

## CONFERENCE EDITION

# Get Ready for the 2012 National Conference: *Campaign 2012: Awareness, Advocacy, Action!*

Register online at [www.oif.org](http://www.oif.org)!

The OI Foundation's National Conference is the premier event for families and individuals living with osteogenesis imperfecta. The three-day conference boasts a full schedule of informational sessions on medical and practical living topics, presentations by leading experts in OI research, social events for all ages, and an abundance of additional activities designed to address important issues for individuals living with OI and their loved ones.

Making its return to the Washington, DC area, the theme for the 2012 National Conference is "Campaign 2012: Awareness, Advocacy, Action!" and the full conference will be held at the Crystal Gateway Marriott in Arlington, VA, on Friday, July 13 through Sunday, July 15.

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### HOW TO REGISTER FOR CONFERENCE

Registration can be done online at [www.oif.org/conference](http://www.oif.org/conference) or directly on the OIF homepage at [www.oif.org](http://www.oif.org). For questions about registration, email [conference@oif.org](mailto:conference@oif.org) or call 800-981-2663.

The online registration program allows users to register all members in their party, receive instant email confirmation, buy Awards Dinner only tickets, and much more. The program also allows you to e-mail the Foundation directly if you encounter problems during the registration process.

#### Conference Registration Fees:

##### (12 months to 12 years old)

Child Early Bird	\$140
Child Regular (after early bird)	\$165
Child on-site at conference	\$190

##### (13 years old to 17 years old)

Teen Early Bird	\$175
Teen Regular (after early bird)	\$200
Teen on-site at conference	\$225

##### (18 years old and older)

Adult Early Bird	\$175
Adult Regular (after early bird)	\$200
Adult on-site at conference	\$225

#### Key Dates:

Early bird registration deadline is April 30, 2012  
Regular registration dates May 1 to June 30, 2012  
After June 30, 2012 all registrations will need to be made on-site

Each conference registration type includes; access to all conference activities (with the exception of the Women's Forum), breakfast on both full days of the conference, the Awards Dinner, and conference materials. Each child registration type also includes the cost of childcare, based on availability. Childcare is somewhat limited and is usually full before the on-site registration date begins.

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**OSTEOGENESIS  
IMPERFECTA**



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**From the Chief Executive Officer**

Dear Friends:

I'm so excited about this issue of *Breakthrough* – in it you will find the registration and program information for the 2012 conference! We are packing a lot into three days including visits to Capitol Hill, medical consultations, inspiring speakers and informative sessions on a number of topics. I know this is a very busy time of year for everyone but I hope you take a few minutes to review the information and make your travel plans for your trip to Washington, DC, in July!

In addition to this time of year being very busy it is also a very important time of year for the Foundation. We are now in the process of searching for members who would like to join our board of directors. The board of the OI Foundation is made up of people committed to helping the Foundation support the mission of the organization, "improving the lives of people living with OI." If you think being a member of the OI Foundation board is something you might be interested in, please send me a note or give me a call to find out more. You can also visit our website and view the job description for a board member.

So, here's to a successful 2012 for the OI Foundation and to all of our dedicated members, volunteers and supporters and thank you for making 2011 so special.

All my best,

A handwritten signature in blue ink, which appears to be "Sharon Trahan".



**From the President**

Happy 2012!

Things are very busy around the office these days! In addition to the 2012 National Conference in Washington, DC, we're also gearing up for the 12th Annual Scientific Meeting, *Assessing the Impact of Osteogenesis Imperfecta on Nonskeletal Systems*, in April. Dr. Laura Tosi is leading a wide-ranging group of OIF Medical Advisory Council members, doctors and researchers in the meeting that will focus on adult health issues in people with OI. New information from the meeting will be a part of the information sessions at the National Conference in July.

I would like to encourage everyone to attend the National Conference in Washington, DC, this July. In addition to hearing about a variety of scientific and medical information, there will be time to educate members of the House and Senate about OI, many peer-to-peer sessions and time for fun. As I mentioned in the last *Breakthrough*, the Foundation is continuing the tradition of subsidizing the cost of the conference. The conference registration fees charged are less than the actual cost, and for those unable to afford the expense, we do have a scholarship program available. Many thanks to the generous donors that make these funds available! There is more information on applying for scholarships in this issue of *Breakthrough*.

Of course, the busyness of the office is also due to ongoing support to the OI community. Information and educational materials continue to be sent out to the community. Resources are shared, volunteers encouraged, our web site is increasingly active, and we continue helping to facilitate the Linked Clinical Research Centers and a variety of research in OI. We appreciate all of you who have helped keep your Foundation fiscally healthy with your generous donations. All this activity is possible because of your commitment and support. Thank you!

Looking forward to seeing you in July!

A handwritten signature in blue ink, which appears to be "Sharon Trahan".

# 2012 National Conference

## 2012 National Conference (continued from page 1)

Visit the 2012 National Conference website, [www.oif.org/conference](http://www.oif.org/conference), often to stay updated on conference information. Attendees can also use the site to register for conference, make their hotel reservations, sign-up for childcare, and download the conference schedule.

## WHERE TO STAY

The full conference will take place at the Crystal Gateway Marriott located at 1700 Jefferson Davis Highway Arlington, VA 22202.

The Crystal Gateway Marriott is offering conference attendees a discounted room rate of \$149 per night. Hotel reservations can be made online at [www.oif.org/conference](http://www.oif.org/conference) under the 'Hotel Reservations' tab or by calling 888-236-2424. To receive the discounted group rate, you must inform the reservations representative that you are attending the OI Foundation Conference or give them the group code "OIFOIFA." If you choose to make your reservations online, enter "OIFOIFA" in the 'Group Code' field when prompted.

### ***If you need to book an accessible (ADA) room:***

Please call reservations representative Megan Aguilar directly at 703-553-5331. Please remember that with every hotel, there are a limited number of ADA rooms available. Please be considerate to fellow attendees and only book an ADA room if a standard room cannot accommodate your needs. ADA rooms are available on a first come, first serve basis, and will sell out early!

To discuss specific questions or special needs regarding guestrooms, contact the hotel directly at 703-920-3230.

Guestroom doorway measurements are as follows:

- Standard and ADA guestroom entrance:** 36 inches
- Standard guestroom bathroom:** 24 inches
- Standard guestroom bathroom:** 36 inches

## HOW TO GET THERE

The Crystal Gateway Marriott is located 1-mile from Ronald Regan Washington National Airport (DCA). The hotel offers a complimentary accessible shuttle. Metro, Washington, DC's subway system, travels from the airport to the hotel and costs \$1.50 for the one-way trip. Taxi fare between DCA and the hotel is approximately \$7. Blue Top Cab offers wheelchair-accessible taxi service and reservations can be made by calling 703-243-8294.



*Young adults officially declaring the start of the 2010 Conference!*

### ***Other local airports:***

**Washington Dulles International Airport (IAD)** located 28 miles from the hotel.

The hotel does not provide shuttle service, but transportation options include:

Washington Flyer, [www.washfly.com](http://www.washfly.com) or 1-888-WASHFLY, fee: \$45 (one way) reservation required.

