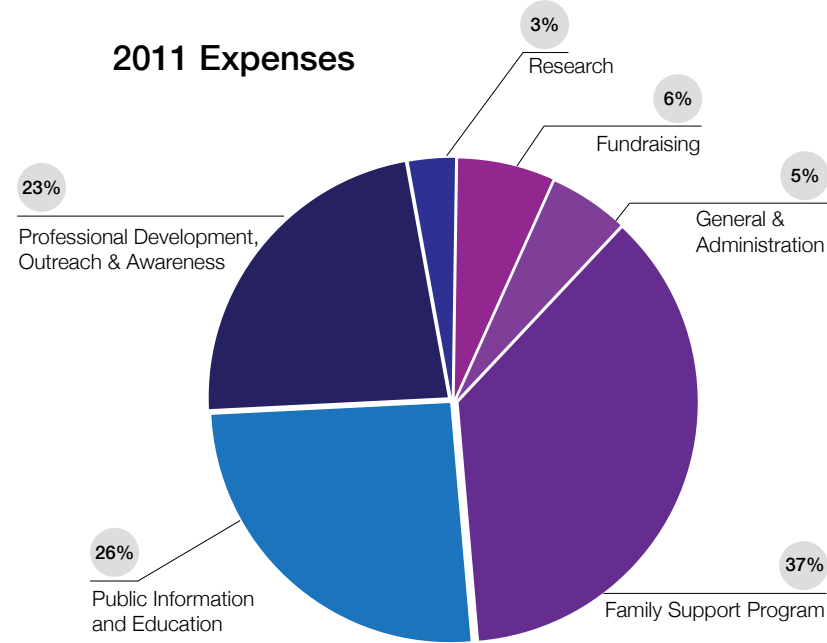


2011 AUDITED EXPENSES

2011 Income and Expense Statement January 1 - December 31, 2011

INCOME	2011 Audited
Individual Donations	30,371
Corporations/Company Donations	3,781
Foundations/Grants	44,256
Major Donors	217,531
Direct Mail/Foundation Drives	62,335
Clubs and Organizations	9,755
Gifts that Count – Memorial/Celebration	77,132
Special Events	479,490
Federated Campaigns	33,548
Program Services Fee/ Nat'l Conference	319
Investment Income	13808
Total Revenue	972,326

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	212,708
Research	28,790
Family Support Program	340,075
Public Information and Education	237,400
Total Program Services	818,973
Support Services	
Management and General	49,085
Fundraising	60,227
Total Support Service	109,312
Total Expenses	928,285
Surplus/Deficit from Operations	44,041
Unrealized Gains/Losses	(37,343)
Total Surplus/Deficit	6,698
Total Net Assets	920,630



The following organizations awarded funds to the CdLS Foundation in 2011:

- American Legion Child Welfare Foundation.
- Build a Bear Foundation.
- Knight of Columbus, Cardinal Gibbons Council #2521.
- William and Alice Mortensen Foundation.
- Odyssey Foundation.
- Special People in Need.

The CdLS Foundation thanks the following individuals and businesses who provided major sponsorships of events in 2011:

- Certified Heating & Cooling
- Crown
- Daniel & Henry
- DRIPS
- KeyBanc
- Madison County Wood Products
- RBC Capital Markets
- Teixeira family
- Weiss & Associates

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Pediatric Dentistry
Pediatric Dentistry
Pediatric Dietetics
Pediatric Dietetics
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Gastroenterology
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Pediatric Otolaryngology
Psychiatry
Radiology
Speech-Language-Feeding
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Annual Report Foundation Heroes



MESSAGE FROM THE BOARD PRESIDENT & ACTING EXECUTIVE DIRECTOR

2011 proved to be the “year of the event,” with several new endeavors and record fundraising income making a big impact on the bottom line. From bake sales and bowl-a-thons, to mud runs and formal affairs, events throughout the country raised \$479,490—an impressive \$72,000 more than the previous year and nearly half of the year’s revenue.

Team CdLS, which had runners in the New York City and Chicago marathons, expanded to the Baltimore Running Festival, Saratoga Palio and several half marathons and 5Ks throughout the country. The culmination of these runners’ fundraising efforts was \$158,000.

The other highly successful event was Toast the Chief, which honored the Foundation’s longtime volunteer and outgoing board president David Fowler and his wife Susan. The Boston event generated approximately \$97,000. The occasion will serve as a model for future events honoring exceptional volunteers and leaders.

