

## Richard Wyman Receives Thelma Clack Lifetime Volunteer Achievement Award



Richard (Dick) Wyman has been selected as the 2008 Thelma Clack Lifetime Volunteer Achievement Award recipient for his outstanding volunteer service to the OI Foundation. Dick's service spans more than 25 years. A former member of the Board of Directors, Dick continued his support of the Foundation by serving on various committees as well as serving as a resource to countless people with OI over the years.

Dick has been known to say, "the harder you work, the luckier you get." His optimistic outlook and determination to succeed has made him an inspiration to many, especially his family which includes his wife, Mary Ellen, his daughters Christine and Michelle and their four grandchildren. Dick has mild OI, as does his father and his daughter Christine along with two of his grandchildren.

Dick obtained his MBA from Babson College in Wellesley, MA and is both a Fellow of the Life Management Institute and a Certified Life Underwriter. He has shared his financial expertise with Foundation members and friends through initiating and managing the Foundation's Planned Giving Program as well as serving as a conference speaker on a number of topics. His expertise has been extremely valuable as the Foundation continues to grow.

*continued on page 3*



## The Love of Dance Benefits the OI Foundation

The first ever Bollywood-Fusion Dance tournament was held at the Tribeca Performing Arts Center in New York City. Eight extraordinary teams provided 18 thrilling performances throughout the evening. "It was the best dance competition I've ever seen" said John O'Brien, Director of Development for the OI Foundation, "The costumes, music and lighting were fantastic."

Bollywood Dancing is a commercial name for modern Indian dancing. It's a combination of classical Indian dance (which is the base), folk dancing such as Bhangra and sometimes has a Latino and Arabic influence. It's fun and very expressive and there's a lot of deep meaning behind music in films. You can actually express what the music means, through the graceful movements of the body.

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**From the Chief Executive Officer**

Dear Friends:

2009 is already in full swing and so are the activities here at the OI Foundation! In this challenging time, the Foundation is so appreciative of the loyalty and commitment we are experiencing from our volunteers and donors. This is the time when people may need our help the most, and we are committed to being that source of information and compassion for our community.

This issue of *Breakthrough* is filled with the latest information on research and global activities the Foundation is part of. It also spotlights some very special people, including 2008 Thelma Clack Lifetime Achievement Award recipient, Richard Wyman. Those who know Dick will agree he is very deserving of this prestigious award.

Another special person, and my partner on this page, Board of Directors President Ken Finkel, will be sharing with you his final letter as President. Please join me in thanking Ken for his outstanding dedication and service to the Foundation as President.

Warmest regards,



**From the President**

Dear Friends,

My journey with osteogenesis imperfecta began almost nineteen years ago, when our daughter, Jessica, was born. When she was diagnosed at eleven months, we were given a long name of a disorder we could hardly spell or pronounce, let alone understand. As we left the hospital that day, we were given the phone number of the OI Foundation.

We immediately called the Foundation office and received all the brochures and written materials available. There was no internet or chat room at that time, just a reassuring voice at the other end of the line, letting us know that the Foundation was there for us. We were also given the name of another family who recently had a child born with OI, and this started our connection with our local support group.

However, it was only after attending our first conference in San Antonio in 1992, that we began to realize what a caring and supportive community this was and the willingness of everyone to share information and their personal stories.

Today, the Foundation is stronger and more important than ever. Not only are we continually updating our fact sheets, but we have a first class web site where most answers can be found with a few clicks of the mouse. We have a dedicated staff who still answers questions by phone every day, making sure each family is cared for.

So, I ask each of you to please help support the Foundation financially. We have an ambitious agenda and will soon begin work on our new strategic plan. However, we need the financial resources to enable us to attain our goals. The Foundation just launched a new membership campaign. When you receive your letter, please join. The Foundation needs your support.

Finally, this is my last article for *Breakthrough*. My board term is expiring on July 1st and you will be served by a new President. It has truly been an honor for me to serve as President the past three years. During my eight years on the Board of Directors, I have had the privilege to work with extremely dedicated people. Each board member has been passionate about furthering our mission and always brought that passion to each meeting.

I want to personally thank the two other Presidents I served under, Bill Schmidt and Jamie Kendall, who brought their own special passion to the Foundation and were my mentors. I would also like to thank the Foundation staff for being so supportive and bringing your own passion to the office every day. And, to our former Executive Director Heller An Shapiro and our current CEO Tracy Hart, you both care so deeply about our community. Heller An had the vision to get us where we were eighteen months ago and Tracy has the vision to see us well into the future.

With Warm Regards,

# Spotlight: Sean Stephenson



You may have met him at an OI Foundation national conference, heard him speak at the Shriners Hospital in Chicago, watched him on a television talk show, read one of his books, listened to one of his CDs, or come across one of his websites. Sean Stephenson is a hard man to miss and impossible to ignore. Born with multiple broken bones from OI Type III, he has packed a lot of living into his 29 years.

Sean calls the Chicago area home, but over the past decade, he has traveled to over forty-seven states

and six countries. After a childhood of coping with fractures, frequent absences from school and other disappointments familiar to kids who have OI, Sean turned his interests and talents into a multi-faceted career. An early interest in politics led to a job in Washington, DC working on Capitol Hill. His gregarious disposition and optimistic outlook on life led to a thriving professional speaking business.

Along the way, Sean graduated with honors from DePaul University in Chicago, Illinois and went on to earn a psychotherapy degree from American Pacific University in Honolulu, Hawaii. He became a board-certified psychotherapist and opened a private practice in the Chicago area. Never one to rest on past accomplishments, Sean is currently working on a doctorate in clinical hypnosis. With encouragement from his parents, mentors and friends, Sean has been able to turn his childhood day dreams into reality.

On May 1, 2009 another accomplishment will be added to Sean Stephenson's list – the

publication of his fourth book. **Get Off Your 'But': How to End Self-Sabotage and Stand Up for Yourself** (Wiley, May 2009) is a hands-on guide for surviving difficult times, eliminating excuses, ending insecurities and standing up for happiness and success in life. In six lessons, the book presents Sean's plan for replacing procrastination and fear with positive action and courage. Based on his personal story, clinical training and experience speaking and teaching, **Get Off Your 'But'** makes the case that overcoming the habit of self-sabotage leads to becoming more self-confident which will lead to greater success in careers and relationships. The book begins with Sean's biography. Each lesson is illustrated with touching and often humorous stories about the people he has met and worked with along the way. This new book will be sold through major book stores, [www.amazon.com](http://www.amazon.com) and [www.barnesandnoble.com](http://www.barnesandnoble.com)

Talking with Sean you realize that he isn't finished yet. He still has a lot to say about living successfully with OI.