Estimated taxi fare: \$45 (one way)

**Baltimore/Washington International Thurgood Marshall Airport (BWI)** located 55 miles from the hotel.

Estimated taxi fare: \$65 (one way)

Super Shuttle, [www.supershuttle.com](http://www.supershuttle.com) or 1-800-BLUEVAN, fee \$61 (one way) reservation required.

## TRAVEL RESOURCES

You can search for travel agents who specialize in disabled travel through the American Society of Travel Agents, using their advanced search options on <http://www.astanet.com/>.

<http://www.disabilitytravel.com/> and [www.accessible.com/tips](http://www.accessible.com/tips) both have a variety of resources, links, and tips for the traveler with a disability.

If you plan to travel by train, visit <http://www.amtrak.com/>, click on the "Traveling With Amtrak" button on the top menu, and scroll down to "Special Needs and Accessibility."

On <http://www.greyhound.com/>, click on "Customers with Disabilities" under the Tickets by Phone telephone number.

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# 2012 National Conference

## 2012 National Conference (continued from page 3)

### Airport Security

For information about Federal regulations governing the use of oxygen and mobility aids in airports and on planes, visit the Transportation Safety Authority's website at <http://www.tsa.gov/Traveling>

### Traveling with Oxygen

For information about regulations governing the use of oxygen in airports and on planes, visit the Transportation Safety Authority's website at <http://www.tsa.gov/> and search for the word "oxygen."

### Medical Supplies / Vans / Wheelchairs

For rental vans, try <http://www.wheelchairgetaways.com/> for lists of available rental companies. Wheelchair and oxygen rentals are available through <http://www.disabilitytravel.com/> and <http://www.disabilityguide.org/>.

## PRE-CONFERENCE ACTIVITIES

The 2012 Conference officially begins with the Opening Session at 4pm on Friday, July 13, but there are several pre-conference activities that attendees may choose to attend. With the exception of the Women's Forum, all pre-conference activities are included in the cost of your conference registration fee.



Longtime volunteer, and former Board of Directors member, Susie Wilson, manages a table of OIF resources at the 2010 Conference.

### OIF Capitol Hill Day

Thursday, July 12, all day

Advocating on behalf of public policy issues that affect the lives of people with OI is an important activity of the OI Foundation. With your help, the Foundation has been able to educate many Members of Congress over the past three years about the work of the Linked Clinical Research Centers and the need for increased research dollars allocated to rare bone diseases, especially osteogenesis imperfecta.

This year, in conjunction with conference, volunteers from the OI Foundation will once again be heading to Capitol Hill to continue our advocacy efforts. Would you like to join us on Thursday, July 12, 2012?

We are looking for volunteers willing to visit their congressional office(s) and talk about their personal experience with OI or as a family member of someone with OI. To participate in Capitol Hill Day you must be able to attend a training the morning of Thursday, July 12th and be willing to visit at least one Member of Congress on that day. You must also be willing to return to the conference hotel and give staff of the OI Foundation a report on your visit(s). We will also ask you to take photos of your visit that the OI Foundation can use on our website and in other materials.

Having a large turnout for Capitol Hill Day will show members of Congress and their staffs that we are strong advocates! Friends of OIF Kyle Mulroy and Spencer Perlman will be coordinating this effort and will be providing all volunteers with information we will be talking to Capitol Hill. They will make sure all of the participants are well prepared and feel comfortable meeting with their representatives.

If you would like to be a part of Capitol Hill Day on July 12, 2012, please e-mail Tracy Hart at [thart@oif.org](mailto:thart@oif.org) or sign-up using the Conference registration form. **You must sign-up by June 1, 2012.** Once we know you're available we will send you more information on the logistics of the day. Remember, Capitol Hill Day will be held the day before the conference officially begins on Friday July 13th.

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# 2012 National Conference

2012 National Conference (continued from page 4)

## Women's Forum

**Thursday, July 12, all day, additional registration is required**

New to the National Conference, the Women's Forum will be a full-day event held on Thursday, July 12. The forum is designed to be a combination of informal presentations and discussions. The morning session will cover the topics of women's health issues, pregnancy and yoga for women with OI. Lunch will be included. The afternoon session will discuss self-image of women with OI, sexuality and sex and disability. The sessions will be led by experts in the related areas, many of the presenters have OI themselves. The day will be topped off with a discussion how women with OI can mentor girls with OI.

Registration will be limited to 30 women with OI over the age of 18. Registration is limited to promote discussion in a relatively small group on these somewhat sensitive issues. There is a \$40 registration fee, not included in the conference registration fee, to attend this event. Attendees can register for the Women's Forum on the main conference registration form.

## Your Journey Begins: Understanding OI

**Friday, July 13, 2-4pm**

This pre-conference session is designed for families and individuals with a new diagnosis or are new to the OI community. This session is a great way to learn the basics about OI, and ask questions. Topics will include genetics, understanding variability and treatments and will be presented by a panel of medical experts and OI parents.

## Medical Consultations

**Friday, July 13, by appointment only**

On Friday, July 13, 2012 before the National Conference officially opens, appointments for a conversation with an OI specialist will be available. This special feature offers people attending the National Conference the opportunity to have a specific OI related question answered by a medical expert. This program is especially helpful for people who do not have access to OI specialists at home. The consultations will be free of charge. Appointments are limited so each person will be able to reserve time with only one or two of the specialists depending on the number of people who request an appointment.

## CONFERENCE SCHOLARSHIPS

The OI Foundation has obtained funding, primarily through individual contributions for a limited number of scholarships to the 2012 National Conference. All those wishing to attend conference but who are unable to due to financial limitations are encouraged to apply.

Application information is available on the conference page of [www.oif.org](http://www.oif.org) or by calling 800-981-2663.

**Applications must be received by March 16, 2012.**

Families and individuals are encouraged to explore all possible sources of funding. In some cases money to help people attend conferences about rare health disorders, like OI, is available from state agencies, school systems or community organizations.

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

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# 2012 National Conference

## 2012 National Conference (continued from page 5)

### *continued from Medical Consultations*

#### ***What is a Medical Consultation?***

This kind of appointment is very different from visiting an OI Clinic. **No examinations will be performed.** This is only a conversation. Your appointment is an opportunity to get a second opinion or get an answer to a particular question. Each appointment is 20 minutes long. All appointments are held at the conference hotel.

#### ***Who are the Doctors?***

Each doctor is an expert in his or her area, and has extensive OI experience. Many are members of the OI Foundation's Medical Advisory Council (MAC). Doctors will be available in the areas of genetics, orthopedics, hearing, physical therapy, respiratory health and more. Detailed information about each physician will be posted on the OI Foundation website as soon as possible.

#### ***How to Request an Appointment***

Appointments will be scheduled on a first come basis beginning at 10 a.m. EST on Monday, April 2, 2012. There are three ways to request an appointment:

- Call the OI Foundation office at 301-947-0083 or 800-981-2663. Be prepared to answer the questions on the Appointment Request form posted on the foundation website.
- Print the Appointment Request form from the foundation website and fax the complete document to 301-947-0456
- Copy the website form into an e-mail and send to [bonelink@oif.org](mailto:bonelink@oif.org)

After your request has been received, a Patient Information Form will be sent to you by e-mail. This series of questions will help the doctor be prepared to talk with you. This form must be returned to the OIF before your appointment can be confirmed.

