



CdLS Foundation 2024 Annual Report

CELEBRATING COMMUNITY AND SUPPORT



Dear Friends,

As I reflect on this past year, I am struck by the power of community to bring light into even the darkest places. In 2024, we witnessed this power in countless ways, through stories like five-year-old Izaak, through the laughter and friendships formed at our East Coast Regional Retreat, and through the raw honesty of caregivers at our UNSEEN documentary gathering. Each of these moments tells a story of resilience, of connection, and of what it means to be truly seen and supported.

At the CdLS Foundation, we know the reality rare disease families face, often having to wait years for a diagnosis, face limited treatment options, and carry the heavy burden of caregiving. The challenges you face drive our work every day. Whether we organize a regional retreat, support a family gathering, host CdLS Specialty Clinics, or speak with you on the phone, our goal is to ensure that families feel less alone and more empowered to continue their journey.

However, none of our work would be possible without you, our donors, partners, and community. Your generosity fuels the moments of joy, belonging, and resilience that sustain us all. Together, we are building a future where every family living with CdLS feels seen, supported, and connected.

With Warm Regards,

Bonnie

TABLE OF CONTENTS

05 ABOUT US

06 RESEARCH AND DEVELOPMENT

08 PATIENT SUPPORT AND ADVOCACY

12 COMMUNITY ENGAGEMENT

16 HOW TO GET INVOLVED

18 INCOME & EXPENSES

22 DONOR RECOGNITION

26 DEDICATED TEAM

THE CdLS FOUNDATION: A BRIEF OVERVIEW

The Cornelia de Lange Syndrome (CdLS) Foundation is a national organization that supports individuals with CdLS and their families to ensure early and accurate diagnosis of the rare genetic syndrome, and make informed decisions throughout their lives. The CdLS Foundation aims to establish a community and enable advocacy for people experiencing CdLS and other isolating conditions. Services include a toll-free hotline where our caring and knowledgeable Family Service Coordinators act as facilitators between families and professionals who lend their expertise.

The CdLS community is a diverse and vibrant group united by their shared experiences. The CdLS Foundation is committed to supporting individuals affected by this rare genetic condition.



Research and Development

“IF NOT US, WHO? IF NOT NOW, WHEN?”

The CdLS Foundation’s mission has always been rooted in care, compassion, and connection. For over four decades, we have walked alongside families, helping them navigate the unknowns of Cornelia de Lange Syndrome. Yet as science advances, our mission must evolve. In addition to support, we are now engaged in a bold and deliberate effort to ensure that the Foundation, and the families we serve, are prepared for the future of therapeutics.

This new direction represents more than a shift in activity; it is a **strategic evolution** in how we think, plan, and lead. Through our multi-year strategic planning process, we are charting a course toward

trial readiness, building the Foundation so that when treatments become available, our community will be well-prepared to participate.

We are exploring the infrastructure and partnerships that will make this future possible: enhancing our data registry strategy, evaluating biobank collaborations, and envisioning digital tools that will empower families to contribute to research. One of the most promising concepts under development is the **CdLS Hub app**, a platform that enables families to securely log their loved ones’ medical symptoms, behaviors, and hospitalizations. These real-world data, in addition to the data held by the Foundation, could one day

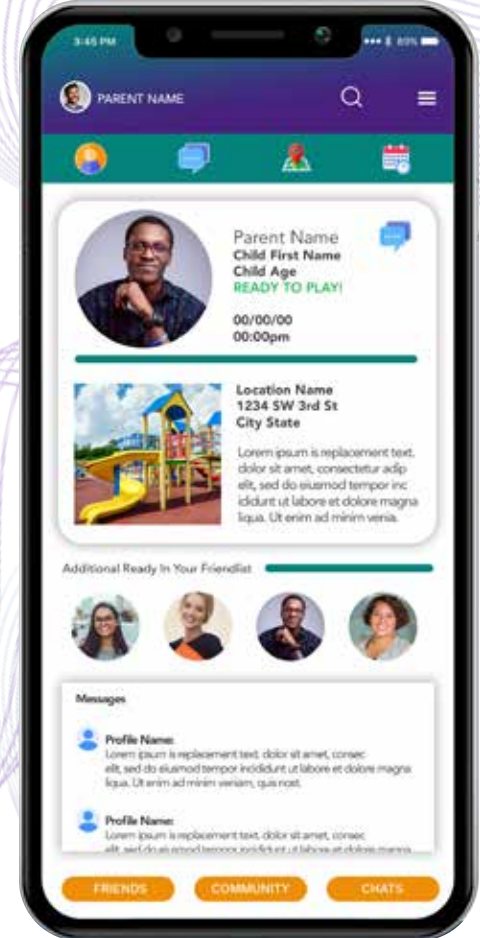
provide the kind of natural history information essential for designing future clinical trials and identifying meaningful outcomes.