## Wyman *continued from page 1*

Dick will receive his award at the 2010 Biennial National Conference in Portland, Oregon and will also be presented with the award at the Massachusetts Making Strides for OI Walk, chaired and coordinated by his daughter, Christine Wyman Rossi, in June of 2009.

The Thelma Clack Lifetime Volunteer Achievement Award is given annually to the volunteer who best exemplifies the qualities of loyalty and dedicated service to the Foundation and its members. They demonstrate a willingness to put others before themselves as demonstrated by the late Thelma Clack.

Merci  
Gracias  
Spasibo  
Dankie  
Do Jeh  
Shukran  
SUKRIA  
Efharisto  
Kiitos  
Danke

There are so many ways to say **thank you!** The OI Foundation would like to thank all of our event volunteers, support group leaders, and donors of all ages for joining the fight to enhance the lives of everyone living with osteogenesis imperfecta. We could not do what we do without you. For that we are grateful.



## Bisphosphonate Studies

By Mary Beth Huber

This is the first in a new series of articles focusing on OI research. The next issue of *Breakthrough* will include information about the foundation's spring science meeting and a look at information from mouse studies relevant to understanding and treating OI.

In recent months a series of important articles have been published reviewing the body of research on bisphosphonate use in children. The purpose of review articles is to give health care providers, the general public, and researchers a reliable summary of information on a topic and to identify the gaps in knowledge. It is hoped that this information will help researchers focus on the unanswered questions and help families and health care providers make decisions about medical care. The authors of these articles follow a process that is carefully designed to be objective and thorough. Each review typically

- Begins by evaluating a large number of studies
- Analyzes the quality of each study
- Analyzes the quality of the information generated by the studies.

The quality of a study and the reliability of the information coming out of it are directly related to the number of people in the study, and whether the study is controlled or observational. The ideal study involves a large number of people, and is double-blinded and controlled. This means that some study participants receive an active drug while the others receive a placebo. Neither the investigator nor the participants know who is in which group until after the outcome data is analyzed. Such studies generate information that can be applied with confidence to many people. Case studies help identify a question that needs further

investigation. Observational studies are important for testing a hypothesis and identifying possibilities.

Even though review articles on health care topics typically only look at studies involving people, it is important to remember that animal studies provide information as well. Often, animal studies are the only way to investigate an important question safely and in a reasonable amount of time.

### Background

Bisphosphonates are a group of drugs including pamidronate (Aredia), alendronate (Fosamax), residronate (Actonel) and zoledronic acid (Zometa or Reclast). They were developed to treat osteoporosis and bone loss in adults. These drugs are called antiresorptive agents; they disrupt the bone modeling/remodeling cycle to allow greater bone formation. Research into possible application to childhood bone disorders began in the 1980's. The publication of the article, *Cyclic Administration of Pamidronate in Children with Severe Osteogenesis Imperfecta*, in 1998 brought attention to the potential for bisphosphonates to benefit children who have OI. This study, conducted by Dr. Francis Glorieux's team at the Shriners Hospital for Children in Montreal (Canada), was small, involving 30 children, and observational. Since then, bisphosphonates have been studied as treatments for children with bone loss caused by OI, kidney disease, steroid treatments, cerebral palsy and many other conditions. OI is the focus in the majority of published studies. At this time, because of the range of unanswered questions especially about long-term use, the US Food and Drug Administration (FDA) identifies most forms of bisphosphonate treatment for children as investigational. The FDA now requires the statement "Alendronate is not indicated for use in children" in the package insert for the drug Fosamax

(alendronate). ([www.fda.gov](http://www.fda.gov), Pediatric Exclusivity Labeling Changes through December 19, 2008.)

Bisphosphonates are a treatment; not a cure. Their use increases the amount of bone, but may not improve the quality of OI bone. The fact that OI bone is inherently imperfect means you cannot assume that information from studies of other conditions applies to OI. Bisphosphonates work on the mineral in bone, while the problem in OI is abnormal collagen in bone. The goal of all treatment is to reduce fractures and improve how well the person functions on a daily basis.

### Summary of the Review Articles

The information provided in the three review articles addressing the use of bisphosphonates in children indicates that since 1998 a great deal has been learned about how bisphosphonates work. Although each group of authors followed a different set of rules for their reviews they agree on several points.

They identified the same limitations in the research.

- Very few studies were controlled or randomized; most of the studies are observational.
- Low number of participants; without larger numbers of people the studies do not have the power to reliably answer the research questions. When numbers are too small it is not possible to tell if the information can be applied to the entire OI community.
- Studies are so dissimilar it is difficult to compare them. The studies looked at different types of OI, and at children of different ages. They used different forms of bisphosphonates at different doses and on different schedules. The studies do not

consistently include directed physical activity and/or dietary supplements.

- Some major questions especially regarding dose and treatment schedule have not been studied in a rigorous manner.

They identified the same facts as reliable.

- Bisphosphonates, in both the intravenous and the tablet form, increase BMD (bone mineral density) in children who have OI.
- It is assumed, but not entirely proven, that increasing BMD reduces fracture frequency.
- Bisphosphonates affect bone and thus may not directly improve other OI symptoms including joint hypermobility or tissue fragility.

Details about the best possible use of bisphosphonates have not been worked out. All of the authors identified the following gaps in our knowledge.

- The optimal dose, treatment schedule, and type of bisphosphonate for use in children
- Long-term effect on infants and children who receive treatment and on the infants born to mothers who received bisphosphonates in the past.
- Who to treat (which types of OI)
- Duration of treatment; risks have been identified for both continuing (over treatment) and discontinuing treatment (fracture risk in untreated bone) in growing children.
- Long-term effects of suppression of bone remodeling
- Threshold for over treatment — when bones become more brittle, and more prone to fracture.
- Relationship between drug therapy and physical therapy relevant to how well the child functions (energy, mobility, self-care).
- Many questions involving pain.

## Review Article #1

*Bisphosphonate Therapy for Osteogenesis Imperfecta (Review)* by Carrie Phillipi, Tracey Remington, Robert Steiner for the Cochrane Collaboration, Wiley Publications, October 2008.

A Cochrane Review is considered by many to set the gold standard for this type of article. The authors surveyed the research literature and analyzed a group of controlled trials, “To assess the effectiveness and safety of bisphosphonates in increasing bone mineral density (BMD), reducing fractures and improving clinical function in people with OI.” On the basis of their review the authors concluded that either oral or intravenous bisphosphonates increase BMD in children and adults who have OI but it is not clear if increasing the BMD leads to fewer fractures or improved function. The authors recommend additional studies that are designed to determine, “whether bisphosphonates improve clinical status (reduce fractures and pain; improve growth and functional mobility).” They also suggest further investigation into the topics of optimal method, duration of therapy and long-term safety of bisphosphonate therapy.