Additionally, golf tournaments raised a record \$97,000.

Total revenue was down from 2010, due to loss of government funding and fewer individual donations, typical in a non-conference year. However, the year ended just \$28,000 shy of the \$1 million mark.

Spending remained in check, with just 11 percent of revenue supporting administrative and fundraising expenses.

We hope you find this annual report informative and that you take a moment to read about some of the “heroes” who go the extra mile (even 4,700 miles) to help this organization. If you have an idea or feedback, don’t hesitate to contact us at 800.753.2357 or mariemalloy@CdLSusa.org.

Marc Needlman
President, Board of Directors

Marie Concklin-Malloy
Acting Executive Directors

Highlights:

- Family service coordinators facilitated 330 Ask the Expert submissions and connected more than 300 families with one another.
- News articles and broadcast stories about CdLS reached an estimated 14 million people in the U.S.
- The Foundation awarded two research grants, one to study immunodeficiency in CdLS and the other to study gene functions.
- Volunteer run fundraisers raised nearly \$104,000.

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.



Foundation Heroes

The definition of a hero is “a person who, in the opinion of others, has heroic qualities or has performed a heroic act and is regarded as a model or ideal.” We are fortunate at the CdLS Foundation to have many heroes in our extended family—all of whom are models for others. Their actions, whether big or small, have a lasting impact on the work of this Foundation. At right, we introduce you to just a few of our heroes.

Event Hero

On June 4, 2011, Ken Fouts finished his cross-country motorcycle trek, Adrian’s Ride, in the shadow of San Francisco’s famous Golden Gate Bridge. Along the three-week, 4,700-mile ride that started in New Hampshire, Ken raised awareness of CdLS, and funds to benefit the Foundation. The ride was in honor of his 17-year-old grandson Adrian. “As I rounded the final curve to the Golden Gate Bridge, there it was: San Francisco. With tears in my eyes, I looked down at the picture of Adrian that I had been carrying and said, We made Adrian, and I did it just for you. He will never be able to verbally thank me, but I know he knows what grandpa did for him.”

Board Hero

David Fowler’s has been deeply involved with the CdLS Foundation since his son Logan was diagnosed with CdLS more than two decades ago. He held volunteer leadership positions with the Foundation on and off since 1992, including time as the president of the Board of Directors from 2006 to 2011. During that time, he was an energetic advocate, leading the Foundation’s charge into Washington, D.C., raising awareness of CdLS among Congress that eventually resulted in \$238,000 in federal funds.

Donor Hero

Mary Lou Bransfield’s grandson Aiden was diagnosed with Cornelia de Lange Syndrome (CdLS) at age three. “It was important to my family that we find a support system of professional help,” says Mary Lou. “When we found the CdLS Foundation, I felt as though we had won the lottery.” Mary Lou was grateful for the “warm, caring, understanding, and knowledgeable voice on the other end.” She wanted to do something to help, so she started donating to the Foundation monthly—and she continues to do so today. Mary Lou believes that the help of extended family members like her can ensure that the needs of families will be met through a strong and growing Foundation—one month at a time.

Volunteer Hero

As a longtime Awareness Coordinator and, more recently, a Regional Coordinator, Felicia Brown-Coleman is an advocate for her daughter Rayven and a support for local parents. She lives just a 20-minute car ride from the Foundation office and enthusiastically supports the organization at local health fairs, events and media opportunities. In 2011, Felicia, her husband Lemon and Rayven were featured along with the Foundation in the annual report of the Connecticut-based National Organization of Rare Disorders (NORD). The report—in both print and video form—raised awareness of CdLS to thousands of people across the country. View the feature at www.rarediseases.org

Sibling Heroes

For two groups of siblings, the 2011 Baltimore Running Festival was truly a family affair. Abbey and Bethany Black, sisters to Alex, and Jennifer and Andrew Vojtecky, siblings to Stephanie, hit the city’s streets as part of Team CdLS—Bethany, Andrew and Jennifer in the 5K and Abbey, who was nursing a broken leg, cheering the team on. “It’s important to show support for my brother, and to raise awareness of CdLS and the Foundation,” says Bethany. However, she confesses she enjoyed the actual race the most. “I’ve never run in anything before and it was exciting.”