REACHING OUT

WINTER 2023

Spotlight:
Early Identification of Developmental Issues

ON THE COVER
Anthony Turner, Jr.

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Despite the many challenges we all face, I love the resilience of our community. You continue to show up for your children, each other, and the Foundation, unselfishly sharing your wisdom and grace. Our resolve at the CdLS Foundation is to continue showing up for you!

We are constantly listening and asking for your thoughts and feedback. This year, we hosted two town hall sessions and multiple focus groups for your input on re-imagining the conference in a relevant and attainable way for most families. We are happy to report that together, we developed a model of Regional Retreats. We are excited to host our first Regional Retreat in September 2024!

This year was filled with exciting new initiatives and the return of in-person events. Under our Healthcare Committee's guidance, we brought you three new webinars to add to our webinar series. We produced two new publications – the CdLS Health Care Notebook and the Know Your Gene Brochure. The Health Care Notebook is a fillable PDF intended to centralize all the information needed to care for your family member with CdLS. Save it electronically or print individual pages as needed (**www.cdlsusa.org/families/**). The Know Your Gene Brochure offers information about the genetics of CdLS in an easy-to-understand format.

Over 770 people contacted us in the first nine months of the year; 21% of those were people connecting with the Foundation for the very first time. The Family Service team welcomed them into the CdLS community with a compassionate ear and the information, guidance, and support they needed with new and updated materials.

With a focus on being more inclusive of all the families that reach out to us – we've contracted with Language Line Solutions ® to provide our staff with immediate access to medically certified interpreters in over 240 languages. We can now assist families with a primary language other than English.

Lastly, we connected in person with nearly 300 of you at Family Gatherings in Texas, California, and Chicago. They were a blast and a wonderful infusion of laughter, love, and support for all who attended. Our sincere thanks to the host families who helped make these events possible.

As we enter 2024, we look forward to growing our partnership with you and continuing to build a Foundation that truly reflects our motto of Reaching Out, Providing Help, and Giving Hope. Best wishes for a joyous Holiday Season and a Happy New Year.

Bonnie

Bonnie Royster, CdLS Foundation Executive Director

Reaching Out
Published Since 1977
(ISSN 1097-3052)
Cornelia de Lange Syndrome Foundation, Inc.
Incorporated December 1981
email: outreach@CdLSusa.org
www.CdLSusa.org

Board President's Message

THANK YOU

Katherina Nikzad-Terhune, Ph.D., LCSW-S, CdLS Foundation Board President

When I first stepped into the role of Board president two years ago, I shared with our CdLS community how I had found my place with the Foundation as a CdLS sibling. In the past two years, I have been privileged to work closely with Foundation staff and board members to help build new resources to support mental health and to help shape new inclusive and accessible practices that meet the needs of our CdLS families. It has been an honor to be part of the CdLS Foundation's mission of reaching out, providing help, and giving hope.

November 8, 2023, marked the 30-year anniversary of my sister Natalie's death. Much has changed in my life and in the world over 30 years, but what has remained steadfast is knowing that in her five years on this earth, Natalie lived a life of genuine love and authentic joy. It was simply who she was, and everyone who encountered Natalie became a recipient of that love and joy. When we lose someone, we seek ways to preserve connection, meaning, and memories. One of the most eloquent ways to do this is to *be what we loved most about the person we lost.* I think about this frequently, and how I can best emulate the most beautiful qualities of Natalie, even 30 years later. I want the people that I encounter to be the recipients of genuine love and authentic joy, the way that others were with my sister. One powerful way in which I have been able to do this is through my ten years of service with the CdLS Foundation, and more so in these past two years as board president. I thank you deeply for the opportunity to do this.

My work with the CdLS Foundation will undoubtedly continue in other forms of service, working closely with Bonnie, our dedicated staff and board, and the CdLS families that I admire so much. As I transition from this role, I ask that we all be unified in our commitment to be what we love most about the people we have lost in our lives. Thank you for your support over the past two years. I am grateful for each of you.

