OSTEOGENESIS IMPERFECTA
OI
FOUNDATION
Unbreakable Spirit®

Breakthrough

VOLUME 39 NO. 1 SPRING 2013

Awareness Week 2013

Ask Me about My Unbreakable Spirit®

The OI Foundation's third annual National OI Awareness Week will be held from May 4-11, 2013. The theme for this year's Awareness Week is "Ask Me about My *Unbreakable Spirit®*."

Join us at one of the following scheduled events as we celebrate our 50,000 Lives, One Unbreakable Spirit® during Awareness Week 2013!

13th Annual Fine Wines Strong Bones Benefit, Arlington, VA – May 4th

Join the OI Foundation at its 13th Annual Fine Wines Strong Bones benefit. This Kentucky Derby themed evening will feature over 100 silent auction items, live auction and raffle items, delectable hors d'oeuvres and fine wines from around the globe. For more information or to buy your tickets to the 13th Annual *Fine Wines Strong Bones* benefit, visit **www.oif.org/FineWines**.

Alle Shea's 5th Annual Walk-n-Wheel for Better Bones, Rochester, NY – May 4th

Alle Shea Collazo was born on April 19, 2009 with Type II OI. While she only lived for five weeks, her Unbreakable Spirit® lives on through her parents, Angelo and Kim, who have created the Alle Shea Project in her memory. This year's family friendly event will include such activities as: a live DJ, clowns with balloon art and face painting, raffles and local sports team mascots. Join the Collazos from 11:00am to 4:00pm at North Ponds Park. For more information or to register to walk in *Alle Shea's 5th Annual Walk-n-Wheel for Better Bones*, visit **www.oif.org/AlleShea2013**.

Celebrating the Kentucky Derby themed 2012 FWSB!

2012 Central Texas Unbreakable Spirit Walk®

Unbreakable Spirit BBQ for OI, Granger, IA – May 4th

Join Jerome and Robin Hawco at the Emmanuel Methodist Church in Granger, Iowa for a barbeque celebrating the Unbreakable Spirit® of the OI community. There will be representatives from Advance Rehab Technologies, Sports Iowa and a wheelchair conversion company along with a clown, hot dogs and music for a day of family fun. Visit **http://www.oif.org/UnbreakableSpiritBBQ** for more information.

Unbreakable Spirit® Walk for OI, Buzzards Bay, MA – May 4th

Cheryl Manduca and her three children have together experienced over 300 broken bones and twenty surgeries. They are once again holding this annual walk for OI at the Buzzards Bay Recreation Area at Cape Cod Canal in Buzzards Bay, MA. The walk will begin next to the train bridge and it will continue 1.5 miles to the Bourne Bridge. For more information or to register to walk in the Unbreakable Spirit Walk for OI: Buzzards Bay, visit **www.oif.org/BuzzardsBay**.

Wishbone Day – May 6th

Wishbone Day is the international day for OI awareness. It began in 2010 and is celebrated each year on May 6th. Help make this world wide community effort to raise awareness by wearing yellow, the official color of Wishbone Day, and teach others about osteogenesis imperfecta. Visit **www.wishboneday.com** for more information.

Restaurant Proceeds Days – May 6th – 8th

Visit the California Pizza Kitchens in Gaithersburg at the Rio Center or in Bethesda at Montgomery Mall on May 6th, 7th, 8th or 9th, simply give your server a copy of the special OIF Flyer found at **www.oif.org/AwarenessWeekCPK** and they will donate 20% of your check to the OI Foundation! It's as easy as (pizza) pie! On May 8th, visit Visit Wendy's on North Bend Road in Cincinnati, OH and 15% of all of their proceeds from the day will be donated to the OI Foundation. No need to show a flyer, just stop by for a meal and your cost will automatically be put towards the total amount donated!

PSA Day – May 8th

The OI Foundation is asking everyone to share our new PSA via social media on May 8th so that everyone can learn about the importance of awareness for osteogenesis imperfecta. Put it on your Facebook page, Twitter, personal blog or simply email it to all of your contacts so that people all over the world can watch it and learn more about OI. You can even ask your friends and followers to share or re-tweet the link to the PSA. This is a great way to educate, spread the word about OI and to participate in National OI Awareness Week.

National Blue Jeans for Better Bones Day – May 10th

The quarterly national Blue Jeans for Better Bones Day will be held during Awareness Week and is a great way for schools or offices to get involved! Days leading up to May 10th people donate money (it can be $1, $3, $5) in order to receive an awareness wristband or sticker. Then, on May 10th participants are able to wear jeans to school or work along with their awareness wristbands or stickers to show their support for OI! If you're already allowed to wear jeans to school or work, that's okay! You can make it a hat day or dress up day instead. The overall idea is to show awareness and support for OI any way you want. Contact Jessica Finkel at **jfinkel@oif.org** or **301-947-0083** if you would like to be a team leader for a Blue Jeans for Better Bones day in your school or workplace!

