REACHING OUT

SUMMER 2019

Coping Corner

My Children's Advocate

Augmentative and Alternative Communication (AAC)

FUNDRAISING for Conference

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

I remember from my early call center days learning about communication with customers. Our teachers shared how important it was to smile because the smile could be "heard" through the phone. I thought how curious and yet over time I discovered so much of what a person communicates is actually non-verbal – a stance, a look, tone and sometimes even a deafening silence.

Many individuals with CdLS are non-verbal. They communicate in their own way without language, forcing us to understand their meaning. Because of them, we know love without the words. Because of them, we get to reimagine language in a different way to convey an experience. In a world filled with things demanding our time and energy, their non-verbalness forces us to be still and pay attention – a gift.

In this issue, we take a deep dive into different augmentative communication tools that help us better understand what your loved ones are wanting to convey. You'll also find different resources including diaper assistance, car seat information and how to participate in wallet-free fundraising. Our Coping Corner features a mother's story of how she advocates for her two daughters through the education system. Please note that if you need assistance in your own advocacy, the Foundation and our Family Service team has a wealth of information and support. Please don't hesitate to call us at 800.753.2357.

Warmly,

Bonnie


Bonnie Royster, CdLS Foundation
Executive Director

> *"Parents of children with special needs create their own world of happiness and believe in things that others cannot yet see." -Unknown*

Reaching Out
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Cornelia de Lange Syndrome
Foundation, Inc.
Incorporated December 1981
email: info@CdLSusa.org
www.CdLSusa.org

International Treatment Guidelines

The First International Consensus Statement for the Diagnosis and Management of Cornelia de Lange Syndrome was published in October 2018 and was recently adapted and distributed to the CdLS support organizations worldwide and families. All information in the article was made by consensus, voted on by 37 experts from many countries. I wanted to share some of the highlights.

CdLS Spectrum: Is what we are now calling CdLS. It describes the phenotype, or clinical characteristics, and emphasizes that there is a range of these clinical findings, including those more typical, as well as those with less common features. The range of intellectual abilities is also a spectrum.

Diagnosis of CdLS Spectrum: Is based on clinical aspects and makes the recommendation when to do testing. There are six cardinal features, each worth 2 points; they include appearance of the eyebrows, nose, philtrum, mouth, fingers/toes and if there is a diaphragmatic hernia. There are 7 suggestive features, each worth 1 point; they include developmental delay, prenatal growth delay, growth delay after birth; small head; hands and/or feet; short 5th finger and excessive hair.

Genes associated with CdLS: Seven genes are cited as leading to CdLS when having variants. The function of all the genes is related to the large protein complex called cohesin, and in general, mutations in each gene has its own characteristics.

Recommendations: There are 68 clinical recommendations throughout the article, each related to a specific aspect. General areas include physical characteristics, causes of CdLS, diagnosis, medical care, health, cognitive and behavioral, changes with age and care planning.

This adaptation can be shared with physicians and allied health providers, and will be useful for those undergoing genetic testing as well. To read the full article, visit the CdLS Foundation website at bit.ly/2YKQfZx.

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

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Augmentative and Alternative Communication (AAC)

By Jennifer Ledford, Ph.D., BCBA-D, Vanderbilt University

Some children have limited expressive communication, meaning they are not able to adequately verbally communicate to meet a variety of needs. These children often benefit from augmentative and alternative communication (AAC) systems.

The American Speech-Language-Hearing Association defines AAC as "all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas. We all use AAC when we make facial expressions or gestures, use symbols of pictures, or write." This includes unaided communication systems that utilize the communicator's own body and aided communication systems that utilize additional materials or equipment to augment communication. Although AAC is often thought of as service an "augmenting" or as an "alternative" to spoken language, it also can be used to support comprehension of verbal (spoken or written) directions. AAC can support both expressive and receptive language/communication.

When deciding which AAC to use, consider the following:

1. Child's current cognitive, visual and fine motor abilities. The child should be able to access the device given their current abilities and level of development.
2. Consistent availability of the device. To be an effective means of communication, the AAC device should be available to the child at all times.
3. Collaborative decision-making. Teams of adults who regularly interact with the child should collaboratively determine how AAC might improve communication for a specific child.

Children using AAC devices typically start by requesting highly preferred items or activities. Before they learn to use AAC devices or other communication methods, children with limited communication abilities often find other ways to communicate their needs and desires. In some cases, they may use non-verbal cues and gestures when preferred items are taken away or are presented. In other cases, they may engage in challenging behavior.

Begin by observing the child, and identifying 2-3 items and activities that they already request in non-verbal ways. These should be highly preferred by the child, such that they will be very motivated to request them with the AAC device.

Children may not initially understand how AAC devices work. Thus, adults will need to prompt correct use of the device and reinforce correct responding so that a child learns that the device allows them to communicate. Here are some tips to get you started:

1. When the child engages in requesting behaviors, prompt them to use the AAC device.
2. When the child engages in challenging behaviors, wait for the behavior to stop, and then prompt them to use the AAC device.
3. Make sure that the AAC device is consistently available.

For more information and tips on this topic, visit: bit.ly/2HnDw80.

Inside Look: Augmentative Communication Systems

Rachel is able to communicate what she needs or wants with her device. This has reduced frustration for her and her family.

