# Reaching Out

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

## Highlights

**Director's Message:**

Family Vacation: CdLS Style

**Spotlights:**

Techniques to Address Self-Stimulation

Toilet Training in Children with CdLS

**Super Friends**

Brooke & Jantzen

302 West Main Street, #100 | Avon, CT 06001-3681 | 860.676.8166 | toll free: 800.753.2357 | fax: 860.676.8337 | www.CdLSusa.org

# Director's Message

## Family Vacation: CdLS Style

Hello all,

Our biennial National Family Conference is less than one year away! I look forward to seeing everyone's smiling faces, hearing your stories and enjoying time as a unified community in beautiful Minneapolis, Minnesota.

Over the next several months, the Conference Planning Committee and staff will come together to choose workshop topics, solicit speakers for the sessions, find professionals to provide consults, and so much more. We are working diligently to seek sponsors to help defray the costs of the event and make it more affordable for all who desire to attend.

Just as the Foundation is seeking financial support, this is a good time for you to begin finding independent resources to offset the costs. Depending on where you are traveling from, registration fees, hotel and travel can easily amount to $3,000 per family. With 11 months to go, now is the time to start putting money away and searching for additional funding. Below are a few non-CdLS sponsored resources to consider:

- Local town/city social service agencies
- State Departments of Education
- Charitable foundations at your local hospitals
- Corporations and businesses in your community
- Local sports team foundations
- Local community foundations

It is our desire to see as many of you as possible at Conference, and these are just a few ways to offset the cost of attendance. You are near and dear to our hearts, and it is truly a life-changing experience for families, professionals, and staff to meet each other in person.

Be on the lookout for more detailed information about dates, accommodations, workshop topics, and more.

Sincerely,

Bonnie

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.

## In This Issue

# Safety Precautions

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

Safety for our children is one of the most important issues for every parent, no matter their age or abilities. Picking up tiny objects, crossing the street, talking to a stranger—all can present a danger depending on age. For parents of children with disabilities, even safety within the home can become a concern. Furthermore, children with Cornelia de Lange syndrome can have additional habits that put them in harm's way. Below are some suggestions that could help avoid these potential dangers, and are meant to educate and advise rather than frighten.

For infants with CdLS, it is very important to have a special hospital fitting for cars seat because of their smaller than average size. Padding might be needed to make certain that the infant fits appropriately in the car seat in case of an accident.

For toddlers with CdLS, typical precautions hold true, such as not leaving tiny objects around that could be swallowed and lead to choking. Toddlers with CdLS can be even busier than typical children, so be extra cautious! Cover plug openings, latch cupboards containing cleaning supplies and glass, and ensure that pet food is stored in a closed compartment.

For school-aged children with CdLS, always be cautious crossing the road. They can be very fast and quickly dash away. They may try to run away from home, so having secure latches on outside doors can be critical. If this is an issue, consider a MedAlert or similar bracelet in case the child gets lost. There can also be a risk for safety issues at school. This should be addressed with a classroom teacher or aide, and also discussed at your annual I.E.P. meetings.

Some children, adolescents and young adults with CdLS need much less sleep than compared to other family members. Keeping children in their own rooms is important, but some families have a bedroom door that can be latched from the outside or a divided door that can be opened from the top, but remains latched at the bottom for safety. Some parents also have special beds that are difficult to climb out of or mattresses very low to the floor. Additionally, if self-injury is present, make sure fingernails are kept short and try to divert attention by providing toys to squeeze, bite or gnaw.

Finally, older children, particularly females, could find themselves in vulnerable situations. Most schools, workshops and workplaces for individuals with disabilities are safe, but not always. It is important to be comfortable with personnel and confirm impressions with other parents and coworkers. For young women who have more mild features of CdLS, unsupervised situations could lead to sexual advances or assault. Providing education about this and considering birth control are important conversations to address.

Your healthcare provider can always help advise and assist in any of these situations, and we at the Foundation are available for any questions or concerns.

*Reaching Out*
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# Techniques to Address Self-Stimulation

*By Joann Fleckenstein, M.S., OTR/L*

As I sit in an early morning meeting, I find myself struggling to stay awake and focused. I begin tapping my toes under the table and sipping my coffee. During a break, I walk around the hall to try to wake myself up and opt to chew some spearmint bubble gum. By stimulating my senses, I was able to pay attention to the details of the meeting and provide appropriate feedback.

