REACHING OUT

SUMMER/FALL 2024

Spotlight:

An Overview of CdLS FoundationClinics

ON THE COVER

Elijah S.

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Greetings Friends,

During these challenging times, we hope this message reaches you in good health. We want to take this opportunity to 'spill the tea' on our fantastic CdLS Multidisciplinary clinics.

Navigating medical care for CdLS can be tough, but these clinics offer families the opportunity to consult specialists who are well-versed in CdLS. Families leave the clinic equipped with enhanced knowledge, strategies to tackle challenges, available resources, and follow-up care information. While each clinic differs, they all share common goals:

- Conducting a thorough evaluation of individuals with CdLS
- Assisting in creating a care plan to be shared with local providers
- Equipping families with strategies and resources for managing concerns
- Facilitating connections and shared experiences for individuals with CdLS and their families

We understand that travel and healthcare expenses can be daunting. To ease this burden:

- Our board has approved up to $500 reimbursement per family for travel costs to visit CdLS clinics
- We have teamed up with Angel Flights and Miracle Flights to coordinate free trips for families in need heading to selected clinics
- The Mairano family has established a travel fund to help ease your clinic expenses

Our commitment to addressing the physical, emotional, and social well-being of our special children distinguishes CdLS Multidisciplinary clinics. None of this would be achievable without the dedicated professionals at ***Greater Baltimore Medical Center, Children's Hospital of Philadelphia, Shriners Children's Salt Lake City , and Boston Children's Hospital.*** We extend our heartfelt thanks to these exceptional professionals for their service to the CdLS community.

The CdLS clinics serve as beacons of hope and healing for many. Please refer to our Clinic Chart for more information.

With sincere appreciation,

Bonnie

Bonnie Royster, CdLS Foundation Executive Director

VISIT PAGE 22, FOR THE PULL-OUT SECTION ON HOW TO ASK FRIENDS AND FAMILY FOR HELP

Reaching Out
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www.CdLSusa.org

CdLS Foundation Clinics

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

One of the major goals of the Cornelia de Lange Syndrome Foundation is to encourage the formation of CdLS clinics held regularly around the United States. We have four regularly held clinics currently, and they are all "multidisciplinary". This means that each child or adult with CdLS who attends the clinics is evaluated by multiple medical specialist health care providers on the same visit. Each family hears from all of the different experts and receives a written report for their primary care provider.

At my hospital outside Baltimore, MD, Greater Baltimore Medical Center, the clinic is held twice a year. Usually about eight to nine families attend, each individual with CdLS and their family members meet with up to twelve health care professionals. These specialists are extremely knowledgeable about CdLS, most having attended this clinic for nearly ten to fifteen years. The specialties include behavioral psychology, child psychiatry, neuropsychology, gastroenterology, genetics and genetic counseling, gynecology, pediatric neurology, pediatric ophthalmology, pediatric urology, speech pathology, and pediatric dentistry. In addition to the clinic's medical aspect, the families typically meet after lunch as a group, and discuss transition and support with a family service coordinator from the Foundation. There is an annual clinic in Salt Lake City, UT held at the Shriner's Hospital, with a similar format but it includes occupational and physical therapy. And there are two monthly or bimonthly clinics at Children's Hospital of Philadelphia and Boston Children's Hospital with a slightly different model but same concept.

Families seem to enjoy the expertise and meet the other families. Connections are made with the experts that can be shared with home-based providers. There are many advantages to attending such a clinic, but there can be some challenges. Children and adults with CdLS can resist travelling or have difficulties with behaviors. Records can be difficult to obtain ahead of time, although electronic medical records can be shared in recent years. Some of the clinics charge for the visits and depending on the insurance company, this can limit who can attend.

If we were able to establish more of these clinics, then travel would be closer and often in state, so insurance would be less of an issue. The major challenge to setting up new clinics is that one provider needs to take on the role of organizing it, and the hospital needs to agree. The Foundation is willing to help with some of the organization, a small amount of funding, and finding a local family to help coordinate the day of the clinic, but the majority of the work has to come from within the hospital. In any case, we appreciate all the work carried out at the current clinics and send a big "thank you" to them!

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Overview of CdLS Foundation Clinics

The CdLS Foundation has long-standing partnerships with four hospitals throughout the United States where families can receive invaluable head-to-toe evaluation by a full complement of experts.

