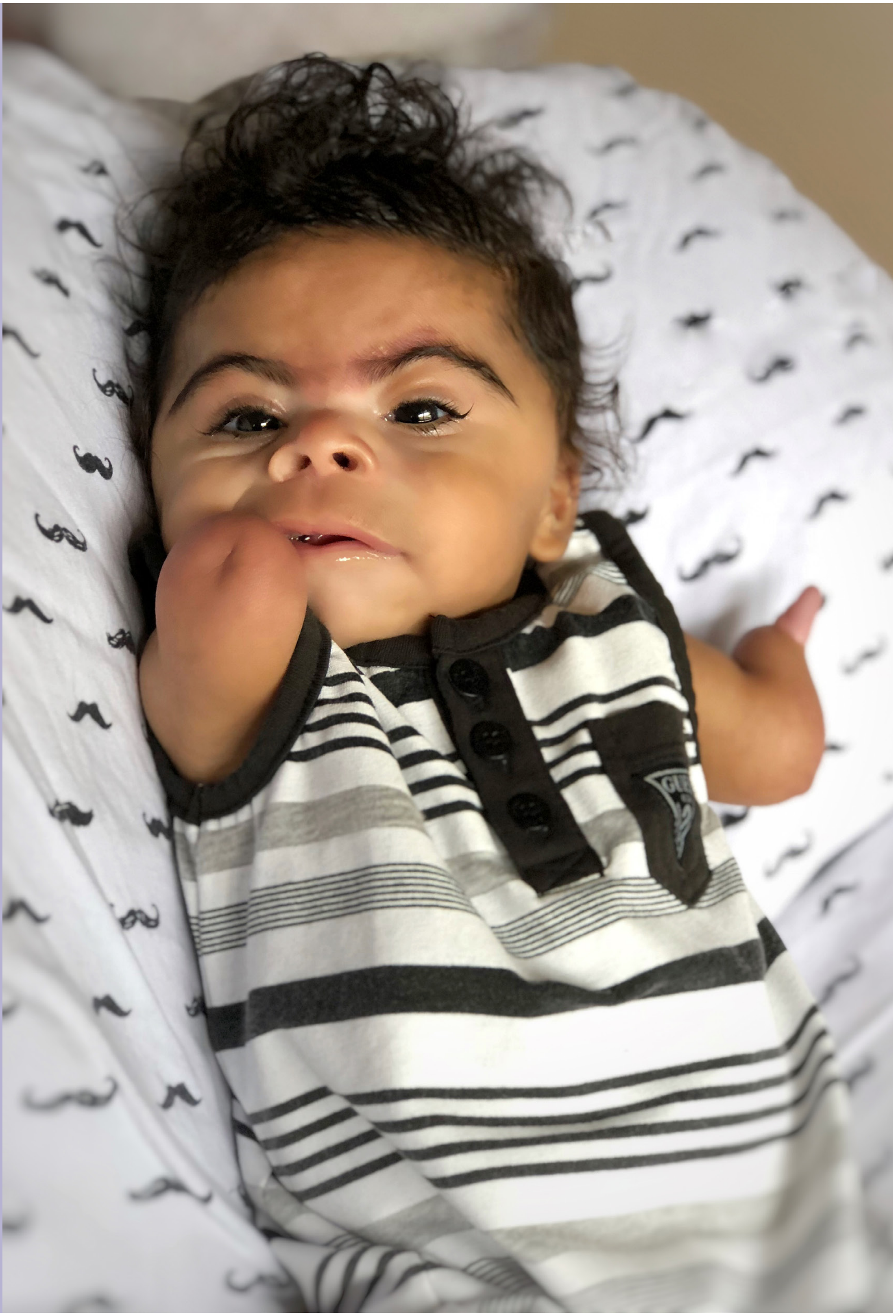
Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc. Third Quarter 2018



Highlights

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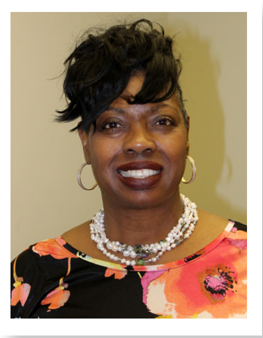
Gratitude, Reflection and Looking Towards the Future

Spotlights:
Feeding Tube Options

Welcome Our Newest de Lange Society Members

Super Siblings
Elizabeth & Eric

Director's Message



Gratitude, Reflection and Looking Towards the Future

We just had our 2018 National Family Conference in the friendly city of Minneapolis, MN. I want to take a moment and thank our friends from the "Land of 10,000 Lakes" for their incredible support and behind the scenes effort to make Conference a success; in particular, Will McDonald, the Dorow Family, the Van Buren Family, David Cataline and our Conference Co-Chairs Angie Young and Norm Winnerman. Without their help, and all others that worked so hard behind the scenes – the success of our Conference simply would not have been possible. The Foundation staff worked incredibly hard to ensure that the experience of the attendees was a good one. Big hugs to all!

