

OI Registry- 1st phase of the LCRCs- is now online!

by Heller An Shapiro
OI Fdn. Executive Director

You can now participate in the first phase of the Linked Clinical Research Centers by joining the **OI Registry**. The Linked Clinical Research Centers are a group of OI Centers governed by a Coordinating Committee and linked together through a central database containing clinical, radiological and genetic data. These Centers will conduct OI research, and provide medical care based on knowledge gained from all Center patients.

Before the Centers open, we will begin collecting data through the **OI Registry**, a confidential database of people with OI. The web-based questionnaire can be filled out by adults who have OI or by parents of children who have OI.

Using the **OI Registry** data, researchers will begin to develop summary data about the natural history of OI,

common or uncommon symptoms, and frequency of symptoms. Your personal data will never be provided to anyone without your permission. To be successful, the **OI Registry** will need to involve as many people who have OI as possible. It will be important that all types of OI are represented.

The benefits of participating in the OI Registry include:

1. An opportunity to participate in clinical trials for new treatments and a cure;
2. An opportunity to participate in research directed towards answering basic scientific questions about OI;
3. A detailed knowledge of upcoming research in the OI community;
4. Opportunities to participate in survey studies to collect specific data to aid research efforts; and

Continued on page 21

This is the
premiere
opportunity to
learn about OI of
all types, from
infancy to
adulthood.

Doctors,
therapists and
people with OI
will share their
knowledge in
educational and
support sessions.

Inside this issue:

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WINTER 2006

The United Parcel Service proves it's more green than brown when it comes to charitable contributions. Through the efforts of Dan Krudys (whose son, Jeffrey, has OI), the UPS family now has champions soliciting donations throughout the nation. Together, they've raised more than \$1 million!

Page 4

Don't miss the 15th National Conference!

The 15th Biennial National Conference on OI, July 20-22, 2006 in Omaha, NE, will feature a program packed with interesting opportunities for everyone—children, adults, singles, families and all types of OI. The medical information sessions will contain the most recent knowledge and advice from the OI medical community, and the social events will provide plenty of opportunities to make new friends and connect with old friends. This year's conference features a day of workshops focusing on living successfully with OI, and a number of new social and educational events.

The theme of this year's conference, *BE FIT!*, reminds everyone of the importance of physical activity in managing OI and promoting overall health. From the opening session on, many of the speakers will present information about how people with OI can include safe physical activity in their day and improve their overall health. Every day opens with a different exercise class, and Saturday morning will feature a new outdoor activity – The OI Foundation Walk and Wheel Personal Fitness Challenge.

Doctors, therapists and people who have OI will share their knowledge in 40 educational and support sessions. Dr. Horacio Plotkin and his team of specialists

Continued on page 18

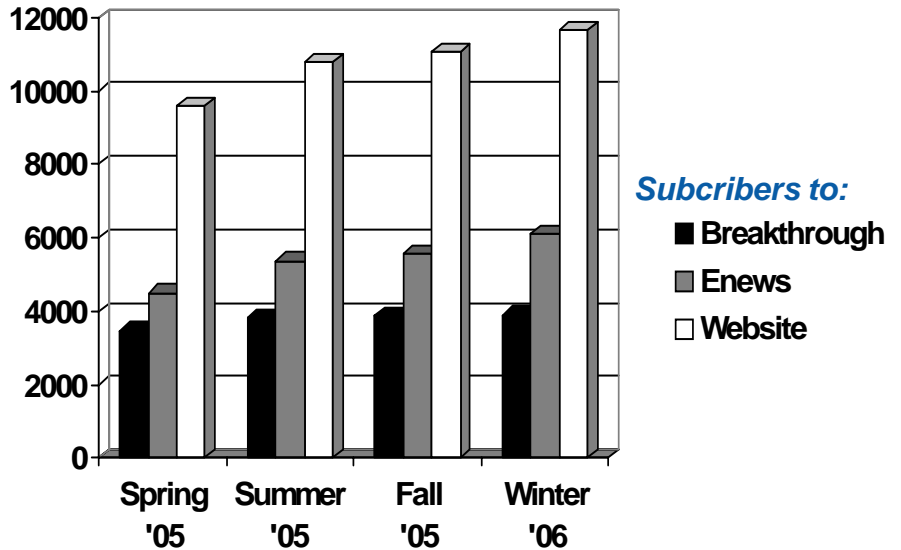
ABOUT THE FOUNDATION

The number of subscribers continues to climb on the *Breakthrough* mailing list, the website, and the e-newsletter distribution list. The OI Foundation is now reaching 3,907 people each quarter with *Breakthrough*, 11,664 people have registered on our website, and we send 6,129 e-mail updates each month, which contain information that can't (or shouldn't) wait for the next issue of the printed newsletter.

Subscriptions to *Breakthrough* are free by writing to us at the address below. E-newsletters will be sent automatically (unless you "opt out") when you register online at www.oif.org.

Register and subscribe today!

Community continues to grow as more people log on, subscribe



BREAKTHROUGH

The quarterly newsletter of the Osteogenesis Imperfecta Foundation, Inc.

Contributing Writers: Mary Beth Huber, Jamie Kendall, Heller An Shapiro, Stuart Tart.

BREAKTHROUGH is published quarterly by the nonprofit Osteogenesis Imperfecta (OI) Foundation, Inc. Opinions expressed are those of the authors and do not necessarily reflect the official position or policies of the Osteogenesis Imperfecta Foundation, Inc.

Because each person's body and response to treatment is different, no individual should self-diagnose or embark upon any course of medical treatment or physical activity program without first consulting with their physician or a qualified medical professional familiar with their medical history.

THE OSTEOGENESIS IMPERFECTA FOUNDATION, INC. (OI Foundation) is the only voluntary national health organization dedicated to helping people cope with the problems associated with osteogenesis imperfecta. Founded in 1970 by Gemma Geisman, the Foundation's mission is to improve the quality of life for people with OI through research to find treatments and a cure, education, awareness, and mutual support.

Executive Director
Heller An Shapiro
hshapiro@oif.org

Director of Communications
Bill Bradner
bbradner@oif.org

Director of Finance & Administration
Tom Costanzo
tcostanzo@oif.org

Administrative Assistant
Hilary Fallow
hfallow@oif.org

Information & Resource Director
Mary Beth Huber
mhuber@oif.org

Information & Resource Specialist
Marie Maffey
mmaffey@oif.org

Director of Development
John O'Brien
jobrien@oif.org

Assoc. Dir. of Events
Erika Ruebensaal
eruebensaal@oif.org

Database Manager
Desiree Swain
dswain@oif.org

Assoc. Dir. of Development
Stuart Tart
start@oif.org

General Correspondence:

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

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

Donations/Contributions:

To support the Foundation with a financial contribution, please send your donation to:

Osteogenesis Imperfecta Foundation
P.O. Box 630342
Baltimore, MD 21263-0342

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



804 W. Diamond Ave., Suite 210
Gaithersburg, MD 20878
(800) 981-2663
(301) 947-0083
Fax: (301) 947-0456
E-mail: bonelink@oif.org
Internet: www.oif.org

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The Osteogenesis Imperfecta Foundation, Inc., is a 501(c)3 non-profit organization, and is in full compliance with the National Health Council's Standards of Excellence.

Dear Friends,

Every day brings new milestones to people with OI. Meeting that exercise or physical therapy goal, or simply making it through the day without pain or without a fracture, each of us count our blessings and accomplishments in different ways.

I'd like to share with you three very significant milestones the OI Foundation and its dedicated volunteers have experienced this last quarter. Volunteers are the backbone of the OI Foundation's work, and without them, we wouldn't exist.

Take Dan Krudys, for example, who mobilized thousands of his fellow coworkers to support the OI Foundation by introducing them to his son, Jeffrey, and simply asking them to contribute through the United Way. Through the Krudys family's generous efforts over the years, UPS regions throughout the country have employees championing OI. This past quarter, the pledges from UPS employees (since 2004) passed the \$1 million mark. We thank you, your family, and UPS for your efforts.

Twenty years ago, the Southern California Petroleum Industry's Charitable Association was introduced to Rob Parke and his mother, Mary. SCPICA decided to make the OI Foundation the recipient of the proceeds from their annual golf and tennis tournament. We are so thankful that they have continued to be involved with the OI Foundation for the last twenty years-- a milestone in itself-- but this quarter, they, too, passed the \$1 million mark in contributions to the OI Foundation.

