Focused on Research

FY 2004 Annual Report
The Foundation staff and volunteers have been improving the quality of life for people with osteogenesis imperfecta through education, awareness, mutual support and research to find treatments and a cure for three and one-half decades. We’ve shared hopes, dreams, setbacks and solutions, always relying on the strong sense of community that reminds us we’re not alone.

The Foundation continues to set new records in reaching out to more people with OI, their families, and their health care providers through our education, information and support services. Our website continues to grow in size and number of registered visitors, and our community of volunteers has grown, as well. Of course, our success isn’t just measured in numbers, it’s measured in the improved quality of life in the OI community.

Just as importantly, the Foundation, with the community’s overwhelming support, has increased its focus on research efforts in the past year and will continue to expand research in the years to come. In FY 2004 alone, the OI Foundation spent almost half a million dollars on our research efforts, while maintaining the same level of support to people with OI.

This money is being spent on new research grants in response to the increased quantity and quality of grant requests received each year. Some of our researchers are featured in these pages.

It’s also being spent on scientific meetings to increase the pace of research, and two exciting new projects; a National OI Registry and Linked Clinical Research Centers.

The registry, still in the initial planning stages, will enable researchers to search through records containing information about thousands of OI cases, and also provide researchers with a large pool of potential research study participants. The end result will be more coordinated research efforts and quantifiable data about how OI affects the body in all stages of life.

The Linked Clinical Research Centers project has a complementary goal. Just as sharing data through the registry will increase the pace of research, sharing information among OI clinics will increase the quality of care for people with OI. Once linked, doctors, nurses, and other medical professionals will have access to a huge pool of data and support. Today, the typical OI clinic sees less than 40 patients, and some see as few as four or five. When the linked centers are online, every clinic, no matter how large or small, will be able to share information about symptoms and treatment protocols. This increase in shared information and knowledge among the clinicians will also increase the pace of research.

It was a great year—one that we all should be proud of, and it has set the stage for incredible advancements in the years to come. As you read about our accomplishments in FY 2004, please consider how you might participate even more actively with the OI Foundation as we continue to serve the OI community, and stay Focused on Research.

Jamie D. Kendall
President, OI Foundation Board of Directors
Osteogenesis Imperfecta

Osteogenesis imperfecta (OI) causes brittle bones which break very easily. A cough or sneeze can break a rib, rolling over can break a leg. When a child is born with OI, parents struggle to handle a child who is in constant pain. Hugging, diapering, dressing, or simply picking the infant up can cause a fracture. Throughout a person with OI’s lifetime, he will have numerous broken bones and surgery to try to correct bone deformities and straighten the bones so he can live independently.

Fractures, which can number in the hundreds over the lifetime of a person with severe OI, lead to other challenges. Casts. Braces. Surgery. Wheelchairs. Absence from school or work. Long periods of recovery. And the effects of OI go beyond fractures. People with OI may also have early hearing loss, spinal curvature, brittle teeth, and respiratory problems.

Fortunately, OI does not compromise intellectual ability or mental health, and people with OI can succeed in school and the workplace, develop satisfying social and family relationships, and live independently. To pursue these goals, they face many challenges—limited mobility and physical pain, societal prejudices and architectural barriers. The Osteogenesis Imperfecta (OI) Foundation helps people face the challenges of coping with OI so that they can live satisfying and successful lives.

Most cases of OI originate with a faulty gene that affects the formation of type 1 collagen, the major building block of bone and other connective tissues. This causes the body to manufacture either too little type 1 collagen or poor quality type 1 collagen.

There are six recognized types of OI, representing a wide variation in severity. People with the mildest form of OI, Type I, may have just a few or as many as several dozen fractures in a lifetime, be of normal or near-normal height, and may experience hearing loss, dental problems, and other complications. Babies born with the most severe type of OI, Type II, often have respiratory problems in addition to very fragile bones, and may die at or shortly after birth. OI Type III causes those affected to have dozens or even hundreds of fractures in a lifetime—including fractures present at birth—as well as very short stature and other health problems caused by bone deformities. Type IV OI usually falls somewhere between Type I and Type III in severity. Types V and VI, novel forms of OI, have only recently been identified and are similar to Type IV in severity. They are characterized by abnormalities in the structure of the bone but do not have a collagen defect.
The OI Foundation funded eight research grants in FY 2004, and spent a grand total of $454,652 on research projects. The increased commitment to research came at the start of a new strategic planning cycle, after an extensive survey of the community.

A New Mandate

“We heard loud and clear that the biggest priority [from our community] was research,” according to board President Jamie Kendall. “We will continue to seek new ways to grow and improve in all areas, but will place research at the forefront.”

The OI Foundation approved a plan to adjust priorities and devote 50% of its overall budget towards research.

“We’re not planning to cut back any other services or programs,” according to Heller An Shapiro, Executive Director.

“We’ll continue to seek grants and alternative funding to support the programs already in place, and find new funding to devote to research.”

The goal is to increase the budget by as much as 50% in the next three years, and devote a large part of that new income directly to supporting research programs.

“This is a very exciting time for medical research,” Kendall said.

An Exciting Time For Research

Dr. David Rowe, Chairman of the Foundation’s Medical Advisory Council, agrees. His excitement and enthusiasm is unmistakable when he talks about the current trends, the pace, and the future of OI research.

“With recent advances in gene therapy, drug therapies and transplant strategies underway, we’re having such an impact,” he said at a recent Board of Directors’ meeting, “both on the clinical side and the pure research side.”

During the fiscal year, the Foundation also demonstrated its commitment to furthering research and improved medical care for people with OI through the launch of two new projects: the Linked Clinical Research Centers and the National OI Registry.

A New Way To Share Information

The Linked Clinical Research Centers are a group of OI Centers governed by a Coordi-

Visit www.oif.org/research for detailed information about OI research, grants and scientific meetings.
nating Committee and linked together through a central database. This will lead to the development of summary data about the natural history of OI, diagnostic and clinical standards, physician training, and research oversight, resulting in significantly improved access to qualified care for patients and families.

Today, the average number of patients (mostly children) seen at existing OI Clinics is 58, but some clinics see as few as five. Linked Clinical Research Centers mean that instead of going to a doctor who has limited experience with OI, you will be able to visit a center where the doctors are knowledgeable about OI and you can benefit from the shared experience of thousands of OI patients of all ages.

Your participation in the center will also benefit you, and everyone else with OI, through the collection of valuable research data.

This is an enormous and vitally important undertaking that relies on an ongoing annual commitment from all involved. Currently, 24 research and/or clinical centers in 21 states are planned. Each center will start from an existing program, expanding on what we have, rather than building from scratch.

The preliminary list of states includes: California, Connecticut, Delaware, Illinois, Indiana, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Nebraska, New Jersey, New York, Ohio, Oregon, Pennsylvania, Texas, Washington, and Wisconsin.

And A New Way To Gather Information

In a few short months, you will be able to participate in the first phase of the Linked Clinical Research Centers, by joining the OI Registry. To enable these centers to conduct OI research, and provide medical care based on knowledge gained from all the Center patients, we first have to gather data about the members of the OI community.

Before the Centers open, we will begin collecting that data through the OI Registry, a confidential database of people with OI. Using the OI Registry data, researchers will begin to develop summary data about the natural history of OI, common or uncommon symptoms, and frequency of symptoms.

To be successful, the OI Registry will need to involve as many people who have OI as possible. It will be important that all types of OI are represented.

