

New surgical rod to be available in the U.S. this year

By **Mary Beth Huber**
Information & Resource Director

Children and adults with OI and their medical teams now have an additional option when rodding surgery is required.

In early February, the Food and Drug Administration (FDA) approved a new intramedullary rod specifically for the surgical treatment of bone deformities and fractures in patients with osteogenesis imperfecta. It is approved for children 18 months or older and can be used in the femur, tibia or humerus.

The Fassier-Duval Telescopic Intramedullary System was developed by Dr. Francois Fassier, Head of Pediatric Orthopaedic Surgery at McGill University and Chief of Staff at the Montreal Shriners Hospital for Children, Canada, and his colleague Dr. Pierre Duval, orthopedic surgeon

at the Brome-Misissquoi-Perkins Hospital, Canada.

In a statement provided by Pega Medical, Dr. Fassier stated, "This nail will not cure the disease, but it may help the patients to live a bit better."

Compared to other surgical rods—or nails—currently in use, the Fassier-Duval System is designed to reduce some of the more common complications of rodding surgery. The rod features a unique screw-type anchor system.

During clinical trials it was reported that time in surgery was shorter, blood loss was less, complications were fewer and rehabilitation was quicker. Only 3 weeks of post-operative immobilization (rather than the customary 6 weeks) was required for most patients. This allowed the patient to receive rehabilitation on an accelerated schedule and return to normal activities

sooner, often with less pain.

According to reports from the developer, the Fassier-Duval rod's design causes less trauma to joints, bone and growth plates. It significantly reduces the risk of rod migration, making it more reliable over time, and allows for longer telescopic range, extending the time between surgeries in a growing child.

During late spring and summer, 2003, Pega Medical Inc., a Canadian bioengineering company, will begin manufacturing the device and make it available for sale to hospitals in the United States. Surgeons can obtain information about the rod and about training opportunities through their web site, www.pegamedical.com.

As surgeons are trained in the use of the Fassier-Duval System, it will become available to patients across the United States during the next year. 

SCPICA continues loyal support to OI

Charitable organization has been raising funds, awareness for more than 17 years

The song says "it never rains in California," but it poured on the day of the 28th annual Southern California Petroleum Industry Charity Association (SCPICA) Golf and Tennis Tournament. Although a few zealous golf fans were willing to play in the rain, Chairman John Aguilar and his hardworking committee were forced to make plans for their 2002 golf tournament not once, but twice! Two volunteer marathons to stuff "goodie bags" for the players, two trips to transport auction items, two additional mailings



Nicole Hoffman (l), Christina Nelson (c) and Rob Parke (r) were on hand to volunteer at the 17th SCPICA golf tournament to benefit the OI Foundation.

for confirmation and postponement announcements, and two attendance rosters to organize. Fortunately, the committee was able to put the event together twice in three short months.

The rescheduled tournament was

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FROM THE EDITOR

BREAKTHROUGH

The Newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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When the OI Foundation Board of Directors and staff began developing our three-year strategic plan, outreach and publicity efforts were high on the list of things to be included. We knew that to grow as an organization, and to increase the impact we might have on the lives of people affected with OI, we needed to focus more effort on creating a stronger public awareness of the disorder and the work of the Foundation.

While it's real easy to write "increase public awareness" into a business plan, the process of doing so may prove to be one of the most difficult tasks the Foundation has ever faced.

Before an organization can begin any outreach, marketing, or publicity efforts, it needs to spend some time and effort determining exactly what the message is—to both the general public and the OI community.

Being crystal clear about our message is essential to developing a marketing and publicity plan that reaches across all our audiences with a minimal impact on our limited resources. We know there are a number of ways the Foundation helps the OI Community—but crushing all the ways that we help the families and folks with OI into a few key concepts is actually pretty difficult.

And we have so many audiences. Type I Teens have different needs, and will respond to different messages, than Type III adults. Parents and single adults have different needs and wants from the Foundation. Medical professionals, researchers, or colleagues all have different demands. We want to be clever about developing a position that works across as many of these groups as possible to achieve the sorts of connections that we want.

We're after involving people—engaging them. The more different the groups are in our world, the more difficult that task is. So what was once a few lines in a strategic plan is becoming a large focus of energy. We've conducted a focus-group meeting, bringing together members of as many different audiences as we could, to help in that process, and the board of directors spent several hours on this issue during the March board meeting. We're in the middle of developing our "brand" – one simple, compelling message to use to reach out to our community and our world. Next we'll present the results of our work to the Board of Directors, membership, and OI community, and start turning the "branding" work into quality, focused PR and outreach efforts.

This won't affect our mission, which remains "...to improve the quality of life for people with OI through research to find treatments and a cure, education, awareness, and mutual support." It affects how we *communicate* that mission to you, and to the rest of the world. How effective that communication is will have a direct impact on how much more we might do in the future.

It's an exciting time for all of us—much more so than those few lines in our strategic plan would lead us to believe.



PRESIDENT'S MESSAGE



Bill Schmidt

Dear Friends,

As we dig our way out of one of the snowiest winters in recent memory, the Board of Directors and staff at the Foundation are preparing for the March 2003 Board of Director's meeting. I see images on television of the incredible perseverance of people coping with the unprecedented snow and ice, and I can't help but think of how symbolic it is of the efforts of the Board members, staff and dozens of volunteers, who have accomplished so much over the past three months.

An Accountability and Ethics Task Force was created by the Board at my request. Its mission is to identify ways in which the Foundation can make its governance, operations, finances and mission readily available and transparent to the entire OI community. The Task Force, chaired by First Vice President David Zenger, has been digging through reams of internal documents and considering "best practices" promulgated by the National Health Council and other non-profit organizations in order to make policy change recommendations to the Board at its March 2003 meeting. Some of their recommendations have already been put into place, including the availability of many of our financial documents on the Foundation web site. This is the first of many changes you'll see as the Task Force continues its important work.

Staff members, along with a group of volunteers, have tackled yet another daunting task: identifying and implementing a "brand" for the Foundation. A progress report will be presented to the Board in March, and the entire Board will participate in the process of identifying and implementing a brand identity for the Foundation. Trying to identify and express all the ways the Foundation serves people with OI and their families/caretakers in just a few sentences is a challenging task. Being crystal clear about the Foundation's message will help us spend our limited dollars, staff and volunteer time wisely and effectively.

It is the extreme diversity of our community that makes this task so difficult, because there are a multitude of ways the Foundation supports the community. Even identifying the types of OI just got more confusing. Two top researchers have now identified characteristics of two new types of OI, as explained in the Q&A (page 8).

The Foundation staff and a small group of volunteers are currently working on four major print resources. They are soliciting input from the community and digging through volumes of information, tips, letters, and personal stories to make these new resources as practical as possible (page 20). Resources include an exercise book, a guide to OI for nurses, a book for adults with OI, and a children's book and accompanying teachers' guide to help integrate young children with disabilities into mainstream classrooms.

I am most pleased to report to you that the members of the Board dug deep (and continue to) in their efforts to meet a \$100,000 matching fund challenge given by a most generous anonymous donor (page 10). Their efforts and imagination are an inspiration to the entire OI community. If fifteen people can accomplish so much, imagine what 50,000 can do!

And of course, the past quarter has been filled with activities, fundraisers, events and challenges involving our entire community. So sit down and relax with news of the triumphs, frustrations, and accomplishments of our incredible community.

My very best personal regards,

A handwritten signature in black ink that reads "Bill Schmidt". The signature is written in a cursive, slightly slanted style.

Bill Schmidt

President, OI Foundation Board of Directors

Events Support the OI Foundation

Allygator classic draws over 100 golfers

The Second Annual Allygator Classic golf tournament was held in Loveland, Ohio on September 23, 2002.

Rob and Janel Thompson created the event in honor of their daughter, Allison (Ally) to help support the OI Foundation's programs and research efforts.

Ally, an energetic 5 year-old, has Type I OI. When she was born, Ally had a broken collarbone, and she endured a long summer when she broke her arm three times. This year, over 100 golfers, sponsors and participants came together at the Oasis Golf Club to raise close to \$8,000. The day's activities included lunch sponsored by Skyline Chili, a silent auction, live raffle, and dinner provided by Outback Steakhouse.

