

Osteogenesis Imperfecta Foundation Launches Campaign to Raise \$10 Million

50,000 Lives, One Unbreakable Spirit® Campaign to raise money to support OI research and programs

In April, the Osteogenesis Imperfecta Foundation publicly launched its **50,000 Lives, One Unbreakable Spirit®** Campaign. The campaign is a national effort to raise \$10 million in four years to fund groundbreaking OI research and to expand valuable programs and services for people living with OI, their loved ones, and the healthcare professionals who care for them.

For over forty years the OI Foundation has provided support and information to parents and individuals living with OI to help them manage the many challenges of living with osteogenesis imperfecta. None of our work is possible without the support of the OI community. If you would like to get involved, visit the OIF website at www.oif.org/50000.

For questions about the campaign, please email ecarter@oif.org.



Thank You for Participating in National OI Awareness Week

Thank you to everyone who helped make the 2013 National OI Awareness Week such a success! Across the country, hundreds of volunteers came together to help raise awareness about osteogenesis imperfecta. Eleven cities and states proclaimed May 4-11, 2013 National OI Awareness Week, members of the OI

community hung official OI Awareness Week posters in their local schools, shops and business, over 300 people participated in the OIF's National Blue Jeans for Better Bones Day on May 10th and more than 50,000 people were reached through our National OI Awareness Week social media campaign!



Participants of the Unbreakable Spirit® Walk for OI in Buzzards Bay, MA.

In addition to the incredible outreach programs, over 400 people attended National OI Awareness Week events, including the OI Foundation's national annual fundraiser, Fine Wines Strong Bones. These events, organized by OI community members who each found their own way to celebrate their Unbreakable Spirit®, helped educate their communities about OI and raise funds for the OI Foundation. The monies raised by these dedicated volunteers will be used to fund OI research and services for individuals and families living with OI.

Your energy and involvement have generated a mass increase of OI awareness making this a very exciting time for the OI community! We know the importance of raising awareness does not end after National OI Awareness Week—now the challenge is to stay connected and keep learning! We urge you to contact us at jfinkel@oif.org if you would like to plan your own OI awareness event. We hope you will continue to check our website www.oif.org and our **official Facebook page**, and invite others to join you, as we continue promoting OI awareness throughout the year!



Young advocates organized a lemonade stand to educate their community about OI!



Roberta Esposito and her husband stand in front of the OI information board she created for her wine and cheese social hour.



Attendees cheer on the Kentucky Derby at the OIF's annual Fine Wines Strong Bones event.



Jaden and her friend swam 100 laps and raised over \$100,000!



OIF logo cupcakes make any awareness week event great!

Save the Date



**Birdies
AND
Bogies**
For Better Bones

Birdies and Bogies: Register Today!

Monday, August 12, 2013 at Belmont Country Club, Ashburn, VA

Registration begins at 8am, with shotgun tee-off at 9am

Our Captain's Choice style tournament includes prizes, contests and a 19th Hole Reception with food and drinks. For more information and to register, visit www.oif.org/BirdiesandBogies

Accessibility Means Access to Your Community

By Mary Beth Huber

When the word “Accessibility” is used, it’s common to think of things like ramps, doorways, and counter heights. After speaking with Karen Braitmayer, the current Chair of the United States Access Board, I learned that accessibility really has a wider meaning. It’s about total access – allowing people with any disability to be engaged in their communities; that the built environment is usable and equitable; and that the products we use allow people with disabilities to fully participate. Accessible design is an important way for creating communities with fewer barriers to people with physical disabilities such as OI, hearing loss, and short stature.

The US Access Board is an independent agency of the Federal government that has a lot of impact on shaping the future of accessible communities. It provides guidance regarding accessible design under the ADA and other laws. It functions as a coordinating body among Federal agencies and directly represents the public, particularly people with disabilities. Half of the 24 members are representatives of Federal departments and the other half are of members of the public who are appointed by the president. Many different professions including architecture, transportation and technology plus many different disabilities are represented. Karen was appointed by President Obama in September, 2010. The OI Community is fortunate to be represented on this important board by a woman who brings both her personal experience as a wheelchair using, person with OI and her professional experience as an architect to this work.