Similarly, many people with neurological differences use **self-stimulation** to meet a sensory need or to maintain their sensory and emotional **regulation**. Some may pick at their fingers while others may need to move often in order to attend to a task. When attempts to self-regulate through stimulation become disruptive to others, the impulse can be to stop the behavior altogether. However, in contrast, we must ask why the person needs to self-stimulate. For example, a person who chews on her clothing or puts non-food objects in her mouth may be seeking a mouth or jaw input, and could benefit from using a piece of chewable jewelry, or "chewelry."

For others, meeting their sensory needs can be concerning or even dangerous, banging their heads or hitting others as a result of an unmet sensory need or emotional **dysregulation**. In these cases, a more in-depth assessment of the reasons behind this behavior is essential for developing appropriate solutions.

An occupational therapist with experience in sensory integration can help identify preferences and activities to meet sensory needs. Always work with your provider directly to ensure that behavior and sensory solutions are tailored to your child's individual needs.

To learn more about occupational therapy, visit www.aota.org. Additionally, the CdLS Foundation has occupational therapists available as professional consultants to provide guidance. Contact your Family Service Coordinator for more details.

| Typical Sensory Solutions: | |
|---|---|
| Noted Behavior | Sensory Solution |
| Chewing on fingers, clothes, or non-food objects | Cold, tart, and sour foods, chewelry, vibrating toothbrush or teether |
| Picks at fingers, face, arms | Velcro bracelet, finger fidgets, keep nails trimmed for safety |
| Making noises with mouth | Blowing and sucking activities such as blowing bubbles, or sucking through a straw |
| Hitting/banging with hands | Drums, receiving joint input through the hands, wrists, and arms such as wall pushups or laying on stomach while propped up on hands or elbows |
| Head banging | Rule out medical reason such as headache or mouth/jaw pain, provide pressure across the head by giving deep hugs directly on the head, especially across the forehead |

**Key Words:**

**Self-stimulation** – The body's need to receive sensory input in order to maintain a balanced sensory and emotional state (regulation).

**Regulation** – The ability to adjust the level of alertness to meet the demands of a given activity.

**Dysregulation** – The inability to maintain the appropriate level of alertness. This may look like a meltdown or withdrawing from others. A person who is dysregulated typically requires the help of another person to regulate him or herself.

# Board Corner

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

As we make our way through 2017, the CdLS Foundation is working through a number of projects to ensure we are providing the best support and services possible. We're also looking ahead and considering changes to help us meet future needs. Executive Director Bonnie Royster has spent the first part of 2017 learning about the wonderful families that make up the CdLS community, but also identifying new areas for us to make improvements, including fundraising and communication. Your input in identifying new services ensures we meet the needs of everyone affected by CdLS.

For many years, the Foundation has relied on generous donors and successful events for financial stability. However, as we think about new ways in which to provide services and support, we also must identify new methods to expand our circle of friends. Deepening and broadening our donor base is essential, as well as fine-tuning our events to raise funds, spread awareness and make these new services a reality.

As we look to expand, we must remember that CdLS continues to remain relatively unknown in many populations. This requires us to reimagine how we communicate. New initiatives will spread the word about CdLS not only to our existing community, but to the broader public. Don't forget that some of us wear dual hats at the Foundation—you can be a parent, medical professional and committee member all in one, so it is essential to consider what will resonate with each of these audiences.

These donor and communication programs work jointly as part of changes meant to improve the outreach of the CdLS Foundation both now and in the future. If you begin to see ways in which you or your family members can help make improvements, contact us to find a role that makes difference.

Feel free to reach out to Bonnie and the CdLS Foundation staff with ideas of how to improve communication or services to make every interaction as smooth as possible. The ability to share your story, insights and the work of the Foundation helps people across the world not only become more aware of CdLS, but of how they can join our community as well.

## 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).

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.

## Meet the Staff

Meet the new CdLS Foundation staff members. Check out Julie, Kati and Whitney's full bios on our website under Meet Our Staff.

# Toilet Training in Children with CdLS

*By Mary Pipan, M.D., Behavioral Pediatrics, Children's Hospital of Philadelphia*

Toilet training a child with developmental disabilities requires commitment, patience and time. The method of learning to achieve continence depends on their development, awareness of bodily functions and motivation to be independent. Children as young as six to nine months developmentally can be trained, but will continue to need adult assistance in maintaining continence.

