

## Record Attendance Numbers at the 2008 National Conference

The 2008 National Conference on OI was the largest in Foundation history with over 800 attendees. Conference attendees chose from over 35 informational sessions lead by top researchers and clinicians in the world. Some of the more popular session topics included Aging with OI, Ask the Doctor: Adults with Type III and IV OI, and Adaptive Equipment. Attendees were also able to schedule medical consultations the day before Conference. Over 85 appointments were made with specialists from across the country.

In addition to the abundance of informational sessions, the 2008 Conference boasted overwhelmingly popular social activities. The Talent Show drew rave reviews from a crowd of over 200! The Kids Game Night, Adults Dance, and Awards Dinner & Dance were other well-attended social events.

The OI Foundation's first ever Advocacy Day was launched at the Conference. Over 20 volunteers made more than 40 visits to their Senators and Members of Congress on Capitol Hill. Volunteers asked their legislators



**Mark Peck, Kristen Antolini and Elizabeth Peck pose for a picture while catching up at Conference.**

to sign a letter to the National Institutes of Health in support of a grant application that could provide \$1.2 million to the OI Linked Clinical Research Centers. Kyle Mulroy and Washington Strategic Consulting donated their time to make this venture possible. Kyle believes that "Advocacy Day was an important first step that will have long term benefits as OI Foundation continues to work with members of the OI community to influence Congress and enact policies that will strengthen awareness, services, and research for OI."



**Talent Show Director, Suzanne Richard, stands on stage with performers after the hit show.**

The success of the 2008 National Conference on OI re-affirmed the importance of the event. No other place can families and individuals with OI come together for support, education, and fun. Ten-time Conference attendee, Ann Marie Geiger says, "Nowhere else can I go and have a doctor answer a question from his personal experience and not from trying to remember the one case of OI he saw back in medical school 30 years ago. Nowhere else can I go and share my stories and my life and get understanding, not pity or abandonment. Nowhere else can I go and laugh at the ridiculous ways to break something!"

***"Advocacy Day was an important first step that will have long term benefits as the OI Foundation continues to work with members of the OI community to influence Congress and enact policies that will strengthen awareness, services, and research for OI."***

***—Kyle Mulroy, Washington Strategic Consulting***

As the Foundation wraps up another successful Conference year, the focus is already moving forward to the 2010 National Conference on OI in Portland, Oregon. Information about participating on Conference Committees will be released in Spring 2009.

See you in Portland!

### In this issue...

President's Message.....	2
From the CEO.....	2
Spotlight: Kyle Mulroy .....	3
2008 Sweepstakes .....	4
OI Legacy Circle Membership .....	4
Upcoming Fall Events.....	5
Recent Events .....	6
Clinic Directory (center insert)	
Q&A: Aging with OI.....	12
Honorariums/Memorials.....	14

**CLINIC DIRECTORY INSIDE!**

**OSTEOGENESIS  
IMPERFECTA**  
**OI**  
**FOUNDATION**

**BOARD OF DIRECTORS**

**PRESIDENT**

*Ken Finkel*

**FIRST VICE PRESIDENT**

*Jeffrey Stewart*

**SECOND VICE PRESIDENT**

*Christine Wyman Rossi*

**THIRD VICE PRESIDENT**

*Anthony A. Benish*

**TREASURER**

*Roger Bache*

**SECRETARY**

*Sharon Trahan*

**MEMBERS**

*Mark D. Birdwhistell*

*Jacqueline R.F. Bourgeois*

*Gil R. Cabacungan, III*

*Anna C. Curry*

*Greg Holman*

*Caren Loguercio, Esq.*

*Chery Sacchetti*

*Sandy Sandhaus, M.D., Ph.D.*

*James Sharples*

*Denise Tarantino*

**CHIEF EXECUTIVE OFFICER**

*Tracy Smith Hart*

**MEDICAL ADVISORY  
COUNCIL CHAIR**

*Richard J. Wenstrup, M.D.*



**From the Chief Executive Officer**

Dear Friends:

Thank you so much for making my first conference such a wonderful experience! I enjoyed making new friends and I'm already looking forward to Portland in 2010. A few of the highlights for me at this year's conference would have to be our Advocacy Day activities, unveiling our plans for a youth leadership program and the "back by popular demand" talent show. Thank you to everyone who participated in these events and all the other events that went on during the conference.

In addition to the activities that were going on at conference, I think what really impressed me was the camaraderie and compassion that was shown by everyone in attendance. You could tell that old friends had missed each other and the new friendships that were being formed will last a life time. I also was impressed to learn about all of the wonderful activities going on in communities all over the country – from walks to golf tournaments to support group meetings – all of it makes our organization stronger. Thank you.

In that spirit I would like to remind everyone that nominations for the 2008 Volunteer of the Year are due to the OI Foundation office by November 1, 2008 – we have extended the deadline to make sure everyone has the opportunity to apply if they'd like to. Applications are available on our website, [www.oif.org](http://www.oif.org). I look forward to hearing from many of you!

Again, thank you to everyone for a wonderful five days in Washington, D.C. I am so proud to be a part of the OIF team!



**From the President**

Dear Friends,

On August 1-3 the 16th Biennial National Conference on OI was held in Crystal City, VA. Over 800 people attended this record breaking conference, coming together as a community to learn, discuss, and share their life experiences with OI.

From the opening keynote address by Dr. Joan McGowan of NIH to the closing session with our own Suzanne Richard, this year's conference was jam-packed with over 60 sessions with topics relevant for infants to adults: there was something for everyone.

One of the highlights of conference was the talent show where over 20 people sang, danced, or played an instrument to a standing room only audience. Of course, there was our popular awards dinner and dance. During this time, the Foundation was able to recognize and acknowledge contributions made by some special individuals. Peter Strauch received the President's Award, Bonnie Landrum received the Thelma Clack Lifetime Volunteer Award, and Michelle Curran received the Pete Dohm Junior Volunteer Award. An Unbreakable Spirit Award was also presented to Carrie Graise-George mother of our friend and board member, the late Randy Graise.

But the most wonderful part of conference is the interaction between attendees. Listening to parents talking together about their experiences with their child and sharing ideas or giving each other encouragement and support, or hearing an adult mentoring a teen, or watching a medical professional stay in the hallway talking to a family and not leaving until they have spoken to everyone, that is what our community and conference is all about.

I hope you will join us in Portland, OR in 2010!

With Warm Regards,

Ken Finkel

# Spotlight: Kyle Mulroy

With our 2008 National Conference scheduled to be held in the outskirts of Washington D.C., it wasn't long before the idea of advocating on the hill began to take form. A wonderful opportunity presented itself to bring the united voice of the OI community to the corridors of power. Standing ready and willing to guide the Foundation through this process was Kyle Mulroy, a long time OI Foundation volunteer.

Kyle grew up in New Jersey, the youngest of three boys and the only one in his family with OI. His brothers, who are seven and eight years older, were a strong influence. It was his brother Gene who took Kyle to his first political event, sparking an excitement about politics and a determination to get involved in the process. It wasn't long before Kyle joined the Young Democrats, and in 1996 served as a New Jersey Delegate to the Democratic National Convention.

While in college at Rutgers University, Kyle interned in Washington, D.C. in the office of Congressman Torricelli. After Torricelli's successful bid for a Senate seat, and upon graduation, Kyle returned to D.C. to work in the new senator's office.

While working for the senator, Kyle developed an expertise in the area of health care policy. He helped coordinate legislative activities related to passage of the Health Insurance and Portability and Accountability Act of 1996. He also continued his studies at George Washington University, graduating with a Master's degree in Legislative Affairs.

Kyle's work in the Senate offered him the opportunity to work with health related associations and foundations on various federal legislative and budgetary issues. He also served as a liaison to the Senate Finance Committee working on Medicare and Medicaid policy.

When Kyle left the Senate, he joined his brother Gene in the lobbying firm of Holt, Ross and Mulroy, based in New Jersey. Kyle opened an office in Washington D.C. and began providing government relations counsel to a diverse group of clients and did extensive work with the federal appropriations process.

In 2006, Kyle teamed up with another former Capitol Hill staffer and founded Washington Strategic Consulting, a bipartisan public policy and advocacy consulting firm. His group specializes in the areas of education, health, and disability policy, developing individualized government relations strategies for their clients.

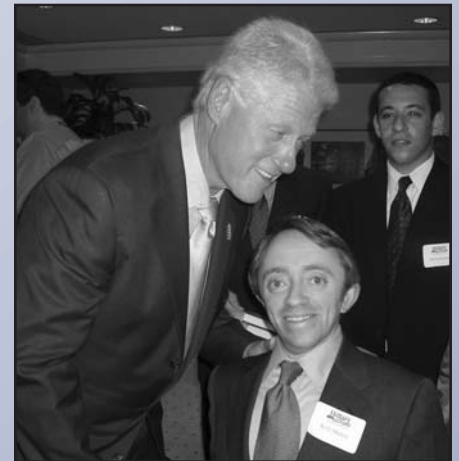
It is easy to see why Kyle was the man tapped to guide us through the process of advocating on Capitol Hill. The OI Foundation goal of receiving federal funding for our Linked Clinical Research Centers is supported by someone who not only knows the strategy, but by someone who has a personal interest in the outcome. That's a great match.

When asked what this opportunity meant to him, Kyle responded with the following:

"It was incredibly, personally fulfilling to use my experience on behalf of other organizations to help pull together an advocacy day for families affected by OI. People with OI make their own best advocates and the message they brought to Capitol Hill caught the attention of many Members of Congress. So long as we keep up the momentum and harness the progress we made on advocacy day, OIF will have an increasingly powerful voice in Washington and be in a strong position to get policies enacted that will benefit the entire OI community."

Having Type IV OI has clearly presented challenges, but doesn't appear to slow Kyle down. He is also Executive Director of the New Jersey State Society, a non-partisan networking organization for Washington area individuals and organizations with ties to New Jersey. He just returned from Denver where he attended another Democratic National Convention and it can be presumed that his calendar will be full into November.

Asked how OI has affected his college experiences and choice of career, Kyle responded that it is "certainly harder for a person to go to college and deal with accessibility issues". He went to a large, old and not very accessible university, but overall reports a positive experience. His affinity for the DC area is partly due to its accessibility, and believes an important component for living independently is to



*Kyle Mulroy with President Bill Clinton*

"find places that are accessible and make each situation work."

Self reliance and independence have always been priorities for Kyle. He worked throughout college in a number of jobs and believes that getting a job and making money to be able to live on his own are what allows him to live independently.

His advice to others with OI is to remain positive. Perseverance is important. When faced with difficult situations, "You either learn how to grow or get stuck." While he believes that it is a bit clichéd, Kyle offers, "You really can do anything you put your mind to. OI can in some ways be a blessing. It comes with its special set of challenges, but oftentimes people with OI have a unique ability to overcome them." It can probably be said that Kyle's parents were instrumental in forming such an attitude. Kyle notes, "Both of my parents were incredibly caring and tenacious when it came to making sure I had the absolute best care. Taking care of me in my younger years was a full time job and they both were incredibly committed."

Away from lobbying and politics, Kyle spends free time with his "wonderful wife Tracy," who also has OI, and 6 year old son Reece. The Mulroys adopted Reece, who has Type I OI, from Bulgaria when he was 3 years old. With the start of football season, it's a good bet that father and son will be cheering on their beloved Redskins.



# The 'Going Places' Sweepstakes Begins in October

## Grand Prize will be a 3 or 4-day Cruise for Two!



The 8th annual "Going Places" Sweepstakes will feature exciting, new prizes this year, including a 3 or 4-day cruise for two, of your choice, valued up to \$1,200!

The cruise, which will serve as this year's Grand Prize, will be arranged by OI community members **Karen and Glen Vowell** of **CRUISESNOYOU.COM**. In addition, the Foundation will offer a \$200 gas card as this year's Early Bird prize. Other prizes were still being finalized at press time.

Watch your mailboxes in late October for your Sweepstakes package. The Early Bird prize drawing will be held before Christmas, while the Grand Prize winner will be selected at the end of January 2009.