Eight years ago John and Beth Shultz were cherishing the milestones in their son's life. Michael was born with very severe OI, and he passed away after eight short months, but not without bringing much joy to their lives. The Shultz's set two goals in memory of their son; they want to see a cure for OI within their lifetime, and they want to personally raise \$1 million to help fund the research towards that cure. This quarter they passed a major milestone in reaching that goal: the annual golf tournament they've hosted each year since Michael passed away has raised more than \$100,000. We thank them for their continued dedication to the mission of the OI Foundation.

These are major milestones, but the individual milestones each of you make to assist the OI Foundation are equally important. Eleven-year-old Kaila Parent, who sold awareness bracelets to friends at her elementary school to raise money and awareness, is *just* as much a hero to the OI Foundation as the Krudys, Parke and Shultz families. The volunteer who donates time, because he or she simply can't afford to write a check, is just as vital to our work. Whether it's \$1 or \$1 million, twenty minutes or twenty years, your gifts make our work possible. Without your time, energy and support, the OI Foundation wouldn't exist. Thank you!

It's the OI community that gives us hope, provides us with the tools to cope with daily challenges, and gives the Foundation the ability to provide support, create helpful information resources, and fund research into treatments and a cure.

This sense of community is vibrantly alive at our biennial national conferences. I know that I am personally strengthened by attending OI conferences and being immersed with my peers. This issue is filled with information about the 15th Biennial National Conference on OI, and I encourage you to talk to friends in the community and find out first-hand how empowering and worthwhile the conference experience can be. More importantly, I encourage you to attend. I'm willing to bet you'll have a great time and come away with new friends and information to manage your daily living with OI in real and concrete ways.

There is no doubt in my mind that attending this conference, and future conferences, will become milestones in *your* life. They certainly have been in mine.

I hope to see you in Omaha!

Jamie D. Kendall
President, OI Foundation Board of Directors

PRESIDENT'S MESSAGE



Jamie Kendall

What can “Brown” do for the OI community?

UPS employees exceed \$1M in contributions

by Stuart Tart
OI Fdn. Assoc. Dir. of Development

NATIONAL EVENTS

OI Foundation staff and volunteers fanned out to several UPS facilities and events this fall, and thanks to the generosity of a large number of UPS employees, a landmark was reached. UPS employees have pledged and donated more than \$1,031,000 to the OI Foundation through workplace giving, golf tournaments, and other activities since 1996.

Past OI Foundation Board President William Schmidt and Board member Jeffrey Stewart visited a UPS facility in Newark, NJ, on October 12, where they spoke with UPS drivers as they prepared to begin their shifts.

“I think that we need to be out there to let them know we exist,” Bill, a former Foundation Board president, said. “By doing so, we make them aware of us and generate some donations.”

Although he noted that the drivers he spoke with were obviously very busy, “they gave me the great courtesy of listening to me.”

Executive Director Heller An Shapiro was invited to speak to UPS employees at the company’s Long Island facility in April of 2005.

“It’s so rewarding to see how the UPS employees open up their hearts when they see the impact of OI on a family,” Heller An said. “When you tell them about OI, they just want to help.”

The Foundation’s relationship with UPS began in 1996, when UPS employee Dan Krudys introduced his co-workers in New Jersey to his son Jeffrey, who was born with seven broken bones. Since then, UPS employees who know the Krudys family, and others who just want to help, have contributed generously to the Foundation’s research, education, and support programs.

We truly appreciate this generosity. Here are some highlights of their efforts during 2005:

Kansas District

In Kansas, where Dan Krudys now works, his co-workers pledged more than \$37,000 to the OI Foundation during the United Way campaign. This district has generated the highest level of gifts for the OI Foundation for several years, and we are touched by these contributors’ willingness to help improve the lives of children and adults with OI.

North Jersey District

For the seventh year in a row, Mike Battaglia and Dean Britt organized the *UPS/United Way North Jersey District Golf Invitational to Benefit the Osteogenesis Imperfecta Foundation*. This event was held in Readington, NJ, on September 12 and raised \$23,000 for the Foundation’s programs, thanks to the generosity of the golfers and numerous sponsors, including Data Reduction Systems and Northeast Great Dane. In addition, UPS employees in North Jersey designated \$1,630 in gifts to the Foundation as part of their workplace giving. Thank you to District Manager Craig Wiltz for his support, to Mike and Dean for their leadership, and to everyone who contributed to this success!



Golfers warm up for the North Jersey UPS tournament. UPS employees throughout the country take part in supporting the OI Foundation.

“It’s so rewarding to see the UPS employees open up their hearts when they see the impact of OI on a family.”

–Heller An Shapiro
Executive Director
OI Foundation



Jeffrey Krudys

Continued on next page

Seven years, \$118,000 and counting . . . Annual golf tournament continues to honor son


The 7th Annual Miracle Michael Fund Charity Golf Tournament generated a record \$30,000 for the OI Foundation this year, to be split between OI research and the Foundation's information and support services to people with OI and their families. This annual golf tournament, held each July in Naperville, IL, now has raised a total of \$118,000.

Although organizers Beth and John Shultz have reached an impressive milestone through their event, their goal is much more ambitious.

"We have a goal in our lifetime . . . we want to see a cure," Beth said. "We also have a goal of having raised at least \$1 million during our lifetime."

More than 250 people participated in this year's 18-hole golf scramble, which was held July 25 at the White Eagle Golf Club in Naperville. The tournament featured prizes for the winning teams, longest drive and longest putt contests, a live auction, raffles, a cocktail party and dinner.

Several local celebrities also came out for the event, including Norm Van Lier and Antonio Davis from the Chicago Bulls; Glen Kozlowski and David Kaplan from WGN-AM 720; and motivational speaker/author Sean Stephenson, who has OI.

The Miracle Michael Fund Charity Golf Outing is held in honor of the Shultz's son, Michael, who passed away in 1999. Michael was 8 months old, and had a severe form of OI. 

COMMUNITY EVENTS

"BROWN" *Continued from previous page*

Metro Jersey District

Emil Soltis led the charge for the OI Foundation, helping to increase awareness of OI among the great drivers he works with. Thanks to Emil and the effective presentations of Jeffrey Stewart and Bill Schmidt, Metro Jersey employees donated generously, directing more than \$17,000 to the OI Foundation this fall.

Long Island District

Thanks to the support of Norman Aquilino and Doug Holland, Long Island District employees opened their hearts to children and others affected by OI and directed more than \$11,000 to the Foundation.

Friends throughout the Nation

In Alabama, Northern California, Northern Florida, Philadelphia, Baltimore and suburban Maryland, UPS employees have learned how OI impacts the lives of young people and adults, and they have responded generously. In addition to our friends mentioned above, we want to offer a special thank you to UPSers who have supported our programs for years, including Don Gately, Nick Kocheck, Bill Schike, Phil Schmidt, Greg Smith, and so many others.

Thank you for making a real difference in the lives of so many! 

BE FIT!

Creativity allows 8-yr-old to continue to play ball

When 8-yr-old Joshua Kutsch was recovering from re-rodging surgery last year on his left femur, he missed playing ball, and was bored with the long hours stuck in bed.

His father, Dave, and Grandfather, Hertel, built a light-weight ball-return system using netting, PVC pipe and a little creativity. The system can be taken apart and stored.

According to Joshua's mom, Teresa, the return helped him pass the time away; even his older brothers enjoyed using it.

It also helped Joshua stay active, an important part of maintaining health and fitness (see the Summer 2005 issue of *Breakthrough* or visit the **BEneFIT!** pages on our website).



OI Fdn's PSA wins international award

VOLUNTEERS

To view the PSA,
and learn how
you can help
distribute it in
your area, visit
www.oif.org

The OI Foundation's Public Service Announcement (PSA) won an "Award of Distinction" in the 2005 Communicator Awards, an international awards competition that recognizes outstanding work in the communication field.

There were 3,059 entries from the U.S. and five other countries in the Communicator Awards 2005 Video Competition. The Crosswalk PSA received an "Award of Distinction." Approximately 17% of the competitors won this award for "exceeding industry standards in production and communication skills."

The PSA was produced using all volunteer resources, from the initial script-writing through the final editing process, for a total cost to the Foundation of less than \$2,000.




