

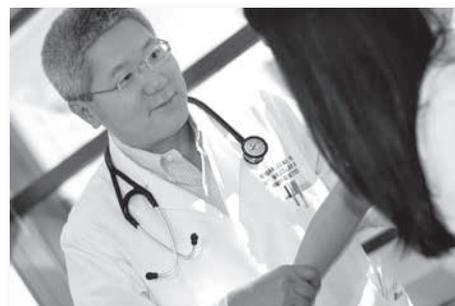
The Osteogenesis Imperfecta Foundation Part of Team Receiving NIH Grant to Lead Brittle Bone Disease Clinical Research Consortium

Baylor College of Medicine has been selected by the National Institutes of Health to lead the Brittle Bone Disorders Rare Disease Clinical Research Consortium, a new, multi-center initiative that will focus on understanding and providing better treatment options for rare diseases characterized by bone fragility and fractures.

The consortium will team up with the Osteogenesis Imperfecta Foundation to train a broad spectrum of health care providers in the diagnosis and treatment of OI.

"This is the first time in the field of hereditary disorders of connective tissue, in this case brittle bone disorders, that we have been able to establish an NIH supported network to coordinate natural history, therapeutic, training and pilot studies," said Dr. Brendan Lee, professor and interim chair of molecular and human genetics at Baylor College of Medicine and the principal investigator of the consortium. "This network is unique in the study of genetic disorders of the skeleton in that

it is a collaboration not only of leading academic clinicians and scientists, but also tremendous lay advocates for this effort, the Osteogenesis Imperfecta Foundation and the pharmaceutical company Genzyme/Sanofi," said Lee.



The consortium has three primary goals. One is to gain a better understanding of all genetic forms of OI. The second is to expand treatment options. Based on recent research Lee published in the journal *Nature Medicine* regarding a new approach to treatment for osteogenesis imperfecta, the consortium will initiate a Phase I clinical trial. Additionally the consortium plans to initiate other pilot studies focused on

(continued on page 2)

OI FOUNDATION REGIONAL CONFERENCE PROGRAM

Make Plans Now to Attend an OIF Regional Conference in 2015

The OI Foundation is thrilled to announce that 3 cities have been selected for the 2015 Regional Conference Program. A one-day regional conference will be held in Los Angeles, CA, in February 2015, in Stamford, CT, in May 2015, and in Minneapolis, MN, in October 2015.

The one-day format includes national and regional speakers on a variety of topics for parents and for adults who have OI. Sessions will cover information related to understanding and living well with OI. In addition, there will be social activities for children and families. A complete registration for any regional conference will cost \$35 per person and will include access to all sessions, lunch, and the closing social

Osteogenesis Imperfecta Foundation Regional Conferences



event. Children 12 years of age and under are free, but must be registered.

The first meeting of the 2015 Regional Conference Program will be held on Saturday, February 7th at the Shriners

(continued on page 2)

OIF PART OF TEAM RECEIVING NIH GRANTS *(continued from page 1)*

developing measures of quality of care and identification of new biomarkers. The third goal is to implement training programs for the next generation of physicians and scientists in the area of genetic bone disease.

“This grant is an extraordinary opportunity to link the OI community with a dedicated group of investigators,” said Ms. Tracy Hart, CEO of the OI Foundation. “All of us involved in this consortium have a shared goal: to expand knowledge about OI and improve care for the people who live with OI everyday.”

The consortium will also include the University of California in Los Angeles; Oregon Health Sciences in Portland; Marquette University in Milwaukee & Shriners Hospital for Children in

Chicago; McGill University & Shriners Hospital for Children in Montreal, Canada; the Hospital for Special Surgery in New York, NY; Children's National Medical Center in Washington DC; the Kennedy Krieger Institute in Baltimore, MD; the University of Washington in Seattle and the University of South Florida in Tampa. The consortium is supported by the National Institute of Arthritis, Musculoskeletal, and Skin (NIAMS), the National Institute of Dental and Craniofacial Research (NIDCR), The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the Office of Rare Diseases in the National Center for Advancing Translational Sciences (NCATS).

OI FOUNDATION REGIONAL CONFERENCE PROGRAM *(continued from page 1)*

Hospital for Children in Los Angeles, CA. The LA Regional Conference will feature the following speakers:

Dr. Gayle Tyerman, Director of Pediatric Services, Shriners Hospital for Children in Los Angeles, CA

Dr. Jay Shapiro, Director of the Osteogenesis Imperfecta Program, Kennedy Krieger Institute, Baltimore, MD

Dr. Deborah Krakow, Attending Physician and Research Scientist, International Skeletal Dysplasia Registry, Cedar-Sinai Medical Center, Los Angeles, CA

Dr. Robert Cho, Orthopedic Surgery Chief of Staff, Shriners Hospital for Children in Los Angeles, CA

Dr. Susan Bukata, Orthopedic Surgeon, UCLA Orthopedic Center, Los Angeles, CA

The full regional conference agenda, registration details, and hotel reservation information are available on the OIF website (www.oif.org/regionalconference). More details will be announced as soon as they are available.