Now that Conference is behind us, we return our attention to enhancing our services and outreach to you. We received your responses for the PBS segment on what you wanted the public to know as part of our awareness outreach. Overwhelmingly, the response was for the public to know how special and unique your children are; that they are human beings having the experience of CdLS. Some of the responses are as follows:

Our children have an amazing quality of life. They are not a syndrome, they are people with a syndrome. They aren't to be felt sorry for, they are to be inspired by! They understand everything that goes on around them even when they don't appear to be paying attention. They have a purpose in this world every bit and as much as neurotypical people.

CdLS is not a "one size fits all" syndrome. Each person with CdLS is unique, with unique challenges.

Our focus group of parents are working to ensure our message resonates the thoughts of all of you while sharing vital information about CdLS with the medical community.

The CdLS Foundation would like to better understand what you would like to read about in *Reaching Out*. What stories do you want you hear more of? What information is helpful to you to learn about? Let us hear from you through our brief online survey. You can find the link on page four.

Together we can educate and inspire the public about the amazing efforts of the CdLS community.

As always, you are in our hearts and on our minds.

Warmly,
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.

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Gastrointestinal (GI) Involvement and Individuals with CdLS

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

Gastrointestinal (GI) involvement is very common in CdLS. For babies with CdLS, feeding problems are the initial type of GI involvement. There can be difficulty with the mechanics of feeding, as well as tolerating an appropriate volume. Often a feeding tube, either a nasogastric tube (through the nose into the stomach) early in life or a gastrostomy tube (through the abdominal skin into the stomach) when the child is older, is required to help maintain the appropriate weight and take in the correct calories and medications. Later, the tube may be able to be removed. Constipation can also occur at any age in CdLS, likely due to slow bowel motility. This can be treated with fiber and/or medications.

The most common GI complication in CdLS is gastroesophageal reflux, where the valve between the stomach and esophagus does not function properly and allows the acid from the stomach to back up into the esophagus. This can occur at any age. Symptoms include frequent vomiting, bad breath, destruction of enamel on the back of the teeth and abdominal pain. Diagnosis is made by either an upper GI series, in which x-rays are done as dye is swallowed, or an esophagogastricduodenoscopy (EGD), done under sedation, in which a tube is passed from the mouth down past the stomach to look for ulcerations or other physical signs and to take a biopsy. It is important to manage this appropriately, either by medications or surgically, since there is a risk for a type of cancer (adenocarcinoma) of the bowel if left untreated. Reflux can be a hidden source of pain in individuals with CdLS.

In about 10% of people with CdLS, malrotation, or an abnormal rotation and tethering of the small intestine when it was formed, can be present at birth. This can be detected by an upper GI series, following it through to the duodenum (first part of the small bowel). If present, malrotation should be surgically repaired. If not repaired, it can lead to volvulus, an acute occurrence in which the bowel twists on its stalk, thus cutting off blood supply to the intestines. Symptoms consistent with possible intermittent obstruction include acute and significant abdominal pain, rigid abdomen, and/or bright yellow vomiting. If these occur, they should be addressed immediately. The child should be brought to the emergency room and/or a surgeon should be contacted immediately. Possibly x-rays and/or a definitive upper GI series should be done. Another significant complication with individuals with CdLS is the risk for bowel obstruction by volvulus, impacted fecal material, or other unknown causes.

There are other rarer GI complications and the most important aspect is for all parents to be aware that these can occur, so signs and symptoms are not missed. The Foundation has GI experts on the Clinical Advisory Board (CAB), who can answer questions related to GI complaints.

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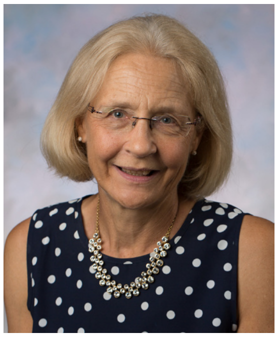
Feeding Tube Options



By, Carol Potter, M.D., Nationwide Children's Hospital, member CdLS Foundation Clinical Advisory Board.

Many choices are available for feeding tubes. They can be divided by where they enter the body, nose, stomach or intestine. They can also be divided by where they end, the stomach or the intestine.

Nasal tubes are inserted into the nose and taped to the face. They are easy to place at home or in the office. They can be left in for prolonged periods of time. The main drawback is if not well taped to prevent a child's fingers from getting them, they can be pulled out. If they end in the stomach they can be used for both bolus and drip feeds. If they go through the stomach and into the intestine, they can only be used for drip feeds. Nasal tubes are an excellent starting option if you are unsure tube feeding will work.

Feeding tubes can also go through the abdominal wall and into either the stomach or intestine. There are a variety of styles and methods to place them. This will depend on the child's size, other medical issues and the expertise of the person placing the tube. They are sometimes placed by a surgeon as a surgical procedure or a gastroenterologist during an endoscopy. The initial tube may have a long tail which is later changed to a tube that is flat with the abdominal wall.

