was very sad to see that the majority of Chinese people that I saw in China that had physical challenges were homeless. I feel so very fortunate to live where I live.

## **Did OI affect your college experiences and/or choice of career?**

Yes, but in a very positive way. Having OI gives me a very unique attribute for my career as an actor in the entertainment industry. It has helped to shape the roles I should go after, and has certainly helped me to find my humor/heart in the characters I portray and the stories that I tell.

## **What techniques did you develop to cope with OI as a child, student and now?**

Throughout my childhood experiences and the wonderful family I have been blessed with – I certainly have developed a strong sense of humor in dealing with my life with OI. I find that I'm able to make people laugh very easily. I like to approach life with a strong element of humor. I feel that that helps people to see me before they see my physical challenge. Good humor makes people comfortable.

## **What do you do so you can live independently?**

I make sure that the living space is fully wheelchair accessible, and that the doors are wide enough! I'm not afraid to ask when I need something changed or corrected in a work or school environment.

## **What are your plans for the future?**

I intend to continue to strengthen my mobility. I intend to continue to develop my career as an actor, comedian and writer. I intend to become a very active member of the OI community!

## **Is there something you want to tell teens or parents or other adults who have OI?**

Go after what you want in life. Dream the biggest dream you can possibly think of, and then manifest it for yourself. Anything is possible! Don't ever let someone tell you "No!"

## *In My Own Words*

### Hearing Loss as a Second Disability

By Rosemarie Kasper

For most of the first half of my life, being a full-time wheelchair user was my major preoccupation. Searching for accessible entrances to public buildings, many of which did not have one, was both frustrating and inevitably confining. As the lack of physical access gradually lessened—largely due to the ADA (Americans with Disabilities Act) and other laws, a new medical disorder asserted itself: hearing loss.

Both disabling conditions were due to my having osteogenesis imperfecta (OI), a genetic disorder that causes brittle bones, short stature, and related problems. Quite recently, it was determined that more than 50 percent of individuals having OI also experience hearing loss. My loss became apparent in my teens.

Initially, my parents attributed my turning up the volume on radio and TV to a youngster's fondness for loudness. Ultimately, tests proved otherwise, and at age 18, I received my first hearing aid. It was not a thrill but helped to some extent. Through the years, my hearing aids were upgraded in accord with my needs and with improved technology. I also learned the value of wearing binaural aids and regretted not trying them earlier.

Then in 1985 the unthinkable happened: I suddenly lost total hearing in my right ear.

It was a spontaneous medical occurrence and caused me immense anguish by greatly decreasing my communication ability. Whereas earlier I had been commended for my good speech discrimination, this changed dramatically—partially because I could no longer benefit from wearing two aids. With the encouragement of a friend, I registered for a lipreading course and then we both took lessons in sign. Nothing helped significantly, although knowledge of basic sign language has been helpful in certain circumstances.

Even before my loss of hearing became so severe, I realized how much greater its impact was on my life than the wheelchair. It did not require a science degree for people to learn how to push a wheelchair and realize the type of help I would need in different

circumstances. They were willing to fold and lift my wheelchair into their cars and push me when shopping. Not so with hearing loss. Most people did not know how to help me to hear and even tended to forget about my loss unless I reminded them—which I did and still do, frequently. And their patience in repeating a conversation is often far more limited than with pushing the wheelchair (even on rough terrain!). As for taking notes, a few people are willing, but others resist.

Certain situations have always carried a special burden. In a vehicle, it is virtually impossible to lipread, and my hearing is useless without that assistance. When someone is pushing my wheelchair, I cannot converse with that individual or with others who are not directly facing me. In small-group situations, every effort will be made to seat me in a convenient location so that no one will stumble over the wheels. However, it is rarely possible to face everyone, and my companions, caught up in the animated conversation, will tend to overlook my predicament.

I learned to expect far more surprises with a hearing loss than with the wheelchair. Normally, if I am able to enter a building, there are no further problems—unless the elevator is down. With a major hearing loss, there can still be a variety of difficulties. An assistive listening system may not be functioning or may not even be set up. Assistive listening devices are not always available for tours, and printed information is frequently lacking. Previously captioning was rarely available, and I was not capable of benefitting from sign language interpreters.

Even the availability of captioning was—and sometimes still is—not helpful. With Rear Window captioning at the movies, it was difficult to hold the device and watch the movie—so much so that I rarely attended. (*Editor's note: the device was designed to be placed in the cup holder next to the patron's seat, but a wheelchair user does not have access to a cup holder.*) However, my advocacy and especially that of my friend Arlene Romoff, a crusader in theater access for people with hearing loss, helped to alleviate this difficulty, and a special holder was developed for wheelchairs!

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# Lifestyle

## *In My Own Words* (continued from page 8)

The captioning of live theater was a tremendous step forward except for the occasions when I discovered that the captions were not readable from the area designated for wheelchairs! Usually, for safety reasons and as mandated by the fire department, wheelchairs are situated on an aisle near an exit, and the location cannot be changed. On one unforgettable evening, an attempt at relocation was made and my friends and I were led to THREE different areas, each with a progressively worse view! We missed a large portion of the first act before finally reaching a place where the captions were marginally readable.

A basic problem is that many theaters do not anticipate that a wheelchair user might also be hard of hearing and thus do not attempt to set up the captioning in a suitable area. Unless the theater is one with which I am familiar, this means that arrangements must be checked out as far in advance as possible.

Overall, coping with hearing loss in addition to using a wheelchair has impressed on me the fact that the most

formidable accessibility problems may not be visible. Expecting the unexpected and having the patience to persevere and follow through are invaluable in a fulfilling life.