Katrina Bache is featured in the Fdn's PSA.



The PSA was filmed on a streetcorner in Arlington, VA, with the help of a crew of more than 20 volunteers.

Virtually everything was donated, including time in a local sound studio, the talents of a nationally-recognized broadcaster, an actor to play the non-OI role in the spot, and the time and efforts of our Filmographer/Editors/Producers, Wayne & Kristin Westbrook.

The OI Foundation wishes to thank Katrina Bache for her role as the "star" of the PSA, Wayne and Kristin, and all the volunteers and donors who made this possible.

Congratulations on a job well done! 

BRIEFLY:

Nominate a volunteer for the 2006 Thelma Clack Lifetime Volunteer Award

The OI Foundation is calling for nominations for future recipients of the Thelma Clack Lifetime Volunteer Award. Please consider nominating someone you feel has made a significant contribution to the OI community.

To nominate someone you know, please fax, email or mail the following information to the OI Foundation:

- Name, address and phone number of nominee
- Your name and phone number
- A description of how the nominee's volunteer activity benefitted the OI Foundation and people living with OI
- Total number of hours spent in volunteer service (last year, or a specified time period)
- Number of years of service to the OI community

Please send the information to:

OI Foundation
804 W. Diamond Ave., Ste. 210
Gaithersburg, MD 20878
Fax: (301) 947-0456
Email: bonelink@oif.org

**For more information about
our awards programs,
visit www.oif.org/awards**


Karen Braitmayer named 2005 Vol. of Year

Puget Sound Support Group Leader and community volunteer Karen Braitmayer was named the 2005 recipient of the OI Foundation's Thelma Clack Lifetime Volunteer Award.

This award honors her 20 years of service to the OI community, including serving as the OI Foundation's home modification expert, writing articles for *Breakthrough*, presenting at national conferences, consulting with families around the country wishing to make modifications to their homes, and participating in the planning and filming of ABC Television's *Extreme Makeover: Home Edition* featuring a family with a child with OI.

It also recognizes her leadership in founding and co-leading the OI Puget Sound Support Group, and her service on the volunteer of the year committee for four years.

Karen is an architect, and her firm, Studio Pacifica, specializes in planning accessible homes. She has also been recognized for her work with local, state and national business code processes in both volunteer and appointed roles. Her expertise and testimony has contributed greatly, and was a leading factor in Washington State becoming the first state certified by the U.S. Department of Justice for meeting the standards of the Americans with Disabilities Act Accessibility Guidelines.

Karen is a recipient of the Orange County Goodwill's Walter Knott Award, which recognizes people for "their contributions and their fortitude to follow their dreams and champion the spirit of ability," and is a member of the American Institute of Architects College of Fellows. 



Karen Braitmayer

VOLUNTEERS

Previous awardees:

1990

Frances Dubowski

1991

Robert Phillips
Rosalind James

1992

Heidi Glauser

1993

Pat Kipperman

1994

Kathryn Stecher
Joe Antolini

1995

Shirley Roberts

1996

Mary Parke
JoAnn Berkenbush
Rosemarie Kasper

1997

Dan Krudys

1998

Jean Mandeville

1999

Angela Mancuso

2000

Jennifer Wilson

2001

David Morrison
Sid Simmonds

2002

Gemma Geisman

2003

Jean-Paul Richard
Pete Dohm

2004

Bill Schmidt

Nicole Hofhine named first recipient of the OI Fdn Pete Dohm Junior Volunteer Award



Nicole Hofhine


The Foundation's board of directors unanimously approved a new award named after Pete Dohm, in honor of his volunteer service to the OI community. Throughout his teen years he was very active in local and national Foundation activities. He eventually served on the Board of Directors, the membership committee, and the board development committee. In 1986 he and his family and friends organized the OI Foundation's National Conference in St. Louis. He was a mentor, fundraiser, and information resource advisor.

"Many people with OI become advocates almost as soon as they learn to speak," said Volunteer of the Year Committee Chair Susie

Wilson. "We wanted to recognize and reward the outstanding youth in our community for their support to the Foundation and others with OI."

The new Junior Volunteer Award Committee presented the board with their first recommendation: Nicole Hofhine, daughter of Michelle and Richard Hofhine in Camarillo, California.

Nicole is being honored for her years of service to the OI Foundation, including her support to the Southern California Petroleum Industry Charitable Association's annual golf and tennis event, as well as her own fundraising, advocacy and awareness efforts, and her participation in the filming of *Extreme Makeover: Home Edition*.

To learn more about this new award, and how to nominate a youth member for the award, visit www.oif.org/awards. 

NATIONAL EVENTS

Don't forget to
check the News
& Events page
and the online
calendar on
www.oif.org
for new
activities!

BRIEFLY:

New peer-to-peer and adult pages published on www.oif.org


The OI Foundation has updated the Adult pages on the website, adding new resources and information specifically for adults with OI. To see the changes, click on the "Adults" button on the top menu on www.oif.org.

Peer-to-peer pages have also been added, where community members are invited to post their stories, suggestions or tips in a variety of categories. They can be accessed from the "About OI" page of the website.

To suggest changes or make recommendations for additions to the website, please email webmaster@oif.org. 

Free crime prevention tips for people with physical disabilities

The National Crime Prevention Council publishes a free brochure filled with crime prevention tips for people with physical disabilities. Volunteers from the council are also available (in most states) to participate in your local support or network group meetings.

For more information, or to order free copies of the brochure, visit their website at www.weprevent.org. 

Sally Foster sales continue to grow

by **Stuart Tart**

OI Fdn. Assoc. Dir. of Development


Who would have thought you could do so much good with wrapping paper, candy, gift items, and a little help from your friends?

This year's holiday sale of Sally Foster items brought in \$8,577 in net proceeds that will support the Foundation's education, support, awareness and research activities, a slight increase over the 2004 total. Approximately 275 people purchased their holiday wrapping supplies and gifts through this sale.

Volunteer Connie Kasputis in Michigan has been central to this successful program since the OI Foundation began participating more than a decade ago. After the Foundation mails out the Sally Foster catalogs in July or August, purchasers make their selections and send their orders to Connie. She then organizes the information into one big order and sends it to Sally Foster, helping to ensure that everyone receives the correct items.

Participants also have the option of ordering from the Sally Foster web site and designating the Foundation as their charity of choice. The OI Foundation receives 50% of the purchase price on these items, minus any taxes, shipping and handling.

Many thanks to Connie for her dedication and efficiency, which makes this fundraiser possible for the OI Foundation!

To be receive a 2006 Sally Foster catalog, contact Associate Director of Development Stuart Tart at start@oif.org or 1-800-981-2663. 

Have you ordered your Bone China Tea invitations?

by **Stuart Tart**

OI Fdn. Assoc. Dir. of Development

It is not too late to invite your friends, family and co-workers to the only event for the OI community you can attend while wearing your bathrobe and slippers!


Bone China Tea is a phantom tea party where you invite friends, family and co-workers to stay at home and have a quiet cup of tea. It is suggested that the money they may have spent on new clothes, babysitters, transportation, and other expenses associated with going out to a formal tea be donated to the OI Foundation.

This year, there are two ways to participate.

You can order printed invitations, free of charge, from event organizers Jenny and Susie Wilson by contacting them at jnwilson@aol.com. These invitations come with a tea bag attached.

If you prefer, e-mail your invitations from the OI Foundation web site. The new online Bone China Tea pages allow you to set up a personal web page with your own photo and personal update and then to track your progress as your guests make their gifts to the Foundation.

To get started on your personal web page, either visit www.oif.org/bonechina or contact Stuart Tart at the OI Foundation at start@oif.org or 1-800-981-2663.

The official date for this year's 'tea' is March 15, 2006. 

Coming Soon!

Many community events planned for spring

by Stuart Tart

OI Fdn. Assoc. Dir. of Development

New York, NY, March 9 – Join the OI Foundation and event organizers **Andrea & Jeffrey Stewart, Ellie Seepes, Robin Wright, and Robin Johnson** for a viewing of *Spamalot* at the Shubert Theatre and a pre-show reception at the Ernst & Young offices. Tickets are \$250 each for presenting sponsors and \$200 for supporting sponsors. For more information, contact the Foundation at development@oif.org or 1-800-981-2663.