Tubes can go through the stomach wall and into the intestine if the child can't tolerate feeding into the stomach because of vomiting. This may not be possible for a baby because the size of the tube may distend the small intestine and cause problems.

Feeding schedules are adapted to the needs of the child. We often use continuous drip feedings at night. They are well tolerated, are less likely to cause intolerance, and the parents don't need to get up to start and stop the feeds multiple times during the night. This type of feed can be used during the day as well but the child is tethered to a feeding pump. Bolus feeds are given more quickly and more like a meal. This allows more freedom from the pump. Pureed diets can be given through larger tubes, but usually clog the nasal tubes.

Granulation tissue can form around feeding tubes. Some children are more prone to it than others. Tubes that are the wrong size are more likely to cause this complication. Both the diameter of the tube and the length of the tube are important and should be measured when there are problems. Tension on the tube can make granulation tissue more likely. We do not recommend a dressing or covering on the tube. When the tube is in use, the connection should be secured to the abdominal wall to prevent movement and pulling. If granulation tissue occurs it can be treated with silver nitrate or topical steroids.

Located on page **seven** is the **Gastroenterology Medical Specialty Card**, which provides valuable care information that can be brought to your doctor.

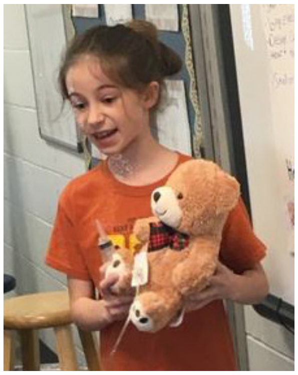
What do you want the future of *Reaching Out* to look like?

Let us know your thoughts about this issue of *Reaching Out* and what you would like to see in the future.

Share your opinion by visiting www.surveymonkey.com/r/ReachingOut18.

Closer Look: Mina and Charlie

Thanks to Mina and Charlie's mom, Maggie, for sharing their story.



During the month of May, many individuals reached out requesting information to share for Awareness Day. One request was for materials for a young girl in third grade. Mina, sister to Charlie, put together a powerful and interactive presentation on CdLS for her class at New Oxford Elementary School.

Mina taught her class about Charlie in general, CdLS characteristics, Hypoplastic Left Heart Syndrome and tube feeding. She brought in a teddy bear that has a G-tube in its belly to show how tube feeding works. Mina's class was very interested in and appreciative of her presentation. With Mina's presentation, 25 more children know how to use an extension set.

Her presentation is important because it teaches younger children not to fear individuals with feeding tubes. Mina feels that more kids and adults should know about CdLS. "Some kids are different," she says, "and they go through a lot. People should know that even though some people are different, they aren't weird. They are just unique!"

Since the day Charlie was born, he and Mina have had an extremely close relationship since he was born. Mina has supported Charlie through three open heart surgeries, countless therapies and doctors' appointments, difficult times, goofy times, and many "firsts."

Charlie and Mina have an unspoken trust and love. Charlie will do things for Mina that he won't do for anyone else, including walking more than three steps by himself. Mina is Charlie's best interpreter and will tell his nurses, teachers, and family member exactly what he wants. They make each other laugh and share a mischievous sense of humor, stubborn streaks and a love of movement. Charlie can lift Mina's bad mood, calm her down and teach her patience and responsibility.

Multidisciplinary Clinic for Adolescents and Adults at Greater Baltimore Medical Center

This Foundation-managed, free clinic occurs twice yearly at Greater Baltimore Medical Center (GBMC) in Baltimore, MD. Foundation Medical Director Antonie Kline, M.D., Director of Pediatric Genetics at the Harvey Institute for Human Genetics at GBMC, has led these free clinics since 2001. Any individual, age 12 or older with CdLS, can attend with their families. Clinics occur each spring and fall and can accommodate up to eight individuals. A Family Service Coordinator from the Foundation always attends to provide support.

Participants receive one-to-one consultations with specialists from pediatric ophthalmology, gynecology, pediatric dentistry, genetics, gastroenterology and nutrition, psychiatry and behavioral psychology.

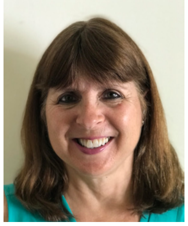
If you're interested in attending, call the Foundation at 800.753.2357 or email familysupport@CdLSusa.org.

CLINIC DATE

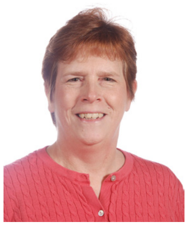
April 6, 2019

Welcome Our Newest de Lange Society Members

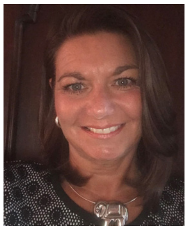
The Cornelia de Lange Syndrome Foundation (CdLS) staff and Board of Directors are pleased to announce the newest members to the de Lange Society, class of 2017 and 2018. The de Lange Society honors the Foundation's most exemplary and inspiring volunteers, their achievements and leadership.