*Rosemarie received her bachelor's and master's degrees from Fairleigh Dickinson University, Teaneck, and was a senior rehabilitation counselor with the New Jersey Division of Vocational Rehabilitation until retiring. She founded the New Jersey Osteogenesis Imperfecta support group 18 years ago and remains its co-chairperson. She is also a co-leader of the Hearing Loss Association-Bergen County Chapter and serves on the advisory board of the Bergen County Division on Disability Services. She has received awards from the latter two groups as well as from the national OI Foundation. Rosemarie lives in Hackensack, NJ, and enjoys traveling, reading and writing. She has published many articles on disability issues, and her advocacy focus has shifted from wheelchair to communication access.*

## Science & Research

LCRC: This last May my son Danny and I traveled to one of the newest LCRCs located at Shriner's Hospital in Oak Park, Illinois. Danny has been treated at Shriner's OI clinic for several years, but this visit, I was able to attend as both a parent and a patient. I have been anticipating becoming involved in the Natural History study currently ongoing at the LCRCs since the Board first approved the creation of the first LCRC. Imagine being able to participate in a study that could help in treatments for adults affected with OI.



*Danny and Tony Benish*

I grew up in the 60s and 70s, when very few knew what OI was, let alone if there were any treatments. I often wondered if there would ever be a facility that specialized in research for children and adults with OI. I had always hoped that there would be a place that could help coordinate treatment for adults affected with OI. I remember the Board's vote to approve the first LCRC, and hoping that Chicago would one day have their own Center.

I placed several calls to Angela Caudill to set up our appointment. I had the crazy idea of being the first adult enrolled in the newest LCRC. However, by the time I got my appointment, there were many others ahead of me. Regardless, I looked forward to my appointment in the hopes of sharing my clinical history.

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# People & Events

## On the Road with the OI Foundation. . . Kansas City

"My son and daughter have OI. Chances are that some of our grandchildren and great-grandchildren will, too, and we want to make life better for them."

These words came from Andrea Hellerich in Kansas City, MO. She and her husband Erich have 3 children – Cameron, Julianne, and Olivia – two of whom live with Type I OI. OI Foundation staff member Stuart Tart traveled to Kansas City from August 18-20 to meet with local families and other supporters and thank them for their involvement. The children's grandmother Linda Mingori also joined her family in discussing the impact of OI with Stuart.

Even though they are on the mild end of the OI spectrum, 15-year-old Cameron has experienced 69 fractures already during his short life, while 11-year-old Julianne has had more than 30. As you would expect, the Hellerich family's concerns have to do with the well-being and daily lives of their kids. Several years ago, Cameron suffered three jaw fractures. Because of the medication he had been taking, a local doctor worried that Cameron may be at risk for developing a particular and serious condition. However, a call to the OI Foundation and a referral to an OI specialist provided much-appreciated reassurance that this would not be a problem for Cameron.

Andrea and Erich also want their children to be involved in as much activity as their bodies will allow. So, Julianne, who fractures less easily than her brother, joined one of the cheerleading teams at Positivity Gym. Although her coaches said that her form was beautiful, Julianne recently was sidelined by injury after she broke bones in her right arm while performing a back handspring.



*(L to R): Olivia, Andrea, Julianne, Erich and Cameron Hellerich.*

Cameron, who is starting his sophomore year at a new high school, has run into an obstacle familiar to many OI families. Some school personnel are actively discouraging him from participating in any sports or even regular P.E. classes, because they fear he will be injured. In fact, when the school counselor learned that Cameron wants to be a medical doctor, this experienced professional actually asked Cameron if that might be too much for him! As you can imagine, mother Andrea was very upset by this conversation!

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*(L to R): OI Dad Dan Krudys of UPS and Jane and Ron McKinney of Positivity Gym.*

Ron and Jane McKinney of Positivity Gym ([www.positivity-gym.com](http://www.positivity-gym.com)) were inspired when they learned about OI and met Julianne and Cameron through the parents of some of their cheerleading students two years ago. When Positivity Gym offered to hold a fundraising walk to assist the family with medical bills, Andrea's response was firm: "I would rather you give the money to the OI Foundation; I want it to help other families who need more than we do."

Ron and Jane were also moved by 6-year-old Sami Binning, another local girl with OI who attended a birthday party at the gym. Ron remembers seeing Sami having a great time playing on a bouncy mat. Due to her small size, Ron thought she was very advanced for her age. Their encounter with Sami led the McKinneys and former co-owners David and Kay Bratcher to learn more about OI. David, in particular, was key in researching information about OI and the OI Foundation and he was passionate about this cause, according to Jane.

"As a gym, we wanted to sponsor a cause that would benefit our community," Jane said.

*continued on next page*

# People & Events

## On the Road with the OI Foundation *continued from previous page*

With the help of an active parent booster club, Positivity Gym's first two annual walks each attracted between 175 and 200 people and together raised more than \$11,000. Kay also worked with the gym's cheerleaders to sell OI awareness bracelets at a competition last Spring, contributing an additional \$1,000. Most importantly, Positivity Gym is proud that these events have brought together eight or nine different families from the OI community.

Ron and Jane, who have no family connection to OI, insist that "We've gleaned more than we could imagine" from their interactions with the OI community. "It's life-changing," they said.

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Dan Krudys and his wife Cher have three children, including 15-year-old Jeffrey, who begins high school this Fall. Jeffrey, who lives with Type III OI and uses a power wheelchair, already has experienced 20 major surgeries and suffered more than 200 serious fractures, according to his father. However, as Dan told Ron and Jane McKinney, "only about 10% of those 200 breaks were hospitalized." For the rest, Cher uses casting material that she received from Jeffrey's orthopedist.



**OI Foundation staff member Stuart Tart speaks to UPS drivers in Lenexa, KS, on Aug. 19.**

Dan, a division manager for UPS, joined Stuart's meeting with the McKinneys and was pleased to learn about this successful local OI walk. In fact, the very next day, he began working with his staff to determine how UPS can help with the 3rd Annual *Julianne's and Cameron's Unbreakable Spirit Walk for OI*, which will be held on Saturday, October 16.

