

The CdLS Foundation Family

PROFESSIONAL STAFF

EXECUTIVE DIRECTOR
Bonnie Royster

MEDICAL DIRECTOR
Antonie Kline, M.D.

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

FAMILY SERVICE COORDINATORS
Lynn Audette, L.M.S.W.
Whitney Rinaldi, B.S.W.

DEVELOPMENT MANAGER
Kristi Larson

DEVELOPMENT COORDINATOR
Susan Salina

COMMUNICATIONS MANAGER
Joanne Kimball

GRAPHIC DESIGNER/WEB MASTER
Francesca Scognamiglio

FINANCE MANAGER
Julie Brodnitzki

MAJOR GIFTS DIRECTOR
Kati Liss-Hensel

OFFICE COORDINATOR
Luz Diaz

BOARD OF DIRECTORS

PRESIDENT
Richard Haaland, Ph.D., GA

VICE PRESIDENT
David Barnes, Esq., NH
Wendy Miller, Esq., CA

TREASURER
Eric Johnson, CT

SECRETARY
Patrick Lyons, NH

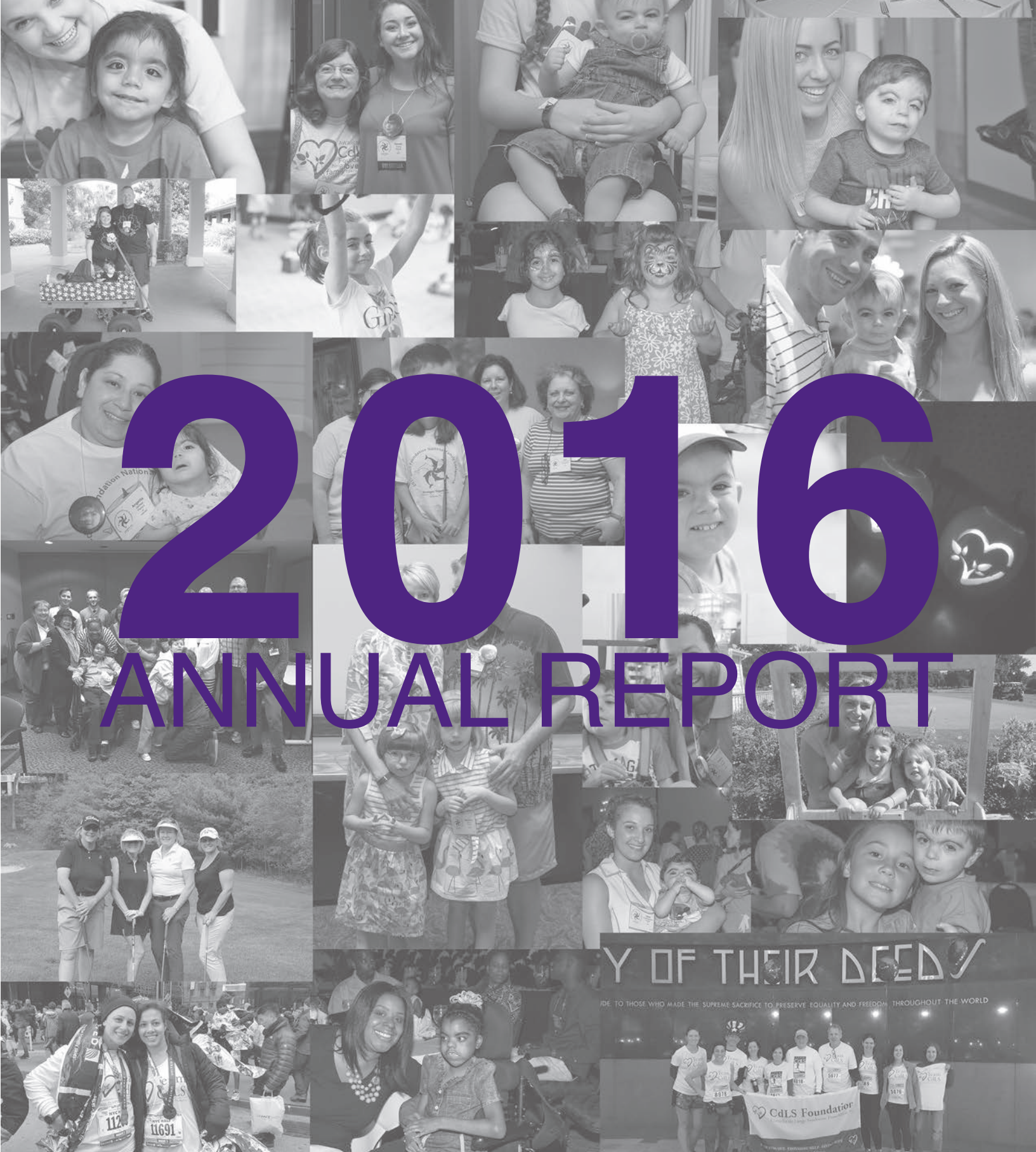
DIRECTORS
Catherine Caron, NH
Dennis Drislane, CA
Mike Feehan, PA
Lynne Kerr, M.D., UT
Jim Kesting, MO
Katherina Nikzad-Terhune, KY
Julia O'Connor, Ph.D., MD
Emily Turner, AL
Angie Young, FL