The benefits of participating in the OI Registry include:

- An opportunity to participate in clinical trials for new treatments and a cure;
- An opportunity to participate in research directed towards answering basic scientific questions about OI;
- A detailed knowledge of upcoming research in the OI community;
- Opportunities to participate in survey studies to collect specific data to aid research efforts; and
- Notification of the opening of the Linked Clinical Research Center near you.

As the OI Registry grows, the valuable data it contains will help researchers learn more about OI. Because the clinical and basic science research agenda in OI is moving at a rapid pace, patient participation in research has never been more critical than it is today. Since OI is a rare disorder, the ability to contact a large number of people with OI increases the likelihood of successful research.

Your participation aids us in our common goal to find treatments and a cure for OI, and makes the Registry an invaluable study tool for the research community.

REGISTER on www.oif.org to be sure you receive email updates on these important projects!
Independent Auditors’ Report
For Year Ending June 30, 2004

To the Board of Directors
Osteogenesis Imperfecta Foundation, Inc.

We have audited the accompanying statements of the financial position of Osteogenesis Imperfecta Foundation, Inc. as of June 30, 2004 and 2003, and the related statements of activities, functional expenses, and cash flows for the years then ended. These financial statements are the responsibility of the organization’s management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with generally accepted auditing standards. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the accounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Osteogenesis Imperfecta Foundation, Inc. as of June 30, 2004 and 2003, and the changes in net assets and cash flows for the years then ended, in conformity with generally accepted accounting principles.

Murray, Jonson, White & Associates, Ltd., P.C.
Certified Public Accountants

August 31, 2004

2004-2005 Board of Directors

<table>
<thead>
<tr>
<th>Member</th>
<th>Professional Affiliation</th>
<th>Home Residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Roger Bache</td>
<td>Raytheon</td>
<td>Olney, MD</td>
</tr>
<tr>
<td>Ken Finkel (1st V.P.)</td>
<td>Nat. Automotive Lines, Inc.</td>
<td>Indianapolis, IN</td>
</tr>
<tr>
<td>Parker C. Folse, III (Sec.)</td>
<td>Susman Godfrey LLP</td>
<td>Bainbridge Island, WA</td>
</tr>
<tr>
<td>Gemma Geisman (Founder)</td>
<td>Community Volunteer</td>
<td>Sebastian, FL</td>
</tr>
<tr>
<td>Robin Johnson (2nd V.P.)</td>
<td>Financial Times</td>
<td>Darien, CT</td>
</tr>
<tr>
<td>Michael Johnston</td>
<td>Interactive Illusions, Inc.</td>
<td>Minneapolis, MN</td>
</tr>
<tr>
<td>Jamie Kendall (President)</td>
<td>Social Security Admin.</td>
<td>Alexandria, VA</td>
</tr>
<tr>
<td>Tracy L. Mulroy</td>
<td>Community Volunteer</td>
<td>Bethesda, MD</td>
</tr>
<tr>
<td>Christine Wyman Rossi</td>
<td>College of the Holy Cross</td>
<td>Framingham, MA</td>
</tr>
<tr>
<td>David Rowe, M.D. (MAC Chair)</td>
<td>Univ. of CT Health Center</td>
<td>Farmington, CT</td>
</tr>
<tr>
<td>Chery Sacchetti</td>
<td>Community Volunteer</td>
<td>Margate, NJ</td>
</tr>
<tr>
<td>Neeru Sharma</td>
<td>General Motors</td>
<td>Sterling Heights, MI</td>
</tr>
<tr>
<td>James Sharples</td>
<td>Level Travel</td>
<td>Philadelphia, PA</td>
</tr>
<tr>
<td>Russell Sneiderman</td>
<td>The Innovia Group, LLC</td>
<td>Atlanta, GA</td>
</tr>
<tr>
<td>Jeffrey Stewart</td>
<td>S2 Group</td>
<td>Rye, NY</td>
</tr>
<tr>
<td>Peter Strauch (Treasurer)</td>
<td>Penguin Putnam</td>
<td>Montville, NJ</td>
</tr>
<tr>
<td>Susan Wilson</td>
<td>Cleveland Clinic</td>
<td>Ft. Myers, FL</td>
</tr>
</tbody>
</table>
## Statement of Financial Position
**June 30, 2004**

### Assets

<table>
<thead>
<tr>
<th>Assets</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CURRENT ASSETS</strong></td>
<td></td>
<td></td>
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<tr>
<td>Cash and Cash Equivalents</td>
<td>386,951</td>
<td>171,959</td>
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<tr>
<td>Accounts Receivable</td>
<td>84,449</td>
<td>20,204</td>
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<td>Pledges Receivable - Note 3</td>
<td>199,408</td>
<td>255,852</td>
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<td>Inventory</td>
<td>7,544</td>
<td>7,185</td>
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<tr>
<td>Prepaid Expenses</td>
<td>7,116</td>
<td>4,201</td>
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<td><strong>TOTAL CURRENT ASSETS</strong></td>
<td>$685,468</td>
<td>$459,401</td>
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<td><strong>INVESTMENTS - Note 4</strong></td>
<td>1,656,006</td>
<td>1,443,482</td>
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<td><strong>PROPERTY &amp; EQUIPMENT - Note 5</strong></td>
<td>36,302</td>
<td>34,646</td>
</tr>
<tr>
<td><strong>OTHER ASSETS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interest in trust - Note 11</td>
<td>15,500</td>
<td>-</td>
</tr>
<tr>
<td>Deposits</td>
<td>4,985</td>
<td>4,985</td>
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<tr>
<td><strong>TOTAL OTHER ASSETS</strong></td>
<td>$20,485</td>
<td>$4,985</td>
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<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td>$2,398,261</td>
<td>$1,942,514</td>
</tr>
</tbody>
</table>

### Liabilities and Net Assets

<table>
<thead>
<tr>
<th>Liabilities and Net Assets</th>
<th>2004</th>
<th>2003</th>
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</thead>
<tbody>
<tr>
<td><strong>CURRENT LIABILITIES</strong></td>
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<tr>
<td>Accounts Payable &amp; Accrued Expenses</td>
<td>133,782</td>
<td>46,720</td>
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<td>Deferred Revenue-Membership Dues</td>
<td>10,500</td>
<td>7,500</td>
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<td>Grants payable-Short Term</td>
<td>412,942</td>
<td>240,664</td>
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<tr>
<td><strong>TOTAL CURRENT LIABILITIES</strong></td>
<td>$557,224</td>
<td>$294,884</td>
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<tr>
<td>Grants Payable-LongTerm</td>
<td>10,000</td>
<td>60,000</td>
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<tr>
<td><strong>TOTAL LIABILITIES</strong></td>
<td>$567,224</td>
<td>$354,884</td>
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### NET ASSETS

- **Unrestricted** General Fund
  - Undesignated: (25,509) (11,565)
  - Designated-Endowment Fund: 1,344,725 1,157,774
  - Designated-2004 Nat. Conference: 60,840 29,141
  - 1,380,056 1,175,350

- **Temporarily Restricted** - Note 9
  - 396,493 373,292

- **Permanently Restricted**
  - Buynak Charitable Fund - Note 11: 15,500 -
  - Endowment Fund: 38,988 38,988
  - 54,588 38,988

| TOTAL NET ASSETS                | $1,831,037| $1,587,630|
| TOTAL LIABILITIES & NET ASSETS  | $2,398,261| $1,942,514|

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### The 2004 Medical Advisory Council

**Chair**
- David Rowe, M.D.
- Peter Byers, M.D.
- Lynn Gerber, M.D.
- Francis Glorieux, M.D., Ph.D.
- Deborah Krakow, M.D.
- Joan Marini, M.D., Ph.D.
- Darwin Prockop, M.D.
- Leon Root, M.D.
- Jay Shapiro, M.D.
- Peter Smith, M.D.
- David Vernick, M.D.
- Priscilla Wacaster, M.D.
- Michael Whyte, M.D.