Multidisciplinary Clinic for Adolescents and Adults at Greater Baltimore Medical Center

Antonie Kline, M.D., our beloved Medical Director and Director of Pediatric Genetics at Harvey Institute for Human Genetics, has spearheaded these FREE clinics for 23 years. This foundation-managed clinic occurs twice yearly at Greater Baltimore Medical Center in Baltimore, MD. Clinics are held on the first Saturday in April and November. This is the only clinic focusing on Adolescents and Adults, bridging a critical gap between pediatric and adult health care. To make an appointment for the next clinic, contact **familyservicesteam@CdLSusa.org**.

The Center for CdLS and Related Diagnoses at Children's Hospital of Philadelphia

Long-time dedicated CdLS experts, Dr. Ian Krantz and Sarah Raible, M.S., manage this clinic. This CdLS Center of Excellence holds multi-disciplinary clinics monthly. Appointments for each family are based on the specialist needed for your loved one's care. Parents can have as many specialists as the schedule allows. Several specialists are seen on day one of the clinic, and if needed, a day two visit is planned. Insurance authorization is required. CHOP submits a claim to the family's insurance, and the family is responsible for any unpaid portion of the bill.

Families going to CHOP must work with hospital staff ahead of time, so they are aware of their financial liability BEFORE the appointment. The wait time for an appointment averages 6 months. To make an appointment for the CHOP clinic, call 1.844.873.4642.

Shriners Children's Salt Lake City

Serving the CdLS Community since 2016, the Shriners clinic is held each year on the second Wednesday in March. The clinic is staffed with medical staff from Shriner's Children's and the Children's Hospital of the University of Utah. Care is delivered in a highly compassionate and family-centered environment. To make an appointment for the next clinic, **familyservicesteam@CdLSusa.org**.

Boston Children's Hospital, Cornelia de Lange Syndrome (CdLS) and Related Disorders Clinic

Led by Dr. Phil Boone, the Boston Children's Clinic hosts monthly visits on an appointment basis. Families see Dr. Boone during their first visit for an assessment and possible referral through the hospital system of specialists. Although multiple services are offered, many are unavailable for scheduling within the same day or on the same campus. Boston Children's submits claims to the family's insurance carrier.

The average wait time for an appointment is 6 months. If you want to make an appointment for the next available clinic, call 617.355.6394.

The chart below illustrates the differences each clinic offers - from ages seen to cost of care.

Data Points	Children's Hospital of Philadelphia	Boston Children's Hospital	Greater Baltimore Medical Center	Shriners Children's Salt Lake City
Ages seen	All ages	New patients: 0-18 Existing patients 0-21. Up to 26 on rare occasions.	12+	0 -17
Capacity at clinic	2 or 3 on scheduled days	2 or 3 on scheduled days	8-9	14 -16
Frequency of clinic	Monthly	Monthly	Twice a year	Once a year
Families may incur a bill for the cost of care	Yes	Yes	No	No

SPECIALTIES AND SERVICES AVAILABLE	Children's Hospital of Philadelphia
Audiology	
Cardiology	If needed, day 2
Dermatology	If needed, day 2
Developmental Pediatrics	✓
Dietary/Nutrition	
ENT	
Gastroenterology	✓
Genetics/Genetic Counseling	✓
Gynecology	
Neurology	If needed, day 2
Orthopedics	
Orthotics and Prosthetics	
Pediatric Dentistry	
Physical Therapy	✓
Psychiatry	
Psychology	
Social Work	
Speech and Language	
Urology	
Wheelchair and Seating	
Interpreter Available	✓
Ability to meet other parents at the clinic	

The chart illustrates the distinct differences in services and specialties available at the various CdLS clinics.

CdLS Clinic Breakdown

Boston Children's Hospital	Greater Baltimore Medical Center	Shriners Children's Salt Lake City
		✓
✓		
✓	✓	✓
		✓
		✓
✓	✓	✓
✓	✓	✓
	✓	
✓	✓	✓
		✓
		✓
	✓	
		✓
✓	✓	
	✓	
		✓
✓	✓	
	✓	
		✓
✓		✓
	✓	✓

Dorian T.
at Greater Baltimore Medical Center

By, Lisa T., Dorian's Mom

On January 17, 2001, Dorian was diagnosed with CdLS after her pediatrician noticed that she had only gained four pounds since birth despite being breast-fed. Despite not showing any limb abnormalities, Dorian's slow growth raised concerns, and a specialist confirmed the diagnosis. One thing that is etched into my spirit was the neuro-specialist we saw that day. During the visit, the specialist completed a physical examination - he held Dorian, weighed her, turned her over, gave her back to me, and said, "Your daughter has Cornelia de Lange Syndrome, named after the person who discovered it. It's children with similar facial features, thick eyebrows, long lashes, and small head sizes. Some have limb abnormalities and gastrointestinal issues; many are non-verbal and experience hearing loss or are deaf and are often retarded or have significant cognitive and developmental delays. You will be responsible for her care for the rest of her life as she will require a great deal of supported care."

