Breakthrough

THE NEWSLETTER OF THE OSTEOGENESIS IMPERFECTA FOUNDATION

OSTEOGENESIS IMPERFECTA OI FOUNDATION

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Unbreakable Spirit

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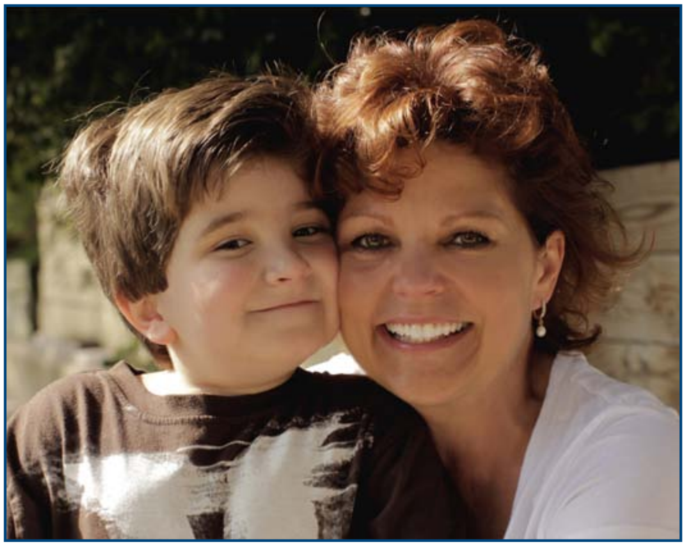
OIF Families in New Public Service Announcement

The OI Foundation recently announced the production of a new public service announcement, which was filmed this summer and is currently in post-production. The PSA includes interviews with OI families and OI experts, and will be used to educate the public about osteogenesis imperfecta. The final product will be edited into segments that can be viewed together, or as shorter clips.

Former OIF Board Member, and current National Chair for the Blue Jeans for Better Bones program, Chery Sacchetti, and her son, Sebastian, are one of two OI families featured in the PSA. "Working on any project for the OIF is always exciting but knowing it could help families dealing with the ups and downs of *Osteogenesis Imperfecta*... priceless!" wrote Chery in an email to the OI Foundation after the filming. The Holman Family of West Chester, PA, are also featured in the video.

The Foundation is working to begin production on two additional videos. One video will focus on infant care, and the second will be an informational piece that features medical professionals from the OI community. Production services for the PSA's were donated to the OI Foundation by a private donor.



Sebastian and Chery pose for a photo during filming for the new OIF PSA.

Throwing a Perfect Strike at the White Sox Game!

Alec Cabacungan, son of OIF Board Member Gil Cabacungan, joined his fellow t-ball teammates at U.S. Cellular Field on June 9th to throw out the first pitch of the White Sox game. Nine-year-old Alec, who has OI, was excited and nervous as he took the field with his father Gil and sister Kristen. With friends, family, and teammates cheering him on, Alec threw a perfect strike to Mark Buehrle, number 56, a pitcher for the White Sox who threw a perfect game in 2009.

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Sister Kristen, and father Gil, cheer Alec on as he throws the first pitch.

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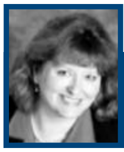

From the Chief Executive Officer

Dear Friends,

I hope everyone had a safe and happy summer. It doesn't seem possible that a new school year is starting and before we know it we'll be talking about the winter holidays! I know, I'm getting ahead of myself, but time really does have a way of moving quickly. Just think: in less than a year we will all be together again at Conference 2012 in Washington, DC!

This summer here at the OI Foundation has been very busy and many new initiatives that we told you about in the spring are now active programs. The Adult Health Initiative (ANHI) Committee has worked very hard over the past two months and you will be hearing more information about the exciting work from that committee in the months to come. Many thanks to Dr. Laura Tosi for her leadership in this effort. This summer also gave me an opportunity to renew relationships, including those with some of the OI community parents. The Desai family graciously invited me into their home this summer to talk about ways the Foundation could partner with parents to improve communication and services for parents with children of all ages. Providing access to social networking sites, adding video to the OI Foundation website, highlighting children and parents participating in all kinds of activities, and increasing communication with our medical community are just a few of the areas we will be working on. More to come on this!

And, lastly, I want to thank everyone for continuing to support the OI Foundation in whatever way you can. As you know, our economic environment is challenging and ever-changing; your support is important now more than ever, so thank you.

I hope you enjoy this issue of *Breakthrough*!

All my best,

Tracy Smith Hart

From the President

I would like to extend a warm welcome to our newest Medical Advisory Council members, Paul Esposito, MD, from the University of Nebraska Medical Center, and Cathleen Raggio, MD, from the Hospital for Special Surgery in New York. They were introduced in the last Breakthrough newsletter, but I wanted to take this opportunity to let people know a little bit more about what the MAC does, and why we're so grateful to Dr. Esposito and Dr. Raggio, and the other 17 MAC members for serving this way.

The Medical Advisory Council is made up of medical professionals that treat patients with OI, and/or are involved in research (including clinical trials) looking for treatments and a cure for OI. These are people who work with OI on a daily basis and are expanding our body of knowledge about OI. They are working with young residents and researchers and spreading their passion for working with OI to a new generation. They speak about OI around the country and the world and are instrumental in keeping the general medical community informed about OI. They also help the foundation with strategic planning and setting research goals and direction, and spend a lot of energy reviewing grant proposals that the Foundation funds. Many of the MAC members, along with other members of the medical community, also participate in our conferences with the Medical Consultation Program. The chair of the MAC, currently Dr. Glorieux from Shriners Hospital for Children in Montreal, sits on the Foundation's Board of Directors.

The most visible way that the MAC interacts with the general membership of our OI community is through work on our fact sheets and web information. Any medical information published by the foundation is run past the MAC to ensure it is up to date with the most current information. These people also serve as resources for the staff at the Foundation with questions from people in our OI community. The time and effort expended in this volunteer role plays a vital part in fulfilling the Foundation's mission to be a credible resource for families with OI.

Welcome again to Dr. Esposito and Dr. Raggio, and many thanks to the entire Medical Advisory Council for all the behind the scenes, as well as the very visible work, that you do.

Sharon Trahan

Spotlight: *Atticus Shaffer*

Atticus Shaffer is an actor and has OI. He lives with his family in California.

Tell me about your mother and father–what are they like?

My Mom has always been a stay at home mom, which means I have always been blessed with her awesome home keeping and cooking. I LOVE home cooked meals and my Mom is a great cook! Both my parents have always been extremely supportive and encouraging to me in all my interests growing up. They would both get caught up in whatever subject or hobby I became interested in and it would become their interest. We have learned to love so many things together from travels or collecting or learning to play chess or Yu-Gi-Oh. The list is too long to write. My Mom has OI, but not the same as what I have. She was always told she was a Type 1, but I am diagnosed as a Type 4 and I have had more fractures and surgeries than she ever did. She definitely understands what it is like to have OI, although it still does not really make it easier. She does not ever want me to be in pain as my Dad does not either.

Who had the greatest influence on you during your childhood so far?

I have to say, hands down, my Mom. She has been there for me every single day and has been my guide and my teacher, as well as being the best mom ever. My Mom has always told me “Be yourself” and that is what I do. She and I have a message for everyone that we always hope to give that the world is made up of different people and that we are all meant to be different. The world would be a very boring place if everyone was exactly the same. So, it really does not matter if you have a physical challenge, such as OI, because it only makes up a part of who you are, not everything about you. I would not be who I am today if I did not have OI, or anything else that I have about me that makes me the person I am. I wish that everyone would get rid of the fact that a physical challenge is a disability. Don’t let it label you. Our bodies have limits, but what’s inside us does not. That’s what really matters. That’s what my Mom and I want to influence on others. Wouldn’t that make the world awesome?

What teacher had the greatest impact on you?

I have always been homeschooled. So, that would be my Mom again.

Did you always know that you wanted to become an actor?

Actually, what happened is that my Mom and I always read books together out loud. We would read in character. When I was seven years old I was chosen to be the poster child for Shriner’s Hospital in Los Angeles, I used to do speeches for banquets and at the charity football game. I was never nervous to speak in front of people and my mom thought that there might be something I could do with that. But mostly thinking that I could read so well and she thought my voice would be cute for cartoons or books on tape or something. Through meeting different people, we met a manager who kind of accidentally sent me on a theatrical audition for a CBS sitcom. I booked the job and I just kept booking theatrical work ever since. The voiceover work in animation came much later. So, I really never planned on being an actor. I was just really, really blessed that I am where I am today. Maybe there are reasons things happen that go beyond what we plan for ourselves?

