

Board & members shape the OI Foundation's future

Board of Directors meeting and Members meeting were held at Conference.

The OI Foundation Board of Directors held its biannual board meeting in Orlando prior to the 2002 Conference. The annual membership meeting was also held in Orlando to give conference participants a chance to provide input and learn more about the Foundation's day-to-day activities.

Both meetings were held in conjunction with the conference activities to minimize the Foundation's expenses and to provide maximum participation.

At the board meeting, Board President Bill Schmidt reported that revenues have been affected by the slowing economy, but are showing signs of improvement.

Just as important to the future of the Foundation, the board unanimously approved the 2002-2004 strategic plan.



New Board Members

The OI Foundation's newest board members are (from left to right) Robin Johnson, Neeru Sharma, and Parker C. Folse III.

Turn to Page 22 to read their biographies and learn about the skills and expertise they bring to the Foundation.

The plan, put into place after exhaustive research by the strategic planning committee which included comments, suggestions and ideas from more than 275 people, itemizes specific goals and achievements for the Foundation for the next two years. The plan is designed to bring the OI community together by reaching out to children, their caregivers and adults with information and support

(see *Highlights*, page 7, for more details).

The board also approved a policy on planned giving, a policy on accepting real property donations, and the 2003 fiscal year budget.

At the Board meeting, a resolution was passed honoring Dan Krudys, whose

Continued on page 6

'01, '02 Volunteer Awards presented

The Volunteer of the Year is awarded annually to the volunteer or volunteers who best exemplify the qualities of loyal and dedicated service to the OI Foundation and its members.

These exemplary volunteers give without thought of reward or recognition, demonstrating a spirit of willingness to put others before self, as demonstrated by the late Thelma Clack.

The 2002 Volunteer of the Year Award was presented to Gemma Geisman at the Awards Dinner at the national conference.

Plaques commemorating 2001 Volunteer of the Year Award winners Sidney Simmonds and David Morrison were also presented at the dinner.

Accepting the award for David was his mother, Susan Hart, and sister, Katie McQuillan.

The awardees are selected annually by committee. To submit a 2003 nomination, write to bonelink@oif.org.

According to OI Foundation Board President, Bill Schmidt, the awards dinner "is an opportunity for the OI Foundation to recognize some of the people who contribute greatly to our successful ability to fulfill our mission of improving the quality of life for children and adults with OI."

"Without the commitment of volunteers," he continued, "the Foundation simply could not exist." 

See Spotlight on page 18

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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.

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A one-year subscription to **BREAKTHROUGH** is free. To add your name to the mailing list, contact:

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Dear Friends,

Several times a year, the OI Foundation asks for your help as we raise funds to support the critically important work that we do. Thanks to the generosity and support of people just like you, the Foundation is able to provide programs, educational resources, research projects, and support services.

Each year, the appeals we send out – our Annual Research Appeal (June), Sally Foster Gift Wrap Sale (August-November), the OI Foundation Sweepstakes (November – February), and Bone China Tea (March) – combined with the efforts of our local event volunteers, individual donors and corporate and foundation grants, raise almost \$1,000,000.

There are many ways that individuals can make a difference and help support the work of the Foundation. Contributions to commemorate a birth, birthday, anniversary, wedding, death, or other occasion offer a generous and thoughtful way to honor a friend or relative and provide meaningful support for the OI Foundation. Writing letters or emails to friends and family letting them know about our work can also encourage contributions toward it. If you are interested in planning an event – a dinner, auction, golf tournament, walkathon, etc. – please let us know. We can help you in your planning and implementation, and give you ideas to help make your fundraiser successful.

Getting local companies, community groups or schools involved can also increase the impact of our fundraising efforts. Many companies offer matching gifts or internal giving programs, or participate in the United Way and CFC campaigns. We can help you connect with your company, workplace or school and explore these possibilities.

A simple and meaningful way to support the OI Foundation is through a bequest in your will or trust, or by making the Foundation a beneficiary of an IRA or life insurance policy. Please contact us about including the OI Foundation in your current or future plans – the Foundation will hold these discussions in strict confidence.

With your help, we have been able to expand the scope of our efforts and the information we offer. Now, over 100,000 individuals reach out to us for information annually. Fact sheets on many of the issues surrounding OI are available on our website or by mail. Researchers are devoting their careers to finding the answers to this often painful disorder. Together, we will find the dollars necessary to meet every need, to answer every question, and to improve the quality of life for every person with OI.

Donations can be mailed to the Foundation at 804 West Diamond Avenue, Suite 210, Gaithersburg, MD 20878 or made online at www.oif.org.

If you would like to sign up for one of our fundraisers, or would like information on how you can support the OI Foundation, please contact me with your thoughts and ideas. If you have any concerns or questions, I would be glad to speak with you about them. I can be reached at 301-947-0083 or jweiner@oif.org.

Julianne Weiner
Development Director

PRESIDENT'S MESSAGE



Bill Schmidt

Dear Friends,

It has been a busy and productive few months for the Foundation, culminating in the three-day, fun- and fact-filled National Conference in Orlando, Florida (pages 10 and 15). The conference greatly exceeded our expectations with more than 600 people in attendance. I cannot thank our volunteers and the Foundation staff enough for all their hard work and tireless effort to make the conference a success.

Preparing for and hosting the conference was in itself both challenging and rewarding, but it was only the tip of the iceberg. In the months (and weeks) preceding the conference, the Board completed a very ambitious two-year strategic plan (page 7), with guidance from over 275 people, including key volunteers, staff members, committees, and members of the OI community. We have mapped out our course for the next two years, and I am sure you will be as excited as I am about our plans for growth.

We're proud to share the result of a six-month survey of OI Clinics nationwide. The pull-out listing (pages 11-14) of clinics and the services they offer is presented to help you make more informed decisions about you or your loved ones' medical care. Visit our website for updates to this listing.

Also during the last three months, the long-awaited OI guide for physical and occupational therapists (pages 8-9) was completed. This is the first of a series of four booklets designed to improve the quality of your care by helping educate your health-care providers. The next booklet, due out in August 2003, will be an OI guide for nurses.

The web site continues to grow and is updated frequently, a new and improved chat service is now online (page 16), and we continue to respond to people and families in need of information or support. In July alone, the Foundation staff replied to more than 500 individual requests for information.

Over the summer we also completed a new fact sheet on dental care, updated the hearing fact sheet, completed and published the combined 2000-2001 Annual Report, held a Board meeting and a Medical Advisory Committee meeting, lobbied on Capital Hill for more OI-related funding (page 16), and began preparing for the annual nation-wide Sally Foster Gift Wrap fundraising campaign (page 7).

The next few months will be just as productive and challenging for the Foundation's staff and volunteers. We are actively pursuing a national outreach publicity campaign, plan to publish eight more fact sheets in the next two years, are in the process of writing and editing the "Bright Start Story Book" to help integrate children into mainstream classrooms (page 5), and have begun research on a book for adults that focuses on life issues such as relationships, marriage, employment, wellness, aging and independence (page 17).

None of this would have been possible (or will be possible) without your support. Volunteers nearly doubled the hours the staff put in over the summer months. From teenagers stuffing envelopes in the Foundation offices to committee members coordinating delivery of items for the resource room at the conference, it was your faithful financial and physical support that made it possible. I know— without a doubt— that we can count on that same dedication and support in the months to come.

It was an incredible experience sharing those three days with you in Orlando, but I feel privileged and grateful *every day* to be a part of such a wonderful community.

My very best personal regards,

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

Bill Schmidt

President, OI Foundation Board of Directors

Events support the OI Foundation

11th Annual Beefsteak scheduled for October

The 11th Annual Beefsteak to benefit the OI Foundation will be held Saturday, October 26, at the Three Saints Russian Orthodox Cultural Center in Garfield, New Jersey.

Cost to attend is \$35 each for adults, \$15 for children.

The "all-you-can-eat" filet mignon dinner and silent auction is expected to raise

as much as \$25,000 this year.

