2020

CdLS Foundation Annual Report

CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

SURVIVING THE STORM

The past year was filled with anxiety, new struggles and challenges for many individuals with Cornelia de Lange Syndrome (CdLS) and their families. The global pandemic changed the landscape of how we cared for our community. However, through the storm, we persevered, enabled by our longtime supporters. We were able to channel your support and use compassion, healing and hope when working with families in need. The goal was to continue to provide the best support services to our families near and far, and let them know we were just a phone call away.

Over the course of the pandemic, we adjusted to a new norm and a way to provide the best care for families. Although long standing events and programs were changing, we were able to remain true to our slogan of reaching out, providing help, and giving hope.

We were able to provide a virtual Conference, Symposium, and clinic. With concerns over the effects of COVID-19 on individuals with CdLS, we hosted a live webinar with top medical experts to ease parents' worries. Although we couldn't meet in-person, we created new events and ways to stay connected. The Empowerment Team, a Foundation run group of high functioning adults with CdLS, began having monthly Zoom meetings to talk to one another about different topics. Team CdLS members created virtual fundraisers throughout the country – an indication that the Foundation mattered even in a time of unease.

We survived the storm because of you. Our donors, Board Members, friends and volunteers supported us when we really needed it. Your generosity shows how important and powerful our programs and services are. Your support provides safety, healing and hope at a time when so many of us are struggling.

Thank you for making our life-changing work possible.

Sincerely,

Bonnie

Bonnie Royster
Executive Director

2020 Highlights

$72,402
was raised at the Amber Gaines Memorial Golf Classic

CdLS Foundation
WELCOMED 85
new families

The Foundation had to pivot in 2020 and host its big events virtually. We were very pleased with the turn out!

VIRTUAL ATTENDEES!

248 Conference
56 Symposium
18 Virtual Clinic

$116,505
was raised by Team CdLS for individuals with CdLS and their families

376
Ask the Experts questions were answered ?

> As human beings we each have a responsibility to care for humanity. Expressing concern for others brings inner strength and deep satisfaction. As social animals, human beings need friendship, but friendship doesn’t come from wealth and power, but from showing compassion and concern for others.”

-Dalai Lama

THANK YOU FOR YOUR SUPPORT

To All of Our Amazing Supporters,

This past year was clearly a challenging one to navigate for our CdLSers, their families and caregivers. We have seen executive orders limit socialization, school services slowed by restrictions and families kept apart from loved ones; all while we tried to help slow the spread.

The team at the CdLS Foundation found themselves adapting to all of these changes with revised office schedules and cancelled or reimagined events. The amazing part that came of all of this was the support from valued partners like you. Many stepped up in the face of this pandemic and enabled the staff to provide essential services to the families that needed it most.

We were able to put on a virtual Conference, have a virtual symposium to bring our research team together, create more clinic opportunities and reimagine fundraising. All of this was possible due to your generosity. Without your sponsorship dollars, the CdLS Foundation would not have been able to maintain the level of service to the community that they did in 2020.

The pandemic is still running its course and we are planning every day how to use what we have learned to make an even better support system for those we serve. I hope I can count on you to help continue that mission.

I speak for the entire board when I say your contributions positively affect the lives of those that need it most.

Thank you,

Mike Christie
President of the Board of Directors

HOPE STA

SUPPORT SERVICES THAT PROVIDE SAFETY, HEALING AND

SUPPORTING INDIVIDUALS WITH CdLS AND THEIR FAMILIES THROUGH A PANDEMIC

The global pandemic changed the landscape for almost every family connected to the Foundation. Around the country schools were closing, in-person therapy services were being canceled and many parents were being told they could not visit their child. With the not knowing of what to do next, feelings of fear, anxiety and isolation began to creep into the hearts and minds of the families. We knew how important it would be to remain in contact with them and provide important resources, as well as different activities to care for their well-being.

Throughout the year, the staff provided personal outreach to many families across the country through phone calls, emails and social media messages. Staff spent extra time listening to concerns and finding answers. They worked on creating specialized content to educate families on what to do if in-person therapies weren't available, how to work at home and help kids learn virtually, and how to take a moment and breathe. Staff was more dedicated than ever to make sure individuals with CdLS and families were heard and not left behind. Even though we couldn't physically hold hands or offer a shoulder to lean on, our hearts were open to help heal the community.

