



2018

ANNUAL REPORT



Our Mission

The Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

Message from the Executive Director

A key goal for the Foundation is to expand our vibrant community and enable advocacy for those experiencing CdLS and other isolating conditions. However, we're not talking growth for growth's sake. We want to grow the number of medical, educational and therapeutic specialists who know about CdLS and are familiar with how to treat it. We also want to ensure that individuals living with CdLS have a meaningful experience with us and know where to turn in times of trouble. Within the pages of our 2018 Annual Report – you will find the story of an agency whose greatest assets are its people and the precious relationships built with you – our parents, grandparents, donors and corporate friends.

In 2018, with the support of 2 special families, we filmed our first PBS special to share the story of CdLS with the public. According to Nielsen analysts it was seen by over 4.4 million viewers. A total of 54 families attended our National Family Conference for the first time. We also convened scientists from around the world at our Eighth Scientific and Educational Symposium to share and advance the knowledge about the condition. Funding this life changing event continues to be a challenge for us.

For individuals living with CdLS, your support continues to make it possible for the Foundation to serve as a trusted source of education, information about management of the syndrome and empowering them to live the healthiest lives possible.

For your belief in our work, your partnership and support, we thank you.

Warmly,

Bonnie Royster

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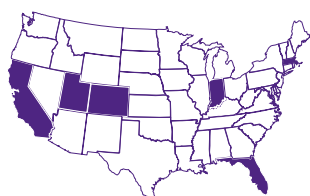
2018 Highlights

\$198,246

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



The CdLS Foundation welcomed **83** new families



6 Foundation sponsored Family Gatherings were held with 138 families in attendance, where friendships were formed

\$125,554

raised at 2 golf tournaments



501

individuals from the United States and surrounding countries attended the 2018 National Family Conference

Over

330

head-to-toe consultations were provided at the 2018 National Family Conference



306

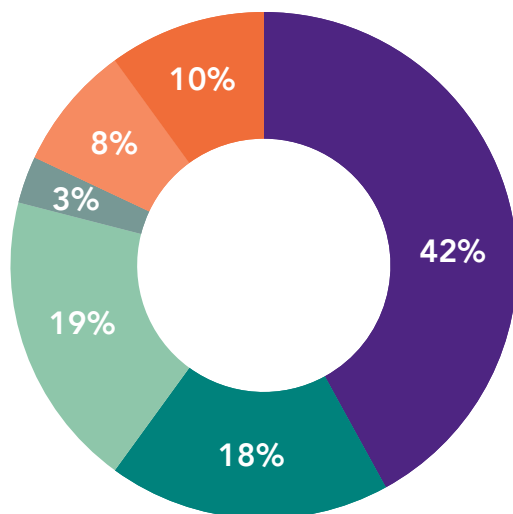
Ask the Expert questions were submitted



2018 Audited Expenses

2018 Income and Expense Statement

January 1 - December 31, 2018



Family Support Program

Research

Public Information & Education

General & Administration

Professional Development Outreach & Awareness

Fundraising

INCOME	
Individual Donations	22,436
Corporations/Company Donations	24,803
Foundations/Grants	-
Major Donors	251,744
PBS Special	30,000
Direct Mail/Foundation Drives	32,296
Clubs and Organizations	4,724
Gifts that Count – Memorial/Celebration	50,494
Special Events/ Third Party Fundraising	442,938
Federated Campaigns	40,645
Bequest	36
Program Services Fee/ Nat'l Conference	114,957
Program Services Fees/Symposia	15,600
Investment Income	10,714
Total Revenue	975,189

EXPENSES	
Program Services	
Professional Development, Outreach and Awareness	225,550
Research	34,420
Family Support Program	517,390
Public Information and Education	216,562
Total Program Services	993,922
Support Services	
Management and General	98,485
Fundraising	125,268
Total Support Service	223,753
Total Expenses	1,217,675
Net Assets, Beg of Year	1,203,182
Surplus/Deficit from Operations	(176,286)
Unrealized Gains/Losses	(51,774)
Total Surplus/Deficit	
Total Net Assets	975,122



Finding a Community in the World of Rare

The 2018 National Family Conference was held at the Minneapolis Marriott City Center from June 28 – July 1. The theme was *Building Bridges Together* and brought together over 500 attendees, including families and their children with CdLS, and medical professionals in the areas of genetics, gastroenterology, internal medicine, behavior, ophthalmology and more.

Over the course of the four-day life changing event, there were 17 specially curated workshops and presentations, over 330 head-to-toe consultations for individuals with CdLS with specialized CdLS experts, as well as events for families to experience acceptance, support and friendships that last a lifetime.

Conference, in conjunction with the Scientific and Educational Symposium, are the most important events the Foundation hosts every other year. They are fundamental support services and give those with the syndrome a voice and a community to gather with.

Sponsors and donors who fund the events continue to ensure every child and adult with CdLS, as well as their family members feel welcome, are taken care of and receive the care needed in a short period of time.

A photograph showing a woman with dark hair holding a young child with short brown hair. The child is wearing a purple t-shirt with a white graphic of a heart and leaves. The child is smiling and reaching out towards another woman with blonde hair who is also smiling. The background is blurred, showing other people at what appears to be a social gathering.