One-day regional conferences were re-introduced in November 2013 in Tampa, Florida, as an effort to bring the latest information about OI to larger audiences in regions all over the country. Join us as we bring the OI Foundation's information resources to a greater number of the 50,000 lives affected by osteogenesis imperfecta!



Attendees at the 2014 Tampa, FL, National Conference

National OI Awareness Week 2015

National OI Awareness Week is a time to work together as a community to educate our world about osteogenesis imperfecta. National OI Awareness Week 2015 is May 2nd-May 9th! Wishbone Day, an international OI Awareness Day that falls during National OI Awareness Week, will take place on Wednesday, May 6, 2015.

Each year, we encourage our supporters to raise awareness for OI by holding Awareness Week events, hanging posters, requesting state proclamations, leading a National Blue Jeans for Better Bones Day and sharing #SHAREforAWARENESS posts. We will begin sharing #SHAREforAWARENESS social media posts on April 9, 2015 (ending May 9, 2015). Keep an eye out for these posts on the OI Foundation Facebook and Twitter pages!

During National OI Awareness Week 2014, we proclaimed OI Awareness Week 2014 in 13 states, received a National OI Awareness Week Resolution from the House of Representatives, educated over 2,000 participants of OI awareness raising events, displayed over 400 OI Awareness Week posters, and reached OVER 300,500 people with our #SHAREforAWARENESS social media posts!

There are so many ways to get involved! Hold an event, become a Bone China Tea host or lead a Blue Jeans for Better Bones Day on Friday, May 8, 2015! Pre-order Awareness Week posters to hang in your community, request an official OI Awareness Week state proclamation, share the OI Foundation's #SHAREforAWARENESS posts, and/or take the 50,000 Laps Challenge! Encourage your friends and family to get involved during National OI Awareness Week 2015!

Kick off Awareness Week with the 50,000 Laps – One Unbreakable Spirit® Challenge and make a wave in your community!



Commit to swimming any number of laps in the month of May 2015 to help us reach our goal of collectively swimming 50,000 laps – to represent the 50,000 people with OI in the United States. With its low impact and high muscle involvement,

swimming is a wonderful way to exercise your mind, body and Unbreakable Spirit®!

You can swim your laps all in on one day or you can have them span through the entire month. You can swim by yourself or consider reaching out to your local swim team to help spread awareness. However you do it, we would like you to register on our page www.oif.org/50000Laps to log your laps, share with your family and friends, and watch as we come together as members of a community and reach our goal of swimming 50,000 laps and raising \$100,000 for the OI Foundation!

For more information, visit www.oif.org/AwarenessWeek.



Unbreakable Spirit Walk for OI – Buzzards Bay, MA



Christine Rossi and family at the 10th Annual Unbreakable Spirit Walk for OI during National OI Awareness Week 2014 – Framingham, MA

The OI Foundation presents the:

OIF Youth Leadership Council



OI Youth Forum Participants from the 2014 OIF National Conference

The OIF Youth Leadership Council is:

- * An exciting outgrowth of the Youth Forum held at the 2014 OIF National Conference
- * Open to all people who have OI ages 18-26
- * A great way to connect with YOUR peers
- * A great way to make a difference in your community

The Council will work with the OIF Program Department to develop activities and organize resources around the needs of young adults during their critical transition years.

To learn more about the OIF Youth Leadership Council and how you can get involved, please visit:

website: www.oif.org/Youth

email: OIYLC@gmail.com



Also, find us on Facebook under "Young Adults with OI"

Bone China Tea 2015

Bone China Tea, the OI Foundation's yearly fundraiser, is back again! This year, Bone China Tea will help kick off National Osteogenesis Imperfecta Awareness Week 2015 on Monday, May 4, 2015! This simple program eliminates the hassle and expenses of attending a live fundraising event, allowing your friends and family to participate from the comfort of their own home. Bone China Tea leaders can create their own personal page online, or host a live event!

Keep an eye out for more information about how to get involved at www.oif.org/bonechinatea.

AUTUMN OI SUPPORT GROUP HIGHLIGHTS

New Group Meets; While a Longstanding Group Holds a Festive Meeting

On October 19, 2014, a new OI Support Group met for the first time in the southeastern region of Virginia. The leader of the new group is John Crandley of Virginia Beach, VA. John is the father of a two year old with mild OI, and he is looking forward to gathering more families affected by OI in the Tidewater, Virginia area in the near future.

On October 25, 2014, the Tampa OI Support Group held a Halloween Costume Party. This meeting featured guest speaker Dr. Paul Duga, a local pediatric dentist. Thirty three members of the OI community—children and adults living with OI, and parents, grandparents, and friends—were in attendance. The group's next meeting will be held on February 21, 2015, and will feature guest speaker Dr. Cathleen Raggio, an orthopedic surgeon from the Hospital for Special Surgery in New York.