Just as importantly, it's a fun-filled night that draws participants from all across the country.

If you would like more information, would like to attend, or wish to donate items for the silent auction, please contact event coordinator Jo Ann Berkenbush at jbcowoi@juno.com. 

UPS Golf Tournament benefits Foundation

UPS employee Larry Baldwin coordinated another successful annual golf tournament to benefit the OI Foundation.

May 4th turned out to be an excellent golfing day for 36 teams- a total of 144 participants.

Special thanks to Larry and the several other individuals who helped make the event successful.

UPS District Labor Manager Al Gudim and District Feeder Manager Dan Krudys, and volunteers Brad Ray, Sue

Richardson, Gail Ferguson, Don Lewick and Sherri Davis all teamed together to make sure everyone had an enjoyable experience.

Three flights were awarded trophies for their efforts in men's and women's divisions, but the most positive result, along with everyone having a great time, was the fact that the golf tournament raised over \$3,700 for the Foundation.

Everyone is looking forward to next year, and another successful event. 

National Council on Disability Seeks Youths 18-25 for Advisory Committee

The National Council on Disability is seeking applicants age 18-25 to serve on their youth advisory committee. To apply, any interested individual with disabilities needs to send a cover letter and resume to ghawkins@ncd.gov (or fax it to 202-272-2022).

Criteria used for selection include assessing the letter and resume, demonstrated leadership experiences, dis-

ability issues/concerns and policy-oriented interests, and work (volunteer or paid) skills.

Address the cover letter to: Dr. Gerrie Hawkins, Designated Federal Official, Youth Advisory Committee, National Council on Disability, 1331 F Street NW, Suite 850, Washington, DC 20004.

Visit www.ncd.gov for more information. 

Winners Selected

The Southern California Petroleum Industry Charitable Association is producing a 2003 wall calendar featuring artwork by children with OI as a fundraiser for the Foundation.

Young people were invited at conference and through the web site to submit drawings for the calendar. From the 34 submitted drawings, the following children's art was selected:

Delores Selivan, 10, of River Grove, IL; Sarah Cramer, 6, of Prescott, AZ (two drawings); Alexander Lovrics, 9, of London, England (two drawings); Lauren Poll, 10, of Shaker Heights, OH; Carmen Sims, 7, of St. Albert, Canada; Noah Cook, 10, of Vineland, NJ (two drawings); Joseph Lovrics, 6, of London, England; J. Neil Wacaster, 10, of Hot Springs, AR; Molly Bryson, 11, of Jonesboro, AR; and Emily Voorde, 10, of South Bend IN.

Winners will receive 5 free copies of the calendar. Watch the Foundation's web site and/or the next issue of Breakthrough for ordering information. 

Correction:

In the last issue of *Breakthrough* there were a number of errors in the "Cornerstone" article about Jacob Everett, including an inconsistency in his reported age and one reference to him as "Caleb," not "Jacob."

Our sincere apologies. 

OI Foundation included in CFC & United Way campaigns!

The Annual Combined Federal Campaign (CFC) is an annual event for all Federal Employees, encouraging them to donate to selected charities through regular payroll deductions. The Foundation is listed in the campaign literature.

**CFC#
1728**

For those who are not Federal employees, the OI Foundation also participates in the United Way's annual drives. You must write in "Osteogenesis Imperfecta Foundation" on the United Way contribution form. 

Foundation names children's storybook editor

The OI Foundation is ready to begin the production of the "Bright Start Story Book" for preschool and kindergarten teachers to use to introduce OI to their students and integrate children with OI into mainstream classrooms.

Valerie Basic has agreed to write and edit the book and accompanying teachers guide, and is extremely excited to help educate teachers, peers and others about OI to help make the lives of children living with OI "a little bit easier."

Valerie's husband and daughter both have OI, as well as many of her husband's sisters, cousins, aunts, nieces and nephews. Her family has dealt with many of the problems that face most families dealing with OI; the numerous fractures, bone pain, pulled muscles, weak teeth, microfractures, surgeries and the psychological effects of living with OI. They have discovered that one of the most helpful tools they can have in dealing with OI is awareness.

Her career began a few years ago when she wrote bedtime stories for one of her foster children who had trouble sleeping at night. The stories were published online for use by foster care agencies as a recruiting/training tool.

She then went on to write a column for Cleveland.com called "It's a Mom's Life," where she wrote often of OI and the affect it had on her family's lives. She recently relocated to Cape Coral, FL, and writes for "The Breeze" newspapers.

The book should be completed within the next year; watch upcoming issues of Breakthrough and www.oif.org for updates. 

Senate Committee OKs Family Opportunity Act

By Julie Rovner
geneticalliance.org

Families with severely disabled children would be allowed to purchase health coverage through the joint state-federal Medicaid program under legislation approved by the US Senate Finance Committee in July.

The panel voted to send the "Family Opportunity Act" to the full Senate, but not before some members expressed concerns that the measure could cost more than the \$5.7 billion over 10 years estimated by the Congressional Budget Office.

Sponsor Charles Grassley (R-IA) said too many families with disabled children have been forced to remain in poverty lest they lose the child's Medicaid coverage. He cited in particular a family from Iowa where the parents had to turn down raises and promotions and a teenage brother was unable to even take a part-time job.

"No hard-working family should have to choose between work and caring for a child," he said.

Under the bill, states would have the option of allowing

families with incomes of up to 250 percent of the federal poverty level to purchase Medicaid coverage on a sliding scale. Families with access to private employer-sponsored insurance would be able to purchase Medicaid coverage for services the private plan does not provide. 

AAPD searching for Henry B. Betts nominees

The American Association of People with Disabilities is searching for nominees for the 2002 Henry B. Betts Award.

The award was created by the Prince Charitable Trusts and the Rehabilitation Institute of Chicago in 1989 to honor individuals whose work and scope of influence has significantly improved the quality of life for people with disabilities in the past, and will be a force for change in the future.

One outstanding living individual is selected each year to receive an unrestricted \$50,000 cash award and a commemorative crystal piece, which is presented publicly at the AAPD's Leadership Gala in Washington, D.C.

While the award is not a lifetime achievement award, the recipient must have professional accomplishments over his/her lifetime that justify receipt of the award. Successful nominees will have demonstrated a strong vision and understanding of how to improve the quality of life for Americans with disabilities, will possess a record of efforts and accomplishments that have affected a wide disability population, and have served as a powerful force for change, enhancing opportunities for people with disabilities to participate in all aspects of society.

For more information and/or to receive a nomination form, contact Tracey Murray at 770-232-9001 or by email at tmurrays@mindspring.com or aapd@aol.com. 

Doctors-to-be get a dose of OI information

The American Medical Association hosts Virtual Mentor, an interactive web-based forum for analysis and discussion of ethical and professional issues that medical students, residents and young physicians encounter during their educational training.

The content is designed to inform, awaken and energize students and young medical professionals to engage in a learning dialogue with experts in medicine, law, humanities and bioethics. It is recommended reading for most medical students.

Ellen Dollar, a former full-time OI Foundation Director of PR and Events, freelance author, and long-time member and supporter of the Foundation, was recently asked to contribute an article about OI to the "Through the Patient's Eyes" section on the site. Her article, entitled "A Maddeningly Complex Disorder" addresses both the need for doctors to be more aware of OI, and their need to listen to patients and family members-- the real experts in dealing with OI. Visit www.virtualmentor.org to see the article. 

ARTICLES

Tri for OI

Triathlete races towards a \$50k fundraising goal

Woody Binnicker is currently racing his way towards a goal of raising \$50,000 to support the OI Foundation.

His son, Cullen, is five years old and has Type I OI. Since learning to walk, Cullen has broken his legs, a forearm, and a number of toes.

To increase awareness for people with OI and to help raise funds to support the Foundation's research, education and support programs, he is

seeking donors to pledge \$1 per mile as he completes his first full year as a triathlete, running, biking and swimming a total of 371 miles.

This is not a "sponsorship." Woody is donating his time and using his own equipment. Every penny pledged toward his goal goes directly to the OI Foundation.

