

# Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc.  Second Quarter 2014

## Highlights

### Director's Message:

Progress

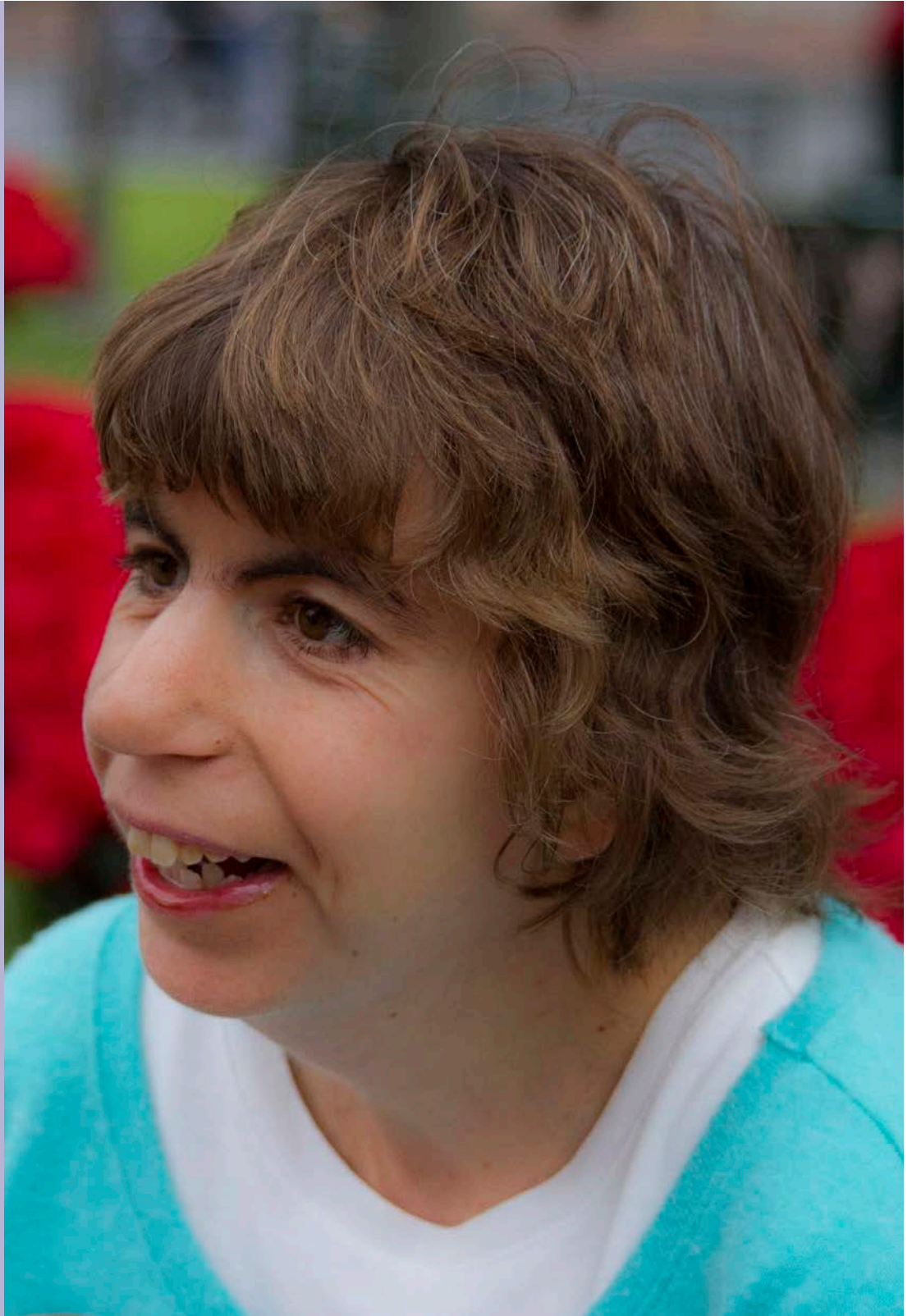
### Spotlights:

Nearsightedness, LASIK  
and CdLS

Feeding Issues in  
Individuals with CdLS

### Super Siblings:

Three Siblings. One  
Race. One Reason





# Director’s Message



## Progress

This spring marks two years since I took the helm of the Foundation. Time has flown by and that can be attributed to how busy staff has been working to add, improve and increase services.