The mission of the board is primarily guidance to Federal agencies and the businesses they work with. The Access Board works to ensure access to federally funded facilities and has become a leading source of information on accessible design. The Board works to investigate access questions and develop design criteria for buildings, telecommunications equipment like cell phones, transit vehicles, and for electronic and information technology including office equipment. Because the Federal government is a major consumer, the accessible design requirements for products it can buy often change the look and function of consumer products available to the general public.

Karen describes her colleagues on the Access Board as a “very talented Board,” and that it is exciting to work with people who all have the same goal. Currently the board is working on possible regulations for passenger vessels such as ferries, improving acoustics in classrooms, access to medical diagnostic equipment such as adjustable exam tables, and making developed outdoor spaces such as parks and beaches more usable. A particular interesting project that may have far reaching consequences is a study about making self-service kiosks accessible to people who use mobility equipment or have hearing loss.

An ongoing concern in the OI community is ensuring that doctor offices and other medical facilities can accommodate them. Karen brought to my attention a brochure by the Department of Justice – “Access to Medical Care for Individuals with Mobility Disabilities.” It can be downloaded free of charge from the website www.ADA.gov. It’s a good explanation of best practices and would be easy to share with the doctors you meet.

Meet Karen Braitmayer



Karen is an architect from Seattle, WA. She is a busy professional, a wife, mother, wheelchair user, OI Foundation volunteer and a woman who has OI. Karen and her family frequently attend the OIF National Conferences where Karen often leads sessions on adapting homes for people who have OI. Accessibility consulting and design services are a focus of her business; Karen Braitmayer FAIA. Karen is an enthusiastic person who also enjoys sailing, and travel. The OI Foundation congratulates her on being named Chair of the US Access Board.

Thank You to OIF Outgoing Board Members

On June 30, 2013 three members of the OI Foundation Board of Directors will complete their six years of dedicated service. Thank you to outgoing Board President, Sharon Trahan of MN; outgoing Treasurer, Tony Benish of IL, and Anna Gualano of AL, for their outstanding service. During their tenure they saw the successful development of the Linked Clinical Research Center program, the creation of the Impact Grant Program, successful national conferences and an increase in the number of people with OI served through the Information and Resource Center. Their leadership and guidance has laid the groundwork for the Foundation to continue growing and supporting the OI community. The OI Foundation looks forward to working with them for years to come.

Board President Sharon Trahan will remain on the Board through June 2014 as Immediate Past President. Mark Birdwhistell of KY will take over as President of the Board of Directors on July 1, 2013.



Sharon Trahan and Mark Birdwhistell



Tony Benish and Sharon Trahan



Anna Gualano and Sharon Trahan

Blue Jeans for Better Bones: A Growing Program

Blue Jeans for Better Bones (BJBB) is an ongoing program that focuses on company, school, and community outreach and awareness. This past year, BJBB has grown not only in how much has been raised, but also in the number of participants and locations across the country. Nearly twenty states have held at least one BJBB day, including Canada, and over \$18,000 has been raised to help the OI Foundation continue to provide programs and services for people and families living with OI.

Participants are also getting very creative with the ways they choose to raise OI awareness! One school had participants donate money in order to decorate a quilt square to make a blanket that was given to a student living with OI. Another school chose to sell OI awareness wristbands at a school dance, and one student promoted his BJBB day at a school-wide assembly. Companies are becoming heavily involved and having a lot of fun celebrating BJBB and sending us some great pictures!

Blue Jeans for Better Bones can become whatever you want it to be! From a community-wide event, to your office, or just friends and family, the options are endless. Another great way to expand your BJBB day is by creating an online webpage. This allows family members and friends from out of town to participate by being able to donate online. The Foundation will mail them stickers or an OI awareness wristband to wear on the day of the event! A webpage also allows you to share the information on your social media sites and spread the word about OI even quicker.

Become part of the growing campaign and get involved in your own Blue Jeans for Better Bones day. Contact OIF Development Associate Jessica Finkel at **800-981-2663** or jfinkel@oif.org to get involved.