His race schedule and progress are posted on the OI Foundation web site

(click on "donate now," then the "Tri for OI" button). Woody raised more than \$13,000 after his first 100 miles, so he's well on his way to meeting the goal!

OI Foundation staff will be present when he crosses the finish line Dec. 14 at the last race of the year. Come join us in Kiawah, SC, as we congratulate Woody on his remarkable achievement and support for OI! 

BOARD & MEMBERS *Continued from page 1*

tenure as a board member ended this year. The resolution thanked Dan for his three years on the board. Dan is a dedicated fundraiser who received the 1997 Volunteer of the Year Award. Although Dan will continue to raise funds for the Foundation, his contributions to the board will be greatly missed.

Achievements Highlighted

At both meetings, Bill Schmidt also listed a number of achievements and activities in which the Foundation has been involved. Highlights include:

- a \$54,000 grant was received to support a research fellowship;
- an article about OI was featured on the American Medical Association's Virtual Mentor website. It is recommended reading for medical students;
- OI Foundation volunteers testified on Capital Hill to increase NIH funding for OI and related bone disorders. As a result of those efforts, the NIH is funding more than \$10 million of research into OI over the next five years;
- several new information resources have been published, including the long-

awaited *Therapeutic Strategies for Osteogenesis Imperfecta: A Guide for Occupational & Physical Therapists*.

Day-to-Day Activities

The annual meeting provided further information about the Foundation's day-to-day activities:

- We respond individually to more than 500 inquiries a month, ranging from parents of newly diagnosed children with OI to older persons concerned with their own OI-related health issues;
- Visits to our new web site have increased by 48% over the past eight months, up to 123,000 visits per year;
- We're supporting the Rare Diseases Act working its way through Congress. The Act will provide authorization for the Office of Rare Disorders at NIH, increase the investment into orphan drug research, and establish regional centers of excellence for rare disorders;
- Volunteers have contributed more than 18,000 hours in the past year to raise funds and help their peers;
- We now have 29 support groups in 24 states;

- Five new fact sheets were researched, written and published covering Rodding, Dental Care, Type I OI, Hearing Loss and Surgical Concerns.

- Since 1970, the Foundation has invested more than \$1.4 million into research for treatments and a cure for OI. This year alone, the Foundation provided \$157,000 for studies to better understand bone formation and bone growth.

- In December, the best researchers in the world participated in the *New Research Strategies in Osteogenesis Imperfecta*, a scientific meeting designed to increase the pace of research.

Bill Schmidt also thanked the membership for their continued financial support. Volunteers continue to raise almost \$300,000 a year, and a recent bequest is moving us towards our goal of supporting the entire operations budget from interest on the endowment fund.

This will allow every penny of each donation to go directly to research and programs. Currently about 80 cents of every dollar goes to research and programs. 

The Foundation's Annual Report is now available

The Fiscal Year 2000 and Fiscal Year 2001 annual reports have been published jointly in one publication.

The report includes highlights from the the Foundation's 30 years of service and support to those affected by OI.

It also contains complete financial statements and a

donor listing from both fiscal years.

To receive a free copy of the report, call or write to the Foundation office, or send a request via e-mail to bonelink@oif.org. Reports are already in the mail for all Legacy Donors and lifetime members. 

Highlights from the Foundation's Strategic Plan

The 2002-2004 strategic plan was unanimously approved by the OI Foundation Board of Directors at the board meeting held prior to the 2002 Conference. Planned activities in the next two years include (but are not limited to):

- **Fundraising:** We will actively seek ways to expand our endowment fund and research funding.

- **Information Resources:** We will continue to be the premiere provider of credible, accurate, medically-verified information about OI. Part of this commitment includes publication of new or improved fact sheets in hearing loss, respiratory concerns, diagnosis, aging, post-surgical care for children, pregnancy, and one specifically designed to help persons with OI prepare the right questions to ask their doctors.

- **Books:** We will publish "Children with Osteogenesis Imperfecta: Strategies to Enhance Performance," the "Bright Start Story Book" for preschool

and kindergarten teachers to use to introduce OI to their students and integrate children with OI into mainstream classrooms, and a book specifically written for adults with OI.

- **Internet:** We will continue to expand our chat program with targeted chat rooms and discussion forums for parents, young professionals, adults and teens.

We will establish a list serve for doctors to post questions and receive medical advice about OI-related treatment(s).

We will provide more opportunities for member input on the web site (including photos and life-stories), and expand the links to increase awareness of available resources.

- **Public Outreach:** We will develop and implement a nation-wide publicity campaign to educate the public about OI.

- **Medical Outreach:** We will actively seek out opportunities to interact with medical providers, including doctors, nurses and physical and occupational

therapists, using educational campaigns to help improve their understanding and treatment of patients with OI.

We will publish an annual national listing of OI clinics, detailing the services they provide, to assist families in finding the best possible medical care.

We will continue to offer fellowships and grants to new researchers, expanding the scope of current research.

This is only a small part of a very ambitious two-year plan designed to meet the needs and expectations of not just our membership, but every person affected by OI.

For a look at the plan in its entirety, visit our website at www.oif.org. Please send any comments or suggestions to bonelink@oif.org.

If you have experience and/or a desire to take part in helping us achieve these goals, please call or write the Foundation.

Our accomplishments are only possible with your input, financial assistance and volunteer support! 

Order your Sally Foster sales kit from the Foundation today

(proceeds from all sales benefit the OI Foundation Research Fund & Support Services)

It's not too early to plan for the holidays, and raise funds for the OI Foundation!

Please help make the Foundation's annual Sally Foster Gift Wrap fundraising project a success. This year, in order to cut down on mailing expenses, sales packets are only being mailed to those who've participated in past years or specifically requested a 2002 packet from the Foundation.

Sales of Sally Foster gift wrap, gifts, accessories and gourmet foods will raise more than \$10,000 to support the Foundation's support and research funding. Everyone is invited to participate, and every sale will make a difference!

Request your catalog and order form today, and share it with friends, family and coworkers... a single sale pays the postage for the Foundation to respond

to a phone or internet inquiry.

Here's how you and your family can get involved:

- Call (301) 947-0083 or email jweiner@oif.org and let us know that you want a Sally Foster Kit.

- Invite friends and family to browse the catalog and order wrapping paper, gifts, or gourmet foods for the up-coming holiday season.

- Return the order form by October 15, 2002, to ensure the items arrive before the Thanksgiving holidays.

Order NOW!
Supplies are limited.

The items you and your friends and family order will be shipped to you to distribute. There are a limited number of sales kits available-- and you **know** you're going to need paper in the coming months... call today for your free catalog!

Catalogs will be available on a first come, first served basis. Less than one hundred 2002 catalogs remain available for distribution.



The following information is an excerpt from a new booklet from the OI Foundation titled **Therapeutic Strategies for OI: A Guide for Physical Therapists and Occupational Therapists**. This is the first in what will be a series of booklets for medical professionals. A new title will be added to the series each year.

The booklets are designed to introduce OI to students preparing for their professions and to update experienced health care providers with the latest information about caring for children and adults who have osteogenesis imperfecta.

Therapeutic Strategies for OI does not provide a prescription for physical and occupational therapies that is right for every person who has OI. Instead, it suggests topics that therapists, parents, adults with OI and their doctors should discuss and consider when designing a therapy program based on an individual's abilities.

The complete 12-page booklet is available free of charge by writing to the OI Foundation or by sending an email to bonelink@oif.org.

Q. How can therapists help people who have OI?

Physical and occupational therapists can help people with OI maximize strength and overcome functional limitations by teaching them and their families about protective handling to

avoid injuries, protective positioning and movement to strengthen muscles and develop motor skills, and use of appropriate adaptive equipment.

Q. Does the type of OI influence therapies?

Although the classification system of four OI types is commonly used to help define how severely a person with OI is affected, it is important to remember that the **features** such as fracture frequency, muscle strength, bone and joint alignment **vary greatly** from person to person even among people with the same type of OI and even within the same family.

