

Miracle Michael Tourney exceeds goals

By Beth Schultz

The Miracle Michael Golf Tournament is held annually in memory of Michael John Schultz, who was born with severe OI and bravely battled complications from the disorder throughout his eight months of life. Despite fractures in more than 100 bones, Michael's smile stands as a symbol of how hopeful the human spirit can be in spite of the obstacles we face.

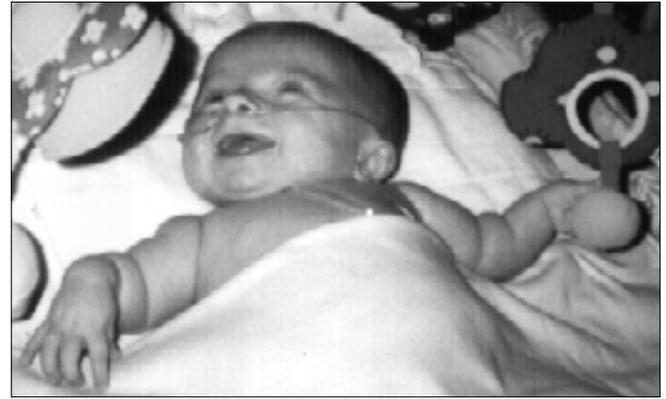
The 2001 tournament, held last August, raised \$20,000 for the OI Foundation, far surpassing organizers' goals of \$15,000.

The 2001 effort was greatly impacted by a donation of \$8,500 from the Bubba Invitational, an annual golf outing held

in Dallas. This year the Bubba Invitational selected the Miracle Mike fund, and the OI Foundation, to be the main recipient of their 2001 tournament proceeds.

Special thanks are due to Bob "Bubba" McGoldrick, Kim Gennette and Carol Anderson for their commitment and generosity.

This year's third annual Miracle Michael tourney was once again blessed with great weather and great people. In total, 130 golfers enjoyed a day of fun, sun and golf at the White



Michael J. Schultz's spirit belied the seriousness of his OI.

Eagle Country Club in Naperville, IL. Evening activities included dinner and live and silent auctions.

Many special guests were on hand, including Chicago Blackhawks legend Keith Magnuson, David Kaplan from

Continued on page 4

2002 Committee lowers registration fees

The OI Foundation's 2002 National Conference may be the most affordable conference ever—a direct reflection of the efforts of the conference committee and the organizers of the Fine Wine, Strong Bones fundraiser held in VA last year.

Committee members were adamant about lowering registration fees for members without decreasing the services, offerings, or quality of the conference itself. The conference fees remained stable for the past six years, and though costs were rising, the committee wanted to do more than just "stay the same" when it came time to set fees for 2002.

In support of that goal, conference committee chairman and OI Foundation

Board Member Jamie Kendall spearheaded the effort to launch Fine Wines, Strong Bones. Proceeds from the VA-based fundraiser are earmarked specifically for the national conference. The

inaugural event raised more than \$20,000. If the event goes as well this May, it may bring the conference into the

black. The Foundation regularly underwrites a portion of the conference out of its program budget in order to keep it as affordable as possible.

"During this difficult financial year, the conference committee wanted to help more people afford to come to the conference," according to Kendall.

This conference includes more ses-

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RESEARCH UPDATE

BREAKTHROUGH

The Newsletter of the Osteogenesis Imperfecta Foundation, Inc.

Editor: Bill Bradner

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Foundation, CBBF host second research strategy meeting



The research meeting brought together more than 30 scientists, doctors and guests.

The New Research Strategies in Osteogenesis Imperfecta scientific meeting was held December 3, 2001. The OI Foundation wishes to thank Joan Marini, M.D., Ph.D., David W. Rowe, M.D., and Matthew Breyer, M.D. for organizing the meeting. Sponsored by the National Institute of Child Health and Human Development (NICHD), National Institutes of Health Office of Rare Disorders (ORD), Children's Brittle Bone Foundation (CBBF), and the Osteogenesis Imperfecta Foundation, this scientific meeting was the result of a unique public/private partnership that is working to increase the pace of osteogenesis imperfecta research. In the next five years, this partnership expects to expand the scope of OI research through a concentrated investment of joint resources.

Following the previous New Research Strategies in Osteogenesis Imperfecta scientific meeting held in 1999, the pace of research accelerated dramatically with approval by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) of five projects totaling more than \$1.6 million. Four of those five new grantees were in attendance to share their progress.

Thirty-nine researchers from laboratories throughout the USA, plus key investigators from Canada and Ireland were invited to come to Chicago, IL and share their knowledge, results and current research questions. More than 20% of the researchers received OI Foundation funding during their early careers and almost a third of those present are members of the OI Foundation's prestigious Medical Advisory Council.

Four Areas of Emphasis

The meeting focused on 4 key areas: bisphosphonate therapy, ribozymes for gene therapy, transplantation and other novel approaches to therapy, and bone biology.

- Discussion on bisphosphonate therapy focused on unresolved aspects of administering the drug to OI patients. What are the long term effects on growth and bone tissue? Is the response of long bone different from the response of vertebral bodies? If bisphosphonates are beneficial, when should they be started and how long should administration continue? Many answers may come from a double-blind study of Fosamax (an oral bisphosphonate) in children with OI being conducted by Shriners' Hospitals and from controlled trials of bisphosphonate treatment in mouse models for OI. All agreed that bisphosphonate therapy does decrease bone pain. There are many new bisphosphonate formulations being tested now. Some of these are more potent and can be administered more quickly, with longer intervals between doses.
- Discussion on ribozymes for gene therapy focused on successful mutation suppression therapy for OI and other disorders. Researchers who have successfully treated retinitis pigmentosa were invited to share their expertise with OI researchers. Ribozyme therapy for retinitis pigmentosa has progressed out of the test tube and into animal models. Several promising methods for suppressing the

Continued on page 23

PRESIDENT'S MESSAGE



Bill Schmidt

Dear Friends,

The 2002 OI Foundation National Conference is drawing closer, and promises to be one of the best conferences the Foundation has ever hosted! The list of speakers and sessions is nearly complete, and we're all extremely excited about the great programs being offered this year. From head to toe (or to be more precise, from hearing loss to foot and ankle problems) the conference committee has selected outstanding and highly renowned experts to inform and educate you during the conference.

This issue of *Breakthrough* is filled with information about the conference itself, but even more importantly, there are articles and information on how to make your visit to Florida fun and exciting for the whole family. The Universal Studios Theme Park is across the street from our hotel, and the many Disney attractions are only a short drive away. With so many friends from the OI community there to accompany you, there may not ever be a better time for you to enjoy these attractions!

In these pages, Jay Mandeville shares his thoughts on why you should attend (page 9), and Dr. Priscilla Wacaster, a member of our Medical Advisory Council, shares a wealth of "lessons learned" from the numerous trips she and her family have taken to a variety of Disney theme parks (page 15). Both Priscilla and her children have OI. The registration form is included in the center of this issue. We have also included as much up-to-date information as we can cram into the other 24 pages. Thanks again to the conference committee for all their hard work!

To help inspire you to stretch your horizons and join us in Orlando, this issue's Spotlight focuses on two young members who have truly inspired their peers and their communities. They were selected to carry the Olympic torch during portions of its relay to Utah! Kristen Antolini and Ryan Roquet both had the honor and opportunity to take part in this historic event, proving once again that OI can't keep you from reaching olympic heights (page 20).

This issue also includes information about nominations for the Foundation Board of Directors (page 9). If you or someone you know would like an opportunity to make a difference in the OI community, help shape and support the Foundation's direction and goals, and increase leadership skills, please contact the Foundation office.

The Board Development Committee is looking for nominees with a personal connection to osteogenesis imperfecta and experience in one or more of the following areas: accounting, finance, fund raising, organizational management, public relations, strategic planning, business, or law. All board members must be committed to helping the OI Foundation raise the funds necessary to achieve its mission. Anyone may submit a brief application or nomination to the national office. Be sure to include the nominees's name, address, phone number and e-mail address, as well as information about paid and volunteer work experience.

While you're thinking about volunteer work, find out who the Foundation 2001 Volunteers of the Year are (page 5), and learn how to nominate someone to the selection committee for 2002. That's one committee that has its work cut out for it. So many of you dedicate so much time and energy to supporting the Foundation and its members, it's extremely difficult to narrow the field down to just one or two!

This year's Bone China Tea (page 5) and "Going Places" Sweepstakes (page 24) are reported on in this issue; both of these unique fund-raising events depend completely on the enthusiasm and efforts of the OI community. Special thanks are due to Jenny and Susie Wilson for their extraordinary efforts coordinating and "hosting" the Bone China Tea, and to Pete Dohm for all his efforts chairing the "Going Places" Sweepstakes. Jenny and Susie's efforts have kept this year's Bone China Tea participation levels as high as ever before, and sweepstakes tickets are pouring into the office in quantities that will help the Foundation "Go Places!"