Thank you to the OIF's Support Group Leaders for all of your efforts to provide local support to individuals and families and connect your communities to activities and resources. See the OIF Support Group Webpage (www.oif.org/SN_findgroup) for more details and contact information of support group leaders across the country.



OTOTOXIC MEDICATIONS

Dr. David Vernick, Harvard Medical School, Massachusetts Eye and Ear Infirmary

The following article is based on a popular session at the 2014 OI Foundation National Conference. The word "Ototoxic" refers to anything that has the potential to harm hearing or balance. Symptoms of ototoxicity can include: developing tinnitus, fullness or pressure in the ears, new or worsening hearing loss, development of vertigo. Factors that contribute to having an ototoxic reaction to a medication include pre-existing hearing loss, age, dose, length of treatment, and interactions with other drugs. This information is provided to help you be proactive about your health: 1) to INFORM your doctors and pharmacist about your hearing/balance issues, 2) to DISCLOSE all drugs or supplements, 3) to DISCUSS benefits and side-effects of current and new medications.

Mary Beth Huber

Everybody takes a pill now and then. Sometimes it is a daily occurrence for chronic conditions. Sometimes it is for temporary problems such as infection or pain. No matter what the reason, the usual decision is based on what the medication can do to improve your life. Most times little attention is paid to the potential problems a medication can bring. Unfortunately even the most common medications can sometimes cause undesirable side effects. The following discussion will focus on those medications that can (but usually do not) affect our hearing.

Drugs that can affect our hearing:

Pain Medication

Salicylates

Example – Aspirin

Can cause tinnitus (a noise in your ears)

Effect is dose related and almost always resolves when medication is stopped.

Non-steroidal anti-inflammatory drugs (NSAIDS)

Examples – Ibuprofen (Motrin, Advil), Indomethacin (Indocin), Naproxen (Aleve)

Can cause hearing loss and/or tinnitus

Effect is dose related and almost always resolves when medication is stopped.

Narcotics

Example – Hydrocodone (Lorcet, Vicodin)

Narcotics have been associated with deafness with very high doses such as in overdose or drug abuse.

Antibiotics

Aminoglycosides

Examples – Gentamicin, Neomycin, Streptomycin, Tobramycin

Medications can cause hearing loss and dizziness when given intravenously or intramuscularly. These medications are used for life threatening infections. Each antibiotic has its own tendency to cause either hearing loss and/or dizziness preferentially. Loss is usually dose dependent and can be permanent. Monitoring the drug levels in the blood can avoid most problems but not all.

When used in ear drops or in creams or ointments for the skin they are unlikely to cause either hearing loss or dizziness.

Vancomycin

This is similar to aminoglycosides in usage. It has very low ototoxicity when given intravenously and almost no ototoxicity when given orally.

Erythromycin

Examples – E-mycin, Pediazole, Biaxin, Zithromax

This medicine can cause hearing loss when given intravenously at high doses; rare for oral medication to cause hearing loss.

Chemotherapy Drugs

Platinum compounds

Examples – Cisplatin, Carboplatin

These compounds can cause hearing loss and loss of balance. Effects are usually related to total dosage given. There is a higher incidence of side effects after radiation therapy. Can monitor hearing to try to avoid severe reactions. Can limit the maximum dose to minimize chances of side effects.

Bleomycin

Vinca alkaloids

Examples – Vincristine, Vinblastin

Can cause hearing loss and balance problems. The effects are usually reversible.

Loop Diuretics

Examples – Bumex, Edecrin, Lasix

This specific group of "water pills" is frequently used to treat hypertension (high blood pressure). They are known to occasionally cause temporary ototoxicity. Hydrochlorothiazide, another diuretic, has not been associated with ototoxicity.

Bisphosphonates

Little is known about the effects of bisphosphonates on hearing – either good or bad. Only a few case reports have been published. There is no convincing evidence that bisphosphonate therapy affects hearing health at this time.

(continued on page 7)

OTOTOXIC MEDICATIONS *(continued from page 6)*

Hearing loss is a common issue in Osteogenesis Imperfecta. When considering medication for any reason, try to balance the expected benefit with the risks that can occasionally occur. Sometimes an alternative medication can achieve the same good benefit with less chance of causing hearing loss. It never hurts to ask.



Dr. Vernick is affiliated with Harvard Medical School, Boston, MA. He is a surgeon in otolaryngology at the Massachusetts Eye and Ear Infirmary and a member of the OI Foundation's Medical Advisory Council.

International OI Scientific Meeting Held in the US

The International Osteogenesis Imperfecta Scientific Meeting was held October 12-15, 2014 in Wilmington, DE. Dr. Richard Kruse of Nemours/Alfred I. duPont Hospital for Children chaired this important meeting that is held every three years in different parts of the world. The meeting provided the opportunity to engage a large group of people who are all working to expand our knowledge about all aspects of OI. Participants included basic scientists, clinical researchers, representatives of University based research centers and OI family associations from around the world. While the centerpiece of the meeting was the formal presentations, there were many opportunities including the Poster Tour, breakfast and lunch meetings and social events to connect with each other. The OI Foundation sponsored a Summary Session at the end of each meeting day which was led by Medical Advisory Council member Dr. Frank Rauch. He provided an overview of the key themes from the day's presentations and answered questions from the non-scientists attending the meeting.

