

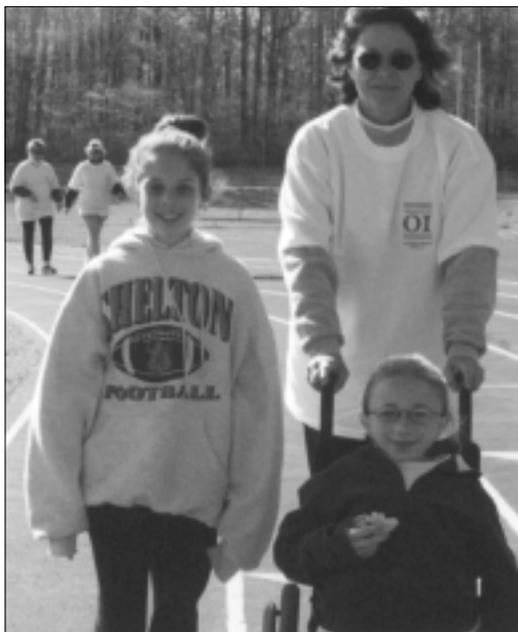
CT family's walk-a-thon raises community awareness and \$22,000

For the second time, Alyse Furber led the charge as more than 250 participants took to the track at her Norwich, CT school and raised \$22,000 to support the OI Foundation.

The thirteen-year old with type III OI has actively participated in fundraisers organized by her family for most of her life. Last year, she decided to create her own event and raised more than \$27,000 with a combination walk-a-thon, dance, and silent auction.

In addition to much-needed funding to help other families, the event greatly increased awareness of OI in her community.

Within thier community, the Furbers are "known as a family to be counted on," according to one participant.



Alyse completes another lap in the ten mile walk-a-thon accompanied by her cousin, Courtney Benanto (L), and aunt, Nancy Radgowski.

"If you need a little league coach, a helping hand, anything, you know that

Kenny or Paula Furber will step in," he continued.

In turn, virtually all of Monteville, CT, turned out to support the Ferbers.

Throughout the day, the strong community connections were unmistakable. Walkers spent all afternoon in the bright sunshine, many of them attaining the ten-mile goal. Alyse's aunts and sisters stepped up and chipped in whenever help was needed, and relatives and family friends pitched in, making the event seem like a combination family reunion/ community-wide fundraiser.

Alyse specifically wanted an event in which *everyone* could participate- regardless of age or ability.

Continued on page 10

A Healing Gift

Remembering loved one heals, brings Mothers Day joy to family

By Gemma M. Geisman

It's a beautiful Sunday morning in May. Beyond our porch windows, the Florida sun magically transforms lingering dew drops into shimmering crystals and a Mockingbird trills as she hurries about our yard gathering food for her babies. To all outward appearances, it's a perfect setting for a happy Mother's Day.

And it will be, I tell myself as I go inward in search of joyful memories to help make it so. But, instantly, I'm confronted with the blistering reminder that, on this date a number of years ago, our son, Mike, was robbed and fatally beaten by an indigent young man whom he had befriended.

Our granddaughter, Emily, is visiting and away from her two little boys for the very first time. She misses them and worries about having left them in New Hampshire with their Dad on Mother's Day.

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FROM THE EDITOR

BREAKTHROUGH

The Newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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Dear Friends,

Many thanks to all who've taken the time to call, write or e-mail with compliments on the last issue of *Breakthrough*. I took great pleasure in creating that issue, and take great pride in the work I do here at the Foundation.

Ask any self-help guru or browse any self-improvement bookshelf, and the one common denominator you'll find, regardless of the source or the subject matter, is the overwhelming importance that's placed on effective, two-way communication. As the Foundation's Communications Director, I recognize that communication and information *sharing* is critical to the health of the organization and to the quality of life for the community the Foundation serves.

In the coming months we'll be expanding the information and services available on the website and reaching out to medical professionals and the general public through media and educational initiatives. This is an extremely exciting time to be a part of this organization, and I look forward to the challenges-- and rewards-- that are sure to come.

I have every intention of continuing to "raise the bar--" with this issue of *Breakthrough* and each succeeding issue, with our web site, and with our outreach and awareness programs-- but I need your help to make that possible.

The newsletter and website won't be effective, timely, relevant, or address *your* needs without guidance from you and all of the OI community.

The OI community is filled with bright, talented, energetic, vivacious personalities, and I want to tell your stories. Not just here in *Breakthrough*, but on our website and in as many local and national media outlets as possible.

You, the members of the OI community, have spent decades solving the same problems that are overwhelming a parent with a newly diagnosed child or a young adult seeking independence *right now*. I want to make sure that those parents and young adults know we're here, have access to the lessons learned and don't think they're alone in the world.

Together, we will grow stronger as a community. I invite you to send me your story ideas, your manuscripts, and your suggestions for improving internal and external communications. I invite you to send pictures, lessons learned, upcoming events, and support group meeting dates to be shared with the community. I encourage you to contact me by phone, email, or fax and let me know what you know.

I look forward to learning how to speak in *your* voice, not just mine-- with you, with the community as a whole, with the nation, and the world.

I am truly excited and honored to be here. I look forward to hearing from you, to learning from you, and to sharing your lives.



Bill Bradner

Director, Communications & Special Events

PRESIDENT'S MESSAGE



Bill Schmidt

Dear Friends,

Each year our Foundation conducts a research appeal that raises funds to support critical cutting edge research into potential treatments and cures for OI. It's fitting that the appeal arrives in the mail in the Spring-- a time of renewal-- and near Mother's Day.

As you know, our Foundation was created by a small group of concerned mothers more than thirty years ago. During those early years they weren't sure how they were going to fund the next edition of their newsletter; funding 1.3 million dollars in grants and fellowships wasn't even a dream.

This issue of *Breakthrough* reinforces the ties between supporting families today and our Foundation's commitment to research. In the center pages (11-14) you will find a pull-out section that describes many of the research efforts currently underway with funding from our Foundation, the Children's Brittle Bone Foundation, and the National Institutes of Health. These articles provide a basic understanding of current research progress, and what the future holds. I encourage you to share this section with your healthcare providers, friends, and family.

The research articles are surrounded by short vignettes (pages 6-7, 22-23) that highlight children, young adults, parents and families coping with the daily struggles and joys of living with OI. Our cover stories and spotlight (page 18), also follow this theme, and feature an article from our founding mother, Gemma Geisman. I hope that these stories will help inspire us all to focus on the hope and joy to be found in our daily lives as the search for treatments and a cure continues.

We've called the section "Cornerstones of our Foundation," alluding to the fact that every one of us is an integral and important part of our Foundation and the OI community. A similar feature will be added to the web site in the near future, with an invitation for you to tell us-- and the rest of the world-- your story. The name may change, but the concept is here to stay; the web site belongs to you. Your stories, your tips and hints, and the information you need should, and soon will be, only a mouse-click away.

Our Foundation is putting the finishing touches on a little research project of its own. Over the past two years, we've surveyed Foundation and OI community members to help us determine where we should focus our future efforts. After compiling the results, a steering committee presented your suggestions to the board of directors at our semi-annual meeting last month. Working together with our Foundation staff members, we are developing a strategic plan to give our Foundation a clearer focus and concrete future goals to work toward.

As you'll see in these pages, anything is possible with a strong vision, drive, and the tools to succeed. One of the tools we plan to use more proactively is our new web site. We'll be adding functions that make the most of today's technology over the next few months, turning it into a truly interactive site that brings us closer together while protecting our individual privacy (page 15). The first steps have already proven to be well worth the time and effort we've invested (page 5).

But nothing is more important than the time and effort you, as individuals and as a community, put into improving the lives of people affected by OI. The Fine Wine Strong Bones event, just held in Washington, D.C., is a prime example of how one person's vision can affect hundreds of lives. The event raised almost \$30,000 through a silent auction and a wine and cheese party. Every penny of that will be applied directly toward the 2002 Biennial Conference-- to improve services, reduce registration rates, and make it possible to bring the absolute best researchers, doctors, and experts to lead our sessions and provide us with current, relevant information (page 20). Some of the people you'll read about in these pages will be coming straight from their labs or clinics to speak to us at conference.

I hope every one of you will make every effort to join us in Orlando this July. Through the generosity of the Million Dollar Round Table, families in need will find attending more economically feasible (page 21). Personally, I can't wait to meet those of you new to the community, see old and dear friends, learn the latest information on OI, and most importantly, come home reenergized and revitalized from a weekend with a dynamic group of people-- our 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

Fund-raising events support the OI Foundation...

UPS goes to bat for OI with softball tournament

The sun rose over a perfect Saturday morning last October, but more than 200 UPS employees and their families passed up mowing their lawns, trimming their mums or raking their leaves. These folks greeted the day at the Black Bob Park to play softball for the OI Foundation.

Close to 250 people gathered in the fall sunshine to benefit the Foundation. Greg Pietrek (UPS Lenexa Twilight Manager) and his wife Nanette organized the tournament and kept the event running smoothly. They even recruited a Minnesota family to help.

The tournament was sponsored by the UPS Lenexa Twilight shift and

money was raised through entry fees, a home run contest, a raffle, and concessions. Volunteers, organized by Nanette, helped keep the area clean and the tournament on schedule. Kids helped run the concession stand.

