

2011
.....
ANNUAL REPORT



LIVING WELL
WITH AN
UNBREAKABLE
SPIRIT™

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The Osteogenesis Imperfecta Foundation, Inc., is a 501(c)3 non-profit organization.

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 real steps forward in research, education, awareness and mutual support.

As you will read in this Annual Report, we have focused our efforts in 2011 in several areas – improving adult health, implementing coordinated research activities, and increasing education and outreach.

In 2011, the work of Dr. Laura Tosi and the ANHI (Adult Natural History Initiative) committee continued. A survey was distributed to a database of adults living with OI asking questions about all aspects of their physical and emotional health. More than 1,000 people returned surveys giving their honest input on their current state of health, what they worry about as they age, and where the gaps in services appear to be. The 2012 scientific meeting focused on those results in an effort to develop a plan of action for improving the health of adults living with OI. Without the input of a concerned OI community we could not have gathered this kind of valuable information.

The work of the Linked Clinical Research Centers continues under the watchful eye of the center principal investigators and their teams at Kennedy Krieger Institute, Montreal Shriners Hospital for Children, Chicago Shriners Hospital for Children, Oregon Health & Sciences Institute and Baylor College of Medicine. The goal of enrolling 500 participants in the natural history study was reached and valuable information will be released in the summer of 2012 based on the data collected by our "LCRC Pioneers."

And, of course, the information and education department at the OI Foundation continues to be very busy – the website traffic increases each month and the OI Foundation now has a significant presence on several social media sites that provide information and support to parents of children with OI and adults living with OI.

None of these successes and activities can happen without the generous support of the many donors listed on the following pages. Thank you for your gifts! We work hard to use the generous funds you donate to the Foundation in the best way possible to support as many people as possible. Please take a minute to read about the many activities the OI Foundation is involved in and how those activities are making a real difference in the lives of people living with OI.

Throughout 2012 we will continue to build on our successes of the past year and move our mission forward. Thank you for your involvement in the work, and for your confidence in your Foundation.



Sharon Trahan

Linked Clinical Research Centers

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. Dr. Reid Sutton, the LCRC's project manager, presented preliminary information at the OI International Scientific Meeting held in Dubrovnik, Croatia in October 2011. Information is now available, based on the data collected, that will permit development of preliminary health guidance recommendations and guide future studies. Health guidance recommendations include new growth and developmental charts for children with all types of OI that parents and health care providers will be able to use. A natural history study gathers information on people over a period of time. This information will help us determine and prioritize research topics. Thank you to those of you who are now a part of the natural history study at one of the Centers. As you may remember, the LCRC project is a cutting edge approach to providing standardized quality care for people with OI by linking information from Centers that will benefit all people with OI. LCRCs are currently active in Portland, Oregon; Baltimore, Maryland; Houston, Texas; Chicago, Illinois and Montreal, Quebec.

Adult Health Initiative

During the strategic planning process in 2010, the OI Foundation Board of Directors made improving the health of adults with OI a priority for the Foundation. In response, the Adult Health Initiative was implemented, which included focusing the 2010 scientific meeting on adult health and the implementation of the OI Adult Health Natural History Study (OI-ANHI) led by Dr. Laura Tosi of National Children's Hospital in Washington, DC. OI ANHI uses an NIH-approved, Internet-based questionnaire to collect information about participants' 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 who have OI and identify areas needing research. Currently 400 people have responded to the survey, surpassing the goal of attaining 300 respondents.

BOARD OF DIRECTORS

Five new members were elected to the Foundation's Board of Directors. The Foundation welcomes:



Kristen D.
Antolini, Esq.



Jody W. Cheek,
M.Ed.



Alcides Ortiz,
Esq.



Carolyn R.
Tipton



Robin
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Delegates of the 11th International OI Scientific Meeting held in Dubrovnik, Croatia.

11th International OI Scientific Meeting

One hundred and fifty people, including the OI Foundation's CEO Tracy Hart, from 30 countries attended the International Conference on OI October 2-5, 2011 in Dubrovnik, Croatia. Dubrovnik, on the Adriatic coast, provided beautiful scenery for this important scientific meeting held every three years in a different country in Europe or North America. The meeting explored topics from leading OI researchers and scientists including members of the OIF's Medical Advisory Council (MAC). MAC member Dr. Joan Marini chaired the meeting's scientific committee, which selected 46 podium presentations ranging from the current research activities in the most prominent laboratories around the world to the broad spectrum of clinical situations that physicians may have to manage. Dr. Marini and MAC chair, Dr. Francis Glorieux presented keynote lectures titled "New Perspectives on Osteogenesis Imperfecta" and "Understanding Pathophysiology and Defining Treatment in OI: From the Past to the Future", respectively. In addition, Dr. Hans Peter Bachinger presented an exciting guest lecture on the latest information on the collagen prolyl 3-hydroxylation complex, in which defects cause the most common forms of recessive OI.