PROFESSIONAL DEVELOPMENT COMMITTEE

Geir Rosvik, M.Ed.,
Julia O'Connor, Ph.D.,
Mary Pipan, M.D.,
Denise Williams, MS,
Urbi Ghosh, Ph.D.,
Rachel Hueston,
Mary Beth Bruder, Ph.D.,
Ingrid Barone, R.N.,
Christine Ackermann, M.S., O.T.,
Joann Fleckenstein, M.S., O.T.,
Amy Metrena, M.S.P.T.,
Mary Levis N.C.S.P.,
Barbara Galyean, M.Ed.,
Roger Woerner, B.S., SpEd.,
Shelly Champion, M.Ed.,
Adaptive Physical Education
Clinical Psychology
Developmental Pediatrician
Early Childhood Education
Education
Education
Educational Psychology
Nursing
Occupational Therapy
Occupational Therapy
Physical Therapy
School Psychology
Special Education Assessments
Special Education Behavior Management
Special Education

CLINICAL ADVISORY BOARD

Dale Dorsett, Ph.D.,
Jennifer Gerton, Ph.D.,
Marco Grados, M.D., M.P.H.,
Robert Greenstein, M.D.,
Ian Krantz, M.D.,
Laird Jackson, M.D.,
Matthew Deardorff, M.D, Ph.D.,
Yves Lacassie, M.D.,
Antonie Kline, M.D.,
Trevor Hoffman, M.D., Ph.D.,
Arthur Lander, M.D., Ph.D.,
Joseph McCleery, Ph.D.,
Alena Egense, MGC, CGC,
Amy Kimball, M.S.,
Sara Noon, M.S.,
Natalie Blagowidow, M.D.,
Michele Lambert, M.D.,
Soma Jyonouchi, M.D.,
Clair Francomano, M.D.,
Soma Das, Ph.D., FACMG,
Anne Calof, Ph.D.,
Ronald Berger, M.D.,
Aaron Zuckerberg, M.D.,
Jeff Rockow, M.D.,
Douglas Clemens, D.M.D.,
Richard Mungo, D.D.S.,
Rochelle Lindemeyer, D.D.S.,
Joni Rampolla, L.D.,
Loretta Gore, R.D., L.D.N.,
Carol Potter, M.D.,
David Tuchman, M.D.,
Kathleen Loomes, M.D.,
Lynette Gillis, M.D.,
Kristen Baranano,
Lynne Kerr, M.D.,
Alex Levin, M.D.,
Christianne Schoedel, M.D.,
Susan Schloff, M.D.,
Carmen Pichard, M.D.,
Stacey Ishman, M.D.,
Katherine Farr, D.P.T.,
Mark Kliewer, M.D.,
Cheri Carrico, Ph.D., CCC-SLP,
Patti Bailey, M.S., CCC-SLP,
Nancy Mathis, M.S., CCC-SLP,
Ming-Hsien Wang, M.D.,
Biochemistry & Molecular Biology
Biochemistry & Molecular Biology
Child Psychiatry
Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Clinical Genetics
Developmental Biology
Developmental Neuroscientist
Genetic Counselor
Genetic Counselor
Genetic Counselor
Gynecology, Genetics
Hematologist
Immunology
Internal Medicine, Genetics
Molecular Genetics
Neurodevelopmental Biology
Ophthalmology
Pediatric Anesthesia, PICU
Pediatric Cardiology
Pediatric Dentistry
Pediatric Dentistry
Pediatric Dentistry
Pediatric Dietetics
Pediatric Dietetics
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Gastroenterology
Pediatric Neurology
Pediatric Neurology
Pediatric Ophthalmology
Pediatric Ophthalmology
Pediatric Ophthalmology
Pediatric Orthopedics
Pediatric Otolaryngology
Physical Therapy
Radiology
Speech-Language-Feeding
Speech-Language-Feeding
Speech-Language Pathology
Urology




