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.
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.

<table>
<thead>
<tr>
<th>88¢</th>
<th>12¢</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family gatherings</td>
<td>Office rent</td>
</tr>
<tr>
<td>Research</td>
<td>State registration</td>
</tr>
<tr>
<td>Staff social workers</td>
<td>Office supplies</td>
</tr>
<tr>
<td>Publications</td>
<td>Family &amp; professional database</td>
</tr>
<tr>
<td></td>
<td>IT expenses</td>
</tr>
</tbody>
</table>
### 2015 Highlights

- **Family service coordinators welcomed over new families**: 80
- **Spanish quarterly emails bulletins, including new translations**: 4
- **$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
- Caldwell family
- Craig Hallum Capital Group
- Donald Sadoski D.M.D.
- Down to Basics
- FGMK, LLC
- Fielder Electric Supply Co., Inc.
- Geoffrey Metals
- Gerome Technologies
- JC Anderson
- KeyBanc Capital Markets
- LPS Equipment & Acquisition
- 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

#### 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: 276,828
- Bequest: 12,624
- Investment Income: 11,572
  
  **Total Revenue**: 892,650

#### EXPENSES

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

---

#### 2015 Income and Expense Statement

January 1 - December 31, 2015

---

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

PROFESSIONAL STAFF
ACTING-EXECUTIVE DIRECTOR
Kelly Brown

MEDICAL DIRECTOR
Antonie Kline, M.D.

FAMILY SERVICE MANAGER
Deirdre Summa, M.S.W.

FAMILY SERVICE COORDINATORS
Lynn Audette, M.S.W.
Justyna Wawrzonek, L.M.S.W.

COMMUNICATIONS COORDINATOR
Brenda Shepard

GRAPHIC DESIGNER/WEB MASTER
Francesca Scognamiglio

OFFICE COORDINATOR
Susan Salina

BOARD OF DIRECTORS
PRESIDENT
Robert Boneberg, Esq., NJ

VICE PRESIDENTS
Richard Haaland, Ph.D., GA
David Harvey, GA

TREASURER
David Barnes, Esq., NH

SECRETARY
Wendy Miller, Esq., CA

DIRECTORS
Catherine Caron, NH
Shelly Champion, MA
Michele Churchman, DE
Dennis Dripline, CA
Eric Johnson, CT
Lyne K err, M.D., UT
Dianne Lessa, MA
Maegan Lowrey, NC
Pat Lyons, NH
Carlos Madrid, Esq., TX
Marc Needleman, IL
Julia O’Connor, Ph.D., MD
Mary Opitz, TX
Fran Rissland, GA
Beth Smisloff, NY

PROFESSIONAL DEVELOPMENT COMMITTEE
Christine Ackermann, M.S., O.T., Occupational Therapy
Ingrid Barone, R.N., Nursing
Mary Beth Bruder, Ph.D., Educational Psychology
Marjorie Goodban, Ph. D., CCC-SLP, Speech Language Pathology
Amy Metrena, M.S.P.T., Physical Therapy
Julia O’Connor, Ph.D., Clinical Psychology
Rachel Hueston, Education
Shelly Champion, M.Ed., Special Education
Mii Cordero, Ed.D, OT/TV, BCP, Occupational Therapy
Barbara Galvane, M.Ed., Special Education Assasments
Jill Knuffman, B.S., SpEd., Special Education
Mary Pipan, M.D., Developmental Pediatrician
Roger Woerner, B.S., SpEd., Special Education Behavior Management
Geir Rosvik, M.Ed., Adaptive Physical Education
Janette Peracchio, M.Ed., Special Education Rights and IEP’s

CLINICAL ADVISORY BOARD
Dale Dorsett, Ph.D., Biochemistry & Molecular Biology
Jennifer Gerton, Ph.D., Biochemistry & Molecular Biology
Marco Gradus, M.D., M.P.H., Child Psychiatry
Robert Greenstein, M.D., Clinical Genetics
Ian Krantz, M.D., Clinical Genetics
Laird Jackson, M.D., Clinical Genetics
Matthew Bezzard, M.D, Ph.D., Clinical Genetics
Yves Lacassie, M.D., Clinical Genetics
Soma Das, Ph.D., FACMG, Clinical Genetics
Antonio Kline, M.D., Clinical Genetics
Arthur Landier, M.D., Ph.D., Developmental Biology
Trevor Hoffman, M.D., Ph.D., Developmental Biology/Pediatrics
Amy Kimball, M.S., Genetic Counselor
Sara Noon, M.S., Genetic Counselor
Natalie Blagowidow, M.D., Gynecology, Genetics
Michele Lambert, M.D., Hematologist
Howard Levy, M.D., Immunology
Clair Francomano, M.D., Internal Medicine, Genetics
Anne Calof, Ph.D., Internal Medicine, Genetics
Ronald Berger, M.D., Neurodevelopmental Biology
Robert Sataloff, M.D., D.M.A., Ophthalmology
Aaron Zuckerberg, M.D., Pediatric Anesthesia, PICU
Jeff Rockow, M.D., Pediatric Cardiology
Douglas Clemens, D.M.D., Pediatric Dentistry
Richard Mungo, D.D.S., Pediatric Dentistry
Rochelle Lindemeyer, D.D.S., Pediatric Dentistry
Joni Rampolla, L.D., Pediatric Dietetics
Loretta Gore, R.D., L.D.N., Pediatric Dietetics
Carol Potter, M.D., Pediatric Gastroenterology
David Tuchman, M.D., Pediatric Gastroenterology
Kathleen Loomes, M.D., Pediatric Gastroenterology
Lynette Gillis, M.D., Pediatric Gastroenterology
Lyne K err, M.D., Pediatric Neurology
Alex Levin, M.D., Pediatric Neurology
Christianne Schoedel, M.D., Pediatric Ophthalmology
Susan Schloff, M.D., Pediatric Ophthalmology
Paul Sponseller, M.D., Pediatric Orthopedics
Carmen Pichard, M.D., Pediatric Orthopedics
Stacey Ishman, M.D., Pediatric Orthopedics
Katherine Farr, D.P.T., Pediatric Otolaryngology
Mark Klineer, M.D., Physical Therapy
Cheri Carrico, Ph.D., CCC-SLP, Speech-Language-Feeding
Nancy Mathis, M.S., CCC-SLP
Ning-Hsien Wang, M.D., Urology