



**CdLS FOUNDATION
ANNUAL REPORT**

2023

ADVANCING OUR MISSION



Dear Friends,

As we reflect on 2023, we extend our heartfelt gratitude to our community of donors, supporters, and advocates. Your generosity has been vital in advancing our mission to support and evolve research, patient support, and advocacy for individuals living with Cornelia de Lange Syndrome (CdLS).

Because of you, our advocacy efforts have strengthened, ensuring the voices of individuals with CdLS are heard and understood.

The CdLS Foundation was able to convene over 85 Parent Advocacy Groups, Industry Sponsors, and NIH Leaders in Washington, DC, to explore how we might work together. This gave us the unique opportunity to share your story with industry and government and ask for their support. Our renewed focus on research initiatives holds the promise to enhance our understanding of CdLS and increase the potential for improved interventions. We have also expanded our patient support programs, providing added resources and creating a sense of community for families navigating the complexities of CdLS.

Looking ahead, we remain dedicated to maximizing the impact of every donation.

Together, we will continue to drive meaningful change for the CdLS Community. Thank you for standing with us and empowering individuals and families affected by CdLS. Your support truly changes lives, and we are deeply grateful for your partnership.

Warmly,

Bonnie

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// No matter what kind of difficult situation one may find oneself in, some opening, some opportunity to fight one's way out, can always be found. What's most important is to hold fast to hope, to face the future with courage. Hope is life's greatest treasure. If you have no hope, create some!"

-Daisaku Ikeda



THE CdLS FOUNDATION: OUR MISSION AND VISION

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. Our key goals are creating community and enabling advocacy for people experiencing CdLS and other isolating conditions. The CdLS Community is a diverse and vibrant group united by their shared experiences and desire to support each other through the journey of living with the rare

syndrome. As we walk with families on the path of loving and caring for their child we are evolving too and learning new ways to stand by them in the digital age.

We envision a future where we work with other rare groups to help our healthcare systems and research community progress toward greater understanding and responsiveness to the needs of our special community.



STRONG AND MIGHTY

RESEARCH AND DEVELOPMENT

RESEARCH CONSORTIUM – SYNDROMES OF GENOME IMBALANCE

On October 31, the CdLS Foundation and the American Foundation of Human Genetics (ASHG) held a research consortium in Washington, D.C. Over 85 experts attended in person and virtually.

The event's goal was to take the first step toward building such a consortium, the major goal of which will be to create therapeutics for families living with these frequently debilitating conditions. We invited researchers, clinicians, and other stakeholders to hear presentations on this topic and help us develop plans to launch an effective consortium.

2023 RESEARCH PROJECTS

Over the past year, we proudly engaged the CdLS community in four impactful research projects, focusing on limb differences and behavior, which we enthusiastically shared with our families in January, April, May, and July.



Characterization of Lower Limb Differences in Individuals with Cornelia de Lange Syndrome (CdLS)

This project is a collaborative effort with renowned experts Dr. Ian Krantz and Sarah Raible, MS, LCGC, led by second-year Genetic Counseling student Kaley Arnold from the University of Pennsylvania. The study focuses on identifying and understanding the variations in lower limb characteristics among individuals with CdLS. A survey was distributed to 2,454 families affected by this syndrome to gather comprehensive data.



Study of Children with CdLS Who Do Not Engage in Problem Behavior

Under the guidance of Principal Investigator John Michael Falligant, Ph.D., and co-investigator Patricia F. Kurtz, Ph.D., from Kennedy Krieger Institute, the research explored the behavioral patterns of children with CdLS who do not display challenging behaviors. This research seeks to deepen the understanding of positive behavioral functioning in this population. A targeted survey was sent out to 601 families, inviting them to share their experiences.

Study of Children with CdLS Who Engage in Problem Behavior

Continuing the previous study, this research, led by John Michael Falligant, Ph.D., and Patricia F. Kurtz, Ph.D., from Kennedy Krieger Institute, examined the factors contributing to problem behaviors in children with CdLS. The objective is to identify potential triggers and improve intervention strategies. A survey was conducted, reaching out to 621 families to gather valuable insights into this critical study area.