With love and solidarity,

Kathrin N. Terhune

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Early Identification of Developmental Issues

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

Early identification of developmental issues is one of the most critical aspects of any child's career, particularly with an underlying condition. Although there is a broad clinical spectrum of involvement in Cornelia de Lange spectrum disorder, most individuals have some intellectual disability, developmental delay, and/or learning disability. It is crucial to detect any of these problems as early as possible because of available therapy and other services, related issues with school placement, and effects on behavior, family, and social interactions.

Public law states that any individual at risk for developmental delays is eligible for early intervention services in the United States. In the 1970s, children at risk would have better outcomes if they had access to these services. The earlier, the better.

By 1980, governmental funding was well established for these Early Intervention Programs, and this persists until today, provided through each state via each county. Each school-aged child at risk has an Individualized Education Program (IEP). An IEP is a written document outlining the services and support that need to be provided to the student for that child to succeed towards a productive adult life. There is an IEP team, including the parents/caregivers, teachers, educators (special educators), therapists (physical therapy, occupational therapy, speech pathology), and often school psychologists, therapists, counselors, and/or advisors. For preschool students, there is a similar plan. If the parents/caregivers feel that services are not being met, they can hire an advocate for the child to help with the IEP meeting.

Early Intervention services must be tailored to each child, with different strategies used depending on the degree and extent of the disability and progression documented. Children who are nonverbal, with delayed or absent expressive speech, commonly found in CdLS, will need to be taught and followed differently than children with better language skills. Infants start with physical and occupational therapy and will have speech therapy added as language emerges. There may be sensory processing issues in CdLS, and all therapists should be made aware of this and issues related to any autistic features that might be present. Areas of strength in learning in CdLS include visual-spatial memory, fine motor skills, and perceptual organization, indicating that using devices, computers, tactile stimulation, and fine motor activities should be stressed in therapy and education. Augmentative and alternative communication systems have been advancing. They are accepted and approved for classroom use. They should be incorporated as children with CdLS enter school years and beyond. With various evaluations, approaches, and outcomes, these services are crucial in maximizing outcomes.

If you have any questions regarding your child's IEP or support services, don't hesitate to contact the CdLS Foundation's Family Service Team at **familyservicesteam@CdLSusa.org**.

SPECIAL EDUCATION RE-EVALUATIONS

Lisa Lightner, A Day in Our Shoes

An IEP special education re-evaluation is the reassessment of the educational needs of a student receiving special education services. It involves gathering information, conducting assessments, and reviewing the student's progress to determine if there are any changes or updates to their IEP. These re-evaluations are necessary, so a student's IEP remains effective. As students develop, their educational needs may change, and re-evaluations help ensure that the IEP continues to address their unique learning needs.

Typically, re-evaluations happen at least every three years. However, a re-evaluation can also be triggered if significant changes in the student's academic performance or if the IEP team, including parents or guardians, determines it is necessary. The process involves the student's parents or guardians, special education teachers, general education teachers, school administrators, and relevant specialists such as psychologists, therapists, or diagnosticians. The IEP team collaboratively reviews assessment results, discusses the student's progress, and determines any necessary updates to the IEP.

During the meeting, attendees review the student's progress and complete assessments to gather current data about their strengths, challenges, and learning needs. The IEP team will analyze this information, discuss the student's present performance levels, and determine what changes need to be made based on the IEP.

IT IS IMPORTANT TO REMEMBER THAT PARENTS OR CAREGIVERS HAVE THE RIGHT TO REQUEST A RE-EVALUATION OF THEIR LOVED ONE'S IEP IF THEY BELIEVE IT IS NECESSARY.

If a parent believes their child's needs have changed or has concerns about the appropriateness of the current services or goals, they can communicate their request to the school's special education department or the IEP team. It is also important to note that re-evaluation may change a student's services. If the IEP team determines that the current services or goals are no longer appropriate or effective. They may adjust based on the updated assessment results and the student's current needs.

Parents who disagree with the re-evaluation results can voice their concerns and request further discussions with the IEP team or an Independent Educational Evaluation (IEE). Parents can provide additional information, seek independent evaluations, or request a formal dispute resolution process such as mediation or due process hearings.

