

## '04 National Conference to be hosted in Dallas, TX

The 2004 Biennial National Conference will be held June 24-27 at the Adams Mark Hotel in Dallas, TX.

This is the premiere educational and social event for people with OI and those who care about them.

"There is just no better place for people with OI to learn about the latest research, treatments, and resources about OI," according to OI Foundation Executive Director Heller An Shapiro.

"It's also an incredible place for them to become part of a larger community; to meet, interact with, and befriend hundreds of people who share the same triumphs and challenges they do."

The conference weekend is packed with more than 40 break-out sessions, led by the world's top researchers, physicians, orthopedists and specialists. Topics range from



*The OI Foundation's 2004 National Conference will be held at the Adams Mark Hotel in the Arts District of Dallas, TX.*

daily living skills to treatment strategies, coping with hearing loss, adult issues related to OI, and even

appropriate exercise and diet programs for all types of OI.

The weekend also includes a number of social events, peer-led sessions to share tips and learn new strategies for living successfully with OI, and programs designed for teens and children.

For many people, the national conference marks the first time they've ever met someone else with OI. For everyone who attends, "it's a chance to make friends that will be with you for the rest of your life," according to Foundation Board Member Jamie Kendall, who met her husband at the National Conference six years ago.

"It's the one weekend that I don't have to explain myself," she said,

*Continued on page 6*

## Nominate a volunteer for annual award

The OI Foundation relies on volunteers to support all aspects of its mission; as members of the board of directors, coordinators for support groups, resources for people in need, conference staff and speakers, writers for *Breakthrough*, fund-raisers for the organization, and many other important jobs. Volunteers also accomplish many other critical activities, in and out of the offices, contributing their time and unique skills as special needs arise.

The OI Foundation would like to take this opportunity to express its heartfelt appreciation to all of the

volunteers who made our many activities and projects possible in 2002-2003. The Foundation has a very limited budget and staff, and volunteers make it possible to achieve our research, education and support goals.

Each year the Foundation identifies particularly significant individuals as our Volunteer(s) of the Year. This award is given annually to the volunteer(s) who best exemplify the qualities of loyalty and dedication to the OI Foundation, its mission, and the OI community. These exemplary

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Register online at  
[www.oif.org](http://www.oif.org)  
to receive e-mail updates!

## BREAKTHROUGH

The Newsletter of the Osteogenesis Imperfecta Foundation, Inc.

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**Contributing Writers:** Paula Furber, Marie Hassett, Mary Beth Huber, Bonnie Landrum and Julianne Weiner.

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

A one-year subscription to **BREAKTHROUGH** is free. To add your name to the mailing list, write to [bonelink@oif.org](mailto:bonelink@oif.org) or request it through our on-line store at [www.oif.org](http://www.oif.org).

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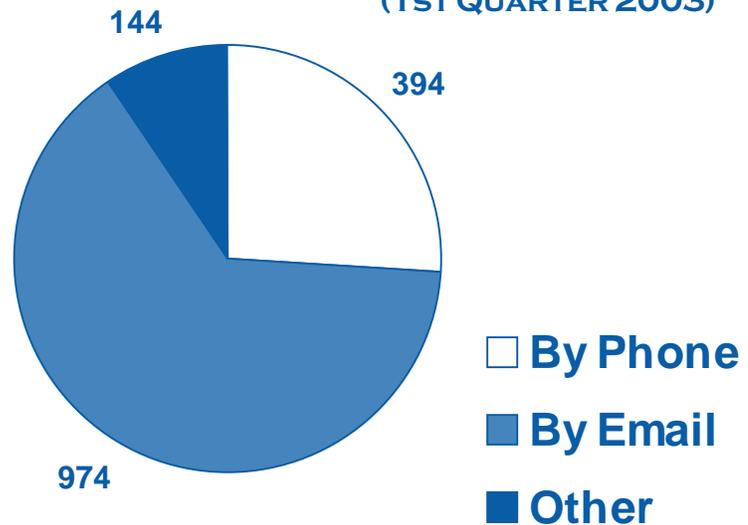
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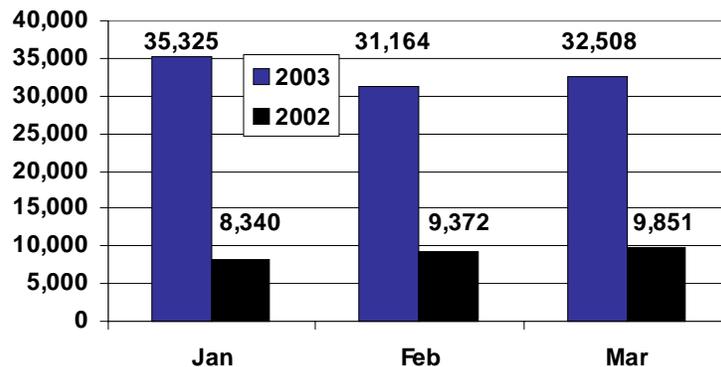
## INFORMATION

### RESOURCE REQUESTS (1ST QUARTER 2003)



## CONNECTING THROUGH WWW.OIF.ORG

### VISITORS, 1ST QUARTER 2003 COMPARED TO 1ST QUARTER, 2002



These two charts provide an at-a-glance snapshot of the support provided to the OI Community by the OI Foundation's national office.

Each quarter we will publish one or more similar charts, on a regular rotation, to help the community members stay informed of the national office's activities and growth.

More detail on the Foundation's activities is provided in each year's annual report. The report for the 2002 fiscal year is at the printer and will be mailed to donors in mid-June. Copies of the report will be available online at [www.oif.org](http://www.oif.org) later this month.

# PRESIDENT'S MESSAGE



**Bill Schmidt**

Dear Friends,

It's hard to believe that two years have passed, and this is my last chance to write to you as President of the OI Foundation's Board of Directors. It has been an exciting two years, and I'm proud to have had the opportunity to serve the OI Community.

I'd like to thank all the board members I've worked with for their incredible support and vision for the OI Community, and wish the current board— and new members joining the board of directors next month— continued success. I remain on the board for one more year, and look forward to working with our new President, Jamie Kendall. Of course, my support for the board of directors and the OI Foundation will continue long after I step down and resume my place as a “member” of this incredible community.

We've accomplished so much; the development of our three-year strategic plan, new scientific meetings, increased partnerships and visibility with related organizations, a vast array of new resources, the expansion of our national office staff, the creation of our new web site, our clinic directory, and the development of our accountability and ethics task force (which resulted in national recognition in the health care community for our business practices and accountability to our community). These are just a few of the key projects that come to mind.

But there's still much to be done.

It's very demanding and rewarding to serve as President for an organization that provides so many needed resources to such a diverse population. It's equally rewarding to see the members of the community step up to the plate and prove, again and again, that *anything* is possible with a strong vision, drive, and the tools to succeed.

Once again, this issue of *Breakthrough* is packed with examples of what is not only possible, but what is being accomplished in our community. The four-page Research Update (page 14) once again illustrates solid advancements in understanding— and potentially treating— OI. None of that research would have been possible without the OI community's continued generous support. Members throughout the country continue to support the Foundation and each other, while raising community awareness, in a wide variety of fundraising efforts (page 4). Our clinic directory continues to grow (page 16), our members continue to set and reach greater personal goals that might not have been possible twenty years ago (pages 18 and 21), and our volunteers continue to make it all possible (page 1).

You'll also find initial information about the 2004 National Conference (pages 1 and 6), our Foundation's premiere educational and social event for people affected by OI. The National Conference will be the most visible task for the new President and board members, but it's only the tip of the iceberg.

We've completed two significant growth years, and our strategic plan calls for more services, programs and materials in the next two years as well. It's a challenge that I'm sure our new president, board of directors and staff will accept gladly, and accomplish magnificently.

With the support, drive and inspiration of the entire OI community, continued success is not only possible, it's inevitable.

Thank you for allowing me to serve you. It has been an honor, and a pleasure.

Sincerely,

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

## Fundraising events...

### Freezing rain doesn't dampen annual CT walk-a-thon success

by Paula Furber  
OI Foundation Member

For the 3<sup>rd</sup> straight year, we were unable to pick a good weather day for the annual CT Walk-a-thon, Dinner Dance and Auction. This year we had freezing cold temperatures, a drizzling mist and eventual heavy showers, but Alyse was still able to pull off another successful day, raising a total of \$20,000 to support the OI Foundation.

If it weren't for Alyse's high school principle and custodian allowing us to hold the walk-a-thon inside the school hallways instead of on the track, the day would have been very unpleasant.

This year we were able to provide a D.J., moonwalk, face painting,



*Alyse Furber walks with the St. Thomas More basketball team inside her high school during the third annual CT Walk-a-thon.*

balloon making and bubble blowing—all free. We did arrange for pony rides and wagon rides, but the weather prevented them from coming. OI Foundation board member Robin

Johnson came out for the day, and we also met two newcomers to the Foundation: Kathy and Mike.

Both the day and evening auctions were successful. We had over 75 auction items donated, and the dinner was attended by more than 250 guests. Our favorite band, Melanea, donated their time to us and they were fabulous.

The St. Thomas More School basketball team also pitched in to make Alyse's efforts more successful. They've been generous in the past three years, raising over \$4,000 as a group to contribute.

Plans are underway for the 4<sup>th</sup> Annual Walk-a-Thon... hopefully, when it comes to weather, the *fourth* time's a charm! 

### Bone China Tea heats up OI support in 2003

The Foundation's National "non event" fundraiser – the Bone China Tea – raised over \$22,000.00 from 596 contributors this year, thanks to the hard work of chairs Susie and Jenny Wilson, and the participation of 50 families and individuals who mailed out more than 2,000 invitations.