Packets of 20 Sweepstakes tickets will be mailed out in late October. Pass out tickets to family, friends, and co-workers, and encourage them to make a gift to the OI Foundation! The suggested donation is \$5 per ticket or \$40 for 10 tickets. When you mail back your ticket stubs with the names and addresses filled out, then you and your friends are entered in the Sweepstakes!

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

Contributions made through the Sweepstakes provide vital funds that enable the Foundation respond to more than 6,000 inquiries each year, produce new information resources, fund research, and facilitate the operation of support groups across the country.

If you do not receive your Sweepstakes packet in late October, or would like to obtain more tickets, e-mail the Foundation at [Development@oif.org](mailto:Development@oif.org).

## Support Groups Forming

### Louisiana

Contact: Samuel Lewis  
337-328-2241 or [ssl\\_1965@yahoo.com](mailto:ssl_1965@yahoo.com)

### Southern Virginia/North Carolina

Contact: Sheri Moore  
252-771-2356 or [moorebscjc@aol.com](mailto:moorebscjc@aol.com)

### Tennessee

Contact: John & Kim Quigley  
865-274-7662 or [quigster@gmail.com](mailto:quigster@gmail.com)

## OI Legacy Circle Membership on the Rise

The OI Foundation's Legacy Circle represents past board members, leadership level donors to the Foundation and anyone who has made the OI Foundation part of their planned giving. "This gives us the opportunity to recognize those individuals who have made such a commitment to the Foundation," said John O'Brien, Director of Development.

Planned giving seems to represent a significant number of individuals included in the Legacy Circle. Planned giving is a set of ways a donor can leave money/assets to a nonprofit at his/her death; or a way to invest money so that the donor receives benefits during his/her life and then bequeaths the remaining funds to a nonprofit. By establishing a planned gift with the OI Foundation, you become a part of the Legacy Circle. Each year, Legacy Circle members convene for a special dinner with guest speaker. Please let us know if you have left a planned gift to the Osteogenesis Imperfecta Foundation. We would like to celebrate that with you today.

# Upcoming OI Fall Events

These events are a great way to meet other OI families living in your area! Come out to enjoy the day and support the cause, or even volunteer to help.

## Garfield, NJ, Oct. 11

The *17th Annual Beefsteak Dinner* will be held at the Three Saints Cultural Center from 6 -11 p.m.

Come out for an all-you-can-eat dinner with filet mignon, french fries, salad, and chicken nuggets for the kids. There also will be hundreds of gift baskets and other items available in the Tricky Tray and silent auction, a 50/50 raffle, and a friendly, social atmosphere.

**Seating is limited, so advance registration is required.** For more information, contact Rosemarie Kasper or Jo Ann Berkenbush at [rkoif@verizon.net](mailto:rkoif@verizon.net), [jbcowoi@juno.com](mailto:jbcowoi@juno.com), or (201) 314-5289.

## Liberty, MO, Oct. 11

Positivity Gym will host the *1st Annual Liberty OI Walk/Run* to benefit the OI Foundation, also known as *Cameron & Julianne's Unbreakable Spirit Walk/Run*.

The event will include a silent auction and drawings, free breakfast, free T-shirts, and fun for all ages. Check-in will begin at 8 a.m. at Positivity Gym, with the walk/run beginning at 9 a.m.

Register by October 1 to be eligible for the free T-shirt. For a registration form or more information, e-mail [david@positivity-gym.com](mailto:david@positivity-gym.com).

## City of Industry, CA, Nov. 14

Volunteer for a half or full day during the *34th Annual SCPICA Golf & Tennis Tournament* at Pacific Palms Conference Resort, or attend the dinner at a discounted rate of \$25 per plate!

Please make your reservation by October 30. For more information, visit [www.scpicharity.org](http://www.scpicharity.org), or contact Heidi Glauser at [glauser@cox.net](mailto:glauser@cox.net) or (949) 248-7541.



## Our Sally Foster campaign is underway!

**Raise support for the OI Foundation by encouraging friends to buy wrapping paper, candy, & gift items for the holidays**

Are you looking for an easy way to support the OI Foundation?

As the holidays approach, we all need gift wrapping supplies and new gift ideas. Why not get a jump on the season and order what you need during the Foundation's annual Sally Foster campaign?

A variety of quality holiday and all-occasion gift wrap designs are available for as low as \$6 per roll. In addition, you and your loved ones will appreciate the selection of gift bags, kids' gifts and stationery, handy kitchen essentials, gourmet edibles, and gadgets and gifts for everyone! **Best of all, 50% of every purchase supports the OI Foundation!**

Simply contact the Foundation at [development@oif.org](mailto:development@oif.org) or 1-800-981-2663 to request your catalog. Then, encourage friends and family to browse the catalog or you can place an individual order for yourself.

If you prefer to shop online, go to [www.sallyfoster.com](http://www.sallyfoster.com). **Please be sure to credit the OI Foundation for your purchase.**

OI mom **Connie Kasputis** will chair our Sally Foster campaign again this year. To allow for delivery by Thanksgiving, your catalog orders are due no later than October 15, please.

# Recent Events

## OI walk-n-roll in TX benefits from mild weather & enthusiastic supporters

**Round Rock, TX** – Thanks to the work of OI mom **Debbie Wiederhold**, her daughter **Erin Weaver**, and the support of numerous local volunteers, the OI Foundation partnered with **Texas Parent to Parent** to hold the *1st Annual Central Texas Walk-n-Roll* on April 26.

About 60 participants walked or rolled in the first annual Texas event to support the work of both organizations. Each provide information, resources, and answers to parents whose children live with disabilities, including OI. Altogether, they raised more than \$7,100 for the work of Texas Parent to Parent and the OI Foundation.



**Event organizer Debbie Wiederhold and her son Daniel (front right corner) joined other families whose children have OI and other disabilities at the front of the group participating in the Central TX Walk-n-Roll on April 26. The event benefited the OI Foundation and Texas Parent to Parent.**

Debbie and her team also held a raffle to raise funds during the event. They provided bottled water, Gatorade, pizza, and even a cake for the supporters who raised pledges, walked or volunteered.

“The weather turned out incredibly beautiful,” Debbie reported, adding

that the temperatures stayed comfortable until shortly after 1 p.m., after the walk-n-roll portion of the event was completed.

Debbie’s co-workers at Texas Parent to Parent helped to bring supporters to the event, and they provided much of the volunteers support during the day. The event was inspired by Debbie’s and Don’s son, **Daniel Wiederhold**, and the many other young people with OI and other disabilities served by the two nonprofits.

Mark your calendars! The 2nd Annual Central Texas walk-n-Roll will be held on April 4, 2009.

## First-time Long Island event raises more than \$37,000

**Seaford, NY** – **Thalia Piacquadio, Nicole Knorr** and other local OI families enjoyed great success by teaming up to hold their 1st OI walk-n-wheel in the Long Island area on May 3.

More than 200 people participated, raising more than \$37,000 for OI! The event featured a deejay, a clown making animal balloons, raffles, and a walk around the track at Cedar Creek Park. In addition, the Town of Hempstead made Child Safety I.D. Kits for the children there.

“It was a great success and . . . I could not have done it without your help,” Thalia wrote to volunteers and participants after the event. “Now that some time has passed, I cannot imagine not doing it again.”

Thalia began work on this *Making Strides for Better Bones* early, participating in an OI Foundation phone training back in November and reserving her site in January. She then recruited neighbor **Susan Parrish** to help with organizational details and errands. To obtain sponsorships,



**Teresa and Paul Schieda pose with their daughter, 4-year-old Samantha, before walking for OI at Making Strides for Better Bones: Long Island on May 3. More than 200 people participated in the event.**

Thalia approached Gabriella’s medical providers and family, and she received some great in-kind items from fitness-oriented businesses.

Nicole, a school social worker, encouraged several school clubs to take on the walk as their community service project, and she persuaded the class of 2010 at one high school to hold a bottled water drive, collecting 600 donated bottles of water for the event.

“I was open about (son) Cooper’s story and asked for the support of my colleagues and students,” she explained. Nicole added that she raised a significant amount of pledges by sending an e-mail to friends, colleagues and family, and asking them to pass it along.

Thalia has tentatively set next year’s event for May 2, 2009.

## Variety of Activities Key To Success of MA Walk-n-Wheel

**Framingham, MA** – More than 250 people came out to walk or wheel for OI at Bowditch Field on June 7, raising more than \$46,000! Participants showed up throughout the



morning and early afternoon to turn in their pledges and take a few laps.

In addition, there were a variety of activities including a local police exhibition with trained dogs, a kids' game tent with basketball shooting and other activities, music, a large silent auction, and a basket raffle.

This is the fourth year that Board member and OI mom **Christine Wyman Rossi** has organized this event, with the help of her relatives in the **Potorski, Rossi, and Wyman** families and other great local volunteers.

"The volunteers were awesome!" said CEO **Tracy Smith Hart**, who represented the OI Foundation staff at the event. "They congratulated people as they came in and made a fuss over the pledges they raised."

The long-term commitment of participants to this event was also clear, Tracy noted.

"It was neat seeing people come in wearing their T-shirts from the year before," she added.

## Family Golf Tournament enjoys 4th Successful Year

**Wood Dale, IL** – More than 100 golfers braved the heat on July 10 at the Maple Meadows Golf Course in a tournament set up to support OI research, education, resources, and information for families.

Afterwards, they gathered for a buffet dinner at Riley's Gathering Place in Elmhurst, where participants also bid on auction items and purchased raffle tickets to win great prizes.

Altogether, the *4th Annual Riley's Gathering Place Golf Outing* brought in more than \$28,000.

The tournament and buffet dinner are organized by volunteer **Patrick**

**Fromelt** and OI Foundation Board

member **Anthony Benish**. This year, Patrick and **Sharon Fromelt** were presented with an award from the OI Foundation, recognizing them for 4 years of service. During this time, they have raised almost \$100,000 to benefit the OI Foundation!

## OI documentary featured at Denver & LA film festivals!

**Denver, CO** – A documentary featuring a young woman with OI has been included in film festivals in Denver and Los Angeles.

In addition, **Myridian Productions** used its July 10 premiere at the Starz Center, Tivoli, in downtown Denver to raise \$942 in contributions for the OI Foundation.

The 28-minute documentary, *Teresa*, follows **Teresa Nguyen** during her senior year in high school. Specifically, the film documents her struggles living with Type III OI as she works to achieve her independence. Myridian Productions also made the documentary available for viewing in the teen room during the *16th Biennial National Conference* on OI in Crystal City, VA.

*Teresa* was subsequently accepted into its 2nd film festival, the Feel Good Film Festival in Los Angeles, which ran Aug. 22-24.

The DVD will soon be available for purchase. To learn more, visit [www.myridianproductions.com](http://www.myridianproductions.com) and click "Contact" or phone (720) 299-6996.

## Rain fails to dampen success of 10th Miracle Michael golf tournament

**Naperville, IL** – The rain came down hard on the morning of the *10th Annual Miracle Michael Fund Charity Golf Tournament*.

Even so, **Beth and John Shultz** and

more than a dozen volunteers unloaded carloads of supplies at White Eagle Country Club on July 21, and hoped for the best. Fortunately, the skies did clear before the 1 p.m. shotgun start, and the weather was beautiful for the rest of the day. Approximately 170 golfers played for OI.

Then, during the dinner that followed, the golfers, their families, and other dinner guests from the OI community bid on a variety of donated items during the silent and live auctions.

A variety of celebrities from the Chicago area lent their time to the event. Celebrities included Chicago Bears Hall of Famer **Dan Hampton** along with **Norm Van Lier** (Chicago Bulls), **Glen Kozlowski** (Chicago Bears and WGN Radio), **Jim "Robocop" Thornton** (Chicago Bears) and **David Kaplan** (Comcast Sports and WGN Radio).

NASCAR driver **Andy Pilgrim** auctioned off a photograph of himself with Dale Earnhardt taken right after the 2001 *24 Hours of Daytona*, raising almost \$1,000. **Sean Stephenson**, a motivational speaker and board certified therapist with OI, provided the keynote address, speaking movingly about how one can choose to be happy.