First, you will need a potty chair on which they feel secure, where their feet are solidly on the floor and that places them in a squatting position. Get your child comfortable with sitting; they can read, watch TV or play on a device. You'll then start placing them on the potty without their diaper at times when they're likely to void or stool, e.g. first thing in the morning or after dinner. Make a routine of putting them on the potty whether they go or not, taking them to the bathroom whenever someone uses the toilet and reading about toilet training during story time.

For children who are unable to dress, have very little bodily awareness and do not have a means to communicate, toilet training requires frequent placing on the toilet, rewards for success and immediately being taken to the toilet with accidents. They then learn to go when placed on the toilet and eventually will go on their own. Some behavior agencies have toilet training teams that will work with the child intensively for a few days at a time to accomplish this.

There are helpful resources when developing tactics for toilet training, such as: *"Toilet Training in Individuals with Severe Handicaps"* by Dunlap, Koegel and Koegel and *"Toilet Training in Less than a Day"* by Azrin and Fox. The Azrin and Fox publication is a program for children who have the readiness skills to train but are oblivious to bladder or bowel fullness. You and your child will teach a doll to toilet train and then spend the next day or two doing the same with your child.

Remember that children may have difficulty paying attention to bodily signals when they are absorbed in another activity, so reminders are often needed to prevent accidents. However, persistent nighttime accidents are common, even after being trained for a while. Developing the ability to hold urine at night comes much later for many children, with or without CdLS.

When you are ready to make the commitment to potty train, prep with some reading materials. Share your plan with everyone who will be helping your child train both at home and school to maintain consistency. Don't be discouraged if it takes several efforts, and consult the experts in your community if you hit a roadblock. With patience and persistence, you'll get there!

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## 2017 CALENDAR

**August 19**
Southwest Region
Family Gathering
San Antonio, TX

**September 16**
Northeast Region
Family Gathering
Wakefield, RI

Family Gathering
Dublin, Ohio

**October 8**
2017 Bank of America
Chicago Marathon
Chicago, IL

**October 9**
29th Annual CdLS
Charity Golf Tournament
Sunset Hills, MO

**October 13-14**
Board of Directors meeting
Minneapolis, MN

**October 14**
Midwest Region
Family Gathering
Minneapolis, MN

**October 21**
2017 Baltimore Running Festival
Baltimore, MD

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

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

## A Closer Look: Samuel

*Thanks to Samuel's mom, Linda, for sharing his story*

Potty training our older, typical son was no big deal. We waited until he was ready and he was potty trained in a weekend. This was not the case with our younger son, Samuel, who has CdLS. Samuel is 12 years old and considered mildly affected with CdLS. He walks, talks, sings, jumps, runs, and more, however, none of these events have progressed typically.

One of our biggest struggles has been potty training. Samuel has a severe gag reflex when he sees or touches certain textures such as cotton balls, silly string or shredded paper. One of the textures that really bothers him is underwear—he cannot see or touch most underwear without vomiting. We tried many kinds with no success, but finally found some that he can handle: boxer briefs with the elastic covered in fabric.

To encourage actually going in the potty, we have practiced following success with a reward. Samuel loves candles, so he gets to blow out one if he pees in the potty and two if he has a bowel movement. To carry over the reward to school, we bought candle stickers. However, we still struggled.

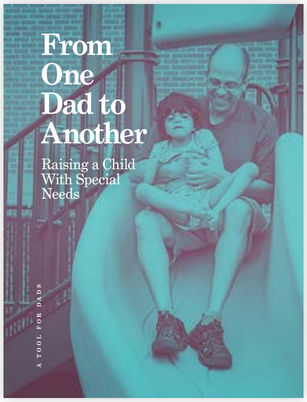
I recently left town for a few days so Samuel stayed at home with Dad, and I discovered that Dad is more stubborn than our preteen! After a lot of struggle, Samuel kept his underwear on for an entire day! It became easier and easier. The first few weeks were full of accidents, but the biggest hurdle was over; the underwear stayed on.

The best lesson I have learned is not to give up, because nothing is typical. Everything is done in Samuel's own way and in his own time. More than 11 years of diapers are behind us and, even now when he goes on the potty, Samuel gets to blow out his favorite candles!

