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Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Developmental Biology
Developmental Biology/Pediatrics
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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 Dietetics
Pediatric Dietetics
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Neurology
Pediatric Ophthalmology
Pediatric Ophthalmology
Pediatric Orthopedics
Pediatric Orthopedics
Pediatric Otolaryngology
Physical Therapy
Radiology
Speech-Language-Feeding
Speech-Language Pathology
Urology

2014
YEAR IN REVIEW



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.





CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

302 West Main Street #100
Avon, CT 06001-3681
800.753.2357 • www.CdLSusa.org



Message from the Board President & Executive Director

Small but mighty

Just like the individuals it serves, the CdLS Foundation is small but mighty. Although we have a small staff and small budget, the Foundation makes big differences in the lives of thousands across the United States.

In 2014, we welcomed 125 new families to the CdLS Foundation, facilitated 411 Ask the Expert questions, and responded to 1,648 requests for service (up 20 percent from 2013). Three new publications were printed, covering the topics of transition, education and grief. Additionally, we collaborated with Santa Clara Valley Medical Center in San Jose, CA, to establish the first CdLS Clinic west of the Mississippi River.

It was another good year for the organization’s finances. Spending was down and revenue up, resulting in a surplus of just under \$138,000. The National Family Conference in Costa Mesa, CA,

saw a \$50,000+ deficit, but increased revenue from special events like Team CdLS (up 18 percent) helped keep the Foundation in the black.


Without the support of families and friends who gave time, expertise and funds, we could not have had a great year. It is their support that truly makes the Foundation mighty.


Sincerely,


Robert Boneberg, Esq.
President, Board of Directors


Marie Concklin-Malloy
Executive Director


2014 Highlights


 A new logo was unveiled

 Attendance at 8 Foundation-sponsored and 3 non-sponsored family gatherings reached more than 600


 Family service coordinators were in contact with close to 850 families over the year

 Three research grants were awarded

 A National CdLS Registry was launched

 Stowers Institue for Medical Research in Kansas City, MO, was named the fifth CdLS Center for Excellence

 \$178,737 was raised by Team CdLS

 \$138,966 was raised at two golf tournaments

The CdLS Foundation thanks the following individuals and businesses who provided major sponsorships of events in 2014:

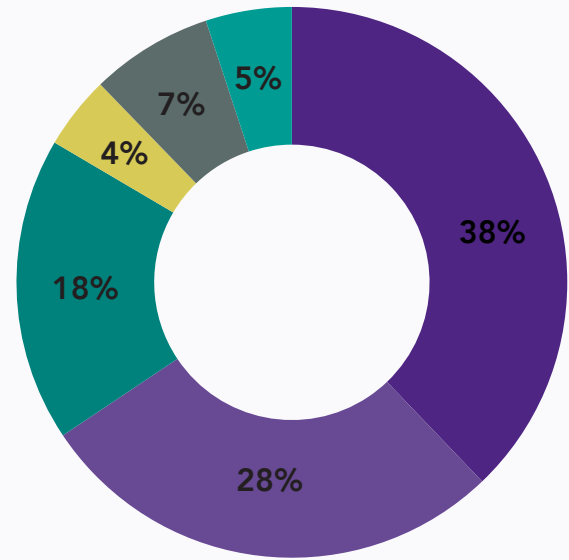
- Bank of Montreal
 - Brean Capital Markets, LLC
 - Caldwell family
 - Craig Hallum Capital Group
 - Donald Sadoski D.M.D.
- FGMK, LLC
 - Fielder Electric Supply Co., Inc.
 - KeyBank National Association
 - LPS Equipment & Acquisition Co Inc.
 - Madison County Wood Products Inc.
- Pallet Logistics Management, Inc.
 - RBC Capital Markets
 - RENMAC
 - Teixeira family

The following organizations awarded funds to the CdLS Foundation in 2014:

- American Legion Child Welfare Foundation, Inc.
- National Institutes of Health
- William and Alice Mortensen Foundation

2014 Audited Expenses

2014 Income and Expense Statement
January 1 - December 31, 2014



- General & Administration
 - Research
 - Fundraising
- Family Support Program
 - Public Information & Education
 - Professional Development Outreach & Awareness

INCOME	
Individual Donations	25,628
Corporations/Company Donations	35,207
Foundations/Grants	24,944
Major Donors	249,239
Direct Mail/Foundation Drives	53,148
Clubs and Organizations	11,252
Gifts that Count – Memorial/Celebration	47,136
Special Events/ Third Party Fundraising	446,132
Federated Campaigns	41,203
Bequest	114,675
Program Services Fee/ Nat’l Conference	83,580
Program Services Fees/Symposia	7,025
Investment Income	12,499
Total Revenue	1,151,669

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	180,938
Research	43,517
Family Support Program	383,788
Public Information and Education	281,405
Total Program Services	889,648
Support Services	
Management and General	51,230
Fund raising	72,818
Total Support Service	124,048
Total Expenses	1,013,696
Surplus/Deficit from Operations	137,973
Unrealized Gains/Losses	17,094
Total Surplus/Deficit	155,067
Total Net Assets	1,196,626

What we do with your dollar

At the CdLS Foundation, our mission drives our actions. We also know that you want your donations to go as far as possible. Because of this, we aim to ensure that as much funding as possible goes towards support services. You can see below that 88 cents of every dollar we receive goes towards supporting families nationwide. The rest goes towards keeping our doors open.



88¢
Family gatherings
Medical Director
Staff social workers
Publications
National Conference

12¢
Office rent
State registration
Office supplies
Family & professional database
IT expenses