

Breakthrough

THE NEWSLETTER OF THE OSTEOGENESIS IMPERFECTA FOUNDATION

OSTEOGENESIS
IMPERFECTA
OI
FOUNDATION

Vol. 36 No. 4 Winter 2011

Unbreakable Spirit

Follow us on Twitter
www.twitter.com/OIFoundation

11th International OI Scientific Meeting Held in Dubrovnik, Croatia

One hundred fifty people from 30 countries, including the OI Foundation's CEO Tracy Hart, attended the *International Conference on OI* from October 2-5, 2011 in Dubrovnik, Croatia. Dubrovnik, on the Adriatic coast, provided beautiful scenery for this important scientific meeting held every three years in a different country in Europe or North America. The meeting explored topics from leading OI researchers and scientists including members of the OIF's Medical Advisory Council (MAC). MAC member Dr. Joan Marini chaired the meeting's scientific committee, which selected 46 podium presentations ranging from the current research activities in the most prominent laboratories around the world to the broad spectrum of clinical situations that physicians may have to manage. Dr. Marini and MAC chair Dr. Francis Glorieux presented keynote lectures titled "New Perspectives on Osteogenesis Imperfecta" and "Understanding Pathophysiology and Defining Treatment in OI: From the Past to the Future," respectively. In addition, Dr. Hans Peter Bachinger presented an exciting guest lecture on the latest information on the collagen prolyl 3-hydroxylation complex, in which defects cause the most common forms of recessive OI.



Delegates of the 11th International OI Scientific Meeting held in Dubrovnik, Croatia.

continued on page 8

New Look for www.oif.org!



Thanks to the generous contribution from a member of OI Community, the homepage of www.oif.org will feature a new look soon! The new homepage features easier navigation for users, new photos, and an updated layout. In addition to the new homepage, a "Meet Me" section has been added to the website. The "Meet Me" section will profile members of the OI Community, and their stories. www.oif.org receives 16,000-20,000 unique visitors every month.

In this issue...

President's Message.....	2
From the CEO.....	2
Lifestyle.....	3
Science & Research	9
Countdown to Conference	10
People in the News.....	20
Health & Wellness.....	22
From the Information Center	25
Q&A.....	26
Honor Gifts/Memorials	27

OSTEOGENESIS IMPERFECTA



BOARD OF DIRECTORS

PRESIDENT

Sharon Trahan

FIRST VICE PRESIDENT

Mark D. Birdwhistell

SECOND VICE PRESIDENT

Caren Loguercio, Esq.

TREASURER

Anthony Benish

SECRETARY

Michelle M. Duprey, Esq.

MEMBERS

Kristen D. Antolini, Esq.

Amanda G. Bergman

Gil R. Cabacungan, III

Jody W. Cheek, M.Ed.

Anna C. Gualano

Greg Holman

Alcides Ortiz, Esq.

Carolyn Redford Tipton

Ian Sacks

Robin Wright, G.G.

CHIEF EXECUTIVE OFFICER

Tracy Smith Hart

MEDICAL ADVISORY COUNCIL CHAIR

Francis Glorieux, OC, MD, Ph.D.



From the Chief Executive Officer

Dear Friends:

In this issue of *Breakthrough* you will find an article about the OI International Scientific Meeting held in Dubrovnik, Croatia, in October. The meeting was excellent, filled with new information on topics like surgical interventions, bisphosphonate therapy and bone biology. The meeting was attended by physicians, researchers and scientists from all over the world and the United States was well represented by the very best in the OI research community, including members of the OIF's Medical Advisory Council.

Before the scientific meeting began I had the opportunity to spend a day and a half with some very special people from countries like Germany, Norway and Switzerland—the delegates from the Osteogenesis Imperfecta Federation—Europe. Led by OIFE president Ute Wallethin and Vice-President Taco van Welzines, the delegates met to discuss issues that are important to them in their everyday lives including access and delivery of care for people with OI. They passionately talked about the underserved in many countries and how the OIFE could make a difference in their lives. I learned so much from my new friends from all over the world and am anxious for the next time we can all be together. They wanted me to share with you all how happy they would be to meet people from the United States during travel to any country with an OIFE organization. If you would like more information on the OIFE, please visit their website at www.oife.org.

Since this will be my last note to you in 2011, I want to wish everyone a wonderful and safe holiday season and a very happy new year! I'm looking forward to seeing many of you in 2012 at various events and activities and especially at the conference in July!

All my best,

A handwritten signature in blue ink, reading "Sharon Trahan".



From the President

Dear Friends:

At the recent OI Foundation Board meeting, a key topic of conversation was the Foundation's biennial National Conference coming this July. We heard about plans in process to accommodate over 600 people in Washington, DC, on July 13-15, 2012.

One of the discussions you might be interested in included the cost of the conference. Many organizations similar to ours use their conferences as fundraisers; they take the actual cost of the conference and use that as a starting point in setting their individual registration costs. The OI Foundation's biennial Conference has always been subsidized by the OI Foundation. For the 2010 Conference, the registration fee per person was *less than half* of the actual cost per person that the Foundation paid. Most of you will be pleased to know that we have decided to continue this tradition!

When we determined the registration fees for our 2012 Conference, we took the cost of the conference per person, and again, have set the fees significantly below that cost. I think it's important to realize that in addition to funding access to information, support and research (see the strategic plan on the website for more details about how we spend your money) we also spend a significant amount of money helping people come together at our biennial conferences.

This does attract attention to the "generating revenue" piece of the strategic plan; we rely on individual donations and fundraisers and are working to make corporate grants a bigger piece of our revenue picture. If you are donor to the Foundation, THANK YOU! If you haven't donated to the Foundation yet, consider making a gift, and if you have ideas for revenue generation, let us know!

Registration fees and information for the 2012 Conference will be posted on www.oif.org and in the edition of *Breakthrough* this February.

Please plan to spend a couple of days in Washington, DC next summer attending medical consultations, advocating for the OI Foundation on Capitol Hill, attending a wide variety of sessions, and having fun!

I'm looking forward to seeing you on July 13th!

A handwritten signature in blue ink, reading "Sharon Trahan".

Spotlight: Tiphannie McNiff

Living with Osteogenesis Imperfecta has not stopped Tiphannie McNiff from living her dreams. For the past four years, she has cheered and danced during NFL games as a member of the Oakland Raiderettes squad.

In fact, Tiphannie said that she didn't learn that she had OI until she was 9 years old. After she shattered her arm doing a backhand spring during a gymnastics lesson, doctors determined that Tiphannie had OI when she went into surgery. Subsequent testing revealed that OI runs in her family, affecting Tiphannie, her mother and her grandmother.

"Before we just thought I was clumsy," Tiphannie explained. "After my bad break, they tested my mom as well. She had broken multiple bones and weren't sure what the cause was.

The oldest child of three, Tiphannie is from Fresno, CA, and currently lives in the San Francisco Bay area.

How did you become part of the Oakland Raiderettes? Did you need a lot of gymnastics and cheerleading experience prior to your audition?

I became an Oakland Raiderette four years ago. I auditioned, and it was quite difficult as there was an interview component as well as dancing.

Prior to being a Raiderette, I was a cheerleader in high school and danced all my life, and I've always wanted to do this. You do need dance experience to be part of the Oakland Raiderettes. We have girls who were competitive gymnasts, dancers, and high school cheerleaders, but you do need to have some dance background.



Photo courtesy of Oakland Raiders team photographer Tony Gonzales

Tiphannie (left) and the Oakland Raiderettes performed with various high school cheerleading teams during the recent High School Spirit Explosion half time performance at O.co Coliseum.

What are some of the most exciting things that have happened since you have been a Raiderette?

I think the most exciting thing was when I had the opportunity to travel to Iraq and Kuwait. We were there for two weeks and performed for the (US) troops.

Second to that, I was selected to cheer at the Euro Bowl, which was in Austria. This was American football played by European teams game, and the Euro Bowl is equivalent to the Super Bowl here in the United States. Our sister team, the Swarco Raiders, were in this championship contest, and they won.

Has your OI had any effect on your experience as part of the squad? Do you do anything differently to accommodate for the possibility of injury?

I think having my bone disease means that I need to take precautions and I know my limitations, but it never really has limited what I do as part of the squad.

I have been really blessed to be part of an organization that accepts me as I am. I have been lucky they have been so supportive. I even cheered in a cast last week. I taped my pom poms to my cast.

You've got to be inventive. The hard part was water-proofing it (my cast), since it rained. I used duct tape to avoid water damage.

How did OI impact your life when you were growing up?

Having OI growing up, I was always known as the girl with the cast. I've broken over 20 bones ... I've lost count at this point.

I worried it would limit what I could do. I was lucky to have such supportive parents who encouraged me to pursue my dreams.

My mom would decorate my cast every day with (colored) Coban Wrap to match my outfit. That was before they had cool colors for casts.

Recently I ran into a girl who went to elementary school with me. She said, "You always had the coolest casts. I wanted to break my arm!"

Who had the biggest influence on you when you were growing up?

My mom has been my biggest fan. She encouraged me to follow my dreams and made it okay to have broken bones. She encourages me to

continued on page 4

Lifestyle

Spotlight: *Tiphonie McNiff* (continued from page 3)

keep dancing, and we never really let our bone disease stand in the way of what we want to do.

What are your interests outside of cheerleading?

I don't have a ton of free time. I like spending time with my family and being with my dogs. We have three Great Danes, and we like taking them out. They look like miniature horses, so it is really funny.

What's the one thing about you few people know?

To be honest, most of my teammates didn't know I had OI until recently.

Most people don't know that about me because I am so active – I teach dance, coach the Fresno State Dance Team. So, people don't know it until you have a cast on.

What are you most proud of?

