Breakthrough

THE NEWSLETTER OF THE OSTEOGENESIS IMPERFECTA FOUNDATION

OSTEOGENESIS IMPERFECTA OI FOUNDATION

Vol. 34 No. 2 Summer/Fall 2009

Climb Every Mountain

A slow recovery from surgery inspires young woman to reach for new heights

In 2006 and 2007, Anna Curry went through a rough patch. An attorney with OI, she was having trouble recovering from two recent surgeries. “I thought that I might set a goal for myself and work towards that while recuperating and rehabilitating,” Anna explained.

Her goal is a bit ambitious. On September 23, Anna will leave for Africa, where she will attempt to climb 19,438 feet to the top of Mount Kilimanjaro. Her father, Ashley Curry, and a small group of fellow adventurers will accompany her for this 9-day trek. Anna and her father also are using their climb as a fundraiser for the OI Foundation, with a goal to raise $19,400, or a dollar for every foot climbed.

Ashley shared that when Anna was growing up, he and his wife were determined that Anna have as normal a childhood as possible. As a result, Anna played softball, and at one point sustained two broken legs in one game. “She told me that evening that if she were able, she would play the next day,” Ashley said. “That desire and unconquerable spirit is what drives her today and keeps her going.”

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Ashley and Anna during a practice climb in August 2008 at Mt. Sherman, in Leadville, CO.

OI Foundation Thanks Out-going Board Members

On June 30, 2009 three members of the Board of Directors completed their six year terms of service. Ken Finkel, Christine Wyman Rossi and Jamie Sharples all leave the board after serving during a time of unprecedented growth in the areas of research, program delivery and advocacy. Members of the board that served during this time are credited with taking the concept of developing linked Centers across the country that would share information and six years later are witness to the implementation of the program that consists of six linked centers.

Ken Finkel

Jamie Sharples

Many of you know that Ken Finkel served as the Board President for three years and guided the Foundation through many changes including the implementation of the Linked Clinical Research Centers. Ken also guided the Foundation through a change in staff leadership, the development of the Foundation’s advocacy efforts and the increase of participation by members of the community in fundraising events among many other changes.

Christine Wyman Rossi

All three board members served in positions of leadership within the Foundation – Christine Wyman Rossi served on the executive committee for three years and continues to chair the Massachusetts walk. She continues the legacy of volunteerism in her family started by her father, former board member and recipient of the 2008 Thelma Clark Lifetime Volunteer Achievement Award, Dick Wyman. Her fellow board member, Jamie Sharples served as the Foundation’s Finance Committee Chair for three years and will continue to serve in this important role for the upcoming year.

The Foundation thanks Ken, Christine and Jamie for their outstanding service and looks forward to working with them in the days ahead.

In this issue...

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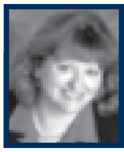


From the Chief Executive Officer

Greetings!

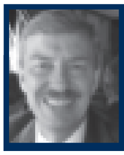
I hope everyone is having a wonderful summer and you're taking the opportunity to relax and spend some time with family and friends. Summer here at the OI Foundation has been busy. We have been busy monitoring the health care reform debate to make sure that the needs of people with OI and other rare bone diseases and disorders are addressed with any new legislation. It will be very important that any reform includes increased access to care, is affordable and eliminates barriers to care such as any wait to receive benefits or services. We will keep you updated through e-news alerts and through the website with any new information between editions of *Breakthrough*.

In addition to advocacy, the Foundation has been working closely with our researchers and physicians to make sure that OI research applications are being submitted to the various institutes at the NIH (National Institutes of Health) to take full advantage of the government's stimulus funds that the NIH received. We hope to give you good news on the selection of grants that include new and innovative research in various areas of OI and bone related research in the very near future.

Lastly, I'd like to thank the many wonderful volunteers who have stepped forward with their donation of time, talent and resources over the past several months. Wonderful events like Bone China Tea, chaired by Jenny and Susie Wilson and the Massachusetts Walk chaired by Christine Rossi continue to be successful because of the hard work and dedication of exceptional OI Foundation volunteers. We are very fortunate to have your support! Have a great remainder of the summer and we'll talk again soon!

Warmest regards,

Tracy Smith Hart



From the President

Over the past 15 years I have been involved with the OIF in one way or another. As a parent of a newborn OI child in 1994, our family relied heavily on the foundation for information and support during a very stressful period in our lives. Similar to other OI families, we have faced many challenges but I have always been thankful that we have a national organization that is dedicated to serving the OI community. I have been actively involved in the foundation as a volunteer, fundraiser and as a member of the board of directors. It is therefore quite an honor to now serve as your OIF board president for the next twelve months.

I cannot say enough about our past board President Ken Finkel. In his three years as board president Ken had many accomplishments which included his superior leadership in getting the Linked Clinical Research Centers up and running, and leading a development team in identifying our current CEO. Although we will miss Ken's leadership on the board, we are grateful that Ken will continue to actively participate in the OI community and we will get to see him at conference in Portland.

In the coming months the OIF staff and board will be busy. One of our priorities will be to update the OIF strategic plan for the next five years. Strategic planning is one of our most important functions because it is a fundamental step in helping us as an organization set our priorities for the future. As a foundation we have multiple priorities which include serving and advocating for the OI community and in funding research that will one day find a cure for OI. We cannot move forward and achieve our strategic goals without your help. This is particularly true in the difficult economic times that we find ourselves in today.

An important part of our job is to raise money so that we can adequately fund all of the important activities and research required to achieve our strategic plan and ultimately to find a cure for OI. We need all of the help we can get so I encourage each of you to consider how you might help in this effort. For instance, starting a walkathon in your local community is easier than you might expect and the OIF staff can help you get started. Whether it is sponsoring a walkathon or a golf tournament, or participating in Bone China Tea or a raffle, it is these types of fundraising activities that are so vital to helping the OIF serve the OI community.

I am honored to serve as your board president and I look forward to working with our board of directors, our CEO Tracy Hart and our outstanding OIF staff to continue moving the foundation forward.

Roger Bache

Traveling is Possible

by Neeru Sharma

Neeru Sharma is a Long Term Vehicle Forecaster at General Motors, and former OIF Board Member.

Traveling with OI can present itself with a challenge if you let it. However, as a person with Type III OI the key elements which have allowed me to travel by plane all over the world whether for business or personal is planning, preparation, flexibility, and creativity. When I need to travel by air to a destination within the US the main things that have made the trips successful are communicating my needs in advance to the airlines, hotels, and if required home care agencies so all of the things needed are in place. The best way for me to describe a typical trip traveling on my own is to share with you my last trip to Washington, DC, last year to attend the OI conference.

1) Airlines — I booked my travel plans one to two months in advance so that I knew I could get the seating which was most convenient for me. For most wheelchair users it is easier to travel either in first class or coach in one of the first few rows. When you book your seat it may be easier to book via phone and explain to the airlines you need to sit where it is easy to transfer or be transferred. Bulk head seats are the rows of seats right behind first class and can be reserved for people with disabilities. Make sure the airlines know if you are bringing your wheelchair and what kind of chair it is — electric with batteries or manual. They will ask details about what assistance you will need to get on the plane so let them know if you can transfer on your own or need assistance. You do not need to divulge your medical condition directly. Also remember airline personnel cannot help you with going to the bathroom on the airplane. So if you can not go to the restroom in the plane using the aisle chairs (small transfer chairs available on the aircraft) then you will need to go the bathroom before taking off. Also you may want to consider wearing an adult size diaper just in case (discreet), which could be necessary if your flight is delayed and you can not reach the restroom in time. Another tip is try to take direct flights to your destination to avoid getting onto too many flights. If you are traveling alone — which I do most of the time — then make sure someone at home knows your flight info and medical emergency contacts in case they need to. Try to travel on your own if you can — being independent is key for adults with OI.

Your wheelchair will be stored by the airlines once you are loaded on the plane. You will need to board 15-30 minutes before everyone else when the airlines announce preboarding so be ready at the gate. If your wheelchair is lost or damaged on route, be ready to put in a claim to the airlines. Things have improved with airline travel but problems still arise so have a backup plan in place or consider renting a wheelchair. Consider bringing your wheelchair tools (screwdriver or other items needed). Last time I went to Washington, DC, I rented an electric wheelchair instead of bringing my expensive wheelchair. Though it is not fun using a different wheelchair it was better than worrying about my wheelchair being damaged on arrival. Rental of wheelchairs is available by finding a durable medical equipment company in the city you are traveling to or by calling 888-441-7575 (Scooter Around).