This community knows that every act of kindness, every contribution, every victory, no matter how small, makes a difference. If it were possible to highlight every single member in these pages, we'd do so.

It's truly a pleasure serving you, and I look forward to seeing you again—or meeting you for the first time—in Orlando this July!

My very best personal regards,

A handwritten signature in cursive script that reads "William H. Schmidt, Jr." The signature is written in dark ink and is positioned above the printed name.

William H. Schmidt, Jr.

President, OI Foundation Board of Directors

Local fund-raising events support the Foundation...

NJ Support Group's 10th Beefsteak Dinner raises more than \$19,500

Emma Johnston surveys the many raffle and silent auction items on display during the 10th Annual Beefsteak dinner.



The 10th Annual Beefsteak Dinner and Raffle, sponsored by the New Jersey Area OI Support Group, raised \$19,520 to benefit the OI Foundation.

The event was attended by more than 400 members, friends

and supporters, and was catered for the 10th year by Hap Nightingale Caterers. It included a steak dinner, entertainment, silent auction and raffle.

Thanks are due to JoAnn Berkenbush, Rosemarie Kasper, Bev Krudys, and Ellen Haley, as well as committee members Gretchen and Peter Strauch, Marita and Bill Schmidt, and Cathy and Tom McGarry. 

Sally Foster sales skyrocketed in '01

This year's Sally Foster paper sales raised just over \$11,000 for the Foundation, which is a 46% increase over last year's sales!

Special thanks to Patricia DeLuccia, Caleb Marston, and Gretchen Strauch, our top three sales persons, who accounted for more than 10% of the total sales!

Thanks also to Connie Kasputis for chairing the event, and to all the members of the community who made this event a success. 

Pass It On! Mentoring program changes leadership

Some names, e-mails may have been misplaced during transfer

Jamie Kendall has, with great enthusiasm, passed the wand of PASS IT ON! over to the most capable hands of Sherry Frost.

Sherry is a former member of the board, and the Foundation is delighted to have her remain actively involved in the day-to-day support of the OI community.

Those interested in participating in the mentoring program should now contact Sherry directly at selvamica@aol.com.

Unfortunately, while the transition was being made, Jamie was "saving" e-mails sent to her about the mentoring program. Her service provider automatically de-

leted the files before they could be forwarded to Sherry. If you'd written to Jamie about the program after reading about it in the August issue of *Break-*

through, please accept the apologies of Sherry and the Foundation, and take a moment to send a new e-mail to Sherry's address. 



Neeru Sharma

Correction:

In the Autumn 2001 edition of the *Breakthrough*, the article on Friendship and Activism (page 15) was written by Neeru Sharma, not Erica Smith.

Accompanying the article, we accidentally identified a picture of Erica with Neeru's name. Neeru's photo appears here.

Our apologies to Neeru and Erica, and to any members who may have been confused by our error. 

Miracle Mike (continued from page 1)

WGN Radio and Heller An Shapiro, Executive Director of the OI Foundation.

Also attending this year were OI Foundation members Steve

Kipperman, the Harshaw Family, Dr. Peter Smith, and Tim Caruso, P.T..

Plans are already underway for Miracle Michael IV, scheduled for July 22, 2002. Once again, it will be held at

the White Eagle Country Club.

We look forward to seeing you there, and thanks again to all the wonderful people keeping Michael's memory and spirit alive! 

Foundation announces volunteers of the year



Sidney Simmonds

Sidney Simmonds served on the OI Foundation Board from 1995 – 2001. During that time, he assisted in stabilizing the Foundation's finances and establishing an investment policy.

He continues to provide financial guidance to the OI Foundation, especially in the areas of investments and planned giving, and currently serves on the Finance Committee.

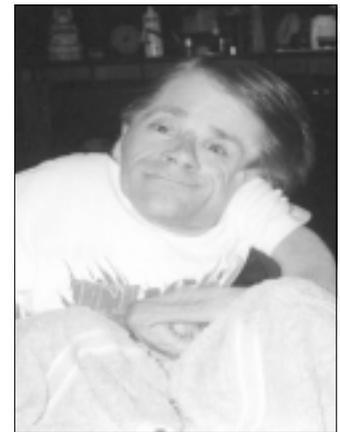
Sid participates actively in all local fundraising events, and has presented sessions on estate planning at National Conferences since 1996.

For nearly two years, David Morrison served as the chat room monitor for the OI Foundation.

He participated in the 1998 and 2000 National Conferences, hosting chat room luncheons and facilitating support group sessions.

In 1998, he founded and coordinated the Fresno area support group.

David never missed an opportunity to provide support and good cheer to people with OI. He passed away March 2001.



David Morrison

To nominate someone for the 2002 VOY Award, visit www.oif.org!

Postal concerns mean changes for Bone China Tea

Imagine a fund raiser where you don't have to worry about attire, transportation, weather, food allergies, babysitters, dancing ability, access, schedule conflicts, or even being on time. In fact, the "event" is delivered to your door with the mail.

The OI Foundation Bone China Tea takes place in the comfort and convenience of the invited guest's own home. You tell the Foundation how many people you wish to invite, and we'll send you formal invitations to address and forward to your friends and family, asking them to "join" the event by staying home and relaxing with a hot cup of tea. It's suggested that the money saved on new clothes, babysitters, transportation, and other expenses typically associated with a fund-raising event be donated to the OI Foundation.

In the past, the invitations included a tea-bag. Postal concerns have prompted us to change the event slightly this year; each invitation will include a coupon from Harney & Sons Fine Teas for a free loose tea sample or \$2 off any order from their web site. Many thanks to Harney & Sons for their generosity and support to this unique fund-raising event.

Since invitation printing and other supplies are usually donated, and volunteers do all the work, virtually all the money donated goes directly to the Foundation. The event last year raised almost \$21,000.

Invitations have already been printed and distributed, but if you would like to invite someone to the Bone China Tea, or would like information about how to participate in next year's event, please contact Jenny Wilson (e-mail JNWILSON@aol.com, telephone (914) 834-6731), or the OI Foundation (e-mail BoneLink@oif.org, telephone (301) 947-0083). A small number of invitations are still available on a first-come, first-served basis. 





(The following article is excerpted from a fact sheet, "Understanding Type I OI," prepared by the Osteogenesis Imperfecta Foundation in collaboration with Ellen Painter Dollar, a freelance writer with OI Type I, and Dr. Michael Whyte, Medical-Scientific Director of the Center for Metabolic Bone Disease and Molecular Research at the Shriner's Hospital for Children in St. Louis, Missouri. Copies are available from the Foundation or online at www.oif.org.)

What is Type I OI?

Type I OI is different from all other types of OI in an important way. A person with Type I OI has approximately half the normal amount of type 1 collagen in his or her body. The collagen that is present, however, is normal in structure. A person with Type II, Type III, or Type IV OI (the moderate to severe types of OI) has not only a reduced amount of type 1 collagen, but also collagen that is abnormal in structure. In other words, Type I OI is caused by deficient type 1 collagen. The other types of OI are caused by low levels of defective type 1 collagen.

What are the signs and symptoms of Type I OI?

OI affects people in several different ways. Even among people with Type I OI, there is variability. The following is a list of signs and symptoms common among people with Type I OI. Many people with Type I OI have only some—not all—of these signs and symptoms:

- Bones predisposed to fracture. Most fractures occur before and during puberty.
- Somewhat predisposed to other connective tissue injuries, such as dislocations.
- Skin bruises easily.
- Normal or near-normal stature, as compared with unaffected family members.
- Loose joints, low muscle tone, and lax

ligaments.

- Sclera (whites of the eyes) usually have a distinctly blue, purple, or gray tint.
- Somewhat triangular face.
- Tendency toward spinal curvature (scoliosis).
- Bone deformity absent or minimal.
- Brittle teeth possible.
- Hearing loss possible, often beginning when the person is a teen or young adult, but which may occur sooner.

Some people with Type I OI are very mildly affected. They may have only a few fractures, be of average or even above-average height, be able to walk and run, and have barely noticeable signs of OI, such as blue sclera or loose joints. In fact, some people are so mildly affected that they are not diagnosed until their teen or adult years, and in some cases only after they have a child diagnosed with Type I OI.

Other people with Type I OI have more distinct signs and symptoms. They may have several dozen or more fractures; sometimes use a wheelchair, walker, braces, or crutches for mobility; be somewhat smaller than the rest of their family; and/or require treatments such as rodding surgery.

In most cases, people with Type I OI experience fewer fractures after puberty, when the bones are no longer growing as quickly. Though it may seem that some people with mild OI "grow out of it" after puberty, the genetic defect still exists, and adults with Type I OI need to be aware of how the disorder may affect them throughout their life, especially women when they go through menopause.

How is Type I OI Diagnosed?