He then began to rummage around in his drawer, mumbling about having a brochure from the CdLS Foundation, but could not find it. He wrote it on an orange Post-it and passed it to my husband. I could not take it because I was shaking so badly. My husband had to grab it and Dorian. The doctor left the room, and his assistant returned and stated she could understand how this news could be "upsetting and would follow up later with a call and next steps." My husband, a physician, later joked, "I wonder how that guy passed bedside manners!" as we sat in the office parking lot and cried for 22 minutes.

Despite the initial hurdles, Dorian has surpassed expectations and become a source of joy for her family. However, her ongoing care presents challenges, from accessing essential services to concerns about her vulnerability.

When we registered for our first CdLS Clinic at GBMC, we were in search of answers. It seemed like we were only addressing the symptoms and not the root cause of many of her issues. She needed a frenulum clip and additional information for the anesthesiologist because of the size of her mouth. Although they were able to intubate her successfully, the anesthesiologist and his staff had never encountered CdLS and recommended that we conduct further research on her skeletal structure due to some dental issues they had noticed, which would require sedation.

Fortunately, the CdLS Clinic at GBMC has been a source of invaluable support and information. Our participation in the Multidisciplinary Clinic at GBMC has equipped us with educational resources and a deeper understanding of CdLS, along with tailored medical insights for Dorian's specific needs.

Dorian's vibrant personality shines through as she embraces life with enthusiasm, enjoying dressing up, making jokes, and connecting with others in her unique way. Throughout the journey, we remain deeply grateful for the unwavering support we have received, and we are thrilled by the progress Dorian continues to make.

Cambria F.

at Shriners Children's Salt Lake City

By, Mark and Lyndsee F., Cambria's Grandparents

Cambria is 14 years old, 3'10', and 40 pounds. The doctor who delivered her was the first to mention CdLS. She was medevacked to Tucson Medical Center, where they formalized her diagnosis, gave her a feeding tube, and were not very positive about Cambria's future. The night Cambria was diagnosed we were on the phone with her mom while on the CdLS Foundation's website. One look at the other children on the site and we knew – this was our introduction to both CdLS and the Foundation. With information from the CdLS Foundation, research and the determination of her parents, the tube was removed when Cambria was a year old and she has continued, with tiny steps, to meet milestones.

Although she started life with significant issues, we are now at a place where we can focus more on preventative than reactive care. She enjoys taking and editing photos on her iPad, texting family and friends, music, and pulling heads off dolls. She is becoming very talkative with her AAC device. She loves going places, seeing new things, and spending time with her teacher, friends, and therapists. If you are paying attention, you will see a new way of looking at things and a great sense of humor.

As soon as we received the notification about the CdLS Foundation Clinic at Shriners, I contacted the Foundation and said we want in! Linda Peirce from the Family Service team was with us through the whole planning process. She encouraged, answered all questions, and suggested organizations that might help with travel and lodging. She was above and beyond and the reason we were able to attend. It was such a pleasure to put a face to the name when we met her at the clinic. A turn in Cambria's health (highly possible) was the only thing that would have kept us from going.

We were able to fly on Miracle Flights to attend the clinic. The suggested hotel had a shuttle service that picked us up at the airport AND shuttled us back and forth to the clinic.

The clinic experience was fantastic. We walked away with more information than we had and with clarity that the support team we had built for Cambria at home. We are blessed with great care for her and great lines of communication. With the help of the CdLS Foundation we have now added Shriners Hospital as another layer of expertise to her care. We returned home with new information and questions for Cambria's medical team, soft orthotics not available at home and the possibility of a new bike.

> "Though she be but little, she is fierce."

Each specialist provided a summary of the examination for us to take with us as well as copies of the x-rays that were taken. We felt heard. I would encourage any family to try to attend a CdLS Specialty Clinic. The Foundation not only hosts but has resources to make it possible. Meeting other families in a small setting allowed for connection, sharing information and personal experience and encouragement given and received.