In addition, Beth & John presented awards of appreciation to **Peter Smith, M.D.**, and **Tim Caruso, PT**, of Shriners Hospital for Children in Chicago, for their work benefiting the OI community. **Stuart Tart**, representing the OI Foundation, presented an award to Beth & John for their 10 years of raising support for OI research and information to families.

The Miracle Michael golf tournament is held annually in honor of **Michael Shultz**, who died at 8 months of age in April 1999 due to complications related to severe OI. The Miracle Michael Fund has contributed more than \$230,000 to the OI Foundation since the inaugural event in 1999.

The 11th Annual Miracle Michael

Fund is set for July 20th, 2009. Hope to see you there!

## Texas supporter involves group in holding actual Bone China Tea for OI

**Kingsville, TX** – Every once in a while, a creative person takes a good idea and makes it even better!

**Sue Miller**, whose husband, son, daughter, and grandson each live with OI, did this when she worked with her family and the FLAIR Department of the Woman's Club of Kingsville to hold a real Bone China Tea on July 27. Normally, Bone China Tea participants send invitations to a phantom event, where recipients drink a cup of tea at home and then send a donation to the OI Foundation.

"We, the Miller Family and the FLAIR Department, had a great time decorating and cooking for this tea," Sue explained. "It was a good learning experience for us."

Sue also sent invitations to people not attending the actual tea. So far, her real and phantom events have brought in almost \$5,000 for the OI Foundation!

## Kroger Charity Golf Tournament Raises \$122,000 for OI Research!

By Kristen Antolini

**Roanoke, VA** – The 22nd Annual Kroger OI Foundation Charity Golf Tournament, held on August 5-6, 2008, was a great success with proceeds of \$122,300 raised for OI research.

**Joe Antolini**, co-founder of the event, made a special presentation to eight individuals who have volunteered every year since the event's beginning. These individuals have tirelessly supported the OI Foundation's research mission through their hard work and financial

support.

**John O'Brien** of the OI Foundation presented a thank you banner signed by OI children and teenagers at the national conference, expressing the foundation's gratitude for Kroger's continued support.

Since 1987, **the Antolini Family** and **the Kroger Company** have hosted this auction and golf tournament to support research for treatments and a cure for OI. Kristen Antolini inspired the charity event when she was diagnosed with OI in 1984. The event brings together many Kroger vendors and sales people for an enjoyable day of golf on a beautiful course, a fabulous networking opportunity, and great auction prizes. The generosity and support of the event's sponsors and donors have raised \$1.75 million for OI research over 22 years.



*Martha, Kristen, and Joe Antolini pose with a banner thanking The Kroger Co. for raising \$1.75 million for OI research during 22 years of charity golf tournaments. Teens at the National Conference on OI in Crystal City, VA, signed the banner.*

## 94 golf in Bennett Clayton Foundation Tournament in MN

By Brenda DeBlicek

**St. Peter, MN** – The 5th annual Charity Golf Event sponsored by the **Bennett Clayton Foundation for Children with OI** on August 8 was another success, with 94 golfers participating.

Many other local and area supporters

joined us for dinner provided by **Famous Dave's Bar-B-Q**. We were pleased that several new friends from the OI community joined us to golf, to volunteer and to participate in dinner and the silent auction.

Nearly fifty businesses, individuals and corporations provided sponsorship, including **Davisco Foods International**, the presenting sponsor. Proceeds from this golf event support local projects including a personal health grant and scholarship for area OI applicants, as well as the OI Foundation's Linked Clinical Research Centers.

Plans are underway for next year's tournament at Shoreland Country Club on August 14, 2009. For more information on the organization or this event, please contact us at [BCFforOI@aol.com](mailto:BCFforOI@aol.com) or through the OI Foundation.

## Weather was perfect for the 3rd Birdies and Bogies golf tournament

**Ashburn, VA** – More than 70 golfers played 18 holes on a luxurious Arnold Palmer Signature Golf Course at the Belmont Country Club on August 11, helping the *3rd Annual Birdies and Bogies for Better Bones* golf tournament raise nearly \$30,000!

Participants enjoyed a day of golf filled with fun, sun and temperatures in the very comfortable 80's. During the 19th hole reception that followed, 14-year-old **Katrina Bache** and adult **David Vurdelja** spoke to participants honestly and movingly about how frequent broken bones, surgeries, and other OI-related health complications had impacted their lives and how the golfers' generosity will make a difference for people with OI.

Board member **Roger Bache** presented appreciation awards to Presenting Sponsor **Booz Allen Hamilton** and to Leadership Sponsor **Simmonds Klima, Ltd.** Event

*continued on page 16*



## People in the News

*Queen Creek, AZ* – **Troy Davis**, who competed in the 2000 Paralympic games in Track and Field, has coached another team member Erik Hightower, a young man with Spina Bifida, to the 2008 Paralympics in Beijing, held in September.

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

*Westminster, CO* – An independent film documentary, titled “Teresa” has been accepted into the Feel Good Film Festival in Los Angeles. The subject of the film is **Teresa Nguyen**, an eighteen year old college student. Also featured in the film is her friend **Lisa Ferrerio**, who has OI and is Teresa’s inspiration for living an independent life.

*Belvidere, IL* – Named a Young American in High School, 46 year old **Judd Daniels** has maintained a lifelong commitment to community involvement. “You have to give back to the community; volunteering, getting on a committee or serving on boards.”

*Auburn, IN* – With her best category in the 200-yard freestyle, 11 year old champion swimmer **Nichol Von Holten** has won numerous ribbons and medals while competing on the Dolphins YMCA swim team.

*Baltimore, MD* – Addressing surgical residents at Johns Hopkins University, JHU student **Beth Simmonds** spoke about OI and handed out copies of our new pediatrician’s guide.

*Omaha, NE* – Sami the Ballerina, aka **Samantha Binning** has been gracing various billboards around the city.

*Hoboken, NJ* – The University of Alabama is one of only four schools in the country to offer women’s collegiate wheelchair basketball and **Emily Seelenfreund** has won a scholarship to play with the team.

*New York, NY* – Active as the Vice President of the Student Senate before graduating with a masters from Columbia Teaching College, **Joe King** has plans to work on his Ph.D. at the University of Washington.

*Charlotte, NC* – “Gotta keep livin’ life” is **Christina Nixon**’s response to broken bones that would sideline many others, but instead present the opportunity for a strength of will and zest for life to shine through, handy attitudes heading off to college.

*Portland, OR* – “Candidate for the Scrapheap” is a memoir written by 42 year old **Anton Borisov** describing his experiences growing up in a clinic in Russia. Now living in Oregon, Anton enjoys freedoms never experienced in his homeland. “How could I tell you what it’s like having a wheelchair? What it’s like seeing blue skies after staring at the ceiling for most of my life before that?”

*Chattanooga, TN* – A teacher for 30 years, and a person with a disability in the public school system in 1962, **Ginger Green** offered an important perspective to the panel which met as part of an annual workshop to help educators learn about teaching children with special needs.

*West Jordan, UT* – A prenatal diagnosis of Type II, with recommendations to make funeral arrangements has been trumped by 2 year old **Nathan Glad**, who continues to beat the odds. Doctors have since retracted any life expectancy estimates.

*Madison, WI* – The Women’s Entertainment network aired a segment “Size Matters: Tall, Small and Extra large” on their series *Secret Lives of Women*. **April Brazier** was one of the women chosen to illustrate how she has “turned physical differences into empowering attributes.”

*AUSTRALIA* – A Ph.D. researcher with firsthand knowledge of OI, **Jo Ragen** is seeking to change the way people think about risk-taking and adventurous play among children with disabilities.

*Cooroy, Australila* – The Sunshine Coast Disabled Surfers Association gives people in the disabled community a chance to experience the thrill of surfboarding. Eager for the ride was 47 year old **Diane Wells** who has both cerebral palsy and OI. Despite her use of a wheelchair, Diane states “I get out there and go for it.”

*Vancouver, CANADA* – Studying art at the Emily Carr Institute, with work on permanent display at the Whitehorse Airport, 28 year old **Elaine Lee**’s art “represents who I am and what inspires me to keep going and not to give up on my own goals.”

*Kanpur, India* – Fifteen year old twin sisters, **Shruti** and **Gore Batla** have been awarded the National Bal Shri award in the creative arts category. The girls have won the hearts of millions of people throughout the country as a result of their singing and drawing.

*Jos, NIGERIA* – Unable to walk or push a wheelchair, 18 year old **Joshua Gidado** coaches the local soccer team, visits friends and shares the gospel from the wagon he has used for most of his life.

*Halesowen, UK* – Ranked 25th in the world in women’s wheelchair tennis, 16 year old **Jordanne Whiley** heads to Beijing to compete with the British team.

*Saltney, UK* – Competing in his third Paralympics, **Scott Robertson** will be traveling to Beijing and hoping to win the gold in the table tennis competition.



## Remembering Frances Dubowski

By Gemma M. Geisman

I am sad to report that a dear friend of people affected by OI, Frances Dubowski, RN, passed away on June 26, 2008 after a long and courageous battle with cancer. Since 1969 she had served many roles in the OI Community. Mrs. Dubowski was the first nurse consultant for the OI Clinic at Shriners Hospital for Children in Chicago, a member of the OI Foundation Board of Directors, an author, a nurse counselor to hundreds of OI families, and the Foundation's first Volunteer of the Year recipient.

Miss Frances, as most of her young patients at Shriners called her, was often the first person they saw upon entering one of the brightly decorated cubicles where they were to be examined on clinic days. Outwardly, Miss Frances tried to appear stern but she could never quite pull it off. A smile that always brought a twinkle to her eyes in the presence of a young patient was definitely her undoing. Frances also knew how to listen to the cries for help from the parents who brought their OI children for treatment. With kindness and reassurance she taught them how to lift, dress and care for their fragile children.

Before long, parents were clamoring to have her helpful instructions on paper and so Frances authored the first ever practical guide on caring for OI infants and children.

Because of her expertise and her devotion to families of children with OI, Frances was elected to the Foundation's Board of Directors. She also served for many years as a medical nurse advisor to the board as well as a nurse consultant. Over the years, many families of OI infants and children deeply appreciated her no-nonsense help and advice. Many of the parents and children who initially knew her as Miss Frances, the nurse, became close, lifelong friends of hers who often heard her say goodbye to them with her signature "Keep smiling!"

And so, just for you, Frances, we say goodbye with tears in our eyes, sorrow in our hearts and great big smiles on our faces. So long friend!

\*\*\*\*\*

### What others are saying about Frances

"Frances has left a wonderful legacy. All who knew and loved her will miss her presence." *Grace Riggs, former Director and OI Foundation Board President*

\*\*\*\*\*

"Frances was a wonderful friend to our Foundation for over 40 years. Her wisdom and compassion endeared her to countless families that she counseled with her thoughtful and sound advice about OI. Her knowledge and advice continue even now with the booklet "Caring For Infants and Children With OI", authored by Frances and still distributed worldwide by OIF."  
~*Rosalind James, former Director and OI Foundation Board President.*

\*\*\*\*\*

"Frances did not have any birth children but it was clearly evident through the years that she considered her many friends with OI as part of her family. Always thoughtful, compassionate and caring, Frances was a dedicated person whose memory I will forever treasure as a dear and special friend."  
~*Rosemarie Kasper, former Board Member and Breakthrough Editor*

\*\*\*\*\*

"Frances Dubowski was one of the first people I met when attending my first conference in Pittsburgh. One of the things that impressed me about her was her ability to listen to anyone at anytime to offer whatever help and advice she could give. She was someone who never stopped giving to the foundation.

"When I became President, the foundation was struggling to raise money. Frances called one day to give me some insight on how to apply for a grant from the Ronald McDonald Children Charities for a large sum of money. When I asked her how confident she was in receiving approval for the grant, she replied that the only way we wouldn't get the money was if we didn't apply. Frances was right. We applied and received that grant and a number of others from the McDonald Charities.

