

# 2010 Annual Report



Living Well with an Unbreakable Spirit

# A Message from the President



Sharon Trahan

The mission of the Osteogenesis Imperfecta Foundation is to improve lives. I am proud to report that the work we have accomplished during FY 2010 reflects real steps forward in research, education, awareness and mutual support.

Our partnership with the Children's Brittle Bone Foundation has enabled us to award 20 grants totaling \$140,000 for adapted vehicles, computers, hearing aids, wheelchairs, van lifts and other products and services in 2010. We have partnered with Shriners Hospital for Children in Chicago to award sixteen Driving Grants in the past two years for driver evaluations, lessons, or adaptive equipment for a vehicle. As a result, dozens of people with OI are working towards increased independence, advancing their education, or simply finding it easier to interact with others. This is the type of difference in people's lives that I and the OI Foundation are extremely proud of!

As you will read in this Annual Report, we have increasingly focused on improving the health and care received by adults with OI during 2010. Adult health was a major focus of the OI scientific meeting in April 2010, *Improving Musculoskeletal Outcomes for Individuals with Osteogenesis Imperfecta*, which was chaired by Laura Tosi, M.D. At our National Conference last summer, Dr. Tosi worked with volunteers to convene more than 50 adults with OI in focus groups with the goal of hearing about their concerns. The resulting program is called the Adult Natural History Initiative (ANHI), detailed in these pages. This initiative is one of several important activities supported by the Foundation that will provide a clearer description of the health needs of people with OI, lead to improved treatments, and with the research funded by the foundation, move us ever closer to a cure.

This years' National Conference brought together more than 500 people to celebrate the OI Foundation's 40th birthday. The energy and enthusiasm in Portland was inspiring! Two of our founders, Gemma Geisman and Renee Gardner, reminded us how the foundation was started around a kitchen table, and the wide range of sessions and activities engaged all ages in learning, sharing and connecting with friends.

None of these successes can happen without the generous support of the many donors listed in these pages. Thank you for your gifts! We work hard to utilize your investments in a way that achieves the greatest progress possible towards fulfilling our mission. We are pleased to report that Charity Navigator awarded the Foundation with its highest 4-star rating this year for our "ability to efficiently manage and grow (our) finances"! The OI Foundation also meets the highest standards of the BBB Wise Giving Alliance and the National Health Council. I'm pleased to have the acknowledgement from these organizations that your dollars are being used wisely.

During 2011, we will work to maintain our high level of consumer support, build on the successes of this past year, and move cutting-edge research forward! Thank you for your involvement in this work and your confidence in your Foundation!

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Sharon Trahan President, OI Foundation Board of Directors

### THE OSTEOGENESIS IMPERFECTA FOUNDATION'S MISSION

The mission of the Osteogenesis Imperfecta Foundation is to improve the quality of life for people affected by OI through research to find treatments and a cure, education, awareness, and mutual support.

# 2010: A Year in Review

By Tracy Hart

The OI Foundation had a very busy 2010! In addition to celebrating 40 years of the OI Foundation, this year included a scientific meeting; our Biennial Conference; the implementation of the Impact Grant Program; expanded work of the Linked Clinical Research Centers; support group meeting activities and much more!

The 2010 National Conference on OI, *Living Well with an Unbreakable Spirit*, attracted more than 500 members of the OI community, caregivers and medical professionals to Portland, Oregon. According to one family who attended the medical consultation session of the conference, "It is so wonderful to have experts in the field at your fingertips... the time they spent with us was like a weight off my shoulders."

In addition to our family conference, the Foundation continued to move forward on research initiatives designed to improve care for children and adults with OI. In April 2010 the Foundation held the 9th OI scientific meeting in Chicago, Illinois. The meeting, titled *Improving Musculoskeletal Outcomes for Individuals with Osteogenesis Imperfecta,* chaired by Dr. Laura Tosi, focused on the orthopedic issues affecting people with OI across the life span, including the importance of exercise and the potential to adopt non-invasive technologies to measure bone quality that are already utilized for osteoporosis patients. Dr. Tosi also attended the National Conference in Portland and held a series of adult focus groups to help shape future directions for OI research relative to adult care.