Area businesses also helped support the fundraiser. Life Fitness, Dick's Sporting Goods, Dillons, Olive Garden and Olathe T-Shirt all donated items or gift certificates for the event. Overall, players and organizers rated this event as a complete success.

Funds raised totalled \$1,428. The Lenexa Twilight Team won first place, the District Staff Team second, and the Lenexa Day Sort Team third. 

Bone China Tea still brewing up success

The Foundation's national "non-event" fund raising event, the 2002 Bone China Tea, raised more than \$12,500 so far this year.

The event 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.

Guests are "invited" to the tea via an invitation that included a coupon for free tea from the Harney Tea Company and a recommendation to stay home and relax with a hot cup of tea. It was suggested that the money they may have spent to attend a formal tea be donated to the Foundation.

More than 420 persons will participate after 2,600 invitations were distributed by more than 60 families.

To participate in next year's tea contact Jenny Wilson via e-mail at jnwilson@aol.com. 

National sweepstakes earns \$19,500

The Foundation's first sweepstakes fund-raising program gave OI community members, as well as their family, friends, classmates and co-workers a chance to win great prizes while helping the Foundation's research projects and support services. The "Going Places Raffle" was our way to heat up our winter fundraising campaign and give back to the community at the same time.

Grand Prize was round-trip airfare for 2, anywhere in the Continental U.S. 2nd & 3rd Chance Drawings were held for \$250 and \$100 cash, and an early bird drawing for \$250 cash was held February 4th; all other drawings were held April 3rd.

Congratulations to our grand prize winner, Paula Terry of Arlington, VA. Paula bought 20 tickets, more as a show of support to a friend of hers with OI than in hopes of winning. She's decided to continue that giving spirit, by passing the tickets on to an elderly friend who travels cross-country by bus to visit her son.

"She needs them more than I," Terry said.

The suggested donation of \$3 per ticket added up fast. Thanks to the efforts of the chair, Pete Dohm, this year the sweepstakes brought in more than \$19,500 to support the day-to-day operations at the Foundation offices... that's 20 times more than last year's winter campaign!

Watch your mailbox, the Breakthrough, and this website next fall for information on how you can take part in this exciting new fundraising event. 

Correction:

In the last issue of *Breakthrough* we referred to the Miracle Michael Golf Tournament as "Miracle Mike Tournery" on the front page in an effort to make the headline "fit" over its accompanying text.

Our apologies to the Tournament organizers. 

Conference Registrants: Log on to www.oif.org

Information about the 2002 National Conference in Orlando, Florida, is changing almost on a daily basis as services, events, sessions and speakers are added to the program or confirmed. Even if you've already received a registration confirmation packet, check our web sight often for the most up-to-date information.

Please note that registration confirmation packets are being shipped in batches as volunteer help is available, and may take up to two weeks to arrive. Thank you for your patience, and we'll see you in Florida! 

Redesigned, reorganized: website breaks records first week on line



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



The OI Foundation's new and improved web presence is already proving its worth, only one short week after going on line.

Due to delays and technical difficulties prior to completion, the Foundation choose to do a "quiet launch," without any fanfare or publicity the day the site actually became available on the world wide web.

In spite of the quiet launch, the site recorded more than 850 visits,

with almost 2,200 page views, in the first 48 hours. That's a twenty percent increase in the amount of visits the old site typically had over the same weekend hours.

In the first week on line, the new Convio-powered site had 1,840 unique new visitors, 3,598 repeat visitors, and more than 11,100 pages viewed.

A typical week on the old site would register 2,234 visits.

The number of visits only tell half the story. Web developers strive to capture a visitor's attention and draw them into the web pages. It's assumed that the visitor has stopped to read only if they stay on the site for more than two minutes. Visitors are staying on www.oif.org for an average of more than 10 minutes, more than five times what industry experts consider a "capture."

Not only are they staying to read, they're taking advantage of the new site's secure on-line services. In the first 96 hours, the Foundation received a number of on-line donations and a query from a prospective major donor. *(For information about the website security, see our privacy policy on page 15.)*

The site also captured more than 300 registrations-- the

first step in developing two-way, internet based communication between the Foundation offices and the OI community.

"Obviously, we're thrilled," exclaimed Heller An Shapiro, OI Foundation Executive Director. "It was a lot of work to get where we are now, and the number of visitors validate the effort."

"The site has so much potential," she said, "we're all eager to see how much more it can do for the community and the Foundation."

Planned upgrades will be spread out over the next three to six months, and will be prioritized based on user input through survey functions on the site. On the schedule are: an on-line calendar where support group leaders can post upcoming meetings and events directly to the site; an improved chat room where visitors will be able to talk

freely in a private, ad-free chat room hosted directly on the site; online glossaries and new fact sheets; and a searchable peer-to-peer guide to successful

"Obviously, we're thrilled. It was a lot of work to get where we are now, and the number of visitors validate the effort."

living with OI.

Visitors can already "customize" the site to deliver the information they are most interested in up front, and to notify them when information is updated.

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

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

Everyone is encouraged to go to www.oif.org; and feel free to send us your input. 

Prenatal testing gives parents a chance to prepare for birth of child with OI

By Melinda Marston

Before my pregnancy, my husband and I hadn't given much thought to genetics. When I did think about it, I wondered if my child would share my hair or eye color.

During our fifth month of pregnancy, genetics became a part of our daily thoughts. At our twenty-week ultrasound, the technician noticed our boy had shortened and bowed legs.

We did not understand how serious this was until we met with a genetic counselor and an obstetric specialist. We were told it was a possibility that our son had OI. No one could tell us for certain that this was what our son had, but it was a possibility. We had never heard of OI before, and the more we read, the more we realized that we needed to be prepared if there was a chance our son would have OI.

Taking advantage of the OI Foundation's resources, I read about everything from diaper changes and special clothing to experimental drugs and surgeries. We planned to have a C-section to give our baby the best

chance of being born with the least amount of fractures. We met with a specialist at Boston's Children's Hospital. And we had a lot of discussions, giving a lot of thought to how to give our son the best and most fulfilling life possible. We knew that if our son did have OI, we would have to work hard to let him be independent and protect him at the same time.

When our son Caleb was born, we were overjoyed. Shortly after birth, the geneticist noted that in addition to what was detected during pregnancy, the white part of Caleb's eyes was gray, and his face was unusually triangular shaped. The signs were pointing to OI, and a skin biopsy confirmed it four months later.

We firmly believe the prenatal testing we had gave Caleb and our family a great advantage. We were able to prepare in some small ways—and that made all the difference.

Today, Caleb is warm, inquisitive and adventurous. He enjoys puzzles and climbing on anything he can. He fractured his thigh twice in his first two years, trying to learn how to stand.

Fortunately, we have the privilege of being involved in a research protocol at the National Institutes of Health.

Through this protocol our family has received help with the physical therapy and other medical issues that are a part of living with OI. Being a part of this program has helped us with Caleb's medical care as well as connecting us with other families facing similar issues.

We hope that our involvement will help in some small way to advance the research to help find effective treatments and eventually a cure.

Being the parents of this wonderful little boy has enriched our lives. As tempting as it would be to make Caleb's life all about preventing fractures, we have tried to make our family's life about appreciating the good times and coping to the best of our abilities with the challenges. 

Reprinted with permission from the Genetics Quarterly, a publication of the Foundation for Blood Research, Southern Maine Genetic Services, 1-800-639-8605.

US Court Further Narrows Disability Act

The Supreme Court recently further limited the scope of protection provided by the Americans with Disabilities Act.

A five-member majority ruled that, in ordinary cases, companies are not required by the act to bend their already established seniority rules to accommodate persons with disabilities.

Robert Barrett, a US Airways employee, sought to keep a less physically demanding job that another employee was entitled to under the company's seniority policies.

The court ruled in favor of U.S. Airways, stating that company policy should not be undermined.

The court left open the possibility for a disabled employee's needs to override company policies in cases where the employer had made other compromises with their seniority plan.

Dissenting Justices noted that "[n]othing in the ADA insulates seniority rules from the 'reasonable accommodation' requirement." 

"We can find nothing in the ADA that suggests Congress intended to undermine seniority systems."

You are our cornerstones

The OI Foundation provides information, support and services to more than 76,000 people every year, and each and every one of you has a story to tell.

Tell us about your triumphs, joy, or sorrows. Send us your newspaper clippings, photos, or videos of local TV coverage, and help us learn from and nurture each other.

The Foundation was built on the concept of sharing and mutual support. We can't tell your story to the community unless you tell it to us!

Write to the foundation at the address found on Page 2, or send an email to bonelink@oif.org. 

“Rough and Ready” 10-yr-old saves life of drowning child

Cole Culler is ten years old, was born with seven broken bones, and has had almost forty fractures since. He’s endured three surgeries, and has telescoping rods in both femurs. But he’s a “rough and ready California boy,” according to family members, who doesn’t let his OI slow him down.

Cole is an avid swimmer and outdoorsman, who not too long ago tackled a climbing wall for the first time, landing him in the local news.

But that wasn’t the first time he’d been noticed by the media and his community.

In the summer of 2000, Cole was at a picnic at the edge of a river near his grandparent’s home in Palos Verdes Estates, California.