In addition, Stuart was invited to speak to UPS pre-load sorters and drivers in Lenexa, KS, about the impact that their United Way donations to the OI Foundation are making. Stuart also met some long-term donors at the Lenexa and Kansas City UPS facilities, thanking them individually for years of generous support. In fact, the UPS employees in the Kansas City area contribute approximately \$30,000 to the Foundation each year. These donations move forward cutting edge OI research, cover the cost for new OI fact sheets and other resources, and make it possible for the Foundation to respond to more than 6,000 individual information requests from members of the OI community each year.

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Jesse Wilkerson, Jr. of Gardner, KS, said that his biggest issue, even now, is finding doctors who will provide him with knowledgeable care. Jesse was born in 1932, but did not learn that he had OI until his first fracture at five years old. Although doctors were able to diagnose him, they had no information for Jesse's family about living with OI. This did not change for Jesse and his family until his sister Dorothy found a magazine article about the OI Foundation during the 1970s. Jesse has received the *Breakthrough* newsletter ever since.

Jesse, his father and his two sisters all lived with OI. In fact, since schools were not equipped to deal with kids with disabilities during his childhood, frequent fractures forced Jesse to leave school in the 4th grade and his sister Dorothy was unable even to complete first grade. Despite having very little schooling, Jesse got his first job when he was 18 years old, and during his career, he worked as a jeweler and an electronics technician.



**Patricia and Jesse Wilkerson, Jr.**

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## “Going Places” Sweepstakes Begins October 1



You truly can go places with the OI Foundation!

The “Going Places” Sweepstakes is a fun and easy way both to support the OI Foundation and even to get your co-workers, neighbors and family involved.

**Don't miss this chance to win 4 great prizes!** The Grand Prize, which will be awarded in January, is a 3- or 4-day cruise for two, arranged by **Karen and Glenn Vowell** of **Cruisesnyou.com**, plus roundtrip travel for two, courtesy of **Southwest Airlines**. If you are the winner, you choose the cruise and it is covered up to \$1,200!

The OI Foundation also will award a 22" HD LCD television, a portable GPS system with touch screen navigation, and \$200 in gasoline gift cards to lucky winners. The gasoline gift cards are donated by the **Finkel Family** of Indianapolis, IN.

**Here is how the Sweepstakes works.** You will receive an information flyer and 20 Sweepstakes tickets in your mailbox some time in late September or early October. Simply pass tickets out to people you know, ask them to fill out their name and contact information, and invite them to make the suggested donation of \$5 per ticket or \$40 per book of 10 (or an amount of their choice).

You also can fill out tickets for yourself and make the suggested donation, if you choose. Then, mail your completed tickets and any donations to the OI Foundation in the enclosed return envelope. If you prefer, you can enter the “Going Places” Sweepstakes online beginning October 1 at [www.oif.org/HH\\_Sweepstakes](http://www.oif.org/HH_Sweepstakes).

There is no donation required to enter, and making a gift does not increase your chances of winning.

**All Early Bird entries must be postmarked no later than November 22.** The winner of the \$200 in gasoline gift cards will be randomly selected from these entries.

**The remaining three prizes will be part of the Grand Prize drawings, with entries due no later than December 20.** Winners will be notified by phone or e-mail, and they will receive their prizes after completing the winners' paperwork that the OI Foundation will mail to you.

**So, where do you want to cruise?** Don't miss your chance to enter and win this Fall!



## Advocacy Update

During the late spring and much of the summer the U.S. House and Senate have been working to form and pass the 12 Appropriations bills that will comprise the FY2011 federal budget. Among these bills is the Labor, Health and Human Services and Education (LHHS) spending bill, which will dictate funding levels for many programs critical to the OI community. Several programs eligible for funding this year were created by the Patient Protection and Affordable Care Act (ACA), the healthcare reform legislation which the President signed into law in March. Both the House and Senate are well on their way to developing unique versions of the LHHS bill, which will be reconciled before becoming law. On the House side, the LHHS Appropriations subcommittee passed its version of the bill on July 15 and in the Senate, the full Appropriations committee passed the LHHS bill on August 2 after it was developed and passed by the Senate LHHS Appropriations subcommittee.

In the Senate LHHS Appropriations bill, the funding level for the National Institutes of Health was set at \$32,007,273,000.00; over a \$1,000,000,000.00 increase from the FY2010 funding level. \$50,000,000 of this increase will fund the Cures Acceleration Network [CAN] a program created by the ACA that has much potential to benefit the OI community. Although the house subcommittee bill has not been officially passed, the funding level has been set at the same level as the Senate subcommittee.

The Cures Acceleration Network was designed by Congress to decrease the time between discovery and implementation of drugs and therapies through new grant making mechanisms at the National Institutes of Health. It proposes to do so by awarding grants and contracts to eligible entities to support research that moves discoveries from the "bench to bedside." The program will also provide additional resources necessary for participating entities to support development of High Need Cures such as those required for Osteogenesis Imperfecta. CAN will work with the FDA to coordinate approval requirements with the goal of expediting development and approval of products.

As it is noted in the LHHS bill, too often basic biomedical research will suggest a promising a path for a cure or treatment, but funding falls short to transition this discovery to a workable therapy. With the additional \$50,000,000 allocated towards the Cures Acceleration Network, the NIH will work to solve this problem. CAN will make grants available to biotech companies, universities, and patient advocacy groups.

Also relevant to OI research and programs, the Senate LHHS bill increased funding for The National Institute of Arthritis and Musculoskeletal and Skin Diseases [NIAMS] to \$54,846,000, nearly a \$15 million increase when compared to FY2010 levels. The Senate LHHS committee urged NIAMS to support research into bone loss in diverse populations in order to develop targeted therapies to reduce fractures and improve bone density, quality, and strength. Finally, funding for the National Institute of Child Health was increased by 38 million. The LHHS committee also proposed more research in the field of bone health in children and adolescents.