## Review Article #2

*Clinical Review: Bisphosphonate Use in Childhood Osteoporosis* Laura K Bachrach and Leanne Ward Journal of Clinical Endocrinology and Metabolism, February 2009.

Pediatric osteoporosis is defined as a genetic or acquired disorder that is characterized by low bone mass and fractures caused by bone fragility. OI falls into this category. The authors stress that bone fragility in children and teens is different from fragility in adults and that it is not appropriate to base treatment decisions for children on information from adult studies. These authors looked at many articles including observational studies. They analyzed studies using different types of bisphosphonates, different doses and different treatment schedules for OI and a number of other childhood

conditions. They conclude that the available information is inadequate to answer all of the safety and effectiveness questions. “For this reason, many experts recommend limiting use of these agents to those children with recurrent extremity fractures, symptomatic vertebral collapse, and reduced bone mass.” Their review also indicates that current information does not support using bisphosphonates in children to treat low bone mass alone. They report that in their analysis, increasing BMD did not reliably predict either fewer fractures or less pain.

This team of authors drew attention to the information from observational studies:

- Bisphosphonate treatment can affect bone shape in growing children; what this means for long-term bone health is unknown.
- Treatment benefit peaks at 3-4 years.

They recommend more research to define when bisphosphonate therapy is needed, as well as the most effective dose, length of treatment and drug formula. Further research is needed to target the gaps in current knowledge.

## Review Article #3

*Effects of Bisphosphonates in Children with Osteogenesis Imperfecta: An AACPDM Systematic Review*

Heidi Castillo and Lisa Samson-Fang Developmental Medicine & Child Neurology, 2008.

This review is based on the American Academy for Cerebral Palsy and Developmental Medicine method. Out of 109 published studies, 70 were closely reviewed. Using this system, only 8 were judged to be designed and executed in a manner that resulted in useable information.

This pair of reviewers concluded that there is evidence that bisphosphonate treatment has the potential to cause benefit to children with moderate to severe OI, but specific details are lacking. New studies are

recommended on treatment of infants, medication choices, optimal dosing, treatment duration, and post-treatment management. They suggest that future studies will need to be multi-centered and that a registry to monitor all side effects especially after treatment would be helpful.

## Conclusions

Research finds answers to the questions the study asks. The three review articles suggest that regarding the use of bisphosphonates as a treatment for OI, many of the necessary questions, particularly about the best dose, type of bisphosphonate to use and duration of treatment have either not been asked or not been resolved. "The lack of randomized trials comparing drugs and doses in various conditions makes it impossible to declare one therapeutic regimen superior to another."(Bachrach & Ward)

Taken as a group, these review articles are a powerful "shout out" to the research community that NOW is the time to do the difficult studies: to directly compare doses and treatment protocols and to design controlled studies that include larger groups of children. Parents and their doctors

need better information for decision making. The reviewers state that it is important to encourage research into the unanswered questions about bisphosphonates.

As the OI community looks to the future it will be necessary to encourage studies to find answers to the remaining bisphosphonate questions. But new research into other treatments including other drugs should also be encouraged. It would be short sighted to conclude that bisphosphonates are the only possible treatment for OI.

Until more information is learned prudence suggests the following:

- Consider participating in a research protocol that monitors bone health and general health if possible.
- When considering treatment with bisphosphonates, discuss with your child's doctor the pros and cons of different doses and treatment protocols.
- If the decision is made to use bisphosphonates in infants, be aware of the potentially serious complications including breathing difficulties and proceed with caution and close monitoring.

- Limit the use of bisphosphonates to children with repeated long bone or spine fractures.
- Do not automatically treat children with OI Type I or others not having repeated long bone fractures.
- Limit the duration of treatment with bisphosphonates. Once therapy is begun, discuss the pros and cons of continuing the medication beyond 3-4 years.
- Include physical activity in the management plan; this was proven to be a benefit prior to the advent of bisphosphonates.
- Promote good nutrition habits and avoid becoming overweight as the basis for life long health.
- Keep long-term goals in mind: helping the child with OI grow into a competent, healthy and happy adult.

Each of the review articles in this series includes an author who is knowledgeable about OI. The Cochrane Review is available free of charge on-line at [www.thecochranelibrary.com](http://www.thecochranelibrary.com). Abstracts for the other two articles and the Cochrane Review are posted on the OI Foundation website under the Research tab.

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## The Love of Dance *continued from page 1*



*Bollywood dancing*

Manoj Bangera, member of Iota Nu Delta and his sister Shashi who has osteogenesis imperfecta, were very influential in making the OI Foundation the charity of choice for this event.



Shashi and Manoj Bangera

Iota Nu Delta Fraternity, Inc. and DesiDance Teams presented this competition as a way to showcase the talents of some of the best dance teams around. A portion of the profits benefited the OI Foundation.



## OI Foundation Helps to Develop National Action Plan on Bone Health

In 2008 the National Coalition for Osteoporosis and Related Bone Diseases – also known as the Bone Coalition – brought together more than 150 individuals representing an array of stakeholders concerned about bone health to develop an action plan and agenda to advance bone health promotion and disease prevention. The Osteogenesis Imperfecta Foundation is a long time member of the Bone Coalition and had an active role in developing the action plan. Other members of the Bone Coalition include the American Society for Bone and Mineral Research, National Osteoporosis Foundation and The Paget Foundation.

Recently the plan was unveiled, which brings action to the 2004 Surgeon's General Report on bone health. The plan outlines specific steps for improving the nation's bone health. Recommendations were grouped into four priority areas:

1. Develop a bone health alliance
2. Promote bone health and prevent disease
3. Improve diagnosis and treatment
4. Enhance research, surveillance and evaluation

Each of these four priority areas includes several action steps to be taken by the bone health community, including the Osteogenesis Imperfecta Foundation and its scientists and volunteers.

During the spring of 2009 the Bone Coalition will be taking the National Action Plan to members of Congress and other key leaders to solicit their support in turning the plan into action. Currently the rate of scientific and clinical advances in bone health is remarkable. The OI Foundation is proud of the contribution our scientists are making to the understanding of diagnoses and treatments.

