

Conference Issue

16th Biennial National Conference on OI

Start making your travel plans! You don't want to miss the 2008 National Conference, August 1-3. This year's Conference features over 30 educational sessions presented by the top specialists in OI, more social activities for all ages, and the invaluable opportunity to be surrounded by people in the OI Community. All of this in a beautiful conference hotel that is located just three miles from the heart of Washington, DC.

The National Conference on OI is attended by people of all ages who have many different ties to OI. From adults, teens, and children with OI, to their parents, spouses, siblings and grandparents, the Conference offers information and support for everyone.

Attendees to previous Conferences have come away with lifelong friends, life-changing information, and a sense of connection to the OI Community. Regardless of your type of OI or relationship to it, this event has something for you.

Do you need a few more reasons to attend? People who attended previous conferences list these reasons for coming:

- Learn how to take better care of yourself and your family members
- Meet and talk with the medical experts
- Share better living tips with people who have OI and their families
- For a few days, in one special place, be in the majority

Everything you need to know about registering for the 2008 National Conference on OI is in this issue of Breakthrough. If you have more questions, please feel free to contact the OI Foundation office at 800-981-2663 or bonelink@oif.org.



Brett Eisenberg: National Award Winner

In an interesting parallel of two lives, Brett Eisenberg has been selected to receive the 2008 Paul Hearne/AAPD Leadership Award. The award is given to an "emerging leader" who has demonstrated leadership qualities in his/her personal and/or professional life, and who is just starting to be recognized at a local, regional or national level.

Paul Hearne was a tireless advocate for the disabled, who as director of the National Council on Disability helped draft and push for the Americans with Disabilities Act. He also helped found the American Association of People with Disabilities (AAPD). The Paul G. Hearne Leadership Award was established in 1999 as a way to honor the memory of Paul, and to help realize his goal of identifying and supporting emerging

leaders with disabilities.

Mr. Hearn should be happy with this year's selection. Brett Eisenberg not only encompasses the necessary qualities for this award, like Mr. Hearne, his accomplishments have been against the backdrop of an OI diagnosis. Both New York natives, they also attended the same school, formerly the Human Resources Center, now called the Henry Viscardi School located in Albertson, NY. While Mr. Hearne relocated to the nation's capital to champion disability rights in the corridors of power, Brett returned to New York from a temporary relocation to Florida and has been working to influence the corporate world to hire people with disabilities.

See Eisenberg on page 18

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Conference Registration Brochure Insert!

FROM THE DESK OF THE CHIEF EXECUTIVE OFFICER



Dear Friends,

I want to take this opportunity to wish all of you a Happy New Year and to thank you for the warm welcome I've received here at the Foundation. As we approach 2008, we have an exciting journey ahead of us, and I am very thrilled to be taking this journey with all of you.

As you can see, this edition of *Breakthrough* is dedicated to providing you with very important information about our upcoming 16th Biennial National Conference taking place in Crystal City, VA. I hope you are as excited as I am about being a part of this wonderful event. This will be my first conference experience and I am looking forward to the opportunity of sharing this special time with you.

My vision for making the OI Foundation an even stronger organization dedicated to finding better treatments and a cure for osteogenesis imperfecta will be shared with you in the months ahead. I am committed to making a difference in the lives of children and adults living with OI in all aspects of their lives.

I look forward to meeting the many volunteers and families who have dedicated themselves to supporting the mission of the OI Foundation.

Thank you and I look forward to seeing you all in Washington, DC for the 2008 Conference!

A handwritten signature in blue ink that reads "Tracy".

Tracy Smith Hart

Board of Directors Nominations Sought

The OI Foundation Board of Directors is seeking nominations for Board members for the 2008-2011 term. By joining the OI Foundation Board, you can expect to work hard, get results, and have a rewarding experience in return.

The Board Development Committee is seeking nominees with a personal connection to osteogenesis imperfecta and experience in one or more of the following areas: accounting, finance, fundraising, organizational management, public relations, strategic planning, business, or law.

If you or someone you know would like an opportunity to shape and support the OIF Foundation's direction, and can make a commitment to helping the OI Foundation raise the funds necessary to achieve its mission, we want to hear from you! Please review the Board member job description and complete the nomination form on the Foundations' website at www.oif.org. Click on "Board of Directors" under "About the Foundation." **Nominations must be received by March 15, 2008.**



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The Osteogenesis Imperfecta Foundation, Inc., is a 501(c)3 non-profit organization, and is in full compliance with the National Health Council's Standards of Excellence.

PRESIDENT'S MESSAGE

Dear Friends,

It seems like just yesterday that many of us were in Omaha, Nebraska enjoying the 15th Biennial National Conference on OI. We had a record number of registrants and first time attendees coming together for three days of learning, caring and sharing. A great time was shared by all who attended.

This year the OI Foundation will host its 16th Biennial National Conference in Crystal City, VA, minutes away from the heart of our Nation's Capital, Washington, DC. The conference will open on Friday, August 1st, and close on Sunday evening, August 3rd. There will be peer to peer sessions that will allow attendees to focus on a specific subject area, medical sessions which will highlight new cutting edge possibilities, medical consultations and much more.

Inside this edition of *Breakthrough* we have provided registration materials, travel tips on visiting Washington, DC, as well as conference scholarship information; essentially everything you will need for this year's conference.

I am excited about having the opportunity to set another record for registrants and first time attendees. So if you have never attended an OI Conference before, I encourage you to attend, it's an experience you won't forget, and if you have participated in an OI Conference before, we look forward to seeing you again!

I wish each of you a Happy New Year and I look forward to seeing you at Conference!

With Best Wishes,

Ken Finkel



It's Bone China Tea Time! Be a Part of our Annual Fundraiser

There is no event to plan! As a tea party 'host,' you simply send printed or e-mail invitations to friends and loved ones. These invitations ask them to have a cup of tea and then make a gift to support the work of the OI Foundation. Set a date for your 'event' that's special to you!

In 2007, 49 volunteers sent out invitations and raised more than \$42,000. Imagine what would happen if 100 hosts stepped forward. Or 200! **We need you!**

To be a host, contact Bone China Tea chairperson Andrea Wisniewski at andreawisniewski@hotmail.com or (330) 721-7637.



BREAKTHROUGH

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

Contributing Writers: Ken Finkel, Mary Beth Huber, Rosemarie Kasper, Marie Maffey, Ilene McBride, John O'Brien, Jody Rosen, Tracy Smith Hart, Sandy Strubhart, and Stuart Tart.

BREAKTHROUGH is published quarterly by the nonprofit Osteogenesis Imperfecta (OI) Foundation, Inc. Opinions expressed are those of the authors and do not necessarily reflect the official position or policies of the Osteogenesis Imperfecta Foundation, Inc.

Because each person's body and response to treatment is different, no individual should self-diagnose or embark upon any course of medical treatment or physical activity program without first consulting with their physician or a qualified medical professional familiar with their medical history.

THE OSTEOGENESIS IMPERFECTA FOUNDATION, INC. (OI Foundation) is the only voluntary national health organization dedicated to helping people cope with the problems associated with osteogenesis imperfecta. Founded in 1970 by Gemma Geisman, the Foundation's mission is to improve the quality of life for people with OI through research to find treatments and a cure, education, awareness, and mutual support.

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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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Financial information and charitable disclosures can be found at www.oif.org/aboutOIF or by calling or writing the Foundation offices.



Preventing and Treating Compression Fractures of the Spine



Introduction

For children and adults with OI the spine is particularly vulnerable to injury. Some activities such as contact sports obviously increase the risk of fracture. Other activities that may not seem to be dangerous may pose a "hidden" threat. The most common injury is a vertebral compression fracture.

What is a vertebral compression fracture?

This occurs when an injury causes the spinal bone or vertebra to fracture and collapse or compress. This type of fracture can be painful when it happens, but can also cause ongoing back pain. It is caused by a severe jolt to the spine or because the spine is weakened by OI and/or osteoporosis. The basics about compression fractures are no different for people with OI than for other people except that they happen more often when OI is involved.

How can I protect my spine?

It helps to learn and practice good techniques for standing, sitting, lifting and even doing ordinary activities such as housework, or gardening. These techniques are the same as for adults who have osteoporosis. It is also important to avoid activities that are likely to cause injury.

What kinds of activities should be avoided?

Avoid anything that jars, twists or puts pressure on the spine. This includes (but is not limited to) heavy lifting, jumping, diving, riding horses, all-terrain vehicles, or motorcycles and most amusement part rides. People with weak spines should also avoid sliding down a slide, jumping from a swing and sledding.

What can schoolchildren do to keep their spines healthy?

It is important to wear seatbelts in cars and avoid sitting at the back of the school bus where the ride is the most bouncy. When possible, keep a second set of textbooks at home to avoid carrying heavy book bags back and forth to school.

What can adults do to protect their backs?

Adults should avoid lifting heavy objects and sudden twisting motions. They should be sure that office chairs and/or wheelchairs are comfortable, and offer good back support. Their feet need to be supported and should not dangle.

What else can be done to protect the spine?

Exercise is important for children and adults. Swimming is an excellent activity that provides joint motion without stress and is good for the heart and lungs and muscles in the back. Walking is also beneficial for many people. Talk to your doctor and physical therapist about what other recreational activities would suit your interests and abilities.

Any other hints?