A two-year old had been playing near the water’s edge, and Cole was the first to notice when the toddler didn’t resurface. Though confined to a wheelchair on land, Cole was a

confident swimmer, and without any thought to his personal safety, he went in the water after the toddler.

It took two dives before he could drag the two-year old to the surface. Cole undoubtedly saved the child’s life.

Cole is considered a hero by all who know him, not just for his actions that sunny day by the river, but for the way he tackles life: headfirst, head high, always with his eyes set on what he *can* do. 

A HEALING GIFT *Continued from page 1*

I reassure her. Still, she frets.

I yearn to talk about the significance of Mike’s life, not the horror of his death. But, I know from past experiences that the mere mention of death sometimes makes others uncomfortable, so I bury the urge.

To lighten the moment, I tell Emily about the Mother’s Day breakfasts that our daughters, Cathy and Cindy, concocted and about the card our youngest son, Rick, made for me when he was a youngster.

In it, he had written, “Mom, I love you and will dream about you every night for the rest of my life.”

Emily chuckles. “I don’t think Uncle Rick dreams about you every night, Grandma!”

Those precious memories rekindle my need to talk about Mike. But, again, I hesitate. I’ve never understood why talk of him occasionally causes people to change the subject, turn away, or avert their eyes. I ask myself whether this is a unique reaction to him, or if it is merely a common response to the painful subject of death.

Emily loves hearing stories about the interesting people in our family, so I finally decide to broach the subject. “Today is the anniversary of Mike’s death,” I murmur softly.

She doesn’t avoid my gaze or turn

her head away. Instead, her lips curl into a pensive smile. “I wasn’t very old when Uncle Mike died,” she offers. “But I still remember the way he looked and how his deep voice sounded.”

Of course she remembers him. Born with a severe form of OI, his growth had been stunted and his limbs deformed by countless fractures. At age twenty-four, he was in a wheelchair, was only 3 ft. tall, had a pot belly, longish hair and a reddish beard that he had grown to prove that he was a man and not the little boy he was so often mistaken for.

Though his body was deceptively small, inside dwelled a man who yearned to be free of all the encumbrances and limitations that his uncommon disability had imposed on him.

Images of our *breakable* little boy stuffing himself with spinach to grow stronger bones; of a fragile teenager in a wheelchair precariously hanging onto the back of a friend’s speeding bike in search of independence; of a disabled young man with useless legs wishing he could dance like John Travolta in “Saturday Night Fever,” lighten my heart.

Mike wouldn’t have qualified as a poster boy for OI, nor would he have been deemed a suitable role model for

other disabled individuals. Not wanting OI to be the dominating factor in his life, he devoted nearly all of his energies to setting himself free of the baggage that came with it so he could be “just like everyone else.”

Along the way, he denied God, then embraced Him. He enrolled in college, dropped out, started back again. He made good friendships *and* disastrous ones.

Finding his way in a “normal” world became a daunting task for Mike, yet he wouldn’t give up.

Determined to be free, he learned to drive, bought a big silver car and moved into a bright, sunny apartment of his own.

Emily muses.

“Remember the day we all went to visit him in his new apartment? He looked so proud as he gave us the grand tour, remember?”

How can I forget the look on his face that day, our last day together? If it could have been captioned, the look would have said, “Look, Mom, I finally made it!”

Thinking about our last day with him used to hurt terribly. Today, it brings me joy.

I close my eyes and give thanks for this healing gift.

It’s going to be a memorable Mother’s Day, after all! 



The following article is excerpted from a much longer fact sheet about the dental care needs of people who have OI. The authors, James K. Hartsfield, Jr., DMD, PhD, and Lawrence P. Garetto, PhD, from Indiana University Schools of Dentistry and Medicine, spoke at Conference 2000 in Milwaukee and will be presenting a workshop at the 2002 Conference in Orlando. Copies of the entire fact sheet are available from the Foundation or online at www.oif.org.

What kind of dental problems do people with OI have?

Osteogenesis imperfecta (OI) is always associated with bone fragility. In addition, OI may affect the growth of the jaws and may or may not affect the teeth. About half of the people who have OI have teeth that appear normal, and their major concerns are routine care. However, the other half has a defect in the teeth called dentinogenesis imperfecta (DI) sometimes referred to as opalescent teeth. These teeth may be misshapen and may chip or break easily and will require special care.

Other oral cavity problems related to osteogenesis imperfecta may include:

- **A skeletal Class III malocclusion.** The bite is affected because the size and/or position of the upper and lower jaw and, therefore, the teeth do not match.
- **An open bite.** There is a vertical gap between some of the upper and lower teeth.
- **Impacted teeth.** The first or second permanent molars do not erupt, or they erupt out of the usual location.
- **Dental development.** Tooth development may be delayed or advanced in some individuals affected by OI.

Gum disease (periodontitis) is not considered to increase because of OI.

What are the major parts of the teeth?

The teeth are made up of four distinct parts.

- **Enamel** composes the outside part of the crown. It is the hardest substance in the body and the point of contact for chewing.
- **Dentin** is the substance under the enamel forming the rest of the crown and surrounding the pulp chamber and almost all of the root structure. It is similar to bone.
- The **Pulp Chamber** is the inner hollow part of the tooth containing blood vessels and nerves.
- The **Dentinoenamel Junction (DEJ)** is the term for where the enamel and dentin are attached to each other.

What is dentinogenesis imperfecta (DI)?

Dentinogenesis imperfecta can be part of osteogenesis imperfecta (DI type I) or it can be a separate inherited autosomal dominant trait (DI type II) without OI. DI occurring with OI seems to run true in families but can vary in severity from one member to another. If someone has OI and DI, all of their teeth may not be affected to the same degree. DI has a variable affect on the color, shape, and wear of both primary and permanent teeth. Teeth affected by DI have essentially normal enamel, but the DEJ and the dentin are not normal. The enamel tends to crack away from the dentin, which wears away more quickly than enamel. The dentin makes the teeth look darker or opalescent and grows to fill in the pulp chamber, causing a loss of feeling in the tooth. Affected teeth will have an increased incidence of fracture, wear and decay.

How is DI diagnosed?

Dentinogenesis imperfecta may be diagnosed with the first baby tooth. If the tooth does not appear white, or if it

is gray, blue or brown, DI should be suspected. Children should be taken to a dentist (if possible a specialist in pediatric dentistry) when the first teeth are erupting. This may happen as early as 6 months to 1 year of age. Radiographs, or X-rays, can be useful but may be difficult to obtain until the child is older. Sometimes there are changes visible on the X-rays that are not obvious just by looking at the teeth. Crowns appear bulbous and roots may be shorter and more slender than standard. Primary teeth are usually more affected than the permanent teeth. Special care will be needed even with the baby teeth. If the teeth are wearing down too quickly, stainless steel crowns can be placed on them.

What special care is needed for a child who has OI and DI?

Children with OI and DI need the same basic care as any child, but they also need to have their teeth carefully monitored for excessive wear. Regular care is needed so the teeth will last as long as possible and to prevent abscesses and pain. If the teeth are wearing excessively, caps, also called crowns, will probably need to be placed on at least some of the teeth. This will serve to keep the teeth in place and encourage proper development of the jaw. More specialized treatment, including veneers, may be more appropriate for permanent teeth.

Is there a product to whiten teeth that are discolored by DI?

No; brushing and cleaning will not make teeth affected by DI whiter, and bleaching is not recommended because the discoloration is not in the enamel.

Do adults with OI and DI need special treatment?

Yes; the condition of the enamel on adult or permanent teeth will need to be monitored. If the enamel cracks away and the underlying dentin starts to wear, some type of coverage such

Q&A: DENTAL CONCERNS

as crowns or an overlying denture is needed. If there is not enough of the tooth above the gum to allow placement of a crown, some additional gum surgery or root canal treatment may be necessary.

When should a child who has OI start seeing the dentist?

A dentist should see a child with OI by 2 to 3 years of age at the latest. Baby teeth require care. They are important for chewing, speaking, holding space for the permanent teeth to grow in, and growth of the jaws.

Should children with OI see an orthodontist?

Starting when the child is 7 years old, an orthodontist should check the child's bite for evidence of an open bite or Class III malocclusion.

What is a malocclusion and can it be treated?

A malocclusion can be defined as an abnormal relationship between the upper and lower teeth and/or their alignment, which creates problems with how the teeth come together. This may be due to the relationship of the upper and lower jaws to each other, the alignment of the teeth, or both. This type of problem includes crooked teeth, "underbite," "overbite" and "open bite." Treatment is usually provided by an orthodontist. The particular treatment plan depends on the specific problem(s) with the bite and the teeth. If the malocclusion is caused by skeletal discrepancies, then orthognathic surgery may be required along with orthodontia.

What is the purpose of jaw surgery?

In some children with OI the upper jaw, or maxilla, does not grow as much

as the lower jaw, or mandible. Sometimes the way that both jaws grow makes it difficult, if not impossible, to bring the teeth together properly, even after orthodontic braces. If the malocclusion is due to a problem with the growth of one or both jaws, then a combination of orthodontic braces and orthognathic surgery may be used to align the teeth. Some period of orthodontic braces is also usually needed after the jaw surgery. There are a few published reports about these surgeries indicating good post-operative healing of the jaws.

About half the people who have OI have teeth that appear normal, and their major concern is routine dental care... However, the other half have a defect in the teeth called dentinogenesis imperfecta.

