

National Osteogenesis Imperfecta Awareness Week – May 2-9, 2015!

National Osteogenesis Imperfecta Awareness Week is a time to share your Unbreakable Spirit® and educate others about osteogenesis imperfecta. Get your family, friends, neighbors and community involved in your effort to raise awareness! Wishbone Day, the international day of OI awareness, will held on Wednesday, May 6, 2015.

There are many ways you can get involved: hang posters; request a proclamation from your mayor or governor; or hold a fundraising event (Blue Jeans for Better Bones Day, Bone China Tea) at school, at work or in your community. We are excited to make National OI Awareness Week 2015 the most successful one yet!



Be sure to share and retweet **#SHAREforAWARENESS** posts posted by the OI Foundation leading up to and during Awareness Week 2015! We can't wait to see how many people we can reach through social media this year!

National OI Awareness Blue Jeans for Better Bones Day will be on Friday, May 8, 2015. Blue Jeans for Better Bones Day is a fun and simple way to raise awareness and get your community

(school, office, etc.) involved! For more information or to start planning your Blue Jeans for Better Bones Day, contact DCymer@oif.org.

OIF Regional Conferences: *Uniting Unbreakable Spirits*

The 2015 series of the OI Foundation's Regional Conferences successfully launched in Los Angeles, CA, on Saturday, February 7. Nearly 200 parents, adults, children, volunteers, and medical professionals attended the one-day meeting at Shriners Hospitals for Children – Los Angeles. Speakers shared current information about managing OI and each session inspired discussions between families, adults living with OI and the experts. Attendees participated in a full day of sessions including *Understanding OI; Managing Bones, Scoliosis and the Spine; Managing More than Bones; Advocating for Yourself; Raising a Resilient and Healthy Family*; and a closing session on *Life with OI: Incorporating Physical Activity*. In addition to the official sessions, several volunteers led lunchtime discussion groups.

We owe a sincere thank you to Dr. Gayle Tyerman and the staff of Shriners Hospitals for Children – Los Angeles for the support, staff availability and generous hospitality. The OIF would also like to thank the meeting attendees, the conference speakers, and volunteers for their participation. Conference speakers included doctors Jay Shapiro, Deborah Krakow, Gayle Tyerman,



Atticus and Debbie Shaffer participating on the Healthy Families/Raising a Resilient Family Panel Session.

OIF Regional Conferences: Uniting Unbreakable Spirits (continued from page 1)

Robert Cho, and Susan Bukata, as well as Susie Wilson and physical therapist Chris Caron. Panelists included OI community members Atticus and Debbie Shaffer, Jessica Mansour, Bill Scarberry, and Tony Jacobsen.

The OI Foundation is looking forward to the next two 2015 Regional Conferences in Stamford, Connecticut, on May 16th and Minneapolis, Minnesota in the autumn.

For more details or to register for the next OIF Regional Conferences, please visit www.oif.org/regionalconference.

We hope to see you at one of the upcoming meetings!



The opening session of the OIF Regional Conference in the atrium of the Shriners Hospitals for Children – Los Angeles. Attendees were asked to raise their hands if they were attending an OI Foundation meeting for the first time.



Dr. Jay Shapiro, Dr. Gayle Tyerman, Dr. Deborah Krakow, and OIF CEO Tracy Hart.



A few youth participants gathered in the Shriners Hospital Atrium for the afternoon social reception.



Photo booth fun with two youth participants displaying their Unbreakable Spirit®.



Family fun captured in a picture through the OIF's Regional Conference Photo Booth.

What is a Child Life Specialist?

Many children's hospitals now offer the services of a Child Life Specialist to patients and their families. According to the Child Life Council (CLC), a Child Life Specialist is "a trained professional with expertise in helping children and their families overcome life's most challenging events." For children who have OI and their parents, going to the hospital because of an injury or to have surgery can be a stressful experience. The special training a Child Life Specialist has can make a major difference in the quality of the experience. Using therapeutic play, the specialist can help explain difficult medical procedures in age appropriate language and reduce the anxiety and stress of a hospitalization. Child life specialists typically work in hospitals, but their reach is now expanding into outpatient facilities and other locations.

Child life specialists provide a wide range of services to children and families. According to the CLC, these include:

- **Easing a child's fear and anxiety** with therapeutic and recreational play activities;
- **Fostering** an environment that incorporates emotional support;
- **Encouraging understanding and cooperation** by providing non-medical preparation and support for children undergoing tests, surgeries, and other medical procedures;
- **Advocating** for family-centered care;
- **Engaging and energize** children and families by coordinating special events, entertainment, and activities;
- **Considering** the needs of siblings or other children who may also be affected by a child's illness or trauma;
- **Directing** pre-admission hospital tours and resources, and consultations with outpatient families;
- **Supporting** families confronting grief and bereavement issues; and
- **Providing information and resources** for parents and members of the interdisciplinary team.

