

REACHING OUT

SPRING 2020

Genitourinary Manifestations

Coping Corner

Caring for a Medically
Complex Child

**CdLS National
Family Conference
is Just Months Away**



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Hello CdLS Family and welcome to 2020. Wishing you all a prosperous and healthy new year! We are living in an exciting time of many promising medical advances. Gene therapies are improving quality of life for many conditions ... below Dr. Kline has provided an overview of this topic. Although there is no cure for CdLS at this moment, our understanding of the mechanism that creates the syndrome has greatly improved. The Foundation's research efforts and dollars are focused on understanding the cohesin complex and finding ways to minimize the effects. We asked and you answered that the top 3 priorities for improved treatments are Communication, GI concerns, and Anxiety (Behavioral) challenges. The CdLS Research Committee and core of expert clinicians are taking deliberate steps to prepare for the day when clinical trials become a reality. ***Until then, to help us prepare please call or email us and let us know your loved one's gene mutation and join the CdLS Registry at bit.ly/CdLSregistry.*** Little by little as grandma used to say ...

- Bonnie



Bonnie Royster, CdLS Foundation
Executive Director

Medical Spotlight Gene Therapy

2020: a new decade for the world ... and for the CdLS Foundation! We are finding now that more children with CdLS are having testing for the genetic variation causing CdLS. Currently, we are aware of seven genes that can lead to CdLS when a variant or mutation is present in the gene. These genes are responsible for making some of the proteins involved in the cohesin complex. The cohesin complex is an important part of cell function and regulating many other genes, starting soon after conception and continuing throughout life. ***When a CdLS gene is unable to make the correct protein because of a specific mutation, the cohesin complex is impacted in some way.*** Since the cohesin complex is an important part of the health of cells within all parts of the body, and begins working so early in life, the range of symptoms



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with CdLS is broad and can start during pregnancy. **Gene testing for CdLS is more complicated than in many other conditions.**

The topics of genetic research and gene therapy in CdLS have been raised periodically. This area is much more clear-cut in conditions in which there is a single gene, having a specific effect on everyone with the condition. All the resources for those conditions can be put towards addressing this and looking for ways to reverse, improve or go around the mutations' effects. For example, in spinal muscular atrophy (SMA), the abnormal gene does not make the protein which directly affects the muscle. Replacing the missing protein directly through gene therapy improves that muscle's function, the main issue in SMA. But, the genes involved in CdLS have an impact on the formation and function of many body systems from the time of the earliest embryo through until at least the first year after birth. Thus, with CdLS, because the genes are many, the mutations are diverse, and our population of individuals with CdLS has a broad spectrum of involvement, the way forward is less clear.

Since the late 90's, researchers have been investigating CdLS and cohesin, both in human samples and in animal models. **Progress was made in identifying the genes, but it has been much slower in finding ways to change the effects of the mutations. Once the effects of the mutations on cohesin are known, then the researchers can turn to ways to reverse, improve or turn back those effects.** They often look at medications, enzymes, vitamins, or other cofactors that are already in use in the general population. But each substance has to be vetted and challenged in animals long before trials in humans. This is the stage that the research is in at this moment. Once the research reaches the point of human trials, every child participating will need to have confirmed genetic testing.

We also have reached out to find out what families are interested in, in terms of future treatment. The majority of families are interested in treatments that could help with developmental and communication skills, and improve organ system functioning. They would also be interested in medications that are FDA approved and used in treatment for other reasons. Almost half would be interested in potential trials of new medications or substances that are not currently in use or aren't approved by the FDA yet. Although it may take many years yet before treatment trials and/or gene therapy are available for CdLS, we are working towards this slowly.

Please note, **Gifts that Count** can be found in our electronic version of *Reaching Out*; which is located on our website: www.cdlsusa.org/resources.

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Genitourinary Manifestations

By Ming H. Wang, Vinaya P. Bhatia and Jordan King, Division of Urology, Department of Surgery, Texas Children's Hospital, Houston, TX and Scott Department of Urology, Baylor College of Medicine, Houston, TX

Genitourinary (GU) manifestations are commonly found in patients with CdLS. These can encompass anatomic and functional anomalies of the kidney, urinary tract, reproductive organs and external genitalia. Up to 40% of patients with this CdLS will manifest structural abnormalities of the kidney, including reflux of urine into the kidneys, improper drainage of the kidneys and abnormal development of the units within the kidney, which can lead to a decline in renal function and recurrent infections. For males, undescended testes are found in 73% of patients, which can affect fertility and increase their risk of developing testicular cancer. In up to 57% of males, hypospadias, where the urethral opening is located on the underside of the penis rather than at the tip, can be found. In females, smaller ovaries or underdeveloped uteri may be observed, with significant implications for future fertility. Underdeveloped genitalia may be seen in either sex. Less common abnormalities of the urinary tract include kidney tumors and clots blocking the veins that drain the kidney. The adrenal glands may be fused and abnormal connections from the bladder to the belly button may also be seen.