What are you most proud of?

I am extremely fortunate that my current role in television is so close to my own self in personality. I have discovered that many have looked to my character, as well as my real life, as a role model for others (especially kids) and this is what I am most proud of. My goal, everyday, is that I will continue to earn that honor that others have given me.

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

I prefer “smooth” peanut butter over “chunky” peanut butter.

What do you like most about your job? What do you like the least?

My job in acting includes theatrical and voiceover for animation. I have to say that I love animation best because I can play with my voice, do different sounds, have accents, gesture with my body and hands all I want, and come into the studio in a pair of shorts and t-shirt.

People don’t realize that working on set requires very long hours even though kids are protected by laws

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Camp Attitude: Having Fun in Oregon!

By Shannon Parker
OI Community member Shannon Parker, lives in Salem, OR and has a young son with OI.

It may sound strange that the one place where kids with Osteogenesis Imperfecta can go to forget about OI for a week, is a place full of kids with OI—but it's the truth. For the past few summers, families from all over North America and even overseas have been making the trek to Camp Attitude in Foster, Oregon for OI Week. If you stopped in like I did on an unpredictable rainy but sunny Oregon day, you might not know what to make of the group. Kids are running around and some wheeling, others climbing up the playground or riding on the wheelchair swing, their parents laughing and catching up, clearly enjoying some carefree adult time. When I think special needs camp, this is not the image I conjure up. This looks like a big family camp out.

OI Week has become a standard for Camp Attitude. This specific week for kids and families with OI is the only one of its kind here.

Assistant Camp Director, Mike Brown, says the idea for an OI specific week was born out of necessity. "We're a general camp for disabilities," Brown said. "The reason we made a specific week for OI was because some of the kids with Down syndrome or autism side by side with kids who break easily aren't always a good combination."


Assistant Camp Director, Mike Brown (a.k.a. "Uncle Mike") holds Nathan Glad, four years old from Utah.

Brown clearly has a soft spot for OI families. Watching him socialize at lunch and dinnertime, you would think he has known each and every one of these campers for years. He can spout off first names of campers and parents weeks after they've gone and been replaced by new kids, new names and new disabilities.

"I think it's the strength of the kids," Brown said, "all kids bounce back as it is, but the OI kids are incredible."

Brown recalls last summer when Robbie Novak, seven years old from Tennessee, suffered a fracture that required immediate surgery. "He was back two days later shooting baskets from a wheelchair," Brown said.

Robbie and his sister Alexia (9 years old, also living with OI) and Mom, Laurie came back to Camp Attitude this year. Alexia flutters about the grounds with a face painted in pale pinks and purples like a fairy. Robbie is donning an impressive vampire face. Their Mom, Laurie is wandering from table to table chatting with parents and eventually settles in next to her friends for some bracelet making.


Alexia Novak, nine years old from Tennessee, with her face painted. Many kids at Camp had their faces painted by Evelia Perez, one of the Moms who attended Camp.

"We came to camp again this summer because we love to see our kids happy and loving life," Laurie Novak said. "It is hard to live a life with OI, so many times we hear 'it just isn't fair,' and I so agree with them... Going to a place like Camp Attitude makes things way more fair."

Laurie takes me back to her cabin so I can change my own son's diaper. Finley is 15 months old and also has OI—he's the reason I'm here. The current rain cloud has driven the kids into the cabin for some wheelchair races. One chair is occupied by Robbie, the other by his camp-assigned buddy. Neither currently needs the chair, but the races make good use of them until the next fracture. A chair with blinking front wheels narrowly misses my leg and I'm reminded once again, this is no ordinary special needs group.

The volunteer buddies chasing the kids around have been instructed on how to handle kids with OI and the idea is twofold; campers have a personal guide they can trust who stays with them all week, and it allows a reprieve for parents who get little time off the rest of the year.

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Growing Stronger: Kroger Celebrates 25 Years of Supporting OI Research

By Kristen Antolini
Kristen Antolini is a newly appointed OIF Board Member, and an attorney practicing in Clarksburg, VA.

The 25th Annual Kroger OI Foundation Charity Golf Tournament and Auction was held on a beautiful August day in Roanoke, Virginia, raising $67,690 for the OI Foundation. Including this year's proceeds, the Kroger event has raised over two million dollars for OI research since 1987.

The Kroger fundraiser is inspired by Kristen Antolini, the daughter of Joe and Martha Antolini. Because of the incredible support the Antolini Family received from the OI Foundation after Kristen's diagnosis in 1984, Joe and Martha Antolini wanted to give back to an organization that had helped them so much. A majority of the funds raised through the Kroger fundraiser have directly supported OI research, and from 1999 to 2010 alone, the event funded 36% of the Foundation's research fellowship and seed grant awards.

The OI Foundation would like to extend a special thank you to the Antolini Family, Art Jaklitsch, the Kroger Company, and all of the dedicated volunteers whose hard work makes this event such a success.

From left to right: Joe Antolini, Martha Antolini, Art Jaklitsch and Kristen Antolini.

From left to right: Joe Antolini, Art Jaklitsch, OIF CEO Tracy Hart and Jay Cummins, President of Kroger Mid-Atlantic Division.

OI Foundation Goes Global!

The OI Foundation is excited to report that it has recently become part of an extensive collection of digital resources that will be installed in universities and non-governmental organizations in Sub-Saharan Africa, South Asia and Latin America. The OIF website will be available to practitioners, advocates and policy makers, as well as individuals and families affected by OI who otherwise would not have access to these materials.

Known as The Global Disability Rights Library (GDRL), the free digital resource serves to bring a wealth of information to organizations that serve people with disabilities in developing countries with limited resources and few ways to obtain vital information.

Many of the subscriber institutions who rely on information from the digital library lack internet access, according to Ellis Ballard, a spokesman for the U.S. International Council of Disabilities.

“Even those who have an internet connection experience slow, unreliable and very expensive service,” he added.

Often referred to as “The Internet in a Box,” the GDRL is an off-line information store that delivers more than 14 million educational resources to people living in underserved areas. The digital library delivers information directly to web servers inside an organization, thereby bypassing the internet entirely, and enabling millions of people around the world to access vast amounts of important resources.

“The OI Foundation was more than happy to accept the invitation from the U.S. International Council on Disabilities to share the contents of our entire website with the Global Disability Rights Library,” said OI CEO, Tracy Hart.

“Rare disorders such as OI can be misdiagnosed or misunderstood in developed countries. In underserved countries, the need for accurate and reliable information and awareness is critically important.”

The OI Foundation joins the Centers for Disease Control and The World Health Organization, among others, in donating its web content to the GDRL.

The GDRL currently provides services to 350 universities, schools, government ministries, health care centers and libraries worldwide.

OIF Announces Focus for 12th Annual Scientific Meeting

The Foundation’s twelfth annual Scientific Meeting titled, *Assessing the Impact of Osteogenesis Imperfecta on Nonskeletal Systems*, will take place on April 18-20, 2012 in Chicago, Illinois. Chaired by Dr. Laura Tosi of the Children’s National Medical Center in Washington, DC, the meeting will focus on the impact of abnormal collagen on health in an effort to broaden professional awareness of the full spectrum of issues faced by persons with OI as they age. A Workshop Report will be compiled following the meeting in order to share these findings with health professionals and the OI community.

The agenda for this innovative meeting includes sessions on how the collagen defects associated with OI impact the body’s nonskeletal structures, such as the cardiovascular, pulmonary, gastrointestinal, and gynecological systems. The program will include representatives from the OI Linked Clinical Research Centers and from the OIF’s new, internet-based Adult Natural History Initiative (ANHI), which seeks to engage the entire OI community in defining the research and care gaps faced by persons with OI.

The annual Scientific Meetings began in 2000 and are funded in part by the Buchbinder Family. The meetings bring together investigators and clinicians around the world who are playing major roles in research in the field of, or relevant to, understanding osteogenesis imperfecta. The collaborative nature of the meetings helps identify future direction for research that will best benefit the OI community.