RTS HERE

HOPE DURING A YEAR OF UNCERTAINTY

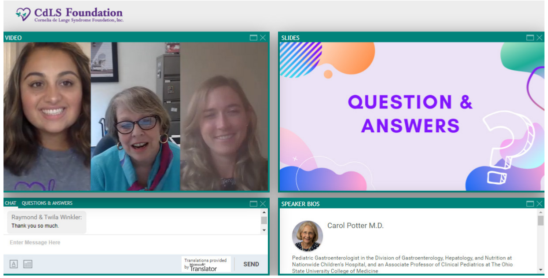
VIRTUAL NATIONAL FAMILY CONFERENCE

The 2020 National Family Conference and Scientific & Educational Symposium were on track to be held in Tulsa, OK. Due to the global pandemic the CdLS Foundation had to quickly pivot.

Still determined to provide some sort of "normalcy" for individuals with CdLS and their families, the staff began to research the best options to host something online. Along with the support of the Board of Directors and generous donors, we were able to host a two-day virtual conference for families from around the world.

Families submitted photos, which were showcased during "Maddy's Ice Cream Social". They were also able to interact with one another through the chat feature and ask the presenters questions.

The event provided an element of relief to many families who were dealing with stress and a new unknown—how to care for a loved one with special needs during a world-wide pandemic. There were over 240 attendees from over 10 different countries. The presenters also hailed from over five different countries and provided wonderful information and resources which allowed families to feel more confident.



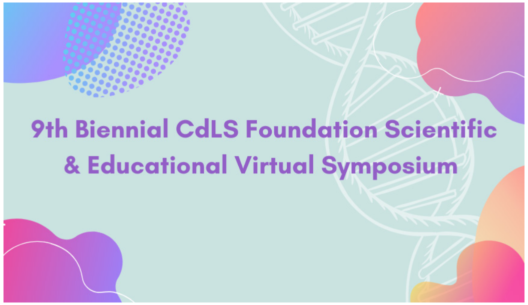
Raymond & Twila Winkler:
Thank you so much.

Carol Potter M.D.

Pediatric Gastroenterologist in the Division of Gastroenterology, Hepatology, and Nutrition at Nationwide Children's Hospital, and an Associate Professor of Clinical Pediatrics at The Ohio State University College of Medicine

HOPE STARTS HERE CONTINUED...

VIRTUAL SCIENTIFIC & EDUCATIONAL SYMPOSIUM



Also, in 2020, virtual Symposium was held in October. Over 50 attendees were present. It was a unique way for researchers and clinicians to share their findings with each other to further knowledge and form collaborations. This event brought together new and seasoned researchers that presented current as well as new information related to CdLS to broaden collective knowledge.

Neither National Conference or Symposium would have been possible without the support of the sponsors and donors who understand their value.

The sponsors and donors who funded these events ensure every child and adult with CdLS, as well as their family members are taken care of and receive the assistance they need.

LIVE WEBINAR DISCUSSING COVID-19 AND UPDATES FROM FOUNDATION'S MEDICAL DIRECTOR

When the pandemic first popped up, many parents were concerned about the impact it would have on their loved one with CdLS. Our Medical Director, Dr. Antonie Kline, stepped into action. She provided resources, as well as two statements to help ease anxiety and worry. She also welcomed open discussion with families who needed more reassurance.

As the CdLS community confronted the COVID-19 pandemic, Drs. Antonie Kline and Soma Jyonouchi held a 30-minute webinar that helped families during the public health crisis. Over 100 individuals attended and many felt the information was extremely helpful and eased their fears. One parent expressed, "Thank you for reaching out. There are so many uncertainties and concerns and it helps to know we are not alone."

THE PATH FORWARD

A new publication entitled *The Path Forward* was created in 2020. Many parents had expressed their need for more information and resources of how to transition their children to adulthood. This special edition of Reaching Out initially went out to over 1,700 families who had a child who was 18 and over. The goal of the publication is to inform parents/caregivers about the many issues they must address to ensure that their loved one will lead a productive and successful life.

Filled with stories from parents who share their experiences, triumphs and insights they've gained from helping their children transition from child to teen and teen to adult. The issue gave families an overview of the challenges and opportunities to consider. It included useful tools and resources that will help families plan for tomorrow. The publication helped ease the burden of many families who were not only helping their child transition, but dealing with the pandemic and how to restructure their lives. One parent remarked "I was thankful and felt connected to a community with similar challenges."