The first step in management is a detailed family, medical and surgical history. This is important to identify genetic or pre-existing risk factors for development of a concomitant GU disease. A history of abnormalities on ultrasound performed prior to birth may also provide information about GU abnormalities. A review of symptoms should focus on a detailed analysis of urinary and bowel habits, nutritional habits, and abdominal or groin pain. A urinary tract infection may be detected by a constellation of symptoms such as poor feeding, fever or malodorous urine. Your physician will perform a physical exam, including an assessment of the abdomen for fullness or masses, curvature and size of the penis, position of the urethral opening, circumcision status, asymmetry or discoloration of the scrotum/labia, location of and ability to examine the testicles, location and patency of the vagina, patency of the anus, and lower back or spine anomalies.

Prior to and after birth, ultrasounds are helpful to visualize the external genitalia or to determine the presence of a uterus or scrotum. In a patient where CdLS is suspected, an ultrasound of the bladder and kidneys should be completed to help detect any GU anomalies, which may prompt further imaging. Ultrasound is an ideal initial study, it is non-invasive, cost-effective and avoids exposing the child to any radiation. It can be used to look at structures across the abdomen or from the perineum. These examinations may help identify the presence or absence of the uterus, vagina, gonads, rectum or urethra. Occasionally, an MRI may be helpful to better define these structures if the ultrasound is unable to identify the location.

A number of these concerns may be identified at home during routine care. If hypospadias is a concern, observing the patient's urinary stream can help locate the urethral opening. A testicular exam is usually best accomplished in a warm bath if presence of testes within the scrotum is questionable. Any concerns should be brought to the attention of your primary care physician. If an undescended testis is diagnosed at birth, it is observed for positional changes during the first six months of life to allow for spontaneous testicular descent. After six months of age, surgical treatment by a pediatric specialist is encouraged. Since hypospadias does not routinely affect the patient's ability to empty their bladder, surgical repair is not recommended until at least six months of age and may require multiple procedures depending on its severity. If renal or bladder anomalies are detected, the patient may be placed on antibiotics to prevent infections or require future interventions. By increasing awareness of the GU manifestations that can present in CdLS, early detection and appropriate management can be better achieved. It is imperative to be vigilant to any change in the patient's exam or symptoms, which may warrant a formal evaluation with a board-certified pediatric urologist.



Inside Look: Lauren

My daughter, Lauren is a happy, funny, hardworking 6-year-old. Her family includes, me (her mom), dad, older brother,(who absolutely adores her) and three kitty sisters. Lauren is nonverbal and is doing well with using about 25 signs in sign language and her communication app on her iPad. She enjoys school and has grown so much both cognitively and socially since starting at age 3. Her strength and ability to adapt to her world has been a life changing journey to watch.

Lauren had her first UTI at 4 months old. She was uncomfortable, crying and running a fever. After checking all the usual suspects, they catheterized her in the office to get a urine sample. Over the next few months she kept getting them which led us to see a Urologist and the start of, what felt like, a lot of testing. She had multiple renal and bladder ultrasounds, voiding cystourethrogram (VCUG) procedure, urodynamics study and rounds of labs. It was found Lauren had a particularly small right kidney, kidney reflux, neurogenic bladder and stage 3 kidney disease. Because of all Lauren's urology issues, she had a tethered spinal cord and had surgery on it at 4 months old.

We tried to treat Lauren's chronic UTIs with a daily antibiotic as a prophylactic as well as another medicine to relax her bladder. Unfortunately, she continued to get them and after repeating the tests above we were offered two courses of

action. One, we could catheterize her ourselves 4x/day to completely empty her bladder since her body wasn't doing that on its own or we could have a surgery called a vesicostomy (a surgical opening in the bladder to the outside of the body (lower belly) that allows urine to drain, preventing urinary tract infection or damage to the kidneys). While a vesicostomy can be closed much like a G-Tube site in Lauren's case she may need it permanently to help prevent any further damage to those organs affected. We went with number two.

If I could offer advice to another family who may be in the same situation, I would recommend to do all the testing doctors suggest and if you are still unsure, get a second opinion.

At first, we were told we only had two options ... surgery or catheterizing her. However, we were able to find a good Pediatrician that wanted to help Lauren and laid out the best care plan for her, which made things easier. It was also helpful to have a Urologist from a reputable children's hospital caring for Lauren and the ability to get a second opinion before deciding to go ahead with surgery.

"Lauren is a firecracker of a little girl. She is full of life and silliness and knows without a doubt what she wants and what she doesn't want."



Caring for a Medically Complex Child

My first-born son has given me a greater voice than I knew existed in my soul. During our twenty-week ultrasound, my husband and I found out that we were expecting a baby boy. At that time, we were referred to a specialist and told he had Congenital Diaphragmatic Hernia (CDH), which would entail many medical complications and specialty care at the hands of Boston Children's Hospital. We were counseled by geneticists and offered amniotic testing to test for an additional syndrome with the CDH diagnosis, we were additionally offered an abortion. I remember that appointment being the starter fluid I needed as a mother to use my voice.

