

10th International Conference on OI Held in Belgium

OI Foundation CEO, Tracy Hart, attended and represented the OI Foundation at the 10th International Conference on Osteogenesis Imperfecta in Ghent, Belgium in October. The meeting brought together scientists, researchers and physicians from all over the world to discuss the current progress in diagnosis and treatment of OI. Besides reviewing important clinical and radiographic aspects of OI, an update on the genetic and molecular aspects of OI was presented and current view points on management and treatment of OI were discussed.

Every 3 years, physicians and scientists from all over the world who are leaders in clinical care, genetics and bone biology related to OI gather to share their latest findings. This year's meeting, attended by 150 people including 20 American physicians and scientists, created a forum where a wide range of medical specialties including orthopedics, rehabilitation, rheumatology, endocrinology, ear-nose-throat, pediatrics, genetics and molecular biology could interact and talk about their current research and programs relative to improving the lives of people living with OI. Participants

included OI Foundation medical advisors Dr. Peter Byers, Dr. Francis Glorieux, Dr. Brendan Lee, Dr. Joan Marini, Dr. Jay Shapiro, Dr. Reid Sutton and Dr. Matthew Warman. Also in attendance was parent and neonatologist Dr. Bonnie Landrum.

The meeting clearly showed how important communication is across the globe in finding new treatments for OI and how important it will be in the future to continue to bring the experts from around the world together to report on their valuable and cutting edge research.

In addition to the scientific portion of the meeting, the OIFE (Osteogenesis Imperfecta Foundation Europe) held their family meeting in a town close to Ghent enabling those attending the scientific meeting to attend portions of the family meeting and the welcome reception. OIFE delegates from all over Europe came together to discuss ways to make their organizations stronger and how to advocate for people with OI all over the world. The OI Foundation is a member and supporter of the OIFE.



Delegates to the 10th International Conference on OI in Belgium.

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IMPERFECTA**
OI
FOUNDATION

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From the Chief Executive Officer

Dear Friends:

In October I had the wonderful experience of representing the OI Foundation at the International Meeting on OI held in Ghent, Belgium. The meeting content was excellent but even more importantly the meeting gave me the opportunity to talk with and learn from physicians, scientists and advocates from all over the world. It provided a forum to ask questions about the next breakthrough in the scientific community that will put us closer to finding a cure for OI, and what new treatments are available for people living with OI. I also had the pleasure of meeting people from the other OI groups around the world. It was especially interesting to find out the kinds of issues that are important to them as people living with OI in their specific country. Dr. Peter Byers, a member of the Foundation's Medical Advisory Council, opened the meeting with wonderful remarks about keeping communication open around the world as we work together on research and how important it is to continue sharing information. His opening remarks set the tone for a very successful meeting.

As we look forward to the next meeting in three years it's very exciting to think about what new topics we will be able to talk about on our quest to find better treatments and a cure for OI. I'm looking forward to the next conference in 2011!

Warmest regards,



From the President

Dear Friends,

The OI Foundation receives most of its funding from individual donors and much of this is received in amounts less than \$100.00 per donation. Some of this money comes from honorariums and memorials, some from our annual and research appeal, but a large amount of our support comes directly from fundraising events held all across the country. It is these events, whether a walk and wheel, a dinner and silent auction, or bone china tea, that allows the Foundation to fund important research and continue our programs.

As you read this current issue of Breakthrough, please take special note of all those who dedicate themselves and allocate their valuable time to do a fundraising event. I would like to extend a heartfelt thank you to all those who undertook this challenge the past year. I would also like to encourage more of you to gather your friends and family and try an event for yourselves. Although this might seem daunting at first, you will be amazed by the results! Please contact Stuart Tart at the Foundation office for more information on putting together your event. The Foundation stands ready to help you.

I would also like to take this opportunity to welcome our new board members, Mark Birdwhistell and Gil Cabacungan. They have already attended their first board meeting and it is clearly evident they bring much expertise and passion to the board.

Finally, please be sure to read the beautiful tribute to Dick Geisman, husband of one of our co-founders, Gemma Geisman. Without the love, nurturing, and dedication of these two people, the Foundation would not exist. Our deepest sympathies are extended to the entire Geisman family.

With Warm Regards,

Ken Finkel

1st Advances in Rare Bone Diseases Scientific Conference

The Rare Bone Diseases Patient Network, a coalition of nine rare bone disease organizations held its first scientific conference October 22-24 at the National Institutes of Health. The OI Foundation is a member of this group and helped to organize the conference. Rare bone diseases are defined as a disorder that alters normal bone development. There can be too little bone, too much bone, bone that stops developing too soon, or bone that grows unexpectedly.

Based on the presentations, future therapies for rare bone disorders could come from a wide range of technologies and new genetic information. Work currently being done in bio-chemistry is expanding the concept of where to look for genes that affect bone. The study of modifier genes may hold the key to figuring out why disorders like OI vary so much from person to person.

Nanotechnology holds the possibility of creating man-made bone to allow the repair of non-healing fractures, and shattered joints. Mouse models are now being used to test the possibility of gene therapy for OI.

All of the disorders represented at this conference stressed the need for interdisciplinary care, a patient registry, a strong advocacy organization and improved education for health care providers.

The osteogenesis imperfecta interest group included OI Foundation CEO Tracy Hart, Board President Ken Finkel, Past Board President and adult with OI, Ms. Jamie Kendall, Dr. Francis Glorieux, Dr. Joan Marini, and Mary

Beth Huber foundation information director. Goals for the next five years that came up during the brainstorming session included:

- Better understanding of the natural history of OI from birth through old age.
- Best care standards that clarify the most effective use of current drugs, and include improved surgical techniques.
- Better access to care for adults who have OI.

4th Clinical Conference on OI

This annual meeting sponsored by the Kennedy Krieger Institute and the Charitable Research Foundation brought together 85 physicians and others involved in the care of children and adults who have OI. Held October 29-31, the program covered translational research, clinical problems, orthopedic and physical medicine issues, and treatment questions.

The sessions on clinical problems stressed the necessity of looking beyond bone to promote the long term health and well being of people with OI.

High tech imaging techniques — Molecular Imaging and Optical Imaging — were described. They represent potential new approaches to diagnosing and treating OI.

The sessions on clinical problems stressed the necessity of looking beyond bone to promote the long term health and well being of people with OI. Areas that need more attention in clinical care and more research to improve that care include heart valve problems, the effects of OI on vision,

respiratory complications, kidney stones and devices to address hearing loss.

The orthopedics and physical medicine sessions provided the opportunity to discuss:

- Leg, ankle and foot problems, and the importance of hip to ankle alignment,
- Spine alignment injuries,
- Surgical techniques for fractures in the neck of the femur,
- Blood loss during surgery,
- Managing bowing and other problems seen in the arms and hands,

The sessions that focused on treatment provided information on the potential use in OI for a new type of drug that is being tested for osteoporosis, updates on bisphosphonate research and the use of DNA testing as part of the diagnostic process for OI. Detailed information about these topics will be provided in the next issue of ***Breakthrough***.

A meeting like this is very important because it brings together specialists who are caring for people with OI. It gives endocrinologists, orthopedists, and others the opportunity to share case histories, and evaluate how to take new information from research and translate it into patient care. The abstracts from this meeting are being prepared for publication.