In addition to our meetings, the OI Foundation has continued partnering with organizations like the Shriners Hospital for Children in Chicago to provide driving grants to young people with OI. To date, the awards have enabled 16 teens and young adults to pay for adapted driving evaluations, lessons or adapted equipment for their car. Another very successful partnership with our friends at the Children's Brittle Bone Foundation is the Impact Grant Program. The program provides funds to support people with OI in need of equipment or services that will improve the quality of their life.

For those who are now enrolled in the study at one of the six active Linked Clinic Research Centers, I hope your experience has been a positive one. The Natural History Study that is being conducted through the LCRCs will help us gather data to begin performing clinical studies that will answer questions about our very complicated disorder.

And, lastly, the Foundation has continued to be a source of information and referral for the OI community. Last year we answered more than 6,000 requests for information and saw a 25% increase in the number of people visiting our website. I'm sure many of you are now connected to the Foundation through our NING social networking site on our website or through our facebook page. You can even follow us on Twitter!

So, 2010 has been a busy one for the Foundation but as always we look to you, our loyal supporters, for your help in making 2011 successful.



OIF CEO Tracy Hart and former OIF Board Members Susie Wilson and Jamie Kendall

# **OIF Celebrates Successful National Conference in 2010**

The 2010 National Conference on OI was held in Portland, Oregon on July 8-10. Over 500 people from all over the country, and world, attended this national event. The three days were filled with informative sessions, social activities, and fun! One of the most notable parts of the Conference was the opportunity to present our founding Gemma Geisman with a Humanitarian Award for her lifetime of work. She is the mom whose article in *Redbook* magazine more than 40 years ago led to the formation of the OI Foundation. At Conference, Gemma also read from her recently published

The day before the Conference began; attendees were given the opportunity to schedule one-on-one medical consultations with an OI specialist. Over 100 appointments were made! That night, everyone gathered for a Welcome Reception, complete with a roaming magician! While the days were filled with important sessions with topics such as: The Genetics of OI, Splinting Workshop, and Home Improvements & Resource Ideas, the nights were filled with social activities. The exclusive movie screening of Broken Dreams, featuring Nicole Gerth, an actress who has OI, was a popular event. Nicole attended the event, and answered questions about the movie and her career.

The highly anticipated Talent Show,

hosted by Katee Shean from *So You Think You Can Dance*, showcased almost two dozen kids. The show was directed by Suzanne Richard, Director of the Open Circle Theater in Washington, DC. These kids felt 10 feet tall while on the stage! After the show, approximately 500 attendees celebrated the Foundation's 40th Birthday by enjoying birthday cake.

"It finally dawned on me that lectures and presentations are secondary to the real reason for the Conference: connecting with the OI community – the folks with OI, the families, the medical and research community entrenched in finding a cure, and the organizers of the event from the OIF. The spirit of the conference is actually visible in the halls of the hotel."

~Laurent Beauregard, first time Conference attendee memoir, *From the Seeds of Sadness*, and answered questions along with her adult daughter Cathy and another early leader, Renee Gardner.

The National Conference plays a vital role in the lives of many people with OI. In addition to the unparalleled informational sessions, and opportunities to meet with leading OI experts, the Conference provides attendees with an inviting and inclusive environment. One Mom repeated her 9-year-old daughter's happy statement that "Everyone gets to play together here!"

The 2012 National Conference will be held in Washington, DC, at the Crystal Gateway Marriott in Crystal City, VA. A major factor in the city selection

process was the opportunity Washington, DC offers to increase advocacy and awareness efforts on Capitol Hill.





# **Education & Mutual Support**



# **Education & Mutual Support**

# **OI Foundation Support Groups**

The OIF Support Groups continue to connect people with OI in cities across the country. With four new support groups forming in 2010, the groups held meetings and social activities ranging from holiday parties, to summer picnics, to presentations by leading OI experts.

