

# Reaching Out

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

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Reimagining Through  
Retrospective

### Spotlights:

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Does Not have CdLS

Impulsive Behaviors and CdLS

### Super Peers

Luke & His 3rd Grade Class





## Director's Message



### Reimagining Through Retrospective

**1970s Johnny Burchett by mother, Faye**—When Johnny was born, no one knew what his condition was. He is now one of the oldest living children with CdLS at 54. The first issue of *Reaching Out* had the look of run-off copies with stapled pages. The magazine is very important because it helps families meet others for support, assistance and sometimes, just an ear for listening.

**1980s Amber Gaines by parents, Doug and Barbara**—Amber was diagnosed with CdLS at three months old, and we were told that CdLS was so rare, there would be very few other cases. Our first contact was with another parent, and it was like turning on a light bulb for the first time. We thank everyone at the Foundation and from *Reaching Out* for all the support you have given us over these beautiful, blessed years with our daughter.

**1990s Devin Miller by mother, Lynnette**—"The Devinator" was diagnosed at four days old. In the early days, *Reaching Out* was our lifeline. Before the Internet, it was the only way to really feel connected. Even today, *Reaching Out* is essential to help families feel supported, informed and included. Devin is now 27 and we continue to look to the Foundation for support and knowledge.

**2000s Lilly Choong by grandmother, Lil**—We were told about the Foundation when Lilly was diagnosed. Our relationship with the Foundation is an ongoing one, either calling or going online. *Reaching Out* is important for parents because you read about experiences from others and know that you're not alone.

**2010s Chase Duff by mother, April**—Once Chase had a clinical diagnosis, my husband found the Foundation. It was our initial go-to. *Reaching Out* focuses on all different areas and it's nice to see other families overcoming struggles. I sometimes see stories from the discussion board published in *Reaching Out*, and it brings the idea that this is a small-knit community full-circle.

We invite you to celebrate the individuals with CdLS that have graced these pages for forty years. Help us continue the tradition of information and support through a donation to the reimagining of *Reaching Out* for families of today, and tomorrow.

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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## Foundation Medical Director Awarded for Long-Time Work with Families



You may have heard the recent news about Dr. Tonie Kline's recognition from Global Genes as the RARE Champion of Hope in Medical Care and Treatment. According to Global Genes, "over 200 individuals and organizations worldwide were nominated by their peers for a RARE Champion of Hope award for their notable efforts in rare disease advocacy, science, collaborative sciences, medical care and treatment."

Not only does Kline provide care for individuals with CdLS, and provide advice and support for their parents and family members as the Foundation's medical director, but she also cares in a very personal way for families around the world, and showcases this in her efforts with the Foundation's running group, Team CdLS. Kline has championed a team in the Baltimore Running Festival for many years, and raises funds for the event with her family members. Her family members volunteer at events, raises money through honey sales, and are always champions of our cause.



Please join us in thanking Dr. Kline for all of her hard work and dedication to the Foundation and the CdLS community, and congratulating her on this well-deserved award.

### Please take our survey!

Dr. Kline has created a survey that will provide important insight into how we can continue to improve the health and lives of our CdLS community. We hope you will participate. You'll find the survey on pages 15 and 16 of this edition of *Reaching Out* or you can take it online at [bit.ly/kline-survey](http://bit.ly/kline-survey).

#### Reaching Out

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Cornelia de Lange Syndrome  
Foundation, Inc.

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

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

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## Ways to Support Your Child Who Does Not have CdLS



*By Katie Nikzad-Terhune, Ph.D., LCSW, Assistant Professor, Northern Kentucky University, Board of Directors, CdLS Foundation*

As a CdLS sibling myself, I remember the joy of growing up with my little sister with CdLS.

I also remember the stress and challenges that having a CdLS sibling brought to our family. Having a child with special needs is a family issue, and it impacts the lives of each person within the family unit. Brothers and sisters of a child with CdLS are frequently faced with the challenges that naturally come with having a sibling with special needs, but do not yet have the emotional maturity or abilities to cope with these stressful experiences. While there are many benefits to being raised in a household with a special needs child, it is wise to be mindful of the common struggles that CdLS siblings may face.

Common feelings experienced by CdLS siblings may include:

- Feeling worried about their sibling, or afraid of losing their sibling
- Feeling resentful about having a sibling with special needs
- Feeling embarrassed about having a sibling who is different
- Feeling pressure to do what their sibling is unable to do
- Feeling jealous about the extra time and attention their sibling receives
- Feeling guilty about having negative feelings
- Feeling guilty about having abilities that their sibling does not have

Being aware of what your typically developing children are feeling and experiencing is the first step to ensuring that their needs are being met, and that they are adjusting

healthily to your current family situation. Here are ways to support your children who do not have CdLS:

**Communicate Regularly:** It is essential to talk regularly to your typically developing child about what they are feeling, and what their needs are. Give them permission to talk about emotions that may be uncomfortable, such as guilt or resentment. Create an emotionally safe environment for them to disclose and be honest.