Anyone who sits a lot either in a desk chair or in a wheelchair needs to change position often. It helps to get out of the chair and either lie down or stand for a portion of the day.

What are the symptoms of a vertebral compression fracture?

- Sudden, severe back pain
- The pain gets worse when you stand up or walk, or bend over
- Chronic back pain that doesn't seem to get better
- Loss of height
- Worsening of pre-existing spine curves
- Other signs can include hip pain, and breathing problems

How is this kind of fracture treated?

It can take two or three months for this type of fracture to heal. The goal of treatment is to encourage healing, keep the spine stable, restore function and reduce or eliminate pain. Doctors familiar with OI recommend starting with:

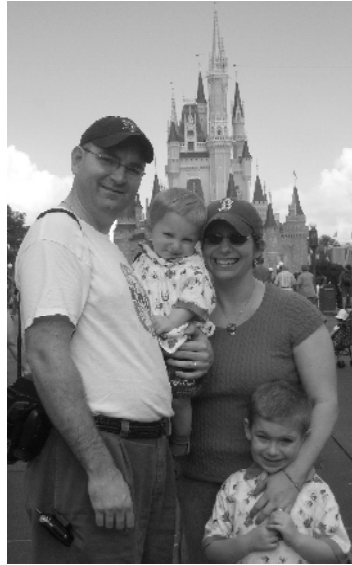
- Limited bed rest
- Pain medicines - often a mix of over the counter and prescription drugs
- Activity modifications: no lifting, bending, or twisting
- Gradual return to activities

When healing is delayed or pain is difficult to manage a soft or rigid brace or back support may be prescribed. These must be carefully fitted and monitored to avoid putting pressure on the ribs that can cause new fractures. Whether a surgical procedure is an appropriate treatment for those with slow healing compression fractures can only be decided on a case-by-case basis.

Information provided by Michael Whyte, M.D., Director of the Center for Metabolic Bone Disease, Shriners Hospital for Children, St. Louis and member of the OI Foundation's Medical Advisory Council.

Fundraising in My Community

By *Ilene M. McBride*



Tom and Ilene McBride, III, with their sons, **Ethan and T.J.,** at Disneyworld in December.

My three year old son, Ethan, has a moderate form of OI. He is currently learning to walk and that is thrilling to me. Even more thrilling is the hope of a cure someday. I am extremely committed in my quest to raise money for the OI Foundation. I am very impressed with the support that the OI Foundation provides to OI families, and I am always happy to read about the research that this organization is actively conducting to find a cure for this disorder. In 2007, I participated in two shopping fundraisers, "The Festival of Giving" and "Macy's Shop for a Cause," which raised just over \$1,000 for the OI Foundation.

My local mall in Massachusetts hosts "The Festival of Giving," which is a holiday shopping night held every November to benefit charities. For the past two years, I submitted paperwork as a volunteer for the OI Foundation and then sold tickets to this private night of shopping. The tickets that I sold to the event cost \$5.00 per ticket, and all of the proceeds were able to be forwarded directly to the OI Foundation. Everyone who bought tickets for this shopping night liked

the chance to get a jump-start on their holiday shopping, while enjoying special discounts, entertainment and door prizes.

I also joined the national "Macy's Shop for a Cause" shopping event as a volunteer for the OI Foundation. This shopping day was held in October and provided a 15 percent discount to Macy's for all those who purchased a \$5.00 pass. Again, I was able to directly forward all of the proceeds to the OI Foundation. Since this was a national event, I also was able to enlist family members who live out of state to help me with sales since the discount passes were able to be used at any Macy's store. This fundraiser was very successful and I attribute that to my family, as the majority of the tickets were sold out of state.

*"I am extremely committed
in my quest to raise money
for the OI Foundation."*

If you are interested in participating in these types of fundraisers, you should contact your local mall to find out if a charity shopping event is held and how you can get involved by selling tickets for the OI Foundation. Typically, all you need to provide is your information and the non-profit identification number for the OI Foundation. Since the "Macy's Shop for a Cause" event is now a national and annual event, you can also contact your local Macy's store to sign up as a volunteer for the OI Foundation and sell tickets to this year's event.

Happy Shopping and Happy Fundraising!

Woman Runs Chicago Marathon for OI

Julia Sagraves used her participation in the Chicago Marathon on October 7 to support the OI Foundation, in honor of her parents, **Dr. & Mrs. James Kilman, Sr.**, and her sister **Jennifer Kilman**, who lives with OI.

Interestingly, she traveled to the United States from her home in Bramley, England to do it.

Julia reported that her Chicago Marathon run was successful, "despite the record heat". Altogether, she raised \$1,750 (in American dollars) for the OI Foundation.

These proceeds were credited to an upcoming motorcycle riding event, *Bikers for Bones* on June 14, being organized by Jennifer in the Columbus, OH area. For more information on *Bikers for Bones*, send an e-mail to contact@bikersforbones.org.



Jennifer Kilman (Front row, center) and a committee of volunteers will hold **Bikers For Bones: "Riding Without Breaks"** on June 14, in the Columbus, OH area. Pre-event donations benefit the OI Foundation, in honor of her parents, **Dr. & Mrs. James Kilman, Sr.** Event proceeds will be donated to two local hospitals -- Ohio State University Hospital and Columbus' Nationwide Children's Hospital -- for research and care for adults and children born with OI. For more information on this motorcycle ride, send an e-mail to contact@bikersforbones.org.

FUND RAISING

16th New Jersey Beefsteak Dinner Makes a Big Impact!

By Rosemarie Kasper, Event volunteer



Beverly Krudys presents a thank you certificate to friend and supporter, **Pat DeLuccia**, for helping secure item donations for the silent auction and Tricky Tray at the 16th Annual Beefsteak Dinner in Garfield, NJ, on October 13.

Like any 16th celebration, the New Jersey support group's annual Beefsteak Dinner held on October 13 at the Three Saints Russian Orthodox Cultural Center in Garfield, NJ, was indeed sweet.

The crowd of 317 guests delighted in the all-you-can-eat filet mignon, and they competed to win almost 250 quality prizes, including overloaded gift baskets

in the silent auction and tricky tray. Attendees agreed it was the best beefsteak dinner ever! Altogether, this year's event raised more than \$19,000 for the OI Foundation.

Chair **Jo Ann Berkenbush** and her efficient and loyal committee, headed by **Beverly Krudys**, sped through the preparations. Like a well-oiled machine, multiple car loads of prizes were carried in and set up, decorations completed, and we were "ready for business" earlier than ever!

Aren and **Philip Berkenbush**, Jo Ann's niece and nephew, called the numbers for the 169 tricky tray prizes. The winner of the 50/50 raffle went home with \$615!

Other members of the committee included **Pat DeLuccia**, **Ellen Haley**, **Rosemarie Kasper**, **Cathy** and **Tom McGarry**, **Bill Schmidt**, **Liz Schmidt**, **Gretchen** and **Peter Strauch**, and **Alisa** and **Craig Zickerman**. We greatly appreciate everyone's work!

The total amount raised through the 16 annual Beefsteak Dinners: \$188,707!

NJ Mom Tries Something New with 4th Event *Dinner dance raised more than \$25,000*

For three years, **Carol Goebel** held annual walk-n-wheel events in Cinnaminson, NJ, bringing together hundreds of people each year and raising more than \$120,000 for OI research.

This year, Carol tried something a little different with her *Making Strides for OI* event. Her 4th annual event, held on October 13, was a dinner dance at the Lenola Fire Hall in Mooretown, NJ.

"It was a wonderful evening. I could not have asked for anything to go any better!" Carol said. "We had lots of dancing, a chinese auction, a silent auction, door prizes, great food and drink."

"There was even a lot of fun rivalry going on at the Silent Auction," she added.

Approximately 175 people came out for the dinner dance, and altogether, it raised more than \$25,000. In fact, several friends and neighbors who were unable to attend still made a donation afterwards.

Carol said she is grateful to the volunteers who helped make the 4th Annual *Making Strides for OI* event happen.

"You have to put time and effort into an event, and people that come need to see that you care about the event. A lot of dedication to the cause."

"There are people who have put 100% into the event each year no matter what is needed from getting items and sponsors to just helping me emotionally get through this event this most precious to my family - **Michael (Goebel)** my husband, of course, **Chris Hanus, Lesley Rusca**, and my group of friends who continually lent their hands in any way possible," Carol said. "I also want to thank **Chris** and Goebel Insurance, **Joe** from Roger Wilco, **Mike** from Georgetti's, **Bob** from Canal's of Delran, and **Maurice** of D'Angelos. In addition, the continued support both financially and attendance wise of Michael's co-workers at Solvay Pharmaceuticals is very much appreciated. Without each of them, the event would not be the success it is each year, and I thank them all from the bottom of my heart."

Third Annual *Jog for Jenna* Sees Strong Results from Online Fundraising

Despite a busy senior year, teen **Michelle Curran** worked with family members to hold her 3rd annual walk-n-wheel event, *Jog for Jenna* in Glen Mills, PA, on October 21.

There were a variety of activities for participants. In addition to the walk-n-wheel, *Jog for Jenna* included face painting for the kids, basket raffles for adults and fun games for everyone. Participants also paid to guess how much a pumpkin weighed, with the best guess winning a prize!

This year proved to be Michelle's most successful one ever. Thanks to several new strategies, she raised almost \$5,500 for OI!