6th Annual Central Texas Walk-N-Roll, Round Rock, TX – May 11th

This wonderful event was launched by Debbie Wiederhold and her daughter Erin Weaver in honor of their son and brother, Daniel, who is living with OI. Join Debbie, Erin and Daniel at the Lakeview Pavilion at Old Settlers Park. In addition to their walk, there will be games and activities for children and adults, a fire truck for kids to explore, food, and a silent auction! For more information about the 6th Annual Central Texas Walk-Hop-n-Roll, visit **www.oif.org/CentralTXWalk2013**.

It is not too late to schedule your own event for OI Awareness Week 2013! Email **events@oif.org** or call **301-947-0083** for more information. You can also check out **www.oif.org/awarenessweek** to find more details about how you can become part of OI Awareness Week 2013 and spread the *Unbreakable Spirit®*.

2012 Alle Shea Unbreakable Spirit Walk®

The OI Foundation is trying to secure proclamations from cities and states across the country declaring May 4-11, 2013, National OI Awareness Week! Getting a proclamation is easy! On our website, **www.oif.org**, we have included the contact information you need for your state, and a sample proclamation template. All you need to do is fill out the required information and send it to your mayor or governor! Once the proclamation has been approved we ask that you send it to the OI Foundation office so we can share with everyone where proclamations are being signed and show how OI awareness is affecting the entire country. Visit **www.oif.org/AwarenessWeek** to find detailed information for your state.

Young People Taking Action

In June, the OI Foundation was contacted by a young man who was interested in holding a community fundraiser in honor of his cousin Chloe Rose, who was born with OI. The surprising part was he was only eleven years old. Over the past six months, Marcus Davis procured donations from the Buffalo Sabres, the Buffalo Bills and both of his previous elementary schools and his current middle school.

With the full support of his principal and a few of his teachers, he has held six events including a week long OIF awareness wristband sale, three bake sales, a Blue Jeans for Better Bones day (all the students paid $1 to wear their pajamas to school!) and an awareness assembly.

Marcus isn't alone in his efforts.

High school student Matthew Weiss organized an assembly addressing the entire student body to talk about osteogenesis imperfecta and his own personal experiences living with OI. The school was so supportive of his efforts to raise awareness for OI, that when he decided to hold a Blue Jeans for Better Bones day in November, nearly all of the 120 students and faculty at his school participated! Matthew has now expanded past his school by organizing a quarterly restaurant proceeds event day at a local eatery to support OI as part of his school service project.

As a senior cheerleader who also has OI, seventeen year old Nicole Weaver knew she wanted to do something to bring attention to OI amongst her schoolmates. After meeting with her school's athletic director and principal, they agreed to hold an OI Awareness Night during one of the last home games of the varsity boys' basketball season on January 15th. Nicole designed a special t-shirt that was sold prior to winter break, organized a bake sale during the game where they sold OI cookies, created temporary tattoos for the crowd, sold awareness wristbands and procured several baskets from community businesses to offer as raffle prizes!

Marcus, Matthew and Nicole have shown us all what it means to have an Unbreakable Spirit® at any age and we look forward to working with them and other young people like them for many years to come!

Nicole performs a stunt with her cheerleading squad during OI Awareness Night

Marcus Davis (right) and his younger brother Desmond (left) accept a check for the donations received during an assembly held at Winchester Elementary School

MARINE CORPS HISTORIC HALF

Calling All *Runners!*

For the first time ever, the OI Foundation has partnered with the Marine Corps to field a team of runners for the Historic Half Marathon being held on May 19, 2013 in Fredericksburg, VA. As an avid runner, former OIF Board Member, Jacqueline Bourgeois will be chairing this event for us!

We have 25 bibs available on a first come, first serve basis for anyone interested in running under Team Unbreakable Spirit® and raising funds for the OI Foundation. To sign on as a participant, please visit **www.oif.org/MarineCorpsHalfMarathon2013**.

