

# Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc.  First Quarter 2017

## Highlights

### Director's Message:

Welcoming the  
New Year and New  
Leadership

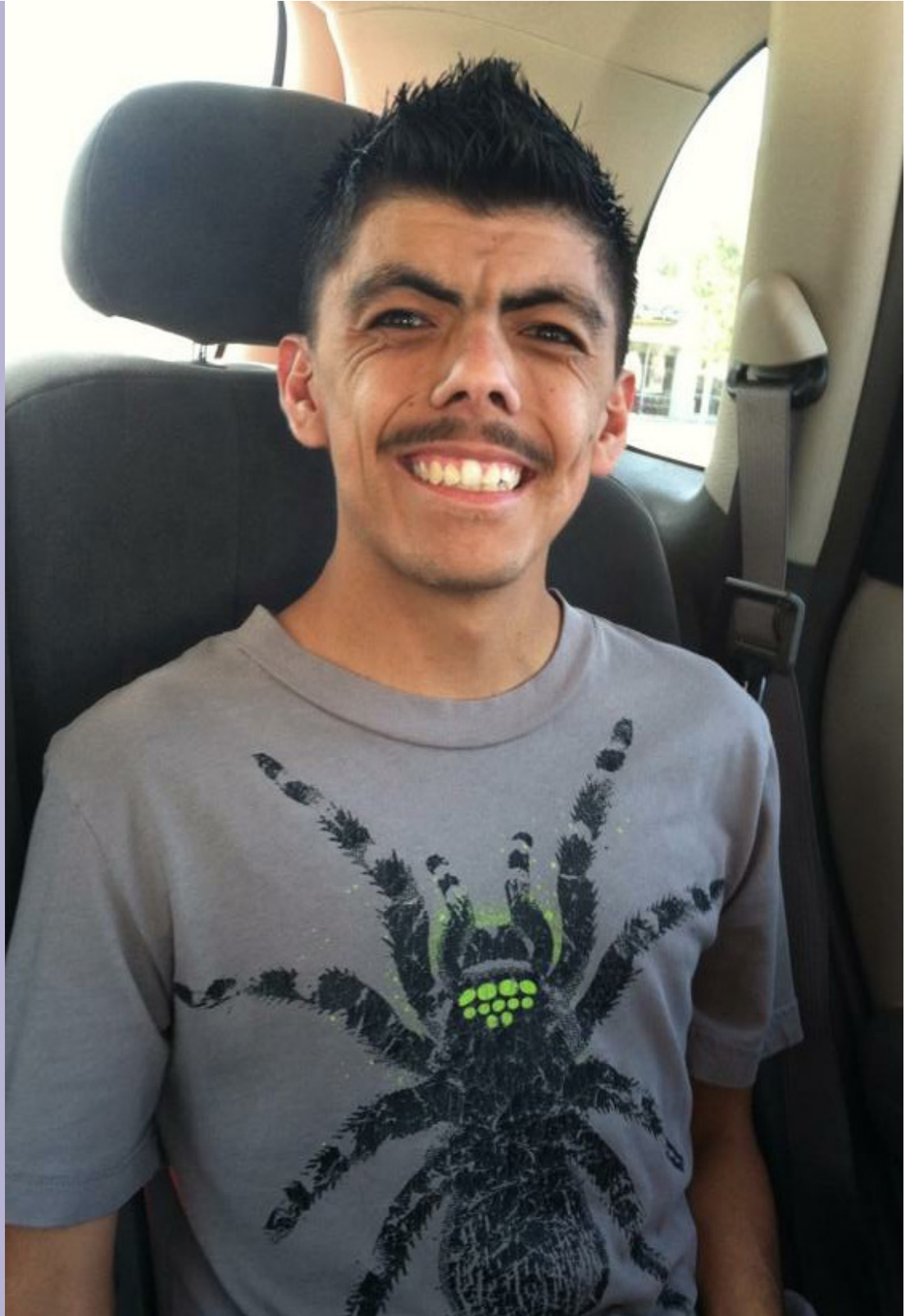
### Spotlights:

How to Identify  
Esophageal Obstruction

Healthy Coping Skills

### Super Relatives

Emily, Colin and  
Samuel





## Director's Message



### Welcoming the New Year and New Leadership

Dear Friends,

I am happy to write to you to introduce myself as the Executive Director of the Cornelia de Lange Syndrome Foundation. I am honored to have the opportunity to work in partnership with all of you to help evolve our Foundation into the future. As I learn more about the details of the work of our great organization, I feel indebted to the many great leaders and volunteers of the past who have put us in a position to step boldly into the future.

Just a word or two about me – my career has largely been focused in the customer service industry and I have held various leadership roles in the non-profit and for profit industries. However, my love and passion is helping young people achieve their full potential. When not working, you will find me talking and meeting with young people, taking walks in nature, or with my nose in a great book. I am a mom of 3 (2 in college) and a wife for 32 years to my friend, Anthony. My husband and I are actively involved in our community and always there to lend a helping hand to our neighbors and friends.

In just the first few weeks of joining the CdLS Foundation family, it has been apparent to me that the Foundation has been a beacon of hope for the families and their loved ones who live with this rare genetic syndrome. The very bones of our organization were built on compassion for others who share our destiny to love and learn from our loved ones with CdLS.