At the same time, we are working to ensure that families are informed, engaged, and prepared to seize these opportunities when they arise. Through transparency, education, and collaboration, we are aligning every facet of our work, from clinical partnerships to family engagement, toward one unified goal: to be prepared.

This evolution would not be possible without your unwavering generosity and belief in our mission. Because of you, the CdLS Foundation has the stability and vision to “turn the ship” toward the future—responsibly, strategically, and with heart.

Together, we are ensuring that when science brings new hope, the CdLS community will be ready to embrace it.

If not us, who? If not now, when?



Bella's Story



Bella Marie is an outdoor-loving, piano-playing 12-year-old with a personality as big as the mountains she loves to explore. Diagnosed with Cornelia de Lange Syndrome (CdLS) within hours of birth, Bella's journey began with immense challenges. She weighed just one pound, twelve ounces, and spent 53 days in the NICU. **But from the very beginning, she's defied the odds.**

Today, Bella lives life loudly and proudly. Whether off-roading in the mountains, swinging in her hammock chair, or riding horses to strengthen her mobility, Bella approaches every experience with joy and curiosity. "CdLS may be Bella's syndrome," her family says, "but it does NOT define who she is."

“Whenever we’ve contacted the Foundation, they’ve responded quickly with information, research, and specialists. We’ve brought those ideas to our doctors and therapists, and seen real change for Bella.”

Behind Bella’s vibrant life is a network of support made possible by donors like you. Your contributions to the CdLS Foundation have provided critical guidance, connections, and care during some of the family’s most uncertain moments.

“Without the Foundation, we’d be feeling around in the dark,” Bella’s mom shares. “The information, the community, and the direction we’ve received have given us hope and a starting point.”

Thanks to your donations, Bella’s family could attend an in-person CdLS Foundation conference, an experience that became a turning point. **Bella met lifelong friends and, for the first time, saw that she wasn’t alone.** For her parents, the event offered a powerful sense of belonging and connection.

Your generosity also helped connect the family with the Children’s Hospital of Philadelphia (CHOP), where specialists helped them understand Bella’s unique needs. This partnership transformed Bella’s feeding and care plan, dramatically improving her health and quality of life.

Beyond medical care, your support funds publications and programs that foster community among families who would otherwise feel isolated. “The Foundation gives us an extended family, people we can lean on, learn from, and walk this path with,” the family says.

Bella’s story is about resilience, love, and the power of showing up for your child and a community. Your donations make that possible. You help families like Bella’s find light in the unknown, connection in the silence, and joy in the journey.

From the bottom of our hearts, thank you for being part of Bella’s story and the story of so many others who are living life to the fullest with CdLS.





Izaak's Story

SMALL AND MIGHTY

At just five years old, Izaak is full of joy, confidence, and a personality that lights up every room. Recently starting Kindergarten, he has already won over teachers and staff with his humor, energy, and determination. While Izaak faces challenges with speech and developmental delays due to Cornelia de Lange Syndrome (CdLS), his resilience and love for making people smile remind everyone around him of his strength.

The CdLS Foundation has been a lifeline for Izaak's family. Even before his official diagnosis, the Foundation provided resources, guidance, and personal support that helped his parents advocate for his care. From detailed medical information that informed Izaak's genetic testing to vital anesthesia guidelines safeguarding his health, the Foundation has been by their side at every step.

Families like Izaak's can only access these resources because of the generosity of donors. Contributions fuel support groups, provide critical medical guidance, and create a sense of belonging for families navigating CdLS. At events like the Amber Gaines Golf Classic, supporters allow children like Izaak to thrive with the proper care, knowledge, and community.

