

## UPS 'delivers' loyal support for the OI Foundation

by Julianne Weiner  
OI Foundation Dir. of Development

A visit to the UPS offices is an awe-inspiring experience. The activity level is intense and constant. Even high-level employees are hard at work at all hours of the day and night. The attention to quality, safety and community is stressed on posters, at staff meetings, and in daily conversation. Because UPS encourages promotion from within, many employees work their way up from loaders, unloaders and drivers to the highest levels of management, and develop strong commitment and loyalty to the UPS family.

So when an employee had a child with OI seven years ago, everyone jumped in to help "one of their own."



The North Jersey District and 72 sponsors helped raise \$23,000 at the 5th Annual UPS/United Way Golf Tournament. OI Foundation Development Director Julianne Weiner accepts a check on the Foundation's behalf from United Way Coordinator Mike Battaglia (c) and North Jersey District Manager Stan Deans (r).

Thousands of employees, from union mechanics to package sorters to district managers, have opened their hearts and wallets after meeting Jeffrey Krudys, whose father, Dan, has been with UPS for 25 years. And

the commitment to contributing to the OI Foundation continues through transfers to new states and new jobs within UPS.

Since 1996, UPS employees have taken a leading role in the struggle to improve the lives of people with OI by contributing more than \$400,000.

In 2003, employees will donate an additional \$231,600 through payroll deductions and stock gifts to the annual United Way campaign and through organizing fund raising events

such as golf, softball and basketball tournaments.

This is more than any other corporation's employees donate and

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## Two OI researchers report results

Dr. Roland Baron and Dr. Nathalie Ortega have both recently submitted final reports to the OI Foundation describing research conducted under grants provided by the Foundation.

Dr. Baron's research was on bone anabolic function of DeltaFosB and its application to the *oim* mouse. He was attempting to determine the molecular mechanism that regulates osteoblast differentiation and function in OI patients. He reports success in identifying that DeltaFosB does interact and lead to a stimulation of osteoblast-specific genes and can interfere directly with processes occurring in the osteoblast lineage. The next step of his research, which will continue beyond

the funding period, is to determine whether expression of DeltaFosB is capable of compensating for the osteoblast-specific defect in bone formation observed in OI patients.

He has established a collaboration with Dr. Joan Marini of the National Institutes of Health, and is confident that by using both his *oim* mouse model and Dr. Marini's *brtl* mouse model, they will be able to determine whether DeltaFosB is capable of correcting the skeletal phenotype in OI mice in the near future.

Dr. Ortega's study was on the role of the angiogenic process (the development of blood vessels) in bone

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# FROM THE EDITOR

## BREAKTHROUGH

The Newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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

To inquire about article submission guidelines and deadlines, or to submit articles or news items, please contact Bill Bradner, at the address or phone numbers below, or by e-mailing to [bbradner@oif.org](mailto:bbradner@oif.org).

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*Dear Friends,*

The OI Foundation receives hundreds of letters or e-mails each month from members of the OI community that are *not* requests for information. They tell us of the triumphs and trials of your daily lives, your inspirations and frustrations, your needs, and your gratitude for the work we do on your behalf.

Nearly all of them start or end with "I'd like for you to tell my story..." or words to that affect. The end result is each time we sit down to plan an issue of *Breakthrough*, we have to make some very tough decisions about what to include, what to hold onto for future issues, and what gets left behind. It is, without qualification, the toughest part of this job.

In a perfect world, we'd leave no story untold... but we simply don't have the resources, and your mailboxes probably couldn't hold a 200-page issue of *Breakthrough*! So we do the best we can, trying to fit in something for everyone.

We're currently resolving logistical and privacy issues that will allow your stories to be told on-line, and in the near future that option will be available. Until that happens we have a very limited space available for a huge volume of information.

Having said that, we'd like to *thank you* for sharing those stories— and encourage you to *keep* sending them! They are daily reminders of who we serve and why we're here. These messages are our richest reward for the work we're doing. They're an indication of your trust, your friendship, and your needs. Your letters and e-mails— even those filled with sadness— are our inspiration.

They are also our guide. The Board of Directors and Foundation staff work very diligently to respond to your needs, aware that we are here to support you and your families. Your letters and e-mails tell us (sometimes in no uncertain terms!) whether or not we're on track. You help shape our strategic plan, guide us in the development of new information resources and programs, and influence the content and production of our website and newsletter.

We simply could not locate (and distribute information about) the volumes of health, advocacy and support programs and information available to our community without your help calling new resources to our attention. Many of the websites, government agencies, programs and pieces of literature featured in *Breakthrough* or on our website were brought to our attention by a member of our community.

*You* are the OI Foundation and the *Breakthrough* is *your* voice... so thank you for writing, and keep the cards, letters and e-mails coming. If your story doesn't end up printed in *Breakthrough*, rest assured it will still make a significant impact on your community in some form.

We're all grateful for your time and efforts.

Sincerely,



Bill Bradner

Director, Communications & Events

# PRESIDENT'S MESSAGE



**Bill Schmidt**

*Dear Friends,*

Once again, I'm very pleased to report that it has been an extremely busy and productive quarter for the Foundation. I recently visited with each staff member at the Foundation offices to receive detailed briefings about their on-going and up-coming projects, and I'm eagerly anticipating the next few years.

The Foundation's three-year strategic plan, implemented after extensive research into your needs and expectations, is well underway. The strategic plan is now on-line in its entirety, so be sure to visit [www.oif.org](http://www.oif.org) and click on the "About the Foundation" page to learn what's in store for the community in the coming years.

The new clinic directory (page 6) is just one of the many examples of what we can accomplish together with a clear direction and purpose. The directory is growing, new clinics are being added (page 10), and we're establishing stronger ties to the members of the medical community serving persons with OI. It's a win/win situation for the entire OI community.

In the coming months, we'll begin writing a book for adults with OI (page 16), complete production on a number of new fact sheets, and kick off our national winter fund-raising campaign, the "Going Places" sweepstakes (page 20).

I'm also very excited to share with you the results of our first attempts to use the website to "push" information your way. Over the last two months, we sent two e-newsletters to registered members of the website informing them of up-coming events that would take place before this issue of *Breakthrough*. Those e-mails had very high "click-through" and very low "unsubscribe" rates— a testimony to your interest and your desire to stay informed. Both e-mails encouraged the readers to forward the information on to friends and family, which resulted in another milestone in the Foundation's history: in October, our website registered over 1,102,000 hits!

As always, you have been generous in your support of the Foundation. Fundraising events such as the Bone China Tea (page 24), Beefsteak (Page 5), and the many UPS events and campaigns across the country (Page 1) continue to be the lifeblood of our organization. We look forward to reporting on the results of the Kroger, Miracle Michael, Bubba Invitational and Allygator Classic Golf Tournaments in future issues, as well. Without your efforts, the Foundation's reach would be far more limited.

In our on-going effort to be good stewards of your contributions, the Foundation's board is undertaking an accountability and ethics review to increase access to the Foundation's financial information, help donors evaluate our effectiveness, and ensure policies are in place to create a fully accountable, ethical and transparent organization.

The new events calendar on our website (page 17) is a great way to keep up with Foundation activities, and the OI Kids' Calendars (page 4) will look great on your wall. Another first for the community, the wall calendars were made possible through the Southern California Petroleum Industry's Charity Association. The artwork featured in the calendar was created by kids with OI at our National Conference, and the SCPICA arranged for the typesetting and printing of the calendars at no cost to the Foundation. Every penny from sales of these calendars supports the Foundation's information and support programs.

I'll use my copy of the calendar to try to keep up— it's going to be a truly exciting new year!

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

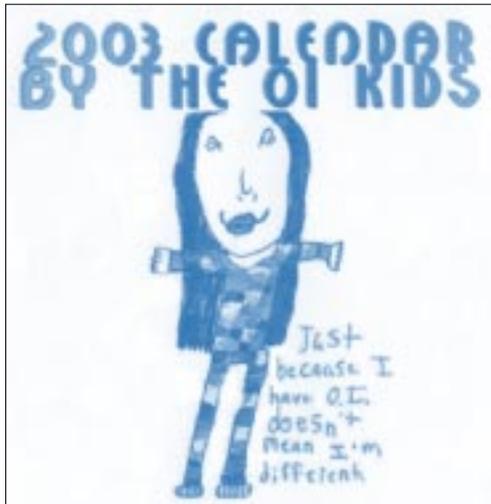
President, OI Foundation Board of Directors

## Events Support the OI Foundation '03 Calendar features artwork by OI kids

The Southern California Petroleum Industry Charity Association's annual golf and tennis tournament was rained out this fall and rescheduled for January 2004.

In the meantime, the organization just unveiled a 2003 Calendar featuring artwork by children with OI.

SCPICA volunteers solicited drawings through our website and at the National Conference, then coordinated the typesetting and printing of a beautiful full-color wall calendar. They donated all their time and production costs, allowing 100% of the sales of these calendars to be used to support the OI Foundation's information, resource and support programs.



Sales are expected to generate more than \$10,000 for the foundation.

Each calendar has a brief description of OI on the back pages, making it a perfect outreach tool as well as decorative conversation piece for your home or office.

Calendars are available for \$12 each in our online store. Go to [www.oif.org](http://www.oif.org) or call (301) 947-0083, or write to the OI Founda-

tion at [bonelink@oif.org](mailto:bonelink@oif.org).

There is a limited quantity available. Order now to receive your calendars before the new year. 