As we take stock of the last 40 years of the *Reaching Out* publication and move forward together we want to share more of your stories. We want to find new and innovative ways to share your struggles, milestones, and triumphs with others who may find themselves having a similar experience. It is our hope, that in this way we can grow our family base and circle of friends.

I am proud of how far we have come, and excited for the future we will create together as we continue growing, learning, and evolving as the premier organization leading the way in supporting the resilience of our CdLS families and friends.

Sincerely,

Bonnie Royster  
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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## New Initiatives



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

In 2017 we will introduce three new family-related initiatives for the CdLS Foundation. These will be relevant for the Foundation parents, caregivers, family members, and adults with CdLS.

### Siblings Program

Siblings have always played a huge part in the CdLS Foundation, not only because they are an intimate part of the family, but also because they are involved in the day-to-day care of a person with CdLS. At the CdLS National Family Conference, siblings meet others of similar age, and often discuss their desire to have a larger role in the Foundation. Over the years, brothers and sisters have combined their creative minds to produce new ideas for sibling-driven initiatives, including: running specific events at Conference, writing articles for *Reaching Out*, and assisting in the day-to-day operation of the Foundation. But that is just the beginning of a sibling's possible journey; we currently have a sibling who is President of the Board of Directors, and another that sits on the board! Thus, we are launching a new siblings group, providing opportunities for those 16 years of age and older. This would be a fabulous and enriching experience to include on your resume!

### New Resources

Resources are some of the most important tools the Foundation has to offer. We have always sent welcome packets to new families and professional providers who express interest. For the last decade, literature written in Spanish has been a growing need, and we now have sufficient resources to be able to provide on a larger scale. The next publication the Foundation will print is *Facing the Challenges* in Spanish, a core resource for caregivers. Various forms of literature are crucial for families, especially at the time of diagnosis of the child. *From One Dad to Another* is a resource for fathers of children and adults with CdLS. This publication highlights coping mechanisms and mindfulness techniques to reduce stress and maintain a positive outlook on diagnosis and life.

### Adults with CdLS Network

Finally, at the past few National Conferences, we have had a private meeting for adolescents and adults with CdLS who want to meet each other, communicate in the future and have an opportunity to expand their world together. This has been so successful that the Foundation is proud to expand the network for Adults with CdLS. The "Connect with Peers" feature is an online form that will allow adults with CdLS to request to be matched with other adults within their state, region, age group, or by hobbies.

These are just some of the new initiatives at the Foundation that we look forward to launching.

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**Cornelia de Lange Syndrome  
Foundation, Inc.**  
Incorporated December 1981  
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## How to Identify Esophageal Obstruction



*By Carol Potter, M.D., Associate Professor of Clinical Pediatrics at the Ohio State University and Nationwide Children's Hospital and member of Clinical Advisory Board/CdLS Foundation*

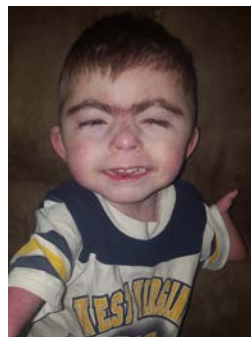
Just because a child doesn't eat, doesn't mean they won't swallow things they shouldn't. I have a little friend with CdLS from whom I have removed several swallowed objects from, including batteries, barrettes and hair ties. None of the events were witnessed, or even suspected until several days later.

Symptoms of swallowed foreign bodies are varied, and may not be present. A child may cough or gag if the object is in the esophagus or airway. They may not want to eat or not be able to swallow their secretions. If the object is in the stomach, they may have intermittent vomiting or discomfort. More serious complications such as bleeding or severe infection may occur if the object erodes through the gastrointestinal tract.

Button batteries in the esophagus are an emergency, as they start to cause significant tissue damage within 15 minutes. Another serious ingestion are high powered magnets like "Buckyballs." These dangerous objects were previously removed from the market, but recently returned to stores. The balls are easy to swallow and cause perforation when tissue is caught between two magnets. They should be discarded so children can't play with them.

Foreign bodies can be hard to find if they aren't metal, as they may not show up on X-ray. A variety of diagnostic tests can be performed to detect them, but you need to think about ingestion with unexplained symptoms if you are going to find them.

## A Closer Look: Eli



*Thank you to Eli's mom, Bethany, for submitting his story*

Eli is a happy, rather healthy 5-year-old. About a year ago he seemed to be congested and had extremely stinky breath. We made an appointment with his primary doctor. He gave us an antibiotic, except it didn't help at all. We went back to his doctor who told us he thought it was MRSA. He gave us a bacterial antibiotic. This took the smell away, but as soon as we completed the medicine regimen, the odor came right back. The odor just kept getting worse.

It got to the point that if you were in the same room as Eli, you could smell it. Our family attended conference in 2016 and saw specialists who we thought could help. We saw a dentist and GI doctor who gave us great advice, but it didn't lead to the source of the odor. We then made an appointment with an ENT. The first one we saw told us that we needed to brush his teeth really well, which we had been doing from the beginning. I tried to push them to do a scope because I had seen other kids with things lodged in their airway. They looked at me like I was crazy.