Prior to *Jog for Jenna*, two teams chose to raise some of their pledges online. Together, they brought in \$1,180 of the event's total.

In addition, Michelle recruited the SADD (Students Against Destructive Decisions) chapter at her high school to hold an additional fundraiser for the *Jog for Jenna*. On October 26, SADD held a coffee house in the school library, where students performed songs and/or read poems. This event raised more than \$117 from admissions and donations for the food provided.

Michelle held *Jog for Jenna* in honor of her cousin **Jenna Cummings**, "a very bright, friendly 8-year-old girl, who happens to have OI."

Southern California Golf and Tennis Event Has a Big Year!

After more than two decades, the Southern California Petroleum Industry (S.C.P.I.) Charity Association Golf and Tennis Tournament continues to flourish, thanks to the work of a dedicated group of volunteers from both the petroleum industry and the local OI community.

More than 245 golfers participated on November 2, 2007, and several additional guests attended the awards dinner, raffle and live auction in the evening. Altogether, approximately \$75,000 was raised for OI research, according to tournament treasurer **Frank Fossati**.

In 2006, the tournament temporarily moved to a smaller facility while the Pacific Palms Resort - Industry Hills Golf Courses were undergoing renovations. That year, the event saw a lower turnout and raised less money.

However, after returning the event to its regular site, "Financial results were almost \$20,000 better than 2006," Frank reported.

Tom Ritchie of Wayne Perry, Inc. served as General Chairman for 2007. Tom also was General Chair in 2006, and asked the S.C.P.I. Charity Association Board for a repeat term to "prove his metal" at Pacific Palms.

"He certainly did that, and we thank Tom for all his hard work, dedication, and superb job of soliciting sponsorships and donations. In fact, Tom won the committee prize for the most sponsor letters sent out," Frank said.

One of the highlights of the day occurred during the live auction. "Once again, 13-year-old **Nicole Hofhine**'s art work went for a tidy sum of money to our

"esteemed" collector, **Roan McRae** of TestAmerica, an environmental analytical laboratory.

"The live and silent auction was tremendous and very well organized," observed OI Foundation Director of Development **John O'Brien**, who joined with Board President **Ken Finkel** to represent the Foundation at the event. "The buyer of Nicole's work (Roan McRae) continued to outbid himself until he was comfortable with his donation. This is just one example of the fun and the dedication that this group continues to exemplify year after year."

During the evening, Ken gave a speech thanking everyone for their many years of service, and he presented a special Presidents Award to Chairman Tom Ritchie, in recognition of his great service to the OI community through this event.

Major "Platinum" level corporate sponsors in 2007 were: **Anthem Blue Cross** and **TestAmerica**.

The SCPICA would also like to extend special thanks to the firm of **C.E. Thomas Company** and owner and longtime committee member **Jerry Thomas**; and CET employee, **Pam Weiner Kleiderer**, for allowing the committee to incorporate credit card use into their payment system, and also for a lot of hard work on prize control and invitation printing.

In addition, Tom added his thanks to **Frank Fossati** for his tireless efforts and dedication to this event over many years.

Strubhart Family Garage Sale Raises More Than \$800

Sandy Strubhart of Aviston, IL wanted to do something to raise money for the OI Foundation. So she decided to have a garage sale with the proceeds from the sale going to the OI Foundation. Sandy wanted Jacob, who was diagnosed with OI shortly after having his first fracture at 9 months, and his younger brother Luke to help in some way. Sandy said "The boys willingly picked toys for the sale, commenting on how another boy would like to have these toys." They were more charitable than even she expected.

Jacob and **Luke** helped make cookies and set up a lemonade/cookie stand. They lucked out on the weather and had two beautiful days for their garage sale. There was a contribution jar along with educational materials and also an opportunity to participate in the OI Going Places Sweepstakes as well. Between the proceeds from the garage sale, lemonade/cookie stand and sweepstakes contributions the Strubhart family raised over \$800.00. "We are very appreciative of the time and effort Sandy, Jacob and Luke gave in order to support this organization," said John O'Brien, Director of Development. "We are very thankful".

Atlanta Family Wins Plasma TV During OI Foundation Sweepstakes!



Catherine Saadat from the auditing firm, **Thompson, Greenspon & Co.**, and Foundation staff person **Stuart Tart** record the name of the Grand Prize winner during the Sweepstakes drawings on December 18, while volunteer **Rosalva Rosas** looks on. Ms. Rosas selected the winning tickets randomly out of the large box at the right.

A family in Atlanta received an unexpected Christmas gift when they were notified that their ticket had been drawn to win a 42-inch plasma TV from the OI Foundation!

Becky Newkirk of Atlanta, GA, has a three-year-old nephew with OI and entered the Sweepstakes at the invitation of her sister, Elaine Mack. Their prize will come in handy! Mrs. Newkirk said the family has an old TV in their family room, which they hadn't planned to replace yet.

Other Sweepstakes winners were:

EARLY BIRD PRIZE - Roundtrip Travel for Two on American Airlines -- **Jeffrey & Nancy Miller**, Holden, MA

2nd PRIZE -- \$250 cash - **Amy Jackson**, Orlando, FL

3rd PRIZE -- \$100 cash - **Trinity Smith**, St. Thomas, PA

Altogether, an impressive 4,909 Sweepstakes tickets were returned this year, and the OI Foundation received more than \$21,000 in contributions. Our thanks to everyone who made a gift or participated during this campaign!

We also would like to thank **American Airlines** for contributing the Early Bird Prize. American has donated a prize to five of our seven annual Sweepstakes promotions. In addition, we appreciate the support of **Advanced AV**, who provided the Grand Prize at a discount and handled the shipping.

Support Your Local OI Event!

Spring OI Walk-n-Wheel Events Planned in 3 Communities

It is a small outdoor family fun day . . .

Imagine . . . Face painting and other activities are available for the kids, and raffles for the adults. As many as 200 people wear OI T-shirts while they walk or wheel around a track, and people with various forms of OI can be spotted at the event. A speaker at the event shares how OI affects lives and what progress has been made in OI research.

Making Strides for Better Bones, the OI national walk-n-wheel program, helps build awareness of osteogenesis imperfecta in communities across the country and it raises critical funds that enable the OI Foundation to provide information and support to people with OI and their families.

There are three *Making Strides* events scheduled during the first half of 2008, with more to come later in the year.

Please help by:

- Coming to the event in your area and bringing as many people as you can.
- Raising pledges.
- Reaching out to one of the volunteers below to help out with their event.
- Contacting Associate Director of Development Stuart Tart to put together a walk-n-wheel activity in your community at STart@oif.org or 1-800-981-2663.

Registration and donation information for the following events will be available in February and March at www.oif.org/oiwalk.

Sat., April 26 - Round Rock, TX

Making Strides for Better Bones - Central TX area

Register or donate at www.oif.org/oiwalk.

Contact: Debbie Wiederhold at DDWiederhold@netscape.net or (512) 791-2292.

Early May - Merrick, NY

Making Strides for Better Bones - Long Island area

Register or donate at www.oif.org/oiwalk.

Contact: Thalia Piacquadio at Salia26@aol.com or (516) 489-2689.

Early June - Framingham, MA

4th Annual Massachusetts Making Strides for OI Walk, Silent Auction, and Family Fun Day

Register or donate at www.oif.org/oiwalk.

Contact: Visit <http://www.walkforoi.org/>, or contact John & Christine Rossi at c.rossi@verizon.net or (508) 620-0991.

Info On Demand Available for You

The OI Foundation information and resource staff responds to more than 500 inquiries each month from the OI Community. Every question, whether it's received by mail, phone or email, gets an individual response with *medically verified information*. There is simply no better place to have your questions about OI answered.

Each quarter, we select one question relevant to the entire OI community and print a full response in *Breakthrough* as our Q&A.

Each month, we select either the most frequently asked question, or a question on a topic that is "timely" or "seasonal," and answer it in our monthly email newsletter. (Register online at www.oif.org to receive the email newsletter.)

No question is too large or too small... we're here to help you. Please call (800) 981-2663, write to bonelink@oif.org, or write to the address on page 4 if you have ANY questions about OI.

1st Annual Style-a-Thon for OI will be Saturday, February 23!

Owner **Jennifer Wenner** and her staff at Posh Salon in Brentwood, CA, want to give back.

Make an appointment to get your hair done at Posh Salon on Saturday, **February 23**, and all proceeds will be donated to the Osteogenesis Imperfecta Foundation! For just \$50, any guest will receive a hair cut, shampoo, blow dry and style.

Posh Salon also challenges other salons - both in northern California and nationwide -- to hold their own Style-a-Thon for OI on February 23.

Lesli Reano, a stylist at Posh Salon, has family members with OI. Her 11-year-old daughter has broken more than 25 large bones, and her 14-year-old son has broken over 20 bones - mostly arm bones. Lesli said she and her fellow stylists hope to inspire a nationwide network of events on the same day, so please ask your stylist if his or her shop will participate.

Afterwards, from 6 - 9 p.m. on February 23, there will be a *Thank You* party for all participating salons and their guests at Posh Salon. All proceeds from the event will be counted during the celebration!!

To make this event a huge success, the staff at Posh Salon also needs your help with donated items for raffle. They are looking for awesome gift baskets and raffle items so that they can raise lots of money!

They would like to receive/pick up all donated items for the Style-a-Thon by the end of January, so gift baskets can be displayed in participating salons throughout the month of February.