The OI Foundation, along with the other members of the Bone Coalition, is now a member of a national committee that is working to fulfill the directive of the Surgeon General's Report:

***“More than enough is known today to get started on any of a variety of critical actions that are needed to enhance the bone health of Americans.”***

If you would like a copy of the National Action Plan for Bone Health, please visit the OI Foundation's website at [www.oif.org](http://www.oif.org)

## Upcoming OI Spring and Summer Events

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

### June 6 – Framingham, MA

#### *5th Annual Massachusetts Making Strides for OI Walk, Silent Auction, and Family Fun Day*

Join us for a few laps, or put together a team to walk. There will be a lot to do for the whole family, and the pledges you raise support the work of the OI Foundation!

**Contact:** Visit [www.WalkforOI.org](http://www.WalkforOI.org), or contact Christine and John Rossi at [c.rossi@verizon.net](mailto:c.rossi@verizon.net) or (508) 620-0991.



### July 16 – Wood Dale, IL

#### *Fifth Annual Riley's Gathering Place Golf Outing*

**Enjoy 18 holes of golf, scramble format.** Then, after a fun day of golf, there will be a buffet dinner. During dinner, you will have the opportunity to participate in a silent auction and raffle for some great items.

**Contact:** Patrick Fromelt at (630) 244-9982 or [pplfro@aol.com](mailto:pplfro@aol.com).



### July 20 – Naperville, IL

#### *11th Annual Miracle Michael Charity Golf Outing*

**This 18-hole scramble** at White Eagle Golf Club will include charity fund-raising holes and sports celebrities. A silent auction and a live auction also will be held.

**Contact:** Beth Shultz at (630) 922-3363 or [jbamshultz@aol.com](mailto:jbamshultz@aol.com). You may also visit <http://www.miraclemichael.org/>.

*The Gryns family of Pekin, IL was featured on the January 11, 2009 edition of the prime time TV program, Extreme Makeover: Home Edition. One of their children, 8 year old Jake, has OI Type III and is not able to walk. Here is their story about being on the other side of the TV cameras.*

## Our Adventure with Extreme Makeover: Home Edition

By Jean Gryns

Well over 3 years ago Jake's Easter Seal occupational therapist convinced my husband Steve and I that major changes in our home would allow Jake to be much more independent and that we ought to try and get a TV program like Extreme Makeover: Home Edition to take on the project. Not being entirely sure what we were getting into, we allowed her to nominate us to be an EMHE family. For the next three years, Angie coordinated a campaign to get our story noticed by the program's decision makers. We submitted an endless stream of videos, photos, letters and forms. After two years we were contacted by a program representative who gave us the opportunity to submit more information, more photos, more newspaper articles, faxes, texts, etc. This went on for another year and as a result we were interviewed, a background check was done, and references were contacted to make sure our story was true.

After years of campaigning, we were told that we were one of 5 finalist families in Illinois for October. We were told the date that, either Ty would come to our door or we would get a phone call. What a tortuous few weeks it was. We were afraid to leave the house in case 'they' called; afraid to talk to anyone for fear of saying the wrong thing; afraid of getting disqualified because someone in the family got a speeding ticket. Then the day arrived. Our family was in the back of the house, eating donuts and laughing, playing a game to pass the time waiting for the phone call. There were people from our town outside our house and we felt bad for them saying how disappointed they would be when no one came. We all planned on working on the chosen family's house. Then we heard the famous bullhorn, "Good morning Gryns Family!" All of the kids took off running. I stood there stunned, picked up Jake and slowly stumbled out the front door. There were cameras and people everywhere. I remember asking "Is this real?"

There were hundreds of people all busy doing things. It looked like a hive of very busy bees. There were interviews, photos, more interviews and we all had a 'deer in the headlights' look on our faces. We asked for it, prayed for it, hoped for it, but when it actually happened we all were in shock. Soon we were tossed into a limo with the clothing we had rapidly packed (one suitcase was full of splints, wraps, fiberglass casting material, scissors, and any other medical equipment I could grab.) At this point they took our cell phones and computers and we were not allowed to watch TV. Isolated from the world—kidnapped by ABC! In the limo I looked at my husband and panic set in. We only had \$60 cash between us! No worries, ABC provided all of our food and lodging for the trip, but it was a helpless feeling being so far away from home and no cash on hand.

We also realized that strangers were going into our home to pack up every single thing we owned. Strangers were going to touch ALL of our stuff. Strangers were going to see the dust bunnies, (or full grown rabbits) behind our refrigerator. Oh well, let it go and move on. It was over and done with.

Next we were put on a plane to Disney World and a wonderful man named Matthew met us in the airport in Orlando. Mathew was a blessing. He made sure the kids got to see and ride whatever they wanted and made reservations so we never stood in a line to eat. A dream vacation! After 4 days it was time to board another airplane to go home. What a weird feeling to not be able to picture your home; the place you expect to be sleeping that night!



We arrived at the set. It is a real TV show with cameras, directors, actors, designers and people watching the filming. We had just adjusted to life

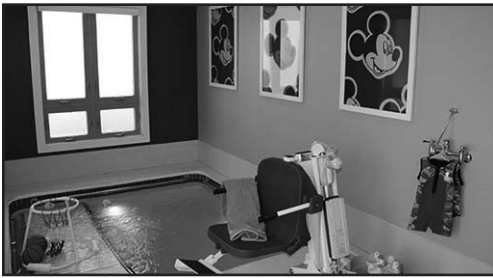
at Disney; being led around by the hand by our hero, Matthew. Now we were in a new world. When that bus moved, our lives would be forever altered. When we climbed out of the limo, thousands of people were screaming our name. Everyone we knew and everyone else in the world it seemed; a sea of smiling faces, yelling our names. So surreal! Then they started chanting "Move that bus." When they finally did move the bus, we were stunned. The house was beautiful! How did they know what colors and styles we liked? But wait, there is more.

We entered the house and it was beautiful. It looked like a big clean beach condo! The consensus was AWESOME!!!



Everyone got to run and look at their bedrooms, but what we all wanted to see was Jake's room. We couldn't wait. THIS was what it was all about. And we have to say that ABC and the designers hit a home run! Touring our wonderful new home, checking out the special features in Jake's room, bathroom and therapy pool we still felt like we were on vacation.





Then came the shocker. All of the volunteers that stood and watched us come home started carrying in boxes. Then more boxes and more

boxes until the basement and garage were full of boxes of our old 'stuff'. We contemplated just sending it all to an auction house, but we needed to find things like our underwear, birth certificates, photos, family movies, high school diplomas...just little things like that. So we started the horror of going through 25 years of 'stuff' gathered by 9 people. We worked for weeks trying to get things straightened out and finding somewhere to put what we still needed to keep. We also need to find somewhere to donate the rest of it and I am talking trailers full of stuff.