Babies with Type I OI may or may not be born with fractures. A baby may have other outward signs of OI, such as blue sclera or loose joints, but these signs may go unnoticed in a family with no history or knowledge of OI. Furthermore, blue sclera can occur even in healthy infants until about 18 months of age. A child with Type I OI may sustain his or her first fracture during some ordinary activity, such as when a caregiver pulls on the ankles when changing a diaper, a doctor does a

physical exam, or a toddler falls while learning to walk. Other children with OI may not experience fractures until the school years, when they begin participating in physical education, sports, and recreational activities.

The occurrence of fractures after little or no trauma is often the first clue that a child may have OI. To diagnose the disorder, a physician can look for other clinical features of OI, and obtain a family history to determine if other family members have a history of fractures or other OI symptoms. Collagen testing of a skin biopsy and/or DNA testing of a blood sample can help confirm a diagnosis of OI in some situations. However, approximately 10 to 15 percent of individuals with mild OI who have collagen testing, and approximately 5 percent of those who have DNA testing, test *negative* for OI despite having the disorder.

Families in which one parent has OI may be able to arrange for prenatal testing through chorionic villus sampling or amniocentesis. In most cases of Type I OI, this type of prenatal diagnosis requires knowledge of the affected parent's genetic mutation, which may be hard to determine. Ultrasound may not detect Type I OI in a fetus, because the child is unlikely to have fractures or bone deformity before birth. When prenatal diagnosis is not possible, or not desired, a sample of the child's umbilical cord can be taken at birth and sent for collagen testing. When a parent has OI, it is recommended that the newborn be tested and examined by a knowledgeable clinician as soon as possible. The information will help parents make decisions about their baby's care, and help protect the family from unwarranted child abuse accusations.

How is Type I OI managed and treated in children?

The cornerstones of treatment for a child with Type I OI are fracture management, therapy to regain strength and mobility after fractures, and an ongoing program of safe exercise and activity to develop muscle control and build strength. Recognizing that prolonged immobilization can weaken muscles and bones, many orthopedists prefer short-term casting of fractures, followed as soon as possible by

Q&A: UNDERSTANDING TYPE I OI

a splint or brace that can be removed for appropriate exercise.

Children with Type I OI should be monitored regularly for OI-related problems such as hearing loss and scoliosis (spinal curvature). Regular hearing tests by an audiologist in a soundproof room should begin after a child's first birthday. An orthopedist should examine a child for scoliosis annually, including x-rays if needed, starting around age six.

Are developmental delays common?

Some infants with mild OI have delays in gross motor skills, such as pulling to a stand, crawling, or walking. These delays may be due to fractures, low muscle tone, loose joints, and/or a child's fear of movement due to previous fractures. Physical and occupational therapy are recommended as soon as such delays are noticed. Therapists can instruct parents in the best ways to hold, position, and encourage their child to learn new skills. Most infants with OI will qualify for their state's Early Intervention Program, which provides therapy and other services free of charge.

What types of exercise are appropriate?

Older children with Type I OI may also benefit from physical and occupational therapy to maximize strength and function. Outside of therapy, regular exercise geared toward the child's interests helps children socialize with peers, as well as develop bone and muscle strength. Water therapy and swimming are particularly good exercises for children with OI, as the gravity-free environment reduces fracture risk. Many children with Type I OI swim, dance, ride regular or adapted bikes, and participate in other recreational and competitive activities. A child's physician and/or therapist can advise the family on safe exercise for a particular child.

How should Type I adults manage their OI?

Osteoporosis (low bone density) is an

almost universal consequence of having OI. It is therefore vital for teens and adults with OI (both male and female) to build bone density and prevent bone loss through safe exercise, diet, and in some cases, medication. It is recommended that adults with OI have a bone density test to establish a baseline, which will allow their physician to monitor whether their bone density is changing over time.

In addition to its importance for bone

behaviors such as smoking and excessive alcohol consumption are vital not only for bone health, but for general health and well-being.

Many adults with OI take bisphosphonate medications (such as alendronate). These medications are FDA-approved for preventing and treating osteoporosis in adults. Several researchers are conducting clinical trials of bisphosphonates for treating OI in adults.

Some people are so mildly affected that they are not diagnosed until their teen or adult years, and in some cases they're diagnosed only after they have a child diagnosed with Type I OI.

Are there special concerns regarding pregnancy?

Adults with Type I OI will typically know about their diagnosis when

deciding whether to have children. There is a 50 percent chance that a person with Type I OI will pass the disorder on to a child. The risk remains the same for each child. A child will usually inherit the same type of OI as his or her parent; however, it is possible that the child's signs and symptoms will be somewhat milder or more severe than the parent's. Adults with Type I OI who are considering having children may wish to consult a genetic counselor, and have a skin biopsy to confirm their own OI diagnosis before conceiving a child. Having this information on file makes it easier to test a newborn for OI, if the parents desire. Type I OI does not appear to affect fertility or predispose women to particular pregnancy complications. Research suggests that pregnancy and breastfeeding may affect a woman's bone density, and may increase the risk of fracture. It is therefore particularly important that women with OI eat a calcium-rich diet and exercise appropriately while pregnant and breastfeeding.

density, exercise is also important for maintaining strength, function, and general health. Swimming and water exercise provide excellent, safe exercise for people with OI. Walking (with or without aids), weight training, and non-contact recreational sports can also be appropriate for some people with Type I OI. Adults with OI are encouraged to consult their orthopedist, physical therapist, or other professional knowledgeable about OI to determine the most appropriate fitness program.

Bone density can also be maintained by eating calcium-rich food. Dairy products are the richest source of calcium, but some vegetables, some nuts, tofu, and calcium-fortified products such as orange juice and cereal are also sources. Adults with OI have the same needs for calcium as other adults; excessive consumption of calcium or use of supplements is neither necessary nor recommended, as it can lead to other health problems. Some medications, such as steroids (for example, prednisone) and corticosteroids, also contribute significantly to bone loss, as does smoking.

Adults with Type I OI seem to have the same risks as the general population for common health problems such as diabetes, heart disease, and cancer. Maintaining a healthy weight, exercising regularly, eating a nutritious diet, and avoiding risky

What should I expect after menopause?

Many women with Type I OI are concerned about menopause and the possibility of more frequent fractures, as additional osteoporosis can develop. The

Continued on page 8

Web advisory committee approves new “look” for the Foundation

The new site features members of the OI community and a more user-friendly interface.

The OI Foundation’s Web Advisory committee has approved the graphic overlay for our new web site, and we are rapidly approaching the launch date for the new and improved www.oif.org.

Look for the new site some time in the coming month!

The new site is the result of months of planning, and will include new features and resources to make it a more effective communication tool than ever before.

Support group leaders will soon be able to post upcoming meetings and events directly to the site, chat room

participants will be able to talk freely in a private, ad-free chat room hosted directly on the site, and regular visitors will be able to “customize” the site to deliver the information they are most interested in up front.

It would not have been possible without the extraordinary effort of the members of the Web Advisory Committee: Pete Dohm, Ellen Dollar, Heidi & Trey Glauser, Kelli Hill, Michael Johnston, Angela Mancuso, and Susie Wilson.

The committee will remain involved in the months to come as we update content, add new features, and improve the web site’s utility as a two-way communication tool between the Foundation and the OI community.

Everyone is encouraged to go to www.oif.org for more information, and feel free to send us your input!

Q&A: TYPE I OI *Continued from page 7*

experience of postmenopausal women with OI varies greatly; some do experience an increase in fractures, while others do not. The strategies mentioned above to maintain bone density and general health will help each woman maximize her chances to stay active and healthy as she ages. Bone density measurements and medicines or hormones to prevent bone loss should be discussed with the physician.

How many people have hearing loss?

Approximately 50 percent of people with Type I OI experience hearing loss starting in their teens or young adulthood. Regular hearing tests by an audiologist are highly recommended. Hearing loss, depending on what type it is, can frequently be treated with hearing aids, surgery, or a combination.

What are some Social, Emotional, and Family Issues I should be aware of?

Many people with OI Type I do not appear disabled, so there is potential for others to misunderstand or underestimate the disorder. To prevent a misunderstanding in an

unfamiliar medical setting, it helps to carry a letter, from the primary care physician, that explains OI.

Parents may provide information about preventing fractures to teachers, babysitters, or other caregivers, only to have the caregivers dismiss them as being “overprotective.” Providing written information— such as materials from the OI Foundation and a letter from the child’s doctor briefly explaining the OI diagnosis and the recommended precautions— can help reinforce the information provided by parents.

Likewise, it is important for a child’s siblings and peers to receive age-appropriate information about OI. It is common for peers to wonder why their classmate does adapted activities during physical education, or can’t participate in contact sports. Some children with mild OI are accused of being “clumsy,” “lazy,” or “faking it” when they have yet another injury. In most cases, such teasing comes out of ignorance, not malice. Many children with OI or their parents give a brief presentation to the class at the beginning of each school year to explain OI. Visual aids and props (such as the child’s braces, or a cast or splint) are particularly well-received by young children.

Why Bother?

(An open letter from an OI Foundation member about why you should consider going to the 2002 national conference.)