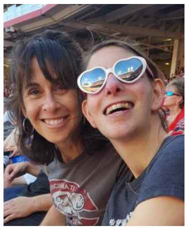
Cheri Carrico, CCC-SLP, Ph.D., is a Professor of Communication Sciences and Disorders (CSD) at Elmhurst College in Illinois, and is in the undergraduate program in CSD. Cheri attended her first CdLS conference, in Minneapolis, in 1998. In 1999, she was invited to be a member of the Clinical Advisory Board (CAB) and of the Scientific Advisory Council (SAC) in 2003. She has attended all of the National Family Conferences since 1998, as well as some of the international gatherings (Australia, Italy and Canada). She conducts research in the areas of speech, language, and feeding. She directed the Speech-Language-Hearing Clinic at Elmhurst College from 1997-2012 and was department chair from 2012-2015.



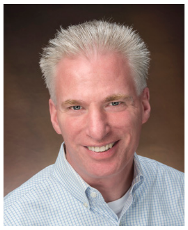
Cheryl Davis is the mother of three children, including Rebecca (age 21) who has CdLS. She is from Lincoln, Nebraska but now lives in Illinois. She has been a Regional Coordinator for many years and has hosted a few family gatherings. Cheryl was a part of the Conference Committees for the 2004 and 2008 National Conferences.



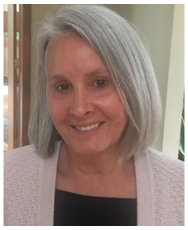
Beth Dixon, Esq., graduated from Converse College in Spartanburg, SC and received her Juris Doctor from the University of South Carolina in 1989. She has been an attorney in private practice, in-house counsel for Food Lion, Inc., and an Assistant District Attorney. In 2002, she was appointed a District Court Judge by then Governor Easley, and has since been elected 4 times. Judge Dixon presides in all areas of district court including misdemeanor criminal, felony probable cause, civil jury and non-jury, domestic relations, and juvenile courts. She is part of the Basic Law Enforcement Training faculty, and teaches at New Judge School for the NC District Court Judges Association. Judge Dixon is currently a candidate for a Master of Laws degree from Nottingham Trent University in Nottingham, England. She and her husband Glenn are the parents of four children, including Grace, 21, who has CdLS. Judge Dixon is a past Board Member of the CdLS Foundation and of her local ARC.



Ava Frank grew up in Allen Park, Michigan and graduated from Eastern Michigan University. She moved to Wickford, Rhode Island and worked at IBM. She progressed through various jobs and landed in management in Boston, Massachusetts. During this time, she also became a 'reluctant' runner. At a CdLS Conference, her friends Frank Mairano and Beth Smisloff recruited her to join Team CdLS and run a marathon. She currently lives outside Boston, working her magic at a data analytics company and is now a dedicated runner. In her spare time, she teaches piano, holds music salons, and pines for the day she can return to Italy while continuing her work with the CdLS Foundation.

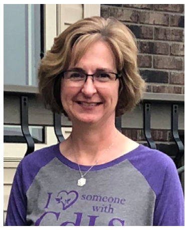


Ian Krantz, M.D., is an attending Physician in the Division of Genetics at The Children's Hospital of Philadelphia and Co-Director of the Individualized Medical Genetics Center. Dr. Krantz is a member of the Foundation's Clinical Advisory Board (CAB). He attended his first Family Gathering in 1998.



Susan Leone, BSN, MPH, has three children, including Frankie, 25, who has CdLS. When Frankie was born, there was very little information about CdLS to provide to Susan and her husband, Frank. At first, the Foundation was a support system for them. Susan began using her education to make a difference as Regional Coordinator. She also felt like she could make more of an impact and help raise awareness so she volunteered to become one of the Awareness Coordinators. Over the past 20 years, Susan has completed numerous swims, biathlons, walks, half iron men and marathon races all to help raise awareness and funds for the CdLS Foundation.

Karen and Jim Miller are the parents to a daughter, Nicole, 25, who has CdLS. They live in Texas and have been involved with the Foundation for the past 20 years. They have been longtime supporters and Jim has been involved with workplace fundraising campaigns and awareness activities for the Foundation. Karen has been a Regional Coordinator (RC) since 2003.



Christy Whetstone is mom to Baylee, age 22, who has CdLS, and two sons. She and her husband, David, reside in Lincoln, NE. Christy is a former CdLS Board Member and served for 7 years. She was also one of the co-founders of the CdLS Online Support Group, facilitating the listserv and internet relay chats in the early days of the internet. She enjoys hosting Regional Family Gatherings and organizing fundraisers/awareness events. Christy works as a substitute teacher as well as for Hy-Vee, Inc. Her family also operates a kettle corn business during the warm weather months.