**Let Them Be Children:** CdLS siblings often develop many caregiving and nurturing skills at a young age. They learn to change diapers, do the feeding and bathing, and they become natural protectors of their sibling with CdLS. This truly is a wonderful experience, but make sure it is balanced. They are still children themselves, and need to experience the lightheartedness of childhood. Ensure that your children are engaging in common childhood activities...time with friends, sleepovers, and extracurricular activities at school. Be mindful about keeping adult conversations private. Finally, make sure that your expectations of your children are reasonable for their age.

**Provide Ample Attention:** It is not uncommon for your child with CdLS to often require extra time, services, and care on a regular basis. Be intentional about providing ample one-on-one time with your other children, and create special traditions that are unique to just you and them.

**Teach Coping Skills:** Teach your children how to cope healthily with life when it becomes difficult. Teach them that it is normal to experience stressors from time to time, and then teach them what to do when life becomes stressful. Help them develop ways to express their emotions and self-soothe when they become upset. Journaling, exercising, deep breathing, and family discussions are just a few coping skills to consider teaching your children. If your child is struggling with coping with challenging situations, consider letting them talk to a therapist or a school counselor.

**Model Healthy Self-Care and Coping:** The best way to teach your children about healthy coping is to let them see you doing it. Practice healthy self-care strategies in front of them, and utilize open communication and problem solving strategies regularly within your household. You are your child's best teacher!



**Provide Reassurance:** Periodically reassure your typically developing children that their sibling with CdLS is receiving appropriate care and services. Highlight the special achievements of your child with CdLS (e.g., walking, language development), and let your children ask questions about the medical, social, and educational services their sibling is receiving.

**Ask for Help:** Providing ample support to all of your family members is sometimes difficult, but you do not have to do it alone. Let other trusted individuals play a role in supporting your typically developing children. The CdLS Foundation is always available to provide family support.

Despite the challenges that CdLS families face, I want to conclude by emphasizing the amazing qualities your typically developing child will develop as a result of having a sibling with CdLS. Children with CdLS siblings are often wise beyond their years. They develop compassion, empathy, maturity, loyalty, gratitude, resilience, and social adeptness. They learn to be patient and accepting of others at a young age, and they are more mindful and empathic of those who are different. Look for these attributes in your typically developing children, and celebrate them.

#### **Resources for special needs siblings:**

1. [Siblingsupport.org](http://Siblingsupport.org)
2. [www.CdLSusa.org](http://www.CdLSusa.org)
3. Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs (Meyer)

## **A Closer Look: Supporting Sofia**



My sister, Sofia, was diagnosed with CdLS when I was four years old. I often say that growing into my identity as a sibling of someone with CdLS came in two phases: coping with Sofia

being sick, and coping with Sofia being special needs. When Sofia was in the hospital as a baby, I was so young that I didn't quite understand what was happening. My parents were always gone with Sofia at the hospital and she was always hooked up to big machines that I wasn't allowed to touch. I was never allowed to play with her and I wondered why other kids in my class spent their weekends playing sports while we spent our weekends playing in the playroom at the hospital. Things were often confusing and frustrating and my other sisters and I struggled with our parents being primarily focused the issues surrounding Sofia's health.

As I got older, Sofia's health improved and we began to navigate what life for Sofia and for us would be like in light of her CdLS diagnosis. Even the smallest of things had to center around Sofia. Decisions about vacations, family dinners, trips to the grocery store and even going to the car wash all had to be made keeping in mind how Sofia might respond or react. She was usually the priority and was constantly the center of our world. I'd be lying if I said there weren't times when having a sister with special needs seemed totally and completely unfair. However, looking back on it, all the challenges and frustrations shaped me into the person I am today in a multitude of ways. I had to grow up faster than most kids my age, but in the process, developed patience, compassion, confidence and independence. Most importantly, however, I learned to trust that Sofia was put in our lives for a reason, and from this, I have learned so much about who I am and who I am meant to be.

My advice to anyone struggling with a sibling's diagnosis is to trust the process, always keep your expectations for your sibling realistic and have an open mind. Having a sibling with CdLS is not easy, but it's the most rewarding part of my day—every single day.

- Isabel T., Sister to Sofia



## Impulsive Behaviors and CdLS



*By Julia O'Connor, Ph.D., Kennedy Krieger Institute & The Johns Hopkins University School of Medicine*

Some individuals with CdLS present with impulsive behaviors. Impulsivity can take many forms such as responding too soon, running off and grabbing items/people. Sometimes, these can lead to an individual becoming angry/explosive which can cause harm to self or others.

The first part is to realize that you are not alone. When challenging behaviors are seen at home, they are often happening in school, day programs and/or in the community, too. Once a behavior has been identified, clearly define the specific behavior, so that you can talk with others. Reach out to staff at the individual's school, day placement and/or home to discuss the behavior and to build a team of individuals who will support and assist you in this process.

If behaviors are severe, persistent or impacting the individual's ability to be as independent as possible, seek a referral from someone familiar with behavior challenges such as a clinical psychologist, Board Certified Behavior Analyst, or psychiatrist. Sometimes, assessment and treatment would incorporate both a behavior plan along with possible medication management. The combination of these has been evaluated to be more effective across a variety of behaviors as well as a variety of developmental disabilities.