We’re finalizing plans for a new CdLS clinic in the San Jose, CA, area. We’ve also launched a program to help families get to that clinic and existing ones in Baltimore and Philadelphia (see page 7).

We’ve created a new awareness video, publications on education and transitioning to adulthood, and we’re putting the final touches on a booklet for parents who’ve lost a child with the syndrome. We’re increasingly utilizing technology, with online tools covering sensory issues, medical home models and, new this year, training for regional coordinators. Staff is also working on online learning resources for behavior and education.

Most of the new programs and services mentioned above were initiated because you told us you wanted them.

So, what would you like to see next?

I’ve put together a Planning Committee to keep the Foundation headed in the right direction, and I want to share your thoughts with the members as we plan for the next three to five years. Share your ideas with me at [director@CdLSusa.org](mailto:director@CdLSusa.org) or the Foundation’s Board President, Bob Boneberg, at [President@CdLSusa.org](mailto:President@CdLSusa.org) (and don’t miss his message on page 12).

Marie Concklin-Malloy  
Executive Director

### 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.

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## For You, The Families



*By Antonie Kline, M.D., CdLS Foundation Medical Director*

The Cornelia de Lange Syndrome Foundation binds all of us together. For many of you, when thinking about the Foundation, national conference comes to mind. Maybe it's a phone call you've received from family service coordinators, or literature you've receive in the mail. Maybe it's establishing contact with families in similar situations. In truth, the CdLS Foundation is

much more than all of these: as Aristotle said, "the whole is greater than the sum of its parts."

One of the Foundation's greatest functions is making contacts for, the families with professionals who are experts in the subject of CdLS. As you might recall, we have a Clinical Advisory Board (CAB) made up of 58 professionals representing 35 specialties. Each member has become an expert in their field in terms of CdLS, and is very willing to answer questions through the *Ask the Expert* tool, and/or talk with your care providers.

For professionals who contact us, they can be referred directly to the CAB member of that specialty and then relay the information back to you. As the medical director of the Foundation, I oversee all of the email communication to and from the professionals before it goes the families make sure that another area is not missed and that the information is accurate.

Other medically-related entities that we offer include confirming a diagnosis of CdLS and/or determining severity. Confirmation of diagnosis is done either by records and photos, or in person at a regional or national meeting. Using only photos can be more difficult, but we try to be as definitive as possible.

You may see professionals off to a corner at a family gathering meeting one-on-one with a family for a specific issue. At the national family conferences, there are formal consults with professionals offered during the course of the meeting. These can be extremely reassuring for families, and can also provide feedback for your local professionals.

Finally, we have information across age groups. There is increasing information about prenatal aspects of CdLS. There are also CdLS-specific growth and developmental charts available to plot the progress of each child with CdLS. I've focused my research on aging and hold twice yearly aging clinics at my hospital at the Greater Baltimore Medical Center for families.

Thus, it is important to know the scope of what we can offer, not only for your immediate family, but also because there could be a way for you to help, participate and share with others in similar circumstances, and for you in the future as individuals get older. Familiarize yourself with our website, [www.cdlsusa.org](http://www.cdlsusa.org). There may be much more there than you realize.

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**Cornelia de Lange Syndrome Foundation, Inc.**

Incorporated December 1981

email: [info@CdLSusa.org](mailto:info@CdLSusa.org)

[www.CdLSusa.org](http://www.CdLSusa.org)

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## Nearsightedness, LASIK and CdLS



*By Alex V. Levin, MD, MHS, FRCSC, Wills Eye Hospital, Thomas Jefferson University, CdLS Foundation Clinical Advisory Board Member*

Nearsightedness (myopia) is not a disease. Rather, it is a description of the length of the eyeball, being longer than average. With glasses (or contact lenses) the rays of light coming into the eye can be bent to fit the longer eyeball, at which point, the eye should then be capable of sending a perfectly clear message to the brain. Nearsightedness is seen in almost 2/3 of children with Cornelia de Lange Syndrome (CdLS). So, why is it that some children with CdLS refuse to wear their glasses?

The first reason is that children with myopia, especially when only mildly or moderately nearsighted, are naturally “near-sighted.” In other words, they see closer objects better than those at a distance. Without their glasses, they have very clear vision at close range and therefore the glasses do not give them any particular benefit that they can appreciate. These children need no treatment for their nearsightedness and their vision will likely develop normally. Although their distance vision, which they rarely use in great detail, will remain blurred, they will see clearly enough to get around and live relatively normal visual lives.