The same concerns that one would have with any surgery in a patient with OI, such as potential bleeding problems and reaction to general anesthesia, still apply. (For more information, see the Foundation's "Surgical Considerations" fact sheet, available on line.)

Can children who have OI get dental braces?

Although there are no published studies regarding orthodontia for persons with OI, it seems to be safe to treat persons with OI if DI is not present. If DI is present, the orthodontist will have to decide if the enamel can withstand gluing brackets for the braces to the teeth and removing the brackets later.

Unfortunately, it is difficult to determine how strong the enamel is until it is tried. If there is concern about the enamel cracking off and treatment is still desired, placing bands on all the teeth to hold the brackets may work. Although bands are considered an "old fashioned" method, the

technique still works. It may be necessary to seek out an older orthodontist who learned to install braces before the current practice of gluing bands directly to teeth was discovered. The orthodontist will need to minimize forces on the teeth as well as movement of teeth over long distances. Caps, or crowns, may be effective in correcting rotations or mildly malpositioned teeth.

Can dental implants be used on people with OI?

Dental Implants are used to replace missing teeth.

Theoretically it is possible to do this successfully for a person with OI and there is anecdotal evidence that this has been accomplished. However,

there are no controlled studies on the use of dental implants in patients with OI. There is only one case report in the literature referring to implants in an OI-affected individual. Normal implant-bone healing seemed to occur, but a greater than 50% implant failure rate within 3 years of surgery was reported. There is not enough data in the literature to fully understand long-term success rates.

How does a dental implant work?

Dental implants are somewhat like screws. In order to function, there must be enough bone in the jaw for the implant to be securely placed. After healing, a "post" is placed in the implant and an artificial tooth is attached. Good, strong healing around the implant is critical.

What are dental veneers?

Veneers are cosmetic coverings

Continued on page 10

Web Shots

Useful or informative sites for the OI community

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

The Children's Brittle Bone Foundation
www.cbbf.org (Page 13)

Computer Retrieval of Information on Scientific Projects (CRISP)
<http://crisp.cit.nih.gov> (Page 12)

Directory of Prescription Drug Patient Assistance Programs
www.phrma.org. (Page 16)

Government Benefits.com
www.GovBenefits.com (Page 16)

The Kaiser Guide to Healthcare Plan Disputes
www.consumersunion.org or
www.kff.org/consumerguide/
 (page 16)

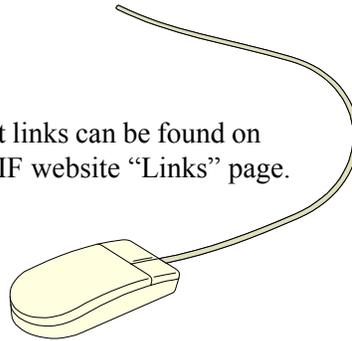
Through the Looking Glass
www.lookingglass.org (Page 14)

Mercy Medical Airlift
www.patienttravel.org. (Page 21)

National Foundation for Dental Health Providers
www.nfdh.org. (Page 16)

Sean Stephenson
www.seanstephenson.com
 (Page 18)

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



WALK *Continued from page 2*

Classmates and family surrounded her as she took her turns around the running track and greeted friends, family, and neighbors.

After the walk, parents and children pushed tired muscles to the limit at a combination dinner/dance/silent auction. A popular local band donated their time in support of the event, and more than 100 filled bid sheets were silent testimony to the support of the local community for the OI Foundation and the Furber family.

The walk-a-thon also receives the support of other local schools and community groups.

Many organizations held separate fund-raisers, and contributed the proceeds to Alyse's event. 

For more information about fund-raising ideas that you can implement in your community, contact the Foundation offices at (301) 947-0083, write to bonelink@oif.org, or visit www.oif.org.

Q&A: DENTAL CONCERNS FOR PERSONS WITH OI *Continued from page 9*

typically placed on the outer surface of the anterior teeth. Anterior teeth are the teeth seen when a person smiles. If veneers are glued to the enamel, the enamel may break off from the dentine, in which case the veneer would be lost.

The enamel can be removed, and the veneers glued to the dentine, with varying degrees of success. Veneers are typically not made to withstand biting forces.

Will bisphosphonate treatment affect my child's teeth?

The class of drugs known as bisphosphonates is being used experimentally in an increasing number of children and adults for the treatment of OI. These drugs work by reducing the remodeling rate.

In general, these drugs do not appear to affect bone modeling which is a factor in wound healing in the jaw. Rates for remodeling in bone surrounding teeth are typically higher than in other bones of the body.

Bisphosphonates reduce this remodeling as well, and it is not clear what impact this will have long term. In the short term, reduction of the remodeling rate produces bone with a greater density, although it is not clear if this results in greater strength.

It is even more unclear what effect bisphosphonates have on young children whose new teeth are erupting as they grow.

Similarly, the effect of bisphosphonates on the necessary remodeling surrounding dental implants is not understood.

How can I locate a dentist who understands OI and DI?

There is no national list of dentists who treat patients with OI. Schools of dentistry or the dental department at major medical centers may be helpful in locating dentists who are familiar with OI and DI. Referrals from others in the OI community may also be helpful. The American Academy of Pediatric Dentistry is a good source of pediatric dentists, although any particular member of this group may or may not see OI patients. Contact the Academy at:

American Academy of Pediatric Dentistry
 211 East Chicago Avenue, #700
 Chicago, IL 60611-2663
 Telephone: (312) 337-2169
 Fax: (312) 337-6329 

Foundation awards new grant, fellowships for FY 2002-2003

Researchers seek new treatment strategies and a greater understanding of OI

The OI Foundation Scientific Review Committee and the Board of Directors agreed to award \$157,000 in seed grants and fellowships in 2002-2003.

Approved for funding were:

Anna Bielli, Ph.D., University of Pittsburgh, Pittsburgh, PA. New Fellowship; for "Phosphoinositides as Regulators of COPII Mediated ER Export."

Antonella Forlino, Ph.D., University of Pavia, Voghera, Italy. New Seed Grant; for "Study of Phenotypic Variability in the Dominant Disorder Osteogenesis Imperfecta by Using a Knock-In Murine Model."

Zana Kalajzic, M.D., University of Connecticut Health Center, Farmington, CT. Second-year Fellowship; for "Transportation of Osteogenic Cells into Murine Models."

Bielli's study is designed to uncover information about collagen. Her proposal asks "How are abnormal molecules recognized within cells and targeted for degradation?"

Her research, at the biological level, will help determine which protein complexes and/or molecular functions provide "quality control analysis" during the assembly of collagen. For some reason abnormal collagens are not eliminated during the sorting or

editing processes. Understanding why is key to understanding and managing collagen quality in OI patients.

The focus of Forlino's work is a better understanding of the variable nature of OI. During her post-doctoral fellowship at NIH under Dr. Joan Marini, Forlino helped develop the mouse model that will be the subject of her research. The mouse's mutation has two very different outcomes; lethal and moderately severe. By characterizing the type I collagen, and studying the proteins and their extracts in affected mice, she hopes to identify the factors that modify the severity of OI, and explain the variability of symptoms.

Kalajzic has focused on a problem that is directly relevant to the *treatment* of OI, which will also have widespread therapeutic application. The goal of her research is to test various strategies, using the mouse model, to optimize conditions for grafting bone marrow stromal cells when performing transplants or transporting curative genes.

Successful transplantation and engraftment has not yet been achieved in OI patients. The project examines conditions that may make the host more receptive to transplantation. Results of her research will provide insight into the effectiveness of bone marrow transplantation and gene therapy as a method of therapy in OI patients. 

Progress potential depends on donors

By Julaine Weiner
OIF Development Director

The potential for progress in OI research is growing with every passing day. Researchers are exploring every avenue that might one day lead us to effective treatments and a cure.

Each spring the Foundation conducts a research appeal and publishes a research update. When you receive your appeal, please consider how crucially important your donations are, and the significant impact they will have on the future for those touched by OI.

People not intimately involved with the Foundation often have questions about what types of research might make a difference to those with OI. Many times, they'd like the opportunity to help but aren't sure how they can or should. If your friends, relatives or acquaintances have expressed interest in OI research, please let us know so we can include them in the appeal.

To the thousands of you who have made gifts to the Foundation in the past; thank you.

Our unwavering commitment to the future of OI research is only possible because of your consistent generosity. 

RESEARCH UPDATE

Largest OI research investment ever

NIH makes \$10.7 million commitment to OI research

The Federally-funded National Institutes of Health is awarding over \$1.8 million in new grants related directly to OI.

A portion of that total (\$312,320) is being funded through the National Institute on Aging. The remainder of the research projects will be funded through the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

The institute has committed more than \$9 million in grants to fund these projects over the next five years. In addition to the new grants, the NIH is continuing previously awarded grants, bringing the total funding commitment to \$2.1 million for the fiscal year, and \$10.7 million over the next five years.

This year's grants were awarded to:

Nancy P. Camacho, Associate Scientist at the Hospital for Special Surgery, New York, NY, for "Anti-Resorptives for Dysregulated Bone Remodeling in OI."

Arnold I. Caplan, Professor and Director, Case Western Reserve Univ., Cleveland, OH, for "Targeted Progenitor Cells Engraftment."