Although this increased funding is very promising, it is important to understand that the LHHS spending bill still has a long way to go before it becomes law. In the next few months, the House Appropriations committee must consider and pass the LHHS bill before it is passed on the House floor. The Senate bill must also be considered and passed by the full chamber. Finally, differences in the House and Senate bills must be reconciled in a conference committee before the LHHS spending measure becomes law. The OIF advocacy team will continue to update the OIF community on the funding discussed above. OIF advocacy will also track and report progress on the continued implementation of health care reform. To become more involved in the advocacy process, please join the OIF advocacy team by emailing [oifadvocacy@wscdc.com](mailto:oifadvocacy@wscdc.com).

## People in the News

*Opelika, AL* – A baseball fan since she was a little girl, 16 year old **Danielle Tadych** has been spending Sunday afternoons announcing games for Miracle League baseball.

*Berkeley, CA* – Berkeley Center for Independent Living is considered the birthplace of the disability rights movement. 38 year old **Yomi Wrong**, a former reporter at the San Jose Mercury News, recently took over as head of the agency.

*San Bernardino, CA* – Interviewed on the 20th anniversary of the Americans with Disabilities Act (ADA), 55 year old **John Anaya**, chairman of the board of directors of Rolling Start, Inc., observed the many changes that have resulted from the legislation.

*Parker, CO* – Courtesy of the Make a Wish Foundation, 11 year old **Lauren Thiessen** had the opportunity to take part in “The Sorcerer’s Apprentice,” starring Nicholas Cage. Look for ponytails and a pink puffy coat in a flashback scene.

*Waterbury, CT* – A lifelong dream to play professional basketball has come true for 28 year old **Josh Rodriguez** who has signed a contract to play French Division I wheelchair basketball in a small town in the south of France.

*Washington, DC* – **Lakendra Nelson** made the evening news when the 2’11” 22 year old delivered baby Lakenzie Miracle, who did not inherit her mother’s OI.

*Beverly Hills, FL* – Appearing on the PBS series “History Detectives,” **Chuck Roedel**, a ham radio operator, asked investigators to examine material he’d been given that turned

out to be a piece from an early space satellite called the Echo Satellon.

*Ponte Verde Beach, FL* – Don’t try to park illegally in a disabled parking spot in 42 year old **Maureen (Mo) Murphy’s** neighborhood. Either she or her mother Helen may serve you with a \$250 ticket authorized by their participation in an auxiliary disabled parking enforcement corps.

*Waycross, GA* – Children’s Miracle Network featured 12 year old **Hannah Tyre** as a spokesperson for the wonderful care she has received at Backus Children’s Hospital.

*Morris, IL* – Little Hands Big Hearts, a local nonprofit helping kids with rare diseases hosted an event to raise awareness about OI and funds for 5 year old **Nick Cook**.

*Indianapolis, IN* – In commemoration of the passing of the Americans with Disabilities Act, **Greg Fehribach** recalled his presence at the White House in 1990 as President George H.W. Bush put his signature on this legislation.

*Ames, IA* – A Montreal Shriners patient from the age of 8 months, and chosen as this year’s Shrine Bowl Queen, 8 year old **Amyra Faisal** attended the 38th Annual Iowa Shrine All-Star Football Classic.

*Bay City, MI* – The story of **Missy Davert’s** delivery of twins Michaela and Austin ten years ago was presented by Pro-Life television in the series “Facing Life Head-On” for which it won an Emmy award.

*Davison, MI* – Acknowledging the help of her steadfast but aging Golden Retriever Sunny, **Valarie Franklin** was awarded a Doctor of Pharmacy degree at Ferris State University.

*Grand Haven, MI* – Selected to participate in the International Junior Wheelchair Tennis Camp in Mission Viejo, CA, 14 year old **Krystal Kelley** was able to attend for free thanks to the Grand Rapids Wheelchair Sports Association.

*Zeeland, MI* – Stating that he has done many aquatic fitness system installations, **Jay Wyllys** observed that he has never seen anyone more deserving and appreciative than 14 year old Tim Bosch, the recipient of Tim’s Tub, a community fundraising project.

*Bloomington, MN* – Helping out at National Pancake Day at IHOP, 8 year old **Tyler Schell** helped the Children’s Miracle Network raise funds for Gillette Children’s Hospital where Tyler receives treatment.

*Moorhead, MN* – Representing Minnesota in the Ms. Wheelchair pageant, 19 year old **Tawnya Taylor** was awarded second runner up as well as the award for most photogenic. Tawnya is studying political science at North Dakota State with plans to be a lobbyist for people with disabilities.

*Rural Frazee, MN* – Persistence paid off and 6 year old **Alexis Mack** convinced her parents that she could handle a bicycle and happily demonstrated her skills to a local reporter.

*MS* – Thanks to the Make A Wish Foundation and Gulf World in Panama City, Florida, 7 year old **Dustin Harrell** realized his dream to swim with the dolphins.

*St. Louis, MO* – A faculty member at the University of Missouri, **Lea-Rachel Kosnik** is a Ph.D. professor and environmental economist receiving many requests for speaking engagements. While a Fulbright scholar in Turkey, she spent a day as Chelsea Clinton’s tour guide.

*Las Vegas, NV* – Wheelchair accessible baseball is now available through the Miracle League of Las Vegas and 7 year old **Daniel McCarty** is playing ball.

*Charlotte, NC* – With plans to attend St. Andrews Presbyterian College, **Xuan Truong** graduated from East Mecklenburg HS while inspiring

*continued on next page*

teachers and fellow students with her diligence in overcoming obstacles.

*Lancaster, PA* – The youngest scout to receive this honor, 17 year old **Justin Walker** was nominated to the Boy Scouts of America's National Hall of Leadership. Justin, who uses a wheelchair, observes that "there's no real reason for me to not show that I can be the same as everyone else."

*State College, PA* – An honorary cheerleader with her sister's team the Nittany Wildkat, 8 year old **Dale Dyke** performs her own routines in competitions as a special athlete.

*Stroudsburg, PA* – "Through Their Eyes," an annual conference featured 22 year old college junior **Kristal Nemeroff**, who shared her experience of being a nursing student with a physical disability.