Three Important Meetings Held in October

Having three meetings on OI and bone health in one month created a rare opportunity to discuss the needs of people who have OI from the point of view of different medical specialties, basic science, current treatments and future treatment possibilities. While each meeting had a different agenda,

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Foundation Board Welcomes New Members

Mark D. Birdwhistell



Mark D. Birdwhistell

Mark is the Director of Federal and Community Relations for University of Kentucky Healthcare. At the end of Governor Fletcher's Administration Mark returned to employment at the University of Kentucky working in the Office of the Executive Vice President of Health Affairs focusing on Federal legislative matters, building relationships with community leaders and the creation of clinical network opportunities for UK Healthcare.

From 2004-2007, Mark was appointed as the Secretary of the Kentucky Cabinet for Health and Family Services (CHFS). From 2004-2005, Mark served as the CHFS Undersecretary for Health, overseeing medicaid, public health, mental health and mental retardation and the Office of Health Policy, which manages the Office of Certificate of Need and all policy-related healthcare and health insurance matters.

Mark and his wife Martha live in Lawrenceburg, KY, and have one son Matt 26 and a daughter, Mary Alice 21 who has OI. Mark hopes to offer his professional expertise in securing new funding, which is so critical for research on prevention, detection and innovative treatments for this condition.

Gil R. Cabacungan, III



Gil R. Cabacungan, III

Gil is a strategic business and management consultant with Integrated Project Management assisting Fortune 500 companies in achieving corporate goals and objectives.

Gil graduated from the United States Military Academy at West Point, New York, in 1984, and he served in the U.S. Army from 1984-1993 achieving the rank of Major.

Gil commanded a M1A2 tank company during Operation Desert Storm in 1991 in Iraq and was awarded the Bronze Star Medal. Leaving the military in 1993, Gil began a business career with Brach's Confections in increasing management roles in operations and finance. Gil obtained an MBA with Honors in finance, accounting, and international business from the Loyola University Chicago Graduate School of Business.

The Cabacungan Family attended their first OI Conference in Omaha, Nebraska, in July 2006. In a show of appreciation, Gil and his wife Alma have been heavily involved in the Bone China Tea fundraising program by raising over \$2700 in 2006 and over \$3800 in 2007. Gil takes every opportunity to promote and broaden the understanding of OI among his family, friends, and personal and professional colleagues through his personal story and various resources from the OI Foundation.

Gil and Alma live in Oak Park, Illinois, and have a five year old son, Alec who has OI, and three beautiful daughters.

Three Important Meetings *continued from page 3*

taken together, the 10th International Conference on OI, the 1st Advances in Rare Bone Diseases Scientific Conference and the 4th OI Clinical Care Conference provided a lot to think about.

- While treatment for OI is better today than 30 years ago, the perfect treatment is still to be discovered.
- Information from bio-engineering or bio-chemistry

may hold the key to understanding OI and developing new treatments. Future treatments may be hidden in the study of protein folding, collagen pathways and shepherd genes; areas unmentioned even a few years ago.

- Awareness that bone and skeleton formation is an incredibly complex process.

- Perhaps most importantly, a reminder that the ultimate goal of all research is a healthy life for people who have OI; to use improved understanding to create treatments that minimize disability and improve each person's ability to function day to day.

Remembering Dick Geisman

The OI Foundation is sad to report that a dear friend, Richard "Dick" Geisman, passed away on September 30, 2008 after a long and courageous battle against pulmonary fibrosis.

When Dick and Gemma Geisman's son, Mike, was born with OI in 1956, Dick was determined that his fragile little boy's life would be as normal as possible. Dick designed and constructed special chairs, beds, and a shower that Mike could use, and carried Mike everywhere the family went, including up the steep steps to the upper deck of Riverfront Stadium to watch baseball games.

There was little or no information available to families when Mike was diagnosed with OI. Gemma's two articles published in Redbook magazine in 1968 and 1970 became the building blocks of the OI Foundation. As OI families throughout the country responded to the articles requesting information and support, Dick and Gemma went into action. By 1970, Gemma had co-founded the OI Foundation. Dick served as the Foundation's greatest cheerleader and provided the necessary support at home as Gemma worked to guide the development of the Foundation.

Dick and Gemma's son, Rick Geisman, wrote "My mother's writing ability and my father's determination led them to their life's work, the founding of the OI Foundation. If my mother was the brains and the heart of the foundation, then my father was the backbone who supported her and helped drive many of the early projects to completion. When my mother needed more space to do her work, he rebuilt our front porch into an office for her. When she wrote the first newsletter, he created the masthead for it. After Mike died in 1980 at the age of twenty-four, it was my parents' unconditional love for Mike and other children like him that motivated them to continue this important work. My mother has said that she could not have gone on with the work of the foundation, without my father's strength and courage to keep her going."



Dick and Gemma Geisman

During his retirement, Dick greatly enjoyed attending the OI Foundation conferences, providing encouragement and support to the young individuals with OI.

As we say goodbye to Dick with tears in our eyes and sorrow in our hearts, we also recognize and celebrate the contribution of our founding families who have always been the greatest cheerleaders for the OI Foundation.

Dick has been an unwavering supporter of the OI Foundation from its inception. His support at home made it possible for Gemma to spend so many hours working, first to help set up the Foundation and later to serve as Executive Director, Breakthrough Editor, President, and Board Member. He cared deeply for people, and had a special compassion for anyone dealing with OI.

My friendship with Dick and Gemma began back in the 1970s, the early years of the OI Foundation, and deepened when I came to live close to them in Florida in 2004. Dick was always there when I needed help to fix anything – I really think he could fix anything! I have shared many wonderful hours with them, and I feel a deep loss for a kind and caring friend.

~ Rosalind James, former Director and OI Foundation Board President

I was fortunate to learn about the OI Foundation soon after it was established and have been blessed with the friendship of Dick and Gemma and inspired by their tireless efforts through the years. Although Dick and Gemma were confronted with many difficult and heartbreaking events during their life together, they complemented and supported each other and ultimately left a fantastic legacy to all families affected by OI: The OI Foundation.

~ Rosemarie Kasper, former Board Member and Breakthrough Editor

With the passing of Dick Geisman, the OI Foundation has lost not only a great supporter, but a great friend. Some of our fondest memories involve attending OI Conferences and being able to spend time with Dick and Gemma. Dick was always full of stories that made you laugh and at the same time offered great support and inspiration. His broad smile and firm handshake gave you the feeling that you were not only with someone who cared about people, but also someone you called your friend. Dick was admired by many and will be greatly missed.

~ Joe, Martha, Ryan, and Kristen Antolini, Co-Founders of the Kroger OI Foundation Charity Event

My Mom was one of those first "OI Mom's" to respond to Gemma's Redbook article. Years later, I was privileged to serve on the OI Foundation Board, and Dick and Gemma became treasured friends. My heartfelt thanks to Dick and Gemma for their vital role in the establishment of the OI Foundation and their desire to support OI families.

~ Sherry Frost, former Board Member

Bone China Tea: Time to Plan Ahead

An easy way to support OI and its Foundation!

By Jennifer Wilson

To learn first hand about this event we hope that you will take a moment to read the following article written by Gail Bunker, co-chair of the Florida Support Group.