To make your hair styling appointment, phone Posh Salon at (925) 516-9996. Posh Salon is located at 8610 Brentwood, Blvd., Suite C, in Brentwood, CA.

To donate a raffle item or sign up your salon to hold its own style-a-thon, please contact Lesli Reano at (925) 457-1947 or Lesliereano@comcast.net.

DC wine tasting event will be March 8

At the end of winter, many of us are looking for a good excuse to get out of the house and spend a nice evening out.

If you live in the Washington, DC-area, you won't want to miss *Fine Wines, Strong Bones*. Good company and a variety of activities make this an entertaining evening, and proceeds support the Biennial National Conference on OI and the OI National Resource Center.

More than 200 people attend this annual gala, which features a variety of red and white wines from across the globe, good food, lively music, a little dancing, and exciting silent and live auctions. Fine Wines will again be held at The Galleria at Lafayette Centre, 1155 21st St. NW, in Washington DC.

Whether or not you plan to attend, you can place bids on vacations, sports packages, and other exciting items by participating in our online auction! Simply visit oif.cmarket.com between February 15 and March 4 to check out the items and get started.

Tickets prices begin at \$50 for full admission to *Fine Wines, Strong Bones*, including the wine tasting, menu samples from area restaurants, and access to the auctions. However, you must make your purchase by March 5 to lock in this price.

Special ticket packages are also available: The \$125 Vintage package comes with a quality bottle of wine to enjoy at home, while the \$250 Connoisseur package includes two bottles of wine and a special gift.

After March 5, all ticket prices increase by \$25, so place your order early!

To learn more or purchase your tickets, visit www.oif.org/FineWines. You may also phone 1-800-981-2663 to request an invitation or order tickets.

Record-breaking Volleyball Game

OI Research will Benefit from Texas Fraternity's Quest to Break a World Record

The men of **Gamma Sigma Phi (GSP) at Abilene Christian University** plan to play the world's longest continuous game of volleyball **beginning April 11 at 3 p.m.**

Further, they intend to use this world record hunt to raise contributions for OI research from corporate sponsors, an on-campus dining service, and a variety of fun activities during the 68-hour event!

According to GSP member Ben Reeves, each team will play four hours at a time, and games will be held continuously until 11 a.m. on Monday, April 14. Activities during the 68 hours of volleyball will include a dunking tank, three-legged races, video game tournaments and other challenges.

Gamma Sigma Phi chose the OI Foundation as the beneficiary of their event, in honor of **Matt Phillips**. Matt's parents, **Mark and Laura Phillips**, teach at Abilene Christian University.

In 2006, GSP members raised more than \$6,000 for OI research through a bike ride from Abilene, TX to Pepperdine, CA. Based on their past events, Gamma Sigma Phi hopes to raise more than \$35,000 for OI research from this event.

For more information about this volleyball challenge, contact GSP member **Blake Browder** at bkb03d@acu.edu or make your gift at www.oif.org/befit.

In 2006, GSP members raised more than \$6,000 for OI research through a bike ride from Abilene TX to Pepperdine, CA.

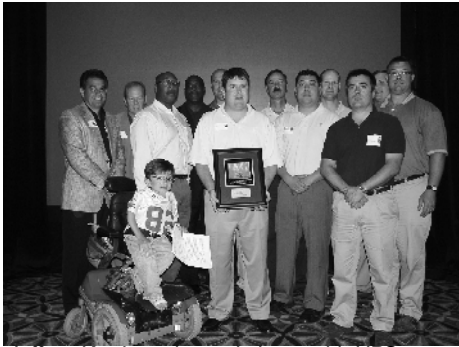
Twelve-year-old Boy with OI Rallies UPS Employees to Give

After **Jeffrey Krudys** was born in 1995, UPS employees responded.

More than 400 employees -- from union mechanics to package sorters to district managers -- opened their hearts and wallets in 1996 after they learned about his painful bones. And the commitment to contributing to the OI Foundation continues through transfers to new states and new jobs within UPS.

Now 12 years old, Jeffrey took a personal role in fund raising for the OI Foundation. In June 2007, he accompanied then Executive Director Heller An Shapiro and spoke to groups of UPS employees in the Kansas District about his life and how their gifts can help the Foundation. In addition, he shared his story in a brochure on the special relationship between UPS employees and the OI Foundation. This brochure was available to employees during the United Way campaigns in the Kansas District and several other UPS districts across the nation.

"When my parents needed help, they found it at the OI Foundation," he stated in the brochure. "When I was a baby, my parents had to learn how to dress me and move me without breaking my bones. And the Foundation is still helping us with answers to our questions, connections to other families, and research to find a cure for me."



Jeffrey Krudys, pictured above with UPS employees

UPS employees support the OI Foundation in many districts: Alabama, Florida, Kansas, Long Island, Metro DC, Metro Jersey, North Jersey, and others.

In fact, for 10 years, the North Jersey District has made annual contributions to the Foundation from its annual UPS United Way Golf Invitational. To date, these gifts have totaled more than \$168,000, just from this one event!

Since 1996, UPS employees nationwide have contributed more than \$1.1 million to improve the lives of people with OI.

NETWORK GROUPS

Local Network Groups offer a way to reach out to more families in more communities

Network Group Profile

We all know that life can be busy, hectic and that often there is just too little time to attend to all that we'd like. Still, members of the OI community continue to reach out to others, offering connections and support. Over a year ago, local network groups were added to the existing support group program as a way to reach out to more families in more communities.

True to the diverse nature of OI, the ways people have chosen to come together also differ, ranging from homey potlucks to dress up gala fundraisers. Support and network meetings have offered the opportunity for listening to presentations by OI doctors, genetic counselors, canine assistance representatives, hospital representatives and people in the OI community who are sharing their particular expertise.

Why get together?

Most importantly, these get-togethers provide the opportunity to share the invaluable knowledge and experience that comes from living with OI. As one Mom said, "We have a nice little group of five families and we get together every few months. The moms keep in touch via email, lunches together on some Thursdays, and phone calls. This has been an absolute blessing in all ways."

More than one group invited a representative from a local canine assistance program to share information about assistance dogs, how to interact with an assistance dog and their companion and how the puppies are selected. Presentations included a graduate and her service dog as well as a trainer and puppy. There was a real benefit to seeing the possible uses of these dogs.

What's going on?

One speaker, having OI, as well as a background in personal fitness, shared important information about maintaining good health. Topics covered included preparing for medical care in the adult years, steps to take to be more healthy and fit, as well as prepared for injury and illness, and being the best advocate for one's own personal treatment.

Members of another group were asked to come prepared to share thoughts and ideas about modifications and adaptations to home, vehicles or traveling that have helped make life easier with OI. Other gatherings included potlucks, barbecues, or meetings in restaurants where members socialized and discussed future fund-raising goals and events.

Getting bigger and better!

This was a banner year for one long standing group, hosting its first annual fundraising dinner. The first Unbreakable Spirit Dinner in Detroit, MI included live entertainment, music, a silent auction and much more. What is a comic hynotherapist?

It is certainly a benefit to have a committed OI physician move to town as the network group in Massachusetts has found. Fostering connections in the medical community can be helpful in obtaining speakers and support for one's local OI community.

What's really important

Attendance at meetings ranges widely, but is not necessarily an indication of a successful event. Two people offering support to each other is time well spent. And, while it is great to invite nationally recognized organizations and speakers, and we are so grateful when they give their time, it isn't a prerequisite for a successful meeting. As one organizer put it, "I learned that the group just liked hanging out and chatting, which is just as important as having a guest speaker."

She went on to observe, "Perhaps the most meaningful thing we learned from this meeting was that you do not necessarily need a huge group to make it a success. We had a smaller group, but people who really are looking for help and input. Sitting in a circle with past participants and new, sharing information about adaptations, school registration and special needs problems etc. are what people are looking for. Having children with OI, their parents, "older OIers," people of all ages with OI, and parents of older "OIers" is an invaluable help to new members."

Don't forget!

One helpful tip is a phone tree or email RSVP to remind everyone that a meeting is just around the corner, as well as to get an idea of attendance numbers. And of course, it goes without saying that it never hurts to have food.

The Network program was initiated as a means of bringing the OI community together in whatever way is most useful and comfortable and which meets the needs of the local group. It isn't a one shoe fits all model. Whether listening to a speaker, digging into a potluck casserole, participating in a fundraiser or chatting with another Mom or Dad with an infant on the knee, the most important part is coming together.

Special Guests Visit NJ Support Group

By Rosemarie Kasper

Forty-three members of the NJ area OIF Support Group, including several first-time attendees, were thrilled to greet two special visitors at the November 3 gathering.

Tracy Hart, the new CEO of the OI Foundation, attended the meeting prior to even starting her new position. Graciously accepting flowers, she expressed her interest in hearing

Dr. Shapiro's presentation and meeting the members as she had heard so many wonderful things about our group.

Jay Shapiro, M.D., Director of the OI program at The Kennedy Krieger Institute in Baltimore and a member of the OI Foundation's Medical Advisory Council, focused on medical issues of adults with OI. These included progressive bone loss and scoliosis, as well as muscle weakness, pain, and frequently-noted vitamin D deficiency.

Dr. Shapiro further commented on bone density, pulmonary function, and bisphosphonates. For persons with restricted pulmonary function, sleep studies can be helpful. In the event of a developing pulmonary infection, antibiotics should be obtained promptly.

