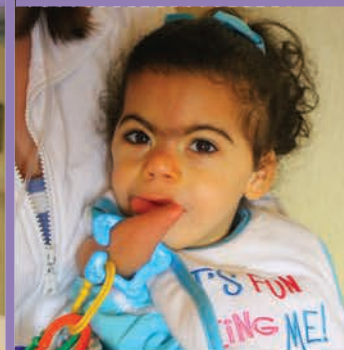
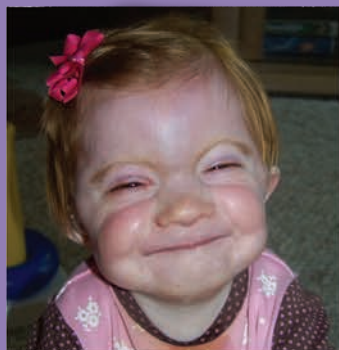


FOCUS Foundation

December 2011

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



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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
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DIRECTOR'S MESSAGE



At the close of 2010, the Foundation reached—and then surpassed—the \$1 million dollar mark for the first time in its history. Accordingly, we opened the new year with a challenge to **Make it a Million** in 2011. This campaign logo has appeared throughout the year on direct mail, in our publications and on the Web site, reminding everyone of our efforts to reach a million again.

Why does it matter? Because the more money this organization raises, the more it can do for families and individuals affected by CdLS. For every dollar we raise, ninety cents goes to our programs. The other ten cents goes to making sure staff has an office to go to and phones that work, so that when a parent calls full of questions, or to share a child's accomplishments, someone is on the other end to help. Simply put, if we raise \$1 million dollars, \$900,000 of it helps families.

Another million-dollar year will keep current programs going, help fund new ideas and research, and support the 2012 National Family Conference, the biggest line item in our ledger every other year.

Please consider a year-end gift to the Foundation. Whether \$5 or \$500, every dollar gets us closer to the hitting the mark—and making a difference.

Liana García-Fresher, R.D., M.S.
Executive Director
director@CdLSusa.org



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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.

Did you know ... the CdLS Foundation was incorporated exactly 30 years ago in December 1981.

JINDI'S LEGACY

Kathy and Gene have been a part of the Cornelia de Lange Syndrome (CdLS) Foundation National Family Conference since the very beginning. And with the renaming of the conference childcare program, they are now part of it forever. Starting in 2012, CdLS childcare at the national conference is known as *Jindi's Place*, named after their daughter, Jindi.

Gene and Kathy were among the families at the first CdLS family picnic in Maryland in 1980. They drove straight to the picnic from a wedding, missing the picnic, but making it in time to meet up with families who were still in the area. Kathy and Gene remember sitting in someone's hotel room chatting while Jindi held onto the sides of the bed, scooting herself around.

"No one could see her though," Kathy says, "because she was so small." And although everyone in the room understood this as normal, not everyone beyond the hotel walls did. For those unfamiliar with CdLS, it was difficult to grasp how a child could be so tiny at age one, but there was no explanation needed when among the CdLS families.

When childcare became a necessity at these gatherings, they knew they could help. Kathy, Gene and their daughters participated in the Girl Scouts of America in their hometown of Bogota, NJ, and knew that bringing in a troop to assist with was the perfect solution. The girls would be trained in CPR and other health related issues common to CdLS before attending, and parents would feel confident about leaving their children with the girls. In addition, because they were already familiar with CdLS and had experience interacting with Jindi, the girls were perfect candidates for caregivers.

The Bogota Girl Scouts have been a staple at every national and international conference (except Denmark in 2011). This not only helped parents, but it also gave many girls from the Bogota community the chance to travel the country and even the world.

Unfortunately, there has been a decline in interest in Girl Scouts. The 2012 conference is the first year time in three decades that there is no troop to bring; however, Gene and Kathy will be there, along with their daughter Kortni—a nurse and their "right hand" for many years—training childcare volunteers and overseeing the program.

Jindi passed away in 2003 at age 22, but Gene and Kathy never let that deter their involvement. Although the news of the renaming brought tears to their eyes, Kathy and Gene say they were "happy tears" and that it's a continuation of the happiness Jindi brought to her family and community during her life.