Rob and Janel's family and friends ensured the event's success with their help and support. OI Foundation Board member Ken Finkel and his daughter Jessica were thrilled to attend and glean inspiration for an event they were planning. The Ayers family, joined by Kara Sheridan, and OI Foundation staff member Julianne Weiner were also in attendance.

Some of the people and companies who make this annual event possible include Joan Wood and Coldwell Banker, James Free Jewelers of Cincinnati, Jude Skove and Mercedes Benz of Cincinnati, Sterling Diamonds of Toledo, J.W. Seligman, M.B.A. Financial Group, Inc., Williams and Oliver, Oasis Lawn and Landscape, Children's Hospital Medical Center, Brian Brellenthin of the Perrier Group of America, Design Continuum, Laura Padgett, Robert Holler, Brian Day, Steve McCoskey, Stacy and Charlie Kuhn, Janet Papp, Angie Kroll, Tina Hohl and Tom Allen.

"We couldn't have done it without the generosity and support of so many people," Janel said. "Thank you all so much, and we hope to see you at next year's event!"

For more information about The Allygator Classic golf tournament in Cincinnati, Ohio, visit www.allygatorclassic.org, or contact the OI Foundation at (301) 947-0083. 



2nd annual "Going Places" Sweepstakes raises \$19,000

The Second "Going Places" Sweepstakes, created by the OI Foundation to replace the annual general fund appeal, raised more than \$19,000 this year.

"We wanted to make supporting the Foundation's services and programs fun," stated Dev. Director Julianne Weiner, "and give people a chance to win some great prizes as a thank you for their continued generosity."

With thanks to Foundation member Amy Ley, who secured grand prizes two years in a row from American Airlines and American Airlines Vacations, the sweepstakes has more than doubled the amount raised in previous holiday appeals.

Winning tickets have been drawn and the winners are being notified. Once all prizes have been accepted, results of the sweepstakes will be published on the Foundation website.

For information on this or other fundraising activities, contact Julianne Weiner using the contact information found on page 2. 

"Bubba Invitational" a success in spite of torrential TX rain

The Bubba Invitational was named after its organizer Bob "Bubba" McGoldrick, who learned about the OI Foundation through John and Beth Shultz, the parents of Michael Shultz, in whose memory the annual Miracle Michael Tournament is held.

This year's Bubba Invitational was a two-part event, made up of a dinner on October 18th, 2002, where the dress code was strict – overalls required, denim optional – and a golf tournament the following day. Dinner attendees were drenched by summer storms, but the live and silent auctions quickly warmed up the evening.

The next day, the golf course had been transformed into a lake due to the prior evening's downpour. However, optimistic participants took part in chipping contests, and enjoyed a

classic Texas Bar-B-Que. Although the would-be golfers weren't able to tee off, the event was a success, raising \$16,895 in the name of the Miracle Michael Fund specifically to help support research into effective treatments and a cure for OI.

Special thanks to all of the volunteers and supporters who helped make the event such a success – Sports Leisure of Lewisville, TX, What's The Big Idea? of Plano, TX, SEI Incentives of Les Colinas, TX, Service Litho of Oshkosh, WI, Incentive Solutions of Atlanta, GA, Midwest Advertising of Cincinnati, OH, the Gallo Wine Corporation, and especially everyone from Dr Pepper/Seven Up, Inc.

And also a big thanks to everyone who participated in this year's event, in spite of the torrential rainfall! 

Miracle Michael raises \$20,000

by John Shultz
OI Foundation Member

The Miracle Michael Fund golf outing is held annually in memory of Michael John Shultz. "Miracle Michael" was born with severe OI and bravely battled complications from this disorder throughout his eight months of life. Despite more than 100 fractures, Michael's smile stands as a symbol of how powerful the human spirit can be, despite the obstacles we are facing.

At the Miracle Michael IV outing, \$20,000 was raised to support OI Foundation research programs. Held on July 22nd, 144 golfers enjoyed a great day of fun, sun and golf at White Eagle Country Club in Naperville, Illinois. Evening activities included both a live and silent auction, along with dinner. Many special guests were on hand including Chicago Bulls legend Norm Van Lier, and David Kaplan from WGN Radio. Also attending this year's event were the Kipperman and the Harshaw families, as well as Dr. Peter Smith, a member of the OI Foundation Medical Advisory Council, Tim Caruso, P.T. and Julianne Weiner representing the OI Foundation.

Plans are already underway for Miracle Michael V, scheduled for June 30th, 2003, with a goal to raise \$25,000. Thanks again, and we hope to see you in July! 

For information about how you can help or participate in the next Miracle Michael Golf Tournament, visit

www.miraclemichael.org

Tournament, organizers inspire family to make a difference

by Steve Kipperman
OI Foundation Member

I know first-hand what it is like growing up with OI and spending a fair amount of time in plaster casts. When I fell and broke something, we would go off to the ER, I would get casted, heal and get on with things.

Knowing that I had the genetic condition, we had our children tested at birth so we would know if they also had OI. Our first child, Ryan, does not have OI. However, I never really appreciated what I put my parents through until the day our second child, Katie, was diagnosed with the disorder.

It becomes a whole different game when your baby girl is affected. Upon learning the news, there was a range of emotional reactions including denial, fear and anger followed by the question "how bad is it?"

We began the search for the answer of what Katie's prognosis would be and where we should start.

Due to the rarity of the condition, we wondered if we would even find a local doctor that is really familiar with OI to answer our questions.

Having been associated with the OI Foundation through my mother's volunteer work with the organization, I contacted Executive Director Heller An Shapiro.

We promptly received the name



Steve Kipperman (l) presents John Shultz with a thank-you for the inspiration and support he found in the Miracle Michael Golf Tournaments.

of a specialist (Dr. Peter Smith) at Shriners Hospital in Chicago and a lot of great information for us to read.

So we scheduled a visit to have Katie assessed. During the time from when we learned the news and when we could get in to see Dr. Smith, I had a lot of nervous energy.

In the meantime, the Miracle Michael golf outing was coming up in about three weeks. The previous year I had the good fortune of being invited to this event that raises funds for OI research, and had met Beth and John Shultz, who put on the event each year in the memory of their son, Michael.

They showed me that you can make a difference and a light bulb went off in my head.

Instead of just sitting back and worrying about Katie's condition and feeling helpless, my wife, Bonnie and I decided to contact our friends, family and colleagues at work to raise awareness and ask for donations to support the research efforts of the OI

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ARTICLES

Foundation reports on growth, NHC recognition

The OI Foundation executive director and staff reported significant increases in all measurable aspects of the OI Foundation's programs and services over the past six months at the semi-annual Board of Directors Meeting in Maryland:

- The number of educational materials distributed increased 43%.
- Web site visitors increased 295%.
- National media exposure in the first six months of Fiscal Year '03 is greater than all of FY '02.
- *Breakthrough* subscribers have increased by 25%.
- More than 3,400 people now subscribe to the online e-newsletter updates.
- One new support group has been added, and the number of support volunteers has increased by 2.5%.
- Chat participation levels have

almost doubled in the past six months.

"We simply could not have accomplished this without the incredible support from the many donors and volunteers who make our growth possible," according to Executive Director Heller An Shapiro.

Heller An also reported to the board that the OI Foundation has been listed as being in "substantial compliance" with the National Health Council's Good Operating Practices. The practices were adopted by the NHC's board of directors to ensure that its 53 health organization members maintain the highest standards of efficiency and integrity.

The standards cover the areas of governance, personnel policies, programs, fundraising, finance and accounting.

The NHC promotes the health of all people by advancing the voluntary

health movement. This movement is driven by volunteers who—as individuals, families and communities—work together toward the prevention, treatment and cure of disease and disability.

The NHC focuses all its activities on three major goals: to promote quality health care for all people; to promote the importance of medical research; and to promote the role of voluntary health agencies.

