

A photograph of a woman with long dark hair, smiling warmly while holding two young boys. The boy on the left is looking down, and the boy on the right is looking up at her. They are all wearing dark blue shirts with small, colorful patterns. The background is a soft-focus floral arrangement with pink and white flowers.

# 2021

**CdLS Foundation  
Annual Report**



**CdLS Foundation**  
Cornelia de Lange Syndrome Foundation, Inc.



## A YEAR OF LOVE AND ACCEPTANCE

What an incredible year 2021 turned out to be. Great highs and lows, but throughout the whole time, you had our backs. Never in a million years did the CdLS Foundation or the rest of the world envision life with a pandemic, social unrest, and inequality all taking center stage. However, we still have a community of believers and supporters during our darkest hours.

We had families and donors step up and help the Foundation move forward during times when many other nonprofits were asking for the same support. **You chose us – thank you.** With the CdLS community behind us, we implemented new services for families who lost a child with CdLS, started investigating ways to better support families in health care settings, and celebrated 40 years of serving our amazing families.

**These fantastic opportunities could not have been achieved without you.**

Our donors, Board Members, friends, and volunteers continue to support us. Your generosity shows how vital our programs and services are. Your support provides acceptance and love to children and adults living with CdLS.

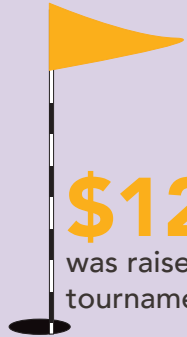
Thank you for making our life-changing work possible.

Sincerely,

A handwritten signature in black ink that reads "Bonnie".

Bonnie Royster  
Executive Director

# 2021 Highlights



**\$121,340**

was raised at our two golf tournaments

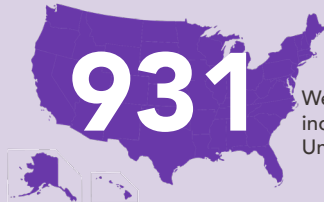


So many fantastic fundraisers happened this year. We could not have done it without the following:

**Mike Feehan's  
Back Yard Mud Run  
\$45,000**

**\$99,163**

was raised by Team CdLS for individuals with CdLS and their families



We connected with 931 individuals across the United States



Ask the Experts questions were answered

**ONE LOVE  
ONE HEART  
\$10,000**

**12<sup>TH</sup> ANNUAL  
BREW & BBQ  
\$6,000**



“**Be messy and complicated  
and afraid and show up  
anyway.”**

— Glennon Doyle



## TO ALL OF OUR AMAZING SUPPORTERS,

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One of my favorite undertakings as a board member is to reflect on and synthesize the accomplishments made in the past year. Witnessing the Cornelia de Lange Syndrome (CdLS) Foundation bring goals and objectives to fruition brings much fulfillment. The integral role you, our supporters, have had in these accomplishments is not lost on us. While we slowly gained some semblance of normalcy in 2021, it certainly was not without its challenges.

We continue to be impacted by unpredictable world events and the residual effects of the pandemic, leading us to continually adapt and re-envision our service delivery, fundraising, and outreach.

Throughout 2021, you were a catalyst in helping the CdLS Foundation navigate these challenges. Some of the many successful ventures you helped support in 2021 included the development of our healthcare committee, expanding regional connections, and forming and delivering impactful support groups. These initiatives are a glimpse of what the CdLS Foundation has done in the past year to reach and support the 3,800 families we serve.

We have much to be thankful for in this past year of work; we are focusing on moving forward with our mission of reaching out, providing support, and giving hope. We are committed to understanding the evolving needs of our families and ensuring that our services align with their needs. We are providing our families with new opportunities to have

their voices heard and have an active role in creating new inclusive programs and practices next year. Our healthcare committee continues to lead initiatives that provide education and support for our families regarding healthcare literacy, medical advocacy, and coordinated care. Our family support services continue to expand, and new CdLS research is underway.