2018 CALENDAR

October 6
Midwest Region
Family Gathering
Denver, CO

October 7
2018 Bank of America
Chicago Marathon
Chicago, IL

October 8
Missouri Golf Tournament
Tapawingo National
Golf Course
Sunset Hills, MO

October 20
Baltimore Running Festival
Baltimore, MD

November 3
Multidisciplinary Clinic for
Adolescents and Adults
Baltimore, MD

November 4
TCS New York
City Marathon
New York, NY

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.
REACHING OUT. PROVIDING HELP. GIVING HOPE.

Gastroenterology

An individual with CdLS should have regular evaluations and immunizations with the primary care provider.

Malrotation and volvulus

- At time of diagnosis, an upper GI series should be done to rule out malrotation. If malrotation is detected, early repair may be indicated.
- Rarely, a patient who has had repair of malrotation (Ladd's procedure) may still be at risk of midgut volvulus.
- Patients with and without malrotation have been reported to present with volvulus or twisting of a part of the intestine, which can result in serious illness or even death without prompt intervention.
- Any sign of potential volvulus (e.g. bilious emesis/vomiting bile or bilious withdrawal from gastrostomy tube, sudden acute abdominal pain or distension) should merit an immediate visit to the emergency room, work-up and potential surgery.
- Ensure that the family has the CdLS Medical Alert Card, available from the CdLS Foundation Web site, which would be helpful in an emergency situation (e.g. risk for volvulus).

Support organization information
should be given to the family
whenever a diagnosis is made:
The CdLS Foundation
1-800-753-2357
www.CdLSusa.org.

Cut this out and share with your child's doctor.

Gastroesophageal reflux (GE reflux)

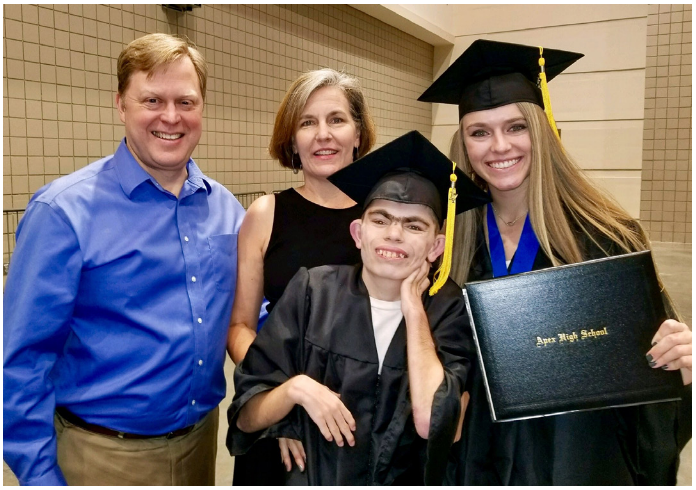
- GE reflux is very common in CdLS.
- Many patients will present in infancy with signs of GE reflux including vomiting and irritability. In this case, empiric treatment is indicated with acid blockers +/- prokinetics.
- Some patients may have silent reflux, with a change in behavior as the only sign. Children with CdLS with undiagnosed GE reflux may present with self-injurious behaviors and outbursts.
- Evaluation for gastroesophageal reflux disease (GERD) may include pH probe/impedance study, nuclear medicine scan and/or endoscopy.
- With any clinical suspicion of worsening or initial signs of GERD, a repeat evaluation should be performed.
- Therapies include medications (acid blockers +/- prokinetics), post-pyloric feeding and surgical fundoplication (Nissen or Thal procedure). Management and treatment guidelines for GE reflux are available www.cdlsusa.org.

Feeding, growth and nutrition

- Many children with CdLS have feeding difficulties in infancy, and some children are dependent on tube feedings throughout their lives.
- Use CdLS specific growth curves to follow weight, height and length.
- Children with CdLS are generally small, but should still grow along their own trajectory. Many children with CdLS require placement of a gastrostomy tube for maintenance of hydration and nutrition.
- Age appropriate formulas may be used. Some families prefer to use blended diets, which may be done safely under the supervision of a registered dietician.
- Aspiration is quite common in CdLS. Concern for swallowing difficulty or pneumonia should prompt further evaluation including a modified barium swallow.
- Manage constipation with fiber and/or medication as indicated.
- Whenever any surgery is performed, all involved specialists should be consulted in order to maximize the use of anesthesia and so that the individual can undergo diagnostic or management studies as needed at the same time.

Cut this out and share with your child's doctor.

Super Sibling: Elizabeth & Eric



Elizabeth is 19 years old and lives in Apex, NC. She is currently attending the University of North Carolina at Chapel Hill with hopes of becoming a Physical Therapist. Her brother Eric, will be 23 in August, and lives in an Intermediate Care Facility (ICF) in Greenville, NC. Eric is nonverbal and mostly communicates through the use of sign.