Frances Dubowski was a godsend to the foundation, Her strong personality and willingness to help others was her great trait. Frances's greatest trait for me was being my friend."  
~*Joe Antolini, former director and OI Foundation Board President*

## Welcome to the 2008 Clinic Directory

The 2008 Clinic Directory is your resource for quality medical care. Find clinics by looking state-by-state, or look only at the Clinics that see adults. Whether it is called an OI Clinic, Bone Clinic, Metabolic Center or Bone Dysplasia Program, you will find doctors who care for people with OI. Since OI is a rare disorder, it can be difficult to find doctors who have experience with OI in your home town. An OI clinic offers people with OI the benefit of a medical team whose members are experienced with OI and able to coordinate care. It is also important to have good health care close to home. Children and adults who must travel to an OI clinic also need a local primary care provider who will handle their routine and emergency needs, in conjunction with the OI Clinic doctors. OI Clinics offer a wide range of services to children and adults.

Regular appointments include time with a primary care doctor, orthopedist and members of the rehabilitation team. Additional appointments with other specialists are available as needed. All members of the clinic coordinate care to meet the person with OI's needs, and send reports to hometown doctors if the family lives in a different city. The OI Foundation has begun development of a group of Linked Clinical Research Centers (LCRC). These Centers will provide quality care and they will also train doctors and conduct research to improve treatment for OI and expand our understanding of this complex disorder. This Directory is one step in the process of locating good medical care. It is the responsibility of parents and adults with OI to verify whether a particular medical team meets their needs.

Only by asking questions can you determine if a particular place is a good fit for you. More information about developing a good working relationship with your primary care doctor or orthopedist is available in the OI Foundation fact sheets, *Talking with your Primary Care Physician and Talking with Your Orthopedist* — which are on the OI Foundation web site [www.oif.org](http://www.oif.org). More information about individual clinics in this directory is available by e-mail ([Bonelink@oif.org](mailto:Bonelink@oif.org)) or telephone (800-981-2663) from the National Resource Center at the OI Foundation.

### KEY TO TREATMENT PROGRAMS

- A. Coordinated care through a clinic
- B. Appointments with individual doctors
- C. Appointments with members of an inter-disciplinary team
- D. Treatment as part of a research protocol

### Arizona

#### Children's Clinic for Rehabilitative Services (CCRS)

2600 N. Wyatt Dr.

Tucson, AZ 85712

Clinic Director: Sydney Rice, M.D.

Clinic Hours: Monday–Friday 8-5

Appointments & Information:

Eileen Woods, LPN 520 324-3254 or

[Eileen.woods@tmcaz.com](mailto:Eileen.woods@tmcaz.com)

First call 520-324-5437 for application

Services: Children to age 21

OI patients seen last year: 29

Treatment Programs: C

### California

#### Cedars-Sinai Medical Center

Program Name:

#### Medical Genetics Clinic

8700 Beverly Blvd. Suite 665

Los Angeles, California 90048

Clinic Director: David Rimoin, M.D., Ph.D.

Clinic Hours: Tuesday 8–1, Wednesday

12:30–4

Information: Tara Funari, MS CGC 310-

423-4495 or [tara.funari@cshs.org](mailto:tara.funari@cshs.org)

Appointments:

Tami Kendra 310-423-9914

Web Site: [www.cedars-sinai.edu/](http://www.cedars-sinai.edu/medicalgenetics)

[medicalgenetics](http://www.cedars-sinai.edu/medicalgenetics)

Services: Children & Adults

OI patients seen in last year: 10

Treatment Programs: A, B, C

#### Shriners Hospital for Children – Los Angeles

Program Name: **OI Clinic**

3160 Geneva Street

Los Angeles, California 90020

Clinic Director: Gayle Tyerman, M.D.

Clinic Hours: Monday 9-4:30

Appointments:

Faviola Ramirez 213-368-3366

Information: Dr.Tyerman at

[gtyerman@shrinenet.org](mailto:gtyerman@shrinenet.org)

Information & contact for families:

Dolores Rangel, RN 213-368-3300

Services: Infants & Children to age 18

OI patients seen last year: 200

Treatment Programs: A, C

#### UCLA School of Medicine

Program Name:

#### Pediatric Bone and Mineral Clinic

10833 LeConte Ave.

Los Angeles, California 90095

Clinic Directors: William Oppenheim,

M.D. & Isidro Salusky, M.D.

Clinic Hours: Monday 9-12

Information, contact for families, &

appointments:

Barbara Gales, RN 310-206-0799 or

[bgales@mednet.ucla.edu](mailto:bgales@mednet.ucla.edu)

Services: Children & Adults

OI patients seen last year: 30

Treatment Programs: B, D

#### Children's Hospital Central California

Program Name:

#### Medical Genetics/Metabolism

9300 Valley Children's Place

Madera, California 93638

Clinic Director: Susan Winter, M.D.

Clinic Hours: Monday–Friday 8–5

Information: Sue Rosenthal, RN

559-353-6400

Appointments: 559-353-6400

Web Site: [www.childrenscentralcal.org](http://www.childrenscentralcal.org)

Services: Children to age 18

OI patients seen last year: 24

Treatment Programs: A, C

#### Kaiser Permanente

Program Name:

#### Skeletal Dysplasia Clinic

280 W. MacArthur Blvd.

Oakland, California 94611

Clinic Director: Katherine Dawson, M.D.



Clinic Hours: 3<sup>rd</sup> Friday mornings of the month (ex. Aug. & Dec.)  
Information, contact for families & appointments:  
Ericka Okenfuss, MS, 916-614-5177 or Ericka.okenfuss@kp.org  
Web site: <http://genetics.kaiser.org>  
Services: Children & Adults  
OI patients seen last year: 9  
Treatment Programs: A, B

#### **Shriners Hospital for Children - Northern CA**

2425 Stockton Blvd.  
Sacramento, California 95817  
Clinic Director: Jennette Boakes, M.D.  
Clinic Hours: Monday–Friday 8–3  
Information: Ary Arauz, PA, 916-453-2000 ext. 3100  
Appointments: 916-453-2180 (must go through admissions office and apply for care 916-453-2000)  
Web Site: [www.shrinershq.org](http://www.shrinershq.org)  
Services: Children to age 18 within general orthopedic program  
OI patients seen last year: 42  
Treatment Programs: B, D

#### **Delaware**

##### **A.I. duPont Hospital for Children** Program Name: **Skeletal Dysplasia Program**

1600 Rockland Road  
Wilmington, Delaware 19803  
Clinic Directors: Richard Kruse, D.O. & Michael Bober, M.D., Ph.D.  
Clinic Hours: Monday-Friday  
Appointments: 302-651-4200 (orthopedics) or 302-651- 5916 (genetics)  
Information: Nadine Shavack 302-651-5916  
Web Site: [www.nemours.org](http://www.nemours.org)  
Services: Children to age 18  
OI patients seen last year: 75  
Treatment Programs: A, B, C, D

#### **Florida**

##### **Shriners Hospital for Children - Tampa**

12502 Pine Drive  
Tampa, Florida 33612  
Chief of Staff: Dennis P. Grogan, M.D.  
Clinic Hours: Monday-Friday 8–5  
Information: Lisa Green, RN  
Care Coordinator 813-972-2250 ext. 7530  
[lgreen@shrinenet.org](mailto:lgreen@shrinenet.org)  
Appointments:  
Applications Department  
813-866-7740 or toll free 888-665-5437  
Web Site: [www.shrinershq.org](http://www.shrinershq.org)  
Services: Children to age 18 within general orthopedic program  
OI patients seen last year: 99  
Treatment Programs: A, B, C, D

#### **Hawaii**

##### **Shriners Hospital for Children - Honolulu**

1310 Punahou Street  
Honolulu, Hawaii 96826  
Clinic Director: Craig Ono, M.D.  
Clinic Hours: Monday–Friday 8-4:30  
Information: Celeste Olivares RN, BSN  
Nurse Care Coordinator  
Appointments: 888-888-6314 or 808-951-3620  
Web Site: <http://www.shrinershq.org/hospitals/honolulu/>  
Services: Children to age 21 within general orthopedic program  
OI patients seen last year: 30  
Treatment Programs: A

#### **Illinois**

##### **Shriners Hospital for Children – Chicago**

Program Name:  
**Osteogenesis Imperfecta Clinic**  
2211 N. Oak Park Ave.  
Chicago, Illinois 60707-3392  
Clinic Director: Peter Smith, M.D.  
Clinic Hours: Monday, Tuesday, Friday  
Information: Jen Joy Rhomberg 773-385-5579  
Web Site: [www.shrinershq.org](http://www.shrinershq.org)  
Services: Children to age 21  
OI patients seen last year: 150  
Treatment Programs: A, B, C, D

#### **Indiana**

##### **Riley Hospital/ Indiana University**

Program Name: **Bone Dysplasia Clinic**  
975 West Walnut St. IB-130  
Indianapolis, IN 46202  
Clinic Director: Bryan Hainline, M.D.  
Clinic hours: 3rd Wednesday of month  
Appointments:  
Iris Pettigrew 317-278-1956  
Services: Children & Adults  
OI patients seen last year: 60  
Treatment Programs: A, B, C, D

#### **Kentucky**

##### **Shriners Hospital for Children - Lexington**

1900 Richmond Road  
Lexington, Kentucky 40502  
Clinic Director: Lynn Campbell, M.D.  
Clinic Hours: Monday-Friday 9–4  
Information:  
Rhonda Weiler, RN, BSN,  
Care Coordinator 859-268-5740  
Appointments: Pam Tuttle 859-266-2101  
Web Site: [www.shrinershq.org](http://www.shrinershq.org)  
Services: Children to age 21  
OI patients seen last year: 45 (last update 2007)  
Treatment Programs: B

#### **Louisiana**

##### **Shriners Hospital for Children - Shreveport**

3100 Samford Ave.  
Shreveport, Louisiana 71103  
Clinic Director: Richard McCall, M.D.  
Clinic Hours:  
Monday-Thursday 8:30–3  
Information: Cathy Taron, RN, Care Coordinator 318-222-4296 or [ctaron@shrinenet.org](mailto:ctaron@shrinenet.org)  
Appointments: Melissa Bouillion 800-830-0606  
Web Site: [www.shrinershq.org](http://www.shrinershq.org)  
Services: Children to age 21  
OI patients seen last year: 35  
Treatment Programs: A, B, C

##### **Matrix DNA Diagnostics** **Tulane University Health Sciences Center**

1430 Tulane Ave., TB-28, Tidewater Room 2140  
New Orleans, Louisiana 70112-2899  
Laboratory Directors: Hans Andersson, M.D. & Marilyn Li, M.D.  
Hours: Monday-Friday 8–5  
Information & Appointments:  
Charlene Crain, MBA, BSMT (ASCP), Laboratory Supervisor  
Telephone: 504-988-7706,  
Fax: 504-988-7704 or [ccrain@tulane.edu](mailto:ccrain@tulane.edu)  
Web Site: [www.som.tulane.edu/gene\\_therapy/matrix/matrix\\_dna\\_diagnostics.shtml](http://www.som.tulane.edu/gene_therapy/matrix/matrix_dna_diagnostics.shtml)  
Services: Genomic testing for children and adults  
Treatment Programs: Genomic Testing Only

#### **Maryland**

##### **The Kennedy Krieger Institute** Program Name: **OI Program at the Kennedy Krieger Institute**

707 N. Broadway  
Baltimore, Maryland 21205  
This program interacts with related Pediatric & Adult services at Johns Hopkins Hospital  
Clinic Directors: Jay Shapiro, M.D. & Paul Sponseller, M.D.  
Assistant Director: Pending  
Clinic Hours: Monday-Friday: App'ts available throughout the week  
Information: Sally Snader, RN, BSN, Clinic Coordinator 443-923-2704  
Appointments: 800-873-3377 or Clinic Coordinator or  
Dionna Hicks 443-923-2703  
Web Site:  
[www.osteogenesisimperfecta.org](http://www.osteogenesisimperfecta.org)  
Services: Children & Adults; referrals to Johns Hopkins Hospital  
OI patients seen last year: 250  
Treatment Programs: A, B, C, D