Rachel will be turning 16 years old in June. She has lived with CdLS her entire life, being diagnosed with the syndrome on day one. Rachel attends School for Children with Hidden Intelligence in Lakewood, NJ where she also resides. She has an incredible support network. They feel extremely fortunate to have her in their lives. She has truly changed so many in the way they view the world, and life in general.

As with most individuals born with CdLS, Rachel has her challenges, affecting both her physical and mental abilities. Although very smart, Rachel is unable to verbally express herself. Before Rachel had a communication device, she had terrible behavioral outbursts, feeling frustrated for not being able to communicate her thoughts and desires. She has been using communication tools ever since she started pre-school.

At first these tools were very basic, simple boards that the aids and therapists helped create. As Rachel got older her communication devices became more robust. Right now she is using an iPad, both at school and home. The name of program she uses is proloquo2go.

Rachel's school had a huge influence in choosing the best device for her. They worked closely with the district, who paid for the device. Rachel was evaluated and continues to be evaluated as she gets older and as her needs change. Communication is a topic at every annual review meeting, but her family is fortunate that the staff dedicated to Rachel keeps a close pulse on her development. They are completely in tune with what she wants to communicate and update the app with new words constantly.

The device is provided by the school, and paid for by the district. Many individuals with CdLS can be destructive, and unfortunately this has been an issue with multiple devices over the years. When Rachel feels upset about something, it is likely that she may toss the iPad across the room or bash it against floor or furniture. When this happens it is certainly upsetting, but the school and district work together to ensure that a replacement device is issued right away.

Although Rachel's challenging behaviors are still present, they have reduced both in frequency and intensity. Her family enjoys communicating with her, she is able to deliver specific instructions on what she needs or wants. For example, when dining at a restaurant they no longer have to guess what Rachel wants. She effortlessly opens up the food category of the app and points to the exact item she would like.

Being able to communicate has reduced frustration for Rachel. She can express herself very clearly. Rachel supplements the audio output from the app with sign language, by gesturing additional thoughts which may not yet be found in her app.

When Yana, Rachel's mom was asked what advice she would give to other parents about AAC devices she said,"Go for it, give it a shot. Our kids are very smart and will be able to figure it out. If there are limb differences it may be more difficult to master, however I am confident that with augmentative support the device can be used with success. Although not your child's natural voice, hearing the device speak what's on their mind is incredible. Most recently Rachel gave me the best gift around by wishing me a Happy Mother's Day in her own words, words I could hear and appreciate. If you would like to see the video of this or keep up with Rachel's adventures in general, please follow her on Instagram @pictureperfect_rachel."

Catherine, pictured with her two daughters and husband, continues to advocate for Alexis and Jessica every day. If you feel as though you need assistance advocating for your loved one with CdLS, please contact the Foundation at 800.753.2357 and our Family Service Team will assist you in finding the resources you need.

My Children's Advocate

By Catherine Rose Schnaderbeck

My two beautiful daughters, Alexis and Jessica, were both diagnosed with CdLS *HDAC8* deletion. They were diagnosed in 2017 and 2018, when they were 11 and 10. Alexis had numerous medical issues when she was born and through her hospitalizations, this is when I learned to advocate for her.

When Alexis and Jessica both started school, my husband and I knew it was important to work closely with the Individualized Education Program (IEP) teams to create environments that would help them thrive. There was one school program where we felt that wasn't helping Alexis improve in her communication goals. We had to explore different options, it was a trying experience but we advocated for Alexis to be placed in another school. The change was hard at the time for all of us but Alexis grew in her environment and uses her iPad with Touchchat (an app) to communicate more now.

In Jessica's case, many of her disabilities are invisible. She works so hard to keep it all together at school and the IEP team did not always see her challenges. We knew she would need extra support to help others understand her needs. We invested in paid advocates – having two children with special needs it is important that we surrounded ourselves with the best team possible. With support of various paid advocates, we got additional testing and even the diagnosis of CdLS has helped us explain Jessica's deficits and how hard she is working to accomplish her schoolwork.

I'm an inquisitive and detailed oriented person. When I see a situation that Alexis or Jessica are facing, I try to put myself into their shoes and imagine what their challenges might be. I ask a lot of questions of people who work with them – physical therapists, speech therapists and even our babysitters – to get perspective that maybe I was missing as a mother. We have paid for numerous evaluations and therapies outside of school.

Alexis and Jessica are doing very well in their schools now. That being said, I don't think the advocating ever stops. There are always ways to improve the environment for our kids to thrive. I'm always seeking answers to questions as new challenges appear. Alexis and Jessica are even beginning to advocate for themselves. For Alexis, it's asking for a break from her chair, stander or walker. For Jessica, it's as simple as asking for a break from the classroom, asking people to repeat themselves when she doesn't hear them, or asking for more information if she doesn't understand something.

My advice to other parents is take a breath. It's easier said than done. Try to look at the situation with the biggest lens and a view of the big picture. Try to keep a focus on moving towards something better, but be prepared with the details. Also, find your tribe – people who have been in your shoes and can help you navigate.