In this time of reflection and celebration, I want to convey deep gratitude to each of you for the incredible impact and difference you make in our CdLS community. On behalf of our Board of Directors and the CdLS Foundation staff, we sincerely thank you for your contributions.

In service together,

*Katherina N. Terhune*

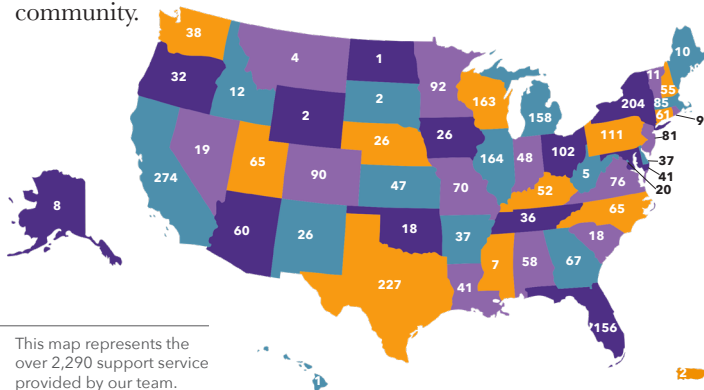
Katherina Nikzad-Terhune, Ph.D., LCSW  
President of the Board of Directors

# ADVOCATE, LOVE

## SUPPORT SERVICES THAT DELIVER EMPOWERMENT, SUPPORT

### SERVICE NUMBERS GREW IN 2021

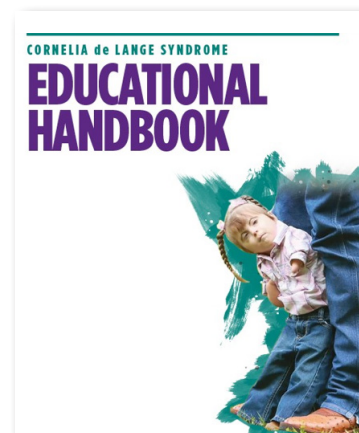
Family Service Coordinators provided over 2,290 supportive services to families across the United States. The top five states with the highest number of families connecting with the Foundation were: California, Florida, New York, Texas, and Wisconsin. They connected with 931 individuals and welcomed 97 new families to the CdLS community.



This map represents the over 2,290 support service provided by our team.

### EDUCATION HANDBOOK

The CdLS Foundation's Educational Handbook was revised and reprinted in 2021. The refreshed guide offers updated information on education, therapies, and additional support. The handbook is an excellent resource for families navigating the world of special education. Families learn about educational services and therapies that are often essential to a child's Individualized Education Plan (IEP).



The cover of the CdLS Foundation Education Handbook.



# VE, AND ACCEPT

## ORT, AND COMPASSION

### POWERFUL SUPPORT GROUPS HELPING FAMILIES NEAR AND FAR

In 2021, The CdLS Foundation added two new virtual support group offerings. The Grief Advisory Task Force and Peer-to-Peer Support Group serve members of the CdLS community.



Example of the Grief Support Care package.

*The Grief Advisory Task Force (GATF)* is a group of passionate parents who have lost a child with CdLS. This group serves two purposes: 1. they act in an advisory capacity to help the Foundation create programs and services that resonate with those who have lost a child, and 2. they serve as a volunteer corps that reaches out to parents that have lost a child by sending a card and offering ongoing support.

Earlier in the year, the Foundation began distributing Grief Support Care packages. The packages go to parents who lost their loved ones with CdLS in 2021. With the guidance of the GAFT, Family Service and Communications carefully selected and created curated personalized items for each child who passed. Packages include a customized candle, bereavement resources, branded comfort items such as a tea cup and tea, a plush teddy bear, and a guide for healing and loss.

*The Peer-to-Peer Support Group* is a pilot program the Foundation created. Mother and professional Eileen Ahearn heads up. The parent-facilitated support group that tackles challenging behaviors parents experience with their children, offers strategies that help address and cope with those behaviors, and creates a safe environment where parents support each other. Foundation staff is working with Eileen to create a best-practices model that can be replicated in other communities.

