

FOCUS

Foundation

Summer 2015

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.



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A publication for donors and friends of the Cornelia de Lange Syndrome (CdLS) Foundation

Foundation Focus

Published Since 2010
Cornelia de Lange Syndrome
Foundation, Inc.

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DIRECTOR'S MESSAGE

BUSINESSES CAN MAKE A DIFFERENCE

From small local businesses to large regional companies, corporate giving is becoming an important part of the CdLS Foundation's annual revenue.

Since 2010, annual corporate giving to the CdLS Foundation has more than tripled to \$35,000 in 2014. This revenue includes donations from a wide range of businesses, including a jewelry maker, an accounting firm, a manufacturer of electrical insulation components and a carpet company. Some are annual donations, others are monthly; several are based on a percentage of sales. As with all donations, nearly 90 cents of every dollar supports programs for families, like the national conference, regional family gatherings and informational publications.

Part of the Foundation's 2016-18 strategic plan is securing one new corporate donor—ideally a monthly donor—per year. This helps the Foundation diversify its revenue and take the fundraising burden off of families, many of whom cannot afford to make a financial gift to the organization.

If you are a business owner interested in supporting the CdLS Foundation through corporate giving, contact Kelly at kbrown@CdLSusa.org or 800-753-2357 to learn more.



A handwritten signature in cursive script that reads "Marie".

Marie Concklin-Malloy
Executive Director

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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.

SAVING FOR THE FUTURE

Timing of revenue for the Cornelia de Lange Syndrome Foundation (CdLS) Foundation is critical. Typically, a surplus from the previous year is held as cash on hand to fund programs and operations for the first three quarters while the Foundation endures negative cash flow. This is because the majority of revenue (65 percent or more) comes into the Foundation during the last quarter. Most of the Team CdLS events take place in the fall, plus donors typically make their annual gifts at the end of the year (which is not unique to the CdLS Foundation).

Fortunately, in 2015 there were multiple first quarter events that had not been included in our budget. These included the New York City Half Marathon (which brought in more than \$30,000), the Tom King Classic in Nashville and the Rock n' Roll Half Marathon in Dallas.

Because of a surplus in 2014 and the timing of these first quarter events, we were able to transfer \$75,000 into our long-term investment account. This account serves as an emergency fund and currently holds enough money to fund the organization for one year should absolutely no revenue come in.

Historically, transfers into our investment account don't occur until the fourth quarter, and not at this high amount. Ideally, a nonprofit has two to three years of operational funds set aside, so wise spending in 2014 and unbudgeted events in 2015 have helped the Foundation get closer to its investment goals.

WANT TO HOST A DRESS DOWN DAY FOR CdLS IN YOUR OFFICE? READY TO STEP UP TO THE STARTING LINE WITH TEAM CdLS? HAVE YOU ALWAYS WANTED TO HOST AN EVENT TO BENEFIT THE CdLS FOUNDATION? CONTACT NICOLE DALTO (NICOLE@CdLSUSA.ORG) FOR MORE INFORMATION ON HOW TO TAKE THE NEXT STEP.

| BOB RUNS OFF THE BOARD |

By the time this issue of *Foundation Focus* reaches you, I will have completed a 5K to support the CdLS Foundation. Although I have supported the Foundation in different ways over the years, this is the first time that I have engaged in a Team CdLS running event. Because this is my last year on the Foundation's Board of Directors, I have called this effort "Bob Runs off the Board."

My running has made me think once again about the many people who support the Foundation in many ways. Some folks run in one or more races a year to raise money for the Foundation, and some do this year after year. Others not only run in races they help organize Team CdLS events, teams of runners, or both.

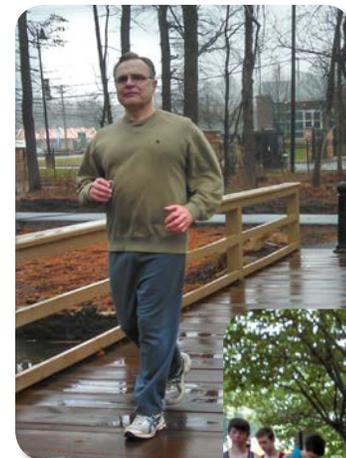
Some folks organize golf tournaments. Others put together garage sales, or bake sales, or dress down days in their office. Others may host or help to support a family gathering. In short, many creative and talented people are supporting the Foundation in many creative and talented ways. Our Foundation could not continue as it is without this support and encouragement.

So, thank you to all those volunteers who, in one way or another, support the Foundation.

If you are not a volunteer, perhaps this is the year that you can do so. As a parent myself, I am very well aware that the needs of our children can be all-encompassing, but perhaps there is some time when you can assist the Foundation in some way. And if you cannot, the next time you come across a person who is volunteering for the Foundation, maybe at a family gathering, or perhaps somewhere else, please take moment to say thank you.

All the best,
Bob Boneberg

PS. Bob and his son Alex completed the race and raised more than \$3,000.



—
| Maria |
—

We would like to thank Maria of Houston, TX, for her dedication and time in translating our new parent packets. This publication is a key resource for Spanish-speaking families who reach out to the CdLS Foundation for help and support.

Yannick is a happy ten-year-old little boy. He is the youngest of three. His two older sisters are two additional little mothers that keep him out of trouble. Yannick started walking about a year-and-a-half ago. His walking was a long awaited milestone. Yannick has had three hip osteotomies resulting directly from his recent walking. Although he will need yet another osteotomy because his legs still dislocate from his hips, he cannot be stopped. He practically runs to get around!