### Active Support Groups Throughout The United States:
- Alaska
- Arizona
- (Northern) California
- (Southern) California
- Colorado
- Delaware
- Florida
- Georgia
- Indiana
- Iowa
- Kansas
- Kentucky
- Massachusetts
- Missouri
- New Jersey
- (Southwest) Ohio
- (Northeast) Ohio
- (Northern) Ohio
- Oregon
- (Central) Texas
- (Houston) Texas
- (San Antonio) Texas
- Utah
- Washington
- Wisconsin

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**OI Foundation FY 2004 Annual Report**
### Statements of Activities as of June 30, 2004

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>SUPPORT &amp; OTHER REVENUE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revenues</td>
<td></td>
<td></td>
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<tr>
<td>Sales</td>
<td>5,196</td>
<td>-</td>
<td>-</td>
<td>5,196</td>
<td>6,808</td>
</tr>
<tr>
<td>Less: Cost of Sales</td>
<td>(1,574)</td>
<td>-</td>
<td>-</td>
<td>(1,574)</td>
<td>(7,951)</td>
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<tr>
<td><strong>GROSS PROFIT ON SALES</strong></td>
<td>3,622</td>
<td>-</td>
<td>-</td>
<td>3,622</td>
<td>(1,143)</td>
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<tr>
<td>Community Fund drives</td>
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<td>116,683</td>
<td>-</td>
<td>156,760</td>
<td>166,367</td>
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<td>Conference Receipts</td>
<td>86,717</td>
<td>-</td>
<td>-</td>
<td>86,717</td>
<td>49,907</td>
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<td>Donations</td>
<td>233,544</td>
<td>154,647</td>
<td>-</td>
<td>388,191</td>
<td>295,660</td>
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<td>Donations - In-kind - Note 8</td>
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<td>-</td>
<td>-</td>
<td>12,795</td>
<td>13,983</td>
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<td>Endowment Income</td>
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<td>67,000</td>
<td>15,500</td>
<td>122,500</td>
<td>24,568</td>
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<td>Fund-Raising Activities</td>
<td>309,294</td>
<td>214,331</td>
<td>-</td>
<td>523,625</td>
<td>416,737</td>
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<td>Grants</td>
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<td>35,805</td>
<td>-</td>
<td>37,130</td>
<td>93,455</td>
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<td>Investment Income</td>
<td>32,942</td>
<td>-</td>
<td>-</td>
<td>32,942</td>
<td>34,054</td>
</tr>
<tr>
<td>Memorials and Honorariums</td>
<td>29,936</td>
<td>2,775</td>
<td>-</td>
<td>32,711</td>
<td>32,686</td>
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<tr>
<td>Realized &amp; Unrealized Gain (loss) on Investments</td>
<td>179,583</td>
<td>-</td>
<td>-</td>
<td>179,583</td>
<td>76,413</td>
</tr>
<tr>
<td>Net Assets Released from Restrictions - Note 9</td>
<td>568,040</td>
<td>(568,040)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>TOTAL SUPPORT &amp; OTHER REVENUE</strong></td>
<td>$1,537,875</td>
<td>$23,201</td>
<td>$15,500</td>
<td>$1,576,576</td>
<td>$1,202,687</td>
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<table>
<thead>
<tr>
<th><strong>EXPENSES</strong></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Services</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Public Awareness</td>
<td>112,931</td>
<td>-</td>
<td>-</td>
<td>112,931</td>
<td>85,948</td>
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<tr>
<td>Education &amp; Support</td>
<td>271,582</td>
<td>-</td>
<td>-</td>
<td>271,582</td>
<td>210,060</td>
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<tr>
<td>Resource Center</td>
<td>5,322</td>
<td>-</td>
<td>-</td>
<td>5,322</td>
<td>74,593</td>
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<tr>
<td>Research</td>
<td>454,652</td>
<td>-</td>
<td>-</td>
<td>454,652</td>
<td>352,411</td>
</tr>
<tr>
<td>Conference</td>
<td>180,879</td>
<td>-</td>
<td>-</td>
<td>180,879</td>
<td>167,167</td>
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<tr>
<td><strong>Total Program Services</strong></td>
<td>$1,025,366</td>
<td>-</td>
<td>-</td>
<td>$1,025,366</td>
<td>$890,179</td>
</tr>
</tbody>
</table>

| Supporting Services |                   |                            |                            |            |            |
| Administrative and General | 87,720          | -                          | -                          | 87,720     | 88,265     |
| Fund-Raising          | 220,083           | -                          | -                          | 220,083    | 179,399    |
| **Total Supporting Services** | $307,803         | -                          | -                          | $307,803   | $267,664   |

| **TOTAL EXPENSES** |                   |                            |                            | $1,333,169 | $1,157,843 |

| **CHANGE IN NET ASSETS** |                   |                            |                            |            |            |
| **NET ASSETS AT BEGINNING OF YEAR** | 1,175,350          | 373,292                    | 38,988                     | 1,587,630  | 1,542,786  |

| **NET ASSETS AT END OF YEAR** |                   |                            |                            |            |            |
| **NET ASSETS AT END OF YEAR** | $1,380,056          | $396,493                    | $54,488                    | $1,831,037 | $1,587,630 |
Parents turn grief into action

Set Lifetime Goal to raise $1 million

Michael John Shultz was a cheerful baby. “No matter how much pain he was in, he could always give you a smile,” his mother Beth remembers.

Michael was born to John and Beth Shultz in August 1998 with a severe form of OI. “Michael would never break just one bone,” Beth explained. “He would break multiple bones at a time.”

Like other parents of a child with severe OI, John and Beth knew the heart-breaking frustration of not being able to prevent the fractures from happening.

Sadly, Michael passed away when he was just eight months old.

John and Beth decided that they didn’t want another child to go through the experience that Michael had. Since John was an avid golfer, the couple decided to hold a golf tournament to raise money for OI research.

The first Miracle Michael Fund Charity Golf Tournament was held in 1999, on the day that would have been Michael’s first birthday. Annual events have been held since, and together, they have brought in almost $100,000.

However, John and Beth have set their goal much higher. “We have a goal in our lifetime . . . we want to see a cure,” Beth said. “We also have a goal of raising at least $1 million during our lifetime.”

Under the microscope...

Dr. Donna King

The objective of Dr. Donna King’s research is to evaluate two different bone therapy strategies using the oim mouse model of OI. One strategy used systematic injections of a synthetic drug that was previously shown to stimulate bone-forming cellular activity in normal rats. The second used systematic injections of a human growth hormone offered to some moderate to severe OI patients.

Initial results of her research were so exciting, she immediately submitted a paper to the Journal of Bone and Mineral Research, a peer-reviewed journal, which will be published in spring, 2005.

Her research on mice with mild OI revealed that the human growth hormone injections caused significant improvement in the bone’s density and mineral composition, and an increase in height.