## New Publications

In early 2017, the CdLS Foundation's Family Services department debuted two new publications. One focuses on self-care for parents and caregivers, while the other provides advice to fathers of children with special needs. We're excited to share a synopsis of the informational publications with you.

Every member of a family who has an individual with CdLS plays an important role, but are you forgetting someone? YOU need to be fit mentally and physically to be well for your family. In the Foundation booklet, *Take Care of Me*, experts provide tips on mindfulness and taking much-needed time for yourself. Reserve a moment alone and learn how to better take care of yourself.



Being the parent or caretaker of an individual with special needs is laden with both struggles and triumphs alike. In *From One Dad to Another*, fathers of children with CdLS share their takes on what they call the most rewarding journey of their lives. This is the first Foundation publication to focus on the unique perspectives of fathers and male parental figures.

Do you believe that you or someone you know could benefit from these new publications? Reach out to the Foundation to secure your copy today! Call 800.753.2357 or email familyservice@CdLSusa.org.

# The Importance of Making Connections: Family Gatherings

*By Deirdre Summa, L.M.S.W., CdLS Foundation Family Service Manager*

The Foundation sponsors eight family gatherings each year, rotating states around the country in hopes of giving every family the opportunity to attend. Families come together and spend an afternoon talking, sharing stories, laughing, and learning from one another. The connections made between parents, grandparents, children, relatives, and professionals can last a lifetime. Who better to talk about what it's like to experience the sleepless nights, the never ending tests and procedures and the concerns that a diagnosis of CdLS can bring, than another parent who also has a child with the syndrome?

At a recent gathering held in Arizona, I had the opportunity to see some of these meaningful, organic connections right before my eyes. One family in attendance was able to meet and see other children with CdLS; a grandfather who attended his first gathering was welcomed by veteran grandparents who shared their experiences; a sibling shared her story of doing a class presentation on disabilities, explaining that her brother had CdLS and what that might look like; and two children with CdLS simply gazed at each other, knowing somehow they were similar. All gatherings are a bit different, but all have one thing in common: for one afternoon, everyone present experiences the unique closeness and support that comes from being a part of the Foundation.

Each year I look forward to traveling to different states and meeting families and their children who I've heard so much about. I enjoy seeing how children have grown; hearing about each person's special accomplishments; snuggling with the babies; and being impressed by the successes of the older children as they enter high school, join Special Olympics or learn to become more independent.

In my years working at the Foundation, I've visited over 20 different states and have met many, many families. I look forward to every gathering and seeing where I may land, and the families I will meet along the way.

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## WELCOME NEW FAMILIES

**Florida**
Betsy and son Hunter,
born March 3, 2009

**Georgia**
Jasmine and daughter Avery,
born December 2, 2015

**Illinois**
April and Jesse and son Chase,
born February 6, 2017

**Illinois**
Molly and Andrew and son
Oliver, born June 1, 2016

**Michigan**
Olga and son Vagan, born
September 8, 2008

**Minnesota**
Cheri and Kert and son Teddy,
born June 25, 2013

**Minnesota**
Desiree and James and daughter
Jade, born November 13, 2015

**Nevada**
Sandra and son Gabriel,
born 2011

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

**Pennsylvania**
Jana and Kenny
and son Marckis
born May 20, 2014

**Texas**
Emily and daughter Ellyson,
born January 17, 2017

**Texas**
Juanita and Antonia
and daughter Mia,
born October 15, 2015

**Texas**
Courtney and son Rian,
born April 13, 2017

**Washington**
Lanvi and Chris and daughter
Chloe, born July 11, 2013

**Washington**
Shaylene and David
and daughter Emmalee,
born January 9, 2016

**Wisconsin**
Rebecca and Ryan and daughter
Ellajean, born May 23, 2016

# A Thank You is in Order…

…for your hard work toward making National CdLS Awareness Day 2017 such a success.

From yard sales to yoga parties, the country was full of our CdLS community celebrating and raising awareness for their loved ones. More than a quarter doubled as fundraisers to benefit the Foundation's ability to provide family services free of charge, and much more.

Thank you for supporting our mission. We can't wait for next year!

**Help raise awareness all year long with our Facebook filter!**

# Team CdLS Recap

We can't believe that it's halfway through the 2017 Team CdLS season! If you haven't heard, the Team expanded its reach from marathons to bike tours, mud runs, triathlons, and more in the past year. Catch some of the highlights so far and consider racing on behalf of the CdLS Foundation.