Contributions to this year's Tea rose by almost \$4,000.00. Nearly 100 new contributors helped ensure the Tea's success. Contributions raised by the event

help provide funding for the Foundation's educational and support services.

The Bone China Tea celebrated its

10th anniversary this spring. Begun in 1994 by Pat Kipperman, the beauty of the Tea is that it takes place in the comfort and convenience of the invited guests' own home. This year, guests received an invitation to the Tea that included a tea bag and a suggestion that rather than spend money to attend a formal tea (new clothes, transportation, a sitter for the kids), they relax at home with a hot cup of tea and make a donation

to the OI Foundation.

To participate in next year's Tea, please contact Jenny Wilson via e-mail at [ijnwilson@aol.com](mailto:ijnwilson@aol.com). 



*Emma Johnson helped raise awareness and support with her own personal appeal during this year's event.*

### Shopping support

If you routinely shop online, a few simple mouse-clicks could benefit the OI Foundation's support and resource programs!

Through a partnership with [www.greatergood.com](http://www.greatergood.com), up to 15 percent of every purchase you make online will be donated to the OI Foundation by the nation's leading on-line vendors when you access them through our website.

Clicking on the "Greater Good" link on our website ([www.oif.org/Foundation\\_Store](http://www.oif.org/Foundation_Store)) automatically logs you into the program. You'll see an on-line mall that includes literally thousands of vendors—chances are the store you regularly shop at is willing to donate part of your purchase to the OI Foundation!

Please bookmark our store page for your future online shopping needs... and support the OI community! 

For more details, go to [www.oif.org](http://www.oif.org)

## Vignettes for Adult Book Needed

The OI Foundation is seeking input and support from the OI Community on a new book project titled “*Taking Charge: Adults Living with OI*.” For a complete list of submission guidelines and subject matter needed, visit the website at [www.oif.org/vignettes](http://www.oif.org/vignettes) or contact the Foundation at [bonelink@oif.org](mailto:bonelink@oif.org).

## AAPD & NOW co-sponsor a joint forum

The American Association of People with Disabilities (AAPD) and the National Organization for Women (NOW) are joining forces to co-sponsor a forum on disability and women’s rights. The forum is scheduled for October 17-19 in Bethesda, MD, and will address issues of mutual concern to the feminist and disability rights movements. For more information, visit [www.aapd-dc.org](http://www.aapd-dc.org) and look for the link to “Women with Disabilities & Allies Forum; Linking Arms for Equality and Justice for All.”

## NIH hosts conference on disabilities

NIH and other Federal agencies will hold a conference on physical disabilities throughout the lifespan, July 21-22 at the Natcher Conference Center, National Institutes of Health, in Bethesda, MD. The conference will focus on the special problems faced by people with physical disabilities—across the lifespan—as they seek more productive roles in society.

Conference organizers hope to attract a diverse group of participants, including researchers, students, policy-makers, advocates and individuals with disabilities. There are no registration fees.

For a detailed agenda and registration link, visit their website at [www.physicaldisabilities.iqsolutions.com](http://www.physicaldisabilities.iqsolutions.com)

## Wheelchair basketball video available

A 57-minute documentary, “Kiss My Wheels” chronicles the efforts of a wheelchair basketball team as they make their way to the 2000-2001 National Championship. Throughout the year their coach boosts the kids’ confidence and athletic skills, while helping them cope with the death of a teammate.

Fanlight Productions is working to distribute the film nationally in libraries, schools and rehabilitation centers as an inspiration to kids on wheels who wish to compete in organized sports. The video is currently available for rent or purchase through Fanlight Productions, 4196 Washington St., Ste. 2, Boston, MA 02131 (800) 937-4113 or [fanlight@fanlight.com](mailto:fanlight@fanlight.com).

## “Special Kids Need Special Parents: A Resource for Parents of Children with Special Needs” now available

Parents of children with special needs face unique emotional and practical challenges every day. These issues are seldom fully addressed by the medical community — and parents’ most compelling questions remain unanswered. Judith Loseff Lavin was thrust into the world of children’s hospitals and special needs when her daughter was born with a cleft lip and palate.

In this book Lavin draws on interviews with health-care professionals, nationally recognized authorities and families of children with special needs to give readers advice, encouragement, and comfort.

In 22 chapters she covers: Boosting your child’s self-esteem; coping with chronic pain; sleep problems; frequent hospitalizations; dealing with feelings of grief and anger; choosing a therapist; finding suitable, reliable

# NEWS NOTES

childcare; coping with teasing; the impact a child with special needs can have on a marriage, siblings, and grandparents; and much more, including Resources and Advocacy Letters.

This resource book is designed for parents who have children with special needs and professionals who work with them. It is available through the Exceptional Parents library by writing [eplibrary@aol.com](mailto:eplibrary@aol.com).

## National Council on Disability’s Youth Advisory Committee seeks student input

Members of the NCD’s YAC know how important it is for people with disabilities to succeed in college and are considering ways that the federal government can help students succeed. Advice from the YAC helps NCD to make recommendations to the President and Congress on disability issues such as special education, the transition to adulthood and independence, independent travel, rehabilitation, higher education, employment, health care, and other topics.

There is little information from people with disabilities about their higher education experiences, including financial challenges, barriers, and level of success. Your stories will help the YAC expand what is known about these issues, so the support services provided to students with disabilities can be improved.

Tell the YAC about your financial aid and disability experiences. Write to [youthfeedback@yahoo.com](mailto:youthfeedback@yahoo.com) to help them understand how disability and financial aid have affected your college experience. Share as much of your story as is needed to explain your circumstances and the relationships between your disability expenses,

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## ARTICLES

### **Dallas shapes up as ideal conference location**

The Adams Mark is located in the center of the Arts District in Dallas, TX, a short walk from the Dallas Museum of Art, hundreds of art galleries, museums, shops, theaters and restaurants. It's located adjacent to a fully accessible light-rail line, putting the entire city—including two major sport and concert venues and the Dallas Zoo—within reach.

The average temperature in late June stays in the mid-to upper-seventies, with virtually no humidity. We can expect sunshine-filled days and cool evenings over the conference weekend.

For the more adventurous, Six Flags over Dallas is less than 30 minutes away, and the Southfork Ranch, "home" of the Ewing family on the T.V. series "Dallas," is within an hour's drive. Both amusement areas are fully accessible and have special accommodations for persons with mobility issues. There are more than 400 other points of interest within an hour of downtown, so you're sure to find something for everyone in your family.

The Dallas/Fort Worth Airport is a hub for American Airlines and is serviced by more than 2,500 flights per day from all major carriers. Love Field, a small commuter airfield with flights from Southwest, Continental and American, is less than ten miles from the hotel. Accessible bus service on the Dallas Metro currently takes visitors from the Dallas/Fort Worth airport to the light rail line, and by 2004 the DART light rail line will connect directly to the Dallas/Fort Worth airport. The Arts District stop on the rail line is across the street from the Adams Mark.

The city has a fleet of accessible cabs and vans, but there may be no reason to ever leave the hotel complex once you arrive. The hotel features seven restaurants, two pools, a weight room and sauna, a beauty salon, and a number of specialty shops. It's also connected by a pedestrian bridge to the Plaza of America, a major shopping mall with scores of restaurants and an 8-plex movie theater.

Information about the city will be posted on the website in the next quarter, and program information about the conference, including registration information and speakers lists, will be available after the first of the year. 

### **CONFERENCE** (Continued from page 1)

"where people with OI are the norm, not the exception. It's a wonderful experience."

A year-long search for appropriate hotel and conference space resulted in the contract with the Adams Mark. (See "Selecting a Site," page 7). Both Foundation and hotel staff are confident Dallas will be an exciting, educational and comfortable conference experience for all attendees.

"We're excited about the facilities and the level of support promised by the Adams Mark," Executive Director Heller An Shapiro said. "Hands down, this facility offers more ADA-compliant rooms, more accessible conference space, and more for each dollar than any facility we've used in the past."

One of the deciding factors in entering into a contract with the Adams Mark is the fact that the hotel has—and will reserve for the OI community—60 fully ADA-accessible rooms. Every room in the hotel has a minimum 30-inch clearance in doors and pathways, making them accessible to community members using mobility aids, as well.

"The conference facility and break-out sessions will be one elevator ride away from the guest rooms, with more than 12 elevators servicing the guest and convention floors, making this the most wheelchair- and walker-friendly site we could possibly hope for," according to Shapiro.

The hotel complex is also connected by a pedestrian bridge to a major shopping mall, making meals, shopping and entertainment extremely accessible for all conference attendees.

Rooms will be \$109 per night for single through quadruple occupancy. Registration materials will be mailed in the February, 2004 issue of Breakthrough. Materials will also be available on line, or through the mail by contacting the OI Foundation, in the same timeframe—but don't wait to start planning to attend the conference, it's a weekend you simply don't want to miss.

Watch for articles about features and events in the city, and the conference program and events in future issues of Breakthrough, on the website, and in e-news updates. 

**Don't want to miss any new National Conference information?**

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

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

## Choosing conference site is a challenge for Foundation

Selecting a conference site is a daunting process.

The site selection process for the 2004 National Conference took more than a year to complete, and included sifting through more than 100 proposals from potential sites all over the United States.

“The challenge is to find a site that’s accessible and affordable” according to Executive Director Heller An Shapiro. “For example, we want all conference sessions on one floor to eliminate the wait for elevators between sessions.”