Our primary doctor finally got us a referral to another ENT who said he believed it was chronic adenoiditis. He recommended a sleep study to see if they should take his tonsils out as well. We had the sleep study and it showed that Eli had sleep apnea. The ENT said that he could not see his tonsils by just looking in his mouth. Therefore, they decided to do a scope, takeout his adenoids, and possibly his tonsils depending on what they found. The day he went in for surgery he was only in the OR for about 20 minutes. The doctor came out with pictures and told us that Eli had a Band-Aid lodged behind his uvula. The adenoidectomy was cancelled, and I went to see Eli in recovery. The smell was gone!

Since we have been home, the smell has not returned. Eli is not congested, his eyes are less runny and he has had no problems with his ears. He is all-around a much happier, more verbal child now.



## CdLS Registry

CoRDS, or the Coordination of Rare Diseases at Sanford, is based at Sanford Research in Sioux Falls, South Dakota. It provides researchers with a centralized, international patient registry for all rare diseases. This program allows patients and researchers to connect as easily as possible to help advance treatments and cures for rare diseases. The CoRDS team works with patient advocacy groups, individuals and researchers to help in the advancement of research in over 7,000 rare diseases. The registry is free for patients to enroll and researchers to access.



Enrolling is easy:

1. Complete the screening form.
2. Review the informed consent.
3. Answer the permission and data sharing questions.

After these steps, the enrollment process is complete. All other questions are voluntary. However, these questions are important to patients and their families to create awareness as well as to researchers to study rare diseases. This is why we ask our participants to update their information annually or anytime changes to their information occur.

Researchers can contact CoRDS to determine if the registry contains participants with the rare disease they are researching. If the researcher determines there is a sufficient number of participants or data on the rare disease of interest within the registry, the researcher can apply for access. Upon approval from the CoRDS Scientific Advisory Board, CoRDS staff will reach out to participants on behalf of the researcher. It is then up to the participant to determine if they would like to join the study.

Visit [sanfordresearch.org/CoRDS](http://sanfordresearch.org/CoRDS) to enroll.

## Equipment Exchange

The CdLS Foundation has researched existing programs that offer equipment exchange. The top sites that were user-friendly and inclusive of many types of medical and adaptive equipment are highlighted. We encourage you to visit the sites to see what is available or consider using them to offer equipment and/or medical supplies you no longer need.

You can find the sites posted at the bottom of the main page of our website [www.CdLSusa.org](http://www.CdLSusa.org) under “Outside Links.”



## Healthy Coping Skills



*Justyna Wawrzonek, L.M.S.W.*

### *Impacts of Stress on Parents, Caretakers and Families*

Parents and caretakers of children with CdLS are likely to experience increased stress due to the challenging realities of raising a child with special needs. They may often find themselves juggling the daily needs of their family with medical appointments, school meetings and advocating for services, in addition to the many other demanding tasks associated with caring for their family.

Parents and caretakers may also be burdened with financial pressures, as not all services are covered by insurance. Siblings may experience a heightened level of stress due to feeling overlooked or overly relied upon, as well.

Stress can impact our health and can greatly affect our relationships with partners, friends and, most importantly, our children. Parents and caretakers of children with CdLS and other disabilities may often feel isolated in their experiences. It is crucial that they take time to recharge and relax, especially in times of high stress.

Adapted from [www.abilitypath.org](http://www.abilitypath.org)

### **Healthy Ways to Cope with Stress**

1. Practice mindfulness
2. Take time for yourself
3. Express and share your feelings
4. Take care of your own health
5. Ask for what you need
6. Accept help
7. Utilize respite care
8. Focus on things you can control
9. Seek support from other parents and caretakers
10. Seek support from a professional

Adapted from [www.abilitypath.org](http://www.abilitypath.org)

### **Characteristics of Positive Coping**

1. Strong spousal relationship
2. Positive self-esteem
3. Being proactive
4. Acceptance of the reality of child's disability
5. Positive thinking
6. Seeking information and resources
7. Accepting help
8. Being an active advocate
9. Seeking social support
10. Focus on internal locus of control
11. Taking direct action to change the situation
12. Validation of one's feelings
13. Gaining a sense of empowerment through helping others
14. Taking pride in child's accomplishments

Adapted from the British Journal of Developmental Disabilities

### **Tips for Parents and Caretakers of a Child with CdLS**

- Learn as much as you can about CdLS
- Know your child's triggers
- Understand what soothes and calms your child
- Find programs and services to help your child
- Talk about how you're feeling
- Don't compare your child to other children
- Join a support group
- Be consistent
- Stick to a daily routine



- Reward positive behavior
- Take it one day at a time
- Create a “safe zone” for your child
- Celebrate child’s successes
- Love and accept your child for who they are

Adapted from [www.womenshealth.gov](http://www.womenshealth.gov)

## Helping Your Child Develop Coping Skills

Providing your child with healthy tools for coping may also have a positive impact on your wellbeing. Giving your child tools for healthy emotion regulation can reduce some stress that is associated with your child’s challenging behaviors as they learn to implement healthy coping skills.

### 1. Give Words to Feelings

Strong emotions can be scary for children, and they can fuel strong reactions. When children are able to express their emotions through a healthy outlet, their emotions may feel more manageable.