At thirty-seven weeks Abel was born and immediately intubated. He was placed on ECMO (a machine that works as the heart and lungs) for an entire month. It felt like time was standing still as he battled pulmonary hypertension and

he still needed to have the hole in his diaphragm patched and his organs surgically moved to where they were meant to be. Geneticists became involved during this time because Abel showed physical characteristics of CdLS. After almost two months the genetic results confirmed that Abel's *NIPBL* gene was mutated. Our truth as parents at that time was that we didn't "care" about his syndrome and didn't talk about it, frankly because his clinical status was too critically ill to put energy into the unknown world of CdLS.

Most of Abel's first eleven months in the ICU stemmed from how sick his heart and lungs were, as well as a long course of sedation caused by being intubated for so long. Abel eventually underwent a tracheostomy and surgical G-Tube placement. After 323 days in the hospital, he came home to New Hampshire.

I was fortunate enough during Abel's stay in Boston to be in driving distance of the hospital. This allowed us to rent an apartment next door to Boston Children's with the help of a military organization, while my husband commuted to the National Guard full-time for work in New Hampshire. My career diminished as I stayed by my son's bedside. The stress of commuting and living in two different places came with its challenges, but we knew that Abel depended on us staying strong as a unit. The "hurry up and wait" military mindset kicked in, but the pressure of keeping our heads above water through the roller coaster of emotions taunted us many times. We wanted so badly to bring our little boy home. Staying bedside was one of the greatest starts to our marathon as a family. We gained so much insight and knowledge on how to properly care for Abel that it became second nature to be his voice. I was his continuity of care around the clock and I knew that I was not only his mother, but I was about to become the advocate that my son needed for the rest of his life.

Some of the hardest things that have come across in our journey with Abel has been knowing that we live in constant fight or flight. Abel is ventilator dependent around the clock and requires twenty-four-hour monitoring. He likes to keep us on our toes with his spit fire personality, glowing smile, his need to be on the move and his love for pianos and music. One of his favorite new tricks is pulling his trach out. Abel has a kind group of nurses both in Boston and at home, which keeps all of our spirits energized and more grounded comfortably at home. Medically and developmentally Abel is reaching milestones that we questioned if ever would reach. In the midst of Abel's day to day care, comes all of his medical coordination. With over a handful of specialists, DME and prescription suppliers, dual insurance companies and in-home supports, it has been quite the juggling act. I rely on coffee, e-mail correspondence and the use of a large shared calendar for effective communication and to not lose track of appointments or deadlines. Some of the hardest things I've had to fight for have been nursing coverage, emergency medical equipment and medications. I live for appealing the denials and knowing Abel's rights by educating myself, researching into the late hours of the night online.

I knew I had found my purpose within the time I've spent caring for Abel. My passion is to help other families advocate for their loved one and to feel like they aren't alone. I opened up a business (*My Hero Calls me Mama, LLC*) as an avenue to share my perspective. Although it is a small advocacy-based business where I share ideas and market medically inspired apparel, the long-term goal for my business will take me into social work. The personal goal is to keep rippling positivity and share the raw and real moments with other families, and to inspire them to do the same. Eventually I hope to assist

others in taking their voices and medical needs and assist in transitioning from the hospital to the home setting. I think it's important to know that although so many of us might share similarities in diagnosis, that our journeys are all very different. Leaning on each other for support is something I am grateful for as a young parent coming into the CdLS community over the last few years. My personal message to others that have a loved one with not only CdLS, but any medical challenge is to remain non-judgmental of the peers around us who might be going through something we deem as a similar situation that we've been through. I am proud to know and be part of the CdLS community. Without my Abel, I would've never been connected to so many others who live around the world and can understand the feelings that I can't put into words sometimes.



It's exceptional to have a community that we can rely on, but we must be gentle with others. We all need to keep our voices strong, but in doing so we first need to be kind to ourselves and others. For every person I've met along Abel's journey I refer to them as "Team Abel". We are all a team in this medically complex world, no matter how similar or different we feel during the ups or downs, the happy moments or through the moments of terrifying grief or loss.

HIGHLIGHTED Events



BREW AND BBQ 10TH ANNIVERSARY

The 10th Annual Brew & BBQ hosted by Fran Rissland, mother of son Riley, and former CdLS Foundation Board of Director was held at Currahee Brewing Co. in Alpharetta, GA. This year's event raised nearly \$10,500 with over 110 individuals in attendance, including the Foundation's Executive Director, Bonnie Royster.



31ST ANNUAL MISSOURI GOLF TOURNAMENT

Jim Kesting and his dedicated committee of volunteers hosted another successful golf tournament at the Tapawingo National Golf Course in Sunset Hills, MO on October 7, 2019. Since the event's inception the tournament has netted over \$714,000 to help individuals with CdLS and their families live better, fuller lives.