2) Medical supplies — Travel with some medical supplies in your carryon and in suitcase. I bring ACE bandages, Bengay and some other items in case I get some bone pain or muscle problems. Being prepared with all of your medications and other required OI items is key.

3) Be flexible — Sometimes traveling will not go as planned so be flexible, polite and firm. Do not allow your mobility to be hampered but at the same time do not become a pest to the airlines or hotel staff. You are an adult so problem solving skills and good social etiquette are essential.

4) Hotel — Hotels have wheelchair accessible rooms but you need to request in advance when you are making your reservations. Make it as far in advance as you can — since only a few rooms in hotels are wheelchair accessible if you require a room with larger doors and specially set up bathrooms. Also realize the hotel will not be quite set up for you so let hotel staff know when you arrive what you need in terms of placement of towels, shower items, shower chair, door handles/ropes to open door etc. Most large hotels will accommodate you if you make your needs known when you arrive at time of check-in.

5) Home Heath Care — If you think managing on your own when traveling is going to be hard, either hire a nurse aide when you arrive to the destination or pay someone to travel with you. I have done both. Working with home health care agencies in advance will allow you to have someone come in when you need help at the hotel. Make sure the agency you choose is accredited and can send someone to the

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Spotlight: Jennifer Kilman

Jennifer Kilman has had a lifelong love of color and style. As an eight year old she attended a beauty pageant in Florida and marveled as she watched the dancing women in wheelchairs. A suggestion at the time that she might grow up to do the same became a reality this spring when she won the title of Ms. Wheelchair Ohio. A wheelchair user from an early age, Jennifer has sustained 350 fractures and 20 surgeries. Acknowledging Jennifer's "outstanding triumphs over life's difficulties" the judges chose her to represent the state at the Ms. Wheelchair USA pageant.

It was predicted that newborn Jennifer would live six months. If she were lucky maybe this could be stretched to a few extra years. Certainly she would never see her teens. Born in 1971 to Dr. James Kilman, a heart surgeon and Priscilla Kilman, a registered nurse, Jennifer was the youngest of three. At the time, her mother taught special needs infant care to parents and nurses. She later remarked that no training could have prepared her for the emotional challenge she was facing as a mother.

The Kilmans believed in the importance of an education and encouraged Jennifer to pursue her dreams, which led naturally to studies in the field of Art and Design. Receiving a merit scholarship to attend the Columbus College of Art and Design, Jennifer graduated with a degree in graphic design and marketing. This led to a job as marketing manager for two Columbus based medical distributing companies. Currently, Jennifer freelances her marketing skills for aspiring small business owners.

In 2007 Jennifer started Bucks for Bones, a non-profit foundation that raises funds to help pay for medical needs that aren't covered by insurance for OI patients at Ohio State University and Nationwide Children's Hospital in Columbus. She is active in the Federation of Christian Athlete fundraising activities and volunteers with various church youth projects. She also offers career counseling to GED and ESL adults at a local career center.

While Jennifer credits her parents as being her biggest supporters, giving her wings and offering possibilities, her mother notes that when her daughter "gets her mind set on something, she just perseveres until she gets it done. All these accomplishments she's made as an adult, she's done it on her own." Jennifer loves to dispel stereotypes and challenges others to look beyond the obvious. She gets a kick out of surprising others with her high level of activity. Her friends call her the Energizer Bunny for good reason.

So, it is no surprise that Jennifer has her sights set on another challenge and what she terms her "next big career dream." The dream is to return to college and obtain a law degree. With plans for a double major in political and family law, Jennifer hopes to further advocate for both children and the disability community. "Every child needs someone who will speak for them when they need to be heard." Advocating for children, Jennifer hopes to "empower and guide them to speak up for their own safety and future lives." Observing that children are drawn to her, Jennifer states "They know I'm not a kid, but I'm not quite like an adult either. It's like a gift that God gave me."

Believing that differences are what allow individuals to make valued and unique contributions in their communities, Jennifer observes that "our unique differences only limit us in our minds if we truly believe we are limited or unable to achieve personal goals. She sees her gift and unique contribution as having the ability to provide compassion and encouragement to those dealing with hardship and loss. Jennifer believes that a true advocate is a good listener and someone that becomes a supportive "superhero when you need one in the boxing ring." Not afraid to step into the ring, Jennifer hopes to pass on her strength and instill in others the determination that keeps her moving forward on what some refer to as "warp speed."

In July, Jennifer brought her can do attitude to Cuyahoga Falls where she competed and placed as first runner up for the title of Ms. Wheelchair USA. Additionally, she was the recipient of the Dane Foundation "Quality of Life" trophy. This award is based on the contestant's platform, community service, empowering influence through outreach, and how she continues to contribute to improving the quality of life for individuals with disabilities. Jennifer was "more touched to receive that than ANYTHING else."

With an upbeat and enthusiastic approach to life, Jennifer is committed to demonstrating to other wheelchair users that they are able to compete and achieve the goals they set for themselves. Believing that the best role model is a loving person, Jennifer shares the following. "Throughout my life, I've learned that without knowing how to give and receive love it's hard to feel and experience being alive. I have discovered when we have faith in each other we can love unconditionally and empower one another."

Spotlight: Julie Hocker

A Call to Teens with OI

If you were at the last national conference, you know that there was one thing not in short supply: teens! Through the halls, in workshops, and in the teen room itself, there was a spirit of friendship and level of energy that, let's face it, seems to come quite naturally to the teenage set. So it makes perfect sense that this high-charged group of teens with OI has already started coming together to make plans for the 2010 National Conference in Portland. They have, in fact, formed a "Teen Team" that will ensure an even greater role for teens when they meet again next year.

Serving as the "Teen Team" volunteer advisor is Julie Hocker of Washington, DC. Julie, who has Type III OI, has been working on federal youth programs and policy since her days as an intern and the first chairperson of the National Youth Summit Committee for the U.S. Department of Health and Human Services (HHS) in 2003.

"The experiences I had with the National Youth Summit Committee were instrumental in forming my career after college, introducing me to friends and mentors whom I still count on, and giving me the knowledge to mobilize youth from coast to coast to get vital work done. I look forward to applying the skills I learned on the Committee to my work with the 'Teen Team'."

Currently, Julie works with the national Mentoring Children of Prisoners program at HHS, where she received the Assistant Secretary's Employee Excellence Award for the Administration for Children and Families in 2007.

"The teen team is a great opportunity for teens to not only tell the OI Foundation what they'd like to do at next summer's conference, but it's an exceptional chance for them to be an important part of it. They're going to have a strong presence. And I'm so happy to be a part of it."

The Foundation is looking to the Teen Team to shape not only the teen room, but workshops, sharing sessions, and activities specifically geared towards the age group. The team will also be charged with hosting the ever-popular talent show and proposing new ideas to add to the fun to come in Portland.

If you are between the ages of 14 and 19 and would like to join the team, email Julie at jehocker@gmail.com. The team will begin meeting via conference calls in early September and has much work ahead. You don't need experience, just energy and a willingness to share ideas and work toward a successful and FUN 2010 National Conference. See you in Portland!!

Children's Brittle Bone Foundation and OIF Launch New Grant Program

In July, the Children's Brittle Bone Foundation, in partnership with the Osteogenesis Imperfecta Foundation, launched the Impact Grant Program to help support people with OI in need of equipment or services that will improve their quality of life. Impact Grants are designed to provide funding that can be used to assist with daily living, to modify an existing home or vehicle; to be used as an investment in a person's education, to help increase a person's employment potential, or to support any other project that may improve the quality of life for someone living with OI. Impact Grants are awarded in amounts from $500 to $20,000, but all requests are considered.

For the first round of applications, the program was open only to residents of Illinois and Wisconsin. The Children's Brittle Bone Foundation and the OIF are excited to begin the next application cycle, which will be open to applicants in every state, sometime in the upcoming year. Information about the next application cycle will be posted on the OI Foundation's website at www.oif.org. Together, CBBF and the OI Foundation are committed to improving the lives of people living with OI.

Graduation Shout Out

Hearty congratulations to the following students who have completed their high school or post secondary studies:

Adam Sanders – Hilo, HI: Adam will be attending Evergreen College in Olympia, WA. Adam graduated in the top quarter of his class and was active in theatre. He is interested in broadcast journalism, mass communication, history and political science.