13th OI Foundation Scientific Meeting

The OI Foundation's scientific meetings allow researchers who study OI and related topics to share their latest work, build relationships that encourage collaboration, and otherwise serve as an incubator to encourage new directions in OI research. This year's scientific meeting was held, April 10-12, 2013 in Chicago, IL. Forty-nine people with experience in OI and in basic research met to discuss "Mouse Models for Dominant and Recessive OI."

Animal models allow researchers to test and compare treatments, to study long term effects quicker than is possible in people, and to lay the foundation for answering questions about how OI changes bone and other tissues. Animal models also make it possible to look for unintended consequences of a treatment and seek answers to questions that are difficult to study in people such as whether increasing the amount of OI bone also increases bone strength. Not that long ago, discussions about Mouse Models for OI, focused on how to create a model of OI in mice. Today, the discussion focused on what has been learned from those models and how to use the different mouse models to learn more in the future. It is important to note that all of the studies reported on at this meeting complied with US federal ethics guidelines and followed the highest standards for care.

An outstanding group of researchers from the US, Canada and Europe were invited to give presentations. Dr. Joan Marini, Chief of the Bone and Extracellular Matrix Branch of the NICHD at the National Institutes of Health served as this year's chair. The meeting provided a cutting-edge update on OI bone pathology

and what has been learned about OI mechanisms in murine models at the molecular, cellular, and tissue levels. Lessons learned from the treatment of OI mice with drug therapies that are still being developed and cellular therapies (cell transplant therapies) were explored. Discussions focused on how to best move both basic and treatment studies in new clinical avenues.

This work is important because learning more about how OI works on a basic level is one way to identify potential new targets for treatments and get a head start on testing drugs or potential drugs that are in the very earliest stages of development.

The presentations suggested a growing awareness that the specific OI mutation may be a key to understanding why people with OI respond to treatments differently. The possibility that there are male/female and age differences in response to treatment was also raised. The program ended with a look at some of the newest mouse models that may hold the key to future breakthroughs.

The OI Foundation is grateful to the Buchbinder Family Foundation for their generous support and to American Society for Bone and Mineral Research (ASBMR) for a grant that allowed several young investigators to attend.

A summary of the presentations will be posted on the OI Foundation website under the Research Heading sometime this summer. Watch the OI Foundation's E-News for an announcement.



Outreach to High Schools

Recently, OIF Development Associate Jessica Finkel attended the Indiana State District Key Club convention in Bloomington, IN, where she gave a presentation about the OI Foundation and

ways to get involved and help support the OI Foundation. Key Club is a High School organization, sponsored by Kiwanis International, whose mission is to serve the children of the world by performing acts of service in the community. It was very successful and the high school students were extremely receptive to getting involved. Many students are interested in holding events at their school and an Unbreakable Spirit® Walk-n-Wheel is already being planned!



OIF Development Associate Jessica Finkel (left) and Key Club member Sinclair Jones (right)

A Letter from 50,000 Lives, One Unbreakable Spirit® Campaign Chair, Mark Birdwhistell

The following is a letter from OIF Board Member and Campaign Chair Mark Birdwhistell about the OIF's new 50,000 Lives, One Unbreakable Spirit® campaign. This letter was mailed to all OI community members. The OIF relies on your support to help fund new research, provide services and programs for individuals and families living with OI, and to help increase awareness about OI. Please visit www.oif.org/50000 to learn more about the campaign and to make a contribution.

In April of this year, the OI Foundation launched its tremendously important campaign to raise \$10 million over four years. The 50,000 Lives, One Unbreakable Spirit Campaign celebrates the determination and resiliency of not only people living with OI but also the many people who are working hard to do the things necessary to improve lives. They are working to accelerate the pace of OI research in the lab and on Capitol Hill; they endeavor to advance the work of the Linked Clinical Research Centers; they reach out and connect with people of all ages who live with OI and they hold events all across the country to support the programs and services of the OI Foundation.

We know that the 50,000 people who live with OI in our country could fill a football stadium but we also know that the people who love, respect and work with them could fill a thousand football stadiums! That is why the leadership of the OI Foundation is convinced that with your help we will not only meet our goal but we will exceed it!