WE LISTEN TO YOU

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THE KEY TO INDEPENDENCE

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WORDS OF WISDOM

PAGE 10

A SPECIAL EDITION OF *REACHING OUT* FOR OLDER INDIVIDUALS WITH CdLS AND THEIR FAMILIES

The Path Forward

CdLS Foundation

EDITION #1

The first edition of *The Path Forward*

A *hopeful* Future with a Supportive Community

Andrea and her family enjoying a day at the beach in Jamaica.

andrea garcia

Andrea was diagnosed with Cornelia de Lange Syndrome (CdLS) at 8-months-old. When her mother, Marie, searched online for answers, she found little information. She reached out to the CdLS Foundation which turned out to be a life-changing experience. The caring social worker on the other end of the line provided support and resources to help Marie understand the syndrome and how to best care for Andrea.

Marie was also connected with a local family in California. This service called Connect with a Family provides relief and a local support system to families who have recently received a diagnosis. When Marie met with the family, she was able to talk about similar experiences and situations which helped her feel less isolated. She also attended her first Family Gathering where she met other families in her region with children on the entire spectrum. At first, she did not know how she would react or feel, however, learning from other families, seeing adults with CdLS in attendance and the range of abilities made the journey ahead easier.

When Andrea experienced malrotation, which required multiple surgeries, Marie relied again on the support from the CdLS Foundation. She was given the tools to advocate for Andrea and herself. Even today, when there is a disagreement with a doctor, Marie has skills that she received from her many conversations with staff to self-advocate and ensure her daughter gets the best care she deserves.

“The CdLS Foundation is a God given blessing for anyone who has a child with CdLS. To have medical information on a rare syndrome before or during an emergency is essential. Knowing resources are available online or through a phone call is amazing,” stated Marie. “I tell parents who I interact with to look up and read the resources on the website, you never know if it might help you in the future.”

Andrea is now 29-years-old; her parents were told she would not live past the age of five—support and medical services provided by the CdLS Foundation offer a continuum of care for the entire family affected by CdLS.

Your generosity allows these life-saving programs to help families across the country each day and brings awareness to many individuals who are undiagnosed and looking for answers.

NORMAN WINNERMAN

A GUIDING LIGHT AND TRUSTED FRIEND

Norm and granddaughter Alison.

Norman (Norm) has been a fixture at the CdLS Foundation for over 30 years. He has volunteered his time, talent and treasure to strengthen the Foundation in many ways. "Norm is unabashedly himself! He brims with wit, charm and incredible tenacity," Bonnie Royster, Executive Director, stated about Norm being an inspiration. "I'm continually inspired by his willingness to learn and his unparalleled support of those living with CdLS."

Norm first became involved with the CdLS Foundation in 1989, when his granddaughter, Alison, was diagnosed with CdLS; she later passed away in 1994 but Norm remained connected. He became heavily involved in one of the Foundation's premiere fundraising events, the New England Golf Tournament in 1992. Since then, Norm has been a driving force of raising funds and awareness for the CdLS Foundation.

Norm attended his first family gathering in 1990. He served as the Conference Planning Committee chair from 1993 to 2006, he then handed the reigns to fellow committee member, Angie Young. However, he continued to be the co-chair until 2020. During the 2020 virtual Conference, Norm announced his volunteer retirement which led to many tears from families and staff alike.

In 2008, Norm was awarded the Sue Anthony Award, the Foundation's highest award, named after our founder and originator of *Reaching Out* (the Foundation's family publication), which represents innovation, commitment, integrity and enduring contribution to families of individuals living with CdLS. He was also inducted into the de Lange Society for the many decades the he has contributed creative vision, innovative ideas and vital assistance to improve the quality of services and programs available to people with CdLS and their families. In February of 2020, Norm was awarded the Rare Impact Award from NORD, which honors his years of service as a pioneer, mentor and advocate.

Deirdre Summa, Family Service Manager, believes, "His dedication, compassion, loyalty and generosity are just a few ways to describe Norm's presence within the Foundation. I so admire his passion to educate others about CdLS and his unwavering support to individuals with CdLS and their families."

Norm's passion to be connected to the Foundation is truly inspiring. His willingness to volunteer countless hours for New England Golf and Conference over the years will never be forgotten. He is the heart of our mission and an important part of the Foundation's history.