Did you miss your local support group meeting? Check this list of states and months in which meetings were held during 2010.

Arizona: March, May Connecticut: March Florida (South): January, March, May, June, December Georgia: May Louisiana: August Missouri: May, September New Jersey: April, September, November New Jersey: April, September, November New Mexico: February, April, May New York (Long Island): April, May, June, July, December Ohio (Cincinnati): March, December Oregon: June Pennsylvania (Pittsburgh): July

To ensure you don't miss the next support group meeting, stay posted for news by going to the Events page or calendar of events on www.oif.org. A full listing of the OI Support Groups can be found under the Support Networks tab on www.oif.org.

# **OI Foundation Receives Top Rating for Sound Financial Management**

The OI Foundation is among the top 25 percent of charities nationwide, according to Charity Navigator, which calls itself "the nation's largest and most-utilized evaluator of charities."

The organization has awarded its highest 4-star rating to the OI Foundation "for its ability to efficiently manage and grow its finances."



"This 'exceptional' designation from Charity Navigator differentiates Osteogenesis Imperfecta Foundation from its peers and demonstrates to the public it is worthy of their trust," according to a letter from Ken Berger, President & Chief Executive Officer of Charity Navigator.

"We are very pleased by this recognition from Charity Navigator," said CEO Tracy Smith Hart. "It reinforces our message to constituents and donors that we work hard to make the very best use of their dollars."

To review Charity Navigator's data on the OI Foundation's financial efficiency, accountability and transparency, visit http://www.charitynavigator.org/index.cfm?bay=search.summary&orgid=8139.

# **Education & Mutual Support**

# **OIF/CBBF Impact Grant Program Continues to Change Lives**



In partnership with the Children's Brittle Bone Foundation more than 20 grants totaling \$140,000 were awarded to people with OI in need of products or services that would improve the quality of their lives in 2010. Grantees received funds to purchase adapted vehicles, computers, hearing aids, wheelchairs, van lifts and other products and services. Since its launch in 2009, the Impact Grant program has received over 240 applications.

The following letter is from Taryn Smith, an Impact Grant recipient who received a new wheelchair lift for her family's van:

#### Dear Donor,

I want to thank you so much for your generous contribution that made it possible for my son, Matthew, to receive an Impact Grant from the OI Foundation. This impact grant has made things so much easier for Matthew. We are now able to transport his power wheelchair wherever we go which gives him a lot more independence than he has ever had before. The lift in the van is great. Matthew is now able to go places in public with friends and family and get around by himself. This gives him such a great feeling of independence. Now that he is getting older, 9, he no longer wants to be pushed around in either a stroller or grocery cart. We are also able to have his chair at home now. We had only been able to keep it at school prior to us having the lift installed in our van. He is now learning how to do and get things on his own at home.

We cannot thank you enough for your generosity.

Sincerely,

Taryn Smith Mom to Matthew, Type III OI



Matthew, age 9, was one of 20 people awarded an Impact Grant in 2010.



2010 Driving Grant recipient Rosemary McDonnell-Horita, Andy Pilgrim Adaptive Driving Grant Sponsor, Dr. Peter Smith, Orthopedic Surgeon at Shriners Hospitals for Children-Chicago.

# Driving Grant Program Continues to Help Young Drivers

In November 2010 four Driving Grants were awarded through a special program sponsored by Shriners Hospital for Children-Chicago and the OI Foundation. The adapted Driving Grant program provides financial aid to help cover expenses faced by young people with OI who wish to learn how to drive. The \$500 grants can be used for driver evaluations, lessons, or adaptive equipment for a vehicle. Since the program began in 2009, sixteen young people have received awards totaling \$8,000.

# Thank You and Congratulations to Our 2009 Volunteer Award Recipients

Frank Fossati, Christine Wyman Rossi and Rebecca Lee Perritt are the 2009 recipients of this year's OI Foundation volunteer awards.