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 RR Donnelley

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

2016 Highlights

\$169,317 was raised by Team CdLS 

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

Family service coordinators welcomed **104** new families 

\$121,573 raised at 2 golf tournaments 

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

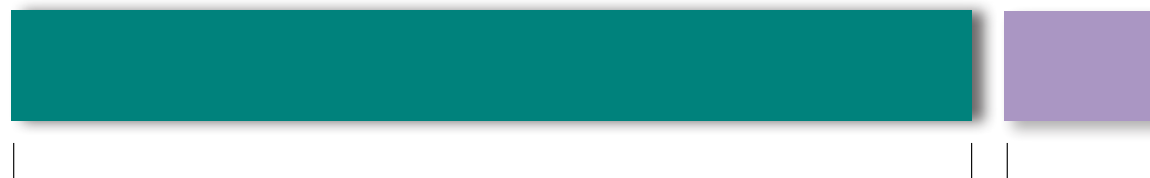
- BMO Capital Markets
- Crown Machinery
- Evercore Partners Services East LLC
- FGМК, LLC
- Geoffrey Metals, Inc.
- Gerome Technologies, Inc.
- KeyBanc Capital Markets
- Lundbeck Pharmaceuticals Services
- Madison County Wood Products, Inc.
- Pallet Logistics Management, Inc.
- RenMac
- Donald A. Sadoski,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

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

- Amergion Legion Child Welfare

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.

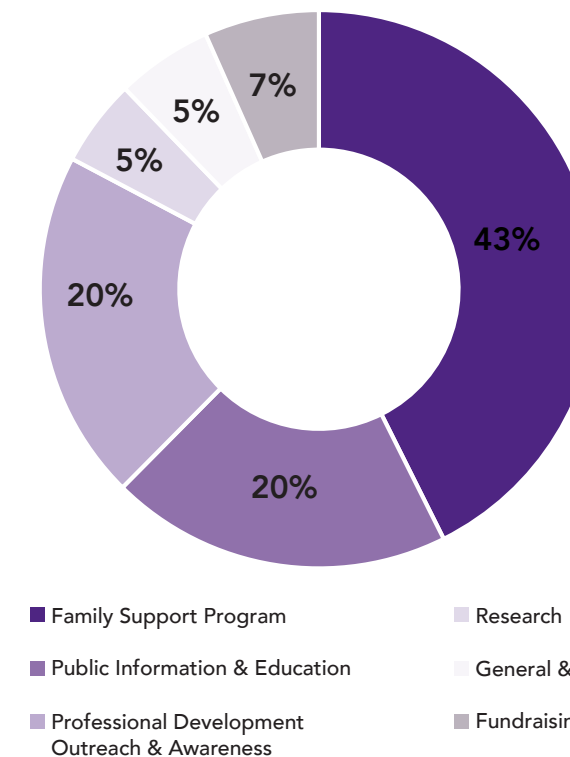


88¢
Family gatherings
Research
Staff social workers
Publications

12¢
Office rent
State registration
Office supplies
Family & professional database
IT expenses

2016 Audited Expenses

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



INCOME	
Individual Donations	28,104
Corporations/Company Donations	27,496
Foundations/Grants	6,800
Major Donors	241,081
Direct Mail/Foundation Drives	36,075
Clubs and Organizations	8,631
Gifts that Count – Memorial/Celebration	49,249
Special Events/Third Party Fundraising	385,798
Federated Campaigns	44,986
Bequest	814
Program Services Fee/Nat'l Conference	123,878
Program Services Fees/Symposia	14,975
Investment Income	7,302
Total Revenue	975,189

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	217,879
Research	54,012
Family Support Program	457,217
Public Information and Education	212,443
Total Program Services	941,551
Support Services	
Management and General	59,741
Fund raising	71,423
Total Support Service	131,164
Total Expenses	1,072,715
Surplus/Deficit from Operations	(97,526)
Unrealized Gains/Losses	45,252
Total Surplus/Deficit	
Total Net Assets	1,259,142