HIGHLIGHTED Events

According to the National Center for Charitable Statistics, more than 1.5 million non-profit organizations are registered in the United States. Located in the small New England town of Avon, CT, the CdLS Foundation is fortunate to have local and national volunteers who devote their time, treasure and talent. Those who support non-profits do so for different reasons. Some want to give back for the services received, others believe in the mission and some feel a sense of personal achievement. These reasons are no exception to those who support the CdLS Foundation.

Like those with CdLS, the Foundation may be small, but we are mighty because of the passion behind thousands who have and continue to offer their time, treasure and talent. If you would like to host a fundraiser, join a team or volunteer on a committee, please contact Kristi at events@CdLSusa.org or 800.753.2357.

NEW YORK CITY HALF MARATHON

Team CdLS kicked off the endurance event season with the United Airlines New York City Half Marathon. This event marked a monumental year, for team veteran, Joann Bardis who made her fourth appearance at the race and raised over $33,000 since toeing the line in 2016. "I am so honored to have been part of Team CdLS and the ability to run for such a great organization. With my biggest fans, Stelios and his twin brother Dimitrios, cheering me on while running, I know I will complete the race and hopefully raise a significant amount of funds for the CdLS Foundation so that families like ours have the resources they need to help their children."

TD FIVE BORO BIKE TOUR

In May, the team cycled their way through at the TD Five Boro Bike Tour. Despite the heavy rain throughout the 40 mile ride, the team took on the challenge and crossed the finish line with a sense of accomplishment and a sigh of relief. Mimi T. and 7 members of her family rode in honor of her sister Sofia. The team shared, "She is a truly special person who makes the world a little brighter for everyone who meets her. Our lives simply wouldn't be the same without Sofia's unconditional love and infectious personality, and we would love to use this opportunity to do something for her after all that she has done for us."

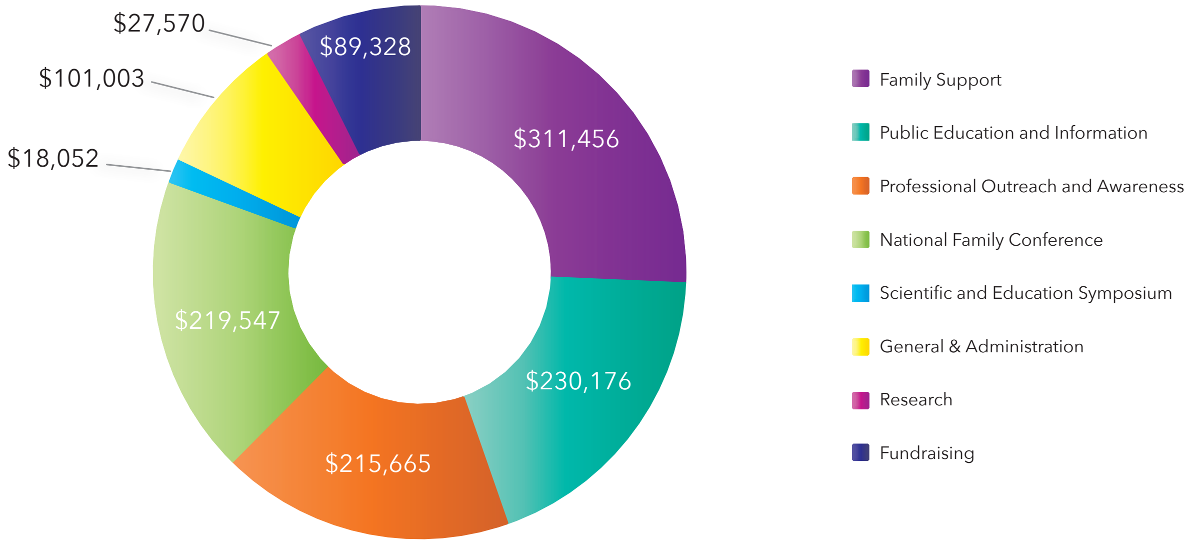
NEW ENGLAND CHARITY GOLF TOURNAMENT

The New England Charity Golf Tournament is fortunate to have a dedicated group of volunteers who actively seek sponsorships, auction and raffle items, invite golfers and volunteer on the day of the event. The event started 27 years ago by a group of parents who were tasked to raise money for the National Family Conference. After a day on the course and a lobster dinner, the committee decided to continue the event. Since its inception, the golf tournament has raised over $900,000! Sponsors: Mainline Information Systems, GreenPages Technology Services, Insurance Recovery Group, Red River, The Teixeira Family, Qumulo.

Finance Message

YOUR DONATIONS HARD AT WORK

The CdLS Foundation will forever be grateful for the generous donations we receive from you. Below is a breakdown on where the donations were used and how you helped the CdLS community. In 2018, the Foundation spent $1,212,797.



THANK YOU for helping to fuel our mission and allowing us to support you in the ever changing journey of life.