Since a number of people with OI seem to be overweight, Dr. Shapiro said the Kennedy Krieger Institute has begun

studying nutritional needs in OI, starting with children ages two to ten. The information on diet will then be related to the child's bone mass.

Although Dr. Shapiro's talk focused on adults, he also addressed a number

of issues concerning children based on questions from parents in the audience.

Dr. Shapiro concluded by urging members to pursue lobbying for research on patient care

issues as funding is simply not available for this. He also encouraged every child and adult who has OI to sign up for the OI Registry. The OI Registry collects information about people who have OI in a secure and confidential manner. This information will lead to a clearer understanding of what it is like to live with OI. The Registry is also a force for encouraging more and better research studies about OI. To join, visit www.osteogenesisimperfecta.org/oir/ or call 443-923-9180.

Rosemarie Kasper and Jo Ann Berkenbush volunteer as support group leaders for the NJ group.



Visiting Washington, DC

Now is the time to start planning your visit! The Washington, DC area is beautiful, historic, and very accessible for wheelchair users and limited walkers. Whether you want to visit the National Monument or the Spy Museum, Washington, DC offers exciting options for all types of visitors! The following web sites can help you get started:

- **www.visitwashington.org** The Washington DC Convention and Visitors Bureau site offers a TON of information on visiting the National Monuments, museums, local tours, shopping, and transportation options. This site offers a free visitors' guide that can be ordered or read online.
- **www.disabilityguide.org** DisabilityGuide.org is a popular site for information about the accessibility of tours, restaurants, bars and places popular with tourists. A handy "Access Guide" can be ordered for \$5.00.
- **www.tourmobile.com** Choose from an exciting list of accessible Washington, DC tours, including; Washington, DC at twilight and Arlington National Cemetery.
- **www.virginia.org** The state of Virginia tourist web site is full of interesting information.
- **www.smithsonian.org** The Smithsonian Institution includes 16 museums and the National Zoo.
- **www.nps.org** The National Park Service manages many of the historic sites and monuments in the area.
- **www.wmata.com** Public transportation is provided by the Washington Metropolitan Area Transit Authority (METRO). The web site contains information for visitors, information about accessibility features of the subway system, and a trip planner.

Scholarships for National Conference on OI

The OI Foundation has obtained funding, primarily through individual contributions for a limited number of scholarships to the 16th Biennial National Conference on OI. Application information is available on the conference page of the foundation web site www.oif.org or by calling (800)981-2663. Applications must be received by April 11, 2008. Awards will be announced by May 9, 2008.

All those wishing to attend conference but are unable to due to financial limitations are encourage to apply.

If you would like to help others attend conference, please make a donation to the scholarship fund by calling the OI Foundation or visiting the conference pages on www.oif.org.

Medical Consultations: Schedule a Conversation with an OI Specialist

On Thursday, July 31 the day before this year's conference officially opens, a limited number of individual appointments with OI specialists will be available. This extra feature offers conference attendees the opportunity to have a specific OI related question answered by a medical expert. This program is especially geared for those who do not have access to OI specialists at home. The consultations will be free of charge. Appointments are limited so each person will be able to reserve time with only one or two of the specialists.

A medical consultation day is different from visiting an OI Clinic. **No examinations will be performed.** This is a conversation. Your appointment is an opportunity to get a second opinion or get an answer for a particular question.

Each doctor who is volunteering their time as a consultant is an expert in his or her area and many are members of the OI Foundation's Medical Advisory Council (MAC). For more information about this conference feature, about each physician and what to bring with you to an appointment visit the OI Foundation web site Conference Pages.

Appointments will be scheduled on a first come basis beginning at 10 a.m. EST on Monday, March 31. To request an appointment

- Call the OI Foundation office at 301-947-0083 or 800-981-2663
- Print the Appointment Request form from the foundation web site and fax the complete document to 301-947-0456
- Copy the web site form into an e-mail and send to mhuber@oif.org

All appointments will be confirmed by April 11. We will fill as many requests as possible. If you have questions about this special program contact Mary Beth Huber at the OI Foundation office at telephone 800-981-2663 or by e-mail at mhuber@oif.org

CONFERENCE



Attendees at the 2006 National Conference in Omaha, NE.

Other Sources of Funding for Conference

In some cases money to help people attend conferences about rare health disorders, like OI, is available from state agencies, school systems or community organizations.

For information

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

16TH BIENNIAL NATIONAL CONFERENCE ON OI

AUGUST 1-3, 2008 • WASHINGTON, DC

SCHEDULE AT-A-GLANCE

Thursday, July 31

Medical Consultations

By appointment only

Registration

8am-7pm

Friday, August 1

Registration

8am-7pm

Childcare

8:30am-12pm; 1-5pm; & 7-9pm

Exhibit Hall

9am-5pm

Teen Center

9am-4pm & 7-9pm

Morning Sessions 9-11am:

Orientation

OI Basics for Parents

OI Basics for Adults

Opening Session

1:30-3:30pm

Welcome Reception

3:30-5pm

Peer-to-Peer Sharing

7:30-8:30pm

Adults Dinner Out

Kids Game Night

Saturday, August 2

Registration

8am-7pm

Exhibit Hall

8am-5pm

Childcare

8:30am-12pm; 1-5pm; & 7-9pm

Teen Center

9am-5pm & 7-9pm

Sessions

9am-12pm & 1:30-5pm

Peer-to-Peer Sharing

7:30-8:30pm

Talent Show

Adults Dance

Sunday, August 3

Teen Center

9am-5pm

Childcare

9:30am-5pm

Sessions

10am-12:30pm & 2-3pm

Closing Session

3:30-4:30pm

Awards Dinner & Dance

6:30-9pm

What's New?

2008 is going to be great! Cliche? Maybe. But true! Based on community feedback and our Conference Committees, some exciting changes have been made to the Conference program.

More social activities! This year's conference will feature new social activities as well as the return of some old favorites including; an Adults-only Dance, the ever-popular Talent Show, Kids Game Night, Adults Dinner Out, and activities for Teens.

Educational Sessions. We've found ways to cater to both returning conference attendees and first-time conference attendees! This year's program will offer sessions tailored not only to veteran or new attendees, but also tracks of sessions for parents, adults with OI, OI Types, and Teens.

Attendee Directory. Due to privacy concerns, the Attendee Directory will now be mailed or e-mailed to attendees AFTER the conference. There is an option on the registration form for you to choose if you would like to be listed in the Attendee Directory. Attendees who do not specify a preference will automatically be listed in the Attendee Directory.

New Conference Days. The conference will open on Friday and close on Sunday evening. This is a different arrangement than in recent years. Moving the conference forward one day, starting on a Friday instead of a Thursday, allowed the conference hotel to offer us room rates that were almost \$70 less per night than their standard group rate! This change does not increase the number of weekdays that attendees will be away from home.

Don't Miss!

Medical Consultations

The Medical Consultations offer an opportunity for Conference attendees to schedule individual consultations with an OI specialist. The Medical Consultations are open to children and adults who have OI and will be held on Thursday, July 31, 2008 from 8:45am-3:30pm. All consultations will take place in the Conference hotel.

Consultations are available with the following OI specialists:

Hearing	Dr. David Vernick, Harvard University
Genetics	Dr. Peter Byers, University of Washington
Adults	Dr. Jay Shapiro & Dr. Azar Khosravi, Kennedy Krieger Institute
Foot & Ankle	Dr. Lynn Gerber, George Mason University
Physical Therapy	Holly Cintas, PT, PhD, National Institutes of Health
Rehabilitation	Dr. Scott Paul, National Institutes of Health
Neurology	TBA
Women's Health	TBA
Orthopedics	TBA

Requests for appointments will be accepted beginning at 10am EST on Monday, March 31. Space is limited and appointments will be made on a first come, first serve basis. To request an appointment, please call the OI Foundation at 800-981-2663.

2008 NATIONAL CONFERENCE ON OI

Good to Know

Airports

Ronald Reagan Washington National Airport (DCA) is located 1-mile from the Conference hotel, the Crystal Gateway Marriott. The hotel offers a complimentary accessible shuttle to and from the airport. DC's accessible metro rail, Metro, also stops at Reagan National Airport and travels to the hotel. Please read the 'Local Transportation' section on this page for more information about Metro and other accessible transportation services. Other local airports include, Washington Dulles International Airport (IAD) and Baltimore-Washington International Airport (BWI), located 27 miles and 37 miles away, respectively, from the Crystal Gateway Marriott.

Local Transportation

Metro, DC's metro rail, is the most cost effective and efficient way of getting around the Washington DC area. Metro is considered one of the most accessible transit systems in the world. For more information about Metro, including maps and fares, please visit their website at www.wmata.com. Taxis are easy to come across in the DC area and are a good option for door-to-door service. Taxi companies that offer accessible vehicles include; Red Top Cab, phone (703)-522-3333 and Blue Top Cab, phone (703) 243-8294. A taxi ride from Reagan National Airport to the Crystal Gateway Marriott costs approximately \$7.

Local Weather

Late July and early August in Washington DC is hazy, hot and humid! Temperatures average in the mid- to high- 80's with moderate to high humidity. Luckily, all buildings in the area are air conditioned, including all of the popular museums and other indoor attractions. Morning and early evening are good times to visit outdoor monuments and memorials.