David J. Goldhamer, Associate Professor, Univ. of Pennsylvania, Philadelphia, PA, for "Osteogenic Progenitor Cells in Skeletal Muscle."

OI Foundation Medical Advisory Committee Member **Darwin J. Prockop**, Professor and Director of Biochemistry, Center for Gene Therapy, Tulane Univ., New Orleans, LA, for "Osteoprogenitors for Potential Therapy of OI."

David W. Russell, assistant Professor, Univ. of Washington, Seattle, WA, for "Collagen Gene Targeting with AAV Vectors." 

Research ranges from cell-based therapies to genetic modifications

It is well established that patients with OI have increased bone turnover, therefore reports of successful therapy in children with OI using anti-resorptive agents (bisphosphonates such as pamidronate and fosomat) were not unexpected. However, there are still unanswered questions related to long-term use.

Nancy P. Camacho's work will develop further insight into the precise cellular and molecular mechanisms that increase bone turnover in people with OI. This could lead to more specifically targeted drugs and results similar to bisphosphonate therapy.

Specifically, she will determine if treatment with osteoprotegerin, a naturally occurring soluble factor in cells, will result in improved bone properties and a reduced fracture rate without compromising fracture healing. The information gained from her studies will make the design of improved therapeutic protocols possible.

Arnold I. Caplan will explore another possible curative therapy based on the transplantation and engraftment of stem cells with normal type I collagen genes. Genetically normal cells are targeted for transplantation using a new procedure that "paints" the outermost surface of the cells. The hypothesis is that delivering only healthy cells back to the marrow will enable the cells to engraft in a sufficient number to affect the bone, providing a curative therapy for OI.

Evaluating cells in transplantation models will provide an essential pre-clinical test of their utility for the treatment of OI and other diseases of the musculoskeletal system. David J. Goldhamer will determine the identity of cells with therapeutic qualities by labelling five types of skeletal muscle tissue cells, then following their fate as they are injected into bone protein.

Darwin J. Prockop will explore the possibility that patients with OI can potentially be treated with their *own* bone marrow cells, genetically altered to correct the mutations in type I collagen that produce OI.

The long-term objective of David W. Russell's research is to develop a new treatment for OI based on the transplantation of genetically modified stem cells. Since severe forms of OI are typically caused by dominant mutations in the type I collagen genes, an effective treatment will require the removal or correction of the defective genes.

Russell will develop several strategies to modify genes, then select gene cells that express normal collagen genes for transplantation, with the goal of simplifying future clinical trials and converting severe OI (due to mutations) to a milder form. 

Children's Brittle Bone Foundation funds fellowships

The CBBF of Chicago awarded **Dr. Joel Chamberlain** at the University of Washington School of Medicine, Seattle, WA, a fellowship for "Targeted Collagen Gene Modification in Stem Cells from Patients with OI." The concept is to harvest stem cells, modify the faulty gene, then reintroduce the cells into the patient.

Dr. Ivo Kalajzic, from the University of Connecticut Health Center, Farmington, CT, was also awarded a fellowship, for "Performance of the Osteoblast Lineage in the OIM Mouse." He proposes to assess the efficiency of conversion of transplanted marrow. 

Seed grant recipients report progress

Shannon Fisher, M.D., Ph.D., described her progress and a change in the experimental approach in her interim report to the OI Foundation.

Her initial objective was to examine the numbers, rate of proliferation and location of osteoblasts in zebra fish that have OI during early development and in adults. She had mapped the mutation to the same location as the collagen I gene, and has since confirmed that the fish is a true model for OI by identifying the mutation in the genetic coding sequence.

Recent advances in genomic tools and technology have made gene expression profiling of the fish possible, and she has modified her experimental approach to take advantage of the new technology.

Dr. Roland Baron's project to determine the molecular mechanism that regulates osteoblast differentiation and function in OI patients is also underway. His interim report states that cell lines are in the final stages of characterization before being used for live targeting experiments.

He has obtained enough mice to allow experimentation to begin. The mating program to increase the in-house colony has not been successful, and the reasons for the high fatality rate are being investigated. The mating is being continued to investigate the effect of the high bone mass line in the mouse model. 

President proclaims National Bone and Joint Decade

Following is the text of President George W. Bush's proclamation to Congress March 21, 2002. The OI Foundation was an early supporter in bringing this matter to the President's attention and making the proclamation possible.

In the United States, musculoskeletal disorders are a leading cause of physical disability.

Conditions such as osteoporosis, osteoarthritis, rheumatoid arthritis, back pain, spinal disorders, and fractures also affect hundreds of millions of people around the world. And many children suffer from crippling bone and joint diseases and deformities, impeding normal development and preventing them from experiencing a full and healthy life.

National Bone and Joint Decade, 2002-2011, envisions a series of international initiatives among physicians, health professionals, patients, and communities, working together to raise awareness about

musculoskeletal disorders and promoting research and development into therapies, preventative measures, and cures for these disorders.

The National Institutes of Health, The National Institute of Arthritis and Musculoskeletal and Skin Diseases, and other Federal agencies support many bone and joint studies.

Industry and private, professional and voluntary agencies support other initiatives.

This work involves scientists examining the possible genetic causes of bone and joint diseases and studying how hormones, growth factors, and drugs regulate the skeleton.

Other researchers are studying bone density, quality and metabolism, and ways to increase the longevity of joint replacements for those whose daily activities have become painful, difficult, or even impossible.

These research efforts can help relieve pain and suffering, and give countless children and adults the opportunity for a better life.

Thanks to the hard work of these dedicated researchers, we have made great progress in understanding and treating musculoskeletal disorders.

I commend their efforts and encourage them to pursue diligently further research that will help those suffering from these disorders. And I hope that all Americans will learn more about musculoskeletal problems, their long- and short-term effects, and the therapies and treatments available to help them.

NOW, THEREFORE, I, GEORGE W. BUSH, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim the years 2002-2011 as *National Bone and Joint Decade*.

I call upon the people of the United States to observe the decade with appropriate programs and activities, and I call upon the medical community to pursue research in this important area. 

RESEARCH UPDATE

U.S. Dept. of Ed. project seeks research participants

Through the Looking Glass, the National Resource Center for Parents with Disabilities, is conducting a nation-wide project to learn more about families in which a parent with a disability is raising a child 11-17 years old.

Parents with disabilities, deaf parents who have teenagers, and teens are asked to participate in a national survey. The disability can involve physical, visual, systemic, hearing, cognitive, learning, developmental, or mental health issues.

Although there are more than 10 million families in which one or both parents have a disability, relatively little is known about the experience of those families.

Teens participating in the survey can receive \$5 in return for their time. Surveys are available in a variety of formats: online and printable at their website, in Spanish, over the phone, and a version specific to deaf parents.

Families local to the San Francisco bay area can also participate in twelve weeks of solution-focused family therapy in their own home.

Deaf parents can participate in a face-to-face interview

in ASL if they live in San Francisco, Seattle, Santa Fe, New York, Kansas City, or Washington D.C.

The National Institute on Disability Research and Rehabilitation, part of the Department of Education, is funding the project.

Through the Looking Glass is a community-based non-profit organization based in Berkeley, CA, that serves families in which a parent or child has a disability. Current projects include The National Parent to Parent Network for Parents with Disabilities.

Their staff is comprised of various specialists with diverse backgrounds, and nearly eighty-percent of the staff members are disabled, parents of disabled children, or members of families with disabilities.

To request a survey by e-mail, write tlg@lookingglass.org or contact Nancy Freed at (510) 848-1112, ext. 174, 800-644-2666, or TTY 800-804-1616.

Online and printable surveys can be found at www.lookingglass.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.

MEMBERSHIP APPLICATION

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

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

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

Total membership commitment \$ _____

- Check VISA MasterCard
 Discover American Express

Account # _____

Exp. Date _____

Signature _____

- I do not want to be listed in the Annual Membership Directory.
 I do want to be listed in the Directory as follows:

Name _____
Address _____
City _____
State _____
Zip or Postal Code _____
Country _____
Phone (day) _____
Phone (evening) _____
E-mail _____

Relationship to OI:

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

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

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

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

Foundation posts new privacy policy for upgraded web site

Protecting your personal privacy is very important to us. We hope that publishing the following policy will help you understand how the Osteogenesis Imperfecta Foundation (“OI Foundation”) collects, uses and safeguards the personal information you provide when visiting our website at www.oif.org.

The OI Foundation is dedicated to preserving your personal on-line privacy. Our goal in outlining our policy on the collection and use of user data is to ensure the highest level of confidentiality and security. When you provide any personal information to the OI Foundation, you have choices about how your data is used.

Collection of personally identifying information: The website collects personally identifying information which a user voluntarily provides when making an on-line purchase or donation, registering on the website, or when requesting access to archived webcasts. The collected information is used primarily for technical administration of this website and for completing the transaction requested by the user. Except for credit card information which is not stored, OI Foundation retains users’ information once the transaction is complete. This information is then used to provide additional information to users, to solicit donations, and may be used for other purposes deemed beneficial to users and related to OI Foundation’s mission. Users may choose to prohibit these secondary uses. The OI Foundation will not give or sell your personal information to any outside company for its use in marketing or solicitation.