Ryan Juguan – Chicago, IL: With a first stop at Parkland Community College, Ryan plans to move on to the University of Illinois and become a member of the men's wheelchair basketball team and track and field team, while pursuing a degree in business.

Daniel Foltz-Morrison – Westfield, NJ: After graduating with a Bachelors of Music from Moravian College in Pennsylvania, Daniel will continue his studies in vocal music performance at Rutgers University where he has already been chosen to sing the lead tenor role in the fall opera production of *Le Pescatrici* on October 30 & 31.

Michael Stewart – Rye, NY: Michael will be attending Brown University in Rhode Island. While in high school he was student body president and active in the drama and music departments.

Summer Burr – Walton, NY: Active in various volunteer organizations, including the local fire department, Summer will be competing in the National Miss New York pageant in August before starting class at Bromme Community College where she has plans of being accepted into their physical therapy assistant program.

Mia Ives-Rubles – Greensboro, NC: Mia has received a Master's in Social Work from the University of North Carolina at Chapel Hill.

Amber Perry – Lore City, OH: Amber will be attending the Bradford School in Columbus with plans to study Medical Assisting.

Evan Anthony – Mt. Pleasant, PA: Evan will be attending St. Francis University in Loretto, PA, with plans to study mechanical engineering. Active in many organizations, he hopes to take his golf game to the collegiate level.

Anna Lennartson – Round Rock, TX: Graduating with honors and in the top 3% of her class, Anna will be attending Hendrix College in Conway, AR, with plans to major in Psychology.

Brittney Woodland – Walla Walla, WA: Brittney is still considering options and may get a job before heading off to college. An avid video game fan, she is thinking about pursuing game design.

Smitty Lynch – Hampton, VA: At 34 years old, Smitty has realized a lifelong dream of becoming an architect and graduated this spring with a masters degree from Hampton University. The busy father will sit for the required testing after completing his internship.

Science & Research

Medical Advisors on the Go

Members of the OI Foundation's Medical Advisory Council (MAC) are highly respected professionals who donate their time and expertise to the OI Foundation. Their participation in conferences is an important avenue for spreading awareness and up-to-date information about OI to medical and research professionals. Here is just a sample of MAC member activities this summer.

5th International Conference on Children's Bone Health, Cambridge, United Kingdom
Francis Glorieux, Michael Whyte, and Laura Tosi attended. Dr. Glorieux gave a presentation titled "The Changing Face of Bone Disease."

International Skeletal Dysplasia Society Meeting, Boston, MA
Matt Warman hosted the meeting. Dr. Deborah Krakow and Dr. Glorieux attended. Dr. Glorieux gave a presentation titled "Do the New Forms Recently Described Warrant Revisiting the Classification?"

In addition
Dr. Glorieux attended the New York Skeletal Biology and Medicine Conference and spoke at the 4th International Workshop on Advances in the Molecular Pharmacology and Therapeutics of Bone Disease.

Dr. Joan Marini gave the featured talk "The New Genetics of OI" at the Pan-Asian Connective Tissue Conference.

Holly Cintas, PT, PhD was invited to the American Physical Therapy Association Research Retreat, attended the APTA Annual Conference and represented the OI Foundation at the 6th International Conference on Conservative Management of Spinal Deformities in Lyon, France.

Signaling in Bone and Targets for Therapy

Eighth OI Foundation Scientific Meeting Held in Chicago

In April 2009, more than 40 of the country's most prominent researchers, physicians and scientists came together at the OI Foundation's annual scientific meeting in Chicago, Illinois. The group included established OI researchers and clinicians, as well as those involved in bone research but new to the field of OI. The meeting's goal, generously sponsored by the Buchbinder Family, was to explore the topic of integrating cutting-edge bone biology into research on osteogenesis imperfecta.

The topic for the meeting was "*Signaling in Bone and Targets for Therapy*." The growth and maintenance of bone strength occurs through a process of constant bone remodeling and new bone formation. This entire process of remodeling and growth is a tightly regulated and coordinated effort between osteoblasts (cells that make new bone) and osteoclasts (cells that remodel bone). The activity level of these cells is controlled and modified by a variety of signals, including hormones, proteins and other signals that the body produces to ensure normal bone growth and normal bone density.

Meeting chairs, Dr. Brendan Lee and Dr. Reid Sutton from Baylor College of Medicine and other meeting presenters spent a day discussing pathways that effect osteoblast and osteoclast activity and function. Researchers and clinicians heard about new treatments in development that act on various pathways. These are existing and emerging therapies that exploit these pathways to treat osteoperosis, another bone related disease.

In addition to new information on bisphosphonates, investigational new drugs were also discussed. Dr. Steven Teitelbaum from Washington University in St. Louis discussed osteoclast signaling and RANK-ligand, followed by Dr. Michael McClung, Director of the Oregon Osteoporosis Center, who discussed the drug Denosumab® that is being developed to treat low bone density by decreasing RANK-ligand signaling in bone. Dr. Nancy Lane of the University of California, Davis discussed parathyroid hormone control of bone density and therapy with Forteo®, which is in clinical trials in adults with OI. Dr. David Ke from Amgen and the University of Utah talked about drugs in development that are antibodies to a signaling molecule called sclerostin. The potential for new treatments that work on a variety of other pathways, including nitric oxide, TGF-beta, hedgehog and notch pathways was explored by the participants. For a community that has had very limited options for treatment in the past, the number of potential new treatments on the horizon is very exciting and is expected to be transformative.

The OI Foundation is grateful to the Buchbinder Family for continuing their support of scientific exploration into finding a cure and treatments for people living with OI.

The OI Foundation Announces New Linked Clinical Research Centers

The OI Foundation announced Shriners Hospital for Children in Chicago, IL, Shriners Hospital for Children in Montreal, Quebec and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), division of Intramural Research, in Bethesda, MD as its newest Linked Clinical Research Centers (LCRC.) A joint initiative from the OI Foundation and the Children's Brittle Bone Foundation, the Linked Clinical Research Centers are a nationwide network designed to provide the highest-quality of standardized medical care for people living with osteogenesis imperfecta (OI).

In addition to providing high-quality standardized care, the LCRCs, through a coordinated effort, will aim to advance standards of care and improve treatment through clinical research. By sharing data, the Centers will be capable of tracking how OI changes across a lifetime, what complications are common, and which treatments are beneficial.

The OI Foundation and Children's Brittle Bones Foundation launched the LCRC program in early 2008 with three pioneer centers; Baylor Medical Center/Texas Children's Hospital in Houston, TX, Kennedy Krieger Institute in Baltimore, MD, and Oregon Health & Science University in Portland, OR.

For more information about the Linked Clinical Research Centers, or the OI Foundation, please visit www.oif.org.

Dr. Francis Glorieux Named Chair of Medical Advisory Council

Francis Glorieux, O.C., M.D., Ph.D. has accepted a 3-year term as chair of the OI Foundation's Medical Advisory Council (MAC). The MAC chair directs the work of that committee and sits on the Foundation's Board of Directors. Dr. Glorieux is a long time member of the MAC and a frequent speaker at OI Foundation family conferences and science meetings. He is the director of research and the founder of the Genetics Unit at the Shriners Hospital for Children in Montreal, Canada. He is also a professor of surgery, pediatrics and human genetics at McGill University in Montreal, the author of numerous scientific journal articles and a leader in OI research. Dr. Glorieux was made an Officer of the Order of Canada, the highest honor for lifetime achievement offered by the Canadian government. He has also been the recipient of the Elsevier Award of the International Bone and Mineral Society and the Jonas Salk Award of the Ontario March of Dimes.

OI Foundation Advocacy Update

The OI Foundation and its grassroots advocates made significant progress in 2008 and early in 2009 toward implementing an effective long-term federal advocacy program. The goals of this program include:

- Educate Capitol Hill staff on osteogenesis imperfecta, the needs of people living with OI and the ways legislators can support the work of the OI Foundation
- Establish the OI Foundation as an influential health policy voice on Capitol Hill
- Secure federal funding for the OIF's Linked Clinical Research Center project and other bone-health related legislation
- Maintain an energized national grassroots network.

Working toward these goals a very successful Advocacy Day was held during the 2008 National OI Conference. More than 40 volunteers made over 25 visits to legislators from their home states. In addition, an Advocacy Page was added to the Foundation's website (under the How to Help tab). It is dedicated to sharing information on public policy matters important to people with OI. The OI Foundation is pleased to announce that it will be working with Kyle Mulroy and his team at Washington Strategic Consulting on these and other priorities in the year ahead. Kyle is an experienced and effective lobbyist as well as a member of the OI community.

