

2013 Audited Expenses

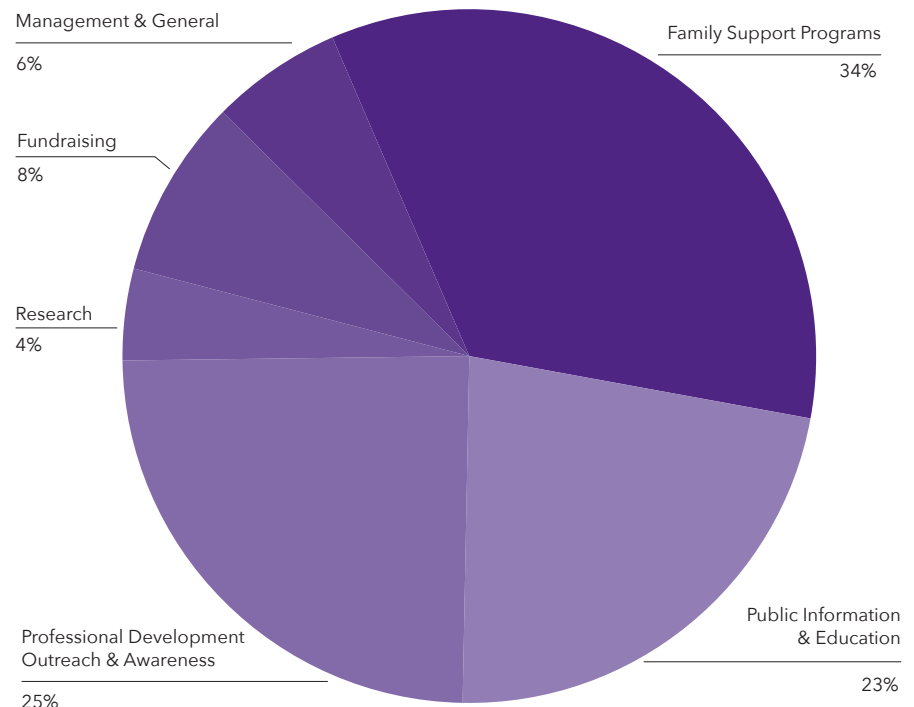
2013 Income and Expense Statement

January 1 - December 31, 2013

INCOME	2013 Audited
Individual Donations	25,628
Corporations/Company Donations	14,364
Foundations/Grants	15,804
Major Donors	254,553
Direct Mail/Foundation Drives	48,672
Clubs and Organizations	14,484
Gifts that Count - Memorial/Celebration	56,923
Special Events/ Third Party Fundraising	468,401
Federated Campaigns	38,265
Investment Income	10,273
Total Revenue	947,367

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	203,539
Research	35,479
Family Support Programs	285,358
Public Information and Education	186,431
Total Program Services	710,807
Support Services	
Management and General	50,901
Fundraising	69,406
Total Support Services	120,307
Total Expenses	831,114
Surplus/Deficit from Operations	116,253
Unrealized Gains/Losses	57,896
Total Surplus/Deficit	174,149
Total Net Assets	1,041,559

2013 Expenses



The CdLS Foundation thanks the following individuals and businesses who provided major sponsorships of events in 2013:

- BMO Capital Markets Marketing & Planning
- Caldwell family
- Drips LLC
- FGK, LLC
- Fielder Electric Supply Co., Inc.
- KeyBank National Association
- Madison County Wood Products Inc.
- Pallet Logistics Management, Inc.
- RBC Capital Markets
- Teixeira family
- UHY Advisors MO, Inc.
- Weiss & Associates

The following organizations awarded funds to the CdLS Foundation in 2013:

- Aiello Home Services
- CVS Corporation
- National Institutes of Health
- William and Alice Mortensen Foundation

The CdLS Foundation Family

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Biochemistry & Molecular Biology
Child Psychiatry
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Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Developmental Biology
Developmental Biology/Pediatrics
Genetic Counselor
Genetic Counselor
Gynecology, Genetics
Hematologist
Immunology
Internal Medicine, Genetics
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
Pediatric Ophthalmology
Pediatric Ophthalmology
Pediatric Ophthalmology
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Radiology
Speech-Language-Feeding
Speech-Language Pathology
Urology

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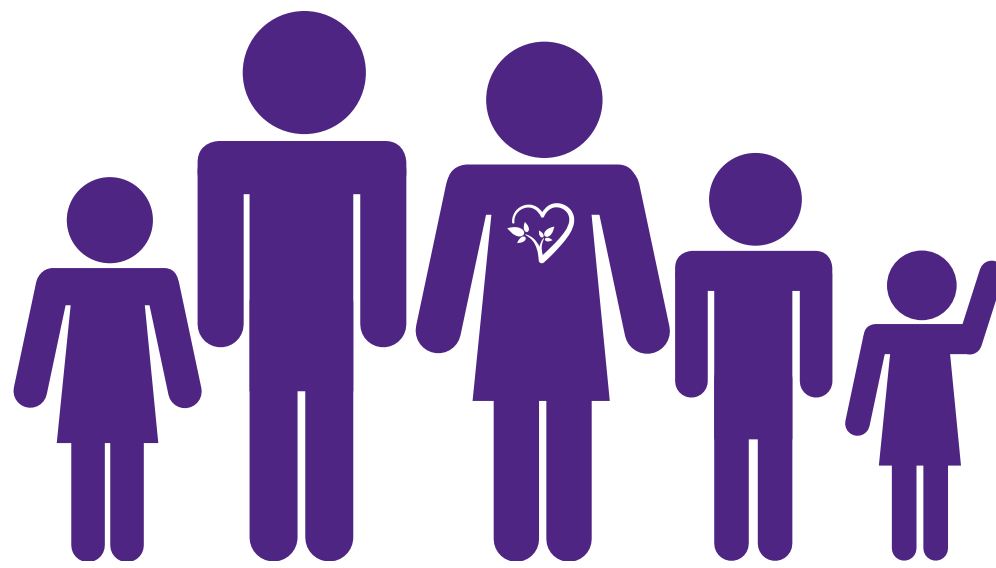
Occupational Therapy
Nursing
Educational Psychology
Speech-Language Pathology
Physical Therapy
Clinical Psychology
Education
Special Education
Occupational Therapy
Special Education Assessments
Special Education
Developmental Pediatrician
Special Education Behavior Management
Adaptive Physical Education
Special Education Rights and IEPs