At the recent launch of the campaign Gil Cabacungan, an OIF board member, spoke about his commitment to the campaign:

"Our family is committed to the 50,000 Lives, One Unbreakable Spirit® Campaign because through the OI Foundation we have been introduced to an incredible world of opportunities that surpass any of our expectations. Now, as part of the OI community, we are connected with very special and unique individuals, who support and challenge people living with OI, including our son."



Gil and his son Alex

Thanks to a matching gift challenge made again by a generous family in Florida, the impact of your donation will be doubled, if you contribute between now and July 30th!

The 50,000 Lives, One Unbreakable Spirit Campaign is about people helping people. At the end of the four year campaign the OI Foundation will be able to report that:

- **10 new scientists are working on treatments that will lead to advances in the quest to find improved treatments and a cure for OI**
- **thousands of people will have been helped by the OIF Information Center and thousands will have seen new on-line videos to help them learn about everyday issues that affect people with OI and how to manage those issues**
- **2,000 people will have attended an OIF National Conference**
- **more than 10,000 people will have connected with each other through the OIF website, Facebook page and other forums.**

It introduces you to real people who will benefit from the success of the campaign. It talks about living with OI day to day...the trips to the emergency room, learning to splint broken bones at home, chronic pain, fear and anxiety. But it also talks about exciting first days of school, riding bikes, joining the swim team, graduations, and building fulfilling careers and happy family lives. OI brings with it a lifetime of challenges and triumphs and it leads each person down his or her own path through life. But, as is displayed in so many different ways, the one thing every person with OI has in common is an Unbreakable Spirit.

Please help the OI Foundation meet our goal of providing more OI research and providing up to date programs and services for those who depend on us. Help us serve every one of the 50,000 people currently living with OI and be prepared to serve those who will receive an OI diagnosis in the years to come.

Thank you for your continued and generous support.

Sincerely,

Mark Birdwhistell
Campaign Chair
OIF Board of Directors

Research to Follow: OI and Dental Problems

An article recently published by the OI team from the Shriners Hospital for Children-Canada in Montreal examined a serious dental-skeletal problem – malocclusions. The team demonstrated that malocclusions were significantly more severe in children with OI than in children without OI.

A malocclusion is an abnormal relationship between the upper and lower jaws or teeth. It creates problems in the way the teeth come together. This may be due to the poor relationship of the upper and lower jaws to each other; the alignment of the teeth, or both. This type of problem usually includes crooked teeth, protrusive or retrusive jaws, “cross-bite,” “over-bite” and “open-bite.” Treatment is usually provided by an orthodontist. For children with OI Type III and IV it is usually necessary to be treated by an orthodontist in a craniofacial center. The particular treatment plan depends on the specific problem(s) with the bite and the teeth. If the malocclusion is caused by skeletal discrepancies then orthognathic (jaw) surgery may be required along with orthodontia. The main goal of all treatments is to provide better chewing function and improve appearance.

This study is the first major look at this specific dental problem in children who have OI. Other dental issues that are associated with OI such as dentinogenesis imperfecta, impacted teeth and delayed tooth development have been studied more often. A group of 49 children with OI, who were seeking orthodontic care, were evaluated at the craniofacial dental center in Montreal. Participants were between 5-19 years old, about evenly split between boys and girls and represented mild, moderate and severe forms of OI. OI Type I was reported in only 16% of the participants. This low number is indicative of the fact that most children with Type I OI can be treated outside a special setting. All of the OI participants were receiving intravenous bisphosphonate therapy. The control group was age and sex matched and were “otherwise healthy children” seeking orthodontic treatment.

This study had two major findings:

- Malocclusions in OI children were much more severe than in the control group.
- Children with moderate and severe OI (OI Types IV and III) had the most severe malocclusions. The malocclusions were not only affecting their appearance but severely impairing their chewing capacities. In fact this study describes that children with Type III and Type IV OI have more complex malocclusions that are much harder to treat.

What does this mean?