**United Airlines New York City Half Marathon**

A powerful team of seven women kicked off the season at the 2017 United Airlines New York City Half Marathon on March 19. The team was comprised of six family members and one friend of the Foundation. They braved chilly downtown weather to race in honor of sons, sisters, cousins, goddaughters, and friends.

In just two months the seven teammates surpassed their fundraising goal raising more than $27,000!

**REVEL Mt. Charleston**

A group of Colorado ladies continued the girl power and conquered the Mt. Charleston Half and Full Marathons in Las Vegas. The team of friends was recruited by captain Rachel Thompson, mother to Wilder, who has CdLS.

After numerous fundraisers with support from local businesses, the team raised over $25,000!

**TD 5 Boro Bike Tour**

Celebrating the Foundation's inaugural year as an official charity partner of the race, a team of determined riders took to the streets of New York City on a blustery May morning. Parents, relatives, caregivers, friends, and even staff members pedaled 40-miles through the five boroughs in honor of those with CdLS.

The team of ten raised more than $9,200, exceeding their goal with each team member far-surpassing the fundraising minimum.

**Mud Run**

For eight years, Mike Feehan has participated in mud run events on behalf of Team CdLS and in honor of his 9-year-old son, Connor, who has CdLS.

On June 4, Mike competed on a course of military-style obstacles, cargo climbs, wild water crossings…and a lot of mud. This year, Mike was able to independently raise close to $26,000 through Crowdrise to benefit the CdLS Foundation, bringing his lifetime fundraising total to nearly $150,000.

In contrast to his athletic charitable endeavors, Mike works as a CPA. He currently shares his skills by serving on the CdLS Foundation Finance Committee and Board of Directors.

**DON'T MISS:** Bank of America Chicago Marathon, Baltimore Running Festival and TCS New York City Marathon!

Eager to join the Team after reading about the success and great experiences of recent members? Contact Kristi at events@CdLSusa.org and explore your options to finish off the year with Team CdLS.

# Event Recap: 25th Annual New England Golf Tournament

Groups of golfers flooded the Ipswich Country Club golf course on a drizzly Monday in May to benefit the CdLS Foundation. Teams of four lined the greens ready to claim the Sponsor Cup Trophy, bid on auction items and make connections.

In 2017 the Tournament celebrated its 25th anniversary. In a fitting show of dedication, the event was generously supported by golfers, sponsorships and in-kind donations. Guests returned home happy after winning silent auction prizes like New England Patriots tickets and a trip to Hilton Head, all while raising money for individuals with CdLS. This year, the Tournament raised approximately $70,000.

Board of Directors member Eric Johnson and his son, Anders, showed off their skills by winning first place with a score of 58, and Board member David Barnes' foursome of golfers winning second place with a score of 59. However, the most important winners were the guestswho had various relationships with CdLS, and who made lasting connections.

Since 1992, the CdLS New England Charity Golf Tournament has raised over $895,000 to help people with CdLS live better, fuller lives. Inspired by their children affected by CdLS, New England parents and their friends have made the success of this tournament an annual labor of love.

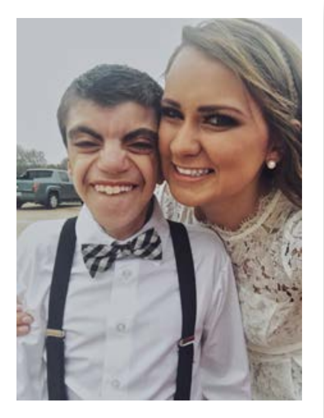
Thank you to the New England Golf Committee, who worked tirelessly to make this event a success: Shelly Champion, Mike Christie, Ava Frank, Anders Johnson, Dianne Lessa, Pat Lyons, David Molzan, Brian O'Keefe, and Denise and Frank Teixeira.

We extend our most heartfelt thanks to our various sponsors: **Eagle Sponsor:** KeyBanc Capital Markets; **Birdie Sponsors:** RBC Capital Management, BMO Capital Markets, RenMac, Evercore ISI, Craig-Hallum Capital Group and D.A. Davidson & Co.; **Registration Sponsor:** Donald Sadoski, DMD; **Lunch Sponsor:** The Teixeira Family; **Hole in One Sponsor:** Acura of Peabody; **Cart Sponsor:** Insurance Recovery Group; **Beverage Sponsors:** The Catrickes Family and JMK System Solutions.