To begin the process, start by ruling out any medical possibilities such as pain or discomfort, especially from gastrointestinal issues. Once medical issues have been addressed, it is important to evaluate the environment to identify any possible triggers for the behaviors. To do this, document what happens before, during and after the behavior occurs. These records will allow you and your team to develop possible hypotheses about why the behavior is occurring and under what circumstances the behavior occurs. Possible hypotheses include: to get attention, to get something the individual wants, to get out of doing something the individual does not want to do or to get sensory reinforcement (i.e., internal stimulation).

Once a hypothesis has been developed, a treatment needs to be designed to match the hypothesis. If a behavior is hypothesized to occur to get attention, the individual needs to be taught an appropriate way to get attention (i.e., raise his/her hand to respond in class) while the challenging behavior no longer receives attention. Treatment strategies could also include: redirecting to other activities, reinforcing appropriate behaviors and teaching coping strategies (i.e., behavioral relaxation training, deep breathing).

For behaviors that are hypothesized to be related to anxiety, make sure the individual knows what to expect in the situation, use a picture schedule, develop a social story and/or provide warnings about any changes.

To evaluate effective treatments, continue data collection throughout assessment and treatment process. It is often the case that challenging behaviors may get worse before they get better, so be prepared. When families change how they respond, the individual with CdLS may continue to use the challenging behavior because the behavior had previously been responded to in a different way. Stick with the treatment and remember to consult with your team of professionals and re-evaluate if the behavior plan is not improving.

### WELCOME NEW FAMILIES

#### Arkansas

Melissa and daughter Coara,  
born February 22, 2017

#### Oregon

Michelle and Joseph and  
daughter Caaz,  
born March 5, 2005

#### Colorado

Tami and Mike and  
daughter Kate,  
born December 23, 2016

#### South Carolina

Jennifer and Gerome and  
daughter Maggie,  
born July 22, 2017

#### Montana

Lyndsey and Chris and  
daughter Brie,  
born July 5, 2016

#### Washington

Ali and son Asher,  
born April 19, 2017

#### New Jersey

Melanie and Joseph and  
daughter Lily,  
born July 18, 2017





## A Closer Look: Annie



*Thank you to Charyn, mother to Annie, for sharing their story with us.*

Annie has some impulsive behaviors, including hair pulling, and most often, it comes down to the main thought that if Annie wants to do something, she's not going to stop wanting it.

In the moment, Annie does exhibit these behaviors when she's more emotionally heightened, but it isn't necessarily impulsive, because she sometimes becomes obsessed with doing things when she's not upset either. With hair pulling and pinching, we feel as though these are actions that she just can't stop on her own. She can't NOT pull the hair.

Her big things that she loves most are taking baths, bringing food into bed, and hair pulling and pinching. Even when we say "no," we're aware that she's going to continue to want to take a bath. She'll go so far as to going up into the bathtub and turning on the water with her clothes on. She knows she's not supposed to do that, and even when we tell her no, she obsesses over wanting to take a bath, because it's something she likes. She knows the word "no," and understands that we're saying "no," but she just can't help that desire. She looks at us, and understands, but continues on her way to the bathroom.

There are certainly triggers that set this behavior off, such as loud noises, crowds and over-stimulation, but we're aware of those and do our best to be prepared. First, consistency has been key for everyone in our household, from our youngest (five-year-old) to my husband and I. All of Annie's siblings know to keep bathroom doors locked, and they know tricks to calm her down.

We do a lot of preventative measures for Annie's impulses to try and stop them before they begin or have a chance to grow. In crowds, like at her sibling's soccer games for example, we bring blankets because Annie loves to cozy up underneath the thick, heavy blankets and on top of the blankets, and must cover her whole body, but it helps her stay calm. We also have large headphones she will wear with built in radio to play music which can

help cut out stimuli, but also because Annie loves music (Christmas music is her favorite right now). She also likes deep pressure, like sitting on our laps and having us hold her hands into her chest; even her siblings help with this. We sing into her ears when she's getting upset, and since she likes music that helps.

Mostly, we just continue to stay on message and be repetitive. We say, "no" and show her the hand sign for it. Sometimes when we know this behavior will keep happening, we'll get her communication device and reiterate the message on that as well.

### CdLS Empowerment Team

Creating a setting where adults with CdLS can come together as a group to support and empower one other in their communities. The team encourages members to socialize, and develop relationships across the country through a variety of opportunities.

Interested in joining the CdLS Empowerment Team? For further information, please contact Whitney Rinaldi at [familyservices@cdlsusa.org](mailto:familyservices@cdlsusa.org) or call 800.753.2357.





## Rugged Maniac - Carr Family

On July 8, Shawn Carr participated in the Spartan Race in Palmerton, Pennsylvania at the Blue Mountain Ski Resort, in honor of his daughter, Layla Ann. Along with his brother, cousins and friends, the group has been fundraising for the Cornelia de Lange Syndrome (CdLS) Foundation and training for the race.



"This year's race was the hardest thing I've ever done physically. I actually thought this was going to be quite a bit easier than last year's 10 mile beach run in Sea Isle that we did for Team CdLS. I was way wrong!" Shawn explained, "We basically started out by running up a mountain. From there it was obstacles such as monkey bars, sandbag carries up and down the mountain, sled pulls, and wall climbs. It was really challenging but everyone finished, took themselves to another level both physically and mentally and we all had a great time," said Shawn.



