The CdLS Foundation Family

PROFESSIONAL STAFF

EXECUTIVE DIRECTOR
Marie Concklin-Malloy

MEDICAL DIRECTOR
Antonie Kline, M.D.

ASSISTANT EXECUTIVE DIRECTOR
Kelly Brown

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

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

COMMUNICATIONS COORDINATOR
Brenda Shepard

GRAPHIC DESIGNER/WEB MASTER
Francesca Scognamiglio

DEVELOPMENT COORDINATOR
Nicole Dolio

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 Drislane, CA
Eric Johnson, CT
Lyneen Kerr, M.D., UT
Dianne Lessa, MA
Maegan Lowrey, NC
Pat Lyons, NH
Carlos Madrid, Esq., TX
Marc Needelman, IL
Julia O’Connor, Ph.D., MD
Mary Optiz, TX
Fran Realidad, GA
Beth Smidloff, NY

PROFESSIONAL DEVELOPMENT COMMITTEE

Christine Askerman, M.S., OT
Ingrid Barone, R.N.
Mary Beth Bruder, Ph.D.
Marjorie Goodban, Ph.D., CCC-SLP
Amy Metena, M.S.P.T.
Julie O’Connor, Ph.D.
Rachel Huouston,
Shelly Champion, M.Ed.
Mili Cordero, Ed.D., OTR/L, BCR
Barbara Galyean, M.Ed.
Jill Knuffman, B.S., CSD
Mary Piper, M.D.
Roger Warner, B.S., SydEd
Gear Rossit, M.Ed.
Janette Peracchio, M.Ed.

CLINICAL ADVISORY BOARD

Dale Dorsett, Ph.D.
Jennifer Harten, Ph.D.
Marco Grados, M.D., M.P.H.
Ian Krantz, M.D.
Laird Jackson, M.D.
Matthew Deardorff, M.D, Ph.D.
Yves Lescasie, M.D.
Soma Das, Ph.D., FACMG
Antonie Kline, M.D.
Arthur Lander, M.D., Ph.D.
Trevor Hoffman, M.D., Ph.D.
Amy Kimball, M.S.
Sara Noon, M.S.
Natalie Blagowidow, M.D.
Michele Lambert, M.D.
Soma Das, Ph.D., FACMG
Howard Levy, M.D.
Clair Francsmaro, M.D.
Anna Catof, Ph.D.
Ronald Berger, M.D.
Robert Sataloff, M.D., D.M.A.
Aaron Zuckenberg, M.D.
Jeff Rockow, M.D.
Douglas Clemens, D.M.D.
Richard Mungo, D.D.S.
Roshelle Lindenmeyer, D.D.S.
Jon Rampaola, L.D.
Loretta Gare, R.D., L.D.N.
Carol Porter, M.D.
David Tuchman, M.D.
Kathleen Losomes, M.D.
Lynette Gillis, M.D.
Lyneen Kerr, M.D.
Alex Lavo, M.D.
Christinne Shwedel, M.D.
Susan Schliff, M.D.
Paul Sponseller, M.D.
Carmen Pichard, M.D.
Stacey Ishman, M.D.
Katherine Farr, D.RT.
Mark Klawer, M.D.
Ceri Carrico, Ph.D., CCC-SLP
Nancy Mathis, M.S., CCC-SLP
Ming-Hsien Wang, M.D.

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

Printing provided by Paladin Commercial Printers L.L.C.
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 national CdLS Registry was launched**

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

### 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.

- **Family gatherings**
- **Medical Director**
- **Staff social workers**
- **Publications**
- **National Conference**

### 2014 Audited Expenses

**2014 Income and Expense Statement**

<table>
<thead>
<tr>
<th>INCOME</th>
<th>EXPENSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Donations</td>
<td>Total Program Services</td>
</tr>
<tr>
<td>Corporations/Company Donations</td>
<td>Program Services</td>
</tr>
<tr>
<td>Foundations/Grants</td>
<td>Professional Development,</td>
</tr>
<tr>
<td>Major Donors</td>
<td>Outreach &amp; Awareness</td>
</tr>
<tr>
<td>Gifts that Count –</td>
<td>Research</td>
</tr>
<tr>
<td>Memorial/Celebration</td>
<td>Family Support Program</td>
</tr>
<tr>
<td>Special Events/Third Party</td>
<td>Public Information and Education</td>
</tr>
<tr>
<td>Fundraising</td>
<td></td>
</tr>
<tr>
<td>Request</td>
<td></td>
</tr>
<tr>
<td>Program Services Fees/</td>
<td></td>
</tr>
<tr>
<td>National Conference</td>
<td></td>
</tr>
<tr>
<td>Program Services Fees/Symposia</td>
<td></td>
</tr>
<tr>
<td>Investment Income</td>
<td></td>
</tr>
<tr>
<td>Total Revenue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Total Net Assets</td>
</tr>
</tbody>
</table>

### 2014 Income and Expense Statement

January 1 - December 31, 2014

- **Total Revenue** $1,151,669
- **Total Net Assets** $1,196,626

88¢

- Family gatherings
- Medical Director
- Staff social workers
- Publications
- National Conference

12¢

- Office supplies
- Family & professional database
- IT expenses

![Diagram showing the breakdown of income and expenses]

### 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