Specific regulations and procedures may vary depending on the educational jurisdiction, so it's always advisable to consult your local education authorities or professionals for accurate and up-to-date information.

Aubrie Schilling

Leslie Schilling

Aubrie Adelaide Schilling was born on September 24, 2021. She was born with a head full of hair and was an adventurous girl from the beginning! I am her mama, Leslie, and my husband is Ryan. She adores her sister Zoey, and our two dogs, Call and Cici. She has always been an overall happy girl with the best smile! She is a fearless, independent individual who LOVES climbing and laughing. She enjoys playing outside, dancing to music, and cuddling with her parents.

Our genetic doctor at NCH recommended contacting the CdLS Foundation after Aubrie's diagnosis appointment. Aubrie did not show any significant health concerns until her one-year pediatrician appointment. With her small size and some physical facial features, our pediatrician decided to send her to Nationwide Children's Hospital. At 15 months, our daughter Aubrie was diagnosed with Cornelia de Lange Syndrome. When we got the diagnosis from NCH, our lives turned upside down. This unexpected diagnosis prompted us to reassess and recalibrate our dreams and hopes for her. We grieved the life we envisioned for her but had to adjust previous expectations and find the positive. I left my career and became Aubrie's biggest support and caregiver. In these trying times, the CdLS Foundation emerged as a beacon of hope, guiding us through the intricate maze of this diagnosis. Their Family Service Team was prompt in offering unwavering support and invaluable information. They introduced us to other families traversing on this similar journey. Their relentless assistance in many different aspects has been our compass in navigating Aubrie's challenges.

Aubrie has brought so much joy to our lives. She is strong, capable, and so charming. Aubrie has had more doctor appointments/procedures in such a short amount of time, yet she still has an open, trusting heart. She has taught me to understand what is most important in life. She has shown everyone around her to enjoy every day and celebrate EVERY win, whether big or small. She is intelligent and wonderful.

She has taught our family many essential life lessons these last ten months. My father, Don, has been vital to me and Aubrie since diagnosis. I asked him what Aubrie has taught us, and he responded, "Aubrie has taught us to celebrate small wins and live in the moment with her. To stop and be thankful for a new word, for that first step, for a good doctors' report, for a hungry appetite, and a big happy smile."

The idea for "Aubrie's Army" Fundraiser started with my niece Harper (9) and nephew Colter (7), who had a Lemonade Stand in the spring. After a successful day, they donated half of their earnings to a nonprofit and chose the CdLS Foundation. Neither one fully understood Aubrie's diagnosis, but they knew they wanted to give their hard-earned money to their baby cousin. I organized this event to support and give back to the CdLS Foundation. The CdLS Foundation stands unmatched in its dedication to CdLS. It is a guiding star for countless families like ours, ensuring the best possible care and spearheading groundbreaking research. I created "Aubrie's Army" Fundraiser for the CdLS Foundation and contacted close friends and family for support.

On September 23, 2023, we hosted the first annual fundraising event for Aubrie's Army. This gathering aimed to amplify awareness about CdLS and generate funds to empower the CdLS Foundation in its mission of providing crucial services and resources. We raised over $14,000 and counting! I cannot thank our village enough for showing up like they did in honor of Aubrie.

I want the world to know that Aubrie is capable of big things - her CdLS diagnosis does not restrict her from being the BEST version of herself. Life can give us unexpected challenges, but that does not define us. We all need to learn to judge less and be kind.

Let's champion together and celebrate the loving spirit of sweet Aubrie and all the individuals with CdLS!

Shaylin Hope Cubeta

Perry and Tonya Cubeta

Our beautiful daughter, Shaylin Hope, passed away peacefully on September 7, 2023, with her family embracing her in their arms. It was a moment we all anticipate but were never ready for. She was the most amazing and incredible person we have ever known. As her parents, we could not be more proud or happy that she was our daughter. Her older brother, Tyler, and younger sister, Kaylee, also could not be prouder she was their sister. She brought so much joy and love into our lives. Every day we looked forward to spending all those precious moments with her. Making and watching her laugh was the biggest thrill for us. That may be what we will miss the most.