Roseburg, OR, April 26 – Don't miss the **3rd Annual Baylee Taylor Memorial Bowl-a-thon** at Lava Lanes. It costs only \$5 to register, and all ages are welcome to participate. There will be a lot going on at this bowl-a-thon — prize drawings, a silent auction, and of course, bowling. Bowlers also are asked to pre-register and raise pledges in advance. For more information, contact event organizer **Jennifer Taylor** at (541) 863-4024 or jtrn@rosenet.net.

Washington, DC, May 4 – **Fine Wines, Strong Bones** moves to a new location to accommodate an expanded event. This wine tasting and auction event also will feature the presentation of new *Unbreakable Spirit* awards, *Sample the City* featuring area restaurants, and the sale of "Fragile Babies," ceramic sculptures created by artist **Patti Warashina**, each decorated by different artists. See the full article on page 4 for more details, or contact the Foundation at development@oif.org or 1-800-981-2663.

Glen Mills, PA, May 20 – **Michelle Curran** will organize the **2nd Annual Jog for Jenna**, in honor of her seven-year-old niece who has OI. The event, which also will include prizes, face painting and food, will be held from 10 a.m.– 2 p.m. at The Walking Trail by the Dream Playground in Glen Mills. To walk, or for more information, please contact Jog4Jenna06@aol.com.

Framingham, MA, June – The **Rossi, Potorski and Wyman** families will host the **2nd Annual Massachusetts Making Strides for OI** walk-a-thon at Bowditch Field in Framingham. Last year's event drew approximately 300 people for a magic show, taekwondo demonstrations, a silent auction, food, and walking for a good cause. Although the date has not yet been finalized, you can obtain a pledge sheet or information on sponsorship opportunities by contacting Christine Rossi at c.rossi@verizon.net or (508) 620-0991.

Cinnaminson, NJ, June 4 – The **Third Annual New Jersey Making Strides for OI** event is again being planned for noon - 5 p.m. at Cinnaminson Memorial Park. This walk, auction and family fun day features food, music, games, crafts, and lots of activities for kids. If you would like information on how you can get involved, please contact volunteer event organizer **Carol Goebel** at ice0698@aol.com.

Scranton, PA, June 25 – **Denise Silfee and Michael Cotton** are organizing **The Walk for Cierra**, a walk-a-thon to benefit the OI Foundation. This event, created in memory of their infant daughter who passed away in July 2005, will be held from 11 a.m. – 4 p.m. at Nay Aug Park in Scranton. To find out how you can walk, make a donation, or become a sponsor of this community event, call Michael or Denise at (570) 341-5520. 

COMMUNITY EVENTS

Save the Dates!

March 9, 2006

Spamalot theater event in New York City

March 15, 2006

Official date for *Bone China Tea*

May 4, 2006

6th Annual *Fine Wines Strong Bones* wine tasting and auction event in Washington, DC

July 20-22, 2006

OI Foundation's 15th Biennial National Conference on OI in Omaha, NE

For more information, contact development@oif.org or call 1-800-981-2663.

BRIEFLY:

15th Biennial National Conference on OI Scholarships available

The OI Foundation has obtained funding through grants, special events and individual contributions for a limited number of scholarships to the 15th Biennial National Conference on OI. Application information is available on www.oif.org or by calling (800) 981-2663. The deadline for applying is April 28, 2006.

All those wishing to attend conference but are unable to due to financial limitations are encouraged to apply.

If you would like to help others attend conference, visit the conference pages on www.oif.org to make a donation to the scholarship fund.



COCHLEAR IMPLANTS

A cochlear implant won't cure deafness, but it can offer significant improvement.

About 50% of people who have OI experience OI-related hearing loss during their lifetime. In some people it can progress to a profound loss or almost total deafness. Hearing aids are the first treatment. Stapedectomy surgery will benefit some people with OI. In recent years, because of improvements in technology and surgical techniques, cochlear implants have become available to people with OI-related hearing loss.

What is a cochlear implant?

The cochlea is an important part of your hearing equipment. It is the major organ of the inner ear. It is often described as looking like a snail. A cochlear implant is a sophisticated device that combines digital technology and information processing. The system consists of two parts: a tiny electrode that is surgically implanted inside the ear and threaded into the cochlea, plus an external part that combines a microphone, speech processor, and power source. A cochlear implant won't cure deafness, but it can offer a significant improvement.

How does it help a person hear?

Our ability to hear depends on two factors:

- the mechanical translation of sound waves into movement within the middle ear, and
- the translation of that motion into a nerve transmission to the brain.

In normal hearing, sound is collected by the outer ear and sent into the middle ear. Here the sound waves make the eardrum vibrate. The vibrations go through three tiny bones including the stapes to reach the inner ear. Next the sound waves are transported to the cochlea by the fluid of the inner ear. Inside the cochlea, sound wave vibrations are converted to electrical impulses by tiny hair like cells. The electrical impulses are sent to the brain through the auditory nerve. The brain interprets this information and recognizes specific sounds. All of this happens much quicker than it takes to explain.

The cochlear implant bypasses the middle ear, and substitutes for the defective inner ear. Sound is captured by the speech processor and coded so it can be sent into the inner ear as electrical signals. These signals are picked up by the auditory nerve and sent to the brain for interpretation.

Who is a candidate for this type of surgery?

Adults with severe to profound sensorineural hearing loss in both ears are candidates for a cochlear implant. Other requirements include:

- A working auditory nerve
- Intact cochlea
- No longer benefiting from hearing aids
- Score of less than 50% of words in sentences on a speech recognition test such as the Hearing in Noise Test
- Generally healthy enough to be able to handle a 2-3 hour surgery. Adults with cardiac or respiratory problems may not be able to tolerate the surgery.

Continued on next page

Reprints of this article can be downloaded from www.oif.org.

How can I find out if this treatment would work for me?

The process for getting a cochlear implant involves a consultation with an otolaryngologist, a number of tests including a CT scan, a psychological evaluation, and a series of informational and counseling appointments.

Are there risks that a person with OI should know about?

There are several possible side effects, but risks are relatively minimal. One reported side effect is facial nerve injury. This occurs when the facial nerve, which runs near the inner ear, is stimulated by the implant and causes twitching. This does not damage the nerve and long term problems do not usually result. This injury occurs in about 1 percent of patients, and facial nerve monitoring is now done during the surgery to minimize this risk. It is possible that people with OI might be more at risk than others for facial nerve injury because OI bone is not as solid or dense as bone in other people. This may allow the electrical signals from the device to travel a little more easily through the bone. Stimulation of the facial nerve can be corrected by adjusting the electrodes.

Dizziness or a sense of imbalance can occur after cochlear implant surgery, but it is usually temporary.

A small risk of meningitis has been reported. This can be prevented with a vaccination before surgery.

It has been discovered that the cochlea is misshapen in some people with OI. This makes implantation of the electrodes more difficult and may lengthen time in surgery.

Will my hearing return to normal after an implant?


Hearing with a cochlear implant is variable. It requires a period of training and adjustment after the surgery. It takes time, training and commitment to learn how to listen through the device. After the surgery there is a required series of follow-up care appointments so the implant can be activated. Hearing does not return to “normal,” but many people adapt well and can even return to talking on the telephone.

Is a cochlear implant expensive?

Newspaper reports indicate that total cost is around \$40,000 (this includes all evaluation tests, out patient surgery, the device itself, and follow-up appointments.) Many insurance companies cover all or most of the cost. Medicare also covers cochlear implants in some situations.

Where can I get more information?

- American Academy of Otolaryngology
www.entnet.org
- Hearing Loss Association of America
(formerly Self-Help for Hard of Hearing or SHHH)
www.hearingloss.org
- The Listening Center at Johns Hopkins Medical Center
601 North Caroline Street
Baltimore, MD 21287-6214
410-955-6554

This information was prepared with the assistance of David Vernick, M.D., Chief – Otolaryngology, Beth Israel Deaconess Hospital, Boston, MA, a member of the OI Foundation Medical Advisory Council. 

Learn more about this, and other health issues, at the 15th Biennial National Conference on OI

INFO TO HELP YOU MANAGE YOUR HEALTH

Info On Demand available for you

The OI Foundation information and resource staff responds to more than 500 inquiries each month from the OI Community. Every question, whether it's received by mail, phone or email, gets an individual response with *medically verified information*. There is simply no better place to have your questions about OI answered.