Therapists are reminded that when they work with an individual who has OI, it is most important to focus on the individual's particular abilities, strengths, and weaknesses, rather than on the OI type.

Q. In what circumstances is physical and occupational therapy an appropriate treatment?

Therapies are an appropriate treatment in the following situations:

- When a child with OI has delays or weakness in motor skills.
- When a person with OI is recovering from a fracture or surgery.
- When a person with OI experiences fear of movement and trying new skills.
- When a person with OI needs to learn a new skill.
- When a person with OI needs

to learn a new way of performing a known skill.

Q. What is the goal of physical or occupational therapy for people with OI?

The long-term goal for people with OI is as much independence in all life functions-- such as self-care, locomotion, recreation, social interaction, education and work-- as possible.

This may require the use of adaptive devices, or in the case of very severely affected people, the ability to direct their own care.

Q. What are the principles of protective positioning?

- Never pull, push, or twist a limb. Avoid passive rotation of the arms, legs, head or trunk.
- Lift an infant with OI with the widest base possible.
- Be aware of where the person's arms and legs are at all times.
- Provide adequate support when the child or adult is in a standing position so the legs don't "crumple" under them.
- Avoid positions and motions of great leverage that stress bones or joints.

Q. Why is water therapy so popular?

Besides being fun, the water provides an ideal environment for people with OI to practice protected movement and learn new skills.

Water not only cushions bones and joints and protects the person from falls, but also provides gentle resis-

tance along the entire length of bones. This resistance helps strengthen bones and muscles, and also helps prevent fractures that can be caused when too much pressure is applied to an isolated area.

Swimming and other water exercises often become favorite fitness activities for older children and adults with OI.

Q. What are the criteria for evaluating adaptive equipment?

Important concepts to consider when choosing equipment – either “homemade” or purchased, include the following:

- **Energy conservation.** Does the equipment help the

individual accomplish the task without excessive strain or fatigue?

- **Joint protection.** Does the device use the person’s strongest muscle group and minimize strain on the joints?
- **Mobility.** How frequently will the mobility aid be used — everyday, most of the time, or only briefly?
- **Accessibility.** Will the device help the individual make better use of the physical environment and perform routine activities in a more independent manner?

Q. Are there certain tasks that therapists should concentrate on helping the person with OI learn how to do?

Toileting, bathing/grooming, dressing, and food preparation are four key self-care tasks. These tasks are often challenging for people with OI, particularly if they are short-statured, use a wheelchair and/or are recovering from a fracture of surgery

Some people will be able to learn to accomplish these tasks completely independently, others will need a modification to the environment or varying degrees of assistance. 

Editor: This resource is not currently available on the web. To order, call or write the Foundation.



Fact Sheets & Resources

Therapeutic Strategies for OI: A Guide for Physical Therapists and Occupational Therapists

Excerpted on these pages, 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.

Plan For Success

Recently revised and reprinted, this 14-page 5x8 booklet is designed to assist children, families, teachers and school officials as they integrate a child with OI into the mainstream classroom. It covers mobility accommodations, fire/evacuation plans, resources, absences, adapting physical activities, and transportation needs. It also has a listing of Federal and State agencies that can assist. The booklet has a companion video and is available for bulk orders.

Celebrating Our Growth: The 2000-2001 Annual Report

The OI Foundation combined the 2000 and 2001 annual reports into one 26-page magazine which contains both Fiscal Year Financial Reports and a 30 year time line of key events in the Foundation’s History.

OI Issues: Hearing Loss

Our hearing loss fact sheet has been recently revised and reprinted. Available on our website.

OI Issues: Dental Care for Persons With OI

This is brand new fact sheet-- authored by James K. Hartsfield, Jr., D.M.D., Ph.D., and Lawrence P. Garetto, Ph.D., from the Indiana University Schools of Dentistry and Medicine-- covers everything from basic dental care to implants and surgery. Available on our website.

Call 1-800-981-2663 or write to bonelink@oif.org

The following material was developed through a detailed survey conducted by the Foundation staff as directed by the Board of Directors. Each survey was completed by a member of the clinic team during the Spring and early Summer of 2002.

This project is intended to assist families and individuals in locating centers that offer interdisciplinary care for people living with osteogenesis imperfecta. The information is offered as a service to the community.

The OI Foundation does not endorse the services or quality of care provided by these institutions. The listing is a resource to assist individuals and families in their search for medical care. It is not the intention of the project to identify individual doctors or health care providers who care for people with OI only through a private practice.

The material from this survey is also posted in its entirety on the Foundation website (www.oif.org). As new information becomes available, the website will be updated. Each clinic will be contacted in the spring of each year to update and verify their listing. As new information becomes available, additional institutions will be contacted and asked to participate in the clinic listing project.

New print listings and comparison charts will be published annually in Breakthrough, or by other means if it grows too large to be included in the newsletter.

If readers are aware of a clinic that is not listed, please contact Mary Beth Huber at the OI Foundation of office by calling 1-800-981-2663 or writing to mhuber@oif.org. 

OI Clinics by geographic region

Key to Treatment Programs

- A. Coordinated care through a clinic
- B. Appointments with individual doctors
- C. Appointments with members of an interdisciplinary team
- D. Treatment as part of a research protocol

OI CLINICS: NEW ENGLAND REGION

No institutions returned a survey.

OI CLINICS: MID-ATLANTIC REGION

A.I. duPont Hospital for Children

1600 Rockland Rd.
Wilmington, DE 19899
Dr. Richard Kruse, Clinic Director
Clinic Hours: M-F
To make an appointment: 302-651-4200
Services: For children to age 18
Treatment Programs: A,B,C,D

OI Clinic at Kennedy Krieger Institute

707 N. Broadway
Baltimore, MD 21205
Dr. Jay Shapiro & Dr. Paul Sponseller, Directors
Clinic Hours: Patient preference
To make an appointment: 800-873-3377
Carole Hickman, CPNP, 443-923-2704
or Cynthia Greene, 443-923-2703
Web Site: www.osteogenesisimperfecta.org
Services: Children and Adults; referrals to Johns Hopkins Medical Center
Treatment Programs: A,B,C,D

National Institutes of Health

10 Center Dr.
Bethesda, MD 20892
Dr. Joan Marini, Principal Investigator
Clinic Hours: Appointment Only
To make an appointment: 301-496-0741
Only patients accepted for Clinical Trial
Contact: Anne Letocha MSN, CRNP
Services: Children accepted into clinical trial and adults being followed post clinical trial
Treatment Programs: C,D

Children's National Medical Center

111 Michigan Ave., NW
Washington, DC 20010
Dr. Laura Tosi, Program Director
Clinic Hours: Skeletal Dysplasia Clinic through the Genetics Department the second Tuesday of the month, 8:30 a.m. - 12:00 p.m.
To make an appointment: 202-884-4167
Deborah Carpenter, Genetics
Fracture Care through Dr. Tosi's office
202-884-5562
Services: For children to age 21. Genetic Counseling is open to adults.
Treatment Programs: A,C

Shriners Hospital - Philadelphia

3551 North Broad St.
Philadelphia, PA 19140
Clinic Hours: Th 1-4 p.m.
To make an appointment: 800-281-4050
Scheduling Secretary ext. 4073
Services: Children to age 21
Treatment Programs: A,B,C

OI CLINICS: SOUTHEAST REGION

Shriners Hospital - Tampa

12502 North Pine Dr.
Tampa, FL 33612
Dr. Dennis P. Grogan, Clinic Director
Clinic Hours: M-F, 8 a.m.-5 p.m.
To make an appointment: 813-972-2250
Nancy Swanson, Application Secretary
ext.7107
Services: Children to age 18
Treatment Programs: A,B,C,D

Shriners Hospital - Greenville

950 West Faris Rd.
Greenville, SC 29605
Clinic Hours: General Orthopedic Clinic M-F,
7 a.m.-5 p.m.
To make an appointment: 864-240-3106
or 866-459-0013
For information: Frances Foley, RN, BSN
864-271-3444 ext. 7318
Services: Children to age 18
Treatment Programs: A (orthopedic care), C