All appointments will be confirmed by May 7. Depending on which specialist you wish to see you will be asked to bring along test results, or digital x-rays. Every effort is made to fill as many requests as possible. If you have questions about this special program contact Mary Beth Huber or Petra Harvey at the OI Foundation office at telephone 800-981-2663 or by e-mail at [bonelink@oif.org](mailto:bonelink@oif.org).



***A newborn and her mother attending their first National Conference***

# 2012 Conference Schedule

**Start Time      End Time      Function**

## Thursday, July 12, 2012

ALL DAY      ALL DAY      Advocacy Visits, requires signing-up in advance  
10AM      5PM      Women's Forum, requires additional registration & fee

## Friday, July 13, 2012

8AM      3PM      Medical Consultations, by appointment only  
1PM      5PM      Exhibit Hall & Resource Center  
2PM      4PM      Your Journey Begins: Understanding OI  
4PM      5:30PM      Opening Session, Keynote Speaker  
6PM      8PM      Welcome Reception  
7PM      9PM      Talent Show Rehearsal  
7PM      9PM      Kids Game Night  
8PM      11PM      Adult Dinner

## Saturday, July 14, 2012

7:30AM      9:30AM      Breakfast  
8AM      5PM      Exhibit Hall & Resource Center  
9AM      5PM      Teen Room  
9AM      5PM      Childcare-provided for registered attendees

SESSIONS ARE MARKED FOR THEIR INTENDED AUDIENCE AS PARENTS, ADULTS, AND YOUNG ADULTS

8:30AM      10AM      Plenary Session: Research Update, panel of experts

10:15AM      11:15AM      Nutrition: Strategies, Picky Eaters, etc. (Parents)  
10:15AM      11:15AM      Your Lungs and You (Adults)  
10:15AM      11:15AM      Rodding Surgery (Parents)  
10:15AM      11:15AM      Self Advocacy in Medical Situations (Adults)

11:30AM      12:30PM      Home First Aid for Parents (Parents)  
11:30AM      12:30PM      Your Opinion Mattered: Results from the Adult Health Study (OI-ANHI) (Adults)  
11:30AM      12:30PM      Healthy Lungs for Children (Parents)  
11:30AM      12:30PM      Dental: Cosmetic Treatments for Fragile Teeth (Adults)

12:30PM      2PM      Lunch

2:15PM      3:15PM      Vision: Cataracts, Glaucoma, Detached Retina (Adults)  
2:15PM      3:15PM      Understanding Pain in Children with OI (Parents)  
2:15PM      3:15PM      Hearing: What the Audiogram Tells You (Parents)  
2:15PM      3:15PM      Good Nutrition for Weight Control (Adults)  
2:15PM      3:15PM      How You Walk Affects How You Feel (Parents)  
2:15PM      3:15PM      Social Scene: Managing a Healthy Social Life (Young Adults)

3:30PM      4:30PM      Dental: DI to Orthodontics (Parents)  
3:30PM      4:30PM      Understanding Pain Medication for Adults (Adults)  
3:30PM      4:30PM      Treating Scoliosis in Children (Parents)  
3:30PM      4:30PM      Hearing: Aids or Surgery (Adults)  
3:30PM      4:30PM      Managing Your Health on Your Own (Young Adults)

4:30PM      5:30PM      Support Group Leader Reception  
4:30PM      7PM      Free time  
7PM      9PM      Talent Show  
9PM      11PM      Adult Social Activity

Schedule is subject to change

# 2012 Conference Schedule

Start Time	End Time	Function
<b>Sunday, July 15, 2012</b>		
7:30AM	9:30AM	Breakfast
8AM	4PM	Exhibit Hall & Resource Center
9AM	4PM	Teen Room
9AM	5PM	Childcare-provided for registered attendees
9AM	10AM	Plenary Session: Celebrate Your <i>Unbreakable Spirit</i>
10:15AM	11:15AM	Building Strong Families (Parents)
10:15AM	11:15AM	Driving and OI: The Practical Process (Adults & Young Adults)
10:15AM	11:15AM	Advocating for Your School-Aged Child (Parents)
10:15AM	11:15AM	Mental Health (Adults)
11:30AM	12:30PM	Get Moving: Physical Activity for Children with OI (Parents)
11:30AM	12:30PM	Social Networking (Adults)
11:30AM	12:30PM	Water Therapy (Adults & Parents)
11:30AM	12:30PM	Self-Esteem for Young Adults (Young Adults)
12:30PM	2PM	Lunch
2:15PM	3:15PM	Landing the Job You Want (Adults & Young Adults)
2:15PM	3:15PM	How to Exercise Safely (Adults)
2:15PM	3:15PM	Principles of Financial Planning (Parents & Adults)
2:15PM	3:15PM	Promoting Self-Esteem in Your Children (Parents)
3:30PM	4:30PM	Peer to Peer Groups: Group discussions on topics including; parenting your young adult, financial planning, siblings and more
6PM	7PM	Closing Reception
7PM	11PM	Awards Dinner & Dance

Schedule is subject to change



*Young attendees socialize between conference activities*



*Former Board of Directors member Dick Wyman and his grandchildren enjoy the Closing Reception*

## Spotlight: Morgan Dumas

### *A Perfect Fit!*

*Morgan Dumas is a young woman with OI who was recently given the opportunity to meet and have a custom coat designed by Izzy Camilleri, a fashion designer who specializes in clothing for individuals who use wheelchairs.*

Ever since I can remember, I loved fashion and often equated looking fashionable with equality amongst my peers, something that is often hard to achieve while sitting in a wheelchair. Now that I am older, the challenge of finding clothing has become much greater.

In my opinion, the biggest issues to consider when searching for clothes as a woman in a wheelchair are: fit, style and adaptability. If you can find an item of clothing that meets these three criteria then you have hit the trifecta!

Over the years, some of the challenges I have personally encountered are; tops that are too tight fitting for my barrel-shaped rib cage or bunch up when sitting and/or pants that sit too high or low or are just too long for my four foot statue. The worst is coats and dresses, because they just never fit or look like they are supposed to on the mannequins in the stores.

Regardless of these challenges thrust upon me, I am content with the clothing I have found, but finding them did not come without great determination and patience. This often involves several trips to my local shopping mall and more recently, many hours of online scouting. Due to my smaller size and curved spine, many items of

clothing in my closet also had to be altered in terms of the length or adding extra buttons or clasps for items that were too tight or awkward to fasten.

The one piece of clothing I have always desired but was never successful in finding was a wool knee-length trench coat. I have always wanted a coat that was not only chic but looked mature and actually fit while sitting in my wheelchair.

Through a generous university graduation gift from a close friend, I was introduced to designer, Izzy Camilleri who made this dream a reality.

