

## Osteogenesis Imperfecta Foundation

Using the Internet to improve service and support for people affected by the genetic disorder osteogenesis imperfecta.

"Convio has improved our ability to cost-effectively reach people who are affected by osteogenesis imperfecta, and to use our Web site and email communication to provide them with resources. There's simply no better place than our Web site for people affected by OI to get information, make new friends in the OI community, become involved in OI-related events and realize their full potential. And, we're able to reach more people through timely email communications and newsletters, while spending less time and money on postage and manual labor."

— Heller An Shapiro, executive director, Osteogenesis Imperfecta Foundation

### ABOUT THE OI FOUNDATION

The Osteogenesis Imperfecta Foundation (OI Foundation, [www.oif.org](http://www.oif.org)) is the only voluntary national health organization dedicated to helping people cope with the problems associated with osteogenesis imperfecta (OI). OI is a genetic disorder, characterized by bones that are brittle and break easily. For example, a cough or sneeze can break a rib. Rolling over can break a leg.

The OI Foundation's mission is to improve the quality of life for people affected by OI through research, education, awareness and mutual support. Every month, the foundation responds to more than 700 inquiries about OI with fact sheets, books, cassettes, videos, referrals to support groups and OI clinics and one-on-one support from trained resource specialists.

### THE CHALLENGE

Since its founding in 1970, the foundation has provided support to people with Osteogenesis Imperfecta. Because the disorder is so rare, people with OI and their medical professionals often do not know where to turn for help.

The OI Foundation realized that the Internet could be a powerful, cost-effective vehicle for reaching out to new and existing constituents, delivering information and resources, building a community and offering ways to support the organization and those affected by OI. However, the group faced significant challenges:

- Its Web site was not easily modified. With only seven employees, the group had limited human resources for updating information, much less making Web site improvements or managing technology. As a result, the organization had few return visitors to the site.
- With no online tools for marketing and fundraising, reaching new constituents and pushing information — such as fact sheets and newsletters — to existing constituents was a manual, costly task.
- The foundation's Web site offered no way for people with OI to easily communicate with each other, share their experiences or help drive support for the OI Foundation, making it difficult for the organization to create community or reach other potential constituents by word of mouth.

### HIGHLIGHTS

In two-and-a-half years of using Convio, the OI Foundation is reaching more people affected by OI and providing them with valuable resources.

#### Outreach

- More than 250 percent growth in Web site visitors (>9,800 per month before using Convio, to >35,300 per month)
- 46 percent growth in clinic directory

#### Efficiency

- 43 percent more educational material distributed, with no extra staff
- Improved level of one-on-one support for those affected by OI (constituents are finding basic information on the Web site, freeing up staff members to answer complex questions about OI)

#### Fundraising

- Increased online fundraising more than 22x (from \$1,300 in 2001 to nearly \$29,000 in 2004)

### THE CONVIO SOLUTION

The OI Foundation chose Convio for an online solution that includes tools for Web content management, online fundraising and marketing, event management and external communications. Convio powers the group's 280-page Web site, which provides visitors with continuously updated news, fact sheets and other resources, and integrates with the foundation's chat and bulletin board features.

Convio software also allows the foundation to personalize the visitor's Web site experience by recognizing registered visitors and greeting them by name. Plus, the OI Foundation uses online surveys to collect information from registered site visitors, and deliver content specific to their interests, making their experience with the foundation more personal and relevant. Because Convio requires little technical knowledge and allows for quick content updates, one person can update the site regularly — a key factor in the foundation's decision to use Convio.

In addition, the OI Foundation uses Convio to manage event RSVPs and ticketing online, and post a calendar of events. The OI Foundation also uses Convio to allow support group leaders and other supporters across the country to publicize their events.

With Convio, the OI Foundation conducts email marketing and fundraising campaigns, sends email updates and monthly email news bulletins, and includes Convio-powered Tell-a-Friend links to spread the word about the organization. These capabilities have

allowed the OI Foundation to create a grassroots outreach program. Now, the group says, its members are doing what it could not easily do itself — get the word out.