## **National Institutes of Health**

### **OI Program**

10 Center Drive  
Bldg 10/Rm 10N260  
Bethesda, Maryland 20892  
Principal Investigator: Joan Marini, M.D., Ph.D.  
Clinic Hours: Appointment Only  
Appointments & Information:  
301-496-0741or  
oiprogram@mail.nih.gov  
Web Site: www.oiprogram.nichd.nih.gov  
Services: Children accepted into clinical trial and adults being followed post clinical trial  
OI patients seen last year: Over 60  
Treatment Programs: A, B, C, D

## **Massachusetts**

### **Children's Hospital Boston**

300 Longwood Ave.  
Boston, MA 02115  
Not an official hospital program  
Dr. Frederic Shapiro sees most of the OI patients & coordinates services throughout the hospital  
Hours: Tuesday & Thursday  
Appointments: 617-355-6753  
Information:  
Frederic.shapiro@childrens.harvard.edu  
Services: Children to age 21  
OI patients seen last year: 20  
Treatment Programs: B

## **Minnesota**

### **Gillette Children's Specialty Healthcare**

Program Name: **Orthopedic Clinic**  
200 E. University Ave.  
St. Paul, Minnesota 55101  
Clinic Director: Stephen Sundberg, M.D.  
Clinic Hours: Varies, depending on specialist being seen  
Appointments & Information:  
Patrick Cavanaugh, RN, Orthopedic Program Director  
651-229-3944 or  
pcavanaugh@gillettechildrens.com  
Services: Children to age 21  
OI patients seen last year: 45  
Treatment Programs: A, B, C

### **Shriners Hospital for Children - Twin Cities**

2025 E. River Parkway  
Minneapolis, Minnesota 55414  
Clinic Director: Deborah Smith-Wright, M.D.  
Clinic Hours: Monday-Friday  
Information: Karen Boyer, 612-596-6105,  
kboyer@shrinenet.org  
Web Site: www.shrinershq.org  
Services: Children to age 21  
OI patients seen last year: unknown  
Treatment Programs: A, B

## **Missouri**

### **Children's Mercy Hospital and Clinics OI services through Children's Mercy Kidney Center**

2401 Gillham Rd.  
Kansas City, Missouri 64108  
Clinic Director: Tarak Srivastava, M.D.  
Clinic Hours: Monday-Friday 8-4:30  
Information: Patricia Swartz, RN,  
816-234-3312, or  
paswartz@cmh.edu  
Appointments: 816-234-3030 or  
800-276-0985  
Web Site: www.childrens-mercy.org  
Services: Children to age 18  
OI patients seen last year: 50  
Treatment Programs: B

### **Shriners Hospital For Children – St. Louis**

Program Name: **Research Clinic**  
2001 South Lindbergh Blvd.  
St. Louis, Missouri 63131  
Clinic Director: Michael Whyte, M.D.  
Clinic Hours: Tuesday & Thursday  
Information: Karen Clements, RN,  
314-432-3600 ext.1637 or  
kclements@shrinenet.org  
Appointments: Applications Department  
314-432-3600 ext. 1119  
Web Site: www.shrinershq.org  
Services: Children to age 21  
OI patients seen last year: 70  
Treatment Programs: A, B, C, D

### **Barnes-Jewish Hospital Division of Bone and Mineral Diseases**

216 S. Kingshighway Blvd.  
St. Louis, Missouri 63110  
Dr. Michael Whyte, Clinic Director  
Clinic Hours: Thursday  
Appointments: 314-454-7775 Option #1  
Services: Adults  
Treatment Programs: B

### **University of Missouri – Columbia Program Name: Skeletal Dysplasia Clinic**

One Hospital Dr.  
Columbia, MO 65212  
Clinic Director: Daniel Hoernschemeyer, M.D.  
Clinic Hours: Columbia: Mondays & Thursdays  
Jefferson City: Wednesday afternoons  
Springfield: Every three months  
Information & Appointments: Holly Wheatley 573-884-2522  
Web Site: www.ortho.muhealth.org/pediatrics  
Services: Children to age 18  
OI patients seen last year: 6  
Treatment Programs: B

## **Nebraska**

### **Children's Hospital**

Program Name: **Metabolic Bone Diseases Clinic**  
8200 Dodge St.  
Omaha, NE 68114-4113  
Clinic Medical Director: Richard Lutz, M.D.  
Clinic Hours: One day a month 9–5  
Information & contact for families: Susan Coughlin, RN 402-955-4179  
Appointments: 402-955-4199  
Services: Children  
OI patients seen last year: 70  
Treatment Programs: A, C, D

## **New York**

### **Hospital for Joint Diseases Pediatric Initiative for Bone Health**

301 East 17<sup>th</sup> St. Rm. 204  
New York, NY 10003  
Clinic Director: Patricia Poitevien, M.D.  
Clinic Hours: Tuesday & Friday 9-12,  
Wednesday 9-4  
Information & Appointments:  
212-598-6412  
Web Site:  
www.nyuhjdcenterforchildren.org  
Services: Children to age 18  
OI patients seen last year: 55  
Treatment Programs: A

### **Hospital for Special Surgery Center for Skeletal Dysplasias and OI Clinic**

535 E. 70<sup>th</sup> St.  
New York, NY 10021  
Program Names:  
1) **OI Clinic**  
2) **Kathryn O. and Alan C. Greenberg  
Center for Skeletal Dysplasias (CSD)**  
Directors OI Clinic: Daniel Green, M.D. & Cathleen Raggio, M.D.  
Directors CSD: Jessica G. Davis, M.D. & Cathleen Raggio, M.D.  
Clinic Hours: OI Clinic: 2<sup>nd</sup> and 3<sup>rd</sup>  
Monday of each month CSD: 2<sup>nd</sup> or 3<sup>rd</sup>  
Monday mornings each month  
Information and appointments:  
OI Clinic: Mary Phelan, RN 212-774-2113  
or Dr. Green 212-606-1631  
CSD: Erin M. Carter 212-774-7332 or  
Dr. Raggio 212- 606-1339 or  
CSD@Hss.edu  
Web site: www.hss.edu/skeletal-dysplasias.asp  
Services: Children & Adults  
OI patients seen last year: 60  
Treatment Programs: A, B, C, D

## North Carolina

### Carolinas Medical Center

Program Name: **Children's Specialty Center**

1000 Blythe Blvd.

P.O. Box 32861

Charlotte, NC 28232-2861

Clinic Director: Charles P. McKay, M.D.

Clinic Hours: Monday 1-5, Tuesday 1-5,

Thursday 8-12

Appointments: Diane Whitfield:

704-381-8800

Web Site:

[www.levinechildrenshospital.org](http://www.levinechildrenshospital.org)

Services: Children to age 21

OI patients seen last year: 30

Treatment Programs: A, B

## Ohio

### Cincinnati Children's Hospital Medical Center

Program Name: **Skeletal Dysplasia & Connective Tissue Clinic**

3333 Burnet Ave., ML 4006

Cincinnati, Ohio 45229

Clinic Director: Brad T. Tinkle, M.D., Ph.D.

Clinic Hours:

Skeletal Dysplasia Clinic – fourth

Thursday each month and as needed

Information: Carrie Atzinger, MS, CGC,

513-636-7604

Appointments: Scheduling

513-636-4760, ext. 1

Web Site: [www.cincinnatichildrens.org](http://www.cincinnatichildrens.org)

Services: Children & Adults

OI patients seen last year: 20

Treatment Programs: A, B, C, D

### Nationwide Children's Hospital Metabolic Bone Disease Clinic

700 Children's Dr.

Columbus, OH 43205

Clinic Director: John D. Mahan, M.D.

Clinic Hours: Tuesday 8-1

Appointments: 614-722-4363

Information: Marney Davis, RN, BSN or

Beth Kossmann, RN 614-722-4363

Web site: [www.nationwidechildrens.org/nephrology](http://www.nationwidechildrens.org/nephrology)

Services: Children & Adults

OI patients seen last year: 50

Treatment Programs: A, B, C, D

## Oregon

### Oregon Health & Science University Bone and Mineral Clinic

3181 S.W. Sam Jackson Park Road, Mail

Code: CR113

Portland, OR 97239-3098

Clinic Director: Robert F. Klein, M.D.

Information & contact for families:

Sandra L. Veith, Research Associate

503-494-5630

Services: Adults

OI patients seen last year: 60+

Treatment Programs: A, B, C, D

### Shriners Hospital for Children – Portland

3101 SW Sam Jackson Park Rd.

Portland, OR 97239

Program Name: **Metabolic & Skeletal Dysplasia Clinics**

Clinic Director: Robert Steiner, M.D.

Clinic Hours: 1<sup>st</sup> Tuesday of month for

Metabolic Clinic

3<sup>rd</sup> Friday for Skeletal Dysplasia Clinic

8:30-12:00

Information: Vonda Vensel, RN,

503-221-3784

Appointments: Barb Flaherty,

503-221-3480 New Patient Coordinator

Web Site: [www.shrinershq.org](http://www.shrinershq.org)

Services: Children to age 21

OI patients seen last year: 55

Treatment Programs: A, B, C, D

### Legacy Children's Hospital

Program Name: **Pediatric Development & Rehabilitation**

2801 N. Gantenbein

Portland, OR 97227

Clinic Director: George Anadiotis, M.D.

Clinic Hours: Monday-Friday 9-5

To make an appointment: 503-413-4505

Services: Birth to Adult

OI patients seen last year: unknown

Treatment Programs: A, B

## Pennsylvania

### Children's Hospital of Philadelphia (CHOP)

Program Name: **Connective Tissue Disorder Clinic**

34<sup>th</sup> St. and Civic Center Boulevard

Philadelphia, PA 19104

Clinic Directors: Paige Kaplan, M.D.

Physician: Michael Levine, M.D.

Clinic Hours:

CHOP – Children: Wednesday 1–5

Information & Contact for Families: Kristi

Koch Fitzgerald, MS, CGC

or Curtis R. Coughlin II, MS, CGC

Telephone & Email: 215-590-3376,

[fitzgeraldk@email.chop.edu](mailto:fitzgeraldk@email.chop.edu) or

[coughlincu@email.chop.edu](mailto:coughlincu@email.chop.edu)

Appointments:

Daria Tolentino 215-590-3376

Services: Children

OI patients seen last year: 25

Treatment Programs: A, C

### Hospital of the University of Pennsylvania (HUP) – University of Pennsylvania Health Services

Program Name: **Connective Tissue Disorder Clinic**

3400 Spruce St.

Philadelphia, PA 19104

Clinic Director: Reed Pyeritz, M.D.

Clinic Hours: HUP – Adults: Monday 12-4,

Thursday 8:30-4

Information & Contact for Families:

Barbara Bernhardt, MS, CGC

Telephone & Email: 215-662-4740,

[Barbara.bernhardt@uphs.upenn.edu](mailto:Barbara.bernhardt@uphs.upenn.edu)

Appointments: Georgia Griffin

215-662-4740

Services: Adults

OI patients seen last year: 12

Treatment Programs: A, C

### Shriners Hospital for Children – Philadelphia

3551 North Broad St.

Philadelphia, PA 19140

Clinic Director: Janet Rocchio, R.N.

Clinic Hours: Wednesday 8–4, Friday

8-12 (Upper extremities)

Wednesday, Thursday & Friday 8–4

(Lower extremities)

Appointments: Scheduling Secretary

800-281-4050 ext. 4073

Web Site: [www.shrinershq.org](http://www.shrinershq.org)

Services: Birth to age 18

OI patients seen last year:

Treatment Programs: A, B, C

### Shriners Hospital for Children – Erie

1645 West 8<sup>th</sup> St.

Erie, PA 16505

Clinic Director:

Clinic Hours: Monday-Friday

Information: Janet Noland, MPT or

[jnoland@shrinenet.org](mailto:jnoland@shrinenet.org)

Appointments: 800-873-5437

Services: Birth to age 21

OI patients seen last year: 30

Treatment Programs: A, B, C, D

## South Carolina

### Shriners Hospital for Children – Greenville

Program Name: **Orthopedic Clinic**

950 West Faris Road

Greenville, South Carolina 29605

Clinic Director: Pete Stasikelis, M.D.