Research Grants

Two new research grants were awarded and one grant was continued in 2011. Funding continues to be available through the Foundation for postdoctoral fellowships to encourage new investigators to begin a career in OI research and for seed grants for preliminary research.



Ron Mack from United Seating and Mobility fits Impact Grant winner Sophia for her new wheelchair.

services. A new cycle of funding begins on December 1, 2011. For more information, please visit our website at www.oif.org.

OI National Information Center

It's estimated that 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, including booklets, brochures and more than 70 fact sheets.

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Awareness Week 2011

The OI Foundation held the first national OI Awareness Week in May 2011. People across the country held awareness and fundraising events that helped spread the word about OI and the work of the Foundation. Thank you to everyone who participated. Awareness Week 2012 will take place May 5-12, 2012, and on May 6, 2012, the Foundation will officially participate in Wishbone Day, an international awareness event that will help to raise awareness about OI all over the world!



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. OIF staff and volunteers visited 35 Senate and House offices in 2011 in an effort to educate legislators on the LCRC project and the importance of funding the program.



U.S. Capitol Building

Scientific Conference

In April 2011, 70 physicians, researchers and other interested persons attended a conference titled *The New Genetics of OI: Presentation, Mechanisms, Population and Natural History of Recessively Inherited Forms of OI*. The meeting was chaired by Dr. Peter Byers, Professor of Pathology and Medicine at the University of Washington and a key member of the OIF's Medical Advisory Council, and Dr. Francis Glorieux, the Director of Research and the founder of the Genetics Unit at the Shriners Hospital for Children in Montreal, Canada and the chair of the OIF's Medical Advisory Council. The conference was made possible by the generous support of the Buchbinder Family Foundation and the National Institute of Arthritis and Musculoskeletal Health and Skin Diseases (NIAMS).

Social Networking



The OI Foundation manages four social networking sites including; Osteogenesis Imperfecta (OI) Foundation Facebook Page, NING, OI Foundation Twitter, and Sunday Night Chat. Each of the Foundation's social networks has seen an increase in members, with the OIF Facebook page seeing the largest increase from approximately 1500 members in 2007, to its current membership of just over 3000 users. In 2011, the OI Foundation added three additional social networking links on www.oif.org, including OI Parents Facebook, OI Dads Facebook, and the OI Parents Yahoo Group. The three sites offer mutual support to specific groups within OI Community, and are managed by volunteers that the Foundation has established a working relationship with.

Social Networking links on
www.oif.org

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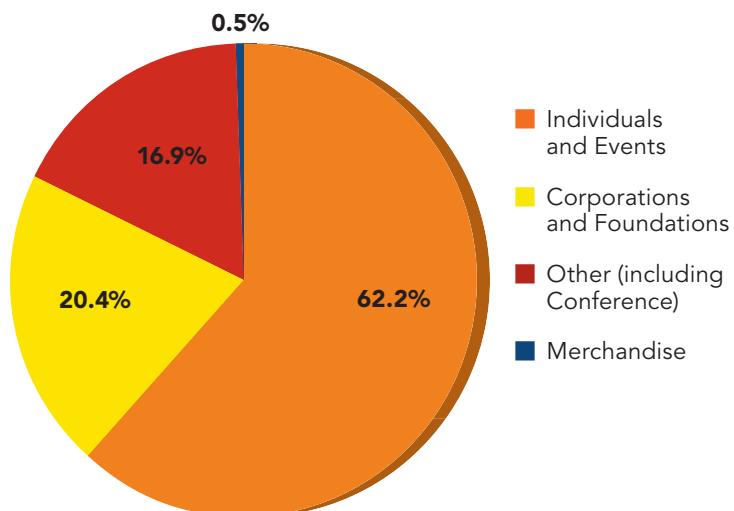
The OIF Florida Support Group