Dr. King is very excited, and expects the results of this research to result in pharmaceutical-funded follow-up research in humans. It already resulted in an invitation from NIH to apply for funding to continue her research.
Illinois couple involves friends, family and employer in supporting OI research

Steve Kipperman says that having Type I osteogenesis imperfecta didn’t really change his life too much when he was growing up. Although he experienced 21 fractures during his life, his family felt it was important that Steve’s activities not be limited by his condition.

“For me personally, I feel the worst is behind me,” Steve said.

Even so, Steve’s mother, Pat Kipperman, who also has OI, served on the OI Foundation’s Board of Directors, and Steve and his wife Bonnie have made annual donations to support OI research since 1992. However, when their daughter, Katie, was born in 2001 with a mild form of OI, the Kippermans decided to do more.

“When Katie was born, we had the genetic testing done at Dr. [Peter] Byers’ facility at the University of Washington,” Steve explained. “The day we learned Katie had OI, it changed everything. All of a sudden, it was my baby and my little girl. It was no longer that I just had to deal with my OI, but now I had a daughter with OI.”

He added, “I could sit there and say, ‘poor me,’ or I could funnel my energies towards something constructive; raising funds for research in the area of OI.”

The Kippermans were inspired after attending the Miracle Michael Golf Tournament in Naperville, IL, an annual fundraising event organized by parents of a baby who died from complications related to severe OI. Steve and Bonnie decided to make their contribution by writing an appeal letter to family and friends, asking for their support for OI research. By Steve’s account, “the money started pouring in.”

“Now, it has become an annual thing,” he said. “We also use the opportunity to give families an update on how Katie is doing.”

The Kippermans have raised more than $30,000 from their family and friends to support the OI Foundation. In addition, Steve’s employer, Abbott Laboratories, has made $12,500 in grants towards OI research since 1996.

Steve said that he and Bonnie plan to continue their fundraising efforts into the foreseeable future.

Steve believes that anyone can make a difference for OI research by writing and sending their own letter to family and friends.

“You don’t have to know 100 people and get 100 to donate,” Steve explained. “Even $50 here and $25 there can help, from Mom and Dad or the neighbors. Talking to friends and families about supporting research can result in substantial support,” he said.

While his Type I OI may not have had an impact in his childhood, the Kipperman’s support to the OI community and OI research through the years has had a huge impact on the lives of countless others.

THE CONTINUED SUCCESS OF THE OI FOUNDATION DEPENDS ON THE GENEROUS SUPPORT OF OUR INDIVIDUAL, CORPORATE, AND FOUNDATION DONORS.

Research Fund
Recent advances in gene therapy, cell transplantation, and drug therapies highlight the extraordinary potential for results in OI research. Gifts designated to the Research Fund significantly increase the impact and speed of this work, allowing us to capitalize on the most promising research opportunities. Donations to the Research Fund will help us find successful treatments and a cure for osteogenesis imperfecta.

Education, Support and Awareness Fund
Over 100,000 people receive information or support services from the Foundation each year via publications, our website, email, telephone calls, support groups or personal interactions. Increasing awareness helps to improve medical care and creates more opportunities for independence for people with OI. Please help us continue these vital functions—to raise public awareness and offer the personalized support that all those affected by OI deserve.

Please Contact Joan Drebing, Development Director at (301) 947-0083 or jdrebing@oif.org
# Fundraising Sources of Income

The continued success of the OI Foundation depends on the generous support of our donors.

Supporting the Foundation is easier than ever before; simply click on the “Donate Now” button on www.oif.org, or call (800) 981-2663 for a complete list of ways to help.

Thank you for helping to improve the lives of everyone affected by OI.

## Statements of Functional Expenses

<table>
<thead>
<tr>
<th>Expenditure Category</th>
<th>Program Services</th>
<th>Support Svcs.</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public Awareness</td>
<td>Education &amp; Member Support</td>
<td>Resource Center</td>
</tr>
<tr>
<td>Advocacy</td>
<td>-</td>
<td>2,187</td>
<td>2,187</td>
</tr>
<tr>
<td>Depreciation Expense</td>
<td>1,903</td>
<td>245</td>
<td>-</td>
</tr>
<tr>
<td>Educational Conferences</td>
<td>-</td>
<td>455</td>
<td>-</td>
</tr>
<tr>
<td>Grants &amp; Fellowships</td>
<td>-</td>
<td>-</td>
<td>342,938</td>
</tr>
<tr>
<td>Insurance</td>
<td>963</td>
<td>1,879</td>
<td>963</td>
</tr>
<tr>
<td>Licenses &amp; Subscriptions</td>
<td>330</td>
<td>1,538</td>
<td>285</td>
</tr>
<tr>
<td>Office Supplies &amp; Expense</td>
<td>6,783</td>
<td>7,108</td>
<td>10</td>
</tr>
<tr>
<td>Postage</td>
<td>148</td>
<td>14,136</td>
<td>1,063</td>
</tr>
<tr>
<td>Printing</td>
<td>3,398</td>
<td>36,671</td>
<td>-</td>
</tr>
<tr>
<td>Professional Fees</td>
<td>2,402</td>
<td>2,402</td>
<td>-</td>
</tr>
<tr>
<td>Rent - Note 6</td>
<td>11,364</td>
<td>11,364</td>
<td>-</td>
</tr>
<tr>
<td>Salaries/Benefits - Note 7</td>
<td>80,594</td>
<td>135,397</td>
<td>3,474</td>
</tr>
<tr>
<td>Special Events</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Telephone</td>
<td>1,068</td>
<td>5,822</td>
<td>450</td>
</tr>
<tr>
<td>Travel &amp; Meetings</td>
<td>79</td>
<td>13,534</td>
<td>65</td>
</tr>
<tr>
<td>Web Site Mgmt./Internet</td>
<td>212</td>
<td>33,109</td>
<td>260</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>$112,931</strong></td>
<td><strong>$271,582</strong></td>
<td><strong>$5,322</strong></td>
</tr>
</tbody>
</table>

*OI Foundation FY 2004 Annual Report Page 11*
Mom involves research community in Type I scientific meeting

My first call to the OI Foundation was a call for help! I needed information to better manage my daughter, Hannah’s, OI. I got the answers I needed and started to think about how I could help the Foundation — as a way of saying “thanks” and also to enable the Foundation to further help my family. I felt if I could make things happen in the “OI world” to help my daughter, then I would be empowered to do other things, too.

I thought the best way to help my daughter would be to get more researchers and clinicians involved in looking at Type I OI. I was concerned that most of the research I learned about was focused on the other types of OI. I hoped that greater understanding of Type I would lead to better understanding of all types of OI. I began exploring the idea of a scientific meeting to stimulate research into Type I OI, and the Foundation was eager to make it a reality.

The meeting, *Mild forms of osteogenesis imperfecta (OI): Molecular basis, natural history, and treatment* was better than we could have ever hoped. It taught us so very much, and stimulated new research.

We’re also pleased to see more people with Type I OI getting involved in the Foundation. The bottom line is that I want to give to the Foundation because I know we’re gaining knowledge and getting closer to a cure — and that’s the best way to help my daughter.