HIGHLIGHTED **EVENTS**

CORNHOLE TOURNAMENT TO BENEFIT THE CdLS FOUNDATION

In early spring, a Cardinal Newman High School senior completed his Community-Based Service Learning (CBSL) Project, in which the student helps an organization through service. The student, Zack, decided to support the CdLS Foundation. His cousin, A.J., was his inspiration. In his words, "My little cousin AJ was born with CdLS. Although he's a little guy, he's FULL of life. His parents, Melissa and Tim, are so grateful for the CdLS Foundation, as they helped them navigate through their diagnosis and have been a valuable resource for the past 10 years … I'm hoping to bring our family and friends together for a fundraiser to benefit the CdLS Foundation, to bring awareness to more kids like AJ."

Zach hosted a Cornhole Tournament to raise funds and awareness for the CdLS Foundation. There were 48 registered cornhole players and over 100 attendees for the dinner. The event raised over $15,000. It was a magical day, and everyone in attendance had a lot of fun.

"The event was a success because AJ has touched so many lives. And although it was a project for school, Zack has always felt strongly about encouraging AJ's potential and setting a good example as the oldest cousin," stated Melissa. "Our community really came together to support Zack's efforts as much as to show support for AJ and the CdLS Foundation."

NEW ENGLAND GOLF CLASSIC

This past May marked the final CdLS New England Golf Classic to benefit the CdLS Foundation. Over the last 31 years, this amazing event has raised 1.2 million. We are filled with gratitude and admiration for the unwavering support of our New England Golf families, volunteers, golfers, and sponsors, who supported the many families who are part of the CdLS community. Your individual and group dedication has truly made a world of difference, and we are deeply thankful for each moment you have generously given.

Your commitment has enriched the lives of your fellow participants and volunteers. You have raised the level of awareness of CdLS while continuing to reach out, provide help, and give hope to individuals with CdLS. The legacy of your support will continue to inspire and uplift the CdLS community for many years to come.

THANK YOU for your extraordinary contributions and dedication. Your support has made a lasting impression, and we are profoundly grateful for your partnership in this mission.

THE PURPLE PICKLE

The inaugural Purple Pickle Pickleball Tournament, hosted by Amelia and Brandon, parents to Wilson, was an astounding success, leaving attendees' hearts overflowing with gratitude. The event saw an impressive turnout, with 32 enthusiastic players taking to the courts and several dozen passionate fans cheering from the sidelines. The vibrant energy and camaraderie present throughout the tournament created a truly memorable experience for everyone involved.

The event raised an incredible $6,200 for the CdLS Foundation. This substantial contribution will undoubtedly make a meaningful impact on the foundation's efforts and the lives of those they serve. The Purple Pickle Pickleball Tournament was more than just a sporting event; it was a celebration of unity, compassion, and the spirit of giving. We look forward to continuing this tradition in the years to come and hope to see even more participants and supporters join us in our mission to create positive change. Thank you, Amelia and Brandon, once again for your unwavering support and generosity.

HAMPTON ROADS CdLS FAMILY GATHERING

On a delightful day in May, two incredible CdLS moms, Emily and Paula, proudly organized a heartwarming CdLS Family Gathering in Hampton Roads, VA. An impressive turnout of 85 individuals graced the event, including 18 amazing individuals with CdLS. It was a particularly touching experience for some families who had never connected with another person living with CdLS. The individuals with CdLS spanned ages from three to 60 years old, showcasing the beautiful diversity within the community.

Witnessing everyone come together and experience a sense of belonging and ease was truly heartening. Generous donations of food, including delightful cupcakes from the local company Libby on the Label, added to the warmth of the occasion. The presence of dedicated volunteers and supportive family friends ensured that all attendees could relish the opportunity to connect and bond with other CdLS families in a relaxed and joyous setting.

Emily said, "Paula and I both were very honored to host this gathering. It was very rewarding to be able to assist with the gathering to get everyone together in the same room. While some families have never met before, a lot follow each other's journeys on social media, we all felt comfortable around each other, and loved one another as if we've all met before.