The OI Foundation continues to be an active partner with other organizations that are working toward similar goals including the Bone Coalition. This well respected group includes leading national bone disease organizations representing thousands of people, research scientists, physicians and surgeons from around the country. The Bone Coalition currently is strongly supporting legislation titled **The Bone Health Promotion and Research Act of 2009**. This legislation provides for a comprehensive national bone health strategy including expanding and intensifying research in bone disease.

Next steps

OI Foundation grassroots volunteers will be called upon to help seek support for this important legislation, **The Bone Health Promotion and Research Act of 2009**. More information will be posted on the Advocacy web page as it becomes available. Instructions for contacting your federal legislators will be posted on the Advocacy Page. As information about federal health care reform proposals becomes available, it will be vital for people living with rare disorders to make their voices heard.

If you are interested in becoming a member of the Foundation's grassroots advocacy network, please call 1-800-981-2663 or e-mail Tracy Hart at thart@oif.org.

Research Grants

For the 12 months starting July 1, 2009, the OI Foundation and the Children's Brittle Bone Foundation (CBBF) will be co-funding three research grants. Each organization also will contribute the money needed to fund three second-year Michael Geisman Fellowships. The OI Foundation will contribute additional funds for two seed grants. Grant recipients will be invited to speak at the OI Foundation's science meeting in spring 2010 on the status of their research.

The Michael Geisman Fellowships are named in memory of Gemma and Dick Geisman's son who died suddenly as a young adult in 1980. Each fellowship goes to a young investigator. The initial award is for one year, but second year funding is available for those who qualify. The following projects have been awarded second year funding.

Akikazu Ishihara, PhD
Ohio State University
Topic: *Cell-based bone morphogenetic protein (BMP) Therapy for OI*
This young cell biologist is studying the possibility of using bone morphogenic protein as a treatment to increase bone density in people who have OI. Dr. Ishihara hopes to build on the successes of the first year and demonstrate that skin cell-based BMP therapy using an animal's own cells will effectively and safely improve bone mineral density. The hope is that this minimally invasive cell-based therapy will provide an economical and feasible treatment option to increase the strength of fragile long-bones and minimize the risk of fractures. The ultimate goal is to substantially improve the quality of life for a large number of people with OI.

Janice A. Vranka, PhD
Shriners Hospital for Children, Portland, OR
Topic: *A Novel Model for Studying Severe Osteogenesis Imperfecta: Consequences of lack of prolyl 3-hydroxylase expression in knockout mice*
In the short period of time since they were discovered researchers are working to increase our understanding of the recessive forms of OI. Dr. Vranka's study seeks to increase our understanding of how mutations in the intracellular collagen modifying enzyme P3H1 cause fragile bones. By uncovering the specific changes to tissues where collagen is deposited it may increase our understanding of the importance of this enzyme for healthy bone and suggest potential new treatments for OI bone.

Arabella I. Leet, MD
Johns Hopkins University
Topic: *The effect of bisphosphonates on human osteoblasts and mouse bone marrow stromal cells*
Studies involving mice bred to have OI characteristics make it possible to evaluate the effects of drug treatment. Dr. Leet's work will provide additional information about the effects of bisphoshphonates on bone cells in OI bone and in healthy bone. Comparing dosing regimes is also part of this study.

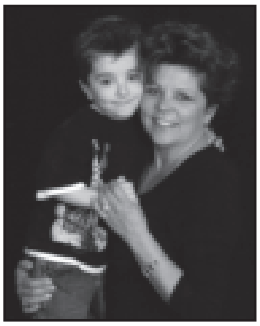
Seed grants are awarded to more established researchers for studies in basic science or clinical care relevant to osteogenesis imperfecta. Grants are for one year.

Matthew Goldsmith, MD
Washington University, St. Louis, Department of Genetics
Topic: *A Zebrafish Model of Bone Accrual in the Axial and Appendicular Skeleton*
Dr. Goldsmith's work is designed to provide new information regarding skeletal development and bone mass. Understanding these fundamental underpinnings of skeletal biology will offer broad insight into the physical changes underlying skeletal disorders such as OI. The ultimate goal is to identify new approaches to treatment for OI.

Christopher Modlesky, PhD
University of Delaware, Human Performance Laboratory
Topic: *Effect of a low-magnitude, high-frequency mechanical stimulus on bone with children with OI: a pilot study*
There are two parts to Dr. Modlesky's research. The first study will use magnetic resonance imaging (MRI) to evaluate the trabecular bone microarchitecture and cortical bone structure in children with OI Type I. This will allow him to develop a model for untreated OI bone. The second part is a pilot study to determine if daily vibration treatment improves bone quality and mass in children with OI Type I.

A Message From Your Blue Jeans for Better Bones Chairperson

I am proud to serve as the National Chair for the 2009 Blue Jeans for Better Bones Campaign. My 6 year old son Sebastian has Osteogenesis Imperfecta (OI), a rare genetic brittle bone disorder that affects approximately 25,000-50,000 people in the US. OI is characterized primarily by bones that break easily often from little or no apparent cause and with extreme variations in severity, ranging, from as few as ten fractures to several hundred to the most severe type that is fatal.


National BJBB Chairperson Chery Sacchetti and her son Sebastian.

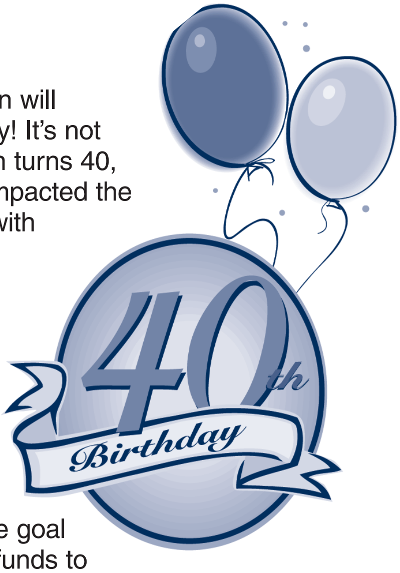
Sebastian was diagnosed before birth after an ultrasound revealed all of his ribs and one leg were fractured. During the first three months of his life he had six more breaks, including two ribs from just a simple sneeze. The care of the fragile little boy at first was almost overwhelming but with the love of family, special friends, and help provided by the OI Foundation, those difficult times were made a lot easier.

Blue Jeans for Better Bones is a community campaign to help raise awareness about OI and money to fund OI Foundation programs. With your help a day will come when Sebastian and all those with OI will no long have to worry about breaking bones with each fall, living a life full of precautions or passing OI onto their children. This is our dream and through your support this dream can someday become a reality.

Please join me in keeping hope alive for every family coping with this life altering disorder. Join the Blue Jeans for Better Bones Campaign!

Visit www.oif.org and click on the Blue Jeans for Better Bones Sticker.

Happy 40th Birthday OI Foundation!



In 2010 the OI Foundation will celebrate its 40th Birthday! It's not every day an organization turns 40, especially one that has impacted the lives of so many people with osteogenesis imperfecta.

To celebrate our 40th Birthday, we have launched a 40 for the 40th Campaign to raise awareness and much needed funding for the Osteogenesis Imperfecta Foundation. Ultimately the goal is to raise much needed funds to continue programs and services to support the 20,000-50,000 people living with osteogenesis imperfecta.

From now until our National Conference in 2010, there will be a "not so well known fact" from the year 1970. A special birthday greeting chosen from a member of the OI Community listed on the back cover of each upcoming *Breakthrough*.

To send your special greeting to the OI Foundation, just e-mail bonelink@oif.org and if you'd like to send a photo, please send it in jpeg format.

Help us continue to change lives through advocacy, education, public awareness and research. Ask friends and family to make a donation of $4, $14, $40, $400 or more to the OI Foundation and then have them ask 4, 40, 400, or 4,000 of their friends and family to do the same before the July 8, 2010 Conference.

To make a donation to the 40 for the 40th Campaign, visit www.oif.org and click on Donate Now.

Foundation Board Welcomes New Members

Amanda G. Bergman

Amanda Bergman has been Treasurer of Rolyn Companies, Inc., headquartered in Rockville, MD, since 1992. Rolyn Companies, Inc. is a disaster restoration/recovery firm licensed to work in over 40 states. During this time, she has been involved in various aspects of the business, including Accounting, Human Resources, IT, Office Management and Licensing. Amanda is also on the board of directors of two other companies within this industry.