Holman Family Will Fund Research Fellowship

After almost 7 years of work, OIF Board member Greg Holman and his family have raised approximately $110,000 for the OI Foundation, enough to support a Michael Geisman Research Fellowship for two years!

This year, the family has chosen to sponsor a research study by Christina Jacobsen, MD, PhD, at Children's Hospital in Boston, titled *The LRP5 Pathway: A Potential New Therapeutic Target for Osteogenesis Imperfecta*. Dr. Jacobsen's study seeks to discover whether a mutation in the LRP5 gene will increase either bone strength or bone mass in mice that have OI.

In 2004, when daughter Mallie was 2 1/2 years old, she faced rodding surgery in her legs to relieve their bowing, which threatened Mallie's ability to walk. At the same time, parents Greg and Leigh Holman found that not enough research had been done at that point to answer their questions about what type of rod to use, how long to keep Mallie in a hip spica cast, and what type of physical therapy would be best. At that point, the family decided they needed to do something.

"I began raising money for research as it gave me purpose in an otherwise seemingly helpless time in our life, when we were faced with uncertainty on the best course of treatments for our daughter," Greg explained. "Raising money gave us hope that someday we would find the answers we were looking for, in terms of the best way to help our little girl."

So, Greg wrote his own letter explaining to friends and family that the OI community needed more money for research, attached it to the OI Foundation's research appeal, and mailed it out to dozens of his own contacts. That first year, he and Leigh raised more than $11,000!

Leigh, Liam, Mallie and Greg Holman

"People want to help, but they need to have someone ask and show them how," he revealed. "The outpouring of support and generosity was tremendous!"

The family then created *Mallie's Friends Research Legacy*, and during subsequent years, they mailed annual fundraising letters, held a poker event, dinner, and bowling outing, and promoted "Cards that Care," which were developed by a friend of Mallie's grandmother and sold at a local elementary school. They even secured a grant from a family foundation to fund an earlier Michael Geisman Research Fellowship for two years!

The goal throughout was to fund a full OI research study through the money they raised. When it was clear this year that *Mallie's Friends Research Legacy* had raised enough to support a fellowship for two years, the family was able to choose from the studies already approved by the OI Foundation's Scientific Review Committee as qualifying for support.

"It's very gratifying to fund research like this. There is so much that we don't know about OI and this will put us one step closer," Greg said. "We're excited that this research will help our daughter, other kids with OI, and really, everyone with OI."

Greg added that he would encourage anyone in the OI community to ask others to help support the OI Foundation's mission.

"It's up to everyone affected by OI to do whatever they can, regardless of how difficult it may be. Raising money, whether to fund research or provide services to the OI community, is something everyone should do. In the end, we are helping ourselves!" he said.

When asked how an individual can get started, Greg offered the following advice: "Start small, and start with a personal appeal," he suggested. "Tell your story and people will help you achieve your goals. The OIF has a variety of fundraising options, and the staff will help you every step of the way."

The OI Foundation is grateful to the Holmans – Greg, Leigh, Mallie and Liam – and to their many family members, friends, classmates, neighbors and co-workers who made the OI Foundation's funding of Dr. Jacobsen's research possible!

Spotlight: *Atticus Shaffer* *(continued from page 3)*

in the entertainment industry, which includes monitored time. But, there is a lot of time where you have to sit and wait and be patient until your scene is ready and you can actually act. That can be draining sometimes.

What are your special interests, and/or hobbies?

I love everything about Legos, building with them and making stop motion animation videos with them. I also LOVE to play a Japanese card game, in tournaments, called Yu-Gi-Oh. I have been playing since I was five years old. I had also played chess for a few years, going to tournaments, too. But, I love to go on day trips to different places, watch movies, I am a gamer, and hang out with my friends on my time off. My best friend and I go to the Yu-Gi-Oh tournaments together.

Have you had the opportunity to travel? If so, when and where?

As a family, I have traveled with my parents on camping trips and lots and lots of other places, like the Grand Canyon, or Utah, Colorado, or San Diego where I love to go to Legoland and Sea World. As an actor, I have been to New York three times and to Chicago for commercials, a movie, and publicity. I was able to visit the Statue of Liberty and the site of the 9/11 tragedy while in New York. It meant a lot to me to see these places in person and the church used for victims of 9/11 across the street from Ground Zero, had a huge impact on me. This year's hiatus from work, I was able to go to Washington, DC, as the Grand Marshall for the Cherry Blossom Festival. My parents and I made a family vacation of it and we visited tons of monuments, the Smithsonian, Mt. Vernon, Gettysburg, and lots of other sites. Then, I was invited to Florida by the people of Legoland, to do a "Fun-ternship" with a Master Lego builder! This was a dream come true for me! Legoland in Florida opens October 15 and they let me see what it was like to build their theme park. I was also an assistant chef with their Chef and learned how to make healthy meals for the park. I also went to Comic Con in San Diego for my Disney animated show. That was an amazing experience, too.

How has OI affected your childhood?

That's the thing. OI does not have to affect anyone's childhood. I don't think about it, so it does not affect me. I know I have it and I know I have physical limitations and I just work around it. But, I don't think about it. I know when I fractured or had surgeries, it hurt and we dealt with it as a family. But, my parents brought the world to me, or took me to the world when I could not and I did not feel like I lost anything. I love my life and love everything about my life.

What techniques did you develop to cope with OI as a child, student and now?

I just follow my interests and passions and let those things guide me. I don't look for what others do, but what I can do. When I was scared when I was little, like being in a hospital, I learned to put myself in a place in my mind where I felt calm. I loved the beach and thought of the smells and the sounds of the ocean. My mom played soothing, soft music. I loved my pets, too, and they loved me and comforted me. I had a favorite stuffed animal that went with me when I needed to go to the hospital, who comforted me. But, there is always a way of doing things as I grew older. I just had to do them differently. It's actually not a big deal and easy if you think about it. It's just how you figure things out.

What are your plans for the future?

My hopes are to become a writer and director of films/television because I am a storyteller and I see pictures and images in my head of how stories could be seen or told.

Is there something you want to tell children with OI or parents of children with OI?

Be yourself! You are exactly who you should be, exactly the way you are. You don't need to be like anyone else. Parents, let them do that.

OI Foundation Elects Five New Members to Board of Directors

On August 1, 2011, five new members of the OI community began their term of service as members of the OI Foundation Board of Directors. The OI Foundation welcomes them:

Kristen Antolini

Kristen is a graduate of West Virginia University with undergraduate degrees in music and political science and a degree in law. Kristen is currently employed as an Associate Attorney, practicing in insurance defense at the law firm of Smith, McMunn, and Glover PLC in Clarksburg, VA. Kristen has served as a volunteer for the OI Foundation in a number of ways including serving as a peer reviewer for the Congressionally Directed Medical Research Programs of the Department of Defense. She has served on a number of OIF committees and has participated in nearly all of the OIF conferences. As a person living with OI, Kristen has visited people with OI at WVU hospitals and worked to connect them to the Foundation.

Jody Cheek

Jody holds a Masters Degree in education with a special education certification from Milligan College and a Masters Degree in English from East Tennessee State University. She is currently a member of the Leadership 2015 class in Johnson City, TN, and has served in a number of leadership positions with the Junior League of Johnson City. Jody is dedicated to advocating for peer support and increased research funding for OI, as both her husband and daughter live with OI.

Alcides Ortiz

Alcidesis a seasoned attorney with coalition-building and advocacy experience, as well as experience with print, radio and television media. He works at the Department of Defense as Associate General, Office of the Secretary of Defense and is fluent in both Spanish and English. Alcides, who is the father of a three-year-old son with OI, cares deeply about the activities and impact of the OI Foundation and will apply his skills and knowledge in the best interests of the greater OI community.

Carolyn Tipton

Carolyn lives in Los Angeles, California, and has extensive experience in the field of broadcast journalism. She was formerly employed by NBC. Carolyn has served on a number of OI Foundation committees, including the corporate initiative committee and the board development committee. Carolyn lives with OI and is committed to helping the Foundation reach its goals.