Childcare Services

Childcare services are provided by ACCENT on Children's Arrangements, Inc. and are included when you register your child for the conference. You must register and pay for a Child Registration with the OI Foundation and also register your child for daily childcare sessions with ACCENT using the enclosed forms. There is no additional fee for childcare services once you have paid for a Child Registration.

Teen Center

For teens with and without OI, ages 12-18, a special set of rooms has been set aside so they may meet and interact with other teenagers during the conference sessions. In addition, a program of group discussions, speaker presentations, and activities will be offered. The teen room is available for full child conference registrants, ages 12-18 years.

Helpful Travel Websites

www.tsa.gov The Transportation Security Administration. This website will provide you with a list of approved carry-ons and general travel safety tips. It also has an extensive section with tips and guidelines for travelers with disabilities and medical conditions; including traveling with oxygen and wheelchairs.

www.amtrak.com Information, fares, and tips for traveling by train.

www.access-able.com In business since 1995, this site has information to assist travelers with all types of disabilities including slow walking. It is known for its practical suggestions regarding transportation options and accommodations.

www.flying-with-disability.org This site provides a wide range of useful information to make travel more enjoyable. Topics are listed along the left side of the home page.

NOTE: Your airline website is also a good resource for tips on traveling with special equipment.

2008 NATIONAL CONFERENCE ON OI

REGISTRATION INFORMATION

REGISTRATION FEES

Adult Registration (\$150)

Early Bird Registration (\$130). You must register before May 16, 2008 to receive the Early Bird rate.

All Adult Registrations Include:

- All informational sessions
- All conference social activities
- All breakfasts and refreshment breaks
- Welcome Reception
- Awards Dinner and Dance
- Annual OI Foundation Membership Meeting

Child Registration (\$115)

Early Bird Registration (\$95). You must register before May 16, 2008 to receive the Early Bird rate.

All Child Registrations Include:

- Childcare services, ages 12 months to 12 years. Children must also be registered for daily sessions through ACCENT on Children's Arrangements, Inc., using the enclosed forms.
- Teen Center, for ages 12-18 years old.
- All breakfasts, receptions, and refreshment breaks
- Awards Dinner and Dance

AWARDS DINNER AND DANCE

The Awards Dinner and Dance is included in all Adult and Child Registrations. Guests who are not registered for the conference may attend the Awards Dinner and Dance at a cost of \$40 per person.

METHOD OF PAYMENT

The OI Foundation will accept U.S. funds in the form of personal check, money order, Visa, MasterCard, Discover or American Express. Payment must accompany registration.

CANCELLATION POLICY

Conference fees will be refunded in full if written notice is received via fax or mail by **July 7, 2008**. No refunds will be provided after **July 8, 2008**.

CONFERENCE HOTEL

Crystal Gateway Marriott
1700 Jefferson Davis Highway
Arlington, VA 22202

www.crystalgatewaymarriott.com

Reservations can be made anytime by calling 1-800-228-9290 or online at www.oif.org/conference. **Guests must mention that they are part of the 'Osteogenesis Imperfecta Foundation' group in order to receive the discounted room rate.** Room rates are \$129 for singles or doubles, with a \$10 extra person charge for rooms with more than 4 guests.

You must make your room reservation by Thursday, July 10, 2008 to receive this discounted rate. There are 18 fully ADA-accessible rooms available for OI Foundation guests. Hand-showers, bathstools, and cots are available on a first come, first serve basis. Arrangements for these items must be made directly with the Crystal Gateway Marriott by calling (703) 920-3230.

The Crystal Gateway Marriott offers a complimentary accessible shuttle to and from Ronald Reagan Washington National Airport (DCA). A list of other local airports and transportation options can be found in this packet or online at www.oif.org. Parking is available at the hotel for \$8 per day. Valet parking is available 24-hours for \$14 per day. Internet access for individual guest rooms can be purchased for \$9.95 per day.

2008 NATIONAL CONFERENCE ON OI

REGISTRATION FORM

PLEASE RETURN TO:
OI Foundation
804 W. Diamond Ave., Ste. 210
Gaithersburg, MD 20878
Fax: 301-947-0456

BILLING/CONTACT INFORMATION

PLEASE PRINT CLEARLY

Name _____ Day phone () _____
Street Address _____ Evening phone () _____
City, ST, Zip _____ Country _____
E-mail _____ Fax () _____

Would you like your registration confirmation sent to you by e-mail? Yes No, please mail it

PAYMENT INFORMATION

Enclosed is my check or money order made payable to the OI Foundation.

Please charge my credit card in full Visa MasterCard Discover American Express

Card Number _____ Exp. Date _____

Name as it appears on card _____

Signature _____

PLEASE READ & SIGN! On behalf of myself and any persons listed on this Registration Form, I release the Osteogenesis Imperfecta Foundation, Inc., its employees, officers and agents (collectively "OI Foundation") from any liability whatsoever arising from any conduct, including any alleged negligence by act of omission of the OI Foundation in connection with attendance at the 2008 National Conference on OI. I understand that group photos of conference attendees are the property of the OI Foundation to use in its materials.

Signature _____ Date _____

IMPORTANT REMINDERS

- **NEW THIS YEAR!** For privacy reasons, the Attendee Directory will be sent out to attendees after the Conference. There is a section on the registration form that allows you to chose to be listed. Any attendee who does not specify a preference will be automatically listed.
- This registration form may be used to register up to 4 people. To register additional people, please photocopy the second page of this form.
- In order to take advantage of the childcare services, you must register your child for the conference with the OI Foundation AND complete the enclosed childcare services enrollment forms. The enrollment forms must be sent to ACCENT on Children's Arrangements, Inc. at the address listed on the forms.
- Name badges will be issued to all full conference registrants. You must wear your name badge to enter all sessions, receptions, social events and meals.

Please list each person separately, including children, who will be attending the Conference.

TYPE OF REGISTRATION: Child registration (\$115) Adult registration (\$150) Awards Dinner ONLY (\$40)
 Child Early Bird (\$95) Adult Early Bird (\$130)

Name _____
(as you would like it to appear on your badge)

Address _____
(for listing in the attendee directory)

City, ST ZIP _____

Relationship to OI:

- Self Child
- Parent Sibling
- Grandparent
- Other

Mobility Needs:

- I use a motor-powered wheelchair
- I use a self-propelled wheelchair
- I use a walker or crutches
- Other _____

Please select a menu option for the Awards Dinner: Chicken Vegetarian (pasta) Kosher

List this person in the attendee directory? Yes No **SUBTOTAL FOR ATTENDEE:** \$ _____

TYPE OF REGISTRATION: Child registration (\$115) Adult registration (\$150) Awards Dinner ONLY (\$40)
 Child Early Bird (\$95) Adult Early Bird (\$130)

Name _____
(as you would like it to appear on your badge)

Address _____
(for listing in the attendee directory)

City, ST ZIP _____

Relationship to OI:

- Self Child
- Parent Sibling
- Grandparent
- Other

Mobility Needs:

- I use a motor-powered wheelchair
- I use a self-propelled wheelchair
- I use a walker or crutches
- Other _____

Please select a menu option for the Awards Dinner: Chicken Vegetarian (pasta) Kosher

List this person in the attendee directory? Yes No **SUBTOTAL FOR ATTENDEE:** \$ _____

TYPE OF REGISTRATION: Child registration (\$115) Adult registration (\$150) Awards Dinner ONLY (\$40)
 Child Early Bird (\$95) Adult Early Bird (\$130)

Name _____
(as you would like it to appear on your badge)

Address _____
(for listing in the attendee directory)

City, ST ZIP _____

Relationship to OI:

- Self Child
- Parent Sibling
- Grandparent
- Other

Mobility Needs:

- I use a motor-powered wheelchair
- I use a self-propelled wheelchair
- I use a walker or crutches
- Other _____

Please select a menu option for the Awards Dinner: Chicken Vegetarian (pasta) Kosher

List this person in the attendee directory? Yes No **SUBTOTAL FOR ATTENDEE:** \$ _____

REGISTRATION FORM (CONT'D)

PLEASE PRINT CLEARLY

TYPE OF REGISTRATION: Child registration (\$115) Adult registration (\$150) Awards Dinner ONLY (\$40)
 Child Early Bird (\$95) Adult Early Bird (\$130)

Name _____
 (as you would like it to appear on your badge)

Address _____
 (for listing in the attendee directory)

City, ST ZIP _____

Relationship to OI:

- Self Child
- Parent Sibling
- Grandparent
- Other

Mobility Needs:

- I use a motor-powered wheelchair
- I use a self-propelled wheelchair
- I use a walker or crutches
- Other _____

Please select a menu option for the Awards Dinner: Chicken Vegetarian (pasta) Kosher

List this person in the attendee directory? Yes No

SUBTOTAL FOR ATTENDEE: \$ _____

TOTAL PAYMENT AMOUNT

REGISTRATION SUBTOTAL: All conference registrations plus any Awards Dinner and Dance ONLY NOTE: If you are registering before May 16, 2008, be sure to use the Early Bird rates.	\$
GROUP DISCOUNT: Save 10% when purchasing 4 or more full registrations.	\$
TAX DEDUCTIBLE CONTRIBUTION: Please add my tax-deductible contribution to offset rising costs in hosting the National Conference on OI.	\$
TOTAL AMOUNT ENCLOSED:	\$

FOR QUESTIONS ABOUT YOUR REGISTRATION, CALL 800-981-2663.