The Osteogenesis Imperfecta Foundation will be holding its 2002 National Conference in Orlando, Florida, from July 18-20.

I would advise anyone and everyone whose lives have been affected by OI to make sure you get there! You'll definitely be able to look back on your weekend fondly.

The only question remaining is which memories you will cherish the most.

Perhaps you will be proud of all the applicable information you learned about OI medical care and research. Various experts in these fields, with strong knowledge of OI, will present up-to-date information.

If research seminars aren't your "cup of joe," you might really enjoy the camaraderie of an all-OI social scene.

Most of my friends are able-bodied. Despite the fact that our friendships are strong, it has been evident to me for more than a decade that an able-bodied friend can never fully understand me. The different life experiences that an able-bodied woman or man has had renders her or him virtually incapable of *completely* understanding the man or woman with Osteogenesis Imperfecta.

Please do not misunderstand me. OIF Conferences are not huge "pity parties" where those with brittle bones

sit around and "share their commonly-held experiences." OI Conference attendees gather to discuss their careers, interests,

hobbies, etc. In the process, they form relationships that last a lifetime.

Finally, as if all that doesn't make you rush to get your airline tickets, we feature an enticing venue.

Orlando, FL is a luxuriously warm place to stretch out in the sun and just relax. The Radisson Hotel Orlando is completely accessible to people who use wheelchairs. Among the featured attractions at this tropical paradise is a mammoth, outdoor swimming pool. The Hotel is at the entrance to Universal Studios Florida. Disneyworld, Epcot Center, and other famous amusements are nearby.

So as you see, attending an Osteogenesis Imperfecta Conference is not a dull experience at all. There is relevant information to learn, and then use, if necessary. There are friendships to begin and existing ones to maintain. There is the posh, pleasurable site, which will cater to you and those you bring.

Which will you treasure most? Never mind. What's not to like?

— Jay Mandeville



Jay Mandeville

Board member nominations sought

Nominees are currently being sought to serve on the OI Foundation Board of Directors. Full position descriptions are available online, or by contacting the foundation offices.

The Board Development Committee is looking for nominees with a personal connection to osteogenesis imperfecta and experience in one or more of the following: accounting, finance, fund raising, organizational management, public relations, strategic planning, business, or law.

Members of the Foundation Board of Directors are responsible for ensuring the OI Foundation's long-term financial stability and integrity.

Directors recognize that in order to foster the OI Foundation's continued viability and growth, diversification of income sources is essential and they pledge to contribute needed resources and talents toward this end.

Anyone may submit a brief application to the national office, including the nominee's name, address, phone number and e-mail address, as well as information about paid and volunteer work experience. **Nominations must be received no later than March 1.**

Board members are elected for a three-year term, serving from July 1 of the first year through June 30 of the third year. They must be able to commit to two board meetings per year (8-12 hours each) and 8-10 hours per month for committee or task force assignments, as well as fund raising responsibilities. [OI](#)

Courts narrow scope of ADA protection at work

The U.S. Supreme Court recently ruled that a person who is "disabled" under the *Americans With Disabilities Act* (ADA) must have substantial limitations of their daily functional abilities, not only limitations that affect their job performance.

The Supreme Court unanimously ruled that the definition of "substantial limitations to major life activities" needs to be "interpreted strictly," and a person is not disabled if their condition does not prevent them from performing daily tasks such as dressing, walking, toileting, etc.

Thus people who do not have serious impairments that interfere with daily functional activities such as Type I OI, may not qualify for the protections of the law. Look for more on this ruling on the web at www.usdoj.gov/crt/ada/adahom1.htm. [OI](#)

2002 CONFERENCE INFORMATION

From head to toe, conference is packed with info

The Conference Committee and OI Foundation are very pleased to be able to provide you with the following list of confirmed speakers and topics for the 2002 conference, and their scheduled session times.

Thursday, July 18

- 11:30 OI: The Basics**
David W. Rowe, M.D.
Michael P. Whyte, M.D.
- 1:00 Opening Session: OI Research**
Joan Marini, M.D., Ph.D.
Mario Lacouture, M.D. *
Francis Glorieux, M.D., Ph.D.
- 3:30 President's Reception**
- 7:00 Support Group Meetings**

Friday, July 19

- 9:00 Orthopedic Surgery for Kids**
Cathleen L. Raggio, M.D.
- Children with Type I OI**
Laura Tosi, M.D.
- OI Genetics:**
Testing and Diagnosis
Peter H. Byers, M.D.
- Pain Management for Adults**
Paul Burns
- Functional Approach/Milestones**
Jamie Winter
- 10:30 Post Surgical Care of a Child**
To Be Determined
- Respiratory Health**
To Be Determined
- Bracing**
To Be Determined
- Nutrition**
To Be Determined
- Improving Kids' Mental Health**
Kay Kriegsmann, Ph.D.

Friday, July 19 (cont'd)

- 1:30 Fracture First Aid**
Priscilla Wacaster, M.D.
Peter A. Smith, M.D.
- Cardiac Health**
To Be Determined
- Neurological Complications**
Lawrence Charnas, M.D., Ph.D.
- OI: The Adult Years**
Jay R. Shapiro, M.D.
- Adaptive Equipment for Kids**
Tim Caruso, P.T.
- Abuse Allegations**
Horacio Plotkin, M.D., Ph.D.
Stephen Lazowitz, M.D.
- 3:00 Fitness for Kids**
Holly Cintas, P.T., Ph.D. *
- Scoliosis and Back Problems**
To Be Determined
- SSI & Insurance**
To Be Determined
- "The Doctor is IN" - Feet, Ankle & Shoes**
Lynn H. Gerber, M.D.
- Pregnancy Pros and Cons**
Deborah Krakow, M.D. *
- 4:30 Estate Planning**
Julianne Weiner
- OB/GYN Health**
Deborah Krakow, M.D. *
- Home Adaptation**
Karen Braitmayer *
- Wheelchair Exercise Workshop**
"No Excuses"
Sean Stephenson
- Infant & Toddler Care**
Horacio Plotkin, M.D., Ph.D.

* Denotes speakers who have been invited but are not yet confirmed.

- 7:00 Support Group Meetings**
- Saturday, July 20**
- 9:00 Strengthening Your Family - Part 1**
To Be Determined
- PANEL: Educating an Elementary or PreSchool Child with OI**
To Be Determined
- Surgical Needs of Adults**
To Be Determined
- Hearing Loss**
David Vernick, M.D.
- The Dr.-Patient Relationship**
Bonnie Landrum, M.D.
- 10:30 Strengthening Your Family - Part 2**
To Be Determined
- PANEL: Educating a High School Child with OI**
To Be Determined
- Dental Care and Orthodontics**
To Be Determined
- Osteoporosis & Prevention**
To Be Determined
- PANEL: Ask the Doctors - OI Kids**
Joan Marini, M.D., Ph.D.
Peter A. Smith, M.D.
Michael P. Whyte, M.D.
- Mental Health for Adults**
Kay Kreigsmann, Ph.D.
- 1:30 Closing Session**
Sean Stephenson
- 5:30 Awards Dinner**
- 7:30 Talent Show**
- Teen Room Topics:
Careers
Driving
"Being Different"
Suzanne Richard
Colleges & Careers

CONFERENCE FEES

Continued from page 1

ions than before, has drawn more top researchers and physicians, and is hosted in a more convenient location than many in the past, according to the committee. It's also being held in a prime vacationing area for families.

"The conference committee and the Fine Wines, Strong Bones organizers really deserve our thanks and congratulations for managing to do all that at a lower overall cost to

This is the first time we've been able to lower registration fees... a direct reflection of the efforts of the committee and the Fine Wines, Strong Bones organizers.

the participants," according to Heller An Shapiro, Executive Director of the OI Foundation.

"When you look at the incredible airfares and hotel rates available right now, this may be the biggest conference yet," Shapiro said. "It may also be the most affordable." 



2002 National Conference

July 18-20

Orlando Radisson Hotel

Registration Information

Dear Friends,

I'm already counting the days until the start of our 2002 National Conference! We've done our best to make sure it will be both informative and enjoyable for everyone attending.

Thanks to the many people who have helped by sharing ideas for everything from session topics to selecting speakers. Our OI Foundation volunteers have been working hard to design the best conference ever!

Don't miss this one-of-a-kind opportunity to make new friends who share your concerns and triumphs, as well as rekindle relationships with old friends.

Just as importantly, take advantage of the opportunity to learn from nationally recognized experts and from people who are living with OI.

And while you're in the area, be sure to visit the area's spectacular attractions and amusement parks. We will include travel tips and information on local attractions in your registration packet. There may never be a better opportunity to make that dream vacation come true for you and your loved ones!

I look forward to seeing you!