Because of donors, Izaak's future is filled with hope, opportunity, and endless smiles.



Izaak and his brother, Kamden.

“Without the Foundation, we’d be navigating blindly. Instead, we have knowledge, resources, and, most importantly, a community that makes us feel we belong.”

UNSEEN VIEWING PARTY

Celebrating Connection and Understanding

The CdLS Foundation hosted a heartfelt viewing party for the documentary "UNSEEN" to honor Rare Disease Day®, a moment devoted to raising awareness about rare diseases' profound impact on individuals and their families. This powerful film sheds light on the often-overlooked struggles of caregivers who dedicate their lives to supporting children and adults with disabilities or complex medical needs. Through its lens, we witness the emotional exhaustion and isolation many face, challenges often unseen by the broader world.



The event brought together 64 community members, each with their own unique journey, offering a safe space for connection and conversation. The sense of togetherness was palpable, as families shared their stories and found solace in the shared understanding of their experiences. Feedback from attendees highlighted the impact of the event: “It validated common issues faced by parents,” one participant shared. Another expressed, “This was my first time participating in a CdLS Foundation event, and it was great to finally break the ice. The documentary was incredibly relatable.” A sentiment echoed by many was, “It was spot on about what we as caregivers experience.”

This gathering was a celebration of community, a moment for families to unite, to share laughter and tears, and to feel less alone in their journeys. In a world where the challenges of caregiving often remain invisible, the "UNSEEN" viewing party provided a platform for voices to be heard, stories to be shared, and connections to be forged.

We are grateful to everyone who contributed to the warmth and spirit of this event. Together, we continue to illuminate the realities of CdLS, fostering understanding, support, and advocacy for all those navigating the complexities of caregiving. Thank you for being a vital part of our mission.

EAST COAST REGIONAL RETREAT

LEARNING, LAUGHTER & LASTING CONNECTIONS

Last September, the CdLS Foundation launched its new Regional Retreat model with the 2024 East Coast Regional Retreat at the beautiful Camp Saginaw in Oxford, Pennsylvania. For three days, 162 attendees, including 43 families, 31 individuals with CdLS, and 21 siblings, came together for an unforgettable weekend of education, community, and joy.

Thanks to the **generosity of donors**, including those who funded **scholarships**, many families who might not otherwise have been able to attend experienced the life-changing connections and resources the retreat offers. Your contributions ensured that parents could learn from experts, siblings could find support, and individuals with CdLS could be themselves in a safe, welcoming space.

Attendees participated in education workshops covering essential topics such as updates on CdLS research, gastrointestinal complications, and behavioral support strategies. The “Meet the Experts” sessions gave families one-on-one time with 17 members of our Clinical Advisory Board, offering personalized guidance and answers to pressing medical questions.

While parents attended workshops, individuals with CdLS enjoyed safe and engaging childcare, and siblings bonded through dedicated camp activities. These moments created

opportunities for every family member to feel seen, supported, and included.

Evenings were filled with campfires, laughter, and relaxed conversations, strengthening the bonds between families who often face similar challenges. For many, the retreat was their first CdLS Foundation event, an introduction to a community they can lean on for years to come.

Because of your generosity, we provided scholarships that allowed families to attend, funded expert-led sessions, and created a safe, inclusive environment for all. These weekends don't just provide information; **they nurture hope, belonging, and resilience.**

From the bottom of our hearts, thank you for making weekends like this possible. You aren't just funding an event, you're building a stronger, more connected CdLS community.

“This was an amazing experience for me, my husband, and my daughters. Thank you so much for all the hard work that went into the event.”

COMMUNITY ENGAGEMENT

“Loved seeing the kids gather and have fun with each other.”



“Camp venue allowed more family time and socializing with others.”

“Seeing the siblings connecting and building friendships was heartwarming.”



“We loved the retreat. As our first event, it was everything we hoped it would be.”

HOW TO GET INVOLVED

VOLUNTEER OPPORTUNITIES

The CdLS Foundation relies on volunteers nationwide to help us raise awareness, host family gatherings, fundraise, and provide family support. Volunteers reach out to other families to share their experiences and help caregivers make informed decisions.