Alma Ramirez, MS, CCLS,

is a Child Life Specialist (CLS) at the Shriners Hospital for Children in Los Angeles. We caught up with her at the OI Foundation's Regional Conference in Los Angeles to talk about her work.



Alma Ramirez, MS, CCLS, is a Child Life Specialist (CLS) at the Shriners Hospital for Children in Los Angeles

Thank you to Alma Ramirez and the Child Life and Recreation Department at the Shriners Hospitals for Children- Los Angeles for coordinating the Kids' Game Room at the February 2015 OIF Regional Conference!

Q *How did you come to be a Child Life Specialist? What is your background/training?*

A I always knew I wanted to work with children in a health care environment, but was not sure where to begin until I heard about the Child Life Council, which is the professional association for Child Life Specialists. Once I learned about the amazing impact a CLS can have, I knew my calling. I became a CLS in 1999, after receiving my undergraduate degree in Child Development. In 2011 I returned to graduate school to become certified as a CLS. Becoming a Child Life Specialist was the best career choice for me, since I enjoy talking to patients and families about what is happening in the hospital, preparing patients for surgeries, and being available for distraction during invasive procedures.

Q *Is there a typical day for you on the job? If so, what does that look like?*

A My typical day begins at 6am. I spend my morning visiting every single surgery patient and assessing them to determine what they know about their hospital visit and where (in their body) the surgery will be. I use a picture book to explain what they can expect from the surgery and how the rest of their day will likely go. If needed, I bring in a doll and medical box with a stethoscope, syringe, blood pressure cuff, etc., to role play with the patient.

After all surgery patients are prepared, I visit the clinic. The clinic can be hectic, with lots of patients coming in for different types of appointments. I provide distraction and support during I.V. placements or blood draws and I help the parents with comfort positions that will best help the patient cope during such procedures. For patients receiving day-long treatments, I provide a video game system or craft to help their day go by a little faster.

I end my day visiting post-operative patients, checking in and providing any support that may be needed.

Accept the 50,000 Laps – One Unbreakable Spirit® Challenge and Make a Splash in Your Community!

The OI Foundation would like to invite you to join our upcoming 50,000 Laps – One Unbreakable Spirit® Challenge. 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®!

Beginning May 1st, start swimming! Come back to your personal page to post updates on your progress. You can swim your laps all in on one day or you can have them span 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, and share with your family and friends.

Follow along with the OI Foundation as we post lap total updates and personal success stories throughout the month of May. 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!

How Do I Start?

GO to www.oif.org/50000Laps and click the link to “Accept the Challenge Today”

REGISTER as an individual swimmer! You can also form a new team or join an existing team.

PERSONALIZE your page! We’ve written a little bit to get you started, but you should take a moment to personalize your page with a picture of yourself and a greeting that explains how osteogenesis imperfecta has affected you. You can set your personal swim and fundraising goals as well as your team goal.

INVITE your friends and family to support you with a donation as you strive to complete your challenge. We’ve created some template emails but telling your personal story will always have a greater impact. Don’t forget to share your page with your friends on social media.

EARN the following prizes—make sure to wear them while you swim your laps!



SWIM between May 1st—31st and log your laps to help us reach our goal to collectively swim 50,000 laps in a month!

BONE CHINA TEA – 19 YEARS AND STILL GOING STRONG!

Bone China Tea will help kick off National OI Awareness Week 2015 on Monday, May 4. As always, hosts will have the option to set up personal online pages, or order paper Bone China Tea invites to send to their friends and family.

We are celebrating the 19th year of our Bone China Tea program! Bone China Tea participants save the costs of attending a live event and donate the money saved to the OI Foundation. Those involved can contribute to the OIF's awareness, support and research efforts by enjoying a cup of tea in the comfort of their own home – we even provide the tea bag!

The success of the Bone China Tea program is possible due to the support and dedication of volunteers involved in the Bone China Tea program. Check out some of our star Bone China Tea hosts:

Bonnie Landrum and **Tracy Bryan** are two hosts who have been incredibly successful in the Bone China Tea program. Hosts like Bonnie and Tracy thrive as Bone China Tea hosts because of their dedication and belief in the program. Bone China Tea hosts invite their friends, families and communities to join them in this simple fundraiser via mailed invitation or online.

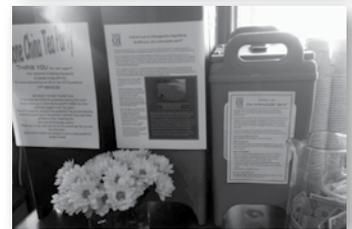
It is important for each host to share their story and connection to OI with the donors involved. Personalization is key! Each year, Bonnie sends personalized Bone China Tea invitations to her friends and family, featuring her daughter, Emma.