Selected for the Thelma Clack Lifetime Volunteer Achievement Award, Frank Fossati has served the OI Foundation for 29 years. Motivated by his love for individuals and families with OI, Frank has been at the helm of the annual golf and tennis tournament sponsored by the Southern California Petroleum Industry Charity Association (SCPICA). Through his efforts, the SCPICA has become the longest running charity event in support of the Foundation, raising over \$1,150,000. While officially holding the title of Treasurer, Frank oversees every aspect of the tournament. It is generally understood that without him, this annual event begun in 1985 would not be realized. A past recipient of the President's Award, Frank has continued to put others before himself in support of the OI community.

The Thelma Clack Lifetime Volunteer Achievement Award is given annually to the volunteer who best exemplifies the qualities of loyalty and dedicated service to the Foundation and its members. Recipients demonstrate a willingness to put others before themselves as demonstrated by the late Thelma Clack.

This year's recipient of the President's (Volunteer of the Year) Award is Christine Wyman Rossi. The President's Award is given to the outstanding volunteer of the past year. The award is given to an individual who best exemplifies the qualities of volunteer service to the OI Foundation and the OI community.

Following in the family tradition, Christine has served the OI community in many capacities. She recently completed six years serving on the Board of Directors, a position she began before the birth of her son Jack who, like Christine and her father Dick Wyman, also has OI. The arrival of Jack, or more specifically the arrival of his first femur fracture, inspired a desire to raise funds for research to find a cure and treatment for OI. So began an annual walk-n-wheel event in Massachusetts, now in its 5th year. As chairperson, Christine is involved in all aspects of what has become a very successful event. In addition, through her role as a local support group leader, the Massachusetts OI community has benefited from Christine's availability in sharing information and support as well as from efforts to coordinate presentations of OI related issues by experts in the field. Most recently, Christine's work on behalf of the OI community were rewarded by her company, EMC Corporation, with a \$10,000 award to the OI Foundation. Christine lives in Framingham with her husband John and sons Jack and 2 year old Hugo.

A volunteer from the age of 2 years old, Rebecca Perritt leads by example. Rebecca is this year's recipient of the Peter Dohm Junior Volunteer Award. The award is given to an outstanding youth volunteer of the past year. Peter Dohm began volunteering for the OI Foundation as a young man when his parents helped organize an OI conference. He continued to volunteer throughout his lifetime.

A strong advocate for people with disabilities, Rebecca lends her support to local endeavors such as Junior Civitan, Special Olympics and as a student board member of Parents of Children with Special Needs, Inc. Rebecca is a strong OI advocate, and from the age of 5, she has spoken about her disability to teachers at Eastern Kentucky University, encouraging them to advocate for their students. She has also addressed Senators and Representatives about healthcare, helping them understand the needs of those with disabilities. Rebecca has done fundraising for the OI Foundation as well as participated in an OI walkn-wheel event in Kentucky. With a perseverance that moves others, her spirit in participate in activities. Some are amazed to see her going and doing what she does in a wheelchair. Rebecca responds, "I'm not handicapped…I just use a wheelchair." If someone needs help, Rebecca is there.



2009 Thelma Clack Lifetime Volunteer Award recipient Frank Fossati poses with OI moms Marybeth Parke (center) and Michelle Hofhine at the Southern California Petroleum Industry Charity Association (SCPICA) Golf & Tennis Tournament on Nov. 13.

# **OIF Unveils Plans for OI Awareness Week**

In October 2010, the OI Foundation announced plans for OI Awareness Week, to be held May 9-15, 2011. OI Awareness Week is designed to be a collaborative effort of both volunteer events, and Foundation sponsored events and programs that serve to educate communities across the country about OI.

OI community members are currently planning Awareness Week events in cities across the nation, including Walk-N-Wheels and Blue Jeans for Better Bones campaigns. OIF Support Groups are being asked to lead outreach programs in their communities by

distributing OI Awareness Week posters to local vendors and requesting proclamations for "OI Awareness Day" from their local elected officials.

In addition to supporting volunteer events, the Foundation will organize an Advocacy Day on Capitol Hill in Washington, DC, and host the popular Fine Wines Strong Bones on Thursday, May 12.