Above left to right: Norm and Brian O'Keefe at the New England Golf Tournament.

From left to right: Angie Young, Bonnie Royster, and Norm Winnerman at the 2018 CdLS Foundation National Family Conference.

> "Every day I know what I am doing is important, because my work can potentially be helpful for a new family."
>
> - Francesca

Francesca Scognamiglio
SUPPORTING THE COMMUNITY THROUGH ART

Francesca Scognamiglio has been a presence at the CdLS Foundation for ten years. She is the Graphic Designer and Web Master who creates the publications, awareness materials, direct mail, as well as the branded imagery that can be found throughout the CdLS community.

As a graduate from Ringling College of Art and Design, Francesca can find the beauty in everything around her. When working on a piece, the chance to tell a story with more than words is something that Francesca enjoys. When a parent finds out their child has a diagnosis of a rare genetic disorder and they receive materials with comforting colors and images, that is something that makes Francesca excited to do her job.

Francesca enjoys working with her co-workers because they are making a difference in the lives of people living with CdLS. Although, much of her work is done behind the scenes, she looks forward to seeing it come to life at events. “I really enjoy seeing my work come to life at the events we hold for families. Seeing families smile or tearing up because of something I put together based on their stories is very fulfilling.”

Her skill-set and knowledge of many of the families allows her to create material that speaks to the CdLS community. “I am a part of a bigger picture. I contribute to the success of the families and individuals with CdLS, even if it is in a small way.”

Image on left: Francesca, Maddi and her brother Miles, and Justyna celebrating CdLS Awareness Day.

Image above: Francesca and Team CdLS at the TD Five Boro Bike Tour.

JIM KESTING

Impacting the Lives of Individuals with CdLS throughout the Nation

Jim Kesting and his wife, Joyce at the Amber Gaines Memorial Golf Classic.

Over 30 years ago, Jim Kesting, learned about CdLS from his business partner Doug Gaines. Doug and his wife, Barbara's, daughter, Amber, was born with CdLS. It was then that Jim knew he needed to do something. With his passion for change, Jim began hosting annual golf tournaments.

"Learning about the degrees of severity these children are born with along with the joy that they bring to their families, my goal has been to help families cope with all of the unknowns that they will face," Jim explained. "The CdLS Foundation is the best resource for those needs, and they need the monetary support for that to happen."

For three-decades, Jim has put together tournaments that touch the hearts of every attendee. Sadly, in 2020 Amber passed away and the golf tournament was renamed the Amber Gaines Memorial Golf Classic. The year also brought along a global pandemic, which caused many in-person events to be cancelled, however, the Amber Gaines Memorial Golf Classic, continued on.

The golf event that Jim started so many years ago is now one of the Foundation's largest annual fundraisers, raising approximately $775,000 since its inception. Now it is time for Jim to pass the torch to his son, Bryan, who is equally passionate about the CdLS Foundation and the families.

In 2020, the Amber Gaines Memorial Golf Classic raised over $72,000 to sustain and enhance our programs.

Thank you for your years of support and dedication, Jim. The CdLS Foundation is stronger for the time, talent and treasure you have provided.