"In 1993 I received a call from another OI Mom telling me about a new fund raiser for OI called Bone China Tea. She asked if I would participate, and when I said yes, she mailed me the last five invitations she had. I was excited about their look. Hanging from the inside was a teabag along with an explanation of sitting down with a cup of tea in your own home and with the money you would save from not going out, make a donation to OI. What a lovely idea!

Now 15 years later, I send out 100 invitations to family and friends with a personal note about my daughter, Michelle, to keep them updated on her OI health. This personal message makes their donations even more special because it puts a face on this disorder.

Michelle has also participated in this event starting in high school when she introduced it to her classmates. They quickly became part of the program, learning more about her disability and excited about helping support the cause. She also introduced it to her Sorority sisters in college and they, too, were eager to help with their donations.

We all say, "Where am I going to find the time to do this?" Printing out labels on our computers saves lots of time. We can even send invitations from a website. No excuses now. There is no easier way to educate, promote awareness, show support and raise funds for OI than through Bone China Tea. It is the best fund raiser ever!"

For 15 years this event has grown steadily. We hope this year, even with our unpredictable economy, we can maintain this growth.

The 2009 phantom tea party will be on April 3rd. The invitations will be assembled and ready for distribution the latter part of January. If you have questions or would like to order invitations, please contact Jenny Wilson (jnwilson@aol.com) or Susie Wilson (OISLW@aol.com) or by phone, 239 482-0643, with your name, mail address, e-mail address, phone number and the number of invitations you would like to send. Please order only as many as you will send to your family, friends and co-workers. If you are unable to participate, we hope that you will consider making a donation to this event.

Information regarding a web site invitation can be obtained from Stuart Tart at the Foundation (start@oif.org) or by calling 1-800-981-2663. To learn more about setting up your personal web page, please join our brief phone information session on **Tuesday, January 13, at 8 p.m. Eastern (7 p.m. Central; 5 p.m. Pacific).**

Join us in this easy, fun way to raise funds to enable the Foundation to provide resources, support and information for families and people with OI, as well as research into treatments and a cure.

Jenny & Susie Wilson
Co-Chairs, OI Bone China Tea



Upcoming OI Winter and Spring Events



Mark your Calendars! You won't want to miss these exciting OI benefit events in your area!

New York, NY, Feb. 21

Iota Nu Delta, a South Asian fraternity at St. John's University, will hold a dance competition at the Tribeca Performing Arts Center, with proceeds benefiting the OI Foundation.

College dance teams will perform to Burga music from the Punjab area of India.

For ticket information, please contact Iota Nu Delta Director of Operations Manoj Bangera at crusader@iotanudelta.com or (718) 696-8418.

Washington, DC, March 21

The 9th Annual *Fine Wines, Strong Bones* gala will be held on Saturday, March 21, at the Galleria at Lafayette Centre, 1155 21st St. NW, in Washington, D.C. This fun-filled evening will feature:

- Exciting items in our online, silent, and live auctions,
- The chance to try a variety of quality wines from across the globe, and
- Tasty menu offerings from participating *Sample the City* restaurants.

Ticket sales will begin in January at www.oif.org/HH_FineWines. You may also phone 1-800-981-2663 to request an invitation or order tickets.

Round Rock, TX, April 4

The 2nd Annual *Central Texas Walk-n-Roll* will be held at Old Settlers Park. Raise pledges, and walk or wheel a few laps to support the cause!

There will be a variety of fun activities planned both for kids and adults. The proceeds from this charity event 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.

To learn how you can get involved, contact OI mom **Debbie Wiederhold** at Debbie@txp2p.org or (512) 458-8600.

New York, NY, April 24

The OI Foundation's Broadway Theatre Benefit is back!

Join us to see the new Broadway blockbuster, *Billy Elliott*, at the Imperial Theatre, 249 W 45th St., in New York City. A pre-show reception and live auction will begin at 6:30 p.m.

Ticket sales will begin in December. Use the website link at www.oif.org/UE_UpcomingEvents, or phone 1-800-981-2663 to request an invitation or order tickets.



Recent Events

2nd Annual Walk with Isaac attracts 150 participants

Aberdeen, MD – Approximately 150 people supported the OI community at Ripken Stadium on September 13 during the *2nd Annual Making Strides for Better Bones: Walk with Isaac* event.

The support from a variety of community groups was obvious ranging from the presenting sponsor, **Stifel Nicolaus**, to walking teams from the **Moms Club of Abingdon North**, **Open Bible Christian Ministries**, and **Citi Smith Barney Operations**. Tables with children's activities, a pick-a-prize raffle, and a silent auction lined the bleacher area. Altogether, this walk-n-wheel event raised more than \$21,000 for the work of the OI Foundation.

Participants walked around the warning track (outside perimeter) of the Ripken Stadium baseball field, while photos and information about OI was rotated on the Jumbo Tron score board. Prior to the walk, **Heidi Wright** spoke about her experience with severe hip pain that temporarily prevented her from walking during and after her pregnancy with son **Isaac**. Heidi and Isaac both have Type I OI.

Teen singer/songwriter **Ashleigh Marie** sang the "Star Spangled Banner," and **Angela Romano from Beyond Fit** led the group in stretching exercises.

OI Foundation Chief Executive Officer **Tracy Smith Hart** also presented **Dan and Heidi Wright** with a special award in recognition of their work in holding two events that raised awareness in central Maryland and brought in more than \$44,000.

Dan, Heidi, and fellow event organizer **Jennifer Snyder** also want to thank all of their sponsors and donors, including **party-wish.com** for

contributing their face painting services, **Caricatures! by Rick Wright & Co.** for lending Rick's talents to draw caricatures of people, and **Old Line Garrison, 501st Legion** and **Terrapin Base Rebel Legion** for coming out dressed as Storm Troopers and other characters from the *Star Wars* movies.

New Jersey Event Volunteer Tries Something New

Collingswood, NJ – **Carol and Michael Goebel** tried something new for their 5th annual fundraising event for OI on September 19.

Bets for Better Bones, the 5th Annual New Jersey *Making Strides for OI* event, provided guests with the opportunity to try their hand at craps, roulette and black jack. In addition, the event included dinner, dancing, silent and chinese auctions, and a raffle for a 27" HD flat-screen television!

The event has brought in more than \$25,000 so far. Through their work on three walk-a-thons and two fundraising dinners, the Goebels have raised more than \$177,000 for OI research!

"WOW is the word I seem to be getting the most," Carol wrote immediately after the event. "I have received SO many emails and phone calls over the weekend. . . . The 5th Annual seemed to be a big success. I could not have prayed for the night to have gone any better."

OI Foundation Chief Executive Officer **Tracy Smith Hart** presented Carol and Michael with a special award in recognition of five years of holding events that raised awareness throughout southern New Jersey.

Sponsors of the event included **Solvay Pharmaceuticals, Goebel Insurance Agency**, and **AccuScan**.

According to Carol, a lot of individuals contributed to the event's success.

"We thank those of you who donated items for the auction, those of you who helped with making the baskets and centerpieces, rounding up sponsors and everything else for the event," she said. "I thank all of you who helped set up the day of the event getting everything over to the hall and setting up and cleaning up."

The New Jersey *Making Strides for OI* events have been inspired by **Garrett Goebel**, Michael and Carol's five-year-old son who lives with Type III OI.

Family Holds Backyard Event for OI to Honor Daughter's Memory

Frisco, TX – Five years ago, **Christopher and Kala Meyering** lost their infant daughter, **Sarah Elizabeth Meyering**, to OI-related complications.