One of Elizabeth's favorite memories growing up is of Eric painting himself with anything he could find. When they were younger their mom would let them paint outside which often led to Eric taking his shirt off then smearing paint all over his entire body. One time he covered the bathroom counter and his hair in Vaseline when he was left downstairs by himself for a few minutes.

Growing up, Eric and Elizabeth were partners in crime. Many times when Elizabeth got intp trouble Eric was somehow involved and vice versa. As they have gotten older their relationship has changed a little. They don't get in quite as much trouble anymore but they still love to play around and have a good time together. Eric now looks to Elizabeth more as someone who can take care of him.

Her favorite memory in recent years is of their high school graduation. They were lucky enough to graduate the same year. The day of graduation Elizabeth walked in her place with the class and then went back stage to get Eric. Eric was the last person to walk, and with the help of his teacher and his sister, he walked across stage in cap and gown to receive his diploma. When his name was called the entire class gave him a standing ovation. It was such an amazing moment for the entire family to get to see him walk across stage.

"Eric inspires me to be who I truly am and not worry about what other people think of me. Sometimes we get so caught up in our own image and we forget to just let go and be who we really are, but not Eric. People have always stared and pointed at Eric in public but it never seems to bother him and to me that's really inspiring."

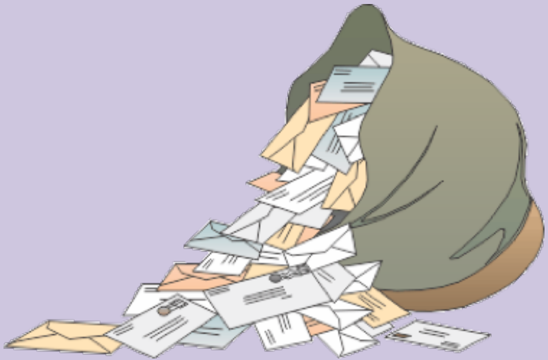
Elizabeth started the sibling Facebook group when she realized that she didn't know any other siblings. She wanted a way for all siblings to easily keep in touch and support each other. It's important to have this group because all siblings go through some things with their siblings with CdLS that most people don't go through. "It's important that we have a way to reach out to each other and find support when we're going through tough times."

"Eric has taught me that life isn't about waiting for the storm to pass it's about learning to dance in the rain."

Submit your Mailbag or Super Sibling Story!

Become a part of the CdLS Story Bank by submitting your story and photo to Gabrielle Nadeau, Communications Coordinator at outreach@CdLSusa.org or visit: www.storybank.cdlsusa.org/submit/.

We are looking to share stories from parents, relatives, friends and caregivers who wish to share their CdLS experience. These stories let others know they are not alone. They also provide inspiration, insight and, at times, a little humor. Help build the CdLS Story Bank.

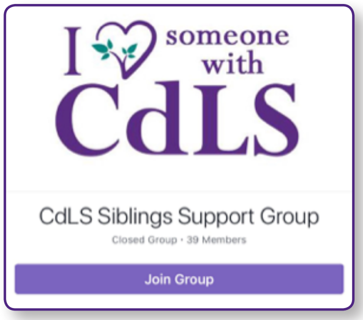


Facebook Sibling Support Group

Elizabeth Loftus had an idea, to create a place where individuals could come, connect, and talk about CdLS. This group would be different because it would be for the siblings of individuals with CdLS.

"My vision for the FB group is for it to grow and become a safe place for siblings to talk about what they're going through and to support each other. I also hope for the FB group to be a place where siblings can go for advice from others who have dealt with similar problems and situations with their siblings."

Similar to the Facebook Discussion Board, it would be a virtual safe place to address fears and frustrations as well as joys and triumphs. The group was created in May 2018 to strengthen bonds and support one another.



If you are interested in joining the Sibling Support Group, search "CdLS Siblings Support Group" and request to be added.

WELCOME NEW FAMILIES

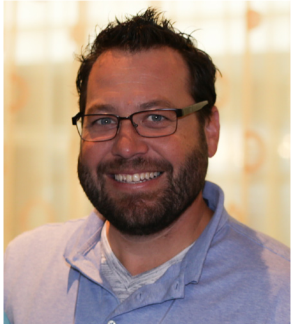
Florida
Amy and Korkut and daughter Eva,
born December 22, 2017

Mississippi
Nichole and daughter Ava,
born May 22, 2014

Oklahoma
Rachel and Chris and son Roman, born March 2, 2016

Texas
Kaya and Josh and daughter Bree, born January 17, 2015

Board Corner



By Patrick Lyons, President, Board of Directors; CdLS Foundation.

Welcome to another edition of *Reaching Out!* We've had a very busy spring and summer with several great events to help raise awareness of Cornelia de Lange Syndrome. From CdLS Awareness Day to local fundraisers and community events, we continue to help educate the public about Cornelia de Lange Syndrome. We can't do this without all the support from you—our families and our friends.