- When your child is upset offer him/her words to use such as mad, sad, frustrated, anxious, and embarrassed. If your child is non-verbal, you can offer a picture representation of emotions and allow your child to identify the emotion.
- Ask your child to tell or show you where he or she is feeling the emotions in the body.

### 2. Find Your Child’s Triggers

Think about which situations are toughest for your child. Children with disabilities generally have specific “triggers” such as words, images or sounds that signal danger or disruption to their feelings of safety and security. Children tend to develop their own “cues” in response to these triggers. Parents and caregivers can learn how to “read” these cues to understand when the child is having difficulty. These cues may include facial expression or nervous tics, changes in speech patterns, sweating, feeling ill, becoming quiet or withdrawn, complaining or getting irritable, exhibiting a fear or avoidance response, etc.

When you anticipate your child’s triggers or observe these cues, it is important to provide your child with assurance,

support and attention. If cues are missed, children may escalate their behavior to a point where they completely lose control.

It may also be helpful to consider how you can change your behavior to help your child cope. For example, if your child’s stress increases as you get dressed each morning, a picture schedule may be helpful for your child to anticipate what’s next.

It is also essential that parents, caregivers, teachers, and all other professionals who spend time with the child work together to share information about his or her cues and triggers.

### 3. Encourage Healthy Ways of Coping

Think about all the things your child already does to feel good. When you see your child getting upset, point out the coping skills he or she can use, such as holding a toy or blanket that elicits comfort, listening to music or other calming activities. Over time your child may turn to these coping skills on their own.

Keep in mind that a crucial part of how children learn to manage their emotions is through modeling. How adults express and manage their emotions will influence the reaction of a child.

### 4. Brainstorm Specific Coping Strategies

If your child doesn’t already have particular activities that calm him or her down, help your child develop ideas. Remind them of these when you begin to notice your child’s “cues”.

### 5. Be Present and Understanding

When your child feels emotional, give him or her your full attention. If your child sees you distracted, he or she may feel even more upset. Being present, offering your full attention, practicing active listening through restating what your child has shared, and asking related questions are helpful ways to help your child manage his or her emotions.

Continued on page 15





## Super Siblings - Emily, Colin and Samuel

*Thank you to Emily, Colin and Samuel's sister, for sharing her story with us.*

My relationship with my brothers is pretty typical of brother-sister relationships. While I sometimes wish I knew what it was like to have a “normal” brother, I wouldn’t trade them for anything.

Growing up, Colin and I were typical siblings. We fought, and sometimes we still do. I recently moved away from home again, and I think that has helped our relationship in some ways because we seem to get along better. Colin loves to send messages on Facebook at all hours of the day. His current obsession is bubble wrap, so he is always asking for “590 bubble wraps” or some other random amount. He also loves to be funny and make jokes to make people laugh.



Colin, Krista, Samuel, Emily, and Rapunzel at Disney before Conference last year.

Parents may say they don’t have a favorite child, but Colin, my sister, and I all agree that we have a favorite sibling: Samuel. I was 18 when we adopted Sam, who was nine months old. I wished for a “little” brother and he is certainly little! Until about a year ago, I lived at home for a while and did respite care for both my brothers. Now that I’ve moved away, I love when I come home to visit because Sam gets excited to see me and does his little “Sam dance.”

He doesn’t care to be picked up and hugged or cuddled, but that doesn’t stop me from trying. He loves to get attention and knows when all eyes are on him because he starts acting goofy. When he gets the giggles you can’t help but laugh with him. He certainly is an entertainer. I’m glad I have my brothers and wouldn’t want them any other way.

## Mailbag – Stephen



If you are reading this, then you must get the CdLS newsletter. If you read them cover to cover as I do, you would have read an update on Stephen in the first quarter of 2016. As my Stephen says, being disabled does not mean unable. How true that was back in July of this year.

My loving and adorable child—adult—saved his father’s life! I was on my way home when my cell phone rang. Being only two minutes from home, I did not answer. I drove around the corner to find an ambulance in front of the house and several other vehicles in the road.

Stephen had his phone in his hand and said Dad fell down the cellar stairs. His father was in a car accident the day before. Due to whiplash, Stephen’s father passed out and fell. He landed on the hard cement floor and was bleeding pretty bad.

I followed the ambulance to the trauma center by myself. I reluctantly left Stephen behind because our pets needed to be taken care of. I could not leave the hospital because his father’s injuries were life threatening; he was bleeding inside his skull and had broken every bone in his face. I had to remain there for three days and two nights. I never even left the room.

The next day I was told by a visitor what a great job Stephen did. He knew to call 911 and get help started before calling me. They kept asking him to check his father for certain things. Stephen told me this was difficult to do and still hold onto the phone. Usually, Stephen’s first reaction about anything is to call Mom. Stephen did an awesome job taking care of himself, the house and his pets. He was very understanding that I couldn’t come and get him to bring him to see his father.

I told Stephen he deserved a very special reward, but I did not know what it could be. Stephen told me he did what had to be done. According to him, he needed nothing. He said he has everything he needs. That is, as long as our cookie jar is never empty!

To all the wonderful CdLS families,  
Robin Marris, Stephen’s mom





## On the Cover: George



George is 27 years old and lives just outside Fresno, California. He attends a daily adult program at the Diamond Learning Center, and really enjoys it. George also loves music and attended his first concert last March. He was so excited to finally see Justin Bieber-live.