Camilleri is a Canadian designer and creator of the IZ Adaptive label under which she exclusively designs and creates all types of clothing for people in wheelchairs all over the world through her studio in Toronto and her interactive website. The great

benefit of IZ Adaptive clothing is each piece is customized to the person buying it, allowing for a perfect fit.

For our initial meeting, I visited Izzy at her studio in the Junction district of Toronto. It was a very exciting and new experience to visit a studio like this, especially one that had mannequins of people sitting in wheelchairs, rather than the traditional standing mannequins seen in most windows. Izzy greeted me and showed me all her fabulous fashions and explained how the design pattern for each had been adapted for someone sitting in a wheelchair. There were so many different pieces to pick from but as soon as I saw the wool trench coat hanging on display, I instantly knew this was the item I wanted created for me. Once I made my selection, she showed four colour swatches for the coat and after a few minutes of deliberation, I decided on the dark grey, mainly because it was classic and chic and also

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*Designer Izzy Camilleri and Morgan discuss design concepts for her winter coat.*

# Lifestyle

**Spotlight: Morgan Dumas** (continued from page 9)



*Morgan having her custom winter coat fitted.*

would not show the dirt from my wheelchair as easily. Before leaving her studio, Izzy took extensive measurements to ensure a perfect fit. When taking my measurements, she made careful consideration to measure both sides of my body separately due to slight differences because of my scoliosis. This was an exciting experience because I had never had a piece of clothing measured perfectly for me. I usually had to alter the already created piece of clothing to fit my unique body shape.

After the first fitting of my wool trench coat, it was clear why this coat was going to be one-of-a-kind. Even in the initial stages, when I returned back to Izzy's

studio, I was able to slip it on easily and it fit perfectly around me without bunching or pulling. One of the reasons for this was because the back of the coat is cut shorter than the front to allow for ease and comfort in the seated position. During this fitting, Izzy and I worked together to determine where the buttons, belt and pockets would be added onto the coat.

Several days later, I was called back for my final fitting. Upon my arrival, Izzy brought out my finished coat from the back room of her studio (where the clothes are all made on-site) and handed it to me to try on. As I tried my completed coat, I made my way

over to the full length mirror by the fitting room and with only one look, I was instantly thrilled. I never had a coat look so amazing on me and fit so effortlessly – and an effortless fit is incredibly important for people like me with OI to avoid strains or broken bones.

Thanks to IZ Adaptive, wheelchair users, including those of us with OI, no longer have to struggle and choose functionality, accessibility and safety over looking fashionable and stylish – we can have it all!!



*Morgan in her new custom-made Izzy Camilleri winter coat.*

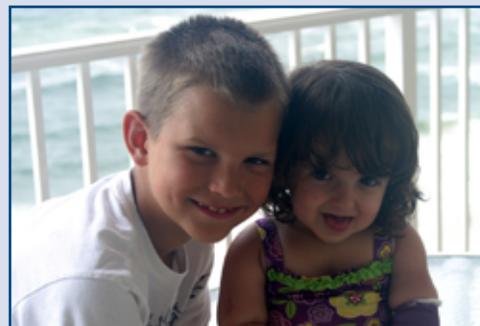
# Lifestyle

## *In My Own Words:* Why I'm Coming to Conference

By Dana Busby, Demopolis, AL

With summer time comes beach trips, zoo trips, and weeks out of school. That is what most people are looking forward to. However, many of us are looking forward to summer for a different reason. It's time for the 2012 National Conference on OI!

For me, along with many others, this will be a first time experience full of excitement, new friendships, and knowledge. According to Kristine Browne, "Of course, we are looking forward to meeting new families and re-connecting with friends, but I'm really looking forward to seminars. I want to learn as much as possible. Besides the obvious swim therapy, rods, PAM, what else can I do for our Sweet Caroline? I know OI is a constant battle and I want to be prepared."



**Aidan and Rhae are excited for their first National Conference!**

I am looking forward to many of these things as well. For the last four years, through the OI Parents Yahoo Heath Group and OI Parents Facebook group, I have developed friendships with many people; some I have met and some I have not. The conference gives me a chance to finally meet many people I consider among my closest friends, as well as catch up with some I have not seen for a while. This is an important aspect of conference, as it helps parents realize we are not alone out there. However, it is not just the parents that benefit. The kids, as well as adults with OI, are able to socialize with others with OI, and for once, not be the only one in the crowd with OI. I am excited for my daughter to spend some time with old and new friends!

With the seminars comes new knowledge! The conference is taking a bit of a turn this year with some of the topics being offered. Not only will there be the standard topics of medical advances and interventions, but this year, focus will also be put on parenting issues, relationships, the IEP process, and ideas for fun physical therapy ideas at home, to name a few. I am looking forward to many of the topics and honestly will find it tough to decide what to attend.

And not to be forgotten are the medical consults the day before the conference begins. I am excited to see a few of those who offer their services for free on this day and get their expert opinions on how my daughter is progressing. What an amazing service this is offered by these individuals and the OIF!

So, as you can see, there is a lot to do at conference. My family is excited about our first conference trip and all that will be accomplished there. We hope to see you and your family as well!

## *In My Own Words:* Why I'm Coming to Conference

By Tracy Thomas, Louisville, KY

In January of 2009 my daughter, Synclaire, broke her leg for the third time. Though I have a great spouse and a great orthopedist I still felt alone and so completely helpless to make my daughter's life better. That is when I started searching for other parents. I found the Yahoo group and then I happened upon the conference information on the OIF website. My family was able to attend the conference in Portland and it was life changing for so many reasons. The doctors were on the cutting edge of research and actually understood that each of our snowflakes is different was amazing. My husband and I learned so much from the sessions, the doctors and the other parents. There were non OI siblings that my 12 year old could hang out with and commiserate! My OI child, Synclaire, had others to talk to and play with and that she could feel normal with. It was only the third time in her life she had ever been around other OI children. For me emotionally it was a time to bond with other moms and feel that even though none of them lived close to me I would always have support.

For all of the reasons above we will do whatever we can to go back to conference next year. This time I think I will be able to take even more in. I will be able to better sort through all the information to glean what I need for my daughter. Conference is a time of learning but it is also a time of celebration that our children are growing and blossoming. It really encourages me to not think about what Synclaire cannot do but to be positive and dream of all the things she will do!!

# \$6.6 Million NIH Grant Awarded for New OI Research

A \$6.6 million, five-year grant from the National Institutes of Health will allow researchers at Baylor College of Medicine (BCM) in collaboration with the University of California at Los Angeles and the University of Washington in Seattle to study newly recognized forms of osteogenesis imperfecta.



*Dr. Brendan Lee*

“There is a whole new class of osteogenesis imperfecta that we need to study to understand from a biochemical and human perspective how they cause bone disease,” said Dr. Brendan Lee, principal investigator on the grant and professor of molecular and human genetics at BCM. Dr. Lee is also the director of the Skeletal Dysplasia Clinic at Texas Children’s Hospital and a Howard Hughes Medical Institute Investigator.

“We’ve known since 2006 that there are other genetic causes of OI beyond Type I collagen. Now we need to understand how they cause bone disease and whether this can lead to more directed treatment approaches,” Dr. Lee said.