Randi Phillips organized her Bone China Tea offline and held a live event in 2014! Randi invited friends, family and community to join her for a cup of "Bone China Tea" at a local café. The event was advertised on social media, fliers, and by word of mouth. Randi also gave her supporters the option to donate online if they were unable to attend. Randi's Bone China Tea event was extremely successful, as it benefitted the OI Foundation and raised awareness for OI!

To start planning for your Bone China Tea (online or live) event, contact **Danielle at dcyMBER@oif.org**



Young attendees enjoying Randi Phillips' Bone China Tea 2014 Fundraiser at Paint Box Café in Osage Beach, MO.



OIF CEO, Tracy Hart, Named to National Institute of Dental and Craniofacial Research Advisory Council



The National Institute of Dental and Craniofacial Research (NIDCR) recently appointed Tracy Hart, CEO of the Osteogenesis Imperfecta Foundation, to the NIDCR Advisory Council. The National Institute of Health National Research

Advisory Councils are consulted by and provide advice to the Director of the NIH concerning pertinent programs. Councils usually meet three times per year at the NIH in Bethesda, Maryland. A major responsibility is to review and make recommendations regarding grant applications to support biomedical research and research training activities. In this connection, Council members have the benefit of the technical and scientific advice of the expert consultants

who performed the initial review of the grant applications for scientific merit. Another continuing and very important responsibility of the Council is the survey of the total research effort in the subject field and recommendation of the action necessary to stimulate additional work.

Each NIH Research Advisory Council includes a member of the patient advocacy community or the general public. Those members are expected to be knowledgeable about the research mission of the Institute.

NIDCR is particularly important to the OI Foundation, since research focusing on dentinogenesis imperfecta and other craniofacial issues related to OI is funded through NIDCR. Tracy will serve a three-year term as a Council member.

Become a Member of the OIF Today!

The following is a letter from past OIF Board Member, Christine Rossi, and her family 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 its future. As a member of the OIF, you are invited to our Annual Meeting, where our leadership 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 envelope to renew your current membership, or become a new member today!

Dear Friends,

My wish today is that you will help support those living with bone disorders like myself, my son, Jack, my father, Dick Wyman, my sister Michelle Potorski, my niece, Siena and other members of my family, so someday we will all be "Break free." We all have a rare brittle bone disorder called Osteogenesis Imperfecta (OI) that affects approximately 50,000 people in the United States today. There are varying degrees of fragility, from moderate- where fracturing could occur when rolling over or when lifted from a crib – to severe – where survival at birth is unlikely because the bones cannot support any weight or impact. Although our OI is a less-severe form, our family has faced many injuries. I personally fractured more than twenty times as a child.



Wyman – www.oif.org/BREAKFREE

We have had an active role in the Osteogenesis Imperfecta Foundation (OIF), for more than thirty years. Things dramatically changed for me when my son, Jack, was born ten years ago with two femur fractures and required a full body cast after birth. That day, I decided I had to do much more. I teamed up with my brother-in-law, Mike, and entire family to organize our first Walk for OI in Framingham, MA. In 2014, we completed our 10th Walk for OI and have raised more than \$550,000 for the OI Foundation. Recently, our family was featured in an article, "Family Shows Unbroken Spirit in Battle with Brittle-Bone Disorder" in The Boston Globe to celebrate the beginning of our newest initiative – the Break Free Challenge.

Amazing volunteers and donors have succeeded in holding similar walks and awareness events across the country, but, as they say in football terminology, we have only made a few first downs. I am passing the ball to you, and asking that you help us make it into the end zone by becoming a member of the OI Foundation today!

Your membership to the OI Foundation helps the OI community by funding research, providing information, developing new resources, expanding support groups and increasing public and professional awareness. Thank you in advance for your support.

Sincerely,
Christine Wyman Rossi

P.S.

Please use the enclosed reply envelope to become a member or renew your membership today!

A Message from Tracy Hart

My Role with the National Health Council



In February the National Health Council held its annual leadership conference. The title of the conference, “Changing the Game,” focused on issues that challenge all voluntary health agencies on a daily basis. I was delighted to serve as chair of this year’s conference in my role as chair-elect of the National Health Council Board of Directors. The National Health Council is a membership organization made up of more than 80 not-for-profit organizations and industries that care about those with chronic conditions. Organizations range in size from small rare disease organizations like the OI Foundation to very large organizations like the American Heart Association and the American Cancer Society. Serving in this role as chair of the meeting and chair elect of the board of directors enables me to showcase the work of the OI Foundation...something I'm very proud to do!

On the health policy front, representatives from industry examined how Congress is addressing the innovation ecosystem through the 21st Century Cures initiative, which includes important policies that will increase patient engagement, realign incentives to focus on the best medicines instead of the best patents, allow for greater data sharing and streamline institutional review boards to create a more efficient clinical trial process. This is especially important to the OI Foundation as we embark on the work of the Brittle Bone Disorders Consortium. As you may remember, one of the pilot projects of the BBDC is a Phase I drug trial. Moving quickly to a new drug treatment will be especially beneficial to people living with OI.