Just as we were getting our feet on the ground, it was time to decorate for the holidays. But all during this time, we had to keep the house



perfect. The program hadn't aired yet and there were people we had to give tours to. We never knew who was going to call next!

Finally, things started to settle down. I stopped acting like I was the keeper of the museum and started 'nesting' in our home. I moved some things and changed a few things. Not much, little decorating touches.

What a gift and joy this experience has been. What a change in our lives. We went from giving total care to Jake to him being totally independent. He



can wash his hands, get a drink, fix a sandwich, answer the phone (bad news!) and open the door to go outside. We are implementing new rules. Things that other kids learn at 2 or 3 or 4 Jake is learning now. You have to ask to use the phone; you don't need 4 showers a day; you can't go outside without asking....and on and on. Our life has changed, but what a wonderful change!

## Announcing the Winners of the "Going Places" Sweepstakes . . .

The OI Foundation thanks everyone who participated for helping the "Going Places" Sweepstakes to raise \$18,447 to support our work! More than 4,200 entries were turned in between October and January!



We are pleased to announce the winners of this year's great prizes:

**Early Bird Prize:** \$200 in gasoline gift cards – Kevin Conlon of Basking Ridge, NJ

**2nd Prize:** iPod nano 8GB - Silver – Dorothy Egidio of Vallejo, CA

**Grand Prize:** A 3 or 4 day cruise for two! – Margaret Nixon of Charlotte, NC

As of press time, one prize has still not been claimed. The Foundation is working through the list of runner-up winners who were drawn during the official drawing on January 30 to get in touch with a winner for the 3rd Prize of a Panasonic Portable DVD Player with 8.5" LCD and Six-Hour Battery.

The "Going Places" Sweepstake is an annual promotion, held each Fall, that raises donations that help the Foundation to provide information to families, fund research, and raise awareness.

# From the Information Center

## ***Handle with Care***

The latest book from novelist, Jodi Picoult, features a family that includes a child who has OI Type III. Published on March 3, 2009 the book was an opportunity to increase awareness about OI in the general public. The OI Foundation distributed Unbreakable Spirit bookmarks at many of the book signings, and placed a special section on its website to provide information to readers who were hearing about OI for the first time. The author met with many OI families in the course of her tour, and provided a signed copy of the book for the annual Fine Wines Strong Bones auction. In response to a question on the Washington Post on-line chat about where to learn more about OI, Ms. Picoult wrote "www.oif.org - that's the OI Foundation website and they are FANTASTIC."

## ***Diabetes Drugs May Cause Fractures***

Recent research suggests that 2 of the drugs commonly prescribed to treat diabetes, Avandia and Actos, increase the risk of broken bones in older women. News reports indicate that long term use of these medications along with patient age affected the level of risk. According to reports men were not affected. People who have OI plus diabetes who currently take Avandia or Actos should discuss these studies with their doctor.

## **Children and Medical Research Web Site**

The National Institutes of Health has launched a new web site, **Children and Clinical Studies** ([www.nhlbi.nih.gov/childrenandclinicalstudies/index.php](http://www.nhlbi.nih.gov/childrenandclinicalstudies/index.php)).

It presents information for parents and healthcare providers about why research in children is important, how studies are conducted and what steps are necessary to protect the child's health and privacy. A 10-minute, award winning video is featured on the site.

## ***Bone Biology for Kids***

Susan Ott, MD Associate Professor of Medicine at the University of Washington in Seattle has created a web site especially for middle school students. Called **Bone Biology for Kids** it is on the university web site <http://depts.washington.edu/bonebio/>. The site contains information about bones, the skeleton, bone health and other aspects of bone biology. The material is not specifically about OI. It can be used by students or as a resource by health, biology and science teachers.

Dr. Ott is also part of a team that developed the **Bone Curriculum** section for the American Society of Bone and Mineral Research website [www.asbmr.org](http://www.asbmr.org). This site is intended for older students and includes a section on OI.

## ***Fact from the OI Registry***

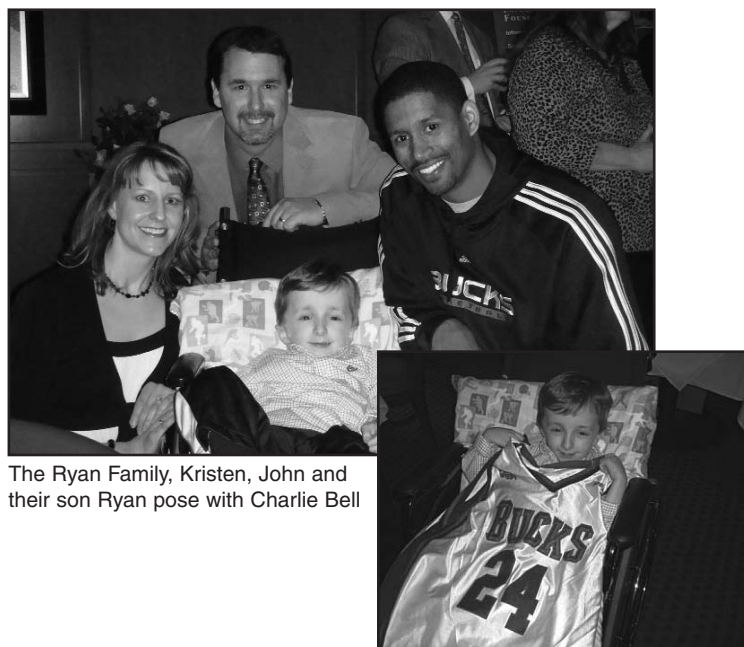
A review of information in the OI Registry indicates that 16 % of adults report receiving treatment for high blood pressure. Until this topic is studied in depth adults are reminded to:

- Get their blood pressure checked (using a manual cuff)
- Include physical activity in their day
- Consider self-care practices that reduce stress

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## **Fleming's and the Milwaukee Bucks TeamUp**

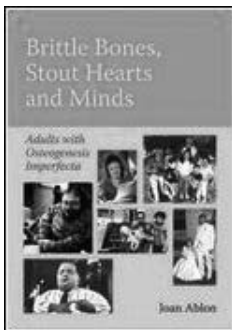
**Brookfield, WI** - More than 40 people gathered at Flemings Prime Steakhouse and Wine Bar on March 19. "It was a great event" said John O'Brien, Director of Development for the OI Foundation, "I think people were moved to hear the impact that OI has on families and were inspired to support this cause" In addition to Flemings hosting a wonderful dinner, those in attendance were treated to an appearance by NBA star Charlie Bell from the Milwaukee Bucks. The OI Foundation, along with John, Kristen and their 5 year old son Ryan Roubik, who has OI, helped spread awareness to those participating in the dinner event. The proceeds from the dinner and auction items donated by Flemings and the Bucks raised \$3,750. Thanks Flemings!