*West Chester, PA* – Information about OI treatment as well as a study at A.I. DuPont looking at the benefits of vibration therapy were part of a profile of 8 year old **Mallie Holman** who receives treatment at the hospital.

*Nashville, TN* – Interviewed about his thoughts on health care reform, **Chuck Lawson** shared concerns that he and his 16 year old daughter will continue to receive the kind of health care that has enabled him to work and his daughter to be a successful student with plans to attend college.

*Mesquite, TX* – Paralympic sled hockey player **Taylor Lipsett** returned from the Vancouver games with a gold medal.

*Milwaukee, WI* – 30 year old **Brianne Schwantes** received a masters in communication from Marquette University. A doctorate is being considered as a way to honor her mother who deferred her own education in order to take care of her daughter.

*Quakers Hill, Australia* – Seeking a career in television or movies, 21 year old **Joshua Taig** recently completed a transition to work program at The King's School in North Parramatta.

*Canada* – Her experience as a volunteer at the 2010 Olympic Games left much to be desired as **Elaine Lee** felt the entertainment department of the Olympic organizing committee to be extremely unaccommodating of her disability.

*United Kingdom* – "Britain's Smallest Mum" is 25 year old **Amanda Moore**.

## People & Events

### T-shirts, Car Magnets, Bears. . . Oh My!

Have you seen the new OI Foundation café press store?  
<http://shops.cafepress.com/OIFoundation/>

Start the school year off with a very clear message "Handle with Care" on your child's t-shirt. Or sip from your Sigg Unbreakable Spirit water bottle while grocery shopping. The shop has t-shirts for men, women and children, along with other fun gifts.

A percentage of all sales go directly to the OI Foundation. Help us to help people with OI. Shop <http://shops.cafepress.com/OIFoundation/> today.

**Did you forget to pick up a car magnet or the new Blue Jeans for Better Bones bear at conference?** Don't worry! We have some now in stock in the OI Store. Just click the link on the OI website [www.oif.org](http://www.oif.org) and they are both listed under "gifts." Gift one to someone you love and help spread awareness one car length away.



#### On the Road with the OI Foundation continued from page 11

As an adult, Jesse's sister, Dorothy, decided to earn her GED (alternative high school diploma). She then continued her education until she had earned a Master's degree in Rehabilitation. Afterwards, Dorothy worked for the State of Kansas.

During his life, Jesse has had more than 40 bone fractures, the most recent one in August 2010. In retirement, Jesse is a licensed Ham Radio operator, an artist and an art instructor. He and his wife Pat also operate a small business through their home, the Old Santa Fe Trail Doll Shop (<http://www.santafetraildolls.com/>), from which the couple donates 10% of all proceeds to the OI Foundation. Pat makes customized dolls and doll clothes and Raggedy Ann and Andy dolls. Bonnets for girls and women are also available.

The couple said they are firmly committed to supporting OI research. "Only through research will we ever find a cure for OI," Jesse explained.

# Recap of Events

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## What's Happening?

The 5th Annual Birdies and Bogies golf event at the Belmont Country Club in Ashburn, VA, on August 9th was a huge success. We had our largest turnout of golfers to date; 85 men and women teed off in the August sun and raised 35 thousand dollars for the OI Foundation. This golf event is organized each year by Karen Orejuela, who does not have OI but was inspired to take action and raise awareness for the OI Foundation after meeting Roger and Gayle Bache and their daughter Katrina. Karen's employer, Booz Allen Hamilton, has been the major sponsor of this event each year. Thank you to everyone who helped make this event such a huge success. We look forward to seeing you again next year!

**Run...Eat...Sleep...Repeat!** John Young and 11 of his pals are doing just that and yes in that order. This 193 mile adventure-fest will push John Young and his 11 pals

through the stunning scenery of the Potomac River Valley. Starting near the town of Cumberland, MD, this team will head east running through the thick forests of the Appalachian Mountains. Around night fall they will run through the quiet streets of many charming historic Civil War-Era towns, ultimately passing within the shadows of the Washington Monument and the Lincoln Memorial. The race (and their stamina) wraps up on the shores of the Potomac River and ends at National Harbor. John Young is the proud father of Matthew Young who has Type III OI, he is passionate about raising awareness and supporting the OI Foundation.

Raising awareness can happen anywhere and in any way. This fall host a **Cocktails for a Cause** party at your house, inviting all of your "friends" on facebook that you haven't seen in a while. Contact Gretchen Schock, [gschock@oif.org](mailto:gschock@oif.org), to help you organize and strategize how you can raise awareness about OI to your community.

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## Where in the World is Flat Stanley?

*By Mary Peterson-Suri*

My children, along with thousands of other elementary aged kids, have had the opportunity to learn how to send and receive a letter with the help of "Flat Stanley." For those of you unfamiliar with this character, Flat Stanley is a children's book series about a boy named Stanley who became flat after a bulletin board fell on him. As a result of being flat, he easily fits in an envelope and is able to go on many adventures to different places.

While driving to work one night and talking to another OI mom about Flat Stanley, I hit upon the idea of sending Stanley off via the internet to visit OI children all around the world. Besides being a fun geography lesson, it would more importantly offer our OI children a peek into the lives of many other children just like them in far away places and possibly help to make a rare disorder less isolated.

OI Flat Stanley started as a thread on Facebook with an overwhelming response. There were over 80 children added within 24-hours. Five Stanley's deployed from Pinehurst, NC, the very next day. Each child posed with Flat Stanley at a local site and sent the photo to the next child in line on the list. Stanley went via emails to many of the 50 States, Canada, England and Wales. He went to the Philippines, Australia, Denmark, Greece and Ireland. The EU Stanley that was mailed ended up falling into the English Channel on his way to Ireland, but luckily, he was able to recover via the internet.