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.



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CdLS Foundation #2013AnnualReport

Message from the Board President & Executive Director

On behalf of the Cornelia de Lange Syndrome (CdLS) Foundation staff and Board of Directors, we're pleased to present the 2013 Annual Report. This report provides a snapshot of the financial state of the Foundation, as well as a summary of the many accomplishments made by staff and volunteers.

Financial Review

Coming off a conference year and deficit of \$102,000, the CdLS Foundation turned red into green in 2013.

Overall, revenue increased \$35,000 from 2012. Expenses were less than budgeted due to staffing changes and overall reductions in travel expenses, IT consultant fees and other expenditures, leading to a surplus of nearly \$130,000. The surplus was achieved in part through the expansion of Team CdLS, generous donations, and increased awareness of events and various giving opportunities.

Special events and third-party fundraising continue to be the main source of income for the CdLS Foundation. In 2013, event income equaled 49 percent of total revenue—a six percent increase from 2012.

Team CdLS ran at record pace, raising more than \$250,000. Nearly \$50,000 of it was raised by members of Team CdLS Manhattan Beach 10K and was earmarked for the 2014 National Family Conference. At the tee, long-standing golf events in Massachusetts and Missouri raised more than \$136,000. Team CdLS and golf tournaments accounted for 83 percent of special events and fundraising revenue.

The Foundation continues to earn high marks from charity "watchdogs," with 86 cents of every dollar raised going directly to programs that support families and professionals. The other 14 cents covers administrative and fundraising expenses.

Strategic Planning

2013 was the first year of a three-year strategic plan, with work focused on the goals and objectives developed in 2012. Highlights included:

- Identifying Santa Clara Valley Medical Center as a location for a CdLS clinic on the West Coast
- Awarding \$20,000 to researchers working on both the clinical and molecular aspects of CdLS

- Networking with physicians at the American Academy of Pediatrics convention
- Adding online resources, including a module on sensory issues

Programs

The Foundation welcomed 121 new families in 2013, up seven from the year prior; and answered 400 Ask the Expert questions—nearly 20 percent more than 2012.

Two new publications were created: the *Guide to Transition* and the *CdLS Educational Handbook*. Both booklets help parents, caregivers and educators navigate the often bumpy road associated with these topics. Work also began on a booklet for parents and relatives who have lost a child with the syndrome.

Compared to the previous year, our Facebook page engagement more than doubled, and all other social media outlets—Pinterest, Twitter, Instagram and more—grew as well. A new awareness video was created and has 5,500-plus views on YouTube to date.

The achievements of 2013 would not have been possible without the remarkable support of our donors, volunteers, staff and board. It is a privilege to work with, and for, all of you. We celebrate our shared results and look forward to what the future years hold.

With thanks,

Robert Boneberg, Esq.
President, Board of Directors

Marie Concklin-Malloy
Executive Director

Since 1981, the Cornelia de Lange Syndrome Foundation has supported families and individuals with CdLS nationwide. The programs and services we provide continue to grow in size and expand in depth with the changing needs of families. This infographic showcases the increased efforts of the Foundation staff and volunteers in 2013.



The CdLS Foundation welcomed **121 new families** from around the country in 2013.

As part of its strategic plan, the Foundation added additional family gatherings around the country.

8 Family Gatherings

5 foundation sponsored | 3 non-sponsored | 465 people attended



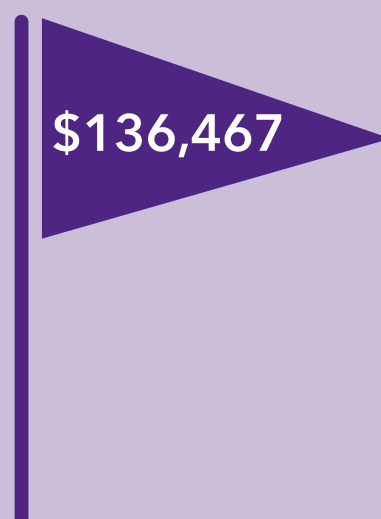
Our Ask the Expert service allows users to email their questions for response from members of our Clinical Advisory Board, or Professional Development Committee. In 2013, **401** Ask the Expert questions were answered.



Many runners say that running has changed their lives. As part of our charity team, Team CdLS runners can say that they have changed the lives of others. In 2013, runners raised **\$252,270** to ensure our services and information are free to families around the country.



It's a birdie, it's an eagle, it's a ... CdLS Foundation golf tournament! Golf events provide the opportunity to network with business associates and, most importantly, help children and adults with CdLS. In 2013, golf tournaments raised **\$136,467**.



The CdLS Foundation's Web site, which had **115,934** unique Web hits in 2013, is a go-to source for medical and research information, publications, event schedules and much, much more.