Prior to the official start of the meeting the OI Foundation held an OI Global Community Meeting that brought together representatives of OI associations around the world. Seventeen countries were represented at the meeting. Dr. Francis Glorieux, chair of the OI Foundation's Medical Advisory Council and a member of the Board of Directors and Dr. Laura Tosi, a MAC member and board member, presented the group with information on pediatric and adult research and treatment updates. Following the global community meeting a workshop on physical therapy and rehabilitation was presented focusing on ways to increase mobility for people with all types of OI.

The scientific meeting began with a very interesting keynote speech by Dr. Francois Fassier titled "OI and the Arts." Dr. Fassier interviewed a number of people with OI and highlighted their artistic accomplishments. He interviewed painters, dancers, writers, musicians and actors.

Dr. Kruse grouped each day's scientific presentations by themes. The opening day presentations focused on basic science and genetics. The first group of talks referred to work being done to understand mutations to COL1A1 or COL1A2. The second group looked at specific factors associated with recessive forms of OI. All of the talks referred to attempts to discover the exact



mechanism responsible for how a mutation on a gene causes OI and to understand why there is such wide variability in OI symptoms.

The second day's meeting theme was therapeutic with speakers addressing multidisciplinary issues and surgical care. Sessions highlighted treatment with bisphosphonates and other drugs, long term evidence that physical therapy is an important factor in surgical and medical treatments, and a review of the data from the OI Foundation's Natural History Study. The afternoon sessions focused on surgical questions especially scoliosis.

The closing day's theme was addressing non-skeletal issues in people with OI. Presentations were made on heart issues, respiratory problems, updating growth charts for children with OI, quality of life studies, health questions of adults who have OI, and dentinogenesis imperfecta.

Many of the speakers were members of the OI Foundation's Medical Advisory Council including Drs. Brendan Lee, Frank Rauch, Cathy Raggio, Paul Esposito, Francis Glorieux, Francois Fassier, Richard Kruse, Laura Tosi, Joan Marini and Jay Shapiro.

Presenters were very specific about what their work was showing. By the end of the conference people were amazed at how much knowledge about OI has increased in the last 10-20 years and energized to continue looking for the next major breakthrough in basic science and clinical care.

End of Year Giving

We are so fortunate at the OI Foundation to have the continued support of the OI community. Because of your generosity, the OI Foundation is able to continue to fund important research, programs and services for families and individuals living with osteogenesis imperfecta. The following letter was recently sent

out to our supporters. Please take a moment to consider giving a gift to the OI Foundation so that we can continue providing a high level of service to the OI community. You can make your gift by using the enclosed envelope or by visiting www.oif.org.
Thank you!



Unbreakable Spirit®

804 West Diamond Avenue
Suite 210
Gaithersburg, MD 20878
(844) 889-7579 toll free
www.oif.org

By now you've probably heard the exciting news—the OI Foundation has been selected by the National Institutes of Health to be part of a multi-center initiative that will focus on understanding and providing better treatment options for people living with osteogenesis imperfecta.

This groundbreaking collaboration, called the **Brittle Bone Disorders Rare Disease Clinical Research Consortium**, is one of 22 rare disease consortiums being funded as part of the Rare Diseases Clinical Research Network. The OI Foundation has been working very hard over the past five years to secure a place in this Network (OI is the first bone disorder to be included) and your support in our efforts has made this possible! There is plenty of work left to be done and **we hope you will consider making a gift to the 50,000 Lives, One Unbreakable Spirit® campaign today!**

The Consortium will launch important new OI-related research studies focused on: scoliosis, dentinogenesis imperfecta treatment, OI and pregnancy, quality of life issues, a new drug therapy and uses for a new OI biomarker. As we move forward, more studies will be added to help answer the questions so many of us have about OI, including what happens as a person living with OI ages. To continue with this rapid pace of research, the OI Foundation must raise the money to add additional research sites to the network. This will allow more people with OI to participate in the Consortium's research studies. In the next year, the OI Foundation would like to add at least two more research center sites to expand our natural history study. With your help, we can do it!

In addition to the research center sites, the OI Foundation will launch new programs to educate medical professionals across the country about OI and treating individuals living with OI. Updated treatment information for children and adults living with OI will be made available to primary care doctors, specialists, nurses, and rehabilitation professionals. Print and electronic reference materials, seminars and peer consultation opportunities are some of the elements planned for the new medical education program.

Even with all of the exciting new Consortium activities, the OI Foundation must still continue to meet its ongoing obligations to the OI community. Existing programs to provide information to families and adults, to provide emotional support and to raise awareness need to continue. The OI Foundation answers over 6,500 inquiries annually from families, adults living with OI, students, educators, health care providers, employers, lawyers and social workers. All of them are seeking information and resources about living with OI. The OI



OIF Medical Advisory Council member, Dr. Brendan Lee is the Principal Investigator for the Consortium.