I am most proud of the fact that I was able to achieve all my goals even though I had obstacles standing in the way, and I didn't let my dreams slip away because I was afraid that I would get hurt.

What are your plans for the future?

Someday I would like to be the director of a professional dance team,

whether it is a football, basketball or college cheering team. I also want to keep doing what I love to do, which is dance.

Is there something you want to say to young people in the OI community?

I would say to never give up on your dreams and never let your disease stand in the way. Having OI doesn't define the person you are, it is just something that affects you.



Photo courtesy of Christopher May, Kennedy Krieger Institute

Stuart Tart, Anat Haimovici, and Dr. Jay Shapiro pose next to a plaque memorializing Miriam Haimovici, who passed away as a baby from OI-related complications in 1974. Mrs. Haimovici toured the Kennedy Krieger Institute in Baltimore in August, after making a contribution to the OI Foundation in support of KKI's work as an OI Linked Clinical Research Center.

Spotlight: Corina Gutierrez

My name is Corina Gutierrez. I am a motivational speaker and a Zumba Fitness instructor. I have spent my life confined to a wheelchair physically, but never in my heart, mind, and soul. I've realized that my biggest disability was not the fact that I was unable to walk, but it was not walking in my purpose. I share my story in hopes that it would encourage you to believe that there are possibilities in seemingly impossible situations. To get you to believe that the only limitations we have are the ones we put on ourselves.

I was born with a brittle bone condition called osteogenesis imperfecta (OI); therefore, am 3 feet tall and I use a motorized wheelchair to get around. I also have severe scoliosis and asthma. Born at 4lbs, with a heart murmur, a fractured arm and leg, dislocated hip and shoulder, 2 broken ribs and quite a few pathologic fractures in utero. Doctors did many tests on me to figure out what exactly it was I had. After three days of testing they finally concluded that I had OI and didn't think I would live very long at all. By the time I was 15 months old I had over 200 fractures. I lived literally in and out of the hospital for the first 9 years of my life due to fractures, surgeries and respiratory issues.

Growing up with this condition I had to overcome many health issues and identity issues. Media will say you need to act, dress, talk or look a certain way to be accepted or to fit in. I've learned not to put my happiness in temporary things because when you put your happiness in temporary things your happiness will be temporary. There's no point in being complete in the outside when you're broken on the inside. Today, I know that I'm more than just a person in a wheelchair. I am to bring hope to

the hopeless. I am to inspire and encourage people be secure in who God created them to be and live a healthy life by exercising regularly.

I was a student of Zumba Fitness for eight months before I became an instructor. I started taking Zumba Fitness classes because I was desperately wanting to have some kind of physical therapy. All I knew was that the program had to do with dance and exercise. I knew I loved to dance and could dance and being that it was affordable to me, I thought I had nothing to lose in taking a chance in trying a class out. By the end of my first Zumba class I was hooked. Within three months of me doing Zumba Fitness regularly, I saw so much improvement in my health! My breathing, range of motion in my arms and legs and my strength improved a great deal, my arms toned up and I actually grew half an inch. Seeing these results got me so excited that I wanted to share it with other people who might be in the same situation as me. It is what persuaded me to become a licensed Zumba Fitness Instructor. I thought that if a wheelchair user sees a Zumba



Corina Gutierrez

Instructor in a wheelchair, they would be more willing to come to class. Having good physical and spiritual health increase one's self-esteem and I am determined to offer it to anyone willing to want it. I am on a mission to break mindsets and cross barriers of putting limitations on people with disabilities and I hope to produce much fruit from it.



Corina Gutierrez leads a Zumba demonstration

In My Own Words

by Kristal Nemeroff, RN-BSN



“It’s not more than I could do, it’s just more than I ever thought I could.”

Although I do not know the origins of this quote, these encouraging words are what got me through four years of nursing school, with Osteogenesis Imperfecta.

I started nursing school in 2007, and to be honest, with all the discouragement from nurses, I never thought I would graduate. I will never forget during one of my clinical rotations, when a nurse looked at me and said, “How are they letting YOU be a nurse?” I was too shocked to know what to say. On another occasion in the Neonatal Intensive Care Unit, I experienced one of the most hurtful and discouraging moments of my life. Our class objectives were to hold babies, feed babies, and participate in their care. When I asked the nurse I was with how I could help her, she turned to me and said, “Sorry, I don’t feel comfortable.” She didn’t want me there, she didn’t want me to touch the newborns, she didn’t trust my competence, and judged me due to my wheelchair. There were several instances when nurses asked my clinical aide, “What can she do?” My clinical aide who believed in my abilities, always stuck up for me. She said, “She can do everything you can do, just a little differently.” I never knew about these remarks until my clinical day ended. I am open and honest about my Osteogenesis Imperfecta, but for some reason nurses were too afraid to ask ME about it.

I had never experienced such ignorance before, but it made me want my nursing degree ten times more. I started searching online for any information I could find about nurses with disabilities when I came across an article by Beth Marks, entitled “Cultural Competence Revisited: Nursing Students with Disabilities.” This article affirmed my beliefs that disabled nurses are necessary for culturally competent care and for improving quality of care. Patients who are facing

sickness, disability, and adversity identify with disabled nurses, as I learned throughout my clinical experience. Nurses who have been personally influenced by a disability often have a special kind of patient understanding that cannot be taught in a classroom. “In this way, increasing the number of health care providers with disabilities can only improve health care for people with disabilities” (par. 12). Disabled nurses are needed to meet the needs of diverse patients. Patients who must face adversity are often inspired by disabled nurses who have had to overcome adversity themselves. Disabled nurses should not be denied their civil rights to be a nurse, for, “...while nature can impair, only society can disable, and it is society that must be fixed to ameliorate disability” (par. 26).

I didn’t just want to be a nurse, I wanted to be a great nurse. I wanted to be like the nurses who’ve impacted my own life. As I kept working through my clinical rotations, I learned that my personal experiences with Osteogenesis Imperfecta were actually a gift that I could use to help others. I have empathy for others because I’ve been on “the other side”, meaning being the patient. I know what it’s like to be terrified of surgery, in a great amount of pain, and feeling like nobody is listening. Many nurses don’t often like to inquire about touchy subjects, and as someone who’s lived with a disability I understand that it is hard to be open with nurses about certain concerns even when they do ask. Usually the nurse is hesitant to inquire about feelings and emotions because they don’t know what to say, they may be uncomfortable, or they may not care. Disability, chronic illness, and facing adversity involve many psychosocial concerns that nurses sometimes put on the back of the priority list. I recognize the psychosocial concerns of patients facing life changing illnesses and situations and have personally strived to address these issues with patients. Addressing these issues contributes greatly to a person’s outcome. Disabled nurses have the ability to help people gain perspective about living with a disability, illness, or life altering situation. To help patients gain a positive attitude greatly contributes to better patient outcomes and achieving a higher quality of life, and happiness.

continued on page 7

Lifestyle

In My Own Words (continued from page 6)

When I first started nursing school, I was almost afraid that I wasn't going to be a good nurse, mainly due to others' negative comments. I had no confidence in myself, and wondered if I belonged in my group of fellow nursing students. I felt that others didn't believe in me, which led me to question believing in myself. Even though my confidence was low, I still worked hard throughout the program because I knew I had to try. I had something to prove to myself, and I did. I graduated Cum Laude and proved that people with disabilities can be great nurses, and that there is a place for disabled people in the health care field. I realize now that I am a very therapeutic and holistic care giver. I am dedicated to helping people, whether it

can be done by cleaning out a wound, or cleaning out an emotional wound.

To the disabled community, I would tell them never say "I can't." Rules and bones are meant to be broken. Society sometimes underestimates people with disabilities. I challenge disabled individuals to prove that society's perception is wrong by following their dreams and not letting those who don't believe in them stop them from trying.

Reference: Marks, Beth. Cultural Competence Revisited: Nursing Students with Disabilities, *Journal of Nursing Education*, February 2007, pages 70-74.

Unbreakable Spirit Snowflake Ornaments and Holiday Cards on Sale Now!

Celebrate the season with the OI Foundation's new holiday gifts! Snowflake ornaments and holiday cards make great gifts for friends, family or teachers! Each snowflake ornament comes in a white bag with an OI Foundation *Unbreakable Spirit* greeting tag. The ornaments are \$5 each.

Each holiday card measures 5.5" by 4.25" and sells for \$6 for a pack of 10 cards and envelopes.

Front of the card reads: *Celebrating the Season...*
Inside of the card reads: *...and the people like you who make it special! Happy Holidays!*

The inside of each card also has a snowflake design. Visit the OI Foundation [Online Store](#) to place your order.



Science & Research

11th International OI Scientific Meeting (continued from page 1)



OIF CEO Tracy Hart, and OIF MAC Chair Dr. Francis Glorieux.

Prior to the start of the scientific meeting, Tracy Hart attended and represented the OI Foundation at the OI Federation of Europe's delegate meeting. Delegates representing 10 countries met to discuss the goals and activities of the OIFE. For more information on this meeting and the work of the OIFE, you can visit their website at www.oife.org.

The meeting was well represented by physicians and scientists from the United States and the Foundation's MAC. Dr. Reid Sutton from Baylor College of Medicine and director of the Foundation's Linked Clinical Research Center project presented information on the progress of the LCRCs noting that there are now 500 participants enrolled in the Natural History Study, meeting the goal of the study and soon the five centers will be announcing "next steps." MAC member Dr. Peter Smith from Chicago Shriners Hospital for Children presented exciting information on his gait study titled "Analysis of push off power of children with Type I OI." The purpose of the study is to quantify the biomechanical factors associated with pes valgus (rigid flat foot deformity) and the reduction in push off power generation in children with Type I OI and use this information to improve their gait.

