



2015 ANNUAL REPORT



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

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.

Message from the Board President & Acting-Executive Director

The CdLS Foundation has accomplished its goals in 2015, and staff members maintain high hopes as we look ahead to 2016. Here are some of the highlights from the year, all made possible due to donors and volunteers like you:

- Four research projects shared \$35,000 in funding. The scientists will look at communication intervention, blenderized diets for gastronomy feeding patients, the role of NIPBL in beocortex organoid development, and an evaluation of autonomic dysfunction in CdLS.
- We welcomed 85 new families to the Foundation, bringing the total number of families we serve to well over 2,700. We also continue to support nearly 500 families who have lost a child with CdLS.
- Our partnership with the Coordination of Rare Diseases at Sanford (CoRDS) to launch a National CdLS Registry has resulted in 60 submissions, and an additional 60 incomplete submissions. This patient-reported database will help Foundation staff and researchers identify clinical trends, among others.
- A new publication for families who are in the process of transitioning their child from pediatric to adult care was created and professionally printed.
- Creation of new medical treatment cards by specialty, and updated version of our publication, Facing the Challenges.
- Team CdLS exceeded its fundraising goals, raising \$210,000.

Looking ahead, 2016 marks the first year of our new strategic plan. We will build on past successes, expand our programs and increase our services. Existing programs to continue to look forward to, include regional family gatherings, nationwide clinics, and the 2016 National Family Conference in Orlando, FL. New projects include online resources for adults with CdLS, a publication for fathers, and increased research funding.

Thank you for your ongoing support. Don't hesitate to contact me should you have any questions.
Kelly Brown, Acting Executive Director

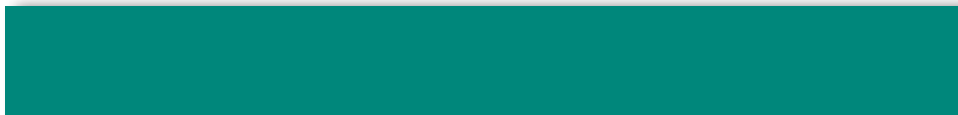
Sincerely,

Robert Boneberg, Esq.
President, Board of Directors

Kelly Brown
Acting-Executive Director

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
Research
Staff social workers
Publications



12¢

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

2015 Highlights



Family service coordinators welcomed over **80** new families



Spanish quarterly emails bulletins, including **4** new translations



\$210,000 was raised by Team CdLS



4 research grants were awarded totaling \$35,000



\$135,000 was raised at 2 golf tournaments

The CdLS Foundation thanks the following individuals and businesses who provided major sponsorships of events in 2015:

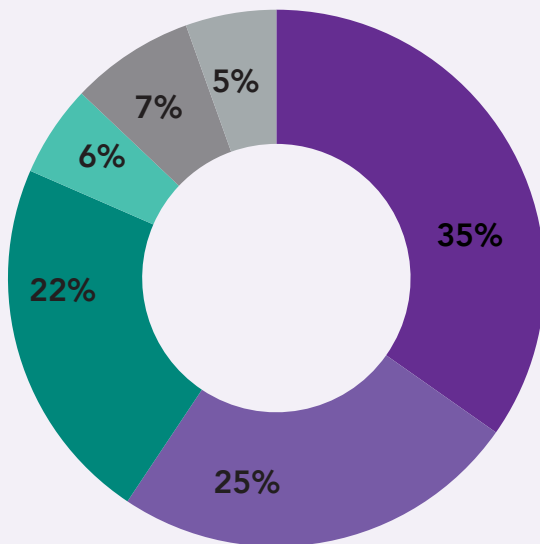
- Bank of Montreal
- Brean Capital Markets, LLC
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- Madison County Wood Products Inc.
- Pallet Logistics Management, Inc.
- RBC Capital Markets
- RENMAC
- Striker
- Teixeira family

The following organizations awarded funds to the CdLS Foundation in 2015:

- Gilead Sciences, Inc.
- William and Alice Mortensen Foundation

2015 Audited Expenses

2015 Income and Expense Statement
January 1 - December 31, 2015



INCOME	
Individual Donations	22,718
Corporations/Company Donations	25,746
Foundations/Grants	8,349
Major Donors	225,525
Direct Mail/Foundation Drives	35,229
Clubs and Organizations	13,782
Gifts that Count – Memorial/Celebration	61,426
Special Events/ Third Party Fundraising	428,959
Federated Campaigns	46,720
Bequest	12,624
Program Services Fee/ Nat'l Conference	0
Program Services Fees/Symposia	0
Investment Income	11,572
Total Revenue	892,650

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	176,679
Research	44,057
Family Support Program	276,828
Public Information and Education	196,053
Total Program Services	693,617
Support Services	
Management and General	43,568
Fund raising	59,425
Total Support Service	102,993
Total Expenses	796,610
Surplus/Deficit from Operations	96,040
Unrealized Gains/Losses	(33,524)
Total Surplus/Deficit	62,516
Total Net Assets	1,259,142

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

The CdLS Foundation Family

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Pediatric Dentistry
Pediatric Dentistry
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Pediatric Dietetics
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Speech-Language Pathology
Urology

 **CdLS Foundation**
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