# ADVOCATE, LOVE, AND ACCEPT CONTINUED...

## VOLUNTEERS SPREAD THE CdLS FOUNDATION'S MISSION

The CdLS Foundation worked on a new initiative with Regional Coordinators in California. Regional Coordinators (RCs) are volunteers who are parents/caregivers of individuals who have CdLS. We turn to them to help local parents facing problems or looking for support in caring for their loved one with CdLS.

The staff wanted a better partnership with these passionate and highly experienced parent experts. Long-time Regional Coordinator, Karen Prada, shared the importance of feeling connected and especially having a mentor to help navigate the many services available. Family Service Coordinators met with families virtually and engaged more RCs in other states in 2022.

Another group of volunteers that Family Service Coordinators engaged with are the Spanish-speaking volunteers. This small group of Spanish-speaking Coordinators has been identified to talk to, translate questions, and support other Spanish-speaking families.



Post cards sent to families in CA introducing them to their RCs.



## HEALTH CARE SUB COMMITTEE

The CdLS Foundation formed a board sub-committee to explore how to improve the health care experience for patients with CdLS and their families. Board member Paul Villani leads the committee. Under his guidance and leadership, the committee convened an excellent team of experts to help guide our thinking. They continue to outreach to parent groups to understand the key challenges most often faced.

The most common themes are:

**Medical Advocacy:** How can I get my child's medical provider to hear me? How can I get appropriate referrals, tests, and procedures for my child?

**Care Coordination:** My child's specialists don't always talk to each other or my child's PCP. I worry that this lack of communication may result in missing something or the interaction of medicines not being considered.

**Lack of Confidence:** Should my child's diagnosis or symptoms be treated as part of CdLS or something else? Should these symptoms or diagnoses be treated differently because my child has CdLS? I need a second opinion.

**Transition to Adult Care:** I have difficulty finding an adult provider. I must re-educate my new provider on the nuances of CdLS.

In the future, the CdLS Foundation hopes to share some enhancements that could make navigating healthcare easier.



Key challenges families face when working with health care providers.



Gene and Kathy Van Buren surrounded by their family.

# The Van Burens

Gene and Kathy have been married for 53 years. They have four daughters, Jodi, Kobi, Kortni, and Jindi, who had CdLS.

Jindi, was born at home with a doctor, midwife, and pediatrician in attendance. It was a cold, dreary rainy day in February 1979. The pediatrician detailed all of his concerns about Jindi - she was 5lbs, but uniformly very tiny - her open hand fit on a quarter, her head about the size of an orange, she had a full head of hair and the most beautiful long eyelashes. He felt there was a potential that Jindi could have physical or developmental delays.

Kathy felt total desperation, wondering what would happen. She remembers Gene saying, “we will deal with each issue as we face it - one day at a time.” They met with the pediatrician three days later. He opened a medical genetics journal, explaining his findings and opinion that Jindi had CdLS. The pictures were horrid, the prognosis worse. A week later, Kathy and Gene met with the head of Genetics in NY, and he felt Jindi had potential. She had already been lifting and turning her head and wiggling about in her cradle. They had hope.



Jindi Van Buren

When Jindi was born, there was no Foundation. In 1980 a friend in California saw a three-line “ad” for a picnic for families of children with CdLS. It turned out it was the day of Gene’s brother’s wedding. Following the reception, they drove to the picnic. It was over when the family arrived. Still, they met a handful of families: Sue Anthony, the Matthesons, the Tharpes, Sheila Penedos, and now dear friends Frank and Julie Mairano. Sue explained she needed help to continue the newsletter she had been sending out. Sheila opened up ideas for awareness,

Kathy offered to be a contributing editor, Frank and Julie to be a hub, and so on. With the support of these wonderful families that Kathy and Gene met – they found a group where they belonged. Now more than 40 years later it has grown into a community which has cared for over 3,800 individuals with CdLS and their families. The CdLS Foundation commitment continues to stand strong from that first meeting.