Scientific sessions addressed both classical dominant OI and the new recessive forms. For dominant OI, there were presentations on collagen defects that impair processing of each end of the procollagen molecule. For recessive OI, there were discussions of the two most recently identified genes causing OI, *FKBP10* and *SERPINF1* (which causes type VI OI). An investigation of the basic biology of the marrow stem cells in the *Brtl* mouse model for classical OI showed that development of *Brtl* bone cell precursors was abnormal and that they had an increased tendency to become fat cells. Another investigation using the *Brtl* mouse focused on the mechanism of hypermineralization in OI bone, and suggested this is not a passive process.

Mouse models were also employed to study the effects of upcoming osteoporosis drugs (such as anti-sclerostin antibody) on OI bone, and to test molecular therapies.

The evolving classification system for OI was a topic of active discussion at the conference. In addition to mutations in type I collagen that cause about 85% of OI cases, OI has been shown to result from mutations in 6 other genes (so far). Two approaches to classification have emerged in the medical literature. A genetic approach has assigned an OI type number for each newly identified gene. For example, Types VII, VIII and IX have been proposed for OI caused by mutations in genes *CRTAP*, *LEPRE1* and *PPIB*, respectively. A clinical approach incorporates the new genetic types into the current type I-IV classification. Each system has strengths and weaknesses, and a new OI classification is still the subject of medical debate. The establishment of a new classification will need to account for both genetic and clinical information, and will also be influenced by the continued rapid identification of new genes causing OI.

Clinical topics explored at the meeting included information on bisphosphonate therapy, surgical interventions, Vitamin D levels in children with OI, OI in adults and secondary features of OI including dental and hearing issues. There was consensus among the group of the importance of a multidisciplinary approach when treating OI including pharmacological treatment, surgical correction of deformities when necessary and access to quality rehabilitative care to promote activity.

The next International OI Conference will be held in 2014, when it will return to the United States.



Dr. Francis Glorieux and Dr. Joan Marini presenting at the 11th International OI Scientific Meeting.

OI Adult Health Research Study

An important new study, a survey of the health status, health needs, and health priorities of adults who have OI, was launched on October 1, 2011. The OI Adult Natural History Initiative Survey (OI-ANHI) will be open to Adults age 18 and older who have a diagnosis of OI (any type) and read and write English until December 31, 2011. The survey is anonymous, internet-based and easy to access.

The OI-ANHI Survey was developed in collaboration with adults who have OI to collect information in a scientific and reliable manner. This information is needed to begin to answer questions about the health issues faced by adults who have OI. Input from the Adult Health Focus Groups held at the 2010 OIF National Conference, from medical specialists and experts in survey writing, went into the design of this survey. Principal Investigator Laura Tosi, MD, orthopedic surgeon and member of the OIF's Medical Advisory Council, led a committee of volunteers who worked diligently to make this survey a reality. Committee members Barbie Simmonds, Beth Simmonds, Kyle Mulroy, Angela Mancuso, Annie Kennelly, Lauren Greco, Carole Tucker, PT, Melanie Rak, MD, Matt Oetgen, MD, Fergus McKiernan, MD, and OIF staff member Mary Beth Huber all contributed their time and talents to this effort.

Information from this study will be used to improve the information available to health care providers and adults who have OI and to encourage new research. Like other medical conditions that begin in childhood, more is known about how OI affects children than about how it affects adults. There are many questions that need answers about how to manage OI during adulthood.

The OI-ANHI Survey is part of the OI Foundation's Adult Health Project which is dedicated to improving the health and well-being of adults who have OI. The goals of the Adult Health Project are to increase knowledge, publish

information for health care providers and adults who have OI and encourage research. The project is based on the belief that by identifying issues that emerge at each stage of adult life it will be possible to equip OI adults and their health care providers with information they need to anticipate problems, and perhaps prevent or minimize symptoms that are aggravated by aging.

The OI-ANHI Survey will expand on and validate information collected through the OI Registry and the Linked Clinical Center (LCRC) projects. The OI Registry collects information across many years and links people to research studies. The LCRC sees a smaller number of people but collects precise test information from their participants. Together these three important studies will lead to improvements in the health and well-being of everyone who has OI.

Paper copies and large print copies are available by calling Mary Beth Huber at the OIF National Office (301-947-0083). The survey uses a validated, secure system called PROMIS (Patient-Reported Outcomes Measurement Information System) to collect and analyze the data. The PROMIS system was developed by the National Institutes of Health.

To enter the study, go to the OIF website www.oif.org. Then click on the Research tab and then on ANHI Survey in the drop down box.

The more people who participate, the more successful this study will be! So don't wait until the last minute, log in and complete the survey right away!

Countdown to Conference 2012!

Start planning your trip to the National Conference on OI which will be held July 13-15, 2012 in Washington, DC! The Conference is a 3-day event filled with educational sessions on a variety of topics related to OI and social activities for all ages! An outline of the Conference schedule, along with registration materials and information about the Conference Scholarship program will be featured in the February 2012 issue of *Breakthrough*.

If you have not already, now is the time to make your hotel reservations! Call the Marriott Reservations line at 888-236-2427 and mention that you are with the OI Foundation National Conference to receive the group rate of \$149 per night. **If you need to book an accessible (ADA) room**, call reservations representative Megan Aguilar directly at 703-553-5331. ADA rooms are limited and available on a first come, first serve basis. **They will sell out early!**



When planning the 2012 Conference, Washington, DC, was chosen as the host city for many reasons, including the opportunity to continue the Foundation's advocacy efforts on Capitol Hill. The Foundation will be planning advocacy visits with members of Congress on Thursday, July 12. If you would like to participate in these visits, please email eruebensaal@oif.org. Participants will be required to be available all day on Thursday, July 12, and must attend the training session held at the hotel that morning.

The following article about accessible travel tips was recently published on www.wheelchairtraveling.com, and contains helpful tips for individuals and families.

Accessible Travel Tips

By Katja Stokley

I love to travel! As a software developer in the aerospace business, there have been times in my career when I've had to travel frequently for business, and I've also been lucky enough to be able to travel a fair amount for pleasure. When I started using a wheelchair, I worried that travel was going to become much more difficult, even impossible, but that's not necessarily the case. There have been real improvements in how airlines, trains, rental car agencies, hotels, and restaurants accommodate disabled travelers, both in the US and in other countries.

That's not to say that the disabled traveler doesn't have to educate herself and perhaps do some advance work. In this article, I talk about some of the things I consider when planning and executing a trip, especially by air. It doesn't attempt to cover the situations encountered by every disabled traveler. For example, I have multiple sclerosis and use a lightweight manual wheelchair—I don't have any experience traveling with a power chair.

PLANNING

A really mellow attitude helps when you're traveling, whether for business or pleasure. I already know that many of my daily activities take longer than they would an able-bodied person, and that goes double for travel. Unlike many business travelers who know to the second how

late they can gallop to the gate, I allow lots of time on travel day. Travel requires more than just additional time, it requires additional energy. If most days you can get by with a cane, but occasionally use a walker (for instance), take the walker when traveling! It's a good idea to "upgrade" your mobility aids when traveling.

Ask for help. It only took me two or three trips to get over my inhibition against asking for help. I ask for hotel rooms closer to the elevator, for help with luggage, for help moving furniture in hotel rooms, for preboarding (over and over and over again). I am liberal with thanks and tips. My employer reimburses tips, so I don't hesitate.

Don't apologize, and don't over-explain. When you're arranging travel, be straightforward and upfront about your needs, but keep it simple. If you can walk up three steps, but ten steps would be too many, say, "No steps."

BOOKING

I get non-stop or direct flights whenever possible. If I must book a connecting flight, I insist on at least an hour between flights. Sometimes this means I wait around (remember? Allow lots of time), but so far I haven't missed a connecting flight. When connecting, I ask to be met and assisted, especially in an unfamiliar airport or when traveling internationally. This way I get someone to push me to my gate, which saves wear and tear on me, as well as saving aimless wandering around. It's

a good idea to check the airport's website for a map, in order to try to get an idea of how far it is from arrival to departure gate. What should you tell the airline about your disability? Every airline has what are called Special Service Request (SSR) codes. SSRs are used by airlines to capture information about special meal requests, special baggage handling requests, unaccompanied minors, and disabled passengers, among other things. Some airline websites allow you to enter this information when booking your ticket or filling out your passenger profile. For example, United's website allows you to choose from "Person needs wheelchair, cannot ascend steps," "Person needs wheelchair, cannot walk or ascend steps," "Person needs assistance, no wheelchair." If there is no way to supply this information when you book the ticket, call the airline afterwards and let them know what your disability is.

What should you tell the airline about your disability? Every airline has what are called Special Service Request (SSR) codes. SSRs are used by airlines to capture information about special meal requests, special baggage handling requests, unaccompanied minors, and disabled passengers, among other things. Some airline websites allow you to enter this information when booking your ticket or filling out your passenger profile. For example, United's website allows you to choose from "Person needs wheelchair, cannot ascend steps," "Person needs

continued on page 11

People & Events

Countdown to Conference 2012 (continued from page 10)

wheelchair, cannot walk or ascend steps,” “Person needs assistance, no wheelchair.” If there is no way to supply this information when you book the ticket, call the airline afterwards and let them know what your disability is.

SEAT ASSIGNMENT

I look for two things in seat assignment: close to the front of the aircraft, and with a moveable armrest on the aisle seat. The travel agent/airline customer service agent can help with the first, but watch out for small planes—I got seat 12B on a trip between Washington and Raleigh once. On a Boeing 777, 12B is very close to the front of economy class, but on a tiny prop plane, it’s the last row! Customer service agents are not much help with the moveable armrests, sadly—the location of moveable armrests doesn’t seem to be documented anywhere reliable. Aircraft with 30 or more seats are supposed to have several rows with moveable aisle armrests, but I haven’t discerned any rhyme or reason in their placement. The newer and bigger the plane, the more moveable armrests there are. On some airlines, the agent has to place a request for a wheelchair before the computer will release one of those seats—go ahead and do it, you don’t have to actually use the airline’s wheelchair.