The Carr family has raised over \$25,000 in memory of their daughter, who died from heart disease associated with CdLS three days after her birth in May of 2014. For this run, Shawn and his wife have raised almost \$3,000.

The family found the CdLS Foundation after Layla's passing and Shawn immediately signed up for a mud run, "It has been over 3 years now since the birth and passing of our daughter, Layla. Over this time we have had a lot of changes, including the birth of our son, who now shares the same birthday as Layla, if you can believe it. During these three years the one thing we have tried to continue is our support of the Cornelia de Lange Syndrome Foundation in Layla's memory," he said.

## American Legion National Convention: A Spotlight on CdLS



The CdLS Foundation was invited to the 99th Annual American Legion National Convention in Reno, NV, from August 17 to 22. The Foundation has been a recipient of the American Legion's Child Welfare Foundation grants for several years, and was asked

to showcase the work that was produced through the grants. Over 9,000 attendees, American Legion members and their family members, had the opportunity to view the following publications: The CdLS Foundation Educational Handbook, Taking Care of Me, and From One Dad to Another—all of which were funded by the American Legion Welfare Foundation.

CdLS Foundation development manager, Kristi Larson, attended the five-day conference and had the opportunity to meet with several of our nation's veterans and their family members, as well as other non-profits who received funding from the American Legion. It was a powerful opportunity to educate people about the syndrome and how the Foundation provides support to the individuals with CdLS and their families. The convention also allowed Larson to meet so many wonderful non-profit organizations, and was able to share program services and administration insight and best practices.





## Battle of the Bands Benefits CdLS



Laurel Springs natives Mike and Lisa Lewin (pictured below) recently secured the Cornelia de Lange Syndrome (CdLS) Foundation as beneficiary of the annual IPC Systems, Inc. Battle of the Bands, which was held on June 29 in New York City.

The cause is close to the Lewin family, as their daughter, Lauren, has CdLS, and Mike works for IPC. This is the second time that the Lewins secured the CdLS Foundation as choice charity of the annual Battle of the Bands.

“With CdLS being so rare, the opportunity to raise awareness to a group of 200 people means so much to our family. I don’t think they’ll ever truly know how important and impactful their donations are to such a small yet critical organization and how incredibly grateful we are,” said Lisa.

Since 2008, IPC’s annual Battle of the Bands charity event has held a dual purpose of showcasing the musical talents of the financial community as well as donating more than \$180,000 to organizations throughout the years.



IPC CEO Neil Barua shares, “IPC is delighted to have had the opportunity to work with the CdLS Foundation – an organization that is a strong and powerful voice and advocate for children and adults with the rare syndrome.” Barua continued, “The event is a great opportunity for our company employees and vendors to get together and at the same time continue IPC’s corporate strategy of giving back to local and global programs that help our communities.”

The Cutting Room, a re-launched nightclub, hosted the night of music, prizes and fundraising on a beautiful summer night. Attendees included IPC employees, CdLS Foundation staff, friends, and many members of the public. In one night, the event raised \$9,000 to benefit individuals with CdLS and their families.

“As a charity, we rely on the generosity of corporations like IPC to help us continue our vital work,” says Bonnie Royster, Executive Director, “Thank you to IPC for choosing the CdLS Foundation as their 2017 charity of choice and helping the CdLS Foundation to continue to reach out, provide help and give hope to the individuals with CdLS and their families.”

## On the Cover: Halston



Halston loves his big sister, Farrah, and they are starting to play really well together. He loves music and he claps and bobs his head to the beat, even when he can barely hear it. If it’s playing somewhere, he will notice. He adores our puppy, George, and will scoot over to him and bury his face in his fur. He is starting to talk, so he will study your mouth and repeat the words you are saying. He does not like vegetables or being cold.

## 2017 CALENDAR

**November 4**  
Multidisciplinary Clinic for  
Adolescents and Adults  
Baltimore, MD

**November 5**  
2017 TCS New York City  
Marathon  
New York, NY

**November 12**  
Sarah’s Bowl  
East Bowl Family Fun Center  
Batesville, IN

**November 17-18**  
CdLS Clinic at St. Louis  
Children’s Hospital, St. Louis,  
Missouri  
St. Louis, MO

**December 2**  
One Love, One Heart 5K  
Decatur, GA



## Board Corner



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

While the last few years have seen a number of positive changes for the Foundation, we're busy looking forward to 2018. That also means it's

time to focus on one of the items the CdLS Foundation is most proud of: the CdLS Foundation National Family Conference. The 2018 CdLS Foundation National Family Conference will be held in Minneapolis, Minnesota next June, and the Foundation staff and volunteers are already hard at work identifying new ways to ensure families attending for the first time or too many times to count will find it to be a memorable and rewarding experience. Conference requires a tremendous amount of staff and volunteer time and effort as well as an enormous amount of financial resources to provide the speakers, health care providers and information for families.

I've attended the past three Conferences, and can attest that it is truly a remarkable event that hits on the core aspects of what the CdLS Foundation strives to achieve. I met a mother at the 2014 Conference in Costa Mesa, California, who proudly showed me three pages of items CdLS experts had given her during consultations that she intended to discuss with her daughter's health care provider back home. As the Foundation tries to ensure each person affected by CdLS receives optimal medical care, we hope families return home from the Conference armed with accurate information from CdLS experts in order to advocate for ideal medical care regardless of their primary health care provider's experience with CdLS.