Heller An and members of the Board of Directors presented a case study on developing a dashboard at the NHC's Leadership Conference in February. A dashboard is a brief report to the board that provides information about the health, direction, and growth of the organization, much like a dashboard provides critical, at-a-glance information to a driver.

The OI Foundation also presented a round-table discussion on creating internet communities. 

Foundation's new on-line chat functions offer peer support

The OI Foundation's new web site continues to grow and evolve as we strive to meet the needs and desires of the OI community.

The latest additions to the website include on-line chat communities, with new "ad and spam free" chat rooms, an instant messaging function, and a peer-to-peer message board. The new features resulted from a survey of more than 100 website chat users. New chat rooms include areas for Parents, Adults, Singles and Open Chatting, and will soon include a Teen room twice a month.

An instant messaging function allows registered users of the website to log in to an IM function, see who else is visiting the website, and invite them to chat live.

The peer-to-peer message board includes sections for adults, parents, singles and teens. They're an ideal location to post questions, comments, ideas, suggestions or tips about

living successfully with OI. It also includes a forum for listing used but serviceable equipment and OI-related goods for sale or exchange.

All three functions require visitors to be registered on the Foundation's website and logged into the site before they can be accessed. This was done in response to recommendations from members and "regular" on-line OI chatters, and is a security measure used only to restrict access to the rooms from the general public and protect the privacy of those with OI that use the functions.

Children under 13 are now required to submit written parental consent before using the rooms, and the teen room will be monitored to prevent inappropriate language or behavior and protect youth from predatory visitors.

For more information, visit the Chat Room page on the website, or write the webmaster at webmaster.oif.org. 

Want to keep up with what's going on throughout the OI community between issues of *Breakthrough*?

Register online at www.oif.org to receive the Foundation's e-newsletter.

Meet the teen chat room hosts; Kelly Laird and Tara Hughes Mentors give teens a place to learn from each other

Three years ago 26-year-old **Kelly Laird**, who has Type I OI, began breaking after years without significant fractures. She contacted the OI Foundation as she began the search for medical treatments, and realized she wanted to give something back to the Foundation and community in thanks for the information and resources she'd received.

She agreed to mentor a teen with OI, and has since discovered that she's even more in debt to the OI Foundation than she was when she started.

"Mary and I have established a relationship where we keep each other going," Kelly said.

"I've learned so much from her, and it's been such a rewarding experience for both of us."

When she was approached by the Foundation and asked if she'd "host" the teen chat rooms, Kelly said "Yes!" with the same enthusiasm and excitement she applies to her entire life.

"This is just such a great opportunity," she said. "I don't want to be the one ten years down the road who regrets not taking action, and I want to pass that on to the OI Community; you can go on with everyday life!"

Kelly, a Wilmington, Delaware native, spent more than half her teenage years on crutches, but literally never let that slow her down.

"I can run faster on crutches than I can without them, I can dance, I can even use crutches as stilts!" she said. "The whole point is to accept life's challenges and don't let them become limitations."

Kelly is an avid snow skier, works out in a local gym five days a week and works out at home the other two. She's a firm believer that a healthy body minimizes the impact OI has on her life.

"Being as strong as possible, physically, helps overcome some of the limitations OI creates," she explained. "Just as importantly, you can't give up."

Kelly completed college last year, more than ten years after she enrolled. "I simply never stopped going," she said. She's now an analyst with MBNA, a major credit card company, and recently married a man she met through her long-time hobby of restoring classic cars... another part of her "everyday life."

She, her husband, and her family spend virtually every weekend in the summer months travelling and showing

their cars.

"I don't like to sit still, but I know my limitations," she said.

"My niece is growing up with OI; she's had more than twenty breaks in her two years of life," Kelly said. "Anything I can do, anything I can pass on to help her in the future or others now... well, the chat room is simply awesome, I can't wait to start."

Tara Hughes has been actively involved in the OI Foundation for the last three years, primarily through the encouragement of board member Jamie Kendall and the annual Fine Wines, Strong Bones event that benefits the OI

Foundation's biennial national conferences. She lives in Alexandria, Virginia, and works for the Department of Defense as a federal financial manager. She graduated from Shippensburg University

in PA, and completed her graduate work at the University of Delaware.

Tara recently returned home to Pennsylvania to recuperate from a broken hip, and is frustrated at how that will limit her mobility over the next few months.

"I really like to keep in shape, I swim three or four times a week," she said. "I also enjoy going to movies, spending time with friends, travelling..."

She's 27 years old, with Type III OI, and is equally excited about hosting the teen chat rooms.

"I wish I'd had something like this when I was growing up," she said. "An outlet—I really support the concept and think that teens are a group that really needs, and will benefit from, the camaraderie." 

The Teen Chat Room is open the 2nd and 4th Thursday of each month, from 7-9 p.m. EST, and is not intended for users under the age of 13. Parents of children under the age of 13 must provide the OI Foundation with written permission if they wish to allow their child access. Permission forms can be downloaded from the website's chat entry page. For more information visit the website or contact Bill Bradner at (301) 947-0083 or by e-mailing webmaster@oif.org.



The following information was prepared by the OI Foundation, excerpted in part from a fact sheet titled "Novel Forms of OI." The fact sheet is available at www.oif.org, by writing or calling the Foundation at the address and phone numbers on page 2, or by sending an e-mail to bonelink@oif.org.

Understanding OI types

The characteristic features of OI vary greatly from person to person – even among people within the same family. To help families, doctors and researchers better understand these differences, the OI Foundation supported Dr. David Silience of Australia's work to develop a classification system that organizes information about OI into four types. The type classification was published in 1979 and 1981, and is based on features that can be observed in a clinical exam and on x-rays, as well as on how severely the person is affected.

OI type I is a mild form, while OI type II is almost always fatal in the perinatal period (before, during or shortly after birth). OI type III is a severe form, with progressive deformity in the absence of surgical intervention. People with OI type IV are moderately to severely affected.

Detailed lists of characteristics by type of OI can be found in many OI Foundation publications including the fact sheet *Fast Facts on Osteogenesis Imperfecta*, or the brochure *OI: A Guide for Medical Professionals, Individuals, and Families*.

The underlying genetic cause in the

majority of people with OI is attributable to mutations in one of two genes which direct the body's production of type I collagen, the major structural protein of bone.

Do I need to know my type?

Knowing the type or general category of OI can sometimes help people with OI and their families gain more understanding about themselves and this complicated, variable disorder.

Features of OI vary widely not only between types but within types. Many individuals with OI have only some – not all – of the clinical features. Children with milder OI, in particular, may have few obvious signs. Some people appear to have characteristics of several types. Some people use type as a kind of short-hand for generally identifying themselves.

It is becoming increasingly common for persons in a non-medical environment to refer to OI as mild, moderate, or severe. When it comes to making decisions about health and life style, knowing the individual's *specific symptoms and capabilities* are often more important than knowing their Silience classification type.

Then why are types important?

Classification by type provides a common language so that doctors, researchers and people with OI can communicate clearly. Researchers have been working to match clinical features listed in the Silience types to bone studies, DNA analysis and collagen studies as part of gaining more understanding about OI.

As part of this commonly understood language, type is used in the medical literature to report research findings, and to describe who can participate in different clinical trials or other research studies.

What are "Novel Forms" of OI?

For a number of years, investigators

in Montreal have been doing special studies on the histology (minute structures) of OI bone. They have been categorizing the *appearance* of the different Silience types of OI bone under the microscope.

They noticed that some people who are clinically within the Silience type IV group had a distinct pattern to their bone. When they reviewed the full clinical presentation of these patients, they found that groups of patients had other features in common. They named these groups types V and VI OI.

This classification continues the numbering of the Silience classification, but is diagnostically based on histology rather than on the same criteria used for types I-IV.

Patients with OI types V and VI do not have evidence of having mutations in the type I collagen genes. The genetic causes are not yet known.

What is type V?

Patients with OI type V demonstrate three findings (the OI type V "triad"). The first is a dense band adjacent to the growth plate of the long bones, which can be seen on x-rays. The second feature is the development of unusually large calluses, called hypertrophic calluses, at the sites of fractures or surgical procedures. A callus is an area of new bone that is laid down at the fracture site as part of the healing process. Finally, patients with OI type V have calcification of the membrane between the radius and ulna, the bones of the forearm. This leads to restriction of forearm rotation, and individuals may note that it is difficult to open a door by rotating the wrist. Instead, they must rotate the entire arm to achieve such a movement.