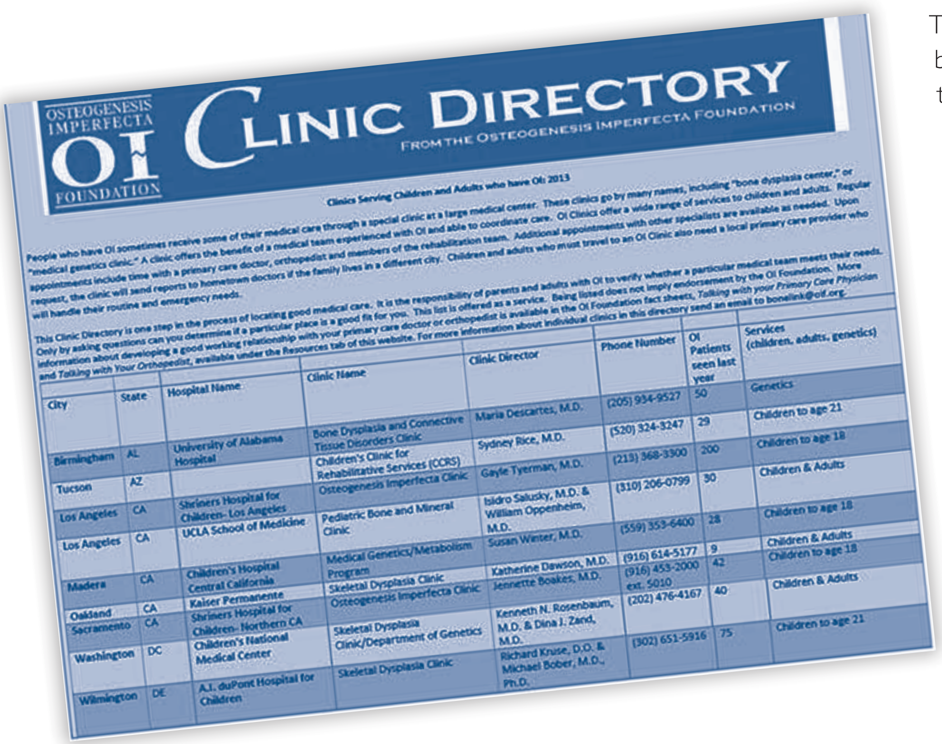
You don't have to run to join us! We will also have a table at the event expo on Friday, May 17th and Saturday, May 18th as well as a tent at the finish line on Sunday, May 19th. We would love to have as many members of the OI community come out and join us to cheer on the team as we run through the streets of historic Fredericksburg and show everyone just what it looks like to have an Unbreakable Spirit®!

For more information, please contact OIF Development Coordinator, Melissa Bonardi at **mbonardi@oif.org** or **301-947-0083**.

No federal or Marine Corps endorsement is implied.

Former OIF Board Member, Jacqueline Bourgeois will be chairing Team Unbreakable Spirit®!

New OI Clinic Directory



OSTEOGENESIS IMPERFECTA OI FOUNDATION

CLINIC DIRECTORY

FROM THE OSTEOGENESIS IMPERFECTA FOUNDATION

Clinics Serving Children and Adults who have OI: 2013

People who have OI sometimes receive some of their medical care through a special clinic at a large medical center. These clinics go by many names, including "bone dysplasia center," or "medical genetics clinic." A clinic offers the benefit of a medical team experienced with OI and able to coordinate care. OI Clinics offer a wide range of services to children and adults. Regular appointments include time with a primary care doctor, orthopedist and members of the rehabilitation team. Additional appointments with other specialists are available as needed. Upon request, the clinic will send reports to hometown doctors if the family lives in a different city. Children and adults who must travel to an OI Clinic also need a local primary care provider who will handle their routine and emergency needs.

This Clinic Directory is one step in the process of locating good medical care. It is the responsibility of parents and adults with OI to verify whether a particular medical team meets their needs. Only by asking questions can you determine if a particular place is a good fit for you. This list is offered as a service. Being listed does not imply endorsement by the OI Foundation. More information about developing a good working relationship with your primary care doctor or orthopedist is available in the OI Foundation fact sheets, *Talking with your Primary Care Physician* and *Talking with Your Orthopedist*, available under the Resources tab of this website. For more information about individual clinics in this directory send an email to bonelink@oif.org.