Shriners Hospital - Lexington

1900 Richmond Rd.
Lexington, KY 40502
Dr. Richard Mier, Clinic Director
Clinic Hours: M-F, 9 a.m. - 4 p.m.
To make an appointment: 859-266-2101
Pam Tuttle
Services: Children to age 21
Treatment Programs: A,D

OI CLINICS: MIDWEST REGION

University Hospitals of Cleveland Center for Human Genetics

Bone Disorders Clinic
Case Western Reserve University
Room LKS-1500
11100 Euclid Ave.
Cleveland, OH 44106
Dr. Matthew Warman & Dr. R. Tracy Ballock
Clinic Hours: 4th Wednesday of the month.
Patients can be seen outside of clinic days
To make an appointment: 216-844-7213
Shauna Heeger, MS Sih3@po.cwru.edu
or Matthew L. Warman, M.D. 216-368-4919
Services: Children and Adults
Treatment Programs: A,B,C,D

CLINIC LISTING

2002 CLINIC LISTING

Cincinnati Children's Medical Center

3333 Burnet Ave.
Cincinnati, OH 45229
Dr. Richard Wenstrup, Genetics Department
Clinic Hours: Wednesday afternoons
To make an appointment: 513-636-4351
Leah Hoehstetter, MS
Services: Children and Adults
Treatment Programs: A,B,D

Shriners Hospital - St. Louis

2001 South Lindbergh Blvd.
St. Louis, MO 63131
Dr. Michael Whyte, Clinic Director
Clinic Hours: M-F
To make an appointment: 314-432-3600
Applications Department
Services: Children to age 18
Treatment Programs: A,B,C,D

Barnes-Jewish Hospital Division of Bone and Mineral Diseases

216 S. Kings Hwy.
St. Louis, MO 63110
Dr. Michael Whyte
Clinic Hours: M-F
To make an appointment: 314-454-7765
Services: Adults
Treatment Programs: B

Shriners Hospital for Children - Chicago

2211 N. Oak Park Ave.
Chicago, IL 60607
Dr. Peter Smith, Clinic Director
Clinic Hours: M, Tu, F
To make an appointment: 773-385-5400
Admissions Office
Services: Children to age 21
Treatment Programs: A

Shriners Hospital - Twin Cities

2025 E. River Pkwy.
Minneapolis, MN 55414
Dr. Deborah Smith-Wright, Pediatric Internist
Clinic Hours: Monday-Friday, 9 a.m.- 4 p.m.
To make an appointment: 612-596-6105
Karen Boyer, Application Secretary
Services: Children to age 21
Treatment Programs: A,B,C,D

Midwest Regional Bone Dysplasia Clinic

University of Wisconsin
1500 Highland Ave.
Madison, WI 53705
Dr. Richard Pauli, Clinic Director
Clinic Hours: Wednesday 8:30 a.m.- 4:30 p.m.
or by appointment Monday- Friday
To make an appointment: 608-262-2507
Gerry Vohs, Clinic Coordinator
Services: Children and Adults
Treatment Programs: A,B

OI CLINICS: SOUTHWEST REGION

Matrix DNA Diagnostics Tulane University Health Sciences Center

1430 Tulane Ave., SL - 99
New Orleans, LA 70112-2699
Dr. James Hyland, Lab Director
Hours: M-F, 8 a.m. - 5 p.m.
To make an appointment: 504-988-7706
Dr. James Hyland or Charlene Crain, MT

Services: Genomic testing, children and adults
Treatment Programs: Genomic Testing Only

Shriners Hospital - Shreveport

3100 Samford Ave.
Shreveport, LA 71103
Dr. Richard McCall, Clinic Director
Clinic Hours: M-Th, 8:30 a.m. - 3 p.m.
To make an appointment: 800-830-0606
Jennifer Schaffner
For information: 318-222-5704
Beth Hayes, RN,
Services: Children to age 21
Treatment Programs: A,B,D

Shriners Hospital - Houston

6977 Main Street
Houston, TX 77030-3701
Dr. D. Auleta, Clinic Director
Clinic Hours: 4th Friday every other month
12:30 p.m. - 4:30 p.m.
To make an appointment: 713-797-1616
Aura Arand, Applications Sec., Ext. 3765
For Information: 713-793-3752
Katie Leonard, RN
Services: Children to age 18
Treatment Programs: A

OI CLINICS: WEST REGION

Shriners Hospital - Intermountain

Fairfax Road at Virginia St.
Salt Lake City, UT 84103
Clinic Hours: January, April, July, October, 2nd
Wednesday, 8 a.m. - 12 noon
To make an appointment: 800-841-0204
Applications Department
For information: 801-536-3565
Angela Bytheway
Services: Children to age 18
Treatment Programs: A,D

The Children's Hospital of Denver

1056 E. 19th Ave.
Denver, CO 80218
Dr. Ernest Sink, Clinic Director
Clinic Hours: Individual appointments
To make an appointment: 303-861-6259
For information: Dr. Ernest Sink at
sink.ernest@tchden.org
Services: Children only
Treatment Programs: B

Children's Hospital Central California

9300 Valley Children's Pl.
Madera, California 93638
Dr. Berkley Powell, Clinic Director
Clinic Hours: M-F, 8:30 a.m. - 5:00 p.m.
To make an appointment: 559-353-6400
For information: Dr. Powell at
bpowell@valleychildrens.org
Services: Children to age 21
Treatment Programs: A,C

Shriners Hospital - Los Angeles

3160 Geneva St.
Los Angeles, CA 90020
Dr. Gayle Tyerman, Clinic Director
Clinic Hours: Every Tuesday 9 a.m.- 4:30 p.m.
To make an appointment: 213-388-3151
Faviola Ramirez
For information: Dr. Tyerman at
gtyerman@shrinenet.org

Services: Children to age 18
Treatment Programs: A,C,D

Cedars-Sinai Medical Center

444 S. San Vicente Blvd. Ste. 1001
Los Angeles, CA 90048
Dr. David Rimoin, Clinic Director
Clinic Hours: Tuesday, 8:30 AM - 5 PM,
Friday, 8:30 AM - 1200 Noon
To make an appointment: 310-423-9914
For information: 310-423-9861
Fiona Field MS, at fiona.field@cshs.org
Services: Children and Adults
Treatment Programs: A,B,C

Shriners Hospital - Northern California

2425 Stockton Blvd.
Sacramento, CA 95817
Dr. Jennette Boakes, Clinic Director
Clinic Hours: M-F, 8 a.m. - 3 p.m.
To make an appointment: 916-453-2180
For information: 916-453-2000 ext. 3100
Marcia Davis, PNP at mdavis@shrinenet.org
Services: Children to age 18
Treatment Programs: B,D (current protocols
closed to new patients)

Shriners Hospital - Spokane

911 W. 5th Ave.
Spokane, WA 99204
Dr. Ron Ferguson, Chief of Staff
Clinic Hours: M-Th
To make an appointment: 888-895-5951
For information: rferguson@shrinenet.org
Services: Children to age 21
Treatment Programs: B,D

University of Washington Children's Hospital

Box 357470
Seattle, WA 98195-7470
Dr. Peter Byers, Clinic Director
Clinic Hours: Tuesday, 8 a.m. - 2 p.m.
To make an appointment: 206-616-2135
Services: Children and Adults
Treatment Programs: A,B,C

OI CLINICS: HAWAII

Shriners Hospital - Honolulu

1310 Punahou St.
Honolulu, HI 96826
Dr. Suzanne Yandoro, Clinic Director
Clinic Hours: M-F, 8 a.m.- 4:30 p.m.
To make an appointment: 808-951-3620
For information: Dr. Yandoro at
syandrow@shrinenet.org
Services: Children to age 21
Treatment Programs: A

OI CLINICS: CANADA

Shriners Hospital - Montreal, Quebec

1529 Cedar Ave.
Montreal, Quebec
Canada H3G1AG
Dr. Francis Glorieux, Clinic Director
For information or to make an appointment:
Nancy Cyr 800-361-7256 Ext.7158
or E- mail: ncyr@shriners.mcgill.ca
Services: Children to age 21
Treatment Programs: A,B,C,D

8-year-old Volunteer testifies before congress



Poised and competent...