CALENDAR

August 17
Missouri Family Gathering
Rocky Mount, MO

September 15
Saratoga Palio Half Marathon & 5K
Saratoga Springs, NY

October 5
Northwest Region Family Gathering
Seattle, WA

October 5
10th Annual Brew & BBQ
Alpharetta, GA

October 7
Missouri Charity Golf Tournament
St. Louis, MO

October 13
2019 Bank of America Chicago Marathon
Chicago, IL

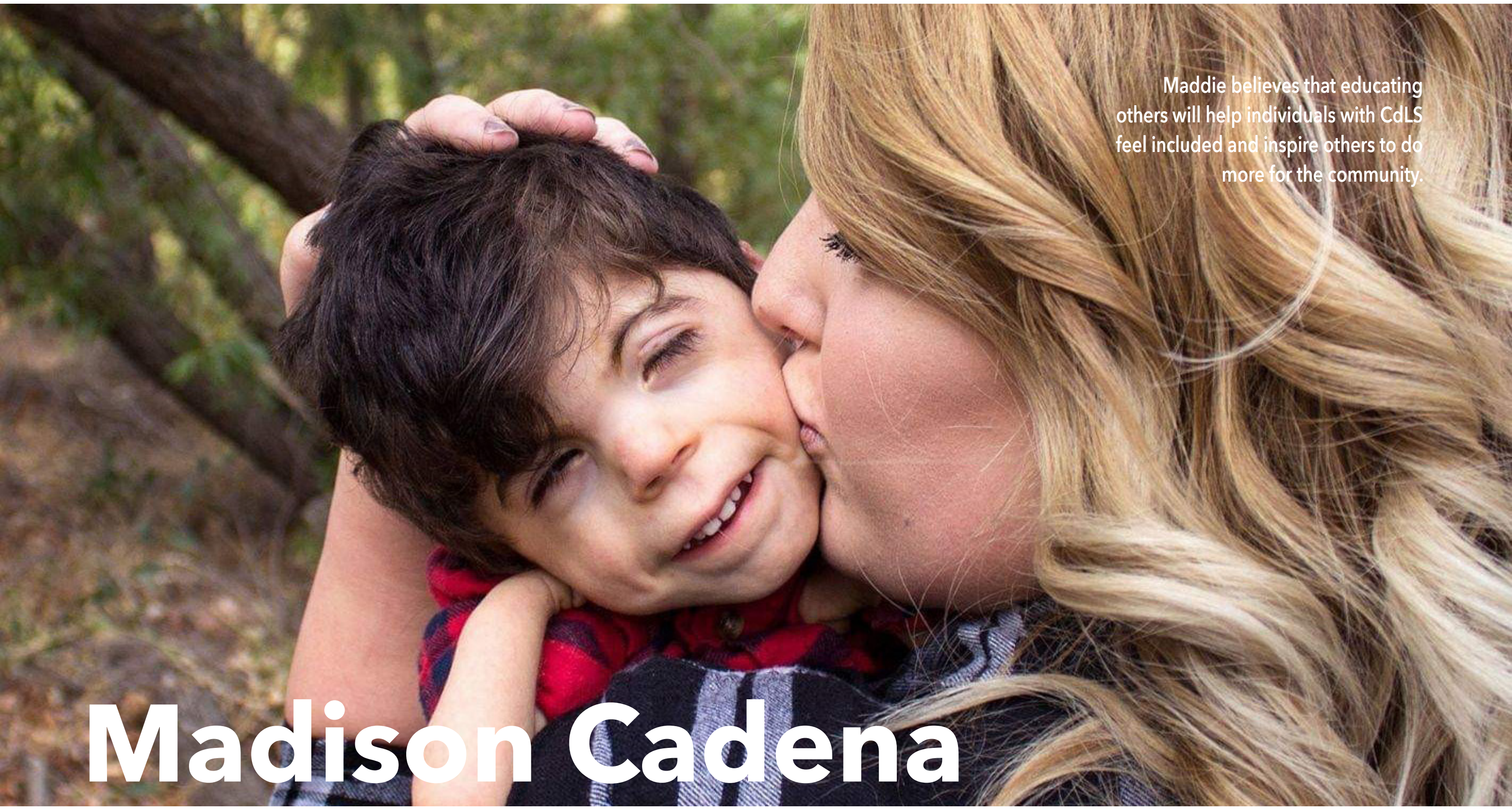
October 19
2019 Baltimore Running Festival
Baltimore, MD

November 2
Multidisciplinary Clinic for Adolescents and Adults
Baltimore, MD

November 3
TCS New York City Marathon
New York, NY

June 24 - 25, 2020
Ninth Biennial CdLS Scientific & Educational Symposium
Tulsa, OK

June 25 - 28, 2020
CdLS National Family Conference
Tulsa, OK



Maddie believes that educating others will help individuals with CdLS feel included and inspire others to do more for the community.

Madison Cadena

I had my son Austin when I was 20 years old and I have been advocating for him since the day he was born. When I was pregnant, he was diagnosed with inner uterine growth retardation because he stopped growing. I had Austin at 38 weeks and went through 17 hours of labor. I was scared to have a child at such a young age, but the second I held Austin all my fears went away. When I laid eyes on him I knew he was just absolutely gorgeous. The doctors put him on my chest but quickly took him to the NICU. By the end of the day we met with a geneticist who confirmed the diagnosis of CdLS. When Austin was three days old, my Grandma contacted the Foundation and when he was one week old, I connected. We were lucky enough to reach out just in time to register for the National Family Conference in Costa Mesa. The Conference welcomed me into a group of other families who understood what it's like raising a child with CdLS and helped me better understand the diagnosis.