**“Jindi’s Place had become part**

**of Conference and part of us.**

**We’ve traveled the world to**

**provide childcare ... It’s a circle**

**of love that we will always thank**

**Jindi for giving us.”**

Jindi was a very easy child and was well known and accepted. In the late 80s, the family attended a clinic day run by Dr. Laird Jackson in Philadelphia and brought along eight Girl Scouts, who helped out - and so began Bogota Girl Scout Childcare, now Jindi’s Place at

Conference. When Jindi was ten and a half, her behavior plummeted. She became extremely withdrawn and self-injurious. There were never clear answers to her outbursts. When she was 17, her behavior escalated, and Kathy and Gene could not keep her safe. The horrendous challenge of finding a place for her began. It took a long time, but perseverance finally in a place they were pleased with, as was she, it seemed, just 30 minutes away. Sadly, Jindi passed away in 2003 from complications of a bowel obstruction. She was just shy of her 24th birthday.

Kathy and Gene have traveled the world to provide childcare and have seen the impact it has had on the multitude of Girl Scout who volunteered conference. They have seen parents who have discovered it can be ok to let someone help with their child, and know the benefits of parent support and networking. And in the end, that is what it is really about.



# Kamisha Coleman

I have been a part of the CdLS community since 2004, when my son, Kamren, was diagnosed with CdLS. Retired Family Service Coordinator Lynn contacted me and provided support and information. Unfortunately, Kamren passed away at the age of 12 in 2016. But I continued to stay involved with the CdLS Foundation. I felt staff and volunteers highlighted issues parents encounter while caring for their children. I wanted to be a part of that and make a difference.

After Kamren's passing, I continued to give because I knew that CdLS is for life, and there is always someone who needs help. Once Deirdre contacted me to be a part of a new task force for parents who lost a child, I reconnected. I was glad about it too!

The Grief Advisory Taskforce is a group of mostly parents who have experienced the loss of their child. We want to provide a safe space for other parents to talk about the death of their child. The Taskforce provides resources, so families know they have support and are not alone if that time comes. A grieving family member can call and talk to someone who has had a similar experience. Children with CdLS are unique and have different life experiences. It eases my mind to know this is an option; even if the family chooses not to utilize it, they see the Taskforce is here.



It allows me to give back, give my time, and better help families. One of the first projects in the Taskforce with staff members was creating a personalized box with a teddy bear, book, and many other things to give the families a keepsake. I have all the box's contents on a stand, and I love it. It brings comfort and great memories.

The most important work the CdLS Foundation does, in my opinion, is that it provides resources and keeps people/families connected. It is like a lifeline that families caring for a loved one with CdLS need.

I hope the Foundation finds ways to be more involved with each child. It may be difficult, but there is something special about knowing families, their child, and their specific needs. Most items are general, but the Foundation could help 3 to 5 families with a particular need each year. For example, if a child wants to take up art and the Foundation pays for a class. Kamren loved music, and I thought about letting him go to a studio to make music regardless of how it sounded. It would have been cool to have the CdLS Foundation sponsor a session. Something meaningful to show the families how deeply the CdLS community cares.



Kamren at shcool.

“I appreciate everything Mrs. Bonnie, Mrs. Deirdre, and all the employees at the Foundation do. Continue the great work.”

*“Working at the CdLS  
Foundation has taught me the true  
meaning of unconditional love that  
our families exhibit daily.”*

- Bonnie K



# Bonnie Kraft

## A WELCOMING VOICE TO ALL WHO REACH OUT

Bonnie (Bon) has been a part of the CdLS Foundation since 2017. She was initially hired as the Bookkeeper/Office Manager and then took on the administrative assistant role for the Executive Director. Her duties change daily, and she is an integral part of each department's success. Bon is often the reassuring voice a new family hears when calling for the first time. Whether they call because their child recently was diagnosed or have a question regarding a donation, Bon directs their call with a caring demeanor that calms the most nervous parent.

