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A Message From the President

The mission of the Osteogenesis Imperfecta Foundation is to improve lives. I am proud to report that the work we have accomplished during the last fiscal year reflects the steps we have made in fulfilling our commitment to you, the OI Foundation contributor and friend.

As you will read in the report, we have continued to focus our efforts in 2012 in the areas of improving the health of people living with OI, implementing coordinated research activities, supporting the OI community and increasing education and outreach.

In 2012 the OI Foundation hosted the biennial conference titled "Awareness, Advocacy, Action." The conference brought together more than 700 people from the OI community. Conference attendees attended workshops from OI specialists and had the opportunity to connect with old friends and make new ones as well. Prior to the start of the conference 105 people traveled to Capitol Hill and visited more than 40 congressional offices, giving legislators and their staff information about OI and our effort to increase OI research at the federal level.

The work of the Linked Clinical Research Centers continued and in 2012 enough data was collected to begin the work of publishing findings, facts and trends. The OI Foundation also continued funding two Michael Geisman Fellows through the research grant process and a clinical research grant was awarded to Dr. Jay Shapiro at Kennedy Krieger, which will hopefully lead to a better understanding of heart conditions in OI.

And, in an age where technology makes it easier to communicate with each other than ever before, the OI Foundation responded to 6,500 requests for information, the website was visited 205,000 times and the Foundation maintained an active presence on various social media outlets.

None of this work could have happened without the generous support of the contributors listed on the following pages. Thank you for your gifts!

The OI Foundation works hard to use the generous support in the best way possible to support as many people as possible.

Throughout the next year the OI Foundation will continue to build on the success of the year before and move our mission forward. Thank you for your involvement in the work, and for your confidence in your Foundation.

Sharon Trahan

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Sharon Trahan

Awareness

n May, the OI Foundation held its second National OI Awareness Week, involving volunteers across the country in holding awareness and fundraising events within their communities. Awareness Week 2013 will take place May 4-11, 2013, and on May 6,



2013, the Foundation will officially participate in Wishbone Day, an international awareness event that will help to raise awareness about OI all over the world! Awareness Week volunteers secured city and state proclamations declaring it OI Awareness Week, 15 new OI fundraising events were held and articles appeared in more than 15 newspapers around the country about OI.

National Conference 2012



In July 2012, the OI Foundation held its biennial National Conference in Washington, DC. More than 700 people attended this conference themed "Awareness, Advocacy, Action!" Prior to the start of the conference, 105 people traveled

to Capitol Hill for the OI Foundation's advocacy day and visited 40 congressional offices giving legislators and their staff information about OI and our effort to increase OI research at the NIH. The advocacy day kicked off with a presentation to Congressman "Dutch" Ruppersberger, D-MD – he was awarded the Advocacy Unbreakable Spirit™

Award for his effort in helping improve awareness about OI. Participants visited their legislators and in one special case were greeted by House of Representatives Speaker of the House, John Boehner.



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Michael Whyte, M.D. Shriners Hospital for Children St. Louis, MO The 2012 National Conference also presented the first Women's Forum coordinated by board members Michelle Duprey and Anna Curry Gualano. The forum, open only to women living with OI, explored issues that directly affect women including nutrition, sexuality, pregnancy and overall women's health. The forum was a success and will be repeated at the 2014 National Conference.

The conference included three days of sessions on topics ranging from home splinting to updates on the most current research being done in the field that may lead to improved treatments.

Linked Clinical Research Centers (LCRC)

The OI Foundation, in partnership with the Children's Brittle Bone Foundation, continued funding five LCRCs and reached its enrollment goal of 500 people in the natural history study in 2011 and increased the number to 605 in 2012. Dr. Reid Sutton, the LCRC's project manager, released preliminary information on findings from the study and has submitted those findings for publication in scientific journals. Publication will take place in early 2013.