It was important to start social media pages and raise awareness for Austin. When I would first take him out in the world, people would stare at him and I would get really annoyed. It took a while for me to realize people were just curious and wanted to know more. Friends and family were constantly asking me about him and wanted to see how he was doing. I also hoped that people I never met would find the pages, start following his journey and learn more about CdLS.

This year I took my knowledge about CdLS to Open House night at Austin's school. Before the event started, I had the honor of speaking to the attendees, afterwards I had so many people come up, ask more questions and take materials – it really felt like I was telling Austin's story. The principal also sent information about CdLS to all the families in the district **which is around 50,000**. We have met with doctors that have never heard of CdLS and there have been times where I had to fight against what a practice was telling me because I knew it wasn't in the best interest for Austin. It was scary but it took courage to make them listen to me. Because of this I put together packets filled with information about CdLS that I bring with me when I meet new doctors. I want to be the best advocate I can with the best tools for the health and well-being of my son.

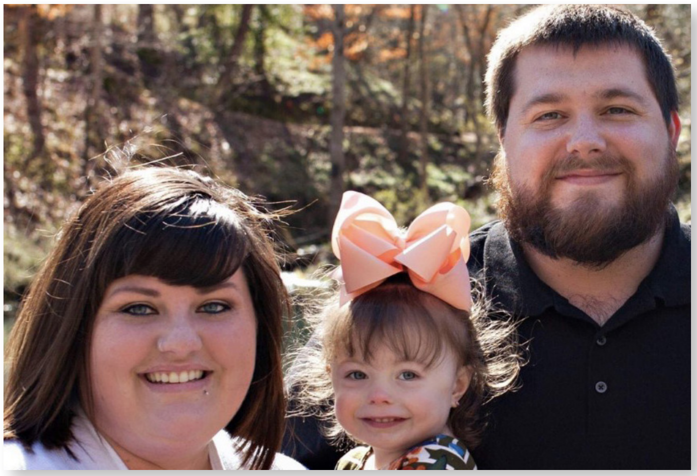
To me it is important that others learn about CdLS because I don't want other kids to look at Austin like he is weird and I want him to be accepted. I want all individuals with CdLS to be and feel included. My family doesn't want Austin to feel different. He is like all of us, he just does things in his own way. CdLS is not known – it is a hidden little syndrome and if people raise more awareness and donations we could find out more.

Austin might be small and may do things differently, but his determination, will-power, and attitude inspires me every day.

WELCOME
New Families

THE WEBERS

We are a family of four. Ben is the youngest and has CdLS, a de novo missense mutation of *NIPBL*. We are so happy with his progress and development. He exceeds expectations every day. And even though he isn't smiling in this photo, he is the happiest little guy!



THE BROWNS

I am Katrina and this is my Husband Courd. We are a proud CdLS family! We received our daughter Ariyah's confirmed diagnosis at 16 months old, she has a gene mutation on the NIPBL gene. Now, Ariyah is two and a half years old and doesn't let her diagnosis slow her down. She loves to run wild and we wouldn't have it any other way!

Arizona
Nancy and Stephanie, born September 11, 1995

California
Wendy and son Adam, born November 10, 2007

California
Angela and Brandon and daughter Charlie, born February 24, 2017

Connecticut
Colleen and Ronald and daughter Katerina, born July 19, 2018

Georgia
Jaylynn and Tyler and son Shug, born January 30, 2019

Illinois
Lena and son Landon, born April 30, 2019

Minnesota
Sidra and sons Rayyan born 2012 and Raed born 2013

New York
Kasey and daughter Esme, born September 3, 2017

Ohio
Megan and daughter Lindsey, born September 12, 2006

Oklahoma
Patti and sister Verna, born December 7, 1959

Pennsylvania
Renee and son Coby, born April 17, 1995

Virginia
Mabel and Trinol and son David, born January 4, 2019

Twins, I'lianah & I'lisiah, are the youngest of six children. They love their older siblings. One of their favorite things is when their sisters turn music on and dance for them.

I'lianah & I'lisiah

I'lianah and I'lisiah are identical twins, and the youngest of six children. The girls were born August 3, 2015 at 32 weeks. During their first year, the girls were diagnosed with failure to thrive, hypertonia, cerebral palsy and I'lianah was diagnosed with Partial Agenesis of the Corpus Callosum. At age two, their parents did genetic testing and discovered the girls had CdLS. Earlier this year they were diagnosed with Growth Hormone Deficiency.

I'lianah and I'lisiah are indeed identical in many ways but their big personalities are quite different. I'lianah is the sweet, sensitive twin, she loves the attention and cuddling. I'lianah tries to be around I'lisiah, but I'lisiah likes to pick on and be rough with her. She's the aggressive twin and will let you know how she feels. She enjoys attention but not for long. She does not mind letting you know when she doesn't want to be bothered. The twins are called Sweet and Sour Patch Kids.

They mirror each other a lot with certain hand movements, sleeping positions and other things. They have this little thing they like to do to tag team their parents, when one twin gets told "no", the other twin will stop what they are doing just to come and do what the other twin was told not to do. They will make sure they are looking at their parents while doing it just to get a reaction.