- Children with Type I OI may be treated like any orthodontic patient as long as they do not have dentinogenesis imperfecta. In addition extra care must

be taken to move the teeth more slowly than the usual practice.

- Children with OI Type III and Type IV in need of orthodontic treatment need to be evaluated on a case by case basis.

What needs more Study?

The effect of IV bisphosphonate use on complex dental procedures needs further study. As much as it helps long bones there is some evidence that bisphosphonates inhibit tooth movement and may have an effect on normal craniofacial development. The effect of specific treatments for malocclusions and other craniofacial problems also needs study.

Recent correspondence with Dr. Retrouvey, one of the authors on this paper, indicated that the Montreal center has begun follow studies on these questions using OI mice. The studies are examining if treatment with a bisphosphonate affects teeth and how teeth may be moved efficiently in OI patients.

Why is this study important?

For the first time, the extent of the problem has been described which is an important first step to improved care options. Current treatments result in variable results due to the severity of the malocclusion and no single treatment could be recommended, for all children who have OI. Future treatments may have to involve prosthodontics rehabilitation. It is hoped that this information about the extent of the malocclusion problem in children with OI will lead to studies for new and improved treatments that will further improve the quality of life for all people who have OI.

Study title: Evaluation of the severity of malocclusions in children affected by osteogenesis imperfecta with the peer assessment rating and discrepancy indexes.

Authors: Jean Rizkallah, Stephane Schwartz, Frank Rauch, Francis Glorieux, Duy-Dat Vu, Katia Muller, Jean-Marc Retrouvey. The abstract is posted on the OI Foundation website.

This article was reviewed by Dr. Jean-Mark Retrouvey, Director, Division of Orthodontics McGill University in Montreal and Dr. James Hartsfield, Director, College of Dentistry University of Kentucky and member of the OI Foundation’s Medical Advisory Council.

(BT article, April 2013 by MB Huber in consultation with Drs. Hartsfield and Retrouvey)

Wheels in Motion—Driving in the Safe Lane

Whether you are just learning how to drive or have been behind the wheel for years, there are a few important necessities to being a safe driver in today's increasingly challenging driving environment. For a person with moderate to severe OI learning to drive safely can require several steps before getting behind the wheel. Besides successfully completing a driver education program, most states require all prospective drivers who have a chronic medical condition to have an evaluation by a Certified Driver Rehabilitation Specialist. Some states also require a letter from your doctor. Your state's Department of Vocational Rehabilitation and the Association for Driver Rehabilitation Specialists and your car insurance agent can help clarify what rules apply to a prospective driver with OI in your community.

Driving assessments cover driving history, medical history, vision perception, functional ability, and reaction time. After the initial assessment, the prospective driver works with a certified driver rehabilitation specialist to identify the adaptive aids such as a smaller steering wheel, pedal extenders, hand controls, etc. your car will need. Whenever possible it is best to use the exact adaptive equipment for on-the-road practice and for taking the driving test. Reevaluations and adjustments may periodically be needed for a person with OI even a long-time driver if strength or hearing ability changes.

Adaptive equipment for cars, vans and trucks is expensive. So it is important to purchase exactly the right piece of equipment, have it correctly installed and keep it well maintained. Especially for a person of shorter stature, "trying on" equipment is an important step. This is one time when shopping on-line might not be the best option. If you are considering purchasing a new vehicle, check if the manufacturer has a "mobility program" Used adapted vehicles are available in some areas. Additional information about reliable sources for adaptive aides is available from the driver rehabilitation specialist and local mobility equipment dealers. Visit the website of the Association for Driver Rehabilitation Specialists, www.aded.net, click on "Membership Directory", and enter your state to find a list of certified driver rehabilitation specialists and mobility equipment dealers.

Live Well—Time to Get Active!

It is almost summertime and longer days and warmer nights usually mean more opportunities to increase your physical activity. Maintaining a healthy weight through good nutrition and moderate physical activity is a goal that all adults and children with OI are encouraged to achieve. It is well established that being overweight is a risk factor for developing many secondary health issues. Adults with OI especially need to maintain a healthy weight to avoid putting extra stress on the skeleton and impeding mobility. Regular and consistent physical activity has benefits for weight control, enhanced cardiovascular and lung health, improved ability to handle infection, and increased physical function to support independence in daily activities such as walking or wheeling.