Study on Changes in Behavior, Emotion, Physical Health, and Mental Health

This extensive study was spearheaded by researchers from the Cerebra Network for Neurodevelopmental Disorders, including Drs. Caroline Richard, Jane Waite, Jo Moss, and Haley Crawford. The project examines the multifaceted impacts of CdLS on behavior, emotional well-being, and overall health. A comprehensive survey was distributed to an impressive 3,362 families, aiming to collect a wide array of information that will contribute to a deeper understanding of the challenges and changes faced by individuals with CdLS.

These research studies are recruiting participants.

If you want to participate in a study or are interested in organizing a research study, please call the Foundation at 800.753.2357 for information.

STRONG AND MIGHTY CONTINUED...

PATIENT SUPPORT AND ADVOCACY

Connections Matter

Rachelle Riedmiller

Joey was born full-term on April 26, 2004. He weighed 7 lbs.—1 oz. We had no indication that anything was going on throughout the pregnancy. We were shocked the next day when the doctors started to tell us they suspected Joey had Cornelia de Lange Syndrome. That day, we started our CdLS journey with Joey.

Joey is currently 19 years old. One thing Joey loves to do is go to school. He thrives on structure and schedule. Joey also loves taking pictures on his iPad.

Joey faces daily challenges due to having CdLS. He is nonverbal, which makes communication difficult. Another challenge we face is Joey is "busy" all the time, never wanting to sit down or take a break from his active ways. He needs constant supervision. Joey also wants food all the time. He doesn't seem to understand being full. He struggles with daily gas/stomach pain. We have medications to help control that, but it is still a problem. He had emergency surgery in June 2020 for a bowel obstruction. It remains a significant concern that he will have another one in the future, so we try to stay vigilant and watch for symptoms. Safety is also an issue. If he gets a chance, he will take off. I'm sure Joey feels frustrated daily when we establish

boundaries for him. Unfortunately, that comes out in the form of self-injurious behavior. It breaks our hearts to see him hurt himself. It's such a powerless feeling.

The CdLS Foundation has been a great help to our family over the years. I hate to admit it, but I spent the better part of Joey's first year of life trying to deny there was anything wrong. Once I finally reached out, they had so much information available. We were connected with a family in our area who also had a child with CdLS. Things got so much better after that. We were empowered with knowledge, and it wasn't as scary anymore. For that, I am forever grateful.



Joey Riedmiller

Supporting Families from the Beginning is Crucial

Mariel Moody

Anthony is a 2-year-old sweetheart who goes by the name Ife. He was born in September of 2021 and weighed only 4.9 lbs. He is tiny but mighty, with a huge personality that he loves sharing with new people. Baby Ife was seven months old when we received his genetic testing diagnosis of CdLS. With his birth so small, we often wondered if something else was happening that we could not visibly see.

CdLS affects Ife in many ways. He is not very mobile besides crawling, struggles to stand independently, learned to sit unassisted at around one, has several medical issues and is slow to grow. He depends on his tube feedings, nurses, and medications daily to have successful days. Feeding, digestion, and excretion are the number one issues Ife has. He currently has a GJ Tube but started with an NG tube at six months and graduated to a G Tube at 12 months old. He has global developmental delays, so life looks a little different through his eyes. Having a child is hard enough, but having a child with a rare genetic condition is very challenging due to the lack of information about his condition.

The CdLS Foundation has helped our family by being there and letting us know we have a solid Foundation to lean on. We can get our questions answered, share and hear experiences, meet other families, and gain access to resources we never knew were available. The Foundation makes us feel less alone because special needs parenting can be very isolating. Ife went to the Irvine Family Gathering in February of 2023 and met some fantastic staff and other kiddos with his exact condition. Without the Foundation, I often wonder where we would be.



Anthony and his mom, Mariel.

STRONG AND MIGHTY CONTINUED...

COMMUNITY ENGAGEMENT

Family Gatherings that Bond the Community

In 2023, the CdLS Foundation Family Service Coordinators joyfully organized in-person family gatherings in California, Texas, and Illinois, providing vital financial assistance and administrative support. These well-attended events brought together over 300 participants, creating a valuable forum for families and professionals to share knowledge and support in a warm, non-clinical environment.