### Statements of Cash Flows for the years ended June 30

<table>
<thead>
<tr>
<th>OPERATING ACTIVITIES</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change in net assets</td>
<td>$243,407</td>
<td>$44,844</td>
</tr>
<tr>
<td>Adjustments to reconcile change in net assets to net cash provided by operating activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depreciation and amortization</td>
<td>10,936</td>
<td>7,386</td>
</tr>
<tr>
<td>beneficial interest in perpetual trust</td>
<td>(15,500)</td>
<td>-</td>
</tr>
<tr>
<td>Gain (loss) on investments</td>
<td>(179,583)</td>
<td>(76,413)</td>
</tr>
<tr>
<td>Loss on disposal</td>
<td>-</td>
<td>280</td>
</tr>
<tr>
<td>Changes in operating assets and liabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Increase) decrease in accounts receivable</td>
<td>(64,245)</td>
<td>(19,317)</td>
</tr>
<tr>
<td>(Increase) decrease in pledges receivable</td>
<td>56,444</td>
<td>41,843</td>
</tr>
<tr>
<td>(Increase) decrease in inventory</td>
<td>(359)</td>
<td>4,044</td>
</tr>
<tr>
<td>(Increase) decrease in prepaid expenses</td>
<td>(2,915)</td>
<td>28,199</td>
</tr>
<tr>
<td>(Increase) decrease in deposits</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increase (decrease) in accounts payable &amp; accrued expenses</td>
<td>87,062</td>
<td>(53,141)</td>
</tr>
<tr>
<td>Increase (decrease) in grants payable</td>
<td>122,278</td>
<td>138,664</td>
</tr>
<tr>
<td>Increase (decrease) in deferred revenue</td>
<td>3,000</td>
<td>(48,704)</td>
</tr>
<tr>
<td><strong>NET CASH PROVIDED (USED) BY OPERATING ACTIVITIES</strong></td>
<td><strong>$260,525</strong></td>
<td><strong>$67,685</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INVESTING ACTIVITIES</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purchase of equipment</td>
<td>(12,592)</td>
<td>(24,541)</td>
</tr>
<tr>
<td>Purchase of investments</td>
<td>(105,545)</td>
<td>(428,315)</td>
</tr>
<tr>
<td>Sale of investments</td>
<td>72,604</td>
<td>5,631</td>
</tr>
<tr>
<td><strong>NET CASH PROVIDED (USED) BY INVESTING ACTIVITIES</strong></td>
<td><strong>$(45,533)</strong></td>
<td><strong>$(447,225)</strong></td>
</tr>
</tbody>
</table>

| Increase (decrease) in cash and cash equivalents | 214,992          | (379,540)        |
| Cash and cash equivalents at beginning of period | 171,959          | 551,499          |

| **CASH AND CASH EQUIVALENTS AT END OF PERIOD** | **$386,951**    | **$171,959**     |
Under the microscope...

Dr. Ari Elson

Dr. Ari Elson’s research seeks to understand, at the molecular level, how a specific protein affects the functions of osteoclasts. Osteoclasts break down bone matter, an important step in the ‘turnover’ of healthy bone cells.

While his research to date appears to substantiate his original hypothesis, Dr. Elson must continue his work to learn more, so the protein can be used to regulate osteoclasts.

OSTEOGENESIS IMPERFECTA FOUNDATION, INC.
NOTES TO FINANCIAL STATEMENTS

NOTE 1 - ORGANIZATION AND SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

Osteogenesis Imperfecta Foundation, Inc. (the Foundation) is a non-profit Georgia corporation. The mission of the Foundation is to improve the quality of life for individuals affected by this bone disorder through research, education, awareness, and mutual support. This mission is being achieved through encouraging medical research into the causes, treatment and cure for osteogenesis imperfecta; promoting a greater awareness and understanding of the disorder among target audiences, communities, and the general public; and, providing comprehensive programs of education and support for persons affected and their caregivers.

The information resources and services provided enhance the dignity, independence, and well-being of persons affected by osteogenesis imperfecta.

(a). Financial Statement Presentation - The Foundation reports information regarding its financial position and activities according to three classes of net assets:

• Unrestricted net assets - includes net assets that are not subject to donor imposed stipulations.

• Temporarily restricted net assets - includes gifts for which donor imposed restrictions have not been met, and unconditional promises to give.

• Permanently restricted net assets - includes gifts that require, by donor restriction, that the corpus be invested in perpetuity and only the income be made available for program operations in accordance with donor restrictions.

(b). Contributions - The Foundation accounts for contributions in accordance with Statement of Financial Accounting Standards (SFAS) No. 116, Accounting for Contributions Received and Contributions Made. Contributions are recognized when the donor makes a promise to give to the Foundation that is, in substance, unconditional. Contributions are recorded as unrestricted, temporarily restricted, or permanently restricted support, depending on the existence or nature of any donor restrictions. All other donor-restricted contributions are reported as an increase in temporarily or permanently restricted net assets depending on the nature of the restriction. When a restriction expires, temporarily restricted net assets are reclassified to unrestricted net assets.

(c). Cash and Cash Equivalents - The Foundation considers substantially all highly liquid investments with a maturity of three months or less when purchased to be cash equivalents.

(d). Inventory Valuation - The inventory is recorded at cost using the first-in, first-out method of inventory valuation.

(e). Recognition of Donated Goods, Services, Facilities and Equipment - The Foundation recognizes the value of donated goods, services, facilities and equipment contributed to its programs at a fair market rate established by the donor, or a rate established by the Board if the fair market rate is not readily available from the donor organization. Volunteer hours are assigned a monetary value only if they are rendered by a professional.

(f). Property and Equipment - Property and equipment are recorded at cost, less accumulated depreciation. Depreciation expense is computed using the straight-line method over the estimated useful lives of the respective assets. Expenditures for maintenance and repairs are charged against income as incurred; betterments which increase the value or materially extend the life of the related assets are capitalized.

(g). Income Taxes - The Foundation is exempt from income taxes and Federal unemployment taxes based upon its qualification as a Section 501(c)(3) organization.

(h). Functional Allocation of Expenses - The costs of providing the programs and services on a functional basis are summarized on the Statements of Functional Expenses. In the statements, costs have been allocated among the programs that benefitted from the expenses. The functional expenses of the Foundation are recorded and reported in the following categories:

• Public Awareness - Represents expenses incurred to increase awareness about osteogenesis imperfecta among the general public and various population segments.

• Education and Support - Includes all expenses related to education and support services designed to assist individuals with Osteogenesis Imperfecta, their caregivers, and medical professionals.

• Resource Center - Includes expenses incurred to maintain a National Resource Center on metabolism of bone disease.

• Research - Includes expenses incurred granting awards to support research training of individuals who aspire to develop long-term and relevant records to understanding and/or treating osteogenesis imperfecta; seed grants to researchers to prepare preliminary data as a basis for potential application to external major research funding resources; and long-term collaborative research efforts; research related activities adopted by the Board of Directors involving medical symposiums, meetings, conferences, and advocacy efforts to encourage research by Federal agencies; and indirect administration of research funds, including actual costs to administer and advance all of the above research efforts of the Foundation.

• Conference - Includes expenses incurred for the biennial conference.

• Administrative and General - Expenses include indirect expenses to operate the Foundation and the programs it funds.

• Fundraising - Expenses include development staff time and benefits, proportionate office, equipment, printing, and mail expenses for development activities; and all expenses of paid solicitors, bonding, permits, and licenses necessary to do fund-raising activities.

NOTE 2 - ENDOWMENT FUND

The Endowment Fund represents those monies which have been permanently restricted by the donor to ensure the future availability of resources to fund the activities of the Foundation.