Each quarter, we select one question relevant to the entire OI community and print a full response in *Breakthrough* as our Q&A.

Each month, we select either the most frequently asked question, or a question on a topic that is “timely” or “seasonal,” and answer it in our monthly email newsletter. (Register online at www.oif.org to receive the email newsletter.)

No question is too large or too small... we're here to help you. Please call (800) 981-2663, write to bonelink@oif.org, or write to the address on page two if you have ANY questions about OI.

INFO TO HELP YOU MANAGE YOUR HEALTH

After successful cochlear implant surgery

“I feel like I have come alive again!”

Cathy Fritz, a long-time supporter and volunteer for the OI Foundation, has been slowly losing her hearing throughout her adult years. As of last November, she had gone completely deaf.

She and her husband, Dave Norwood, who also has OI, were both at the point where their hearing loss was severely affecting their ability to communicate with each other and function in their daily lives. They made the decision to face the loss head on and do something about it together.

Their first step was joining a local support group for deaf and hard of hearing people.

“Our world was slipping away,” Cathy explained. “Loss of hearing means a loss of social life.”

They hoped to learn better coping skills, and to connect to others who would understand and help them overcome their hearing loss. What they discovered was a surgical procedure that changed their lives.

“At the first meeting, someone mentioned the cochlear implant,” Cathy said. “Dave and I immediately started looking into it.”

After numerous consultations with their regular doctors and with Dr. Peter Roland, the surgeon at Southwest Medical Center in Dallas, TX, who would conduct the surgery, they both decided to have the implant.

“It wasn’t an easy decision,” Cathy admitted. “My first fear was that it wouldn’t work, my second, that they wouldn’t be able to do it because of our OI, and my third was just a fear of being in a hospital environment again.”

Since results with the implant vary, there would be no guarantee that the implant would work. Their medical team, however, did everything they could to resolve her other fears.

“The tests they took were *extensive*,” Cathy said, “xrays, CAT scans and MRIs were done so the doctor had everything to the smallest detail.”

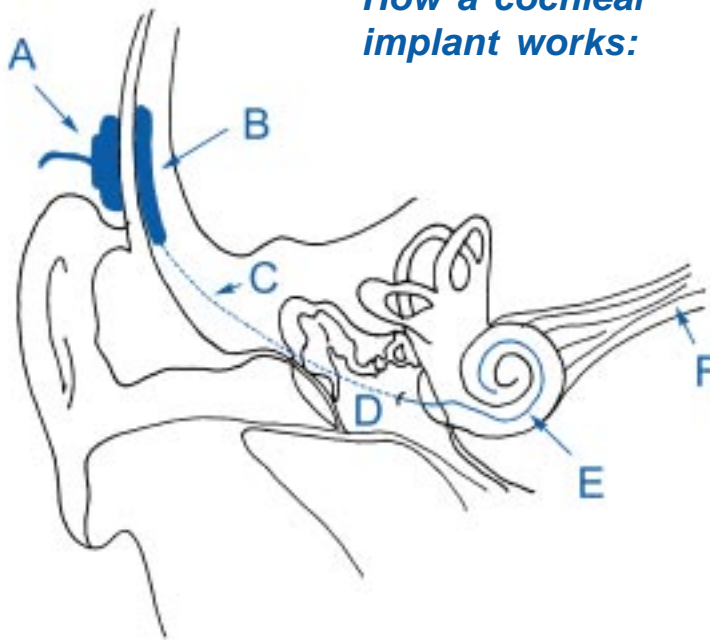
“Dr. Roland said our skulls are not proportioned like most people’s, and he did all the extra tests to be sure where the implant would sit before he began the surgery.”

To put her fears to rest about being in a hospital environment, the doctor allowed Dave into the operating theater, and even let him sit on the edge of the bed to hold her hand as the surgery was conducted.

“They listened to every detail about my OI,” Cathy explained. “They propped me up on pillows since I can’t lay flat, took special care in handling me. I’ve spent enough time in hospitals to know that I need to explain to them the best way to handle me!”

Continued on next page

How a cochlear implant works:



- 1.) Sound is picked up by a microphone and converted to an electronic signal by a processor. The microphone and processor can be worn on the ear or elsewhere on the body.
- 2.) A transmitter (A) takes the signal from the processor and sends it to a receiver implanted under the skin behind the ear (B).
- 3.) The electronic signal is sent via wire (C) to the inner ear (D), where an electrode system directly stimulates the cochlea (E), bypassing the damaged parts of the inner ear.
- 4.) The cochlea then relays the signals to the auditory nerve (F), which sends them to the brain to be interpreted as sound.

Traveling with oxygen requires planning

In July of 2005, the Federal Aviation Administration (FAA) issued a final regulation allowing the use of two specific portable oxygen concentrators—by AirSep Corp. and Inogen, Inc.—aboard airplanes.


Shortly afterwards, the U.S. Department of Transportation (DOT) suggested a regulation that would require airlines to provide free in-flight medical oxygen to anyone who needs it.

For the time being, the FAA regulation will only relieve problems for a small number of oxygen users, as the two devices range from \$3,500 to \$5,000. Unless or until the DOT regulation comes into effect, most flyers will need to comply with the individual airline's policies and prohibitions.

Oxygen is classified as a hazardous material, and only airlines that have chosen to pursue FAA certification can provide it on their flights. Some airlines don't offer supplemental oxygen at all, and most regional carriers (using turboprop or propeller aircraft) do not allow oxygen on their flights.

Depending on the airline, you must make arrangements up to seven days in advance, and fees range from \$64 to \$1,500. All U.S. airlines require you to provide a doctor's letter, and the FAA also requires a physician's statement.

You cannot bring your own oxygen on board, and requirements vary greatly between carriers. Check with your airline well in advance of your travel date.

You should also make arrangements with a local company at your destination to have oxygen available during your stay. Most vendors will deliver directly to the airport, and pick up their equipment at the airport as you travel home. 

Editor's Note: The Inogen oxygen system can be rented at www.oxygentogo.com.

ALIVE AGAIN... *Continued from previous page*

It wasn't more than a few minutes after the device was activated that Cathy's initial fears were put to rest, as well.

"I could hear right away!" Cathy exclaimed. "Sounds, at first, and people sounded like Mickey Mouse, but I was hearing!"

There was a period of adjustment to the device. "People hear with their brains, not their ears," Cathy explained. "I needed to learn how to interpret the sounds again, and had to teach the brain how to hear all over again in some things."

"People who haven't heard for a long time might need speech therapy and hearing therapy to help them get used to the implant, but all I needed was a couple follow-up appointments to check the surgery site!"

Her processor sits on her ear, like a hearing aid, but without the earpiece. It comes with two processors and attachments to assist her when using a phone, and there are multiple settings on the device.


"I still have trouble in crowded rooms, or really noisy places," Cathy admitted, "but I can adjust the microphone and the volume, and I can hear *almost* everything."

There's a small piece that is attached to her head with a magnet, so she can not go through metal detectors or have hand-held detectors near her head. She's also still legally deaf, since the implant has to be taken off at night.

Like all surgical procedures, there are risks, and she wasn't prepared for the pain following the surgery. The doctors have to cut a small groove into the side of the skull for the implant, and according to Cathy the pain feels like "someone has hit you on the side of the head with a baseball bat... for a couple days!"

"But if you can stand the pain, and you're eligible for the surgery, it's worth it," she said without hesitation.

Cathy now has 90% of her hearing back. Dave's surgery was equally successful. They couldn't be happier with their decision to have the implants.

"I can use the phone again... even a cell phone!," Cathy said. "I feel like I have come alive again!" 

INFO TO HELP YOU MANAGE YOUR HEALTH

For more information:

For tips on traveling with oxygen by air or train, and other helpful information for the traveler with a disability, visit www.access-able.com/tips

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

In Omaha:

For a list of medical equipment rental outlets in Omaha, visit <http://www.thecityofomaha.com/hospitalequipment/index.html> or <http://www.mobilitysales.com/rental.shtml>

INFO TO HELP YOU MANAGE YOUR HEALTH

40% of children
without OI
treated in April
for fractures at a
Canadian hospital
had low levels of
Vitamin D

Developing News:

Vitamin D levels may drop during winter months, increasing the risk of fractures in the spring.