Some of his favorite pals are not what you'd expect—they're animals! George currently has a box turtle and three tarantulas; his most recent is a Mexican Red Knee tarantula. He is very fascinated with other spiders and reptiles as well, and has decorated his entire bedroom with three feet replicas. George is so fearless that he even lets some lizards climb on his chest and shoulders!

Though his family has regretfully missed the most recent gatherings in California, they hope that another is scheduled soon so they can spend time with friends from the CdLS community.

### WELCOME NEW FAMILIES

#### California

Jeitzen and Steven and son  
Steven born August 25, 2014

#### Massachusetts

Krystal and daughter born  
December 16, 2011

#### Illinois

Megan and Russell and son  
Charles born May 11, 2016

#### New York

Shanshan and daughter Hannah  
born on May 17, 2016

#### Kansas

Samantha and Jake and  
daughter Alice  
born August 7, 2016

#### North Carolina

Destiny and Nicholas and son  
Kristian born July 13, 2014

### Share your Mailbag or Super Sibling Story!

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

## 28th Missouri Golf Tournament

The CdLS Foundation held its 28th annual CdLS Charity Golf Tournament at the Tapawingo National Golf Club in St. Louis, MO., on October 10, 2016.

Anniversary Sponsors, Madison County Wood Products and Pallet Logistics Management, hosted the annual event in honor of Vice-President Doug Gaines' daughter, Amber, who has CdLS.

Jim Morton works for MCWP, and is a longtime friend of Gaines'. "The event was a success as we raised so much for the Foundation. Doug's daughter has CdLS, so it is very near and dear to our hearts," Morton said.

One hundred and sixty five people attended the tournament, which is an average turnout, according to Morton. Participants enjoyed 18 holes of golf, lunch, dinner, beer, soda, and snacks on the course, along with the opportunity to win both skill and door prizes.

Since 1989, the CdLS Charity Golf Tournament has raised more \$607,000 to help people with CdLS live better, fuller lives. This year over \$45,000 was raised, all of which will benefit the CdLS Foundation.

The tournament was sponsored by Madison County Wood Products; Pallet Logistics Management; TAG Truck Center; Crown Machinery; Weiss & Associates; Rustic Wood Products; Pennsylvania Indiana Lumbermans and Mutual Insurance Company; Union Machinery; Magnum Fasteners; Montgomery Bank; PECO Pallet; MFA Oil; Walt's Drive-A-Way Services, Inc.; Cass Commercial Bank; United Lumber & Reman, LLC; and the Kesting and Dieck family.

Missouri Golf Committee Members, Jim Kesting, Doug Gaines, Bryan Kesting, Paul Gaines, Jim Morton, Cheri Colby, and Steve Snodsmith are grateful of the continuous support of the sponsors, donors and attendees of the events.

Interested in being a part of a Golf Tournament Committee or attending the 2017 event? Contact: Kristi Larson, Development Manager, 800.753.2357 or [Klarson@CdLSUSA.org](mailto:Klarson@CdLSUSA.org).



## Event Highlights:

### One Love, One Heart 5K



On Saturday, December 3, crowds lined up at the starting line of the annual One Love, One Heart 5K in Decatur, GA. Runners donned fuzzy hats and long sleeves in the chilly start to winter in honor of the CdLS Foundation.

After a television news program mention, spirits were extra high for the annual race. Jim and Jen Pomfret started the One Love, One Heart to honor their daughter Maya, now 13 years old, who has CdLS.

Board of Directors member Fran Rissland coordinated a segment for the race on Atlanta & Company's Top Things to Do This Weekend through local traffic reporter Christopher "Crash" Clark. Fran met him back in August at the CdLS Brew & BBQ. Mr. Clark even attended the 5K to show support for "a cause near and dear to [his] heart."

Seventy-four runners blazed the trail and countless others showed their support along the route, all to raise funds for the Foundation. Attendance increased an astonishing 27% from last year's race.



The top three female runners were Paula Johnson at 21:20; Amanda Hollingsworth at 24:08 and Ninetta Violante at 25:37. The top male runners were Patrick Ollinger at 17:04; Fred Glass at 20:09 and Bryce Allen at 21:09.

One Love, One Heart raised more than \$13,000 for the CdLS Foundation. Thank you to the Pomfret family for their continuous efforts in hosting this event. We can't wait for next year!

### Walk for Will and Hope

Maureen Feighan-Kurth and husband Joel held their annual Walk for Will and Hope in Shelby Township, Michigan on October 16. The event is in honor of their two children with CdLS: daughter, Hope, and late son, Will.



Maureen said to friends on Facebook, "We are touched, humbled, honored, and awed by your generosity."

The leisurely 2-mile walk through the beautiful Stony Creek Metropark was met with its rainiest forecast ever. However, the dedication to the Foundation was demonstrated in the more than \$5,000 in funds raised. This brings the total raised to roughly \$35,000 since the walk began in 2009.

### Sarah's Bowl



On November 13, the 8th Annual Sarah's Bowl for CdLS rocked Batesville, Indiana. Teams gathered at East Bowl Family Fun Center and competed not only in bowling, but in

fundraising as well. Recognition was given to the teams bringing in the most donations for the CdLS Foundation.

