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.

**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

As we look back to 2016, we see it was a year to celebrate for so many reasons. The Board and staff of the Foundation set some ambitious goals based on feedback from families, and we are proud and pleased to report that we met and, in many instances, exceeded these objectives.

To better support our ever-growing community, we accomplished a broad spectrum of exciting initiatives:

- We opened a new multi-specialty clinic in Salt Lake City, Utah
- To better meet the needs of our families we created 2 new publications – Taking Care of Me and From One Dad to Another – that focused on caregiver well-being and on the important role fathers play in the care of their special needs children
- More than 550 families attended 11 Family Gatherings in towns and cities across the country: March - AZ, GA; April - AL; May - NC; July - IN; September - PA; October – MO, FL, WI, UT; December - CA
- A record-breaking 546 people (families, volunteers, professionals) attended our National Family Conference that took place in Orlando, Florida
- 104 new families contacted the CdLS Foundation
- 58 Team CdLS participants helped raise awareness and $169,317 for the CdLS Foundation

The Foundation also expanded our network of donors to include not only families, but friends and corporations that have been touched by someone who is affected by Cornelia de Lange Syndrome. The generosity of our donors in 2016 funded the following new services:

- Medical Specialty Treatment Cards
- Anesthesia Guidelines
- Navigating Healthcare Transitions from Pediatric to Adult Medical Care publication
- Additional research funding of $20,000

As our National Conference theme stated and 2016 proved, we are stronger, together. Thank you for your ongoing support and helping all of us to continue to dream of new ways to improve the lives of everyone affected by CdLS each and every year.

Sincerely,

Richard Haaland, Ph.D.
President, Board of Directors

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
- 12¢ Office rent
- 7¢ Research
- 5¢ State registration
- 5¢ Office supplies
- 4% Family & professional database
- 4% IT expenses
- 2% General & Administration
- 2% Fundraising
- 2% Professional Development
- 2% Outreach & Awareness
- 2% Public Information & Education
- 2% Family Support Program
- 1% Research

The CdLS Foundation thanks the following individuals and businesses who provided major sponsorships of events in 2016:

- BMO Capital Markets
- Crown Machinery
- Evercore Partners Services East LLC
- FGMK, LLC
- Geoffrey Metals, Inc.
- Geroma Technologies, Inc.
- KeyBanc Capital Markets
- Lundebeck Pharmaceuticals Services
- Madison County Wood Products, Inc.
- Pallet Logistics Management, Inc.
- RenMac
- Donald A. Sadocki, DMD
- Tag Truck Enterprises of Missouri, Inc.
- Teixeira Family
- Weiss Attorneys at Law

The following organizations awarded funds to the CdLS Foundation in 2016:

- Amerigion Legion Child Welfare

2016 Highlights

$169,317 was raised by Team CdLS

546 People attended the 2016 CdLS National Family Conference in Orlando, FL

104 Family service coordinators welcomed new families

$121,573 raised at 2 golf tournaments

2016 Audited Expenses

2016 Income and Expense Statement
January 1 - December 31, 2016

INCOME

<table>
<thead>
<tr>
<th>Source</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Individual Donations</td>
<td>26,104</td>
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<tr>
<td>Corporations/Company Donations</td>
<td>27,499</td>
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<tr>
<td>Foundations/Grants</td>
<td>6,800</td>
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<td>Major Donors</td>
<td>281,081</td>
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<tr>
<td>Direct Mail/Foundation Drives</td>
<td>36,073</td>
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<tr>
<td>Grants and Organizations</td>
<td>8,627</td>
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<tr>
<td>Gifts that Count – Memorial/Celebration</td>
<td>49,242</td>
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<tr>
<td>Special Events – Third Party Fundraising</td>
<td>385,794</td>
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<tr>
<td>Federated Campaigns</td>
<td>44,983</td>
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<tr>
<td>Bequests</td>
<td>814</td>
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<tr>
<td>Program Services Fees/ Nat’l Conference</td>
<td>123,878</td>
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<tr>
<td>Program Services Fees/Symposium</td>
<td>14,975</td>
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<tr>
<td>Total Program Services</td>
<td>597,164</td>
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<tr>
<td>Total Surplus/Deficit</td>
<td>(57,140)</td>
</tr>
<tr>
<td>Total Revenue</td>
<td>975,189</td>
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EXPENSES

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<tr>
<th>Category</th>
<th>Amount</th>
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<td>Program Services</td>
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<td>Support Services</td>
<td>941,551</td>
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<td>Management and General</td>
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<tr>
<td>Fundraising</td>
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<tr>
<td>Total Support Service</td>
<td>131,164</td>
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<tr>
<td>Total Expenses</td>
<td>1,274,127</td>
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<tr>
<td>Surplus/Deficit from Operations</td>
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<tr>
<td>Unrealized Gains/Losses</td>
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<tr>
<td>Total Surplus/Deficit</td>
<td>7,202</td>
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<tr>
<td>Total Net Assets</td>
<td>1,259,142</td>
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</table>

INCOME AND EXPENSES 2016:

- Family Donations 88¢
- Office rent 12¢
- State registration 7¢
- Office supplies 5¢
- Family & professional database 4%
- IT expenses 4%
- General & Administration 2%
- Fundraising 2%
- Professional Development 2%
- Outreach & Awareness 2%
- Public Information & Education 2%
- Family Support Program 2%
- Research 1%