Foundation's National OI Information Center is the only information program in the United States dedicated to helping people understand and cope with this rare disorder. Information provided by the center is reliable, and medically verified, and personal support is provided to inquirers in a timely manner. This information helps people understand the medical and genetic facts about OI, diagnosis and testing, treatment options across the entire life-span, basic and clinical research, and techniques for caring for infants and young children.

The OI Foundation relies on the support of outstanding individuals, like you, who support our mission through your generous contributions and valuable time raising awareness about OI. People of all ages are involved! Thirteen year old Andersson Dyke, attendee of six OIF National Conferences, raises awareness for OI in her community by sharing her story with first-year medical students at Baylor College of Medicine learning about OI. Andersson, also an aspiring author, recently published her first book, *Missy*. Seeing the value in the work of the OI Foundation, this remarkable young lady chose to donate all of her book's proceeds to the OIF. To date, Andersson's book sales have raised over \$11,800 for the OI Foundation!



Andersson reading her book, Missy, at a book signing in Houston, TX.

With the help of generous supporters, like you and Andersson, the OI Foundation has accomplished so much over the years—and with your continued support, the OIF will continue to work to improve the quality of life for all people affected by OI.

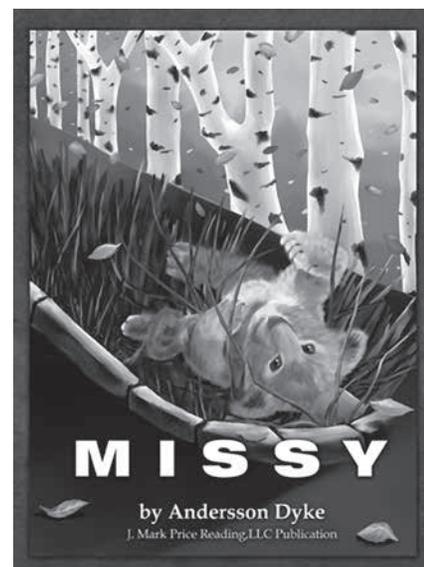
Please consider making a gift of \$50, \$100 or more to the 50,000 Lives, One Unbreakable Spirit® campaign using the enclosed envelope or online at www.oif.org.

Thank you, as always, for your generous support and have a wonderful holiday season!

All my best,

Tracy Hart
Chief Executive Officer
Osteogenesis Imperfecta Foundation

P.S. Gifts over \$500 will receive an autographed copy of Andersson's book, *Missy*!



Information From the 2014 OIF National Conference on OI

Rodding Surgery

At this summer's OIF National Conference, the role of rodding surgery for people who have OI was discussed by Dr. Paul Esposito, a pediatric orthopedic surgeon from Omaha, NE, and Dr. Francois Fassier, a pediatric orthopedic surgeon from the Canadian Shriners Hospital in Montreal.

Rodding surgery involves inserting metal rods, either telescoping or non-telescoping, into the intramedullary canal within a long bone. Both types of rods have advantages and disadvantages. The main indications for surgery are progressive deformity of a long bone or recurrent fractures which interfere with the comfort or development. Children with straight bones that are not fracturing do not need rods. Complications are possible. The most common complications are:

- Related to the surgery such as infection or a reaction to the anesthesia.
- Related to the rod itself such as migration of the rod.
- Related to OI such as new fractures or a bone curve that gets worse.

The doctors reminded their audience that the isolated use of plates and screws without rods for the treatment of fractures or bone deformity correction in OI is **NOT RECOMMENDED**. Treatment for OI is a team effort and a well-planned post-operative plan of splinting and rehabilitation is key to a successful outcome.

Aquatics Therapy

Although this session was offered to two different audiences, parents and OI adults, the basic information was very similar. Karen Josefyk, PT from Nemours duPont Hospital for Children in Wilmington, DE, stressed that aquatics therapy is good for people in many important ways—it's fun and social; it contributes to overall fitness and it is useful during rehabilitation after an operation or injury. Key points from this talk included:

- Begin by touring the pool facility and developing a plan for safely getting around on slippery surfaces at pool side and in the locker room.
- There are many types of equipment that can solve problems and enhance the experience in the pool. Talk with the instructor about options for chairs or lifts that help people with mobility limitations enter and exit the pool safely as well as different flotation devices for the non-swimmer.
- Aquatics therapy is not the same as swimming lessons and it is beneficial regardless of a person's swimming ability.

At every age, beginning in infancy, activities in the pool can help the individual reach personal goals for fitness and improve function. Working with a certified and experienced water therapist is important to selecting the most appropriate activities. But, no matter if you walk in the water, paddle and splash or swim laps, time in the water is meant to be enjoyable.

