2010 AUDITED EXPENSES

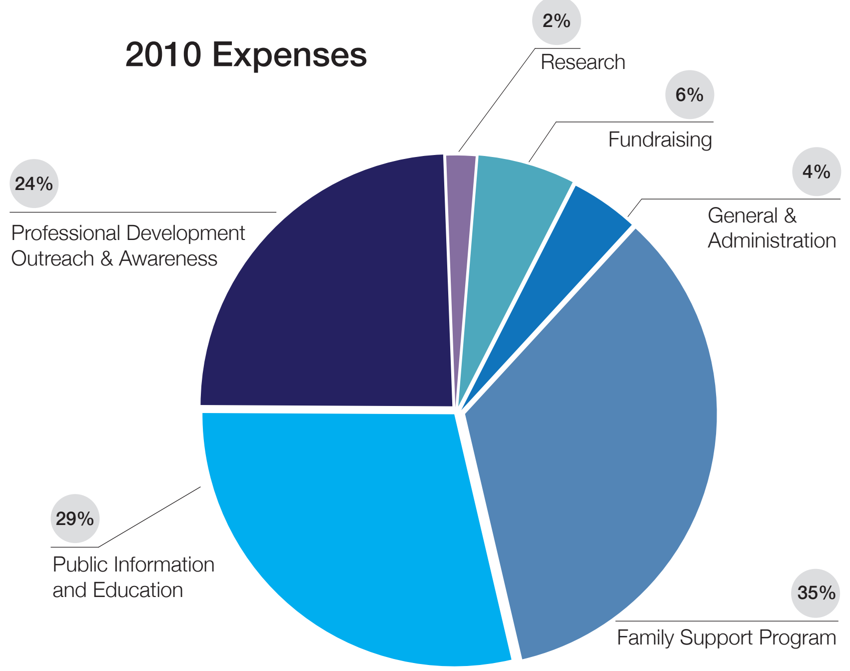
2010 Income and Expense Statement

January 1 - December 31, 2010

INCOME	**2010 Audited**
Individual Donations	58,322
Corporations/Company Donations	10,386
Foundations/Grants	246,720
Major Donors	187,238
Direct Mail/Foundation Drives	93,704
Clubs and Organizations	6,826
Gifts that Count – Memorial/Celebration	62,207
Special Events/ Third Party Fundraising	407,754
Federated Campaigns	37,440
Program Services Fee/ Nat'l Conference	69,931
Investment Income	13,529
Total Revenue	1,194,056

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	255,492
Research	19,631
Family Support Program	362,303
Public Information and Education	301,619
Total Program Services	**939,045**
Support Services	
Management and General	45,509
Fundraising	65,319
Total Support Service	**110,828**
Total Expenses	**1,049,873**
Surplus/Deficit from Operations	144,183
Unrealized Gains/Losses	30,809
Total Surplus/Deficit	174,991
Total Net Assets	**913,932**

2010 Expenses



In 2010, the Foundation launched the 21st Century Conference Fund, a dedicated fund to provide support for the national family conference now and into the future. The Foundation acknowledges these "founding families" who contributed a minimum of $1,000.

- Amie and Bradley Bruggeman
- Susan and David Fowler
- Liana and Michael Fresher
- Christine and David Fry
- Julie and Roy Gonella
- Kimberly and Trevor Ingold
- Julie and Frank Mairano
- Beth and Paul Patitucci
- Janette and Bill Peracchio

The CdLS Foundation thanks the following individuals and businesses who provided major sponsorships of events in 2010:

- Daniel and Henry Company
- Key Banc Capital Markets
- Macquarie Capital, USA
- RBC Capital Markets
- Anita Schoenky
- Denise and Frank Teixeira
- University of Chicago Genetics Services Laboratory
- Margaret Walters
- Weiss and Associates, P.C.

The following organizations awarded funds to the CdLS Foundation in 2010:

- American Legion Child Welfare Foundation, $22,295.
- Knight of Columbus, Cardinal Gibbons Council #2521, $5,000.
- William and Alice Mortensen Foundation, $3,483.
- Build-A-Bear Workshop Bear Hugs Foundation, $1,000.
- Special People in Need, $750.
- Avon-Canton (CT) Rotary, $300.

THE CdLS FOUNDATION FAMILY

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*indicates term ended in 2010
**indicates term started in 2011

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Julia O'Connor, Ph.D.	Clinical Psychology
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Rachel Seipts	Education
Ingrid Barone, R.N.	Nursing
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CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street, #100
Avon, CT 06001-3681
800-753-2357 • www.CdLSusa.org

ANNUAL REPORT
2010
A WEEK IN THE LIFE

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

MESSAGE FROM THE BOARD PRESIDENT AND EXECUTIVE DIRECTOR

We've been witness to many "firsts" over the years: the first issue of Reaching Out printed in color, the first CdLS growth chart, the first Foundation Web site, and the first CdLS gene, to name a few. In 2010, we reached another first: We raised more than $1 million. $1,194,056 to be exact.

We are proud of the Foundation staff, which pulled together to make every fundraising event, from bake sales to dinner dances, go on without a hitch and who stayed late to write grant funding proposals or recruit runners for Team CdLS.

We are equally pleased by the parents, relatives and friends of people with CdLS who supported the Foundation in 2010, both with time and treasure. Without that support, we never would've reached the million-dollar mark.