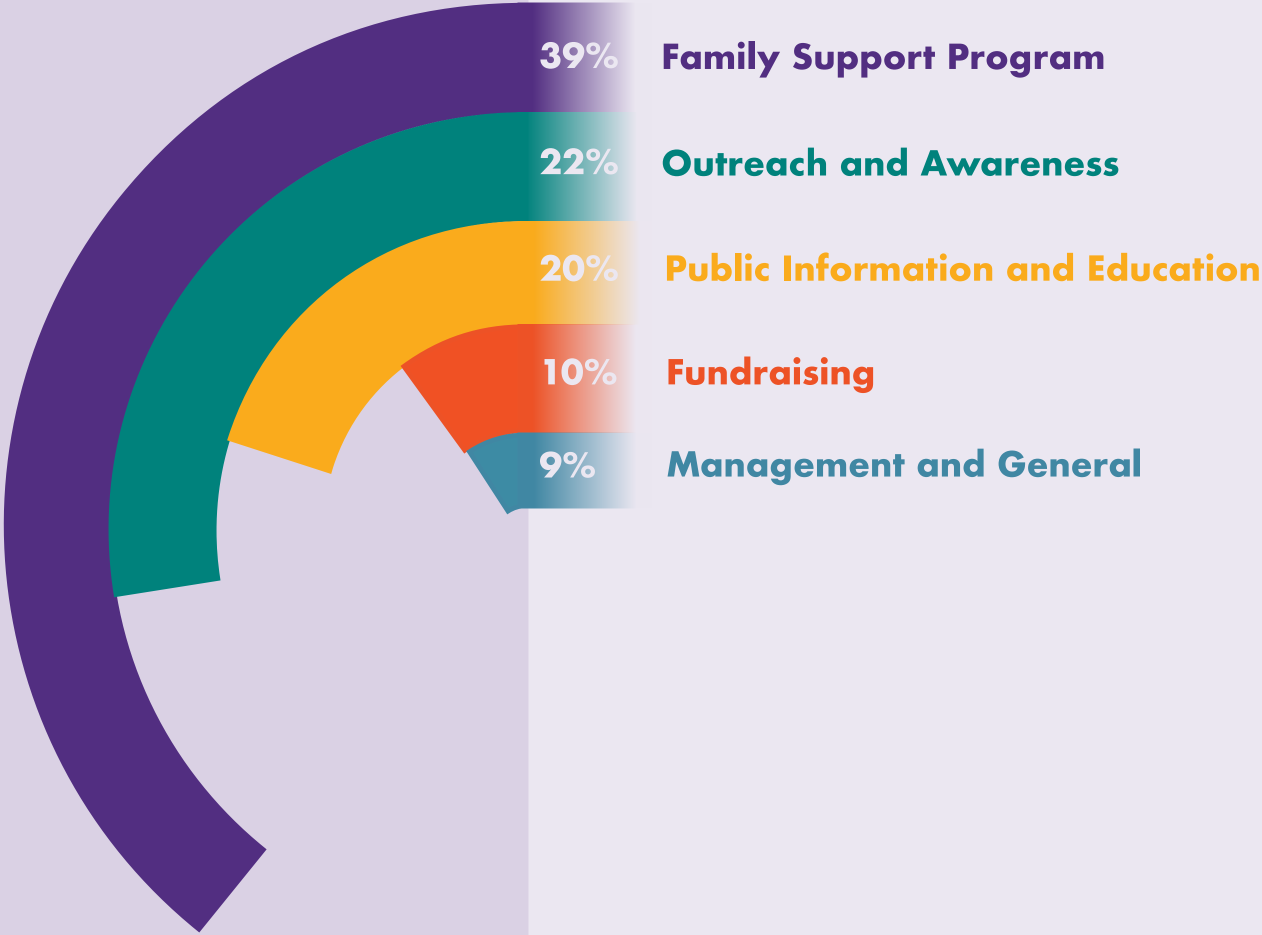
> "…my goal has been to help families cope with all of the unknowns that they will face."
>
> - Jim Kesting

2020 Audited Income & Expenses

INCOME	
Individual Donations	41,305
Corporations/Company Donations	24,450
Foundations/Grants	47,244
Major Donors	280,435
Direct Mail	49,915
Gifts that Count – Memorial/Celebration	62,847
Special Events/ Third Party Fundraising	295,935
Federated Campaigns	56,665
Bequest/ Clubs & Organizations	2,028
Nat'l Conference & Symposium	18,773
SMC1A Research	3,000
PPP Loan Grant	122,197
Total Operating Revenue	**1,004,794**
Investment Net Income	278,513
Total Revenue	**1,283,307**

EXPENSES	
Program Services	
Outreach and Awareness	208,851
Research	153
Family Support Program	368,291
Public Information and Education	195,609
Total Program Services	**772,904**
Support Services	
Management and General	85,215
Fundraising	95,226
Total Support Service	**180,441**
Total Expenses	**953,345**
Net Assets, Beg of Year	**2,430,453**
Surplus/Deficit from Operations	329,962
Total Net Assets	**2,760,415**

2020 OPERATING EXPENSES



Your Gifts Made a Difference

As difficult as 2020 was due to the pandemic's affects and the halt on most of the CdLS Foundation's special event fundraisers, 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 gifts to the Foundation are greatly appreciated, and there are multiple ways to give to the CdLS Foundation. 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.

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Our Major Donors

Thank you to our generous donors. You helped us serve nearly 1000 families and 70 medical and educational professionals in 2020.

Legacy Leaders (Planned Giving)

Gayle McCue (deceased) and Steve McCue

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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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