The Foundation is partnering with local and national sponsors support the success of OI Awareness Week.

# OI Family Selected to Appear on ABC's "Extreme Makeover: Home Edition"

The Sharrock Family of Chattanooga, Tennessee was selected as the latest family to appear on the ABC popular show "Extreme Makeover: Home Edition". The Sharrock's son, Patrick, has OI. The show will air in late April 2011. The Sharrock's are the third OI family to be chosen for the show.



# Science & Research

# **Adult Health Initiative Update**

It is a fact that little is known about growing older with osteogenesis imperfecta (OI). It is well known that OI is a complex disorder and a great deal is known about OI during infancy and childhood. But there is a lack of reliable information about how OI affects people during the different stages of adulthood. Concern about this lack of information for both persons with OI and their physicians was emphasized at the Osteogenesis Imperfecta Foundation Scientific Meeting in April 2010 and again through the focus groups at the OI Foundation National Conference in July 2010. In response, a committee composed of adults with OI and doctors was formed and began developing a research study called the **Adult Natural History Initiative** (AHNI, pronounced "Annie").

The ANHI study proposes to survey as many adults with OI in the United States about their health status as possible. Participation will be voluntary and anonymous. All of the personal health related information will be stored in a fully secure manner and there will be no means of tracing it back to the participant.

The results will be combined with information from the OI Foundation's Registry and Linked Clinical Research Centers to develop not only a clearer description of the health needs of adults with OI but also identify areas where research is needed.

The ANHI study will use a health survey instrument designed at the National Institutes of Health called PROMIS. Using the PROMIS system will make it possible to make the survey widely available and to analyze the information quickly. PROMIS also allows the survey to be repeated periodically, making it possible to track how health needs change in the future.

#### Results from the ANHI survey will be used to

- · Identify health needs and concerns of adults with OI
- · Improve the quality of communication between adults with OI and their health care providers
- Expand the focus of medical care for adults with OI beyond "brittle bones"
- Ultimately improve best practices and care recommendations available to health care providers

#### How You Can Help Now

At this stage, an Adult Advisory Committee is being formed. The committee will be representative of adults all ages and types of OI. Members will be asked to review the draft of the survey for content and style. Input from the adult OI community is necessary to create the best-possible survey that gets at the heart of the questions adults with OI face about their health. If you are interested in applying to join the Adult Advisory Committee, please send an email to AdultHealth@OIF.org and include your contact information, age and type of OI.

#### How You Can Help in the Future

You can plan on taking the survey when it is available later this year. You can also plan on recruiting every adult with OI you know to participate in this important study.

# Science & Research

# 2010 Research Funding

The OI Foundation funded the following grants in 2010:

A Zebrafish Model of Bone Accrual in the Axial and Appendicular Skeleton Dr. Matthew Goldsmith, Washington University, St. Louis, Department of Genetics – Basic Seed Grant

*Effect of a Low-magnitude, High-frequency Mechanical Stimulus on Bone with Children with OI: A Pilot Study* Dr. Christopher Modlesky, University of Delaware, Human Performance Laboratory – Clinical Seed Grant

*Efficacy of RANKL Inhibition in Adult OIM/OIM Mice* Dr. Nancy Pleshko, Hospital for Special Surgery, New York, Research Division – Basic Seed Grant

# Linked Clinical Research Center Program Continues to Grow

In 2010, the OI Foundation was pleased to announce the expansion of the Linked Clinical Research Center program and the "Longitudinal Study of Osteogenesis Imperfecta." The addition of new LCRC sites to those previously announced expands the network to 5 sites, including one in Canada. All of the new sites have a multidisciplinary group of specialists with extensive experience caring for children who have OI. All of the new sites will be participating in the natural history of OI study.