In addition to this OI type V triad, people with this type of OI have white sclerae and normal teeth. The bone has a "mesh-like" appearance when

viewed under the microscope.

OI type V is dominantly inherited, which means that if a parent has the condition, there is a 50% chance that it could be passed onto a subsequent child.

What is type VI?

People with OI type VI are more difficult to identify from physical features or x-rays. These individuals are moderately to severely affected. They have normal (white or slightly blue) sclerae and the teeth are not affected. The alkaline phosphatase (an enzyme linked to bone-forming cell activity) level is slightly elevated in OI type VI. This can be determined by a blood test.

Because the clinical features are so similar to other moderate forms of OI, a bone biopsy is the only method to diagnose type VI with certainty. The bone from people with this form has a distinctive “fish-scale” appearance when viewed under the microscope.

Eight people with this bone histology have been identified. None of them

have affected parents and none have had children. Thus, the inheritance of OI type VI is unknown.

As in OI type V, the genetic basis for OI type VI remains to be determined, but there is no evidence of type I collagen abnormalities.

How does this relate to current treatments?

People with type V and VI OI have received bisphosphonates. Numbers are currently too small to draw conclusions, but it appears that those individuals classified as type V rapidly increase bone density, while type VI do so much less evidently. The specific bone lesions in type VI may explain that difference.

Where can I find more information?

The original scientific references for these types are:

Glorieux, F.H., Rauch, F., Plotkin, H., Ward, L., Travers, R., Roughley, P.J., Lalic, L., Glorieux, D.F., Fassier, F. and Bishop, N.J. Type V Osteogenesis

Imperfecta: A new form of brittle bone disease. *J Bone Min Res*, 15:1650-1658, 2000.

Glorieux FH, Ward LM, Rauch F, Lalic L, Roughley PJ, Travers R. Osteogenesis Imperfecta Type VI: A Form of Brittle Bone Disease with a Mineralization Defect. *J Bone Miner Res*, 17: 30-38, 2002.

The investigators who have described types V and VI OI can be contacted for further information:

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E-mail: frauch@shriners.mcgill.ca

Both doctors can be reached by writing to:

Shriners Hospital for Children
1529 Cedar Avenue
Montréal, Québec, Canada
H3G 1A6 

Have you been to the OI Foundation website recently?

We've made a number of changes and additions to our web site since the last issue of *Breakthrough*, including new chat rooms, new items in the Foundation Store, several new fact sheets, an events calendar and dozens of pages of new information about the OI Foundation and current activities in the community. Our complete line of fact sheets are on-line, including:

Fast Facts
Bisphosphonate Q&A
Bone Densitometry
Bone Structure in OI
Child Abuse Facts
Child Abuse (Is this OI?)
Clinical Trials
Dental Care
Education

ER Management
Fracture Management
Genetics
Glossary
Guidebook: About OI
Hearing Chat Transcript
Hearing Loss
Infant & Child Care
Nutrition

Novel Forms of OI
Osteoporosis
Pain Management
Pregnancy
Psychosocial Needs
Care Provider Relationships
Rodding Surgery
Surgical Considerations
Understanding Type I OI



ARTICLES

Board members raise \$97,800 in new funds

by Julianne Weiner
OI Foundation Dir. of Development

At the beginning of 2002 the Board of Directors received a challenge from an anonymous donor that called for commitment, creativity, and lots of hard work. The challenge: to raise new and increased funds to help people with OI. The results of those efforts would be matched dollar for dollar, up to \$100,000.

Board members took on this challenge immediately, and over the last twelve months have reached out to new donors and past supporters in a variety of ways, resulting in \$48,912 in new and increased gifts to the OI Foundation, for a total of \$97,824 after the match.

Personal commitments

Before asking others for donations to the OI Foundation, many members of the Board increased their own giving. By offering their personal commit-



Board Member Paul Burns is spearheading the "Steer Around Town" campaign to raise awareness and funds in the Denver, Colorado area.

ments to support the work of the Foundation, Board members did much more than lead by example. Their generosity enables the continued success of the programs and services that offer hope, support and information to thousands of families every year.

Reaching out

In order to meet the Board Challenge, members of the Board reached

out to their relatives, friends and business associates with letters or emails describing the impact of OI, and the role it has played in their lives. At the same time, they offered a way for their friends to make a real difference in the lives of people with OI through gifts to the OI Foundation. Knowledge that all new or increased gifts would be matched by the Challenge Fund acted as incentive, and motivated a phenomenal outpouring of support.

One Board member used the Challenge as a way to make holiday giving give twice, sending out beautiful cards to family and friends letting them know that a donation had been made in their name to the OI Foundation.

For those whose employers offer matching gift programs, personal donations resulted in a "triple gift,"

Continued on page 17

Create a lasting legacy of support through bequests

Consider one of the simplest and most rewarding gifts you can make to the Foundation: a bequest in your will or other estate plan. Many of us want to provide generously for our loved ones *and* the organizations we cherish. A bequest of any size in your estate plan can help shape the future of the Foundation and ensure that adequate resources are available to fund the programs and projects that are needed by the members of the OI community.

A bequest can be "specific" (for a predetermined amount) or "residual" (where a percentage of your estate is specified, after other obligations have been met). Bequests also differ in terms of how they may be used. An "unrestricted" bequest may be used where the funds are needed most, or bequests to the OI Foundation can be directed specifically to the Research Fund, the Education, Awareness and Support Fund, or the Endowment Fund.

Income from the OI Foundation Endowment Fund can be used to finance operating expenses for the Foundation. The Endowment Fund will enhance the Foundation's overall ability to serve the OI community by providing a solid base of support for ongoing programs and projects. According to

Foundation President Bill Schmidt, there are additional benefits to a strong endowment, as well.

"Endowment support of administrative costs gives the Foundation a significant advantage in requesting grants from public and private groups willing to help further the Foundation's work," he said. "Our goal is to grow the Endowment large enough that its income can support all the operating expenses of the Foundation (including office and fundraising expenses) and, when that is achieved, every single penny that is donated by individuals or through grants can be used to support the Foundation's programs and projects."

A named endowment fund (created through a gift of \$100,000 or more) can offer a permanent memorial or honorarium through which you can support specific Foundation programs and projects in perpetuity.

For anyone interested in including the Foundation in your estate plans, we offer free, confidential resources, including bequest language to share with your attorney. Contact Julianne Weiner, Development Director, at 301-947-0083 or jweiner@oif.org for information. 

USB&J MEETING

Continued from page 14



we must communicate effectively that it is in everyone's self interest that basic and clinical musculoskeletal research leads to better, longer, more active lives.

Noting President Bush's declared focus on bone and joint disease, Dr. Zerhouni underlined the administration's high-level realization of the importance of issues related to musculoskeletal disease.

The Federal Working Group on Bone Diseases was cited as an example of public-private partnership activity. The initiative, established in 1993 under the leadership of NIAMS, with participation from NIA, NIDCR and NIDDK, works to expand and intensify research and research-related programs in osteoporosis, OI, Paget's disease, and related bone disorders.

Currently the Group is comprised of representation from 11 NIH Institutes, centers and offices, 11 other Federal agencies, and five liaison representatives from voluntary organizations and professional societies including USBJD members, the American Society for Bone and Mineral Research, the National Osteoporosis Foundation, the American Academy of Orthopaedic Surgeons, the Osteogenesis Imperfecta Foundation, and the Paget Foundation.

In summary, this first-of-its-kind meeting laid the ground work for a unified approach to eradicating or diminishing the effects of musculoskeletal diseases in the United States.

The USBJD anticipates that this effort will contribute to the global Bone and Joint Decade initiative, increasing awareness and support worldwide. 

SCPICA SUPPORT *Continued from page 1*

held on a beautiful sunny day in January, 2003.