Shaylin was born on November 4, 1988, in Goldsboro, NC. She was diagnosed at birth and had nearly all the associated medical issues; Tetralogy of Fallot, reflux, cleft palate, etc. Upon hearing her prognosis, we knew our lives were going to be very different than what we had anticipated. Despite this, we vowed to give her as much of a normal life as possible. We love to travel, so naturally Shaylin traveled with us. As a result, she has been all over the world. Shaylin loved going on cruises and had been on at least ten; from Transatlantic, Alaska, the Panama Canal, to the Caribbean. She required medical equipment, such as oxygen tanks, oxygen concentrator, suction machine, feeding pump, and more. We didn't let those things slow us down. She traveled well on airplanes too, from around the US, Hawaii, and multiple times to Europe. She loved listening to music toys, so on long flights we put a blanket on the floor, and she would lay down and listen to her music.

She lived nearly 35 years and was in the hospital almost once a year. Some stays were up to two months long. We had been told a few times that she probably wasn't going to make it, but she always did. She had unbelievable strength. What her little body had to endure for 35 years is a medical miracle. We never left her side while she was in the hospital. We both would be on shifts 24/7. We did this not only because she would know we were there but also so we could be her voice when communicating with hospital staff. Nobody knew her like we did so we could tell through her facial and body expressions what was going on with her.

Everyone who has met or knew her has a special story. It's a gift that children with special needs possess. When Shaylin would meet someone, she would just stand there for a moment and stare at them. Then she would walk up to them and either put her hand on them, hold their hand, or give them a hug. It was as if she took that moment to analyze them and determine what they needed at that moment in their life. We would ask ourselves, "What kind of person does this sort of thing?" We know the answer. An angel. **Shaylin was a living angel that we and everyone who knew her had the privilege of being a part of her life. She blessed us with her presence and loved everyone in her world.**

Anyone who has lost a loved one says they will not be forgotten. Shaylin was no exception, she is unforgettable. We believe the best way to never forget is to teach others what your loved one taught you. Shaylin taught us love and compassion towards everyone we meet. If you meet someone who may be going through a difficult time, don't be afraid to put your hand on them to show support, or hold their hand to show you care, or even hug them to show you understand. If you do this and teach it to others, then Shaylin's legacy will live on forever. And if someone says, "Thank you, I needed that," just tell them you learned it from an angel. A little angel named Shaylin.

HIGHLIGHTED **EVENTS**

FEEHAN BACKYARD OBSTACLE COURSE SMASHES GOAL AGAIN

Mike Feehan, his family, and friends have once again hosted a successful Backyard Obstacle Course this past summer. The fun group smashed their original goal of $20,000 by raising over $50,000 for the CdLS Foundation. The annual event celebrates Mike's 12-year-old son Connor and all individuals with CdLS.

"I have been raising money for the CdLS Foundation since Connor was two years old. I started by participating in street races and mud run races. When COVID impacted the world and mud run races were canceled, I created a backyard obstacle course race that my family and I (along with Connor) could participate in to continue raising money for the Foundation." Commented Mike, "Our inaugural backyard obstacle course was a success. We made it a lot of fun, and Connor had a wonderful time as he could participate and share in the enjoyment of the event. We decided to do it again the following year and have made it an annual event. While Connor generally has anxiety in social situations, he has enjoyed participating in the event. As he gets older, I expect him to continue being involved and feel included. I couldn't be happier that we created this fundraising event to help support CdLS families nationwide."

WALK FOR WILL AND HOPE HIT 15 YEARS

More than 70 walkers turned out for the 15th annual Walk for Will & Hope, the only annual fundraising event for the CdLS Foundation in Michigan. The Kurth family organized the walk in memory of their son, Will, who was born with CdLS and would have turned 19 this year. The event also honors their daughter, Hope, who also has CdLS. The walk, held at a beautiful suburban park north of Detroit, included the Smith family, whose daughter, Liz, also has CdLS, and the Bajema family, who walked in memory of their daughter Adrian. The Walk for Will & Hope has raised over $75,000 since 2009.