The Ryan Family, Kristen, John and their son Ryan pose with Charlie Bell

Ryan shows off his autographed Charlie Bell Jersey

# New Book About Adults Who Have OI



The OI Foundation is pleased to report the publication in February 2009 of **Brittle Bones, Stout Hearts and Minds: Adults with OI** by Joan Ablon, PhD. Dr. Ablon, an anthropologist who studies how people cope with being different, began her research with adults who have OI in the mid 1990s. She spent more than 8 years conducting extended interviews with 55 adults, across the United States, age 19-69

all of whom had OI Type III or IV. This group of adults grew up in the era before the ADA and when children diagnosed with a pediatric condition often spent long stretches of time in the hospital away from family and friends. A preface by Peter Byers, MD places this book in its historical context. This readable book not only is a window on a time that isn't so long ago, but also brings to life, using their own words, a very interesting and diverse group of OI adults. Dr. Ablon undertook this project, supported by the OI Foundation and the National Science Foundation, because she was repeatedly told that so little information was available on the lives of people with OI after their teen years.

Dr. Ablon groups the interview excerpts to illustrate the range of experiences and opinions on many topics including early medical experiences, education, employment, dating, marriage, stigma and careers. The interviews are summarized and linked together by her insightful comments on psychological and social issues. The adults in this book

show emotional endurance in the face of physical pain, difficult situations, and physical challenges; persistence in their efforts to achieve goals and strong personalities. If there is a theme it might be that these adults did not want to be stereotyped. In their comments they stress that they are:

- Physically different but not ill
- Short in stature, but not perpetual children
- Good at coping, but not euphoric or pain free
- In need of adaptations to the physical environment, but capable adults who raise families and have careers
- Never passive

*“Hopefully, people everywhere will realize the value of the human is not based on the vessel that they are in, but on the spirit and the mind that exists within that body.”*

*Lea, page 217*

The book illustrates how much the child health care system has changed and how much it needed to change. This pioneer generation also has a lot to say about the delivery of health care to adults. Near the end of the book, a very timely and useful section summarizes their suggestions for maintaining health. The reader is reminded that living with OI is a life long challenge, and that it takes fortitude to cope with being physically different.

**Brittle Bones, Stout Hearts and Minds: Adults with OI** can be purchased at any bookstore. If the bookstore doesn't have it on

the shelf they can order it for the customer without any problem. The book is also available on-line through the publisher's website [www.jbpub.com/catalog/9780763760052](http://www.jbpub.com/catalog/9780763760052), at Amazon.com, or the Barnes and Noble website.

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## The OI Registry Improves in Response to Member Feedback

By Yimei Wu, OI Registry Manager

Since the OI Registry opened in March 2006 over 1,340 people from the United States and 30 other countries have joined. Based on member suggestions, the OI Registry recently began a series of important improvements. New features have been added to improve ease of use and to gather additional information. The following changes have been made:

1. **Multi-user capability:** The original version allowed only one person to register under one email—thereby creating a problem when more than one person in a family has OI (what do you do when Mom has OI and an email address, but Junior has OI and is only 2 years old?). This new feature allows Mom to set up her account, and then press “Add Another User” to add Junior (as a separate individual with his own questionnaire) under her email address. The process allows family members to be linked and every individual to be accounted for.
2. **Hearing loss questions:** Additional checkboxes and textboxes have been added to collect more detailed information on the age of hearing loss onset and testing history.
3. **Child abuse question:** A new checkbox on this topic has been added due to requests from individuals with OI and investigators.

*continued on page 14*



# Recap of Events

## In its 34th year, the Southern California golf and tennis tournament continues to thrive!

During its 34th year overall and its 25th year supporting OI, the annual golf and tennis tournament organized by the Southern California Petroleum Industry Charity Association (SCPICA) continues to thrive.

During the recent event on November 14, more than 300 golfers and numerous tennis players and dinner guests helped SCPICA to raise \$60,500 in support of the OI Foundation.

"I am proud to be a part of the Southern California Petroleum Industry Charity Association (SCPICA) and appreciated the opportunity to be its General Chairman this past year," 2008 Chairman **Mark Passarini** wrote. "My hat is still off to the many folks who contributed to the event this year, and I extend best wishes to the OI kids and their families in 2009."

The organizing committee — led by 2008 Chairman Passarini — found new ways to keep things interesting for the donors who participated. This year, the LA Clipper Basketball team cheerleaders assisted the committee in selling raffle tickets. Later, during the evening, two young people with OI produced items for the live auction that raised significant money. A book written by **Christina Nelson** was auctioned for \$1,000. Also, a painting by **Nicole Hoffine** raised \$1,600 during the auction.

OI Foundation CEO **Tracy Smith Hart** spent the day at the event and spoke to guests during the dinner.

"All enjoyed a great dinner after a full day of great golf and tennis in deliciously sunny weather," Mr. Passarini added. "It seemed so much like business as usual for the OI



*(L to R) Trey Glauser, Christina Nelson, Rob Parke, and Nicole Hoffine all volunteered during the SCPICA event on Nov. 14. They are among the 'kids' who have inspired this event during the past quarter century.*

Tourney this year, a good day in the outdoors, the camaraderie of it all, and the opportunity to again contribute importantly to the fine OI cause."

The OI Foundation wants to thank Mark Passarini, SCPICA Treasurer **Frank Fossati**, the **Glauser, Hoffine,** and **Parke** families, and the other volunteers and members of the SCPICA committee who made this event so successful.

## Two supporters made Fall online auction possible

In November, two supporters from different parts of the country each came up with a creative way to raise money for the OI Foundation.

The gifts of these two individuals enabled the OI Foundation to hold an online auction this Fall that raised almost \$3,400.

**Rhoda Greif**, an artist in New York City whose daughter-in-law and granddaughter have OI, offered to sell her oil, pastel and water color

paintings during an online auction and contribute 15% of her proceeds to the OI Foundation. Four of her paintings sold during the three-week auction.

At about the same time, former Board member **Richard Wyman** offered to sell his family's Orlando timeshare and donate the entire sale amount to the Foundation. Interestingly, a mother of young children in Indianapolis with no connection to OI, found our auction online and purchased the property.

The staff and Board of the Foundation are grateful to Ms. Greif and Mr. Wyman for their support.