THE FLIGHT

Checking-In

Despite the horror stories about checked luggage going astray, it may be necessary if you use a wheelchair. Keep carryon baggage to a minimum. Now that I travel with a laptop, that’s a little more difficult, since my employer (understandably) prefers that I not check the laptop. One solution to the laptop problem is to pack all of the laptop accessories in my checked luggage and carry only the computer itself. You also need to pack whatever is necessary for wheelchair maintenance—I pack a small toolkit, a bicycle pump with an attached pressure gauge, an extra tube, a patch kit and tire levers. If you have a flat in a strange city, a bicycle shop is probably easier to find than a wheelchair repair shop, and it costs less, too.

Security Check

Wheelchair users are checked by hand, but whatever you’re carrying still has to

go on the conveyer belt. In the US, the Transportation Safety Administration (TSA) says that you have the right to maintain eye contact with your belongings. If you are traveling alone, don’t hesitate to point this out if you are asked to do something that will separate you from your stuff. I ask the security officer who takes my bag to wait for it and bring it back, since it has my laptop and my wallet in it. Allow a little extra time for that and for the fact that security may have to track down a male/female officer to do the body check. (There’s something surreal about having a woman approach you and say very sweetly, “Madam, may I pat you down?”) In the post-911 travel environment, the hand check is taken very seriously. You may be asked if you can stand and walk. Even if you can, you do not need to say so. If you prefer not to take off your shoes, just say that you can’t, and your shoes will be swabbed on your feet to check for traces of explosives.

At the Gate

Although you probably will have gotten your boarding pass from a kiosk, you should check in again at the gate. This is where you ask for a gate check tag for your equipment and for an aisle chair if you need one. An aisle chair is a (very) narrow chair that bears an unfortunately resemblance to a handtruck. If you cannot walk at all, the aisle chair is used to convey you from the door of the plane to your seat.

In the last several years it’s been my experience that either the airline does not do public preboarding at all, or that when the preboarding announcement is made, over half the people waiting stampede to the door. I have had several fairly embarrassing experiences boarding in the middle of a crowd of people all of whom were waiting very impatiently for me to struggle out of my wheelchair and down the aisle of the plane.

The two reasons for preboarding are first, to get enough space for your carryon, and second, to get a manual folding wheelchair stowed in the cabin (see Wheelchair Stowage). Occasionally the airline will preboard me privately (i.e., without making a public preboarding announcement). I station myself near where the gate agents will see me when they think about starting to board, and this sometimes helps. If it’s important to you

to get your chair stowed in the cabin, you need to be persistent. In general I’ve found that even if you get to the gate very early, the gate agents tend to forget about you in the boarding rush, so you have to keep reminding them that you’re there.

More about the aisle chair: you will be able to use your own chair down the jetway to the door of the plane, where you will be met by (hopefully) two workers with the aisle chair. You’ll need to instruct them on how to help you transfer to the aisle chair. You are strapped into the aisle chair with one belt around your legs, and two diagonal belts from shoulder to hip. Remember to take your wheelchair cushion, transfer board and any other loose items with you; they are not likely to stay with the chair in the baggage hold. Keep your elbows/arms tucked in tightly as you are pushed down the aisle to your seat. If you’ve gotten a seat in a row with a removable armrest, you’ll be able to transfer directly from the aisle chair; otherwise you may need to instruct your helpers in lifting you over the armrest or doing a standing pivot transfer.

Wheelchair Stowage

Where other business travelers worry about losing luggage, I worry about baggage handlers breaking my wheelchair. There are two options for a manual folding wheelchair: in the cabin, or in the baggage compartment. If you have a rigid wheelchair, or a powerchair, it will be stowed below with the baggage.

Cabin Stowage

Every wheelchair traveler should know about the Air Carrier Access Act. The ACAA is the airline equivalent of the Americans with Disabilities Act (like churches and private clubs, airlines are not covered by the ADA). The Air Carrier Access Act says the airline must stow one manual folding wheelchair in the cabin if the passenger preboards. I carry a copy of the act with me (I’ve never actually had to pull it out, though!), and quote it to the flight crew if they object. Objections I encountered when I was using a folder chair included “We don’t have room” (my chair folded very small), “This closet has a weight limit” (my chair weighed 18 pounds), “We already have an aisle chair” (the ACAA specifies the passenger’s wheelchair). Many flight attendants have

continued on page 12

People & Events

Countdown to Conference 2012 (continued from page 11)

never heard of the ACAA and so I try to educate them as painlessly as possible. I managed to get the chair stowed in the cabin about 90% of the time. Note that you're supposed to preboard to get this perk—I've had some success asking a gate agent to talk to the head flight attendant.

Baggage Compartment Stowage

If the chair is going into the baggage compartment, label every piece—this means chair, footrests, wheels, everything. I use a metal tag (the kind you can get a pet stores for your dog's collar) around a tube underneath my seat, and business cards taped to anything that is separate. Because I have a rigid chair, I worry that an aggressive baggage handler, used to chairs that fold sideways, will manage to do something interesting to it. When I have a connecting flight, I ask for the chair to be brought to me between flights rather than trusting that it will get to my final destination. Check the chair for damage before you leave the jetway—if anything has happened it's best to try and get it resolved immediately. If you don't get satisfaction, ask to speak to the airline's Complaints Resolution Officer—every airline is required to have such a person.

HOTEL CONSIDERATIONS

I call the hotel and ask for an ADA compliant room, but you can't stop there. I ask about bathrooms, carpets, doors, restaurant, bathrooms, and transportation options.

- How wide is the bathroom door? (You need to know what your minimum clearance is.)
- Is it a straight shot from the room, or do you have to maneuver around corners?
- Is there a tub or shower? Is there a shower chair or bench?
- How about grab bars?
- How deep are the carpets in public areas? (Sadly, the more expensive the hotel, the deeper the carpets. Deep carpets are very hard to push on. I've tried asking the hotel how deep their carpets are, but I haven't had much luck there.)
- How heavy are room doors? (Heavy room doors are good for security and

fire safety, but are really tough for a wheelchair user to open. When I stayed at the Fairmont in San Jose, I had to get somebody to accompany me up to the room to open the door for me. I won't stay there again (they also have deep carpets) even though the service was extraordinary. It was too much work.)

- Is the restaurant accessible?
- If you haven't rented a car, what kind of transportation is available to get you where you're going?

Hotel Parking

Frequently I get to a hotel and the handicapped parking isn't anywhere near the lobby. I have parked in the drive, checked in, and then handed the bellman the keys and asked him to get the luggage and park the car. This is another example of asking for what you need.

Hotel Room Furniture Arrangement

I've found in some hotel rooms that I need to move some furniture to have space for the wheelchair, and to get to the electrical and phone outlets. If necessary, I call the desk and ask for someone to help move the furniture. The first night, I leave a tip for the chambermaid in an envelope that says "Please don't move the furniture back." Sometimes it works. If I have to move the furniture two days in a row, I call the manager, and politely explain the situation. Sometimes that works. You can also ask for another room.

Hotel Comment Card

I'm very big on communication, because hotel and other travel service workers frequently are unaware of a problem until someone (guess who?) educates them. I fill out a comment card at hotels when I leave. I try to say at least one good thing before commenting on problems. If I have gotten particularly good service, I write a letter to the manager after my trip and do my best to name the employee(s) involved. At the Regal University Hotel in Durham, North Carolina, a hotel concierge had a prescription filled for me in the middle of the night. At the Fairmont Hotel in San Jose, California, a hotel security employee went to a downtown drugstore and rented a wheelchair for me when mine broke, and the hotel would not allow me to reimburse them for the rental cost.

On trips I encounter two kinds of people: those who have apparently never dealt with a wheelchair user, and those who have and think they know it all. Keep in mind that you are the expert on your needs, and don't let people push you around (literally or figuratively). I needed to keep this in mind on a recent trip to San Francisco; San Francisco airport has shuttle service to the rental car agencies quite a distance away from the terminal. The dispatcher insisted on calling for a special handicapped accessible van (extra wait about 20 minutes). When this van arrived, it turned out that the ramp into the van was about 1/2 inch narrower than my wheelchair. I had to be very firm that we weren't going to try to get the wheelchair into the van that way—close only counts in horseshoes! We wound up doing what I do in my own car—I transferred to the front passenger seat, folded up my chair, and the driver loaded it in the back.

Wheelchair using business travelers are thankfully more common than they were when I started traveling for business, but we still have to approach the situation with humor, patience, and a willingness to educate. Perhaps I have been lucky, but while I have frequently encountered ignorance, I have rarely seen outright abuse from travel industry workers. Most people will try to help if they know what you need, and the only person who's going to tell them is you!

RENTING A CAR

I drive a car with hand controls, offered by the major car rental agencies. I also request a two-door car—because the doors are bigger it's easier to get the wheelchair in—that's not too low. Of the major US agencies, I've found Hertz to be the most reliable in having hand control equipped cars available at most locations. I bring my handicapped parking placard with me on trips to use in the rental car—it is valid in any state in the US, and in many European countries.

Car Pick-Up and Drop-Off

Hertz and Avis both provide what they call curbside service—someone will bring the rental car to the terminal when you arrive. When I drop off the car I ask to be driven in the car to the terminal, and this request has always been cheerfully granted. Allow some extra time for this.

People & Events

Year-End Letter Tells Story of OI's Impact on a Young Girl's Health and How the Foundation Helps Her Family and Others Secure the Best Possible Outcomes

Your gift by December 31 will be doubled by a Matching Gift Challenge!