More than 300 golfers and tennis players participated in a day of golf, a spectacular live and silent auction and an exciting raffle. Donated auction items included a ride in the Goodyear blimp, Mighty Ducks hockey tickets, a week in an Orlando, FL condo, DVD players, a personalized story written by

Christina Nelson (a college English major with OI) and much more.

Participants followed the auctioneer's instructions to reach into their hearts and give, raising more than \$55,000, an increase of \$3,000 (6 percent) over last year.

OI Foundation Executive Director Heller An Shapiro attended the Tournament.

"I truly admire the committee's hard work. This is an enormous event that runs very smoothly," she said.

"Many of the golfers told me they were thrilled to be part of it and couldn't wait to return next year."

"It was an honor to attend this event and thank each person for making a difference in the lives of people with OI," she concluded.

Generous SCPICA tournament participants have been supporting the OI Foundation's research and support programs for 17 years. Last year the tournament contributed almost 8 percent of the Foundation's total annual revenue.

Seventeen years ago, SCPICA committee members met Robbie Parke and were inspired to try to help him and others with OI. Now that Rob is a successful college student, other young people with OI



Jerry Thomas (l) and Roan McRae (r) display one of hundreds of donated items used to raise funds during the live and silent auctions at the SCPICA charity event. More than \$55,000 was raised this year.

and their parents have joined the committee and volunteered their time to help make the tournament a success.

OI Foundation members Trey & Heidi Glauser, Christina & Catherine Nelson, Nicole, Rick & Michelle Hofhine, Rob, Philip & Mary Parke and Ron Frost join forces with the committee each year.

The Tournament committee includes dedicated members who have served more than ten years, including John Campbell, Frank Fossati, Kathy Laderman, Mike Ledbetter, Bill Richter, Jerry Thomas, Bob Watson, Pam Weiner and Martin Zaldo.

Major sponsors of this year's SCPICA event include Anheuser-Busch, Inc, Chick's Sporting Goods, Del Mar Analytical, Environ Products, Inc., Filter Recycling Services, Gregg Drilling and Testing, Kinko's-Tustin/City of Industry, Printed Promotional Products, QED Environmental Systems, SignResource L.A., T & D Sales, U.S. Filter/Westates, Veeder-Root, and Wayne Perry, Inc.

To find out about how you can help in the next tournament, Nov. 7, 2003, visit the SCPICA website at www.scpicharity.org. 

ELA Foundation announces scholarships for women with disabilities

The Ethel Louise Armstrong Foundation, Inc. (ELA) is pleased to announce that the 2003 ELA Scholarship application is now available in the scholarship section of the ELA web site at www.ela.org.

The ELA Scholarship provides financial assistance to women with physical disabilities who are enrolled in a college or university graduate program in the United States. ELA Scholarship awards are based on merit and are given on an objective and nondiscriminatory basis. Scholarships range from \$1,000 to \$2,000 per year. The application deadline is June 1st, 2003.

Career Fairs for persons with disabilities to tour US

A multi-state career fair series for persons with disabilities has just been announced.

The 2003 HireDisability Expos will be at the following locations:

- April 11-13 Edison, NJ
- June 6-8 Long Beach, CA
- June 10 St. Louis, MO
- Aug. 6 Dallas, TX
- Aug. 15 - 17 Chicago, IL
- Sept. 12 -14 Boston, MA
- Sept. 18 -20 Orlando, FL
- Oct. 14 Philadelphia, PA
- Oct. 16 New York, NY
- Nov. 14 - 16 San Francisco, CA

Businesses interested in participating and individuals interested in attending should send an e-mail requesting info to ijklare@equalitystaffing.com.

National Parks offer free admission, reduced fees to visitors with disabilities and thier families.

The National Park' Golden Access programs allows travelers with disabilities get free lifetime admission and reduced rates on fees and services to all U.S. national parks and forests.

The Golden Access Passport is available at all national park sites. This pass permits you and a carload of traveling companions free access to all national parks, as well as a 50 percent discount on camping, boating, and other facilities. Visit the National Park Service website at www.nps.gov for more details.

NSDA sports festival to be held in New London, CT

The NDSA National Sports Festival will once again bring hundreds of athletes with disabilities from across the United States to Connecticut College, New London, CT, to compete in national championships and open competitions, June 22 – 29, 2003.

The nation's biggest event for athletes with physical disabilities, the NDSA National Sports Festival offers

excitement and challenge to all participants and draws recognition and involvement from several countries.

Events focus on showcasing talent, as well as providing opportunity for competition against others of similar ability. There are a number of "open competition" events.

The National Disability Sports Alliance and the NDSA National Sports Festival provide athletic opportunities for athletes with physical disabilities, just as the Special Olympics movement provides similar opportunities for people with mental retardation.

Admission to the National Sports Festival is free for the public.

For more information, please call (860) 267-6757 or visit their website at www.nationalsportsfestival.org.



Raising support and awareness... one step at a time

Woody Binnicker raced more than 360 miles in triathlon and marathon competition to raise funds and awareness in honor of his 5-year-old son, Cullen.

His "Tri For OI" raised \$19,866 in pledges and direct contributions to the OI Foundation. Woody sent e-mail and internet appeals seeking sponsors for each mile, and competed in 14 races throughout the Southeast in the '02 season.

He's determined to "beat his personal best" both in competition and in support and awareness raised for the Foundation, and is now seeking pledges, sponsors, and athletes to join him in his Tri For OI during the 2003 racing season.

To see the results of the 2002 Tri For OI, visit the news and events page on the website. To get involved in '03, write jweiner@oif.org.

Red Cross publishes emergency preparedness information for persons with disabilities

The American Red Cross has published a guidebook on Disaster Preparedness for People with Disabilities that is available on their website, www.redcross.org. Go to Disaster Services/Be Prepared/Special Needs & Concerns.

New organization takes the search out of searching for airbag support

If you're having difficulty weeding through the red tape necessary to have an on/off switch installed on your car's airbags, Sensible Solutions can help. Since they also manufacture the switches, they have an extensive list of authorized installation locations nationwide, as well. Visit their website at www.airbagonoff.com for more information. For those without internet access, call (877) 773-7908.

OI Foundation seeking volunteers to host teen chat rooms on website

The Foundation is seeking two or more volunteers to take turns "hosting" the teen chat room on Thursday evenings, from 7-9 p.m.

The Hosts' primary responsibility will be to ensure the safety of the teens using the chat room by banning predatory visitors and enforcing basic language and behavior standards.

The ideal host would be out-going and college-aged; someone who can "relate" to and mentor teens, while accepting minor administrative and oversight duties and responsibilities. The host must have a basic understanding of OI through personal or direct experience, be familiar with the Foundation's resources and programs, and have a moderate level of computer literacy.

All hosts must complete a mentor application and pass a basic security screening. Training is provided. For more information, contact Bill Bradner by writing to webmaster@oif.org.



Supporting each other, building communities...

OI Foundation Executive Director Heller An Shapiro (2nd from left) had an opportunity to meet with the members of the Northern California Support Group at their winter meeting, held at the home of Shirley and Bo Roberts.

Heller An shared information on current Foundation activities, OI research projects, new developments and future directions for the OI Foundation. Many people were new to the support group or hadn't attended a meeting in several years. The reinvigorated group is making plans for future activities.

"It was an exciting meeting!" Heller An reported. "People were very interested in our new web site and chat rooms, the Growing Up with OI books, medical research progress, and our plans for new resources like the book for adults, the exercise book and the children's story book."

Web Spots

Useful or informative sites for the OI community

The following organizations or services were featured in the pages of this newsletter:

Allygator Classic (Page 4)
www.allygatorclassic.org

American Red Cross (Page 13)
www.redcross.org

Ethel Louise Armstrong Foundation (Page 12)
www.ela.org

Family Center on Technology (Page 7)
www.fctd.info

Miracle Michael Fund (Page 5)
www.miraclemichael.org

National Health Council (Page 6)
www.nationalhealthcouncil.org

National Park Service (Page 10)
www.nps.gov

National Sports Festival (Page 6)
www.nationalsportsfestival.org

Pega Medical (Fassier Rods) (Page 10)
www.pegamedical.com

Sensible Solutions (Page 13)
www.airbagonoff.com

Southern California Petroleum Industry Charitable Association (Page 1)
www.scpicharity.org

Direct links to these organizations can be found on www.oif.org.