When browsing our site, we allow our users to maintain control over their personal data while attempting to provide a more interactive online experience. If you provide a mailing address or e-mail address, our intention is to send correspondence only to those who have chosen to receive

such communications. All communications are carefully designed to meet our quality standards. Our goal is to provide information that will help you as we accomplish our mission of improving the quality of life for people with OI. The OI Foundation provides users with an easy method to decline receiving future e-mail or direct mail communication or offers. At any time you may request to discontinue receiving these offers from us by simply replying to the e-mail address included in every e-mail message you receive, calling us at the phone number listed on page 2, or by writing to us.

Use of outside vendors or web services: Users should be aware that the OI Foundation chatroom “OICHAT” is made possible through Web Crossing (webcrossing.com) and OI Foundation does not control nor take responsibility for any use of the information collected by or submitted to Web Crossing. For the terms and conditions of participating in the OI Foundation chatroom, please see the OI Foundation chatroom information page.

Users should also be aware that the OI Foundation store is made possible through Yahoo Store and OI Foundation does not control nor take responsibility for any use of the information collected by or submitted to Yahoo.

The resource links located on the website will direct users to websites outside www.oif.org. OI Foundation does not control nor take responsibility for any use of the information collected by or submitted to these websites. Please be careful and responsible whenever you are online. If you post personal information online that is accessible to the public, you may receive unsolicited messages from other parties in return.

Collection of User Information: In general, the website gathers information about users as a group, such as

which areas users visit most frequently and what services users access the most. The website automatically collects information about users’ IP address, browser type, domain name, date and time of access, and general location (country of access). OI Foundation only uses such data in the aggregate to analyze site traffic and to determine what is most relevant to users.

Once users log in to the website, the pages which they browse are tracked automatically in order to deliver materials relevant to the user’s search. This information is not shared, sold, or accessible to any other party or website.

Registering on the site: To open a user account, order a product on-line, make a donation through the OI Foundation Resource Center, or request access to archived webcasts, OI Foundation requires personally identifying information from users. This information may include the user’s name, address, e-mail address, telephone number, credit card information (which is encrypted), or other information. OI Foundation uses this information for the purposes of completing the transaction as requested by the user.

If children (under age 14) choose to register on the OI Foundation web site, parental approval will be requested by e-mail to the account address provided by the child. The OI Foundation does not knowingly solicit data from children, and we will not knowingly mail to or market services to children. Should you discover that your child is on our e-mail or direct mail list, simply reply to the e-mail address included in every e-mail message you receive, call us at the Foundation offices, or write to us at the address shown on page 2 or on the direct mail piece. We will immediately remove him or her from any

Continued on page 17

NEWS NOTES

Financial help may be available for prescription drugs

There may now be an option for individuals whose insurance does not include prescription drug coverage. Some pharmaceutical companies have instituted patient assistance programs for people who cannot afford their medications.

The “Directory of Prescription Drug Patient Assistance Programs 2001-2002,” put out by the PHRMA, lists company programs that provide drugs to physicians whose patients may be in financial need. Manufacturers, covered medications, information on eligibility and how to request assistance are all included in this resource.

To request a copy of the booklet, call PHRMA at 1-800-762-4636 or download it from their site at www.phrma.org.

National Foundation for Dental Health provides donated dental services

Persons with disabilities and elderly people unable to afford dental care may be eligible for a program that provides free or discounted dental services. The National Foundation of Dentistry for the Handicapped set up the Donated Dental Services Program in 1985 to meet the needs of indigent, disabled, or elderly persons by matching them with volunteer dentists.

If your health insurance does not include dental coverage and you are on a fixed income, visit www.nfdh.org or contact NFDH at (303) 534-5360.

Guide to handling health plan disputes now available

A free online consumer guide about handling health plan disputes was

recently launched by the Kaiser Family Foundation and Consumers Union, the publisher of Consumer Reports Magazine.

“A Consumer Guide to Handling Disputes with your Private Employer Health Plan” provides practical information to plan enrollees who are seeking a way to resolve a dispute with their health plan or to better understand their coverage before a problem arises.

Today, 40 states plus the District of Columbia have legislated procedures for resolving disputes outside the health plan through “external review” systems, yet studies show these systems are not well utilized. The guide helps consumers navigate their plan’s internal grievance procedures, as well as their state’s external review process.

A recent survey by the Kaiser Family Foundation reported that 48 percent of privately insured adults have had a problem with their health care plan in the last year. The guide includes sections that will help people understand their health plan’s rules and coverage, its internal review process, and the external review process for those states that have one.

The guide can be found at the Kaiser Family Foundation website at www.kff.org/consumerguide or in the health section of the Consumers Union website at www.consumersunion.org.

In addition, a link to the guide is posted in the free consumer advice section of the Consumer Reports Magazine website, www.consumerreports.org. More information is available by phone at the Kaiser Family Foundation, (650) 854-9400.

More federal funding approved for rare disease office

After a contentious legislative year, at the end of December 2001 the House and Senate Appropriations Committees approved an increase of funding for the National Institutes of Health (NIH) amounting to almost 15 percent.

We are very pleased that for the first time Congress increased funding for the **NIH Office for Rare Diseases (ORD)** to \$10,341,000. Funding for the Office had stagnated at approximately \$2 million per year, so this five-fold increase is a reflection of the letters, phone calls, and visits people with disabilities made to their federal elected officials asking for more funding for the ORD.

A bill is currently pending before Congress (*The Rare Diseases Act*, S.1379), which would make the NIH Office for Rare Diseases permanent by writing it into law, and appropriate \$24 million to the Office next year. We greatly appreciate this interim step, providing over \$10 million to the ORD during 2002.

New benefit information web site from U.S. Dept. of Labor

Almost 100 government programs and benefits are already listed on www.GovBenefits.gov, a Dept. of Labor web site designed to help users find assistance or benefit programs.

Visitors respond to a series of questions about their situation, but are not required to provide any identifying information. The site then produces a list benefits the user may be eligible for, including contact information and application information for each program.

More than 300 programs are scheduled to be included on the site.

OI Foundation seeks editor for book project

The OI Foundation is seeking an experienced editor for the *Bright Start Story Book* Project. The story book will serve as an age-appropriate way to introduce the concept of OI-- and mobility limitations-- to kindergarten and first grade students.

The goal is to ensure that children with OI or other mobility impairments are welcomed into the classroom.

The Bright Start Story Book will provide students with the answers and positive reinforcement they need to see a child with a disability as an equal peer. It will have an accompanying Teachers Guide, which will provide basic steps for successful integration of students with OI and other mobility limitations into classroom and school activities.

The Teachers Guide will also help teachers and parents work together to ensure that these children are able to fully participate in all educational activities.

Applicants should have experience developing children's books and working with artists and volunteer advisory committees. The project must be completed by June, 2003. Please send resumes to Heller An Shapiro, Executive Director, at hshapiro@oif.org.

Thank you to the Braitmayer Foundation for their generous support of this project. 

PRIVACY POLICY *Continued from page 15*

future communications.

OI Foundation may also request additional information on a voluntary basis from users, such as information regarding interests, opinion of this website, and the types of products and information in which users are interested. Such information is used only to guide website and program improvements.

The website uses cookies only to facilitate on-line purchases and donations, and to provide the "remember me" function at the user's request.

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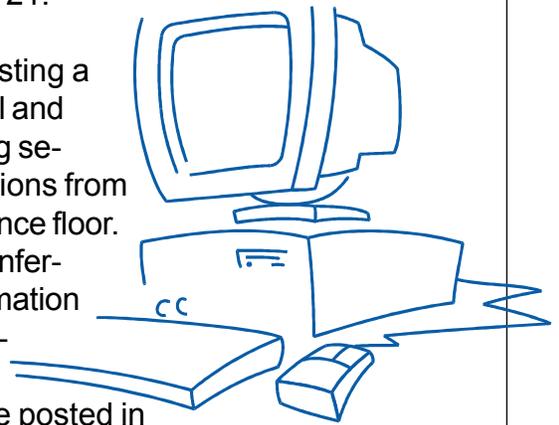
Can't Make it to the 2002 Conference in Orlando?

Keep your eye on www.oif.org between July 18 and July 21.

We'll be posting a daily journal and web-casting selected sessions from the conference floor.

After the conference, information from conference sessions will be posted in

Breakthrough or on the OIF website.



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

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A billboard with a message that inspires

Twenty-three year-old Sean Stephenson has had a number of choices and labels thrust upon him in his lifetime. He faces the curves life throws his way with a cheerful determination to make the most out of the challenge. He tries to resist the labels.

"I shy away from 'author' or 'inspirational speaker' as labels," he explained, "because those aren't who I am. I am a personal example of how to recognize potential on a mind, body, and spiritual level."

If pushed, he'll concede the title "personal development expert," but even then he's hesitant. It's quite possibly the only thing he's hesitant about.

Sean was born with such a severe form of OI that the doctors told his parents at birth he wouldn't survive the night. He proved the doctors wrong and attended grade, middle and high school "like everyone else," though he was often out of school or "sidelined" by the 200-plus fractures and three surgeries he had before his eighteenth birthday.

During grade school, when dealing with an agonizing femur break, Sean's mother asked him a question that would shape the rest of his life.

"Sean, is this physical condition going to be a gift or a burden in your life?"

He realized that "there is no meaning in life-- unless you *make* it have meaning."