2008 NATIONAL CONFERENCE ON OI



Camp OI
Crystal City, VA • August 1-3, 2008
Space is limited - Register NOW!
 www.accentoca.com



CAMP OI – Welcomes children ages 12 months – 12 years. Children participate in age-appropriate activities including arts and crafts projects, active games and much more in a safe, nurturing environment. Parents should plan to pick up their child for lunch. Parents can also send or bring snacks to the center.

REGISTRATION: To assure that your child has a place, please pre-register by July 18, 2008. Your child(ren) is not registered until conference registration is received. We will assume your child will attend during the hours registered. If your schedule changes, we need as much notice as possible. We will accommodate you as best we can, based on availability. This policy is to ensure proper staffing, which is in the best interest of your child(ren).

NOTE: For the safety and security of your child(ren), OI Foundation/ACCENT has the right to refuse care to any child based on space availability and appropriateness. OI Foundation/ACCENT also has the right to refuse care to any child unable to adapt to group situations as well as any child whose presence or behavior may disrupt the program or endanger the health or safety of other children. ACCENT staff do not administer medication and any child who is ill will not be admitted to the center.

****PLEASE PRINT****

Day/Time	Times	Check-in Time	Check-out Time	# of Children
Friday 8/1/08	8:30AM-5:00PM			
	Lunch (12:00PM-1:00PM)			
	7:00PM-9:00PM			
Saturday 8/2/08	8:30AM-5:00PM			
	Lunch (12:00PM-1:15PM)			
	7:00PM-9:00PM			
Sunday 8/3/08	9:30AM-12:30PM			
	Lunch (12:30AM-1:40PM)			
	1:30PM-5:00PM			

Child's Name _____ Age _____ Sex _____ Birth Date _____

Child's Name _____ Age _____ Sex _____ Birth Date _____

Child's Name _____ Age _____ Sex _____ Birth Date _____

Check here if your child has needs under the Americans with Disabilities Act. We will contact you.

Does your child have experience with group care? Frequently Seldom Never

I/we agree that a fax or photocopy of my/our signature(s) on this form shall be deemed original and shall not affect the validity of this form. The child(ren) named above will be released ONLY to the person(s) signing this application.

Parent/Guardian Full Name _____ Signature _____

Parent/Guardian Full Name _____ Signature _____

Address _____ City/State _____ Zip _____

Daytime Phone () _____ Fax () _____ E-mail _____

Please print and keep a copy for your records. DO NOT SEND THIS FORM TO THE OI FOUNDATION.

Send to: **Camp OI/ACCENT on Children's Arrangements, Inc., 615 Baronne St, Suite 303, New Orleans, LA, 70113**

Phone: (504) 524-0188

Fax: (504) 524-1229

E-mail: registration@accentoca.com



CAMP OI 2008 GENERAL RELEASE AND WAIVER



I/we, the undersigned parent(s)/guardian(s), in consideration of ACCENT on Children's Arrangements, Inc. ("ACCENT") providing the children's activity programs for our child (ren)/ward(s), at the Osteogenesis Imperfecta Foundation ("The Foundation") National Conference in Crystal City, Virginia, August 1-3, 2008 as designated below, do for myself/ourselves, my/our heirs, executors, administrators and assigns, hereby release and discharge ACCENT and the Foundation, its officers, directors, employees and agents, from any and all claims, demands, damages, actions, causes of action, or suits of any kind or nature whatsoever, which may arise from my/our child(ren)'s presence in the children's activity programs except for gross negligence or willful misconduct on the part of ACCENT's officers, directors, employees or agents.

Furthermore, I/we agree to indemnify and to hold ACCENT and the Foundation harmless against loss from any and all claims, demands, damages, actions, causes of action, or suits of any kind or nature whatsoever, that may hereafter be made or brought by my/our child (ren)/ward(s) or by anyone on his/her/their behalf and I/we waive any and all rights of exemption under any federal and/or state laws against such claims. I/We authorize the Foundation and ACCENT to use my child's name and video or photograph at any time and in any manner in connection with its advertising, publicity, and public relations program. The video/photo may only be used by the Foundation or ACCENT. No further claims will be made by me/us. ACCENT staff is present to assure the safety and well being of all program participants. All participants are expected to respect themselves, other people and their property. The Foundation and ACCENT are not responsible for acts caused by the willful misconduct of the youth. I/We hereby recognize and accept ACCENT's policies.

Form with three rows for child name and age. Each row has a line for (Child's Name) and a line for (Age).

Our child(ren) has/have the following allergies, language and/or special needs:

Horizontal line for listing allergies, language and/or special needs.

Since this is a group care center, does your child have experience with group care? Frequently _____ Seldom _____

PLEASE NOTE:

Children who have fever or any communicable disease will not be accepted in the Children's Activity programs. The Foundation/ACCENT has the right to refuse care to a child unable to adapt to group situations. The Foundation/ACCENT has the right to refuse care to any child based on space availability and appropriateness.

We have read the above and understand this release. Furthermore, in the event of an emergency, the Foundation/ACCENT has our permission to administer first aid or obtain emergency medical treatment in our child's best interest. We agree to pay all expenses incurred due to an emergency involving our child. I/We agree that a fax or photocopy of my/our signature(s) on this form shall be deemed original and shall not affect the validity of this form.

Two signature lines for Parent or Guardian.

Address, City, State, Zip lines.

Home Phone and Alternative Phone lines.

Conference Program Highlights

Every other year since the OI Foundation was started, the OI community has gathered for a National Conference on OI. The 2008 National Conference on OI will feature a blend of new and repeat sessions and events. There will be sessions on genetics, orthopedics, lung health, protecting hearing and exercising safely.

New sessions include:

- Three bonus sessions on Friday morning for first time or infrequent conference attendees: Orientation, OI Basics for Parents, OI Basics for Adults.
- Sessions on cochlear implants, joint replacement surgery, intimacy and sexuality, home adaptation for renters, Type V OI, Recessive OI, and Respiratory Rehabilitation.
- A presentation by Paul Hearne Award Winner, Brett Eisenberg on employment issues related to having OI.
- Interactive sessions that combine an informative presentation and group discussion on adaptive equipment and home modification.
- Discussion groups for adults and youth brothers and sisters of people who have OI.
- A wider range of peer sharing topics to include travel and coping with short stature.

Popular returning features include; the Medical Consultation Day, Ask the Doctor Sessions and morning exercise classes. The teen program returns with space to meet and sessions on; driving, living independently, fitness, dating, and sports and recreation. Teens will also have the chance to meet the Foundation's new CEO and discuss a Youth Leadership Program.

Time has been set aside for a Shabbat Dinner on Friday evening and a Christian prayer service on Sunday morning.

A menu of social activities for families and adults of all ages will provide more opportunities to get together, meet new friends, and have fun every evening.

The youth Talent Show returns! Watch for details about how to enter on the OI Foundation web site and in the May issue of *Breakthrough*.

As details are finalized, a complete list of topics, speakers and events will be posted on the conference pages of the foundation web site. Please check www.oif.org often.

Child Care at Conference: Benefits Everyone

Child care is available at conference for all children who are at least 1 year old and who are registered for the conference. The child care center is open mornings, afternoons and during evening sessions. Care is provided by a professional organization whose employees all receive extra training in OI. Parents who use the center have several opportunities to provide additional information about their child's needs. Parents are encouraged to take advantage of this service. It gives their children the opportunity to meet other kids who have OI, and enjoy age appropriate activities that are more interesting to a child than sitting in a meeting room. Knowing that their child is being well taken care of will also free parents to get the maximum benefit from the information sessions they attend.

Thank you to our sponsors for your continued support of the OI Foundation and the 2008 National Conference on OI.



The Alliance for Better Bone Health



Sponsorship opportunities are still available.

Please contact Stuart Tart, Associate Director of Development at 800-981-2663 or start@oif.org.

Upon learning of his selection, Brett was beyond excited. Although he didn't know Paul (Brett is 26 and Paul died in 1998 at the age of 48), he has many contacts who were good friends with him and has learned much about the man through them. "Knowing that Paul had OI and went to the same school I did and worked with similar organizations really made this even more personal for me. Having my name in the same sentence as someone like Paul Hearne who is legendary in the disability movement is amazing. Actually getting (the award) made me so proud and honored especially knowing how much support I had from people who were close to Paul."

Brett grew up in the Bronx. As an only child, his earliest memories are happy ones and he recalls a determination that painful injuries wouldn't change a happy disposition. He credits his parents with his strength and independent spirit. Watching his father overcome his own struggles was an example and model for dealing with adversity. "There could be no better role model than my father, although faced with his own struggles he has always overcome them and always put his family first." His mother was very determined that Brett develop into an independent person and he states that "by helping me become independent she gave me strength and determination needed to overcome any obstacle." Brett is most grateful to his parents for always being available when he needed them and despite their own differences (they separated when he was 10) they "really made sure that I was taken care of and worked together to get the job done."

At the age of five, Brett boarded the bus for the 45 minute ride to the school where he would remain through graduation from high school. It was here that he found lasting friendships, teachers who encouraged and believed in him, an internship that became a springboard for his present employment, and where he met his wife Christina, also a Viscardi student.