Sincerely,

William H. Schmidt, Jr.
President
OI Foundation

Conference Highlights

Child care services provided for children ages 1-12
Teen Room with special topics and activities
Annual OI Foundation Membership Meeting
Information and Resource Center with resources on virtually every aspect of living with OI
Wheelchair rental and repair services available on site
Hearing loop available in all sessions, CART in general sessions
Exciting new session topics and research information
Ideal family vacation location, just minutes from most major Florida attractions

Schedule at a Glance

Wednesday, July 17

Registration 4:00 p.m. - 7:00 p.m.
Welcome Reception 7:00 p.m. - 9:00 p.m.

Thursday, July 18

Registration 9:00 a.m. - 12:00 noon
OI: The Basics 11:30 a.m. - 12:30 p.m.
Child Care 12:30 p.m. - 6:00 p.m.
6:30 p.m. - 9:30 p.m.
Opening Session 1:00 p.m. - 3:30 p.m.
President's Reception 3:30 p.m. - 5:00 p.m.
Support Sessions 7:00 p.m. - 9:00 p.m.

Friday, July 19

Child Care 8:30 a.m. - 12:30 noon
1:00 p.m. - 6:00 p.m.
6:30 p.m. - 9:00 p.m.
Breakout Sessions 9:00 a.m. - 5:30 p.m.
Support Sessions 7:00 p.m. - 9:00 p.m.
Dance Party 9:00 p.m. - Midnight

Saturday, July 20

Child Care 8:30 a.m. - 12:30 noon
1:00 p.m. - 3:30 p.m.
Breakout Sessions 9:00 a.m. - 12:30 p.m.
Closing Session 1:30 p.m. - 3:00 p.m.
Awards Dinner 5:30 p.m. - 7:30 p.m.
Foundation Talent Show 7:30 p.m. - 10:00 p.m.

General Conference Information

Registration Fee

Registration fees cover all conference sessions and receptions, child care, all teen room activities, a continental breakfast each morning, one seat at the Awards Dinner, and admission to the Dance Party. Additional guests not registered for the conference may attend the Dinner at a cost of \$35 each.

Method of Payment

The OI Foundation will accept U.S. funds in the form of check, money order, Visa, MasterCard, Discover or American Express. For checks and money orders, payment must be made in full. Two options are available for credit card users. (1) Full payment can be made on your credit card; or (2) You can divide your total registration fee into three equal payments to be billed in April, May and June. The deadline for using this payment option is **April 12, 2002**.

Cancellation Policy

Conference fees will be refunded in full if written notice is received by **June 7, 2002**. Notice may be mailed or faxed. One half of the registration fee will be refunded for all written cancellations received by **June 28, 2002**.

Airports

Orlando International Airport is 15 minutes from the Orlando Radisson. The airport is served by most major airlines.

Hotel

The Orlando Radisson Hotel offers a special group rate of \$99 per night, single, double, triple or quad. Children under 18 may stay free of charge in their parent's room. This special rate is available from July 12 - July 25.

Register early. To qualify for the special room rate, it must be reserved by June 27. The hotel has **14 ADA accessible rooms**, 5 of which have roll-in showers. These rooms are available on a first-come, first-served basis, and preference will be given to those who require roll-in accommodations.

You must mention the OI Foundation to receive the special room rate. To make a reservation, call the **Orlando Radisson Hotel** directly at 407-351-1000, call the National Radisson Reservation Office at 800-333-3333, or link to it through www.oif.org.

Transportation

Several ADA accessible shuttle services are available for transportation between the airport and the hotel. Most **require a reservation with a minimum of 48 hours notice**. A list of the available shuttle services will be included in your registration confirmation packet.

More than a dozen major rental car agencies have fleets in the city, and over half offer services and vehicles for handicapped drivers.

Awards Dinner

The awards dinner will take place on Saturday, July 20 from 5:30 p.m. - 7:00 p.m. and will be followed by the OI Foundation Talent Show. The cost of admission to the dinner is included in your registration fee. Additional tickets may be purchased in advance for \$35 each (\$40 at the door). Please select your dinner preference for Chicken, Vegetarian or Kosher meal when registering.

Childcare

Childcare services for children ages 1-12 are being offered through ACCENT on Children's Arrangements, Inc., during all sessions. ACCENT is a world-wide childcare agency whose employees are qualified, screened, bonded and experienced. ACCENT will be trained in handling children with OI before the conference and will offer specially designed age-appropriate arts & crafts and activities.

Teen Room

For teens with and without OI, ages 12-18, a special room has been set aside so that they may meet and interact with other teenagers during the conference sessions. Special topics and activities will be offered for this group.

Tours and Attractions

The Orlando Radisson Hotel is conveniently located near many of Florida's world famous amusement and theme park attractions.

Visit www.oif.org and check out the winter newsletter for ideas on how to turn the conference into a family dream vacation! All major parks now provide accessibility and accommodations for persons with disabilities. With a small amount of planning, it truly is practical for any members of the OI community to enjoy Orlando's unique attractions.

Osteogenesis Imperfecta Foundation 2002 National Conference Registration Form

Main Registrant (see next page for additional names if registering as a group or family)

Name ^{Mr. Mrs.} _____ Day phone () _____
^{Ms. Miss} _____
 Street Address _____ Evening phone () _____
 City, ST, Zip _____ Country _____
 E-Mail _____ Fax () _____

Registration Fees

There is no charge for infants (under 3 years).

Conference registration fees include all sessions, child care, two continental breakfasts, dance party, receptions and the awards dinner.

	Members	Non-Members	No. of Persons	Amount	
Early Bird (by 4/12)					<div style="text-align: center;">OI Foundation Membership</div> <p style="text-align: center;"><i>Join</i> the OI Foundation to qualify for the member rates!</p> <p><input type="checkbox"/> Friend membership \$20</p> <p><input type="checkbox"/> Family membership \$60</p> <p><input type="checkbox"/> Supporting membership \$120</p> <p><input type="checkbox"/> Patron membership \$240</p> <p><input type="checkbox"/> Benefactor membership \$500</p> <p><input type="checkbox"/> Sustaining membership \$1,200</p> <p><input type="checkbox"/> Legacy membership \$10,000</p>
Adult	\$90	\$140	x _____	\$ _____	
Child (3-17)	\$65	\$110	x _____	\$ _____	
Regular (after 4/12)					
Adult	\$120	\$170	x _____	\$ _____	
Child (3-17)	\$95	\$140	x _____	\$ _____	
Awards Dinner Only	\$35	\$35	x _____	\$ _____	

Total Registration and/or Dinner Fees \$ _____

Subtract 10% Group Discount for groups of 4 or more \$ _____

Add Membership Fee if you're joining or renewing today \$ _____

Add a Tax-deductible Contribution to offset rising costs \$ _____

Total \$ _____

The OI Foundation is pleased to announce reduces fees this year!

Help defray the expense of the conference by making a tax-deductible contribution.

Payment Information

Enclosed is my check or money order made payable in U.S. dollars to the OI Foundation.

Please print all information exactly as it appears on the credit card.

Please charge my credit card in full. Please charge my credit card in 3 equal installments.
(you must register by 4/12/02 to use this option)

Visa MasterCard Discover American Express

Card Number: _____ Exp. Date: _____

Name: _____ Signature: _____

Additional Attendees

List your entire party as you wish the names to appear on name badges and in the conference directory.

Full Name (e.g. Mr. John Doe, Ph.D.)	Address (If different from previous page)	Relationship to OI	Childcare Needed (Age)	Teen Room Needed (Age)	Awards Entree
					<input type="checkbox"/> Chicken <input type="checkbox"/> Vegetarian <input type="checkbox"/> Kosher
					<input type="checkbox"/> Chicken <input type="checkbox"/> Vegetarian <input type="checkbox"/> Kosher
					<input type="checkbox"/> Chicken <input type="checkbox"/> Vegetarian <input type="checkbox"/> Kosher
					<input type="checkbox"/> Chicken <input type="checkbox"/> Vegetarian <input type="checkbox"/> Kosher
					<input type="checkbox"/> Chicken <input type="checkbox"/> Vegetarian <input type="checkbox"/> Kosher

Have you attended an OI conference before? Yes No Date of planned arrival at Conference _____ Are you staying at the Radisson? Yes No

Please indicate special needs for conference sessions: Assisted listening device Sign language interpreter Wheelchair access Other: _____

Please read & sign!

On behalf of myself and any persons listed on this Registration Form, I release the Osteogenesis Imperfecta Foundation, Inc., its employees, officers and agents (collectively "OIF") from any liability whatsoever arising from any conduct, including any alleged negligence by act of omission of OIF in connection with attendance at the 2002 OIF National Conference.