WALK FOR WILL AND HOPE

Friends and family members of the Kurth/Feighan family gathered at Stony Creek Metropark in Shelby Township, MI for a leisurely 2-mile walk at the 11th Annual Walk for Will & Hope on October 13, 2019. Maureen and Joel, parents of Hope and their late son, Will, dedicate their children's birthday month to this event. This year's event raised \$6,200 in honor of Will and Hope.



BALTIMORE RUNNING FESTIVAL

With five distances to choose from, the Baltimore Running Festival is a must see and do for anyone interested in running, walking or strolling through the Inner Harbor waterfront area, historic Federal Hill and even through the Maryland Zoo, right past the penguin exhibit.

Led by the CdLS Foundation's Medical Director, Dr. Tonie Kline, and Tasha H., parent to Peyton, the duo helped recruit over 23 runners and raised approximately \$11,100. Since the first year of the event, the team has raised over \$122,858!



CHICAGO CELEBRATES \$1,000,000 RAISED

Team CdLS made its debut on October 22, 2000 at what is formerly known as The LaSalle Bank Chicago Marathon. Over the course of 19 appearances the team grew from 1 member upwards to nearly 30 and raising an average of \$55,000 per year. In 2019, led by one of the CdLS Foundation pioneers, Frank Mairano, the team raised \$70,000.

On October 13, 2019, the team celebrated yet another milestone – over \$1,000,000 raised since the program's inception! With deep gratitude and passion, Frank thanked all those who have made Team CdLS a success over the years. The hours of dedicated training and fundraising done by the runners, the curb crew members who support the runners along the course and the donors who so willingly invest into the Foundation were all honored.



NEW YORK CITY MARATHON - WORD OF MOUTH CREATES A TEAM

My name is Bree M. While I was in the O'Hare Airport after the Chicago Marathon, I had the privilege to meet a wonderful gentleman who had just run the Chicago Marathon, too! He had overheard a conversation I was having about running the New York City Marathon in 2019 and injected with a business card for a charity that he runs for. He stated to me it was a wonderful charity and that if I was serious, I should investigate it.

On Sunday, November 3, Bree, along with her friend and Team CdLS alumni Anna Smith and Lauren Palentino toed the line on the Verrazano Bridge to begin their journey through the 5 boroughs of New York City and raise awareness to the nearly 1,000,000 spectators and 50,000 runners.

CALENDAR

March 11

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

March 15

United Airlines NYC Half
New York, NY

April 4

Multidisciplinary Clinic For
Adolescents And Adults
Baltimore, MD

April 18

Spare Some Love for CdLS
Nori, MI

May 3

TD Five Boro Bike Tour
New York, NY

May 9

National CdLS
Awareness Day

May 18

New England Charity
Golf Tournament
Ipswich, MA

June 24 - 25

Ninth Biennial CdLS
Scientific & Educational
Symposium
Tulsa, OK

June 25 - 28

CdLS National
Family Conference
Tulsa, OK

October 5

Missouri Golf
Sunset Hills, MO

October 11

Bank of America
Chicago Marathon
Chicago, IL

MaryBeth & Hugh Ochoa

MaryBeth and Hugh Ochoa were looking for a way to engage with their daughter in a different way to help her behavior issues. They found a creative outlet in the outdoors ... here is their story.

Our daughter, Sarah, is 13 years old and was diagnosed with CdLS at 6 months. Raising a child with a rare disorder has been quite a journey so far. We were terrified at first, not knowing what the future would hold for her. However, watching her overcome obstacles and reach goals we were told that she would never reach, has been incredible. Sarah makes us appreciate every moment. Watching her learn new skills, even now at age 13 is just as exciting as it was when she was 2. She just seems to keep reaching milestones that we never thought she would. It's such a blessing to be her parents.



Last summer, Sarah was struggling with behavioral issues. My husband suggested we try a change of scenery. We live in the Catskills, so there are many parks and recreation areas nearby. We chose one that we had taken our older children to before. I was amazed at the total remodel New York state (NYS) had done, everything was beautiful and wheelchair accessible, including the trail around the lake. The day was fantastic, Sarah was calm and happy, and we decided right then and there to have a weekly outing.

After seeing the updated trails at the first park, I went online to search for accessible trails in NYS. I was very pleasantly surprised at the number of places that were at least partially accessible. We made a list and started our adventures. Sarah even started to get her backpack out and put things in it in anticipation of a trip. My husband retreaded her wheelchair tires to make some of the gravel trails easier to navigate. Our first stop on each trip is the Visitor Center to inquire about accessibility. At one trail, we were granted an Access Pass for

Sarah, which now allows her and anyone accompanying her free entrance to all National Parks and Federal Recreational Lands. It's definitely worth applying for.

If someone had told me that hiking and outdoor recreation would be a big part of our lives with Sarah, I would have told them there is no way. But just getting out there, researching, asking questions, trying new places has really been a huge turnaround for her. She loves to go on her adventures and we love watching her enjoy the experiences. You just never know what you will find unless you get out there.

"Life with Sarah has taken us completely off the beaten path. It was scary at first. We had no clue where we were going and there were no markers to guide the way. But we wound up experiencing and feeling things we would have never known existed had we stayed on the main road. I wouldn't trade one second of it for anything in the world."