FAMILY GATHERINGS RETURNED WITH EXCITEMENT AND GRATITUDE

Family Gatherings are one of our community's most impactful programs. Gatherings are a spectacular way to meet, make friends, and get a refreshing dose of family support. Family Gatherings enable families and professionals to come together and share knowledge, insights, and smiles in a relaxed, non-clinical setting.

In 2023, the CdLS Family Service Coordinators facilitated, attended, and provided financial assistance for in-person family gatherings in California, Texas, and Illinois. Family Service Coordinators also provided administrative support, without financial aid, to families who hosted g Family Gatherings in Iowa, Wisconsin, and Kansas. Over 300 people participated in these fantastic events, providing all who attended an extra boost of hope and support.

AMBER GAINES MEMORIAL GOLF CLASSIC CELEBRATED ANOTHER SUCCESSFUL YEAR

The Amber Gaines Memorial Golf Classic was held in early October and celebrated its 35th anniversary. With over 80 golfers in attendance, the event raised over $80,000 for individuals living with CdLS.

Barbara Gaines, mom to Amber, stated, "It was another beautiful day for our 35th Amber Gaines Memorial Golf Tournament! We are so grateful and feel blessed that our daughter's legacy lives on thanks to the dedicated golfers, all the sponsors, volunteers, team MCWP, PLM & our partners Jim & Joyce Kesting and Melissa Snodsmith. Their efforts help give much-needed support to all the families who struggle to care for their children with medical & physical challenges that come with CdLS! This means more than words can say!!! We are very grateful Amber continues to inspire and help all her friends born with CdLS."

TEAM CdLS HITS THE GROUND IN CHICAGO AND BALTIMORE

Runners of Team CdLS took to the streets in Chicago and Baltimore this fall, raising more than $76,700 to support individuals with CdLS and their families!

Fifteen runners from across the country and Mexico raised over $64,000 by pushing themselves to the limit for the October 2023 Bank of America Chicago Marathon. This year was extra special because many more families than usual attended with their children. Throughout the pre-and post-race events, you could hear children giggling as they played joyfully together. Matt Evans, a newcomer to the team, was joined by his family of nine, including his wife, Christina, his sister-in-law, Mandy, and his thirteen-year-old niece, Sydney, who has CdLS. Christina summed up her experience, "The Chicago Marathon experience with CdLS was just something I will cherish forever. We were so honored to be able to race for Sydney and other kids and adults who cannot and to raise awareness and money for them too."

Team CdLS in Baltimore had a record number of people attending the event. This year, the team raised over $12,700. This group had members participating in the full marathon, half-marathon, 5k, and walk. The team's co-captains are Dr. Tonie Kline, the CdLS Foundation Medical Director, and Tasha Howland, who runs on behalf of her precious daughter Peyton, who has CdLS.

Thanks to our runners, curb crew volunteers, and staff for making this year's Team CdLS events the best! Your dedication has made a difference.

CALENDAR 2024

February 12, 2024
International CdLS
Remembrance Day

February 29, 2024
Rare Disease Day
Unseen Viewing Party

March 13, 2024
Multi-Specialty Clinic for
Children with CdLS
Salt Lake City, UT

April 10, 2024
National Sibling Day

April 13, 2024
Adolescent and Adult
Multidisciplinary Clinic
Baltimore, MD

May 11, 2024
35th Anniversary of
International CdLS
Awareness Day

September 13-15, 2024
Regional Retreat
Oxford, PA

November 2, 2024
Adolescent and Adult
Multidisciplinary Clinic
Baltimore, MD

ANTHONY TURNER, JR.

Mariel Moody

Anthony is a 2-year-old sweetheart who goes by the name Ife. Ife (Ee-Fay) means LOVE in the Yoruba language, and he lives up to his name. He was born in September of 2021 and weighed only 4.9lbs. He is tiny but mighty, with a huge personality that he loves sharing with new people. Baby Ife was seven months old when we received his genetic testing diagnosis of CdLS. With his birth so small, we often wondered if something else was happening that we could not visibly see. After a visit to the Pediatrician Dr. Diaz, we were referred to Dr. Woods, a Geneticist at Valley Children's Hospital. We received our diagnosis a few months after the blood draw.