On September 20, they honored their daughter's memory by holding a backyard luau fundraiser to benefit the Foundation. The food, tables, backyard, and serving areas all employed a tropical theme, and Hawaiian music was played. In addition to offering lots of great food, the event included a silent auction and several raffle drawings. Altogether, the couple raised \$7,285 in contributions from friends and family.

"Our life will be forever changed by the loss of our precious little girl. But as a result of our experience, and our brief time with our daughter Sarah, we made a personal commitment shortly after she passed away to someday have some sort of event in the hopes of raising public awareness for OI...as well as to celebrate Sarah's life and memory," Kala and Chris explained.

They added, "We sincerely hope that the money we were able to raise will contribute to someday improving the

lives of other families affected by OI, and that maybe we had some small impact in improving the life of a small, innocent little child with OI.”

Sacramento families work together on first area OI walk-n-wheel

Sacramento, CA – Approximately 150 participants gathered on September 20 next to the State Capitol building for the city’s first-ever *Making Strides for Better Bones* walk-n-wheel event for OI.

“For our first event, we think that 150 people was outstanding,” Bill Scarberry, one the volunteers who organized the event, wrote. “I have received numerous emails from people who were happy we had the event and are already committing to come next year and bring more people.”

A local Boy Scout troop, **BSA Troop 1 of Roseville, CA**, helped set up tents and tables for the Saturday event. Then, shortly after 11 a.m., adults and children turned in pledges and walked or wheeled their chairs around the perimeter of State Capitol Park. Entertainment was provided by 10-year-old singer **Brynna Finley**, 13-year-old violinist **Riley Finley**, a youth hip hop group, **Antigravity**, and guitarist **Sue Reano**. Volunteers from the local Job’s Daughters group, **Jobs Bethal 115 of Antioch**, contributed a sound system for the day and helped Sue to keep the music going.

Kids enjoyed the treats from the snow cone and cotton candy machines, as well as face painting and a clown who made balloon hats and other creations. **Chick-fil-A** donated a delicious lunch, and there also was a silent auction at the event. Altogether this first-time event raised approximately \$8,000!

Four area families pooled their energy to make this event a success. **Jane Fowler, Beth Gero, Lesli Reano, Bill Scarberry**, and their families spent much of the summer seeking donations, planning activities for the



Approximately 150 participants gathered next to the State Capitol building in Sacramento for the Making Strides for Better Bones walk-n-wheel for OI on September 20.

day, and encouraging colleagues, friends, and family to participate. We thank them for their hard work in making this event a success!

Bash by the Bay attracts local notables and 250 other supporters

Margate, NJ – The weather was “wonderful” on September 20 for *Bash by the Bay*, the 5th Annual fundraiser organized by Board member and OI mom **Chery Sacchetti**.

Between 250 and 300 people attended the afternoon seafood festival, and about a dozen young people raised pledges and walked for OI earlier in the day. Altogether, the event raised about \$22,000.

A number of special guests supported this year’s event. Chery and her husband **Tony Sacchetti** said they were privileged to have **U.S. Rep. Frank Lobiondo (R-NJ)** and **Atlantic County (NJ) Executive Dennis Levinson** attend. Entertainment was provided by Philadelphia jazz vocalist **Juanita Holiday** and by Margate’s

dynamic duo, **Ed Anthony & Frank Dougherty of The Hurricane Band**.

“The motivation for holding these fund raisers is naturally our son, Sebastian, who is an inspiration to us all,” Tony explained. “It is gratifying to know that there are now thousands of people in our area who now know what OI is, and are aware of the effects of this disease.”

Chery and Tony said they are grateful for the help of a number of people and businesses whose generosity made *Bash by the Bay* a success:

“We would like to specially thank **Matt Reale**, who after suffering five severe breaks after a fall at school took the time to raise \$500.00 for OI and **Brett Denaf of Stewart’s Famous Hamburgers of Ocean City**, who each year provides music, hot dogs, chicken and so much moral support.”

Special thanks also go to Chery’s mother, **Darlene Lemmerman**, and her sisters, **Kim Lemmerman** and **Linda Hanneman**, for the hours they spent helping Chery assemble more than 100 baskets for the chinese auction and volunteering in numerous other ways.

Tony also expressed admiration of his wife for her work.

“Chery does this out of love and compassion for all OI children, and I can’t express how amazed and proud I am each year to see her and our family do this,” he said.

Heavy rains fail to completely dampen Central NY Walk-n-Wheel

Walton, NY – A 2nd annual OI walk-n-wheel event was held in central New York this year, thanks to the cooperation between two area families.

Sharon Brennan, an adult with OI, organized this year’s *Making Strides for Better Bones: Central NY* event at the Delaware County Fairgrounds on Sept. 27. Sharon’s three children and half sister also have OI.

This event was created in 2007 by another OI mom, **Diane Curtin**.

“The highlights for me were continuing new friendships started last year, and getting to educate more people in the media,” Sharon said. “And, the biggest highlight for me personally was the fact that a young woman who I consider a stepdaughter formed “The Friendship Team” with her boyfriend and one of their co-workers and raised \$524.00!!”

Despite pouring rains, the event has brought in more than \$1,000 for OI so far. It also had one additional benefit for Sharon.

Sharon explained, “I didn’t know that there was a man with OI right on the street to the fairgrounds, and I’ve lived here 33 years!”

Missouri Gym holds Walk/Run event for OI

Liberty, MO — Two kids with OI inspired a community gym that focuses on cheerleading to hold a fundraiser for OI.

“We have never met more positive people” explained **Ron McKinney**, co-owner of **Positivity Gym** in Liberty, MO. **Andrea and Erich Hellerich’s** two children – Julianne, 10 and Cameron, 13, have OI and have experienced almost 60 breaks between them.

When the owners of Positivity Gym decided to hold a fund raiser, the Hellerich family asked that all proceeds benefit the OI Foundation.

Approximately 150 participants showed up early on a Saturday morning to walk, wheel or run for OI during *Cameron & Julianne’s Unbreakable Spirit Walk/Run* on October 11. Positivity Gym offered breakfast and T-shirt to all participants, and they held a silent auction and raffle drawings. Altogether, the walk/run event raised approximately \$5,100.

According to Ron, families came to this event from as far away as St. Charles (near St. Louis) and Topeka. In addition, the Hellerich family met another family dealing with OI who lived right there in Liberty!

“These families had no idea of each other’s existence and it was so thrilling to see them connect!” explained **Jane McKinney**, another co-owner of Positivity Gym.

Thanks to the Hellerich family, the owners and staff of Positivity Gym plan to hold a 2nd event for OI in 2009.

More than 360 attend 17th NJ Beefsteak Dinner

Garfield, NJ — Some guests have a special eating strategy during the annual NJ Beefsteak Dinner . . .

Servers visit your table regularly to offer slices of juicy filet mignon on small pieces of white bread during this all-you-can-eat dinner. As the night progresses, stacks of white bread on a plate in the center of the table grow taller.

By forgoing the bread, you can eat more beefsteak, one guest explained.

More than 360 supporters gathered at the Three Saints Cultural Center in Garfield, NJ, on Oct. 17, helping the New Jersey OI Support Group to raise more than \$21,000 for OI! Tables filled the large hall as the event enjoyed one of its larger turnouts in its 17-year history.