29th Annual CdLS Charity Golf Tournament

The 29th Annual CdLS Charity Golf Tournament tees off on Monday October 9, 2017 at Tapawingo National Golf Club in Sunset Hills, MO

## Super Friends - Brooke & Jantzen



*Adapted with permission from "How Special Needs Kids Will Change Your Life," by Brooke Fleming, 2017, https://brookeflemingblog.wordpress.com/*

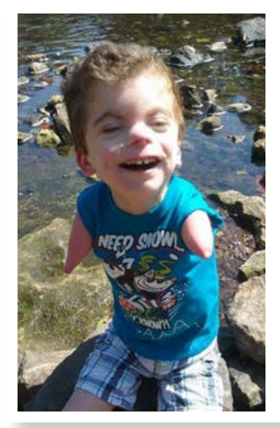
I met Jantzen through a special needs program called Circle of Friends during my freshman year of high school. I had no idea at the time that he would change my life and become my best friend. Throughout my years of working with special needs kids, I learned a lot about how they change lives.

- They don't care about your "status." These kids don't care about how cute you are, how many friends you have, or what you own. They love you for who you are and that is the purest form of love there is.
- Their love for you is so deep and pure. They don't only love you when you give them what they want or when they need you; their love for you is unconditional.
- They are the definition of pure joy. Their laughs over a dance party or because you tickled them is infectious. You can't help but feel their joy radiate off of them onto you. They contain more joy than we could ever imagine.
- They teach you to enjoy the simple things. They make just listening to music or watching television ten times more fun. Life with them is so much better.
- They put things into perspective. They make our petty problems seem so small. You no longer take your ability to walk or attend school for granted.

These kids will change your life and you won't even realize it. Kids with special needs are the biggest blessing and I am forever grateful that I have had the opportunity for my life to be forever changed.

I am so blessed that this sweet and handsome boy was brought into my life four years ago. I had no idea the impact he would make on me and the people at my high school. He is the truest form of pure joy and radiates it to everyone he comes into contact with. Thank you, Jantzen, for being the best friend I could have ever asked for and completely changing my life.

## Mailbag – Jermiah



*Thanks to Jermiah's mom, Shannon, for sharing his story.*

This is Jermiah. He came into this world a natural born fighter. Jermiah weighed in at 1lb 11oz and 13¼ inches tall. He was born at 32 weeks due to in utero growth restriction on July 14, 2004. After a three-and-a-half month stay in the NNICU, I finally got to bring my bundle of joy home.

Though he is still a tiny little man, he has made a big difference in the world around him. Jermiah is now twelve and enjoys the outdoors, especially the sunshine. He has many, many friends and is always making new ones. There is nothing better than seeing him smile. We look forward to reading and sharing more stories with the CdLS Family.

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

Send your story and photo to outreach@CdLSusa.org.

# Services for Adults with CdLS

The CdLS Empowerment Team is a group for individuals with CdLS 18-years-old and older. The group's vision is to create a venue where adults can support and empower one another in their communities. The Team encourages members to socialize and develop relationships across the country through a variety of opportunities. Team members are also urged to participate in the development of resources specific to the needs identified by the CdLS adult community.

The Adults with CdLS page on the Foundation's website is also now available! This page is dedicated to providing resources and support to adults with CdLS. The easy-to-navigate section includes a number of helpful resources, including links to connect with a peer, join a peer support group, and Ask the Expert, where users can email their questions and receive a response from professionals in the fields of medicine, therapy and more. This addition to the Foundation website was developed after adults with CdLS requested a place of their own for resources, developing peer relationships and having their voices heard.

Looking towards the future, the CdLS Empowerment Team is developing printable resources to utilize when speaking to professors, employers, case workers, and other members of the community to assist in promoting self-advocacy and independence. You can access the Services for Adults with CdLS webpage at www.CdLSusa.org/what-we-do/adults-support-services.htm.

Would you or someone you know be interested in joining the CdLS Empowerment Team? For further information please contact Whitney Rinaldi at familyservice@CdLSusa.org or call 800.753.2357.