Robin Wright

Robin is currently employed by Sotheby's, where she is Assistant VP/Jewelry Specialist. She has earned a coveted graduate gemologist degree from the Gemological Institute of America. She resides in New York City and retains residences in Colorado where her husband, Joseph, is a marketing consultant for the hospitality and real estate industries. Robin lives with OI and is particularly interested in advocating for improved insurance coverage for hearing aids due to hearing loss.

Handmade Quilt is Featured Early Bird Prize in "Going Places" Sweepstakes

Enter the OI Foundation's "Going Places" Sweepstakes, and you could win a handmade quilt, an Amazon Kindle e-reader, $200 in free gasoline, or a cruise for two to a destination of your choice!

The Grand Prize during the "Going Places" Sweepstakes is a 3- or 4-Day Cruise for Two to a destination of your choice!

The "Going Places" Sweepstakes is an annual promotion that offers you a fun and easy way to both support the OI Foundation and involve your friends and family. You will receive your tickets and all of the information in the mail sometime in September.

Entering is easy. Simply fill out your ticket stubs and return them by mail, or you can enter online at www.oif.org/Sweepstakes beginning September 15. If you don't receive your tickets in the mail, simply e-mail the OI Foundation at Development@oif.org or call 1-800-981-2663.

When you return your tickets, there is a suggested donation of $5 per ticket or $40 per book of 10. So, if more people make a donation and enter, then the benefit to the OI Foundation's mission grows!

However, a donation is not required to enter, and making a gift does not have any impact on your chances of winning.

Real members of the OI community win! Last year's cruise was won by **Angela Paul of Princeton, IN**. She, husband Jeffrey and their two teenagers, Cassie and Alex, took their cruise to the Bahamas and back in July to celebrate Cassie's graduation from high school.

"We chose a cruise to Nassau through Royal Caribbean and had a fabulous time—it was great to share special family time together," Angela shared.

"The ship was fantastic, as were the ports that we were able to explore. We all went parasailing on Royal Caribbean's private island and then had a day of adventure on Nassau."

You don't want to miss your chance to win this year's prizes! The Early Bird Grand Prize is a handsome 80" x 80" cotton quilt that was pieced and appliqued by the "Dear Jane" Quilting Guild of Clinton, NJ. Anchored by the Sebastianville railroad station (named for a New Jersey boy with OI), this fictional country town and landscape includes several trains at the station, an old mill, red barn, beehive, water tower, horse drawn buggy (with button wheels), along with animals, hills and streams. Enter no later than Nov. 15 to be eligible for the drawing to win this early bird prize!

One lucky Early Bird Grand Prize winner will receive this beautiful hand pieced and appliqued cotton quilt.

After Nov. 15, you still have the chance to enter the Grand Prize drawing. The third prize winner will receive $200 in gasoline gift cards, courtesy of **the Finkel family**. The second prize will be an Amazon Kindle Wi-Fi with free 3G and a leather case.

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Camp Attitude: Having Fun in Oregon! *(continued from page 10)*

Robbie Novak, seven years old from Tennessee, rides one of the horses at Camp Attitude for the first time. Horseback riding is one of many activities OI kids get to experience at Camp Attitude in a safe way.

"Wednesday night we have a parent dinner and for some couples, it's their first dinner alone in years," Brown said.

Rachel Glad, Mom to Nathan Glad, four years old of Utah, appreciates the time with her husband, and with parents of other kids with OI.

"As a parent looking at it, its not so much the activities, its not so much what they do," Rachel said. "Its a week where we're a normal family. We're not the strange family that has to do things differently."

I'm about ready to leave for the day when another Mom offers to let my son try out her son's pediatric walker. We show Finley how to use it and he takes a shuffle or two with a big grin on his face and I see my joy reflected on the faces of the other Moms who have seen their kids defy the odds too. These are the moments that happen when people of like circumstances come together in a unique place like Camp Attitude and remind each other that one special need we all have, is to feel normal every once in a while.

For more information about Camp Attitude email camp@campattitude.com

Throwing a Perfect Strike at the White Sox Game *(continued from page 1)*

Alec met with dynamic White Sox manager Ozzie Guillen, who autographed a baseball and cheered him on! "Alec's team, coaches, parents and family and friends were so very proud of Alec that night!" says Gil.

Alec and White Sox manager Ozzie Guillen.

Alec with his family and White Sox pitcher Mark Buehrle.

Longtime OIF Volunteer Combines Love of Art and OI Awareness

Love of art has always been a part of Rhoda Greif's life.

Her love and enjoyment became more of a *passion*, though, when she had the good fortune to study under two prominent masters while a student at Brooklyn College. The internationally-known Russian-born abstract expressionist, Mark Rothko, served as her first important mentor.

Rhoda also studied techniques that would influence her later paintings with renowned American watercolorist, Ed Whitney.

Rhoda's approach to art combines her love of travel, a keen appreciation of nature's beauty, as well as a rich imagination. She travels extensively and is often inspired to paint scenes she has captured on film.

"But I always add my own little interpretation of what I remember," she said.

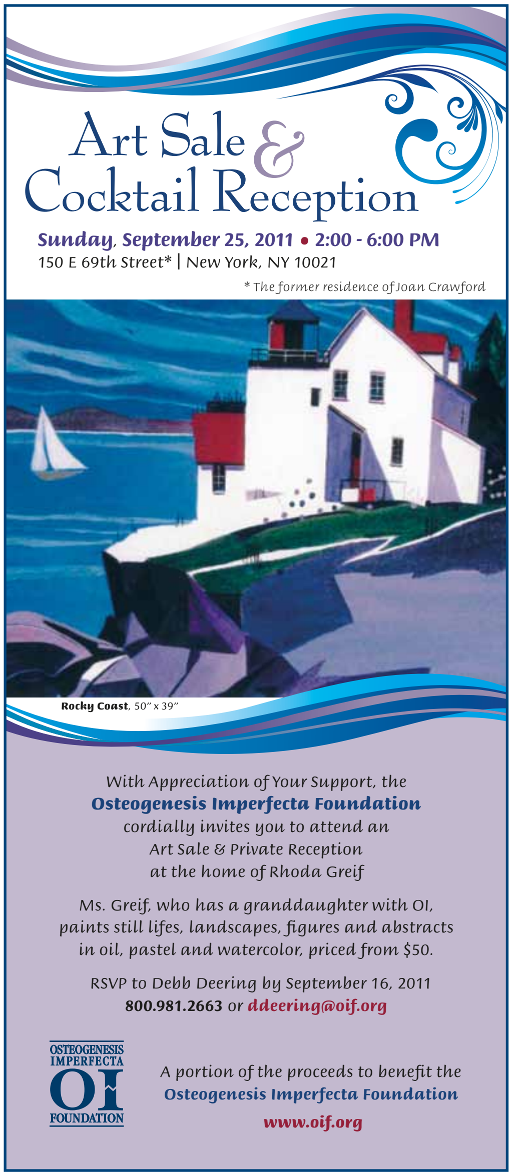
"Painting is a game in which I set the rules and violate them. It is a series of discoveries, losses and adventures… Some paintings emerge from my imagination, while the source of others is from the beautiful things in nature that surround me."

The native New Yorker enjoys working in multiple art mediums including oil, watercolor and pastel.

Her work has been exhibited at various group shows across New York City, including the Cork Gallery at Lincoln Center and the Cornell Medical Library, among others. She has had one-person shows at the Bridgeton Gallery in New Jersey, as well as several major New York City banks. Rhoda is the recipient of many first place awards at shows along the East Coast. Her paintings are also held in numerous corporate and private collections, including Morgan Stanley, Dean Witter and the California office of Visa, Inc.

Artist Rhoda Greif with her granddaughter, Rachel Weinberg.

Rhoda, who has a granddaughter with OI, is a generous supporter of the OI Foundation. She is hosting her 3rd Annual Art Sale & Cocktail Reception at her New York City home on Sunday, September 25 to help raise funds and awareness for OI.



Art Sale & Cocktail Reception

Sunday, September 25, 2011 • 2:00 - 6:00 PM
150 E 69th Street* | New York, NY 10021

** The former residence of Joan Crawford*

Rocky Coast, 50″ x 39″

With Appreciation of Your Support, the
Osteogenesis Imperfecta Foundation
cordially invites you to attend an
Art Sale & Private Reception
at the home of Rhoda Greif

Ms. Greif, who has a granddaughter with OI,
paints still lifes, landscapes, figures and abstracts
in oil, pastel and watercolor, priced from $50.

