

FOCUS Foundation

December 2012

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope



Photos by Rick Guidotti

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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

During the holiday season, we often take time to reflect on the things we are grateful for. Here at the CdLS Foundation, we have found much to be thankful for in 2012, including growth, expansion, new friends and new opportunities.

Highlights from 2012 include:

- More than 580 people attended the National Family Conference in Lincolnshire, IL. With 136 families, it was among the biggest conference we've held. Approximately, \$35,000 in scholarships was awarded to first-time attendees. Planning is already in progress for the 2014 conference in Costa Mesa, CA.
- Team CdLS runners participated in 5Ks, mud runs and half and full marathons from Hawaii to Maryland. The culmination of the runners' efforts in 11 races exceeded \$155k.
- We welcomed more than 100 new families to our CdLS Foundation family.
- Researchers from the Children's Hospital of Philadelphia announced the discovery of a fourth gene (*HDAC8*) associated with CdLS, as well as a gene (*RAD21*) that causes CdLS-like features.
- We reached our \$10,000 goal for the 21st Century Conference Fund Match It! Challenge. An anonymous donor will match it with another \$10,000.
- Staff facilitated nearly 250 *Ask the Expert* questions and answers.
- A strategic planning process was initialized, resulting in a three-year plan for the organization.

You have been a huge part of these opportunities for those that we serve. As we get ready for a new year here at the Foundation, we want to make sure you know how truly thankful we are for each and every one of you, and your support throughout the year.

Happy holidays!

Sincerely,



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.

TEAM CdLS CURB CREW MEMBER

Brian S., In His Own Words

My first event with the CdLS Foundation was the first Chicago Marathon for Team CdLS 12 years ago. I have been working with the “Curb Crew” there ever since.

After working so hard to prepare for their 26.2 miles, the runners bring such energy to the days surrounding and the actual marathon itself. Then there are the members of the “Curb Crew,” who run all over Chicago during the race trying to keep track of a dozen or two runners and keeping one another energized, all just to see the runners for about 10 seconds at various miles.

Every Team CdLS family at the Chicago Marathon gives so much of their time and energy: it’s simply tremendous and inspiring. Everyone has different backgrounds, but the common goal that they are working towards unites them instantly. Being in the same room with other volunteers makes you want to do more and give more of yourself.

The memories I have from this event I will always keep with me: Stuart K. bringing coffee and hand warmers, or Mark S. showing up with his entire family and showing off his mastery of duct tape. It’s also the constant smile and positive attitude of Andrea N. and her children or David F. somehow driving around the city on the day of the marathon (something the Chicago Police don’t even do).

I’ll also always remember watching Julie M. and my mom, Maureen (who has been involved with the Foundation for many years too) running across the marathon route while it is in progress, trying desperately not to trip anyone.

It’s a group of people with such motivation for a singular goal. It makes you feel that anything can be accomplished.



Brian with mom, Maureen

“THE INGENUITY AND DEDICATION OF TEAM CdLS CURB CREW - CHICAGO IS SOMETHING TO BEHOLD. IN REALITY, I JUST POINT TO A SPOT ON A MAP AND THIS GROUP ALWAYS FINDS A WAY TO BE THERE FOR THE RUNNERS. THE ENTIRE GROUP MAKES THE DAY OF THE MARATHON AN AMAZING EVENT.”

| RICH & JOSEPH |

Losing a sibling is never easy. The bond between siblings is very strong, even from a very young age. This rang true for Rich and his brother, Joseph, who had CdLS and passed away at the age of two when Rich was only five years old.

“You have to grow up very quickly,” said Rich. “My sister was born a year and half after my brother was born, so being the oldest I felt a lot of responsibility even at a young age, making sure he didn’t roll off the blanket or out of sight.”

Although Joseph passed away in 1982, Rich’s ties to the Foundation are strong. He serves on the Board of Directors and supports two Atlanta-area events, Brew & BBQ and the One Love, One Heart 5K Walk/Run.

“When you get older, you find that you want to be involved in something that makes a difference. I started thinking about what I wanted my time to go towards and I naturally gravitated to the Foundation,” said Rich.

“I know what it’s like for families and the struggles they may face with CdLS, so if I can be involved with helping another family, even if it’s donating money so that someone at the Foundation is there to answer the phone, I know it’s worth it. It takes an enormous weight off family member’s shoulders when they have someone to talk to.”

Through his involvement, Rich has gotten to know families from around the country and uses his experience to connect with them on a deeper level. “My family has learned how important it is to reach out to others. I love the One Love, One Heart 5K because it becomes sort of like a family picnic, with families and children all enjoying one another and supporting one another.”



Rich and Joseph

One of Rich’s most inspiring experiences with the Foundation was attending the 2012 National Family Conference in June.

“It’s one of the most important things the Foundation does—connecting families so that they don’t feel alone. I loved getting to meet entire families—moms, dads, aunts, uncles, grandparents, siblings. It’s really an all-encompassing thing. I met a mother who was overwhelmed because she realized that she wasn’t alone and people cared about her concerns. It was really touching.”