Clinic Hours: Monday-Friday 7–5

Information: Kellie Mason, RN, BSN,

Clinical Coordinator Outpatient Dept.

Appointments: 864-240-3137

Web Site:

Services: Children to age 18

OI patients sent last year: 22

Treatment Programs: A



## Texas

### Baylor College of Medicine at Texas Children's Hospital

#### Program Name: **Skeletal Dysplasia Clinic**

6701 Fannin St. CC-1510  
Houston, Texas 77030-2399  
Clinic Director: Brendan Lee, M.D., Ph.D.  
Clinic Hours: 2<sup>nd</sup> Friday of month  
1:30–5:00  
Appointments, Information & Contact for Families: Marie Prescott 832-822-4298  
Web Site:  
www.texaschildrenshospital.org  
Services: Children & Adults  
OI Patients seen last year: 28  
Treatment Programs: A, B, D

### Shriners Hospital for Children – Houston

#### Program Name: **Osteogenesis Imperfecta Clinic**

6977 Main Street  
Houston, Texas 77030-3701  
Clinic Director: Lynnette Mazur, M.D.  
Clinic Hours: 4<sup>th</sup> Thursday every other month 1:00-4:30  
Information: Jenice Haines, RN, MSN  
713-797-1616  
New Applications: Aura Arand, Applications Secretary  
713-797-1616 Ext. 3765  
Services: Children to age 17  
OI patients seen last year: unknown  
Treatment Programs: A, C

## Utah

### Shriners Hospital for Children – Intermountain

#### Program Name: **OI Multidisciplinary Clinic**

Fairfax Road at Virginia St.  
Salt Lake City, Utah 84103  
Clinic Hours: January, April, July, October  
2<sup>nd</sup> Wednesday 8–12  
Information: Angela Bytheway, RN,  
801-536-3565  
Appointments: Applications Department,  
800-841-0204  
Web Site: www.shrineshq.org  
Services: Children to age 18  
OI patients seen last year: 50  
Treatment Programs: A, B, C

## Washington

### Children's Hospital & Regional Medical Center

#### Medical Genetics Clinic & Skeletal Health Program

Box 359300 (CH-47)  
Seattle, Washington 98105  
Genetics Clinic Director:  
Ian Glass, M.D.  
Skeletal Health Director:  
Michael Goldberg, M.D.  
Medical Genetics Clinic Hours: Tuesday  
8–5

Skeletal Health Clinic Hours:  
Monday 8:30-1  
Appointments: 206-987-2056 (Genetics)  
or 206-987-2109 (Skeletal Health)  
Services: Children & Adults  
OI Patients seen last year:15  
Treatment Programs: A, B, C

### University of Washington Medical Center

#### Program Name: **Medical Genetics Clinic**

Box 357720  
Seattle, Washington 98195-7720  
Clinic Director: Peter Byers, M.D.  
Clinic Hours: Tuesday 8–2  
Appointments: 206-598-4030  
Services: Children & Adults  
OI Patients seen last year: 5  
Treatment Programs: A, B, C

### Shriners Hospital for Children - Spokane

911 W. 5<sup>th</sup> Ave.  
Spokane, Washington 99204  
Chief of Staff: Paul Caskey, M.D.  
Clinic Hours: Monday-Thursday  
Information: Dr. Caskey,  
pcaskey@shrinenet.org  
Appointments: 888-895-5951  
Web Site: www.shrinershq.org  
Services: Children to age 21  
OI patients seen last year: 25  
Treatment Programs: A, B, C, D

## Washington, D.C.

### Children's National Medical Center Skeletal Dysplasia Clinic/Department of Genetics

111 Michigan Ave., NW  
Washington, DC 20010  
Clinic Director: Cynthia Tift, M.D.  
Clinic Hours: Genetics Department  
2<sup>nd</sup> Tuesday of the month 8:30-12:30  
Appointments and Skeletal Dysplasia  
Clinic information:  
Deborah Copenheaver, MS 202-476-4167  
Fracture care through Orthopedics Dept.,  
Laura Tosi, M.D. 202-476-5562  
Orthopedic information and contact for families Nancy Harry, LICSW at  
nharry@cnmc.org  
Web Site: www.dccchildrens.org (go to genetics)  
Services: Children to Adults  
Genetic counseling is open to adults  
OI patients seen last year: 40  
Treatment Programs: A, B, C

## Wisconsin

### Midwest Regional Bone Dysplasia Clinic University of Wisconsin

1500 Highland Avenue  
Madison, Wisconsin 53705  
Clinic Director: Richard Pauli, M.D., Ph.D.  
Clinic Hours: Wednesday 8:30- 4:30 and/  
or Thursday 8:30-4:30  
Information & Appointments:  
Sue Kalscheur, PA, Clinic Coordinator  
608-262-2507 or  
skalscheur@waisman.wisc.edu  
Services: Children & Adults  
OI patients seen last year: 10  
Treatment Programs: A, B

## Canada

### Shriners Hospital for Children – Canada Program Name: **OI Clinic**

1529 Cedar Ave.  
Montreal, Quebec  
Canada H3G 1A6  
Clinic Director: Francis Glorieux, M.D., Ph.D.  
Information, Contact for Families & Appointments:  
Aileen Coronel 800-361-7256 ext.6999 (in Canada)  
514-282-6999 (from USA and elsewhere)  
or  
acoronel@shriners.mcgill.ca  
Web Site: www.shriners-genetics.mcgill.ca  
Services: Children to age 21  
OI patients seen last year: 150  
Treatment Programs: A, B, C, D

### The Hospital for Sick Children Skeletal Dysplasia Clinic-Genetics

555 University Ave.  
Division of Clinical & Metabolic Genetics  
Toronto, Ontario, M5G 1X8 Canada  
Clinic Director: Roberto Mendoza-Londono, M.D.  
Clinic Hours: Once a week  
To make an appointment: Lucie Dupuis,  
MSc 416-813-6387  
Services: Children to age 21; Adults evaluated and referred elsewhere  
OI patients seen last year: 15  
Treatment Programs: A, C

## United Kingdom

### Sheffield Children's NHS Trust Metabolic Bone Disease Team

Western Bank, Sheffield  
S10 2TH, UK  
Clinic/Team Director: Prof. Nicholas J. Bishop  
Clinic Hours: Clinic: Tuesday 9-12:30

Inpatient therapy: Monday-Friday  
Information & Contact for Families:  
Elaine Walker,  
Clinical Nurse Specialist (+44)  
01142267890 or  
Elaine.walker@sch.nhs.uk  
Appointments: Medical Practitioner  
referral only.  
Web Site: www.sheffieldchildrens.nhs.uk  
Services: Children to age 21  
OI patients seen last year: 265  
Treatment Programs: A, B, C, D

#### **Australia**

**The Children's Hospital at Westmead**  
Program Name: **Connective Tissue  
Dysplasia Clinic (CTDC)**  
Corner Hawkesbury Road & Hainsworth  
Street  
Westmead NSW 2145  
Postal Address: Locked Bag 4001,  
Westmead NSW 2145  
Clinic Director: Professor David Sillence  
Clinic Hours: Tuesday 9:30-1:30  
Information: Ms. Cheryl Cotton (+61-2)  
9845-0000 or  
CheryC3@chw.edu.au  
Web Site: www.chw.edu.au  
Services: Children to age 18 with  
coordinated care for transition to adult  
services  
OI patients seen last year: 112  
Treatment Programs: A, B, C, D

#### **SERVICES FOR ADULTS**

All of the programs listed in this directory see children who have OI. The following centers also see adults with OI. See the state-by-state list for complete contact information. The range of services offered differs a great deal from place to place. Contact the clinic directly, or the OI Foundation National Resource Center for details.

#### **California**

Cedars-Sinai Medical Center  
UCLA School of Medicine  
Kaiser Permanente

#### **Indiana**

Riley Hospital/Indiana University

#### **Maryland**

The Kennedy Krieger Institute

#### **Missouri**

Barnes-Jewish Hospital

#### **New York**

Hospital for Special Surgery

#### **Ohio**

Cincinnati Children's Hospital Medical  
Center  
Nationwide Children's Hospital

#### **Oregon**

Oregon Health Science University  
Legacy Children's Hospital

#### **Pennsylvania**

Hospital of the University of Pennsylvania

#### **Texas**

Baylor College of Medicine

#### **Washington**

Children's Hospital & Regional Medical  
Center  
University of Washington Medical Center

#### **Washington, D.C.**

Children's National Medical Center

#### **Wisconsin**

Midwest Regional Bone Dysplasia Clinic

#### **Canada**

The Toronto Hospital for Sick Children

# A Man and His Dog: My Experiences as a College Student

written by Ryan J. Donnelly

College life is never a breeze, but attending as a student with a disability brings its own unique challenges, especially when adding a service dog into the mix. Megan, my Yellow Labrador Retriever, has been my faithful companion for 8 years. Just as I made a transition from high school to college, so did she. I've been attending the University of New Hampshire in Durham for four years. I've learned many things, both in and out of class, and have made friends I'll keep for the rest of my life.

Initially, I thought living on campus was going to be a great challenge, but dorm life actually isn't so hard. With help from Granite State Independent Living, I was able to hire my own Personal Care Attendants. They assist me with everyday things such as getting ready for classes in the morning, and going to the dining halls. The room I stay in was modified to suit my needs. For example, the pressure on the door hinge was loosened so I can get in and out more easily. I have a single, which means I don't have a roommate. Since the added bulk of my wheelchair, plus my service dog, required more space than most dorm singles provide, I was assigned a room intended for two people just for myself! The added living area proved to be just perfect; providing ample room for both myself and Megan. The bathroom right next door is accessible; with a transfer bench by one of the toilets, and a fold-down seat in the larger handicapped shower stall.

Campus is as accessible as one can expect. UNH has a long history, and because many of its buildings are quite old, not all of them are totally accessible. There are several academic buildings and dorms I simply can't visit, but the good people at Disability-Services work with any student with a disability (even if it's temporary, like an injured football player) to relocate class to an accessible area. With this service, I'm free to take any class I wish without fear of not being able to physically attend.

But life at UNH isn't all sunshine and roses either. I've had my share of challenges. The winter months can be difficult. New Hampshire snow can accumulate rather high, and the shoveling crew can only do so much. A few inches of slush can bring my power wheelchair to a full, dead stop. Even Megan isn't able to pull me out of that kind of mess. Thankfully, I can rely on my friends or other students to get me out of a jam fast. In the winter months I usually leave for class a bit earlier than usual, just in case I happen to get stuck.

Of course I've had some adventures too. During the brief time I volunteered at the Institute on Disabilities, about a mile away from campus, my van needed an oil change. I had to rely on UNH's "Wildcat Transit" bus service. I got to my volunteer job fine, but a bus never came to pick me up. Rather than go through the hassle of placing another call, I drove my wheelchair along the side of the road back to campus, with Megan walking along beside me, wagging her tail happily. As far as she was concerned, we were just going for a nice big walk! All in all it took about fifteen minutes, and while it was a little nerve-racking to have cars whizzing by me at 30 or 40 miles per hour, I made it back in one piece.

Not all of my adventures have been so harrowing. I've had great times with friends, visiting the nearby Fox Run Mall (even the dog likes to shop!), catching a movie at the cinema, or just hanging out and jamming away on video games for an evening. While being a student with a disability at UNH has brought its challenges and excitement (both good and bad), I like to think that my overall experience at college isn't much different from anyone else's. I attend the same classes, eat the same food, and live in the same dorms as anyone else. I study, write papers, and have a good time like any of my friends. It's been an exciting four years and I'll be sad when it all ends, but I'm thankful for the opportunity I've had, and I know I'll never forget my time at the University of New Hampshire, and neither will Megan!