The OI Foundation now partners with Donate for a Cause to facilitate charity timeshare sales. In addition, we are a registered charity on eBay through the MissionFish program, and we have the capability to host online auctions. For more information on these and other giving opportunities, visit [www.oif.org/HH\\_Donate](http://www.oif.org/HH_Donate), or contact Stuart Tart at [development@oif.org](mailto:development@oif.org).

## Seattle-area artist raises more than \$1,900 for OI

**Seattle, WA** — An artist, whose wife and son live with OI, used his Seattle gallery show to raise awareness of osteogenesis imperfecta and support for the work of the OI Foundation.

**Andy Eccleshall** was the featured artist at Marni Muir Gallery from November 5 – 29. During his time as the gallery's featured artist, Andy held a special fundraiser for OI on November 22, where he auctioned his acrylic painting, *Glass Boy*.

In the painting, a boy stands facing the ocean, holding a bucket and sand shovel. Although he wears a colorful shirt and shorts, it is clear that he is made of glass.

"The boy in the image is just like any other boy you may see at the beach, bucket and shovel in hand, feet in the water. He experiences the same excitement and sensations as any other boy, only his structure is different," Andy explained.

"Glass Boy" brought in a bid of \$1,200, and donors at the event contributed an additional \$742. We sincerely thank the Eccleshall family for their generosity! This is the family's second fund raising event in two years for the OI Foundation.

## OI Health Walk and Fundraiser

By Amanda Petri

**Killeen, TX** — My name is Amanda Petri. I am a senior at Ellison High School in Killeen, Texas and a member of the Leadership Academy. In order to graduate as an Academy member, one must complete a project their senior year. Projects done by previous seniors have varied from composing a march to supporting

cancer research, yet all projects have one thing in common: topics are close to the senior's heart.

I had so many ideas for my project, even before senior year hit. I was going to associate it with sports! I love playing sports and I could always tie it in with childhood obesity. But that just didn't seem to set right. Yes, I really enjoy playing soccer, but is this worth a project that will be my legacy? It just didn't fit. So I started to think.

I believe I was going through old pictures, or maybe I was just reminiscing but then it hit me! Ashley! See, Ashley is the little sister of my best friend, Amanda. She has type III OI. I have known Ashley for twelve years. I have watched her grow up with cast after cast, surgery after surgery, and it just became part of the norm. When Amanda and I were younger, we always said we would find a cure for her. We knew she shouldn't have to live like this: come on, she was only five! This was the inspiration for my project. The will that Amanda had to find a cure is the drive

I used to complete my project. I decided to do an Osteogenesis Imperfecta Health Walk and Fundraiser.

I held the actual event on November 22, 2008 at Ellison. My walking area was around the student parking lot. Since it's so large, participants could choose when to loop back. I also had a bake sale table for those who did not want to walk but still wanted to contribute. It was a fairly cold day, so the bake sale went over a lot better than the walk itself. My goal was to raise \$500.00 to go towards research. I wanted to raise awareness in my community, and to educate the people around me. The best part about doing my walk was when the "Money Thermometer" was getting more and more full. It was a realization that my project was a success. I know that my OI Health Walk and Fundraiser may have been too late for Ashley, but hopefully it will help bring about a chance for a change in someone else's life. That was the objective all along.



**Ashley Jones (R) and event organizer Amanda Petri take a break to pose in front of the bake sale table at the OI Health Walk and Fundraiser, held Nov. 22 at Ellison High School in Killeen, TX.**

## People in the News

*Demopolis, AL* – “Rhae of Hope” is how the article describes 9 month old **Rhae Busby**, diagnosed as having Type II with no expectation of being born alive. Mom Dana states “she has a spirit that you just wouldn’t expect out of a baby. She has taught us all so much.”

*Los Angeles, CA* – The recent creation of UCLA’s wheelchair basketball program has provided **Nik Patel** the opportunity to “participate in team sports which able-bodied athletes usually play”, and allows him “to be involved in the sport that I love.”

*Simi Valley, CA* – An independent filmmaker has created a script that includes actors with disabilities and has written a part specifically for 24 year old actress **Nicole Gerth**.

*New Haven, CT* – Though it is hard to imagine how it was driven, thieves still managed to take off with **Michelle Duprey’s** extensively modified van. Fortunately, it was recovered after a

local news station aired the story, telling how the lawyer, Director of the Department of Services for Persons with Disabilities left an evening meeting to find her van had disappeared.

*Ft. Morgan, CO* – For 17 year old **Cody Anderson**, bull riding is like dancing. He is passionate about the sport despite being diagnosed with OI at the age of 13 when he was the star quarterback on his middle school football team.

*Auburn, IN* – Hard work has paid off and 12 year old **Nicol VonHolten** will be heading to Austria next summer where she will compete at the Young Friendship Games in the swimming competition.

*Gardner, KS* – For 36 years **Jesse Wilkerson** and his wife Pat have been creating and selling handmade dolls. Since 2007, a portion of the sale of each doll is donated to the OI Foundation in support of research. To see the dolls go to [www.santafetrailsdolls.com](http://www.santafetrailsdolls.com).

*Mt. Pleasant, PA* – Forty broken bones and a leg brace can’t keep **Evan Anthony** off the golf course where he can be found playing on his varsity golf team. He notes, “My swing is all upper body, but there is no leg drive as with other golfers. I swing from my waist, but it gets the job done.” And that’s what matters.

*Wynnefield, PA* – His wheelchair basketball coach calls 15 year old **Andrew Reid** “a born point guard, a general on the court”. Andrew doesn’t know what he’d do if he couldn’t play basketball, stating that “It’s really helped me out in life”. Every day includes numerous suicide sprints, basket shots and weight lifting three times a week, all preceded by shuttling himself around the streets of Philadelphia, using mass transit.

*Fisherville, VA* – He plays the mandolin at church, but at the Woodrow Wilson Rehabilitation Center’s hunt event, **Bill Knight** was focused on bagging a deer. An avid hunter, his wheelchair is fitted for a gun and worked to reduce recoil.

*Ballarat, Australia* – Mourners packed St. Patrick’s Cathedral to say goodbye to **Shane Everard** who died at the age of 57. Well known for his roles as a disability advocate and sports writer, it was noted that “his charismatic nature, cheeky smile and engaging nature had a magnetic pull on people.”

*N. Sydney, Australia* – The services of JobAccess were used to make accommodations at the South Australian Film Corporation, improving the workplace and allowing actor and filmmaker **Quentin Kenihan** to “do my job better and more comfortably. They came in and assessed my needs thoroughly.”