New research, first done in Dr. Lee’s laboratory and then followed up by other researchers, has identified six new genes associated with forms of the OI disorder for which no previous cause was known.

“We’re very excited about this collaborative research because it may answer the question as to a common theme or mechanism that is the cause of this disorder. It may also lead to a common final pathway,” Dr. Lee believes.

The NIH grant will enable the researcher to go beyond the common mechanisms that link to OI, and to eventually improve current treatment methods, he said.

Some of the current approaches to treating OI, such as bisphosphonates, are promising, according to Dr. Lee, but do not address the underlying problem.

One part of the new study will include understanding the various genetic and biochemical aspects of OI. Another part of the research will use techniques through BCM Human Genome Sequencing Center to identify new genes and another will test possible therapies, he explained.

Drs. Deborah Krakow and Don Cohn at UCLA and Dr. David Eyre of the University of Washington will join Dr. Lee in this important collaborative five-year research study.

# People & Events

## Nominate a Deserving Volunteer!

Do you know either a young person or adult who has contributed their time in 2011 to improve lives in the OI community? How about a long-term volunteer who has done important work for the OI Foundation for 10 years or more?

If so, nominate them to receive one of the OI Foundation's top volunteer awards! Forms are available at [www.oif.org/HH\\_volrecognition](http://www.oif.org/HH_volrecognition) or request one by e-mailing [Development@oif.org](mailto:Development@oif.org). All nominations must be received or postmarked no later than March 15, 2012.

The OI Foundation is accepting submissions for three awards. In each case, we seek candidates who have served the OI community or Foundation in one or more of the following areas: awareness, education, volunteerism, fundraising and advocacy.

**Thelma Clack Lifetime Volunteer Award**—The recipient of the Thelma Clark Lifetime Volunteer Award will be someone who has served the OI community for ten or more years. They give their time without thought of reward or recognition demonstrating a spirit of willingness to put others before self, as demonstrated by the late Thelma Clack.

**Peter Dohm Junior Volunteer Award**—The Peter Dohm Junior Volunteer Award is given to the outstanding youth volunteer(s) of the past year. The winner(s) will be 18 years old or younger at the time of his or her service.

**President's Award (Volunteer of the Year)**—The President's (Volunteer of the Year) Award is given to the outstanding adult volunteer of the past year. This will be an individual who best exemplifies the qualities of volunteer service to the Foundation and the OI community. The winner will be an adult 19 or older who represents people with OI positively within their community.

Don't let someone's dedication and hard work go unrecognized! Complete an OIF Awards Nomination Form and send it in before March 15!



*Peter and Gretchen Strauch of Montville, NJ, pictured with daughter Shannon (center), were winners of the 2010 Thelma Clack Lifetime Volunteer Award.*

# People & Events

## Wear Your Blue Jeans on Friday, February 24th!



Looking for a fun and easy way to make an impact and support countless children, teens and adults in the OI community? Plan a **Blue Jeans for Better Bones Day (BJBB)** within your office, school, church and/or organization on **Friday, February 24th**.

A Blue Jeans for Better Bones Day is a quick and easy fundraiser which aids the OI Foundation in its continued efforts to be your go-to source for up-to-date, medically verified information and funds research and educational programs like the upcoming National Conference on OI.

Participants shed their business suit or uniform for a day and wear their favorite blue jeans, blue shirt or even blue hat by making a donation of \$3, \$5, or more. Have fun while generating support and awareness of osteogenesis imperfecta.

Not able to plan a BJBB day on February 24th? No problem! Plan your BJBB day during **OI Awareness Week** scheduled from **May 5th – May 12th**.

Contact Development Coordinator Alisha Matlock at [amatlock@oif.org](mailto:amatlock@oif.org) or 1-800-981-2663 to receive a free BJBB kit. Each BJBB kit includes suggested guidelines, stickers or wristbands, and fliers. **Sign up today!**

## Osteogenesis Imperfecta Awareness Week 2012

Events are already being planned across the country to commemorate the 2nd national OI Awareness Week scheduled from May 5–12, 2012. Join the OI Foundation and hundreds of volunteers as we take steps towards increasing awareness. OI Awareness Week is held in conjunction with **Wishbone Day** on May 6, an international community awareness effort. For more information about **Wishbone Day**, visit [www.wishboneday.com](http://www.wishboneday.com).



The excitement generated for Awareness Week last year was truly inspirational, creating interest around what this year will bring. Events ranged from walks, and marathons to yard sales, touching thousands of neighbors, co-workers and friends across the country.

Together we can continue to educate the greater community, leading to additional funding towards research programs and vital information and resources for our caregivers, doctors, nurses, teachers, and the OI community.



Take part in an activity already scheduled in your town or bring the excitement to your community by planning your own event. Your activity can be as simple as setting up a Blue Jeans for Better Bones Day at work, school, or church. Or, you can organize an Unbreakable Spirit Walk for OI, rummage sale, dinner or other activity of your choice! For a complete listing of events happening across the country, visit [www.oif.org/awarenessweek](http://www.oif.org/awarenessweek). Please check back often as the list continues to grow!

Have questions or ideas on how to increase awareness that you would like to share with the OI Foundation? Contact Development Coordinator Alisha Matlock at 1-800-981-2663 or [amatlock@oif.org](mailto:amatlock@oif.org).

[www.wishboneday.com](http://www.wishboneday.com)

# People & Events

## Meet Me! The OIF Welcomes New Staff Members

Welcome to the OI Foundation's newest staff members, Petra Harvey and Alisha Matlock!



**Petra Harvey**  
Health Educator

As the OI Foundation's new Health Educator, Petra's primary responsibility will be to provide information about OI to constituents and the general public. Petra will be responsible for the preparation and distribution of education materials that reflect the many needs of people living with OI. She also manages the OI support groups and maintains databases, mailings lists, telephone networks, online social networks and other

information to facilitate the functioning of the health education program.

Very similar to Petra's current position with the OIF, her previous work with the DC, Maryland, and Virginia Chapter of the Lupus Foundation of America has given her extensive experience in research analysis, oral/written communication, and general support in the development and health education departments. Petra graduated from The College of William and Mary three years ago with a bachelor's degree in Community Health. She is very excited about fulfilling her role in the mission of the OI Foundation and thrilled to meet more people from the *Unbreakable Spirit* community.

Also new to the OI Foundation staff is Development Coordinator Alisha Matlock. As the Development Coordinator, Alisha will be responsible for the coordination and support of fundraising and awareness campaigns by membership and members of the OI community. She will also support member-driven and board-driven fundraising efforts.



**Alisha Matlock**  
Development Coordinator

Alisha graduated from Howard University with a bachelor's degree in marketing and gained much of her experience with fundraising, volunteer recruitment and event planning at the National Center for Children and Families (NCCF) where she served as the Director of Volunteers & In-Kind Resources for four years. Her desire to support others while making a difference in the community steered her in the direction of the OI Foundation. She is eager to meet and work along with the Foundation's lineage of supporters as well as its newcomers.

Welcome, Petra and Alisha!