Family Spotlight

The Devlin Family, Our First Experience at Conference

Hughie Devlin was diagnosed at 4 months with CdLS and after the diagnosis, his parents immediately reached out to the Foundation. Breda, Hughie's mother, is a NICU Pediatric Respiratory Therapist, but knew there was so much they needed to learn about their son's condition. When they connected with the Foundation, they learned about the biennial National Family Conference, an invaluable experience, however for the Devlin family it was a prohibitive expense.

Breda and her family wanted so much to go to the 2018 Conference, but her husband was laid off at the time, so they thought it was out of range for them financially. Thankfully, the Foundation's scholarship program helped the Devlin's dream of going to Conference turn into a reality. "The first-time family scholarship made it possible for us to attend, however, after this experience, we vowed NEVER to miss a Conference from now on."

"We had been in touch with a number of CdLS families on Facebook before Conference and Hughie had made friends with boys his own age. We called them 'the three amigos'. Well, when the three boys met in-person at Conference, it was amazing to see them just take off, play and get into mischief! I truly felt the other families and the Foundation staff loved my son as much I as I do. You simply cannot put a price on that kind of family connection and love."



Staff Spotlight

Deirdre Summa – A Source of Inspiration for Families

Deirdre is a vital part of the Family Service team who help, encourage and guide individuals with CdLS and their families every day. Her impact allows those who talk to her realize their true potential to take on any challenge they are faced with. Deirdre has been part of the Foundation for over 12 years and still finds excitement in meeting families for the first time. If she has been talking with them for a number of years, welcoming them to the Foundation, or meeting them in person for the first time, it is exciting and emotional. It is important for her to stay in touch with families, as well as understand what they are experiencing so she can steer her recommendations for new services, publications and projects.

"I often find inspiration when families are facing uncertainty, particularly when their child is diagnosed with a rare syndrome and they find courage in that moment," Deirdre shared. "I really enjoy working with our families; they are an incredible group of people with some really amazing children. Being able to spend time with the families whether at a family gathering, a CdLS clinic or our Family Conference, it warms my heart to see and experience the level of support and caring shared so openly between everyone."

In moments of joy and triumph or sadness, Deirdre knows the importance of just being with the person. Being in their space and at their tempo, that is what makes her a priceless component to the work the CdLS Foundation focuses on daily.



Family Spotlight

The Hegarty Family – Strong Bond in the CdLS Community

Steve and Courtney have been married for 11 years and have two daughters, Marlie (9) and Cassidy (7, CdLS). Cassidy was diagnosed with CdLS when she was 9 months old, she has developmental delays, immune system issues, hearing loss and ear tubes and GI issues. After Steve and Courtney received Cassidy's diagnosis, Courtney reached out to the Foundation. The warm and welcoming voice she heard on the phone was that of Deirdre. "My first impression of Deirdre was, she's sweet, kind and caring. *She made me feel comfortable in a call I was not comfortable making in the first place.* The thing I remember most is that she wasn't pushy and just let me talk...From the very first call I was treated like family. Even to this day I feel like I can reach out to Deirdre or anyone at the Foundation even if it's just to talk, vent or cry."

With all the obstacles that Cassidy has faced, one thing is certain, the Foundation has been there to help every step of the way. Courtney and Steve received information on who to contact for Division of Developmental Disabilities (DDD) early intervention; which was a huge help. The information learned allowed Cassidy to start therapy and obtain Arizona Long Term Care Insurance almost immediately. "If I wouldn't have called the Foundation, I would have never known who to call or where to go."

The family also found great information from the National Family Conference. It was an amazing experience as they were able to participate in everything from consultations to workshops. They learned the importance of finding the right GI doctor and that their hometown genetic doctor was on track caring for their daughter.

Cassidy is doing well - the last year and a half have posed new challenges with her GI system. However, Cassidy is thriving and climbed so many mountains and made so much progress this year. When Courtney was asked how the Foundation has made a difference in her life, she responded, "Deirdre and the Foundation are family. *Family is forever and is there to support you when you need it.* And that is what the Foundation is and does!"



Fundraising Highlight

Team CdLS Surpasses Goal to Support Community

In 2018, Team CdLS Bank of America Chicago Marathon runners celebrated a record-setting fundraising milestone. The team, which consisted of parents, siblings and friends of individuals with CdLS crushed their goal and broke all the previous 18 years of fundraising records by raising \$104,000!

Team CdLS made its debut on October 22, 2000 at what is formerly known as The LaSalle Bank Chicago Marathon, "Running the Chicago Marathon started as an idea hatched during a run on the beach in the Outer Banks of North Carolina," shared Frank Mairano, "Thanks to the dedication of the Team pioneers, Team CdLS has grown to become nationwide with athletes participating in a variety of athletic events from walks to Ironman races."

The CdLS Foundation annually applies to be a charity partner for several endurance events, including the Bank of America Chicago Marathon. The charity partner program provides runners the opportunity to make their Chicago Marathon experience more meaningful by setting personal bests in their marathon time as well as in fundraising dollars.

Frank shared, "For all our Team members the experience of completing 26.2 miles is always amazing. The countless hours that one puts into training for a marathon and raising funds changes the lives of children with CdLS and their families – it really lifts your spirit and changes your life forever."

The Current CdLS Foundation Family

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CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

30 Tower Lane, Suite 400

Avon, CT 06001-3681

800.753.2357 • www.CdLSusa.org