"The CdLS Foundation has provided our family with education, hope and support over the last 11 years," said mother, Anne. "We chose to organize Sarah's Bowl for CdLS because we want the Foundation's mission to continue. The supporters of Sarah's Bowl are my family's biggest supporters. They, just like the Foundation, have always been there whenever we needed them."



## Guest Bartender

Many thanks to our friend David Fowler, brother to Logan, and member of Team CdLS. David served as a Host Bartender in New York City on December 1. All his tips were designated to the CdLS Foundation, and over \$2,500 was raised. Talk about creative fundraising ideas—and blazers!



Do you have a creative idea on how to raise awareness and funds for the CdLS Foundation? Contact Kristi Larson at [events@CdLSusa.org](mailto:events@CdLSusa.org).

## Team CdLS Review

We're sure that no group ran harder this year than Team CdLS. From mud runs to marathons, the team had a big event to look forward to almost every two months!

The 55 Team CdLS members proudly wore their race shirts throughout the country. Collectively, the team raised over \$161,000 in 2016 for the CdLS Foundation.



The New Year has us doing more than jumping for joy—Team CdLS will be running, biking and much more this season. Our full list of events is available on the calendar below and spots are filling up quickly. Can we count on you to team up for CdLS in 2017?

Contact Kristi Larson at [events@CdLSusa.org](mailto:events@CdLSusa.org).

## 2017 CALENDAR

**March 4**

Southwest Region  
Family Gathering  
Mesa, AZ

**March 8**

CdLS Clinic at  
Shriner's Hospital  
Salt Lake City, Utah

**March 19**

2017 United Airlines NYC  
Half Marathon  
New York, NY

**April 1**

Multidisciplinary Clinic for  
Adolescents and Adults  
Baltimore, MD

**April 29**

2017 REVEL  
Mt. Charleston  
Las Vegas, NV

**April 22-23**

Board of Director's meeting  
Hartford, CT

**April 30**

Southeast Region  
Family Gathering  
Johns Creek, GA

**May 7**

2017 TD Five Boro  
Bike Tour  
New York, NY

**May 13**

CdLS Awareness Day  
Nationwide

**May 22**

25th Annual CdLS Charity  
Golf Tournament  
Ipswich Country Club  
Ipswich, MA

**October 8**

2017 Bank of America  
Chicago Marathon  
Chicago, IL

**October 9**

29th Annual CdLS Charity  
Golf Tournament  
Sunset Hills, MO

**October 21**

2017 Baltimore  
Running Festival  
Baltimore, MD

**November 5**

2017 TCS New York City  
Marathon  
New York, NY





## Then and Now: A Review of the First Edition of *Reaching Out*

Technology has been astoundingly revolutionized within the past decade, let alone the last 40 years that *Reaching Out* has been published. Imagine in 1977, without internet or social media, how you would have obtained information about the little-known Cornelia de Lange syndrome? Would you have even heard about the diagnosis with such minimal resources and a seemingly vast world?

Forty years ago, families of children with CdLS were connected through newspaper and magazine articles. The first and only program our founders Sue Anthony and Carol Welsh debuted in 1977 was *Reaching Out*. Nine families received the five-page newsletter, in the hopes of learning something to benefit their children. There were no Facebook discussion boards, no biennial conferences and certainly no crucial multidisciplinary CdLS clinics.

This is what families faced less than half a century ago.

Today, a quick phone call or email to the Foundation can result in a plethora of informational resources and contacts for knowledgeable professionals. Numerous publications have been also tailored for different people caring for those with CdLS. At the end of 2016 two new booklets were published; one directly for fathers and the other for caretakers about self-help. This year, the CdLS Foundation reflects on where we've been and where we're headed, and we want to pay homage to the *Reaching Out* that started it all.

The first issue introduced a grassroots effort to share and learn about CdLS in hopes that "a national organization will meet this need." Carol and Sue wrote, "We chose *Reaching Out* as our name because that is our purpose—to reach out and offer encouragement to as many families as possible." Their original goals were to offer ideas on a variety of topics such as homecare, behavior, reading materials, personal experiences, and professional opinions. The Foundation strives to continue to incorporate the same sentiments into each newsletter since.

Original families had to apply for membership, sending in their name, address, phone number, and a check for

the nominal membership fee to the home address of Sue. Today, families receive all of our services free of charge due to fundraising and grant funding; an innovation in and of itself after the Foundation's official non-profit incorporation in 1981.

Sue's 12-year-old daughter Kathy was highlighted for a large portion of the newsletter, with her mom doting about accomplishments and struggles throughout her life. Aside from individual correspondence with the founders of the publication, this was the first long form of what we'd call a "Mailbag" today.

Sue and Carol were developing a parent booklet at the time of the newsletter. Just as revisions were beginning to take place they decided to not publish it and instead they suggested reading material they found helpful. A few examples of their suggestions were *Exceptional Parent Magazine*; *New Dimensions for Parents of Persons Who Are Retarded*; and *Feed Me, I'm Yours*. Today, there are countless brochures and pamphlets available for parents regarding CdLS-specific information on medical treatments, adult transition, education and more.