Family Gatherings – Host a Gathering Near You!

A family gathering is a wonderful opportunity to meet with other families and share stories, resources, and information. Each year, the Foundation sponsors and our families and volunteers host gatherings throughout the country.

FUNraising

When it comes to fundraising ideas, the sky is the limit! Host an event – either virtual or in-person- to raise funds to help the CdLS Foundation continue to offer crucial services and resources to our incredible families. A few ideas to consider: Pickle Ball Tournament, Brew Fest, or an Obstacle Course in your backyard.

Awareness Coordinator

Awareness Coordinators (ACs) are volunteers who raise awareness about CdLS through community activities, events, and outreach. ACs are typically family members or caregivers of an individual with CdLS and are passionate about increasing awareness of the syndrome.

Support Group Facilitator

Support Group Facilitators are parent/ caregiver volunteers who lead the Foundation's support groups. They introduce topics of discussion or provide educational instruction for the session. They foster the group, ensuring the participants feel supported and heard.

SPONSORSHIP OPPORTUNITIES



CdLS Clinic Sponsor

Support nationwide CdLS clinics and the potential opening of a West Coast clinic.



Media Sponsor

Help us tell our story to medical professionals, government agencies, and potential grant funders.



Technology Sponsor

Provide the opportunity to create new programming in the digital age. This would include App development, Event Support Software, and Research Database.



Event Sponsor

Join us as a sponsor at our pivotal events! Showcase your support for the community, enhance your brand visibility, and connect with passionate individuals and organizations dedicated to making a positive impact.



Scholarship Sponsor

The CdLS Foundation brings families together at large regional retreats. The scholarship program breaks down the expense barrier, allowing a family to attend without a registration fee.

DONATION OPPORTUNITIES

Donating to the CdLS Foundation through your employer, sponsorships, or legacy giving program allows us to help educate medical professionals, provide research opportunities, and keep support lines open for families in need.