8-year-old Katrina Bache delivers persuasive testimony to Congress as her mother, Gayle, looks on. They were on Capital Hill on behalf of the National Institutes of Health, requesting additional funding for research into OI and other related bone disorders.

As a result of ongoing advocacy efforts by Foundation members, the NIH is funding more than \$10 million of research into bone-related diseases over the next five years.

Chat News

After two difficult months, with a service provider going off-line just weeks before the National Conference and an intensive search to find a safe, user-friendly interface, the OI Foundation Chat Room is back online and better than ever.

The Foundation's chat room is now powered by DigiChat, a third-party service provider.

The room is currently open Sunday nights from 8 to 10 p.m. EST.

In the next few months we will expand the chat services to include rooms specifically for teens, parents, adults and others.

Access the chat room through the web site by clicking on the "Chat" button on the main menu.

No additional software is required, but the service does run on a Java-script applet.

You may need to upgrade your browser and/or revise security settings before you can access the chat. See the "having problems" page for more details. 

Web Spots

Useful or informative sites for the OI community

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

Sean Stephenson

www.seanstephenson.com
(Page 24)

Department of Transportation

www.nhtsa.dot.gov.com
(Page 21)

Adapted Driving via the iCan! community

www.ican.com
(Page 21)

National Council on Disabilities

www.ncd.gov
(Page 4)

The Genetic Alliance

www.geneticalliance.org
(Page 5)

The Braitmayer Foundation

www.braitmayerfoundation.org
(Page 24)

American Association of People with Disabilities

www.aapd.com
(Page 5)

American Medical Association Virtual Mentor

www.virtualmentor.org
(Page 5)

William C. McGowan Charitable Fund

www.mcgowanfund.com
(Page 17)

The Million Dollar Roundtable Foundation

www.mdrtfoundation.org
(Page 24)

Direct links to these organizations can be found on the OIF website "Links" page.



OI Foundation seeks input for new fact sheet

The OI Foundation has just begun research on a new fact sheet, titled “Post Surgical Care of a Child with OI.”

The fact sheet is intended to be a compilation of hints and strategies to make the transition from the surgical ward to home as comfortable as possible. YOU are the experts on this topic, and the Foundation would like to include your first-hand experience in this resource.

Please send any advice, tips, or guidance you think may be useful to a parent whose child is recovering from surgery. If you’ve “been there,” you could make a huge difference in the life of someone facing it for the first time.

Send your tips to bonelink@oif.org, with “Post Surgery Care Tips” in the subject line.

As always, the fact sheet will be carefully reviewed by our Medical Advisory Committee, and will be available free through a grant from the National Institutes of Health Osteoporosis and Related Bone Diseases National Resource Center. 

Didn't Make it to the 2002 Conference in Orlando?

Keep your eye on www.oif.org in the next few weeks.

We'll be posting web-casting transcripts and selected sessions from the conference floor, as well as photos submitted by conference participants.



We're committed to ensuring everyone affected by OI has access to the most current research and daily living information!

Grants provide Foundation with means to succeed

The OI Foundation relies heavily on outside grants to be able to provide funding towards research, fellowships, and services to the OI community. A number of new grants have been obtained in the past year, including:

The William G. McGowan Charitable Fund was established to promote, nurture and fund promising programs in health care and medical science research, create educational opportunities, and develop the gifts and talents of children.

A recent \$54,000 research grant was provided to create the William G. McGowan Research Fellowship.

The Braitmayer Foundation supports organizations and programs which enhance the quality of life for children in Kindergarten through 12th

grade.

They recently granted the OI Foundation \$30,000 to develop, write, illustrate and publish the “Bright Start Story Book” and its accompanying teacher’s resource. The storybook will help teachers introduce children with OI into mainstream classrooms, increasing understanding and acceptance.

The Million Dollar Roundtable Foundation is a public charity. Their grant programs are designed to support organizations that serve to enhance the quality of life for handicapped or disabled persons, among others.

They recently provided the OI Foundation with \$15,000 to be used in our 2002 conference scholarship program.

Eleven families attended conference through the MDRT’s generous support.

The Maryland Home and Community Care Foundation is dedicated to improving the quality of life for those in need of health and supportive services at home and in the community.

They provided the OI Foundation with a \$15,900 grant, funding the development and production of a guidebook for adults with OI that focuses on life issues such as relationships, marriage, employment, wellness, aging and independence.

Many thanks to these and the many other organizations and individuals that make our work possible through their generous support! 

SPOTLIGHT

Gemma Geisman named '02 Foundation Volunteer of the Year



Gemma reacts to the surprise announcement that she won the Volunteer of the Year award.

Gemma Geisman

has been an active volunteer serving people with OI and their families for 32 years. Gemma wrote two articles, published in Redbook Magazine in 1968 and 1970, that were instrumental in getting the OI Foundation started.

In these moving articles, she wrote candidly about being the mother of a child with OI. In response, she

received hundreds of letters from other mothers, and she answered every single one, creating lifelong friends who became the backbone of the OI Foundation.

At the same time, she helped organize the first medical conference for physicians and geneticists at Shriners Hospital in Chicago in 1972.

Gemma's two enduring interests, supporting families and encouraging research to find treatments and a cure, continue to shape the Foundation's vision today.

She was editor of our quarterly newsletter *Breakthrough* from 1970 to 1987 and continues to write articles. Her most

recent article, titled "Mother's Day Joy" appeared in the spring 2002 issue.

Gemma also edited and wrote many of the OI brochures and resource materials, as well as contributing to the books on OI. Her most recent contribution is the Foreword to "Growing Up with OI".

Gemma was a one-person support group by correspondence and telephone with many families in the early days when little or no written information was available. She helped organize, and was the keynote speaker at, several OI Foundation National Conferences.

After her son died in 1980, she helped set up the Michael Geisman Memorial Research Fellowship Fund.

She was President of the OI Foundation from 1978-1981 and became the first Executive Director. Although this was a paid position, she gave many more hours than she was ever paid for. She believes in keeping the OI Foundation focused on the caring and support of people who have OI and the families who deal with it.

Gemma served on the Advisory Council and on the Nominating Committee for many years and is a lifetime member of the OI Foundation's Board of Directors.

Gemma has inspired so many other volunteers, this award is just a small token of the love and respect we all feel for her. 



Custom Holiday Greeting Cards

(proceeds benefit the OI Foundation)

Limited numbers of Holiday Greeting cards created by children with OI are still available from the OI Foundation. These cards were printed over the past two years in partnership with the Children's Brittle Bone Foundation, and contain the inscription "Warmest Wishes for a Wonderful Holiday Season."

On orders of 50 or more, and for a nominal inscription fee, the cards and envelopes can be custom printed with your family name or personal message.

Cards can be ordered in groups of 25 for \$29.50.

To receive an order form, write to bonelink@oif.org (with "Holiday Card Form Needed" in the subject line), or the Foundation offices at the address listed on page two. To order by credit card, call (301) 947-0083.

Order NOW!
Supplies are limited.

Filled on a first come, first served basis. Identify cards by "Reindeer" (top), "Melting Snowman" (center) or "Snowman" (bottom).

HONORARY AND MEMORIAL DONATIONS

APRIL 1 TO JUNE 30, 2002

In Honor Of ...