Linked Clinical Research Centers:

**NEW** Shriners Hospital for Children, Chicago, IL **NEW** Shriners Hospital for Children, Montreal, Quebec Canada Baylor Medical Center, Houston, TX Kennedy Krieger Institute, Baltimore, MD Oregon Health & Science University / Portland Shriners Hospital, Portland, OR

#### What is a Natural History of OI Study?

"The Longitudinal Study of Osteogenesis Imperfecta" is a natural history study. It will collect and analyze information about the health of people who have OI. To be successful, this study must include as many people as possible and include children and adults of all ages from infancy through senior citizen and all types of OI from the mildest to the most severe. The goal is to enroll 500 people. Each study center will be collecting exactly the same type of health information in the same way from all participants. This information is then entered into the LCRC secure, anonymous, central database.

#### **Study Information**

Study participants are required to visit the Linked Center once a year for 5 years. Each person will be asked for a detailed medical history and receive an extensive annual physical exam including various diagnostic studies such as a DEXA. Participating in this natural history study does not replace a person's regular health care team and does not interfere with any other research studies he or she may already be enrolled in.

#### **Contact Information for all Study Sites**

For detailed information about participating, please speak with a study coordinator at one of the following sites. Information is also posted on the OI Foundation website under the "Research" tab.

The following are two personal accounts from OI community members who visited a LCRC in 2010:

# Science & Research

#### My Visit to the Linked Clinical Research Center

By Tony Benish, OI Foundation Board of Directors

This last May my son Danny and I traveled to one of the newest LCRCs located at Shriner's Hospital in Oak Park, Illinois. Danny has been treated at Shriner's OI clinic for several years, but this visit, I was able to attend as both a parent and a patient. I have been anticipating becoming involved in the Natural History study currently ongoing at the LCRCs since the Board first approved the creation of the first LCRC. Imagine being able to participate in a study that could help in treatments for adults affected with OI.I grew up in the 60s and 70s, when very few knew what OI was, let alone if there were any treatments. I often wondered if there would ever be a facility that specialized in research for children and adults with OI. I had always hoped that there would be a place that could help coordinate treatment for adults affected with OI. I remember the Board's vote to approve the first LCRC, and hoping that Chicago would one day have their own Center. I placed several calls to Angela Caudill to set up our appointment. I had the crazy idea of being the first adult enrolled in the newest LCRC. However, by the time I got my appointment, there were many others ahead of me. Regardless, I looked forward to my appointment in the hopes of sharing my clinical history.



OIF Board Member Tony Benish, and his son Danny.

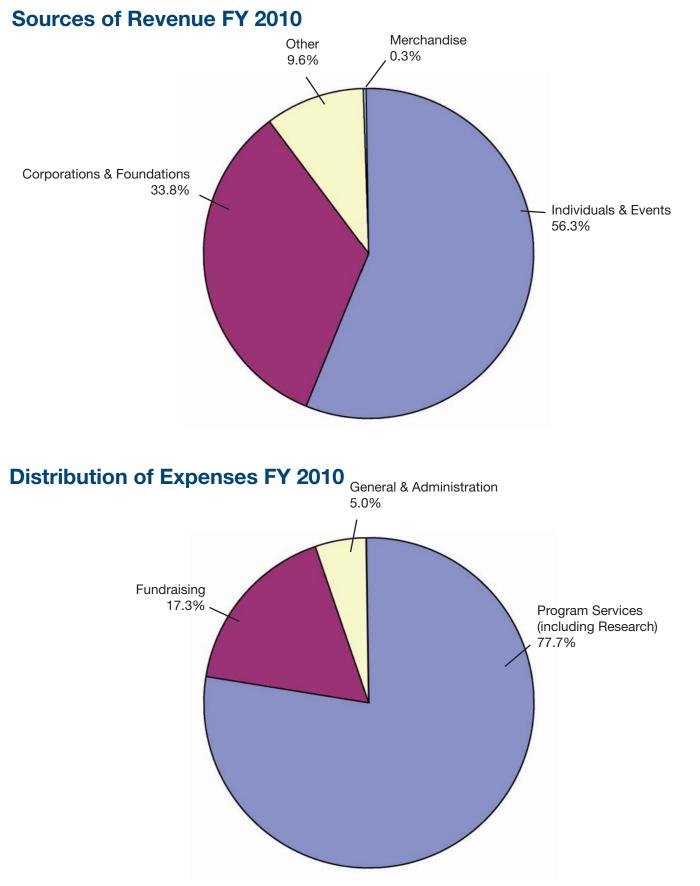
#### My Appointment at the Linked Clinical Research Center in Baltimore, Maryland