The handouts from these sessions are posted on the National Conference page of the OIF website. Go to www.oif.org, then click on the "Events" tab and then on the words "National Conference." If you do not have computer access, please call the OI Foundation to receive a printout.



CHILDREN'S BRITTLE BONE FOUNDATION



Impact Grants Coming Soon!

Applications for Impact Grants will be available on January 5, 2015! Funded and administered by the Children's Brittle Bone Foundation and OIF, the Impact Grant program offers direct support to individuals and families by providing products or services that will greatly improve their quality of life. Items that have been awarded in the past include wheelchairs, orthotics, hearing aids, and modified vans. Applications and eligibility requirements can be found at www.oif.org/impactgrant. Remember, applications will not be available until January 5 and the deadline for submitting applications is February 10. If you have any questions please email impactgrants@oif.org.

Reserve Your Table for the 15th Annual Fine Wines Strong Bones Today



We are very excited to announce the OI Foundation's flagship fundraising event; *Fine Wines Strong Bones* will be celebrating its 15th anniversary on **Saturday, February 28th from 6:00 pm to 10:00 pm at the Gaylord National at Washington, DC's National Harbor.**

We hope that you will join us for a fun-filled evening of silent and live auctions, a casino with blackjack, craps, roulette and poker, and delicious food and wines from around the world. Proceeds from the event will help the OI Foundation respond to more than 7,000 inquiries each year, produce new information resources, fund research, facilitate the operation of support groups across the country and aid the nearly 50,000 people in the United States affected by osteogenesis imperfecta.

Individual tickets are now available for \$75 per person or reserve one of our tables of eight for \$500 before they sell out!

Let us make a weekend of it for you! The OI Foundation has partnered with the Gaylord National to bring you a very special package – valued at over \$600. You will receive a one night stay at the Gaylord National Resort, complimentary overnight parking, two tickets to the 15th Annual Fine Wines Strong Bones event, and Sunday brunch for two at Pienza restaurant - located in the Gaylord atrium – for \$500. But act quick, this offer ends December 31st.

If you would like more details on sponsorship or you would like to purchase tickets, please visit www.oif.org/FineWines or contact Melissa Bonardi at mbonardi@oif.org or 301-947-0083.

November is National Family Caregiver Month

In the press release from the Family Caregiver Association, they stated that everyone at some point in their life has to take on the role of being a care giver. Within the OI Community caregiving is a necessary and valuable role. We often think about the special level of care that children who have OI require. The following story is short, but very special; how one young woman went from being cared for, to filling the important care giver role in her family.

A Sister I Admire: by Aileen Potter



Born in 1966 with OI, Colleen is our family's example of strength, courage, wisdom and selflessness.

A college graduate, Colleen is the youngest of 6 siblings and is to be admired for her daily diligence in caring for

our 88 year old father, Donald Dillon. When our mother died in 1994 Colleen became the matriarch of the family.

I would like other families to know that a child with OI is not only "different" but exceptional. So, for this reason I would like to pay tribute to my sister and friend, Colleen. She is truly the wind beneath our wings.



OIF Awards First SCPICA Grant for OI Research

For the past 28 years, the OI Foundation and the Southern California Petroleum Industry Charity Association have had a long and successful partnership that has enabled the OIF to continue funding groundbreaking research that has helped develop improved treatments for people with OI. At the 2013 SCPICA Golf and Tennis Tournament, we announced that in 2014, a young scientific investigator will receive the **SCPICA Grant for OI Research**. Now we are very pleased to announce that the grant in the amount of \$50,000 has been given to a very promising young investigator – Brya Matthews – a postdoctoral fellow at the University of Connecticut who is working to find that next breakthrough in OI research. What follows is the lay summary for her grant:



Brya Matthews

Bisphosphonate therapy, through increases in bone mass and reductions in fracture rate, has improved the quality of life for osteogenesis imperfecta (OI) patients. However there are potential negative effects of bisphosphonate treatment in children including decreased bone remodeling, delayed healing of osteotomy sites and atypical femoral fractures. Previous studies have shown that in addition to impairments in the bone forming osteoblasts due to defective collagen matrix production, children with OI, and a number of mouse models of OI also show increased activity of bone resorbing osteoclasts. In this study we plan to determine whether the changes in osteoclast numbers are due to increased osteoclast precursor cell numbers in the bone marrow of the osteogenesis imperfecta murine (oim) mouse, or a change in their ability to differentiate. We have also shown that a proinflammatory molecule, TNF α , is elevated in oim mice, which may contribute to increased bone turnover. TNF α is important in diseases like rheumatoid arthritis, and there are a number of FDA approved drugs available that block TNF α . We therefore plan to test one of these drugs, etanercept (Enbrel, Amgen), which also works in mice, in the oim mouse to determine if treatment can improve bone density and strength in these animals. Since these drugs are already approved for use in children with other diseases, promising results would potentially allow rapid clinical translation of these findings, providing an alternate treatment approach for children with OI.