Knowing your body mass index (BMI) gives you a good sense if you are at a healthy weight. The normal range for adults in the general population is between 18.5 and 24.9. People with OI who are shorter than average or who have rods tend to have higher values and are more likely to range between 26-27 — a BMI that would indicate overweight in the general population.

You can calculate your BMI with the following formula:

$$\text{BMI} = \frac{(\text{weight in pounds})}{(\text{height in inches}) \times (\text{height in inches})} \times 703$$

When developing a new personal fitness plan, start by talking to your doctor about your exercise interests, capabilities and limitations. Rehabilitation or exercise specialists who are familiar with OI or with osteoporosis can help design an appropriate program. Some physical fitness experts are now emphasizing the fact that *physical activity does not have to be strenuous for you to gain health benefits*. With the summer fast approaching, now is the time to plan how you'll make the most out of warmer weather. Feel the benefits of healthier decisions this summer by incorporating positive wellness habits into your everyday life.

OI Registry Update

The OI Registry is an on-going program of the OI Foundation that is managed through the Kennedy Krieger Institute in Baltimore, MD. The OIR contains contact information for people who have OI of all ages and many different nationalities. In addition, it contains self-reported information about each

person's health and experience with OI. The OIR is designed to protect the privacy of registry participants. The information is used to promote more research about OI. Registrants are asked to begin by filling out an on-line questionnaire, and then to follow up each year by reviewing and updating their information. Registrants are contacted by the Registry Manager when new questions are added to the questionnaire and to alert them to a research study they are eligible for. Today, 1,980 people from 40 different countries are registered. The power of Registry cannot be underestimated. The de-identified data (information without names) provides researchers with ideas for new studies related to OI. In addition the Registry makes it possible to alert eligible people about new studies. Finding enough people with a rare disorder who can participate in a study is often very challenging. Studies that are too small rarely completely answer a question.

Current studies using the resources of the OI Registry include an ongoing project evaluating a potential link between heart problems and OI, an awareness project about OI and skin conditions by the Dermatology Department at Johns Hopkins Medical Center, a survey about physical therapy and OI by the Physical Therapy Department at the Kennedy Krieger Institute and a glaucoma study. To expand outreach around the world, a Chinese language version of the OIR is now available.

We are very grateful to the many adults with OI and parents of children with OI who are currently members of the OI Registry. For this valuable effort to continue to

go forward, the active participation of the OI community is needed. If you are already registered login and update your profile this month. If you aren't sure you are registered, contact the OI Registry Manager. If you are new to OI or not yet registered, **please join today**. Please contact the OI Registry Manager at **443-923-9180** or through email at **oiregistrymanager@kennedykrieger.org** if you have any questions, suggestions or concerns regarding the OI Registry.

Heart Disease Study Continues to Recruit Participants

To better understand the occurrence of heart and blood vessel conditions in osteogenesis imperfecta (OI), the Bone and Osteogenesis Imperfecta Department at the Kennedy Krieger Institute (KKI), Baltimore, MD, is recruiting children and adults with OI who have a current or previous diagnosis of heart valve problems, problems with the aorta or other blood vessel problems, or who have had surgery for these disorders. For details about the study, please visit: <http://osteogenesisimperfecta.org/OI-heart-research-project.php>. The principal investigator is Jay Shapiro, MD.

Dr. Ingo Grafe Receives Michael Geisman Fellowship



Dr. Ingo Grafe from Baylor College of Medicine in Houston, Texas, was recently awarded a Michael Geisman Fellowship from the OI Foundation. Dr. Grafe's research is titled "Dysregulated matrix-cell signaling as a mechanism of Osteogenesis Imperfecta in the *Crtap^{-/-}* mouse". His preliminary data suggest that dysregulation of certain signaling pathways contributes to the OI phenotype and that modulation of these pathways through specific antibodies has beneficial therapeutical effects on the bone and also on lung abnormalities.