Ife did not move much during pregnancy, and around 37 weeks, he was ready to enter the world. The doctors worked very hard to keep him in the womb so he could continue growing. Around that time, the provider noticed he weighed an estimated 4.2 lbs, and they were unsure why. After careful consideration, we found it best to be induced at 38 weeks and 2 days, and a tiny 4.9lbs baby boy came. During the hospital stay, NICU was recommended due to his small size and issues with feeding. We stayed five days in the hospital and went home with high hopes. Once home, Ife struggled with weight gain and formula/breast milk tolerance.

CdLS affects Ife in many ways. He is not very mobile besides crawling, struggles to stand independently, has learned to sit unassisted at around one, has several medical issues, and is slow to grow. He depends on his tube feedings, nurses, and medications daily to have successful days. Feeding, digestion, and excretion are the number one issues Ife has. He currently has a GJ Tube but started with an NG tube at six months and graduated to a G Tube at 12 months old. He has global developmental and delays, so life looks a little different through his eyes.

Ife is a very sweet little guy who likes meeting new people. He enjoys studying facial expressions and copying noises he may hear you make. He loves the ABCS and rock songs his nurses play for him. He crawls around, explores this new world, and tries tasting everything and everyone within his reach. Ife enjoys being outdoors, feeling the breeze blow through his hair, watching passersby, looking into the bright blue sky, and checking out the clouds. He is the kind of guy who enjoys the simple things in life.

Having a child is hard enough, but having a child with a rare genetic condition is very challenging due to the lack of information about his condition. Taking it upon ourselves, we studied his condition, joined groups, and reached out to other families of special needs children and other CdLS families. We often worry and wonder about his capabilities and overall quality of life, but he always surprises us. He exceeds our expectations every time. Though he is "mild appearing," people make comments that can be seen as offensive due to their lack of understanding and not being used to dealing with children who may be disabled. Having a child with a rare condition makes you feel like you are in the spotlight, and some comments feel filled with pity or misunderstanding. People judge you for what your child should be doing at their age based on neurotypical standards for growing children. People often assume this is something that gets better with time or something he will grow out of. We still grieve the loss of the life we thought our child would have. To not be judged or ostracized, not to struggle with basic necessities of life skills. We will continue to worry for him but also embrace, cherish, and pour into him.

The CdLS Foundation has helped our family by being there and letting us know we have a solid Foundation to lean on. We can get our questions answered, share and hear experiences, meet other families, and gain access to resources we never knew were available. The Foundation makes us feel less alone because special needs parenting can be very isolating. Ife went to the Irvine Family Gathering in February of 2023 and met some fantastic staff and other kiddos with his exact condition. Without the Foundation, I often wonder where we would be.

Celebrate every negative test result, and
NEVER STOP ADVOCATING.

My Brother Will

Cale Elcano

As my Kyrie infinities squeak against the newly waxed gym floor, my feet shuffle to keep up with my brother as he dribbles in the paint for a layup. I get the rebound, bring the orange Wilson basketball back to the 3-point line and drain a 3. However, my victory is short lived, and I wake up drenched in sweat. I realized my mind had taken me to an alternate reality. I rip off my tank top to go take a cold shower. Cold, wet drops of water snap me back into reality. The truth is that my brother, Will, has CdLS.

Although my brother may not seem to be your average 13-year-old, I still think he's super cool. The coolest thing about Will is the fact that he shares all of the same qualities as me, but just shows them in different ways. With Will, not everything is easy. Some things are very hand. For example, the hardest thing about having a brother with a disability is the fact that he is nonverbal. This is hard, because I always wanted to have a brother that I can talk to, tell anything to, but I can't do that with my brother. The fact that Will can't talk is also very hard, because he can't tell us what he wants which makes him very unpredictable. Sometimes he may pull hair or hit someone which scares me, because I would never want him to hit a kid and the kid to hit him back. If Will starts to throw a tantrum he likes to do puzzles and play with his bouncy ball to calm himself down.

I always love spending time with my brother, even if it means playing at his pace. Some of my favorite activities to do with Will include playing ball because it is a fun way for Will to get active and run around. Another thing that we do is snuggle and watch Disney movies. This is a good way to spend time with Will and to help put him to bed.