The gatherings had a significant positive impact, promoting socialization, forging new connections, and offering essential support to families.



1. Group photo of the California family gathering.
2. Monasmith family at the California family gathering.
3. Huffman family at the Illinois family gathering.
4. Woods family at the Texas family gathering.

Clinics Shape the Way Health Care Should Be

In 2023, the CdLS Foundation worked alongside Greater Baltimore Medical Center (GBMC) and Shriner's Children's, Salt Lake City, to host three clinics. Over 80 attendees from across the United States attended the clinics.

Dr. Tonie Kline, CdLS Foundation's medical director and director of pediatric genetics at Harvey Institute for Human Genetics, runs the Multidisciplinary Clinic for Adolescents and Adults at GBMC. She has spearheaded these FREE clinics for 23 years. This clinic occurs twice yearly and is the only clinic focusing on Adolescents and Adults, bridging a critical gap between pediatric and adult health care.



Dorian T., and her family.

"Fortunately, the CdLS Clinic at GBMC has been a source of invaluable support and information. [It] has equipped us with educational resources and a deeper understanding of CdLS, along with tailored medical insights for our daughter Dorian's specific needs." Lisa T.

Serving the CdLS Community since 2016, the Shriners clinic is held each March. Medical staff from Shriner's Children's and the Children's Hospital of the University of Utah staff the clinic, which is staffed with highly compassionate, family-centered care. Families with a loved one aged birth to 17 can attend this life-changing clinic.

"With the help of the CdLS Foundation we have now added Shriners Hospital as another layer of expertise to her care. We returned home with new information and questions for Cambria's medical team, soft orthotics unavailable at home, and a new bike." Lyndsee F.



Cambria.

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.

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. .



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 every two years. The scholarship program breaks down the expense barrier, allowing a family to attend without a registration fee.

Contact Details

Bonnie Royster, Executive Director

860.899.1219

director@CdLSusa.org

30 Tower Lane, Suite 400

Avon, CT 06001

Future Plans at the CdLS Foundation

With your invaluable support, we are thrilled to enhance our efforts in uplifting the CdLS community for years to come! One of the exciting initiatives we are rolling out includes specialized workshops and support groups tailored to the unique needs of families and individuals living with CdLS. We plan to introduce gene-specific workshops, a dedicated parent support group, and age-specific gatherings designed to enrich the lives of diverse members of our vibrant community.

Moreover, we are optimistic about advancements in CdLS research. After years of tireless study, we are gaining insights that promise to improve the quality of life for individuals with CdLS. Researchers are uncovering valuable information about behaviors and therapies, as well as the aging process in CdLS. Thanks to your ongoing generosity, we can continue our deep dive into the science of CdLS, paving the way for future generations to thrive.