Stanley had to hurry because we wanted to produce something for the National Conference on OI, in Portland in July. We felt that would allow the biggest opportunity for many OI children and families to see it. We had a folder on Facebook that told of his adventures and I then made a slideshow with the song "I Hope You Dance." This depicted all the OI kids with Stanley and the locations he had visited. Intermingled in those pictures were pictures of little OI girls dancing ballet. Stanley tried to show all the faces of OI in his journeys.

The internet has allowed a rare disorder to become more visible and understood. It has also helped families feel less isolated and alone. People affected by OI now have access to other people affected with OI to share ideas, accomplishments and setbacks like never before. We live in a time of extraordinary change and the face of OI is changing dramatically, in a positive way.

One of the things most important to me for my two OI children is letting them know that they are not alone. We routinely meet up with our OI family and friends all over the country. My children look at posts on Facebook with me and scan our OI Parents Yahoo Site for updated pictures of their friends all over the world. OI is a rare disorder and it can be a challenge being the only child in a school system, country or region. Flat Stanley was one more way to make it all seem less different.

# People & Events

## Bone China Tea Hosts Raise More Than \$31,000!

A small number of committed people truly can make a real difference!

Bone China Tea Co-chairs Jennifer and Susan Wilson, along with 45 volunteer Bone China Tea hosts, together have raised \$31,019.60 so far to support the OI Foundation's work to fund research, provide answers to families and raise awareness. Each volunteer simply sent either a card or e-mail – provided by the OI Foundation – to their friends, colleagues and family members that invited them to a 'phantom' event. Each recipient was asked to enjoy a cup of tea at home and then make a gift to the OI Foundation in the amount they saved by not attending an actual event.



This small action produced impressive results. Our hosts brought in 539 donors, many of whom may not have been involved with the OI Foundation otherwise!

Parents Michael Johnston and Bonnie Landrum of Minneapolis generated the most impressive results again this year, moving 91 donors to contribute \$7,700! The Cabacungan family of Oak Park, IL; Cynthia Nolan of San Diego; and Susan Wilson of Ft. Myers, FL, all raised more than \$2,000, and five other hosts each persuaded their loved ones to contribute a combined \$1,000 or more.

The OI Foundation thanks each of the 45 hosts below who made the OI community stronger by contributing their time to write personal notes, share photos, address envelopes, and ask the people they know to help!

### 2010 Bone China Tea Hosts

#### **\$5,000 and up!**

Michael Johnston & Bonnie Landrum

#### **\$2,000 - \$4,999**

Alec Cabacungan  
Cynthia Nolan  
Susan Wilson

#### **\$1,000 - \$1,999**

Sarah Cramer  
Michelle Duprey  
Jacob Gadberry  
Jason & Susan Reazor  
Greg Trahan

#### **\$500 - \$999**

Judith Clarke  
Kelly Laird

#### **\$250 - \$499**

Donna Ayers  
Gail & George Bunker  
Debra Iachini-Lux  
Ashley Jones  
Claudette McDonald  
Michelle Moscardelli  
Barbara Panowitz  
Robin & Mickey Rowland  
Tracy Russell  
Jessica Scoggins  
Lisa Thompson  
Karen Vowell

#### **Up to \$249**

Thomas Acquafredda  
Taphan Blatt  
Cynthia Cain-Hunter  
Natasha Dafney

The Dias Family  
Paula & Alyse Furber  
Michael Loguercio  
Marty McCambridge  
Alexa McDonough  
Wanda Mills  
Linda Morehouse  
Mari Petree  
Bob & Linda Phillips  
Karla Robinson  
Richard Rowe  
Tamm Sharp  
Heather Starkey-Pannullo  
Linda Stewart  
Diane Tierney  
Kay West  
Rebecca Wingo-Wasson  
Jason Ziegler

## Support Group Update

New support groups are forming and others have undergone a change in leadership, as the reins have been handed over to a new group of dedicated volunteers. The newly formed Tri-State Support Group serves southeastern Ohio, West Virginia and Kentucky. Founder and Ohio resident Cassie Gillland has been joined by Wendy Shiflett-Barb from West Virginia and Angie Wallace-Skaggs from Kentucky with hopes of creating a strong OI presence in their neck of the woods. Check out the Tri-State Facebook page where you can meet members and learn about enthusiastic plans for future meetings.

Reflecting recent changes, the online support group page now lists both support group leaders and local contacts. In some instances, previous group leaders are now serving as local contacts.



In addition to offering support and information, **Support leaders** listed on the page represent community based groups of people affected by OI who gather periodically to enjoy each other's company, share information and encourage each other. Those listed as **Local contacts** are not responsible for holding meetings, but are available to offer support, answer questions and direct to resources. If your state has a new support group leader, think about calling to share your own thoughts and ideas for creating a supportive local community. Check the online calendar for information about upcoming meetings or contact your regional support group leader if you are interested in joining a group.

## Blue Jeans for Better Bones ~ Update

If you are looking for an easy way to raise awareness for the Osteogenesis Imperfecta Foundation, this is a winner!



Our *Blue Jeans for Better Bones* campaign has raised nearly \$10,000 so far and we're just getting started. Organizing a Blue Jeans for Better Bones day at your place of business, or school is easy and can be done any time of year. Participants simply donate a gift amount of \$5, which allows them to wear blue jeans or an awareness bracelet for the day. Encourage your employer to match funds raised and add to the package.

With your help, our mission to find better treatments, educate, increase awareness, and provide support to the osteogenesis imperfecta community will continue to make great strides.

For more information about Blue Jeans for Better Bones or OI, please visit [www.oif.org](http://www.oif.org), or contact Jennifer Redding at 301-947-0083 or [jredding@oif.org](mailto:jredding@oif.org).

## New OIF Board Members

The OIF Board of Directors welcomed its two newest members, Ian Sacks and Denise Bedeian, this past June. Mr. Sacks is a managing partner for TowerBrook Capital Partners in New York, NY, and has a 5 year old daughter with OI. Ms. Bedeian is the Director of Membership Development & Corporate Affairs for the Nassau County Museum of Art, in Roslyn Harbor, NY, and has a 2 year old son with OI.