When Sophia was born almost five years ago, doctors at their local hospital had not seen a child with osteogenesis imperfecta (OI) for 20 years, according to parents Cathy and Robert.

Yet, when a scan was taken of little Sophia, "the whole screen lit up" both with healing fractures and current breaks, her parents said. At that point, doctors told them about OI, and the family received pamphlets, facts sheets and a book on osteogenesis imperfecta.

Cathy and Robert recently agreed to share Sophia's story for the OI Foundation's year-end letter to current and potential supporters to ensure that other individuals and families also will have the latest information about OI when they need it, whether a new baby has just been born with brittle bones or an adult is facing an unexpected medical crisis.

As mom Cathy explained the dilemma faced by many families, "*When you go to a doctor and the doctor doesn't know (about OI), where do you turn?*"

If you make a new gift or increase your past donation between now and December 31, the difference will be doubled by a Matching Gift Challenge! This challenge

has been issued for a third time by a generous family committed to helping the OI Foundation grow both our services and our base of support. In these tough economic times, each donor and every dollar counts! When you give \$40 this year, it becomes \$80, and a \$250 contribution is worth \$500 in support of the OI Foundation's mission. Your impact on OI research and services to families in the OI community is magnified!

Did you know that the OI National Information Center on the Foundation's website currently offers booklets, brochures and more than 70 fact sheets, many of which can be downloaded free of charge? In addition to the free information that is available any time on our website, staff members are available by phone or e-mail to answer individual questions from a doctor, parent, or adult with OI about daily living or caring for an individual with this rare genetic bone disorder.

Soon, parents like Cathy and Robert will be able to access an online video that will demonstrate safe handling techniques for a baby with OI, thanks to production services contributed by a private donor. A second new video on the OI Foundation's website will be an informational piece that features medical professionals discussing treatment options. There also will be a new public service announcement featuring two OI families.

Please watch for your letter from the OI Foundation this November, and respond with the most generous gift possible. Or, visit www.oif.org to make your year-end donation today.

Your gift will help the OI Foundation move its research initiatives forward and continue serving as an important resource for families in the OI community for years to come. Help us to grow stronger!

The OI Foundation, our Board of Directors and our staff extend our best wishes to you and yours for the happiest of holiday seasons and a successful 2012!



Robert, Sophia and Cathy

People & Events

First Time Unbreakable Spirit Walk Involves Community Groups and Garneres Local TV Coverage

On a warm, sunny October day in Long Island, between 200 and 250 people gathered for a fun family event that raised awareness of OI and just under \$12,000 to support the mission of the OI Foundation.

Music played as families, students, members of the OI community and other supporters visited with each other, examined raffle items and enjoyed food donated by volunteers for the event. Student athletes from various sports at the New York Institute of Technology campus in Old Westbury helped set up tables in the morning and they then served food and painted children's faces. Another volunteer dressed as a clown to entertain the children present, and his outfit was donated by a local costume shop. Local vendors sold coffee and bottled tea, handmade jewelry, candles and car air fresheners and a variety of other products and donated a percentage of their earnings to the OI Foundation.

However, the highlight of the day occurred when participants walked or moved around the track. One group of adult sisters walked with the photograph of their college-age sister who passed away from OI-related complications 20 years ago. This young woman was adept at advocating with the New York transit agencies for accessible transportation, according to one of her sisters.

Another large extended family, led by parents **Max and Diana Santana-Nunez**, wore matching blue T-shirts emblazoned with the words "Armani's Team" and a photo of Max's and Diana's infant son, **Armani**.

The walk was led by 4-year-old Sophia in her wheelchair, parents **Cathy and Robert Resti**, and other family and friends. Sophia's aunt and uncle, **Joe and Cathy Zago**, were inspired by their niece to organize the *Unbreakable Spirit Walk for OI: NYIT*, which was held October 2.

"Until 4 years ago, I myself never heard of this or knew anyone with OI," Cathy Zago explained. "Then my niece Sophia Lily was born into this world with 17 fractures throughout her body."

Despite many medical issues associated with her OI, Sophia "is always smiling and laughing and brings pure joy to everyone's life," according to her aunt Cathy. "This walk was inspired by her strength and courage, and we need to promote more awareness and more funds to help the quality of life."



Photo courtesy of Fred Rodriguez Photography

Walk organizers Cathy and Joe Zago and their niece Sophia were among the OI community members interviewed by The "My Life TV" program on Verizon Fios 1 in Long Island.

The "My Life TV" program on Verizon Fios 1 in Long Island filmed the event and interviewed several representatives of the OI community, including the Zago and Resti families with Sophia, Long Island Support group Leader **Paul Granger**, adults **Taniya Faulk** and **Antonella Verderosa**, parents Max and Diana Santana-Nunez, and OIF Director of Development Stuart Tart.

The TV coverage and the involvement of NYIT students and local business people resulted from a conscious effort by Cathy and Joe Zago.

"The NYIT Athletic department was very interested in having athletes from many of their teams participate in the event. Their participation was excellent, giving us time to focus on the event," Cathy said.

continued on page 15

People & Events

First Time Unbreakable Spirit Walk *(continued from page 14)*

“Joe Zago and (business partner) **Tom Hayes** have developed a professional relationship with the University over the past years, and NYIT was very willing to host the event at the university. Through personal and professional contacts, a lot of phone calls, emails, face to face ‘asking’ for involvement in the event, and telling the OI story was how they became ‘involved’,” she explained.

Cathy added that there will be a second *Unbreakable Spirit Walk at NYIT*, scheduled for Sept. 23, 2012.

“Our event this year has exceeded our expectations in fund raising already. The attendance was excellent,” Cathy remarked. “However, we want to increase numbers on both fronts and just as importantly, we want to bring awareness of Osteogenesis Imperfecta to the community and to our personal and professional circles of life.”



Photo courtesy of Fred Rodriguez Photography

Parents Max and Diana Santana-Nunez and their infant son Armani (center) walked with family members who each wore matching blue T-shirts emblazoned with the words “Armani’s Team” and his photo.



Photo courtesy of Fred Rodriguez Photography

Among those enjoying the day were (L to R) Antonella Verderosa, Nick D’Alessandro, Kristina Diaz, Taniya Faulk, and Long Island Support Group Leader Paul Granger.

Trio Makes Philadelphia Triathlon Race a Family Affair

College Student With OI Joins Dad and Uncle to Compete and Raise Funds

Three men recently made a family affair out of their participation in a city triathlon by each competing in one event while also raising \$575 in donations to support the OI Foundation.

John Broadbent, a Duke University student who has OI, competed with his father **Arthur Broadbent** and his uncle **Joel Mrosek** in the Philadelphia Insurance Triathlon on June 26. John swam 0.9 miles, Art biked 26.2 miles, and Joel competed in the 6.2 mile running leg of the race.

Joel said that he had been involved in races for many years, and that Art and John were regularly present to cheer him on.

“I came up with the idea to do a relay so that we could all share this as a family experience with a reversal of roles,” he explained. “We knew John could do the swim but might struggle with the bike or run. Art could do the bike, but the run might be tough on his hips. It worked out perfectly that the 3 of us could complement one another.”

John reported that having OI causes him to have poor body alignment. As a result, running was out of the question for him, and his reduced muscle tone also made it difficult for him to bike. Thus, swimming was the most realistic option for John.

According to his Uncle Joel, John trained hard to prepare for the race: “What inspired me is hearing about John training in the Duke pool and making a mile,” Joel said. “He also swam to the dam at the manmade lake his grandmother lives on. The dam is .9 mile away and always a rite of passage for everyone in our family for 50 years.”

At one point, John’s mother Wendy was concerned about John completing the training swim to the dam on the manmade lake. However, Joel was not worried. Instead, “I was incredulous because John would die before quitting. He IS the toughest member in our family.”

For his part, John said being in this race proved to be an important personal milestone.

“I know that what I wanted to prove to myself went far deeper than whether or not I could swim a mile,” John explained. “With my disabilities, I’ve always been the one who couldn’t do things—the one whose lack of body

control held other people back, especially in my family, where my twin sister could effortlessly hit grand slams and be a piano prodigy at the same time.”

He added, “The Philadelphia Triathlon meant more to me than simply proving to my family members that I could do what they do. It meant proving to myself that—after 19 years of constant struggle and always being told that I would never quite be as physically capable as others—I in fact could physically do things that even “normal” people would be impressed with.”

John added that he raised funds for the OI Foundation both to build awareness and move research forward.

“I hope that the donations I raised will help support OI awareness, because I do not think that many people know what this condition is, even though they know everything there is to know about cancer, obesity, diabetes, high blood pressure, etc.,” he explained. “I also hope that some of the donations go toward OI research.”

Joel’s goal from this experience is a bit different. “I hope the money raised and John’s story will inspire some young people with OI to persevere and flourish as John has,” he said.

Joel added, “His intellectual prowess, positive attitude and sheer determination inspires all around him. I am very proud to be his Uncle.



(L to R) Joel Mrosek, John Broadbent and Arthur Broadbent after participating in the Philadelphia Insurance Triathlon on June 26

People & Events



OI Awareness Week Activities Already in the Works!

Events are already being planned in hometowns across the country to commemorate the 2nd national OI Awareness Week from May 5-12, 2012. Think of the impact if there are OI-related activities in 100, 200 or more communities nationwide, including your own!

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!

We thank the following volunteers who already have indicated that they will be holding an Awareness Week activity. To discuss holding your own OI Awareness Week activity, please contact Development Coordinator Alisha Matlock at AMatlock@oif.org or 1-800-981-2663.