When asked what drew her to the Foundation, her answer was simple; “Our mission on how we support the families. It spoke to me.” After retiring from Higher Education, Bon found her part-time job right down the street from her home was just convenient. Now, it is her “where have you been all my life” job.

One of Bon's proudest moments while working at the CdLS Foundation happened when she suggested the “Forty for Forty” initiative. This event, held in 2021, celebrated the 40 years the organization has been operational and helping families across the country. This boost of confidence not only helped all staff realize how important the Foundation has been to families for so long but also Bon, as she knew her ideas could move mountains – just like the rest of the staff she works with daily.



Bon is motivated by her fellow staff members. Each day she sees how much time and effort they put into making the world a better place for individuals with CdLS and their families. Bon knows that the families can count on the staff and volunteers. She is grateful to work alongside her colleagues to make a difference for those who have a need.



Image on left: Bon doing one of her favorite activities... fishing!

Image above: Bon with staff at office celebration.



The first family gathering,  
Maryland, in the 1980s.

# The CdLS Foundation Turns 40

This year, 2021, marked a special milestone for the CdLS Foundation. The organization celebrated four decades of serving families and individuals affected with Cornelia de Lange Syndrome (CdLS).

It was in 1981 that co-founders Frank and Julie Mairano worked with a handful of other parents to obtain 501©3 nonprofit status for the Foundation. Within those forty years, the organization has grown exponentially, serving close to 4,000 families across the United States, and is considered the world leader in support, discovery, and research. To this day, the CdLS Foundation remains the only nonprofit organization in the nation dedicated to CdLS.

In June of 2021, members of the Foundation's Board of Directors, past and present, as well as long-time supporters and volunteers, were invited to a special 40th Celebration held at the CdLS Foundation headquarters in Avon, CT.

Attendees were treated to lunch and then joined the staff on a special walk on one of Connecticut's beautiful rail trails. They followed timeline signs featuring information and photos of some of the Foundation's achievements over the past forty years.

An inspired donor gave \$40,000 anonymously towards the Chicago Marathon and the Baltimore Running Festival because of the significance of the 40th milestone. Other donors also wanted to show their support and sent donations as part of our \$40 for Forty campaign.



Board Members Celebrating the Foundation's 40th anniversary.

**With the support of such a loving community and donors like you, there is no telling what achievements we will reach in the next forty years!**