I was so inspired on Awareness Day as I scrolled through social media and saw all the photos, stories and videos that families and friends shared with their online communities. I was blown away by how so many families made the day special in their own personal way. Some families worked with their local towns, creating proclamations for "CdLS Awareness Day", others held lemonade stands, and there was even some who simply shared their very personal stories. We feel passionate about our loved ones with CdLS, and bringing awareness to this little-known syndrome builds empathy, community support and services for our kids, grandkids and siblings. The CdLS Foundation did a great job supplying press kits with valuable information to help spread our message. I look forward to seeing what we can do next year!

Congratulations to the New England Golf Committee for another outstanding golf tournament! This tournament started 26 years ago with a handful of parents looking to raise some money and build awareness. The tournament has grown to be an incredible event that—this year—raised nearly $50K. We look forward to continuing the vision of the golf tournament trailblazers. Sometimes all it takes is a group of like-minded individuals to get together and make a massive impact. This year we had the most beautiful weather and it was an absolute blast. It's fun to spend time talking to the golfers and volunteers that have participated in the tournament for the past 26 years. I'm hopeful that the new memories made will keep us going for another 26 years.

In an effort to get "down and dirty," our Board Treasurer, Mike Feehan, completed his 9th Mud Run for Team CdLS. Over the past nine years, Mike has raised more than $180,000 for the Foundation! Congratulations Mike! What an amazing accomplishment! Team CdLS is a great way to use your athleticism to help improve the lives of people with CdLS.

Team CdLS took to the streets of NY in May and pedaled their way through the 5 Boro's of NY with a 40-mile bike ride to raise awareness including board member, Angie Young. Congrats to the team for raising over $10,000!

We have some amazing Team CdLS events still to come. In October, we have the Chicago Marathon, and Baltimore Running Festival. In November, we have the New York City Marathon. Thanks to all the past and present Team CdLS members that put so much effort into training and raising awareness for the CdLS Foundation!

We have an amazing staff who would love to help you raise awareness or fundraise. If you have an idea for an event you think would be successful, don't hesitate to bring up the idea. We have seen success with so many fun and creative events, even the simplest of ideas can make a big impact. Our Yard Sale program or virtual Grandparents Tea could be just what you need to get going. We can't do this without you and appreciate all the support.

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.

Thank You for Making Awareness Day 2018 Successful.

Your hard work, passion and drive to raise awareness throughout your communities for your loved ones is inspiring. From horse shows and balloon launches to school presentations and state proclamations, the country was full of empowered individuals celebrating and raising awareness.

We will be forever grateful for your support in our mission. We can't wait for next year!

If you haven't yet sent in pictures of your Awareness Day activity, please forward it to Gabrielle Nadeau at outreach@CdLSusa.org so we can celebrate you!

Event Highlights

TD 5 Boro Bike Tour

Team CdLS was welcomed back as an official charity partner of the TD Five Boro Bike Tour. The team of parents, relatives and staff members pedaled 40-miles through the five boroughs in honor of those with CdLS. The team of 11 raised more than $10,000, exceeding their goal with each team member far-surpassing the fundraising minimum set by the bike tour.

Teammate Angie Y., ventured up from Florida to take on the streets and bridges of New York City, "My weekend in NYC for the TD 5 Boro Bike Tour has to be one of the best times I've had. I had no idea what to expect with anything associated with the ride. Getting to Brooklyn to pick up my registration, going to the exhibit hall, to taking the ferry back into Manhattan was just so nice. The reason for doing it is that I figured why not combine two of my passions, bike riding and doing what I can for CdLS and the Foundation. I also wanted the personal challenge. I usually ride by myself so on the morning of the ride, I was a little taken aback by the other 31,999 riders. The 40 miles weren't so bad but those bridges were another story. Being from Florida, I'm a true flatlander! It was a great feeling crossing that finish. It was a great experience and a honor to represent the Foundation. I'm already thinking about doing it again next year."

This year's team traveled near and far to participate and represent the following states – New York, New Jersey, Connecticut, Massachusetts and Florida! Thank you to the following participants for spreading awareness and raising funds: Clint B. and Evena L. (cousins to Joey), Rebecca M. (friend to Sofia), Francesca S. (CdLS Foundation Staff), Buck, Jonathan and Kendal S. (cousins to Sofia), Anna S. (sister to Jessica), Denise T. (mom to Sofia), Angie Y. (mom to Aaron) and phantom rider, Susan S. (friend of the CdLS Foundation).

Mud Run

Mike Feehan celebrated his 9th year as a participant of an annual mud run event on behalf of Team CdLS and in honor of his 10-year-old son, Connor. On June 9th, Mike competed on a course of military style obstacles getting dirty as he ran, climbed and crawled through mud. This year, Mike hit a major milestone in his fundraising efforts as he brought in over $30,000 to benefit the CdLS Foundation, bringing his lifetime fundraising total to $180,000!