The Foundation’s policy is to place Endowment Fund donations in a separate account. Earnings on this account are designated by the Foundation’s Board to be used to increase the Endowment Fund balance.

NOTE 3 - PLEDGES RECEIVABLE

The Foundation received pledges from the United Way and the Combined Federal Campaign for the next fiscal year. These pledges are shown net of an estimated allowance for uncollectible pledges.

The Foundation received pledges from the United Way and the Combined Federal Campaign for the next fiscal year. These pledges are shown net of an estimated allowance for uncollectible pledges.

These pledges and other miscellaneous pledges are shown below as of June 30:

<table>
<thead>
<tr>
<th>Pledge Source</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Osteoporosis Foundation</td>
<td>-</td>
<td>37,484</td>
</tr>
<tr>
<td>United Way Campaign</td>
<td>95,806</td>
<td>119,211</td>
</tr>
<tr>
<td>Combined Federal Campaign</td>
<td>20,978</td>
<td>27,557</td>
</tr>
<tr>
<td>Million Dollar Round Table</td>
<td>15,724</td>
<td></td>
</tr>
<tr>
<td>McGowan Charitable Fund</td>
<td>-</td>
<td>54,000</td>
</tr>
<tr>
<td>The Brainymayer Foundation</td>
<td>67,000</td>
<td></td>
</tr>
<tr>
<td>American Legion Child Welfare</td>
<td>-</td>
<td>17,100</td>
</tr>
</tbody>
</table>
| OweSt | 500
| TOTAL | $199,408 | $259,852 |

Continued on page 10
suggests that the enzyme may have a therapeutic role in treating more severe forms of OI. For the remainder of the funding period, Dr. Poirier will study the cause of death associated with the mutation. He will also investigate whether the enzyme ceramide has a more positive therapeutic effect than bisphosphonates on inhibiting bone resorption in the mouse model. His preliminary data in vitro suggests that the enzyme may have a therapeutic role in treating more severe forms of OI.

NOTE 4 - INVESTMENTS
Investments are stated at fair value which is based on quoted market prices. Investments are summarized as follows:

<table>
<thead>
<tr>
<th>June 30, 2004</th>
<th>General Research Endowment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and money market funds</td>
<td>13,657</td>
<td>1,023</td>
</tr>
<tr>
<td>Mutual funds</td>
<td>94,899</td>
<td>172,444</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$98,566</td>
<td>$173,467</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>June 30, 2003</th>
<th>General Research Endowment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and money market funds</td>
<td>13,892</td>
<td>1,017</td>
</tr>
<tr>
<td>Mutual funds</td>
<td>80,229</td>
<td>151,562</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$94,121</td>
<td>$152,599</td>
</tr>
</tbody>
</table>

NOTE 5 - PROPERTY AND EQUIPMENT
The following is a summary of property and equipment at June 30:

<table>
<thead>
<tr>
<th>Description</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office equipment</td>
<td>66,469</td>
<td>76,231</td>
</tr>
<tr>
<td>Leasehold improvements</td>
<td>3,887</td>
<td>3,887</td>
</tr>
<tr>
<td>Software</td>
<td>10,389</td>
<td>8,899</td>
</tr>
<tr>
<td>Less: Accumulated depreciation</td>
<td>(46,443)</td>
<td>(54,371)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$36,302</td>
<td>$34,646</td>
</tr>
</tbody>
</table>

NOTE 6 - LEASES
As of September 1, 2001, the Foundation entered into a lease agreement for office space commencing on September 1, 2001 and ending on August 31, 2006.

The following is a schedule of future minimum rental payments required under the lease:

<table>
<thead>
<tr>
<th>Year Ending June 30</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and money market funds</td>
<td>60,294</td>
<td>60,294</td>
<td>60,294</td>
<td>60,294</td>
</tr>
<tr>
<td>Mutual funds</td>
<td>23,413</td>
<td>23,413</td>
<td>23,413</td>
<td>23,413</td>
</tr>
<tr>
<td>TOTAL</td>
<td>$83,707</td>
<td>$83,707</td>
<td>$83,707</td>
<td>$83,707</td>
</tr>
</tbody>
</table>

NOTE 7 - DEFINED CONTRIBUTION PLAN
On September 1, 1998, the Foundation adopted a defined contribution plan (the Plan) covering all employees with at least six months of service who agree to make contributions to the Plan. The Foundation matches up to 50% of employee contributions to the Plan each year up to a maximum of 2% of the participants’ compensation. Participants are fully vested in the matching contribution after three years of service. Total expense for the years ended June 30, 2004 and 2003 was $2,469 and $2,296, respectively.

NOTE 8 - DONATED GOODS, MATERIALS, AND SERVICES
Donated goods, materials, and services are received for the various programs. The value of these donations is recorded at the fair market value as provided by the donor and totaled $12,795 and $13,983 for the years ended June 30, 2004 and 2003, respectively.

In addition, the Foundation has estimated that total volunteer time donated during the year ended June 30, 2004 and 2003 was approximately $455,492 and $332,034, valued at $17.19 and $16.54 per hour, respectively. These services are not recorded in the accompanying financial statements, as they did not meet the requirements of SFAS No. 116.

NOTE 9 - TEMPORARILY RESTRICTED NET ASSETS
Temporarily restricted net assets are available for the following purposes:

<table>
<thead>
<tr>
<th>Purpose</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Osteoporosis Foundation - Resource Center Grant</td>
<td>37,959</td>
<td>-</td>
</tr>
<tr>
<td>United Way funding for the next fiscal year</td>
<td>199,210</td>
<td>199,210</td>
</tr>
<tr>
<td>Combined Federal Campaign funding for the next fiscal year</td>
<td>27,557</td>
<td>27,557</td>
</tr>
<tr>
<td>Estate bequest</td>
<td>7,050</td>
<td>-</td>
</tr>
<tr>
<td>Bright Start Story Book project</td>
<td>26,500</td>
<td>26,500</td>
</tr>
<tr>
<td>Registry Project</td>
<td>60,499</td>
<td>60,499</td>
</tr>
<tr>
<td>Biennial Conference</td>
<td>1,524</td>
<td>-</td>
</tr>
<tr>
<td>Miracle Michael Golf Fundraiser</td>
<td>-</td>
<td>20,000</td>
</tr>
<tr>
<td>OIF Type I Science Workshop</td>
<td>-</td>
<td>15,724</td>
</tr>
<tr>
<td>General OI Research</td>
<td>7,477</td>
<td>-</td>
</tr>
<tr>
<td>Services to Benefit Hearing Impaired</td>
<td>3,580</td>
<td>-</td>
</tr>
<tr>
<td>Exercise Book for Children with OI</td>
<td>19,400</td>
<td>19,400</td>
</tr>
<tr>
<td>Adult Book on OI</td>
<td>14,900</td>
<td>14,900</td>
</tr>
<tr>
<td>Development of Career Investigators</td>
<td>55,499</td>
<td>55,499</td>
</tr>
<tr>
<td>American Legion Nurses Guide Project</td>
<td>34,200</td>
<td>-</td>
</tr>
<tr>
<td>TOTAL NET ASSETS RELEASED FROM RESTRICTION</td>
<td>$396,483</td>
<td>$373,292</td>
</tr>
</tbody>
</table>

Net assets were released from restriction by incurring expenses satisfying the restricted purposes or by occurrence of other events.