ARTICLES

US Bone and Joint Decade leaders meet with NIH

As a sponsor of the United States Bone and Joint Decade (USBJD), the OI Foundation is pleased to report on recent activities.

Chairman Stuart Weinstein, MD, and representatives of 15 other USBJD Founding Members leading their organizations' BJD efforts, met with top leaders of the National Institutes of Health (NIH) to explore areas of mutual interest and pledge to work together on specific programs to foster research and clinical advances in the care of patients with musculoskeletal disorders. Additionally, the USBJD was invited to participate in the upcoming *Surgeon General's Report on Osteoporosis and Bone Health*.

Chaired by Stephen Katz, M.D., Ph.D., Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the meeting drew the directors and staff of other institutes as well as Elias A. Zerhouni, MD, Director of the NIH.

NIH also invited representatives from Canada to the meeting; Dr. Cyril Frank, MD, Director, and H el ene Plante, Assistant Director, Institute of Musculoskeletal Health and Arthritis, Canada. The Canadian government officially proclaimed its support for the Bone and Joint Decade in October, becoming the 43rd nation to do so.

From the outset it was clear that all are eager to see the decade succeed in bringing about greater public awareness of musculoskeletal disorders, increased patient education activity, and benefits to the research community.

Several themes emerged from the discussion, including the importance of:

- Establishing and enhancing the lines of communication

between medical groups involved in the care of patients and with the public;

- Increasing the number of musculoskeletal researchers in general and clinician scientists in particular;
- Developing new opportunities and resources for musculoskeletal research; and
- Enhancing the image of musculoskeletal medicine in the eyes of the public, policy makers, and the medical student population.

In the words of Dr. Weinstein, "musculoskeletal disorders are under-recognized, under-appreciated, and under-resourced."

When discussion turned to specific issues, the inclusion of the musculoskeletal system education into medical school curricula, increasing the stream of medical students in these specialties, the number of researchers and clinician scientists, and the number of grant applications to NIH were the focus of discussion. Opportunities for new partnerships, and an image change in the presentation of musculoskeletal disorders, were viewed as primary areas of activity for the Decade to bring about these goals.

Dr. Katz led a discussion on the importance of developing new researchers to work on musculoskeletal diseases and basic science issues. All of the groups have an interest in this area, including basic and clinical research. The group agreed on the need to try to target earlier stages of education (i.e. high school and college) so that more students value a career in medicine or clinical research.

Dr. Weinstein supported Dr. Katz's comments saying that

Continued on page 11

FCTD compiles resources for accessible education

At this time of year, many students are searching for the right college to attend or have recently entered college and are preparing to take college exams. The Family Center on Technology and Disability provides some information about assistive technology in the post secondary education environment.

Their online newsletter can be found on their website at <http://www.fctd.info>. The current issue includes an article on Assistive Technology Planning for Post secondary Education from the Simon Technology Center of the Parent Advocacy Coalition for Educational Rights (PACER), a Family Center Partner.

Look for more information in the "Colleges and Careers" webcast and supporting documents, found on the fact sheet page of our web site.

It also includes resources that will aid in the search for more information on post secondary education, accommodations, and assistive technology needs for students with disabilities. Although this is not an exhaustive list, the articles and resources will be of use to students and their families, educators and professionals in their search for more accessible higher education.

If you don't have access to the internet, request a copy of the information by mail by writing to the Family Center on Technology and Disability (FCTD), 1825 Connecticut Ave. NW Suite 700S, Washington, DC, 20008 or by email at fctd@aed.org. 

HONORARY AND MEMORIAL DONATIONS

OCTOBER 1 TO DECEMBER 31, 2002

In Honor Of ...

| | | | |
|--|--|--|--|
| Children at Christmas Jim & Martha Miller | Miss Elizabeth Geller Ms. Nancy Czerkies | Haley Lapkin Richard & Frieda Klein | Cody Robbins Tom & Willa Holmes |
| Christmas Mr. & Mrs. Norman Wilcox | Mr. & Mrs. Bernard Greenbaum Mrs. Addie Boyar | Michael Loguercio Ms. Leslie Sikora | Nicole Schettler Clyde & Pat Weisbrod |
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| Ivy Geisman Mrs. Gemma Geisman | Rosemarie Kasper Mrs. Gloria Lieberstein | Lima Radio Hospital, Inc. | Ms. Sylvia Leaf |

In Memory Of ...

| | | | |
|--|--|---|--|
| Sydney Grace Bennett Terry & Pamela Wilson | Mr. & Mrs. Norbert Duello Robert & Dorothy Ebert | Mrs. Bernice Prost Ms. Sondra K. Rippetto | Charles & Janice Honig Ms. Dorothy Lapham |
| Garrett C. Berry Peter & Janet Droste | Gary & Patricia Eisenhart Lawrence & Bertille Emming | Mrs. Nelda Roehm Ms. Helen Sage | Mrs. Judy Picciallo Viola Kern |
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| Mr. Donald Dillon Mr. & Mrs. Donald Lott | Ms. Jamie Kendall & Mr. Tim Dombro David & Tana Kettner | George & Betty Glauser Ms. Sharee Vistaunet | Peter David Ray Mr. & Mrs. Joseph Hayes |
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| Ms. Barbara Breen William & Antoinette Carson | John & Pat Mosier Mrs. Satish Nair & Office Friends | Hubert Jensen Wendell & Joann Helland | William W. Theodore Mrs. Phyllis Theodore |
| Jeff & Sally Comparato Donald & Judy Connor | David & Alice Neville Charles & Iola Newton | Barbara A. Kane Ms. Mary Delisle | David Toussaint Mr. Leo Dean |
| Terry & Kimberly Cooper Ms. Helen Cordani | Dan & Kathy O'Keefe & Diane & Tony Harry & Sharon Pendergraft | Ms. Irida Ferullo Mr. & Mrs. John Pascucci | John & Katherine Treffeletti Jean Zabinski |
| Ms. Pat E. Dahm | Evelyn Pontius Mr. & Mrs. Dale Poslosky | Alma Kasper Matthew & Cheryl Anderson | Nicholas & Eldred Vurdelja |

Contributions to commemorate a birth, birthday, anniversary, wedding, or other occasion offer a generous and thoughtful way to honor a friend or loved one while supporting the OI Foundation. The contribution can be designated to any of the Foundation's funds-- the Education, Support and Awareness Fund, the Research Fund, or the Endowment Fund. Gifts should be sent to: OI Foundation, 804 W. Diamond Ave., Suite 210, Gaithersburg, MD 20878. Gifts may also be made online at www.oif.org or by calling 1-301-947-0083.

CONTINUED...

INSPIRED *Continued from page 5*

Foundation in conjunction with the Miracle Michael outing.

We were floored by the responses we received.

What started out as a need to channel energy in a productive direction has resulted in an annual campaign that coincides with the Miracle Michael event.

The first year we raised \$7,500 toward the OI Foundation's research funding program. This year I am pleased to say it increased to just under \$10,000.

More importantly, it continues to raise awareness in our communities, and build friendships that will last lifetimes.

Had I not met the Shultz family at the Miracle Michael event, we probably never would have thought to do this.

We cannot thank our friends, family and colleagues enough for their generosity, kind words and moral support. 

VIGNETTES NEEDED *Continued from page 20*

professionals, medical information, and peer support for medical concerns?

Healthy Lifestyle: How do you maintain optimal physical health through exercise, diet, or other means?

Planning for Hard Times: Adults with OI may be more likely than others to face a medical crisis that will influence their ability to work, care for family members, and/or accomplish daily living tasks.

What steps have you taken to plan for potentially difficult times? When you have had a fracture, surgery, or other medical problem, how have you restructured your life and responsibilities?

Mental Health: How do you deal with social stigmas surrounding OI (e.g., disability, short stature, hearing loss)? What mental health issues have you struggled with internally (e.g., anxiety, fear, depression) and how have you coped with them?