Here are some financial and highlights from 2010:

- Revenue increased by $339,000 from 2009. Consistent with 2009, 70 percent of income came from major donors, special events/third-party fundraising and grants.
- 2010 ended with a surplus of $175,000—just a $1,000 increase from 2009. However, this surplus is significant because 2010 was a conference year. In 2008, the previous conference year, the Foundation had a deficit of $273,000.
- 2010 expenses increased by $338,000. The increase was a result of conference expenses and grant-funded programs such as the diagnostic checklists, Web site overhaul and Spanish translations.

We hope you find this annual report informative and that it provides a sense of what goes on at the CdLS Foundation. If you have an idea or feedback, don't hesitate to contact us at 800-753-2357 or director@CdLSusa.org.

David S. Fowler
President, Board of Director

Liana Fresher
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 cause and manifestation of the syndrome, and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

A week in the life ...

While no two weeks are the same at the CdLS Foundation office, what remains constant is the hard work and dedication of staff as they try make the world a better place for everyone affected by CdLS. Below are some highlights of that work in the organization's five areas of focus: Family Service, Fundraising, Outreach, Research, and Professional Development.

MONDAY

8:45 a.m.

Family Service Coordinator Deirdre Summa is going through her email from the weekend, when the first call of the day comes in. It's a dad. His 16-month old daughter was just diagnosed with CdLS the previous week.

Deirdre spends the next hour on the phone with him. She follows up by mailing copies of the New Parent Packet and Facing the Challenges, both of which provide basic information about CdLS. She also sends a list of other parents in the family's region so that they can reach out to others when they're ready. She tells the dad she'll call back in a week to check in on the family.

That call is the core of what the Foundation does. As the only organization dedicated to CdLS in the nation, the Foundation is a key source of information and support to families. That dad is one of 840 parents who contacted the Foundation for help in 2010.

TUESDAY

1:15 p.m.

Development Manager Gail Speers is elated as she finds out Team CdLS is accepted into the charity program of the ING New York City Marathon. The news comes after multiple years of unsuccessful attempts to get into this prestigious race. Ten runners sign up. They are mothers, siblings and friends of people with CdLS. Two even run the Bank of America Chicago Marathon the month before. The culmination of runners' efforts in this race and four others is more than $175,000, a new record.

While Team CdLS is the Foundation's biggest fundraiser, golf tournaments, walks, dinner dances and Foundation sponsored programs like Cornelia's Garden, Leaps of Love and Yard Sale Across America are critical to the organization's financial health. All in all, fundraisers brought in one-third of the Foundation's revenue in 2010 – which reached $1 million for the first time ever.

Highlights:

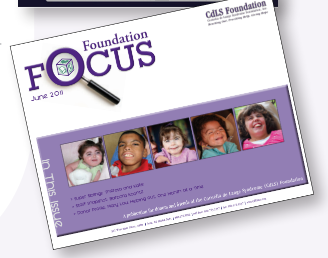
- Family service coordinators facilitated 380 Ask the Expert submissions.
- Seventeen articles were translated into Spanish.
- News articles and broadcast stories about CdLS reached an estimated 6.6 million people in the U.S.
- More than 500 people attended the National Family Conference in Dallas, TX.
- The Adult Services Committee was formed to address the unique issues facing individuals transitioning from childhood to adulthood.

WEDNESDAY

10:30 a.m.

After months of editing, designing, reviewing, and reorganizing, we hit the switch on the new CdLS Foundation Web site. The new site is easier to navigate, better organized and features all new graphics. It is a key part of educating families, professionals and the public about CdLS, logging more than 80,000 unique hits annually.

Also debuting in 2010 is Foundation Focus, the new twice-yearly publication geared toward friends and donors rather than families and professionals. Unlike the longtime Reaching Out newsletter, Foundation Focus does not include articles about medical or educational issues.

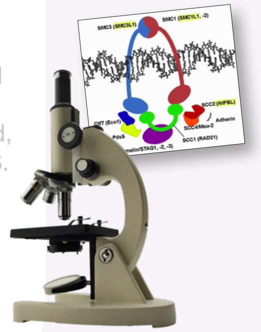


THURSDAY

4:30 p.m.

The Research Committee approves the Foundation's participation in the National Institutes of Health's (NIH) new Rare Disease Registry program. As part of this pilot program, individuals with CdLS will have their medical information included in a database, anonymously and only with their consent. Clinical and basic science researchers can access the database and, hopefully, generate studies to find out how to best help people with CdLS. The program is set to launch in late 2011.

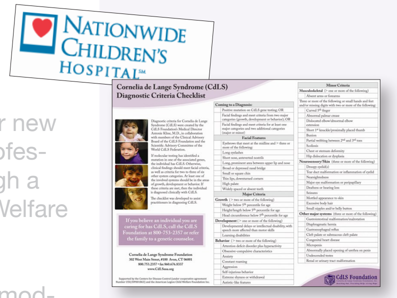
CdLS research continues to thrive with several projects undertaken by clinicians around the country. Topics include psychiatric medications, behavior, immunology, thrombocytopenia (low blood platelets), and hearing.



FRIDAY

11:45 a.m.

A pediatrician calls to say she's diagnosed a child after reviewing our new CdLS Diagnostic Criteria Checklist. She is one of 76,000 medical professionals who receive information about CdLS and the checklist through a nationwide postcard mailing, funded by the American Legion Child Welfare Foundation and the Centers for Disease Control.



We also educate professionals through our first-ever online learning module, created by Clinical Advisory Board Member Carol Potter, M.D., and focusing on common gastrointestinal issues. Suitable for professionals and parents, it's sponsored by Nationwide Children's Hospital and provides one Continuing Medical Education credit to doctors. The project inspires plans for additional modules in coming years, including behavior, education and sensory issues.