At the 2012 Conference in Lincolnshire, Illinois, I was struck during the first session by the reactions of two parents with a young son with CdLS. The two of them were sobbing by the end of the session, and when I met with them afterwards, they described how they came to the Conference feeling there was no hope for them and their child. However, after just a single session they quickly became overwhelmed with the realization that the Foundation was providing nothing but hope for their young family, and an abundance of resources to help them and their child through this journey.

I somehow never quite got around to eating dinner at the final banquet during the 2016 Conference in Orlando, Florida, so I managed to convince someone in the hotel restaurant to make me a sandwich and I finally began to head back to my room well after midnight. As I passed one of the hotel pools, I found a dozen CdLS families who met each other only few days earlier, yet had fully taken over the pool and were still busy playing and sharing time together as if they were all on one big family reunion.

So, while the CdLS Foundation National Family Conference continues to take an enormous amount of time, energy and resources, it also continues to be the single event that encompasses all the CdLS Foundation strives to achieve. It's perhaps the one event where we are able to offer optimal medical care consults for those affected by CdLS and their families, provide hope and resources, and give families the opportunity to connect, share experiences and support each other during every step of this journey. If you've never been to a Conference, make plans to join us in 2018; if you've attended several, contact the CdLS Foundation office to see how you can help make the 2018 CdLS Foundation National Family Conference spectacular.

## CdLS Registry: Enroll Today!

There are so many questions that accompany a diagnosis of CdLS. Questions you have are probably the same as many other families across the country, and world. To get answers, medical professionals rely on information from families to guide their hypotheses and research. This is why the CdLS Foundation has established a CdLS Registry at the Coordination of Rare Diseases at Sanford (CoRDS).

### CoRDS Registry

Coordination of  
Rare Diseases at Sanford

You can help researchers progress forward into determining more about the causes and manifestations of CdLS. For those of you interested in participating in this registry, visit <http://bit.ly/CdLSReg> to begin the process.



# Building Bridges Together in Minneapolis



While the calendar still says 2017, Foundation staff and conference planning committee volunteers have been looking ahead to 2018 since the beginning of this year. Plans are well underway to make this year's conference special and memorable for families from around the country.

Over the next several months, our committee members and staff members will work together to determine workshop topics, solicit speakers for the sessions and professionals to provide consults, start planning menus, room setups and much more. A big piece of the conference planning puzzle, includes seeking financial support from various sources, from large national corporations to small local business, to help offset the costs. Conference is not a fundraiser for the Foundation—in fact, registration fees don't cover the true costs of this event, so finding financial support is key in being able to keep the event viable.

As we get closer to the conference, be on the lookout for more information and tips. We hope to see as many families as possible at the event. It's truly a highlight for staff to see families in person, so we'll see you on-site and look forward to handshakes and hugs in Minnesota!

## FAQs

### *When can I register for conference?*

Registration for conference is scheduled to open February 15, 2018. The early bird registration and scholarship request deadline is March 29; the final deadline is May 25. Registration is available online or through a paper form. Conference can accommodate up to 150 families. Once that number is met, registration is closed.

### *What does registration cover?*

The registration fee covers all workshops and sessions, medical and educational consultations, and the following meals: Thursday night ice cream social; Friday breakfast, lunch and dinner; Saturday breakfast, lunch and dinner; and Sunday continental breakfast. It does not cover hotel or travel expenses.

Registration Fees	before 3/29	after 3/29
Adult (18+)	\$350	\$390
Person providing childcare	\$220	\$235
Children 3-17	\$180	\$205
Children 2 and under	no charge	no charge
Person with CdLS	no charge	no charge
One- day professional	\$110	\$110
Banquet guest (adult)	\$50	\$50
Banquet guest (3-17)	\$35	\$35

### *Where are we staying, and when can I book my room?*

The conference takes place at the Marriott Minneapolis City Center, Minneapolis MN, about 30 minutes from Minneapolis–Saint Paul International Airport.

Attendees are responsible for booking their own rooms. Hotel reservations should be booked once you have registered for conference. We will provide you with a code to get the reduced room rate of \$129/night, plus tax. All non-registered guests using the conference room rate will be removed from the room block and be required to pay the regular room rate.

### *What are my childcare options?*

Children with CdLS (any age) can attend Jindi's Place at no cost. Activities include arts and crafts, movies, games, toys, reading, and a quiet room. Arrangements can be made for tube and bottle feedings. Programs for siblings on Friday and Saturday:

**Tiny Tots:** for siblings aged six months to seven years. This program closes down during lunch each day (parents are responsible for picking up their child during this time).

**Kids Explore!:** for siblings ages five to 17. Participants go off-site. Lunch is provided. Individuals with CdLS over the age of five can participate in Kids Explore! if they have a paying chaperone over the age of 18 to accompany him/her. The cost is \$125 per child for two days and \$80 for one day, with discounts available for each additional child. There is a mandatory meeting Thursday at 7 p.m. for those using any of the childcare programs.