Support Groups

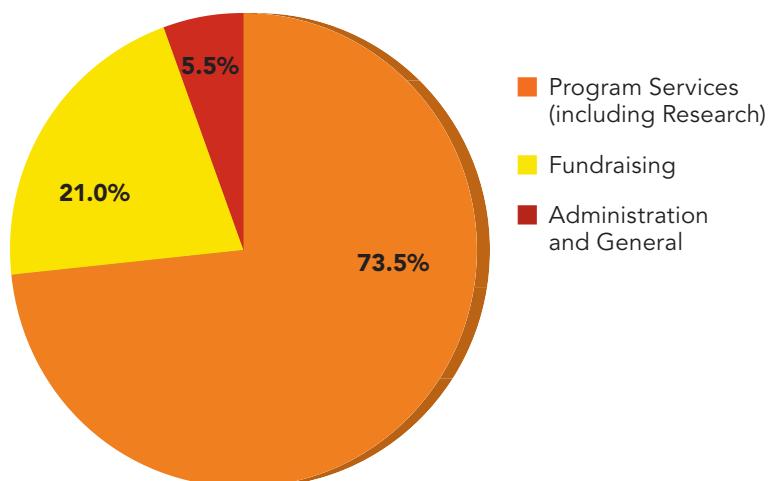
Thirty-eight support groups that operate across the country held 52 meetings that helped connect people. We welcomed four new groups to the Foundation in 2011! Support groups held informational meetings with presentations by physicians and researchers, and many held fun meetings that included holiday parties. Each edition of the OI Foundation newsletter, *Breakthrough*, highlights the activities of the support groups.

This is just a short overview of the many activities and events that happened in 2011. I encourage you to visit our website at www.oif.org to find out more about what's going on at the OI Foundation. Please know that your continued and generous support enables us to provide support and resources for people living with OI and those that love them.

Sources of Revenue FY 2011



Distribution of Expenses FY 2011



REVENUES FY11

INDIVIDUALS AND EVENTS	
PERCENTAGE	62.2%
AMOUNT	\$1,162,198
CORPORATIONS AND FOUNDATIONS	
PERCENTAGE	20.4%
AMOUNT	\$381,885
OTHER <i>(including Conference)</i>	
PERCENTAGE	16.9%
AMOUNT	\$316,393
MERCHANTISE	
PERCENTAGE	0.5%
AMOUNT	\$9,104
TOTAL REVENUE	
PERCENTAGE	100%
AMOUNT	\$1,869,580

EXPENSES FY2011

PROGRAM SERVICES <i>(including Research)</i>	
PERCENTAGE	73.5%
AMOUNT	\$1,255,565
FUNDRAISING	
PERCENTAGE	21.0%
AMOUNT	\$359,187
ADMINISTRATION AND GENERAL	
PERCENTAGE	5.5%
AMOUNT	\$94,516
TOTAL EXPENSES	
PERCENTAGE	100%
AMOUNT	\$1,709,268

Statements of Financial Position — June 30, 2011 and 2010

ASSETS	2011	2010
Current Assets		
Cash and cash equivalents	\$ 253,076	\$ 348,323
Pledges receivable, net of allowance for uncollectible pledges	375,584	603,982
Other receivables	80,102	7,027
Investments	1,693,836	1,681,630
Prepaid expenses	10,948	38,515
Inventory	19,565	11,300
 Total Current Assets	 2,433,111	 2,690,777
 Fixed Assets		
Furniture and equipment	146,241	161,813
Leasehold improvements	-	4,206.00
 Total Cost	 146,241	 166,019
Accumulated depreciation	(92,712)	(105,907)
 Net Fixed Assets	 53,529	 60,112
 Other Assets		
Long-term pledges receivable, net	91,948	21,429
Funds held in perpetual trust	15,500	15,500
Deposits	6,762	6,762
 Total Other Assets	 114,210	 43,691
 Total Assets	 \$ 2,600,850	 \$ 2,794,580

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.