Selecting a conference site is a balancing act, trying to find the optimal combination of accessibility, amenities and cost, while finding a location that offers attractions for before and after the conference to fit in with family vacation plans.

“We recognize that for some families, the conference is their one ‘family vacation’ that year,” Shapiro said. “So it’s important that we accommodate the entire family.”

This in itself poses difficulties, since resorts generally don’t have adequate conference space, and those convention and meeting facilities that do have adequate space are often not in family vacation areas.

The conference space and hotel rooms are a critical factor. While a hotel might advertise ample space for a 500-plate dinner, when you factor in additional space for wheelchair access at the tables and between rows of tables, what appears at first glance to be perfect suddenly becomes unworkable. Many facilities are reluctant to use their larger banquet and meeting halls to accommodate fewer people than their published capacity, as that affects their bottom line.

The Foundation’s national conference requires a disproportionate amount of space for the number of

attendees. Some hotel/convention centers with ample space withdrew from competition due to the small number of guests using the space. Others were willing to work with the Foundation, but only during off-peak seasons and not within the time-frame needed to accommodate the Foundation’s biennial schedule.

Additionally, fully ADA-compliant hotels are only required to have a small percentage of accessible rooms to be legally compliant... and often that percentage is far lower than the OI community’s requirements.

“We start by sending out a 10-page request for proposal that details our needs to hotels and convention/visitors bureaus all across the country,” explained Bill Bradner, the OI Foundation’s Communications and Events Director. “When proposals come in, we have to weed out the ones that *think* they’re able to meet our needs, leaving anywhere from 50 to 100 proposals to consider.”

“At that point, the balancing act begins,” he continued. “Is it truly accessible? Is it a viable vacation destination? Is the hotel big enough? Are there enough ADA rooms? Can we keep the room rate at an affordable level? Can they really accommodate hundreds of wheelchairs? And most of all, how do we prioritize all those answers and narrow down the field?”

The Board of Directors provide guidance, and a conference task force helped establish a 5-page list of criteria to consider when evaluating proposals. But even that assistance isn’t infallible.

In the site search for the 2004 Conference, Salt Lake City, the recent site of the 2002 Special Olympics, seemed like the perfect location and was given priority in the search process. The city did an incredible job of hosting thousands of disabled athletes, their families and spectators,

and three hotels in Salt Lake seemed tailor-made to meet the Foundation’s accessibility needs.

“We were making plans to travel to Salt Lake and visit three very competitive hotels, when someone forwarded an article to the Foundation about how the athletes had to become acclimated to the high altitude in Salt Lake City,” Bradner said. “After a series of conversations with our Medical Advisory Council, we realized that the location simply wouldn’t work. There was a risk of respiratory problems for some of our attendees.”

“Altitude wasn’t on our list of criteria to evaluate. It is now,” he said.

Another factor that limits the search is transportation from the closest airport or hub. Many airport hotels can accommodate the community with meeting space and accessibility, but who wants to spend their vacation in an industrial complex adjacent to a major airport?

“They’re still tempting,” according to Bradner. “With an airport hotel you completely eliminate any transportation issues involving moving 400 people, many in wheelchairs or with limited mobility, from the airport to the hotel.”

Again, a compromise must be made between travel time and the quality of the hotel and the neighborhood surrounding the hotel.

“One airport hotel we looked at was almost perfect when it came to meeting space and size,” Bradner said, “but the only view was the airport runways and there was nothing accessible within 45 minutes for families to enjoy.”

Of course, moving to a more scenic location increases the room costs for attendees— another factor critical to a successful conference. And just when you think you have the perfect solution,

*Continued on Page 10*



## What is the Human Genome Project?

The Human Genome Project began in 1990, when the U.S. National Institutes of Health and the Department of Energy joined forces with international partners in an effort to determine the sequence of all three billion bases of DNA within the human genome. The project was originally expected to take decades to complete, but advances in DNA sequencing machines, computer processors, and laboratory tools made it possible for the Human Genome Project to announce, in June of 2000, that they had completed the first working draft of the human genome.

The Human Genome Project's ultimate goal was to generate a high-quality reference DNA sequence for the human genome's three billion base pairs, and to identify all the human genes in that sequence. In April of 2003, scientists completed a high-quality reference sequence of the entire human genome and placed it on the world-wide web, making it available to doctors and scientists free of charge.

Coincidentally, this was the 50<sup>th</sup> anniversary of Watson and Crick's publication of their description of the triple helix model of DNA structure that launched the era of molecular biology.

## What is a genome?

A genome is defined as a complete set of a living organism's DNA—which contains the set of genetic instructions for building, running and

maintaining the organism. Every aspect that makes "you" unique is controlled by the genes contained in your DNA; your size, hair color, metabolism—and the structure of your body's collagen.

The human genome contains more than three billion DNA strands, each containing more than 30,000 genes.

## Why is it important to map the entire genome?

In any two humans, 99.99 percent of their DNA is identical. However, the entire set of genetic instructions is so large that the remaining .01 percent variation allows for millions of possible differences. Knowledge about the effects of those variations can lead to a better understanding of diseases, and significant advances in medicine.

The differences cannot be properly compared unless we have a complete understanding of the basic structure of the genome.

## If we've mapped the human genome, why can't we eradicate diseases and genetic disorders like OI?

Now that the human genome is mapped, we can identify which genes cause diseases and disorders.

However, there is still a great deal to learn about how the genome works. Scientists are still analyzing what factors cause variations or mutations in those genes, and how the mutations affect the human body.

For instance, scientists have pinpointed sequences in the genes that are associated with breast cancer, OI, deafness and blindness—but haven't yet developed techniques to prevent the variations or correct variations once they've occurred.

In some cases, the mapping can help people *manage* the isolated disease or disorder. If an individual has a mutation associated with colon cancer, their doctor can prescribe regular

colonoscopies and "catch" any cancer before it becomes life-threatening.

Scientists now believe that the key to human complexity is not in identifying the genes, but in learning how the gene parts are used to build different variations. There are thousands of chemical modifications made to the proteins that make up each gene, further complicating research efforts.

According to a group paper published by the Human Genome Project at the 2003 announcement of the completion of the human genome sequencing, "the more we learn about the human genome, the more there is to explore."

## Do we know which genes cause OI?

More than 300 genetic mutations associated with OI have been identified. Each family seems to have a unique mutation. Most of the mutations causing OI affect type 1 collagen and are found on the COL1A1 or COL1A2 gene, but the research is not complete. It has been suggested by researchers that other genes may also be involved in OI and to date no collagen gene defect has been found in people diagnosed with OI Type V and VI.

## Can't we simply replace the faulty gene?

This is still an experimental field. Gene transfer and gene therapy do have the potential for curing genetic diseases by using normal genes to replace defective ones or to bolster normal functions. There are more than 600 clinical trials related to gene therapy, involving 3,500 participants, worldwide.

Most trials are still studying or establishing the techniques to safely transfer genes, or suppress the defective gene, not the effectiveness of gene therapy in treating diseases or disorders. Scientists working on gene

# Q&A: THE HUMAN GENOME PROJECT

transfer and gene therapy still face many challenges and obstacles before they might find a practical way to prevent or treat disease.

For OI Types II, III and IV, we need to suppress the gene that causes the weakened collagen. This can be done in the test tube, and it's now being tried in animal models. For OI Type I, we need to add a new collagen gene to double the amount of collagen.

Complex disorders like osteogenesis imperfecta that affect multiple organ systems present additional challenges in the search for a workable method for gene therapy.

## Does the human genome map have any practical medical use now?

The genome map is a blueprint of how the human body is built, and how it functions. Just as a repairman might refer to a set of blueprints before trying to fix a structure or electrical component, doctors in the near future will consult your individual genome map before prescribing treatments or medication. Your personal genome map may help in diagnosing potential medical conditions before you show symptoms, so you and your health care team know what to watch for and what tests you might need regularly to catch an illness or disease before it becomes life-threatening.

The .01% of the genome that is unique to each of us contains millions of different combinations. Doctors and scientists must now learn all the possible variations, and the factors that cause the genes to malfunction or

variations to occur, before practical applications are widespread.

## Does the human genome map have any other practical use?

The most visible and widely used application of the genome research project was the development of genetic—or DNA—identification of individuals. We're currently using DNA throughout most developed countries as a way to identify crime suspects, exonerate the wrongfully accused, identify victims of crimes or catastrophes, establish paternal and family relationships, and successfully match organ donors in transplant programs.

## Aren't there moral or ethical considerations to consider?

So far, genetic research has outpaced public policy and legislation. Decisions about how and when genetic technology is used are still largely in the hands of scientists and clinicians, though the courts have taken interest in genetic identity issues.

There is a potential for misuse, as there is with any new technology. However, there is also a great potential for immeasurable good. Genetic research could be the path to the reduction of suffering from most diseases and disorders (including OI), could give hope to infertile couples, can be key in assessing the risk of contracting—and therefore controlling—life-threatening illness, and has the potential to provide a cure for all forms of cancer.

The legal, moral and ethical issues

associated with the human genome project are too complicated and diverse to address in this brief article. Visit [www.backbonemedia.org](http://www.backbonemedia.org) or [www.genome.gov](http://www.genome.gov) for further information.

## Where can I go to learn more?

Most major medical centers today have a genetics department, and virtually all medical colleges and research hospitals have significant amounts of staff dedicated to genetic studies. However, your primary care physician may be the best person to explain how the human genome project might impact your life specifically.

Medical geneticists or genetic counselors can provide information about heredity patterns. Genetic tests are also available to identify the specific mutation in a person with OI.