Signature: _____

Date: _____

Interest Survey -- Please mark the sessions you plan on attending *

Medical Issues:

- Opening Session: OI Research
- OI Genetics: Testing and Diagnosis
- Pain Management for Adults
- Developmental Milestones
- Respiratory Health
- Bracing
- Nutrition
- Fracture First Aid
- Cardiac Health
- Neurological Complications
- Scoliosis and Back Problems
- OB/GYN Health
- Surgical Needs of Adults
- Hearing Loss
- Dental Care and Orthodontics
- Osteoporosis and Prevention
- Reflexology

Parenting/Children:

- Orthopedic Surgery for Kids
- Children with Type I OI
- Post Surgical Care of a Child
- Mental Health for Children
- Ask the Doctors: OI Kids (panel)
- Infant and Toddler Care
- Educating the Child with OI (panel)

Living with OI:

- OI: The Basics
- OI: The Adult Years
- Pregnancy Pros and Cons
- Home Adaptation
- Strengthening Your Family
- The Doctor/Patient Relationship
- Adaptive Equipment for Kids
- Mental Health for Adults
- Careers (Panel)

Exercise:

- Fitness for Kids
- Fitness for Adults: Foot & Ankle
- Exercise Workshop: "No Excuses!"

Finances/Legal:

- SSI and Insurance
- Estate Planning
- Abuse Allegations
- Advocacy
- Fundraising

Please return to:
 OI Foundation, 804 W. Diamond Ave.
 Suite 210, Gaithersburg, MD 20878
 Credit Card Orders, fax: 301-947-0456
 Questions? 800-981-2663

* Indicating your interest here does not obligate you to attend the session(s). The information gathered by this survey will be used by the committee to determine interest, allocate appropriate room sizes and develop supporting materials. This list is not inclusive. Sessions may be added or changed at the discretion of the conference planners. A final list of available sessions and a schedule of events will be included in your registration confirmation package and will be available on our website at www.oif.org.

How To:**Make your trip to Orlando an adventure for everyone!**

by Priscilla Wacaster, M.D.

In January, 2000, my family and I started on an adventure: travelling the U.S. in a camper with our two kids. Both of the children and I have Type I OI, but that didn't stop us from making Disney World the first place we visited!

After our first day at a Disney park, it was obvious that we couldn't see everything we wanted to see, so we upgraded our tickets to annual passes. Over the next 12 months, we spent a total of 19 days in Disney parks. Part of that time was spent with everyone ambulatory (one person with a walker or crutches) and part of that time was spent with one person in a wheelchair because he had rodding surgery only a few weeks earlier! Here are a few things we learned.

Get plenty of rest

This is an Unhappy Scenario: The family is out late doing whatever, gets a few hours of sleep, then awakens to a rush of getting ready for the day,

including grabbing a donut at the continental breakfast provided by the hotel. About the time they arrive at the park of their choice, pay \$55 each for tickets for the day, and get in the gate, the sugar high from the donut is wearing off and everyone is cranky. But, as Dad points out, too much has been paid for tickets to even think about leaving before the park closes. The day is hot, the lines are long, and somebody thinks, "If this is what family fun is all about, I'm staying home next time."

Start early

Here is our suggested schedule: Get a good night's sleep. Get up early and eat a good breakfast. Pack lunch and snacks in a backpack—there is no regulation against it at Disney World. Then be at the park when it opens. Lines are usually shorter early in the day and the temperatures are cooler. Eat a mid-morning snack. Leave the park around lunch time to go to the hotel for a couple of hours of rest during the hottest part of the day, then return to the park for the

evening and fireworks. Take or buy snacks and pause in the fun every couple of hours to eat a bite. Snacks also make long waits more bearable.

Remember, Florida is hot in the summer. A small bottle of water is worth its weight in gold for drinking and for splashing on hot bodies. Take one in or buy it inside then refill it from the drinking fountains.

Get special guest passes

The first place to head upon entry to one of the parks is Guest Services. The Disney parks will issue a guest with a disability a small card that identifies the guest as having a disability so that accessible entrances and seating may be used. Universal Studios and Sea World have similar programs, and I suspect that all theme parks across the country have something if you go by and ask.

This is good to have even if the disability is obvious, such as use of a power wheelchair. They will also issue a card that will allow the family to use a stroller like a wheelchair.

Continued on page 17

RESERVATION INFORMATION

To **reserve your accommodation** at the Orlando Radisson Hotel at the entrance to Universal Studios, call 1-800-333-3333 or 1-407-351-1000. Remember to mention that you are with the OI Foundation group in order to get the discounted group room rate.

Make your reservations online using the URL below, or visit the OI Foundation's website and click on the link for conference registration on the homepage.

http://www.radisson.com/RAD/Special_Offers/OfferDetail.jsp?offerId=6691

If you made reservations at the Orlando Airport Marriott and now need to cancel those reservations, call 1-800-228-9290, or 1-407-851-9000.

ARTICLE

Traveling with wheelchairs, oxygen requires planning

Traveling today is daunting enough, but when you add in the need for a power wheelchair or oxygen, it may seem even more overwhelming.

With careful planning, the need for a wheelchair or oxygen should not prevent you from joining us in Orlando. While there's no substitute for a travel agent who's experienced with assisting travelers with disabilities, the following questions and answers should help relieve some of the apprehension.

What is the best way to travel by air with a wheelchair?

There have been many horror stories about what airlines have done to power wheelchairs by the time they arrive at their destination. However, most—if not all—of those stories might have never happened with some simple preparation. Here are some tips to prevent mishaps:

- Arrive early and always check the chair or scooter at the boarding gate. Request that it be delivered to you at the destination 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 arrive early



to make your request.

- If you need assistance transferring to a plane seat, take responsibility and 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 are even too narrow to safely navigate with crutches). Some airlines offer aisle chairs, which are narrower and provide easier access to restrooms, if needed, but you need to call in advance and request it be brought to the plane.

How do I travel with oxygen?

Air travel with oxygen can be accomplished comfortably and safely with advance planning. All US 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 must use airline-supplied oxygen. Requirements vary between carriers, but they may require advance arrangements ranging from 48 hours to 7 days.

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; see the "Wheelchair/Equip Rentals" item in the "Travel Tips" section on page 19.

This article was excerpted from a Q&A published in the Jan/Feb 2000 issue of Breakthrough. Rosemarie Kasper contributed to the original article. 

Additional Disability Travel Resources

Emerging Horizons

P.O. Box 278
Ripon, CA 95366
(209) 599-9409
Accessible travel newsletter.

Paralyzed Veteran's Association

(800) 444-0120
Call for a free booklet on air travel or to subscribe to their air travel newsletter.

Access for Disabled America

436 14th St., Suite 200
Oakland, CA 94612
(510) 419-0523
Donation-based.

How To: Make your trip enjoyable for everyone

Continued from page 13

This is invaluable if the child cannot walk (or if the adult cannot carry the child) for long distances.

Many of the buildings or lines require that strollers be left in parking areas, but with the card, the child can use the stroller inside the buildings (which are often immense) or the child can have a nice place to sit while waiting 30 minutes or more for a ride or show. It also entitles the family to sit in the seating reserved for persons with disabilities for parades and shows, which is often the front row.

Alternate entrances

Watch carefully for the familiar “person in a wheelchair” blue and white sign, which indicates alternate entrances, especially at rides.

Show the card to the first employee you see at each ride and they can help you. The employees are good about treating persons with disabilities like V.I.P.’s.



Also, most rides will allow a person with a disability and their party to go through the ride more than once, if desired. The 3D rides where the seats move as you watch a visual image on a big screen have one place where the seats do not move or shake. And if a ride is not appropriate for a younger member of the party, one person can stay at the head of the line with the youngster while the others ride, then someone else can stay behind while that person goes in with the next group instead of having to wait in the long line again.

Many of the shows have areas that allow persons with disabilities to wait that are not as crowded and often allow entry prior to opening the doors to the masses. Especially for a person who breaks bones easily but has no immediately visible indication of it (I’m speaking to those of us with Types I and IV OI), this feature alone justifies getting the card.

Equipment Rentals

Every park has strollers and wheelchairs, including a few power chairs, for rent. For a person who ambulates freely, but tires easily, renting a wheelchair can make the day less exhausting and much more fun.

Parades: To go or not to go?

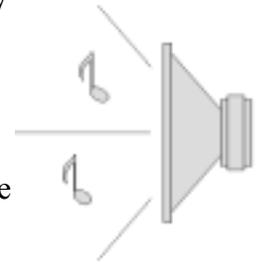
They are wonderful and a lot of fun, especially for the kids, but the areas roped off for persons with disabilities fill up early. Plan to be in place at least an hour before the parade starts (maybe even longer if the park is really crowded). Our family thought they were worth the wait.

If you can bring yourself to miss the parade, all those people lining the streets mean that there are fewer people in line everywhere else and you may be able to get a character’s signature or catch a ride with less waiting.

Sign here, please

If you like to see characters, you will notice a lot of kids with autograph books that the characters will sign. Purchased in the park, the books are a bit pricey. I bought small, spiral-bound books for much less and took them with us. The kids really enjoyed seeing the familiar faces, having their

picture made with them, and getting the signatures to take home. The parks will take a picture for their profit making, but allow you to make video or still photos with your own cameras. We even had several occasions where an employee offered to take a picture of all of us with our camera. The characters were always very gentle and sweet with the kids, despite bulky costumes.



Hearing protection

Many of the shows have loud special effects, but often just the regular speaking or music can be loud as well. Consider taking ear plugs if one of your party is sensitive to this.