By Maria Semprini-DeMartino, RN

In September I had an appointment at the Kennedy Krieger Institute in Baltimore, Maryland one of the OI Foundation's linked centers. My purpose was to participate in the Natural History of OI Study, to get a good physical and to get some of my questions answered about my OI. I live in New York and I'm part of a large, multi-generation family that has Type I OI. Like every other adult I know I'm busy with my family and I'm concerned about how OI might affect the next part of my life.

I corresponded with Dr. Jay Shapiro and his research nurse Pamela Melvin before my appointment so I was able to have some of the required tests done at home before going to Baltimore. These included the PFT (pulmonary function test), DEXA scan and hearing tests. If I had not been able to have them done in my home town, they would have been done as part of my KKI visit. None of the tests were invasive and the only physical thing I had to do was try to walk for 6 minutes. Everyone I met was very nice and easy to work with. The nurse stayed with me the whole time. I also spent about 90 minutes with Dr. Shapiro. He will answer any question you might have and I had a lot. I stayed one night at a nearby hotel, the Hampton Inn, where the KKI gets a discount. I'm glad I enrolled in the LCRC Natural History Study. I hope you will too.

# Financials



Financials

#### OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

#### STATEMENTS OF FINANCIAL POSITION JUNE 30, 2010 AND 2009

	2010	2009
ASSETS		
Current Assets		
Cash and cash equivalents	\$ 348,323	\$ 576,064
Pledges receivable, net of allowance for uncollectible pledges	603,982	611,854
Other receivables	7,027	1,124
Investments	1,681,630	1,422,583
Prepaid expenses	38,515	13,411
Inventory	11,300	10,669
Total Current Assets	2,690,777	2,635,705
Fixed Assets		
Furniture and equipment	161,813	141,507
Leasehold improvements	4,206	4,206
Total Cost	166,019	145,713
Accumulated depreciation	(105,907)	(90,080)
Accumulated depreciation	(105,907)	(90,080)
Net Fixed Assets	60,112	55,633
Other Assets		
Pledges receivable, long-term	21,429	28,572
Funds held in perpetual trust	15,500	15,500
Deposits	6,762	6,762
Total Other Assets	43,691	50,834
Total Assets	\$ 2,794,580	\$ 2,742,172

For a complete copy of our annual audit report, conducted by Thompson, Greenspon & Co., P.C., visit the OI Foundation's web site at www.oif.org/AB\_Statements.

	2010	2009
LIABILITIES AND NET ASSETS	 	 
Current Liabilities		
Accounts payable	\$ 157,908	\$ 107,067
Accrued expenses and vacation	27,201	20,425
Deferred revenue	48,177	-
Promises to give to others	 462,497	 531,425
Total Liabilities	 695,783	 658,917
Net Assets		
Unrestricted net assets	1,200,229	1,332,141
Temporarily restricted net assets	844,080	696,626
Permanently restricted net assets	 54,488	 54,488
Total Net Assets	 2,098,797	 2,083,255

Total Liabilities and Net Assets	\$ 2,794,580	\$ 2,742,172

For a complete copy of our annual audit report, conducted by Thompson, Greenspon & Co., P.C., visit the OI Foundation's web site at www.oif.org/AB\_Statements.