Amanda has been a member of the Board of Associates of The National Rehabilitation Hospital in Washington, DC for the past six years and co-chaired the 20th Anniversary Victory Awards and Gala. Amanda visits with patients and assists the Development staff with the planning of this annual gala regularly. This year she was invited to join the Communications & Development Committee of the hospital.

Amanda was a founding member of the Sisterhood Board for her synagogue and remained on the board for several years. She was also a member of the Montgomery County Fire & Rescue Volunteer Committee for several years while a member of the Bethesda-Chevy Chase Rescue Squad. She has lived in the Washington area for the past 20 plus years and is a graduate of The American University.

Amanda and her husband, Sam, have three sons, Harris, Parker and Shafer. All three boys and Sam have a unique genetic mutation causing very mild OI. After Harris' fourth fracture, Amanda found the OI Foundation on the web and considers it to be an incredible resource for all families coping with OI.

The Bergman family feels very fortunate to have the mildest form of OI and have committed themselves as a family to help support the OI Foundation.

Michelle Duprey

Michelle is an attorney and currently a Director in the Department of Services for Persons with Disabilities for the City of New Haven, CT. She is an advocate for the disability community on issues of public accommodations, transportation, housing and employment. She has served on a number of boards and committees in Connecticut including the Governor's Commission on Human Rights and Opportunities Advisory Group; Chair of the Connecticut Bar Association Human Rights and Responsibilities Section and the Connecticut Women's Education and Legal Fund.

When asked why she wanted to serve on the Board, Michelle stated, "I decided to join the board because I feel that there needs to be more emphasis on living successfully as an adult with OI. While the work on kids issues are valuable, I feel there are lots of adults out there with OI who need information, resources, and research on the issues we face daily and the OI Foundation has the opportunity to be a valuable resource for us. I wanted to help get the OI Foundation there."

Joseph P. King

Joe is currently a doctoral candidate in the Special Education program at the University of Washington in Seattle. He has worked for the Department of Health and Human Services in their Office on Disability working on implementation of the Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. As a student he served on Columbia's Student Senate and was a Disability Senator at East Central University as an undergraduate student. When asked why he wanted to serve on the Board, Joe stated "I am hoping to achieve on the board more support for support groups, especially for young adults who are transitioning from high school to college or to work. This includes informational support and support groups. I also want to keep up to date with the current research and do what the OIF can to forward to work of medical researchers while spending funds wisely between medical research and support for those already coping with OI."

Thank You for Another Successful Bone China Tea Event

By Jennifer Wilson
Co-chair, Bone China Tea

The OI Foundation is pleased to be able to announce that this year's Bone China Tea event raised more than $35,950, despite the state of the country's economic situation. On behalf of the Foundation, we would like to thank the 50-plus individuals and families who sent out card and website invitations that received 716 donations, making this total possible.

This fund raiser continues to be a popular event for a number of individuals who return year after year to participate. It also draws new participants each year who acknowledge that it is an easy way to support the Foundation's programs.

Plans for the 2010 event will be starting within the next month, and invitations will be ready for distribution by the middle of January. Next year's event will take place during April, date to be announced in the next **Breakthrough**.

Anyone interested in finding out more about Bone China Tea is welcome to e-mail us or the Foundation for additional information.

Jenny Wilson (jnwilson@aol.com)
Susie Wilson (OISLW@aol.com)

We are grateful to these Bone China Tea hosts for their time and amazing results!

2009 Bone China Tea Hosts

$5,000 and up!

Michael Johnston & Bonnie Landrum

$2,000 - $4,999

Alec Cabacungan
Mark & Martha Birdwhistell
Cynthia & Chris Nolan

$1,000 - $1,999

Sarah Cramer
The Glickmans
Susan Reazor
Susan Wilson

$500 - $999

Carmellya, Breman Jr. & Alana Anderson
George & Gail Bunker
Judith Clarke
Breanna & Linda Kaye Coleman
Craig, Cathy & Jacob Gadberry
Ashley Jones
Kelly & Jeff Jones
Joanna Keith
Michelle Moscardelli
Tim & Laura O'Connor
Grace & Lenee Reiman
Robin & Mickey Rowland
Karen Vowell

$250 - $499

Shelby, James & Jessica Carter
Alyse & Paula Furber
Carmela Hurt
Neeru Sharma

Up to $249

Thomas Acquafredda
Adam & Donna Ayers
Rebecca Carden
Bev Coffin
Ryan Lynn Connor
The Dias Family
Willie M. Etchison
Lexy Hancock & Trevor Stine
Kristie Honeycutt
Barbara Hurt
Isaiah & Ylena Juggins
Marty Krzewinski
Marty McCambridge
Jennifer McLeod
Linda Morehouse
Keisha & Joshua Phillips
Stacey Ripley
Elle Sheehan-Sawyer
Stacie Stacy
Rachel Stevens
Brianna Suarez
Sarah Sylvia & Family
Peg & Halley Szpaichler
Stuart Tart
Lisa Tyerman
Kay West
Debbie Wiederhold
Kevin Wohler

People in the News

Demopolis, AL – Looking for transportation to Omaha for her daughter **Rhae's** surgery, Dana **Busby** was referred to "Pilots for Christ" and within hours of contacting them had the trip arranged.

Clovis, CA – Chosen as an ambassador to the Children's Miracle Network, 11-year-old **Milca Gutierrez** visited Disney World in Florida and then traveled to Capitol Hill where she shared her experience of receiving treatment through the program.

Tangerine, FL – Local Rotarians built a wheelchair ramp into the home of 11 year old **Drew Tanner**.

Atlanta, GA – A benefit was held at Hard Rock Café to raise funds for the Unbreakable Music Foundation, a charitable organization started by music producer **Simon Illa**.

Catonsville, MD – Receiving the Baltimore County Public Schools' Teacher of the Year award, Cecily Anderson spoke of the life changing time nine years ago when she learned that the son she was carrying had OI. Raising her son **Nicholas** has reinforced her commitment to provide a "rigorous and relevant education for every child."

Merrimack, NH – Asking a local group of fans if they knew of anyone with OI, Jodi Picoult was led to the **Smith** family where she spent a day with seven year old **Matthew** learning how OI affects his life.

Rochester, NY – Teacher Debby Merritt was honored as a News 8 Golden Apple Award winner. As the kindergarten teacher for 5 year old **Perryion Harvey**, she was honored for making the last few months of his life in school happy and meaningful.

Ashtabula, OH – A motorist nabbed 14 year old **Tiffany Manning's** beloved schnauzer Bubba. The dog, given to her as a Christmas gift when she was four years old, has been her constant companion and she can't imagine life without him.

Portland, OR – A local fire district hosted an annual Easter Egg Hunt and provided six year old **Bryten Figgins** with her own buddies who escorted her around the festivities and set up an egg hunt just for her.

Newtown, PA – A magazine for occupational therapists featured **Nicholas Atkinson** and the therapeutic tools used by his medical team.

York, PA – Make-a-Wish Foundation will be donating a handicap accessible play set for 3 year old **Irelyn Verno**.

Chippewa Falls, WI – A local family eatery recruited customers and friends to help the family of 1 year old **Susan Bergeman** by organizing the basement and re-landscaping their backyard.

Taipei, China – Representing Taipei in last year's National Disabled Games was 26 year old **Tseng Kuan-hua**, an architecture student and nationwide wheelchair ballroom dancing competitor.

Belgaum, India – In preparation for a national level swimming competition to be held in October, 12 year old **Mohin Mustaque** is practicing each morning with laps in the pool.

Mumbai, India – Writing his exams lying down, 16 year old **Parikshit Shah** scored high marks on his SSC exams. His plans are to become a chartered accountant.

Malaysia – Awarded The Outstanding Young Malaysian Award in 2001 and the Asia Pacific Outstanding Young Person Award in 2002, 40 year old lawyer **Datuk Sim Ooi Hong** has written an autobiography entitled *I Must Stand Up*.

Abu Dhabi,UAE – Speaking at a recent Women's Health Conference, **Nada al Bustani** hoped to raise public awareness about the need to increase help for those with special needs and to integrate them into society by creating quotas for disabled people in the worklplace.

Chessington, UK – Dubbed one of Britain's most inspirational children earlier this year, 12 year old **Jack Binstead** took first place competing in the 100 meter wheelchair event at the London Youth Games. He also won silver for the 200 meter. His sights are set on the 2012 Paralympics.