The twins require more time due to appointments and medical needs. Having twins with CdLS can be challenging at times. The family misses out on a lot of events and outdoor festivities because of the unknown with the twins. Their feeding schedule is pretty strict because of their low weight. They also have acid reflux which causes issues as well. However; their parents consider themselves blessed, as they get to be parents to these two unique and amazing girls.

Tasheika, the twins' mom, has a saying; "Instead of teaching children that we are all the same; teach them that we are all different and that's OK!"

Wallet Free Fundraising

Rachel A. inspires her employer to make purchases through Amazon Smiles to benefit the CdLS Foundation:

I work for Dr. Kawa Orthodontics and Oral Surgery. Since the birth of our son, Kaden my co-workers and employer have been very supportive of our family. Whether it has been fundraising for Kaden and the Foundation or just being there for support, they have always been behind us 100%.

My job knows how important the Foundation is to me and other parents. One of the easiest ways that people can help is through AmazonSmile. My co-workers all have selected the CdLS Foundation as their charity when shopping at www.smile.amazon.com. Every little bit counts and adds up.

Shopping at AmazonSmile is such a great way to get extra funds for the Foundation. I hope more people jump on the bandwagon and spread the word! Thank you **ALL** at the Foundation for what you do. Wouldn't be where I am now without you!

The CdLS Foundation has experienced a positive trend of support with the "Wallet Free Fundraising" opportunity with the AmazonSmile program. Since the program's inception in 2015, the Foundation received over $7,445.

We thank all those who have designated the CdLS Foundation as your charity of choice when you shop at www.smile.amazon.com. **Whether you are using AmazonSmile for business or personal reasons, you can choose the CdLS Foundation as your charity of choice! Use the steps in the column to the right to learn how.**

Donate Through AmazonSmile

1. In your internet browser go to **smile.amazon.com** and log in using your Amazon credentials.
2. Under **"pick your own charitable organization"**, type in Cornelia de Lange Syndrome Foundation, Inc.
3. Click **"Search"** and from the list, select **Cornelia de Lange Syndrome Foundation.**
4. Check the **YES** box to confirm. You must visit smile.amazon.com each time you shop to support the CdLS Foundation.
5. When redirected, bookmark your AmazonSmile page so it comes up automatically when ordering items.
6. **That's It!**

Helpful Hints

COMMUNICATION APPS

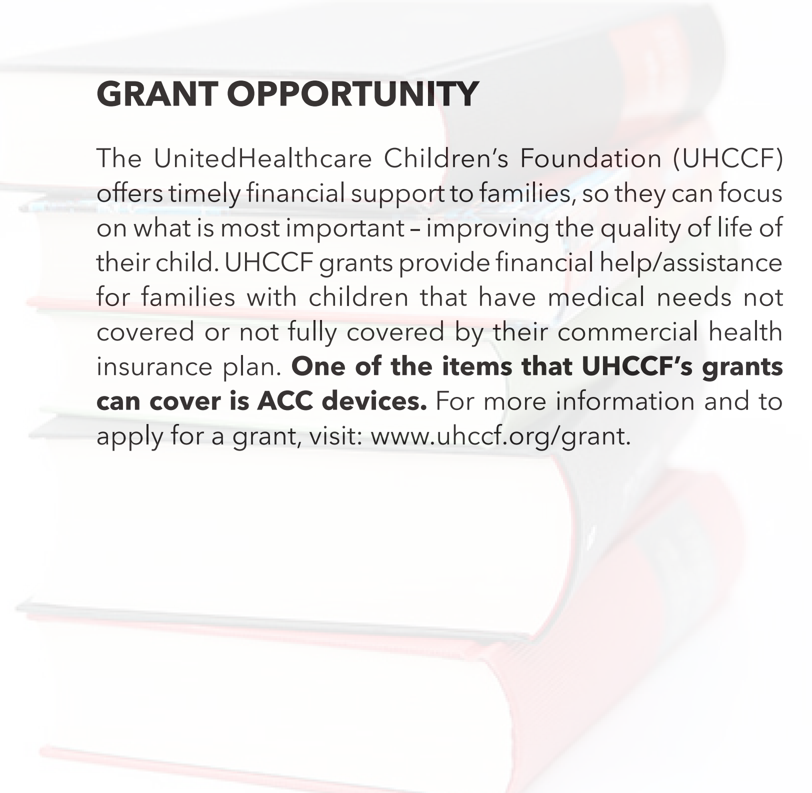
Apps for Augmentative and Alternative Communication:

- tobii dynavox Compass ($179.99) Short-Term Subscriptions: ($99.00/year or $19.00/month) - iOS operating system (iPad2 and above support no iPad1 support and Windows 7 or higher support)
- Proloquo2Go ($249.99) - iOS operating system only
- GoTalk NOW LITE (FREE) - this only allows 3 personalized communication pages. GoTalk NOW is an upgraded version that allows you as many communication pages/books as you need ($79.99), iOS operating system only
- TouchChat HD AAC ($149.99) - there is a TouchChat HD Lite ($9.99) version with NO Voice Output and a TouchChat HD-AAC with WordPower ($299.99) for those with Literacy Skills, iOS operating system only
- SoundingBoard (FREE) - iOS operating system only
- TalkTablet ($79.99) - for Android, iOS operating system, Windows and Kindle handheld and tablet devices
- iSpeak Choices ($5.99) - iOS operating system only

For more information on apps for Augmentative and Alternative Communication, visit: bit.ly/2YrEoz8.