Scientific Meetings

n April, 100 scientists gathered for the OIF annual scientific meeting in Chicago, IL. Dr. Laura Tosi chaired the meeting L titled, Assessing the Impact of Osteogenesis Imperfecta on Nonskeletal Systems, which focused on the impact of abnormal collagen on health in an effort to broaden professional awareness of the full spectrum of issues faced by person living with OI as they age. A workshop report was compiled and submitted for review. This meeting was a continuation of the ANHI (Adult Natural History Initiative) addressing health concerns that were identified by more than 1100 adults living with OI who responded to a survey. The meeting will contribute to research that will enhance knowledge of the natural history of OI and lead to the development of educational resources for patients and providers that provide reliable, relevant and understandable information about treatment options and their risks and benefits. The conference was made possible by the generous support of the Buchbinder Family Foundation.

In September 2012, the OI Foundation took the lead role in presenting a scientific meeting focusing on rare bone diseases, including OI. The meeting titled *Rare Bone Disease Research Summit – Future Directions*, brought together the leaders in rare bone disease research and was chaired by Dr. Jay Shapiro of Kennedy Krieger in Baltimore, MD and a member of the OI Foundation's Medical Advisory Council. The meeting goals included presenting a status update on the most current rare bone disease research and developing strategies to accelerate such research in the future. Speaker abstracts were submitted to the journal *Seminars in Arthritis and Rheumatism* and were published in February 2013.

Additionally, Dr. Shapiro, on behalf of the OI Foundation, led a working group at the 2012 ASBMR (Association for Bone and Mineral Research) meeting in Minneapolis, MN. The working group focused on rare bone disease research and continued the discussion from the Research Summit on how to collaborate in an effort to accelerate rare bone disease research. Young investigators and senior scientists attended this "sold out" working group. Another working group will be held in 2013 and led by the OI Foundation.

Research Grants

n 2012, the OI Foundation continued funding two Michael Geisman Research Fellowships to researchers at Children's L Hospital in Boston and the University of Washington in Seattle. Each of these studies examines specific genetic mutations that may someday lead to new treatments to strengthen bones, once they are better understood. Both researchers have been successful in moving their research forward. Their reports will be available on the OIF website shortly. In addition, the OI Foundation funded a clinical research grant that will lead to a better understanding of heart conditions in OI including heart valve problems, problems with the aorta or other blood vessel problems. A greater understanding of heart surgery in OI patients and the results after heart surgery is an additional goal of this study. It is being conducted at the Kennedy Krieger Institute by principal investigator Dr. Jay Shapiro.

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Adult Natural History Initiative (ANHI)



The ANHI committee met at the 2012 OIF Annual Scientific Meeting

with approximately 1100 adults living with OI completing the survey for this ambitious study, led by Dr. Laura Tosi of Children's National Medical Center in Washington, DC. ANHI uses an NIH-approved,

Internet-based questionnaire to collect information about participant's current health status, quality of life, and health concerns. Combining this information with the OI Registry and the Linked Clinical Research Centers will create a clearer description of the health needs of adults living with OI and identify areas needing research. Results from the survey were used to develop the agenda for the April 2012 scientific meeting.

OI Registry

The OI Registry is a joint effort between the OI Foundation and the Kennedy Krieger Institute. Participants complete a profile of their medical characteristics, family history, fracture history, and treatment. Based on one's profile, people are contacted about institution and IRB-approved clinical research study opportunities. Since the Registry opened in March 2006, more than 1,500 people from the United States and 39 other countries have joined.

Impact Grants

In partnership with the Children's Brittle Bone Foundation, 10 grants totaling \$131,000 were awarded to people living with OI in need of products or services that would improve the quality of their lives in 2012. Grantees received funds to purchase adapted vehicles, new mobility devices, computers, hearing aids, dental work and other products and services. A new cycle of funding began on January 1, 2013.

OI National Information Center

A pproximately 6,500 requests for information were provided during the year, and the OI Foundation website was visited 205,000 times in search of information. The Center also offers a variety of resources, many of which can be downloaded free of charge on **www.oif.org**, including booklets, brochures and more than 70 fact sheets.

Social Networking

he OI Foundation manages four social networking sites — Osteogenesis Imperfecta (OI) Foundation Facebook Page, NING, OI Foundation Twitter, and Sunday Night Chat. The OI Foundation continues to offer on **www.oif.org** links to other social networking sites that might be helpful or interesting to parents and young people living with OI. The additional sites are managed by volunteers that the Foundation has established a working relationship with.