Other conference topics included: how to put big data to use; how voluntary health agencies can better align their efforts with the Patient Centered Outcomes Research Institute (PCORI) to strengthen our mission-driven initiatives; and how social media driven campaigns like the Ice Bucket Challenge can be replicated in other organizations. We learned that data, while not a “fun” topic to talk about really, is very important to an organization like ours. Since we have a relatively small cohort of people available for clinical trials, it is very important to collect data in a thoughtful and meaningful way. It's also important to make sure our constituents know that any data they contribute is safe and will be used appropriately. Soon the Brittle Bone Disorders Consortium Contact Registry will be announced and we will be asking people to register so that they will be able to participate in upcoming studies and clinical trials.

The contract registry will supplement the hard work already accomplished through the KKI/OIF Registry and the Linked Clinical Research Networks longitudinal study.

And, while it was exciting to hear about the social media Ice Bucket Challenge Campaign from the folks at the ALS, it was also interesting to hear how having a research agenda is critically important for all organizations so that money raised – through a windfall or raised dollar by dollar – is used to support an agreed-upon mission agenda. The OIF will be meeting in April at the annual scientific meeting to begin working on a revised research agenda led by OI experts in a variety of fields including genetics, orthopedics and clinical care.

The two day conference was really very good and I was proud to be representing the OI Foundation in a leadership role with the National Health Council at the meeting. I'm looking forward to my term as board chair and will continue updating you with information from this important organization.

To learn more about the National Health Council, visit <http://www.nationalhealthcouncil.org/>



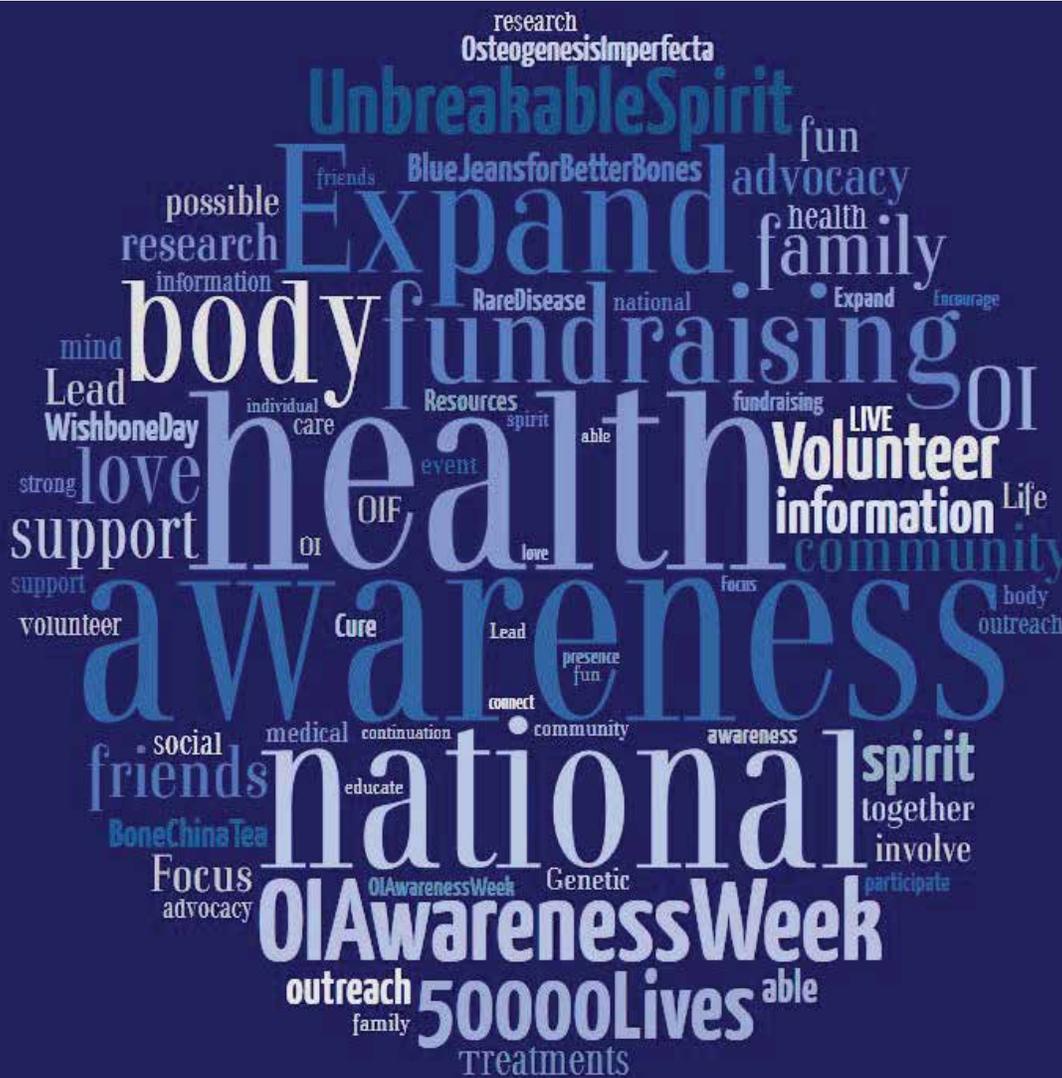
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NATIONAL OSTEOGENESIS IMPERFECTA AWARENESS WEEK