Sometimes Will just wants to do his own things. People always assume that I don't like having a disabled brother, and **I always tell them that I am blessed to share a birthday with someone so cool as him.**

WELCOME

New Families

Alabama
Yvette Nemeth and Steve Jones, and son Alec
born June 5, 2013

Georgia
Reba and Dean,
and son Whitt
born August 10, 2022

Tennessee
Morgan and Connor Dodson, and
daughter Emery
born February 10, 2023

New York
Joanne and Ben,
and son Jonas
born July 23, 2013

Over the past few years, the CdLS Foundation staff has collaborated with our families and board of directors to re-imagine the CdLS Foundation National Family Conference. Our previous National Conference model was no longer sustainable because many families found the cost of travel, hotel, and Conference prohibitive and because the CdLS Foundation historically assumed an overwhelming portion of the Conference's expense.

Our goal was to design a new way for families to convene that provides fellowship with other families, social activities for young siblings of individuals with CdLS, and allows families to obtain accurate information and guidance from our experts. In addition, it is important to offer the opportunity to attend an in-person event to families for whom the Conference has not been financially feasible.

Guided by your input, we're excited to announce we've hit on something that will work!

Beginning in 2024, the CdLS National Family Conference will become a series of Regional Retreats. The regions will be the East Coast, West Coast, and Central US. We will kick these off in 2024 on the East Coast. Our first Regional Retreat will be **September 13 -15, 2024, at beautiful Camp Saginaw in Oxford, PA.**

Where is It?

The Camp is just over an hour away from Baltimore and less than 1.5 hours from Philadelphia.

The Camp's beautiful landscape is perfect for learning, sharing, and relaxing. As the only group on site for the weekend, families will enjoy the fantastic activities and landscapes Camp Saginaw offers. The Camp features modern facilities for workshops, socializing, and lodging.

What Will We Be Doing?

Opening night (Friday) will include a welcome dinner for first-time families followed by s'mores and conversation around any number of the Camp's huge firepits. Families can meet and connect in a relaxed setting. Saturday will be a full day, including presentations, an active day of sibling camp, and multiple opportunities for parents and caregivers to Meet the Experts.

After a full day of programming, we will have a mocktail hour and a special dinner. Saturday evening also includes time for families to continue to bond after dinner. We will close out the event on Sunday with a presentation by veteran parents and guardians willing to share their wisdom and answer questions. We will say our goodbyes on Sunday.

Meet the Expert sessions are blocks of time throughout the day when clinical experts will be available for families to ask questions, share information, and seek guidance in an informal, small group setting. Unlike previous events, these are not private 1:1 sessions but drop-in conversations, allowing families to meet with experts throughout the day.

Siblings of individuals with CdLS ages 5+ will have an active, full day of camp activities led by Camp Saginaw staff. They will have a blast with activities like go-karts, canoeing, kayaking, riding ATVs, arts and crafts, and more!

Although we will not offer daycare for individuals with CdLS, individual caregivers can enjoy the Camp's facilities with the child or adult with CdLS they are chaperoning.

Families will have ample time to take advantage of the Camp's facilities. In addition to more active options, there are miles of walking trails and multiple large firepits to enjoy well into the evening (more s'mores, please!).

Where Are We Staying?

Lodging at the campsite includes a mix of individual and bunk-type cabins. All lodging options at the Camp have electricity, full indoor bathrooms (showers). Linens are available, or if you prefer, you can bring your own.

For any family that chooses not to stay at Camp Saginaw, we are working to arrange a group rate with local hotels approximately 25 minutes from Camp.

What Is the Cost?

We want to make the Regional Retreat as affordable as possible. We are reviewing costs and our resources to determine an all-inclusive per-person rate that will include programming, sibling camp, all meals, and lodging, which we hope all families interested in attending will find manageable. Individuals with CdLS will attend for free. Families staying off-site will have a "program only" rate and are responsible for hotel costs.

When Can I Register?

Registration will open in mid-summer to families on the East Coast. Registration will then open to the rest of our community in late summer.