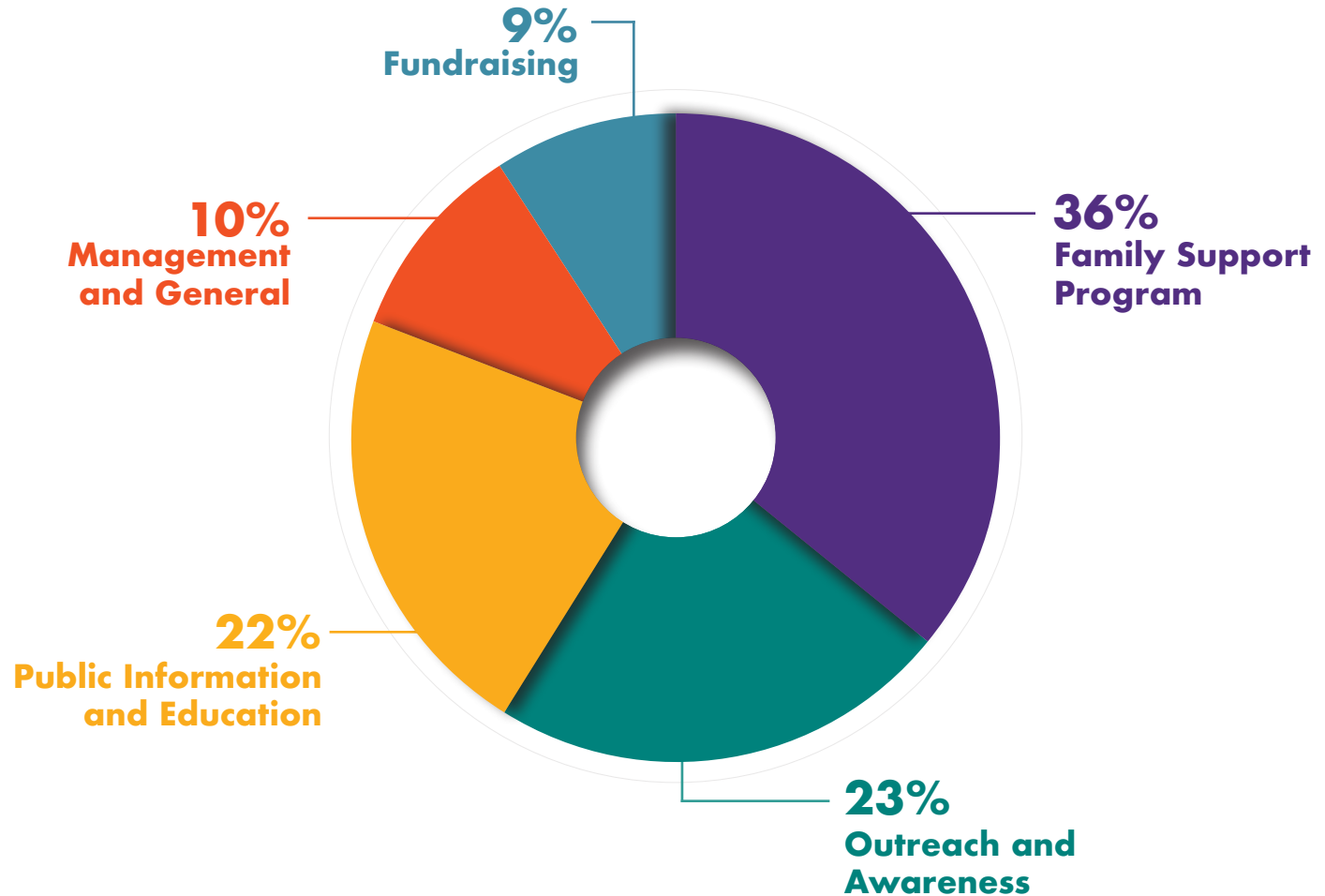
# 2021 Audited Income & Expenses

| INCOME  |                  |
|---|------------------|
| Individual Donations                                  | 48,364           |
| Corporations/Company Donations/ Clubs & Organizations | 26,150           |
| Foundations/Grants                                    | 12,686           |
| Major Donors  | 291,990          |
| Direct Mail   | 44,691           |
| Gifts that Count – Memorial/Celebration               | 70,677           |
| Special Events/ Third Party Fundraising               | 354,641          |
| Federated Campaigns                                   | 63,133           |
| Bequest   | 53,978           |
| Restricted Nat'l Conference & Symposium               | 13,184           |
| Restricted Research                                   | 23,187           |
| ERC Credit  | 64,721           |
| PPP Loan Grant  | 123,428          |
| <b>Total Operating Revenue</b>                        | <b>1,190,830</b> |
| Investment Net Income                                 | 281,271          |
| <b>Total Revenue</b>                                  | <b>1,472,101</b> |

| EXPENSES                         |                  |
|----------------------------------|------------------|
| Program Services                 |                  |
| Outreach and Awareness           | 207,719          |
| Research                         | -                |
| Family Support Program           | 333,243          |
| Public Information and Education | 202,273          |
| <b>Total Program Services</b>    | <b>743,235</b>   |
| Support Services                 |                  |
| Management and General           | 91,197           |
| Fundraising                      | 86,996           |
| <b>Total Support Service</b>     | <b>178,193</b>   |
|                                  |                  |
| <b>Total Expenses</b>            | <b>921,428</b>   |
| <b>Net Assets, Beg of Year</b>   | <b>2,760,415</b> |
| Surplus/Deficit from Operations  | 550,673          |
| <b>Total Net Assets</b>          | <b>3,311,088</b> |