Atchison, KS – *2nd Annual Unbreakable Spirit Walk for OI: Atchison, KS*

Volunteer: Heidi Johnson, heidizeit@yahoo.com

Rochester, NY – *Alle Shea 4th Walk-n-Wheel for Better Bones*

Volunteers: Angelo and Kim Collazo, allesheaproject@yahoo.com

Seaford, NY – *4th Annual US Walk for OI: Long Island*

Volunteer: Thalia Piacquadio, salia26@aol.com

Washington, DC – *12th Annual Fine Wines Strong Bones*

Contact: OIF Development Coordinator Alisha Matlock, AMatlock@oif.org

There also are other Spring 2012 events in the works that may not fall during OI Awareness Week, but will make a real difference for the OI community. We greatly appreciate these dedicated volunteers!

Washington, DC – *Rock 'n Roll Half Marathon Run for OI by Jacqueline Bourgeois on March 17*

Follow her progress: www.facebook.com/UnbreakableStride

Framingham, MA – *8th Annual MA Unbreakable Spirit Walk for OI*

Volunteers: Christine Wyman Rossi and Dick Wyman, c.rossi@verizon.net

Melrose, MN – *2nd Annual Unbreakable Spirit Walk for OI, in memory of Cheyenne*

Volunteer: Brenda Breitbach, brendabreitbach@hotmail.com

Round Rock, TX – *5th Annual Central Texas Walk-Hop-N-Roll*

Volunteers: Debbie Wiederhold and Erin Weaver, ddwiederhold@netscape.net

People & Events

National Blue Jeans for Better Bones Day—What a Success!

The very first National Blue Jeans for Better Bones Day (BJBB) held on Friday, November 18, 2011 can be summed up with one word—SUCCESS!

The BJBB campaign was developed in 2009 with the principal goal to increase awareness of OI. Eighteen groups held a BJBB day within their neighborhood, office, school and/or church, spreading our reach from Delaware to California and even to Canada. The overwhelming support from the OI community enables the foundation to touch hundreds unaware that osteogenesis imperfecta (OI) even exists.

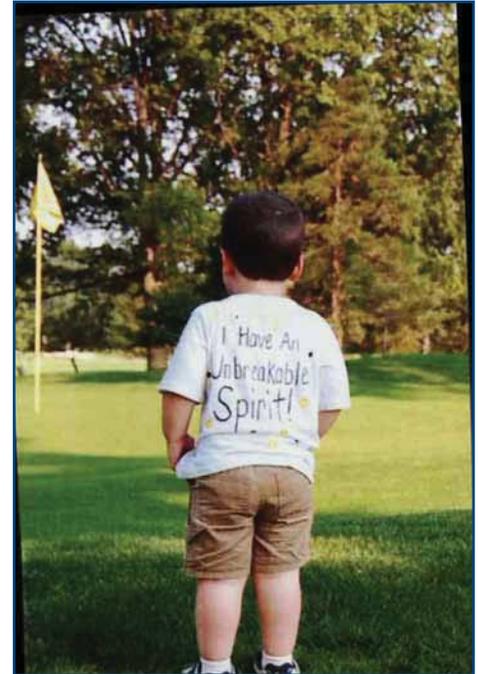
Individuals like Renita Davis, an OI parent who organized a BJBB day at her daughter's school in Valdosta, Georgia, help to call attention to the needs of the OI community. She notes, "People really want to help. They need only to be aware of the problem and to see a way to help...." This theme has resonated with several other campaigns held across the country, leaving BJBB team leaders in awe at the greater community's willingness to support those affected by OI.

When asked what advice she would give to someone interested in planning his or her own BJBB day, Renita said, "Go the extra mile..... they might just surprise you and give even more!"

The OI Foundation attributes the success of this campaign to each BJBB team leader and the entire OI community—We thank you for going the extra mile!



The students and staff at Westside Elementary school held a Blue Jeans for Better Bones week and raised over \$1,300.



The Lesjak Planning Corporation and the Wilkinson Family of Venedocia, OH, hosted a golf outing that raised over \$3,000 for the OI Foundation in honor of their son Cayden.



The Kiddie Lodge preschool in Framingham, MA, held a raffle for OI during the students' Halloween festivities on October 28, raising \$100 in support of the OI Foundation's mission. MaryEllen Wyman is director of the Kiddie Lodge and three students are pictured here.

People & Events

NJ Beefsteak Dinner Celebrates 20th Year!

Gretchen and Peter Strauch Receive Lifetime Volunteer Awards

A “record” 415 people crowded into Three Saints Russian Orthodox Cultural Center in Garfield, NJ, to celebrate the New Jersey OI Support Group’s 20th Beefsteak Dinner.

Co-chair **Jo Ann Berkenbush** estimated that 24 people who attended this event on October 22 were also part of the very first Beefsteak Dinner in 1992! **Rosemarie Kasper** and **Beverly Krudys** also serve as co-chairs of the event.

During the evening, veteran volunteers **Gretchen and Peter Strauch** were presented with the Thelma Clack Lifetime Volunteer Award by CEO Tracy Smith Hart. The couple was recognized for more than 20 years of service. In addition to helping to organize the Beefsteak Dinner each year since its beginning, Gretchen has volunteered at OI National Conferences and as a regular online chat room monitor, while Peter has served on the OIF Board of Directors and Finance Committee.

During the week after the Beefsteak Dinner, volunteer **Patricia DeLuccia** was also honored for her contributions to the event’s success. On Oct. 28, Ms. DeLuccia was one of nine recipients of the Salute to Champions Award in Bergen County, NJ, for making a difference in the lives of people with disabilities. Congratulations and thank you, Pat!

The annual NJ Beefsteak Dinner is a fun, family-oriented event featuring all-you-can-eat filet mignon, French fries and salad, along with a vast silent auction, Tricky Tray, and raffles. Since 1992, it has raised more than \$309,000 in support of the Foundation’s mission!



Some of the 20th Annual NJ Beefsteak Dinner’s organizers and key volunteers posed for a picture: Front: Gretchen Strauch and Rosemarie Kasper. Back: Liz Schmidt, Shannon Strauch, Peter Strauch, Bill Schmidt, Beverly Krudys, Pat De Luccia, Jo Ann Berkenbush and Ellen Haley.

DC-Area Golf Outing Tops \$180,000 During Six-Year History

Thanks to the loyalty of its top sponsors and key volunteers, the Birdies and Bogies for Better Bones golf outing in Ashburn, VA, is on track to raise just under \$26,000 in its sixth year, bringing its six-year total to more than \$183,400!

This year’s event on October 24 proved to be a comfortable, sunny day. Golfers appreciated a format change to Captain’s Choice, or scramble, which enables a foursome to work as a team by all playing off of the best shots at each hole. This change emphasized fun and made the event accessible to casual golfers.

For the sixth year in a row, **Karen Orejuela** chaired the golf outing. Although there is no OI in her own family, Karen said she is motivated by Katrina, a teen with OI whose family are longtime friends.

Booz Allen Hamilton has served as the event’s Presenting Sponsor since the very first year. The OI Foundation wants to offer a special thank you to Booz Allen, **Insperity**, sponsor of the 19th-hole reception, and the Golfer Goodie Bag Sponsors—**Simmonds & Klima, Ltd.** and **LT Business Dynamics**.

We also appreciate the work of longtime volunteers **Roger Bache, Tim Hawkins, Eric McNutt, David Vurdelja, and Charlotte and Tony Preuss**, who each have worked since the beginning to recruit teams and sponsors and/or help the big day to run smoothly.

People in the News

People living with Osteogenesis Imperfecta are making headlines and increasing awareness about OI, and showing their Unbreakable Spirit!

Congratulations!

Bradley Marcello, age 15 OI Type III of Wisconsin went on his first bear hunt and shot his first bear on September 17, 2011. The hunt took place in Northern Wisconsin and the bear weighed in at 211 pounds. The hunt was made possible by three good friends and a number of volunteers. The other hunters were able to strap Bradley's wheelchair into a 6-wheeler to get him into the woods where he needed to be. This included traveling across rugged terrain and a small creek. A friend built a special tripod that swiveled and tilted which enabled Bradley to handle the rifle without getting hurt. The rifle was equipped with a laser so he could "sight in" his target. It was an exciting day for everyone. Congratulations to Bradley and to his team of friends who went the extra mile to help make his dream come true.



Bradley on his first bear hunt.



Austin and Michaela during filming.

Austin and Michaela Davert, twins who have OI, are featured in a new commercial and a set of other promotional materials for the University of Michigan Mott Children's Hospital. Austin's picture was produced on a two-story banner now hanging in the hospital, and Michaela's photo became a light-pole banner outside the hospital! Acting has now joined their list of special interests alongside of flying (Austin) and fashion design (Michaela).

Patricia DeLuccia was recognized this autumn as one of nine Champions by the Bergen County, NJ Division on Disability. She was honored for her efforts to increase awareness about OI and raise needed funds for research through the Beefsteak fundraiser.

Welcome!

Energy Maburutse is a young adult who has OI, a citizen of Zimbabwe and a college freshman at Lynn University in Florida. The story of his remarkable journey from Africa to Florida was reported in a *New York Times* article by Frank Bruni. Energy hopes to pursue a career as a human rights advocate in the future. Although he has never walked, empowered by his wheelchair and his unbreakable spirit he has already covered a lot of ground!

People & Events

BONE CHINA TEA An Easy Way for All of Us to Support OI

Bone China Tea is one of the Osteogenesis Imperfecta Foundation's oldest fund raisers. Started in 1993, it has consistently grown, raising just under \$32,000 this past year.

It is now time to plan for the 2012 event, which will be held on March 21st. Our goal this year is to lure more hosts (46 this past year) to participate so that we can increase our support of the Foundation's ability to provide new information resources for families and people with OI, fund research, and facilitate the operation of support groups throughout the country.

As many of you know, Bone China Tea is a 'phantom' event that people participate in from the comfort of their own home. There are two ways to become involved: either by sending printed invitations (tea bag included) to family, friends, co-workers and neighbors or by registering on the OIF web site and using your personal web page to send e-mails. People who receive these invitations are invited to sit down for a cup of tea on March 21st and make a donation to the Foundation with the money saved by not attending a live event.