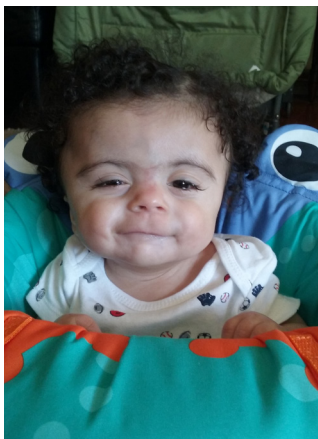
*More details on conference, as well as registration links, and transportation information will be on the conference web page, [www.cdlsusa.org/what-we-do/biennial-cdls-conference.htm](http://www.cdlsusa.org/what-we-do/biennial-cdls-conference.htm).*





## Mailbag – Kaden

*Thanks to Kaden's mom, Rachel, for sharing his story.*



Kaden was officially diagnosed with CdLS at four months of age. He was born 18 inches, 5 lbs 14 ounces. He is now nine months old, and weighs about 11 pounds. I hadn't even held my precious boy yet and the nurses were telling me all sorts of things about his features and their concerns. I turned to look

at my mother and I could see the emotion on her face. I then looked to my husband and he was just smiling and said, "he is perfect."

They believed Noonan Syndrome (NS) was a possible diagnosis. Although he was a small baby and other features were noted, I am only 4'10" so the doctors thought maybe he is just going to take after his mommy. I learned that NS does not come up on a chromosome test so his father and I decided we wanted a consultation with the geneticist. If Kaden had a medical condition, we preferred to stay ahead of it so we could help him in every way possible. We met with the geneticist and in less than a minute of looking at him she said, "It's not NS, but there is something there." She told us she believed him to have Cornelia de Lange Syndrome. She did show us a few pictures of children with CdLS and I could see the similarities in the facial features.

That moment when you know your child has a disability, a flood of fear and heartbreak sets in. I was scared for my baby's health, life and future. As parents, all we want is for our children to be healthy and live a good life. So much ran through my head at that time but I quickly made appointments with specialists and followed through with exams, X-rays, ultrasounds, EEG, etc. It was a busy few weeks but I wanted to search Facebook for a group of families with the same condition and that's when I came across the CdLS Foundation.

I sent a message with a few questions and the next morning I had a reply from Deirdre, who answered my questions and suggested I give her a call. The next day I did just that and had over an hour conversation with

her. At first, she just listened to me talk about Kaden and our experience. It felt so good to let go. I hadn't realized I needed to talk and just say it all out loud but she must have known. Talking to someone familiar with everything going on made me feel much better. She sent me some information and recommended a few other specialists and sent me these great cards for guidance along with growth and development charts.

The Foundation has provided me with not only support and guidance, but the tools for direction. I really felt understood and in more control of the situation. On days when the worries slip into my mind, my best friend playfully tells me, "please call your friend at the Foundation because you always feel better after that."

Kaden does have a developmental delay and continues with therapy. We take him to therapy weekly but Kaden was approved for a program called "Early Steps" that provides physical, occupational and speech therapy. A therapist comes to the house once a week for an hour and shows us what exercises to do with him daily. Besides the therapy, we are very blessed to have Kaden's nanny, Nina, who takes care of him when we are at work. She plays a big part in his development as well, and he loves her.

Overall, Kaden is doing great and we continue to stay positive. He is such a happy baby and loves his big brother. I have my days when the unknown scares me and worries set in. Then he smiles at me and I'm reminded that the most important thing he is that he's happy. My mother plays a big role in his life. I don't take for granted how blessed we are to have her on this journey with us. We couldn't imagine a life without our precious baby boy. We call him our little warrior. Although he has already been through so much and we have a long road ahead, with his daddy, older brother, uncles and cousins we think he's going to be a pretty tough kid.

**Share your Mailbag or  
Super Sibling Story!**

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



## Super Peers - Luke & His 3<sup>rd</sup> Grade Class

Dear CdLS Foundation Staff,

We are The Write On Company from Miss Fagan's 3<sup>rd</sup> grade class at Dondero School in Portsmouth, NH. We sell personalized pencils that we design and stamp ourselves.

Every year we donate part of our profits to a charity or organization that we care about. We also donate some of our money because we want to be a helpful community. Another reason why we donate is because we know how important it is to be generous and caring.

We picked the CdLS Foundation because one of our classmates, Luke, actually has CdLS. Luke is an important member of our classroom community who makes us smile, gives us friendship and makes us laugh. Luke is so special to us and makes us happy every day.

Thank you for the book, pencils, tattoos, and bookmarks you sent us. We loved learning more about CdLS when we read the book. We can't wait to wear our tattoos!

We appreciate what you do to help other people who have CdLS. We hope that our donation is useful towards all that you do.

Sincerely,

The Write On Company



## 2017 CdLS Research Grants Program Winners Announced

This year the Foundation received eight high quality applications across multiple disciplines representing approximately \$200,000 in funding. We're pleased to announce the winners of its research grant program for 2017:

**Suhas Rao (Stanford):** *Probing the role of chromosome architecture in the pathophysiology of Cornelia de Lange Syndrome.*

This project will address this basic gap in our knowledge of how members of the cohesin complex regulate genome folding and cellular function and will map how 3D genome topology is dysregulated in patients affected by CdLS. The study will be the first to systematically and comprehensively examine the role of the spatial organization of the genome in the pathophysiology of CdLS.