## Mark Your Calendars!



**12th Annual Fine Wines Strong Bones**  
Saturday, May 5, 2012  
5:00 pm – 9:30 pm  
Sheraton National Hotel, Arlington VA 22204

Join the OI Foundation at its 12th Annual *Fine Wines Strong Bones* event. This year's theme is Kentucky Derby, so guests will watch the most exciting two minutes in sports while donning their favorite hats. The event will also feature over 100 silent and live auction items and delectable hors d'oeuvres and fine wines from around the globe.

Don't miss this unique and fun opportunity to enjoy great company and food, while supporting the OI Foundation and community. We look forward to seeing you there!

Visit [www.oif.org/FineWines](http://www.oif.org/FineWines) for additional information. Please contact Alisha Matlock at [amatlock@oif.org](mailto:amatlock@oif.org) or 1-800-981-2663 with questions, to make a donation to the silent auction, or to purchase your ticket.

# People & Events

## Congratulations, Sweepstakes Winners!

Four friends of the OI Foundation found something a little extra in their holiday stockings this year.

They were each selected as prize winners during the 2011 "Going Places" Sweepstakes, during random drawings held on November 30 and December 21.

Members of the OI community submitted almost 4,300 Sweepstakes entries this autumn, and supporters contributed more than \$18,000 to benefit the OI Foundation's mission.

The OI Foundation thanks everyone who participated, and we congratulate the following prize winners:

**Grand Prize:** Batzion Berman of Hollywood, FL, won a 3- or 4-Day Cruise for Two to a destination of her choice.

**Early Bird Grand Prize:** Rebecca Ann Callighan of Rocky Hill, CT, received an 80" x 80" cotton quilt donated by the Dear Jane Quilting Guild of Clinton, NJ.

**2nd Prize:** Michele Tooker of Rochester, MN, will enjoy her new Amazon Kindle Wi-Fi with free 3G and a leather case.

**3rd Prize:** Sherry & Bob Runco of Bellefonte, PA, will travel a bit less expensively with \$200 in gasoline gift cards, contributed by the Finkel Family of Indianapolis, IN.



*Volunteer Lisa Lamari (left) and Mallory Werth of the auditing firm Thompson, Greenspon & Co. conducted the drawing on December 21 for the Grand, 2nd and 3rd Prize winners.*



## Have You Ordered Your Bone China Tea Invitations?

This year's Bone China Tea is scheduled for March 21. Are you ready?

As many of you know, Bone China Tea is a 'phantom' or virtual event that people participate in from the comfort of their own home. Guests receive invitations to sit down for a cup of tea at home on March 21st and then make a donation to the Foundation with the money saved by not attending a live event.

Printed invitations are free and even come with a tea bag! We need you to help the OI Foundation have the resources necessary to fund research and respond to urgent requests for information from individuals and families! Please help us exceed the \$32,000 raised by 46 'hosts' in 2011.

### There are two ways to become involved:

- Order printed invitations and send them to family, friends, co-workers and neighbors, or
- Register on the OIF web site and use your personal web page to send e-mails.

**To learn more:** Please join us for a Web conference on Tuesday, January 31 at 8 p.m. Eastern. Bone China Tea Chairs Jennifer Wilson and Susan Wilson and Director of Development Stuart Tart will provide tips for success with printed invitations and offer step-by-step instructions for using the online system. Simply e-mail Stuart at [Development@oif.org](mailto:Development@oif.org) to learn how to log in. You also can find the information you need at [www.oif.org/HH\\_BoneChina](http://www.oif.org/HH_BoneChina).

**To order free printed invitations:** Contact Jenny and Susie at [jnwilson@aol.com](mailto:jnwilson@aol.com), [OISLW@aol.com](mailto:OISLW@aol.com), or (239) 482-0643. Just let them know how many invitation packets you will use and where to send them. Please also include an e-mail address and phone number where you can be reached.

# People & Events

## Are You a Member of the OI Foundation?

The OI Foundation owes much of its strength to the many loyal, supportive individuals in the community who donate their time and/or make gifts. Thank you!

However, membership places you in a special category of supporters, as defined by the OI Foundation's bylaws. Please do a little extra to move forward the OI Foundation's mission this year **by becoming a member or renewing your membership during our annual Membership Campaign in February and March!** You can sign up at [www.oif.org/BecomeAMember](http://www.oif.org/BecomeAMember) or by responding to our membership letter.

"I became an OI member because of the support the (OI Foundation) gives their members and families," Karen Vowell of Ohio explained. "I felt it was also important for me to support the foundation to give back to them for all they had done for me and my family throughout the years."

### What is Membership?

"Membership in the OI Foundation is open to all people who support the mission of the OI Foundation," according to our bylaws. How do you become a member? Our bylaws indicate that "A membership shall become effective upon receipt of dues at the OI Foundation headquarters office."

You can become a member of the OI Foundation for as low as \$30 for the year, and a family membership is available for \$60.



**Karen Vowell and husband Glenn of Ohio became OI Foundation members because they felt it is important "to give back ... for all (the Foundation) had done for me and my family throughout the years."**

"I became a member of the OI Foundation as a way of showing solidarity and making a small financial contribution to much needed research funds," said Sharon Werner of Connecticut, whose son Josh lives with OI. "We started a small support group in our area with the intent of helping others, but instead we have been blessed by the people in our group."

She added, "With OI being such a rare disease we need every person touched by OI to become a member of the OI Foundation to increase awareness, improve the quality of life for people with OI and create opportunities for funding research. Remember "The squeaky wheel gets the grease." Make your voice heard through your OI Foundation Membership!"

### What are the Benefits of OIF Membership?

Membership gives you a voice in the OI Foundation's future. Specifically, members enjoy voting privileges in our annual elections for the Board of Directors. In addition, they are invited to a special Annual Meeting, where the leadership of the OI Foundation updates members on the organization's accomplishments and future directions. This meeting is often offered by telephone and Web Conference, so that individuals can participate from across the country.

In addition, members receive:

- A membership card,
- Special membership designation on OI Conference nametags,
- Recognition in the Annual Report, and
- A special gift (to be announced).

### Please Join

The OI Foundation counts on your membership to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI.

"Anyone who knows someone with OI, has a family or friend with OI, or is living with OI should become a member," urged Karen. "The support the foundation gives to everyone is very valuable, and the foundation needs others to support them to continue."

Please join or renew your membership today at [www.oif.org/BecomeAMember](http://www.oif.org/BecomeAMember)!