Restriction accomplished:

<table>
<thead>
<tr>
<th>Description</th>
<th>2004</th>
<th>2003</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Osteoporosis Foundation Resource Center Grant</td>
<td>37,959</td>
<td>50,066</td>
</tr>
<tr>
<td>Biennial Conference</td>
<td>49,577</td>
<td>-</td>
</tr>
<tr>
<td>Research</td>
<td>317,307</td>
<td>198,169</td>
</tr>
<tr>
<td>Expiration of Time Restriction</td>
<td>146,767</td>
<td>110,070</td>
</tr>
<tr>
<td>Education and Public Awareness</td>
<td>14,430</td>
<td>20,920</td>
</tr>
<tr>
<td>TOTAL NET ASSETS RELEASED FROM RESTRICTION</td>
<td>$568,040</td>
<td>$369,625</td>
</tr>
</tbody>
</table>

NOTE 10 - CONCENTRATIONS OF CREDIT RISK
Financial instruments which potentially subject the company to concentration of credit risk consist principally of temporary cash investments. The company places its temporary cash investments with high credit quality financial institutions. At times, such investments may be in excess of Federal Deposit Insurance.

NOTE 11 - MARJORIE D. BUYNAK CHARITABLE FUND
The Foundation was named as a beneficiary of a charitable remainder annuity trust upon the death of the annuitant. As a result, $15,500 has been invested in a perpetual trust administered by a third party. The Foundation has the right to receive income earned on this asset in perpetuity, but the asset itself will never be received and is considered permanently restricted.

NOTE 12 - RECLASSIFICATIONS
Certain items in the June 30, 2003 statement of functional expenses have been reclassified to conform to current year presentation. These reclassifications have no effect on new income previously reported.

NOTE 12 - SUBSEQUENT EVENTS
On September 9, 2004, OIF signed a letter of intent to renew their current lease. The new lease agreement increases their total office space by 1,601 square feet. The new lease takes effect on December 1, 2004, and ends on November 30, 2007.

The following table outlines the future minimum rental payments required under the lease:

<table>
<thead>
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Dr. Poirier in his lab.
THE CONTINUED SUCCESS OF THE OI FOUNDATION DEPENDS ON THE GENEROUS SUPPORT OF OUR INDIVIDUAL, CORPORATE, AND FOUNDATION DONORS.

Endowment Funds
Income from the OI Foundation Endowment Fund will be used to finance operating expenses for the organization. The fund enhances our overall capability to serve the OI community by providing a solid base of support for ongoing programs and projects. The fund’s support of administrative costs will give the Foundation a significant advantage when requesting grants from public or private groups willing to further our work.

Bequests and Planned Gifts
A simple and meaningful way to support the Foundation is through a bequest in a will or trust, or by making the Foundation the beneficiary of an IRA or life insurance policy.

Please Contact Joan Drebing, Development Director at (301) 947-0083 or jdrebing@oif.org
The OI Foundation celebrates 35 years of support to the OI Community this year. In 1970, in response to an article in Redbook Magazine by Gemma Geisman about how her family was coping with a child with OI, the first group of parents gathered at the Chicago Shriners Hospital with Dr. Edward Millar to discuss how they could improve the quality of life for their children through information, support and research into better treatments and a cure.

The Foundation’s mission remains the same 35 years later.

Since that initial meeting, the Foundation has conducted thousands of grassroots and national awareness activities, established support groups and one-on-one support volunteers in 40 states, funded more than $2 million in research towards better treatments and a cure, hosted 14 national conferences, participated in a number of international scientific conferences and meetings, and conducted four scientific meetings in the U.S. to foster better communication and cooperation within the OI research community.

Over the years, the Foundation has responded to tens of thousands of individual requests for support and information.

“Our information and support program will always be an integral part of the OI Foundation’s activities,” states Heller An Shapiro, Executive Director. “Our increased commitment to research activities is an expansion of our services. As long as parents, adults, students, medical professionals, educators—in fact anyone—have questions or need information about OI, we’ll be here to provide answers.”

The OI Foundation recently fielded a question from an adult with OI who was shocked and pleased at the specific, individual information he received in response to a simple query.

“I knew they provided information,” he said, “but I had no idea how much support they could offer me until I made the phone call. I felt like I’d come home, to someplace where people understood me.”

The OI Foundation responded to almost 5,000 information requests in FY 2004 alone. The requests come by phone, mail and email, and every single question is answered individually, usually within 24 hours, by one of two staff members.

...and resources

The OI Foundation has a wide variety of resources readily available to respond to requests. At any given time, staff members are in the process of updating and/or publishing at least one new resource. Often there are three or four publications in various stages of completion.

The Foundation completed a children’s book, Jason’s First Day!, during the last fiscal year, and published almost a dozen fact sheets or information resources. The Foundation is also completing two new books, and revising the Caring for Infants & Children with OI and Introduction to OI pamphlets.

Breakthrough, the Foundation’s quarterly newsletter, remains free and contains news and information relevant to the OI community, and a monthly e-newsletter keeps the community informed between issues. The Foundation has expanded the website to more than 300 pages of information, with links to an additional 200 downloadable files.

Virtually all of the resources are available through the website or by mail, most free of charge.

When a new resource is being developed, the Foundation seeks grant money or donations to ensure it has the widest distribution possible.
The 18th annual Kroger OI Foundation Charity Golf Tournament, organized by former board president Joe Antolini in honor of his daughter, Kristen, raised just over $70,000 this fall. That brings the total amount raised by the tournament to more than $1.3 million, or 66% of what the Foundation has spent on research during the past 34 years.

“Because of the Kroger funds, OI research is producing new treatments and is on the verge of finding a cure” according to Executive Director Heller An Shapiro.

The inaugural Kroger tournament, held in 1987, raised just over $4,500. Dedication and persistence paid off—over the next three years the donations increased steadily, and in 1991 the event raised almost ten times the original amount—$44,000. In the years since then, it has averaged $90,000 per year in contributions, all designated to support the OI Foundation’s research funds.

“This event is a testament to the dedication of the Kroger company to giving back to their community,” according to Antolini. “It is a real team effort and everyone at Kroger is proud of our contributions to breakthroughs in OI research.”

Part of the success stems from the active involvement of Kristen Antolini in the event. Kristen has type IV OI, and her enthusiasm and unwillingness to let OI slow her down are an inspiration to all who know her.

Kristen is a senior with a double major at West Virginia University and was a recently a finalist for a Rhodes scholarship.

Another key to the event’s continued success is the dedication of a handful of core volunteers.

Coworkers and senior executives alike have “stepped up to the tee” to help Joe put on each year’s tournament. Norm Slocum, Art Jaklitsch, Gary Wyland and Pete Williams, among others, have returned year after year to pitch in wherever needed.

“It’s hard not to want to help once you’ve met Kristen,” Joe explained.

...and outreach.

In the past fiscal year, the Foundation distributed more than 30,000 nursing guides throughout the U.S., free of charge, and more than 10,000 children’s books.

In the next few months, an additional 10,000 children’s books, packaged with the Living with OI book set, will be shipped to public libraries throughout the country.

We’ve conducted similar campaigns in the past with Therapeutic Strategies for OI and OI: A Guide for Nurses.

Not only are we reaching out to the OI community and the medical support community, we’re also spreading awareness of OI among the general public through public service announcements, radio and newspaper interviews, and television appearances. A new 30-second PSA was produced in FY 2004, and will be on the air in early 2005.