The other reason that children with CdLS often don’t wear glasses is their behavioral characteristics, which cause them to reject any types of manipulations on or around their face. In a prior study, we estimated that this was seen in 50 percent of patients. This overrides the benefit that they might have from seeing more clearly. These children, and those that are so severely nearsighted that even their near vision is subnormal, might benefit from having their nearsightedness corrected in ways other than glasses. Children with severe myopia (more than -5) may also have impaired vision development, meaning even if they start wearing glasses, their vision will never correct to normal.

Some families have tried contact lenses with some success, although more often fail. Imagine how hard it would be

to get contacts in and out. However, once in, contacts are difficult for the child to reject. Another option is refractive laser eye surgery, commonly referred to as LASIK. This would require general anesthesia. The procedure is still considered experimental (research based) for children in most medical facilities and requires special permissions and protocols. The procedure involves cutting the surface of the eyeball (cornea) to allow it to bend the light itself without the need for glasses or contact lenses to do so. Although the procedure does expose the child’s eye to a small incremental risk of complications, the benefits of seeing more clearly have been observed subjectively by the few parents of children with CdLS who have undergone this procedure.

Unlike some other conditions associated with developmental delay and nearsightedness, the cornea surface of the eye in CdLS has no significant inherent abnormalities and therefore may be considered “safer” for the laser procedure. The one exception might be that children with CdLS sometimes do suffer from severe swelling or inflammation of the eyelids (blepharitis) and these children may not be able to have the laser procedure unless the blepharitis is treated.

Individuals with severe nearsightedness have very long eyeballs, and this can also cause the inner lining of the eye (retina) to become stretched. This can lead to retinal detachment, which although rare, can cause blindness. LASIK surgery does not prevent the risk of retinal detachment as it does not alter the length of the eye. Careful, sequential, detailed eye examination, even if requiring anesthesia, might be considered in children with very severe nearsightedness (for example, more than -10) to screen for tiny breaks or tears in the retina which, if identified, can be lasered shut (different kind of laser, not research based) to prevent retinal detachment. Retinal detachment in CdLS can also be a result of self injury. Children who have a propensity for self injury may also be poor candidates for laser refractive eye surgery.

We still don’t know all the answers about the indications, risks and benefits of laser eye surgery in children with developmental delays and nearsightedness. Discuss the options with your eye doctor if your child is very nearsighted, and refusing to wear eyeglasses or contact lenses.



## A Closer Look at Eye Treatment: Sydnee's Story

*We want to thank Sydnee's mother, Teala, for sharing Sydnee's story with us.*



Sydnee was diagnosed with High Bilateral Myopia and Secondary Isoametropic Amblyopia in November of 2010. Her prescription was OD -11.75 and OS -15.00 (Dilation) OD -13.50 and OS -15.50.

Her recommended treatment was Photorefractive Keratectomy (PRK) Surgery. The surgery went great. I noticed a difference in Sydnee's vision immediately: her vision increased to -1.00 myopia in both eyes (OU).

Her recovery was minimal and there were no complications. Sydnee used eye drops four times a day for six months, and also had to take 500mg of vitamin C each day during the six month recovery period.

Sydnee also had to have splints on her arms during the recovery period so she wouldn't reach for her eyes and disturb her recovery.

She went in for a follow up six months after surgery, one year after surgery and has gone annually for three years.

I would highly recommend any parent to consider the surgery. It was priceless for me to watch Sydnee notice raindrops on the window for the first time. Correcting Sydnee's vision has increased her development and her ability to learn.

*Ophthalmology consultations will be available for those attending the upcoming CdLS National Family Conference.*

## A Closer Look at Eye Treatment: Michael's Story

*We want to thank Michael's mother, Carol, for sharing Michael's story with us.*

Michael was diagnosed with severe myopia in his right eye. He was prescribed corrective lenses when he was about 10 years old (1981) by our ophthalmologist. In 1989 he suffered a detached retina in his right eye. He had surgery, which was unsuccessful. The retina had been detached for quite some time resulting in the optic nerve being shredded. He is totally blind in his right eye.

Michael (shown below) had a retinal tear in his left eye and underwent emergency surgery repairing the tear. The lens was removed and he required a tarsoraphy (permanent suturing) of the eyelid to alleviate dryness. Michael requires an annual check of his retina under general anesthesia.