The final article of the first *Reaching Out* included survey results. Over three years, Carol had corresponded with approximately 16 families and sent out a voluntary questionnaire; 13 families returned it. Landmarks for children with CdLS were established by the results, including average birth weights, response to affection, and the average age of parents. The most frequent medical problems mentioned by families included: feeding difficulties, sitting, upper respiratory infections, regurgitation, and external physical anomalies.

As the CdLS Foundation continues to improve its outreach and fill gaps in literature for families and professionals, it is important to reflect on the progress we have made in just 40 years. From five pages to nearly twenty, *Reaching Out* has remained a staple of the support continuously provided to families. We are proud to carry on the tradition today and hope you will remain a loyal reader for years to come.

The Foundation also takes this opportunity to extend our most heartfelt thanks to our founders, Sue Anthony and Carol Welsh, for starting the tradition of *Reaching Out*.





## Celebrate Reaching Out's 40th Anniversary



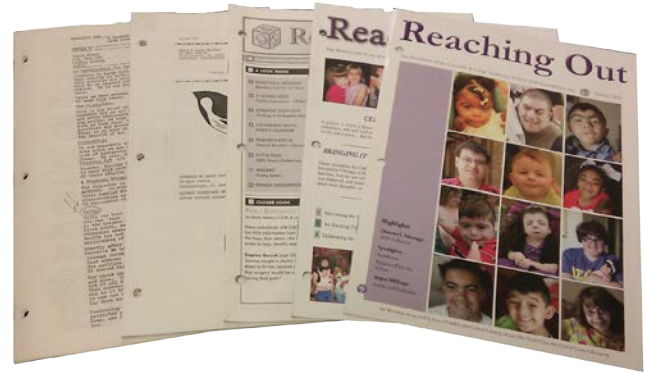
It's hard to believe that the first edition of *Reaching Out* was published nearly half a century ago. In those times, founders Sue Anthony and Carol Power (pictured left), had just begun organizing a grassroots support group for families of children with CdLS. Though they had met only years before through

a newspaper article, the cross-country friendship sparked what would later be an accredited nonprofit organization we know as the CdLS Foundation.

The *Reaching Out* newsletter was the pair's only program in the summer of 1977. The first edition was created using a typewriter and mimeograph machine—the photocopier of the time, complete with a windup handle and stencil.

Though only nine families were known at the time of the first publication, Sue and Carol sent them the publication. They realized early on how crucial it was for CdLS families to know they are not alone.

In 1980, Sue submitted a letter to *Exceptional Parent Magazine*, to which 18 families responded by convening for a picnic in Maryland. And thus, a community blossomed; a support network grew out of two women's dedication and dream.



In 2017, the Foundation asks you to consider a donation in honor of *Reaching Out's* 40<sup>th</sup> anniversary, to keep this dream alive. A commemorative gift of \$40 will support the reimagining of the iconic newsletter that sits before you. Our team is looking forward to creating an updated design. Your gift will ensure that *Reaching Out* will continue to serve as a vital resource for all of our CdLS families.

Make your commitment by filling out the form below and returning it to the Foundation.

**Love** something in this issue?  
 Want to see **something else** in here?  
**Let us know** your thoughts about *Reaching Out*, and what you'd like to see in future issues, by visiting  
<https://www.surveymonkey.com/r/TKSFMLQ>



### 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)

Yes, I would like to contribute towards a reimagining of the iconic *Reaching Out* newsletter!

Enclosed is my tax-deductible gift of:

- ☐ Other \$ \_\_\_\_\_ ☐ \$500 ☐ \$250  
☐ \$100 ☐ \$50 ☐ \$40

☐ I have included the CdLS Foundation in my will or trust.

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Donate online at [www.CdLSusa.org](http://www.CdLSusa.org).



## Board Corner



*By Richard Haaland, Ph.D., President,  
Board of Directors; CdLS Foundation  
Research Committee Chair*

As we begin 2017, the CdLS Foundation Board of Directors recognizes that we need insight from various viewpoints to ensure we are able to enhance the well-being of all people and families affected by CdLS. The Board welcomes three new members this year who each bring a much-needed voice in aspects we deem critical to helping the Foundation improve its current efforts, but also to build new services that meet the needs of everyone affected by CdLS.

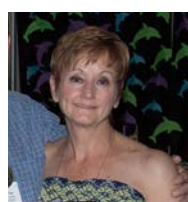
Much of the success of the biennial CdLS National Family Conference can be traced back to Angie Young, who has spent a number of years tirelessly working with the Conference Committee to ensure its success on several levels. We welcome Angie's insight on how to help continue the great tradition of the Conference, but also identify ways to improve future Conferences.

It has become evident that the Foundation serves a growing number of talented and wonderful adults with CdLS, a growing focus of the Foundation. As an Awareness Coordinator and young adult with CdLS, Emily Turner has been a vocal advocate for all people with CdLS. We look forward to Emily's insight in helping the Foundation craft new ways to meet the needs of adults with CdLS and their families.

As the Foundation looks to meeting the growing needs of everyone affected by CdLS, it must strive to efficiently use its current financial resources and identify novel ways to support new fundraising efforts. Mike Feehan has worked with the Finance Committee for several years to ensure that the CdLS Foundation is a responsible steward of its resources, and has sought ways to meet our changing needs.