We are very excited to see what Dr. Matthews' research yields. The ongoing partnership between the OI Foundation and SCPICA is one we greatly value. If you would like more information about SCPICA or to attend next year's golf and tennis tournament at the Pacific Palms Resort in City of Industry, CA, please visit their website at www.scpitcharity.org.



Dr. Glorieux is Honored at ASBMR

Dr. Francis Glorieux was awarded the William F. Neuman Award at The American Society for Bone and Mineral Research (ASBMR) annual meeting. The William F. Neuman Award is the ASBMR's oldest and most prestigious award. It recognizes an ASBMR member for outstanding and major scientific contributions in the area of bone and mineral research and for contributions to associates and trainees in teaching, research, and administration.

At the 2014 OIF National Conference, Dr. Glorieux was awarded the OI Foundation Humanitarian Award for his outstanding commitment to people with osteogenesis imperfecta. Dr. Glorieux, Chairman of the OIF's Medical Advisory Council, is currently an Emeritus Professor at McGill University. Among many accomplishments, Dr. Glorieux developed a model center using a multidisciplinary approach to treating OI; trained physicians from all around the world; and built a career that combined patient care and research.

Enter the Good Stuff Sweepstakes to Win



42" HD LED TV

Registration for 4 and a
3 night hotel stay at the
2016 National Conference



WALT DISNEY WORLD
SWAN



7" Dual Screen
Portable DVD Player

Do You Like Good Stuff?

Enter The OI Foundation's Sweepstakes TODAY!

Your chance to win one of four amazing prizes is within your reach. Send in your tickets for the OI Foundation's Good Stuff Sweepstakes today!

The Good Stuff Sweepstakes is an annual promotion that offers you a fun and easy way to both support the OI Foundation and involve your friends and family. There is a suggested donation of \$5 per ticket, but no donation is necessary to win. The more people who make a contribution and enter, the more the OI Foundation can support the 50,000 people affected by OI in the US!

Prizes include: a 7-Inch Dual Screen Portable DVD Player, valued at \$200; a 42" LED TV with HDMI cable, valued at \$400; and a trip for four to the 2016 OIF National Conference complete with four full conference registrations and a room at the Walt Disney World Swan & Dolphin for three nights which is valued at \$1200. Act soon because entries received before December 8th will be eligible for the early bird prize of a \$200 gift card to Amazon.

To request additional tickets or to enter online, visit www.oif.org/sweepstakes. To be entered to win the early bird prize, entries must be post marked by December 8, 2014. All other entries must be post marked by January 19, 2015 to be entered to win one of the grand prizes. Good luck!

www.oif.org/sweepstakes



From the Information Center

It's Cold and Flu Season

This is your annual reminder! If you haven't done so already, everyone over age 6 months should get a flu shot. Flu is a respiratory disease that can lead to serious illness in people who have OI. People who have asthma, who have a short rib cage or barrel shaped chest, or any difficulty breathing are especially at risk. If you are allergic to eggs, had a reaction to a previous flu shot, or if you have any questions be sure to talk to your doctor.

Hand washing is the best first line of defense against the flu and other seasonal illnesses. Additional suggestions include staying away from people who are sick or coughing and to stay home if you are not well yourself.

Interesting Product

A wheelchair user brought this product to our attention. Called the E-Z Pull door closer, it makes it easier to close doors both inside and outside the home. This item is lightweight, easy to use and more effective than a rope. To learn if this might be the problem solver you're looking for, visit www.e-zpulldoor.com.

Know Your Numbers

From the time we're little children there have been numbers that are important to know – street address, phone number, credit score, and social security numbers – to name a few. When it comes to taking charge of your health, there are several key numbers worth knowing. These include **Blood Pressure, Cholesterol, and Bone Mineral Density.**

Blood Pressure

It is reported that 1 out of every 3 adults in the United States has high blood pressure. Several small studies suggest this is also true for adults who have OI. High blood pressure is serious because it increases the risk of many serious problems including stroke and heart attack. Arteries carry blood from the heart to all parts of the body. Blood pressure (BP) measures the force of blood pushing against artery walls. A blood pressure reading is made up of two numbers. The top number is the systolic blood pressure (the pressure when the heart is pumping the blood out) and the bottom number is the diastolic blood pressure (the pressure just before the heart pumps again.) To be in the normal range the top number should be less than 120 and the bottom should be less than 80.

When having your BP tested people who have OI need to avoid automatic blood pressure cuffs because they can cause fractures. Small adults may need to be tested using a pediatric cuff. Talk with your doctor to make sure that you are getting accurate BP readings if you are short in stature, or have arm deformities.

For more information about understanding blood pressure numbers see the FDA consumer health fact sheet, "Medications for High Blood Pressure." (www.fda.gov).

Cholesterol

Knowing your cholesterol numbers is another important step to reducing your risk for heart disease. Cholesterol is a waxy material that can build up in the walls of your arteries. Too much of the wrong kind can narrow the arteries and make it harder for blood to get to the heart. Cholesterol is measured through a blood test that is typically part of an annual physical for teens or adults. In the United States the test results are given in milligrams per deciliter (mg/dL) of blood.