Climb Every Mountain *continued from page 1*

"This Kilimanjaro trip will certainly be risky. If we succeed (and we will), it will be the greatest achievement for this father/daughter team," he added. "If we don't summit, it will still leave an indelible memory of her spirit."

Anna explained, "I know that a lot of people with OI can't go climb Mt. Kilimanjaro, and I don't want anyone to think my message to kids with OI was 'Go climb Mt. Kilimanjaro'," she said.

However, Anna feels like this is a realistic goal for herself, partly because Mt. Kilimanjaro is a unique experience for climbers. Trails up the mountain enable one to walk or hike, rather than climb or rappel up.

"I have researched it. A lot of people with disabilities have done this," Anna told us. "The biggest issue is the altitude."

Even so, this will not be an easy task. Both Anna and Ashley have been training for months, and Anna admitted that they are prepared for her father to carry her, if and when that becomes necessary.

Despite the risks, Anna maintained that "There is no downside to it, even if we don't summit" especially "if I end up in better shape at age 29, than the rest of my 20s."

At press time, Ashley and Anna had already raised almost $11,000 of their goal from supportive friends, family, co-workers, and other members of the OI community. You can follow the progress of Anna, Ashley, and their team through the blogs and photos at www.climbkilimanjarofor-oif.com. They also invite you to make a contribution at www.oif.org/UE_ClimbKilimanjaro.

Upcoming OI Summer and Fall Events

These upcoming OI community events are not only fund raisers, but they are also opportunities to get together with other adults living with OI, families from the local support group, and their friends, neighbors, co-workers and other supporters. More details are available on the OI Foundation website calendar at http://www.oif.org/site/Calendar?view=MonthGrid.

We encourage you to find the OI activity closest to you, and make plans to attend!

August 23, 2009 – Rochester, NY

Alle Shea's Walk-n-Wheel for Better Bones

Join with walkers and wheelchair users as they either walk or roll their wheelchairs at West Irondequoit High School to help others living with Osteogenesis Imperfecta (OI). This Making Strides for Better Bones event is organized by Kim & Angelo Collazo, in memory of their infant daughter who was born with the most severe form of OI.

Contact: Kim & Angelo Collazo at allesheaproject@yahoo.com or (585) 266-5115.

Aug. 26, 2009 – Aberdeen, MD

3rd Annual Walk with Isaac

Your purchase of a special ticket to see the Aberdeen Ironbirds play the Lowell Spinners at 7:05 p.m. will benefit the OI Foundation! Four-year-old Isaac will walk the bases before the game with his parents, Dan and Heidi, and this game night for OI also will include a silent auction and raffle.

Contact: Heidi and Dan Wright at heidijwright@hotmail.com, daniel.wright@stifel.com, or (443) 794-9172.

Aug. 31, 2009 – Atkinson, NH

2009 OI Classic

Don't miss this 3rd annual golf classic to support Osteogenesis Imperfecta! Held on the top notch 18-hole championship golf course at the Atkinson Country Club, the format for this outing is four-person scramble.

Contact: Teresa Gudek at 603-498-7483 or TMGudek@comcast.net.

Sept. 19, 2009 – Margate, NJ

7th Annual Bash by the Bay Seafood Festival

Enjoy All-you-can-Eat Steamed Crabs and U Peel Um Shrimp, along with hamburgers, hot dogs, cotton candy and root beer, compliments of Stewart's Famous Hamburgers of Northfield. In addition to the great food, don't miss the fabulous music, wine and beer, silent auction, and gift basket raffle. For the kids, there will be games & prizes, face painting, crafts, and a Bouncy!

Contact: Chery Sacchetti at (609) 823-7702, (609) 350-9560, or CheryLemmerman@aol.com.

Sept. 19, 2009 – Ames, IA

Amyra's Walk-n-Roll for Better Bones

Recruit a team of family, friends, neighbors, or co-workers to walk or roll at Ada Hayden Heritage Park to help others living with Osteogenesis Imperfecta (OI). There also will be other fun activities for kids and adults, so come join the fun!

Contact: Latifah Faisal at latifahfaisal@yahoo.com or (515) 291-9804.

Sept. 26, 2009 – Afton, NY

Spaghetti Dinner for OI

You are invited to a Spaghetti Dinner at North Afton United Methodist Church to benefit the OI Foundation and help with finding a cure for osteogenesis imperfecta. All dinners include salad, dessert and beverage.

The church has generously offered the use of their facilities, to split all profits with us, help cook and serve, and provide the food with help from the church members.

Contact: Diane Curtin at (607) 639-2159 or dmcclean@tds.net.

Oct. 4, 2009 – New York, NY

Cocktail Party and Art Sale by New York City artist, Rhoda Greif

Rhoda Greif, who has a granddaughter and daughter-in-law with OI, is a graduate of Brooklyn College, where she studied with the internationally known artist Mark Rothko, as well as with the renowned watercolorist Ed Whitney. She is a representational artist whose emphasis is on florals, landscapes, and still lifes. She has exhibited in many group shows as a member of the Metropolitan Artists Coalition, the National League of American Pen Women, and Women in the Arts. As part of these groups, she has also shown in the Cork Gallery in Lincoln Center, where her work received a very favorable review from *Gallery and Studio* magazine.

Prices on Ms. Greif's art start at $50. The artist will provide refreshments for this event, which will be held from 1 – 5 p.m. in her home on the Upper East Side, an apartment that was previously owned by the late actress Joan Crawford. Twenty percent of the proceeds from the art sold will benefit the OI Foundation.

RSVP: to the OI Foundation by Wednesday, Sept. 30, at development@oif.org or 1-800-981-2663 x27.

Oct. 10, 2009 – Garfield, NJ

18th Annual New Jersey Beefsteak Dinner

The New Jersey Area OI Support Group invites you to an all-you-can-eat dinner with filet mignon, french fries, salad, and chicken nuggets for the kids. There also will be hundreds of gift baskets and other items available in the Tricky Tray and silent auction, a 50/50 raffle, and a friendly, social atmosphere. This is a family event, so plan to bring the kids!

Contact: E-mail Rosemarie Kasper at rdkoif@verizon.net or Jo Ann Berkenbush at jbcowoi@juno.com, or phone Jo Ann at (201) 314-5289.

Oct. 17, 2009 – Sacramento, CA

Making Strides for Better Bones: Sacramento

Walk or wheel around State Capitol Park, listen to music, and enjoy a variety of fun activities for kids and adults! The pledges you raise will support the work of the OI Foundation.

Contact: Bill Scarberry at billathp@yahoo.com or (916) 955-0978 or Beth Gero at abgero@sbcglobal.net or (925) 516-6439.

Oct. 24, 2009 – Seaford, NY

2nd Annual Making Strides for Better Bones: Long Island

There will be a variety of fun activities planned for the day at Cedar Creek Park, along with raffles of items for kids and adults. Raise pledges, and walk or wheel a few laps to support the cause!

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

Nov. 13, 2009 – City of Industry, CA

35th Annual SCPICA Golf & Tennis Tournament

This longtime event by the Southern California Petroleum Industry Charity Association (SCPICA) is held at the beautiful Pacific Palms Conference Resort. Tennis will take place nearby, at the La Habra Tennis Center. Volunteer either for daytime (8 a.m. – 4 p.m.) or evening (3 p.m. – 9 p.m.) activities. Also, all OI Families are invited to attend and enjoy dinner at a special discounted rate. Volunteers' food is complimentary! Raffle and auction prizes are also needed to make this a very successful event for the OI Foundation.

Contact: Visit http://www.scpicharity.org/, or contact Heidi Glauser at glauser@cox.net or (949) 248-7541.

Volunteers Make a Difference with Events in their own Communities

Tim Dombro (seated on the right) catches up with friends at Fine Wines Strong Bones in Washington, DC, on March 21. This event offered a vast silent auction, a variety of wines for tasting, and menu samples donated by area restaurants.

Many friends of the OI Foundation quietly raise awareness and support by organizing fun activities close to home. They involve their neighbors and co-workers, contact local media outlets, and solicit contributions from local businesses, thus greatly expanding the circle of support for the entire OI community!

The OI Foundation offers our heartfelt thanks to the volunteers listed below for their energy, leadership, and dedication, as well as the countless hours they spent ensuring that their events successfully entertained, educated, and raised money.