# On the Cover: Taryn

Taryn is 9 years old and has CdLS, but that does not define her as a person. It merely helps explain some of the challenges she faces like with her motor skills, receptive language, focus, and comprehension. However, she is very expressive in language and storytelling, and is learning math skills fairly well. Taryn loves music and movies and when you combine them, she's in heaven (i.e. Frozen, Moana or Annie). Taryn loves animals too, so we have dogs, cats and a guinea pig. Some of her favorite foods are spaghetti, chicken nuggets and peanut butter and fluff sandwiches. Recently, Taryn has shown an interest in community service and attended a Red Nose Day event in Rhode Island to help raise awareness around childhood poverty. Taryn definitely gives us a run for our money some days, but it is so worth it when she figures things out and is so proud of an accomplishment, like riding her balance bike or reading a book for the first time. We are so grateful for the support and network we have built through the CdLS Foundation. Taryn couldn't ask for a better group to help her and her family through this journey.

## See Yourself in Reaching Out

Have you planned an event, hosted a family gathering or have a story to share? We want to hear about it! *Reaching Out* represents the voices of the CdLS community, so let yours be heard. Email outreach@CdLSusa.org with your story submission and see yourself in a future edition of this publication.

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

# Gifts that Count - In Honor/Celebration

Amy Kline
Bonnie J. Coates

Alexys Spencer
Intertek USA, Inc

Andrew Patitucci
Joan and David Hanisco

Austin J. Staggs
Jina Homan
Charles Staggs
Cynthia Hallett

Barb and Shreve Johnessee
Luther Memorial Church

Brian Winter
Margie Reed-Winter

Brynnlee Beekman
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Mary Dehaven

Caitlin Igoe
Michael Igoe
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CdLS Foundation
Morrisette “Bonnie” Royster

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Judith and Michael Cole

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Melissa and Jerry Koelling

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Andrew Ethridge

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Logan Fowler
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Sharon Winston
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Debra Wolk
Sydney Hariton

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Jeff Bornino

Tyrone Beaty
Norma James

Vicki Fisher
John E. Fisher

Aiden Bard
Shirley Lubowich

## Our Deepest Sympathy

**Devon Jean Downs**
February 3, 1996 – February 28, 2017
Granddaughter of
Karen and Kenneth Downs
1270 Little Oak Circle
Titusville, FL 32780

**Tracy Snawder**
September 7, 1969 – March 15, 2017
Daughter of Sharon and Darrell Gilpin
7907 Windgate Dr
Louisville, KY 40291
and
Mike and Carolyn Snawder
3765 Edwardsville Galena Rd
Georgetown, IN 47122

**Ethan Russell**
August 24, 2012 – March 23, 2017
Son of Torieca and Brandon Russell
3953 Meeks Circle
Fort Sam Houston, TX 78234

**Anthony Chacon**
January 6, 1974 – March 28, 2017
Son of Eileen and Aristeo Chacon
PO Box 416
Ojo Caliente, NM 87549

**Anya Janoski**
June 12, 1984 – April 2, 2017
Daughter of Margi Stern
359 Grandview Dr
Vacaville, CA 95688

**Marissa Ann Salas**
June 14, 1991 – April 22, 2017
Daughter of Miriam and Adolfo Salas
8841 Habersham Dr
Jonesboro, GA 30238-4472

**Devin Dahl**
September 7, 1966 – April 29, 2017
Son of Judy Dahl
Scottsdale, AZ

**Jimmy B. Crawford**
September 18, 1984- April 30, 2017
Son of Marlene and Jim Crawford
345 Garrett Dr. Trinidad, CO 81082

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**CdLS Foundation**
Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street #100
Avon, CT 06001-3681
800.753.2357 • www.CdLSusa.org

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

Enclosed is my tax-deductible gift of:
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☐ Once ☐ Monthly for ________months
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Donate online at www.CdLSusa.org.

Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street, #100
Avon, Connecticut, USA 06001

# Celebrate *Reaching Out's* 40th Anniversary

Forty years ago, founders Sue Anthony and Carol Power began 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 the accredited nonprofit we know as the CdLS Foundation.

*Reaching Out* was the pair's only program in the summer of 1977. Sue and Carol sent the first publication to the nine families that were known. They realized early on how crucial it was for CdLS families to know they are not alone. And thus, a community blossomed; a support network grew out of two women's dedication and dream.

The Foundation asks you to consider a donation in honor of *Reaching Out's* 40th anniversary, to keep this dream alive. A commemorative gift of $40 will ensure that *Reaching Out* continues to serve as a vital resource for all of our CdLS families of the present and future. Use the Coupon on the back of this page for your convenience.