Gene, Jindi and Kathy at conference in 1993

BALTIMORE RUNNING FESTIVAL: SIBLINGS GO THE DISTANCE

For two groups of siblings, the 2011 Baltimore Running Festival was truly a family affair. Abbey and Bethany, sisters to Alex, and Jennifer and Andrew, siblings to Stephanie, hit the city's streets as part of Team CdLS—Bethany, Andrew and Jennifer in the 5K and Abbey, who was nursing a broken leg, on the sidelines cheering the team on.

It wasn't the first time the group has come together. The siblings—who range in age from 16 to 23 and hail from western Pennsylvania—have known each other most of their lives due to their families' involvement with the CdLS Foundation.

For Andrew, a high school cross-country runner, the race was a perfect way to support the Foundation. "The Foundation has done so much for my family, this was a way to give back. Plus, it was a lot of fun to be with all of our friends that we haven't seen in a while."

His sister Jennifer, a special education teacher in Maryland, had never run a 5K before and decided it would be fun to join Andrew and to cheer on her father, Mark, who ran the half-marathon. "It's important to be involved with CdLS events because they help to raise awareness and promote positive things to do with other families who are in the same situation."

For Bethany, who relocated to Baltimore after college, it was her first 5K too. "It's important to show support for my brother, and to raise awareness of CdLS and the Foundation," says Bethany. However, she confesses she enjoyed the actual race the most. "I've never run in anything before and it was exciting."

Alex and Stephanie (who was the Team CdLS ambassador), both age 20, attended the race. All the siblings agree that it was pretty special seeing the excitement in Alex and Stephanie's faces as they cheered from the sidelines.

"Stephanie doesn't say a lot, but I can tell when she likes something or not," says Jennifer. "She was happy we were all together, doing something fun. She was all decked out and cheered us on as we ran." After the race, Stephanie—who loves animal prints—presented Jennifer with a cheetah print sweater, just like one she has herself.

Andrew finished in 21:47; Jen in 25:12; and Bethany in 34 minutes flat. Abbey plans to run next year.



From left: Abbey, Jennifer, Bethany, and Andrew

Did you know ... Team CdLS is the organization's largest fundraiser, bringing in more than \$145,000 this year from nine races.

WHY I GIVE

Jim, In His Own Words

Supporting and standing by my family has always been a priority for me, and when my sister, Maureen, welcomed a baby girl in 1990, this became more important than ever. My niece, Meghan, was diagnosed with Cornelia de Lange Syndrome (CdLS). At first, it was overwhelming and confusing for us all, and we knew then that our family needed to grow and learn.

That year, Maureen and her husband, Bruce, attended the CdLS Foundation National Family Conference in Atlanta and began this growing process. There, they met other families affected by the syndrome and gained insight and support no book or brochure could provide. Over the next couple of years, these families and the CdLS Foundation became a part of our own.

Although I could see how much the Foundation and this support system was helping Maureen, Bruce and Meghan, it wasn't until 1992 that I experienced this first hand at the family conference in Boston. I spent most of my time helping at the registration desk, and though I had a great time meeting people and contributing to the event, it wasn't until later that weekend that I finally understood the true significance of the Foundation.

After the conference had ended, the Boston families hosted a party to celebrate their success. As we were sitting around the room, talking and laughing, I could feel the love and warmth emanating from each person involved. Not only did these people donate time and money to help others affected by CdLS, but a part of their heart was extended as well. For families like mine, who feel lost and alone upon diagnosis, having a group so welcoming, supportive and knowledgeable was vital.

Each conference since then, I sit at the registration table, just as I did nearly 20 years ago. When returning home, I always feel good about the time I spent with my CdLS family.

I donate annually and never worry that my donation is not used for its intended purpose because I see first-hand my contribution going to further the work of the Foundation.

After experiencing the power these connections, friendships and support networks provide, I know it is important for me to do what I can to ensure that this resource remain available to help other families caring for children, like Meghan.

– Jim K., California, annual donor since 1990



Jim, in brown, with Meghan and her siblings

THANK YOU TOUR

This fall, the Cornelia de Lange Syndrome (CdLS) Foundation continued its *Thank You Tours*, making two stops in California during November. For Executive Director Liana Fresher, there's nothing like hitting the road and meeting face-to-face with the people who care about the CdLS Foundation.