GRANT OPPORTUNITY

The UnitedHealthcare Children's Foundation (UHCCF) offers timely financial support to families, so they can focus on what is most important – improving the quality of life of their child. UHCCF grants provide financial help/assistance for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan. **One of the items that UHCCF's grants can cover is ACC devices.** For more information and to apply for a grant, visit: www.uhccf.org/grant.



CAR SEAT INFORMATION

There are a variety of child restraint options available for individuals with CdLS.

No matter what type of seat you choose, there are some general guidelines that you should keep in mind:

- Talk to your pediatrician or surgeon about your child's positioning and transportation needs
- Check the label on the car safety seat and make sure it states that the seat meets or exceeds Federal Motor Vehicle Safety Standards
- Never try to alter a car safety seat to fit a child with special needs. Never use a car safety seat that has been altered to fit a child with special needs unless it has been crash tested with the change
- Stay up-to-date on what might be available for your child
- Keep your child in the type of car safety seat that gives the most protection until your child reaches the top weight or height recommended by the manufacturer

Car safety seats for children with special needs are often expensive. However, you may be able to get help with the cost. Insurance, including Medicaid, may cover the cost of a specialized restraint in some cases. For special needs car safety seat programs in your area, contact:

- Your pediatrician
- A local children's hospital
- Your rehabilitation therapist
- A Child Passenger Safety Technician in your area. To find one call 1.888.DASH.2.DOT
- Contact Easter Seals at 1.800.221.6827

For more information, visit: www.heartsfrc.org/car-seat-safety.

Our Deepest Sympathy

Apollo Gabriel Adams

August 12, 2013 - February 27, 2019
Son of Joy Morreale and Ernest Adams
7 Kenyon Ct
Utica, NY 13501

Alexandra "Allie" Boteler

December 29, 1995 - April 15, 2019
Daughter of Stephanie and Jerry Self
5 Feliciana Ct
Harvey, LA 70058

> "Cherish the good memories of your child and remember: hold on to hope, rest when you're weary, take time to grieve, and let your heart mend."

–Excerpt from *"When Angels Take Flight: the Loss of a Loved One with Cornelia de Lange Syndrome"*

If you would like to speak with Foundation staff or connect with other families who have lost a child with CdLS, please call 800.753.2357.

Fundraising for Conference

By Tasha Howland, Certified Life Coach, mom of Peyton

With the National Family Conference approaching in just over 365 days, families are beginning to plan and save. I'd like to offer a few tips that you may find helpful with fundraising.

1. KNOW THE COST. We know there are two or three major costs – registration, hotel and transportation. There may be some other expenses that need to be considered, like local transportation, souvenirs, snacks and personal items. Be sure to consider all expenses to ensure that cost estimates are correct. Research all transportation options to maximize your available funds. Are you able to drive to the conference location? Would a train ride be less expensive? Are there multiple airports from which I can depart?

Next, determine the total cost for your trip; how much you have, will, or can save; and how much you need to raise. Now that you're armed with an accurate fundraising goal, it's time to identify potential funding sources.

2. THINK OUTSIDE THE DOLLAR. It may seem daunting, but you will be surprised to find that people, businesses and organizations willing to support you are not hard to find.

Start with your family and friends, then look to your community. Because you know your cost for attending conference, you can think beyond the dollar and make your ask very specific. Are you flying a particular airline? Ask family and friends if they have frequent flyer miles they are willing to use to purchase tickets for you. What hotel is the conference being held? Do you have family or friends that would be willing to book your hotel room using their hotel loyalty points? Are you driving? Your request can be for gas cards or restaurant gift cards to cover meals and snacks.

Research local organizations that traditionally support families and children. Are there conference participation funds that you can take advantage of? One possible funding source is through your State Special Education Department. Each year, an amount of money is set aside in the IDEIA (Individuals with Disabilities Education Improvement Act) budget to support parent involvement. This money is used for parents who have children with special needs and can be used as stipends to attend conferences. Other possible funding sources might be:

- Lion's/Elks Club
- School for the Deaf or Blind
- YMCA/YWCA
- Rotary Clubs
- Kiwanis
- PTA/PTO
- Church groups
- Urban League
- Local Businesses
- Local Parent Training and Information Center (PTIs)*
- Community Parent Resource Center (CRCs)*

*Find yours here: parentcenterhub.org

3. SHARE YOUR TRUTH AND MAKE A REQUEST. It's best to put your request in writing. A written note will help you spell out your financial needs, give donors a way to get involved and help create an emotional bond through true, powerful messaging. If you're comfortable, include a picture. If you're sending an email, you can attach pictures and videos! Our kids are so darn cute, who could say no.

<Begin with an emotional appeal, a success story that will tug on the heartstrings> I can't believe the progress that Peyton has made over the past few months. We've been working diligently on her walking and she's now able to walk in her gait trainer 50 feet without getting tired…insert momma's happy dance! She's 6 years old and we've never given up on the possibilities of her being able to walk. Can you imagine when she's able to walk down the aisle for her kindergarten graduation this year? Insert daddy's crocodile tears.