This year, why don't you try something new with your loved one with CdLS and go off the beaten path?



After years of being told she would never walk unassisted, watching her take her first independent steps at age 7 is memory I will never forget. It was amazing. Sarah puts a smile on the face of everyone she meets.

WELCOME

New Families



THE MALIKSI FAMILY

Hello world! My name is Ryeighn Faith. That's pronounced "Ryan" but my parents, Sonny and Heidi, are a little odd. I have a 3-year-old sister, Charleigh, whom I still haven't met since I've been cooped up in this thing since my birth on Sept 28, 2019. I love music, playing with my mobile and oh, I just got my G-tube and hope to be home soon.



THE COLLINS FAMILY

Our son Grayson was born on May 5, 2019. During birth, we learned of his missing digits and received his CdLS diagnosis a month later. We live in Orange County, CA so most days Grayson can be found at the beach or with dad at the skatepark. He is excited for his first plane ride to Maui this spring. Grayson is our greatest joy and we thank God for choosing us to be his parents.

1.800.753.2357

California

Leslee and son David, born August 23, 2019

Pennsylvania

Jessica and Michael and Zoie, born October 26, 2016

California

Heidi and Sonny and daughter Ryeighn, born September 28, 2019

Wisconsin

Niki and Corey and daughter Kaleigh, born December 8, 2013

Massachusetts

Micah and son Mal'akhy, born April 24, 2018

Wisconsin

Jennifer and Paul and daughter Naomi, born July 10, 2011

Minnesota

Michelle and Ben and son Graham, born March 14, 2013

Texas

Jennifer and Edwin and daughter Catalina, born August 18, 2019

Mississippi

April and daughter Mary Frances, born December 1, 2017

Florida

Sarah and Ernesto and son Emmanuel, born August 6, 2018

Missouri

Miranda and son Tony, born April 10, 2012

Pennsylvania

Gabrielle and son Vincent, born October 11, 2018



Milan's favorite activities include playing with anything that makes noise, vibrates or lights up. She also enjoys watching videos on any device.

Milan Williams

Milan Ava Williams was born and diagnosed with CdLS on November 27, 2005. She was the most beautiful little baby girl that I have ever seen. Milan presented with a cleft palate, perfectly arched eyebrows, fluid in her ears, a curved finger (5th), low set ears, long eyelashes, excessive amounts of body hair and low birth weight despite her being delivered full term. She was so small; weighing 4lbs. Her diagnosis was made on the CdLS characteristics she met.

She does not communicate verbally; however, she shows such compassion in other ways. Milan will be fourteen and has typical teenage behaviors. She can be temperamental around strangers, becomes agitated when she's getting her menstrual cycle, does not like going to the doctor, gets annoyed if we kiss and hug her too much and will scoot away to be alone in her room. Milan is non-ambulatory and only walks with assistance if she is in a setting that she is comfortable in. Milan currently has hearing loss in both ears, but weirdly enough, she responds when her name is called or when speaking to her by making direct eye contact. She has GI issues which are controlled by a strict diet and medication. Milan recently experienced two seizures that are being treated by a neurologist.

She attends a school that meets her needs in a small setting in Brooklyn, NY. She is fed orally every 3 hours in small portions, which consists of only mashed and/or puréed foods along with thickened liquids. She can sign "eat" and if she is home, she will scoot into the kitchen and sit there; sometimes even opening the refrigerator.

She has 3 younger siblings; Morgan and twin brothers, Micah and Mason. Milan has her own way of interacting with her siblings. She's kind of a sweet rebel. She loves to grab toys away from her younger sister and pinch her. To a person who doesn't understand Milan, they would think she's being mischievous but that's just how she expresses herself. Since her brothers are newborns, she does not interact much with them, but she stares at them often, she is particular in touching and stroking her baby siblings softly and gently. She often mimics rocking a baby.

What I would want the world to know about Milan is, what makes her different is what makes her beautiful. As stated in Jeremiah 29:11; "she is fearfully and wonderfully made."



To the Special Needs Moms Who Question Themselves

Michelle Haxby, The Mighty

TO YOU, the mom sitting in the waiting room of your child's doctor's office. You're waiting on your child's latest test results. You've done this a hundred times before, but your stomach is still in knots. Your hands are fidgety. This never gets easier. You're scared and you feel alone. Your eyes scan the room as you admire the other moms who are calm, reading books to their children.

You suddenly feel guilty. I should be reading, too, you scold yourself. Then it happens. The nurse at the door calls your name. It's your turn. You panic because you're not ready to hear the news. You swallow the lump in your throat with your child in hand and walk through the door. You begin to wonder what's wrong with you.

To you, the mom who placed her child with special needs in a sports program. Your continual lip biting has left you with permanent indentions on your lips. Your nails are down to nothing from you chewing on them.