CONTACT DETAILS

Bonnie Royster, Executive Director

860.899.1219

director@CdLSusa.org

30 Tower Lane, Suite 400

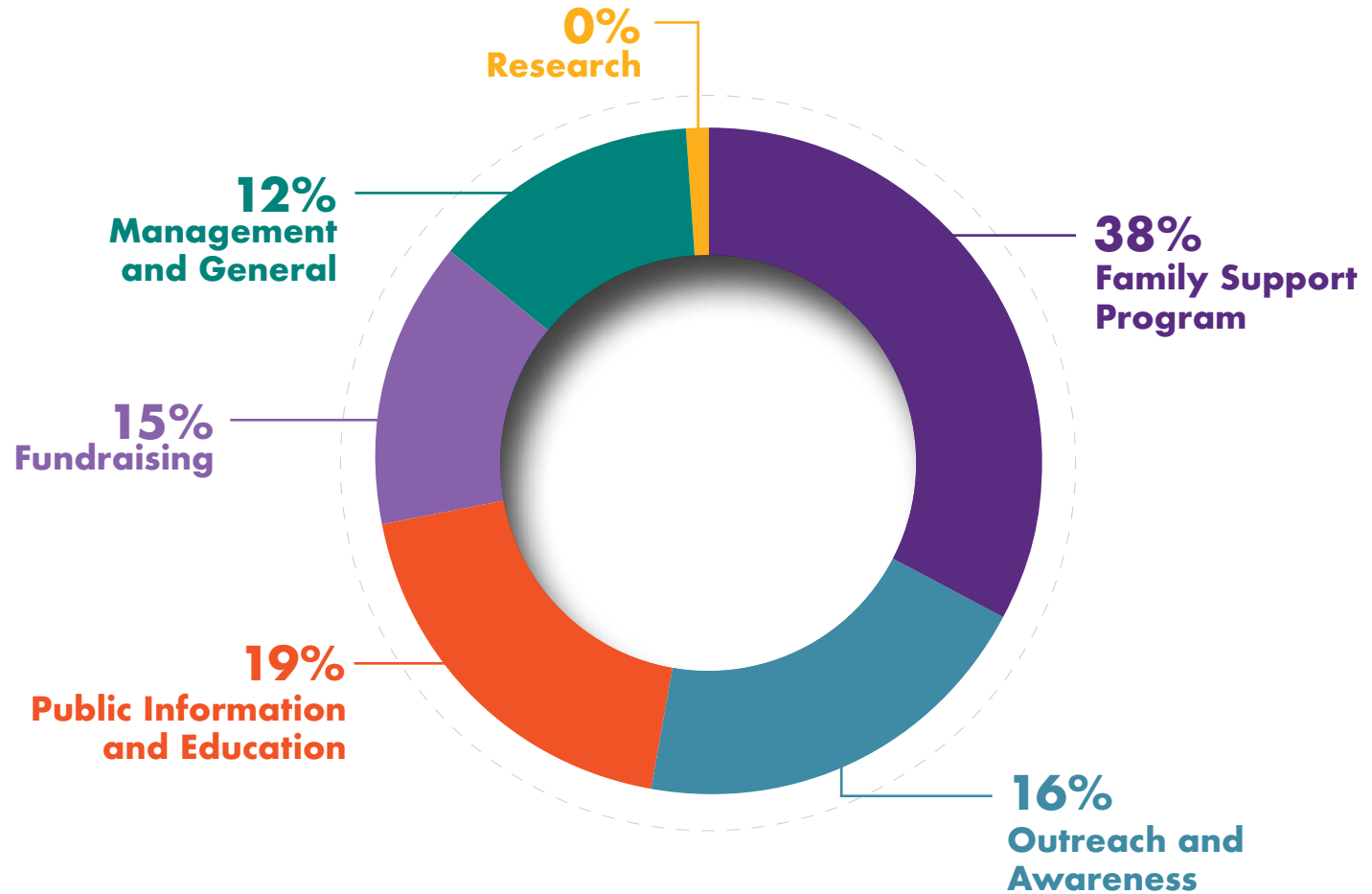
Avon, CT 06001

2024 Audited Income & Expenses

INCOME	
Individual Donations	317,112
Corporations/Company Donations	8,750
Foundations/Grants	9,000
Direct Mail	51,856
Gifts that Count – Memorial/Celebration	160,889
Special Events/Community Fundraising	398,145
Federated Campaigns	26,626
Restricted Nat'l Conference & Symposium	40,895
Restricted Research	205
Total Operating Revenue	1,013,478
Investment Net Income	71,984
Total Revenue	1,085,462

EXPENSES	
Program Services	
Outreach and Awareness	180,130
Research	4,816
Family Support Program	440,175
Public Information and Education	220,921
Total Program Services	846,042
Support Services	
Management and General	144,007
Fundraising	172,458
Total Support Service	316,465
Total Expenses	1,162,507
Net Assets, Beg of Year	3,103,734
Surplus/Deficit from Operations	165,706
Total Net Assets	3,268,440

2024 OPERATING EXPENSES



Your Gifts Made a Difference

Our donors and sponsors sustained the organization in many ways. Due to the generosity and thoughtfulness of these supporters, the Foundation did not miss a step in continuing to offer the kind of support and resources that our families and the medical community have come to rely upon.

The next few pages of this report are dedicated to those who dug deep and gave in ways that truly touched our hearts. We are forever grateful to them.

All the gifts we receive are greatly appreciated, and there are multiple ways to give. Some of those ways help us plan for the future of the organization, while others help us sustain our day-to-day operations. As we know, we can count on those funds regularly. As a result, we wish to show special recognition to the following:

VISIONARIES CIRCLE - IMPACTFUL GIVING

As our most distinguished donors, the members of our Visionaries Circle have made generous donations totaling more than \$100,000 for the year. Their incredible commitment to the CdLS Foundation has influenced not only the Foundation's day-to-day operations but also the opportunity to plan for future success in serving our families. We owe a debt of gratitude to these very special donors, who are the CdLS Foundation's Visionaries:

Wendy Miller, Esq. and Andrew Miller

LEGACY LEADERS - PLANNED GIVING

These forward-thinking donors have made a bequest or other planned gift to support the CdLS Foundation's future, leaving a legacy for generations to come. We are extremely grateful for our CdLS Foundation Legacy Leaders:

Gayle McCue (deceased) and Steve McCue

○○○ SUSTAINERS CIRCLE—RECURRING GIFTS ○○○

These generous donors have a significant impact by contributing a fixed amount either weekly or monthly, which helps sustain the CdLS Foundation with reliable gifts. Some donate online by selecting the “recurring” option, while others donate through direct deposit from their paychecks, or simply send in payment. For information on becoming part of our Sustainers Circle contact the Foundation.