Yannick's hearing has improved from severe to moderate throughout the years. He has had behind-the-ear hearing aids and a BAHA. We are currently re-assessing Yannick's hearing to determine what type of hearing aids best suit him, given his hearing improvement. Although Yannick suffered from acid reflux during his first few months of life, his situation improved by the time he turned one. It wasn't until approximately a month ago that the acid reflux returned. He has been on medication for a few weeks now, and the reflux seems to occur less frequently. Yannick is myopic and has been prescribed glasses, but it is impossible to keep them on him.

Yannick always has a smile on his face. His laugh is infectious. He has a whole audience laughing before we know it. Although Yannick is only about thirty-six inches tall and weighs about thirty pounds, he eats like a champ. We always wonder where he puts his meals. He has a sweet tooth and loves any "carbs." He loves to shower and bathe. Yannick is a true musician and tests our ears and patience when he plays his mini grand piano, his snare drum and his cymbal, but we love his recitals.



“YANNICK ALWAYS HAS A SMILE ON HIS FACE. HIS LAUGH IS INFECTIOUS. HE HAS A WHOLE AUDIENCE LAUGHING BEFORE WE KNOW IT.”

— MARIA

FUNDRAISING AND AWARENESS: ALL IN THE BORGIA FAMILY

Eight months ago Dena and Daniel Borgia welcomed their first child, Luca, into the world. Dena and Daniel anticipated certain complications that can come with having a premature baby. What they had not expected was a diagnosis of Cornelia de Lange Syndrome (CdLS) that came one month later. The news of their son's diagnosis was a shock and life quickly became overwhelming as they learned more about caring for a child with special needs.

Dena, having always been a runner, was using her runs as much needed "me time." While she ran, Dena was able to set aside her worries for her family and the fear that friends and family may not accept Luca because of his differences. Having been in contact with the CdLS Foundation, Dena discovered the opportunity to become part of Team CdLS and run to raise money and awareness for the Foundation. Fundraising and spreading awareness soon became a family affair.

"Running was my own time. I didn't have to worry about anything," said Dena. "This was my own way to cope and take control of the things that were out of control," she said. "Then, when I asked my sister-in-law to run the New York City Half Marathon with me she said, 'anything for Luca,'" said Dena.

Fundraising and sharing information about CdLS became their way to cope. In the last eight months, with the help of family and friends, the Borgia family had raised over \$25,000 in honor of Luca.

Having their whole family involved helped to ease the initial worries that Dena and Daniel had about the

acceptance of their son. Not only did Dena's sister-in-law, Carina, run the half marathon, but she was the second largest fundraiser on the team. Other family members have gotten in on the action too. Maggie, Daniel's sister, will be running a "rugged maniac" race this summer in honor of Luca, and one of Dena's cousins is making a donation to the CdLS Foundation as the favors for her wedding. Dena's parents and in-laws provide support, and even babysit Luca so she can train for her races.

Having the support of their family has been life changing and some of the most heartwarming moments for the Borgias.

"People really do care. I was nervous to do it," said Dena. "I was afraid of the response to our story. I was afraid people wouldn't understand, but we received so much support. Don't be afraid to dive in and give it your all. Wear it all on your sleeve and just go for it."



Dena with Foundation Assistant
Executive Director Kelly Brown

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2015 CALENDAR

July 25
Indiana Family Gathering
St. John, IN

August 24
27th Annual Golf Tournament
for CdLS
Sunset Hills, MO

September 9-12
CdLS World Conference
Lisbon, Portugal

September 12
Northeast Region Family
Gathering
Fort Washington, PA

September 20
Saratoga Palio
Saratoga Springs, NY

October 3
Midwest Region
Family Gathering
St. Paul, MO

October 11
2015 Bank of America Chicago
Marathon
Chicago, IL

October 17
Baltimore Running Festival
Baltimore, MD

October 23-24
Board of Directors Meeting
Orlando, FL

October 24
Southeast Region
Family Gathering
Orlando, FL

November 1
2015 TCS New York City
Marathon
New York, NY

The CdLS Registry: Working Toward Understanding

How many individuals with CdLS have immunodeficiency? How many have sleep apnea? How many take medication for reflux? These are just some of questions the CdLS Foundation is trying to get answers to as part of its Cornelia de Lange Syndrome Registry.

Launched last fall and hosted by the Coordination of Rare Diseases at Sanford (CoRDS), the registry aims to collect, store and curate data that can then be used for a variety of reasons—including establishing prevalence of certain aspects of the syndrome and connecting families with researchers.

As investigation into the syndrome continues to move forward, the CdLS Registry is just another way the Foundation plays an important role in helping advance understanding of the syndrome and improving the quality of care for those affected by it.

To learn more about the CdLS Registry at CoRDS, www.sanfordresearch.org/cords.

CoRDS Registry

Coordination of Rare Diseases
at Sanford



WISH LIST

At the CdLS Foundation, we try to do a lot with a little. You can help us achieve our goals by contributing to our organization through our Wish List and providing a valuable resource for us to achieve our goals and better serve families.

- **Pro-bono app developer** – A CdLS Foundation app would contain some basic info on CdLS, as well as emergency information families can use.
- **Pro-bono editor(s)** – We are in need of an editor (or two) to assist us in upcoming projects.
- **Postage stamps**
- **Office supplies gift cards (Staples, Office Max, Best Buy)**

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