The first event was held November 9 in the southern California city of Costa Mesa, with Dr. Richard Mungo, a Foundation Clinical Advisory Board member, and his wife Kristin hosting. Dr. Mungo became familiar with CdLS in the early 1980s when he was department chair of Pediatric Dentistry at Children's Hospital of Los Angeles/University of Southern California School of Dentistry and treated three patients with CdLS.

When Dr. Mungo was asked by one of the parents to address a group of CdLS families at a nearby gathering, he obliged and "fell in love with all of the kids and parents," he says. "My wife and I have been privileged to be a part of the CdLS extended family ever since."

For the Mungos, hosting the event was another way to stay involved with the Foundation. "We knew that through social events we can get to know one another, learn from each other and form strong bonds that take us into the future with our mutual quest to help families, children and fellow professionals," he says.



The Mungos



The Millers

The next stop on the *Thank You Tour* was up the coast in Burlingame, near San Francisco, two days later. The reception was hosted by Wendy and Andy Miller, parents of a child with CdLS and recent transplants from Boston.

"It's important to us to strengthen and spread the roots of the Foundation in the area, as our nuclear family of four grows new roots of its own," says Wendy. "Having a group with a common identity and a community who understands on the basis of shared experience, cannot be understated."

As the Millers begin a new chapter far from the home they knew, they hope to help the group of Foundation friends and donors increase in number, strength and knowledge so that ultimately more research into CdLS can be done, more awareness spread, and more individuals and families assisted and encouraged. "Meeting others with similar goals is a large step in this direction," Wendy says.

SARAH'S BOWL & MADDY'S RUN

Sarah's Bowl for CdLS



Sarah and Anne

Sarah's Bowl

In Batesville, IN, November 6 was all about swing shots, side-arming and lofting as bowlers came together to raise money in honor of a little girl named Sarah. Families and friends gathered to participate in the Third Annual Sarah's Bowl for CdLS, a bowl-a-thon organized by Sarah's mom, Anne.

In between each strike, spare or inevitable gutter ball, a silent auction encouraged friendly bidding wars. Bowlers and non-bowlers alike mingled in their official Sarah's Bowl t-shirts, while enjoying food and drinks throughout the day.

Everyone who attended saw how much hard work and dedication Anne puts into this annual event—getting sponsors and donations, recruiting bowlers, and working out every detail so the day would go without a hitch.

All of her hard work paid off, with the event raising over \$10,000 for the Foundation.

Maddy's Run

On an early September morning, 200 walkers and runners descended on Liberty Park in Salt Lake City, UT, for Maddy's Run. For some, the 5K was a race to beat the clock, but for the majority, it was to honor the life of Maddy—a young woman with CdLS who passed away in August 2010. Throughout her 18 years, she brought a tremendous amount of joy and



perspective to her family, and “she was a pure spirit and a bright light in the lives of so many she touched,” according to her parents.

The event organizers wanted to acknowledge the positive impact that Maddy had on others, while raising money for the CdLS Foundation, which provided Maddy's family and thousands of others with support, advice and friendship. “Every year, every day, there are more children and more families in need of support. And, as we all know, those sources of support are getting harder and harder to find,” said her father, Hunter. The 5K raised more than \$17,000.

After the event, Maddy continued to inspire others. Six runners from Maddy's Run—including her parents and older brother—joined Team CdLS in the ING New York City Marathon.



Red and yellow balloons were released by her family after the race.

Did you know ... the CdLS Foundation Web site was visited by nearly 100,000 people from 154 countries this year.

Join us for a CdLS Charity Golf Tournament

Help kick off the CdLS Foundation National Family Conference at Crane's Landing, a certified Audubon Cooperative Sanctuary in Lincolnshire, IL, offering golfers an array of challenges and an opportunity to support the CdLS Foundation.

The Tournament takes place Wednesday, June 20, and precedes the national family conference.

For more information or to volunteer on the Golf Committee, contact Gail at 800-753-2357 or events@CdLSusa.org



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