RSVP to Debb Deering by September 16, 2011
800.981.2663 or **ddeering@oif.org**

OSTEOGENESIS IMPERFECTA OI FOUNDATION

A portion of the proceeds to benefit the
Osteogenesis Imperfecta Foundation
www.oif.org

Florida OI Support Group Meeting
Saturday, November 5, 2011
12:30-4pm

Tampa Shriners Hospital
Hospital Auditorium
12502 North Pine Drive
Tampa, FL

The program will include speakers Kenny Knedler & Clayton Cramer of Ocean Conversions & Mobility. Come learn about car & van modifications, home modifications, and wheelchair and walker modifications! Lunch will be provided!

Please **RSVP by November 1st!**
Gail Bunker at gbunker1@aol.com or 813-657-0049 or
Susie Wilson at oislw@aol.com or 239-482-6892

MA and NH Support Group Leader Sean Bevan accepts a check from Ken Gudek, Teresa Gudek and Steve Gudek of Technical Needs at the New Hampshire Fisher Cats play-off game on September 7. The New England-based temporary staffing company worked with the baseball team and the OI Foundation on a 'Broken Bats for Broken Bones' promotion, through which Technical Needs donated $50 for every team bat broken during a 2011 home game. Ultimately, the company donated $1,850 through its Fisher Cats partnership and an additional $850 through its promotion with the Lowell (MA) Spinners and intends to participate again in 2012.

Going Places Sweepstakes

(continued from page 10)

The Grand Prize, once again, will be a 3- or 4-day cruise for two, valued at up to $1,200! **Karen and Glenn Vowell of Cruisesnyou.com** will arrange this travel, as they have done for several years.

According to Angela, Karen "was wonderful to work with!! She was so helpful in choosing the cruise that would be right for our family, and she took care of every little detail that made our trip such a success. She was always patient and so helpful with the tons of questions that we had."

All Early Bird entries will also be eligible for the Grand Prize Drawing, and new entries for this drawing will be accepted through December 12.

Your participation in "Going Places Sweepstakes campaign helps everyone in the OI community by generating vital support for OI research, new resources for families, the national conference, and many other OI Foundation activities.

"We will also always support fundraising activities that help raise money for OI research," Angela said. "Our son has benefitted from the research that has been done on OI, and we hope generations to come continue to benefit from new information and treatment options."

Family Works Together to Impact OI Community in Minnesota Region

"We decided we had to do something!"

On a sunny, comfortable Friday in August, more than 100 golfers and other volunteers gathered in St. Peter, MN, to improve lives in the OI community. Nine-year-old **Bennett Clayton DeBlieck** opened the charity golf outing on August 12 by hitting a ceremonial drive across the course.

The *Eighth Annual Bennett Clayton Foundation Charity Golf Outing* employed a Western theme this year. Several volunteers and even golfers arrived dressed in cowboy hats and other Western gear. Adding to the fun, several holes had Western-themed contests. At one hole, golfers attempted to lasso a sawhorse to earn the benefit of teeing off from a closer mark. On another hole, golfers had to switch their clubs for a polo mallet once their ball made it onto the putting green.

This event is just one part of the strong commitment that the DeBlieck and Coomer families have made to the OI community since Bennett suffered his first two femur fractures within a few weeks of each other, when he was just 11 months old.

Bennett's grandmother, **Brenda DeBlieck**, said the experience was "frightening," explaining that "We thought … Where do we go now? … What do we do to figure this out and prevent it from happening?"

Each year, 9-year-old Bennett Clayton DeBlieck hits a ceremonial first drive to open the charity golf outing.

In keeping with the event's Western theme this year, volunteers Rhonda Hall (left) and Nettie Jubie and 'held up' golfers at one contest hole, encouraging them to make a donation and putt for a prize.

"We had a lot of learning to do," she added.

Doing something began with holding a golf fundraiser and organizing a nonprofit organization, the **Bennett Clayton Foundation for Children with OI**.

"Before we knew about the OI Foundation, we decided we had to do something," Brenda explained. "We wanted to raise money to help others, and awareness was important to us at the time."

After 8 years, the golf outing and the Bennett Clayton Foundation are going strong and making an impact, both nationally and in Minnesota and surrounding states. The whole family is involved: Brenda and her husband **Duane DeBlieck**, Bennett's parents **Chad and Erin DeBlieck**, Chad's sisters and their husbands **Paula and Ron Coomer** and **Shannon and Bill Rantz**, Bennett's siblings, cousins and uncles, Brenda's sisters, and quite a few family friends.

So far, the Bennett Clayton Foundation for Children with OI has contributed $90,500 from its annual golf event to OIF to support the Linked Clinical Research Centers, conference scholarships, and services and information for families.

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Family Works Together *(continued from page 14)*

In addition, they have:

- Formed an OI Support Group, bringing Minnesota families from the OI community together on a regular basis;
- Provided three scholarships to young people with OI to attend college, each of which offers $2,000 per year that is renewable for up to four years; and
- Presented six personal health grants of up to $2,500 to help families whose children with OI have a special need, including dental work, a stair lift, a composite (non-wooden) deck, and a special stroller.

From the beginning, the Bennett Clayton Foundation has partnered with the OI Foundation.

"The OI Foundation has done several things for us," Brenda explained. "First and foremost, it has been a resource for us as we learn about OI. From the standpoint of operating the Bennett Clayton Foundation, OIF has assisted us in reaching out to OI families in our area while protecting their privacy and has referred other families to us who would benefit from a 'local' connection. On a larger scale, OIF has administered funds provided by BCF for research and clinical projects that we would be unable to conduct as a small, family foundation."

Erin revealed that she is most proud of the personal health grants because "we have been able to help people with things they may not have been able to afford."

For her part, Brenda said that bringing families together through the Meet and Greet activities has been "most rewarding" for her.

Erin added, "We've had people tell us they've never known a person with OI." One family traveled 350 miles to be part of the very first Support Group gathering that BCF hosted!

Personal health grants must benefit children with OI who reside in Minnesota. These grants are awarded twice each year.

Scholarships are available to high school seniors and undergraduates who live in a five-state area that includes Minnesota, Iowa, North Dakota, South Dakota and Wisconsin, and they may be renewed for up to three additional years or until a bachelor's degree or equivalent is earned, whichever occurs first. The annual deadline for scholarship applications is March 1.

For more information on the Bennett Clayton Foundation, or the personal health grant and scholarship programs, simply visit www.bcfforoi.org, e-mail BCFforOI@aol.com, or phone (507) 931-3454.

At one hole, golfers had to shed their golf clubs for polo mallets, once they reached the putting green.

Volunteers check in golfers prior to the start of the 8th Annual Bennett Clayton Foundation Charity Golf Event on August 12.

Support Group and Volunteer Events

Over the summer, many OIF Support Groups hosted meetings and social gatherings, including:

Mesa Arizona Support Group Leader Jen Adler hosted a meeting at the Mesa 1st Street Firehouse where a new OI family was welcomed. Planning is in the works for a Holiday gathering.

Southern Florida Support Group Leader Missy Monokian hosted a meeting at the home of the Nader family. A new OI family was welcomed. Planning is underway for a Blue Tie-Banquet and an OI Day at Sun Life Stadium for the fall.

The Puget Sound Support Group Leader Diane Wysocki hosted a barbeque at the home of Jeanne and Dave Slonecker. There were 18 members in attendance and all enjoyed a beautiful Puget Sound day.

In addition to Support Group events, many OIF volunteers continue organize awareness and fundraising events for the OIF.

Todd Ames completed 86 jumps in 24 hours on July 7 and 8, raising awareness for OI.

Six-year-old Isaac Wright (center of front row) enjoying the Ironbirds baseball game at Ripken Stadium in Aberdeen, MD, during OI Night on July 7.

Hike for OI. On May 27th – 30th, Mark Malcein (pictured with Catherine Haggarty) embarked on the beautiful and difficult 60-mile Loyalsock Trail to raise money for the OIF.

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People & Events

Support Group and Volunteer Events *(continued from page 16)*

The 6th Annual Birdies and Bogies for Better Bones golf event in Ashburn, VA, will take place on October 24th. Register to golf or become a sponsor at www.oif.org/BirdiesandBogies! Don't miss the opportunity to play on the Arnold Palmer Signature Golf Course at Belmont Country Club.