Because Convio is a hosted solution in which the company manages the technology, the OI Foundation benefits from an integrated online solution, without the headache of maintaining applications and servers. A small organization, the OI Foundation leaves installation and maintenance of its online tools to Convio while foundation staff members focus on using these tools for more effective communication with its constituents.



#### Set Your VCR!

#### 1-Hour documentary on OI to air next week...

[Discovery Health](#) will air an hour-long documentary about OI Wednesday, Oct. 23, at 9 p.m. EST. The show will be entitled "Children of Glass" in the U.S., and "Brittle Bones; A Genetic Mystery" in Canada. The show features a number of OI Medical Advisory Council members, including Drs. Byers, Rowe, Glorieux and Smith, as well as OI Foundation members Sean Stephenson and Karen Braitmeyer.

#### Dateline coverage of an OI child abuse case wraps up next month...

[Dateline](#) aired a [special segment](#) last July on a case in which OI was misdiagnosed as child abuse. Charges were dropped, and Dateline joined the family at the [National OI Conference](#) in Orlando, FL, to film a follow up story. The final segment airs in early November, as part of the normal Dateline lineup. Check your local listing or watch our website for more details.

OIF uses Convio to send email marketing and fundraising campaigns as well as monthly email news bulletins with Tell-a-Friend links to help spread the word.

## SOLUTION BENEFITS

The OI Foundation not only met its goal to improve online services, but also broke even on its investment in Convio through increased online donations and a reduction in paper-based mailings. The foundation also has dramatically increased its Web site traffic, built stronger relationships with constituents, improved support for those affected by OI and boosted its online donations.

**Increased Outreach** — Spreading the word through emails, online newsletters and Tell-a-Friend capabilities, the OI Foundation has increased the number of Web site visitors more than 250 percent, from more than 9,800 per month to more than 35,300 per month. In addition, after posting and promoting an online directory of clinics experienced in working with OI patients, the organization received letters and phone calls from additional clinics requesting to be listed in the directory and on the Web site. As a result, the listing grew 46 percent in two years.

**Improved Efficiency** — More constituents are getting basic information about OI from the Web site, rather than calling or emailing the foundation. Staff members now have more time to develop new informational materials and give one-on-one support to constituents who have more complex needs. The result: the group has improved the quality of its support for people affected by OI, without spending more money or adding staff members.

In addition, the foundation uses Convio to provide information and resources for its board members through secure pages on the Web

## SOLUTION AT-A-GLANCE

The OI Foundation chose the following Convio software for its online solution:

- **Web Site Content Management** — for easily creating and managing personalized Web content
- **Fundraising and Membership** — for building donor relationships and raising funds online
- **Email Marketing** — for expanding the support base via email
- **Event Management** — for calendars, RSVP forms and online ticketing

site, rather than through mail or email. Before, two staff members took three days to assemble and mail hard copies of quarterly board meeting packets. Today, one staff member uploads all of the board packet files in minutes.

**Increased Donations and Reduced Costs** — After two-and-a-half years, the foundation has increased online donations from just \$1,300 to nearly \$29,000. And, because Web site visitors now get the information they need in just a few clicks online, the foundation has reduced the time and money spent assembling and mailing information packets. In fact, the group now sends about one-third of the paper-based mailings it used to send.

**Comprehensive Online Strategy** — The OI Foundation now designs all of its products and resources with cost-effective online marketing in mind. Before, the Web site was simply a place to advertise the foundation. Now, the Internet is an integral part of the foundation's strategy. For example, the group maintains frequent communication with constituents through emails and monthly online newsletters. Plus, every time the foundation creates a new fact sheet, the group considers how it will be promoted through the Web site and email marketing to ensure constituents get the newly published information immediately.

## ABOUT CONVIO

Convio is the leading provider of software and services that help nonprofits and higher education institutions use the Internet to build strong constituent relationships that drive support and participation. Convio has online solutions for fundraising and membership, advocacy, special events, volunteer fundraising, Web site management and email communications.

## FIND OUT MORE

To learn more about how Convio can help your organization manage constituent relationships more easily and productively, contact us today:



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