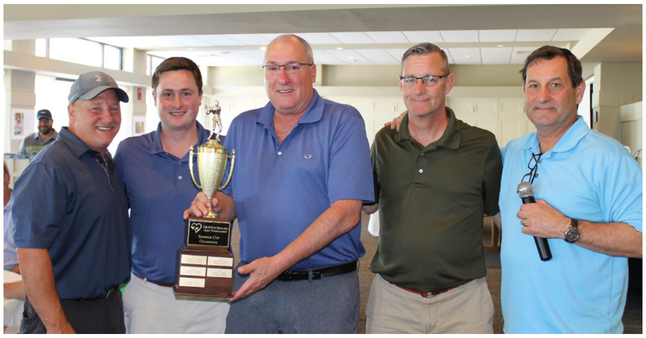
Mike shared with his friends, family and community members the importance of why their support of his fundraising efforts makes an impact to their daily life, "Connor, who is now 10 years old has been challenged with delays in his speech/communication, cognitive development, and his occupational and physical development. Connor is currently in third grade and continues to progress in school. He is doing great with t-ball, loves to swim and ride his bike. He enjoys puzzles, Pokémon, and anything with numbers. We continue to have our challenges, but the support we have from friends, family and the CdLS Foundation is instrumental in helping Connor continue to develop."

When not crawling through piles of mud, Mike shares his professional skills by serving on the CdLS Foundation Finance Committee and is the Treasurer of the Board of Directors.

NE Golf Tournament

Golfers and volunteers of the CdLS Foundation enjoyed a picture perfect day of golf on May 21st at the Ipswich Country Club in Ipswich, Massachusetts. The 26th annual event, started by family members who lived in the New England region, was generously supported by golfers, sponsors and in-kind donations which raised approximately $50,000. Over the course of the 26 years, the tournament has brought in over $940,000 to help individuals with CdLS live better, fuller lives.

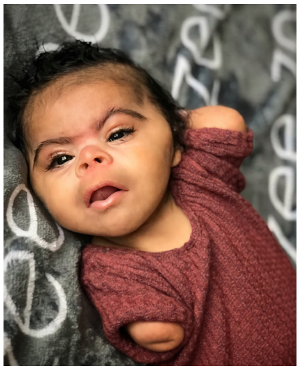
This year's sponsor cup trophy went to the tournament's Title Sponsor, Mainline. Board of Directors member Eric Johnson and his son, Anders, continued their quest to secure first place for the overall tournament championship. With a score of 58, the group took home the tournament trophy and will return to Ipswich in the fall for the Ipswich Country Club Day of Appreciation.



We extend our most heartfelt thanks to the sponsors of the event: Title Sponsor: Mainline; Birdie Sponsors: Craig-Hallum Capital Group and D.A. Davidson & Co; GreenPages Technology Solutions; KeyBanc Capital Markets; Registration Sponsor: Donald Sadoski, DMD; Lunch Sponsor: The Teixeira Family; Hole-in-One Sponsor: Acura of Peabody; Cart Sponsor: Insurance Recovery Group; Beverage Sponsor: Team Taryn; Contest Sponsors: The Catrickes Family; Friends of Tanaya Maine Molzan; and RenMac.

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.

On the Cover: Zee



Zee LOVES to be kissed, especially by mommy! He loves his "grey giraffe Gracie". He loves to watch *Color Crew* on BabyFirst™ TV. He is now eating baby food, and bananas are his favorite. He can detect daddy's voice anywhere, and starts searching when he hears him. He loves getting tickled by his brother and sister.

Our Deepest Sympathy

Araya Cummings
August 2, 2011 – April 15, 2018
Daughter of Bethany Cummings and Webster Patrick
2071 Amanda Way #12
Chico, CA 95928

Pamela Strait
February 3, 1969 – April 19, 2018
Daughter of Elizabeth Strait
1000 O'Kelly RD
Clarkesville, GA 30523

Charles Newcomb
June 21, 1972 – May 22, 2018
Son of Joyce Newcomb
1931 Farm Rd
Lake Forest, IL 60045

Marcaylin Edelbrock
December 23, 2013 – May 17, 2018
Daughter of Fawn and Craig Edelbrock and sister to Carys
338 Second Street NE
Sartel, MN 56377

Kayla Marie Taylor
August 23, 1997 – November 15, 2015
Daughter of Erin and Shawn Taylor

Donations from 03/31/18 - 6/30/18

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Join the Team!

When you run, swim, bike or tough mud this year, make your miles count for more than just distance. Join Team CdLS and help provide programs, services and support to families across the country at no charge to them.

Participate in an event in your community, start your own Team CdLS event, or join our established teams throughout the country. For a full schedule visit: www.cdlsusa.org/events/team-cdls

Email TeamCdLS@cdlsusa.org or call 800-753-2357 to learn more.

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October 7, 2018
Chicago, IL

Baltimore Running Festival
October 20, 2018
Baltimore, MD

2018 TCS New York City Marathon
November 4, 2018
New York, NY