20th Annual Beefsteak Dinner

Three Saints Russian Orthodox
Cultural Center
Garfield, New Jersey
Saturday - October 22, 2011 at 5 p.m.

We hope you will join the New Jersey support group in celebrating their 20th annual Beefsteak Dinner. Over a quarter of a million dollars has been raised for OI Foundation programs; please help us make this our best event ever! All profits go to support the OI Foundation programs.

For more information about this event, or to register, visit http://www.oif.org/site/Calendar/1447229377?view=Detail&id=9521.

In My Own Words

Sam Moses is a 13 year old boy from Colorado who recently raised close to $2,000 for the OI Foundation through his swim team fundraiser and Bar Mitzvah gifts. Below is his letter to the OI Foundation.

August 16, 2011

Dear OI Foundation:

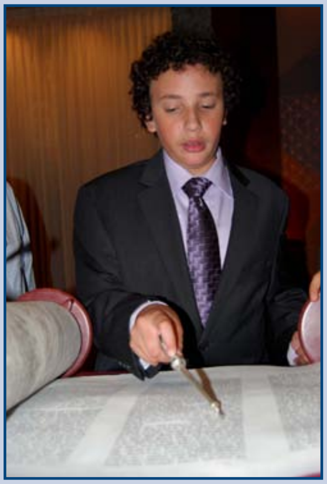
My name is Sam Moses and I am diagnosed with Type I of Osteogenesis Imperfecta. I am 13 years old and recently had a Bar Mitzvah. I was required to have a Mitzvah project. So, I had the idea of using my swim team's yearly fund raising event, called a swim-a-thon. I asked the Board if I could incorporate the OI Foundation within the event. They said yes and agreed that 20% of all the earnings would go to the OI Foundation. I was able to raise $619.15 just from the swim team. Then, from other generous donations, we were able to raise an additional $1,167, adding up to a total of $1786.15 for the OI Foundation. I even donated $200.00 of my own earnings from my Bar Mitzvah.

Not only was I able to raise money, but I was able to raise awareness about OI.

I hope that this money is able to help the OI Foundation find ways to treat and support all people (and their families) with OI.

Sincerely,

Sam Moses



13-year-old Samuel Moses used his Mitzvah project and his swim team's annual fund raising event to raise both awareness of OI in Centennial, CO, and $1,786.15 for the OI Foundation.

Countdown to Conference 2012!

The next National Conference on OI will be held July 13-15, 2012 in Washington, DC! The National Conference is a 3-day event filled with social and educational activities for all ages. The full conference will be held at the Crystal Gateway Marriott, located at 1700 Jefferson Davis Highway in Arlington, Virginia. Arlington, VA, is situated directly across the Potomac River from downtown Washington, DC.

Whether you are a first-time attendee, or a conference veteran, the National Conference is a great way to stay connected to the OI Community! The National Conference is designed to encourage attendees to learn and share information not only from leading experts in OI, but also with their peers. In addition to countless educational and peer-sharing sessions, the program includes social activities for all ages, and even childcare for the little ones!

Young attendees take a break to chat at the 2010 National Conference in Portland, OR

Medical Consultations will be held on Friday, July 13. Medical Consultations allow attendees to schedule one-on-one conversations with OI specialists including hearing, orthopedics, physical therapy and dental. Medical Consultations are by appointment only, and information about scheduling appointments will be published on www.oif.org and in the National Conference issue of *Breakthrough*, due out in February 2012.

It is never too early to start planning your trip!

Mary Alice Birdwhistell and Don Gardner, Jr. having fun at the Awards Dinner & Dance.

Plan Your Travel

With airfare at an all-time high, planning a trip early will save you money! Start shopping for travel deals by checking out discount airfare websites like www.priceline.com and www.kayak.com. Many sites offer email alerts when prices drop for your destination of choice. Websites like www.travelzoo.com will also email you travel deals on a daily or weekly basis.

Washington, DC, is easily accessible by bus or train. Greyhound and Amtrak have customer service departments designed to assist travelers with disabilities.

Greyhound Customers with Disabilities Travel Assistance Line
Phone: 1-800-752-4841 Website: www.greyhound.com
Amtrak Reservations
Phone: 1-800-872-7245 Website: www.amtrak.com

When you book your travel, be sure to discuss any special needs, such as traveling with oxygen or a power-wheelchair, with your transportation provider.

Budget for Conference Registration and Hotel Rooms

The hotel room rate for the Conference will be $149 per night. Remember, if you need an ADA room, please book your hotel room early! Accessible rooms are limited and on a first come, first serve basis. Conference registration rates have not been confirmed, but will be announced in the Enews, Breakthrough and on www.oif.org when they are available.

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People in the News

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

Ryan Berger

An Assistant Detective in the Santa Ana, California police department, Ryan Berger is involved in news-making events every day. He works on many aspects of criminal investigations, including interviewing victims and suspects. At three-feet-2-inches tall, Detective Berger may be the shortest police officer in California, but his unbreakable spirit shows through in his mental toughness, dedication to his work and respect for his co-workers.

Congratulations!

These two women have shown their unbreakable spirit by excelling in their studies. Congratulations and best wishes to:

Lillie Christine Emmelhainz who recently started medical school at the University of Florida.

Caroline Muster who was awarded the Ima Hogg Scholarship to continue her studies in Social Work at Texas State University. This scholarship is awarded once a year to graduate social work students who demonstrate a strong commitment to providing quality mental health services. Ms. Muster has worked with high-risk youth. In an interview, Caroline stated that she wants to be an advocate for the elimination of the word “disabled.”

Grace Riggs: OIF Pioneer

July 23, 2011 was a day of celebration in honor of the amazing life of Grace Riggs. A diverse group of friends, family, and city officials gathered across generations and many miles to surprise Grace on her 80th birthday. Guests reminisced about how she brought intelligence, warmth and graciousness to everything she did.

Her daughter Gay, who has OI, inspired Grace to devote her talents to raising awareness about OI. Grace was active in the OI Foundation almost from the very beginning. Starting in 1972 she laid the ground work for the Houston, Texas, Chapter and continued for many years to organize meetings, social events and awareness activities. She served on the OI Foundation Board of Directors from 1978-1984, becoming First Vice-President in 1979 and President in 1980. One of her many activities was organizing one of the first national fundraisers–the Cookbook Project–to raise money for OI research. Grace was a master at getting media attention about OI. She was skilled at doing interviews on radio and TV and even after her years on the Board, continued speaking to students, religious organizations and other groups in her efforts to promote knowledge about OI.

Countdown to Conference 2012 *(continued from page 18)*

Funding for Conference

The OI Foundation offers a Conference Scholarship program which covers registration fees and hotel costs for the conference. The scholarships are awarded based on an application process which will begin in early 2012. Attendees seeking funding are also encouraged to apply for an Impact Grant to cover the same costs. Applications for Impact Grants will be available on www.oif.org on December 1.

Capitol Building

Plan Your Stay in Washington, DC

Whether you want to see the National Monuments, visit the Capitol Building, or spend and afternoon at the National Zoo, Washington, DC, is a great vacation destination!

The Washington, DC Convention and Visitor Bureau’s website, www.washington.org, is a great place to begin your search for attractions and tours.

While Washington, DC is known as an accessible city, it can be helpful to research locations you choose to visit before your trip. http://www.disabilityguide.org/museums.html has a thorough review of accessibility at many popular attractions.

We look forward to seeing you in at the 2012 National Conference on OI in Washington, DC!

Bone China Tea Hosts Raise Almost $32,000!

Despite a difficult economy, Bone China Tea grew in 2011!

Forty-six volunteers proved once again that this phantom, or virtual, tea party is a fun and easy way to get others involved in supporting the mission of the OI Foundation. Together, they raised $31,971.92 in gifts from 596 contributors, simply by sending out printed or e-mail invitations to people they know. That is $950 more dollars and 57 more donors than in 2010!

Bone China Tea Co-chairs **Jennifer and Susan Wilson** recruited the hosts, assembled the invitation packets for volunteers, and ensured the success of this annual promotion. Each January and February, hosts are provided with free invitations to a virtual tea party; recipients are asked to enjoy a cup of tea and then make a gift to the OI Foundation in the amount they saved by not attending an actual event.

