

# 2012 AUDITED EXPENSES

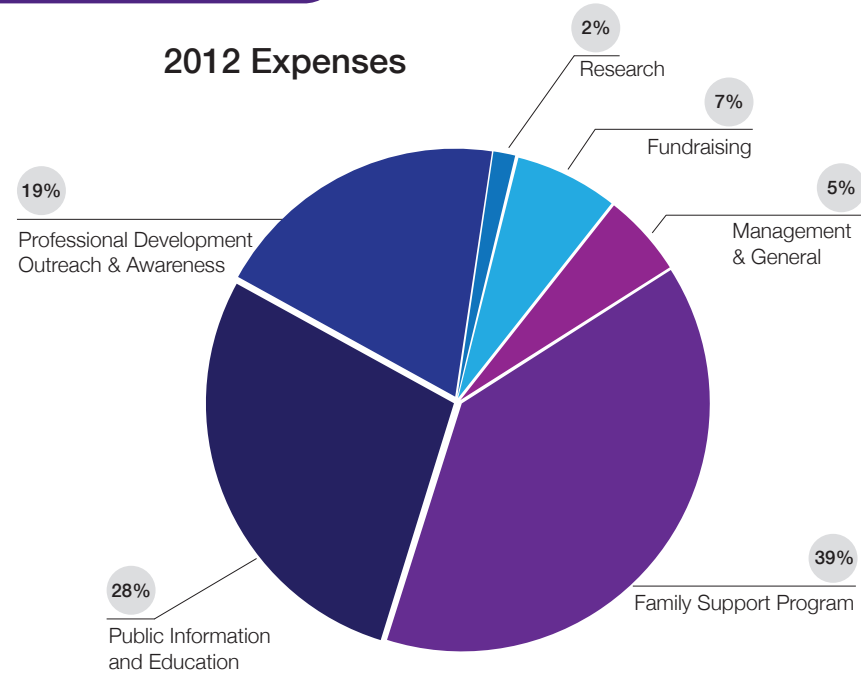
## 2012 Income and Expense Statement

January 1 - December 31, 2012

INCOME	2012 Audited
Individual Donations	55,936
Corporations/Company Donations	8,415
Foundations/Grants	16,191
Major Donors	212,997
Direct Mail/Foundation Drives	63,172
Clubs and Organizations	793
Gifts that Count – Memorial/Celebration	42,809
Special Events/ Third Party Fundraising	391,273
In kind donations	1,999
Federated Campaigns	35,933
Program Services Fee/ Nat'l Conference	72,589
Investment Income	10,217
<b>Total Revenue</b>	<b>912,324</b>

EXPENSES	
<b>Program Services</b>	
Professional Development, Outreach and Awareness	196,351
Research	14,416
Family Support Program	394,859
Public Information and Education	286,424
<b>Total Program Services</b>	<b>892,050</b>
<b>Support Services</b>	
Management and General	54,543
Fundraising	68,038
<b>Total Support Service</b>	<b>122,581</b>
<b>Total Expenses</b>	<b>1,014,631</b>
Surplus/Deficit from Operations	(102,307)
Unrealized Gains/Losses	49,087
Total Surplus/Deficit	(53,220)
<b>Total Net Assets</b>	<b>867,410</b>

## 2012 Expenses



- Major event sponsors:
- Arthur J. Gallagher & Co
  - Crown Machinery
  - Denise and Frank Teixeira
  - Julie and Roy Gonella
  - KeyBanc
  - The Lighthouse Project
  - Macquarie Capital
  - Madison County Wood Products
  - Pallet Logistics Management, Inc.
  - RBC Capital Markets
  - Susquehanna Financial Group
  - Weiss Attorneys at Law, P.C.

- Organizations that awarded funding:
- Chase Community Giving
  - Mortenson Foundation
  - National Institutes of Health
  - University of Chicago



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# THE CdLS FOUNDATION FAMILY

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Nursing  
Occupational Therapy  
Occupational Therapy  
Physical Therapy  
Spanish Language  
Speech-Language Pathology  
Special Education  
Special Education  
Special Education  
Special Education  
Special Education

Biochemistry & Molecular Biology  
Biochemistry & Molecular Biology  
Child Psychiatry  
Clinical Genetics  
Clinical Genetics  
Clinical Genetics  
Clinical Genetics  
Clinical Genetics  
Clinical Genetics  
Developmental Biology  
Developmental Biology/Pediatrics  
Family Medicine  
Genetic Counselor  
Gynecology, Genetics  
Immunology  
Internal Medicine, Genetics  
Neurodevelopmental Biology  
Ophthalmology  
Otolaryngology  
Pediatric Anesthesia, PICU  
Pediatric Cardiology  
Pediatric Dentistry  
Pediatric Dentistry  
Pediatric Dentistry  
Pediatric Dietetics  
Pediatric Dietetics  
Pediatric Gastroenterology  
Pediatric Gastroenterology  
Pediatric Gastroenterology  
Pediatric Gastroenterology  
Pediatric Neurology  
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Speech-Language Pathology



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## MESSAGE FROM THE BOARD PRESIDENT & EXECUTIVE DIRECTOR

### Our Mission

The Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

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 sent in memory or celebration.

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 substantially increasing and diversifying 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

Marie Concklin-Malloy  
Executive Director