Tools for Independent Living: How have you maximized your independence in one or more areas of life (e.g., mobility; homemaking; daily living tasks such as grooming, dressing, cooking, etc.)? How have you chosen which mobility aids are best for you (e.g., wheelchair, crutches, walker, etc.)? What resources have you turned to for maximum independence (e.g., personal aides, assisted living facilities, paratransit, TTY, etc.)?

Travel: What strategies have you developed for traveling (e.g., riding on public transportation, taking trains or airplanes, getting around in unfamiliar cities, traveling with tour groups, etc.)?

Home Adaptations: How have you adapted your home to be as accessible as possible for all members of your family?

Making Decisions About Parenting and Family:

Attn: Young OI Entrepreneurs!

If you are 17 years old or younger, and have started your own business or have a unique way of earning your pocket money, we want to hear from you!

Breakthrough is planning a feature story on young entrepreneurs in an up-coming issue.

Send a brief description of how you earn your pocket money to bbradner@oif.org or write to Bill Bradner at the address on page 2.

If your business venture is chosen to be featured in the article, we'll arrange an interview and appropriate releases through your parents.

How have you made decisions about parenting (e.g., having biological children, adopting children, not having children)? What sources of information and support did you consult? How did you/your partner cope with the emotional issues surrounding these decisions?

Day-to-Day Parenting Issues: How have you dealt with daily challenges (both practical and emotional) related to being a parent who has OI (e.g., caring for young children when you have mobility limitations, decreased strength, or pain; addressing your child's and his or her peers' questions about OI; caring for a child who also has OI; etc.)?

Dating, Sexuality, and Marriage: What difficulties and successes have you had in meeting potential partners, casual or long-term dating, marriage? How have you coped with particular problems that have come up? What advice or strategies can you offer to others with OI?

Career Planning: How has OI influenced your career path? Where did you turn for information, resources, and assistance in your chosen career? How did you overcome challenges or barriers?

Finances and Insurance: How has OI influenced your finances, in terms of health and life insurance, retirement planning, investment strategies, use of government assistance programs, etc? What information and resources were particularly helpful to you?

Practical Legal Issues: Have you ever used the legal system to address discrimination against you as a disabled person/person with OI? Where did you turn for information and assistance? What advice would you offer to others?

Retirement and Aging: How has OI influenced your plans for retirement and beyond, in terms of finances, living arrangements, career and volunteer pursuits, etc? 

BOARD MEMBERS RAISE ALMOST \$98,000 *Continued from page 1*

with the original contribution being matched by the company, and the entire amount being doubled by the Challenge Fund.

Events

Several Board members held fundraising events that raised awareness about OI and brought in thousands of dollars in increased revenue to be matched by the Board Challenge. The annual Bone China Tea, spearheaded by Board member Susie Wilson and her mother, Jenny Wilson, raised \$5,255 from new donors last year. Board Member Jamie Kendall and Tracy Johnson chaired the Fine Wines, Strong Bones silent auction and wine tasting in the Washington, D.C. area, raising \$2,750 in increased donations from the previous year.

Another fundraising avenue explored by Ms. Kendall with the help of Barbie and Sid Simmonds was a night at Baja Fresh, a local Mexican restaurant, that donated 15% of the evening's proceeds to the OI Foundation.

On October 26, 2002, in Indianapolis, IN, Ken Finkel and his wife Ann, along with their daughters Jessica and Sally, organized the first Mini-Golf-A-Thon to support the OI Foundation, with outstanding assistance from Sarah and Terry Grevel. Close to 30 mini-golfers teed off at Ben and Ari's mini-golf and gaming center in Fishers, IN. The course time was donated by owner Leonard Gurin, and over \$3,000 was raised.

According to Ken, "It was great to come together and have fun for such a good cause. We are already looking forward to next year!"

On November 2, 2002, Robin Johnson and his family hosted the "Skeleton Crew" fund-raiser – a pirate-themed costume party and silent auction that raised \$3,000. Over 50 people gathered in the Johnson's home for an evening that featured live entertainment, delicious food, and information about OI. Special thanks go to Jeffrey Eslinger, Paula and

Alyse Furber, Dr. Ivo Kalajzic and Dr. David Rowe for helping to make the evening a success.

In Colorado, Paul Burns is spearheading the on-going "Steer Around Town" campaign, in which businesses and organizations can sponsor ceramic steers which will be on display throughout the city of Denver. Much like the celebrated "Cow Parades" held in Chicago and New York, these decorated bovines will raise funds for OI through their sponsorships and through an auction to be held next winter. If you have connections to the Denver area and would like to get involved, please contact Julianne Weiner at jweiner@oif.org.

Challenged Again in 2003

The challenge has been re-issued for 2003, and once again the donor will match all new and increased donations made to the OI Foundation through the efforts of the Foundation's board members, up to \$100,000. This generous support will make a difference in every life touched by OI, and in the ability of the OI Foundation to continue meeting the needs of everyone we serve. To offer your assistance or suggestions to the Board, please contact the OI Foundation Development Director, Julianne Weiner, at 301-947-0083 or jweiner@oif.org.

How can you help?

Last year the Board of Directors raised almost \$50,000 through the programs and efforts described above. But you do not need to be on the Board to help support the critically important work of the OI Foundation.

If you want to make a difference, the OI Foundation can help you with your own local fundraiser. Letter or email campaigns, silent and live auctions, golf tournaments, corporate philanthropy and direct support all help change the future for families affected by OI by providing them with the answers and the resources they depend on. 

There have been a number of additions to the OI Clinic Directory!

**Visit www.oif.org for information
about clinics and services
available to the OI Community.**

**A new directory and services comparison chart will be
published in the Summer issue of Breakthrough.
Updates are posted on our website under the "Medical
Treatments" button as they become available.**

Please make a note of this new clinic on your list:

Riley Hospital/Indiana University

Bone Dysplasia Clinic

975 W. Walnut St.

Indianapolis, IN 46202

Dr. David D. Weaver, Clinic Director

Clinic Hours: Third Wed. of each month

To make an appointment:

Iris Pettigrew (317) 274-1057

Services: Children and Adults

Treatment Programs: A,B,C,D

The view from the bottom can be fascinating, too

by Sandy Ho
OI Foundation Member

I dreamed one night that I was walking, and everything about me was 'normal.' I didn't go to school in my wheelchair; I walked to all of my classes, ran the fastest mile in Phys. Ed., and was just as tall as the rest of my fellow peers. When I woke up and told my brother about this vision, I began by asking, "want to hear about this horrendous nightmare I had?"

After I finished he replied, utterly confused, "but I thought you always wished you could walk like me." So I had for quite a while, but then I realized that being a person with a disability adds to the confusion of life. It makes me who I am, as I challenge it to gain the most of what I can through every passing day.

I must confess however, that I haven't always regarded the concept of being handicapped with such awe and bliss. It seemed only yesterday I came home from my first day of kindergarten and threw a colossal tantrum. Through my tears and screaming my mom learned a kindergarteners' worse nightmare: I had to sit in the shade during recess. In the meantime my other squeaky little friends ran freely about the playground. "I want legs that work!" I repeated in my childish innocence, not understanding why mommy and daddy couldn't make that happen. This was one of the few demands my parents were and are unable to meet, although through the years my parents have shown me how I can surpass challenges which far outweigh a set of working limbs.

It was one of the rare times when I become eager and envious of my younger sibling as I watched his feet brush past me. I looked on with an immense longing, and felt as though I was window shopping. Just peering, feasting my eyes, but I can't buy it, no

matter how much money I might offer. His feet roll from the back of his heels to the tips of his toes, back and forth, back and forth. Such a simple pattern that I could never do without the assistance of a walker, and even then it would look awkward, I would never walk like him. So what choice do I have? I'd made up my mind long ago that having a disability means to never allow for it to inundate my life.

"You can't get anywhere if you dwell on the negative. Go around the wall and you'll feel good. Climb over the wall and you'll feel great. Go through it and you'll feel pain," I quote from my dad; a saying that has sailed me through the roughest of seas.