“It was a successful event, and some of us feel the beef was better than ever. Even the fries seemed extra-good!” remarked event co-chair **Rosemarie Kasper**.

In addition to enjoying the good food, guests dropped tickets into containers to win more than 150 Tricky Tray raffle items, bid on dozens of valuable silent auction offerings, and took home quite a few door prize items.

“This Beefsteak brings us to a grand total of over 1/4 million raised for OI!!” co-chair **Jo Ann Berkenbush** said. “Never in our wildest dreams did we think we would raise that much.”

Many families in the area participated in the success. The **Krudys’** family and friends once again came out in full force with guests and prizes. Other dedicated committee members include the **Strauch, Schmidt, Zickerman, McGarry, DeLuccia, and McLean** families.

Tips For Year-End Giving

Like most people, you probably do the majority of your charitable giving toward the end of the year. Each year the OI Foundation sends direct-mail to friends and families. The year end reminder prompts donors to make a contribution to OI prior to the end of the tax year.

We hope these tips help:

OI FOUNDATION'S MONTHLY GIVING PROGRAM

More and More donors in the OI Community are taking advantage of the Foundation's monthly donor program by joining "The Leaders Club" As a member of the Leaders Club you are electing to send monthly contributions automatically through a checking account or credit card. Many join at a level of \$10.00 per month, which comes out to \$120.00 per year.



EMPLOYER MATCHING GIFTS PROGRAM

Does doubling, tripling or even quadrupling the impact of your donation to the OI Foundation—at no cost to you sound appealing? The OI Foundation's matching gift program is a great way to do just that.

The OI Foundation is now providing donors with instant online access to their employers' matching gift programs. With more donors making gifts online, this program makes it easy to identify which companies match employee giving to charitable organizations.

To see if your employer will match your gift, go to www.matchinggifts.com/oif.

AN HONOR GIFT

This is a great way to help others while honoring those you love*. By giving a gift to the Foundation as a Memorial (in honor of those who have passed away) or as an Honorarium (to celebrate a birthday, anniversary or other occasion), you'll be helping us continue to meet the needs of thousands of people who have OI, and all those who care about them.

MAKE A PLANNED GIFT

Making a planned gift to the OI Foundation is an excellent way to include charitable giving in your current and long-term financial plans. Planned gifts can reduce estate tax, avoid capital gains tax, and increase future income. We can help to structure a wide variety of planned gifts including:

- Charitable Remainder Trusts
- Charitable Lead Trusts
- Life Insurance Transfers
- Bequests

These are only a handful of ways to support the Foundation. To learn more contact John O'Brien, Director of Development at 800-981-2663 or visit us online at www.oif.org and click on "**how to help.**"

First Birthday Benefits the OI Foundation

The OI Foundation would like to thank John and Kerry Stetz for their very generous contribution to support our mission to enhance the quality of life for people living with osteogenesis imperfecta.

John and Kerry planned a birthday party for their one year old daughter Alison who has osteogenesis imperfecta. In lieu of gifts the Stetz family asked that friends and family members make a gift to the OI Foundation.

A total of \$550.00 was raised around this wonderful celebration. Please join us in wishing Alison Stetz a very Happy Birthday!

People in the News

Sept-Nov 2008

Palmer, AK – Profiled in her college newspaper, Washington State University junior **Leanne Whitmore** shared her experience of being a student with a disability. A genetics and cell biology major, Leanne has not let her situation slow her down or deter from her ambitions. Her advice is to “Go out and meet people and don’t let your disability prevent you from putting yourself out there and doing what you want to do.”

Fayetteville, AR – Interviewed on the eve of her high school graduation, **Amelia Faulk**’s advice to other students who live with a disability was “Don’t give up,” and referring to the high school years, “Make it worthwhile.”

Lodi, CA – Joining 55 other students with disabilities, 17 year old **Jeremy Hixson** attended a week-long Youth Leadership Forum at California State in Sacramento.

Alamosa, CO – Writing for the local paper, sports editor **Lloyd Engen** eloquently notes “With all the broken bones I had growing up with osteogenesis imperfecta, never knowing what was going to happen next, baseball was my panacea and the World Series was the ultimate cure – an excursion into a world where imagination had no boundaries, helping keep me sane.”

Colorado Springs, CO – Peyton’s Footprints is a nonprofit that distributes comfort boxes to families facing the loss of their unborn babies. The organization was founded in memory of **Peyton Isabella McBride**.

Commerce City, CO – Bandimere Speedway was the location of a Make-A-Wish Foundation benefit which featured an assortment of racecars and dragsters. While sitting in one of the big dragsters, 9 year old **Cayley Olsen** shared her wish for a hot tub.

Rome, Georgia – A straight A student who loves math, **Anna Marie Ballinger** is also an active participant in the school group Choosing Healthy Methods and Promoting Safety – CHAMPS.

Pekin, IL – Ambassador for Easter Seals, 8 year old **Jake Gry**s wins friends and entertains crowds with his positive attitude, sense of humor and stockpile of knock-knock jokes. He’ll have the opportunity to entertain more than his local community when the family is profiled in an Extreme Home Makeover to air early next year.

Louisiana – Aided by local civic organizations, **Jowanna Williams**, a senior at the University of Louisiana, was provided with a replacement for the wheelchair she lost during Hurricane Gustav.

Paulina, LA – Sporting a post-surgical halo, **Tyler Roques** remains undaunted by his challenges, even after enduring a surgery that could have robbed him of his ability to talk and eat normally, or to participate as a tenor in his local choir.

Whitman, MA – The voice of Whitman-Hanson athletics, **Ted Sellers** is in his last year of High School broadcasting. He’ll be pursuing his dream in college, majoring in mass communications with plans for a broadcasting career. Remarking on the preconceived notions of others, Ted shares, “It definitely motivates me, knowing I have to prove to people I’m able to do it. That’s what motivates me each broadcast to be the best.”

Sterling Heights, MI – As part of a GM Mobility Program, **Neeru Sharma** will be appearing in a YouTube ad for people searching for information on GM adapted vehicles for wheelchair users.

Omaha, NE – Sami the Ballerina, aka

Samantha Binning has been gracing various billboards around the city as well as advertisements in airline magazines. Recently celebrating her 5th birthday, Sami has defied predictions that she would die within 24 hours of birth.

Huntington, NY – Thirteen years as a social worker didn’t prevent Nicole Knorr and her husband from being investigated on allegations of child abuse. Fortunately, charges were dropped when **Cooper Ryan** received a diagnosis of OI.

Raleigh, NC – The recent opening of orthopedic urgent care centers means fewer trips to the emergency room for **Amanda McLain**. Her mother notes that being able to “get in and get out quickly takes some of the stress off of the situation.”

Cleveland, OH – The **Wagners**, an extended family with Type I OI, was the subject of a local story about living with OI, illustrating how the advances in treatment over the years have made such a difference in the quality of life.

Bellefonte, PA – **Dale Dyke** was featured in a story which illustrated the everyday concerns and challenges of managing and living with OI. A benefit dinner to provide funds for an adaptive van was held in March. At home, 5 year old Dale scoots around on “The Lovebug” her red skateboard.

Ft. Worth, TX – After hosting the Moslah Shrine Children’s Hospital Gala, NBC anchor Mike Snyder offered the following remarks about 8 year old **Leigh Dittman** who sang the Star Spangled banner. “Anytime you feel like you have it bad, or your problems are just too much to handle, think about little Leigh. The positive attitude of this tiny angel in a wheelchair provides a lesson in humility and graciousness for us all.”