Veronica Airey-Wilson

Ellen Graper

Ty Lusk

Steven Seide

Joyce Bell

Jim and Lorraine Handley

Heidi and Sonny Maliksi

Donna and Eugene Shuford

Brooke and Travis Bender

David and Livia Harvey

Debi and Bob Marks

Julia and Peter Swanson

Chris Bernhardt

Maggie Haynes

Mark McFadden

Nicole and Phillip Tiongson

Praveen Bhagavatula and Padmini
Renduchintala

Weber Hoen and Hein Nguyen

Sebastian Messier

Carmen Valentin and Michael
Swerling

Jenai Cromartie

Deb Hood

Lynnette and Dean Miller

Debbie and Darl Vandermeulen

Darlene Davis

Pat Johnson

Mary Beth Mulicka

John Dayton

Penelope Keating

Katie and Jon Nikzad-Terhune

Robyn and Paul Dietzinger

Lexi Kendall

Beatriz and Domingo Pena

Eric and Janice Duff

Rachel Killings

Anabel Perez

Katherine Frank

Aimee Kirsch

Jose Perez

Gigi Fry

Dorothy and Greg Laumann

Fran and Karl Rissland

Linda Fry

Dianne Lessa

Morrisette Royster

Michelle and Tim Luce

Charlene Ruiz

Our Major Donors

Thank you to our generous donors. You helped us serve nearly 700 individuals including over 50 medical and educational professionals in 2024.

Legacy Leaders (Planned Giving)

Gayle McCue (deceased) and Steve McCue

Visionaries Circle (\$100,000+)

Wendy Miller, Esq. and Andrew Miller

Heroes Club (\$20,000—\$99,999)

Diana Ekholm

Susan and David Fowler

Gail Hitchcock

Nancy Kear-Johnson and Eric Johnson

Julie and Frank Mairano

CdLS Leaders (\$10,000—\$19,999)

Mike and Kellie Feehan

Mary Ann and Pat Feehan

Barbara and Doug Gaines

Lesa and Jeff Giberson

Julie and Roy Gonella

Jia Gupta

Anurag K and Purvi Lad Gupta

Dianne and Richard Haaland

Jina and David Homan

Drs. Lynne Kerr and Hunter Jackson

Mary Opitz

Frank and Denise Rhodes Teixeira

Rob and Clara Rodriguez

Victor M. Torres

Debbie and Darl Vandermeulen*

Champions (\$5,000—\$9,999)

Ava Frank and David Molzan

Erin Gifford

Caitlin Gifford

Joan and David Hanisko

Dianne Lessa*

Ruth and Michael Pryor

Susan and Donald Radkoski

Deneta Sells

Amelia and Brandon Simmons

Margaret Walters

Kathy Whisenant

Tricia and Doug Wise

Advocates (\$2,000—\$4,999)

Lisa and Tom Alicata

Marios Assiotis

Kendall Bergman

Melany and David Brundage

Emily Burchardt

Luis Chiappy

Megan and Russell Dahl

Ching-Shu Jing and Shih-Che Fang

Anthony Fernandez

John Fisher

Don and Amy Franco

Alyson Hardin

David and Livia Harvey

Kathleen Hickey

Jim and Joyce Kesting

Randi Kieffer

Eileen Ahearn and Mark Kliever

Sara Lair

Ruth Lee

Advocates continued

Bill Lewis
Stacey Massa
Mark McFadden*
Chris Naab
Thomas O'Brien, C.P.A.
Karen and Larry Prada
Diane and Paul Radkoski
Robert Ring
Charlene Ruiz
Beth and Mark Smisloff
Crystal and Jerry Smith
Kathleen Suchdeo
Jenni Timmons
Kathryn and Peter Wagner
Catherine and Hal Wilson