Michael Johnston, Bonnie Landrum and daughter Emma Johnston of St. Paul top the results list once again by raising $6,375 from 76 donors by press time! **Tracy Bryan** of Palm Harbor, FL; **the Cabacungan family** of Oak Park, IL; Cynthia Nolan of San Diego; and **Susan Wilson** of Ft. Myers, FL all raised more than $2,000, and three other hosts each brought in $1,000 or more to support research, resources and awareness.

The OI Foundation gratefully thanks Jenny, Susie and each of the 46 hosts below who improved lives and made the OI community stronger through their participation!

2011 Bone China Tea hosts

$5,000 and up!
Michael Johnston & Bonnie Landrum

$2,000 - $4,999
Tracy Bryan
Alec Cabacungan
Cynthia Nolan
Susan Wilson

$1,000 - $1,999
Gail & George Bunker
Mark Byam
Michelle Duprey

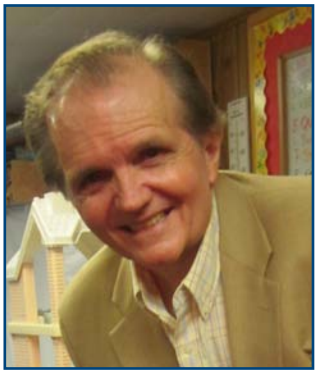
$500 - $999
Katie Carter & Family
Judith Clarke
Michelle Iachini-Dellapenta
Michelle Moscardelli
Suzanne Polerecky-Matthews
Christopher Reynolds
Robin & Mickey Rowland
Jessica Scoggins

$250 - $499
Breman, Carmellya & Alana Anderson
Donna Ayers
Denise Bedeian
Hope Christie
Gail Flanagan
Alyse & Paula Furber
Michelle Bunker Fynan
Debra Iachinii & Family
Karen Kurbis
Saundra Long

Up to $249
Thomas Acquafredda
Ruth Atkinson
Marge & Jeannine Collins
Brandi Edmonds
Jeffrey Erbland
Susan Hart
Jennifer McLeod
Susan Munson
Tim & Laura O'Connor
Greg & Peggy Parsons
Bob & Linda Phillips
Valerie Ramage
Candy & Emily Shirai
Heather Starkey-Pannullo
Lisa Thompson
Greg Trahan
Sabrina Wagner
Gary & Catherine Williams
Jenny Woodard
Maria Zanetti

My Experience with Heart Valve Surgery

By Dick Wyman



Note: The Summer 2011 issue of Breakthrough *included a report on a research study from Norway that found that all adults with OI are at risk for a number of heart problems and recommended that cardiovascular screenings be included in their routine health care.*

I am now well on my way to recovery from heart surgery that went extremely well and my new aortic cow's valve is doing great! It has truly been an eye opening experience since I was diagnosed three years with what they called "aortic insufficiency." Translated this means the blood is not being pumped effectively from the aortic valve to the heart. A "flap" on the aortic valve is not closing properly and a portion of the blood drains back into the valve. This puts stress on the heart itself. Except for tiredness there are few warning signs until there is a serious problem.

This whole "journey" really started almost 50 years ago when my father, also a Type I OI, died suddenly at age 55 of an aortic aneurysm. Although just a teenager I often thought about whether I might face a similar fate some day because I have Type I OI also. This concern was probably a good thing as I have always been pro-active about monitoring my health, being active with physical fitness, and have asked for all diagnostic testing available to me at my annual physicals. We all hear this advice from all the doctors who have been involved with OIF over the past 25 years but how many "OI'ers" really take it seriously and do something about it? If nothing else comes from your reading my article I hope every reader with OI or a parent with a child with OI takes a pro-active approach to monitoring their heart health regularly. Then, God forbid, if there is a problem you can catch it early and address it while they are in relative good health as I did!

Because of my family history and my pro-active approach my primary care doctor included an echocardiogram (echo) in my annual physical. This test produces ultrasound images of the heart that yield significant information regarding the function of the heart valves, walls, and chambers. In late 2008 my doctor detected my heart problem from an echo at my annual physical. At that point I began to seriously look for more information about OI and aortic insufficiency. I asked Dr. Jay Shapiro at the OI Clinic in the Kennedy Krieger Institute in Baltimore, MD for his opinion and he connected me with Dr. Duke Cameron, a heart surgeon at John Hopkins Medical Center. He had a number of OI surgical patients with problems similar to mine. After Dr. Cameron reviewed my echo he referred me to Dr. Lawrence Cohn, one of top heart surgeons in the Boston area where I live, and we began to monitor my mild aortic insufficiency. During the three year period when we were watching and waiting, Dr. Shapiro continued to consult with Dr. Duke Cameron, about my situation and all their feedback was directed to my heart surgeon to use in preparation for surgery. Three years later after an echo every six months the "mild" became "moderately severe" aortic insufficiency and Dr. Cohn and Dr Cameron both agreed that surgery should be done this year while my health was very good. They also felt that if we waited much longer surgery may not be an option because of declining health. I honestly believe that had I not been pro-active on having the echocardiograms done then the problem would have gone undetected and I would have faced similar circumstances like my father and perhaps with similar results at some point in time.

Now faced with surgery, I reached out to the resources that are available to everyone through the OIF. Dr. Shapiro who is one of the OIF's medical advisors and an extremely valuable resource provided information with respect to how OI might pose a problem to this surgical procedure. Mary Beth Huber at OIF was an excellent resource for information on the tissue fragility and potential bleeding problems related to the OI's collagen defect. She led me to MedLine where there were case studies describing the problems experienced by patients with OI during this surgical procedure. I shared all of this information with my surgeon, Dr. Lawrence Cohn, so he was aware of these potential complications. I totally trusted his ability as my surgeon because he has successfully done 11,000+ heart procedures like mine, including some with tissue disorders, but none with OI. I learned after surgery that my surgical team included specialist for any potential tissue or bleeding problem!

There are a number of studies and opinions out there to support the idea that everyone with OI needs to take precautions with respect to heart health. The recent Norway study, after reviewing the records of 99 OI

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FROM THE INFORMATION CENTER

What is a Rare Disease?

The National Institutes of Health defines as rare any disease or disorder that affects fewer than 200,000 people in the United States. Including OI, there are approximately 7,000 identified rare conditions. This means that almost one in 10 people has a rare condition. A spokesperson for the National Organization of Rare Diseases has stated that nearly everyone in the US knows someone or is related to someone with a rare condition. Maybe "rare" is a little more common than people think.

Medication Safety

Over the summer the Food and Drug Administration and others published articles encouraging people to be proactive about using over the counter pain medicines in a safe manner.

In July, Johnson & Johnson, the company that makes Tylenol products, announced that it was reducing the maximum daily dose of Extra Strength Tylenol to lower the risk of accidental overdose. Experts all agree that acetaminophen, the active ingredient in Tylenol, is safe when used as directed. But because it is found in hundreds of over-the-counter medicines and in prescription drugs such as Percocet and Vicodin, it is easy to take too much by accident. Overdose of acetaminophen leads to serious liver damage. Consumers are advised to read labels and talk to their pharmacist to make sure they know what is in their medicines.

Dosing recommendations for acetaminophen in Tylenol and other medicines for children have also been changed. A detailed explanation is available in a fact sheet from the Mayo Clinic, ***Acetaminophen and Children: Why Dose Matters*** http://www.mayoclinic.com/health/acetaminophen/HO00002.

Resources for People with Hearing Loss

The Hearing Loss Association of America has published several booklets that are useful to people with OI who use hearing aids. ***A Consumer's Guide to Hearing Aids*** and a fact sheet on ***Hearing Aids and Cell Phones*** can be found on the website www.hearingloss.org under the Learn/Assistive Technology tab.

Ease Swelling Under a Cast

The American Academy of Orthopaedic Surgeons recently updated their suggestions on this important topic.

- Make sure the cast or splint stays dry.
- Take care to prevent sand, powder and dirt from getting between the cast and skin.
- Don't remove padding from the cast or splint.
- Never use an object to reach beneath the cast to scratch.
- Regularly inspect the cast for soft spots.
- Check surrounding skin for signs of irritation.
- Contact your doctor at the first sign of any problem.