# People & Events

## TJX Foundation Makes 4th Annual Award to the OI National Information Center

For the fourth year in a row, the TJX Foundation in Framingham, MA, has contributed \$5,000.00 to support the OI Foundation National Information Center.

The TJX Foundation focuses its charitable giving on programs that provide basic-need services to disadvantaged women, children and families. In 2009, The TJX Foundation supported more than 1,100 nonprofit organizations in the United States. Specifically, the foundation focuses its giving on five mission areas: Civic/Community, Domestic Violence Prevention, Education, Health, and Social Services.

The TJX Foundation was set up by the TJX Companies, which operates several well-known apparel and home product stores in the United States, Canada, and Europe, including T.J. Maxx, Marshalls, HomeGoods and A.J. Wright. In addition to awarding grants, the TJX Companies encourages its associates to be involved with their communities. For example, the companies have a number of school partnerships that give their Associates the opportunity to share important job-related skills that will help prepare students to enter the job market successfully.

The OI Foundation extends our sincere appreciation to the TJX Foundation for its dedicated support, which enables us both to offer a variety of free fact sheets, booklets and other resources and to provide thousands of people each year with individual and medically verified responses to their concerns. We also thank volunteers **Christine Wyman Rossi** and **Michelle Potorski**, who first alerted us to the philanthropic goals of this generous organization!

## It's Never Been Easier to Prepare for the Holidays!

When you purchase gift-wrap and other holiday supplies through Sally Foster, 40% of every dollar will benefit the OI Foundation.

New this year Sally Foster Gift Cards!

Shop at your convenience all year round. Free shipping on orders of \$50 or more and best of all purchases are shipped directly to you.

Sally Foster offers over 200 top-quality items including: gift-wrap, home decor, gourmet chocolates, candles, cookbooks, kid's interactive books and more! There is something for everyone on your shopping list.

Simply contact Jennifer Redding at 1-800-981-2663 or [jredding@oif.org](mailto:jredding@oif.org) to request a Sally Foster packet.

If you prefer to shop directly online, go to [www.sallyfoster.com](http://www.sallyfoster.com). **Please be sure to click on "Support a Fundraiser" and credit the OI Foundation for your purchase, using either our full name or account number 362042.**

To allow for delivery by Thanksgiving, your orders are due no later than October 15.



SHOP [WWW.SALLYFOSTER.COM](http://WWW.SALLYFOSTER.COM) AT YOUR  
CONVENIENCE YEAR-ROUND

## From the Information Center

### ***CaringBridge***

Are you a CaringBridge user? Over the summer CaringBridge announced three new features to expand and improve their service: a mobile website, a free iPhone app and text message notifications whenever a journal is updated. CaringBridge is a free, nonprofit web service that connects family and friends to share information, love and support during a health crisis, treatment and recovery. It takes just a few moments to set up your own CaringBridge website. You can learn more about this service through [www.caringbridge.org/oif](http://www.caringbridge.org/oif) or on the Support page of the OI Foundation website.

### ***New NIH Website***

The National Institutes of Health has a new web resource for information on bone health and bone disease. Visit [www.bones.nih.gov](http://www.bones.nih.gov) for information on many bone topics including osteogenesis imperfecta.

### ***Suggestions for Managing Radiation Exposure***

Reports about the effects of ionizing radiation have been in the media all summer. ALARA, an acronym for “as low as reasonable achievable” is a useful term to know when deciding whether you or your child should have an x-ray or CT scan. Here are some suggestions for minimizing radiation exposure.

- Ask if the hospital emphasizes ALARA.
- Ensure that the Radiation technologist shields the patient and confines the areas being exposed to ionizing radiation.
- Ask if the technique being used has been adjusted to the size of the child or adult.

*(Source: HealthFinder.gov July 19, 2010)*

### ***Preventing Back Pain Resource***

Back pain is one of the most common problems in the United States. People affected by OI are not immune. Parents who lift children encased in heavy or awkward casts, children and adults who sit in wheelchairs all day are all at risk for back pain. The American Pain Foundation has developed a useful online guide to preventing and managing back pain. Their “Online Guide on Persistent Back Pain” is available at [www.painfoundation.org](http://www.painfoundation.org). This informative guide includes suggestions to help you have productive conversations with your doctor about your pain.

### ***Follow Us on Twitter***

The OI Foundation is on Twitter – go to [Twitter.com/OIFoundation](https://twitter.com/OIFoundation) and stay connected.

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### ***LCRC continued from page 9***

My son and I arrived on a Friday to participate in the Center. I got to meet Angela for the first time, and we went through my medical history (at least as much as I remember). I did pretty well, except for not knowing my birth weight, but all in all I was able to provide important information. Danny and I proceeded to get our DEXA scans done, as well as other simple exams. I was also able to participate in a respiratory exam. We had some other exams done and followed up with a meeting with Dr. Peter Smith concerning current health issues with both Danny and I.

I know from my work with the Foundation that OI is an extremely rare disease. Those of us affected by OI can help tailor treatments and help to secure funding by sharing our histories with the Centers. Physicians and researchers can learn from our information to help narrow down the avenues best suited for finding a cure and establishing the best treatments for OI. The OI community finally has a place that caters to our unique disorder, and I urge everyone to participate if they are able. We are at the beginning of the path that I feel will lead to successful treatments for OI and, one day, a cure.

## Tips for Staying Healthy in the Autumn and Winter

By Hollis Chaney, MD

Osteogenesis Imperfecta puts people at risk for lung infections. Back to school season can also be the beginning of cold and flu season. Now is the time to arm yourself with the information you need to stay healthy and reduce the chance that a minor respiratory illness will become a serious problem.