You sit, watch and pray through every game. Please, you think, don't let anyone hurt my child's feelings. Please don't let her get hurt. You wonder if the other parents are judging you and your child. Although you're tormented by your own fears and uncertainty, you smile and high-five your child. But nonetheless, you drive home exhausted from the whirlwind of emotions you just went through. Yet again, you wonder what's wrong with you.

To you, the mom who just walked into her child's school for the fifth meeting of the school year. You know everything you need to know about your child, but you constantly have to explain things to a room full of educators. Your words

become winded as you talk. Your eyes blink back tears because you refuse to let them see you cry. They push their ideas on you. You push back, too. Their words become final as you realize you're losing ground. Just like that, you're no match compared to them. You drive home feeling defeated. Your head is buried in the steering wheel as you sit in your driveway and cry uncontrollably. How did I let this happen, you think to yourself, as you wonder what's wrong with you?

Time and time again, we question ourselves and struggle with our own decisions. We're constantly criticizing ourselves. Is there something wrong with wanting the best for your child? I say most certainly not.

Is there something wrong with you because you worry endlessly? No, it's because you love them. Are you abnormal because you feel isolated, tired and scared? No, you feel all of that, and no one blames you.

Are you judged because some days you don't have any of the right answers? Nope, no one does. No mom in the world, I promise you.

To you, the mom who deserves a thousand praises for loving and fighting for their child endlessly.

To you, the mom whose fears never shadow their courage to try.

To you, the mom who's doing everything right and doesn't even know it.

You're not alone – I see you.

I am that mom, too.

FIND YOUR PARENT CENTER

Did you know there is an organization called Parents Helping Parents in California, that supports, educates, and inspires families and the community to build bright futures for youth and adults with special needs.

In New York there is an organization called INCLUDEnyc, which is the leading provider of training and information for young people with any disability, their families and the professionals who support them. They create access to educational, employment and independent living opportunities, and advocate with families for meaningful inclusion in the broader community.

The Utah Parent Center, which guides parents in helping their children, youth and young adults with all disabilities to live included, productive lives as members of the community.

For parents or caregivers, it can be overwhelming to find one main guide that houses resources for all states. The answer can be found at the Center for Parent Information & Resources (CPIR). CPIR provides websites to state specific resources that include, but not limited to civil rights law and policy centers, organizations that work to increase inclusion and so much more. The ages they support range from birth to age 26. To find your state or local parent center, visit: www.parentcenterhub.org/find-your-center.

10 GOALS FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS TO KEEP:

1. I will take time caring for my own mental and physical health because I recognize that if I am not at my best, I cannot be the best parent possible.
2. I will celebrate as many small achievements throughout the year as I can observe.
3. I will schedule activities that get my entire family out into the community.
4. I will laugh more. Raising a child with special needs is hard and laughing provides immediate stress relief and a reminder that there is joy interspersed among the challenges.
5. I will get more comfortable with asking others for help.

6. I will try to make it easier for others who want to help us to do so in a manner that will be welcomed by our family.
7. I will continue to advocate on behalf of my child while encouraging him/her to enhance his/her own self-advocacy skills.
8. I will seek new relationships with other parents facing similar challenges.
9. I will find more information to assist my family with our activities or our challenges.
10. I will hug and kiss my children every day.

SERVICES AVAILABLE TO INDIVIDUALS WITH DISABILITIES AND THEIR FAMILIES

Many agencies and non-profits in the United States are available to help an individual with CdLS and their families. Whether it is for general advocacy purposes, housing needs or education.

The National Center on Disability and Journalism has compiled a list of resources for individuals with special needs and their families to use to help them make informed decisions and help them get started. Under the section call **Employment & Business**, **Incight** is listed, which is a non-profit that aims to eliminate stigma associated with disability and expand inclusion by helping students and jobseekers in particular. Under **Family & Social Services**, **American Association of Caregiving Youth** is listed, which is a national resource for children who sacrifice their education, health, well-being and childhood to provide care for family members who are ill, injured, elderly or disabled.

To learn more, visit ncdj.org/resources/organizations.

Our Deepest Sympathy

Maddi Kouns

March 7, 2014 - August 23, 2018
Daughter of Cierra Davis
Scottsville, TX 42164

Mikee Mondor

November 30, 1987 - October 8, 2019
Son of Ute and Ron Mondor and brother of
Chris Mondor
PO Box 4
Shapleigh, ME 04076

Nellie Summerford

February 15, 2011 - October 25, 2019
Daughter of Lisa Watts
802 SW 3rd AVE
Okeechobee, FL 34974

Malik Wells

February 1, 2000 - November 14, 2019
Son of Kizzie Edwards
PO Box 6359
Philadelphia, PA 19139

Blake Lee Crutcher-Remmer

January 22, 2000 - December 7, 2019
Son of Mona Crutcher
2421 South Carrier Pkwy, Apt 1429
Grand Prairie, TX 75051

Madalyn "Maddy" Gilchrist

November 22, 1996 - December 27, 2019
Daughter of Kim and Doug Perkerson
7024 San Fernando Dr.
Fortworth, TX 76131
And
Daughter of Tom and Tracy Gilchrist
6285 S Dixie Highway
Franklin, OH 45005

"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.