Supporters (\$1,000—\$1,999)

Jan Abbott
Elise Ahearn
Karen Aschenbrenner and Robert Boneberg
David Barnes
Mark Bryson

Stacey and Ted Cassimatis
Hugo Castro
Michele and John Champion
Olga Cherkasova
Mike and Karey Christie
Karen Clautice
Cody Currie
Denise Doan
Lauren Dreifus
Dennis and Sarah Drislane
Mary Anne Ehlert
Ashley Evans
James Galyean
Joanne and Stephen Gersuk
William Goldfarb
Ellen and Thomas Heile
Alora Honiball
Don and GERALYNN Huffman
Nancy Johnson
Matthew Junkin
Aimee Kirsch
Antonie Kline, M.D. and Doug Clemens, DDS
Barbara and David Kliwer

Connie and Robert Knapp
Ian Krantz, M.D., and Nancy Spinner, Ph.D.
Ryan Linton
Patrick and Karen Lyons
John Mairano
Janis and Joe Mamayek
Michael Mantia
Debi and Bob Marks
Maureen and Bill Goldfarb
Renee and John McCune
Steve and Kate McCurdy
Mary McLaughlin and Michael Walsh
Wendy and Andrew Miller
Sandra D. Moore
Conni Morgan
Robert Myrthel
Keiko and Daniel Nishiyama
Philip O'Keefe
Christopher Ortega
Mary Paloyan
Sue Peterson
Matthew Rafuse
Alexis Resnick

Valerie Rhodes and John Schlapp
Anthony Roth
Morrisette Royster*
Rebecca Runge and Tyler Bajema
James Schumacher
Anita Suchdeo and Christopher Zuehlsdorff
Andrew Sutherland
Julia and Peter Swanson*
Richard Thomas
P.R. Torres
Kevin Trevisan
Robyn Truslow
Samuel C. Sichko Trustee
Paul and Nora Villani
Adam Weirich
Lynn and David Wells
John Whittle
William Willhite
Nicole Winchester
Ken & Jan Wolfram
Stephanie * Indicates recurring donor
Wolkin

Our Major Sponsors

Whether they are supporting one of our special events, providing grant funding or matching employee donations, we are very grateful for our incredible business and organization sponsors who partner along with us in our important mission to serve our families by their generous giving.

SILVER (\$5,000—\$9,999)

Crane Fund for Widows and Children
Equitable Foundation
Gerome Holdings, Inc.
Gifford Homes, Inc
Madison County Wood Products Inc.
Pallet Logistics Management, Inc.
Physicians' Alliance of America, Inc.

BRONZE (\$2,000—\$4,999)

Enterprise Holdings Foundation
Lakenan
Mid Continent Steel and Wire
Swinford Realty, LLC
Tag Truck Center

UHY

William and Alice Mortensen Foundation

PURPLE (\$1,000 - \$1,999)

Bethel Southern Methodist Church
Botkin Lumber Company, Inc.
Drips LLC
Jewish Community Federation
John T Whittle LLC
KMJ Pallet & Lumber
Lumber Premium Group Inc
Marsh McLennan Agency
McCoy Construction & Forestry
Microsoft Matching Gifts Program
Missouri Forest Products Association

Montgomery Bank

National Christian Foundation Twin Cities
Odyssey Group Foundation
Pennine Industrial Equipment Limited
Union Machinery

**Thank you for helping
individuals and families
affected by CdLS.**

Our Dedicated Team

FOUNDATION STAFF

Executive Director

Bonnie Royster

Medical Director

Antonie Kline, M.D.

Research Coordinator

Victoria Duke, MS, CGC

Program Director, Family Services

Whitney Rinaldi, B.S.W.

Family Service Coordinator

Mindy Graham, B.S.W.