## Your on-line purchases can generate donations for the OI Foundation

When you shop online, up to 15 percent of the money you're spending could be donated directly to the OI Foundation. The Foundation gets paid whenever you shop at GreaterGood.com through the link on our website.

GreaterGood.com is an on-line mall, with full search capabilities and links to virtually every on-line store, including most of the nationally-known on-line ven-

dors where you probably already shop!

When you access those stores through the link on our Foundation Store page on [www.oif.org](http://www.oif.org), up to 15 percent of every purchase is credited directly to the OI Foundation.

By taking a few extra moments to access your on-line shopping through our link, you're making your dollar stretch and benefitting the Foundation. 

## OI Foundation named as beneficiary, receives \$59,000

Recently we received notice that Pete Dohm made the OI Foundation a beneficiary of his life insurance policies. Although our dear friend has passed away, his devotion, generosity and commitment to the OI community remains with us. The Foundation will receive a gift of over \$59,000.

With help from his thoughtful contribution, we will con-

tinue meeting the challenges posed by OI, and supporting all those affected by it.

Remembering the OI Foundation in a will, trust or insurance policy is a thoughtful, lasting way to help support those affected by OI for generations to come.

Please remember us in your will, insurance, or trust. 

## Tax Tip: Volunteering counts!

Most people are familiar with claiming donations of cash and goods as deductions on their income taxes, but they overlook the donations that they make as volunteers.

Volunteers can often deduct costs associated with their volunteer work such as stamps, office supplies, and long distance phone charges. Volunteers who travel may be able to claim 14 cents per mile (if they drive) and the cost of fares, tolls, parking, and overnight expenses.

You'll need adequate records, and limitations apply, but be sure to ask your tax preparer if you qualify for volunteer-related deductions! 

## Texas residents:

Did you know you could designate the OI Foundation as a charity recipient when you shop at Randall's food stores?

By designating the OI Foundation as your preferred charity and linking us to your Randalls' shopping card, up to 15 percent of every purchase is donated to the Foundation. Simply feeding your family supports your OI community!

For more information, stop by the customer service desk at any Randall's store. 

## Correction:

On the back page of the last issue, we incorrectly spelled Sean Stephenson's name as "Stevenson."

Our apologies to Sean, his friends, and his family. 

## Year-end is a great time for giving...

Edited by Sid Simmonds

Reprinted by permission from the Tallahassee Memorial HealthCare Fdn.

A gift to the OI Foundation not only supports the programs, information, resources and research that make coping with OI easier, but can also result in substantial tax savings.

The end of the calendar year marks the time when many people think about making charitable gifts. If you itemize deductions on your income tax returns, you're able to deduct your charitable contributions during the past year. Then, when you calculate your deductions and the resulting tax savings, you may discover that you can make an even larger gift than you thought possible.

### The Income Tax Deduction

**Why does it help?** Because the true cost of a charitable gift is less than the value received by the charity. Let's look at an example:

A person who pays taxes at a 31% federal rate makes a gift of \$1,000. It's as if that person has actually spent only \$690. The \$310 difference is the tax that the donor would have paid if no gift been made.

Without the income tax deduction, the donor might make a gift of only \$690. Because of the deduction, the charitable organization benefits by

## NJ Support Group raises \$17,500

### Local volunteers make 11<sup>th</sup> Annual Beefsteak Dinner a huge success

On October 26<sup>th</sup>, months of hard work by local volunteers paid off with this successful and exciting event.

Nearly 350 people came out to enjoy the delicious filets provided by Hap Nightingale Caterers and to take home silent auction items and raffle prizes. Hundreds of donated objects left with the highest bidder, and many more items were won

through mini-raffles.

The evening was filled with great food, good friends, and unwavering purpose – to make a difference in the lives of people affected by OI.

Special thanks to JoAnn Berkenbush, Rosemarie Kasper, Beverly Krudys, Ellen Haley, Bill Schmidt, Gretchen and Peter Strauch, Cathy and Tom McGarry, Pat and John DeLuccia, Irene and Ed Puzio, and Alan Berkenbush.

Make sure you mark your calendars for next year's Beefsteak on October 18, 2003! 

\$310 more. This means that the gift generates 45% more benefit to the charity because of the deduction. The effect of the deduction is that the higher your income tax bracket, the more you'll save in taxes. Most states also allow a state income tax deduction for charitable gifts, so the tax savings are greater than those generated by the federal income tax alone.

**What Can You Donate?** You aren't limited to giving cash. In fact, your tax benefits can be even greater if you donate other property, such as assets that have appreciated in value.

**Long-term capital gain property** includes securities (like stocks and bonds) and real estate (like a home and land) that are worth more now than when you acquired them, and

have been held for over a year. You receive a charitable deduction for donations of these assets **based on fair market value on the date of the gift. And there's a bonus... you avoid all federal capital gains tax that would otherwise be due on a sale of the assets.**

You receive a significant tax benefit when you make gifts of appreciated property... in effect, a 0% capital gains tax rate. Since you pay *no* federal capital gains tax on an outright gift of an appreciated asset, this gift is much less expensive than a gift of cash.

### Don't Wait Too Long !

**The law allows a deduction to be**

*Continued on page 10*

## 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 a new chat room, new Foundation Store, several new fact sheets, an events calendar and dozens of pages of new information about the OI Foundation, the 2002-2004 strategic plan, and current activities in the community.

Visit  
[www.oif.org](http://www.oif.org)  
today!

## ARTICLES

# New OI Clinic Directory generates positive response

### Community members and OI clinics praise publication of comprehensive list of services

The Directory of OI Clinics, published by the OI Foundation in the August, 2002 issue of *Breakthrough*, has generated a lot of interest among families living with OI, and just as importantly, at various hospitals around the country. In the past two months, more than 500 people have viewed the list on our web pages, and we've distributed almost 200 additional copies through the mail.

The directory has generated interest throughout the medical community as well, and the number of clinics listed is growing. Two clinics have been added to the directory since we published it: one in Texas and one in Nebraska. (Their complete contact information is listed on page 10 and on the OI Foundation web site.) We've also developed stronger ties with existing clinics, and are updating the listing of programs and services that the clinics offer on a regular basis.

"We knew the clinic directory was a service the community wanted. The interest it generated in the medical community is a great bonus," according to Heller An Shapiro, OI Foundation Executive Director.

"We now have a number of clinics and hospitals contacting us, asking to be listed, which is great news for the members of our community searching for medical care."

We anticipate adding several additional clinics from other parts of the

country over the next few months as more clinics complete the registration process.

One of the newest additions to the clinic directory just opened their doors. The new OI Clinic in Omaha, Nebraska is the result of several years of effort and planning. The Clinic operates as part of the Metabolic Division of Children's Hospital in Omaha. It represents a collaboration between the Children's Hospital and the University of Nebraska Medical Center.

Several years ago, the Children's

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*"Never before have we been able to offer such a comprehensive breakdown of what's available to the community..."*

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Hospital administration and their Board of Directors saw the need for a program to treat children with osteogenesis imperfecta in their region which includes the entire state of NE, all of North and South Dakota, parts of KS, IA and MO. Then they worked to provide the resources and to assemble a team of doctors, therapists and other specialists who possess a high level of expertise.

"We are here to serve families in the region, and will welcome OI families in need of care from elsewhere," said Dr. Stephen Lazowitz, vice president for medical affairs and a doctor with many years of interest in OI.

Dr. Horacio Plotkin, the clinic director, echoed this hospitable attitude

and stressed that they plan to develop into an international center for treatment and research for osteogenesis imperfecta. A key to the clinic's approach is close cooperation within the multidisciplinary team and with the child's primary care physician.

"Our team will see patients, draft a care plan and then work with the child's hometown doctor," Dr. Plotkin explained.

He was especially pleased that clinic patients will have access to the University of Nebraska's Gait Lab, for the study of walking. An additional

feature is the Carolyn Scott Rainbow House, which offers inexpensive accommodations to children and their families from outside of Omaha when seen as out-patients.

Adults who have OI will be seen through the Munroe-Meyer Institute of the University of Nebraska Medical Center in a parallel program also under Dr. Plotkin's direction. For additional information about services for adults, contact the OI Foundation.

The fact that the clinic directory is a "living document," and new information can be regularly loaded onto the internet version, makes it possible to keep the directory as current and inclusive as possible.

"We've always been able to help the OI community find medical care, but never before have we been able to offer such a comprehensive and up-to-date breakdown of what's available to the community," Shapiro said. 

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### Can't wait for the next issue of *Breakthrough*?

Register online at [www.oif.org](http://www.oif.org) to receive the Foundation's e-newsletter.

Registration is easy, and ensures you'll always know what's happening in the OI Community!

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## Foundation increases support, programs for adults

The OI Foundation's mission is to *improve the quality of life for people with OI, through research to find treatments and a cure, education, awareness and mutual support.*

That should sound familiar to you, because we've been working to fulfill this mission for over 32 years.

People who were infants in 1970 have now grown to adulthood. Many of them now have their own children, along with productive careers and full lives. The OI Foundation is proud to be here for everyone affected by OI throughout their entire life-span, serving as the premiere source of medically verified information to help improve your lives and the lives of those you love.

All of the information resources developed in recent years, such as the Occupational and Physical Therapy handbook, and fact sheets about Type I OI, Hearing Loss, Surgical Considerations, Clinical Trials and Dental Concerns, is geared toward people of all ages.

The 2002 national conference contained a number of new or expanded sessions and workshops where teens, young adults and older adults learned how to cope with the issues they'll face in the coming years. The 2004 national conference will feature expanded back-to-back sessions on key topics— one will focus on children's issues, one will focus on adult issues.