How to Participate

Order your invitations by sending an e-mail or phoning us, using our information below. Please include your complete name, address, phone number and e-mail address, along with the number of invitations you plan to mail. The invitations come assembled with tea bag and OI tag, along with a return donation card and envelope. They will be ready for distribution by the middle to end of January.

If you are interested in sending e-mail invitations for Bone China Tea, send an e-mail to Director of Development Stuart Tart at the OI Foundation at STart@oif.org. He will then alert you when the web pages will be "live" after the first of the year.

Please join us in this easy, fun way to raise funds to support the incredible work the Foundation does.

Jenny Wilson
JNWilson@aol.com
239-482-0643

Susan Wilson
OISLW@aol.com

Co-Chairs, OI Bone China Tea

Author Corner

Information about authors and books connected to living with OI

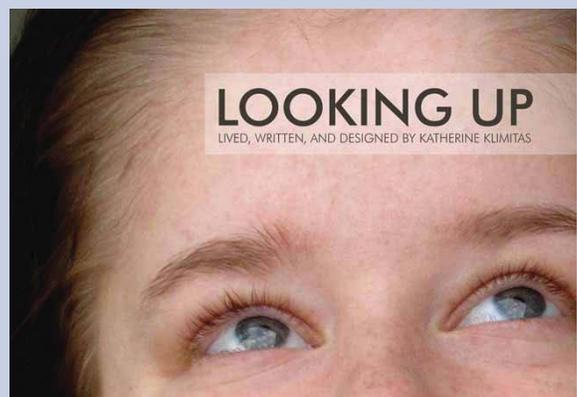
Looking UP

By Katherine Klimitas

A recent college graduate and a talented designer, Katherine Klimitas has written a book about being a young woman who has OI Type III. In photos and short essays, Ms. Klimitas uses wit, humor and design skills to share her challenges, triumphs and frustrations. Other adults who have OI and parents of children with OI will enjoy reading about life from Ms. Klimitas' perspective. The soft cover book can be purchased for \$19.95 through Katherine's website, www.kakartnola.com.

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 to suggest a book or author to include in future columns.



Health & Wellness

Funding Available for Individuals and Families Living with OI

Now in its third year, the CBBF/OIF Impact Grants program is accepting applications until **January 16, 2012**. Individuals and families living with OI may apply for funding to purchase equipment or services that will improve their quality of life. Recipients of past Impact Grants were awarded equipment such as computers, hearing aids, new wheelchairs and walkers and services including aquatic therapy, college tuition, and driving evaluation fees. In 2011, the Impact Grant program funded 28 grants for a total of \$163,000.

To apply for an Impact Grant, you must complete the online application which can be found on www.oif.org/impactgrant, and meet the following eligibility requirements:

- Finalists will be required to provide written documentation of a diagnosis of OI.
- Financial need – if application is chosen as a finalist, income verification will be required.
- Request improves the applicant's quality of life.
- Grant must serve immediate needs and used within 12-months of being awarded.
- Those receiving an Impact Grant are not eligible to apply for additional funding for one year.
- Applicant must be a United States resident, and funds may only be allocated within the United States.

Applicants are asked to limit their application request to only one item, such as:

- Orthotics/braces/walkers
- Travel, hotel and registration fees to attend the 2012 National Conference on OI
- Manual/electric wheelchairs or scooters
- Prescribed exercise therapy equipment; physical/occupational therapy
- Education related items such as tuition assistance, pre-school to post-doctoral support
- Adaptive technology such as computers, hearing aids, etc.
- Vehicle modifications such as lifts, pedal extensions, etc. or vehicle purchases
- Travel reimbursement to receive specialized care
- Outdoor ramps that provide access to a home
- Accessibility aides such as walkers, canes, reachers, shower chairs, kitchen carts, etc.

Impact Grants may not be used to pay financial debts including credit cards, school loans and mortgages. Impact Grants cannot be awarded for extensive home modifications that include plumbing. For more information about the program, call 800-981-2663 or email impactgrants@oif.org.



CHILDREN'S BRITTLE BONE FOUNDATION



What a Peek into the Past Can Reveal About Your Future

People who have OI are not able to ignore the other health problems that arise in families. Every year since 2004 the US Surgeon General urges everyone to think about their family's Health History when they get together over the holidays. Family health history is more than just the diseases that run in your family; it includes the eating habits, lifestyle, culture and environment your family shares.

How can family health history affect my health?

You inherit many things from your parents and grandparents. They pass on culture and family values. They also pass down the genes that determine how you look—for example your eye and hair color—and how your body works.

Changes in some genes make it more likely that you will get certain diseases. This means that when members of your family have health problems, you might be at risk for getting the same health problems in the future. You may be able to prevent some of the symptoms and complications of these conditions by knowing your family health history and by making healthy choices.

How do I collect my family health history?

Talk to your family! Holidays, and family events like birthdays, or reunions provide a great opportunity to ask family members about their lives. Then you can plan individual conversations to get more information. You probably already know quite a bit. Existing family trees, photo albums, and baby books are good places to start. Personal letters, or an email survey can also help you learn more about your family members.

It's always a good idea to start by writing down what you already know, like how old your family members are and if they have any children. Then pick the questions that you want to ask to fill in the gaps. Besides collecting health information this can be an excellent opportunity to preserve your family's memories.

What information should I collect?

Try to gather information on at least three generations of your family. Collect this basic information for you, your parents, siblings, and children. Then you can move on to your extended family.

- Name and relationship to you (myself, parent, child, etc.)
- Ethnicity, race, and/or origins of family
- Place and date of birth
- If deceased, age and cause of death
- Health history—include conditions such as heart disease, diabetes and cancer, and write down how old the person was when the disease started
- Lifestyle (occupation, exercise, diet, habits such as smoking and regular doctor check-ups)

This information helps paint the whole picture of your family health history, the good (healthy behaviors) as well as the bad (illness and disease) that contribute to your overall health.

continued on page 24

Health & Wellness

What a Peek into the Past Can Reveal About Your Future *(continued from page 23)*

What should I do with the Information I collect?

- Organize it. You can write it in a narrative or draw a family tree. The most important thing is to organize the information so it makes sense to you, your family, and your healthcare provider.
- Bring it to your healthcare provider. S/he can help you understand if you are at risk and might refer you to a genetics specialist or recommend early screening.
- Use it to make healthy lifestyle choices. You can change your diet and exercise habits to reduce your risk for many conditions.
- Share it with your family. Shared knowledge can lead to support.

Keep adding to your family health history. It is a lifelong process.

Are there free tools to help me?

Yes, there are several to choose from.

- Does it Run in the Family? (www.familyhealthhistory.org). This online tool kit lets you customize family health history booklets.
- The U.S. Surgeon General's My Family Health Portrait (www.familyhistoryhhs.gov). This is useful for organizing your family health history information once you collect it. It builds a family tree for you that you can easily share with relatives and doctors.

What else should I know?

As you talk to family, start with older relatives. They are often good sources of information about multiple generations. Keep in mind that family members may not clearly identify all diseases. For example, someone who suffered from "the blues" may have had depression. Ask family members to talk about how relatives acted. Ask about all health problems, even ones that may not seem serious such as benign colon polyps. Also look for patterns in your family history that could be a sign of an undiagnosed condition like multiple sudden unexplained deaths. Don't expect people to answer all of your questions. Some relative may not know their family history and some may not want to share. It is important to respect your family's wishes and give them the time and space they need to have the conversation.

If you are adopted, you may be able to learn some of your family history through your adoptive parents or may ask to see the adoption agency records. If no information on your biological relatives is available, start your family health history with you, so you can pass it down to your children.

There's a lot to do!

This may seem overwhelming: too many relatives to talk to about sensitive subjects, too much information to collect. Don't worry, you don't have to do it all at once! Use multiple conversations over the course of months and years to gather a comprehensive family health history. These conversations should be ongoing, not a one-time topic to be discussed and forgotten. What you learn can shape your future and even save your life.

So as you gather with family over the holidays and all through the year, consider including family health history conversations as a new tradition. For more information please visit www.geneticalliance.org/hff.

Note: This article is based on "A Peek into the Past Can Reveal a Lot about Your Future" by Aileen Palmer; Vaughn Edelson and Alyson Krokosky, MS, CGC. It appeared as the Genetic Alliance column in the November 2011 issue of **Exceptional Parent Magazine**. The OI Foundation is grateful for their permission to share this information in **Breakthrough**.

FROM THE INFORMATION CENTER

Respiratory Health

Flu Season is here but it's not too late to get a flu shot! Flu (influenza) is a serious illness. It's caused by a virus that infects the nose, throat and lungs. It can lead to pneumonia and other medical problems that require hospitalization. Children and adults who have OI are considered an "at risk" group. Because of respiratory problems like asthma, flu can quickly go from a mild illness to pneumonia.

OI Foundation medical advisors recommend:

- Everyone with OI older than 6 months and the people they live with need protection from the flu
- Get the shot (injection) NOT the nasal spray and stay away from people who have just received the spray vaccine
- One shot covers all types of flu this year
- **Important**—Do not get the vaccine if you are allergic to eggs, or latex. Talk to your doctor first.

You can protect yourself and others by hand washing, and by covering your nose and mouth with a tissue when you sneeze or cough. Using disinfectant wipes to clean surfaces that lots of people touch in your home such as doorknobs or elevator buttons can help reduce the spread of viruses too.