When Will We Have More Details?

We are so pleased that the focus groups we have engaged have been so enthusiastic about this new model. We hope you are as excited as we are for this wonderful event. Thank you to all those who shared their knowledge and expertise to help shape this event.

We look forward to this new and special event and hope you are also excited by it! It promises to be a wonderful time for all. Be on the lookout for more information coming your way over the next few months in your inbox and on social media.

If you don't receive our emails, please contact Family Service at **familyservicesteam@CdLSusa.org**, and they will ensure you are on our email list.

Our Deepest Sympathy

Shaylin Hope Cubeta
November 4, 1988 –
September 7, 2023
Daughter to Perry and
Tonya Cubeta
1321 Pineapple Avenue
Melbourne, FL 32935

Danielle Dale
June 28, 1985 - July 27, 2023
Daughter of Deborah Dale
2202 Mayflower Drive
Lynchburg, VA 24523

Daniel Ulloa
October 26, 2006 –
July 18, 2023
Son to Early and
Edwardo Ulloa
11111 Piedmont Landing Drive
Fredericksburg, VA 22407

THE GRIEF SUPPORT ADVISORY GROUP IS HERE TO HELP

When a parent loses a child, the Foundation is here for them in many ways. Our Family Service Professionals are standing by to listen, guide and provide support. We also can connect a parent with another parent who has lost a child. Our unique team of 10 Grief Support volunteers understand, perhaps better than anyone else, what this kind of loss feels like. We also provide helpful and inspirational resources on our website's Bereavement page, as well as an In-Memoriam page where families can share loving memories and stories about their loved one. Visit: **bit.ly/CdLSbereavement.**

*If you have experienced the loss of a loved one with CdLS and are in need of support, be sure to reach out to **familyservicesteam@CdLSusa.org**.*

ADVICE FROM A LITTLE BOOK ABOUT GRIEF

New grief publication by the CdLS Foundation

Those who experience the loss of a child with special needs can be especially affected, as not only is their child gone, but often so is a way of living. Parents are totally involved with meeting the needs of that special child throughout his or her lifetime and now, suddenly, that is gone. It can create a crisis of identity and direction that provides another layer to the grief already felt. It is difficult to deal with such grief alone, but by seeking out other parents who have lost a special needs child, you can find the support that can help you through this difficult time of transition.

Accepting the support of others who have already experienced this horrible reality can help ease this transition and help process the grief.

Nothing will change your loss, nor will it take away the grief, but it can help you through the difficult days ahead and move you along in a more positive direction. Our resolve to live a good and meaningful life honors our departed children. It is good to talk to those who know and who understand and offer not judgment, but caring support.

Tribute Gifts 07.01.23 - 09.30.23

In Honor/ Celebration

Max Balthazar
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Marilyn Eskew Wassmer
Rick and Victoria Boehman
Clara Mae Braunecker
Julie Buechler
Annie and Phil Gramelspacher
Carol and Arthur Martin
Karen and Douglas Schulte
Regina and Fred Tone

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The Board and Staff at the CdLS Foundation

YES! **I want to continue to support the CdLS Foundation.**

☐ **$150** ☐ **$100** ☐ **$75** ☐ **$50** ☐ **$25** ☐ **$**____________

☐ Check (payable to the CdLS Foundation)

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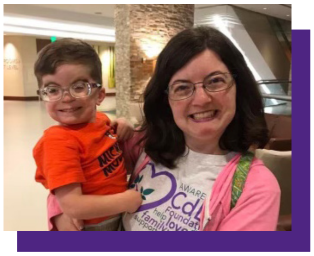

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CdLS Foundation | 30 Tower Lane, Suite 400, Avon, CT 06001

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

30 Tower Lane, #400
Avon, Connecticut, USA 06001
800.753.2357
www.CdLSusa.org

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CdLS Foundation Family Gatherings!

Family Service has put together a Guideline for Hosting a Successful Family Gathering to help you through the planning process.

Want to get in on the fun?

If you are interested in planning a Family Gathering in 2024, contact Family Service at familyservicesteam@CdLSusa.org!