Perhaps not everyone has gone through the same ordeals. However, at some point, disability or no, we've all questioned the world and the role we play. If there's one aspect which we could all agree upon, it's that life can make absolutely no sense when we think about the situations we are put through. Even through the physical barriers, there are activities in life all of us will experience. From the pressures of school to waking up in the morning, the majority of the time we — believe it or not — **are** in control of our own steering wheel. In some cases it may seem as though someone else is driving; but in fact we are our own driver. We may just need to view the problem through the eyes of someone else. However, at times when we put the key into the ignition and expect the roar and rumble, all we get is a sputter and then a devastating silence.

I remember one such time on a sixth grade field trip to the aquarium. There was one section of the exhibition with a gigantic glass tube of water that went vertically; it was as round as the thickest tree and as tall as a three-storey house. I remember the long line that seemed to inch along; finally I got to the beginning of the stairs. Before I

could blink, my friends were off racing up the spiraled stair-steps. I looked up at the teacher who tried to make the best of the situation by pointing out all the neat things on the ocean floor. I paid no attention to what she was saying and looked up, and I couldn't get over how fascinating the view was from the bottom.

Through anything it's imperative that one doesn't give up, even when it means relying on the last thing on the list. I've fallen back onto hope to make what sense I can out of walking. I'll continue watching my brothers' feet with careful scrutiny, mentally photographing each detail, so the next time my physical therapist and I go for walks I'll be able to imitate it, and I will find my own way of walking with ease and grace.

My place and your place in the world will not always make sense. There will be frustrations, ups and downs whether we ask for them or not. The same goes for how some of us have obvious differences, whether we want them or not. Yet in the end we're all humans. Even if you can't walk, can't run and can't do about a billion other things like your younger brother, think about all that you can do because they'll always outnumber those that you can't.

Act like sponges; absorb the most you can even when times do seem like a weak sputter. The shipwrecks in this vast ocean are normal. Remember: how you mend your ship is what makes you yourself. Catch as much fish as you can and trust me, you'll survive. 

Sandy wrote this essay for her high school paper, then shared it with the online community through the OI Foundation's chat room. Regulars in the chat room encouraged her to share this with Breakthrough subscribers as an inspiration to all.

Father of two pleased to see greater OI awareness

by Mike McDonald
OI Foundation Member

My name is Mike McDonald. I was born in March of 1972 and am 31 years old. I wasn't diagnosed with OI until I was about 3 years old.

When I was 18 months old and had just learned to walk, my parents thought that I had broken my leg and took me to the emergency room. When the doctor finally saw me, he proceeded to tell my parents that it was nearly impossible that I had broken my leg from merely walking. The doctor told my parents that they were babying me too much. He told my parents to walk to the other side of the room while I was standing slightly in front of the doctor with his hands holding mine. I still wasn't standing on my leg at this point. The doctor instructed my parents to call my name so that I would walk over to them. At that time the doctor let go of my hands.

Since my leg was broken and I still didn't want to apply any pressure to the broken leg, I grabbed the nearest thing to me-- the doctor's private area. With a red face and a slightly higher pitched voice, the doctor quickly admitted that I might indeed have a broken leg and sent me in for x-rays.

Since OI was still not widely known, I was not diagnosed at that time. It wasn't until my next broken leg that a very young doctor whom my mother believed was fresh out of medical school diagnosed me as having OI.

While we were waiting to be seen by the doctor, my mother was sitting in the waiting room and this young doctor walked by and took a look at me, looked into my eyes and said, "Yep, blue sclera, definitely osteogenesis imperfecta." My mother was a bit awestruck and chased the young doctor down, actually halting the elevator he was on and asking "What did you say, definitely osteo what?"

The young doctor said, "Your son has been diagnosed with OI, hasn't he?" I was diagnosed shortly thereafter with OI Type I. It wasn't until then that my father was also diagnosed with this condition.

I had many more subsequent breaks throughout my young childhood. I even broke my leg just stepping off a curb.

Every teacher I had through elementary school was informed of my "bone disease." And that is where it was born—the phrase I would use repeatedly for the rest of my life: "bone disease, it means I have brittle bones." Every teacher was very quick to point this out to every one of my classmates. It wasn't long before everyone in my school had heard of the kid with the "bone disease."

My parents, my teachers and even my schoolmates did

not allow me to do certain things, a lot of which were in my best interest. But, the more they disallowed me to do some things, the more I was likely to sneak and do it on my own, and I would pay the price. It seemed as if the more I was restricted and the more people knew about my "bone disease" the more I had to prove myself. I even at one point joined the wrestling team and wrestled for quite some time until I broke my ankle. Needless to say, because of my need to prove myself, my medical record now comes in volumes

one, two, three and four. I have broken nearly every bone in my body.

It is nice to see that in the last few years more and more people have heard of OI. I have

always dreaded answering that one question whenever I went to the doctor or the emergency room. The conversation was almost always the same:

"Do you have any medical conditions?"

"Yes, osteogenesis imperfecta."

"Huh? What's that?"

I'd either get this response, or the puzzled look with the head slightly cocked to one side. Then the term that best describes it and that has stuck with me since elementary school always comes back, and I explain: "bone disease, it means I have brittle bones."

I am now the father of two boys and I admit that I am relieved to say that neither have this condition. Although Type I is definitely manageable, I'm happy that neither of my sons inherited that one genetic trait (even if they did get stuck with my nose, instead).

I commend the OI Foundation for the work they do and for informing people about OI. Knowledge is key, and we've come a long way in educating the public and the medical community about OI.

Just as importantly, now that I've "discovered" the Foundation's web site, I especially look forward to using the peer-to-peer and chat sections on the website, since I think it is very important for people with OI to be able to talk to one another and find ways to help each other cope, especially parents.

I know that every time I was in the hospital with something broken it was especially hard on my parents, who felt as though somehow they were responsible for me being there. I won't have to go through that with my children, but I look forward to being able to offer my insight to other parents. 

"Knowledge is key, and we've come a long way in educating the public and the medical community about OI."



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Gaithersburg, MD 20878 (USA)
(800) 981-2663 or (301) 947-0083
Fax: (301) 947-0456
www.oif.org

DON'T WASTE ME!
If you are not going to read me or
share me with a friend, please
call the OI Foundation at
(800) 981-2663 to have your name
removed from the mailing list!

Vignettes needed for new book project about adults with OI

By Ellen Dollar
OI Foundation member

The OI Foundation is developing a new book for adults with OI, titled *Taking Charge: Adults Living with OI*. The book will have approximately 25 chapters divided into two sections: Managing Your Health (focusing on medical and health issues) and Building a Life (focusing on family, social, daily living, and emotional issues).

Each chapter will include short "vignettes," or real-life stories, from adults living with OI. These vignettes will enhance the book chapters by providing different perspectives on chapter topics. If you are an adult with OI, we hope you will consider submitting a vignette, or even several. The OI Foundation will edit submissions for length, readability, grammar, and style. While we will use as many vignettes as possible,

we cannot guarantee that we will publish every vignette we receive.

To submit a vignette:

1. Choose a topic, or several, from the list below. Write a short vignette (approximately 250–500 words) about how you have dealt with that particular topic in your life.
2. Include your name, address, phone number, and e-mail address with each vignette you write.
3. If possible, include a good quality snapshot of yourself to accompany your vignette. Please note that we *cannot* use digital photos, as they are generally not high enough resolution for quality printing. If you submit your vignette via e-mail, please send a snapshot separately via regular mail.
4. If you are sending a photo, please also send a signed photo release, which gives the OI Foundation permission to publish your photo.

Photo releases can be downloaded from the "media" section on the OI Foundation web site.

5. Send your vignette(s), photo(s), and photo release to:

Ellen Dollar, Editor
119 Randal Avenue
West Hartford, CT 06110
E-mail: ddollar@snet.net

Vignette Topics:

Medical Concerns Related to OI: Orthopedics, osteoporosis, OB/GYN, genetics and reproductive technologies, neurology, dental/oral, pulmonary, physical therapy/rehabilitation. How have you made decisions about treatments or surgeries? How have you dealt with particular medical concerns or crises? How have you gone about finding medical

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