Souvenirs from home

There are some things you can only get inside the Disney parks. But, if you have time and access to a vehicle, make a run to Wal-Mart for a great selection of Disney souvenirs, including postcards, at great prices. For an even better deal, go to your hometown Wal-Mart to buy Disney products such as beach towels and surprise your kids with them while in Orlando. The same towel will cost more at the Orlando Wal-Mart.

Plan ahead, revise at will

Resign yourself to the fact that you will not be able to see everything. Take a few moments with a guide book or the park map to decide what you simply cannot miss. For example, can you go to Sea World and not see the whales perform? Formulate a general plan that includes the “must see” items and then fit in whatever else you can. 

TRAVEL TIPS

Discount Tickets

Most area theme parks, including Disney World, offer discounted admission to persons in town for conferences or meetings. At Disney World, for instance, you can save on admission after 2 p.m. by wearing your conference ID when you purchase the passes.

Online Airfare

Airlines are offering discounted fares across the board to encourage vacation travel. Since the OI Foundation cannot negotiate lower group rate fares than are currently being offered on line, we encourage you to surf the web now while the specials are being offered.

The OI Foundation will not be recommending a single airline based on a discount group rate.

IDs are Essential

Having a state-issued picture ID is now essential to air travel, due to increased security at airports and ground transportation centers. You will be asked repeatedly as you make your way through the airport to provide proof of identity.

While a driver's license is the most common and preferred ID, passports are permissible, as are work or student picture IDs **only if accompanied with a government issued ID** such as an **original** birth certificate or Social Security card.

To be safe, carry multiple IDs in separate bags, if possible. For convenience and safety, you might also want to pick up a badge holder or ID holder at any office supply store, and **wear** your ID.

Extend Your Stay

If you're interested in staying a few extra days to explore Orlando, you might want to check out Bernstein & Associates' accommodations at their website, www.villasinorlando.com.

Founded by a disabled veteran, the organization lists fully handicapped accessible rental vacation homes in the Orlando area, often at rates that are cheaper than the resort hotels!

Accessible Transportation

There are a number of agencies in Orlando that specialize in renting accessible vans, and they often deliver directly to your hotel or the airport. Check out pinacletravel.com (888-894-8747) or wheelchair-getaways.com (800-242-4990) for more information.

Sweepstakes

Continued from back cover

The response so far has been incredible. We're fielding dozens of calls daily from members requesting more tickets to distribute, and the sweepstakes shows every indication that it will outperform our expectations. At the current rate of response, it should bring in more than our traditional winter appeal!

If you haven't received a sweepstakes packet in the mail, log on to www.oif.org and let us know. If your tickets are distributed but you haven't sent the stubs to the OI Foundation, please do so soon. Ticket stubs must be received no later than April 1, 2002, to be included.

Thanks for your enthusiasm! This campaign would not have been so successful—a win/win proposition for the Foundation and it's members—without your support. 

Dear Friends,

Many of you reading this newsletter have by now received information about (and tickets for) the OI Foundation "Going Places" sweepstakes. As chairperson for this fund-raiser I have good news and bad news. First the good news: The response has been overwhelming, and hundreds of people are already eligible for the drawing. The bad news? There is not much time left before the grand prize drawing. I urge you to distribute as many tickets as possible before the deadline of April 1, 2002. Please contact the OI Foundation offices for additional tickets as soon as possible.

I want to take this opportunity to thank a very loyal supporter of the foundation, Amy Ley, for her efforts in obtaining the grand prize and to American Airlines for making the donation.

This fund-raiser is being conducted in lieu of the annual education appeal letter that is generally sent out in the winter months, and therefore is a very important source of funding for the foundation. While this is the first time we have attempted a sweepstakes of this kind, we are really excited about its potential, and we hope that you can help us make it a real success.

Thanks to all those who've already sent in tickets—but don't stop now, there's still time!

Good luck in the drawing!



Pete Dohm

"Going Places" Sweepstakes Chair

Wheelchair/Equip. Rentals

If you'd rather not travel with a powered wheelchair or oxygen, but need it after your arrival in Orlando, go to caremedicalequipment.com (800-741-2282), rainbowwheels.com (800-910-8267), or walkermobility.com (888-726-6837) to enquire about rental equipment for your stay in Florida.

Getting Beyond Checkpoints

While posted security signs say none without a boarding pass may go beyond the checkpoints, persons assisting someone with a disability are allowed access all the way to the boarding gate. The escort **must** have a valid ID.

Airports and/or airlines will also provide curb-to-gate assistance to those with a disability who are travelling alone.

Medical Carry-ons

Travellers are now limited to two carry-on bags each, but that restriction **does not** apply to medical equipment, supplies, or assistive devices.

Pediatric Aisle Chair

Dee and Bruce Baraw wrote to the Foundation to let us know about a pediatric-sized aisle wheelchair, 18 inches off the floor, that is now available on some airlines. Call in advance to find out if the chair is available.

Oxygen, Wheelchair Info

Excerpts from a Q&A on travelling in the March/April 2000 issue of *Breakthrough* appear on page 16. Reprints are available by contacting the foundation offices, or online at www.oif.org.

More Travel Information

Access-Able Travel Source is a one-stop resource for disabled travel planning and information, which includes:

- Lists of equipment rental and repair shops,
- Reviews of attractions and details about handicapped accessibility,
- Lists of lodgings with roll-in showers, alert kits, TTYs, closed caption TV, or any combination of services,
- Airport accessibility tips and support information, and
- An extensive list of disability lodging and travel and web sites.

www.access-able.com
(303) 239-2979

MEMBERSHIP APPLICATION

I/We want to become a member/members of the Osteogenesis Imperfecta Foundation, Inc.

- | | |
|--|----------|
| <input type="checkbox"/> Friend membership | \$20 |
| <input type="checkbox"/> Family membership | \$60 |
| <input type="checkbox"/> Supporting membership | \$120 |
| <input type="checkbox"/> Patron membership | \$240 |
| <input type="checkbox"/> Benefactor membership | \$500 |
| <input type="checkbox"/> Sustaining membership | \$1,200 |
| <input type="checkbox"/> Legacy membership | \$10,000 |

International memberships: Please add \$11 (US) for postage costs for Individual, Associate, Supporting and Patron memberships. International Benefactor, Sustaining, and Legacy members, please add \$50 (US).

Total gift commitment \$ _____

- Check VISA MasterCard
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Account # _____

Exp. Date _____

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Inclusion in the Annual Membership Directory is a membership benefit. Please indicate your preference:

- I do not want to be listed in the Annual Membership Directory.
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Relationship to OI:

- Person with OI
 Parent of person with OI
 Other relative of person with OI
 Member of medical community
 Other (describe) _____

Make checks payable to the OI Foundation. Gifts are tax deductible to the extent allowable by law. Memberships are for a 12-month period and include a subscription to *Breakthrough*.

Osteogenesis Imperfecta Foundation
804 W. Diamond Ave., Suite 210
Gaithersburg, MD 20878
Fax: (301) 947-0456

SPOTLIGHT

Two teen members carry Olympic torch on it's relay to Utah

Two members of the OI Community, Kristen Antolini and Ryan Roquet, recently participated in the historic Olympic Torch Relay by carrying the torch in a segment of its trip from Atlanta, GA to Salt Lake City, Utah.

Torch bearers were selected because of their “embodiment of the Olympic Spirit” and their inspiration to others, according to relay officials.

The bearers are nominated by friends, family or co-workers, and the nominations are then reviewed by a community judging panel.

Kristen, a freshman at West Virginia University, was diagnosed as having OI as an infant. While she’s been forced to enjoy sports only from the sidelines, it hasn’t dampened her Olympic spirit according to her mother, Martha, who nominated her to carry the torch.

“We were told she wouldn’t grow— wouldn’t walk,” Martha said, “but luckily that hasn’t happened.”

Unable to participate on the field, Kristen soon discovered a talent for music, and she’s been unstoppable ever since.

She is a vocal performance major at WVU, and a pianist. She also acts as a cantor at St. Mary’s Catholic Church in Stary City.

Kristen has performed in “A Christmas Carol,” “Cinderella,” and “Everything Goes” in the West Virginia Public Theater. She’s a volunteer for SteppingStone and has assisted the OI Foundation by providing the youth’s point of view while serving on the advisory committee, by operating the youth e-mail forum, and by assisting in the editing of “Growing Up with OI, A Guide for Children.”

Kristen was suprised to learn she was chosen to bear the torch, but her mother was certain she was a natural candidate.

“When you live with a disability, you don’t particularly think you are an inspiration to others,” Martha said. “It’s your normal life.”

“But [participating in the relay] is our way to show Kristen that she is an inspiration,” she continued.



Top to bottom: Kristen Antolini, the Olympic Torch, and Ryan Roquette (in wheelchair) with his assistant, Kim Holmes-McClung

“She’s always been an inspiration to us.”

Ryan Roquet was also suprised to learn he was chosen to carry the Olympic torch. In fact, his entire family was suprised.