Norfolk, VA – Attending a professional baseball game as part of Military Family Appreciation Night, were members of the **Helms** family, **Anna, Jacob** and **Madison**.

Zimbabwe, AFRICA – Traveling from

King George VI Centre for the Disabled with his musical group Liyana, 19 year old **Energy** will be performing in January and February in New York and California.

Haigslea, AUSTRALIA – Bingo ladies and a pub helped with the purchase of **Shandelle Winley's** specially designed trailer which allowed for transportation of her motorized wheelchair. Unfortunately it was stolen while Shandelle was away in Sydney for an OI conference.

Kirrawee, AUSTRALIA – Born with both OI and a brain tumor, **Brandon Hughes** has defeated great odds. As his school principal says “To Brandon, nothing is impossible. His positive attitude to life has earned him respect from his peers to the level that they have voted him school captain this year.”

Westmead, AUSTRALIA – The Children’s Hospital at Westmead has launched a pet therapy program and 4 year old **Hayley Sparkl** is having fun with the physiotherapy she’d begun to lose interest in.

Montreal, CANADA – A benefit was held for the Shriners Hospital by the Land O’Lakes Cruisers, a band that features the grandmother of 8 year old **Nolan Robinson**, who has been receiving treatment from the hospital since birth.

East Behala, INDIA – Excelling in poetry recitation and winning awards at competitions, 8 year old **Debarnita Bose** has won many fans with her particular style of recitation. As one notes, “It’s as if the words come out from the depths of her heart.” While her ability to read has suffered due to lack of schooling, Debarnita has still managed to memorize over 150 poems.

Mumbai, INDIA – Because the way he lives his life is an inspiration to others, 26 year old **Mandeep Matharu** was a winner in the recent CNN-IBN Main Bhi King contest. A movie buff, he was rewarded with the opportunity of

meeting a favorite celebrity.

Senawang, MALAYSIA – As part of their project to assist those in need of wheelchairs, the local Rotary Club presented a wheelchair to 13 year old **Fu Jit Yoong**. The club has given away more than 50 wheelchairs.

Pahang, MALAYSIA – Stating that he is one of the first disabled students at his college, 17 year old **Daniel Lee** has been asked to help identify ways to make the college more disability-friendly. He was also recently awarded the Star Education Fund scholarship for a diploma in counseling. His advice to others? “Have more confidence in yourself. Don’t let people tell you what you cannot do. Focus on what you want and go for it.”

Invercargill, NEW ZEALAND – It’s the first year that his parents have allowed him to wheel himself to school, and 10 year old **Brodie Giller** is managing the 15 to 20 minute trip just fine. His mum states that her son is “not cotton-wooled at all,” though he is “cheeky.” Don’t you just love those “down under” expressions.

Dundee, SCOTLAND – With her job title being Dance Agent for Change, 36 year old **Caroline Bowditch** is Scotland’s first disabled dance coordinator. This position follows 15 years experience dancing with mixed ability companies and founding member of Weave Movement Theatre and the FATHoM Project.

SINGAPORE – Former President of the Handicaps Welfare Association, 40 year old **Tam Ah Hock** reports in an article about disabled diving that as a person with Type III OI, “once in the water, I’m just like any other person, free to move everywhere.”

UK – An actress who began her career in the BBC soap “Eldorado,” 34 year old **Julie Fernandez** is also an activist with the disability community, founding The Disability Foundation which offers one of the largest disability information databases in the

UK.

Chessington, UK – After appearing as a special guest on the Paul O’Grady show, a popular British comedy chat show, the TV crew offered to film 12 year old **Jack Binstead's** upcoming wheelchair race where he beat his personal best and took third place.

Gainsborough, UK – “A real busy bee” is how **Holly Girven's** mum describes her 11 year old daughter. She credits pamidronate treatment given at Sheffield Children’s for the “incredible” difference and improvement she has seen. “It was like having a new daughter for my husband Jim and I.”

Hasbury Close, UK – Impressed with the skill and dedication he saw in a television campaign to promote the recent Paralympic games, Beatles legend Sir Paul McCartney sent a dozen pink roses to wheelchair tennis player **Jordanne Whiley**.

London, UK – Reach for a Dream Foundation organized a trip to the East London Aquarium for 3 year old **Sinothando Kilani** who loves dolphins. Other gifts included a much needed bed (or cot as they say across the pond).

London, UK – A local news story reporting on a family’s need to raise funds for 4 year old **Steven Aghanti's** rodding surgery resulted in an outpouring of donations. Steven no longer faces a return to his home country of Nigeria without having this surgery, the reason for coming to London.

St. Albans, UK – The Redrow Foundation, through the Snowdon Award Scheme has awarded funding to 19 year old **Dom Hyams** to assist in living costs at Warwick University.

Thuong Tin District – VIETNAM – 24 year old **Dang Phuong Thuy** was the subject of a story profiling the resolve she and her parents have shown in obtaining treatment and in working towards a college education.

Update: Linked Clinical Research Centers

The LCRC is an ambitious initiative between the OI Foundation and the Children's Brittle Bone Foundation. Its goals include:

- Develop a network of care centers so all people who have OI have access to care of the highest standard.
- Define the standard of medical and surgical care.
- Advance the standard of care and improve treatment through clinical research.

Each center will see children and adults who have OI for regular medical care, and keep track of their information in an identical manner. By pooling all of this information it will be possible to answer many of the questions about how OI changes across a lifetime, what complications are common and which treatments are beneficial.

Earlier in 2008, three pioneer centers were identified:

- Baylor Medical Center/Texas Children's Hospital, Houston, TX,
- Kennedy Krieger Institute, Baltimore, MD/DuPont Hospital for Children, Wilmington, DE,
- Oregon Health & Science University/Portland Shriners Hospital.

To date the centers have been at work finalizing all of the systems and setting an example for how linked centers can work together. So far they have accomplished the following:

- Identified a list of procedures to keep multiple sites linked and coordinated.
- Completed the patient data form that will be used by all centers.
- Submitted applications to their Institutional Research Boards for permission to participate in the LCRC studies.
- Hired an experienced data collection center.
- Applied for a major grant from the National Institutes of Health.

What happens next?

- Representatives from each center will meet for training on data collection.
- The centers will advertise their programs to people with OI in their communities and surrounding areas.
- In 2009 all three centers will begin seeing patients.
- Additional centers will be added to the network as funding permits.

Happy Halloween from the FL OI Support Group

We had a wonderful Halloween Party at our October 25th support group meeting. There was a fantastic variety of costumes that included the Saturday Night Live Spartan Cheerleaders, a Doctor, a cool Greaser, a lovely Be-Bopper, a "Rays" fan, a pretty mermaid, an array of colorful fall leaves, a very sweet witch, and even Sarah Palin! Everyone brought snacks to share- Graveyard Crunch Munch seemed to be a favorite. There were fun Halloween themed arts and crafts and fantastic games for the children to play.



Those in our group who were unable to attend the conference in Arlington were thrilled to hear about the large attendance and the first OI Advocacy Day. Our members who did attend the Advocacy Day shared their experience about speaking to their congressmen and senators. They urged everyone there to write to their political leaders that funding is needed to help expand the OI Linked Clinical Research Centers. We also told everyone to mark their calendars now for the next conference in Portland, OR in 2010.