City	State	Hospital Name	Clinic Name	Clinic Director	Phone Number	OI Patients seen last year	Services (children, adults, genetics)
Birmingham	AL	University of Alabama Hospital	Bone Dysplasia and Connective Tissue Disorders Clinic	Maria Descartes, M.D.	(205) 934-9527	50	Genetics
Tucson	AZ		Children's Clinic for Rehabilitative Services (CCRS)	Sydney Rice, M.D.	(520) 324-3247	29	Children to age 21
Los Angeles	CA	Shriners Hospital for Children- Los Angeles	Osteogenesis Imperfecta Clinic	Gayle Tyerman, M.D.	(213) 368-3300	200	Children to age 18
Los Angeles	CA	UCLA School of Medicine	Pediatric Bone and Mineral Clinic	Isidro Salusky, M.D. & William Oppenheim, M.D.	(310) 206-0799	30	Children & Adults
Madera	CA	Children's Hospital Central California	Medical Genetics/Metabolism Program	Susan Winter, M.D.	(559) 353-6400	28	Children to age 18
Oakland	CA	Kaiser Permanente	Skeletal Dysplasia Clinic	Katherine Dawson, M.D.	(916) 614-5177	9	Children & Adults
Sacramento	CA	Shriners Hospital for Children- Northern CA	Osteogenesis Imperfecta Clinic	Jennette Boakes, M.D.	(916) 453-2000 ext. 5010	42	Children to age 18
Washington	DC	Children's National Medical Center	Skeletal Dysplasia Clinic/Department of Genetics	Kenneth N. Rosenbaum, M.D. & Dina J. Zand, M.D.	(202) 476-4167	40	Children & Adults
Wilmington	DE	A.I. duPont Hospital for Children	Skeletal Dysplasia Clinic	Richard Kruse, D.O. & Michael Bober, M.D., Ph.D.	(302) 651-5916	75	Children to age 21

The **OI Foundation's Clinic Directory** has been updated and has a new format! Replacing the 11 page PDF document is a three page chart that is organized by state, name of hospital/clinic, clinic director, phone number, number of OI patients seen last year, and services provided. The OI Clinic Directory is one step in the process of locating good medical care. It is the responsibility of parents and adults with OI to verify whether a particular medical team meets their needs. The clinics listed offer inter-disciplinary care and responded to the OI Foundation's update survey. For more information about the clinics listed, and other physicians familiar with OI in your area, please email **bonelink@oif.org**.

Bone China Tea – An Exciting Fundraiser for the OI Foundation

Bone China Tea has been an annual event for many years, but that does not mean the event gets less exciting for participants each year. Some of our hosts have been participating in Bone China Tea since they were young and find continuous joy and success year after year. Emma Johnston and her family have been hosting Bone China Tea since she was young and use it as a way to keep their friends up-to-date on what Emma has been doing throughout the past year. This is what Emma says about her Bone China Tea experience.

"The Bone China Tea is something I can remember doing as long as I've been alive. Throughout the years, my family and I have developed quite the system for getting the invitations out every year. We send envelopes stuffed with a tea bag and the donation envelope (postage paid). In addition, we add a picture of me from that year with the caption "Thank you! Love, Emma," and a short update on my life, something I've written for that last couple of years. With all the components in place, we stuff and send about 300 invitations each year. It is definitely a huge effort that consumes our dining room table for a week and three to four people, assembly-line style, but nothing compares to the tangible invitation on good old-fashioned paper. I have family friends who receive the invitation tell me, months later, that my picture is still hanging on their refrigerator. I find that, though no easy task, doing BCT this way is the most rewarding. While the fundraiser remains the same year after year, invitees can follow my story as I grow and change. It bolsters awareness and allegiance to the Foundation in a very intimate way, showing people a face and a personality instead of just a disease."

It is not too late to get involved and become a host for Bone China Tea 2013. Order printed invitations, like Emma and her family or create your own webpage and email invitations. To order printed invitations contact Jenny and Susie Wilson at **jnwilson@aol.com** or **239-482-0643**. For any questions regarding becoming an online Bone China Tea host, contact Jessica Finkel at **jfinkel@oif.org**.

Be Your Own Best Advocate

By Melanie Rak, MD

Like many adults with OI, I can tell stories about not being treated as an intelligent adult and how annoying and hurtful it is to be treated like a child. After delivering babies all night as a medical student, I was shocked when I was handed a children's menu at a restaurant the following morning. I think I still was wearing hospital scrubs. My 12-year-old brother was equally offended when he was given a children's menu as well, though I thought my offence was more justified. In many situations, but particularly when medicines are involved, it is critically important to be seen exactly as we are. An accurate perception of our age, height, and weight needs to accompany the general sense that we are adults.

As a physician practicing pediatric rehabilitation, I routinely dose medications based on a patient's weight. It's second nature for those of us who treat children. The situation is different for physicians treating adults, however, because most "adult" medications have a standard dose. When I was hospitalized for an infection several years ago, I was alarmed to discover that the doses of acetaminophen and the antibiotic I was receiving were much too high for my body weight. Overdosing medications can be dangerous. For example, excessive acetaminophen can cause irreversible liver failure.

Adults living with OI need to become comfortable acting as advocates for ourselves in medical settings. If your stature is small and your weight is less than a typical adult, discuss this with your health care providers when they order medications. The provider can use a pediatric dose, based on weight in kilograms unless that exceeds the usual adult dose. This can happen if you weigh more than about 80 pounds.