Family Service Coordinator

Ashley Fernandez

Events Manager

Lisa Schroeder

Development Data Manager

Vanessa Hatten

Communications Director

Gabrielle Nadeau, MA

Communications Coordinator

Ashley Kus, MS

Graphic Designer/Web Master

Francesca Scognamiglio

Bookkeeper/Office Manager

Bonnie Kraft

Finance Director

Maureen Lord

BOARD OF DIRECTORS

President

Paul Villani, Connecticut

Vice President

Mike Feehan, Pennsylvania

Treasurer

Eric Johnson, Connecticut

Secretary

Nicholas Jackson, Utah

Directors

Yvonne Alston, Connecticut

Mary Anne Ehlert, Illinois

Arthur Lander, M.D., Ph.D., California

Rob Rodriguez, Texas

Steven Snodsmith, Missouri

Tricia Wise, Connecticut

CLINICAL ADVISORY BOARD

Christine Ackermann, M.S., O.T., Occupational Therapy

Michael Asike, M.D., Gastroenterology

Kristin Baranano, M.D., Ph.D., Pediatric Neurology

Ingrid Barone, R.N., Nursing

Natalie Blagowidow, M.D., Gynecology

Philip Boone, M.D., Ph.D., Clinical Genetics

Anne Calof, Ph.D., Neurodevelopmental Biology

Cheri Carrico, Ph.D., CCC-SLP, Speech-Language-Feeding

Patti Caudill, M.S., CCC-SLP, Speech-Language

Kari Cunningham-Rosvik, DNP, PMHNP, "Doctor of Nursing Practice Psych/Mental Health Nurse Practitioner"

Soma Das Ph.D., FACMG, Molecular Genetics

Matthew Dearnorff, M.D, Ph.D., Clinical Genetics

Alena Egense, MGC, CGC, Genetic Counselor
Katherine Farr, D.P.T., Physical Therapy
Joann Fleckenstein, M.S., O.T., Occupational
Therapy
Clair Francomano, M.D., Internal Medicine
Jennifer Gerton, Ph.D., Biochemistry &
Molecular Biology
Urbi Ghosh, Ph.D., Education
Lynette Gillis, M.D., Pediatric Gastroenterology
Loretta Gore-Harvey, R.D., L.D.N., Pediatric
Dietetics
Marco Grados, M.D., M.P.H., Child Psychiatry
Dorothy Grange, MD, Professor of Pediatrics
Richard Haaland, Ph.D., Research
Trevor Hoffman, M.D, Ph.D., Clinical Genetics
Rachel Hueston, Education
Stacey Ishman, M.D., Pediatric Otolaryngology
Soma Jyonouchi, M.D., Immunology
Lynne Kerr, M.D., Pediatric Neurology
Su Jin Kim, M.D. , Pediatric Dentistry
Amy Kimball, M.S., Genetic Counselor
Mark Kliewer, M.D., Radiology
Antonie Kline, M.D., Clinical Genetics
Ian Krantz, M.D., Clinical Genetics

Michele Lambert, M.D., Hematologist
Arthur Lander, M.D, Ph.D., Developmental
Biology
Alex Levin, M.D., Pediatric Ophthalmology
Mary Levis, N.C.S.P., School Psychology
Kathleen Loomes, M.D., Pediatric
Gastroenterology
Linda Manwaring, M.S., CGC, Genetic
Counselor
Nancy Mathis, M.S., CCC-SLP, Speech-
Language
Joseph McCleery, Ph.D., Developmental
Neuroscientist
Amy Metrena, M.S.P.T., Physical Therapy
Richard Mungo, D.D.S., Pediatric Dentistry
Rowena Ng, M.D., Pediatric Neuropsychologist
Julia O'Connor, Ph.D., Clinical Psychology
Mary Pipan, M.D., Developmental Pediatrician
Sarah Raible, M.S., Genetic Counselor
Joni Rampolla, L.D., Pediatric Dietician
Geir Rosvik, M.Ed., Adaptive Physical
Education
Raul Sanchez, M.D., Pediatric Gastroenterology
Claire Shannon, M.D., Pediatric Orthopedic
Surgery

Siddharth Srivastava, M.D.,
Neurodevelopmental Pediatrician
Katherina Terhune, Ph.D., LCSW, Mental
Health
Ming-Hsien Wang, M.D., Urology
Denise Williams, MS, Early Childhood
Education
Aaron Zuckerberg, M.D., Pediatric Anesthesia



REACHING OUT. PROVIDING HELP. GIVING HOPE.

www.CdLSusa.org