The Bone China Tea fundraiser will be April 3, 2009. Contact Susie and Jenny Wilson to place your orders for invitations via email at JNWilson@aol.com. And we hope everyone will be able to attend our next meeting January 24th, 2009, to be held at the Tampa Shriners Hospital. We are thrilled that our CEO of the OIF, Tracy Hart, will be our guest!

Co-Chairs-Susie Wilson and Gail Bunker

Team Youth Kicks Off!

The Team Youth initiative here at the OI Foundation kicked off this month with a conference call that marked the first official meeting of Team Youth. The group talked about activities young volunteers could be involved with including awareness, fundraising and advocacy. The Team Youth initiative will include a National Youth Council which will be made up of appointed members who will be helping to shape the direction of a the OI Foundation's youth volunteer program. The group agreed that the first activity of Team Youth will be the "Who's Wearing Our Blue Bracelet" community campaign. Youth volunteers will be asking well known members of their communities to wear our blue awareness bracelet. Those being asked to wear our bracelet include professional football players, town mayors, local news anchors and school principals. Youth volunteers will be writing about their experience in recruiting the "celebrities" in the communities to wear the bands. Go blue!

We are looking for young people between the ages of 14 and 21 to be a part of the youth program at the Foundation. If you would like to be a part of Team Youth, please contact the Foundation or e-mail Tracy Hart at thart@oif.org to receive information on the next meeting. And, be on the look out for information on the "Who's Wearing Our Blue Bracelet" campaign!



SAVE THE DATE

April 24, 2009
8 pm showtime, 6 pm pre-party
Imperial Theatre
New York City

To receive an invitation or for more information
E-mail: development@oif.org
Phone: 800-981-2663



Spotlight: Marilee Harrald-Pilz

Marilee Harrald-Pilz, the illustrator of our recently published *Emily's First Day*, is a self-employed free-lance illustrator, specializing in children's books and educational materials. Her clients have included Scholastic, Houghton-Mifflin, McGraw-Hill, Highlights and Humpty Dumpty Magazines. Marilee also writes and hopes someday to have one of her own stories published.



A graduate from the University of Illinois, Marilee has a BA in Art Education and has taken post-graduate classes in illustration and design. Marilee lives in Downers Grove, Illinois, with her husband David, 21 year old son Matthew, and 18 year old daughter Laura, who shares her mother's OI diagnosis. Also in residence is their Westie Eddie and parakeet, Perky.

Growing up in Elmhurst, Illinois, Marilee was the youngest of four children and the only member of her family with an OI diagnosis. Here, she shares her experience of growing up with OI. Check out her website at www.marileeharrad-pilz.com.

I have osteogenesis imperfecta and am the only person in my family to have this disorder. Diagnosed at eleven months, I had about five fractures in my younger years, much less than would be expected from my identified type of III/IV. When I was growing up in the late 50's and early 60's, there was virtually no support or information about OI. It was very difficult for my mother, who did the best she could to protect me. My parents, doctors and I thought OI was something I'd eventually outgrow. Despite the type, my OI was rather mild, more hidden, and I didn't really think much about it. Yet I always wondered why I was so small, why I didn't really look like my sisters, why my teeth were so small and dark,

why I was such a "klutz," falling and turning my ankles so much. We didn't relate my hearing loss to OI at all.

I fractured my femur right before I was to start school, so I missed kindergarten and spent my first school years in a special education classroom. In the early 60's that meant being bused to a special school and being in a classroom with 20 other kids of all ages and disabilities, taught by one teacher. It was like a one room school house. My first teacher, Robert Leach, was amazing, being able to deal with all of us. I was mainstreamed to my neighborhood school in fourth grade and had to face the challenge of trying to fit in with the other kids. I wish *Emily's First Day* had been available for us back then!

After I married and decided to have children, my husband Dave suggested I see a genetic counselor. Learning that I could pass on OI to my children was devastating and the lowest point of my life. Yet, seeking out more information about OI and finding the OI Foundation was a revelation. For the first time in my life I met and communicated with others who had OI, and learned how much we share. Learning the symptoms of OI explained so much about myself and I found there was a reason for all my physical problems. It was actually a relief to find this out.

Ultimately, we decided to take our chances with having children. Matthew doesn't have OI, while Laura, whose symptoms are mild, seems to be doing much better than me. I have tried to never hold her back from trying anything, and I'm amazed at how well she's done, even doing well at tap dance and ballet. The thing that I am most proud of in my life is my children.

I'm still walking, although I have skeletal deformities, scoliosis and have had one hip replaced. I developed the hearing loss associated with OI (diagnosed as cochlear otosclerosis) when I was a teen, and by now it's the biggest challenge, since it has become progressively worse. I've had two stapedectomies, am deaf in the left ear and have less than 25% hearing in the right. OI has caused me more problems as I've aged, and now that I'm middle-aged with osteoporosis, I have to worry about fractures again.



I think it was my hearing loss that mostly affected my college experience. As my hearing grew worse, I had great difficulty hearing in class and realized I wouldn't be a very effective art teacher. So I turned to my first love of illustration. I didn't have a very active childhood because of fractures and my mom tried to limit what I did. Consequently, I spent a lot of time looking at picture books, reading, drawing and making up stories. I suppose it was natural that I would grow up to love books and want to become an illustrator.

I think this may be the best career for me. I can work from home and do most of my communication with clients through email. Also, having OI and learning to cope with its frustrations and setbacks was probably good training for someone seeking a career in the arts, as you have to deal with so much rejection. It's part of the job because the arts are so subjective. It's difficult to get a start and to make a go of it. You have to persevere and never give up your dream.

My special interests are reading, writing, nature, animals, history, antiques, all of the arts, and old classic movies. When I was younger I traveled to England, France, and various parts of the United States and hope to have the opportunity to travel more in the future.

I'm not sure I'm a good one for giving advice, since I struggle with the reality of OI every day, yet I think people with OI have to focus not on what can't be done, but on what can, and never give up. And somehow, through it all, I think it helps to always keep a sense of humor about life.

There is still time to enter the “Going Places” Sweepstakes!



You have until January 19 to enter this year’s “Going Places” Sweepstakes. Don’t miss your chance to win one of four great prizes!

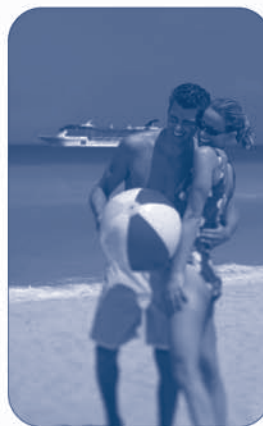
This year’s Grand Prize is a 3 or 4 day cruise for two, valued at up to \$1,200.00, arranged by OI community members **Karen and Glenn Vowell** of **CRUISEYOU.COM**. You also could win an iPod nano 8GB – Silver or a Panasonic Portable DVD Player, our 2nd and 3rd prizes respectively.

If you submit your entry by December 8, you also will be entered into our Early Bird drawing for a \$200 gas card.

Enter the Sweepstakes at www.oif.org/HH_Sweepstakes or by mailing back your ticket stubs with names and addresses filled out on each one. Your contribution during the Sweepstakes will help the OI Foundation to provide information to families and to fund research. The suggested donation is \$5 per ticket or \$40 for 10 tickets.