Confirming this novel mechanism could also translate to other forms of OI and potentially help to develop more effective therapies for OI.

The Michael Geisman Fellowship award allows the OI Foundation to increase and facilitate OI research through development of career investigators. In addition to the value of the research project, this grant encourages investigators to enter and stay in the field of OI research. An increase in the number of investigators will speed the course of OI research, putting treatments and cures within the reach. The Fellowships, up to \$50,000, are awarded on a one year basis, with the possibility of a second year, depending on review of the progress report by the Scientific Review Committee.

Thank You Bone China Tea Participants

Thank you to everyone who participated in Bone China Tea this year! It was a great success and donations are still coming in. A huge thank you also goes out to our wonderful co-chairs, Jenny and Susie Wilson, without them, Bone China Tea would not be possible. We cannot wait for next year! If you would like to host your own Bone China Tea event, please contact OIF Development Associate Jessica Finkel at **800-981-2663** or jfinkel@oif.org.

Managing Your Health: Know Your Health History

One of the challenges everyone faces is keeping track of health information. This is particularly important for young adults who have OI. Getting ready to go to college, living independently in a new city, and traveling are all occasions when it is critically important to know one's general and OI history. Often parents know their child's health history in great detail, but the young adult is not as well informed.

Basic personal information should be accessible if you have a doctor's appointment or need emergency medical treatment. More detailed personal information should be kept in an organized manner that could take many forms from a 3-ring binder to a secure web-based system. It is also important for people who have OI to become familiar with their family's health history. Learning as much as possible about your parents' and grandparents' generations will help identify if different conditions "run in your family," such as diabetes or a type of cancer. This will help you and your doctor work out a plan for healthy living. OI affects many body systems, but it is not your entire health profile.

Students over age 18 and people who are not married should consider making arrangements to designate an agent who has permission to review their medical records and speak for them in an emergency. A parent, other close relative or a trusted friend can be a good choice.

In general, your health record should include basic information for filling out forms, your current health status and medicines, a list of surgeries, and a list of information about OI.

Basic information to know would include:

- Name, address and phone number(s) for your primary care doctor and any other doctors you see on a regular basis such as an orthopedist, or endocrinologist
- Insurance information – Company, membership number, group number, contact phone number(s)
- Name, phone number, and social security number of the person who is the primary person on the insurance policy
- Name and phone number(s) for your emergency contact person
- Your social security number

Current Health Information would include:

- OI Diagnosis, including degree of severity (mild, moderate, severe) and/or OI Type plus how you were diagnosed

- Medicines you are taking including prescription AND over-the-counter medicines, or supplements and the name of the person who prescribed them
 - ♦ If you are taking drugs to control pain, especially if one is a narcotic, carry a letter with you from the prescribing doctor describing the need and the dose
- If you are currently or have in the past been treated with a bone building drug such as one of the bisphosphonates be sure to list which one, how you received it (oral or intravenous) and the exact dates you started and stopped
- Chronic health problems including: asthma, diabetes, high blood pressure, depression, constipation and anything else you regularly receive treatment for including vision or hearing
- OI related health information such as
 - ♦ Presence of dentinogenesis imperfecta
 - ♦ History of bleeding, or bruising
 - ♦ Most recent fracture
 - ♦ Pain history
- Know your numbers for blood pressure, cholesterol, and vitamin D status
- Allergies to any drugs or foods
- A list of information about the rods and other medical implants that are currently in your body. This information should include the location, type of rod or implant, the kind of material it is made of (for instance rods can be titanium or stainless steel), and when each one was implanted. This is important if you need x-rays or other imaging tests.
- Women need to know at what age they began menstruating
- Mobility information including wheelchair, cane, crutch models, description of braces and contact information for your medical equipment supplier
- A list with contact information of ALL your doctors including whether you receive some of your care at an OI or Bone Dysplasia Clinic
- Life-style information including whether you exercise, smoke, have experienced depression or have problems related to misuse of drugs or alcohol

Past health history is also important. Keep an up-to-date list of:

- Surgeries, including date and hospital
- Other hospitalizations
- Major illnesses such as pneumonia
- Approximate number of major broken bones
- Immunization record including date of latest flu shot
- Records of vision and/or hearing checkups
- Records of any other screenings you have had such as an echo-cardiogram, mammogram, colonoscopy or cholesterol test

Information about OI

- OI is a life-long genetic condition that causes fragile bones, and also makes other connective tissues fragile; it is not solely a pediatric condition
- OI symptoms range from mild to severe depending on the specific type of OI and the person's response to treatments
- OI affects lung tissue so all people who have OI, even those without scoliosis, may have at least a slight degree of respiratory compromise; asthma is common
- Approximately 50% of adults who have OI have hearing loss; many use hearing aids and some have cochlear implants

- Baring respiratory and cardiovascular complications, people who have OI can usually expect to live an average life span

Family health history information to collect

- Ethnicity of relatives in parent and grandparent generations
- Medical conditions
- Mental health conditions including alcoholism or other substance abuse
- Pregnancy complications
- Hearing loss, heart disease, diabetes and the age when each condition was diagnosed
- For deceased relatives give the age at time of death and cause of death.

Through the Linked Clinical Research Center project, researchers are gathering information about the health of children and adults who have OI across the entire life span. We believe that adults who have OI seem to have similar risks as their non-OI peers for many conditions such as diabetes but more work is needed to be able to make specific recommendations. We know that OI can complicate treatment for some conditions such as heart valve repair. We also know that staying healthy and fit helps people enjoy life to the fullest. So begin now to assemble your vital health information as part of making a plan for a healthy life.

Are You a Member of the OIF?

Members are the lifeline of the Osteogenesis Imperfecta Foundation. We count on your support to help fund research, provide information and support, develop new resources, expand support groups and increase public and professional awareness about this disorder that affects 50,000 people.

Membership Levels and Benefits

All members receive:

- A membership card
- Voting privileges in our annual board member elections
- An OI Foundation lapel pin

Membership Levels

Friend (\$36/year, just \$3 per month)

Family (\$60/year, just \$5 per month)

Professional Member (\$100/year)

Healthcare professionals will receive recognition in the OIF Annual Report; a subscription Breakthrough as well as first access to the latest published scientific research and materials; Invitations to local area events including scientific meetings and professional meetings

Unbreakable Spirit® Member (\$120/year, just \$10 per month)

You will receive recognition in the OIF Annual Report along with early bird pre-registration for our most popular events that sell out quickly such as Medical Consultations or Women's Forum at the OIF National Conference

Corporate Member (\$1,000/year)

Your OI Clinic or healthcare organization will receive: recognition in the OIF Annual Report along with logo placement on the OIF website; a subscription and half-page ad in *Breakthrough*; invitations to local area events; Priority as an exhibitor and recognition at the OIF National Conference on all conference materials as well as the opportunity to include one promotional item or flyer in the gift bag and an invitation to Professional Series at the OIF National Conference

To become a member, call the OI Foundation at **800-981-2663** or visit **www.oif.org/hh_membership**.



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Do you live in the Southeast? Save the Date November 2nd –

OIF Regional Conference “Uniting Unbreakable Spirits”

The OI Foundation invites you to join us at a **One Day OI Regional Conference in Tampa, Florida**, on **Saturday, November 2, 2013** to learn more about managing osteogenesis imperfecta and connect with members of the OI community. This full-day OI education event will feature the following experts:

- ◆ OI Foundation Medical Advisory Council Chair Dr. Francis Glorieux,
- ◆ OIF Medical Advisory Council Member Dr. Cathleen Raggio,
- ◆ St. Petersburg-based Orthopedic Trauma Specialist Dr. Scott Beck,
- ◆ and Mental Health Counselor Michelle Fynan.

Join other people from your region for a wonderful opportunity to meet face-to-face with leading medical experts to hear the latest information on living well with OI. If you've attended OI Foundation National Conferences in the past, or if this is your first OIF Meeting, you won't want to miss this dynamic and informative event!

The meeting will be held at The Embassy Suites in Tampa, Florida (USF/Near Busch Gardens). For more details and registration information, please visit www.oif.org/regionalconference.