Putting Words into Action **MAY 2 - 9, 2015**



Also known as brittle bone disease, osteogenesis imperfecta is a rare disorder characterized by fragile bones.

GET INVOLVED in National OI Awareness Week - Hang posters, hold an event and take part in our social media campaign, **#SHAREforAWARENESS!**



WWW.OIF.ORG/AWARENESSWEEK



From the Information Center

Vaccinations

The question of vaccines has been in the news a lot lately. The basic recommendations for people who have OI remain the same. There is no medical reason for not giving a vaccine to a person who has OI. Children and adults who have OI benefit from being protected from these serious illnesses.

Many childhood illnesses affect the respiratory system and can make a child who has OI very sick. Flu and pertussis (whooping cough) can be more serious than in other children. Dr. Frank Rauch from Shriners Hospital for Children – Canada advises parents to follow the vaccination schedule for the province or state where they live. Dr. Eric Rush from Children's Hospital in Omaha, Nebraska also advised parents to follow the standard immunization schedule as published by the Centers for Disease Control (CDC). He said, "It's what I recommend for patients, and what I do for my own children as a parent." Dr. Jay Shapiro from the Kennedy Krieger Institute in Baltimore, MD reminds us that adults who have OI should keep current on their vaccinations.

The flu vaccine is reformulated each year in an attempt to target the types of flu that are anticipated for each annual "flu season." Even in years when the vaccine is not completely effective, it still offers some degree of protection. Because the short stature, chest shape issues and altered lung tissue seen in people who have OI can make respiratory infections more likely and potentially more serious, protection through vaccination and good health hygiene makes sense.

Because eggs are involved in the manufacture of many vaccines, including the one for flu, anyone with an allergy to eggs should make sure their doctor is aware of that information before being vaccinated.

Summer Activities

Spring may just barely be in the air, but it's not too soon to think about summer activities. Many children's hospitals and civic groups sponsor special camps that offer safe and fun experiences for children with medical conditions including OI. If your child is interested in a day or sleep-away camp experience, now is the time to look into what is available in your area. Your pediatrician or local children's hospital may have lists or camps that offer special programs for children with various medical conditions.

Camps are not the only pathway to summer fun. Many children who have OI participate on neighborhood swim teams or play

adapted sports. Summer can also be a time to learn a new skill, start playing a musical instrument, or spend more time on a favorite hobby. Community colleges, museums, community recreation departments and hobby centers often offer summer programs. Whether your child is a budding scientist, a cook, a computer game designer, or a future entrepreneur, there is a summer activity he or she will enjoy. Summer activities are excellent ways to help a child who has OI gain experience, improve their self-confidence and make new friends.

Recruiting: A Few Good Support Group Leaders

As the weather improves, everyone looks forward to getting together with friends and family. This is especially true in the OI Community. Spring opens the busy season for local support group gatherings. Meetings are posted on the OIF on-line calendar as soon as they are announced.

To see if there is a support group or a contact person in your state, visit the OI Foundation website at www.oif.org. Under the "Information and Support" tab, there is a link to a list of support groups.

Spring is also an excellent time to start a new group, or re-start a group that has been hibernating for a year or two. If you are interested in becoming a support group leader, contact Petra Harvey, the OI Foundation's Health Educator. She can explain the process and send you a step-by-step guide.

Protect Your Hearing from Noise Damage

Noise-related hearing loss affects over 26 million Americans under the age of 60. It can come from extremely loud bursts of noise, but the most common hearing loss problems develop slowly over time from ongoing exposure to loud noise. Audio players with ear buds, and power tools are often set loud enough to cause permanent damage. Because OI can cause hearing loss, it is especially important for children and adults who have OI to protect their hearing. Here are a few tips from the National Institutes of Health:

- Turn down the volume on devices, especially if you wear ear buds or headphones.
- Avoid noise—just walk away.
- Block the noise by wearing earplugs or earmuffs.