No purchase is required to enter the “Going Places” Sweepstakes, and a donation does not affect your chances of winning.

For tickets, contact the Foundation at Development@oif.org or 1-800-981-2663.



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Please bookmark our new website and use it whenever you travel!

Book your travel where it makes a difference! Visit the Osteogenesis Imperfecta Foundation travel website at:

www.OIFtravel.com

- You’ll find the same airlines, hotels, rental cars and cruises as on other travel websites!
- You’ll get great travel prices!
- Each time you book travel a portion of the travel commissions will go to support the OI Foundation!

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Vitamin D Recommendations

In mid October the American Academy of Pediatrics issued a statement recommending a higher level of vitamin D for infants, children and teens. The new recommendation raises the recommendation for the minimum amount of vitamin D to 400 international units (IU) per day. Most of the vitamin D in our bodies is made from sunlight absorbed through the skin. It is also available in fortified foods and in dietary supplements in the form called D3. This recommendation refers to vitamin D from food and supplements.

Why is vitamin D important?

- Maintaining proper levels are necessary so the body can absorb calcium and make bone.
- New research suggests that it plays an important role in regulating the body's immune system.
- Research links low vitamin D status with an increased risk for broken bones.
- Research also suggests that low vitamin D status contributes to bone pain.

Why is the AAP recommending a change?

- There is increasing evidence that many, children and adults are vitamin D deficient.

- Using sun screens to prevent skin cancer from sun exposure prevent the skin from naturally manufacturing vitamin D.
- Many people spend less time out of doors especially during the winter months and have less opportunity to naturally make vitamin D through their skin.
- Low vitamin D status causes the disease rickets and there has been an alarming increase in the number of cases seen in the United States.

Are there special reasons why people who have OI need to be aware of vitamin D research?

- Reports from OI Clinics indicate that many children who have OI are vitamin D deficient.
- Vitamin D levels are influenced by sun exposure and are often higher at the end of the summer than they are in mid to late winter.
- Studies of children who do not have OI, but who broke bones in early spring found evidence of low vitamin D status.

How do people know if they are getting enough vitamin D?

- A blood test that measures 25(OH)D is the only way to tell the level of vitamin D in a person's body.
- Researchers recommend that blood levels on this test should be in the 32-70 ng/ml range.

Are there different recommendations for children who have OI?

- The new AAP recommendation of 400 IU per day applies to infants and children who have OI.
- Since 2006, the OI Foundation has been publicizing vitamin D recommendations based on body size and weight rather than age. This information is based on research conducted in Canada and through the Kennedy Krieger Institute in Baltimore, MD with older children.

Suggested Vitamin D-3 Intake for People with OI:

Weight	IU per day
50 lbs. (20 kg)	600-800
90 lbs. (40 kg)	1100-1600
110 lbs. (50 kg)	1200-2000
150 lbs (70 kg) and above	2000-2800

- Children receiving a bisphosphonate such as pamidronate usually require calcium and vitamin D supplements and should follow their doctor's recommendation.

Where can I find more information?

- Since 2006 the OI Foundation has been encouraging research about vitamin D levels in people who have OI. On the OIF website see articles in the newsletter archive for Winter 2006, May 2006 and Winter 2007.
- The fact sheet **Nutrition and OI** currently on the OIF website also contains information about vitamin D.
- Useful websites include the American Academy of Pediatrics www.aap.org and the NIH office of dietary supplements <http://ods.od.nih.gov>.

Before starting on a vitamin D supplement, talk to your doctor, and get your vitamin D level tested at different seasons of the year. If you do take supplements retest after several months and adjust the dose until your vitamin D level is within the healthy range.



57 Bone China Tea ‘hosts’ raised more than \$33,000!

OI volunteers from across the country requested almost 4,200 Bone China Tea invitation packets this year, which they used to invite friends and family to support the work of the OI Foundation.

In addition, 19 volunteers set up Bone China Tea web pages and used e-mail to seek contributions.

Together, these volunteer ‘hosts’ raised more than \$33,000 for OI, simply by writing a note or an e-mail, stuffing and addressing envelopes, and placing them in the mail

Bone China Tea is a phantom tea party, not an actual event. Each year, guests receive a nice printed invitation in the mail with a tea bag inside, or they may receive an e-mail invitation. 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. No one has to dress up, hire a babysitter, or even gas up the car!

2008 Bone China Tea chairperson **Andrea Wisniewski** contributed countless hours assembling and mailing invitation packets for volunteers, following up with hosts, and even leading an information session for interested volunteers at the *National Conference on OI* last August.

Andrea, whose eight-year-old daughter Addie has Type IV OI, has been asking her family and friends to give through Bone China Tea for four years.

“The Bone China Tea event gives our friends and family who want to ‘do something to help’ a chance to make a difference for all people with OI,” she explained.

The OI Foundation expresses our deepest gratitude to Andrea and to all of the Bone China Tea hosts listed below:

2008 Bone China Tea hosts

\$5,000 and up!

Michael Johnston & Bonnie Landrum
Sue Miller

\$2,000 - \$4,999

Alec Cabacungan
Cyndi & Chris Nolan

\$1,000 - \$1,999

Breman, Carmellya & Alana Anderson
Judith Clarke
Andrea & Addie Wisniewski

\$500 - \$999

George & Gail Bunker
James, Jessica & Shelby Carter
Jacob Gadberry & Family
Sylvan Ganz
Ellen Manson
Michelle Moscardelli
Nancy Overbury

\$250 - \$499

Adam & Donna Ayers
Jennifer & Emily Crane
Amy & James Dias
Roxanna Ellis
Emily Enright
Andrea & Erich Hellerich
Megan Price
Robin & Mickey Rowland
Halley & Peggy Szaichler
Carol Valenti
Karen Vowell
Kay West

Up to \$249

Thomas Acquafredda
Kami Allen
Tillie Allen
Nancy Bieber
Sally Brashears
Cecile Camden
Jacqueline Carroll
Bev Coffin

Laurie Compher
Daniel Family
Janine Donnelly
Madeline Eddy
Jeff & Carla Edmisten
Nathalie Fajbik
Bernice A. Freudensprung
Don Gardner, Jr.
Karen Kimbrough
Peggy Miller
Linda Morehouse
Claudine Moscardelli
Charles & Maria Murray
Julie O’Brien
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Jackie Roberts
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New Medical Guide from the OI Foundation

The OI Foundation is pleased to announce the publication of a **Guide to OI for Pediatricians and Family Practice Physicians**.

This 30-page booklet is an introduction to medical management of OI. Designed for easy reference, it covers basic information about OI and its diagnosis, treatments, clinical issues, general health care issues and infant care. A discussion on providing social and emotional support and a resource section are included. Dr. Francis Glorieux, Director of the OI Program at the Shriners Hospital for Children in Montreal, Canada served as the editor. An experienced group of physicians, other health care providers and parents provided input as reviewers.

Families are encouraged to obtain a copy of this free publication for themselves as well as one for their primary care doctor.

This booklet was developed by the OI Foundation for the National Institutes of Health Osteoporosis and Related Bone Diseases~National Resource Center. Print copies are available free of charge from the OI Foundation. The booklet can also be read on the NIAMS website at www.niams.nih.gov/bone or on the OI Foundation website at www.oif.org.

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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