**Anupriya Razdan (Johns Hopkins):** *N-Acetylcysteine in the Treatment of Repetitive and Self-Injurious Behaviors in Cornelia de Lange Syndrome (CdLS)*

This project focuses on a pilot clinical trial for individuals with CdLS that will help advance therapeutic options for repetitive and self-injurious behaviors, to improve the health and quality of life for people with CdLS.

Winners are required to present their findings at the next CdLS Scientific Symposium (June 2018, in Minneapolis, MN) and will write an article about their study results for this newsletter. Our joy over the quality of these winners is matched only by the disappointment we feel over not being able to fund more deserving projects.



## Kindness Has to Start Somewhere



*This previously appeared in The Detroit News. Thank you to Maureen, Mother to Hope who has CdLS, and Will had CdLS as well.*

The little boy took one look at my daughter, scrunched his face and walked away.

“Your sister,” he said to my son who was nearby as we all waited for the school bus to arrive, my daughter’s small hand in my own. “I can’t stand her.”

My stomach dropped and yet I was used to it. As the mother of a special needs child for almost a decade, staring comes with the territory. So does the occasional unfriendly comment. That doesn’t make it easy – or right.

Still, we’ve all been that parent — the one horrified by an unpredictable, filter-less child saying something that makes us want to crawl in a hole. My son went through a phase at 4 years old of being very aware of different body shapes. We were visiting Mackinac Island one summer when he marched up to a woman and declared, “You’re fat.”

As cringe-inducing as our children can be, their bluntness often doesn’t come from a malicious place. They’re learning to navigate this weird thing called life.

Still, it’s up to us as parents to steer them. Sometimes that’s as simple as having a conversation about people or things they’ve never encountered. After my son’s “fat” declaration, my husband and I talked to him quite a bit about how people come in all sizes, colors and shapes.

But we as parents set the lead. Our kids are watching our every move. Be kind. Teach your kids that different isn’t bad. Expose them not just to different experiences, but people. How will our children ever know how to interact in our incredibly diverse world if he or she is only around people like them?

For children or even adults unsure of how to act around someone with disabilities, start simple. Start with “Hi” and a smile.

Without saying a word, a smile speaks volumes. It says there is no reason to be afraid. It’s a starting point, an icebreaker and a common connection. It’s amazing how quickly a simple smile or “Hi” says “It’s OK. We’re more alike than we are different.”

The reality is people with disabilities make up a significant percentage of our population. According to the U.S. Census Bureau, about 56.7 million people — 19 percent of the population — had a disability in 2010.

My daughter, who is now 9, is blissfully unaware she’s “different.” She couldn’t care less if someone is staring. She just lives her life. If you have a problem, it’s your problem.

Still, I’ve seen the way parents sometimes scramble when their children stare at her or even make a comment. Or sometimes parents don’t scramble at all. We were at our local library recently when two young kids stared at my daughter for a solid minute before their mom looked up from her phone. But I did what I always do: I made eye contact, smiled and said “Hi.”

If we want people to be kind, then it has to start with us. We have to model the behavior we want to see in the world.



My husband and I recently visited my son’s first grade class to talk about our daughter and what’s the best way to treat people who are extra special. We talked about how we all talk without using words, how my daughter’s birthday is in October and why she wears glasses. I soon learned that at least 12 other children in the same class have October birthdays and that many of their parents wear glasses or contacts. In the end, we all shared Goldfish crackers because everyone likes Goldfish.

As for the little boy at the bus stop, I introduced him to my daughter, explaining that she’s really not that different from him. He might’ve been put off, but he’ll get used to her. Kindness has to start somewhere.





# Parental/Caregiver Survey: Therapies and Trials in CdLS

Please complete this anonymous questionnaire about your child and return to the CdLS Foundation Office. This is a voluntary questionnaire for which choosing to complete it will have no bearing on your involvement in activities related to the CdLS Foundation. (Your “child” can also be your ward or guardian.) “Improved quality of life” refers to your impression of the general status of your child (for example, could include: more enjoyment of activities, less medical complications, better developmental skills, less behavioral issues, etc). Let us know if you have any questions about this. Otherwise, please answer the following:

**1.** Which of the following things would you think would be helpful to be addressed in a study to improve the quality of life for your child with CdLS? Number in order of importance to you from #1 (#1 being the most important and then continuing), including as many as you would like or filling in your own:

- |                                       |                                    |
|---------------------------------------|------------------------------------|
| ____ a. Hearing                       | ____ k. Cardiac status             |
| ____ b. Vision                        | ____ l. Puberty                    |
| ____ c. Gastrointestinal status       | ____ m. Communication              |
| ____ d. Pain episodes                 | ____ n. Social skills              |
| ____ e. Self-injury                   | ____ o. Other developmental skills |
| ____ f. Seizures                      | ____ p. Other _____                |
| ____ g. Anxiety                       | _____                              |
| ____ h. Growth in height              |                                    |
| ____ i. Weight gain or loss           |                                    |
| ____ j. Oral care and/or cleft palate |                                    |

**2.** From the developmental skills point of view, which of the following would be helpful to be addressed in a study to improve the quality of life for your child with CdLS? Number in order of importance to you from #1, including as many as you would like:

- \_\_\_\_ a. Gross motor skills (e.g. walking, running)
- \_\_\_\_ b. Fine motor skills (e.g. feeding, writing)
- \_\_\_\_ c. Communication (e.g. speech, language, sign language)
- \_\_\_\_ d. Social and emotional development (e.g. interact with others, toilet training)

**3.** Would you consider enrolling your child in a study related to feeding (e.g. specific formula or type of diet) that might improve the quality of life for your child with CdLS?