Advocacy





Volunteers and staff continued to educate legislators and key decision makers on the importance of increasing bone research at the NIH and other agencies.

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2012 MEMBERS continued on pg. 12

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REVENUES FY2012

INDIVIDUALS	AND EVENTS
PERCENTAGE	63.9%
AMOUNT	\$1.074.247

CORPORATIONS AND FOUNDATIONS

148,671
8.8%
ference)
448,264
26.7%

0.6%
\$9,967

TOTAL REVENUE

PERCENTAGE	100%
AMOUNT	\$1,681,149

EXPENSES FY2012

PROGRAM SERVICES

(including Researc	ch)
PERCENTAGE	76.3%
AMOUNT	\$1,118,217
FUNDRAISING	
	4 - 70/

15.0%
\$228,686

ADMINISTRATION

AND GENERAL	
PERCENTAGE	8.1%
AMOUNT	\$117,985

TOTAL EXPENSES

PERCENTAGE	100%
AMOUNT	\$1,464,888

Sources of Revenue FY 2012



Distribution of Expenses FY 2012



Statements of Financial Position — June 30, 2012 and 2011

	2012	2011
ASSETS		
Current Assets		
Cash and cash equivalents	\$ 425,472	\$ 253,076
Pledges receivable, net of allowance for uncollectible pledges	466,635	375,584
Other receivables	42,500	80,102
Investments	1,646,353	1,693,836
Prepaid expenses	42,070	10,948
Inventory	22,048	19,565
Total Current Assets	2,645,078	2,433,111
Fixed Assets		
Furniture and equipment	139,873	146,241
Accumulated depreciation	(105,157)	(92,712)
Net Fixed Assets	34,716	53,529
Other Assets		
Long-term pledges receivable, net	60,226	91,948
Funds held in perpetual trust	15,500	15,500
Deposits	6,762	6,762
Total Other Assets	82,488	114,210
Total Assets	\$ 2,762,282	\$ 2,600,850

Statements of Financial Position — June 30, 2012 and 2011

	2012	2011
LIABILITIES AND NET ASSETS		
Current Liabilities		
Accounts payable	\$ 64,432	\$ 44,254
Accrued expenses and vacation	110,437	102,324
Deferred revenue	66,912	-
Deferred rent	2,302	2,302
Promises to give to others	198,329	184,996
Total Current Liabilities	442,412	333,876
Long-term Liabilities		
Deferred rent, net of current portion	5,563	7,865
Total Liabilities	447,975	341,741
Net Assets		
Unrestricted net assets	1,554,552	1,607,759
Temporarily restricted net assets	705,267	596,862
Permanently restricted net assets	54,488	54,488
Total Net Assets	2,314,307	2,259,109
Total Liabilities and Net Assets	\$ 2,762,282	\$ 2,600,850

		2(2012			20	2011	
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Support and Revenue								
Contributions and grants	\$ 363,946	\$ 476,795	\$ '	\$ 840,741	\$ 356,633	\$ 465,712	، ج	\$ 822,345
Event revenue	412,018	83,690	ı	495,708	448,296	116,700	ı	564,996
Direct mailing revenue	159,948	ı		159,948	156,742		'	156,742
Conference revenue	16,125	26,450		42,575	1,201	56,822		58,023
Product sales, less cost of goods sold of								
\$2,618 for 2012 and \$2,956 for 2011	7,384	ı	ı	7,384	9,104	'	ı	9,104
Investment income	60,019	59	ı	60,078	257,681	445	ı	258,126
In-kind contributions	14,015	,		14,015	244	,		244
Net assets released from restrictions	478,589	(478, 589)			886,897	(886,897)		1
Total Support and Revenue	1,512,044	108,405	ſ	1,620,449	2,116,798	(247,218)	ı	1,869,580
Expenses								
Program services								
Conferences	56,336			56,336	193,854	'		193,854
Education and support	530,827			530,827	543,090	'		543,090
Research	469,414			469,414	432,112			432,112
Public awareness	61,640	ı	ı	61,640	86,509	ı	ľ	86,509
Total Program Services	1,118,217	ı	·	1,118,217	1,255,565	·	ı	1,255,565
Gumost convicos								
General and administration	117,985		ı	117,985	94,516	I	ı	94,516
Fundraising	329,049			329,049	359,187			359,187
Total Support Services	447,034	'	'	447,034	453,703	,	'	453,703
Total Expenses	1,565,251	ı	ı	1,565,251	1,709,268	ı	ı	1,709,268
Change in Net Assets	(53,207)	108,405	·	55,198	407,530	(247,218)		160,312
Net Assets, beginning of year	1,607,759	596,862	54,488	2,259,109	1,200,229	844,080	54,488	2,098,797
Net Assets, end of vear	4 1 55 <i>4</i> 552	\$ 705.267	\$ 54 488	\$ 2314307	\$ 1 607 759	\$ 506 867	\$ 54 488	\$ 2259109