Most recently, his retina has been fine, with no issues. He hasn't had any recent surgeries. He did however go to Philadelphia to see Dr. Alex Levin to have an exam to check the retina under general anesthesia. He did fine. Our advice to other parents or caregivers is that if they feel there could be a visual issue, get the retinas checked. Ideally, they should be checked every 6-12 months for retinal changes.





## Feeding Issues in Individuals with CdLS: What Should We Be Considering?



*By Cheri S. Carrico, Ph.D., CCC-SLP, Elmhurst College, CdLS Foundation Clinical Advisory Board Member*

Many people with CdLS experience feeding issues at some point in their lives. Health concerns, anatomic and physiologic differences, and sensory issues can impact the

ability and desire to eat. A history of tube feeding; gastroesophageal reflux disease (GERD); esophagitis; low muscle tone in and around the mouth; a small jaw (micrognathia); a high, arched palate (roof of the mouth); a cleft palate; side effects of medications; food allergies; oral defensiveness; and aspiration of food or liquids can make oral feeding challenging and undesirable for an affected individual.

Among individuals with CdLS, oral feeding challenges can include food aversions; eating limited varieties of food; consuming small amounts of food during meals; taking very tiny bites; eating very slowly; spitting food out; being a messy or picky eater; and even refusing to eat. On occasion, however, some individuals may “stuff” food in their mouths and food may collect at the roof of the mouth. Symptoms of oral feeding difficulties include choking, coughing, gagging, vomiting, a “gargly” sounding voice after feeding, aspiration (food or liquid enters the lungs, which can lead to pneumonia), and food aversions.

In infancy, children with CdLS may exhibit difficulty sucking or coordinating sucking, swallowing and breathing. Some difficulties may not be observed until infants are a few months old, when anatomical changes in the mouth and neck, as well as shifts in body positioning during feeding, may make it difficult to control food to swallow it safely. During early infancy, the tongue fills the mouth and the cheeks have sucking pads. These offer stability during feeding. In addition, the epiglottis protects the airway. With this type of anatomy, it is easier to control liquids in the mouth, and babies can swallow and breathe at the same time, reducing the likelihood of choking.

During infancy, babies begin to lose liquids from the sides of their mouths as the natural body position moves from a primarily flexed position (elbows and knees bent) to a more extended position (arms and legs straighter). The muscle tone of infants in the flexed position helps them to keep from losing liquids from the sides of their mouths. As they moved to a more extended position, some loss of liquids from the sides of the mouth may occur.

Around 3 to 4 months of age, the neck grows, and the epiglottis no longer is in the same position as it was earlier in infancy, so it loses its protective function. Infants who previously did not choke during feeding may start to do so at this time because of the changes in their bodies and the need to coordinate feeding and swallowing with breathing.

Around 4 to 6 months of age, when the mouth is growing, infants’ tongues and cheeks have to learn to better control food in the mouth because the sucking pads are diminishing and there is greater space in the mouth as the jaw bones grow, preparing for more solid food consistencies. Additional challenges may become present as children move from liquid to solid foods, and their mouths have to learn to manage food that is thicker or needs to be chewed. Children also have to learn to manage multiple consistencies in food, such as yogurt with fruit chunks and the small, soft pieces of vegetables, rice, and pasta in baby food.

If a child has low muscle tone in and around the mouth, this can impact feeding because there may be a lack of strength to bite and chew foods. In addition, because of the extra effort associated with biting and chewing, the child may fatigue easily and not want to continue feeding. When a micrognathia is present, the chin is in a retracted (pulled back) position and the tongue is further back in the mouth. When the tongue is in a more retracted position, the infant’s ability to breathe during feeding can be affected, particularly if the infant is fed in a reclining position, where gravity naturally pulls the tongue toward the back of the mouth. This position could potentially block the airway. When micrognathia is present, the relationship between the upper and lower jaw is shifted. Because the lower gums and teeth are in a compromised position, biting and chewing can be more challenging.

*Dr. Carrico will be providing individual consultations for families at the upcoming CdLS National Family Conference.*





## A Closer Look at Feeding Options: Anna's Story

*We want to thank Anna's mother, Susannah, for sharing Anna's story with us.*

One of the feeding difficulties Anna has is that she resists feeding by mouth. At birth she experienced a large reflux issue and couldn't keep much down, and was in a lot of pain. She started refusing feedings. The decision was made around two months old to give her a gastronomy tube (or G-Tube). She is now completely tube fed.