The combination of chest shape with defective type 1 collagen in lung tissue is the reason for the increased risk. Because of a small chest and distortion of the chest wall from scoliosis and breastbone abnormalities (pectus excavatum), the respiratory muscles cannot work efficiently. Weak inspiratory muscles result in an inability to take in very deep breaths. Without occasional deep breaths parts of the airway in the lung close down. Weak expiratory muscles lead to a weak cough, and, therefore, inability to expel mucus. When secretions are stuck in the airways, they get thick and clog even more airways leading to more atelectasis (areas of lungs that are closed down). This creates a dark and moist and warm environment that is attractive to bacteria. Therefore, a cold can lead to pneumonia.

### Hints to Stay Healthy

#### 1. Avoid the spread of germs.

- Effective hand washing with soap and water or alcohol based hand gels is an important habit to develop. Remind kids to always wash before eating. Schools often have hand gels readily available, if not, they are easy to slip into the backpack or desk.
- Avoid unnecessary contact with people who have a cold. This includes teaching kids to not share drinks or kiss anyone with a cold, including siblings.
- The flu (influenza) is highly contagious, and spreads by direct contact, coughing, and sneezing. Additionally, any surface like door knobs and railings that have been touched by an infected person will be a source of germs.

#### 2. People with OI can develop more serious cases of the flu, so be certain to talk to your health care provider about immunizations.

- Influenza vaccines: these are modified every year to adjust to the changes in the virus. This year's

seasonal flu shot will include protection against the H1N1 virus. The vaccination produces immunity after about 14 days and lasts for 6 months to 1 year. A child must be over the age of 6 months in order to be immunized. Anyone with lung disease such as asthma should not receive the live attenuated vaccine given as a nose spray.

- Pneumococcal vaccines: these are for a specific type of bacteria, *Streptococcus pneumoniae*. There are two types: one contains 7 serotypes (protection against 7 strains of these bacteria) and is part of the routine primary immunization schedule at 2, 4, and 6 months of age. The second contains 23 serotypes, and is given after the age of 2 years, including children who already received the 7-valent vaccine.

#### 3. Other suggestions for children and adults:

- Avoid obesity: extra body weight further restricts breathing.
- Avoid heavy, large meals, and constipation. These may push on the diaphragm, restricting breathing.
- Avoid extremes of temperature, humidity and crowded areas.
- Exercise: learn different kinds of exercise that can be done safely on a daily basis.
- Don't smoke and keep the environment smoke-free.

#### 4. During colds take good care of yourself!

- Drink lots of fluids; fluids hydrate the lungs and help keep mucus thin for easy clearance
- Avoid cough suppressants and sedatives; they interfere with the ability to clear mucus
- If fever, cough or shortness of breath occurs, contact the doctor.
- Possible treatments:
  - Aerosols: a method of delivering medications directly into the lungs
  - Mucolytics (break down thick mucus), bronchodilators (albuterol, opens the airways)

*continued on page 22*

continued from page 21

- Antibiotics: even though colds are caused by viruses, they may easily turn into a bacterial pneumonia
- Cofflator: a device that helps clear the secretions

Finally, remember to have routine pulmonary assessments which can help determine changes in lung function, and the risk of complications.

*Dr. Chaney is a member of the OI Foundation's Medical Advisory Council. She sees patients through Children's National Medical Center in Washington, DC.*

## Apply for Grants for Medical Researchers

The Osteogenesis Imperfecta Foundation invites applications for research grants. There are two types of research grants available for qualified applicants:

**Michael Geisman Fellowship** awards to post-doctoral trainees (that is, those with an MD, DDS, DO, or PhD) who are currently working on projects with clear relevance to OI, or who have projects that will enable them to develop expertise in OI research.

**Seed grants** for new or established Principal Investigators who seek to initiate basic or clinical research studies with clear relevance to OI.

**Applications and all letters of recommendation must be received by December 1, 2010.** For more information, and to download the application, please visit [www.oif.org](http://www.oif.org), and click on 'Research & Studies'.

## OI Foundation Receives Top Rating for Sound Financial Management

The OI Foundation is among the top 25 percent of charities nationwide, according to Charity Navigator, which calls itself "the nation's largest and most-utilized evaluator of charities."

The organization has awarded its highest 4-star rating to the OI Foundation "for its ability to efficiently manage and grow its finances."



"This 'exceptional' designation from Charity Navigator differentiates Osteogenesis Imperfecta Foundation from its peers and demonstrates to the public it is worthy of their trust," according to a letter from Ken Berger, President and Chief Executive Officer of Charity Navigator.

"We are very pleased by this recognition from Charity Navigator," said CEO Tracy Smith Hart. "It reinforces our message to constituents and donors that we work hard to make the very best use of their dollars."

To review Charity Navigator's data on the OI Foundation's financial efficiency, accountability and transparency, visit <http://www.charitynavigator.org/index.cfm?bay=search.summary&orgid=8139>.

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February 1 – July 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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*continued on page 24*

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February 1 – July 31, 2010

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The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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thart@oif.org

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Tom Costanzo  
tcostanzo@oif.org

## Director of Program Services

Mary Beth Huber  
mhuber@oif.org

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Marie Maffey  
mmaffey@oif.org

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Erika Ruebensaal  
eruebensaal@oif.org

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Jennifer Redding  
jredding@oif.org

## Administrative Assistant

Jenny Stup  
jstup@oif.org

## Database Manager

Desiree Swain  
dswain@oif.org

## Associate Director of Development

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start@oif.org

## Development Coordinator

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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*.

## Osteogenesis Imperfecta Foundation

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## **New! *Breakthrough* is Going Paperless!**

Help us go green as we transition *Breakthrough* into its new electronic format. Starting in the winter of 2010, three of the four yearly editions of *Breakthrough* will be emailed to readers. The fourth edition will continue to be printed and mailed. The electronic version will be sent to the email address we have on file for each reader at [www.oif.org](http://www.oif.org). To confirm your preferred email address, add your email address, or to remove yourself from the mailing list, please visit [www.oif.org](http://www.oif.org) and click on the 'login' button on the to right-hand side of the page. Contact the OIF at [eruebensaal@oif.org](mailto:eruebensaal@oif.org) or 800-981-2663 with any questions.