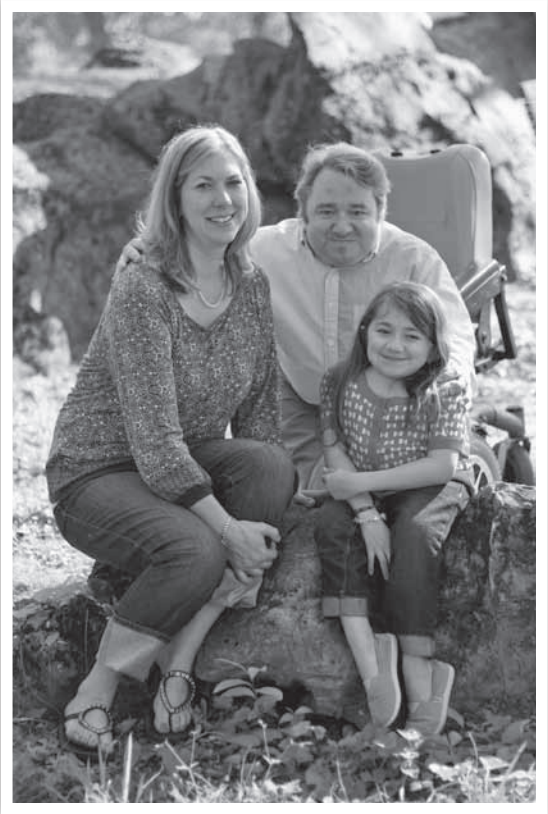
A good physician or nurse should be willing to discuss medication dosing and be open to learning about OI. I know it can be frustrating that some people in health care do not know much about OI and our needs. This makes it all the more important for those of us with this rare condition to learn what we can about our OI and advocate for ourselves.

Dr. Rak is an OI adult living and working in Chicago, IL.

A Letter from OIF Board Member, Jody Cheek

The following is a letter from current OIF board member, Jody Cheek about the OI Foundation's membership program. The OI Foundation counts on your membership to help fund research, provide information and support, develop new resources, and increase public and professional awareness about OI. In addition to supporting the work of the Foundation, membership gives you a voice in the OI Foundation's future. As a member of the OIF you are invited to our Annual Meeting, where the leadership of the OI Foundation updates members on the organization's accomplishments and future directions, and you will have voting privileges in our annual elections for our Board of Directors. Please use the enclosed reply membership to renew your current membership, or become a new member today!

Dear Friend,



Being married to someone who has OI brings advantages with it. It meant that when I was pregnant and we received the diagnosis of OI, Vance and I somewhat knew what to expect. However, many people are not in the unique situation that I have found myself. Although treatments and situations have progressed since Vance was born, the mission of the OI Foundation has stayed the same—to help families like ours. My mother-in-law, Joann Cheek, would tell me stories of the first OIF newsletters that were handwritten and mailed from person to person—whether a parent or an adult with OI. Joann fully supported the OIF and I believe that she is the reason I wholeheartedly believe in the Foundation. If a fledgling organization can make such a difference in people's lives when Vance was a child through the connection of letters, the same organization can only enhance our lives in today's advanced technological world!

The OIF staff is some of the finest I have ever had the privilege with whom to work—even before I was voted onto the board, the OIF was always at the ready to help me. They are willing to help anyone, regardless of your membership status. However, the more members we have, the more educational materials we can provide, the more help and support we can provide, the more connectivity we can make happen, the more we can take away that "being alone" feeling.

The OI Foundation counts on memberships to help fund research, provide medical information and support, develop new resources, and increase public and professional awareness about OI. The OI Foundation owes much of its success to its loyal, supportive members, and the organization's future strength depends on the support of new and continued members to provide these vital resources. I would ask that each person receiving this letter truly consider joining the OIF in order to further the advances being made daily. Joined together we truly do have an Unbreakable Spirit®.

Sincerely,

Jody Cheek

Jody Cheek
Member, OIF Board of Directors

NEW, NEW, NEW

An exciting new feature has been added to the OI Foundation website – a Video Learning Center.

The first video, an introduction to home splinting for OI families features OIF Medical Advisory Council member Dr. Paul Esposito from Children's Hospital in Omaha, Nebraska, and Dr. Mary Peterson-Suri from North Carolina, is now available for viewing. Dr. Esposito is an orthopedist and member of the OIF Medical Advisory Council. Dr. Peterson-Suri is an emergency room physician and the parent of two children living with OI. The video was filmed during the 2012 OI Foundation National Conference. To view the video, visit the Information Center section of the OI Foundation website, **www.oif.org**.

Additional videos based on interviews with medical experts, parents of children living with OI and adults living with OI will be added as they are completed. All information in the videos is reviewed by OI Foundation medical advisors.