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|---|--|---|--|---|
| <i>Cullen Binnicker</i> Woody & Janice Binnicker <i>Atty. Michael Blanchard</i> Mr. Jared Levin <i>Bill Bradner</i> Ms. Heller An Shapiro <i>Carolina Canida</i> Ms. Carolina Canida <i>Mrs. Marian Cole</i> Heidi Glauser <i>Jenna Cummings</i> Bill & Jill Shaddock & Family | <i>Joel Davis</i> Ms. Nancy Acree <i>Jacob Everett</i> Andy's Distinctive Designs <i>Laura Hope Haney</i> Ms. Linda S. Wooldridge <i>Emma Johnston</i> Michael & Patricia Cadenhead Mrs. Corinne Landrum <i>Harriet Judd (80th Birthday)</i> Marvin & Edith Churney Simon & Emmy Kate David Ms. Harriet Dieter | Harry & Carol Geisberg Mr. & Mrs. Harold Green Ivan & Renee Greenspan Fred & Suzanne Hammel Mrs. Sam Jacobs Morris & Helene Ruth Judah Ms. Shirley Kozlove Ms. Goldye Opper Albert & Ellen Rieser Ms. Beverly Rosenblum Mrs. Elsie Sales Ms. Peggy Sloss Arnold & Eunice Switow | Ms. Betty Turnheim Mrs. Elliot Wainer Alvin & Betty Younger <i>Arnold & Harriet Judd (60th Wedding Anniversary)</i> Harry & Carol Geisberg Fred & Suzanne Hammel <i>Dick Klein (70th Birthday)</i> Larry & Deborah Lapkin <i>Josh Langford</i> Mr. Joshua Dorsey <i>Amy Ley</i> Beta Sigma Phi-Beta Theta | Theta <i>Kyle Mulroy</i> Mr. & Mrs. Charles A. Buck, Sr. <i>Kari Roll (Birthday)</i> Ms. Ruth Hovden <i>Dawn Marie Shaffer</i> Mr. Fred Shaffer <i>Heller An Shapiro</i> Orrin T. Shapiro Mem. Fn. <i>Dawn & Derek Sloan</i> Ms. Kathleen Provin <i>Shannon Strauch</i> Ms. Frances Donohue |
|---|--|---|--|---|

In Memory Of ...

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|---|--|--|--|---|
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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 or by calling 1-800-981-2663.

ARTICLES

Legacy Donors receive inside look at latest research

The Foundation's second annual Legacy Dinner was held July 17 in Orlando, FL. This dinner offered opportunities to learn about cutting edge research to develop effective treatments for OI, and to recognize the invaluable support of our major donors.

The highlight of the dinner was a presentation by Yale University School of Medicine professor Roland Baron, D.D.S., Ph.D., who described his Foundation-funded research. Dr. Baron has published over 184 scientific papers on cell biology and orthopedics.

Dr. Baron's groundbreaking research uses a transcription factor called Δ FosB, which is a protein that regulates gene expression.

While bisphosphonates work to decrease resorption by slowing osteoclast activity (bone breakdown), Δ FosB works to increase the activity of osteoblasts (cells that build new bone).

Dr. Baron's research showed that Δ FosB can regulate osteoblast activity in vivo (in mice), and can increase bone mass even after the mouse reaches skeletal maturity.

The next steps to developing a new drug treatment for OI are to determine if this increase in bone mass will occur in OI bone, and then to better understand the mechanism that makes Δ FosB work.

By identifying the genes that are

activated by Δ FosB, additional or better targets for drugs may also be discovered.

It is important to remember that the drug discovery process is lengthy and expensive. One out of 250 compounds tested may develop into a drug that can take 8-10 years and \$5-800 million to bring to the marketplace.

Fortunately, interest in developing osteoporosis drugs stimulates development of OI Drugs.

Dr. Baron presented a similar version of his talk during the 2002 National Conference Research Update session. This session will be available on the OI Foundation web site at www.oif.org.

Don't want to cut up your copy of *Breakthrough*?

Apply for membership or make a donation to the OI Foundation on-line at www.oif.org.

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

- | | |
|--|----------|
| <input type="checkbox"/> Friend membership | \$20 |
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| <input type="checkbox"/> Patron membership | \$240 |
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Total membership commitment \$ _____

I would like to make a \$ _____ tax-deductible donation to the Foundation's Research Fund.

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Relationship to OI:

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

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

Osteogenesis Imperfecta Foundation
804 W. Diamond Ave., Suite 210
Gaithersburg, MD 20878
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How to:

Select or adapt the right vehicle for your driving needs

By Neeru Sharma
GM Mobility Program

Driving is one of the most important and exciting steps to becoming an independent person. For people with mobility issues, driving can pose special issues in terms of being able to enter the vehicle, maneuver the vehicle, and feel safe while driving.

Many automakers, including GM, provide a reimbursement program to defray the cost of modifications to their vehicles, and have dedicated staffs working on driving issues for those with impaired mobility. Regardless of who you purchase your next vehicle from, there are a few basic steps you can take to make sure you get the right vehicle and adaptations.

Selecting the right vehicle

When trying to decide which vehicle will work for you, remember you are not restricted to just a van. Extended cab pickups are an option; there's easy entry and stowage of equipment through the third drivers-side door or in the bed of the truck. Compact pick-ups feature low driver and passenger seat-to-ground height, for easier entry and exit. Even three-door coupes could be considered; drivers-side third doors have no post between the first and second doors.

More Tips to Consider

Once you are at the dealer, make sure you practice entry and exit from the vehicle and stowage of your mobility aid. Bring a blanket to protect the vehicle, but do as much of this as possible on your own. When you drive, you want to be independent and won't have a salesperson there to assist you.

Practice entering and exiting on different seat surfaces like vinyl, leather or cloth. Let your dealer know what kind of mobility equipment you will require (hand controls, seat modifications, lifts) so he can measure the vehicle and double-check compat-



Photo courtesy of GM Mobility

Most three-door sports coupes do not have a center door post, making them a fun, accessible alternative to full-sized vans or mini-vans for persons with disabilities.

ibility. Also be sure to ask about financing through the dealership. It may be required to qualify for accessibility reimbursement programs.

If you are receiving reimbursement through a state or private institution, make sure you know the balance of the loan you will need to buy the vehicle *and* modifications.

Adapting Your Vehicle

There are many variables involved in obtaining adaptive equipment for vehicles. We recommend you obtain a copy of the Department of Transportation brochure "Adapting Motor Vehicles for People With Disabilities." It is available by calling 1-888-327-4236 or by visiting www.nhtsa.dot.gov.

There are some basic steps to take in adapting a vehicle:

1. **Obtain an evaluation.** Contact a driver assessment facility in your area for an evaluation (through your state Dept. of Vocational Rehabilitation). Request a report containing a complete list of recommended modifications from the evaluator.
2. **Contact your state licensing Agency.** In most states, a person is required to report a change in their medical status to the licensing agency.

3. Select the proper vehicle.

Before you select and purchase a vehicle, consult with your evaluator, equipment installer and dealer. Be sure to consider your type of driving and how your needs may change.

4. Select a qualified equipment installer.

Shop around, asking about their qualifications, capabilities, experience, warranty, and service policies. Be sure to ask for references and use them. Ask the dealer if they can recommend a reputable installer.

5. **Obtain proper training.** The equipment installer and/or driver evaluator should provide training in the proper use and maintenance of the adaptive equipment and vehicle control system. Don't forget basic driver's education, as well... there's more to safe driving than just knowing how to use your own vehicle!

In Conclusion

The transition to independent driving is daunting, but with common sense, and by relying on experts and those who have already learned the hard way, it is possible.

It's a great step towards independence; the time and effort spent **before** you buy is well worth it. **01**

Three new members bring diversity, vision to board

Parker C. Folsie, III



Parker is a partner in the law firm of Susman Godfrey, LLP, with offices in Seattle, Houston, Dallas and Los Angeles.

His area of expertise is antitrust cases, but he has a wide range of experience in representing corporate clients. Before entering private practice, he served as a law clerk for Supreme Court Justice William Rehnquist. He currently serves on several American Bar Association committees and is a frequent speaker on antitrust and other commercial litigation issues.

He is a magna cum laude graduate of Harvard University and received his law degree with high honors from the University of Texas.

As a member of the OI Foundation board, Parker feels he can bring corporate contacts, strategic thinking and advice about the Foundation's direction.