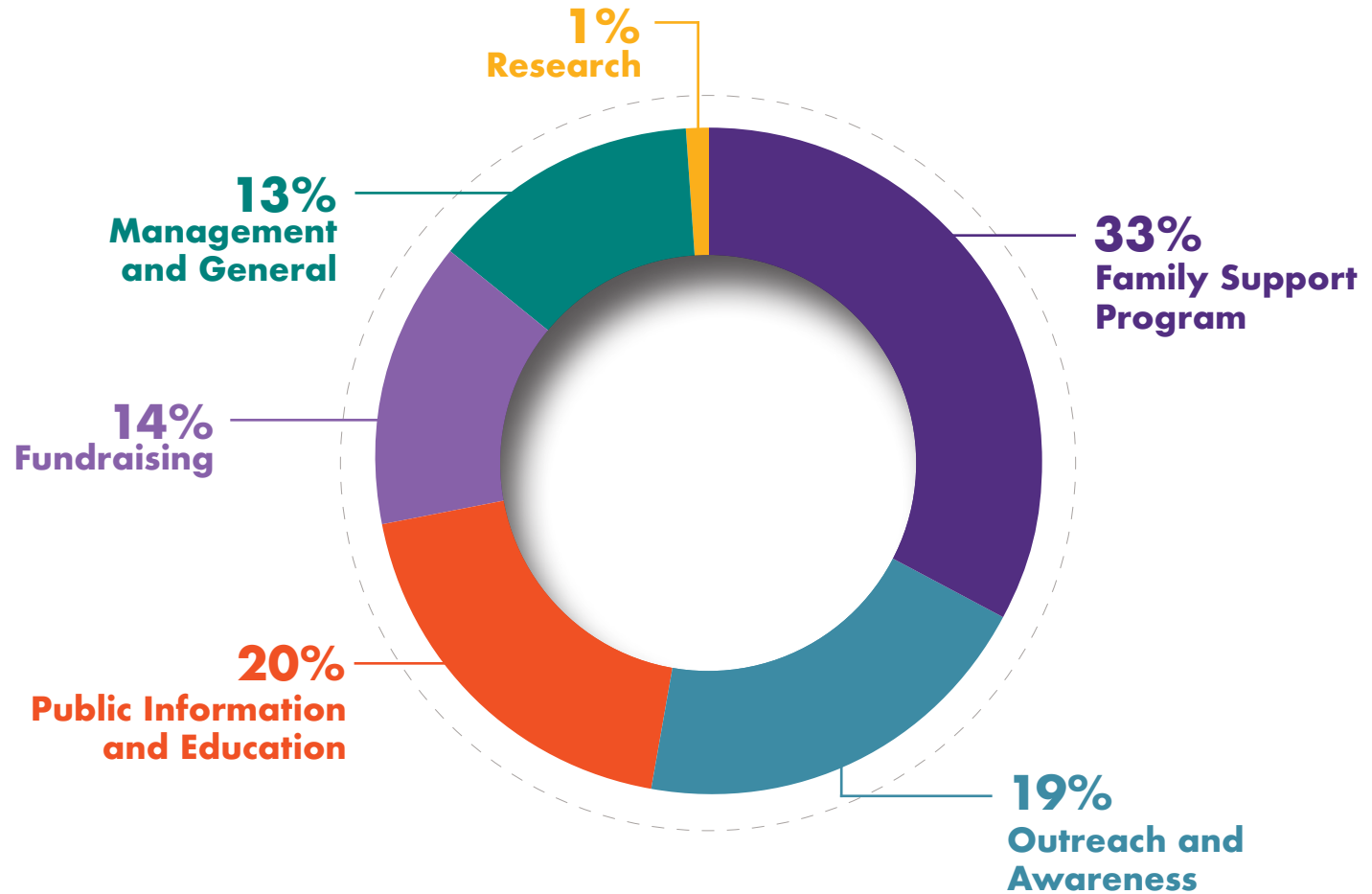
Additionally, we are launching “The Voice of the Community” survey, which will enable us to gather critical data from families, much like a census. This invaluable feedback will empower us to craft more targeted and impactful grant funding requests than ever before. Together, we can achieve remarkable outcomes for our community!

2023 Audited Income & Expenses

INCOME	
Individual Donations	384,665
Corporations/Company Donations/ Clubs & Organizations	21,268
Foundations/Grants	10,782
Direct Mail	42,289
Gifts that Count – Memorial/Celebration	76,455
Special Events/ Third Party Fundraising	336,854
Federated Campaigns	44,609
Restricted Nat'l Conference & Symposium	500
Restricted Research	1,682
Total Operating Revenue	919,104
Investment Net Income	17,772
Total Revenue	936,876

EXPENSES	
Program Services	
Outreach and Awareness	196,173
Research	12,907
Family Support Program	338,936
Public Information and Education	208,804
Total Program Services	756,820
Support Services	
Management and General	131,893
Fundraising	144,665
Total Support Service	276,558
Total Expenses	1,033,378
Net Assets, Beg of Year	3,082,096
Surplus/Deficit from Operations	185,406
Total Net Assets	3,267,499

2023 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.

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Thank you to our generous donors. You helped us serve nearly 700 individuals including over 50 medical and educational professionals in 2023.

Legacy Leaders (Planned Giving)

Gayle McCue (deceased) and Steve McCue

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REACHING OUT. PROVIDING HELP. GIVING HOPE.

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