For the seven-year-old crying in pain from a leg that broke while crawling across his living room floor, that meant he could give the *pain* meaning and allow the frequent breaks to control his life, or he could give his life meaning by showing his friends, family, world, and even self what could be accomplished in spite of the pain and fractures.

In the years since, he's been constantly reading, learning and training, trying to find the most effective tools to improve the mind, body and spirit.

For Sean, it boils down to the concept that "OI is a *gift*. Even amidst all the pain, the gift is that you are living, you have the experience of life, and you can relate to others in pain," he explained.

People often place destructive meanings on their lives and situations. Sean helps them realize the potential of assigning empowering meanings to those same lives and situations.

"I used to think having OI was not fair," Sean admitted, "but I *choose* the meaning to be 'OI makes me look different.' People notice me, so it's up to me to use myself as a billboard with a message that empowers."

He shares his message with schools, businesses,

churches, organizations, hospitals-- through a speaking schedule that covers the world, his web site, a book, a bi-monthly magazine, an audio program, a series of exercise tapes and connections with some of the most powerful politicians and celebrities in the U.S.

His career had "chosen" him as a junior in high school, when he met then President Clinton through a school project in Washington, D.C. As he shook the president's hand, Sean quipped, "stop by when you get to Chicago."

Much to everyone's surprise, he did. Clinton was so impressed with Sean's spirit and outlook on life, that he invited Sean to join him in the Presidential Skybox at the United Center during the Chicago Democratic National Convention.

In the years that followed, Sean became a legend among Congressional Interns for his bold insistence that Newt Gingrich move his motorcade away from the handicapped access ramp. His friendship with Clinton grew during a subsequent White House internship, and he was a frequent dinner guest of the Clintons in the Rose Garden.

But it was at DePaul University, across the street from the hospital where doctors had informed his parents he wouldn't live through the night, that his vocation began to emerge.

Sean felt that he wasn't making enough impact on young adults, so he decided to write a book on how to turn dreams into realities. In spite of many outspoken critics, Sean wrote and self-published "How YOUth Can Succeed" to spread his message of self-empowerment. Following the book, he produced an audioprogram on healthy eating, and a video exercise program for people with and without physical limitations. At the same time he managed to graduate from college, appear in more than a dozen national news outlets, and begin a public speaking career.

Sean will be joining the Foundation in Orlando to conduct a wheelchair exercise workshop called "No Excuses," and to close the three-day conference with a session entitled "What's Possible With OI."

The lack of a question mark is intentional. If that were posed as a question, the answer would simply be "anything." Sean's session, like his life, will be a lesson in how to release psychological pain and become empowered to attain any dream.

"OI is a gift," he asserts. "I can't tell anyone they can't be upset that they have it, but I do want them to know they don't have to be." 



Sean Stephenson

HONORARY AND MEMORIAL DONATIONS

JANUARY 1, 2002 TO MARCH 31, 2002

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2002 CONFERENCE INFORMATION

From head to toe, conference is packed with info

Thursday, July 18

11:30 OI: The Basics

David W. Rowe, M.D.
Michael P. Whyte, M.D.

How to Benefit From Conference

1:00 Opening Session: OI Research

Joan Marini, M.D., Ph.D.
Francis Glorieux, M.D., Ph.D.
To Be Determined

3:30 President's Reception

7:00 Peer Support Meetings

Friday, July 19

9:00 Orthopedic Surgery for Kids

Cathleen L. Raggio, M.D.

Children with Type I OI

Laura Tosi, M.D.

OI Genetics:

Testing and Diagnosis
Peter H. Byers, M.D.

Pain Management for Adults

Paul Burns, DC, CCSP

Independent Living

Eileen Teachout Smith

10:30 Post Surgical Care of a Child

To Be Determined

Respiratory Health

To Be Determined

"The Doctor is IN" - Bracing and

Foot Management

Lynn Gerber, M.D.

Nutrition

To Be Determined

Parenting a kid with OI who feels good about him/herself: Viewing the world through a clear lens

Kay Kriegsman, Ph.D.

1:30 Fracture First Aid

Priscilla Wacaster, M.D.
Peter A. Smith, M.D.

Cardiac Health

To Be Determined

Neurological Complications

Lawrence Charnas, M.D., Ph.D.

OI: The Adult Years

Jay R. Shapiro, M.D.

Adaptive Equipment for Kids

Tim Caruso, P.T.

Abuse Allegations

Horacio Plotkin, M.D., Ph.D.
Stephen Lazowitz, M.D.

3:00 Planning and performance strategies for infants and young children: Ask the Physical Therapist

Holly Cintas, P.T., Ph.D.

Spinal Problems in OI

John Lubicky, M.D.

SSI & Insurance

Leslie Kitterman

"The Doctor is IN" - Feet, Ankle & Shoes

Lynn H. Gerber, M.D.

Pregnancy Pros and Cons

Deborah Krakow, M.D.

4:30 Estate Planning

Julianne Weiner

OB/GYN Health

Deborah Krakow, M.D.

Home Adaptation

Karen Braitmayer

Wheelchair Exercise Workshop

"No Excuses"

Sean Stephenson

Planning and performance strategies for middle childhood and adolescence: Ask the Physical Therapist

Holly Cintas, P.T., Ph.D.

Infant & Toddler Care

Horacio Plotkin, M.D., Ph.D.

7:00 Peer Support Meetings

Saturday, July 20

9:00 Strengthening Your Family - Part 1

To Be Determined

Educating an Elementary or PreSchool Child with OI

Maureen McCabe, P.T.

Surgical Needs of Adults

To Be Determined

Hearing Loss

David Vernick, M.D.

The Dr.-Patient Relationship

Bonnie Landrum, M.D.

10:30 Strengthening Your Family - Part 2

To Be Determined

PANEL: Educating a High School Child with OI

Grace Sisco, facilitator

Dental Care and Orthodontics

James Hartsfield, DmD, Ph.D.
Lawrence Garretto, DmD

Osteoporosis: Prevention and Treatment

Richard Wenstrup, M.D.

PANEL: Ask the Doctors - OI Kids

Joan Marini, M.D., Ph.D.

Peter A. Smith, M.D.

Michael P. Whyte, M.D.

Let's get on with the program:

"Time out" for adults with OI to focus on their concerns, discover ways to deal with them, and move on

Kay Kriegsman, Ph.D.

1:30 Closing Session

"What's Possible with OI"

Sean Stephenson

5:30 Awards Dinner

7:30 Talent Show

Teen Room Sessions

Careers Panel

Jamie Kendall, facilitator

Driving

To Be Determined

"Being Different"

Suzanne Richard

Colleges and Careers

Paralympic Athletes

Mia Ives-Rublees

Kara Sheridan

Being Your Own Best Advocate

Becky Sisco

Lunch Sessions

Saturday, July 20

12 - 1 p.m.

Advocacy

Vance Cheek, Jr., Commissioner

Chat

Susie Wilson

Fundraising

Julianne Weiner

As of May 10, 2002. Visit www.oif.org for the latest conference information.

Don't miss these photo opportunities-- now and at conference!

Don't forget to bring photos of your used but servicable equipment or clothing to post on the exchange bulletin board at the conference... then bring your camera and plenty of film for the talent show Saturday night!

Daunting Task:**Committee wades through scholarship applications**

More than 30 applications for scholarship assistance to the 2002 National Conference in Orlando, FL, have been received by the Foundation in the last month.

The scholarship committee now faces the daunting task of narrowing all the applicants down to approximately 15 families.

The scholarships will cover all conference-related costs, including travel, hotel and registration fees, so the final number of scholarships awarded may be affected by the family size of the applicants.

“There are so many families that qualify, and a limited amount of money available,” according to Heller An Shapiro, the Foundation’s Executive Director.

“The committee will have to make some very tough decisions.”

A generous grant from The Million Dollar Roundtable Foundation made the scholarships possible. It was up to the scholarship committee to determine criteria for awarding the money.

Applications will be weighed based on a point system.

“We don’t *want* to say ‘no’ to anyone,” Shapiro said.

The Foundation is already pursuing similar grants to help increase the numbers of scholarships available for the 2004 conference. 

**In the public eye...**

This photo of Anna Miriam Lennartson, daughter of Cynthia and Shawn Lennartson, was recently featured in an advertisement for her local children’s hospital.

Patients may qualify for free or reduced rate airfare

Patients with genetic disorders or rare diseases can receive travel help when they need to get to distant specialists for evaluation, diagnosis or treatment. The service is available anywhere in the United States.

A patient in Maryland who needs to make multiple trips to specialists in Washington State can get either free or highly-discounted airline tickets as many times as is needed—even with last minute reservations. Fares can be as low as \$350, as opposed to a typical last minute fare of \$1,500 or more.

A patient in Virginia can travel to destinations such as Boston, MA, Gainesville, FL, or Chicago, IL for free—as many times as necessary. In most cases, a patient escort may also travel at the free or reduced costs.

This is made possible by the National Patient Travel Center, a non-profit organization headquartered in

Virginia Beach, VA. Their 24-hour hotline is 1-800-296-1217, or you can visit their web site at www.PatientTravel.org.

The organization helped more than 60,000 patients since 1998. It provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help.

They can also help provide lodging and support to families in medical emergencies and to patients who must travel for necessary outpatient care.