Our website now features separate sections for parents, youth, and adults, along with an active chat room. In the next month you'll see specialized chat rooms for adults, parents, teens and more.

Our recently expanded clinic directory is the first-ever listing of treatments and programs available for children and adults. It was specifically designed to help identify and

publish the names and services of clinics across the board to help everyone in the OI community find the health-care resources they need.

And we are working to help encourage new research into treatment for adults. Our latest grant offering specifically calls for research into the entire OI community. It's an opportunity for new research to identify the needs, and ultimately search for answers to those needs, of the adult OI community.

We're in the process of producing a number of new resources for adults, including a new book specifically addressing the needs of the older OI population, and fact sheets about pregnancy issues for women who have OI, pregnancy issues for women expecting a child with OI, and an overview of OI during the adult years.

These fact sheets are in various stages of being written or reviewed by the OI Foundation Medical Advisory Council (MAC) and people with OI.

These resources are being developed in direct response to the concerns the community raised during the survey to develop the three-year strategic plan. That plan also includes advocacy and public awareness efforts that will benefit the entire OI community, regardless of age.

In the meantime we're also producing new resources for children and parents, in a direct response to *their* needs and requests.

It's a balancing act, trying to stretch very limited resources and use them in a way that will benefit the greatest number of people in our community.

We are your Foundation, regardless of your age, type, or severity of OI. We have always been, and always will be, responsive to your needs, throughout your life.

### Help us keep the OI Clinic Directory up-to-date!

If you are aware of a clinic, or of an OI-related service or program offered at a hospital or research facility that is not listed on the OI Clinic Directory, please encourage the medical facility administrators to contact the OI Foundation via e-mail at [bonelink@oif.org](mailto:bonelink@oif.org) or by calling or writing the OI Foundation offices.

The directory is constantly updated by Foundation staff. As new information is made available, we verify the programs, services and contact information through the clinic or hospital administrators, then update our directory files. Text-based updates and additions to the listings are posted on the website as soon as the information is verified.

The comparison chart is updated annually and will be printed in future issues of *Breakthrough*, or distributed by other means if it grows too large to be included in the newsletter.

To view the current directory of OI Clinics, visit [www.oif.org](http://www.oif.org), write to [bonelink@oif.org](mailto:bonelink@oif.org), or write to the OI Foundation.

To recommend an addition or request changes to the directory listings, contact the OI Foundation's Information and Resource Specialist by writing to [detris@oif.org](mailto:detris@oif.org) or calling 1-800-981-2663.

Changes will be made after the new information is verified by the clinic or medical facility staff. 



## How is human subject research into treatments and a cure conducted for conditions such as OI?

People concerned about osteogenesis imperfecta (OI) often ask about medical research. Research is part of the process for learning and gaining understanding about OI. Research is also the process that leads to new and improved treatments.

There are different types of medical research, including case studies, observational studies and clinical trials.

- A **case study** is a report of a single case: of how one doctor treated one patient.
- An **observational study** is a report of the doctor or researcher's observations about how a group of patients responded to a course of treatment.
- **Clinical trials** compare the way different groups of patients respond to courses of treatment. A controlled clinical trial compares patients receiving a course of treatment with patients receiving no treatment (controls), to assess how much of an effect the treatment has.

## What does peer-reviewed mean?

Following the completion of a study or trial, the publication of research information in a peer-reviewed medical journal is one of the standards for determining whether medical

information is scientifically sound. A peer-reviewed journal is one that requires expert reviewers to critique and accept the report before it is published.

## What are controlled clinical trials and how do they work?

A controlled clinical trial is the most rigorous and regulated form of medical research. It is a type of medical research designed to help determine the safety and effectiveness of new medicines, new treatments, or a new use for existing therapies. Before medications or other medical treatments are approved for widespread use, they need to be shown to be safe and effective.

Controlled clinical trials are necessary to show that a medication's effects are not subjective (relying on the patient's or physician's interpretation). Otherwise, a researcher might, perhaps unintentionally, test the medication only in patients who already show signs of responding well to treatment. Or a patient, knowing that the medication is supposed to reduce pain, could experience pain relief due to some other factor, but attribute the relief solely to the new medication.

In a controlled clinical study, or trial, patients in one group receive the investigational drug (or course of treatment), while patients in another group—the control group—receive no drug at all, a placebo (an inactive substance that looks like the investigational drug), another drug known to be effective, or a different dose of the investigational drug.

The investigators will compare the effects of the drug in the two groups on objective endpoints (i.e. blood test results, bone histology or density) and subjective endpoints (symptoms such as pain and endurance). If the group receiving the new drug shows significant improvements, which can be

validated by statistical testing of the data, but the control group does not, researchers can reasonably conclude that the new drug was responsible for improving the health of the treatment group.

## How are participants chosen?

To ensure that comparisons between a treatment group and control group are scientifically valid, researchers select people for both groups who are similar in age, weight, health status, and other factors. The most common way to accomplish this is through **randomization**. Researchers first gather a group of people with similar characteristics. They then randomly assign each person to either the treatment group or the control group. This ensures that certain patients aren't "hand picked" for a group because of their characteristics.

## What is a "blind" study?

The final step in ensuring that a research study is objective is **blinding**. Blinding is used to eliminate the effects of personal beliefs and biases (on the part of both researchers and patients). In a **single-blind** study, the patients do not know whether they are in the treatment group or the control group, but the researchers do know. In a **double-blind** study, no one involved—not the patients, researchers, or data analysts—know which patients are receiving the new drug and which are not. A **controlled, randomized, double-blind** trial therefore produces the most objective and scientifically valid results.

## How are clinical trials organized?

Before a medicine or treatment can be tested on people there must be evidence of prior success in laboratory experiments, case studies or observational studies. The researcher must write a **protocol**, a detailed plan, that

explains the goal of the study and the existing information that supports the likelihood that the new drug or treatment will be beneficial. The protocol also describes every aspect of the proposed study, from who will be eligible to participate to the schedule of tests and medication dosages, to follow-up at the end of the study.

## How are trials supervised?

Every clinical trial in the United States is required by the Food and Drug Administration (FDA) to be approved and monitored by an **Institutional Review Board (IRB)**. This is an independent committee of medical professionals who review protocols that are proposed by researchers in their institution. Their job is to ensure that the study is scientifically well designed and to protect the rights and safety of the participants.

Many research protocols are also reviewed by **Data Monitoring Committees**. This is a committee of medical professionals who are independent of the researchers and who review the information that is being collected by the clinical trial while the trial is still in process. If there is evidence that the new medicine or treatment is unsafe or of no benefit, this committee can stop the study. If there is evidence that the treatment is significantly better than existing alternatives, this committee can approve the investigator's request to offer the new treatment to all participants before the trial is complete.

## How is a new medicine approved for use by the FDA?

Clinical trials of new medicines usually go through four **phases** before the drug is fully approved by the FDA. Safety, side effects, effectiveness and proper dosage are the key elements of each phase.

- **Phase 1 clinical trials**
  - small groups of 20-80 people
  - study effectiveness, dosage, safety, identify side effects
- **Phase 2 clinical trials**
  - larger groups of 100-300 people
  - study effectiveness and safety
- **Phase 3 clinical trials**
  - larger groups and comparison to existing drugs
  - confirm effectiveness, monitor side effects, safety
- **Phase 4 clinical trials**
  - after the drug has been marketed this stage monitors unforeseen side effects from long-term and wide-spread use.

## How do I decide whether or not to participate?

Choosing to participate in a clinical trial, or to have your child do so, is not an easy decision. Participating in a clinical trial is different from going to an OI clinic. Many individuals who participate in clinical trials experience a considerable sense of satisfaction in knowing that they are helping to advance medical understanding and treatments for themselves and others who come after them. In addition, participation in trials can provide access to new drugs before they are generally available.

However, if a new medication is ultimately proven to be effective, those who were randomly assigned to the control group must accept in advance that, for the length of the trial, they did not receive treatment that could have improved their health. Those assigned to the treatment group also risk experiencing adverse effects from the medication, or learning that the treatment was not effective.

In addition to the potential health risks, trials may require significant investments of time and money (for example, transportation to and from a study site), as well as physical discomfort (such as having regular blood tests

or bone biopsies). All well-designed clinical trials teach us something—even if the medication turns out to be ineffective, those results help guide researchers away from treatments that don't work, allowing them to explore other possibilities.

*The decision to participate in a trial or not ultimately rests with individuals, after they have been fully informed of what is involved. If you are considering participating, or having your child participate in a study related to OI, discuss the idea with your physician(s) and gather as much information as you can about the study.*

All study participants are asked to sign an **informed consent form**. Before signing, participants and their families should receive answers to all of their questions about the study. The researchers should provide detailed information about what they hope to discover, the potential risks and benefits of participation, what medical tests, exams and procedures will be done, and whether other patient care might be provided. Individuals also need to be clear on what alternative treatments are available besides the experimental treatment.

For additional information about clinical trials, including lists of questions to ask before agreeing to participate, visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov), a searchable website with extensive information on clinical trials.

The FDA ([www.fda.gov](http://www.fda.gov)) and the National Cancer Institute ([www.cancertrials.nci.nih.gov](http://www.cancertrials.nci.nih.gov)) also provide information on participating in clinical trials through their websites. 