## Aging With OI

*This article is based on the presentation of the same name that was given on August 2, 2008 at the National Conference on OI by Dr. Laura Tosi, Dr. Jay Shapiro and Dr. Jim Hartsfield, Jr.*

Age related changes, to collagen, hormones and bone, affect skeletal health and occur in everyone. In people who have OI these changes occur on top of already lower than standard bone mass and greater than average standard fragility. It is not clear how these changes specifically influence OI or how OI influences these normal changes. What can a person with OI do about aging? Many things are possible, but only one is certain. The sooner you consider thinking about these problems the greater your ability to prevent them from happening or work to minimize their effect on you.

### What happens to the musculoskeletal system as people age?

Collagen fibers in bone and skin become stiffer and less flexible with increasing age. This can increase the brittleness of bone. Age related changes to bone cause mobilization of calcium out of the skeleton resulting in loss of bone mass and loss of bone strength. These changes are caused in part by drops in levels of the hormones estrogen and testosterone. Vitamin D levels also drop as the skin becomes less effective in converting

sunlight and vitamin absorption from food falls with age.

One of the reasons people get cataracts in their eyes as they age is because of changes in collagen in the lens of the eye. These collagen changes can also affect blood vessels and the heart valves that contain collagen.

### What can a person do to live as independently as possible, as long as possible?

- Reduce fracture risk, particularly around the home
- Reduce muscle weakness
- Exercise
- Pay attention to nutrition
- Take good care of teeth and gums
- Prevent and manage pain by limited use of medications
- Address hearing loss by periodic evaluation
- Start good habits in childhood and maintain them throughout life
- Learn about bone and bone health and apply the lessons

### Why exercise?

Science demonstrates that exercise is extremely important for making bone strong no matter who you are. The mantra of orthopedics, "Move it or lose it," applies. People with OI need to begin exercise programs early and continue being active throughout their lives. Before puberty, exercise changes bone, after puberty regular exercise can assist in maintaining fitness and bone strength. Besides general fitness, cardiopulmonary activities, and weight bearing exercise, it is important for skeletal health to develop a daily program of stretching and flexibility training.

### What aspects of nutrition are important?

Besides eating a balanced diet and maintaining a healthy weight it is important to get enough calcium and to keep vitamin D levels in the good range. Studies show a resurgence of rickets among kids with all kinds of disabilities. Low vitamin D prevents development of bone mass and probably contributes to increased pain. It is not known exactly what

makes bone strong but elements including vitamin K, magnesium and phosphorous found in natural foods like milk and green vegetables probably are necessary for bone strength.

### How does age affect options for treating bone loss?

The goal of treating bone loss is reducing fracture risk. Your age influences your doctor's approach and your decision about which drugs to take. Estrogen or an estrogen-like drug can be effective for reducing the often significant bone loss that occurs during the first years of menopause. Taken later, it may increase the risk of heart disease. Risk factors for cancer will affect the discussion about taking estrogen. Testosterone levels can be tested and replacement therapy can help maintain bone density in men.

Antiresorptive therapy with a bisphosphonate affects adult bones differently than the bones of the still growing skeleton. Studies using these drugs to treat osteoporosis suggest that 5 years of treatment may be enough to get maximum fracture protection.

### Is it worthwhile to move from one bisphosphonate to another?

No one knows for sure. Changing is probably not needed if a person has been on a bisphosphonate long enough to saturate the bone because bisphosphonates stay there for a long time. The possible benefits of switching to a bone forming drug like Forteo are being studied.

### Why is dental care important?

Your mouth is a window on your general health. Mouth infections can affect your entire body, including your heart and other organs. Infections in other parts of your body and the medicine you receive can affect the health of your gums, teeth and jaws directly or by a decrease in your saliva. Saliva is not just water in your mouth. It has natural minerals and antibodies in it that protect your teeth

and gums. Changes in collagen on top of poor oral health, and poor habits increase the risk of infection. Tooth loss is not an automatic part of normal aging if you receive and take proper care.

### **What causes tooth loss?**

Inflammation of the gums (gingivitis) is reversible with home brushing, and flossing; and professional cleanings. If allowed to persist, it can spread under the gums to the bone and cause bone loss around the teeth called periodontitis. Sometimes this can be to some degree reversed, but most of the time it can only be stopped from progressing. Tooth loss is caused by losing so much bone around the tooth that they are no longer supported by the remaining bone when you chew. Tooth loss can also occur if they need to be extracted because of chronic infection at the end of the tooth (an abscess) or in the tooth. However, there are often treatments to heal the infection and restore the tooth to healthy function if treated early enough. Bottom line, don't keep putting it off. It is not going to get better by itself. There is no evidence of increased gum inflammation directly because of OI, but having OI may make it more difficult to brush and floss your teeth, which would have an indirect effect. Bottom line again, keep the inflammation (bleeding) of the gums to a minimum so it does not spread to the underlying bone around the teeth.

### **Are there other dental problems associated with aging?**

A lack of saliva and various types of oral cancer are often associated with aging, the later especially if you smoke cigarettes or cigars, or use spit tobacco. Dentinogenesis imperfecta and its risk of broken teeth is an ongoing problem for some people who have OI.

### **Are dentures and other dental procedures available for people who have OI?**

Implants are possible and some have reportedly been successful, but there

are no good studies on the longevity of dental implants in OI patients, especially if they are on bisphosphonates, which could affect the longevity of dental implants. Dentures are possible, but extracting the natural teeth inevitably leads to bone loss in the jaws. Over time this bone loss makes a good fit more difficult to maintain. If only one tooth in an area with remaining teeth on both sides of the missing tooth is to be replaced by an implant, then there is less general bone loss to deal with, but special procedures may still be needed. But if all the teeth have been extracted, there is much more generalized bone loss, which may make implant placement more involved or impossible. Caps (Dental Crowns) are frequently used, but are not intended to last a lifetime and need to be regularly inspected by a dentist.

### **How can chronic pain be managed?**

Pain, often chronic, has many causes including microfractures, old fractures, migrating rods, and low vitamin D levels. Age-related osteoarthritis can be superimposed on joint wear and tear associated with OI. There is some evidence that people who took Fosamax without getting supplemental calcium and vitamin D seemed to be predisposed to bone pain. The FDA recently announced that the possibility that some people may experience an increase in bone pain while taking a bisphosphonate.

Treatment strategies can include getting vitamin D level into healthy range via supplements, getting adequate calcium and keeping mobile and flexible. Research indicates that increasing your endorphins — your body's natural pain fighters — through exercise, yoga, meditation etc has long lasting benefits. Non-steroidal pain killers also known as NSAIDS affect bone metabolism. They are best used short term. As you look for a balanced approach to pain management consider that drugs will get you through the moment, but you need strategies to get through the decades.

### **Are there issues in finding care for adults with OI?**

Currently, health insurance, hospitals, and health care systems are not ready for a rapidly growing population of adults with disabilities. There are few orthopedists with training and/or experience caring for the adult with a life long bone disease. Pediatric orthopedists find that there is hardly anyone to turn their patients over to when they become adults. Adults need to be vocal advocates for their health care needs.

### **What are some topics that need to be studied?**

There are many topics related to aging with OI that need studying including

- Vibration Therapy
- Effects of aging on the abnormal collagen that occurs in OI
- Length of time a bisphosphonate remains active in adult OI bone.

### **Apply for Grants for Medical Researchers**

The Osteogenesis Imperfecta Foundation and the Children's Brittle Bone Foundation invite applications for OI Foundation Research Grants. Funding is available for fellowships for young investigators working to develop expertise in OI research or seed grants for either basic or clinical studies with relevance to OI. Applications are due by November 1, 2008. Please visit [www.oif.org](http://www.oif.org) for more information.

# *In Honor Of*

April 1 – June 30, 2008

**Miss Brianna (Happy Mother's Day)**

Junior, Michi, Samy & Brinny Suarez

**Miss Siena**

Ms. Marybeth Celorier

**Wayne Beckner**

Karen & Stephanie Shields

**Jaime Bellerose**

Ms. Dawn Hammett

**Brian Breest**

Mr. Brian Breest

**Amelia & Whitt Byrd**

Ms. Ellen Manson

Mr. Wayne Wilson

**Chuck Cahn (Happy Birthday)**

Mr. Robert Nussbaum

**Miss Sarah Rebecca Calmus**

Ms. Katherine Baiocco

Ms. Holly Calmus

Craig & Karen Chambers

Thomas & Colleen Gillon

**Miss Allie Cannington**

Larry & Vivian Bartholomew

**Taylor Carpenter**

Mr. & Mrs. Franklin Booth, Sr.

**Miss Alexis Charbonneau**

Mr. Ryan Ahern

**Austin Dahlenburg**

Ms. Christina Allen

**Don Dillon (Happy Father's Day)**

Ms. Aileen Potter

**Martin Dimino**

Mr. Merle Dimino

William & Judith Hable

**Tim Dombro (Birthday)**

Ms. Sylvia Cahill

**Jay Fleming**

Mr. John Fleming

**Don Gardner**

Butch & Marta Kinzer

**Jessica Geisinger & Her Sisters**

Ms. Laura Warren

**Nicholas George**

C. & L. Kavanaugh

Grant & Darla Krause

Ms. Elizabeth Lovett

Douglas, Kelli & Allie Thaman

Kevin & Sheryl Uerling

Kenneth & Julie Wolfe

**Allie Thaman (Birthday)**

C. & L. Kavanaugh

Ms. Elizabeth Lovett

Kevin & Sheryl Uerling

**Shirley Hartsfield**

Jim, Karen, Kennedy & Tessa Hartsfield

**Jason & Cari Hawn**

Ms. Judy Easley

Ms. Bettina McCormick

**Mallie Holman**

Advanced Audio Visual Sales, Inc.

Advanced Staging Productions

Angelo & Heidi Capetola, Jr.

Ms. Marcia DiGiallorenzo

Mr. Thomas Duffy

Brendan & Colleen Duffy

Ms. Sharon Lee Envall

Donald & Barbara Hagy

Greg & Leigh Holman

Seth & Shighla Jackson

Dennis & Jennifer Krebs

Lewis & Barbara Masters

MC3, Inc.

John & Patricia Morris

Robert & Jessica Paul

Christopher & Melinda Roberts

James & Heather Sharples

Ms. Laura Wilkinson

Ms. Mary Anne Wooster

Carla, Denny, Lindsay &

Rachel Zajac

**Emma Johnston**

Bruce & Shari Douglas

Bill & Corinne Landrum

**Daniel Jones**

Mr. Donald Dennis

**Cooper Ryan Knorr**

Michael & Marie Ann Baggio

Ms. Francesca Barberio

Ms. Laurie Burke

Ms. Elizabeth Marshall

Ms. Mary Modica

Gary & Providence Occhiogrosso

N. & D. Ponzini

**Sean McCarthy**

Mr. Michael Bernard

Mr. John Fleming

Mr. Adam Forman

Ms. Maria Perkins

Mr. Robert Shanahan

Mr. Michael Skok

James & Cathleen Stone

The Plymouth Rock Foundation

**Todd McCarthy**

Mr. Izhar Armony

**Andrew McNutt**

Dr. & Mrs. Richard Derian

**Lauren Miller**

Philip & Bess Shockey

**Dominic Moscardelli**

Ms. Claudine Moscardelli

**Christopher Nolan**

James & Rosemary Quinn

**Cindy Nolan**

Ms. Karen Convery

**Gabriella Piacquadio**

Ms. Sophia Brogna

Mr. Luis Lopez Ducret

**Megan Price**

Michael & Kimberly Perkins

**Jazmin Reano**

Pittsburg Elks Lodge 1474

**Susan Reazor (Happy Mother's Day)**

Robert & Jennifer Prybolsky

**Ajani Riggs**

Ms. Aiesha Oliver

**Kari Roll (Birthday)**

Ms. Ruth Hovden

**Jack Rossi**

Samuel & Laura Earnest

Christopher & Mary

Michael & Tamy Slattery

**Master Jack Wyman Rossi**

Ms. Marybeth Celorier

**John Roubik & Family**

Bayside Middle School

**Ryan Roubik**

Fox Point-Bayside PTO

**Liz Schmidt**

Ms. Gail Masteller-Kane

**Heller An Shapiro**

Robert & Linda Phillips

**Russell Sneiderman**

JPMorgan Chase Foundation

**Michael Stewart**

George & Laura Bouton

Mr. & Mrs. Paul Donlin

Mr. & Mrs. Peter Duncan

Mr. Robert Laughlin

Mr. Bruce Meyer, CPA/PFS

Mr. & Mrs. Greg Nabhan

Mr. Michael Pellegrino

Mr. & Mrs. Andrew Selden

Marsha Gorelick & Lydia Soifer

**The Stewart Family**

Mr. & Mrs. Donald McCree

**Kay West**

Ms. Carmen Guzman

**Daniel Wiederhold**

Ms. Laura Warren

Louis & Lillie Wiederhold, Jr.