Finally, the human genome project has a website ([www.genome.gov](http://www.genome.gov)) that lists hundreds of links to affiliated organizations around the world, includes scores of publications written in layman's terms and available for download, and describes the entire project, its future implications to health and science, and its current and potential impact on society. You can request copies of their free primer, *“Genomics and Its Impact on Science and Society... The Human Genome Project and Beyond,”* by calling (865) 574-0597.

The OI Foundation also has limited resources available online and can answer questions via e-mail at [bonelink@oif.org](mailto:bonelink@oif.org) or over the phone at 1-800-981-2663. 

## Have you been to the OI Foundation website recently?

We're constantly updating our web site, adding new fact sheets and information resources. Since the last edition of Breakthrough we've added 3 new fact sheets, expanded our glossary and clinic directory, and published a new abridged bibliography of all the published works of our Medical Advisory Council. Be sure to stop by regularly to stay current on the latest news and information from the Foundation!

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

## Host a summer “fun” fundraiser

If you swim for exercise or pleasure, you can turn your time in the water into support for more than just your body weight. The Foundation has put together a “how to” package that tells you all you need to know to organize a swim-a-long so you and your friends and family can turn laps in the pool into support and awareness for the OI Community. For more information, call (301) 947-0083 or write to [jweiner@oif.org](mailto:jweiner@oif.org).

## Make your contribution a tribute

Any gift or contribution to the Foundation may be designated as an honorarium or memorial, to honor those you love. Each quarter’s tributes are printed in *Breakthrough*, and cards are sent to those being honored to inform them of your thoughtful contribution. To make a tribute gift to the OI Foundation, please include with your donation: your name and address and the name and address of the person you are honoring. For memorial gifts, please provide the name of the deceased and their family’s name and address. For more information, contact the Foundation or click on the “Donate Now” button on the website.

## CHOOSING A SITE *Continued from page 10*

like reasonable rates at an island resort in the San Diego Bay just minutes from the airport, unanticipated problems arise. The resort was built with a bungalow concept, meaning attendees would have to travel as much as a quarter mile from their rooms to the meeting rooms on picturesque—but brick or cobblestone—paths. It was simply not accessible to our guests.

Once the proposals have been weeded down to two or three per city, the Foundation asks local community members to conduct a site visit. When possible, a staff member combines a site visit with other Foundation business to the city and arranges to tour all the potential sites in a weekend, as well.

The cobblestone paths weren’t an obvious problem until a site visit to San Diego was conducted. Nor was the fact that half the meeting rooms in another “perfect on paper” convention center were accessible by only one small elevator or two escalators. While fully ADA-accessible in the legal sense, it would have been a nightmare for moving people between sessions.

Therefore site visits are an absolute necessity. Foundation staff members and volunteers comb through potential sites with tape measures, hotel management, and five-page checklists to ensure nothing is left to chance. Since canceling a contract can cost tens of thousands of dollars, in the two previous examples they saved the Foundation from making very costly mistakes.

The final step, once the site selection and visits have been

## ***Intimidated talking to your doctor? Help is available from the Foundation.***

The OI Foundation recently published three new fact sheets to help you work with your health care team. The first is a reprint of “Bringing Out the Best in Your Healthcare Team” from the National Health Council’s “You Call the Shots” educational program, detailing how and why you should take charge of your health care regimen. The second two fact sheets are entitled “Talking with Your Orthopedist” and “Talking with Your Doctor,” and include listings of typical questions that you should ask to ensure you understand—and are in a position to take charge of—your health care.

The fact sheets are available by calling or writing the Foundation, or can be downloaded from the website at [www.oif.org/FactSheets](http://www.oif.org/FactSheets). Bulk reprints are available upon request, and the NHC site has additional relevant resources including “Take Charge of Your Insurance,” at [www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org).

See “Asking Questions” on Page 24

conducted and the board has decided on a location, is contract negotiations. The original contract offered by the Adams Mark was five pages long. The Foundation’s counter-proposed contract was 27 pages. The final result, after numerous conference calls, faxes, and conversations with lawyers on both sides, ended up right at twenty pages.

“Everything is negotiable, and everything is contracted” Bradner said. “From how many towels in each room to where the remote is placed by the maids to whether or not door stops will prop open heavy doors throughout the complex. We negotiate basic room rates, amenities, audiovisual requirements, reduced portions on meals for our smaller guests, and even negotiate who pays to have a lift placed in the hotel swimming pool or to have more disability spaces painted into the parking lot.”

“If it’s done right, we know *today* exactly what will be provided and how much it will cost two years before the event actually takes place,” he said.

Writing that kind of detail into a contract takes willing compromises from both sides, and time.

“We’re absolutely confident that the Adams Mark will be an ideal site in 2004, and are already working with hotel staff to make the conference successful,” Shapiro said. “Now work begins on designing another fun, educational program for the community that surpasses 2002.”

Work has also already begun on another conference project: finding a site for the Foundation’s 2006 National Conference. 

## Foundation continues funding for two research projects, funds new fellowship

The OI Foundation Scientific Review Committee and the Board of Directors agreed to award continued funding for two fellowships in OI research and one new fellowship for the 2003-2004 fiscal year. Approved for funding were:

**Anna Bielli, Ph.D.**, University of Pittsburgh, Pittsburgh, PA. Second-year William G. McGowan OI Research Fellowship; for “Phosphoinositides as Regulators of COPII Mediated ER Export.”

**Zana Kalajzic, M.D.**, University of Connecticut Health Center, Farmington, CT. Second-year Michael Geisman Research Fellowship; for “Transportation of Osteoprogenitor Cells into Murine Models.”

**Anton Persikov, Ph.D.**, University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School, Piscataway, NJ. New Michael Geisman Research Fellowship; for “Bioinformatics and Peptide Approaches to the Molecular Basis of Osteogenesis Imperfecta.”

**Bielli's** work, now entering its second year, focuses on the formation of proteins within cells and how those proteins are exported for use in the body. Severe forms of OI are caused when the cell creates and exports deformed collagen proteins that cannot function properly. In the future, it may be possible to address mistakes in the cell's export process to prevent dysfunctional collagen proteins from impacting the body, therefore preventing the most severe forms of OI.

**Kalajzic's** project continues to focus on a problem that relates directly to potential treatment for OI. Using a mouse model, Dr. Kalajzic is examining the way that bone producing cells work when transplanted. She continues to search for the optimal conditions needed for effective transplantation. This work may result in genetic therapy coupled with bone marrow transplantation as a method of treatment for OI.

**Persikov's** new study is designed to examine mutations in the genetic structure of collagen. It is thought that certain areas in the collagen molecule are more stable than others, and that

any irregularity in these stable areas can develop into a more severe form of OI. Dr. Persikov's work will test this idea, and will attempt to clarify how changes within specific areas of the collagen molecule translate into different severities of OI. The results may develop into new treatment methods for OI.

Two additional projects that seek new treatment strategies and a greater understanding of OI await a funding decision. They are:

**Donna King, Ph.D.**, Northeastern Ohio Universities College of Medicine,

*Continued on Page 13*

### Foundation announces two research meetings to sharpen future strategies

The OI Foundation is pleased to announce two new scientific meetings on OI. These meetings bring together the best and the brightest researchers to look at what we know, what we need to know, and where we can go with shared information and resources. The result is a clear map of where to focus research efforts in the coming years and how to reach our goal of better treatments and a cure for OI.

*New Research Strategies in OI*, chaired by Leon Root, M.D., Adele Boskey, Ph.D., and Cathleen Raggio, M.D., will be held at the New York Hospital for Special Surgery, October 17-18, 2003.

This meeting has been expanded to two days to cover multiple research and clinical issues related to all aspects of OI, with a focus on bone biology, genetics, new therapies, and new clinical applications.

*New Strategies in Type I OI*, chaired by Peter Byers, M.D. and Michael Whyte, M.D., will be held in Chicago, IL in Spring, 2004.

This meeting, the first to focus solely on Type I OI, is being funded by the family of a child who has Type I OI. The focus will be on what is known, what strategies should be followed to find treatments and a cure, and how these strategies may differ from those for Types II, III or IV. 

## Scientists share data, identify areas for future research

More than 100 researchers from around the world presented information in forums, lectures, poster displays and round-table discussions, at the 8th International OI Research Conference, while meeting with their peers to share published and unpublished findings.

Highlights from the various presentations include:

**Pain:** A study from France found that 80-85% of children with OI reported chronic daily pain. This pain was most often in the back or at the site of old fractures. Pamidronate treatment seemed to significantly reduce the perception of chronic pain. According to reports, acute pain from a new fracture tended to be undertreated by the medical community.

**Fatigue:** Work done in the Netherlands related fatigue to low aerobic exercise capacity in people with Type I OI. In this study, people with OI Type I had reduced lung capacity and performed a limited amount of aerobic exercise, which contributed to fatigue.

**Dental:** Two studies from Scandinavia focused on dental issues. A group from Finland reported that OI affects the development of teeth, as well as bone in the skull and neck. People with OI were found to have difficulties in eating, problems with temporomandibular (jaw) joints and soreness of the chewing muscles.

A group in Sweden compared teeth in people with dentinogenesis imperfecta (DI), people with OI plus DI, and people with OI but with no signs of DI. They found that the dentin of people who have OI but have no clinical signs of DI was clearly abnormal. The researchers suggest that investigation of dentin may, in the future, be useful in diagnosis of OI.

**Hearing:** Three presentations focused on hearing issues and OI and

## International research conference attended by 110 scientists

*By Mary Beth Huber  
OI Foundation Info. & Resource Dir.  
& Bonnie Landrum, M.D.  
OI Foundation Member & Volunteer*

Every 3 years researchers from all around the world hold a conference to increase understanding of osteogenesis imperfecta. The purpose is to bring each other up-to-date on published and unpublished research findings, discuss best practices for medical and surgical management of OI and identify promising areas for future research.