We had a feeding consultation with Dr. Carrico, who suggested that we introduce puréed baby food little by little. We keep trying and most importantly have learned not to give up.

We're still working on it. Anna tolerates some things better than others, but she is still solely tube fed. Dr. Carrico's advice was encouraging. We're still trying puréed foods, making small progress. She seems to like carrots and ice cream the best!

## Foundation to help families get to CdLS clinics

Up to \$250 in support is available to families attending one of two CdLS clinics. The funding, which is reimbursed after the trip, is available to up to three families per month attending the Center for CdLS and Related Diagnoses at Children's Hospital of Philadelphia and for up to eight families per clinic at the twice-yearly Multidisciplinary Clinic for Adolescents and Adults at Greater Baltimore Medical Center.

The funds will cover travel and lodging expenses. It is only available once per family.

If you are attending either of the clinics and would like to apply for support, call 800.753.2357 to speak with a family service coordinator.

The funding is made possible by a grant from the Alice and William Mortensen Foundation and a gift from Gerome Technologies.

## Sueña, Explora, y Descubre con nosotros

Únase con nosotros para la Conferencia Nacional de la Familia de la Fundación de Síndrome de Cornelia de Lange (SCdL), el 26 hasta 29 de junio 2014, en Costa Mesa, CA. La tema de la conferencia este año –Sueña. Explora. Descubre- se inspira en nuestra ciudad anfitriona.

La conferencia tendrá lugar en el hotel Hilton del Condado de Orange/Costa Mesa, a sólo 10 minutos del aeropuerto del condado de Orange (SNA) ya 45 minutos del aeropuerto internacional de Los Ángeles (LAX). Todas las habitaciones están equipadas con un refrigerador. Hay un servicio de transporte gratuito desde y hacia el aeropuerto del condado de Orange. Las atracciones cercanas incluyen Disneyland y Seaworld.

Para hacer reservaciones de hotel:

Teléfono: 714.513.3448

Online : [www.hilton.com](http://www.hilton.com)

Código de grupo (Group Code): CDLSF

Fecha límite de reserva: La tarifa con descuento termina el 26 de mayo, o tan pronto como la cuadra de la habitación se llena (el bloque de habitaciones agotó en 2012).

### WELCOME NEW FAMILIES

#### Georgia

Jillian and Darius and son Zion,  
born November 3, 2009

#### New York

Joy and Ernest and son Apollo,  
born August 12, 2013

#### Illinois

Chaitali and Alkesh and son  
Nihaar, born October 22, 2013

#### Ohio

Kristen and Derek and daughter  
Nicole, born August 1, 2011

#### Iowa

Alli and Matt and son Jameson,  
born May 3, 2013

#### Oklahoma

Sarah and Derek and son Noah,  
born August 20, 2013

#### New Hampshire

Jocelyn and Jennifer and daughter  
Julianna, born January 6, 2013

#### Texas

Sarah and Brandon and daughter  
Kinsley, born April 12, 2011



## Three Siblings. One Race. One Reason

Karyn Beaumont of Palatine, IL (pictured right), trained hard in preparation for the Bank of America Chicago Marathon this past October. She was joining her brother, Jeff Beaumont of Mount Prospect, IL, in his seventh Chicago race and sister, Katie Beaumont of Chicago, IL (pictured far right), in her second marathon.



When Karyn found herself struggling during her marathon training, she looked to her niece for motivation.

“There are times when every minute of training is hard,” says Karyn. “When Annie joined our family, she was not able to walk. She worked so

hard that first year and I think about all the pain and hard work she put in. I try and have that motivate me.”

Karyn, who has worked in special education for nine years, hopes that all families who are affected by CdLS find love and support in the Foundation.

“I’m doing nothing compared to parents and siblings out there who celebrate their children with CdLS every day. Keep on working. Keep on loving. Keep on being you. When rough patches get a little too rough, I want others to know we will always be here, as a CdLS family.”

While training at different paces for the Chicago Marathon, these siblings were all running for the same reason. Karyn, Katie and Jeff Beaumont, ran in honor of Jeff’s 11-year-old daughter, Annie, who was born with CdLS and who was the 2013 Team CdLS Ambassador.