**Debbie Wiederhold**

Ms. Laura Warren

**Elliot Winograd**

Sydney Morris

**Isaac Wright**

Mr. John Wright



# *In Memory Of*

April 1 – June 30, 2008

## **Ruth Bergman (Great Grandmother of Ryan J. Roubik)**

Ms. Carol Caputa  
Greg & Helen Cherney  
Russell & Nancy Fahn  
Charles & Sandra Farmer  
Eddie & Arlene Fenney  
Mr. Kenneth Fenney  
Ms. Audrey Gressen  
Ms. Sherri Hiller  
Mr. Aaron Hoffman  
Ed & Jackie Landry  
Mr. Richard Lee  
James & Barbara Lucht  
Mr. Gary Lucht  
David & Toni Lucht  
Larry & Sandy Lucht  
Jack & Janice Lucht  
Ms. Jane Lucht  
Clarence & Marjorie Masshardt  
Scott & Marian Meyer  
Bill & Kathie Quarles  
Mr. D. Preston Rizor  
Ronald & Janet Schiedemeyer  
Fred & Mary Schmidt  
Greg & Jeanine Schmirler  
Douglas & Gayle Siegel  
Jeffrey & Kristen  
Ms. Hazel Tornow  
Brian & Margaret Tornow  
Dave & Jackie Tuszkiewz

## **Koln Butler**

Mr. Gregory Schultz  
Eilene Copenhagen  
Ms. Stacey Bush  
Mr. Benjamin Butler  
Mr. Arthur Jacobson  
Stephen & Bonnie Litton  
Ms. Whitney Luneau  
Ms. Tatyana Terletskeya

## **Sally Jean Couser**

Bonnie Landrum & Michael Johnston

## **Christopher Michael Cressman**

Ms. Robin Foerster  
Jerry & Carol Gressley  
Ms. Carol Kratzer

## **Mark Crotty**

Mr. & Mrs. Bill McNutt

## **Angela Dellapenta**

Ms. Debra Iachini-Lux

## **Marion Demuelle**

Mrs. Cecile Mason

## **Francis E. Dias**

Mr. William Acklin  
Ms. Madeline Gamble  
Krishna & Sangeetha Pendyala  
Ms. Deborah Pinheiro

## **Mary P. Dillon**

Ms. Aileen Potter

## **Joseph Dunbar**

Mrs. Cecile Mason

## **John C. Harris**

Wilbur & Nancy Harris  
Ms. Sally McElroy

## **Rachel M. Hitch**

Joan Ablon, Ph.D.  
Ms. Dorit Bergen  
Paul & Susan Berthouex  
Paul & Joan Bollenbach  
Ms. Marcia Bradley  
Ms. Deb Burns  
Mr. Hank Cetola  
Community Pharmacy  
Ms. Mary Cucchiarella  
John & Linda Daly  
Ms. Debbie DesMarais  
Alan & Linda Ginsberg  
Ms. Lana Grant  
Robert & Georgia Graves  
Jon & Myra Hajny  
Daryl & Virginia Hanson  
Edward & Sheila Helmke  
Mr. Lawrence Hitch  
Ms. Margaret Jensen  
Mr. Brian Kane  
Mr. Richard Kilmer  
Ms. Leslie Larsen  
Bettine, Sarah & David Lipman  
Anne Lucas & Kris Anderson  
Ms. Marla McFadden  
Ms. Joy Miller  
John & Janet Parks  
Ms. Eileen Pauli  
Timothy & Cynthia Pendorf  
Evan, Jane & Laura Pizer  
Brian & Annette Porter  
Stanley & Marla Richter  
Ms. Peggy Ross  
Mark & Laurie Sayer  
L. Joseph & Marlys Sloup  
Ms. Aelita Warwick  
Ms. Virginia White

## **Walter Irvin**

Mr. & Mrs. Donald Trahan

## **Jason Jimenez**

Ms. Elizabeth Barbera

## **R. Gordon Johnston**

Mr. & Mrs. David Farrish

## **Teresa Kennedy**

Natural Resources Conservation Service

## **Dan Krudys, Sr.**

John & Phyllis Benanti

## **Howard Lawrence**

John & Mary Comford & Family

Ms. Antoinette Dombeck  
Ms. Nancy Engel  
Robert & Phyllis Engstrom  
Mr. & Mrs. Victor Lyons  
Mrs. Pearl Nelson  
Mr. David Nordli  
Ms. Lee Perish  
Tom & Colleen Raasch  
Joni Sutton & Chip Williams  
Herbert & Mary Willetts

## **June Lawrence**

Tom & Colleen Raasch

## **Frank V. Marino, Sr.**

Mr. William Bird  
Michael & Frances Capizola  
Les & Jean Cook  
Vince & Marlene Daliessio & Children  
Bob & Kathy Jost  
Ms. Sandra Jost  
Richard & Donna Moratelli  
Robert & Jo Ann Paolini  
Albert & Linda Pustizzi

## **Leon C. McKenzie**

Mrs. Elke White

## **Eleanor McPherson**

Bonnie Landrum & Michael Johnston

## **Laurence Melzer**

Gerald & Dixie Hertel

## **Sarah Meyering**

Ms. Marina Tebben

## **Richard Mitchell**

John & Phyllis Pascucci

## **Lisa Molony**

Mr. Denham Griffin  
William & Orlean Lewelling  
Robert & Nancy Littleton  
Gerald & Donna McIntire  
Paul & Joan Ortiz  
Mr. Davis Roeske  
Mr. James Smith  
William & Deddy Wesely

## **David Morrison**

Mr. George W. Williams

## **Eric O'Brien**

Mary Helen Cagle  
Mrs. M.S. Fountain

## **Salvi A. Pascucci**

Ms. Mary DeLisle  
William & Joan Marsell  
Paul & Frances Mitchell  
Edward & Rosalie Pavia  
Ralph & Sylvia Spring  
David & Lois Welch

## **Libbie Ranslem**

Ms. Linda Diane Anderson  
Ms. Marian Burson  
Ms. Emily Hurlbert

*In Memory Of* continued from page 15

Ms. Lois Larson  
Ken & Jolene Mueller  
Thomas & Beth Pfortmiller  
Mr. & Mrs. Richard Pinney

**David Sanchez**

Ms. Amy Salazar

**Paul J. Sauerland**

Nancy & Alan Skolnick

**Robert H. Schmidt**

John & Jackie Anderson

Mrs. Sherry Hausman & Staff of SSM

**Julia Schroder**

Mrs. Bernice Freudensprung

**James R. Seybold, Sr.**

Nicholas & Eldred Vurdelja

**Kate Skram**

Mr. & Mrs. Richard Turner

**Edmond Somekh**

Ms. Odille Hansen

**Moshi Somekh**

Ms. Odille Hansen

**Grace Sonneborn**

Steve & Alice O'Brien

**Sally Thomas**

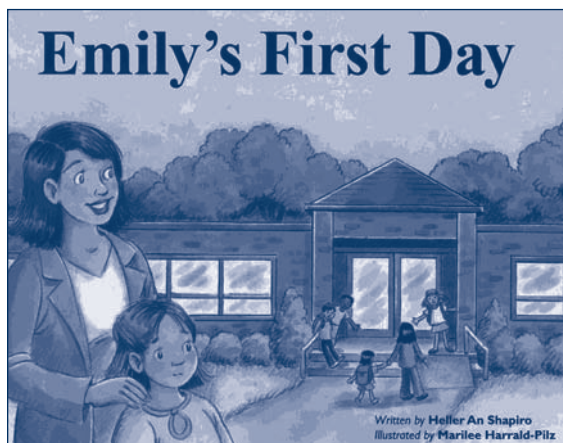
Lesley, Peggy, Angie, Glen & Elke White

**James Varon**

Blair, Ginger & Will Jennings

Dan, Molly, Henry & George Lyke

Elise, Farley & Chad Russell



## Latest OI Book

*Emily's First Day* is the latest book from the OI Foundation. It tells the story about the first day of school for a child with **Type I OI**. This picture book is meant to be read to children in kindergarten and the early elementary grades. It explains Type I OI in terms that young children can understand. A resource section for teachers is included. *Emily's First Day* is available for purchase through the OI Foundation's on-line store for \$9.00 plus shipping.

## BIRDIES AND BOGIES continued from page 8

chairperson **Karen Orejuela** and her husband **Henry Orejuela**, and committee member **David Vurdelja** also received awards.

The OI Foundation would like to thank Karen, Roger, David and the other committee members — **Tim Hawkins**, **David McGraw**, and **Paul Greenfield** — for their work and ideas over several months that made this event a success.

In addition, we greatly appreciate **Charlotte and Tony Preuss**, **Priyanka Lamichhane**, and **Bill Bradner** for graciously volunteering their time during much of the day.

## Golfer at NH OI Classic Wins \$5,000 Hole-in-One contest

**Atkinson, NH** – Big things happened at the *2008 OI Classic* on August 25 at the Atkinson Country Club! This

annual golf tournament is organized by **Ken and Teresa Gudek**.

Now in its second year, the OI Classic



**Ken Gudek presents a \$5,000 award to the winner of the hole-in-one contest during the 2008 OI Classic in Atkinson, NH, on August 25. This is the 2nd golf tournament for OI organized by Ken and Teresa Gudek.**

attracted 132 golfers and raised an estimated \$47,785! The day proved to be lucky for one golfer, who scored his very first hole-in-one shot on the 11th hole and won \$5,000 in the process!

Golfers teed off at 7:30 a.m. and then

enjoyed a lunch buffet and auction. During lunch, **Matthew Warman, M.D.**, Professor of Genetics and Orthopedic Surgery at Children's Hospital Boston, spoke about OI from a medical perspective and shared with participants how the OI Foundation helps its constituents connect to the services they need. OI Foundation CEO **Tracy Smith Hart** also attended the event.

"What a great day we had yesterday. Everyone enjoyed themselves," Teresa said. "What makes this event special for us is the amount of support we get from the community and the members of the committee, not to mention our family and friends."

## Breakthrough

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

**Contributing Writers:** Kristen Antolini, Brenda DeBlieck, Ryan J. Donnelly, Gemma M. Geisman, Tracy Smith Hart, Dr. Jim Hartsfield, Jr., Mary Beth Huber, Marie Maffey, John O'Brien, Erika Ruebensaal, Dr. Jay Shapiro, Stuart Tart and Dr. Laura Tosi.

### Chief Executive Officer

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

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

### Osteogenesis Imperfecta Foundation

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

**Donations/Contributions:** To support the Foundation with a financial contribution, please send your donation to:

### Osteogenesis Imperfecta Foundation

P.O. Box 630342  
Baltimore, MD 21263-0343

Financial information and charitable disclosures can be found at [www.oif.org/aboutOIF](http://www.oif.org/aboutOIF) or by calling or writing the Foundation offices.





# Electronic Version of **Breakthrough** Now Available

Save time and trees! Receive **Breakthrough** faster online and help protect the environment by choosing to receive an electronic version. You will be notified by an e-mail alert once the new issue of **Breakthrough** is ready for you to view.

To make the switch, e-mail [bonelink@oif.org](mailto:bonelink@oif.org).



**Osteogenesis Imperfecta Foundation**  
804 West Diamond Avenue, Suite 210  
Gaithersburg, MD 20878

NON-PROFIT  
U.S. POSTAGE  
PAID  
Suburban, MD  
PERMIT #5857