Statements of Activities and Changes in Net Assets — Years Ended June 30, 2012 and 2011

The No

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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, 2011 to June 30, 2012. We regret any error or omission and ask that corrections be brought to our attention.

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TOM ACQUAFREDDA

Thomas Acquafredda, 58, passed away unexpectedly on December 25, 2012. Thomas was a longtime member of the OI Foundation and Little People of America. He traveled the country attending national conferences for both organizations. He worked in the volunteer service industry for various facilities throughout Westchester, where he received numerous awards and acknowledgements for his devotion. He was most proud of The Certificate of Distinguished Service from Westchester County, for his time and devotion in helping those in need. His family remembers him having "can do spirit' and a strong determination to function as independently as possible.

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HONOR GIFTS (continued)

Kari Roll Ms. Ruth Hovden Jack Rossi Mr. Douglas Gibson Ms. Marta LaCasse Peter & Carol Maher McIntyre Loam, Inc. Paul & Judi Rossi lan & Wendy Sacks (Anniversary) **Mitchell & Geraldine Sacks** Jaden Sacks (Birthday) Ms. Lauren Brickman Wendy Sacks (Birthday) Ms. Courtney Goldsmith Angelo Schwartz Ms. Jennifer Shulman Sierra Scoggins Dr. Amee Stambaugh **Emily Seelenfreund Rachelle Grossman** & Robert Seelenfreund Maggie Shae Sheridan Mrs. Christine Hull Bob & Stacy Kogut L.J. Sherman, Cousins & Pets Ms. Sylvia Leaf Matthew Smith Patricia & Emma Heath

Miss Mikayla Sorensen Action Properties And Investments, LLC R.J. & Doris Baker Mr. James Belden Ms. Jeannine Caldwell Ms. Barbara Lippert **Colby & Shalene Sorensen** William & Lucille Sorensen L M Winter Mr. & Mrs. Paul Spira, Barbara, Louie & Family Ms. Sylvia Leaf Bobbie Stahoski & John Strelow Ms. Sylvia Leaf Shirley Stern Ms. Shelly Saperstein **Trish Stouder** Mr. & Mrs. Wayne Kaltenberger Mr. & Mrs. Richard Szabo & Family Ms. Sylvia Leaf Denise Tarantino Ms. Linda Hardy Ms. Karen Konecky Cheryl Thompson Nurses at South Okanagan Gen. Hospital Vivian Toporcer Ms. Merri-Lynn Smith

Sharon Trahan Mr. & Mrs. Donald Trahan William Vogel Ms. Suzanne PolgarJoan Von Entress (Birthday) Ms. Dee Von Entress **Dave Vurdelia Reston Masters Swim Team** Brother of Regina Wagner Mr. Neil Milner Esther Alicia Watson Ms. Sarah Roberts **Charles & Holly Weilbrenner** Atlantic Planning Group, LLC Kay & Ralph West **Robert & Louisa Matthias** Norman & Joyce Wilcox **Miss Ariella Whitaker** Mr. Travis Giese **Daniel Wiederhold** Ms. Carolyn Sharpe Mr. & Mrs. Ethan Winner & Family Ms. Sylvia Leaf Mr. & Mrs. Chuck Winner, **Justin & Family** Ms. Sylvia Leaf Miss Jackie Yafanaro Mark & Lori Acree Ethan Yamashita Paul & Geraldine Yamashita Matt Young Mr. Kenneth Young



804 W. Diamond Avenue Suite 210 Gaithersburg, MD 20878 301.947.0083 www.oif.org