From the Desk of Michael Geisman Fellow, Dr. Christina Jacobsen

Dr. Jacobsen

My work has focused on using mouse models of Osteogenesis Imperfecta to test potential new therapies. Patients with mutations (changes) in a gene known as *LRP5* have high bone density and very strong bones. I created mice that have both moderate OI and a mutation in *LRP5* and found that their bones are denser and stronger than their siblings that have OI without an *LRP5* mutation. I am currently testing the effects of an *LRP5* mutation in other mice that have either a mild OI phenotype or a more severe OI phenotype with frequent fractures and the initial results show that *LRP5* mutations can improve bone density in both.

In addition, using a medication that has a similar effect as an *LRP5* mutation, I treated mice with moderate OI mutation for six weeks. Once again, the treated mice have increased bone density and strength compared to their untreated siblings. I am currently treating mice with the severe form of OI that fracture bones more frequently. Although I have only looked a few mice so far, the treatment seems to reduce the number of fractures the mice develop. A human version of this medication is currently in clinical trials and I am very hopeful that it will be as effective as I have seen in mice.

Air Charity
NETWORK™

Air Charity Network Helps with Transportation

Sometimes the special medical care needed by a person living with OI is not available in their home town and a trip to a city with a larger medical center is necessary. When air travel is the only option, there are organizations that can help. The Air Charity Network is made up of member organizations who are all dedicated to helping people who need specialized medical care that isn't available in their home community. Each group serves a specific geographic area. Angel Flight, Airlift Hope and Mercy Flight all coordinate volunteer pilot missions in the United States. Mercy Medical Airlift coordinates free airline or reduced price tickets for missions over 600 miles. For information about eligibility, instructions on how to request assistance and links to each organization's website, visit **www.aircharitynetwork.org** or call **877-621-7177**.

On the Road with the OIF: Why We Attend Professional Conferences

The year 2012 was a very busy one at the OI Foundation. For much of the year, the focus was on preparing for the biennial National Conference on OI. Even with all of the preparations for the OIF National Conference, the regular, every-day work of the OIF went on. People from every state in the US plus 43 other countries contacted the OIF Information Center in search of information and resources. Over 5,000 questions were handled on everything from the genetics of OI to independent living. In addition, 240,000 people visited the OIF website. By the end of 2012, thirty OIF Support Groups were available in twenty-four states.

While 2013 might be an "off year" for the biennial OI Foundation National Conference, the OIF staff will still be on the road spending time in hotels and convention centers during the next several months. The Foundation will be participating in five professional conferences around the country. These conferences are important opportunities to increase awareness about OI, network with other organizations, and learn about new ideas from leading experts in fields related to OI. The meetings on this year's agenda provide the opportunity to expand the Foundation's connections with pediatric orthopedists, pediatricians, endocrinologists who see adults, and the medical professionals who are doing bone research. At each conference an OIF representative attends lectures, and manages a resource table in the exhibit hall. Participating in these conferences raises the visibility of the OI Foundation and makes more people in a variety of medical fields more aware of the needs of people who have OI and the services and resources available from the OI Foundation.

Listed below are the national meetings that representatives of the OI Foundation are planning to participate in this year:

- The National Health Council Leadership Meeting – February 2013 in Jacksonville, FL
- The Pediatric Orthopedic Society of North America (POSNA) Annual Meeting – May 2013 in Toronto, Ontario
- The Endocrine Society Meeting – June 2013 in San Francisco, CA
- The American Society for Bone and Mineral Research (ASBMR) – October 2013 in Baltimore, MD
- The American Academy of Pediatrics conference – October 2013 in Orlando, FL

Through our participation in conferences such as these, we are empowering the OIF to become a better organization and resource for the community. Look for highlights of these meetings in future issues of *Breakthrough*.

Role of the OIF Information Center

- » To give people affected by OI the information they need to:
    - Understand the causes and symptoms of OI
    - Be active participants in their health care
    - Communicate clearly with their doctors
    - Make informed decisions about treatments
    - Be confident problem solvers
    - Make healthy life style choices
- » To help health care professionals access information they need to care for people with this rare disorder.
- » To increase awareness and understanding about OI in the wider community.