CALENDAR 2024

September 13-15
East Coast Regional Retreat
Oxford, PA

September 28
CdLS Bulls & Barrels Series
Carter's Arena
Chiefland, FL

October 5
Wisconsin Road Race
Menomonee Park
Menomonee Falls, WI

October 13
Bank of America
Chicago Marathon
Chicago, IL

October 14
MCWP & PLM Amber
Gaines Memorial
Golf Classic
St. Louis, MO

October 19
The Baltimore
Running Festival
Baltimore, MD

October 26
CdLS Bulls & Barrels Series
Carter's Arena
Chiefland, FL

November 2
Adolescent and Adult
Multidisciplinary Clinic
Baltimore, MD

November 16
CdLS Bulls & Barrels Series
Carter's Arena
Chiefland, FL

December 3
Giving Tuesday

Host a Dress Down Day to Support the CdLS Foundation

Gabrielle Nadeau, MA, Communications Director, CdLS Foundation

Organizing a dress down day at your workplace or child's school is an easy, fun, and impactful way to raise funds and awareness for the CdLS Foundation. It provides an opportunity for colleagues or classmates to express their unique style while sporting shades of purple and teal, the colors associated with the foundation. This simple concept not only generates significant support but also fosters a sense of community and empathy among participants.

Victor Torres, a proud new dad to Olivia, recently spearheaded a heartwarming dress-down fundraiser at his workplace, raising an impressive $19,000 for the CdLS Foundation. This event not only generated significant funds but also played a crucial role in raising awareness about Cornelia de Lange Syndrome (CdLS). Through his efforts, Victor sensitized his co-workers to the unique challenges and joys experienced by families of children with special needs, fostering a more inclusive and empathetic workplace environment. His dedication and the collective generosity of his colleagues have made a meaningful impact, highlighting the power of community and compassion.

To begin, check with your employer or school administration to get approval for organizing a Dress Down for CdLS event. Once you have the green light, contact the CdLS Foundation at 860.676.8166 to request your Dress Down kit. This kit includes branded flyers to hang up and stickers for each participant, helping to promote the event and engage more people.

After receiving your flyers, decide on the date for your event and determine a participation fee. Add these details to the flyers and distribute them to your colleagues or students. On the day of the event, encourage participants to take lots of photos and, if possible, share them on social media. Tag the Foundation (@cdlsfoundation) and use the hashtags #DressDownforCdLS and #CdLSAwareness to broaden your outreach. Finally, once the event concludes, collect and send all donations to the CdLS Foundation. This straightforward yet effective fundraiser can significantly support the Foundation's mission and make a meaningful difference.

To learn more, contact the CdLS Foundation at outreach@CdLSusa.org.

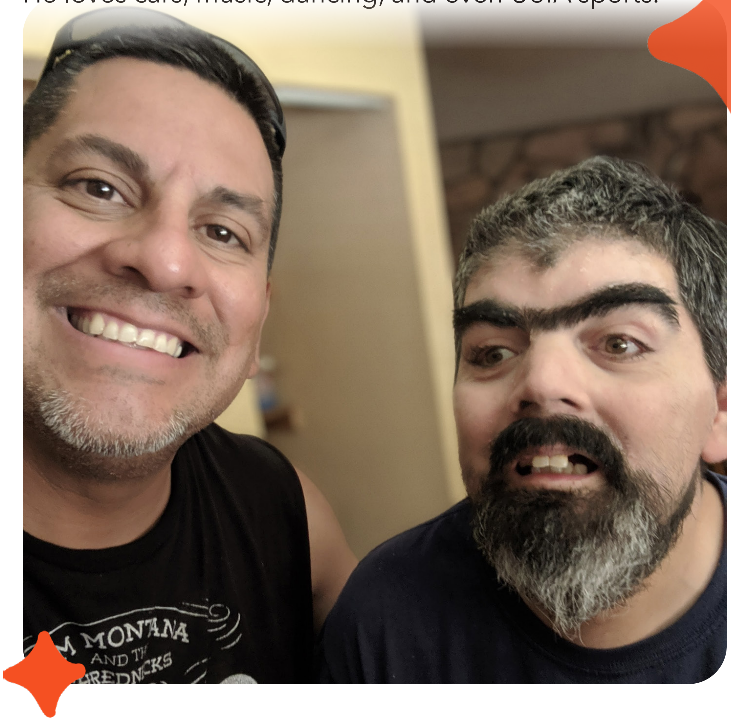
Joe and William M.

By, William M.