The study:

- A recent study in Canada looked at Vitamin D levels in children who were treated for fractures at a hospital emergency room during the month of April. None of these children had OI. 40% of these children had low levels of Vitamin D.
- This suggests that low levels of Vitamin D may contribute to the risk of a fracture.
- Of particular interest is that this study matched Vitamin D levels to the child's weight, not age.

What we know:

- Maintaining proper levels of Vitamin D is essential for healthy bones. It is needed for calcium absorption.
- Sunlight and food are the main sources of Vitamin D.
- Too much Vitamin D is just as unhealthy as too little Vitamin D.
- Current USDA Vitamin D recommendations are based on age, not weight, and are difficult to apply to people with OI due to their shorter stature.
- Recent studies suggest that standard recommendations for Vitamin D levels used around the world may be too low. Because Vitamin D plays an important role in bone health and immune system function, it is being intensely studied at this time.

What this means for people with OI:

- This study presents preliminary information about people without OI. It suggests that increased indoor time and less time spent on outdoor activities during the winter months may decrease the amount of Vitamin D in the body. Lower Vitamin D levels contribute to a decrease in bone mineral content and may weaken bones.
- Adequate calcium and Vitamin D, along with exercise, are important for developing and maintaining bone density.
- In response to this study, Dr. Jay Shapiro and his nutritionist, Eileen McMahon, of the Kennedy Krieger Institute, Baltimore, MD, are working with the senior investigator of the Canadian study, Dr. Adrian Jones, Department of Pediatric Gastroenterology at the University of Alberta in Edmonton. They are trying to apply this information to children with OI. In the future, they hope to have a set of guidelines for Vitamin D for children who have OI, based on weight.


What you can do now:

- Talk to your primary care physician and/or a nutrition specialist about diet, exercise and Vitamin D.

Locating the study:

Are National Vitamin D Guidelines Sufficient to Maintain Adequate Blood Levels in Children? By D. Roth, P. Martz, R. Yeo, C. Prosser, M. Bell and A. Jones. Canadian Journal of Public Health, 2005 November-December; 96 (6) pages 443-449.

Caveat:

This is based on preliminary information. When Dr. Shapiro's investigation is ready for publication the information will be brought to the attention of the OI community through *Breakthrough*, the OI Foundation website, and e-newsletters. 

Fine Wines, Strong Bones

DC wine tasting & auction growing into gala affair

by Stuart Tart
OI Fdn. Assoc. Dir. of Development

Fine Wines, Strong Bones started from a simple question.

In 2000, Jamie Kendall and other area members of the OI community wondered how they could raise money for the OI Foundation and have a good time.

The question became, "What kind of event could they create?"

Jamie decided, "I know how to throw a party, and I know how to drink wine."

From that idea, *Fine Wines, Strong Bones* was born. During the planning for the initial event in 2001, Jamie served as event chair, Tracy Mulroy chaired the auction, and volunteers Kyle Mulroy, Roger & Gayle Bache, Deb Jacobs and J.P. & Mary Richard served on the planning committee.

For five years, *Fine Wines, Strong Bones* has been a wine tasting and silent auction affair, with a few hors d'oeuvres for guests to enjoy and performances donated by local band, Seisuin. After expenses, this event has raised between \$25,000 - \$35,000 each year for the Foundation's biennial National Conference, helping to keep registration costs low so that more families can attend. More than 230 people came out for the wine tasting event last May.

"What makes *Fine Wines, Strong Bones* special is that people come who care about osteogenesis imperfecta," Jamie explained. "They come year after year, and they are very, very generous."

In 2006, this event will grow into an even bigger affair, as the volunteer committee and the OI Foundation really get this party started! The organizers have set out to add new attractions, increase attendance by at least 50%, and double the funds raised. Beginning this year, proceeds from *Fine Wines, Strong Bones* will be split between the National Conference and the Foundation's support services for people with OI and their families.

Fine Wines, Strong Bones will be held on Thursday, May 4, from 6:30 – 9 p.m., at the Galleria at Lafayette Centre in Washington, DC. The event has been moved to this new location to accommodate a larger crowd; the Galleria offers an enchanting 50-foot sky-lit atrium complete with a dramatic split staircase, balconies, exquisite marble floors, beautiful glass and wood finishes, lush greenery and specialty lighting.

The Foundation is inviting some of the best area restaurants to participate in *Sample the City*. This will allow our guests to sample the cuisine from a variety of local dining establishments and perhaps discover a new favorite place.

For the first time, *Unbreakable Spirit* awards will be presented to businesses, organizations and community leaders who have made a significant contribution towards improving the lives of people with OI or the disability community in general. Recipients will be selected each year in some or all of four different categories: Public Awareness, Government Service, Research, and Individual/Personal Achievement.

Most exciting of all, world-class artist Patti Warashina has generously

FOUNDATION EVENTS

This annual event has raised more than \$125,000 over five years... helping to keep conference registration fees at a minimum.



Guests rush to place last minute bids at the 2004 *Fine Wines, Strong Bones*.

Continued on page 21

Artist honors daughter's memory

PERSONAL STORIES

Gretchen Guzak was born with moderate to severe OI in August, 1962. The doctor immediately whisked the fragile baby with a broken humerus out of the delivery room. She was two and one-half days old before her mother, Karen Guzak, was allowed to hold her.

"The first time I held her," Karen recalled, "she looked right at me and smiled. I had this connection-- I just knew that there was a great soul in this little baby."

Gretchen didn't cry at birth, in spite of her fractures. "We all knew right away that she was a special person," Karen said.

Throughout the years, Gretchen continued to exhibit qualities that would make any parent proud.

"I can't begin to tell you the things I learned from her, the gratitude I have," her mother explained. "The courage she exhibited, the life energy, intelligence, and sense of humor..."

Gretchen was always focused on sports, in spite of her small size and fragile body. In high school she hung out with the various sports teams, and in college she responded to an ad for "short, loud people" to act as coxswains. She participated in the rowing team at Seattle Pacific University for a short time, until she discovered that the coxswain is traditionally thrown in the water if the team wins the race.

While at college, she became an advocate for people with disabilities, lobbying for more accessible parking on campus. The president of the college was so impressed with her determination and spirit, he gave up his personal space until more accessible parking could be created.

Upon graduation, she started her own sports promotion company, blending her love of sports with her humor and creativity. In one stunt, she bid on a one-hour lesson with Jack Sikma at a charity auction.

The 3'7" sports promoter had 6'11" tall Sikma help her perfect her "slam dunk" at a mini-basketball clinic she was promoting for inner city kids; his presence brought the media, and success to the event.

According to Rick Meeder, a Seattle-based sportscaster, Gretchen "had some tough things to overcome from the very beginning, but she was *never* discouraged."

It's that spirit that Karen remembers; and the great soul that she recognized instantly that she wants to honor.

When the OI Foundation was seeking a way to increase interest and revenue through its annual *Fine Wines, Strong Bones* fundraiser, Karen was quick to involve her friends in the art community in the "fragile baby" art auction being conducted as part of the evening's activities.

"Art is such a powerful means of communication," Karen explained. "I think this is a great idea, and I want to help in the continuing success of the OI Foundation."


Karen found an artist to create & donate "blank" ceramic babies, and assisted the Foundation in finding nationally-recognized artists to decorate and sign the babies for auction.

"My participation is a tribute to Gretchen and to the impact she had on our family, on her friends, on everyone she met," Karen explained.

Gretchen passed away December 11, 1991, after a battle with a number of health complications, including kidney failure and sleep apnea.

It is a measure of the impact she had on those around her that her family and friends are continuing to support the OI Foundation and the OI community.

"I'm excited by what I hear and read about OI research," Karen explained, "and I'm always impressed by the strength and determination of the OI community."

"If there is some way that I can lighten the load-- even the slightest amount-- for someone else, it would be just wonderful," she said. 



Gretchen Guzak with retired professional basketball player Jack Sikma.

SCPICA exceeds \$1 million in donations through tournaments

by Stuart Tart
OI Fdn. Assoc. Dir. of Development

The 2005 annual Southern California Petroleum Industry Charity Association (SCPICA) golf tournament in California raised an estimated \$64,000 for OI research this year.


During the past twenty years, organizers of the SCPICA Golf & Tennis Tournament have donated more than \$1,150,000 to the OI Foundation. The 2005 event was held November 4 at the Industry Hills Golf & Tennis Club in City of Industry, CA.