The latest conference, the 8th International Conference on Osteogenesis Imperfecta, was held in Annecy, France, August 31-September 3, 2002. It was attended by 110 scientists and clinicians from 22 countries.

As in past years, the OI Foundation was a sponsor, and many members of the Foundation's Medical Advisory Council—as well as Foundation research grant recipients—were participants.

This international conference is a very important opportunity for doctors, scientists and clinical researchers to share the latest information about OI. It encourages collaboration and quickens the pace of research.

The discussions and presentations were organized around 5 themes: Fundamental Aspects (molecules, genes, and genetics), Classification and Diagnosis, Medical Management, Orthopedic Management and Rehabilitation, and New Perspectives. Important topics within these broad themes included bisphosphonates, prospects for cell and gene therapies and rehabilitation.

The program closed with a presentation that urged physicians to take a greater interest in the psychosocial aspects of living with OI. Problems linked to brittleness, daily unpredictability, and pain impact family relationships, access to education, and mental health.

The psychosocial needs of people with OI significantly impact traditional areas of physical health and medical management. It was recommended that all physicians become more knowledgeable about the resources in their countries that can address these issues.

*The 9<sup>th</sup> International meeting will be held in the United States in 2005. Dr. Joan Marini (NIH) and Dr. Cathleen Raggio (Hospital for Special Surgery, New York City) are chairing the organizing committee.* 

indicated that the problem is more prevalent and complex than previously thought. A study from the United States reported a detectable hearing loss in 46.2% of children with OI age 6-19 years. This is significantly higher than the 14.9% prevalence found in a survey of otherwise healthy American children.

Presentations from Finland and France focused on the use of stapes

surgery to correct hearing loss in people with OI. Both studies found there were unique challenges due to the poor quality of the stapes footplate. Outcomes for the surgery were reported to be less satisfying than for people from the general population and varied with OI type and bone quality. They concluded that a surgeon with OI

*Continued on Page 14*

## Stem Cell Research receives five new NIAMS grants

Five new grants funded by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health will focus on using adult stem cells to treat bone and muscle that may have been altered by disease.

Scientists are also looking at how stem cells may regenerate or repair these tissues.

“Research on stem cells is important in the search for prevention and cure of debilitating musculoskeletal diseases,” said Stephen I. Katz, M.D., Ph.D., director of the NIAMS. “These studies will have a solid impact on a variety of diseases.”

Two of the new studies specifically address osteogenesis imperfecta. David Rowe, M.D., University of CT School of Medicine, Farmington, CT, and a member of the OI Foundation’s Medical Advisory Council, is conducting a study on programmed cell activity using the Brl mouse.

“Development of a GFP Sensitive Apoptosis Marker Gene” will follow

programmed cell activity— specifically, the life and death of a cell— and show how that activity generates a form of stem cells that are a factor in maintaining adult bone mass.

“Stem Cell Therapy for Diseases of Bone in a Mouse Model,” by Christopher Niyibizi, Ph.D., University of Pittsburgh, PA, uses a mouse model of osteogenesis imperfecta to evaluate possibilities of regeneration or repair of bone marrow using mouse stem cells.

Niyibizi is continuing research begun with an OI Foundation Michael Geisman Research Fellowship.

All five studies will help further research into treatments or a cure for OI by promoting better understanding of how cells affect bone growth, bone mass and bone regeneration.

The other three new grants are described below:

“Matricellular Proteins and Mesenchymal Stem Cells,” Kurt D. Hankenson, D.V.M, Ph.D., University of MI, Ann Arbor. This study investigates the growth factors and hormones

that influence how stem cells develop, which should guide the development of therapies in bone diseases.

“Muscle Regeneration Through Stem Cell Transplantation,” Johnny Huard, Ph.D., Children’s Hospital of Pittsburgh, PA, University of Pittsburgh Medical Center Health Systems. Stem cells are sometimes used in the body for regeneration. This study further examines the potential of stem cells from muscle for treating problems of musculoskeletal structure.

“Epidemiology of Connective Tissue Progenitor Populations,” George F. Muschler, M.D., Cleveland Clinic Foundation, Cleveland, OH. This study examines how musculoskeletal stem cells contribute to the repair and remodeling of connective tissue. 

*For more information about NIAMS, call the information clearinghouse at (301) 495-4484, toll-free at (877) 22-NIAMS, or visit their web site at [www.niams.nih.gov](http://www.niams.nih.gov).*

### SEED GRANTS AWAITING FUNDING (Continued)

Rootstown, OH. Seed Grant pending; for “Anabolic Therapies for OI.”

**David Rowe, M.D.**, University of Connecticut Health Center, Farmington, CT. Clinical Seed Grant pending; for “Complementation of Anti RNA Vectors for OI.”

**King’s** project looks at two different therapies for the treatment of OI using a mouse model, but with a clear goal of a future application in children. Her hypothesis is that both therapies will result in the increased production of bone forming cells, and therefore a greater amount of bone will be produced. One strategy examines the use of synthetic steroids and one observes the effects of growth hormones. The

results of these experiments will be analyzed by measuring bone density, architecture, quality and performance.

**Rowe’s** work proposes a way to stop the production of deformed collagen by “turning off” the gene that produces it. If successful, this work would have a broad application beyond treatment for OI. OI is often seen as a good example of other inheritable genetic disorders of connective tissue, and it is possible that Dr. Rowe’s findings may play an important role in changing the future for an entire class of genetic disorders.

The OI Foundation looks forward to funding these studies as soon as possible. 

**Visit**

**WWW.OIF.ORG**

→ View the webcast from the 2002 Research Update presented by Drs. Marini, Glorieux and Baron at the National Conference.

→ Learn about the on-going bone marrow, bisphosphonate, and pamidronate studies.

→ View our on-line clinic directory or download fact sheets on a variety of research-related subjects.

→ **Support OI Research with an online donation!**

# RESEARCH UPDATE

## HIGHLIGHTS FROM INTERNATIONAL RESEARCH CONFERENCE (Continued)

experience made it more likely that stapes surgery would be successful.

**Gene and Cell Therapies:** A group from the United States, led by Dr. Darwin Prockop\*, reported on important developments in their work to develop a treatment for OI based on the use of adult stem cells from bone marrow stroma (referred to as mesenchymal stem cells).

A group from Ireland reported on progress in developing a tool for gene therapy for OI.

The model for the potential benefits of cell therapy is mosaicism. This occurs when a person does not have any signs of OI, but carries an OI related mutation in some of their cells.

A study directed by Dr. Joan Marini\*, from the U.S., reported progress in identifying the ratio of normal to mutant cells that allows the person to be free of OI symptoms.

**Genotype/Phenotype:** Discussions indicated that many elements are still missing from our understanding of what is seen in the gene (genotype) and what is seen in the living person (phenotype). Different studies suggest that additional genes beyond the two type 1 collagen genes that have already been identified may contribute to the severity of symptoms seen in people with OI. The location of the mutation on the gene may also have more importance than previously thought.

**Bisphosphonates:** A round table discussion on bisphosphonates was led by Dr. Francis Glorieux\* from Canada and Dr. Meunier of France. The discussion reviewed what is known about how bisphosphonates, especially pamidronate, act on bone and bone modeling. Progress reports for the ongoing bisphosphonate trials were given.

Dr. Marini's\* trial at the National Institutes of Health in the United States is in the process of doing an 18-month interim analysis. This trial is a randomized, controlled trial of pamidronate and growth hormone.

Results from a French controlled, double blind, randomized, placebo trial of alendronate in adults with OI are expected in autumn, 2003.

The Shriners study, a double blind trial of alendronate in 139 children, was nearing completion. Results are expected in summer, 2003.

A new trial comparing zoledronate to pamidronate in multiple centers is planned to begin in summer, 2003.

The rest of the discussion focused on current unanswered questions.

These include:

- When to start and stop?
- What are the long-term effects on growth? On bone?
- What are the long-term side effects?
- Should bisphosphonates be combined with other therapies

such as growth hormone or parathyroid hormone?

Dr. Fassier, from Canada, provided an overview of orthopedic management in the era of bisphosphonates. Based on his experience, he found that bisphosphonate treatment impacted many aspects of orthopedic management of children with OI. While there was less need for rodding surgery in babies, more of the older children were capable of walking and thus needed rodding surgery.

Over the last several years there was an increased need to correct deformities of the arms in children receiving bisphosphonates. Long-term effects of bisphosphonates in the orthopedic management of OI are yet to be described.

He stated that he had observed a few cases of delayed union of osteotomy sites, but it is not yet possible to determine whether surgical technique (how the bone was cut), mechanical stability with intramedullary rods, anatomic contact between bone ends or bisphosphonates are the cause.

Dr. Fassier concluded by stating that efforts should remain targeted on reducing postoperative complications through the development of improved rods, less invasive surgical techniques and increased understanding of the effects of treatment on bone. 

*\* A member of the OI Foundation's Medical Advisory Council*

### **Progress depends on your support...**

The potential for progress in OI research is growing faster than the Foundation's ability to fund promising projects. Researchers are exploring every avenue that could lead us to effective treatments and a cure.

Each spring the Foundation conducts a research appeal for donations 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 everyone living with 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. If your friends, relatives or acquaintances have expressed interest in OI research, please let us know so we can send them a research update.

To the thousands of people 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. 