# People & Events

## *Author's Corner*

**Information about authors and books connected to living with OI**

**Book Title: *No Easy Choice: A Story of Disability, Parenthood, and Faith in an Age of Advanced Reproduction***

**Author: Ellen Painter Dollar**

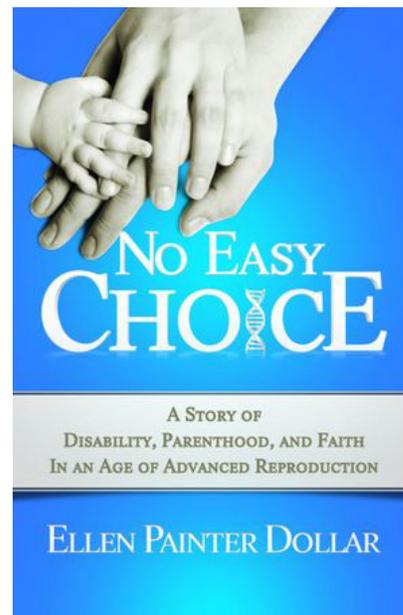
In ***No Easy Choice***, Ellen Painter Dollar tells her story of living with osteogenesis imperfecta (OI)—a disabling genetic bone disorder that was passed down to her first child—and deciding whether to conceive a second child who would not have OI using assisted reproduction. Her story brings to light the ethical dilemmas surrounding advanced reproductive technologies. What do procedures such as in vitro fertilization (IVF) and preimplantation genetic diagnosis (PGD) say about how we define human worth? If we avoid such procedures, are we permitting the suffering of our children? How do we identify a “good life: in a consumer society that values appearance, success, health and perfection?”

Dollar considers multiple sides of the debate, refusing to accept the matter as simply black and white. Her book will help parents who want to understand and make good decisions about assisted reproduction, as well as those who support and counsel them, including pastors and medical professionals. This beautifully written and thoroughly researched book combines a compelling personal story, with clear explanations of the science involved in reproductive technologies and reflections on the ethical questions faced by parent today.

Ellen Painter Dollar is a writer, wife and mother of three. She is also a person who has OI. She has written about faith, motherhood, and disability for a variety of organizations and blogs including the American Medical Association and the OI Foundation.

***No Easy Choice*** was published on January 17, 2012. It is available for purchase from many online book retailers including Amazon and Barnes & Noble.

*Disclaimer:* This information is provided as a service. The OI Foundation did not participate in the preparation of this book. All of the information and opinions expressed in this book is the responsibility of the author. Readers are encouraged to contact [Bonelink@oif.org](mailto:Bonelink@oif.org) to suggest a book or author to include in future columns.



## People in the News

**People living with osteogenesis imperfecta are making headlines, and increasing awareness about OI and showing their Unbreakable Spirit!**

**Mark Baker**, an adult living with OI, was recently featured in the *Winston-Salem Journal* announcing his plans to run for the Forsyth County Board of Commissioners. Mr. Baker is the high school principal at Salem Baptist Christian School in Winston-Salem and is serving his second term as a Tobaccoville council member.

**Dan McCarty**, an eight year old with OI, was given the opportunity to appear in a photo shoot with The Brunswick Players of the Professional Bowlers Association 2011 World Series of Bowling. Dan befriended one of the players and was invited to attend the World Championship. The event, which aired on ESPN in early January, quickly spotlighted Dan in his yellow jersey, cheering on his team.

**Kayla Smoot**, a fourth grade student with OI, was selected the 2011 Official Christmas Tree Lighter of Hoover, Alabama. Past lighters have ranged from National Merit semi-finalist students to students battling cancer. Kayla's principal, who recommended her to the selection committee noted that she was a trooper, a very sweet child, and very well-liked by her peers and teachers.

**Mady Chidester**, a twelve year old student with OI, was chosen by Special Spaces Houston and a

couple of other collaborating local community organizations to have her dream bedroom built. Special Spaces Houston is the Clear Lake branch of the national non-profit organization that designs dream bedrooms for children with disabilities and life threatening illnesses. A few of the things she requested was "Justin Bieber paraphernalia, a TV, and a place to put her makeup."

Congratulations to **Robert Steiner, MD**, a member of the OI Foundation's Medical Advisory Council, who has been named Deputy Editor for the medical journal, *Genetics in Medicine*, the official journal of the American College of Medical Genetics. The American College of Medical Genetics is the largest professional association of medical geneticists in the United States. Dr. Steiner is a professor, in the department of Pediatrics and Molecular and Medical Genetics at the Oregon Health Sciences University School of Medicine in Portland, OR.

## Health & Wellness

### FROM THE INFORMATION CENTER

#### Report: Growing Up with Brittle Bones

Last summer, the worldwide OI community responded in record numbers to a call for research on the mental health of children and teens with OI. Over 500 individuals responded to the OIF's call for participants and 246 parents met requirements for inclusion in this study. Kara Ayers PhD, principal investigator of the study "Growing up with Brittle Bones," expresses her gratitude for the impressive response and reports that a number of important findings have resulted from the research.

This study investigated the relationship between age and type of OI to psychosocial adjustment. It also examined the impact that having a parent with OI or receiving pamidronate has on one's developing psychosocial health. Analysis of the data revealed that one's age or type of OI does not predict psychosocial adjustment. Having a parent with OI may be a useful protective factor to the psychological development of children with OI and despite the assumptions of many medical researchers, that pamidronate is not associated with gains in psychosocial health. "This will allow us to better guide families as they find ways to support the psychological and social development of their children with OI," states Dr. Ayers. "This study was the first of its kind because rather than simply compare the

psychosocial development of children with OI to typical children, we sought to better understand the unique resiliencies and strengths within our community." Dr. Ayers will present her results and implications for these findings in upcoming publications and at OI Foundation National Conference this summer in Washington, DC. She can be reached at [writkara@gmail.com](mailto:writkara@gmail.com) for more information.



**Dr. Laura Tosi**

#### Thank You From the Adult Health Study Team

Dr. Laura Tosi, principal investigator for the Adults Health Initiative Study (ANHI), and the research team want to extend their deepest thanks to the OI community for the outstanding response to the Adult Health Survey. During the time the survey was open, 854 people completely filled

it out. Now that the survey has closed, the team is working to analyze the data. Results will be presented at the OI Foundation's scientific meeting in April 2012 and at the National Conference in July 2012. A summary will be posted on the OIF website in late April.

## Q&A

### Research Update: Bisphosphonate Treatment and Adults with OI— Two New Studies

By Jay Shapiro, MD



**Dr. Jay Shapiro**

In the United States, the bisphosphonate family of drugs now includes four oral and two intravenous drugs. Names such as Fosamax (alendronate), Actonel (risedronate),

Aredia (pamidronate) and most recently Reclast (zoledronic acid) have become familiar to people who are concerned about bone health. Originally used as treatments for bone loss related to cancer and cancer treatment, in 1973 bisphosphonates were identified as a treatment for age-related osteoporosis. By the middle of the 1980s groups from around the world began investigating these drugs as a treatment to decrease fracture risk in children and adults with OI. Studies have typically looked at bone mineral density of the hip and spine as a way to measure increases in the amount of bone in the skeleton. It has been assumed that more bone, even poor quality OI bone, will result in fewer fractures.

The widespread use of bisphosphonates in adult osteoporosis and as a treatment for children with OI led to its use in adult OI. However, unlike in children,

the effect of bisphosphonates on adult OI has not been thoroughly studied. There are a limited number of reports on clinical trials of bisphosphonates in people age 18 years and older.

Two recent studies provide new information on the effectiveness of bisphosphonates in decreasing fracture rate in adults. These studies suggest that the type of OI affects the response to bisphosphonate treatment and that in most cases fracture rate was not improved.