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OI and the Lungs: Know Your Numbers

Lung problems are among the most common issues facing people with OI once you look beyond brittle bones. The sobering fact is that respiratory problems are the most common cause of death in OI. There are many reasons that a physician or healthcare provider well-versed in OI bone problems may not know a great deal about pulmonary (lung) issues in OI. Even specialists in respiratory disease (pulmonologists) may need some coaching about what to look for in a person with OI.

An important aspect of respiratory management is testing lung function. People with OI, especially those with short stature, can present problems in the usual testing that's done to monitor lung function. Since all lung function testing is standardized by comparing the results to people of similar height, race, sex, and age, OI can make that comparison difficult. In people without OI, a person's height allows an estimation of the expected size of the lungs. In OI these proportions can be quite different. That's why it is recommended that even people without lung symptoms have their lung function tested on a regular basis if they have OI. Rather than comparing someone with OI to the general population, the important comparison is the person's own lung function over time.

So, how to get this done and what do these tests mean?

■ See a pulmonologist.

Among your healthcare providers, you should consider seeing a pulmonologist on a regular basis. As with most doctors you see who aren't at OI centers, you'll need to educate your pulmonary doc about OI. Most pulmonologists learn that the

respiratory problems of OI are related to kyphoscoliosis and rib fractures; in other words, problems with chest wall architecture. Recent studies have shown that OI, which generally causes the production of deranged collagen in the bones, does the same in the lungs. So people with OI can have problems with the lung tissue itself, in addition to problems with the chest wall.

Pulmonary doctors will also initially wonder how to interpret lung function testing they might order. Reassure them that while the initial lung function tests may be tough to interpret, they will serve as the baseline of comparison for future testing.

■ Tests involved in a pulmonary evaluation

Testing for lung function is fairly well standardized and includes a variety of breathing tests that measure the amount and flow of air in and out of the lungs. In addition, your oxygenation is often followed either with an arterial blood gas (ABG) or oximetry. Also, evaluation of breathing during sleep can be important. Here we'll concentrate on the breathing tests done in a doctor's office or a pulmonary function laboratory.

■ What are they? Spirometry, lung volumes, diffusion capacity.

The simplest of the breathing tests that can be done is called spirometry and the machine that measures it is a spirometer. This testing can often be done in a doctor's office. Sometimes you'll see this done at health fairs. This test involves putting a mouthpiece in your mouth that's attached to tubing leading to a machine that measures the amount of air you can breath

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From the Information Center (continued from page 9)

Preparing for College

Parents are reminded to provide their college bound student with lessons on taking charge of their own health. Although these suggestions from the American Academy of Pediatrics are meant for everyone, they are particularly important for the teen with OI.

- Students need to know how to make a doctor appointment.
- They need to understand how health insurance works.
- They need to know their own health history.
- They should be familiar with the prescription and over-the-counter medicines they commonly use.
- Parents and students need to be familiar with the general and emergency health care options at college.

- If college is more than a short distance from home, locate an orthopedist with OI experience before the semester begins.
- Plan ahead what to do if the student feels sick or gets injured at school.

Congratulations Dr. Ingo Grafe!!



Dr. Grafe, who is a recipient of an OI Foundation Michael Geisman Fellowship, has been named an outstanding young investigator by the American Society for Bone and Mineral Research (ASBMR). Each year the ASBMR-Advances in Mineral Metabolism selection committee identifies 10 young investigators from around the world for recognition.

OI and the Lungs: Know Your Numbers (continued from page 10)

and how fast it's moving. Some spirometers are small enough that you actually hold the spirometer in your hands and breath directly into it. Some patients even get home spirometers so they can measure their lung function themselves.

The maneuver you're asked to perform during spirometry is taking in a deep, deep, deep breath followed by blasting out all your air into the spirometer; continuing to exhale as long and as hard as you can. Usually, a nose clip will be placed on your nose to make sure all the exhaled air goes through the spirometer.

The most important numbers generated are the Forced Vital Capacity (FVC) and the Forced Expiratory Volume in 1 Second (FEV1). FVC represents the total amount of air you were able to exhale from top to bottom, usually expressed in liters. FEV1 is the amount of that total breath that is exhaled during the first second of the total exhalation, again expressed in liters. The machine will also express these values as a percent of the predicted normal, but in OI, this is a value to be ignored because predicted values are based on people with "normal" stature.

There are a multitude of other numbers generated by spirometry, but **the FVC and FEV1 are the numbers to remember.**

A formal complete pulmonary function test, usually done at a free standing pulmonary function laboratory or a hospital, adds lung volumes and diffusing capacity to the mix. Lung volumes are usually measured by locking you into what looks like an old fashioned glass phone booth and having you pant through a mouthpiece. In diffusing capacity measurement, you inhale a mixture of various gases, like helium and carbon monoxide, and then doctors measure the concentrations of those gases in your exhaled air. Lung volumes can help your doctor know if you have any air trapping and give a reading of the maximum amount of air your lungs should be able to hold as well as the diffusing capacity, which measures the ability of oxygen to move from the lungs into the blood.