Statements of Financial Position — June 30, 2011 and 2010

LIABILITIES AND NET ASSETS	<u>2011</u>	<u>2010</u>
Current Liabilities		
Accounts payable	\$ 44,254	\$ 157,908
Accrued expenses and vacation	102,324	27,201
Deferred revenue	-	48,177
Deferred rent	2,302	-
Promises to give to others	<u>184,996</u>	<u>462,497</u>
Total Current Liabilities	333,876	695,783
Long-term Liabilities		
Deferred rent, net of current portion	<u>7,865</u>	-
Total Liabilities	<u>341,741</u>	<u>695,783</u>
Net Assets		
Unrestricted net assets	1,607,759	1,200,229
Temporarily restricted net assets	596,862	844,080
Permanently restricted net assets	<u>54,488</u>	<u>54,488</u>
Total Net Assets	<u>2,259,109</u>	<u>2,098,797</u>
Total Liabilities and Net Assets	<u>\$ 2,600,850</u>	<u>\$ 2,794,580</u>

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.

Statements of Activities and Changes in Net Assets —

Years Ended June 30, 2011 and 2010

	2011			2010				
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Unrestricted	Temporarily Restricted	Permanently Restricted	Total
Support and Revenue								
Contributions and grants	\$ 356,633	\$ 465,712	\$ -	\$ 822,345	\$ 397,448	\$ 676,165	\$ -	\$ 1,073,613
Event revenue	448,296	116,700	-	564,996	467,041	139,977	-	607,018
Direct mailing revenue	156,742	-	-	156,742	155,985	-	-	155,985
Conference revenue	1,201	56,822	-	58,023	500	60,875	-	61,375
Product sales, less cost of goods sold of \$2,956 for 2011 and \$2,061 for 2010	9,104	-	-	9,104	7,361	-	-	7,361
Investment income	257,681	445	-	258,126	122,563	420	-	122,983
In-kind contributions	244	-	-	244	2,754	-	-	2,754
Net assets released from restrictions	886,897	(886,897)	-	-	729,983	(729,983)	-	-
Total Support and Revenue	2,116,798	(247,218)	-	1,869,580	1,883,635	147,454	-	2,031,089
Expenses								
Program services	193,854	-	-	193,854	99,435	-	-	99,435
Conferences	543,090	-	-	543,090	502,096	-	-	502,096
Education and support	432,112	-	-	432,112	902,935	-	-	902,935
Research	86,509	-	-	86,509	62,604	-	-	62,604
Public awareness	-	-	-	-	-	-	-	-
Total Program Services	1,255,565	-	-	1,255,565	1,567,070	-	-	1,567,070
Support services	-	-	-	-	-	-	-	-
General and administration	94,516	-	-	94,516	100,555	-	-	100,555
Fundraising	359,187	-	-	359,187	347,922	-	-	347,922
Total Support Services	453,703	-	-	453,703	448,477	-	-	448,477
Total Expenses	1,709,268	-	-	1,709,268	2,015,547	-	-	2,015,547
Change in Net Assets	407,530	(247,218)	-	160,312	(131,912)	147,454	-	15,542
Net Assets, beginning of year	1,200,229	844,080	54,488	2,098,797	1,332,141	696,626	54,488	2,083,255
Net Assets, end of year	\$ 1,607,759	\$ 596,862	\$ 54,488	\$ 2,259,109	\$ 1,200,229	\$ 844,080	\$ 54,488	\$ 2,098,797

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.

Honor Roll of Donors

BREAKTHROUGH SOCIETY

\$100,000 or more Cumulative lifetime giving

Bennett Clayton Foundation
for Children with OI

*Birdies and Bogies for
Better Bones*

Bone China Tea

Broadway Theatre Benefit

Henry and
Gilda Buchbinder

The Charitable & Research
Fn., Inc.

Children's Brittle
Bone Foundation

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Invitational*

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DONORS

July 1, 2010 to June 30, 2011

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, 2010 to June 30, 2011. We regret any error or omission and ask that corrections be brought to our attention.

Breakthrough Society

\$100,000 and greater

Children's Brittle Bone Foundation
Parker & Carol Folse, III

Harold A. Sofield Society

\$50,000 to \$99,999

Henry & Gilda Buchbinder
Kroger Food Stores
S.C.P.I. Charity Association

Mildred "Midge" Peck Society

\$25,000 to \$49,999

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Fine Wines Strong Bones (DC)
MA Unbreakable Spirit Walk for OI
Miracle Michael Fund
New Jersey Beefsteak Dinner
Riley's Gathering Place
Golf Outing (IL)
United Way Truist

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Unbreakable Spirit Walk for OI:
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Mr. Blake Mather
Meltzer Carroll Life
Microsoft Matching Gifts Program
Navistar, Inc.
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Mr. Isaac Slade
Sharon & Ted Trahan
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Mr. & Mrs. Michael Dimino
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