### OI Registry *continued from page 11*

4. **Relatives with OI not related by blood:** In the previous version, there were textboxes only for relatives related by blood. Several individuals with adopted family members made the point that these categories were not enough. The section has been expanded to list adopted children, adoptive parents, spouses, etc.
5. **Type II OI:** A radio button has been added for Type II OI.
6. **Deceased relative:** A textbox and comment box has been added in the Family History Section to include deceased individuals. However, the best way to account for a deceased person with OI is to register them either separately or as a dependent through the “Add Another User” mechanism and adding a comment to identify the person as deceased.
7. **How did you hear about the OI Registry?:** This question has been added at the end of the form. The information will help identify which sources of information are working well and where we may have more success reaching out to people with OI.

Interest in using the OI Registry is growing. Whether it is graduate students working on their thesis topics, or seasoned clinical investigators seeking to increase the power of their studies, people are finding that the opportunities associated with the OI Registry are invaluable. If you are already a member, please log into your account to update your information. If you have not yet joined, please go to: [www.osteogenesisimperfecta.org/oir](http://www.osteogenesisimperfecta.org/oir) to join the OI Registry.



# *In Honor Of*

November 1, 2008 – February 28, 2009

**Nicholas Anderson**

Carver Center's National Honor Society  
Ms. Suzanne Meier

**Nicholas Atkinson**

Auren S. Weinberg, M.D.

**Adam Ayers & Kara Sheridan  
(Engagement)**

Joe & Tonya Treinen

**Paricia L. Baker (Christmas)**

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**Miss Flora Ball**

Ms. Leslie Davis

**Donald & Ruth Barringer**

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**John D. Bartram**

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**Mary Alice Birdwhistell**

Mark & Martha Birdwhistell  
Sigma Kappa Sorority Georgetown College

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Ms. Kim Blackwell

**Ryan Bose**

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**Patricia Boyd**

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**Dr. Peter Byers**

J. Eric & Laura Gould

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Bennett Clayton Foundation

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**Tim Dombro, Jamie Kendall & Jorge**

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Mrs. Peg Dombro

**Glenda Easley**

Duncan and Ada Sutherland, III

**Jack Eccleshall**

Gaetan & Deborah Binder

**Jacob Everett**

Amos & Doris Everett  
Jim & Leah Everett

**Robert, Debbie, Grant & Mason Harwell**

**Mark & Randi Farage (Christmas)**

Mike & Marianne Farage

**Jessica Finkel**

Joel & Cydney Fox

**Stan Freitas**

Ms. Carolyn Varner

**Craig Gadberry**

Mr. Ron Dare

**Geoff & Anne Geis**

Ms. Mary Huck

**Peter & Mary Geis**

Ms. Mary Huck

**Ron Glickman**

Jason & May Carol Long

**Dr. Francis Glorieux**

J. Eric & Laura Gould

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Ms. Alana Burkle  
Francois & Christine  
Lara & Suddha Graves & Family  
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Ms. Susan Norman

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**Christopher Nolan**

Mrs. Kathryn Phillips

**Abigail Riley Norris**

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David & Tyler Jennings  
James & Maria Pimley  
Ms. Kimberly Prann

**Megan Price**

Jack & Marla Wills

**Lynn Rappaport Reid**

Ms. Dorothy Marcus

**Troy Read**

Ms. Nancy Deutsch

**Gavin & Owen Reazor**

Robert & Jennifer Prybolsky

**Jonathan Reed**

Lima Radio Hospital, Inc.

**Anne Held Reeves (Christmas)**

Robert & Pat Reeves

**Neal Rochford**

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Mr. Gary Moss

Ms. Linda Peters

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Ms. Sylvia Leaf

**Trisha Stouder**

William & Charlotte Stouder

**Jacob Strubhart**

Jerome & Sandy Strubhart

**Molly Sloan Sullivan**

Ms. Marcia Solberg

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Ms. Sylvia Leaf

**Palmer Szavuly**

Eric and Jackie Palmer

**Denise Tarantino**

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**Sharon, Ted, Greg & Kata Trahan**

Alison, Chris & Tyler Schell

**Regina Wagner's Brother**

J.C. & Neil Milner

**Holly Weillbrenner**

Sarah & Alex Weillbrenner

**Brian & Amy Weiss**

Ms. Mary Huck

**Anthony Welch**

Thomas & Mary DiSisto

**Kay & Ralph West**

Norman & Joyce Wilcox

**Mr. & Mrs. Chuck Winner & Justin**

Ms. Sylvia Leaf

**Mary Ellen Wyman**

Christopher & Mary Klotz

**Andrew Yarborough**

Mr. John Yarborough (Skip & Liz)

# *In Memory Of*

November 1, 2008 – February 28, 2009

**Christopher (Phyllis Bernard's Grandson)**

Mr. Roland Blais

**Jean C. Adams**

James & Grace Sisco

**Alex Aminto**

Ms. Benita

**Robert Anderson**

Bonnie Landrum & Michael Johnston

**Mike Belden**

Gerald & Dixie Hertel

**Megan J. Blackwood (18th Birthday)**

Charles & Emille Blackwood

**Charlotte Brown**

Mrs. Elke White

**Mathew Cherpak**

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**Donna A. Christman**

Ms. Mildred Berry  
Bruce & Kimberly Bumgarner  
Michael & Susan Kime  
Travis & Tonya Strete  
Larry & Cheryl Watson

**Florence H. Cianci (Mom-Mom)**

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**Maureen Elizabeth Comford**

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**Herbert Cox**

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John & Tammy Fricker

**Michael Geisman**

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Mark & Linda Geiger  
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Tracy Smith Hart  
thart@oif.org

## Director of Finance and Administration

Tom Costanzo  
tcostanzo@oif.org

## Administrative Assistant

Jenny Stup  
jstup@oif.org

## Information & Resource Director

Mary Beth Huber  
mhuber@oif.org

## Information & Resource Specialist

Marie Maffey  
mmaffey@oif.org

## Director of Development

John O'Brien  
jobrien@oif.org

## Assoc. Director of Events

Erika Ruebensaal  
eruebensaal@oif.org

## Database Manager

Desiree Swain  
dswain@oif.org

## Assoc. Director of Development

Stuart Tart  
start@oif.org

## Newsletter Design/Layout

Marcia Kennedy

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## Osteogenesis Imperfecta Foundation

804 W. Diamond Ave., Suite 210  
Gaithersburg, MD 20878  
(800) 981-2663 Fax: (301) 947-0456  
www.oif.org  
bonelink@oif.org

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**Osteogenesis Imperfecta Foundation**  
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