■ Knowing your numbers

So you've been through some lung function testing and you've seen a bunch of numbers, How can you keep tabs on how you're doing? You need to know your numbers. The most important ones are the simplest: the FVC and the FEV1. You need to know these because you need to know if they are changing for better or worse. The FVC (check above if you don't remember what this is) is an important indicator of your chest capacity and breathing mechanics. If it stays stable over time, your kyphoscoliosis (if you have any) is not worsening and your ribs are not encroaching on your lung volume. If the FVC is declining then you may need to look at ways to improve the capacity of your chest cavity, including surgical approaches. The FVC can also drop if the lungs become stiff due to derangement of the lung collagen. The FEV1 measures how fast the air moves out of your lungs and can be decreased by things like asthma, emphysema, bronchitis, and pinching of your windpipe if your neck is short. If either the FEV1 or FVC drops compared to previous measurements, it's time to consult with your pulmonary doctor to find out what the cause is and what can be done to correct the change.

■ What's special about the numbers in OI?

As mentioned, the numbers in OI can never be evaluated in isolation. They should always be compared to that individual's previous values. That's why it's important to check lung function early and often (or, at least, early) and to know your numbers so that if a change occurs, you'll be the first to know it and do something about it. Doing something about it usually means heading to your pulmonologist.

Dr. Sandhaus is a pulmonologist at the Colorado School of Medicine and National Jewish Health in Denver, CO. He is a member of the OI Foundation's Medical Advisory Council and a frequent speaker at OI Foundation conferences.

Limited Edition Wristbands for Awareness Week

The OI Foundation is excited to announce a new product to the online store! These limited edition wristbands are made of 100% silicone, feature a fun blue and yellow swirl, and are embossed with "Unbreakable Spirit®."



Pre-order your wristband today at www.oif.org.

Calendar of Events

The OI Foundation is very lucky to have a large number of volunteers around the country who hold fundraising events, awareness events and support group meetings. Here are some of the events being held in the upcoming months. Try to attend one near you and share our Unbreakable Spirit®!

April

- April 14th** Alle Shea Project Dough Raiser – Rochester, NY
- April 25th** Unbreakable Spirit® Walk-n-Wheel: Buzzards Bay – Buzzards Bay Recreation Area/Cape Cod Canal, MA

May

- May 1st** 50,000 Laps – One Unbreakable Spirit® Challenge begins
- May 2nd** Tampa OI Support Group Meeting – Shriners Hospitals for Children – Tampa, FL
- May 2nd & 3rd** Frederick Running Festival 5k and Half Marathon – Frederick, MD
- May 4th** Bone China Tea
- May 8th** National Blue Jeans for Better Bones Day
- May 9th** Unbreakable Spirit Walk-n-Wheel: Nashville – Centennial Park, Nashville, TN
- May 16th** OI Foundation North East Regional Conference – Sheraton Stamford, CT
- May 16th** The 2nd Annual 5k for OI – Mt Pleasant, TN
- May 30th** South Shore Massachusetts Support Group Picnic – Weymouth, MA
OI Meet and Greet Activity Day – Houston, TX

June

- June 7th** The 5th Annual Unbreakable Spirit® Walk for OI, in Memory of Cheyenne – Sauk River Park, Melrose, MN

July

- July 9th** The 11th Annual Riley's Gathering Place Golf Outing – Wood Dale and Elmhurst, IL
- July 13th** The 17th Annual Miracle Michael Fund Charity Golf Outing – Naperville, IL

August

- August 17th** The 8th Annual OI Golf Classic – Atkinson Country Club, Atkinson, NH

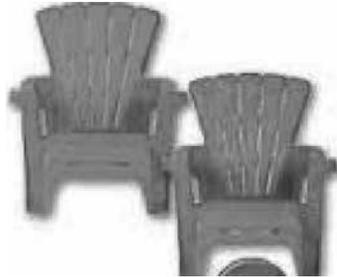
New events are being added all the time. Visit the events calendar at www.oif.org for up-to-the-date details.

Are you interested in holding awareness
or fundraising events for the OI Foundation?
Contact events@oif.org for more information today!

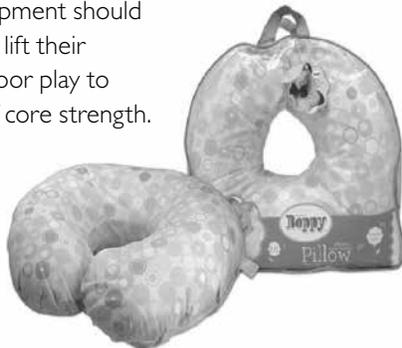
Adaptive Equipment for Children: PVC Pipe, Pool Noodles and Pinterest®

In the world of limited insurance dollars for durable medical equipment, creative strategies are always needed to help with mobility, access to play, and independence. Maureen Donohoe is a physical therapist at Nemours A.I. DuPont Hospital for Children in Wilmington, DE. At the 2014 OIF National Conference, she shared some of her best ideas for adaptive equipment to help kids with OI play, learn, and live more safely and independently. She gave examples of items available for purchase, as well as equipment that can be easily crafted at home from simple materials like **PVC pipe, duct tape, and pool noodles**.