"The golf tournament was a huge success, and we had a great time," OI mom Michelle Hofhine wrote. She is part of a group of young people with OI and their parents—including Michelle and her daughter, Nicole; Heidi Glauser and her adult son, Trey; Mary Parke and her adult son Rob; and Stephanie Dysthe, among others—who have teamed up with leaders of the SCPICA to make this event such a success year after year.

In addition to the golf and tennis tournaments, this year's event featured pre-tournament contests, an on-course lunch, silent and live auctions, and an awards dinner for golfers and local OI families. Roan McRae of Del Mar Analytical served as the event's general chairperson this year.

"I know it was successful," reported SCPICA treasurer and Shell Oil retiree Frank Fossati. "No one got a hole-in-one. But, many had a great time with friends, and at the same time raised money for the OI Foundation."

In recognition of their roles in forming the partnership between SCPICA and the OI Foundation twenty years ago, Frank Fossati, Mary Parke and Rob Parke each received President's Awards from the OI Foundation at the dinner.

The OI Foundation thanks all of the volunteers from both the petroleum industry and the OI community who have made this partnership so special during the past 20 years. Your work has been critical to the advancement of OI research, and we can truthfully say, "You've made a major impact on research progress." 



Mary Parke and her son, Rob, have participated in the SCPICA event since its inception in 1985.


New network groups forming!

Last quarter the OI Foundation expanded its national volunteer program by introducing Local Area Network Groups. The purpose of the groups is to enable people living with OI to meet each other and get connected in their own communities. The new format allows people to support each other, gives parents and children the opportunity to learn from OI adults, and creates a caring community.

In the past three months, more than forty volunteers have expressed interest in starting a network group in their community! New network groups are already formed or forming in Northwest Florida/Lower Alabama, Arizona, Pittsburgh and Iowa. Others are in the planning stages throughout the country.

To view a complete list of network and support groups, click on the "Support Groups" button on the top menu on www.oif.org.

If you register on the website and check "accept e-mail" in the registration process, you'll receive notification by email if a group is forming in your area, and you will receive e-mail announcements prior to each group meeting.

For more information, contact Marie Maffey by e-mail at mmaffey@oif.org, bonelink@oif.org, or by calling (800) 981-2663. 

COMMUNITY EVENTS

Visit
[www.oif.org/
supportgroups](http://www.oif.org/supportgroups)
to see if there's a
group forming
near you!

15TH BIENNIAL NATIONAL CONFERENCE ON OI

Although the cost
to the OI Fdn.
is more than
\$400 per person,
registration fees
are only
\$145 for adults,
\$110 for children.

from Omaha Children's hospital, Drs. Peter Byers, Holly Cintas, Lynn Gerber, Francis Glorieux, Joan Marini, David Rowe, Peter Smith, Michael Whyte, and other members of the OI Foundation's Medical Advisory Council are just a few of the world-renowned OI specialists scheduled to attend.

While this is the premiere opportunity to learn about OI of all types, from infancy to the adult years, there is also ample time for families and new and old friends to simply relax, socialize, and build relationships with peers that will offer years of support and camaraderie.

The popular Teen Room returns with an expanded program of activities and speakers just for teens. Topics will include Dating, Learning to Drive, Coping with being Different, Sports, Makeup for Sensitive Skin, and an opportunity for Teens and their brothers or sisters to ask a panel of doctors their own questions about OI. The Game Night for pre-teens features an evening of fun, friendship and prizes.


Thursday morning, July 20, will feature an expanded Wellness Fair. Representatives from a wide range of health and service groups will be on hand with displays and short programs. Service Dogs, Home First Aid, Social Security, Advocacy, Wheel Chairs and Hearing Assistance Devices are just a few of the exhibitors. Along with the Fair, and continuing all through conference, will be exhibits showcasing products for people with OI.

The world famous Henry Doorly Zoo will be open Friday evening, July 21, only to people attending the 15th National Conference on OI.

Omaha Children's Hospital will provide around-the-clock first aid, with nurses familiar with OI, at the hotel throughout the conference. They are also sponsoring a very important new event at this conference: a Continuing Medical Education program for medical professionals (see next page).

Although the cost to the OI Foundation to host this conference is more than \$400 per attendee, through gifts, grants and fundraising efforts such as *Fine Wines*, *Strong Bones*, we have been able to keep your registration fee at a minimum. The cost to attend three days of meetings, demonstrations, exhibits, peer-to-peer group sessions, receptions and the awards dinner and dance party is only \$145 per adult and \$110 per child (12 months to 18 years old). If you register before May 15, you'll save an additional \$30 per person!

The Hilton Omaha is offering a special group rate of \$114 per night, single and double occupancy. There is a \$10 surcharge (per person, per night) for triple and quadruple occupancy rooms. You must make your room reservation by June 30 to qualify for this special rate. Call 1-800-HILTONS and give the operator the Foundation's group code OST to receive the reduced rate, or make your reservations online through the OI Foundation's conference pages on www.oif.org.

Schedules, additional information and scholarship applications are available on the Foundation's website, and registration forms are included in this issue of *Breakthrough*. 



Visit the conference pages on www.oif.org!

Come early to the conference for Medical Consultations


On Wednesday, July 19, a limited number of individual appointments will be available with OI specialists from Omaha and across the country. They will be able to provide consultation on OI questions related to a single medical specialty. Each person will be able to make appointments with two different specialists.

At this time we expect to have experts in foot/ankle issues, women's health, genetics, neurology and physical therapy. Several other specialties may be added in the

next few weeks.

Children's Hospital will also offer a number of free hearing screening sessions with their audiologist, Dr. Charles Bee, at the hospital.

For more information, visit the OI Foundation web site or contact Mary Beth Huber at the OI Foundation office (800-981-2663).

Appointments will be allocated on a first-come, first-served basis beginning April 20 at 10 a.m. (EST). 

Conference program at-a-glance:

(The program is subject to change. Updates will be posted on the OI Foundation web site and printed in the next issue of *Breakthrough*.)

Wednesday

Medical Consultations (by appointment)
Registration Opens
Welcome Reception

Thursday: Welcome Day

Networking for Network & Support Group Leaders
Wellness Fair
Orientation to Conference for First Time Attendees
OI The Basics
Opening Session
President's Reception
Peer-To-Peer Evening Sessions
Young Adults: Dinner Out

Friday: Medical Information Day

Morning Seminars:
Managing OI: Information for Adults
Managing OI: Information for Parents
Afternoon Workshops:
Special Needs of Type I OI
Adult sessions:
Osteoporosis, Hearing, Knees & Hips, Women & Pregnancy, Vitamin D
Parent sessions:
Nutrition, Dental, Hearing, Infant Care, Teens, Neurological

Saturday: Living Successfully with OI

Adult sessions:
Adaptive Equipment, Pain Management, Personal Exercise Programs
Parent sessions:
Children/Surgery/Pain, Healthy Families, Writing the IEP, Medical Insurance, Financial Planning/Trusts, Adaptive Equipment
Sessions for All:
Home Adaptation, Spine and Scoliosis, Wheelchairs: Selecting and Financing, The Internet & Medical Information
Closing Session:
OI Foundation Annual Meeting and Special Guest Speaker
Awards Dinner
Dance Party

15TH BIENNIAL NATIONAL CONFERENCE ON OI

Expanded: Ask The Dr.

Expanded ask the Doctor sessions will be offered at different times throughout the weekend. The following sessions are confirmed:

- Focus on Type I OI
- Questions from Parents
- Questions from Adults
- Questions from Teens
- Questions from Siblings

NEW!

NEW!

BYOD: Bring Your Own Doctor for CMEs at conference

Invite your favorite doctor, nurse, or physical/occupational therapist to join you at the OI Foundation's 15th National Conference on OI.

On Friday, July 21, Omaha Children's Hospital and the OI Foundation are sponsoring a Continuing Medical Education course specifically for physicians and other health care professionals. "Managing Osteogenesis Imperfecta in Children and Adults" will include information on genetics, orthopedics and medical management. Participating medical professionals will earn CME credits through the University of Nebraska.

The afternoon session will feature a series of case study question-and-answer opportunities. Please encourage your doctors, nurses, physical and occupational therapists to attend. These sessions will assist them in keeping up-to-date on the latest medical technologies and therapies, and provide them the opportunity to interact directly with other medical professionals treating members of the OI community.