Shapiro et al. (United States 2010) in a non-randomized study reported the results of 90 OI adults treated with intravenous pamidronate (28), oral alendronate (10) oral risedronate (17), or not treated (35). There were 63 type I, 15 type III, and 12 type IV OI patients. Bone mineral density (BMD) results were observed for an average of 52 months of treatment.

In the Type I group, bone mineral density of the spine increased with either pamidronate or oral bisphosphonate treatment. Hip BMD only increased in with oral bisphosphonate treatment.

In the Type III/IV group, bone mineral density of the spine increased with pamidronate treatment. Significant increases in total hip BMD was seen in people receiving either pamidronate or an oral bisphosphonate.

Bisphosphonate effect on fracture rate was assessed for five-year periods before and after treatment in 51 treated and 22 non-treated individuals matched for age at which bisphosphonate was first administered to the treated group. Bisphosphonate treatment did not decrease fracture rate in Type I OI patients. There was a marginally significant decrease in fracture rate ( $p=0.05$ ) in Types III/IV patients following pamidronate, but not following oral bisphosphonate treatment.

These results suggest that people with different types of OI have different responses to bisphosphonate treatment. These results also underscore a need to consider whether IV bisphosphonate treatment is appropriate for all adults with OI.

Consistent with the results above, Bradbury et al (Australia, 2011) reported the effect of risedronate in 32 adults with type I OI. Risedronate resulted in modest but significant increases in BMD at the lumbar spine. However, in these patients, the high fracture rate continued.

In summary, limited data published to-date suggests that unlike the response in many children, bisphosphonates, either oral or IV, do not decrease fracture rate in adults with Type I OI. Pamidronate may have a marginal effect on fracture rate in Type III and IV OI but the number of people who have been studied are small. These studies do not look at other possible benefits of taking these medicines.

In light of this information, adults considering treatment with bisphosphonates should discuss treatment options with their physicians.

The study titled “Bone Mineral Density and Fracture Rate in Response to Intravenous and Oral Bisphosphonates in Adult Osteogenesis Imperfecta” by Jay Shapiro, C. Thompson, Y. Wu, M. Nunes and C. Gillen was published in the August 2010 issue of *Calcified Tissue International*.

“Risedronate in Adults with Osteogenesis Imperfecta Type I: Increased Bone Mineral Density and Decreased Bone Turnover, but High Fracture Rate Persists,” by L. Bradbury, S. Barlow, F. Geoghegan, R. Hannon, S. Stuckey, J. Wass, R. Russell, M. Brown and E. Duncan was published in the January 2012 issue of *Osteoporosis International*.

# *In Memory Of*

November 1, 2011 – December 31, 2011

**Kathy H. Alsum**

Mr. Ronald Alsum  
Ms. Bev Anderson  
Ms. Marlene DeYoung  
Larry & Linda Dykstra  
Lawrence & Angela Dylak  
Mrs. Mary Hansen  
Clinton & Harriet Robson  
Philip & Cheryl Herfort  
Jason & Jean Syens  
Ms. Mary Jo Wentz

**Melissa Marie Brooks**

James & Patricia Brown  
Thomas & Sandra Thurlow

**Lorraine M. Burke**

Mrs. Suzanne Burke  
Ms. Megan Sayago  
Ms. Erin White

**Judd Daniels**

Ms. Angela Daniels  
J & D Oil, Inc.  
R.J. Daniels Fuel & Tire

**Jeremy Dickinson**

Robert & Rebecca Dickinson

**Mary P. Dillon**

Mr. Carl Bergman  
Mrs. Mary Ellen McCollom

**Roben Dudek**

Ms. Patricia Klebes

**Anthony Giusto**

George & Gail Bunker

**John C. Harris**

Wilbur & Nancy Harris

**Jace Ryan Jones**

Kenton & Marilyn Thompson

**Jackson Koal Jones**

Jeff & Kelly Povroznik Jones

**Ilene McBride**

Mr. Ralph Jakoby  
Mr. Paul J. O'Connor

**Persephone Grace Olds-McKinney**

Ms. Michelle Hagenson  
Ms. Shelly Retikis  
Ms. Cathie Schmit

**Zayana Grace Mendez**

Ernesto & Christina Mendez

**William J. Mullen**

Developmental Services Center  
Ms. Barbara Pritchard  
Derek & April Reynolds

**Simon P. Nadeau**

Ms. Judith Ernst  
KC Coombs School-Sunshine Fund  
Paul & Joann Nadeau

**Jeffrey L. Nelson**

Tim & Susan Pardy

**Brenda Rakolta**

Steve & Linda Selman  
Mr. & Mrs. Donald Wedding

**Peter David Ray**

David & Sharon Ray

**Mary C. Richard**

Mrs. Gemma Geisman  
Mrs. Debra Giles  
Mrs. Rosalind James  
Tim Dombro & Jamie Kendall  
Mr. & Mrs. Richard Putney  
Ms. Susan Wilson

**Angelo Schwartz**

Rachael & Brian Schwartz  
Malcolm & Sandy Smith  
Ms. Robin Smith

**Paul Silverstein**

Seymour & Faye Bross

**Kate Skram**

Mr. Ronald Alsum

**Alma D. Strauch**

Mrs. Gladys Strauch

**Alex John Thompson**

John & Angela Thompson

**Phillip John Todd**

Mr. William Brady  
Ms. Elaine Dillon  
Stephen & Miranda Hires  
Mrs. Sinclair Lee

**Owen Mark VanDenBergh**

Ms. Andrea VanDenBergh

**James Wells**

William & Phyllis Weiss

**Shaun Whitmore**

Ms. Elizabeth Jones

# *In Honor Of*

November 1, 2011 – December 31, 2011

**Ruth Abels**

Mr. David Abels

**Ed Adcock**

Gerald & Dixie Hertel

**Olivia Alexander**

Ms. Susan Alexander

**Nicholas Anderson**

G.W. Carver Center For Arts & Technology

**Joe Antolini**

Ms. Kristen Antolini

**Dr. Kara Ayers**

Robert & Donna Ayers

**Mr. & Mrs. Donald Barringer**

W.C. and Evelyn Barringer

**The Benish Family**

Mr. Howard Kraus

**Cullen Binnicker**

Mr. Woody Binnicker, Jr.

**Dylan Breen**

Betty & Larry Hannan

Mr. Harvey Spielman

**Alec Cabacungan**

Gil and Alma Cabacungan

**Miss Sarah Calmus**

Mrs. Terilyn Esse

**Allie Cannington**

John & Diane Eckstein

**Jackson Carter**

Ms. Marcia Carter

**Alle Shea Collazo**

Kim & Angelo Collazo

**Dom & Fran Confetti**

Neno & Betty Battaglia

**The Cramer Family**

Glen & Mary Ricard

**Jenna Cummings**

Knights of Columbus

**Tim Dombro & Jamie Kendall**

Ms. Amy Dombro

Mrs. Peg Dombro

**Lee Ann Dozier**

Neno & Betty Battaglia

**Jacob Everett**

Hardwood Creations

Robert & Debra Harwell

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# Breakthrough

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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