KNIGHTS IN ACTION

For almost 20 years, the Knights of Columbus Chapter #2521 out of Baltimore, MD, and its 900 members has held a wide range of events to fundraise for the Cornelia de Lange Syndrome (CdLS) Foundation. Leading the charge has been John M, whose granddaughter Lindsey had CdLS and passed away five years ago at age 20.

“Even with so many members, when Lindsey was alive everyone knew who she was. She seemed like the poster child for the chapter and it’s why everyone is so happy to still be involved to this day,” said John. “Each year, when it came time to give out the fundraising checks, my daughter Karen and Lindsey would be there to accept the check on behalf of the Foundation.”

From bake sales at local fairs to “Spring Fling” dances to selling Tootsie Rolls, this group of men and their families has embraced the Foundation, as well as three other charities. “We’ve done various events throughout the years,” said John. “One day this October, we went out to an intersection near a major mall and raised \$2,300 in just five hours.”



“Our hearts are with the CdLS Foundation and we want to do whatever we can to support it. I’ve been with this chapter for close to 40 years. We’ve been fundraising for the CdLS Foundation for half of that time,” said John. “The Foundation has helped my granddaughter and my daughter tremendously. As long as I’m around, this organization will continue to support the CdLS Foundation.”



John M.

“OUR HEARTS ARE WITH THE CdLS FOUNDATION, AND WE DO WHATEVER WE CAN TO HELP.”

| BREWING UP SUCCESS |

Brew and BBQ

On September 15, more than 80 people came out to Sweetwater Brewing Company in Atlanta, GA, for the 3rd Annual Brew and BBQ to benefit the CdLS Foundation. Event organizers Fran R. (pictured at right below) and Suzanne M. put together a night of food, friends and fun with more than 33 silent auction items up for bid. Thanks to the generosity of those who attended the event, over \$3,800 was raised for the CdLS Foundation.



2013 CALENDAR

May 11, 2013
Northeast Family Gathering
Maryland

May 11, 2013
National CdLS Awareness Day
Nationwide

May 20, 2013
21st Annual New England Golf
Tournament
Ipswich Country Club
Ipswich, MA

Thank you for an awesome 2012 season!

It's never too early to organize a team for 2013



Visit www.TeamCdLS.org or
call 800.753.2357 to step up to
the starting line.



Marathon • Half Marathon • Mud Run • 5k • Walk

GO GREEN!

SEND US YOUR EMAIL
ADDRESS TO RECEIVE
THIS NEWSLETTER
ELECTRONICALLY

Monthly Giving: The Easiest Way to Support the Foundation

Make a resolution to support the CdLS Foundation in 2013 by becoming a monthly donor.

Monthly giving is the most convenient and efficient way to support the Foundation. You can commit to a monthly, tax-deductible donation (as little as \$10) that is automatically deducted from your credit/debit card or bank account. If things in your life change, you can increase or decrease the donation amount or cancel it at any time.

Here's how monthly giving adds up over the course of one year:

- \$15 a month keeps the web site up and running, allowing 24/7 access to features such as *Ask the Expert* and emergency medical information.
- \$50 a month provides 100 new families with our New Parent Packet, which contains critical information for families learning about the syndrome.
- \$100 a month pays for three months of our Toll Free HELP Lines, allowing parents, relatives and others to call for support at no charge.
- \$300 a month supports one family gathering, where families come together to share and learn.

To set up monthly giving in 2013, call Kelly Brown at 800.753.2357.

Dress Down for CdLS

Get comfy for a good cause. It's simple to raise funds and awareness for the CdLS Foundation by organizing a Dress Down Day in your school or workplace. It's fun, easy and gets everyone involved.

The Foundation provides everything you need to make the day a success. All you need to do is schedule the date and publicize your event. Everyone who makes a donation receives a special gift.

For more information, please email specialevents@CdLSusa.org or call 800-753-2357.

MONTHLY GIVING PROGRAM

HELPING OUT ONE MONTH AT A TIME

Make a resolution to support the CdLS Foundation in 2013 by becoming a monthly donor.



START TODAY!

800.753.2357

WWW.CDLSUSA.ORG



Be a hero. No cape required.

At the Cornelia de Lange Syndrome (CdLS) Foundation, we have the privilege of knowing many heroes, just like Ken, pictured below, and others who give their time, energy and financial resources to support a cause close to their hearts.

You can be a hero too. With your support today, you can secure the future of the services and program that the CdLS Foundation offers individuals with CdLS and their families. Your year-end donation—big or small—turns into a greater gift when everyone joins together to improve the well-being of others.

Thank you for being our [super]hero.

Ken rode his Harley across the country for children with CdLS, like his grandson Adrian



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Charge my gift to: VISA MC AMEX

Card #: _____ Expiration: _____ Security Code: _____

Print name on card: _____ Signature: _____

Email address(es): _____

One hundred percent of your contribution is tax deductible.

Donate online at www.CdLSusa.org.