\_\_\_\_ a. Yes   or   \_\_\_\_ b. No

If no, please state why: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



4. Would you consider enrolling your child in a study based on Early Intervention therapy (eg physical, occupational, speech therapy) that might improve the quality of life for your child with CdLS?

\_\_\_\_ a. Yes      or      \_\_\_\_ b. No

If no, please state why: \_\_\_\_\_

\_\_\_\_\_

5. Would you consider enrolling in a clinical trial for a medication or drug already approved by the FDA in other conditions and/or syndromes that might improve the quality of life for your child with CdLS?

\_\_\_\_ a. Yes      or      \_\_\_\_ b. No

If no, please state why: \_\_\_\_\_

\_\_\_\_\_

6. Would you consider enrolling in a clinical trial for a new medication or drug not already approved for use by the FDA that might improve the quality of life for your child with CdLS?

\_\_\_\_ a. Yes      or      \_\_\_\_ b. No

If no, please state why: \_\_\_\_\_

\_\_\_\_\_

7. If you would not be interested in having a family member participate in a therapy or treatment trial, please let us know why: \_\_\_\_\_

\_\_\_\_\_

8. What would be important to how you and your family function in relation to a treatment trial or specific therapies for your child? \_\_\_\_\_

\_\_\_\_\_

9. Please feel free to write in any additional thoughts or concerns you would have about your child participating in studies addressing therapies or treatment trials: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you very much for participating! Please send back by mail, fax or scan then email.



## Host with the Most: A Q&A with a CdLS Gathering Host, Dianne Haaland

You may have been to multiple family gatherings, maybe one, or none at all. If you've attended a gathering, and have received the benefits of this experience, you may have wondered how an event like this comes together. To share a bit more about the experience, we've asked one parent to share their experience about hosting with you.

### Q: How did you get involved in hosting a gathering?

A: *I am not really sure how we got involved to host a gathering, I believe we had discussed the idea and mentioned this to someone in the Foundation office, and they told us what would be involved in hosting.*

### Q: Had you attended a CdLS gathering before?

A: *Yes, we had attended a family gathering several years ago and thought it would be fun for several families in our area to get together.*

### Q: What was involved with the planning?

A: *Really, not much. We selected that date that would work best for us and then a Foundation staffer sent out the invitations and took the RSVP emails and phone calls. We just booked the amenities room in our building, and we decided we would provide food and beverages (the families brought desserts). We provided the food and beverages because we did not have to travel, and we thought it would make coming easier on the families.*

### Q: What did you learn/experience at the gathering?

A: *How truly fun and uplifting it is to interact with families that are dealing with children/siblings with CdLS. I think that the information provided about the lives of older CdLS individuals-even if your child is young it is never too early to start thinking and understanding this process.*

### Q: What was your favorite part?

A: *Just interacting with everyone! Being with each other is not something we can enjoy daily or weekly, so gathering together is a really big deal.*

### Q: Would you recommend other families attend one?

A: *Absolutely! This is a great opportunity and I certainly hope that others gain experiences and knowledge by getting together. So often we feel alone, so when we can come together it's a special experience for us all.*



If you're interested in hosting a gathering in your state, or just learning more about what this entails, please contact [familyservice@CdLSusa.org](mailto:familyservice@CdLSusa.org) to inquire.



### Our Deepest Sympathy



#### Noah Salazar

May 14, 1999- May 19, 2017  
Son of Andrea and Erwin Salazar  
4358 Wildwest Circle  
Moorpark, CA 93021

#### Nathan Larsen

October 22, 1978 – August 26, 2017  
Son of Reta and Merwin Larsen  
16175 E Baker Pl  
Aurora, CO 80013-1408

#### Corvohn Coleman

November 22, 1999 - July 28, 2017  
Son of Corliss and Kantrell Shaw  
3610 N38th Street  
Milwaukee, WI 53216





Donations from 3/6/17- 6/1/17

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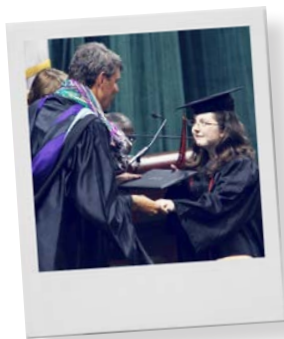
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*"Years ago, doctors told my parents 'not to expect very much from me.'  
The doctors were wrong. Today at age 25, I've graduated from college,  
learned to drive and now have a job.*

*Now you might be thinking, 'these things are not going to happen for my  
child.' But my message is, don't let other people tell you what your child  
can or cannot do. Don't let someone else put limits on the dreams for  
your child's future."*

*Emily*

Emily Turner  
CdLS Foundation Board of Directors