Jeff and his wife, Charyn, adopted Annie and her twin sister Danielle, (who does not have CdLS) after the girls came to them as foster children at age three.



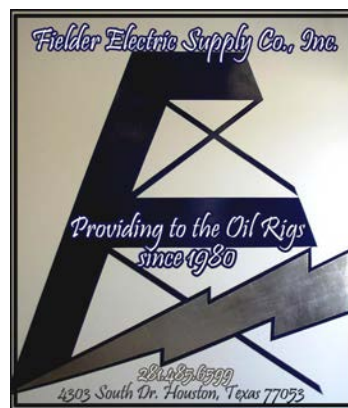
“I love that Annie has a very unassuming nature and is friendly with everyone, and for the most part this is reciprocated,” says Jeff. “She’ll go up to complete strangers and sit

on their lap, and she is usually greeted with a warm hug when she does that.”

“I like to go running or walking with Annie. She must find it very peaceful; she’ll sit calmly and take in her surroundings the whole time we’re out,” says Jeff. “She also loves the pool. She’s so excited to be in the water splashing around.”

Katie agreed with Annie’s love of water, explaining her recent babysitting experience. “I found Annie fully dressed in the empty bathtub, playing,” said Katie. “So I got in too. With our clothes on, it probably looked strange to the rubber duckies, but Annie and I didn’t mind!”

### Thank you to our 2014 Team CdLS Sponsors



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## Mailbag

### - Caitlin & Carol's Story -

*It is an honor and privilege to share our story, Caitlin, as you have touched my heart in ways I never imagined possible.*



I received a call from the school's special needs office in the beginning of September 2013. I was asked if I would be interested in the nursing job of transporting you. I was intrigued.

At first, I was consumed with your g-tubes feeds, since that was supposed to be my main nursing focus. Observing for seizures was also very important, along with keeping your hands occupied so you didn't pull out your g-tube or bite on your fingers.

I wish others could have seen the day I gave you an acoustic guitar, as you have a passion for anything musical. Other favorites are a rock and roll battery operated guitar, plastic hand clappers, and anything that plays music. One day I gave you bells on a plastic ribbon and you loved to hear the jingle.

Many days, I can only wonder what you're thinking when you laugh out loud, making me laugh with you. Every day after school, I read about your day and try to reinforce what you are learning, especially sign language. When I try to sign "hi," you are more interested in the shadows my hand makes. Now, I make different hand puppets, since you love to watch.

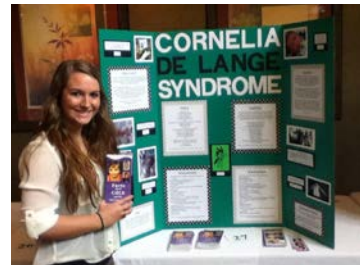
"Life is not measured by the number of breaths we take but by the moments that take our breath away." Caitlin, you took my breath away, as you returned a sign I had been teaching you for the past couple days. The sign was blowing kisses and today you blew five kisses at me. I will never forget your first sign and am very hopeful it will not be your last.

Miss Carol, Caitlin's aide, Massachusetts

Share your Mailbag or  
Super Sibling Story!

Send your story and photo to  
[bshepard@CdLSusa.org](mailto:bshepard@CdLSusa.org).

## Let Your Story Inspire Many



An inspirational story impacts lives. One of the most powerful ways you can help the Foundation, is simply by spreading the word and sharing your CdLS experiences with everyone back

home. Your story may touch one life, or the lives of many.

One of the most common questions asked following a presentation about CdLS at a local club or organization is, "What more can we do to help?"

If you, a family member or a friend belong to a club or an organization, reach out to them. Many clubs and organizations in your community welcome and encourage speakers to attend their weekly or monthly meetings. They take advantage of the opportunity to educate and inform their members of different interest groups, even a little known syndrome like CdLS.

We'll provide you with a customized power point presentation to reference while you speak, CdLS brochures for all attendees, and promotional items to distribute to your audience. It's that easy.

How should you start?  
Contact a local club or organization in your community and share your story.

Call 800.753.2357 or email [cduggan@CdLSusa.org](mailto:cduggan@CdLSusa.org) with any questions, or to get started.





## Dress Down for CdLS



At the CdLS Foundation office, the first Wednesday of each month is dress down day. Staff each give \$5—which adds up to \$540 annually. We figured, if we're on board, you might be too!