WASHINGTON, DC – Event chairperson **Lyn Reid** and a committee of more than a dozen volunteers organized the 9th Annual *Fine Wines Strong Bones* on March 21. More than 170 guests sipped a variety of wines, enjoyed menu samples from area restaurants, and placed bids during the online, silent and live auctions. Award winning speaker and best-selling author **Willie Jolley** emceed the affair. We thank Lyn and her team for raising more than $39,000!

* * *

ROUND ROCK, TX (written by Debbie Wiederhold) – Co-event leaders **Debbie Wiederhold** and her adult daughter **Erin Weaver**, mother and sister to 17-year-old Daniel, held the *2nd Annual Central TX Walk-n-Roll* on April 4. Debbie and Erin partnered with another nonprofit, **Texas Parent to Parent**, for this fun event, raising more than $7,000 for the two organizations! This was our first year to actually have a Committee and they all worked hard on the event, too! Committee members were: Shirley Rowland, Laura Warren, Wayne Archer, Susan Prior, Kathy Harrington and Yvonnilda Muniz. We had approximately 75 people attending, including some new faces and even some bikers! We were also able to not only give participants their Walk-n-Roll T-shirt, but also cool water bottles sponsored by Amerigroup Community Care! Major Sponsor JetBlue Airways also donated two round-trip ticket vouchers to one lucky door prize winner, Sandy Noster! We're already talking about next year's "3rd Annual Walk-n-Roll" on April 24, 2010, so SAVE THE DATE! Call or e-mail Debbie Wiederhold for more information at (512) 458-8600 or debbie@txp2p.org.

* * *

ST. LOUIS, MO – On April 19, approximately 30 people gathered at a local church to participate in Bunco for

The 2nd Annual Central TX Walk-n-Roll on April 4 attracted approximately 75 children and adults, who walked for both the OI Foundation and Texas Parent to Parent. In the front (from left to right) are: Daniel Wiederhold (seated), Debbie Wiederhold, Shelby Weaver, Shirley Rowland (seated), Brenda Baker and Kristen Archer.

Bones, a bunco tournament to benefit the OI Foundation. Bunco is a parlor game played in teams with three dice. This friendly competition brought in $931 in donations! Bunco for Bones was organized by **Lois Wolff, Terrie Wolff** and other family members, in honor of four-year-old **Nicholas George**.

* * *

NEW YORK, NY – More than 140 OI Foundation supporters saw the musical *Billy Elliot* on Broadway on April 24. Before the show, ticket buyers gathered for a reception, where they bid on *Billy Elliot* memorabilia and a 7-Night Autumn Escape to the Hamptons. Our thanks to **Jeffrey & Andrea Stewart, Caren Loguercio**, and **Robin Wright** for raising more than $35,000 during this memorable evening!

* * *

FRAMINGHAM, MA – The *5th Annual Making Strides for OI Walk, Silent Auction, and Family Fun Day* enjoyed one of its biggest turnouts ever on June 6! During the day, **Richard Wyman** received the 2008 Thelma Clack Lifetime Volunteer Achievement Award, and State Senator Karen E. Spilka's office provided event organizers with a citation naming June 6 "Osteogenesis Imperfecta Day" in Massachusetts. Altogether, the event raised more than $35,000, thanks to the work of **Christine & John Rossi, Richard & Mary Ellen Wyman**, and **Mike & Michelle Potorski**.

Use Our Sally Foster Campaign to Prepare for the Holidays!

If you purchase your gift wrap and other holiday supplies through Sally Foster, 50% of every dollar will benefit the OI Foundation.

This year's catalog includes a snow man kit, complete with a hat, carrot nose, pipe, buttons, eyes and a mouth! In addition you will find wrapping paper suitable for Christmas, Chanukah, or any occasion, in styles ranging from elegant to festive.

The catalog features several new sections, including Wellness and Eco Friendly, where you will find reusable shopping bags, dryer balls, and aromatherapy candles. Plus, you can select from the normal assortment of ribbons, gift tags, candies, and interactive gifts for kids.

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

If you prefer to shop online, go to www.sallyfoster.com. ***Please be sure to click on "Support a Fundraiser" and credit the OI Foundation for your purchase, using either our full name or account number 362042.***

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

OI Awareness Raised at Elementary School

During the OI Foundation's Blue Jeans for Better Bones Kickoff in NY, sixth-grade Shore Road School student **Leah Rennert** and her classmates made and sold beads and rings during recess to raise funds for the Osteogenesis Imperfecta Foundation. Leah has OI but says although she can't participate in most sports, she can swim! Leah and friends have raised nearly $500.00. "To see Leah's classmates rally around her especially during recess, when others are involved in more physical activities was great to see," said John O'Brien of the OI Foundation. "The entire Shore Road School is now aware of osteogenesis imperfecta and how it impacts some young people's lives, and we owe that all to Leah."

John O'Brien, Leah Rennert and OI Board of Directors member Caren Loguericio

Did you Miss This Event in Your Neighborhood?

In addition to the enjoyment of getting together with friends, this spring offered members of three support groups the opportunity to learn more about appropriate exercise, efficient breathing and infant development.

To the theme of "Keep Moving: Get More Exercise" a presentation to The Puget Sound Peer Group offered tips from a physical therapist on healthy ways to start and maintain an appropriate exercise routine.

The Northern California OI support group listened to a presentation about infant development given by a nurse from the county office of education. After the talk, parents compared notes while enjoying potluck BBQ.

On the other side of the country, the New Jersey support group was learning how to breathe correctly, through *BreathPlay*, a system that promotes efficient breathing. With the injunction to "Be the Bellows," the following tips were offered:

- Purse lips/pull in belly
- Focus on exhalation
- Relax for inbreath
- Use images/imagination
- Exhale on exertion
- Think Positive: I CAN DO THIS
- Be patient – You are changing habit patterns. Muscles are slow learners
- Use BreathPlay every day
- When in DOUBT, BLOW OUT

Look What's Coming to a Town Near You!

New groups are forming in the following states: Arizona, North Carolina, New Mexico Oregon and Southern Florida. Contact the following new group leaders for more information and to offer your great ideas and support.

Arizona: Mesa/Phoenix area – Jen Adler – mesabutterfly46@aol.com or 4801668-4754
North Carolina: Ryan Jones – ibreakaleg@comcast.net or 910-242-9408
New Mexico: Curtiss Wilson – Clwilson911@gmail.com or 505-296-8403
Oregon: Julie Schlafle – jschlafle@yahoo.com or 503-285-2283
S. Florida: Missy Monokian – missymonokianministries@comcast.net or 305-528-2336

Submit Your Choice for a Volunteer Award—Recognize Someone Who Makes a Difference

The OI Foundation could not exist without dedicated volunteers providing peer support services, serving on the Board of Directors, raising funds and helping develop new information resources. The Foundation recognizes outstanding volunteers by presenting three awards to recognize significant and/or lasting contributions to the OI community—a dedicated service award, a youth award and a volunteer of the year award. Two of the awards are named after volunteers, Thelma Clack and Peter Dohm, who personified the ideal volunteer.

Details about requirements for the Thelma Clack Lifetime Volunteer Award, the Peter Dohm Junior Volunteer Award, and the President's Award (Volunteer of the Year) and the nomination process can be found on the OIF Foundation website. Just click on "Volunteers" under the How to Help tab.

Gemma Geisman's Memoir: *From the Seeds of Sadness*

This spring Gemma Geisman the founder of the OI Foundation published her memoir **From the Seeds of Sadness**. In it Gemma shares her personal story about raising a child with OI and the behind the scenes story about the early formative years of the OI Foundation. This inspiring story gives us a glimpse of the world before the Americans with Disabilities Act (ADA), or the Internet. It is a reminder of how little was known about OI 50 years ago and the difficult challenges faced by OI families. This book is a fitting memorial to the families and doctors whose past efforts made a difference for people living with OI today. **From the Seeds of Sadness** can be ordered through Amazon.com or at www.gemmageisman.com.

From the Information Center

Making Sense of Your Genes

The National Society of Genetic Counselors and the Genetic Alliance have published **Making Sense of Your Genes: A Guide to Genetic Counseling**. This easy to read introduction to genetic counseling explains when to seek counseling and what to expect during an appointment. It is available free of charge on the Genetic Alliance website (click on Publications), www.geneticalliance.org or call Amelia Chappelle at 202-966-5557 extension 216.