The 2020 CdLS National Family Conference is Just Months Away

The Biennial National Family Conference is set for June 25 – 28, 2020 in Tulsa OK. We hope you're ready to register and attend this lifechanging event. Not only will individuals with CdLS receive free head-to-toe consultations, the Foundation is streamlining the workshop schedule so you can receive the knowledge you need to bring home with you. Above all, Conference is a place where you can experience acceptance, support and connection.

Here is some important information to help you get ready to attend the 2020 National Family Conference.

Registration Information

The registration link will be located on our website, www.cdlsusa.org/conference. Early Bird Registration begins on March 3, 2020 and ends April 7, 2020. The last day to register for Conference is May 19th.

Once you register, you will receive an email with directions on how to sign up for specific consults. You will also receive a passkey that will bring you to the hotel block so you can book your rooms for your stay during Conference.

Registration Fees		
	Before 4/7	After 4/7
Adult 18+	\$370	\$410
Person Providing Childcare	\$250	\$280
Children 3-17	\$190	\$215
Children 2 and Under	No cost	No cost
Person with CdLS	No cost	No cost
One-day Professional	\$150	\$150

Again, Early Bird Registration will launch on March 3rd, and you will be able to register online through our website. While registration is open until May 19th.

The registration fee covers all workshops and sessions, medical and educational consultations, and most meals. It does not cover hotel or travel expenses.

Registration does not cover hotel or travel expenses. Access to booking hotel rooms is through online registration. The reduced room rate is \$125/night plus tax and is only for people registered for conference.

Please note the difference between connecting and adjoining rooms when booking. Connecting rooms have a door in between that open, adjoining rooms do not.

Scholarship Information Q & A

Q: Who can apply for a scholarship? **A:** First time attendees that are parents (adults ages 18+). There will also be 2 first time attendee grandparent scholarships.

Q: What does a scholarship cover? **A:** The registration cost to attend Conference.

Q: How do I apply for scholarship? **A:** There will be a specific drop-down through registration that you will be able to apply for Adult 18+ Scholarship.

Q: When will I find out if I received a scholarship? **A:** The first round of awardees will be notified on March 25, 2020. Scholarships are awarded on a first come first serve basis. The grandparent scholarship awardees will be on April 1, 2020.

Support Conference and Your Community even if you can't Attend Conference.

There are other ways to support the CdLS Foundation as we prepare for this event. The following items are needed for putting together raffle baskets and raising much-needed funds to offset the cost of this event:

- Gift cards (national brand stores and online stores: ex. iTunes, Barnes & Noble, Amazon)
- Entertainment items (new movies, iPods, iPads, etc.)
- Baby/child toys/care items
- Spa/body care items
- Encourage your employer to become a sponsor
- Sponsor another family who may be seeking support through scholarships

For more information or if you have questions, please call the Foundation at 800.753.2357 and we can help you. We look forward to seeing you in Tulsa!

IDEAS FOR ATTENDING CONFERENCE

We understand that raising a child with CdLS can create extra strain on family finances. With that in mind, the conference planning committee works hard to find hotel properties that can accommodate the special needs of our children and provide reasonable travel access.

We are looking at different ways to mitigate the cost. Did you know that we offer First Time Attendee Scholarships? We are currently raising money to fund this crucial program so parents of individuals with CdLS can have their registration covered so they can attend this life changing event.

For more information about our first-time attendee scholarship, please read our Conference Update article.

We also offer payment plans. When registering for Conference, you have the option to pay in full or a portion of the cost*. If you chose to pay a portion you will be billed in April and May. This is an affordable way for you to be able to achieve your goal of attending Conference.

Our website offers a variety of resources to help you fundraise for Conference, including requesting funds through your child's IEP, budget templates and more. Visit: www.cdlsusa.org/fundraising-for-conference to learn more.

We take tremendous pride in creating this special event for you every two years. We continue to look for ways to make it sustainable and affordable. If you have questions, please contact Tim Hurlock, Finance Director at thurlock@CdLSusa.org or 800.753.2357.

*Please note, the later you register, the larger the payment portion.



Select a car to be displayed at the CdLS Foundation National Family Conference:

\$100.00
(Large)
Hot Rod



\$60.00
(Medium)
Convertible



\$30.00
(Small)
Roadster



(Please indicate how you wish the name to appear on the car)

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To: _____ From: _____ ☐ Hot Rod ☐ Convertible ☐ Roadster



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
30 Tower Lane, Suite 400
Avon, CT 06001-3681
800.753.2357 • www.CdLSusa.org

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You may also dedicate your car by contacting us at 800.753.2357.

Charge my gift to: ☐ VISA ☐ MC ☐ AMEX

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Expiration: _____ Security Code: _____

Print name on card: _____

Signature: _____

Email address(es): _____



NEW BOARD PRESIDENT

The CdLS Foundation is proud to announce our new Board President, Mike Christie. Mike has been on the board since 2018 and is a proud father to three beautiful daughters. Taryn, who is 12 years-old, was born with mild CdLS. Mike and his family embarked on a long journey to eventually find Taryn's CdLS diagnosis, and now he is eager to help other new families in the CdLS community.