Through a generous sponsorship from Children's Hospital, the continuing medical education program will be **free of charge** to any medical professional who accompanies an OI family to conference, and only \$15 to other members of the medical community wishing to attend.

More information will be posted online at www.oif.org/06conf_CME as it becomes available. 

15TH BIENNIAL NATIONAL CONFERENCE ON OI

Travel Links

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

www.accessfordisabled.com has a variety of resources, links, and tips for the traveler with a disability.

Visit www.amtrak.com if you plan to travel by train.

Visit www.greyhound.com for information on accessible bus service.

For rental vans, try www.wheelerz.com or www.wheelchairgetaways.com for lists of available rental companies.

Wheelchair rentals are available at www.scootaround.com, or through many Omaha-based companies.


Visit <http://www.thecityofomaha.com/hospitalequipment/index.html> or <http://www.mobilitysales.com/rental.shtml> for a list of medical equipment suppliers in Omaha.

This information is provided as a service to our community, and does not constitute an endorsement of the services or products by the OI Foundation.

Registration & namebadges required

Childcare available for registered children

Childcare will be available for registered children, ages 1 through 12, during all session hours. "Camp OI" will include age-appropriate activities and qualified childcare personnel, specifically trained to attend to the special needs of children with OI, through ACCENT on Children's Arrangements, Inc. ACCENT provided childcare services for the 2002 and 2004 conferences.

Children's registration is \$110, or \$80 if you register before April 28. Children must be registered conference attendees, and must also complete ACCENT's childcare registration form, to participate in the childcare sessions. 

Namebadges must be displayed at all events

The OI Foundation will require all registered attendees to display their namebadge at all times when participating in scheduled events at the 15th Biennial National Conference on OI.

The Hilton Omaha reserves the right to restrict access to the hotel and convention areas to registered guests, for security reasons. Your name badge identifies you as an authorized guest and will ensure your ability to enter the hotel property without delay.

By requiring the name badge to be displayed at all functions, hotel and Foundation staff members can also ensure that only registered attendees have access to the continental breakfasts, break beverages, receptions and awards dinner. This will prevent other hotel and conference center guests from helping themselves to breaks and adding to the Foundation's catering bills during the weekend.


Name badges will be given to all registered guests upon arrival, including children and teens. They may be pinned or hung from mobility devices or strollers or worn, but must be displayed at all times.

For more information, contact the Associate Director of Events, Erika Ruebensaal, at eruebensaal@oif.org or by calling (800) 981-2663.

Information is also available online at www.oif.org. 

Community members offer travel tips

Here are some tips provided by other members of the OI community to prevent mishaps or unnecessary inconvenience when travelling with a wheelchair:

- Arrive early and always check the chair or scooter at the boarding gate. Request that it be delivered to you at the gate, not at the baggage claim area.
- If possible, use gel- or foam-filled batteries in your power wheelchair or scooter, and carry the paperwork about the batteries with you in case the airline has any questions.
- Standard acid-filled batteries will be removed by ground crews and packed in special containers for transport, so if you must use them, be sure to tape instructions on removal and installation in plain view on the chair or scooter.
- If you use a fold up chair, request that it be stored in the on-board closet. There is usually only room for one wheelchair, so make your request early.
- If you need assistance transferring to a plane seat, tell the staff how to help lift and/or move you. You're always safer assuming that they do not know what works for you.
- Before landing, make sure that you remind an attendant that you will need your chair waiting for you at the gate. They can radio ahead to make arrangements.
- Request an aisle seat, near the front of the plane, since most aisles in coach are too narrow to accommodate chairs. Some airlines offer aisle chairs, which are narrower and provide easier access, but you need to call in advance and request it be placed on board. 

OI REGISTRY *Continued from page 1*

5. Notification of the opening of the Linked Clinical Research Center near you.

As the OI Registry grows, the valuable data it contains will help researchers learn more about OI. Because clinical and basic science research in OI is moving at a rapid pace, patient participation in research has never been more critical than it is today. Since OI is a rare disease, the ability to contact a large number of people with OI increases the likelihood of research in OI, and the Registry's desirability as a study tool. Your participation aids us in our common goal to find treatments and a cure for OI.


The OI Registry staff will notify you about approved research studies. As an OI Registry participant, you will not be obligated to participate in any study. It is important to realize every research effort is not appropriate for all participants. Some are excluded by distance, medical condition, or economics. However, everyone can make a contribution, since completing the OI Registry questionnaire provides valuable demographic and medical information. Research studies promoted through the OI Registry will come in many forms, with different levels of commitment. Individual consent forms will accompany each research invitation, allowing you to choose whether or not to participate. Some studies are as easy as filling out a questionnaire in the comfort of your own home. Others may require travel to a study site to participate in clinical trials for new medicines and treatments.

The three major goals of the Linked Clinical Research Centers are:

- Define the natural history of OI from birth to old age so doctors will be able to identify and describe the effects of OI over the lifespan;
- Recruit families for participation in natural history and other studies through the Centers; and
- Integrate research to find treatments and a cure for OI into routine care at the Centers.

The OI Registry is key to meeting these goals. The result will be well-trained clinicians and researchers who will be able to design a fact-based treatment plan for anyone with OI, improved research opportunities, and speedier research to find treatments and a cure.

The Osteogenesis Imperfecta Foundation and the Kennedy Krieger Institute have joined resources in a close collaboration to develop and operate this national OI Registry. This effort has received substantial funding from the Charitable and Research Foundation in Gaithersburg, MD. The OI Registry will initially be housed at the Kennedy Krieger Institute in Baltimore, MD.


Watch for updates about this exciting project in future issues of *Breakthrough*. 

FINE WINES *Continued from page 15*

donated 20 ceramic "Fragile Babies," which will each be decorated by a different artist friend of the OI Foundation and sold during our auction. Ms. Warashina's artwork has been exhibited at museums in New York City, Los Angeles, Seattle, Japan, South Korea and Australia. Her work is featured in museum collections in the U.S. and abroad, including the Renwick Gallery, the Smithsonian's American Art Museum and the American Craft Museum in New York.

Fine Wines, Strong Bones is an event you do not want to miss.

"People who come to this event feel like they are making a difference," Jamie said. "When you give to a rare disease like OI, you feel that more, because we don't have a large base of support to draw from like the larger nonprofits."

For tickets or more information, contact the Foundation at development@oif.org or 1-800-981-2663. 

INFO TO HELP YOU MANAGE YOUR HEALTH

Get involved!

Join the OI Registry by visiting www.osteogenesisimperfecta.org/oif or by visiting the Foundation's website at www.oif.org.

If you don't have Internet access, or have questions as you register, OI Registry staff based at the OI Clinic at the Kennedy-Krieger Institute will be available to assist you. Call (443) 923-2703 to speak to someone at the registry office.

Representatives from the registry office will also be available at the 15th National Conference on OI in Omaha, NE, to assist you in filling out the registry information.

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Special thanks to the

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for their donation of \$1,500 to offset the costs of mailing this issue of Breakthrough to our subscribers.

Sponsorship and exhibitor opportunities

There are a number of sponsorship opportunities and booth spaces available for the 15th Biennial National Conference on OI, to be held July 20-22, 2006, in Omaha, Nebraska. If your company or organization would like to take part in this unique opportunity to support families affected by OI, or would like the opportunity to promote your product or service, please contact Associate Director of Development Stuart Tart by email at start@oif.org or by calling (800) 981-2663.

**Conference
Info!**

Information on the 15th Biennial National Conference on OI, and travel tips to help you get there, can be found on:

Pages 1,9,13,18-20

WHAT'S INSIDE

President's Message	3
What can "brown" do?	4
Community Events	5,9,17
Volunteers	6-7
National Events	8
Q&A: Cochlear Implants	10-11
Successful Implant Surgery	12
Travel with Oxygen	13
Vitamin D	14
Foundation Events	15
Personal Stories	16
Honorariums	22
Memorials	23
Conf. Registration	Insert

Breakthrough is distributed quarterly, free of charge, to members of the OI community: people with OI and their friends, family, coworkers, and medical service providers. Please contact us to subscribe (page 2).

For more information about the OI Foundation, please visit www.oif.org.



The Osteogenesis Imperfecta Foundation

804 West Diamond Avenue, Suite 210
Gaithersburg, MD 20878