### 2012 Audited Expenses

**Incomes**  
- **2012 Audited:** $912,324  
- Investment Income: $10,217  
- National Conference: $72,589  
- Program Services Fee/Special Events/Memorial/Celebration: $42,809  
- In-kind donations: $1,999  
- Direct Mail/Foundation Drives: $63,172  
- Foundations/Grants: $16,191  
- Corporations/Company Donations: $8,415  
- Corporate/Medical: $3,491  
- Government/Other: $1,085  
- Public Information and Education: $286,424  
- Family Support Program: $394,859  
- Outreach and Awareness: $196,351  
- Professional Development, Program Services: $19,651  
- Support Services: $54,543  
- Management and General: $54,543

**Expenses**  
- **Total Program Services:** $892,050  
- Public Information and Education: $286,424  
- Family Support Program: $394,859  
- Outreach and Awareness: $196,351  
- Professional Development, Program Services: $19,651

**Revenue**  
- Total Revenue: $912,324  
- Investment Income: $10,217  
- National Conference: $72,589  
- Program Services Fee/Special Events/Memorial/Celebration: $42,809  
- In-kind donations: $1,999  
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**Unrealized Gains/Losses:** $49,087

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**2012 Income and Expense Statement**  
January 1 - December 31, 2012

**2012 Expenses**

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Information and Education</td>
<td>$286,424</td>
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</tr>
</tbody>
</table>

**Total Revenue:** $912,324

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**Unrealized Gains/Losses:** $49,087
The Cornelia de Lange Syndrome (CdLS) Foundation continues to rely on event-driven revenue, with special events and third-party fundraising contributing 43 percent of revenue in 2012. This was due to the success of such long-running events as the New England and Missouri golf tournaments and Team CdLS, which raised $180,000 ($22,000 more than 2011) in races throughout the country.

Friends and families answered our first Match It! Challenge for the 21st Century Conference Fund, initiated in 2010 with the goal to raise $2 million for a conference endowment. An anonymous donor challenged us to raise $10,000 for the fund during 2012 and promised a $10,000 match if we hit the goal. We surpassed it by more than $1,000. The balance of the fund at the end of the year was $46,606.

More than 570 people, including 118 individuals with CdLS, attended the 2012 National Family Conference in Lincolnshire, IL. While the four-day event was a wonderful and educational experience for families and professionals, it operated at a loss. Travel, food, childcare, scholarships, and hotel space expenses exceeded $200,000, while registration fees and fundraising totaled just $125,000—for a loss of more than $75,000. This had a direct effect on the year’s bottom line, which, before unrealized gains, was a $102,000 deficit.

Additional financial highlights include:
- Although 2012 expenses were $86,000 higher than 2011, this is noteworthy because 2011 was a non-conference year. Decreased printing/mailing, mindful purchasing of supplies, and staffing changes kept expenses lower than originally budgeted.
- Just 12 percent of revenue supported management and fundraising expenses.
- Total revenue was down from 2011, due to loss of grants and fewer individual gifts in support of CdLS and our important work.

A significant project in 2012 was creating a three-year strategic plan for the organization. The process involved surveying families and stakeholders and holding focus groups. Five goals came out of the process:

1. Improve awareness of the syndrome and the organization.
2. Make clinics for all ages more accessible.
3. Provide more opportunities for personal interaction for all ages and all points on the spectrum.
4. Increase funding and support for basic science, education and clinical research.
5. Build a strong, sustainable infrastructure through substantial diversification of revenue to enhance current services and provide for the long-term future as well as recruit, develop and retain skilled staff.

Within the five goals were 10 objectives, which Foundation staff will work on through 2015. The strategic plan has become a “playbook” of sorts, giving staff direction on what is most meaningful to families, as well as what is needed to sustain the organization.

The Foundation staff and leadership are committed to the CdLS community and to fulfilling this organization’s mission. With your continued support and encouragement, we will continue to be here for our families well into the future.

Marc Needlman
President, Board of Directors
Marcin Condon-Malloy
Executive Director

We welcomed 114 new families to the CdLS Foundation family.

More than 570 people attended the CdLS Foundation National Family Conference in Lincolnshire, IL.