*The Clinical Trials fact sheet was prepared by the OI Foundation and is available at [www.oif.org](http://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](mailto:bonelink@oif.org).*

## FROM PREVIOUS PAGES...

### GIVING *Continued from page 5*

**taken for the year during which the gift is made.** As far as the IRS is concerned, the date a gift is made is the day the owner loses control of the asset and the charitable organization takes control.

**Some gifts, such as land or publicly traded securities electronically sent from a broker, require follow-up.**

For example, stock gifts sent from a brokerage house are in the hands of your broker. You may instruct your broker to send the stocks on one day, but the IRS cares only when they are actually transferred.

If you call or write your broker, be sure to follow up and make sure the transaction is complete before the end of the year. Because this tends to be a busy time for brokerage houses, the

earlier you send your instructions, the more likely it is that the transfer will be made on time.

Gifts of land create timing concerns as well. Charitable organizations carefully evaluate all offered gifts of real estate. You should contact the charitable organization as early as possible if you want to make this type of donation. The gift has not been made until the deed of transfer has been recorded.

### **What Really Matters**

The availability of the income tax deduction helps a charitable person be even more charitable. The focus on the end of the year is designed to remind donors the date by which a gift must be made to take advantage of the tax deduction benefits.

Nothing is a substitute for the desire to help charitable organizations. We know that you support us because you believe in our mission to improve the quality of life for people with OI. For that, we thank you.

Please contact Julianne Weiner, Development Director, at 301-947-0083 or email [jweiner@oif.org](mailto:jweiner@oif.org) for more information about how you can help support the OI Foundation. 

***Editor's Note:** The OI Foundation offers neither legal nor tax advice. Please seek the counsel of legal and/or financial advisors with regard to your personal finances. A gift envelope is inserted in this issue for your convenience in making a year-end gift to the OI Foundation.*

### RESEARCH RESULTS *Continued from page 1*

growth and repair of mouse models with OI. Since the control of bone modeling and remodeling appears to be strongly related to the angiogenic process, the deregulation of angiogenesis may be an important factor in OI.

The data generated by Dr. Ortega's research showed that the *oim* mouse has a growth retardation correlated with a delay in vascular invasion and osteoclast recruitment. A better understanding of the cellular sources of these activi-

ties and their regulation will be useful to design better treatment targeting the collagen degradation pathways. Dr. Ortega's research shows that the treatment already in use to increase bone resistance through stimulation of bone matrix synthesis might be improved with specific drugs slowing down bone matrix degradation.

For more information about OI research, visit the website at [www.oif.org](http://www.oif.org) or contact the OI Foundation. 

## ***Additional listings for the OI Clinic Directory:***

### **Children's Hospital and University of Nebraska Medical Center**

8200 Dodge St.

Omaha, NE 68114-4113

Dr. Horacio Plotkin, Clinic Director

**Clinic Hours:** Thursdays, 9 a.m. – 5 p.m.

**To make an appointment:**

402-955-3871

**Services:** Children and Adults

**Treatment Programs:** Coordinated care through the clinic; appointments with members of an interdisciplinary team; and treatment as part of a research protocol.

### **Baylor College of Medicine at Texas Children's Hospital**

6621 Fannin St. CC-15

Houston, Texas 77030-2399

Dr. Brendan Lee, Clinic Director

**Clinic Hours:** 2<sup>nd</sup> Friday every month, 1:15 – 5 p.m.

**To make an appointment or for information:**

Marie Prescott at 832-822-4298

**Services:** Children and Adults

**Treatment Programs:** Coordinated care through the clinic; appointments with individual providers; and treatment as part of a research protocol.

***Please make a note of these new clinics on your copy of the 2002 Clinic Directory!***



# *Resource List*

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*The OI Foundation is the premiere provider of credible, accurate, medically-verified information about osteogenesis imperfecta. Information about additional programs and support for the OI community can be found at [www.oif.org](http://www.oif.org) or by calling (800) 981-2663.*

*“When we found out our son had OI, all our doctor gave us was a list of symptoms. It was completely overwhelming. After talking to the staff at the OI Foundation and reading their free resources, we began to see OI as one part of who our son would be. The OI Foundation has been a wonderful resource for our family, doctors, and care providers.”*



804 W. Diamond Avenue, Suite 210  
Gaithersburg, MD 20878 (USA)  
(800) 981-2663 or (301) 947-0083  
Fax: (301) 947-0456  
[www.oif.org](http://www.oif.org)

## Books, Pamphlets and Videos

### Growing Up with OI:

#### *A Guide for Families & Caregivers* (book)

Addresses the most common questions parents, family members, and caregivers have about raising a child with OI. The focus is on maximizing a child's abilities and proactive problem solving. The book covers the medical aspects of OI, as well as the emotional, financial, and relationship challenges that families living with OI face. Chapters are written by people with OI, their parents, and medical professionals.



#### *A Guide for Children* (book)

A guide especially for elementary school-aged children, it focuses on the same issues as the adult version. It encourages children to focus on their strengths and

abilities, and provides problem-solving advice for challenges they may face.

Price: \$10 individually;  
Both books for \$17

### Caring for Infants and Children with OI (booklet)

Covers the basics of caring for a child with OI from birth to 3 years old. It includes specific examples and advice regarding handling, adaptive equipment, medical treatments, education, and the emotional issues involved in raising a child with OI. One of the Foundation's most popular resources, it is a companion to the video *You Are Not Alone*.

Price: FREE

### You Are Not Alone (video)

A 15-minute video featuring parents discussing the emotional and practical concerns of caring for a child with OI. It provides both practical tips (such as how to change a diaper or carry a child with OI) and candid accounts of the challenges and rewards of parenting a child with OI. It is an excellent companion to the *Caring for Infants and Children with Osteogenesis Imperfecta* booklet. (Available with open captions.)

Price: \$5

### Managing Osteogenesis Imperfecta: A Medical Manual (book)

Written to provide physicians and other medical professionals with a basic understanding of OI, this book is also useful for parents and adults with OI who want to be more proactive and better understand medical issues. Authored by medical professionals with extensive knowledge and experience with OI.

Price: \$20

### Therapeutic Strategies for OI: A Guide for Physical and Occupational Therapists (booklet)

This 14-page photo-illustrated booklet is intended for medical professionals or for families to use as a resource while working with a medical professional. The book is compiled from information from PTs, OTs and physicians familiar with OI. Sections include basic information about the disorder, the role of physical and occupational therapy in managing OI, safe handling of children and adults with OI, and specific strategies for safe, successful therapy for patients with OI.

Price: FREE

### Osteogenesis Imperfecta: A Guide for Medical Professionals, Individuals, & Families (booklet)

Basic information about the types of OI, inheritance, diagnosis, and treatment. Available as an individual booklet or as part of a information display kit.

Price: FREE

### OI Information Display Kit (kit)

Includes a desktop booklet holder/display, Rolodex card, OI resource list, and 25 *Osteogenesis Imperfecta: A Guide for Medical Professionals, Individuals and Families Affected by OI* booklets. Designed for use in hospitals or health care provider offices.

Price: FREE

### Going Places (video & discussion guide)

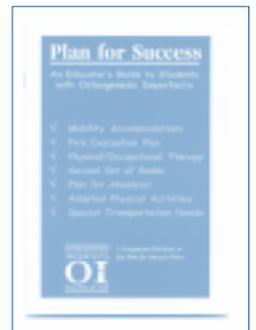
*Going Places* follows Blair Smith, a ninth-grade student with OI through a day of classes, extracurricular activities, shopping at the mall, and spending time with her family. Blair discusses the impact OI has on her life, including accommodations that help her fully participate in school, friendships, plans for an independent future, and some of the ways OI affects her daily routine. The 15-minute video is suitable for pre-teens and teens, whether they have OI or have a friend or classmate with OI. Each video comes with 25 copies of a discussion guide with talking points and questions to stimulate group discussion in a classroom or youth group.

Price: \$5

### Plan for Success: An Educator's Guide to Students with OI (video & booklet)

A 15-minute video that guides educators and parents through planning steps that will help children with OI to fully participate in all school activities. The video comes with a complementary booklet for educators and parents that provides detailed information on applicable education laws and requirements, adapted physical education, mobility accommodations, overcoming architectural barriers, what to do when a fracture occurs at school, and how educators can help a student's peers understand OI.

Price: \$5 for video & 10 booklets;  
\$1/per booklet for more than 10  
Booklet only: FREE



### Within Reach (video)

A 50-minute video featuring in-depth interviews with adults living with OI. They talk candidly about how they have achieved independent and satisfying lives, addressing such issues as mobility, travel, career, marriage, and family.

Price: \$7.50

### Fragile: Handle Me with Care (8 1/2 x 11" poster)

Designed to be placed over the bed of a hospitalized person with OI. It explains how hospital personnel should care for a person with OI. (Text is in English and Spanish.)

Price: FREE

## Audiocassettes

Medical professionals addressed a number of topics related to OI in a series of teleconferences. Recordings of the teleconferences include a 15-minute introduction to the topic, followed by 45 minutes of questions and answers from persons affected by or living with OI.