Brett attended college in New York and Florida, earning a BS in accounting, with a concentration in management. Currently, he is a Disability Coordinator at

American International Group (AIG) in Manhattan. He leads the organization's disability initiative programs and has created programs that serve both AIG and the disability community. "The most rewarding part of my job is when I am able to find employment for a person with a disability". When asked if and how OI



has affected his choice of career, Brett responded that "it has certainly had an impact as I would never had the opportunity to do what I do if it wasn't for having the experiences I have had because of my OI."

Beyond his work with AIG, Brett contributes his time to five Business Advisory Councils, including Abilities, Inc., Just One Break, Inc. (JOB), and Fedcap. Brett is also the founder of the OI Network group in New York City, and this year hosted a reception featuring a panel discussion with Dr. Jay Shapiro of the OI clinic at the Kennedy Krieger Institute in Baltimore, MD.

When asked to participate in this profile, Brett kindly responded to the following:

What techniques did you develop to cope with OI as a child, student and now? "In general I have never let OI stop me from achieving what I want to do in life. I firmly believe that life is all about living out your dreams and not letting anything come in your way. If I had to name a technique or characteristic that has gotten me through, I would say determination. I am so determined to reach my goals I never let bumps in the road get in the way."

What do you do so you can live independently? "To live independently I have learned to adapt and to be patient. Most importantly I have learned how to think outside the box and be creative in solving problems so that I can be more

independent. Something I have learned that is important is also not to be ashamed to ask for help when you really need it. The key however is to only ask when it is necessary."

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

"Don't ever let OI stand in your way of what you want to do. It is so important to believe in yourself and your abilities. Although we might get many setbacks in life they make you a stronger person. I am still a young guy and I have had over seventy broken bones and over a dozen surgeries and I would never change any of it. Everything that has happened to me has made me into who I am today. As long as you believe in yourself and your abilities you can overcome any obstacle in your way. I know that in bad times it is easy to get discouraged but if you stay focused on what you want in the end you will be able to overcome anything."

With an attitude like this, it is no surprise that Brett has been chosen for this prestigious award. While clearly successful in his professional life, Brett is most proud of the life that he and his wife Christina are creating for each other and for their future family. Though the award presentation at the March 2008 Leadership Gala in DC will surely be a high point, it probably won't eclipse Brett's wedding day as the happiest day of his life.

Selection Criteria for the Paul G. Hearne/AAPD Leadership Award

- Leadership achievements that show a positive impact on the broad community of people with disabilities or within their area of disability interest.
- Connections they have made between individuals with disabilities and others in their communities.
- A positive vision for the disability community and a continuing commitment to their leadership activities.
- The demonstrated ability to collaborate with other leaders, to follow when necessary, and to cultivate new leaders within their organizations and communities.
- Potential to contribute at a national level.

People in the News

(November 2007 - January 2008)

Clarksville, GA - **McKenzie Coan** has her sights set on Beijing. The 11-year-old swimmer is seconds away from qualifying in the breaststroke to go to the United States trials for the 2008 Paralympic Games.

South Bend, IN - 15-year-old freshman **Emily Voorde** organized a wheelchair basketball tournament which pitted teams of students against the River City Rollers a wheelchair team made up of people of all different ages and different abilities. The event raised over \$300 for the OI Foundation.

Auburn, NY - **Anthony Reuter** is playing Power Soccer and loving it. The 15-year-old recently traveled to Washington with his team for their first national tournament. For information about the sport go to www.powersoccerusa.net.

Madras, OR -It was celebrity time for 8 year-old **Isaiah Beeson** when he met movie star Jennifer Aniston who was filming an upcoming movie in his hometown.

Lawrenceville, PA - The family of 3-year-old **Jessie Hilson** benefited from the Goodfellows Toy Fund. Since 1947, readers of the Pittsburgh Post-Gazette have helped make the holidays brighter for children by donating to the Goodfellows Toy Fund.

Mudjimba, Australia - A local Lions Club has asked for donations to assist **Diane Wells** whose car broke down and so needs a replacement to maintain her independence and ability to work.

Singapore - A determined spirit was evident in the story about **Mohd Salleh Abu Bakar**, a 25-yearold project analyst whose sister reports, "He never gives up, the more situations try to stop him, the more hungry he gets."

Taipei, Taiwan - An official measurement by the Taiwan OI Foundation has pronounced 35-year-old **Cheng Chien-chih** the shortest taxi driver in Taiwan. The father of two, states, "Driving is something that makes me feel really happy." He goes on to say, "I think it is probably safer to ride in my taxi than the average taxi in Taipei because of my condition, I drive very carefully." Cheng donates 5% of his earnings to a local OI charity.

Coventry, UK - Her boyfriend's successful recovery from brain surgery was what 21-year-old **Anna Chandler** wanted for Christmas. Both in wheelchairs, Anna says, "We do everything to support each other. The best way to describe us is we are like two little pieces in a jigsaw puzzle. We both have missing pieces but together we make the whole picture."

London, UK - A celebrity tribute to Britain's bravest youngsters included 11-year-old **Jack Binstead** who competed in the Mini London Marathon.

Donegal, Ireland - The headline reads *Little Sarah forced to return to UK for "proper care,"* illustrating the dilemma her parents face in attempting to return to their home in Ireland and be with family when the only adequate care can be found at Sheffield Hospital in England.

IN HONOR OF:

(October 1 – December 31, 2007)

Dr. Richard Alexander

Mr. Albertus Flowers

Andy & Kim Atkinson

Jenna, Scott & Zachary Steckler

Don & Ruth Barringer

Gordon & Jane Douglass

Mr. Anthony Benish

John & Ellen Benish

Jessica Bernstein

Ms. Alice Gahn

Patricia Boyd

Mr. & Mrs. James Kendall

Jennifer Boyd Harter

Warren & Susan Kendall

Lisa Newmark & Rick Brenner

(Marriage)

Ms. Dorian Krausz

Allison Cannington

John & Diane Eckstein

Bennett Clayton DeBlieck

Bennett Clayton Foundation

Scott Clifford

Andrew & Susan Clifford

McKenzie Coan

Ms. Ruby W. Coan

Dom & Fran Confetti & Lee Ann

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Harry & Jackie Cramer

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Donald R. Dillon

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Margaret Dombro

Mr. & Mrs. James Kendall

Lee Ann Dozier

Anthony & Elizabeth Battaglia

Jim & Jane Early's Grandson

Mr. Dennis English

Glenda Easley

Duncan and Ada Sutherland, III

Jacob Everett

Pat & Eileen Ball

Amos & Doris Everett

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Arleen Feller

Neal, Phyllis & Josh Feller

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Rosemarie Kasper

Ms. Nancy Post

Mr. & Mrs. Arthur Tuttle

James & Kathee Kendall

Mrs. Patricia Boyd

Mrs. Peg Dombro

Brett & Colleen Kendall

Rick & Susie Kendall

Mrs. Patricia Boyd

Mr. & Mrs. James Kendall

William & Pat Waggoner Kendall

Mrs. Patricia Boyd

Mr. & Mrs. James Kendall

Warren & Susan Kendall

Jamie Kendall, Tim Dombro & Jorge

Bicycle Bridge Foundation

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Mrs. Kathee Kendall

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A. Wynn & Katherine Bailey

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Ms. Patricia Frees

Mrs. Julia Sagraves

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Mr. Stephen Simon

See Honorariums on page 21

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Ms. Virginia Zittel
- The Landrum-Johnston Family**
Tom, Pat, Rosemary & Patrick Lelich
- Corey Leaf**
Ms. Sylvia Leaf, Tyler & Mel
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Ms. Sylvia Leaf & Your Children
- Mark Leaf, Jenna, Tyler & the Dogs**
Sylvia & Corey Leaf
- Mr. & Mrs. Bruce Leaf, Kyle & Lewis**
Sylvia & Corey Leaf
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Sherwood & Britta Lennartson
- Heather Lindeburg**
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Jason Fond, M.D.
Michael & Nicole Marian

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(October 1 – December 31, 2007)

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Louise
Andrew & Susan Clifford
Miss Megan Blackwood
Mrs. Amy Menster
Michael Lee Cadenhean
Bonnie Landrum & Michael Johnston
Chaplain & Mrs. Roy Johnston
James Frank Cane
Steven & Cynthia Blind
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See Memorial Gifts on page 23

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Ms. Andrea VanDenBergh
Theresa Voorde
Jacqueline Badics
Ms. Elizabeth Peiffer
Josh West
Mrs. Lourdes Miller
Robert Woolard
Glen & Elke White

Joining a Network or Support Group

Many network and support groups are planning spring meetings. Check the Events Calendar at www.oif.org to find a meeting in your area, or contact the support or network group leader. For more information, contact Marie Maffey at mmaffey@oif.org.

Joining the OI Registry

Join the OI Registry by visiting www.osteogenesisimperfecta.org/oir or by visiting the Foundation's website at www.oif.org.

If you don't have Internet access, or have questions as you register, OI Registry staff based at the OI Clinic at the Kennedy-Krieger Institute are available to assist you at (443) 923-2703.

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Breakthrough is a free quarterly newsletter for members of the OI community: people with OI and their friends, family, coworkers, and medical service providers. Please contact us to subscribe (page 4).

For more information about the OI Foundation, please visit www.oif.org.



Osteogenesis Imperfecta Foundation
804 West Diamond Avenue, Suite 210
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