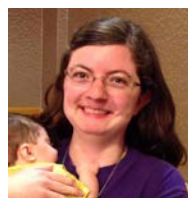
We thank Angie, Emily and Mike for taking time out of their schedules to bring their insight and talents to the Board of Directors. The CdLS Foundation depends on people like them to help ensure it's ability to meet the ever-growing needs of all people and families affected by CdLS.

## Meet the New Board Members



### **Angie Young, Florida**

Angie attended her first family gathering in 1993 in Maryland with her son, Aaron, and has been active with the Foundation ever since. She began as a Regional Coordinator and currently serves as an Awareness Coordinator in Florida. Angie hosted her first regional gathering in 2001. She continues to bring people with CdLS together, providing families with the opportunity to meet one another in order to foster support in their areas. Furthermore, she has served on the Conference Planning Committee as both co-chair and chair, and was host family for the national conference in 1995. In 2014, Angie was inducted into the de Lange society for her more than 20 years of service.



### **Emily Turner, Alabama**

Emily earned her Associate of Arts degree in 2015. She was a Girl Scout for 14 years, participating in various leadership programs in her community in Alabama. Along with traveling four times on church missions to Guyana, she has presented at Conference several times and also volunteers. Since 2012, Emily has served as a CdLS Foundation Awareness Coordinator. Emily is also a member of the Family Service Committee and actively participates in the Adults with CdLS Network. She has tremendous support from her family, who has pushed Emily to live a typical teen and young adult life.



### **Mike Feehan, Pennsylvania**

Mike is the Vice President of Finance and Treasurer for PQ Corporation, a leading global producer of specialty inorganic performance chemicals, catalyst, sulfuric acid, and engineered glass materials. He is a graduate of the University of Notre Dame and earned his Master of Business Administration degree from Villanova University. Mike serves on the finance committee and has been a Team CdLS runner for seven years – raising more than \$125,000 for the Foundation. He also runs in honor of his eight-year-old son, Connor.



## Healthy Coping Skills cont.

### 6. Seek Help When Needed

When you rely on others for help, you show your child that there are many components to a healthy coping strategy. Connecting with parents, professionals and other resources in your community are a few ways you can obtain help and support, as well as model a healthy way of coping for your child.

Adapted from [www.understood.org](http://www.understood.org) and [www.naspoonline.com](http://www.naspoonline.com)

### Tips for Non-Verbal Coping

Teaching your child healthy coping skills does not have to rely on language as the form of communication for expressing feelings and emotions. You communicate with your child by the way you look, the way you touch, the tone of your voice, and your body language. Your child is also communicating to you in many non-verbal ways. It is important to learn and understand your child's language in order to best help them cope.

1. Look for non-verbal cues. Observe the kinds of sounds your child makes, the facial expressions and the gestures he or she uses when tired, hungry, etc.
2. Figure out the need behind the tantrum. When non-verbal children act out, it is often because you are not acknowledging their non-verbal cues. They

feel misunderstood or even ignored. Throwing a tantrum or demonstrating other challenging behaviors is their way of communicating their frustration and getting your attention.

3. Make time for fun. A child coping with CdLS needs more to life than medical care, therapy and other clinical services. It is important to figure out ways to have fun as well. Think about the things that make your child smile, laugh and become outgoing. There are tremendous benefits that result from enjoying your child's company and from your child's enjoyment of spending unpressured time with you. Play is an essential part of learning and should not feel like work.
4. Pay attention to your child's sensory activities. Some children with CdLS are hypersensitive to light, sound, taste, and smell. Other children are under-sensitive to sensory stimuli. It is important to figure out what sensations trigger your child and what elicits a positive response. This understanding can help manage stressful situations and create a more positive experience for yourself and your child.

Adapted from [www.helpguide.org](http://www.helpguide.org)



### Our Deepest Sympathy



**Tyrone Beaty**  
June 7, 1986 – September 27, 2016  
Son of Sherry Beaty  
222 Waddell Road  
Woodruff, SC 29388

**Darlene Hill**  
June 25, 1978 – May 25, 2016  
Daughter of Christel and William Hill  
14573 Handsdale St  
Adelanto, CA 92301

**Conrad Alan Hersberger**  
March 25, 1990 – November 8, 2016  
Son of Tammy and Scott Hersberger  
PO Box 427  
Lapel, IN 46051-0427

**Dallas Charles Corbett**  
November 27, 2000 – November 5, 2016  
Son of Tonya Baker and John C. Corbett  
Tonya and Dustin Baker  
806 Merestone Dr  
Winnabow, NC 28479-5196

And  
John and Stephanie Corbett  
4041 NC Highway 11  
Kelly, NC 28448-8697

**Randy Hoglund**  
May 31, 1986 – November 15, 2016  
Son of Patty Hoglund  
4144 53rd Ave. W., Apt. 911  
Bradenton, FL 34210

**Brian Lynch**  
March 20, 1971 – January 1, 2017  
Son of Marilyn and Larry Lynch  
502 SE 22nd Street  
Mineral Wills, TX 76067

**Amanda Liby**  
March 10, 1992 – December 9, 2016  
Daughter of Lora Wooten and Brian Liby  
560 General Banks Lane  
Madison, VA 22727



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## CdLS Family Map

Below is a map of the number of families we are in contact with from each state, as of December 2016.