## Communications suggestions for those with hearing loss:

Even with the best-fitted hearing aids, there will be times when you misunderstand what someone has said. To minimize the frustrations that may occur when this happens, try the following:

- Minimize noise distractions. Noisy areas can create difficult listening situations, even for those with normal hearing. When possible, turn off competing sound sources (T.V., radio, dishwasher, running water, etc.) or move away from the sound source. If your hearing aids have directional microphones, position yourself so that sound distractions are behind you.
- Strive for a clear view of the speaker's face. An optimal distance for communication exchange is three to six feet. Position yourself so that the speaker's face is well lit and so that the light is not in your eyes. Watch the speaker's face for expressions and lip movements that can add to the meaning of what you hear.
- Do not say "Huh?" or "What?" Tell the speaker why you misunderstood so that the message is not repeated in the same fashion. For example, "Please raise your voice a bit," or "Please repeat that a bit more slowly." As a courtesy to your speakers, provide guidance so that they do not need to repeat the full message. For example, "What time did you say you were going to visit your sister on Saturday?" This requires a much briefer response than "Huh?" would.
- Write out important information. Instructions, or key words such as addresses, telephone numbers, measurements, dollar figures and so on, should be written down to avoid confusion.
- Do not bluff! Bluffing robs you of opportunities to practice good communication skills. Not informing others about your hearing loss increases the occurrence of misinterpretations and the possibility of damaged relationships.

## Suggestions for speaking to someone with hearing loss:

Hearing aids, while very helpful, may not solve all communications problems. When difficulties persist, try these suggestions:

- Get the listener's attention first, before you speak. Saying the person's name and waiting for a response can decrease the need for repetitions.
- Speak clearly and decrease your speech to a slow-normal rate to allow the listener to "catch up." Pausing between sentences can be helpful. The best distance for effective communication is three to six feet.
- Do not shout. Shouting can actually distort the signal in the listener's ears. Be sure the listener has a clear view of your face so that your facial expressions and lip movements are visible, and speak slightly louder than normal.
- Rephrase rather than offering a repetition. Quite often, the same one or two words in a sentence will continue to be misheard with each repetition. Rephrasing eliminates many frustrations.
- Avoid conversation if the television or radio is playing, the dishwasher is running, and so on. Noisy distractions can create difficult listening situations even for those with normal hearing. Always invite the person with a hearing loss to a quieter side of the room, or turn off the noise distractions.
- Remain patient, positive and relaxed. Communication can be difficult sometimes. When partners become impatient, negative and tense, it will become more difficult. When in doubt, ask the person with the hearing loss for suggestions of ways to be better understood.

*Reprinted with permission from Hearing Loss, The Journal of Self Help for Hard of Hearing People, copyright 2003. For more information or assistance with hearing-related issues, visit their website at [www.hearingloss.org](http://www.hearingloss.org). *

### **A designated gift helps provide services for the hearing impaired to members of the OI Community.**

A generous gift to the Foundation is designated to provide services for people who have OI-related hearing loss. The funds have already been put to use developing a hearing loss fact sheet, providing CART (computer-assisted real-time translation) service for 2002 National Conference sessions and close-captioning two webcasts (*Research Update* and *Becoming a Paralympic Athlete*). CART service allows participants to read the text of a lecture on a computer screen.

In future, the funds will be used to provide CART or other hearing assistance services for support group meetings and during the 2004 National Conference. For more information about making designated gifts or about OI-related hearing loss, contact the OI Foundation at (301) 947-0083 or [bonelink@oif.org](mailto:bonelink@oif.org). 

college financial aid, vocational rehabilitation services, and other sources of support. Please return your comments by October 30, 2003 to:

Dr. Gerrie Hawkins  
Youth Advisory Committee  
National Council on Disability  
1331 F St., NW, Suite 850  
Washington, DC 20004  
Fax: (202) 272-2022  
E-mail: [youthfeedback@yahoo.com](mailto:youthfeedback@yahoo.com).

## Plan now for the next school year

Even though summer vacations are just about to begin, parents of school-aged children and college students need to be thinking ahead to the fall. Obtaining special education services for your school-aged child is an involved process that may take months. For a primer on what services and assistance is available and information on where to go for support, check out the education fact sheet on the Foundation's website at [www.oif.org/educat](http://www.oif.org/educat). (Under the "Living with OI" or "Parents" menu buttons.)

The Foundation also has a number of videos, pamphlets and resources available through the website or by contacting our offices to make the transition to mainstream school successful. These resources can be ordered through the online store in bulk, downloaded directly from the website, or requested by writing to [bonelink@oif.org](mailto:bonelink@oif.org).

## Resources are available for college students online

For students entering or returning to college, the "Colleges and Careers" and "Living with OI and Succeeding" webcasts are two valuable resources to read or review now, while there's still time to implement some of the suggestions to make the transition to college smoother. The webcasts are

accessed from the "Fact Sheet" page at [www.oif.org/FactSheets](http://www.oif.org/FactSheets).

Older students might also want to visit the "Adults" page ([www.oif.org/Adults](http://www.oif.org/Adults)) on the website for tips on flying or travel if they plan to attend a school away from home.

## Learn from others in the online OI community

For both parents of school-aged children and young adults going off to college, it might be very beneficial to log onto the website any Sunday evening, from 7-11 p.m. EST, and join one of our on-line chats. The chat rooms are populated by members of the OI Community and OI Foundation volunteers, and are a great way to get first-hand tips and suggestions from those who've "been there and done that" and have already learned a few lessons about making the transition to school successful. The chat rooms are also a great way to find new friends and build a support structure that will be available no matter where your

future plans might take you.

The chat rooms are usually busiest between 8-10 p.m.; visit [www.oif.org/chatpostandIM](http://www.oif.org/chatpostandIM) for more details.

## Wheelchair transportation study needs input

If you use a wheelchair and sit in it while riding public buses, and if you can complete a survey on the Internet or have a family member or personal assistant help you complete it, we have an opportunity for you! The University of Pittsburgh is investigating the real-world usage patterns of wheelchair transportation safety equipment on public buses, and would like your input.

To participate in the study, you must be eighteen years of age or older, sit in your wheelchair while riding public buses, have access to the Internet, and live in the United States. If you would like to participate or would like more information about this study, go to [www.wheelchairnet.org/survey/bus.html](http://www.wheelchairnet.org/survey/bus.html).

## Help the Foundation make the Clinic Directory as complete as possible

The OI Foundation's Clinic Directory is a comprehensive listing of multi-disciplinary clinics and hospitals in the U.S. and Canada that have experience in treating persons with OI. It covers all Types and age groups, and includes an easy-to-use comparison chart that lists each clinic's available services.

The Directory is published annually in the Summer issue of *Breakthrough*, and is available online on our website.

We would like your help to make this Directory as accurate and

complete as possible. If you know of a hospital or clinic that provides services to the OI Community that is not currently listed in the Directory, please contact the Foundation, or have a staff member at the clinic contact the Foundation, no later than June 30, 2003.

Before a clinic can be added to the directory they must complete a short clinic survey and return it to the Foundation offices.

Clinics are added to the online version of the Directory throughout each year as they're verified. 

**Visit [www.oif.org/ClinicList](http://www.oif.org/ClinicList) to make sure your clinic or hospital is listed, or to refer a clinic for inclusion.**

## VOLUNTEER AWARD NOMINATIONS *Continued from page 1*

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

We are now calling for nominations for the 2003 Volunteer of the Year. Please consider nominating an individual that you feel has made particularly significant contributions to the OI Foundation in the past year. To nominate someone, send the following information by fax, mail or email to the Foundation by July 11:

✓ Name, address and phone number of nominee.

✓ Your name, address and phone number.

✓ Description of the nominees volunteer activities.

✓ Total number of hours spent in volunteer service to the Foundation (estimated).

✓ Number of years actively involved with the Foundation.

✓ Description of how the nominee's volunteer activities have benefited the OI Foundation and people living with OI.

Sent the information to:

The OI Foundation  
VOY Nominations  
804 W. Diamond Ave. Ste. 210  
Gaithersburg, MD 20878  
Fax: (301) 947-0456  
Email: [bonelink@oif.org](mailto:bonelink@oif.org) 

## Web Spots

### Useful or informative sites for the OI community

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

**American Association of People With Disabilities**  
[www.aapd-dc.org](http://www.aapd-dc.org)  
(Page 5)

**Backbone Media (The Human Genome Project)**  
[www.backbonemedia.org](http://www.backbonemedia.org)  
(Page 9)

**Greater Good .com**  
[www.greatergood.com](http://www.greatergood.com)  
(Page 4)

**The Human Genome Project**  
[www.genome.gov](http://www.genome.gov)  
(Page 9)

**The National Health Council**  
[www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org)  
(Page 10)

**National Institute of Arthritis and Musculoskeletal and Skin Diseases**  
[www.niams.nih.gov](http://www.niams.nih.gov)  
(Page 13)



**National Institutes of Health Conference on Disabilities**  
[www.physicaldisabilities.iqsolutions.com](http://www.physicaldisabilities.iqsolutions.com)  
(Page 5)

**Self Help for Hard of Hearing People**  
[www.hearingloss.org](http://www.hearingloss.org)  
(Page 15)

**University of Pittsburgh Wheelchair Transportation Study**  
[www.wheelchairnet.org/survey/bus.html](http://www.wheelchairnet.org/survey/bus.html)  
(Page 6)

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

## Previous OI Foundation Volunteer of the Year Award Recipients

1990	Frances Dubowski
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**Congratulations... and Thank You for Your Support!**

## Watch Your Mailbox!

The 2003 Research Appeal is underway, and should be arriving in your mailbox in the coming weeks.