From the Information Center

Use Acetaminophen Safely

Acetaminophen is the active ingredient found in Tylenol and many other medicines, both prescription and over-the-counter (OTC). It is an effective pain reliever when taken carefully and correctly but too much can lead to severe liver damage and even death. "Double Check, Don't Double Up" is a program from the Acetaminophen Awareness Coalition. Its purpose is to keep consumers informed about the benefits and dangers of this common drug. More than 600 over-the-counter and prescription medicines contain acetaminophen. Many are among the most popular medicines used to treat colds, the flu, headache and other pain including Alka-Seltzer Plus, Benadryl, Robitussin, and Dayquil. Acetaminophen also shows up in unexpected places; it is a major ingredient in the powerful pain reliever Vicodin. The problem often arises when consumers take more than one medicine at a time and are not aware that they are doubling up on the amount of acetaminophen they're actually taking. Here are some suggestions about how to protect yourself from an overdose and still get the maximum benefit from your medicines.

- Know the contents of your medicines. Check the labels on OTC medicines and ask your pharmacist if a prescription contains acetaminophen. Common abbreviations you might see include APAP and Acetamin.
- Do not take more than one product containing acetaminophen.
- Follow directions for how much to take and how often.
- Adults who are short in stature or very thin should talk to their doctor and/or pharmacist about the safe dose for both prescription and OTC medicines containing acetaminophen. The so called "standard adult dose" may be too much.
- When giving a medicine containing acetaminophen to a child, be sure to match the dose to the child's weight. If that information is not on the label, ask the pharmacist or your pediatrician.

Support for Caregivers

It is reported that 65 million Americans care for a family member who has a chronic condition, a disability or is frail due to old age. The **Caregiver Action Network** is an organization that offers emotional support and practical suggestions for caregivers. Membership is free and allows people to post to the forum, add their story to the story project and contact the volunteer peer network. The website and newsletter cover many topics from self-care to working with insurance companies. To learn more, visit the Caregiver Action Network website **www.caregiveraction.org** or call **301-942-6430**.

Home Improvement Ideas

Are you looking for ideas to make it easier to live in your home? A recently published book, *The Accessible Home: Designing for All Ages and Abilities* by Deborah Pierce might be just the inspiration you need. The author asks the question, "What does it take to make a home where a person with a disability can live a normal life?" The book follows 25 families as they work to answer that question for themselves. The guiding principal of the suggestions is "not more or bigger, just smarter." The book features homes of every size and of course, beautiful photographs. It was published by Taunton Press and is available on **Amazon.com** and as an electronic book from the book section on iTunes. An article by the book's author is in the February issue of *New Mobility* Magazine.

Managing a Stay in the Hospital When Surgery is Planned

Being an informed health care consumer is always important, but especially when a hospital stay is in your future. When a complex and rare disorder like OI is part of the picture being a well prepared consumer is extremely important. In general, three situations require children and adults who have OI to go to the hospital – a planned surgery, a sudden injury requiring an emergency room visit, and other medical problems that may or may not be connected to OI.

This article is the first in a series that will explore issues connected to being a hospital patient. It will look at some key topics related to a planned surgery. Future articles will present information about using the hospital emergency department and about other medical problems, such as pneumonia that require a hospitalization.

Often a surgery can be scheduled ahead of time. This might be rodding surgery or spine surgery or surgery to repair a hernia. Whether a parent is taking a child to a Children's Hospital or an adult with OI is using a community hospital there are things that can be done ahead of time to help improve the chance for a speedy recovery. Planning ahead and good communication can help minimize problems.

Start out Healthy! Every health advice article today starts out with reminders about healthy eating, exercise, weight control and managing stress. Although the specifics may differ for children and adults with different types of OI, the general advice still applies. Managing OI and coping with fractures are important and necessary, but does not excuse anyone from working to have a healthy weight, getting immunizations, and monitoring cholesterol and blood pressure numbers. In addition, people who have OI should also pay extra attention to their respiratory health. Research clearly shows that people with better general health recover more quickly from illness and from surgery.

Develop a good relationship with the doctors in your life. Because OI is a rare disorder, it is not uncommon for primary care doctors such as pediatricians or internists to have little experience with it. This fact increases the importance of getting to know them and helping them learn about OI before there is an emergency. If some treatment takes place in an OI Center, make sure that the records are shared with your local doctors.

In some hospitals, care is provided not by your primary care doctor, but by hospitalists, doctors who work for the hospital. As part of planning for a surgery find out whether your regular doctor will be seeing you during your hospital stay or have input into your care. Ask for the opportunity to meet and talk with the hospital staff people who will be in charge of your care. This can include care coordinators, the surgeon, and the anesthesiologist. This can be a good time to share information about OI. This is also a good time to discuss how to prepare for surgery and if any regularly taken medicines need to be changed or temporarily stopped. Because complications can happen, learn ahead of time what the procedures are if a patient needs to be transferred to a larger medical center for special care.

Experience counts when picking a surgeon or hospital for complex procedures. This is especially true for spine surgery.