Mike shared, "I am excited and energized to begin my term as the President of the CdLS Foundation Board of Directors. I want to thank Pat Lyons, our exiting President, for his leadership and mentorship. He will be key in the success of the board and Foundation staff for years to come. I also want to thank the current board, staff and researchers for their future time commitment as the decisions we make and the actions we take will help to inform and serve our families across the country and influence CdLS Foundations across the globe! You can see why I'm excited!!

Two years go by fast, so the objectives need to be simple. Raising awareness, increasing family services, delivering an impactful and successful Conference and solidifying the sustainability of the Foundation for the support of our families are our priorities.

Success lies in how we all work together to support and serve our amazing kiddos and their families in the journey through life with CdLS. Not everyone's journey is the same, however, if we work together, we can make all of those journeys a little happier and a little healthier."

ANNOUNCING SPECIAL EDITION REACHING OUT

Coming this summer, the CdLS Foundation will be releasing a special edition of Reaching Out. It will feature adults living with CdLS. If you are interested in learning more, please email the Foundation at outreach@CdLSusa.org.



AWARENESS DAY 2020

Awareness Day will be held on May 9th. Each year the Foundation encourages families and volunteers to host a variety of awareness raising initiatives throughout the United States to educate and inform others about CdLS. Some different ways you can participate include, requesting a proclamation from your local government official, set up an awareness booth at a local farmer's market or host a dress down day at work.

If you are interested in learning more about hosting an Awareness Day event or have questions, please email Gabbie at gnaudeau@CdLSusa.org or visit www.cdlsusa.org/raise-awareness.

FOUNDATION E-COMMUNICATIONS UPDATE

In 2020, we are trying to reduce our carbon footprint even more. That means, less paper and more important emails. Please make sure our emails are not getting stuck in your "junk" or "spam" folders! If they are, be sure to move them to your inbox, mark them as "not junk", and add us to your contact list. Questions? Email outreach@CdLSusa.org.

WELCOME NEW CdLS FOUNDATION STAFF



Tim joined the Foundation in December of 2019 as the Finance Director. He holds a B.S. degree in Business Administration from the University of Hartford and an MBA degree from Rensselaer Polytechnic Institute. Prior to joining the Foundation, he worked for over 20 years in the

Connecticut Community College system as a finance and administrative professional. Most recently, he served as CFO for Catholic Charities-Archdiocese of Hartford. Tim lives in Farmington, CT with his wife.



Alisicia joined the Foundation in 2019 as a Family Service Coordinator. She earned her Master's in Social Work from Springfield College in May 2019 and her Bachelor's Degree from CCSU in 2017. Prior to joining the Foundation, she learned at organizations who provided support to the homeless community and developed a passion for working with families.



Vanessa began at the CdLS Foundation in February as the Development Assistant. Prior to joining the Foundation, Vanessa worked in the corporate world for over 30 years before retiring. She lives in Springfield, has two sons and three grandchildren. Fun fact, Vanessa enjoys baking in her spare time and has perfected a recipe for pound cake.

9th Biennial Scientific & Educational Symposium on Cornelia de Lange Syndrome & Cohesin

Researchers and scientists around the world are working to change the future of CdLS. The Foundation is the hub that brings them all together. A unique way that researchers get to share their findings with each other is at the Biennial Scientific and Educational Symposium.

Symposium brings together new and seasoned researchers to present and publish current and new information related to CdLS and broaden their collective knowledge.

This prestigious 2-day event precedes the Foundation's Biennial National Family Conference. Having the two conferences back-to-back makes it convenient for a panel of individuals with CdLS and their families to make a presentation at Symposium...a rare and inspiring opportunity for researchers to interact with the real people they are trying to help.

Attendees include physicians in various clinical disciplines, clinical/molecular geneticists, genetic counselors and research scientists.

Please share this information with your local doctor if you think this would be a good opportunity for them to attend. They can learn more by visiting: www.cdlsusa.org/scientific-symposium/

If you, your employer, or anyone you know, might be interested in becoming a sponsor for Symposium, please contact Alex at alex@cdlsusa.org for more information.



In Honor/ Celebration

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Brandt Anderson
Fran and Wayne Shull

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Embrace the Adventure


Sponsor a car on our route to Embracing the Adventure. 

Help us embrace the adventure as we honor the individuals with CdLS at our National Family Conference this summer. Inspire your loved ones to celebrate the milestones they have reached and the friendships they will make at Conference - many that will last a lifetime!

All funds raised will support Conference taking  place on June 25 - 28 in Tulsa, OK.

Choose from three different "car" sizes (one name per car):

**Hot Rod (Large) \$100, Convertible (Medium) \$60,
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To purchase your car, use the coupon inside this issue or call Kristi Larson at 800.753.2357. 



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