Available Tapes:

- OI and Osteoporosis**, Dr. Jay Shapiro
- Hearing Loss in OI**, Dr. David Vernick
- Spinal Deformity, Respiratory Function, and Health Outcomes in Adults with OI**, Dr. Roger Widmann
- Coping with Life After a Child's Diagnosis**, Dr. Cathleen Raggio and Lorraine Montuori, CSW)
- Exercise Interventions for Infants and Children with OI**, Dr. Holly Cintas
- Dental Concerns and OI**, Dr. James Hartsfield

Price per tape: \$10

## Free Fact Sheets

The OI Foundation, in cooperation with the National Institutes of Health's Osteoporosis and Related Bone Diseases National Resource Center, has developed a series of fact sheets on OI health and social issues. Single copies of the fact sheets are **FREE**, and may be reproduced as long as all author and accreditation remains on the copy. Topics include:

- Bone Densitometry in Children and Adults**
- Child Abuse**
- Dental Care for persons with OI**
- Education**
- Emergency Department Management of OI**
- Fast Facts on Osteogenesis Imperfecta**
- Fracture Management**
- Genetics**
- Hearing Loss**
- Hearing Loss and Bone Disorders**
- Hypophosphatasia**
- Medical Research/Clinical Trials**
- Nutrition**
- Osteoporosis**
- Pain Management**
- Pregnancy**
- Psychosocial Needs of the Family**
- Rodding Surgery in Children**
- Surgical Considerations**
- Type I OI**
- Understanding the Structure of Bone in OI**

## Webcasts

The OI Foundation has sponsored seven webcasts - interactive broadcasts over the Internet - on OI issues. The transcripts are available on the OI Foundation Website, [www.oif.org](http://www.oif.org), along with information on how to access future webcasts live.

- College and Careers for People with OI**
- A Team Approach: Caring for Infants & Children with OI**
- OI Treatments: Getting & Staying Strong**
- Families Coping with Infant & Toddler Care**
- Living with OI and Succeeding**
- OI Research Update**
- Becoming a Paralympic Athlete**

Price: FREE (online at [www.oif.org](http://www.oif.org))

## Gifts

### Identification Key Chains

Clear plastic keychains include a paper insert that says "I have osteogenesis imperfecta. My bones break easily." and explains what OI is. Includes room for name and emergency contact information. Ideal for keychains, backpacks, strollers or chairs.

Price: \$2

### Ballpoint Pens

Easy-to-grasp three-sided ballpoint pens are bright blue and white, imprinted with the OI Foundation's contact information. Buy a few for your office or home so you'll always have our number handy!

Price: \$1

### Deluxe Pens

This executive-style ballpoint is navy blue with the OI Foundation's logo and contact information imprinted in gold. Complete with a felt-covered sleeve, these pens are perfect gifts for your personal "friends of the Foundation"!

Price: \$3.50

## Coming in 2003!

- *A book written for adults with OI*
- *A children's storybook for educators*
- *An exercise book for children with OI*

Visit [WWW.OIF.ORG](http://WWW.OIF.ORG) regularly to stay informed about the latest information resources available from the OI Foundation!



## Get Involved!

### Subscribe to Breakthrough

*Breakthrough* is the OI Foundation's **FREE** quarterly newsletter. It includes up-to-date information on medical advances, tips for healthy living, legal issues, news from and about OI Foundation members, and updates on Foundation activities. (There is a small charge for international subscriptions.)

### Become an OI Foundation Member

Members are at the core of OI Foundation activities. As volunteers and contributors, they provide the resources required to fulfill the Foundation's mission of research, awareness, education, and mutual support. Request a membership brochure now, or enroll online!

### Visit [www.oif.org](http://www.oif.org) (and register!)

Our website is updated regularly, and is the fastest gateway to access all the Foundation's resources, get answers to your specific questions, and connect with the OI community. Register on the site to receive periodic e-mail updates and news bulletins!



## Is telecommuting the right answer?

by Ellen Alcorn, reprinted with permission from Monster.Com

Here's a statistic that may startle you: disabled people suffer an unemployment rate of 70 percent. Common reasons cited by disabled people in the unemployment ranks are job discrimination and lack of transportation. However, many people with disabilities have found a solution: Working from home. If you are a job seeker with a disability, you may want to consider telecommuting with an employer or opening your own business.

If you decide to look for an employer who is open to telecommuting, remember: you may find potential bosses are reluctant to allow full-time telecommuting, as many still consider face time an essential part of teamwork. Before your interview, prepare a plan carefully outlining how you will keep in touch, whether calling in regularly or sending emails. You might also propose logging your hours and setting up quarterly reviews at which you can present the work you've done. Find out whether your particular disability — in combination with your chosen profession — makes telecommuting a reasonable accommodation under the Americans with Disabilities Act.

These are tricky waters to navigate, but fortunately there are excellent resources at your disposal. Two of the best are the Job Accommodation Network and Disability and Business Technical Assistance Centers.

Opening your own business requires another set of strategies. As with anyone starting a new business, disabled or not, the first step is to go through a self-employment process, which includes developing a business plan, identifying your target market and proving to yourself and others that your

business idea is viable.

Another crucial step is getting out there to network like crazy. If you have a disability that makes transportation an issue, use email or the telephone rather than face-to-face meetings, or consider hiring someone to be a public presence for you. Find local vendors who will deliver office supplies to your home office. Figure out how to best capitalize your business.

"People with disabilities often have less capital, or they have poor credit rating due to the financial impact of their disabilities," says Nancy

Arnold, research director for Employment and Economic Development at the Rural Institute on Disabilities at the University of Montana in Missoula.

She says it's important for people with disabilities to remember that a variety of financial services are available, including the Locational Rehabilitation Agency, the Social Security Administration, and bank micro-loan programs targeted to low-income people looking to capitalize start-up businesses.

But before you completely pull the plug on office life, make sure you're clear about your reasons. If your disability really prevents you from leaving your front door or if you've always wanted to be your own boss, fine. But if you've given up on ever finding a job in a workplace before you've even started to look, think twice about working from home.

"By telecommuting, you remove face-to-face contact," says Andrew Houtenville, PhD, research associate at the Program on Employment and Disability at Cornell University.

"People may become disconnected from social roles, and so I think there needs to be some care used with that.



## Member wins NFL award for volunteerism

Thomas Acquafredda, a volunteer for more than ten years at the New York United Hospital Medical Center, was selected by the New York Giants organization to be a recipient of the NFL Community Quarterback Award.

The award, which recognizes the vital contributions of volunteers in local communities nationwide, included a \$1,000 check.

Thomas donated the money to the hospital's volunteer services department.

"I was surprised when they nominated me," Thomas said. "I just like being around people and helping. Volunteering gets me out of the house!"

Three days a week, for 7 hours at a time, Thomas assists in the medical records office by compiling records, delivering correspondence and chipping in wherever he's needed.

He's also volunteered at the American Heart Association and the March of Dimes.

"I'd be here five days a week if I could," he said. "I enjoy it."

Thomas was recommended for the award by his supervisor from a pool of over 250 volunteers.

Working from home creates limited interaction with people, places and things, and that might be problematic."

*Reprinted from "A Path to Employment for People with Disabilities," by Ellen Alcorn, Monster Contributing Writer. Copyright 2002 - TMP Interactive, Inc. All Rights Reserved. You may not copy, reproduce or distribute this article without the prior written permission of TMP Interactive. This article first appeared on Monster, the leading online global network for careers. To see other career-related articles visit <http://content.monster.com>.*

## Adult OI book in progress

The Adult Book Advisory Committee has completed the first stage of work on the new book. Topic ideas have been organized into chapters and lists of potential authors have been developed. The book editor, Ellen Dollar, is in the process of contacting potential chapter authors. The book will be organized in two parts: part 1 will deal with health issues related to OI and part 2 will deal with the practical issues related to building a life as an adult who also has OI.

"The committee did a terrific job," stated Mary Beth Huber, the Foundation staff person coordinating this project. "There were so many excellent ideas to be shared."

"A very important part of this book will be the personal stories or vignettes which will be used to illustrate concepts in each chapter," added Ellen Dollar.

"Even more so than in the *Growing Up with OI* book series, vignettes will add personal experiences that expand on the chapter author's message."

Vignettes are short personal essays that tell a brief story about a person's life. Adults who would like to submit an essay for consideration for publication can send it to [bonelink@oif.org](mailto:bonelink@oif.org). Stories that are not published in the book will be saved for possible inclusion in a future section of the OI Foundation web site.

## Up-coming Fact Sheets

The next 3 new fact sheets—Pregnancy Issues for Women Who Have OI, Pregnancy Issues for Women Expecting a Child with OI, and An Overview of OI During the Adult Years—are all in various stages of being written or being reviewed by the OI Foundation Medical Advisory Council (MAC) and people with OI.

They should be available from the OI Foundation by mail or online in the next quarter.

## Online job announcements

The HalfthePlanet Foundation has announced a new feature on their website: the JOB CORNER.

The HalfthePlanet Foundation is featuring jobs in the bottom left hand corner of the web site. Current listings include Director of Development for Access Living Chicago and CEO for Northwest Lions Foundation for Sight & Hearing. The site only features jobs whose employers are making an effort to hire in the disability community. Visit [www.halftheplanet.org](http://www.halftheplanet.org) for details.

## Call for Personal Stories by Adults with Disabilities

Stan Klein and John D. Kemp, President and CEO of HalfthePlanet Foundation, are co-editing a new book. Adults who have grown up with

disabilities and/or health care needs are invited to write short essays for parents of children with disabilities about what they wish their own parents had read or been told while they were growing up. All essays must be received by February 15, 2003, and authors of published essays will receive \$125 in compensation.

Guidelines for essays: 1) Write an essay of 1500 words, with a biography of 150 words or less, that includes your mailing address, telephone number, fax number, and email address. 2) Submit your essay as an email attachment in Microsoft Word or paste your essay into the body of your email to [stan@disabilitiesbooks.com](mailto:stan@disabilitiesbooks.com) or send by mail on a disk to Stanley D. Klein, Ph.D., DisABILITIES BOOKS, Inc., P.O. Box 470715, Brookline, MA 02447-0715.