There are 4 numbers you need to know.

- Total blood cholesterol level.
- Low-density lipoprotein (LDL) is the so called "bad" cholesterol.
- Hi-density lipoprotein (HDL) is the "good" cholesterol.
- Triglycerides are another type of fat in the blood stream that is also measured.

Your doctor will explain your test results and if necessary recommend a course of action to improve your numbers. Information about cholesterol testing and test results can be found on www.webmd.com and www.mayoclinic.org. Search for "cholesterol numbers." The following chart from the Mayo Clinic website will get you started.

Total Cholesterol	Rating
Below 200 mg/dL	Desirable
200-239 mg/dL	Borderline High
240 mg/dL and above	High

(continued on page 15)

FROM THE INFORMATION CENTER (continued from page 14)

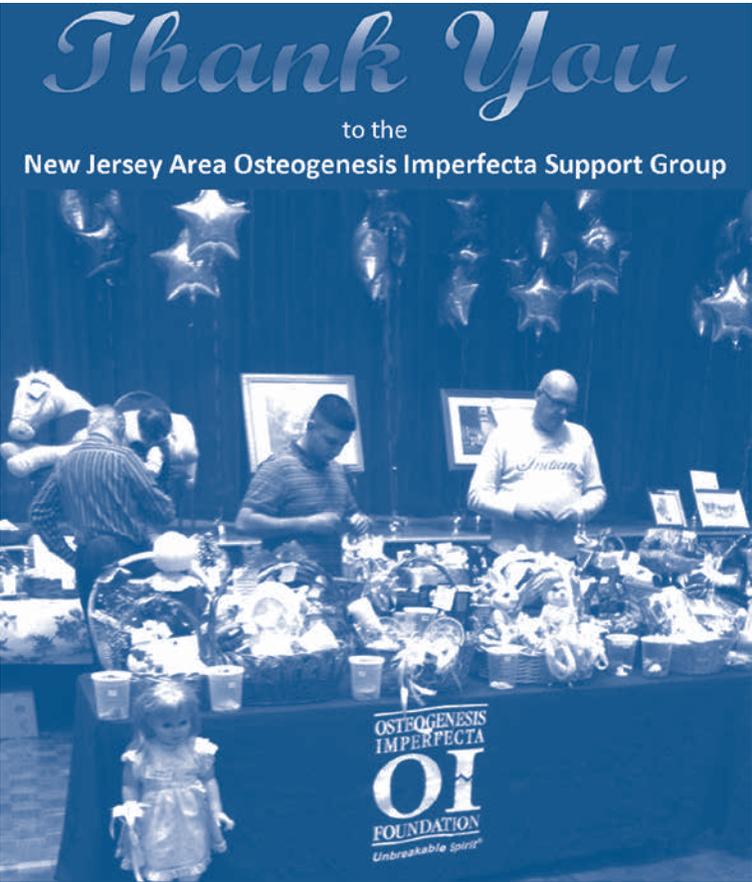
Bone Mineral Density (BMD)

The hallmark sign of OI is a fragile skeleton. A bone mineral density (BMD) test is often used to estimate bone strength. The most common way to measure BMD is called dual-energy x-ray absorptiometry or DEXA. This test is simple, painless and uses a very low dose of radiation. People who have OI may receive a BMD test at any age. Because increasing bone density is often the goal of treatments used for OI, people may receive a DEXA before starting a new treatment and then again later on to determine whether the treatment was successful.

Results from a DEXA are given as Z-scores or T-Scores. For children the BMD is given as a Z-score which compares to the normal range for children the same age. Z-scores do not take into account the child's height or body size or if their rate of growth is slower than the average child's. Adult scores are reported as T-Scores. The T-score compares to a healthy 25-year old person of the same sex. The standard is based on adults with average height and weight.

Here are some facts to remember:

- Most people who have OI will be characterized as having low bone density based on national standards.
- It is useful to self -compare bone density scores over time.
- Weight bearing exercise and muscle action contribute to building and keeping bone density.
- BMD may change over time depending on many factors including growth, fracture immobilization and normal aging.
- Some common medicines contribute to bone loss including aluminum-containing antacids, antidepressants, corticosteroids and some diabetes drugs. It is important to check product labels for over-the-counter and prescription medicines and talk with your pharmacist.



Thank You
to the
New Jersey Area Osteogenesis Imperfecta Support Group

Congratulations on the success of your 23rd Annual Beefsteak Dinner which featured 150 tricky tray items, 47 silent auction items, a 50/50 raffle, Basket of Cheer, Lottery Tree and a raffle of a Cal Ripken jersey, to raise over \$15,000 for the OIF!



Osteogenesis Imperfecta Foundation
804 West Diamond Avenue, Suite 210
Gaithersburg, MD 20878

NON-PROFIT
U.S. POSTAGE
PAID
SUBURBAN, MD
PERMIT #5857

**Look inside for exciting new
information from the OI Foundation!**