Join us to make Dress Down Day a weekly, monthly or even an annual event to help raise funds and awareness for the CdLS Foundation.

Here's what to do:

1. Get the okay from your employer.
2. Visit <http://www.cdlsusa.org/events/dress-down.htm> to request a CdLS Dress Down Day kit, which includes fliers to circulate and stickers for each participant.
3. Set the donation amount per participant, then select your Dress Down Day.
4. Complete the submission form after your event and mail it to the CdLS Foundation along with the money you collected.

Your workplace is awarded a certificate acknowledging your efforts and the Foundation's gratitude. If you have any questions, call 800.753.2357 or email [cduggan@CdLSusa.org](mailto:cduggan@CdLSusa.org).

## 2014 CALENDAR

**April 4**

Thank You Reception  
St. Louis, MO

**April 5**

Board of Directors Meeting  
St. Louis, MO

**April 12**

Multidisciplinary Clinic for  
Adolescents and Adults  
Greater Baltimore  
Medical Center  
Baltimore, MD

**April 19**

Kennedi's Bowl  
Lexington, KY

**May 10**

National Awareness Day

**May 10**

Northeast Foundation  
Sponsored Gathering  
Mt. Kisko, NY

**May 19**

22nd Annual CdLS Charity  
Golf Tournament  
Ipswich, MA

**June 22**

Merrell Down & Dirty  
National Mud Run  
Hartford, CT

**June 25-26**

CdLS Scientific &  
Educational Symposia  
Costa Mesa, CA

**June 26-29**

CdLS Foundation National  
Family Conference  
Costa Mesa, CA

**June 29**

de Lange Society Induction  
Costa Mesa, CA

**September 15**

26th Annual CdLS Charity  
Golf Tournament  
St Louis, MO

**September 27**

Northeast Foundation  
Sponsored Family Gathering  
Whitinsville, MA

**October 18**

Southeast Foundation  
Sponsored Family Gathering  
Sweetwater, TN

## Don't Miss the Boat!

There is still time to register for 2014 CdLS Foundation National Family Conference in Costa Mesa, CA. Join us as we dream, explore and discover at this special Foundation event. The registration deadline is May 26. Visit <http://www.cdlsusa.org/what-we-do/biennial-cdls-conference.htm> and reserve your spot.





## Donor Profile: Caring for Charlie All Year Long



Betty spends her time shuttling between the west and east coasts. With nine grandchildren, this “professional” grandmother wants to be there for all the special moments in their lives, especially with her two-year-old grandson, Charlie, who was born with CdLS. That’s why Betty, a supporter of the

Foundation, needed the convenience that becoming a monthly donor offers.

Betty’s priority is focusing on her grandson, and secondly on the fact that he has CdLS. During her visits with Charlie and his family, she celebrates each bite of food, each moment of eye contact, each sound, and step of Charlie’s. She relies on the Foundation’s quarterly newsletter, *Reaching Out*, to learn about medical and genetic issues that may relate to him. Her monthly gift provides the CdLS Foundation an ongoing, reliable source of funding to ensure services, like this publication, continue.

Just like Betty, the CdLS Foundation knows what it means to be there.

To learn more about the Foundation’s monthly giving program, contact Gail at [gspeers@CdLSusa.org](mailto:gspeers@CdLSusa.org) or call 800.753.2357. With monthly giving, it doesn’t matter when you start. It matters that you care.

## On the Cover

“Lindsay is 31 years old and has lived in a group home with four female residents for the past eight years. On weekdays she attends a community based day program that emphasizes behavior management. We bring Lindsay home on the weekends, and she loves music and enjoys sessions with a music therapist.”

“A recent trip to Disneyland served as a metaphor for all of us who share our lives with CdLS. Lindsay has enjoyed her past visits to Disneyland, but as we rode the escalator from the parking lot to the Disneyland shuttle bus, Lindsay was suddenly very apprehensive.”

“Lindsay only agreed that day to riding the Autopia cars, and slowly drifting through ‘It’s a Small World.’ At one point, suggesting even the gentlest of rides, she blurted out, “I don’t want a go to Disneyland!” That was a speech for Lindsay. This day was hers, not ours. We opted for a nice burrito lunch, and later enjoyed ice cream and posed for pictures with Goofy. The cover photo captures Lindsay smiling on Main Street USA, just before leaving. We asked Lindsay if she enjoyed her day at Disneyland. She nodded affirmatively.”