Coping with Pain

An interesting study from the University College London was recently reported in the journal Pain. The researchers found that the simple movement of crossing your arms in front of you can significantly reduce a person's perception of acute pain.

The American Pain Foundation has developed some materials for people coping with chronic pain. Their new fact sheet ***Finding a Health Care Provider for Your Pain*** is available at http://www.painfoundation.org/learn/publications/files/finding-a-hcp-for-pain.pdf.

The Pre-Existing Condition Insurance Plan

The Pre-Existing Condition Insurance Plan, established by the Affordable Care Act, and administered by the US Department of Health and Human Services (HSS) is already changing the lives of people who private insurance companies refuse to insure because they have a pre-existing condition. New eligibility standards and lower premiums in many states, announced by the Department of Health and Human Services on May 31, now make it a lot easier and more affordable for people to enroll in this program. The program provides comprehensive coverage at the same price that healthy people pay. Enrollees receive primary and specialty care, hospital care, prescription drugs, home health and hospice care, skilled nursing care, preventive health and maternity care. To learn how the program works—**what benefits it offers, how much it costs, how to qualify for the program, and how to apply** visit www.pcip.gov and select "Find Your State." In addition, a Call Center is open Monday-Friday from 8 a.m. to 11 p.m. at: **1-866-717-5826**

continued on page 23

From the Information Center *(continued from page 22)*

(TTY: 1-866-561-1604). For more information see the fact sheet Pre-existing Condition Insurance Plan: Update. (link to fact sheet).

Research to Follow

Children and Hospital Care

A study published in the August issue of the Journal of Clinical Nursing reported that children age 7-18 wanted more information about their hospitalizations. According to the study, children and teens want to be included in discussions about their care, and have their concerns taken seriously by their adult caregivers. Study authors encourage caregivers and parents to use age appropriate language, provide clear explanations and allow time for questions. They believe that clearer communication will help children and teens develop self-care and decision-making skills that they will need all of their lives. In connection with this study, the Children's Hospital of Eastern Ontario published an outline on how to prepare a child for a hospital experience. You can read the whole list at http://kids.cheo.on.ca/en/preparingchild.

My Experience with Heart Valve Surgery *(continued from page 21)*

adults, recommended that all adults with OI include cardiovascular screenings in their routine health care and OI adults and their doctors should be alert to symptoms of heart disease. The bottom line here is there has been enough research done to make a strong argument that anyone with OI needs be aware that they face a potentially greater risk for heart disease. Early detection from an echo is where I started and it should be where every adult with OI should start as well. Heart health for anyone, especially for anyone with OI, should become a priority and there is no reason to wait! I'm one of the lucky ones. My heart problem was found early enough to be successfully repaired.

My personal journey has made me really aware that significantly more research into understanding and treating heart issues connected to OI is needed. In fact more research is needed on all adult related OI issues. Like everyone with OI, I pray for a cure for OI in my lifetime and I know that it will take our collective efforts to reach these goals. I am hopeful that creative and effective fund raising ideas will continue to come along. I'm proud of the fact that my daughter, Christine, raised almost $500,000 in charitable donations through her seven Walks for OI. Facing heart surgery is a sobering experience so I'm also taking a second look at the OIF's Planned Giving program as part of my estate planning. I know I can make a difference by doing this and I encourage those who are in a position to do so to let OIF explore this opportunity with you as well!

Applications for Impact Grants Available on December 1

The 2012 application cycle for the CBBF/OIF Impact Grant program will begin on December 1, 2011 and applications must be submitted by January 16, 2012. The application will be posted on www.oif.org.

The Impact Grant Program was started in 2008 as joint partnership between the Children's Brittle Bone Foundation and the OI Foundation. Since its launch, the program has funded close to $300,000 in products and services for people living with OI.

How to apply for an Impact Grant

On December 1, the Impact Grant application will be posted on www.oif.org. The application is electronic, and you will fill it out and submit it online. If you do not have access to the internet, you may contact the OI Foundation to make other arrangements. Applications are reviewed by a committee of members of the CBBF and OIF Board of Directors. During the review process, applicants may be asked to provide additional information to support their application.

In order to apply for a grant, you must meet the following eligibility requirements:

Eligibility

- OI Diagnosis. Documentation will be required.
- Financial need – if application is chosen as a finalist, income verification will be required.
- Request improves the applicant's quality of life.
- Grant must be used within 12 months or less.
- Those receiving an Impact Grant are not eligible to apply for additional funding from the OI Foundation for one year.
- Applicant must be a United States resident, and funds may only be allocated within the United States.

Allowable Use of Funds

Funds may be used for one of the following:

- Orthotics/braces/walkers
- 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, etc.
- Adaptive technology such as computers, hearing aids, etc.
- Dental intervention (due to OI)
- Vehicle modifications such as lifts, pedal extensions, etc or vehicle purchases. Grants for vehicle purchases are extremely limited, and in most cases only cover pre-owned vehicles.
- Travel reimbursement to receive specialized care
- Outdoor ramps that provide access to a home
- Accessibility aides such as reachers, shower chairs, kitchen carts, etc.
- Grants may not be used to pay off existing debt
- Grants will not cover extensive home modifications, including plumbing

For questions about the Impact Grant program, contact the OI Foundation at impactgrants@oif.org or 800-981-2663.

CHILDREN'S BRITTLE BONE FOUNDATION

OSTEOGENESIS IMPERFECTA
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Q&A

Planning for a Family

In the 21st Century there are many different types of families. Here we present information on some of the most frequently asked questions related to family planning and OI.

Can people who have OI have children?

Yes. Many men and women who have OI have biological children. OI does not affect fertility.

What are the odds of passing OI on to your children?

When one parent has OI there is a 50% chance with each pregnancy that the child will have OI. If both parents have OI there is a 75% chance that the child will have OI. Usually the child will have the same OI-causing mutation as the parent. For reasons that are not yet understood, sometimes the child's symptoms are milder or slightly more severe than the parent's even though DNA analysis will show that they have the same OI-causing mutation.

When the parents do not have OI, what are the odds of having more than one child with OI?

It is estimated that at least 30% of the children who are diagnosed with OI each year are born into a family with no history of the disorder. They are said to have a "new" or "spontaneous" dominant mutation. If OI testing shows that the child has a new dominant collagen mutation then the parents are not at any greater risk than the general population for having another child with OI. If testing indicates that the parents have a rare condition called "Parental Mosaicism" or that they are both carriers of a non-working gene that causes a recessive form of OI then the chance of having other children who have OI will be higher. In these cases, conferring with a geneticist or genetic counselor will be necessary to answer each family's questions. For more details about how OI is inherited, please see the OI Foundation fact sheet **Genetics**.

Is it possible to change the type of OI a child inherits?

Once a child is conceived, there are no treatments, or diets, or diet supplements that can prevent the fetus from having OI or that will make the type of OI milder. Options that couples might consider before conception include using a sperm or egg donor, a surrogate mother for the pregnancy or preimplantation genetic diagnosis (PGD). Detailed information about each option can be obtained from your doctor, a genetic counselor or from a fertility clinic.

Will being pregnant harm a woman who has OI?

It is important to be in good general health before becoming pregnant. All women who have OI need expert medical care during pregnancy. OI-related issues that can affect pregnancy include short stature, a history of pelvic or spine fracture, respiratory problems, and bleeding. It is reported that it takes women with OI longer to recover from the bone loss associated with any pregnancy and that they may have more back pain during and after the pregnancy than other women.

Can women who have OI use birth control pills?

In most cases, the answer is yes. Women who are short in stature should consult with their doctor about whether a low dose pill is more appropriate for them. Some birth control pills have been associated with bone density loss, so all women should talk with their doctor about this potential side-affect.

Can couples who have OI adopt children or become foster parents?

Yes, many people choose this route to expand their family. For information on becoming a foster parent contact your local government's department of social services or the National Foster parent Association www.nfpainc.org. One of many places to learn about adoption is the National Adoption Center www.adopt.org. The organization Through the Looking Glass www.lookingglass.org offers information and support to people with disabilities who wish to adopt. The OI Foundation's website also has information about adoption and often lists children who have OI and are available to be adopted.

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May 1, 2011 – July 31, 2011

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May 1, 2011 – July 31, 2011

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The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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