Parker lives in Seattle, WA and has a 12 year old son with Type IV OI.

Robin Johnson



Robin recently joined the Caron Foundation, as the President of Caron New York. Caron is a leader in drug and alcohol addiction

recovery. Robin's responsibilities there include management of the New York

metropolitan region, development responsibilities and marketing in the Northeast. Prior to this Robin founded an advertising technology company based on the graphic organization of material and data. He is responsible for several patents pending with the company (Sticky Networks) and also led it through several successful rounds of financing.

He was one of the early visionaries in the Internet, as CEO of the search portal Infoseek. He successfully took the company public and raised over \$65 million in capital, shepherding its growth from a small technology company to one of the leaders in advertising and traffic on the Web.

He is a past publisher of the Atlantic Monthly, and has held senior management positions at US News and World Report, People, and Time magazines. Robin lived with his family in Hong Kong in the early 90s, where he managed Time Inc. in Asia, which included magazines such as Time, Asiaweek, and local publications in Hong Kong, Taiwan and Japan. Robin has an engineering degree from Princeton University.

He served on a number of for-profit boards. He volunteers with his Church, family schools, and the local scouts.

As a member of the OI Foundation board, Robin feels he can help with media, public relations, management and fund raising. He believes board discipline and management should be used to secure a strong future for the Foundation.

He hopes his experience in media and connections in New York will enable him to be a strong contributor to the overall direction and success of the OI Foundation.

Robin lives in Darien, CT and lost a niece to Type II OI.

Neeru Sharma



Neeru works in the North American finance division of General Motors where she is involved with the business case develop-

ment and budget process for GM's truck products. She is also a member of the GM Mobility committee, which provides resources for GM about disability issues including modifications to vehicles. She completed her BS in Management from Kettering University and MBA from Oakland University.

Neeru serves on the OI Foundation Conference committee and has made presentations and facilitated sessions at National Conferences. She participates in the Bone China Tea fundraiser, writes articles for Breakthrough, and mentors young people with OI through the Pass it On! program.

She served on the board of a local Center for Independent Living. She co-authors a monthly column for iCan!, a web site for people with disabilities. She is also starting a business and engineering scholarship for people with disabilities attending Kettering University.

As a member of the OI Foundation board, Neeru would like to bring new ideas she learned from serving on other disability committees. She would like to develop programs to further promote the Foundation to the mainstream community. Neeru brings marketing and business skills as well as a multicultural perspective.

Neeru lives in Sterling Heights, MI, and has Type III OI. 

What I Did On My Summer Vacation...

By Mary Alice Birdwhistle

Most teenagers look forward to vacations at the beach, daily visits to the swimming pool, attending camps, or just sleeping late during summer vacations. While these are all great activities that any teen loves, I personally look forward to the Biennial Osteogenesis Imperfecta National Conference. This year, the conference was a phenomenal success, and all attendees had a great time. After all, it was held in one of the happiest places in the world: Orlando, Florida.

Finding A Teen Perspective

For teens, the conference was an excellent opportunity to meet other people with OI and to build friendships. However, I met some amazing teens who really inspired me with their strength and happiness despite their many difficulties.

It was so fulfilling to meet teens who have the same struggles and problems that I face in life. In peer support sessions, we teens were able to share our knowledge about driving, dating, going to dances, finding freedom from our parents, and the other difficulties we face with OI. However, we didn't focus on the negatives.

It motivated me to see how so many teens with OI focused on the positive aspects of their life. I met many remarkable teens this year from all over the United States (from Florida to even Hawaii), but it was also exciting to see old friends that I spend time with every two years at the conference.

I will definitely keep in touch with many people I met, but I will always cherish the times we had together and the memories we made at the conference.

Another positive aspect of the OI

Conference was all that I learned about osteogenesis imperfecta. Having OI, and being a stubborn teenager, I thought I knew EVERYTHING there was to know about OI. I was an expert. However, I met doctors and scientists who know even more!

Learning About OI

It was so intriguing to attend the Opening Session where I was able to learn all about Dr. Glorieux's research on bisphosphonate therapy and Dr. Marini's studies of mice with OI and "making brittle bones better." (Actually, I want to be a research scientist for OI when I grown up, so I thoroughly enjoyed learning about the doctors' studies in Canada. Maybe I will give a presentation on my research to find a cure for OI in a few years!)

I was also able to talk with Dr. Peter Byers about genetics and how osteogenesis imperfecta is passed on through the genes. I even had the opportunity to talk with Dr. Glorieux about his opinion on different surgeries I may need to have.

What an experience it was to be able to further my knowledge about OI and the research being conducted to strengthen our brittle bones!

Having Fun

Why did I truly enjoy the conference? The answer is fairly simple: IT WAS FUN!!! The restaurants, the days at the pool, the dance, the banquet, the talent show, Disney World, Universal Studios! What could be better? The Radisson Hotel had a great pool where we teens could swim and tan in the sun. (Well, actually, I burned... I'm so fair skinned!)

Playing in Orland's Theme Parks

The conference was also in a great

location, in walking distance or a cheap taxi ride to Universal Studios, the Hard Rock Cafe, Motown, the Nascar Restaurant, and many other great shops and restaurants. And what can be better than Disney World?

Though I was quite busy at the conference, my family and I were able to go to the Magic Kingdom, the happiest place in the world! We ate chocolate-covered frozen bananas and rode many rides, like the Pirates of the Caribbean, the Haunted Mansion, and the Tikki Room! My personal favorite part of Disney World, however, was the laser light parade. It was a phenomenal, bright and beautiful parade that one can only imagine in their wildest dreams. All the Disney characters, like Mickey, Donald Duck, Goofy, Cinderella, Ariel, Snow White, and Mary Poppins made their way down Main Street to greet the excited people of all ages. I'd say that going to the Magic Kingdom was quite an exciting opportunity!

A Perfect Ending

But what could beat the banquet at the end of the conference? All of the teens dressed up and had a great time watching each other dance, sing, or tell jokes in the talent show. It was a perfect ending to a perfect week!

The OI Conference was the experience of a lifetime for those of all ages. It was certainly an inspiration to meet people with OI who don't let their disorder stop them from attaining their goals and reaching their dreams.

The conference was closed by a motivational talk from Sean Stephenson, and it really inspired me. I learned that I'm not burdened by a life with OI, but I have been blessed with it. OI has molded me into who I am today, and I wouldn't change that for the world. 

OI Clinic List & Comparison Chart! (pull-out section)

The 2002 Conference is over... so now what?

By Sean Stevenson

My first conference was in Pittsburgh, PA in 1990. I remember it being very overwhelming. I had never seen so many little people in my life, and honestly it freaked me out. I wondered if I would grow up and lose my hearing, need to be on oxygen, or have to live at home forever. What calmed my nerves were the friends I made.

The relationships you develop at an OI conference are priceless. Nowhere else in the world can you congregate with individuals who know what it's like to go through rodding surgery, who could break a rib from sneezing, or are constantly stared at in public.

Most people leave an OI conference with a binder filled with notes,

a bag crammed with pamphlets, and a mind stuffed with research. However I hope you also left with a fist full of telephone numbers and email addresses. The connections you make at a conference are only good if you follow up with them.

As you know there are days with OI that can be very frustrating. It is very helpful to call someone who has already gone through what you may be experiencing. Having a personal OI soundboard to bounce your feelings and ideas off of can make your life much easier.

To feel comfortable contacting someone in the OI community, remember that when you ask for advice you are making someone else feel needed, which is extremely rewarding.

Whether you attended the confer-

ence or not, I encourage you to take the following positive risk: reach out to at least two people that have or are connected to OI-- one whom you are going to offer mentoring to and another you are going to request mentoring from.

Contact someone you know who really could benefit from your life experiences. Simply offer them the ability to contact you anytime.

Although you might think that the invitation is already implied, it's not. When you give someone permission to call on you, you make them feel welcomed.

When you ask to be mentored you honor a person, again making them feel needed.

I hope you take this positive risk; I know it will make a HUGE difference in your life. 