Please consider carefully how important this appeal is to the future of OI research, and to the quality of life for people affected by OI.

This year the appeal will be sent via e-mail, as well, to make it easier to share with your friends and relatives.

Reprints of the appeal are available by calling or writing the OI Foundation (see page 2), or can be downloaded from the website.

## Wheelchair tennis competitor strengthens bones on and off the courts

Chris Lamoreaux was born in Denver, Colorado. He believes he was born with 9 fractures. He lived in Denver with his mother until he was 6 years old, then they moved to Hopkins, Minnesota, where they lived through his high-school years.

While growing up, Chris' parents pushed him to do things on his own and to test his own limits. He credits their support and encouragement with his development.

"If they hadn't pushed me... to get in and out of bed on my own, climb stairs, walk on a walker, push my chair on my own, get in and out of the bathtub, etc... I definitely would not be as independent as I am today," he said.

Pushing the limits wasn't always the safest route for Chris. He played wheelchair basketball for approximately 10 years during his childhood.

"I finally realized that it was a pretty stupid idea for me to play basketball when I was around 18," he said. "I don't think I went through many seasons without breaking something."

"But, I'm still glad I played," he admits. He learned a lot through the competition and made life-long friends on the court.

Chris decided that wheelchair tennis might be safer, and began playing tennis at age 13.

"I think I played in my first tournament around age 16 or 17," he said, "in Minnesota."

Even though tennis is less of a "contact" sport, Chris still managed to break two bones during competition.

"But, that doesn't stop me from playing," he said. "I've played off and on, sometimes competitively, ever since I picked up a racket."

Chris graduated with honors from high school in '96 and started college at Tufts University, in Boston, MA. Going so far to college was just another challenge to overcome, and one he welcomed.

"I truly loved college," Chris said. "I was finally independent. My parents support and my hard work while I was growing up finally paid off. I lived in the dorms and lived a normal college student lifestyle."

He thrived in the college environment, but that was no real surprise to his friends and family back home. Throughout most of Chris' life, he forced OI to take a

"back seat."

"I try not to let the fact that I have OI bother me, nor do I let it get in my way... except where it's obvious and can't be helped."

He pursued a degree in Mechanical Engineering at Tufts. At the end of his freshman year, the disability coordinator at the university gave Chris a pamphlet describing an internship available with the National Air and Space Agency (NASA).

The program was called Entry Point, made possible through the American Association for the Advancement of Science.

"The internship is specifically targeted at students with disabilities who want to get into a technical field," Chris said. "So I took the opportunity, and applied for the internship."

Chris interned at Johnson Space Center (JSC) in Houston, Texas, for the first time during the summer of 1998. While there, he applied to the co-op program at the JSC and came back to intern again during the spring and summer of 1999.

The hard work as an intern paid off.

"I graduated *summa cum laude* from Tufts in the summer of 2000, and started my full time position at Johnson Space Center in September of 2000."

Chris has been working in Houston ever since, and lives in Webster, TX. Currently, he's an engineer on a project to build a new weightlifting machine for the astronauts aboard the International Space Station.

"The lack of gravity weakens bones by preventing weight-bearing exercise," Chris explained.

"Strengthening bones is something I can be proud to be a part of."

Chris didn't play a lot of tennis during college. The Collegiate wheelchair tennis circuit had just started up during his senior year, and he only played that one year.

"Since I started working, I've been more financially able to pursue tennis as a hobby," he said.

He's participated in a handful of tournaments each year and wishes there was more of a wheelchair tennis program in Houston.

"Regardless of whether I'm playing in competition or just for fun, in work and play I'm doing what I can to build stronger bones—for myself and my colleagues." 



*Chris Lamoreaux on the courts.*

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# CONTINUED...

## ASK QUESTIONS *Continued from page 24*

### Keep a journal

The easiest way to ensure you're receiving the best quality care is to keep a medical journal. This is meant to supplement your medical records with your own personal notes and observations about your change(s) in health. Take the notebook to every appointment with every doctor or specialist, and take notes during any conversations you have with any member of his or her team. Jot down instructions, questions to ask other specialists, and any suggestions they offer for changes in your health care regimen. Refer to the book before each appointment to refresh your memory, and to develop a list of questions to ask the doctor or nurse at your appointment.

Between visits, make notes about how you feel, how the changes in medication or exercise

are affecting your health and progress, and questions about any new or different potential treatments you've encountered. You might think you'll remember that weird feeling in your back during your physical training when you see your therapist again, but when you're in the middle of an exam room trying to remember all the new instructions you're receiving, it quite possibly will slip your mind.

Having a medical journal with you...and asking the doctor to wait a moment while you flip through it... could make a big difference in your long-term medical care plan.

### Ask Questions

It's often intimidating, in the sterile environment where you're the patient and the doctor is the expert, to ask your own questions. It's imperative that you do so. When it comes to your health, there's no such thing as a dumb question. There is, however, a smart way to ask questions. Having a list prepared, and space to jot down answers, will make the process easier on you and your doctor. Be sure to listen to the answer completely. Don't make the mistake of scanning the list for your next question while the doctor's still talking; you may miss something important.

If the doctor doesn't have time to answer a long list of questions, ask if there's a nurse or other specialist who can take a few minutes to respond. Alternatively, if you have a good working relationship with the doctor, ask if you can fax or email your questions in advance. Be sure to have your journal open during the visit, and review the questions while you're in the waiting room. Your doctor will probably answer most of your questions before you ask.

### Research

Spend time talking with other families facing (or who have faced) the same problems. Join a support group, surf the internet for qualified information, read appropriate medical journals and magazines. Specialists tend to focus on their particular specialty, and general practitioners have more relevant information thrust upon them daily than they could ever hope to retain.

It is possible that you'll introduce your health care team to a new concept, treatment plan or procedure that they

weren't aware of. Again, a good set of notes in a journal, including a list of sources, might give your health care team new insight into your specific health care plan.

Remember, it's

human nature (and often healthy!) to be skeptical and resistant to change. Give your health care team time to do their own research if you've truly come up with something new. Make plans to discuss the idea at a later date, when they've had time to look into it.

### Respect

While "respect your elders" and "the doctor is the expert" are the very tenets that might hold you back from asking questions and taking charge of your own health care, they're still true. You must respect the doctor and his expertise... even while you're asking questions about the care they've recommended. By asking intelligent, thoughtful questions and listening to the answers, you shouldn't offend anyone.

If you share your complete health care plan with everyone on the team, keep an accurate and organized journal, exhibit trust and recognize that their time is valuable, too, they'll understand you're serious about your health care. In most cases they'll be willing to spend more time with you as you become more involved.

If you interrupt with queries that insinuate you're smarter than the health care professionals, ask questions they've already answered, demand that they stop and respond to a laundry list of questions and irrelevant symptoms, you're not helping anyone, including yourself.

A good leader can lead without those being led ever knowing they've been led.

It is your health, your health plan, and your health care team. Lead it well. 

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*It's often intimidating, in the sterile environment where you're the patient and the doctor is the expert, to ask your own questions. It's imperative that you do so.*

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## Runner completes 1st marathon in landmark year

by Marie Hassett  
OI Foundation Member

Last year, I celebrated my remarkable 36<sup>th</sup> birthday. 36 is not an age that most people see as special, but for me, it was huge: for the first time in my life, I was older than the number of bones I had broken. Four months later, in honor of this milestone, I ran my first marathon.

I have Type I OI, and most of my thirty-six fractures were the result of accidents. In fact, I remember going to my orthopedist once with a broken wrist, and having him tell me, “Well, anyone could have broken a wrist this way—you just happened to break clean through.” As most people with OI know, it’s something of an achievement to know that the disease itself is not entirely responsible for the state of your skeleton.

I’m sure that many other people with Type I have broken fewer bones just by being more cautious than I have been for much of my life. But I wouldn’t trade places with them for a minute. Bones heal; a lack of daring can permanently cripple your soul. My challenge has been learning when daring is a way to grow, and when daring is a needless risk that creates suffering for me and for my family.

My last broken bones (five at once, a record for me) were the result of a rollerblading accident.

Yes, that’s right, the girl with OI decided it would be a good idea to try inline skating. It was the first time I’d ever broken a bone while I was out by myself, and it offered me proof of the old saying that God watches over fools and small children: I fell directly across from a softball field where the Massachusetts General Hospital Orthopedic Nurses team was playing. No kidding. That’s a level of triage you can’t get in many hospitals, never mind large municipal parks.

I met my current orthopedist as a result of this injury. He came out of surgery to talk to my husband and started yelling at him, wanting to know why he’d *let* me get on skates. Ben, exhausted and worried, said, “YOU try to tell her not to do something she’s decided to try!” Dr. C took him at his word. He told me in no uncertain terms that I was never, ever to get on skates again. Given my condition,

I was a pretty easy sell.

A year after that accident, I decided to start running. It seemed like a relatively safe sport (no wheels), with a minimum of training and equipment necessary. I mentioned this at an appointment, and asked Dr. C how much running was safe. Ever the pragmatist, he said, “If it hurts, stop.” I thought this would be easy advice to follow. And it was, for a while.

I don’t know exactly when I decided that I wanted to run a marathon. I’d been running for almost four years, an average of 12-18 miles per week. I entered local races a couple of times each year. I could have continued that way indefinitely, but my natural appetite for big challenges eventually led me to the biggest of running challenges; the marathon; 26.2 miles. I went back to Dr. C, and asked him if a marathon was a reasonable goal. He said he didn’t see why not.