Know what's coming. The more you know what to expect during the operation and the hospital stay, the easier it will be for everyone. Be sure everyone in the family understands what will happen during the operation, how long it will take, and what happens afterwards. Parents are encouraged to make use of child life specialists to help prepare their children. Parents and OI adults need to be clear about hospital procedures for having a family member stay with the patient and what services are available before, during and after the hospital stay.

Understand your medicines. Provide the hospital with a complete list of all of the medicines and supplements that are being taken along with exact dose. Because many people who have OI are small for their age, it is important to talk about safe doses for medicines. Find out as much as possible about the medicines, especially pain medicines that are likely to be prescribed during the hospital stay. Many of the powerful pain fighting medicines that are given in the hospital can slow down a person's breathing. This can be a dangerous side effect for the person who has OI since their respiratory system may already be compromised by the OI. If the child or adult with OI is already being treated for chronic pain or has special needs for pain medicines, ask the prescribing doctor for a letter that explains the treatment. Be sure to have that information in the medical file and carry a copy along with you.

Stay safe in the hospital. Be sure that information about OI is in the medical chart and hang "Handle with Care" posters in the room. Remind the hospital staff that OI causes more than a fragile skeleton. Skin and blood vessels are fragile too, and there is a risk of bleeding and respiratory problems. If hearing loss is part of the picture, be sure that the nurses and aides are aware. Today parents routinely stay with their children after surgery. Adults are reminded that they need to have a friend or relative stay with them as much as possible to act as their advocate. This person needs permission to discuss your condition with your doctors and nurses. Consumer Reports advises that advocates can ask questions on your behalf, monitor hand washing and the administration of medication, make sure catheters and IV lines are kept clean and removed when they're no longer needed and speak up in general if something doesn't seem right. ("Before Surgery, Make a Plan" Consumers Union of the United States, Inc. as printed in the Washington Post, January 1, 2013).

Understand privacy rules. When a child is 18 years old or older, parents do not automatically have access to all of his/her medical information. It is important that older teenagers, college students and adults who are not married make arrangements so their doctors know that their medical information can be discussed with a designated advocate such as a parent.

From the beginning, plan ahead for the recovery period. Find out what will be needed after leaving the hospital. Understand how long the recovery usually takes, whether the person can recover at home or if a rehabilitation center is needed and what kinds of special equipment and physical therapy will be needed. Many advisory groups suggest making appointments for follow up visits with the hospital doctor and your personal doctors before leaving the hospital.

Parents of children who have OI and OI adults often have a lot of experience with going to the hospital for surgery. This can be put to good use to prepare for the next time.

Vision: Complex Corneal Disease and OI

The changes in Type I collagen that cause OI affect many parts of the human body besides the skeleton. For a long time, people have associated OI with hearing loss. Gradually, we are learning more about how changes in the amount and quality of Type I collagen affect the eyes. Current research suggests that people with OI may have an increased risk for problems with the cornea.

The cornea is the clear part of the surface of the eye that allows light to enter. It is well supplied with nerve endings which explains why injuries to the cornea are often very painful. Type I collagen provides strength and affects the shape of the cornea.

An eye disease called keratoconus has been reported in people who have OI but the exact frequency is not known. Symptoms include a history of being near-sighted, blurred vision that is not improved with glasses, seeing halos around objects, and night vision problems. Like other complex corneal diseases, keratoconus can cause eye pain, light sensitivity and a loss of the ability to see clearly. Traditional treatments include contact lenses, wearing sunglasses outdoors and eye surgery.

A new treatment called Prosthetic Replacement of the Ocular Surface Ecosystem, or PROSE@, has been developed at the Boston Foundation for Sight. It is reported to restore vision and significantly reduce eye pain and light sensitivity. The treatment involves a custom designed lens that exactly matches the individual's unique eye shape. Over a few days, a series of different prescription lenses are fitted and fine-tuned until there is an increase in the patient's visual acuity. A key benefit of this treatment is that no surgery is needed. The Boston Foundation for Sight has been working with eye institutes across the United States to make this treatment more widely available.

Adults who have OI are urged to be vigilant about changes in their vision. If they have been diagnosed with keratoconus and are not being helped by traditional treatments, they may want to talk to their ophthalmologist about whether PROSE@ is something to consider. The OI Foundation has received reports that this treatment has been used successfully with adults who have OI. One adult with OI reports that he has been pleasantly surprised with his PROSE@ lenses. "The lenses are larger than regular contacts. After getting trained on how to insert and take them out each day, they are much more comfortable then my old lenses," says OI adult Tim Dombro, "I can see clearer than I have seen in quite awhile. They have made life easier at home and at work."

> **"I can see clearer than I have seen in quite awhile. They have made life easier at home and at work."**

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