PatientTravel.org is provided as a service of Mercy Medical Airlift, a national charity that receives its support through charitable giving by individuals, corporations, foundations, churches, civic clubs, the Combined Federal Campaign and the United Way Campaigns. 

10-yr-old opens lemonade stand-- then gives his earnings away

As summer approaches and temperatures climb, residents in Joplin, MO, will be watching for Jacob Everett and his borrowed lemonade stand outside his parent's furniture store.

Last summer, in spite of a broken leg, Jacob raised \$1,160 one quarter at a time selling glasses of lemonade. If that's not extraordinary enough, the seven-year-old didn't use the money for a new toy, or even tuck it away in a savings account for college.

Jacob sent a check to the Osteogenesis Imperfecta Foundation for the full amount. "I'm not doing this just for me," Jacob said, "but for everyone who has this disease."

Jacob is home-schooled and attends the Granby Christian Church. He had broken his leg shortly before opening his lemonade stand, but wasn't going to let that stop him.

"Unfortunately, he's all boy," said his

mother, Leah, "and he likes to do all the boy things. Trips to the hospital are nothing unusual," she said.

"I'm happy," Jacob avows, "and I want people to know that I'm just like any other kid."

"I can't do some things like other kids," he continued, "but not all kids can do everything."

Jacob is an avid sports fan, and considers volleyball his favorite sport, though he cannot play.

The 8-year-old was born with 11 broken bones, and has broken more than 40 bones since.

He spends a lot of his time with Georgette Wartchow, a playmate who challenges him to board games.

"He's an inspiration to others," she said, "because he goes to the front of the church and he asks for prayers for others."

"He's always asking for prayers for someone else," she said.

Jacob says he believes there are others who need help more than he does, and refuses to allow OI to affect his outlook on life.

He plans to continue to raise money for the Foundation, and his mother is considering whether or not to make the lemonade stand an everyday fixture outside the family business.

"Supporting him helping others is important," she said.

His parents helped instill his sense of giving by visibly supporting the community and the Foundation. The same summer Caleb opened his lemonade stand, his parents hosted a gospel concert featuring local talent. The community rallied by donating time, talent, and a concert hall, and the Everetts raised an additional \$6,000 for the Foundation.

OI Foundation board member Dan Krudys attended and spoke on behalf of the Foundation. 

College graduate finds comfort, support in mentoring others with OI

Kelly Howell Laird is 24 years old, and has two younger sisters, Stacey and Jody. Her parents are Vaughn and Susan Howell.

Kelly graduated from Delcastle Technical High School in Wilmington, DE, with a high school diploma and a graphics art certificate. She graduated from the Wesley College Center for Adult Studies with an Associates Degree.

OI runs in her dad's side of the family. He broke 20 or more bones when he was younger, and his siblings have all broken bones at one time or another. Of their children (Kelly's cousins), 5 of 9 have broken bones, and one niece has been positively diagnosed as having OI. Kelly broke sixteen bones in her first sixteen years of life.

She was very active as a teenager, playing softball for seven years, taking ice skating, roller skating and dance lessons. She never broke any bones playing sports, and her doctors never discouraged her from participating in sports or in gym class. She did, however, have numerous problems with schools allowing her to participate. She would have to bring in multiple doctor's notes, and even then the schools

were hesitant. This has taught her over the years to know how far to push things and when to take it easy. She enjoys hiking, mountain biking, and attending car shows.

Kelly has always kept up on the latest research on OI, and frequently visited the Foundation's web site. She first came in contact with the mentoring program through the site, and she thought it would be nice to give someone the support and help that her family and husband had given her over the years. She became a mentor last year, and has been trading e-mails about broken bones, complaints, and aches ever since.

Kelly quickly discovered that being a mentor works both ways. She and her partner *both* learn from each other. They talk about everything from school to the mall to friends, and best of all have become friends and established a friendship that won't soon be broken.

Even though they are miles apart sometimes it feels to Kelly "like we are close together."

"I think the program is great," Kelly said. "I hope to see it grow." 

*To learn more about the
mentor program, visit
www.oif.org*

High school student learns to embrace differences at 2000 conference

Niko Cheronis wrote the following essay as part of his college enrollment process.

All my life I have known that I am different. Something has never been quite right. By the time I was in ninth grade, I had broken about twenty bones, had surgery four times, and was diagnosed as being clinically deaf. Since then I have had three more surgeries and multiple fractures.

Doctors always said that I was unlucky. However, there is more to it than that. Something the doctors themselves had overlooked.

When I was eleven, I was diagnosed as having OI. I was small in stature; I actually fell off the growth charts between one and twelve years of age. Throughout my life I have spent every last ounce of strength attempting to prove that I am "normal," picking up every stereotype in hopes of finally fitting in, trying to convince myself and everyone else that there is no difference.

Yet the more diligently that I fought, the more depressed and troubled I became, and the more I injured myself. Daring to raise my voice in indignation, I even blamed God for the way I am. I could not fathom why my own Creator would neglect me the way He had.

Gradually, I have begun to embrace

my difference, and I can finally see the light at the end of the tunnel.

During the summer of 2000, I attended the OI conference in Milwaukee. For the first time in my life, the walls that I had built up around me began to fall and the scales were removed from my eyes. I met some incredible individuals who should have had an even more bleak outlook on life, yet they decided to make the most of what they had. These individuals impacted me in a way that will forever change my life.

One of these individuals was a young boy named Nicholas. He was 12 years old and had been confined to a wheelchair for his entire life. He could not walk; his legs were too weak, they would break under his own weight if he tried. His chest cavity and upper body were terribly deformed because his spine and ribs were not strong enough to support his weight. However, with all these "curses" placed upon him, he had the greatest outlook on life of anyone I had ever met, young or old. Just my presence brought a smile to his face that could make a robin sing. As he looked into my eyes, almost searching my soul, I learned something. No matter what or who you are on the outside or inside, it is a blessing to be able to open your lungs and taste the breath of life as air

rushes in to fill you up.

Another person I met was a man named Donovan. He had the gift of humor and the most wonderful personality of anyone I had ever met. He could even make the Grim Reaper crack a smile. Yet, he had been looked down upon by society because he was confined to a wheelchair.

Donovan showed me that if there is a will, then you can make a way, and not to let the physical parameter govern your life. Donovan did not let his societal difficulties affect him. He has since fulfilled his dream and become an inspirational speaker and comedian.

Coming back from the conference, I had to face the most challenging and difficult situation of my life. I have chosen to receive an experimental treatment that consists of an IV infusion twice every three months in order to stabilize my bone density and mass. I have come to appreciate life on a different level.

Life is not about how fast you can run or how high you can jump, because these abilities can be taken away from you with not a moment's notice.

Life for me is far from normal. However, my differences are not limits. They are doorways leading to even more doorways of endless opportunity. 

Growing Up with OI: A resource for parents, sibs, children & friends

(Excerpted from the forward by Gemma Geisman.)

As I look back on my family's life with OI, I can honestly say that I now perceive it as an exceptional gift of many dimensions that taught me how to love unconditionally, how to understand the incomprehensible, and how to change things I could not accept.

I feel very privileged to have been part of the movement to bring information about living with OI to

those who need it the most-- the affected families.

This extraordinary effort has involved countless volunteers and staff members working diligently over a long period of time to bring families a series of fact sheets, brochures, books and videos, and has culminated in a double-book set, *Growing Up with OI*.

It is difficult to contemplate how different my family's life with OI might have been had such a book existed when our child came into the world.

Growing Up with OI addresses the special needs of children with OI, their parents, siblings and friends. It was written with passion, conviction and hope by those who have already experienced the inevitable heartaches and tremendous joys of living with OI. 

The book set can be purchased on-line at www.oif.org, or by sending a check or money order to the Foundation offices.

**2002
Research
Update!**
(pull-out section)

A Family Focus for Spring

With Mother's and Father's Day both just around the corner, we thought we'd dedicate this issue to the extraordinary family members in our community.

The OI Foundation began with a group of concerned parents sharing their stories, their strength, and lessons learned the hard way; through trial and error.

We do the same in this issue, with brief stories and vignettes that highlight the members of our community.

"Cornerstones of our Foundation," will become a feature of our new and updated Web Site in the fall of this year. We couldn't think of a better time to debut the concept than in the issue that spans the two months honoring our parents.

These stories are compiled from letters, e-mails, and phone calls received over the past year. We invite every one of you to tell us *your* stories.

Cornerstones

A Mother's Joy

page 1

Testing Prepares Parents

page 6

10-yr-old Life Saver

page 7

Lemonade Fund-raising

page 22

Mentoring Works Both Ways

page 22

Embracing Differences

page 23

"Growing Up" Resource

page 23

It's Lighter!?

If you are a regular subscriber to *Breakthrough*, you may have noticed a change in the paper stock.

While we all loved the look and feel of the heavier bond paper, we simply can't justify the added expense in paper costs and postage.

By using a lighter paper we've managed to slightly offset the difference between bulk and first class postage rates.

This is very important, since bulk-rate non-profit mail receives the lowest priority from the U.S. Postal Service.

We want to improve the delivery rate and eliminate "lost" issues, so from now on we're sending *Breakthrough* to you via first class mail.

The paper change represents a significant savings in postage and increase in speed of delivery.