“For most, \$92 per person entry tickets for two slow rides and an ‘I don’t want a go to Disneyland!’ would spell disappointment. For us, a burrito, an ice cream, a big smile and an acknowledgement from Lindsay of a good day was all we needed. It’s a small world after all.”

*We thank Don and Amy for sharing Lindsay’s photo with the rest of the CdLS Foundation family.*



## CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
302 West Main Street #100  
Avon, CT 06001-3681  
800-753-2357 • [www.CdLSusa.org](http://www.CdLSusa.org)

Select a boat to be displayed at the Foundation’s National Family Conference:

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You may also dedicate your boat online at [www.CdLSusa.org](http://www.CdLSusa.org) or by contacting us at 800.753.2357.

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## Board Corner

*Bob Boneberg, President, Board of Directors*



It is my privilege to serve as president of the CdLS Foundation's Board of Directors. The board is made up of folks from across the country who are united by their interest in ensuring that the Foundation thrives as it meets the needs of our community not only today, but in the future.

Our 18 board members come from many backgrounds and have had many experiences that help them be effective board members. Many of us, like me, are the parent of a person with CdLS. We also are graced by the insights of board member Maegan Lowrey, who herself has been diagnosed with CdLS.

Foremost among our thoughts is: How can the Foundation be improved? As Marie highlighted in her Director's message, we're always seeking ideas, suggestions, and comments. We hope that you will share any insights or ask any questions by writing me at [President@CdLSusa.org](mailto:President@CdLSusa.org) or in care of the Foundation.

I look forward to seeing many of you at the family conference this June.

## Meet the Board: Dennis Drislane



Dennis Drislane is the newest member to join the CdLS Foundation's Board of Directors. Dennis currently serves as Chairman of BelHealth's Operating Committee. He also sits on the Boards of numerous other companies.

"Through my friendship with a parent of a young adult with CdLS, I came to understand how challenging it can be not only for individuals with CdLS, but also their families," said Drislane. "I look forward to helping educate people about CdLS, understanding that increased awareness means a better opportunity to find individuals who may not have received a diagnosis."

Dennis received his master of science in business administration, management information science, and his bachelor of science in business administration, computer information science, from California State University in Sacramento.

"I've become interested in genetics and how the genome impacts human health. I understand that the better we understand cell structure, the more potential there can be for therapies and treatments."

Dennis lives in Newport Beach, CA, with his wife, two teenage daughters and their dog.

### Registration for the Sixth National Cornelia de Lange Syndrome Scientific & Educational Symposia is now open.

Symposia will take place on June 25 & 26 in Costa Mesa, CA. The event brings together physicians in various clinical disciplines, scientific researchers, teachers, and allied health professionals. CMEs and CEUs are available for attendees. We encourage families to share this information with their healthcare professionals and educators.

Visit <http://www.cdlsusa.org/professional-education/cdls-symposia.htm> for more information or to register.



Donations from 12/1/2013-2/26/2014

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### Our Deepest Sympathy



**Tara Maureen Joyce**  
October 29, 1978 – November 17, 2013  
Daughter of Patricia and Gerard Joyce  
9214 Ridge Blvd Apt 6D  
Brooklyn, NY 11209-6212

*The date of Tara's passing was printed  
incorrectly in the First Quarter 2014 issue of  
Reaching Out.*

*The information provided above is correct.*

**Alex Copeland**  
August 3, 1982 – January 4, 2014  
Daughter of Marlene and Ron Copeland  
911 E. Moore Ave  
Searcy, AR 72143



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## CdLS Foundation

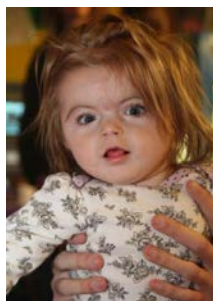
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May 10, 2014

Awareness Day



CdLS

Cornelia de Lange Syndrome Foundation

**Ideas to spread awareness for CdLS:**

- Share your family's story with the Foundation at [bshepard@CdLSusa.org](mailto:bshepard@CdLSusa.org) so we can distribute them throughout the year
- Share our new awareness video or a CdLS presentation to educate your friends and community
- Request a customizable CdLS Awareness Day proclamation from the CdLS Foundation



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