I gave myself nine months to prepare. That’s far longer than a typical marathon training program (usually 18-24 weeks), but I wanted to have enough time to build my mileage gradually. Most coaches recommend a minimum of 30 miles per week for at least 10 weeks prior to the race, and I didn’t want to increase my mileage so dramatically that I ran the risk of a stress fracture.

So, starting from my base of about 12 miles per week, I focused on upping my mileage every week, through the spring and summer, and on into the fall. I would be running a January marathon, which meant training in the cold of an early New England winter, but I figured that I’d be tough enough to handle a little cold by the time November rolled around.

When I got to about 20 miles per week, I began to recognize that Dr. C’s advice (if it hurts, stop) would be more complicated to follow than I’d originally thought. Like most people with OI, I associate pain with injury. Having never trained for an athletic event in any serious way, I was unfamiliar with the kind of pain that is really your body’s way of adapting to new demands. When I woke up in the mornings sore and stiff, when I found myself limping a little



Marie Hassett has Type I OI. She successfully completed her first marathon at age 36 after more than nine months of training.

*Continued on Page 22*

## CORNERSTONES

for the first hour of the day (past broken ankle, you know), I drove myself crazy worrying that I wasn't going to be able to keep going.

A couple of things helped me to get past my fear. First, I read everything I could about marathon training to make sure that I wasn't building up enough without pushing too hard. I also posted on running chat boards on the internet, to get the advice of more experienced runners and coaches. And of course, I combed the Web for information about OI and the effects of exercise.

One of the most interesting things I learned was that my naturally hypermobile joints could actually be a liability for running. Overly stretchy Achilles tendons, for instance, work against calf muscles that have tightened up from miles of running. For about a week, I thought I had tendonitis. The real problem was a too-large range of motion, keeping my heel from rising at the right point in my stride and aggravating the point where the tendon meets the calf muscle.

On the other hand, once I learned to distinguish between the pain of injury and the pain of effort, I knew I had an enormous advantage over many other first-time marathoners. As anyone who has broken multiple bones knows, orthopedic pain is the hands-down winner in the "severe pain" category. I figured, if I could make it through multiple fractures with a little Tylenol, some ice, and a heating pad, a few sore muscles were no match for my endurance.

Once I convinced my family that even my orthopedist said marathoning was safe for me, they became my biggest fans and supporters. Ben routinely showed up at the finish line of local races to scream my name, and he and my Aunt Barbara decided to go to Orlando with me for my marathon. They listened to me talk about running, training, diet, and famous runners ad nauseam, and managed never to look as bored as I'm sure they felt.

The race I chose was the Walt Disney World Marathon, for a couple of reasons. First, I love Disney, and thought it would be great to run there. Second, with Disney's history of handling huge crowds, I knew that the course would be properly staffed and maintained. And finally, I figured that after 26.2 miles, it would be great to high-five Mickey Mouse as I crossed the finish line.

I have a Disney CD from 2000, "Celebrate the Future," and I listened to it frequently when bad weather or travel meant I had to do my training on a treadmill.

We left for Orlando early on a Friday morning. The plan was to get to our hotel, then go to the race expo to pick up my number and t-shirt, then have dinner at Epcot. Because we took a *very early* flight, we were all up at 2:00 in the morning. By the time we got to the race expo at 3:00 in the afternoon, we were already tired, but so excited to actually be there that we didn't feel like napping. We had dinner reservations for 7:00, which gave us plenty of time to wander through the expo. I decided to stand in line for Bill Rodgers' autograph.

If you don't follow road racing, you may not know Bill Rodgers, Boston's marathon poster-boy. He won both the Boston and New York marathons four times each, and is one of the most successful American runners of all time.

That he is also from Massachusetts, and trained for his marathons on the same trails I ran when I lived in Boston, made it a kind of moral imperative for me to

talk to him. We had a nice chat when it was my turn, and he signed my race number: "To Marie, Congratulations on your 1<sup>st</sup> marathon! Bill Rodgers '03."

During the race that Sunday, at about mile 22, when a man

turned to me and said, "Please tell me we'll make it to the end," I said, "I have to—Bill Rodgers already congratulated me!"

We spent Saturday in Epcot, going on rides, taking photos with Mickey, Minnie and the gang, and eating pasta. The Disney marathon ends in Epcot, and I wanted to see that last mile before the race. I like being able to visualize the end when I'm tired.

We ate dinner at a restaurant in the Italy pavilion, and I entertained Ben and Barbara by pointing out all the people that I thought were runners, loading up on carbs before the big day. The race began at 6:00 on Sunday morning, and we were on the bus to the starting area at 3:30. Between



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*At about mile 22 a man turned to me and said,  
"Please tell me we'll make it to the end."  
I said, "I have to—  
Bill Rodgers already congratulated me!"*

---

the marathon and its accompanying half-marathon, there were over 15,000 runners, plus their friends and families. With a crowd like that, you need to allow extra time. I had to go to the staging area for the start line at 4:30; Ben and Barbara said they'd see me along the course.

While I was waiting for the race to begin, I had the chance to talk to lots of other runners. Disney is one of the races that supports Team in Training, the Leukemia & Lymphoma Society's fund-raising runners, and there were purple TNT t-shirts as far as the eye could see. I also met people from Joints in Motion, the team that raises money for the Arthritis Foundation.

But there were many unaffiliated runners also doing the race for specific causes. Some ran in memory of family and friends, some for the victims of 9/11. One woman ran for child abuse victims—she's a nurse, and works with those children at her hospital.

Someone asked me what I was running for, and I told them about my "older than bones broken" milestone. As I was explaining OI to them (they had never heard of the disease) I started to think about all of the other people I'd met and read about who have OI who would never be able to run a marathon, or who could, but wouldn't dare.

A very famous running coach says that the first ten miles of a marathon are

social, the second ten are an effort, and the last six are the ultimate physical and emotional test. He's right.

For the first ten miles, the sheer thrill of being there, after so many months of preparation, carry you along. By the time you get to that second ten miles, you're still happy, but the novelty has worn off with a long way left to go. And when you cross the twenty-mile mark, you're entering another world, where the only thing that counts is the next mile marker or water station.

You don't dare think of the finish line.

When I entered Epcot for the last 1.2 miles, I finally dared to tell myself, "You've done it—you're about to complete a marathon." I let myself think about all the

training I'd gone through, all the long weekend runs, all the days when I was tired and had too much work to do and couldn't imagine why I was taking time out to run.

And then I thought of all the people who'd said to me over the years, "It must be tough to be so *fragile*," and I tried to imagine them finishing a marathon. Not likely.

A few hundred feet from the finish line I heard my name. When I looked up, I saw Ben and Barb screaming and waving, pointing a camera in my face.

I think I started to cry then, but it's hard to remember.

Moments later, I was crossing the finish line, and Mickey Mouse really was there to high-five me.

I walked through the chute and let a race volunteer drape my finisher's medal (golden mouse ears) around my neck. I took the sports drink offered by another volunteer, and kept walking toward the family reunion area.

Ben spotted me first, and ran over to pick me up. "I'm so proud of you," he said, and I started to tear up again.

I finished the marathon in 4:30:42, the 3,465<sup>th</sup> of 9,404 finishers. That afternoon, and all the next day, I didn't walk; I hobbled. But I felt like I was walking on air.

I wore my finisher's medal until we left for the airport on Tuesday morning, and I enjoyed every "Congratulations!" I heard.

This fall, I will be running the Chicago Marathon. And this time, in addition to celebrating another fracture-free year, I will be running to raise awareness about OI. 



**Marie Hassett is greeted by Mickey Mouse as she crosses the finish line of her first marathon in the Magic Kingdom in Orlando, FL.**

*To learn more about exercise, participating in competitive sports, and safely improving your overall health through a physical fitness program, check out the OI Foundation's "Becoming a Paralympic Athlete" webcast, the "Exercise Interventions" cassette, and the "Therapeutic Strategies-- A Guide for Occupational and Physical Therapists" booklet. Visit our website at [www.oif.org](http://www.oif.org), write to [bonelink@oif.org](mailto:bonelink@oif.org), or call the OI Foundation at (800) 981-2663 for more information.*

## Asking questions & keeping a log can improve health care

Years of good upbringing may be affecting the quality of care you're experiencing from your medical support team.

According to recent studies by the National Health Council, most patients receiving regular healthcare rely on their medical professionals to dictate to them what they need to do to improve their general health or address specific health problems. People are conditioned to accept their doctor's word, since "they are the professionals," and are reluctant to ask questions or be actively involved in the development of an integrated health-care plan.

The National Health Council has recently published a series of advertisements, public service announcements and brochures encouraging people to take charge of their health. Titled "You Call The

Shots," the project encourages patients to ask questions, and become the "captain" of their health care team.

"Your doctors, nurses, and therapists all work for you," according to the National Health Council. "Of course, you need to cooperate with treatments they prescribe. But they can do their best for you when you step up and become an active player on your team."

This is especially true with disorders affecting smaller populations, like Osteogenesis Imperfecta. For many people with OI, chances are they were their pediatrician's or general practitioner's first exposure to the disorder. By taking control of your health care team, you can ensure you receive quality, integrated care and medical support.

Your doctor, regardless of how

knowledgeable he or she is about OI, does not always know what is being prescribed or proscribed by other specialists on your health care team. It's up to you to ensure every member of your team knows what's going on in other aspects of your overall healthcare plan.

Your nutritionist and cardiologist must know how much exercise your occupational or physical therapist has prescribed. Your general practitioner must know how and when your diet changes. Your orthopedist must know what medications you're taking.

While most doctors freely exchange such information, they at least have to know who to ask. You simplify matters greatly by offering the information first hand.

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