Ryan’s nomination came from a third party, Tim McClung, the husband of his school-assigned aide. Kim Holmes-McClung has been with Ryan-- a freshman in high-school-- since the 4th grade, helping him navigate the crowded halls either in his wheelchair or on crutches. Her husband has been so inspired by tales of Ryan’s courage and spirit over the years, when he heard about the relay he didn’t hesitate to nominate Ryan.

“I watched Ryan’s arm break at a school basketball game when another kid gave him a high-five,” Tim explained, “and he didn’t say a word. He waited a few minutes, turned to Kim and very quietly told her he thought his arm was broken.”

That unbreakable spirit, combined with his low-key response out of concern for the other student, had a lasting impact on Tim.

“If anyone has the right to complain, it’s Ryan,” Tim said, “but he’s always up, always smiling. His bones may break, but his spirit never will. And I couldn’t think of a better picture than the two of them carrying the torch,” he said.



Ryan considers himself “just another student.” He plays in the marching band at school and enjoys typical teenager past times; playing on the computer, hanging out with his friends, even playing basketball. There are a

few differences, of course. His friends “high five” him on the court by slapping him on the chest, and Kim had to learn marching band maneuvers so she could push him on the field. However, all in all, he treats every day just like any other kid, according to Kim.

“He’s simply a wonderful person,” she said. “Not because of what he’s done in spite of his disability, but simply because that’s who he is.”



HONORARY AND MEMORIAL DONATIONS

OCTOBER 1, 2001 TO DECEMBER 31, 2001

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Bill & Helaine Davis

To make a tribute gift to the OI Foundation, please include with your donation: your name and address and the name and address of the person you are honoring. For memorial gifts, please provide the name of the deceased and their family's name and address. Gifts should be sent to: OI Foundation, 804 W. Diamond Ave., Suite 210, Gaithersburg, MD 20878.

ARTICLE

Here's a short take on a few more popular attractions

by Priscilla Wacaster, M.D.

The EPCOT Center

EPCOT offers an opportunity to visit many foreign countries in a very accessible manner. There are great science-type rides and exhibits, too. Most rides require transfer out of a wheelchair, but there are alternate entrances to avoid pushy crowds. There is a spectacular lights and fireworks show in the evening. The shortest lines to meet characters were here, but the location is easy to miss if you aren't looking for it. The attractions are mostly indoors with air conditioning, but between the buildings is a lot of walking. Young kids may not find this park as interesting as older elementary and teenagers.



The Magic Kingdom

Disney's oldest and smallest park is often so crowded that it closes to additional guests. The newer rides or recently renovated ones allow wheelchairs to move through the usual que lines, but have alternate accessible areas as you near the ride. Most require transfer out of a wheelchair, but, for example, "It's A Small World" has a boat that the wheelchair can be wheeled onto. It has some great roller coasters for the big kids, but really is designed more for the younger set. Show the pass card to an employee before you wait in any lines.



MGM Studios

Everything is very accessible. The tram that takes you back onto the filming lots has a ramp to put the wheelchairs directly on the tram. It is fun to see how movies are made. The evening show, *Fantasmic*, is interesting, but has some scary elements that our kids found alarming. Seating opens two hours prior to the show and it is a good idea to



get there early. This park is designed with teenagers in mind, but has some parts for younger kids, too.

The Animal Kingdom

This is a zoo, of sorts, but the best zoo I've ever seen. On the safari ride, the driver of the wheelchair accessible vehicle can push a button to avoid the big shaking and jerking of a bridge "collapsing." The shows have seating on the front row, if desired, for persons with disabilities. The outdoor area for meeting Disney Characters is the nicest of all the parks. For animal lovers, it is great!



Other venues

This may come as a surprise to some, but there is more to central Florida than the major theme parks. There are dinner theaters, outlet shopping centers, and several nearby lakes and state parks. There is even a farm that advertises that every visitor gets to milk a cow, and Olde Town, which is sort of like a carnival with rides and novelty shops.

The Kennedy Space Center

If you have only one day or part of one day, I suggest visiting Kennedy Space Center. The free areas are very nice and an interested person can easily spend several hours in them. Most of it is indoors or on air-conditioned buses. The educational building has a great library for teachers and a wonderful hands-on room for kids, if it is not being used by a school group. There are nice IMAX films, for which tickets can be purchased separately or in combination with the other attractions. The full tour tickets are about two-thirds the cost of a day ticket at one of the big theme parks, and any unused portions remain good forever.

The tour of the Space Center has been upgraded recently, so even if you've visited before, you may want to go again.



Continued on page 23

Match This!**Anonymous donor pledges \$100K**

Here in *Breakthrough* we read a lot about members of the OI community who confront challenges. These challenges are often met with creativity, strength, and “can do” attitudes that seem to foster success.

This year, our board of directors is facing an incredibly exciting challenge, one that is calling out for all the creativity, strength and “can do” we’ve got.

A generous supporter has offered to match all new and increased donations *raised by the OI Foundation*

board members in 2002, up to \$100,000. Issued anonymously, this challenge serves as an extra source of motivation for our board, and it will be a terrific source of funding for the programs, research and support services the Foundation provides to the community.

If you would like to assist the board of directors in their fund raising efforts, please contact Julianne Weiner, the Foundation’s Development Director, at (301) 947-0083 or by writing to jweiner@oif.org. 

Do you have a creative fund-raising idea? Have tips you’d like to share, or lessons learned? The OI Foundation would like to help you share what you know with the rest of the community. Call, write, or e-mail, and help us keep the community informed!

New website for “adaptive” ideas

If you’ve adapted a piece of sports equipment to accommodate the special needs of yourself or your child, a new federally-funded non-profit organization has a website that can help you spread the word.

It’s also a great resource if you or your child is frustrated by sitting on the sidelines and want to get in the game.

The site lists adapted equipment, with photographs and instructions. It’s new, so the list is limited but growing rapidly, and your contribution can make a difference!

www.ranchorep.org

OTHER ORLANDO ATTRACTIONS *Continued from page 22*

The reenactments will give you goosebumps and may even bring a tear to your eye. The buildings are all accessible, though the buses are not. But they have a special shuttle for those who must remain in a wheelchair, and wheelchairs are available at each bus stop free of charge for guests who tire from long walks.

The space shuttle launch schedule can be viewed from the NASA website. They average about one per month.

The Space Center facilities are closed for a window of time around a launch, but there are nice, free areas where a

launch can be seen, if you are interested.

The causeway passes to see a launch on the Space Center property must be requested months in advance, or from a NASA employee, if you know one.

One final reminder...

Orlando is a great place to visit and there is something for everyone to enjoy. My final advice is to stay as long as you can to allow time to experience some of the fun without totally exhausting everyone, and don’t forget the water bottles! 

RESEARCH UPDATE *Continued from page 2*

expression of the gene that synthesizes the mutant collagen in OI were explored.

- Discussion on transplantation focused on how to get the appropriate cells into the bone, how to determine if they are working, and how to keep the new cells active. Again, experts who are not investigating OI directly were invited to share their experiences. Novel treatments included work with a transcription factor that would enhance the number of osteoprogenitor (bone building) cells.
- Discussion of bone biology included information about minerals and proteins that affect bone growth. Improved knowledge of bone biology may help to identify possible treatments. Studies of bone turnover in mice may help to determine how age influences OI.

For more information

The meeting ended with a proposal to develop internet-based working groups, so researchers could work faster by regularly sharing their results and learning from each other’s progress. This meeting certainly expanded the scope of OI research and accelerated the search for treatments and a cure. For more information about this meeting, or about how you can partner with the OI Foundation to support OI research, contact Heller An Shapiro at 301-947-0083 or hshapiro@oif.org 



Osteogenesis Imperfecta Foundation, Inc.
804 West Diamond Ave., Suite 210
Gaithersburg, MD 20878 (USA)
(800) 981-2663 or (301) 947-0083
Fax: (301) 947-0456
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**Conference
Registration
Inside!**

SWEEPSTAKES IS WIN/WIN FOR FOUNDATION, MEMBERS

Since September 11th, Americans have been asked more times and in more ways to give to charities than in any other time period in recent history. Non-profits throughout the country have noted significant decreases in donations and year-end gifts, as Americans gave all they could to the various disaster relief agencies, support funds and even local civic and church groups conducting fund-raisers.

The OI Foundation was no exception, yet in spite of the effect the slowing donations and slowing economy were having on the organization, we didn't want to add to the hundreds of appeals you've been exposed to in the past four months.

After careful consideration, we replaced our usual winter appeal with the brand new "Going Places" sweepstakes. This is our way of making it fun to support the OI Foundation by giving you, your friends and your family a chance to win great prizes!

The early bird drawing takes place when this newsletter goes to the post office, but there's still time to send in ticket stubs and be eligible to win free airfare for two, anywhere in the continental U.S., thanks to American Airlines, or 2nd and 3rd chance drawings for \$250 and \$150!

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