Amusement Park for Kids with a Disability

Morgan's Wonderland in San Antonio was tailor-made for fun-loving people who have a disability. Designed to be enjoyed by children in wheelchairs, or with cognitive disorders, Morgan's is advertised as the world's first ultra-accessible family fun park. Set on 25 acres, it includes rides, interactive exhibits, playgrounds, gardens a fishing lake and live entertainment. If you're in Texas or considering a family trip, check out www.morganswonderland.com

Pain Medicines in the News

News reports over the last several months pointed out the importance of carefully managing your use of all pain medications including those sold without a prescription. Too much acetaminophen (the main ingredient in Tylenol)

can cause liver damage. And a group of medications called nonsteroidal anti-inflammatory drugs (NSAIDs) can cause stomach problems especially if taken over long periods of time. These medications include ibuprofen, aspirin and naproxen and are sold under the brand names of Advil, Motrin and Aleve. Stay healthy by:

- Talking to your doctor about all the medicines and supplements you take. Include information about how much and how often.
- Checking over-the-counter medicines for cold and flu to see which pain relief medicine is in each dose.
- Do not take a prescription and over-the-counter pain-relief medicines at the same time.
- Take all medicines exactly as directed.

In case of an emergency, make sure someone is available who can tell the doctors about the medications, herbs and other supplements you take. Some herbs and supplements depending on the dose can cause serious complications if surgery is necessary. It is a good idea to keep a list including prescriptions, over-the-counter, herbal and supplements in your wallet next to your insurance card.

Hospitals and Infections

It is a sad fact that hospitals, clinics and emergency centers can be a source of infections. Here are a few suggestions about how to reduce your chance of catching an infection.

- Insist that health care workers wash their hands before touching the patient.
- Parents should wash their hands or use hand sanitizer before touching their child.
- Wipe off commonly touched surfaces—lamp switches, bedside tables and doorknobs with a disposable disinfectant wipe.



Sleep Apnea

Sleep apnea is sometimes mentioned as an issue for adults and children who have OI. How many people have this problem is unknown at this time. As awareness about sleep apnea is growing among people who do not have OI it is possible that your primary care doctor may bring up the topic. The Agency for Healthcare Research and Quality (AHRQ) has prepared a booklet that summarizes information on treatment. This is part of AHRQ's Effective Health Care Program. For more about this program you can visit www.ahrq.gov. This Q & A is based on the publication "Treating Sleep Apnea: A Review of the Research for Adults."

What is sleep apnea?

Obstructive sleep apnea is a chronic or ongoing disorder. An affected person will stop or "pause" their breathing or have shallow breathing when they sleep. Almost everyone has brief times when they stop breathing while they sleep. This becomes a problem when a person does this more often than normal. This leads to lower oxygen levels in the person's blood, tiredness and sleepiness during the day. Many people who have sleep apnea snore loudly, or start breathing again after a "pause" with a loud snort or choking sound.

How common is sleep apnea?

A growing body of research indicates that sleep apnea is very common, affecting people of all ages. Middle-aged and elderly people, people who are very overweight, and anyone with scoliosis and/or chest deformities is more likely to have this condition.

Is sleep apnea serious?

Untreated sleep apnea can become serious. It causes poor sleep quality, leading to daytime sleepiness and low energy. There is the increased risk of work-related or driving accidents due to sleepiness. Sleep apnea also increases the risk of serious health problems, including diabetes and even death. Among people who have OI, sleep apnea may contribute to chronic fatigue.

How is sleep apnea diagnosed?

Diagnosis often begins when people mention tiredness, snoring or daytime sleepiness to their primary care doctor. Your doctor may decide to use a home monitor or prescribe a "sleep study" to determine if sleep apnea is the problem. A sleep study is an overnight stay at a special clinic where trained professionals watch your breathing, heart rate, and other vital signs while you sleep. People who have OI, especially those who need careful positioning or an adjustable bed to sleep should talk to the sleep center ahead of the test so that special arrangements can be made.

How is sleep apnea treated?

There are two common treatment options. The most frequently prescribed is a Continuous Positive Airway Pressure Machine (CPAP). A CPAP machine pushes a stream of air through a mask you wear when you sleep. There are many kinds of CPAP machines and a wide variety of masks. Some fit over the nose and others cover both the nose and mouth. It is important that the mask fits correctly and is comfortable. The other treatment option is a Mandibular Advancement Device (MAD). This is a mouthpiece you wear when sleeping. It keeps your jaw forward and your airway open. It is important that this mouthpiece is correctly fitted so it is comfortable and effective.

In Memory Of

August 1, 2011 – October 31, 2011

Lamar Baker

Dr. Holly Gilkeson

Shana Benedict

John & Angela Dunn

Sydney Grace Bennett

Mr. Stephen Wilson

Dorothy Brown

William & Rose Berger

The Tacoma Fashion Doll Club

Dorothy E. Brown

Mr. Frances Lott

Ms. Lisa Pasin

Ms. Joann Sparks

Dorothy Elaine Brown

Ms. Karen Weber

Mary Clayton Fancher

Mrs. Reagan Jhee

Jenny J. Cubero

Salvatore & Karen Assante, Jr.

Congie DeVito

John & Mary Comfort

Ms. MaryAnn Neblock

Jeremy Dickinson

Rick & Pamela Hicks

Miss Violet Karis Fichtner

Mrs. Amy Fichtner

Konie S. Gardner Pipes

Mrs. Nedra Covington

Ms. Judy Warrick

Miriam Haimovici

Mrs. Anat Haimovici

John C. Harris

Wilbur & Nancy Harris

Jackson K. Jones

Mr. & Mrs. Stephen Povroznik

James Nicholas Keller

Mrs. Angela Fuggiti

Blake William Lassey

Mrs. Renee Skipsey

Simon P. Nadeau

Ms. Judith Ernst

Mr. Richard Fagan

Ms. Jeanne Gardner

Ms. Ann Zacharchuk

Persephone Grace Olds-McKinney

Ms. Sarah Alfieri

Ms. Sarah Bennett

Mrs. Jo Buechler

Mrs. Kimberly Hancock

Mrs. Nancy Long

Mrs. Jennifer Miller

Ms. Angela Moore

Mrs. Maria Neesman

Bracston & Myrtis Olds

Ms. Myshell Olds

Ms. Susan Sealy

William (Bill) A. Poole

Joseph & Karen Bennett

Ms. Marcy Mancuso

Kirton & McConkie

Ms. Audrey Weber

Jeffrey & Jane Westra

Mary C. Richard

Mr. Paul Dauphinais

Dr. Edward Marut

Carla & Kristal Nemeroff

Ms. Heller An Shapiro

Ms. Susan Wilson

Mr. Harry Yeomans

Edna Schettler

Randall & Deb Warner

Neeru Sharma

Gurdev & Vimla Sharma

Edmond Somekh

Ms. Odille Hansen

Alex John Thompson

John & Angela Thompson

Barbara Tobias

Mrs. Betsy Manela

Anne M. Urbanski

Mr. Ken Urbanski

James Wells

Mr. Mario Nardone

Shaun Lee Whitmore

John & Ruth Hill

In Honor Of

August 1, 2011 – October 31, 2011

Caden Amador

Mr. Tom Wedell

Isabelle Anaya

The Northern Trust Company

Oliver Bellant

Ms. Diana Kilty

David & Cynthia Seeds

Sarah Calmus

Hunt Ridge Montessori, LLC

Geoffrey & Ellen O'Connor

Ms. Janice Portentoso

Colin & Rachel Thornton

Timothy & Kathleen Zwahlen

Miss Marin Olivia Clarkson

Mr. Warland McKinzie

Jenna Cummings

Ken & Diane Dieterich

Pat DeLuccia

Thomas & Yvonne Fallon

Nora Epstein

Philip H. Corboy Foundation

Jack Frost

Tim Dombro & Jamie Kendall

Mallie Holman

Ms. Mary Ridgway

Katie Kipperman

Dr. Larry Kipperman

Michael and Mabel Lux

Ms. Joan Marcus

Randolf & Annette Von Oepen

Jeffrey Krudys

Aerotek Aviation, LLC

Kevin & Ellen Haley

Ms. Ann Marie Miskewicz

New Jersey Sports Production, Inc.

Glenn & Laura Schechter

Ms. Kathleen Wedral

Elise Ludwig

Larry & Deena Ludwig

Mike & Meghan Moran

Mr. Brett Keintz

My Awesome Mother

Saurabh Mittal, Ph.D.

Christopher Nolan

Mrs. Kathryn Phillips

Sophia Resti

Ms. Mari Del Gais

Kaiden Scott

Mrs. Charleen Judy

Robert Sikora (65th Birthday)

Ms. Sheri Shiels

Matthew Smith

Liberty Mutual Group, Inc.

**Harvey & Lorraine Starr
(Wedding Anniversary)**

Faye & Betsy (Bross)

Brian Verhoeven

Schwab Charitable Fund

The Weinstein Wedding

Ms. Amy Eckelmann

Townsend "Cayden" Wilkinson

Ms. Julie Douglass

Lesjak Planning Corporation

Johnathan Williams, M.D.

Mr. David Abels

Addie Wisniewski

Ms. Pat Mitchell, RN

Ethan Yamashita

Paul & Geraldine Yamashita

Breakthrough

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

Chief Executive Officer

Tracy Smith Hart
thart@oif.org

Director of Finance and Administration

Tom Costanzo
tcostanzo@oif.org

Director of Program Services

Mary Beth Huber
mhuber@oif.org

Director of Marketing/Communications

Erika Ruebensaal
eruebensaal@oif.org

Director of Development

Stuart Tart
start@oif.org

Development/Events Associate

Alisha Matlock
amatlock@oif.org

Program Associate

Debb Deering
ddeering@oif.org

Administrative Assistant

Jenny Stup
jstup@oif.org

Database Manager

Desiree Swain
dswain@oif.org

Health Educator

Petra Harvey
pharveyk@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 824061
Philadelphia, PA 19182-4061

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