For babies with OI, equipment is needed for bathing and playtime, for example. For bathing, Donohoe recommends regular **padded baby bathtubs** for infants, followed later by simple laundry baskets for easy transfers in and out of the tub. For older kids, a **child-sized plastic Adirondack-style chair** provides stable support.



For playtime, toys and equipment should encourage babies to reach, lift their heads, and spend time in floor play to encourage development of core strength. For example, **crenated-shaped pillows** provide support for babies to sit unassisted or lie down on their stomachs or backs.



As the child grows, adaptive equipment may be needed for using the toilet, encouraging standing, and playtime. **Potty seats** should provide support side to side but may need to have a shorter seat depth to support smaller hips and thighs. Step stools can provide access to taller toilets (and support feet while using the toilet). A **folding ring reducer** helps with toileting when travelling in public. When the child is in a cast, an upright toilet can be improvised by placing a **bed pan** on a sturdy surface.



High-quality **easels, weighted shopping carts, and play kitchens** can encourage kids to stand, while providing support during playtime.

Sturdy ride-on toys can encourage feet-on-the-floor mobility, while other ride-on toys can be adapted to provide motorized mobility, like those at Go Baby Go! (www.udel.edu/gobabygo/), for toddlers seeking independent mobility. As a child becomes more mobile, **tricycles**, then **training wheels**, then a support bar (which attaches to the bike and is held by the adult) can help the child transition safely to pedaling a two-wheeler.



Since children's bodies vary in size and ability, many items may need to be custom designed or modified, but that does not necessarily mean expensive. For example, everyday items such as pool toys, (**noodles, swim rings, foam balls**) are useful for cushioning hard surfaces and edges, and for positioning children in casts.



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Adaptive Equipment for Children: PVC Pipe, Pool Noodles and Pinterest® (continued from page 14)



Cardboard boxes can be cut to make tables that fit a child's specific needs in sitting as well as in a reclined position.

PVC pipe can be used to adapt many commercially available items, or even for making assistive devices for walking, early wheelchairs, or other equipment.

Many homemade adaptive equipment ideas can be found on **Pinterest®**. There are many creative ideas on Pinterest®, but one has to be careful when constructing items. It is important to test for stability and safety prior to attempting use with a child who has fragile bones.

Are you a problem-solver? Have you "engineered" a solution to a mobility, safety or other problem for your child (or yourself)? The OI Foundation would love to hear your innovative ideas, so we can share them with other members of the OI community. Send your tips and tricks (with photos, if possible!) to syoung@oif.org.



RARE DISEASE DAY

The Osteogenesis Imperfecta Foundation was proud to take part in Rare Disease Day 2015 on Saturday, February 28, 2015. Rare Disease Day is an international event to spread awareness and education of rare diseases and how they impact the lives of patients. Each year, Rare Disease Day is observed on the last day of February (Feb. 29 in leap years, Feb. 28 in other years). The goal is to draw attention to rare diseases as an important public health issue that cannot be ignored.

The international awareness-raising event has an ever-growing number of participating countries with the involvement of over 1,000 patient organizations.

To learn more about the global initiatives supported through Rare Disease Day, please visit rarediseaseday.org.

Event Spotlight: Fine Wines, Strong Bones



On Saturday, February 28th, the OI Foundation held the 15th Annual Fine Wines Strong Bones benefit at the Gaylord National Hotel in Washington, DC's National Harbor. A record-setting 275 people attended this annual fundraising event and spent the evening playing casino games, tasting delicious food and wine from around the world, bidding on over 100 auction items and participating in the Fund-the-Mission portion of the live auction. By the end of the night, over \$100,000 had been raised to help the OI Foundation continue its support of the OI community.

Thank you to all of the evening's attendees and a special thanks to event sponsors: Kennedy Krieger Institute, Smith & Nephew, The Mitchell and Louis Shulman Charitable Foundation, Greenberg Traurig, Veris Consulting, Evensky & Katz/ Folds Financial and Trilogy Federal.

Fine Wines Strong Bones could not be held without the help and support of the its Planning Committee members: Gayle & Roger Bache, Vivianne Coutts, Tim Dombro & Jamie Kendall, Jeffrey Eslinger, Bill McNutt, Mary McNutt, Kyle & Tracy Mulroy, Lisa Parman, Suzanne Richard, and Allison & Lawrence Schwartz.





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