Medicare Basics for Caregivers

Medicare is the federal health insurance program for adults 65 and older and people of any age with disabilities. A new website sponsored by the National Institutes of Health offers an easy to use guide to understanding and getting the most out of this program. Visit www.NIHSeniorHealth.gov and click on "Medicare Basics for Caregivers."

Do You NICHCY?

The National Dissemination Center for Children with Disabilities is a program of the Office of Special Education Programs of the US Department of Education. Through several name changes this organization continues to provide up to date information to parents, care givers and educators on many topics related to caring for, educating and enjoying children with disabilities. The website www.nichcy.org is easy to use. Under the Newsletter tab it's possible to sign up for their free electronic newsletter. The latest edition featured articles on recreation, transition to adulthood, preparing for college and PE options for high school graduation.

Free Publications from the Food and Drug Administration

The FDA has created a series of booklets and fact sheets on dozens of topics including Allergies, Arthritis, Flu, Osteoporosis and CT Scans. All of the publications are free of charge and available at www.fda.gov/womens. The brochure, **My Medicines**, available on this website, offers a clear and easy way to keep a record of the medicines you take regularly and would be useful for college students or anyone living on their own.

Planning for College

The website **Going to College** was recently launched by Virginia Commonwealth University as a resource for teens with disabilities. At www.going-to-college.org young people will find a wealth of information to help them make the most of high school, handle the college application process and prepare for campus life. Students with disabilities are featured in each section and specific information related to managing physical and learning style challenges are clearly discussed.

Additional information about preparing for college for students who have OI is available on the OI Foundation website www.oif.org under the Resources tab.

2009 OI Clinic Directory is On-Line

As part of the OI Foundation's effort to "go green" the 2009 update for the OI Clinic Directory is available on the OI Foundation website www.oif.org. A direct link to the directory is under the Resources Tab. Each year the OI Foundation updates its list of centers that provide coordinated care for children and adults who have OI. The state-by-state listing provides contact information, a description of services and the number of people served. Programs on the list may have different names such as OI Clinic, Bone Clinic, Metabolic Center or Bone Dysplasia Center, but all offer care for people with OI. Print copies of this year's list can be obtained by contacting the OI Foundation office.

E-News from the OI Foundation

Do you get the OI Foundation's monthly electronic newsletter? If you haven't signed up you missed updates on Swine Flu, Recreation, Free Driving DVD, and Employment/Internship resources. Future editions will include updates about next summer conference! To sign up for the E-News, go to the main page of the foundation's website, www.oif.org and click on "Subscribe to the E-News." Past editions of the E-news are available on the website under the Resources tab.

The OI Registry

The OI Registry is an up-to-date listing of people with OI. It stimulates interest in OI research by making it possible for researchers to contact enough people to do a reliable study. By reviewing the information that members have posted important facts about living with OI can be identified. Membership in July reached 1,431 children and adults with OI. Joining is easy. Look for information under the Research tab on the OI Foundation website.

Fact: 52% of OI Registry members, representing all types of OI, report that they have loose ligaments.

Updates on Pain Medications

Medicines used to treat pain and respiratory infections have been in the news this summer. New labels and package inserts are now required for over the counter and prescription medicines such as Darvon and Darvocet and those containing acetaminophen. The drug Levaquin used to treat respiratory infection has been linked to tendon injuries.

Opioids

Widely prescribed medications such as Darvon and Darvacet belong to a group of drugs called opioids. The active ingredient is the drug propoxyphene which has been linked to death from overdoses. The Food and Drug Administration (FDA) review found evidence that the drugs are effective treatments for certain types of pain, but carry particular risks. The FDA has ordered new labels and warnings on the packages, as well as a series of safety studies. It rejected a petition from the public interest group Public Citizen to order phased withdrawal of propoxyphene, but has urged physicians to thoroughly discuss the safe use of these drugs with their patients.

Acetaminophen

Acetaminophen is the active ingredient found in more than 600 over-the-counter and prescription medicines used to relieve pain or reduce fever. It is found in common brand name drugs such as Tylenol as well as in prescription medicines such as Vicodin and Percocet. Generally safe if taken at the recommended dose, these medicines have been proven to cause serious liver damage at higher doses. Research shows that taking a higher dose than recommended does not provide more relief. Consumers are reminded to check the ingredients if taking several medicines such as a pain reliever and a cold medicine. The combined dose of acetaminophen may be too high. Acetaminophen is sometimes listed as APAP under “Active Ingredients.” Consuming alcoholic beverages when taking these pain relievers will increase the risk of liver damage. In addition parents and care givers are reminded to use the proper dose for their child’s weight and to keep track of how many doses the child receives in 24 hours. More information can be found in the FDA Consumer update: Acetaminophen and Liver Injury: Q & A for Consumers. June 24, 2009. (www.fda.gov/ForConsumers/ConsumerUpdates/ucm168830.htm)

Levaquin and Tendon Injury

Levaquin is the brand name for the antibiotic levofloxacin. This medicine is commonly prescribed to treat pneumonia, chronic bronchitis and sinus, urinary tract, kidney or skin infections. It has been linked to an increased risk for developing tendonitis or rupturing a tendon either during treatment or in the months immediately following. Physical activity involving a joint—such as propelling a manual wheelchair—may increase the risk of injury while on this medicine. The most commonly affected tendons are those in the shoulder, hand, or back of the ankle. Tendonitis is a painful swelling of the tissue that connects bone to muscle. A tendon rupture occurs when the connective tissue tears. It has been brought to the attention of the OI Foundation that a few people with OI have experienced tendon injuries associated with this drug.

The news this summer reminds all of us that one key to living well is to discuss all prescription medicines, over-the-counter medicines and dietary supplements with our primary care physicians and/or pharmacist and to read the package inserts.

Traveling is Possible *continued from page 3*

you choose is accredited and can send someone to the hotel on time. Understand their payment requirements in advance so you know what to do. Insurance companies may not cover the cost so know what your responsibility may be.

6) Clothing — Wear clothes which are easy for you to get/on when traveling so you can do it on your own. Do not wear tight pants or outfits which require help since you will be on a plane and being comfortable is important. Make sure shoes you wear do not result in swollen feet or are too loose that they fall off. Wear shoes which are appropriate for travel and do not interfere with your transfering.

7) Phone — Always have a cell phone with you that can work in the area you are traveling. Make sure to have friends/family and doctor phone numbers with you in your cell phone. Be prepared to call anyone you need while traveling. You will need to be able to communicate with others so charge your cell phone before leaving.

Well, these are the major areas of travel where I can provide some guidance based on my own travel experience. If you plan on traveling, know that you can do it with the right attitude and preparation.

In Honor Of

March 1, 2009 – June 30, 2009

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Mrs. Mary Bevan
Mr. & Mrs. Robert J. Brennan, Jr.
Mrs. Gladys Strauch
Courtney Carroll
Mrs. Marilouise Petree
Ryan Lynn Connor
Ms. Catherine Connor
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Mr. Michael McCulloch, P.C.
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Earl & Susan Ehlers
Amyra Faisal-Ford
Ms. Mary Thompson
Jessica Finkel
Mrs. Lois Surber
Peggy Fond (65th Birthday)
Ms. Barbara Kelly
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Ira & Ruth Neiterman
Merrick Graves
Francois & Christine Estellon
Steve & Terry Gudek
(60th Wedding Anniversary)
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Mr. Lawrence Hitch
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Mr. & Mrs. Ronald Flechsig

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Breakthrough

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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

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Countdown to Conference 2010

The next OI Foundation National Conference will be held July 8-10, 2010 in Portland, OR. Besides providing the opportunity to share information about living successfully with OI and to learn the latest medical information, this conference will include a celebration of the OI Foundation's 40th Anniversary. In August, 1970 a new organization, the Osteogenesis Imperfecta Foundation was formed. From the beginning it was dedicated to improving the quality of life for people affected by osteogenesis imperfecta through research, education, awareness and mutual support.

What was life like back in 1970? The voting age had just been dropped to age 18. The average cost of a new house was $23,450, a gallon of gas cost 36 cents and a US postage stamp was 6 cents. Paul McCartney announced that the Beatles had disbanded and popular TV programs were *Marcus Welby, MD* and the *Mod Squad*. The first "Earth Day" was celebrated and the US Environmental Protection Agency opened for business.

Future issues of **Breakthrough** and the foundation's monthly **E-News** will include details about registration and the conference program, as well as stories about how treatment for OI has changed in 40 years. Plan now to join the celebration in Portland, OR!