## Web Spots

### Useful or informative sites for the OI community

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

**Southern California Petroleum Industry Charity Association**  
[www.scpica.com](http://www.scpica.com)  
(Page 4)

**Food & Drug Administration**  
[www.fda.gov](http://www.fda.gov)  
(Page 9)

**National Cancer Institute**  
[www.cancertrials.nci.nih.gov](http://www.cancertrials.nci.nih.gov)  
(Page 9)

**Clinical Trials**  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)  
(Page 9)

**Half The Planet**  
[www.halftheplanet.org](http://www.halftheplanet.org)  
(Page 16)

**U.S. Dept. of Labor**  
[www.disabilityinfo.gov](http://www.disabilityinfo.gov)  
(Page 17)

**The Able Trust**  
[www.abletrust.org](http://www.abletrust.org)  
(Page 17)

**Caregiver's - U.S.A.**  
[www.caregivers-usa.org](http://www.caregivers-usa.org)  
(Page 17)

**National Health Council**  
[www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org)  
(Page 17)

**Ten Speed Publishers**  
[www.tenspeed.com](http://www.tenspeed.com)  
(Page 17)

**Chicken Soup for Sisters**  
[www.chickensoup.com](http://www.chickensoup.com)  
(Page 17)

**Program on Employment and Disability**  
<http://www.ilr.cornell.edu/ped/>  
(Page 15)

**Monster.Com**  
[www.monster.com](http://www.monster.com)  
(Page 15)

Direct links to these organizations can be found on [www.oif.org](http://www.oif.org).

## OI documentary airs on Discovery Health channel

Discovery Health aired an hour-long documentary about OI last month, entitled "Children of Glass" in the U.S. and "Brittle Bones; a Genetic Mystery" in Canada.

The documentary featured the struggles of three families as they've dealt with OI over the years. It also included interviews with OI Foundation Medical Advisory Council Member Drs. Glorioux, Byers, Rowe and Smith, and presented a basic overview of the effects of the disorder, the search for a cure, and the painful surgical procedures.

According to the producer, the show was the top-rated show for the week in both the Canadian and U.S. Discovery Health networks, and is expected to win awards in the coming year. The chances of it airing again or being picked up by the parent Discovery network are high.

Copies of the program are available through the Great North Production Company. Phone or write to George Williams, c/o Great North Productions, 3720-76 Ave., Edmonton, Alberta, T6B 2N9 (780) 440-2022 for more information.

Copyright laws prevent the OI Foundation from making the tape available to our members directly from the Foundation.

## Apply now to attend the FL Youth Leadership Forum on Students with Disabilities

The Able Trust is accepting applications for the Florida Youth Leadership Forum that will take place July 24-27, 2003, in Tallahassee.

Fifty current high school sophomores and juniors who have disabilities will be selected as delegates.

The forum, which is co-sponsored by The Able Trust and the Florida Developmental Disabilities Council, is

a leadership program for students with disabilities designed to bring together young people with disabilities and leadership potential to help prepare them for the future.

Applicants should have demonstrated leadership skills, academic achievement, community involvement, and extracurricular activities.

There is no fee for delegates to attend the forum. The Able Trust will pay all travel and living/meal expenses. The deadline for applications is December 6, 2002. Applications can be downloaded from The Able Trust web site at [www.abletrust.org/news/press\\_releases/20020930.shtml](http://www.abletrust.org/news/press_releases/20020930.shtml).

## National Health Council addresses caregiving issues

The National Health Council is assisting in the promotion of the book *And Thou Shalt Honor... The Caregivers' Companion*. The book is a companion piece to a combined television and internet promotion that illustrates the issues and challenges facing both family and professional caregivers of those with disabilities.

The book is a practical resource, containing a step-by-step guide through the journey of caregiving. Not all the information contained in the book is relevant to OI, but it contains many resources and ideas that might be helpful to our community.

For more information, visit their website at [www.thoushalthonor.com](http://www.thoushalthonor.com), [www.Caregivers-USA.org](http://www.Caregivers-USA.org), or NHC's [www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org).

## Updated job-hunting book

Richard Nelson Bolles, author of the famous career-planning and job hunting guide *What Color is Your Parachute*, recently teamed up with Dale Susan Brown, author of *Learning for a Living* to release a new edition of *Job Hunting for the So-Called Handicapped or People Who Have Disabilities*.

The book provides an upbeat but realistic picture of the Americans with Disabilities Act, job hunting, and the future job market for persons with disabilities. It also includes information about negotiating accommodations, avoiding self-sabotage, and creative strategies for finding a job.

Call 800-841-2665 or order the book through the publisher's website at [www.tenspeed.com](http://www.tenspeed.com).

## OI featured in "Chicken Soup for the Sister's Soul"

Jodi Severson recently wrote about her sister, Debbie Carpenter, for the newly released *Chicken Soup for the Sister's Soul*. Jodi's family has lived with OI for 40 years—her mother wasn't diagnosed until her sister was born with OI.

Her story, "Imprints," centers on her sister's struggle to walk after years of using a wheelchair. The book is available at [www.chickensoup.com](http://www.chickensoup.com).

## OI Foundation's on-line calendar now available

The OI Foundation's on-line events calendar is now active and available for visitors to the site. The calendar is a listing of all known support group meetings, fundraising events, and relevant foundation-generated events and deadlines. It can be reached directly from the home page or from the "News and Events" page on [www.oif.org](http://www.oif.org).

To submit events to be included on the calendar, send an e-mail with a brief description of the event and all relevant time/location information to [webmaster@oif.org](mailto:webmaster@oif.org).

Since we prefer not to publish home phone numbers on the website, please be sure to include an e-mail point of contact that can be included in the event summary.

There is no limit to the number of events on the calendar, but space is limited and descriptions may be edited.

## Piccolo twins find Foundation after 47 succesful years of living with OI

Leslie Picolo Kitterman was attending a conference with the Goodwill Industries last year, as the Chairman of the Board of Directors for the Goodwill Big Bend region, when she was reminded of how small this world was.

She was approached by John Huber, husband of the OI Foundation's Information Resource Director, Mary Beth Huber, and asked if she was involved with the OI Foundation.

Leslie wasn't; she has always preferred to be involved with mainstream society, and had met few persons with OI in her 47 years of living with the condition. Always focused on what is possible despite OI, rather than the disabilities and limitations OI presents, she and her family were very self-sufficient growing up.

They relied on her mother's resources as an RN and the support of her family members.

"Shortly after meeting him, I was contacted by the OI Foundation," Leslie said. "I was very curious about the organization and interested in meeting others with the same disability."

When the OI Foundation learned she was an administrator in the FL Department of Insurance, she and her sister, Lynn Picolo, were asked to participate in the Foundation's National Conference in Orlando. The identical twins presented the session "Obtaining SSI & Insurance," providing inside information about the system, hints on acquiring SSI and Medicaid, and answering questions from more than 50 session participants.

Leslie has "been involved in a lot of organizations and conferences" through her volunteer work with Goodwill, a board position in a local school for children with learning disabilities, and her church, and said she was "impressed with the amount and quality of information available through the conference for persons living with OI."

"It was incredible; it was wonderful to see how much support and information was out there," she said.

Leslie and her twin, Lynn, were born in in New Orleans. Her mother's doctor had seen OI in the past and recognized the blue sclera and broken bones at birth as being symptoms of OI, so the family had the advantage of early diagnosis and knew what to expect.

They didn't, however, have anyone else to turn to. The OI Foundation wouldn't be created for another fifteen years, so the family became it's own support system.

"At some point, we moved to Florida, in part *because* there was a doctor there who was very familiar with OI,"

Leslie said, but that was one of the few concessions the family made to their disorder.

"At fifth grade, my parents decided that Lynn and I were falling behind academically in a special education school, so they fought to get permission to include us in mainstream education," Leslie said. "This was before anyone had even heard of 'mainstreaming' students."

The lesson taught by her parents was to always be accepting of the disability, but not allow it to impose limitations.

"You have to learn to live in the world as it is," she said. "And our family realized it would be much easier to do that if we *started* dealing with the challenges early on that we'd have to face our entire life."

Leslie and Lynn completed school and college in mainstream classes, breaking as many as 200 bones each over the years but relentlessly following their dreams.

Lynn is now a vocational supervisor with the Division of Vocational Rehabilitation, for Florida's Department of Education. Leslie has been happily married for 18 years to Thomas, a long-time friend who she met during her college years. She's worked her way up from an insurance sales rep to her current position managing the licensure of insurance agents for the state of Florida.

"It's much more open today," she said. "People with a variety of disabilities are out there and are much more vocal. More kids are mainstreamed, and entering the workplace."

When she started working, she had to prove herself and show she was capable, and she believes persons with disabilities have more opportunity now than ever before.

"...but you still have to help people understand that there are ways for you to live in this world and contribute to society," she said.

"Ours is just one of many disabilities," she continued, "and I feel very fortunate that it's not worse than it is."

Leslie and Lynn have "between Type II and Type III," but they're less interested in diagnosing what their severity is than they are in learning what they can accomplish despite the disorder.

"We don't make an issue of our disability, we encourage solutions," she said. "Because it's not just about us, it's about everyone who comes after us."

"We've had a wonderful and very full life," Leslie asserted, "and are very fortunate to be living in this day and age." 