## 2021 OPERATING EXPENSES



# Your Gifts Made a Difference

We continued to feel some of the pandemic's affects in 2021, but thankfully our donors and sponsors sustained the organization in so many ways. It is due to the generosity and thoughtfulness of these supporters that 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 in 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 of the gifts that we receive are greatly appreciated, and there are multiple ways to give. Some of those ways help us to plan for the future of the organization, while others help us to sustain our day-to-day operations, as we know we can count on those funds on a regular basis. 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 had an impact not only on the day to day operations of the Foundation, but also has given us the opportunity to plan for the future success of the organization 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 thoughtful donors make a big impact by contributing a set amount either weekly or monthly, helping to sustain the CdLS Foundation with gifts that we know we can count on regularly. 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 E. Airey-Wilson  
Joyce Bell  
Brooke and Travis Bender  
Vincent A. Berardini  
Sherri Besch  
Bonita Boxell  
Cheri Carrico  
Patricia Cockerill  
Kamisha and Robert Coleman  
Scott and Tami Cooper  
Megan and Russell Dahl, Ph.D.  
Darlene Davis  
Mary Lou and Glen Dehaven

Beth Dixon, J.D. and Glen Dixon  
Nancy and David Drach  
Janice and Eric Duff  
Jill and Charles Dupuis  
Katherine Frank  
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Megan and Russell Gilbert-Dahl  
Gina and Fernando Gonzalez  
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# Our Major Donors

Thank you to our generous donors. You helped us serve nearly 1000 families and 90 medical and educational professionals in 2021.

## **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)**

Julie and Frank Mairano

## **CdLS Leaders (\$10,000—\$19,999)**

Mary Ann and Pat Feehan

Kellie and Mike Feehan

Susan and David Fowler

Julie and Roy Gonella

Nancy Kear-Johnson and Eric Johnson

Lynne Kerr, M.D. and Hunter Jackson, Ph.D.\*

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Debbie and Darl VanderMeulen\*

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Amy and Don Franco

Barbara and Doug Gaines

Lesa and Jeff Giberson

Joan and David Hanisco

Karen and Larry Prada

Dawn and Rolfe Rauscher

Clara and Rob Rodriguez

Dallas and Bill Schubert

Beth and Mark Smisloff\*

Kathryn and Peter Wagner

## **Advocates (\$2,000—\$4,999)**

Eileen Ahearn, M.D. and Mark Ahearn

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Seth and Samantha Barnes

Kamisha and Robert Coleman\*

Judy Donnell

Sarah and Dennis Drislane

Ching-Shu Jing Fang and Jack Huang

April and Mark Ferron

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Ava Frank and David Molzan

Dianne and Richard Haaland

Livia and Dave Harvey\*

Karen and Andrew Huang\*

Kimberly and Trevor Ingold

DeeDee and Jeff Kearney

Joyce and Jim Kesting

### **Advocates continued**

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Doug K. Clemens, D.M.D.  
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Amy Long  
Daniel Lynch  
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Paul and Karen Villani  
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Thomas Wang  
Sharon and Donald Weins  
Lynn and David Wells  
Claire and John Whalen  
Ruth Wilson  
Christopher Zuehlsdorff

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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.

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Odyssey Group Foundation  
Walgreens Family of Companies

**SILVER (\$5,000—\$9,999)**

AmazonSmile Foundation  
Madison County Wood Products  
Microsoft Matching Gift Program  
PLM Companies

**BRONZE (\$2,000—\$4,999)**

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Crane Fund for Widows and Children  
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State Farms  
Tag Truck Center  
UHY Advisors MO, Inc.

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

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CT Solutions, LTD  
Hogan Truck Leasing  
International Process Solutions  
Kiwanis Club of Hampton Midtown  
Lakenan and Sonus  
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UMB  
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Western NY Oldsmobile/GM Club  
WILsquare Capital LLC

**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.

*Program Director, Family Services*

Linda Pierce, M.S.W.

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