<A statement of the problem being solved> The CdLS Foundation knows how important it is for families to be educated as well as interact with other families facing similar challenges. So they organize a biennial National Family Conference in various parts of the U.S. and offer families educational workshops and free consultations from specialists well versed on CdLS.

<A statement of our goals in attending conference> This is one of the few opportunities that some families have where their child is seen by world renowned doctors and therapists. The next conference will be held <*insert date*> in <*insert city, state*> and we would love to have the opportunity <*fill in the blank and how this will benefit your child and family*> While our family has been able to save some funds towards this trip, day to day expenses of raising a child with special needs are very demanding and we need your help. A donation from your organization can <*be specific…help offset the cost of the airline ticket or hotel for example*> and assist us with getting Peyton to <*city*> in <*month*> to <*repeat goal for attending conference*>.

<one final note> Thank you in advance for your consideration. Here are the ways you can make a donation:

- If you have a GoFundMe page, add link here
- Call us and we will be happy to meet you to pick up your contribution

Or mail a check made out to <*insert name and address*>

Timing is crucial. If you're trying to raise money for conference, **be sure to make your asks at least two months prior.**

4. FOLLOW-UP. Be sure to send thank you notes. They are just as, if not more, important as the request. Donors always like to know they made a difference and that their gift was impactful.

I hope this information will be helpful as you plan for conference and I look forward to seeing you there! For more information and some fun fundraising ideas, please join my webinar Thursday, September 19th at 12:00p EDT. You can download the sample letter, visit the CdLS Foundation website, www.cdlsusa.org/conference.

COST OF CONFERENCE

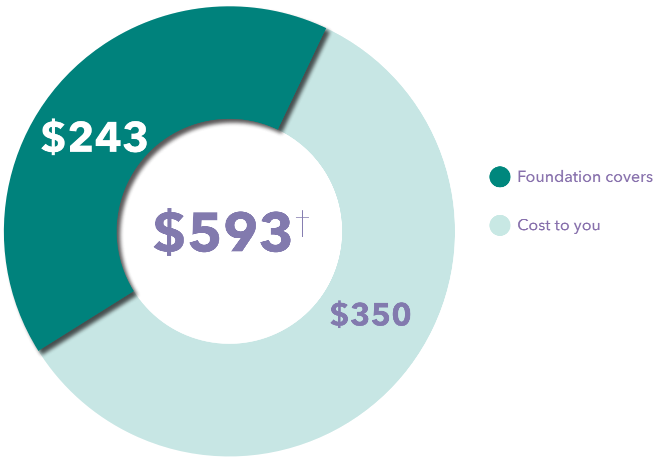
Every two years, the Foundation and the conference planning committee work hard to provide a rich and structured conference. We want to show you what it financially takes to run this life-changing event.

TOTAL COST
$219,547*

REGISTRATION FEE & FUNDRAISING INCOME
$116,722*

BILL TO FOUNDATION
$102,825*

DID YOU KNOW YOU GET A 40% DISCOUNT ON YOUR REGISTRATION FEE?



* NUMBERS BASED ON 2018 CONFERENCE

† ACTUAL COST PER ADULT ATTENDEE

CdLS Awareness Day 2019 – A Day of Inspiration

Thank you to our AMAZING community who came together and rocked this year's National CdLS Awareness Day! There were bake sales, dress down days, tree planting ceremonies, video reminders and so much more that cannot even describe the magnitude of love that was felt around the country. Thank you for your time, drive and continued support of not only the Foundation but for all of those who you advocate for.

This is just a small sample of the incredible events that happened on Awareness Day. **THANK YOU for raising awareness and being #cdlsstrong!**

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Celebrate your loved one with CdLS by making a gift in their honor. By supporting the CdLS Foundation and your loved one, you are shedding light on this often misdiagnosed, little known syndrome.

Enclosed is my tax-deductible gift of:

☐ Other $________ ☐ $500 ☐ $250 ☐ $100 ☐ $50 ☐ $40

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

Donate online at **www.CdLSua.org**

One hundred percent of your contribution is tax deductible.

Donations from 3/27/19 - 6/30/19

In Honor/ Celebration

Zackery Arrowood
Theta Mu Sorority

Emberlynn Baker
Shannon and Jaran Baker

Hunter Barrett
Carolyn and James Fulks
Gary Hartman

Brynnlee Beekman
Bonita Boxell
Mary and Glen Dehaven

Colin A. Bell
Cheryl La Roe

Johnny Burchett
Faye and Sam Burchett

Jordan Campos
Lynnette Oliver

Douglas R. Canning
Maria and Maury Paslick

Kaydence Clark
Whitney Wilson

Ketchel Clements
Barry B. Clements

Deanna Cochran
Whitney Wilson

Toni Davis
Whitney Wilson

Hugh Devlin
Whitney Wilson

Charlie Donald
Brian Price

Chase J. Duff
Lynnette Oliver

Connor M. Feehan
Mary Ann and Pat Feehan

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John E. Fisher

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Anonymous

Logan Fowler
Anonymous

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Lynnette Oliver

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Connor Willey
Jordan Ghannam

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2019 CdLS Foundation Webinar Series

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