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*"You have to live in this world as it is... but you still have to help people understand that there are ways for you to live in this world and contribute to society."*

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# HONORARY AND MEMORIAL DONATIONS

JULY 1 TO SEPTEMBER 30, 2002

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*Cullen Binnicker*  
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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. Gifts may also be made online at [www.oif.org](http://www.oif.org) or by calling 1-301-947-0083.

## ARTICLES

# 2nd Annual Sweepstakes prize value: \$11,500!!!

by Julianne Weiner  
OI Foundation Dir. of Development

The OI Foundation has come a long way, thanks to your generous support. In the last thirty-two years we've grown from a small group of parents and doctors into a nationwide community numbering in the thousands.

Together we support groundbreaking research projects and provide information resources to more than 100,000 people each year. With more families, people with OI and medical professionals reaching out to us, we're determined to meet their changing needs in the years to come.

We're about to kick off our second annual sweepstakes fundraising program, which gives OI

community members, as well as their family, friends, classmates and co-workers, a chance to win great prizes while supporting the Foundation's research and support services.

Grand prize is a 5-day vacation for two at the 4-star Maui Prince Hotel, including first-class air travel, hotel accommodations, and a free round of golf, courtesy of American Airlines Vacations and thanks to the efforts of Amy Ley, OI Foundation member.

2nd and 3rd Prize Drawings will be held for \$250 and \$100 cash. An Early Bird Drawing for \$250 cash will be held January 24, 2003, all other drawings will be held February 24, 2003.

The suggested donation of \$3 per ticket will add up fast... last year the sweepstakes brought in more than

\$19,500! With bigger and better prizes, the sky's the limit on what we can raise this year!

Ticket kits (including a flyer and two books of 10 tickets) will be sent to everyone who helped solicit donations and participated in last year's sweepstakes.

If you would like to help distribute tickets this year and do not receive a kit, or need some help with your own fundraising plans, please contact Julianne Weiner at the OI Foundation by calling (301) 947-0083, or by email to [jweiner@oif.org](mailto:jweiner@oif.org).

No purchase is necessary, for complete rules and regulations see below or visit our website at [www.oif.org](http://www.oif.org). 

## OFFICIAL RULES for the OI Foundation's Sweepstakes

By entering the sweepstakes, participants agree to follow these official rules and any decisions made by the Osteogenesis Imperfecta Foundation ("OI Foundation"). Failure to comply may result in disqualification. **The sweepstakes is subject to all applicable federal, state, and local laws and is void outside the US, and elsewhere as prohibited by law.**

**HOW TO ENTER:** The OI Foundation sweepstakes will commence on December 1, 2002. To enter, return a complete and legible official ticket stub to OI Foundation at 804 West Diamond Avenue, Suite 210, Gaithersburg, MD 20878. Tickets may be requested from OI Foundation by mail at the same address, limit twenty (20) per request. **No donation is required to enter and making a donation does not improve the chances of winning.** All entries must be received by January 22 to be eligible for the early-bird drawing on or about January 24 and by February 21 for the final drawings on or about February 24. All entries become the exclusive property of OI Foundation and will not be acknowledged or returned. OI Foundation is not responsible for and shall not be liable for any late, lost, misdirected, stolen, damaged, illegible, or incomplete entries. The odds of winning are dependent upon the number of eligible entries received.

**ELIGIBILITY:** To enter the sweepstakes, participants must be 18 years old or older at the time of entry. Participants must be a legal US resident (50 U.S. states and District of Columbia). Directors, Officers, and employees of OI Foundation and its contractors, and their immediate families, are not eligible to enter.

**PRIZES:** One (1) early-bird winner will receive \$250 and will remain eligible for the final drawing. For the final drawing, only one (1) prize per person will be awarded. One (1) 2<sup>nd</sup> place winner will re-

ceive \$250 cash. One (1) 3<sup>rd</sup> place winner will receive \$100 cash. One (1) grand prize winner will receive roundtrip first-class air travel aboard American Airlines for two from the commercial airport served by American Airlines nearest the winner's home to Maui, Hawaii, four (4) nights and five (5) days standard double-occupancy at the Maui Prince Hotel in Maui, Hawaii, and a round of golf for two at the Maui Prince Hotel. The total retail value of the grand prize is \$11,500. Travel must start and end between February 22 and July 1, 2003 and blackout dates and other restrictions apply. The winner shall be solely responsible for all expenses not expressly stated above, including but not limited to ground transportation, food and beverage, and telephone and Internet charges. Prizes are non-transferable and non-cash prizes are not redeemable for cash. OI Foundation reserves the right to substitute the grand prize for one of equal or greater value, and no substitutions will be allowed in lieu of offered prize. OI Foundation's interpretation of these rules and determination of winners and prizes shall be final. Each winner is solely responsible for filing all reports and paying all taxes associated with the prize received.

**SELECTION AND NOTIFICATION OF WINNER:** From among all eligible entries received, one (1) early-bird winner will be selected by random drawing on or about January 24 and one (1) grand prize, one (1) 2<sup>nd</sup> place, and one (1) 3<sup>rd</sup> place winner will be selected by random drawing on or about February 24, with the grand prize winner selected first, and then the 2<sup>nd</sup> place winner, and then the 3<sup>rd</sup> place winner. Each winner will be notified by mail, phone, or e-mail within two (2) business days after the drawing. If the winner cannot be contacted or does not respond to an attempted contact within fourteen (14) calendar days, the winner will be deemed to have forfeited the prize

and an alternative winner will be selected by random drawing from the remaining eligible entries. OI Foundation is not responsible for and shall not be liable for any late, lost, misdirected, or unsuccessful attempts to notify a winner. All prizes will be awarded. Receipt of prizes is contingent upon confirmation of the winner's eligibility and execution of a liability and publicity release. Entry constitutes permission to use each winner's name, photo, and likeness to publicize the sweepstakes without additional compensation unless prohibited by law. A list of winners may be obtained by sending a self-addressed stamped envelope to OI Foundation at 804 West Diamond Avenue, Suite 210, Gaithersburg, MD 20878.

**PARTICIPANT ASSUMES ALL LIABILITY:** By entering the sweepstakes, each participant assumes, and agrees to be solely responsible for, all liabilities and costs arising out of his/her participation in the sweepstakes and releases the following parties from the same: OI Foundation, American Airlines, Maui Prince Hotels, the accounting firm of Murray, Jonson, White & Associates, Ltd., and their directors, officers, employees, volunteers, and agents. OI Foundation reserves the right to cancel, suspend or modify the sweepstakes in the event of any event beyond OI Foundation's reasonable control that renders holding the sweepstakes impractical.

**REMOVAL OF NAME:** Participants wishing to remove their names from the sweepstakes mailing list should call OI Foundation at (301) 947-0083 or write to 804 West Diamond Avenue, Suite 210, Gaithersburg, MD 20878. 

*Editor's note: for more information or if you have additional questions, please contact our development director via e-mail at [jweiner@oif.org](mailto:jweiner@oif.org).*

## UPS DELIVERS *Continued from page 1*

each year's contributions represent more than 10% of the OI Foundation's annual budget.

The UPS – OI Foundation partnership provides free information and support services and is a vital component of the OI research program that seeks treatments and a cure.

This year's UPS – OI Foundation campaign spread from coast to coast and all across America. Highlights of their efforts include:

### North Jersey

In New Jersey, the place where Dan started work with UPS and the place where these efforts began, Mike

Battaglia organized the 5<sup>th</sup> Annual Golf Invitational to benefit the OI Foundation.

Through that event and the United Way Campaign, the North Jersey District raised over \$71,400 this year.

"Everyday, more and more people are diagnosed with OI. This is a terrible illness to live with; hopefully one day there will be a cure," Battaglia said.

"On behalf of the North Jersey District, I would like to thank all UPSers, sponsors, family and friends for their efforts and support," he continued.

Special thanks go to Stan Deans, North Jersey District Manager, whose outstanding support and leadership helped drive the success of both the golf tournament and the United Way Campaign on behalf of the OI Foundation.

### Metro Jersey

Bill Schike and the people he works with have joined in the fight against OI, and have had a huge impact. With Bill's encouragement, over \$20,000 was raised to ensure that kids like Jeffrey get the answers they need.

"It makes you feel good to donate to a worthy cause," Bill said. "It makes you feel even better when that worthy cause has a direct impact on the UPS family."

Emil Soltis reached out to his coworkers and asked them to support the OI Foundation and make a difference in the lives of people with OI. His coworkers at UPS answered emphatically, and contributed \$15,000 this year.

"When you meet Jeffrey, that's all it takes," Emil said.



*Jeff Krudys (r) and his father, Dan, meet with Bill Schmidt (l), President of the OI Foundation Board of Directors, at the National Conference in Orlando, FL.*

"His positive outlook on life inspired me and my partners to get involved and make a difference."

### Southeast California District

Mike Dizinno worked closely with Dan and his family when they all lived in New Jersey. Now, Mike has moved to Southern California, and has spread the message about OI there. As a result, his coworker Major Warner and the UPS employees in Southern California have committed to support the OI Foundation.

### East Bay District

Up in Northern California, Nick Kocheck has been talking to his coworkers about Jeffrey Krudys and the OI Foundation. Dan and Jeffrey made a short video explaining what OI is for each of the UPS districts that participated in these efforts, and Nick feels that showing the tape helped.

"That was really the home run," Nick said. "That was real life."

To date, the Northern California District UPS employees have designated \$15,000 for the battle against OI.

### Southern Illinois District

Don Gately and the UPS employees in Southern Illinois took Dan's message and Jeffrey's needs to heart, and together have raised over \$4,000 in contributions.