Researchers are working as hard as they can to reach the day when no one will have to cope with the pain and difficulties of living with OI, and the OI Foundation is doing everything in its power to bring that day closer.

Until that day arrives, the community will have a place to turn for answers, support, and hope.
Under the microscope...

**Dr. Anna Spagnoli**

Dr. Spagnoli’s research will improve fracture repair in people with poorly healing (non-union) fractures by seeking to better understand fracture repair at the cellular level. This has potential for developing an injection that can cure non-union fractures and enhance repairs in those who fracture frequently.

She recently thanked the OI Foundation for “the support that you’ve provided to my research.”

“We have very exciting results in the lab, and I feel proud to be a recipient of the OI Seed Grant. I hope our research will improve the health of patients with OI.”

Under the microscope...

**Dr. Anton Persikov**

Dr. Persikov is working to match known mutations of different regions of the collagen triple helix with the clinical severity of OI. He is also measuring the affects of different chemical interactions that affect the molecule’s formation, which may identify possible treatments for OI.

He’s pictured here outside his lab with a three-dimensional model of the collagen molecule.
Information Resources available from the OI Foundation:
- Adult Health Issues
- Bisphosphonates Q&A
- Bisphosphonates Statement
- Bone Density
- Bone Structure in OI
- Child Abuse Facts
- Child Abuse (Is this an Abused Child?)
- Clinical Trials
- Constipation
- Dental Care
- Early Intervention
- Education
- Emergency Room Management
- Fast Facts About OI
- Fracture Management
- Genetics
- Glossary of OI Terms
- Guide for Nurses
- Guide for OTs / PTs
- Hearing Loss
- Hearing-Impaired Communication Tips
- Hypophosphatasia
- Infant & Child Care
- Living with OI
- Managing Your Health Care Team
- Nutrition
- Novel Forms of OI
- Osteoporosis
- Osteoporosis and OI
- Pain Management
- Post Surgical Care
- Pregnancy (Women with OI)
- Pregnancy (Non-affected Women)
- Psychosocial Needs of the Family
- Relationships with Providers
- Respiratory Concerns
- Rodding Surgery
- Surgical Considerations
- Talking With Your Doctor
- Talking With Your Orthopedist
- Understanding Type I

Plus books, cassettes, videos, posters, pamphlets and more!

Visit www.oif.org or call (800) 981-2663 to find the right resource for your needs.
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July 1, 2003 to June 30, 2004

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S. CA Petroleum Industry Charity Association
United Way of the Midlands

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CT Walk-a-Thon
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Making Strides For OI-NJ Walk-A-Thon
NJ UPS Golf Tournament
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United Way of Tri State Inc.
William G. McGowan Charitable Fund

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We invite you to join our Monthly Donor Program.

Your contributions can be made automatically, monthly, which reduces overhead expenses, allowing us to apply even more of your donation directly to research or education programs for families and children living with OI! You’ll also be providing the OI Foundation with a source of income that we know we can count on each month.

To find out how to join the Leaders Club, please call us toll free at (800) 981-2663 or (301) 947-0083 or e-mail jdrebing@oif.org
$100 - $499

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Ms. Cindy Pugh
Ms. Irene Puzio
RPT Development
Edward P. Raccio, D.M.D.
Ms. Nancy Radgowski
Donors
July 1, 2003 to June 30, 2004

The OI Foundation gratefully acknowledges the generous individuals, foundations and corporations whose support helps us fund research and provide services to people with OI and their families. This is a partial listing of supporters from July 1, 2003 to June 30, 2004. We regret any errors or omissions, and ask that corrections be brought to our attention.
UPS employees nationwide supporting Fdn for 9th year

UPS employees have taken a leading role in the struggle to improve the lives of people with OI, contributing more than $935,000 to the Foundation during the past nine years.

UPS North Jersey employee Mike Battaglia feels a responsibility to help others by actively supporting organizations like the OI Foundation.

“I think that everyone has a responsibility to give what they have to offer, and to make use of their job descriptions when they give you the opportunity to support organizations that need your help financially and spiritually,” Battaglia explained.

Battaglia’s spirit of generosity and his commitment to the OI Foundation are not unique within the UPS organization. In 1996, UPS employee Dan Krudys introduced his co-workers in New Jersey to his son, Jeffrey, who was born with seven broken bones and since then has broken more than 110 bones and experienced several rodding surgeries.

With the support of Dan’s supervisors and co-workers, Dan, Mike and numerous others have involved hundreds of UPS employees nationwide in making payroll deductions and stock gifts to the OI Foundation through area United Way campaigns, and in raising revenues through golf, softball and basketball tournaments.
Thank You to everyone who helped make this year’s UPS United Way Campaign a success!

Employees are listed on these pages as reported by the United Way or by UPS regional fund-raising event organizers.

We regret any errors or omissions, and ask that corrections be brought to our attention.

To contribute through the United Way, you must write in the following information on the contribution form:

United Way of Central MD, FOR Osteogenesis Imperfecta Foundation
804 W. Diamond Ave., Suite 210
Gaithersburg, MD 20878
The Osteogenesis Imperfecta Foundation

The Osteogenesis Imperfecta Foundation, Inc., is the only national voluntary health organization dedicated to helping improve the quality of life for those coping with the problems associated with osteogenesis imperfecta. The Foundation’s mission is to fund research to find better treatments and a cure, provide education resources to the community, improve awareness, and facilitate mutual support:

✓ **Research** Since 1970, the OI Foundation has doubled funding for research every five years, for a total investment of more than $2 million. That commitment to research continues to grow; the Foundation recently committed more than $400,000 to fund research during this fiscal year. Funding is available for postdoctoral fellowships to encourage new investigators to begin a career in OI research, and seed grants for preliminary research. The potential for results in OI research is growing, with recent advancements in gene therapy, drug therapies, and bone marrow transplant strategies currently under study.

✓ **Education** The Foundation’s principal educational event is the biennial national conference, which provides more than 500 people and their families with medical and research information and successful living strategies. Topics include schooling, pain management, psychosocial needs of the family, adapting environments, fracture management, independent living, and osteoporosis, to name a few. For many, the conference is their first opportunity to meet others who are living with OI. The Foundation continually develops new information resources in response to the needs of families, individuals, and medical professionals working with those affected by OI.

✓ **Awareness** The Foundation strives to build public awareness and generate additional support among individuals, community organizations, public agencies and medical professionals. Up-to-date information on OI—from medical issues to daily living strategies—is available by phone, Internet, fax, and mail. The Foundation reaches out with print publications, press releases, public service announcements, videos, free resources distributed to the OI and medical communities, and an informative interactive web site (www.oif.org).

✓ **Mutual Support** Improving the quality of life is a continuing challenge that our small staff and enormous army of volunteers constantly strive to achieve. From hosting 25 support groups in 20 states to our online chat and message boards, the OI community and Foundation staff provide support services to more than 100,000 people each year.

For more information about the OI Foundation and our programs and services, visit www.oif.org, contact our information resource specialists at 1-800-981-2663 (or bonelink@oif.org) or write to:

The OI Foundation
804 W. Diamond Ave., Ste. 210
Gaithersburg, MD 20878

If you would like information on contributing to the OI Foundation through donations, bequests, planned gifts, corporate giving programs or foundation grants, please contact our development staff at (800) 981-2663 or by writing to bonelink@oif.org.