# OSTEOGENESIS IMPERFECTA FOUNDATION, INC.

# STATEMENTS OF ACTIVITIES AND CHANGES IN NET ASSETS YEARS ENDED JUNE 30, 2010 AND 2009

		20	2010			2009	60	
		Temporarily	Permanently			Temporarily	Permanently	
	Unrestricted	Restricted	Restricted	Total	Unrestricted	Restricted	Restricted	Total
Support and Revenue								
Contributions and grants	\$ 397,448	\$ 676,165	\$ '	\$ 1,073,613	\$ 472,381	\$ 590,689	۰ \$	\$ 1,063,070
Event revenue	467,041	139,977	I	607,018	398,998	247,159	ı	646,157
Direct mailing revenue	155,985		ı	155,985	156,300		ı	156,300
Conference revenue	500	60,875	ı	61,375	6,657	81,301	ı	87,958
Product sales, less cost of goods sold of								
\$2,061 for 2010 and \$3,788 for 2009	7,361	ı	ı	7,361	7,480	ı	ı	7,480
Investment income (loss)	122,563	420	ı	122,983	(113,927)	2,711	ı	(111,216)
In-kind contributions	2,754		ı	2,754	20,392		ı	20,392
Net assets released from restrictions	729,983	(729,983)	1	1	1,141,021	(1, 141, 021)	T	I
Total Support and Revenue	1,883,635	147,454	ı	2,031,089	2,089,302	(219,161)	ı	1,870,141
Expenses								
Program Services								
Conferences	99,435	ı	I	99,435	233,146	ı	I	233,146
Education and support	502,096	ı	I	502,096	286,208	ı	I	286,208
Research	902,935	ı	ı	902,935	1,036,353	·	ı	1,036,353
Public awareness	62,604	ı	·	62,604	58,839	ſ	ı	58,839
Total Program Services	1,567,070	ı	1	1,567,070	1,614,546	ı	'	1,614,546
Support Services								
General and administration	100,555	ı	I	100,555	126,312	ı	I	126,312
Fundraising	347,922	'	'	347,922	298,034	'	ı	298,034
Total Support Services	448,477	ï		448,477	424,346	ı	ī	424,346
Total Expenses	2,015,547	,		2,015,547	2,038,892		ľ	2,038,892
Change in Net Assets	(131,912)	147,454		15,542	50,410	(219,161)	ı	(168, 751)
Net Assets, beginning of year	1,332,141	696,626	54,488	2,083,255	1,281,731	915,787	54,488	2,252,006
Net Assets, end of year	\$ 1,200,229	\$ 844,080	\$ 54,488	\$ 2,098,797	\$ 1,332,141	\$ 696,626	\$ 54,488	\$ 2,083,255

For a complete copy of our annual audit report, conducted by Thompson, Greenspon & Co., P.C., visit the OI Foundation's web site at www.oif.org/AB\_Statements.

# Financials

# **Breakthrough Society**

#### \$100,000 or More Cumulative Lifetime Giving

Birdies and Bogies for Better Bones Bone China Tea Broadway Theatre Benefit CT Walk-a-thon and Dinner Henry and Gilda Buchbinder The Charitable & Research Fn., Inc. Children's Brittle Bone Foundation Connecticut Walk-a-thon and Dinner Eichenberg-Larson Charitable Foundation Fine Wine Strong Bones Parker & Carol Folse, III Estate of Randv Kohler Estate of Peter A. Willmann Estate of Mabel Vogelsang **Kroger Food Stores** Mallie's Friends Research Legacy

Massachusetts Unbreakable Spirit Walk for OI William G. McGowan Charitable Fund Miracle Michael Fund New Jersey Beefsteak Dinner New Jersey OI Charity Fundraiser OI Golf Classic (NH) Frank & Denise Quattrone Foundation Riley's Gathering Place Golf Outing Sally Foster Gift Wrap Sale S.C.P.I. Charity Association UPS United Way North Jersey District Golf Invitational **UPS** Employees

#### **Donors** July 1, 2009 to June 30, 2010

The OI Foundation gratefully acknowledges the generous individuals, foundations, and corporations, whose support helps us respond to thousands of inquiries each year, produce new information resources, fund research, organize the biennial National Conference on OI for families, and facilitate the operation of support groups across the country. These are listings of donors from July 1, 2009 to June 30, 2010. We regret any error or omission and ask that corrections be brought to our attention.

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