### Atlantic District

In Baltimore, Maryland, Norman Aquilino encouraged support of the OI Foundation, and his teammates responded by raising nearly \$9,000. According to Annette Auger, a staff member at the Atlantic District, Norm's efforts inspired Greg Smith, who works in both Baltimore and the District of Columbia, to approach the UPS staff at the D.C. location.

### Kansas District

In Kansas, where Jeffrey and his family now live, the outpouring of support and donations was astounding. Kelly Hale and Chuck Henry organized "Jammin for Jeffrey," a three-on-three basketball tournament that attracted a crowd even in the rain.

Thanks to the leadership of Glenn Rice and the Kansas District staff, supporters in Jeffrey's new home came together, raising \$87,200 for the OI Foundation through the United Way Campaign administered by Cindy Rosen and Cindy Pugh. 



# Pete Dohm— friend, advocate & clown— passes away

Pete Dohm, an important part of the OI Foundation's activities for most of our 32-year history, passed away this month. He was 46 years old.

Pete was born with 16 fractures, diagnosed with OI, and not expected to live. While his body and physical development was affected by OI, his mind, enthusiasm and spirit impressed everyone he met. He began school at the St. Louis Special School District, but entered mainstream schools at the Cross Keys Junior High School, and graduated on time from McClue High School in Florissant, MO. His friends carried him onto the stage for graduation ceremonies.

He received a bachelor's degree in business administration four years later from the University of Missouri at Columbia, and began work as an accountant in the engineering school.

Pete's independent attitude inspired many people to strive for their own independence in spite of their disabilities.

"As long as I have my voice, I can make it... with others' help," he often quipped.



*Pete Dohm*

He spent much of his time using his voice, and his energy, as an advocate to improve not only his own life, but the lives of everyone with disabilities. For the past 23 years he served on the board of directors of the mid-Missouri Barrier-Free Housing for the Physically Disabled, holding several offices, including board president in 1985.

Pete often said, "If I was going to be born handicapped, I'm glad it was in this day and age..." He was grateful for the opportunities afforded him, but

always searching for ways to improve the lives of all persons with disabilities.

He helped bring a 13-unit apartment community to Columbia in the early 1980s, and lived in the first accessible home ever built by the Columbia Habitat for Humanity, where he volunteered as an accountant.

He was a member of his local Knights of Columbus Council, where he served in the clown ministry, visiting hospitals and spreading cheer with balloon animals and stickers.

According to his sister, Juanita Gruenloh, he joined the clown ministry "just as another way of touching people's lives."

Pete was an avid supporter of the OI Foundation as well, devoting many years to the OI Community.

According to his mother, Clara Dohm, Pete was devoted to [what she referred to as] his Foundation "... he attended every conference there was."

Peter was a board member for 6 years, and he and his family almost single handedly coordinated our national conference in St. Louis in 1986.

In recent years he participated as a mentor to people of all ages, was an able fund raiser, a peer support session leader and an advisor on Foundation materials and the new website.

Heller An Shapiro, Executive Director of the OI Foundation, remembers Pete with affection.

"Pete was not shy. He assumed everyone was his friend and always saw the good in people," she said. "One hardly needed to ask before he would offer to help, and you could always trust him to do what he said he'd do."

Pete will be remembered for his strong spirit, and for being smart, funny, hard working and engaging.

He will be missed by the Foundation and the OI Community. 

## Kasper awarded for life-long service

Rosemarie Kasper has spent her entire adult life as an advocate, not letting her hearing loss, stature or confinement to a wheelchair slow her down.

"She's small in stature but a dynamo force," according to Jim Thebery, director of the Bergen County Division on Disability Services.

Thebery was speaking at the Salute to Champions awards ceremony last month. Rosemarie was honored by the Division on Disability Services for her decades-long efforts for people with disabilities.

Kasper earned three college degrees and held a full-time job most of her life— raising awareness about the challenges confronting the disabled every chance she had. She's written newspaper articles, speaks at civic and public meetings, lectures at colleges, and is a volunteer serving on numerous committees and fund-raisers to help persons with disabilities.

"She's my role model," according to Jack Milligan, co-chairman of SHHH (Self Help for Hard of Hearing People). "Many times she has encouraged me to do things I was reluctant to try."

"I enjoy making friends, keeping busy," Kasper said. "I like being involved. I have as many friends who don't have disabilities as those who do."

"We're all people, with the same needs and desires," she said. 

## Rearing a child with OI is a delicate balancing act

by Steve Kipperman  
Reprinted with permission from  
the Shriners Chicago newsletter

Having grown up with OI and experiencing twenty-one fractures (starting at the age of five with a broken collarbone from falling out of bed), I know first hand the challenges and decisions that my parents faced.

Having reflected on my fractures over the years, I told my parents once that if they had been more restrictive with some of my activities I could have cut the breaks in half. I was a fairly active child growing up in rural Wisconsin with OI, doing what boys do—climbing trees, running around and occasionally falling down. I even had a motorcycle and snowmobile that we drove on trails through the woods.

My parents could have not let me have a motorcycle or a snowmobile or been much more restrictive. I am sure they agonized on those decisions. I was aware of my condition, as we have a family history of OI that has affected my grandmother, my mother, uncle, two cousins, myself and now my fifteen month old daughter, Katie. By being aware that I had “brittle bones,” I know at times I was a little more cautious in what I did—but kids will be kids. My parents took the approach of letting me do what I was capable.

Now that my wife and I are parents, I have found it is a delicate balancing act of wanting to protect your child from harm and letting them do what they can do. It is a natural parental instinct that is in all of us. No one wants to see their child get hurt and be in pain. It is as if you would like to wrap them in a bubble. But you can't. It is a wonderful world, and children need to explore and experience it.

I have become painfully aware how you can be overbearing and want to follow your child around all day to catch her as she falls or tell her not to do something that you think may result



*Katie Kipperman is an active, inquisitive child. Knowing when to curb that healthy inquisitiveness and “protect” our children is a challenge for all parents-- but especially for those of children with OI.*

in a fall. My wife has to remind me constantly to relax and to tell me that Katie is fine.

To date, Katie has had four fractures. Three fractures were discovered at her six-month appointment at Shriners Hospital in Chicago when some baseline x-rays were taken. It appeared that she had broken her right collarbone, probably at birth, and two minor leg fractures where you could not see any clear breaks but the bone had a shadow on the x-ray showing that it had healed at some point.

The most recent break was the first instance that we really knew she had a break. Katie had been walking for about two weeks and took a tumble, landing on her right shoulder. I got the call from my wife while I was at work. I rushed home to take her down to Shriners with my wife. It was the longest drive. A range of emotions went through my head. I was concerned that she was hurt and at the same time blaming myself for her having this condition.

It turned out to be another broken

collarbone. Katie was a trooper. I really think it was much harder on my wife and I than her. The first few nights were not easy as she moves around a lot in her sleep. She would roll over onto the shoulder and start to cry. It made for long nights of cradling and comforting her in a rocking chair. I found it to be physically and emotionally draining. I also found that you have to look down at your little one and say to yourself that it is going to be all right, right now it is tough, but you have a wonderful daughter who has some special needs, and that is OK.

Katie has been taking swim lessons and just started going to Montessori in a mother and child class. We want her to be involved in as many activities as possible, just as I was. We want to allow Katie the opportunity to explore and experience the world around her. She is going to be a challenge, as she likes to get into everything. The hardest part of being a parent with a child with OI is going to be knowing when to really pull in the reins and say “no you can't do that” and when to let them try their wings.

Every break will be difficult. You can't place blame on yourself for having passed on the disorder. You can't blame the person who is with the child when a break occurs. You really need to focus your energy on positive things. You have to believe that everyone will get through it and that everything will be all right.

There are two lasting bequests we can give our children: one is roots, and the other is wings. Give your kids the room to try their wings, and when they fall, be there to comfort and support them as best you can. 

“Parents are often so busy with the physical rearing of children that they miss the glory of parenthood, just as the grandeur of the trees is lost when raking leaves.”

— Marcelene Cox

**2002 Resource  
List & Order Form  
Enclosed**

## Plan now to participate in the 9th Annual Bone China Tea

By Jenny Wilson

OI Foundation member and volunteer

Imagine a fundraiser 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 event, the OI Foundation Bone China Tea, is the brainchild of Ms. Pat Kipperman, who came up with the idea in 1994. The beauty of the tea is that it takes place in the comfort and convenience of the invited guests' own home. It is a phantom tea party where you invite friends, family and co-workers to stay at home and have a quiet cup of tea. It is suggested that the money they may have spent on new clothes, babysitters, transportation, and other expenses associated with a formal tea be donated to the OI Foundation.



More than 420 people "participated" in last year's tea, netting well over \$18,500. With your help this year we hope to significantly increase that amount.

This is a wonderful way to keep in touch with your family and friends while raising money to support the OI Foundation.

Please participate in this year's event by requesting invitations to send to your family, friends and co-workers. Event coordinators Jenny and Susie Wilson are in the process of ordering the invitations and tea bags. In order to keep the overhead of this

event reasonable, they need a close count of invitations to be sent out by each participant.

To participate in this year's tea event please send your complete name, address, phone number and email address, along with the number of invitations you are requesting, by **January 6, 2003** to Jenny Wilson, 4 Briar Close, Larchmont, NY 10538 phone number (914) 834-6731, via email: [jnwilson@aol.com](mailto:jnwilson@aol.com).

"Besides raising funds for the OI Foundation, this is a great way to let friends and relatives know what's been happening in your life," according to Susie Wilson.

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. 