Joe turned 41 this year on April 12. He was diagnosed with CdLS in his earlier life, and initially, doctors didn't think he would live very long. He currently lives in an assisted living facility and has tremendous support from some great staff and my father, Bill. My dad made the difficult decision to let Joe live on his own a few years ago.

There have been several rough transitions, but my dad has been a constant through it all. He regularly attends all of Joe's medical and financial meetings and continues to be Joe's biggest advocate. My dad also still picks Joe up every weekend and drives him around town, showing Joe his favorite places to visit. His favorites are my house, Dad's house, and, of course, Dairy Queen.

My relationship with my brother in our early lives was such a blessing. He was the life of the party and had a fantastic sense of comedic timing and a sense of humor. Honestly, he has shown me more about what it means to love someone unconditionally than I have ever been able to teach him. He loves cars, music, dancing, and even UofA sports.



Our time together is fleeting these days as time has become harder to share with one another. He has had some medical issues these last couple of years that have taken their toll, but he is a fighter and continues to enjoy the things that keep him close to family.

I will always cherish each year I have with him. I celebrate his birthday by buying him his favorite magazine or sweet treat. We take a selfie on every visit. I'm thankful for the people at the CdLS Foundation and all their efforts to bring awareness to those who've been blessed to know someone with CdLS. They are special people who deserve all the beauty and love the world offers. I'm sharing that I want to try to acknowledge my brother Joe and help show other families that maybe, entering this new journey, there is hope for a long and rewarding life for their loved ones.

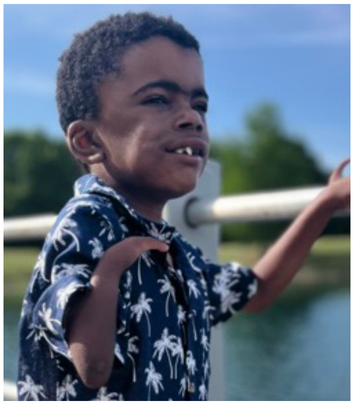
The love I've received in knowing my brother Joe and anyone who knows Joe is immeasurable and will be cherished forever. He is such a blessing to our family.

> "He has shown me more about what it means to love someone unconditionally"

Elijah S.

By, Sharonza P., Elijah's Mom

Elijah may be smaller in stature when compared to other nine-year-old kids; but he's big on personality, energy, wit, kindness, and snacks. He'll start 4th grade in the fall, he's a great help at school with his classmates. He's very observant and quite mischievous. He enjoys getting into anything and everything. He also has his "firecracker" moments. He can be quite expressive and disruptive.



When he was born, the doctors immediately told me everything that was wrong with him and all of the things he wasn't going to be able to do, by the time he was four weeks old, I had a meeting organized by the NICU with the hospital parishioner discussing the plan in the case he didn't survive. It was like "the world" gave up on Elijah without even giving him a chance. I didn't know much about CdLS when he was born, but from the look in his eyes, he assured me he was going to be just fine. And that he certainly is. He runs, he no longer needs hearing aids, he can eat and drink by mouth with a few modifications, he utilizes his communication device quite well, and he knows some sign language.

Elijah was diagnosed when he was two days old, it was a complete surprise. Elijah had most of the distinct characteristics of individuals with CdLS. He was transferred to Cooks Children's and the genetics team immediately confirmed his condition.

When Elijah was diagnosed, I went through all the emotions and feelings, and through them all I'm grateful. Our life could be made into a Lifetime movie with all the challenges, changes, difficulties and victories we've faced.

I didn't know I was going to have a baby with special needs, let alone, a baby with a syndrome I had never heard of … and needed to have surgery soon to have a g-button placed because he was aspirating. All these new terms were thrown at me while I was still trying to grasp being a new mom at 39 and having a fragile child. It was hard. My life was flipped upside down. I knew what was going to be required of me, regarding his care – I wanted to do everything to ensure his well-being and happiness. But while doing that, I was falling apart mentally, physically and emotionally. I love Elijah with all my being, but for so long I grieved the child/life I thought I was going to have. No one in my immediate family/circle could understand my pain. It was and sometimes still is a heartache that I can't put into words. I felt like I lost everything. But by the time Elijah was 6 years old, God revealed to me that I didn't lose anything; I gained so much more by being on this journey as his mom. Our story was unique and we'll both be able to share testimonies of how God turned everything around and kept us in HIS perfect peace.

Elijah has his fair share of doctor appointments with specialists, and weekly speech and occupational therapy sessions. He's not able to be as independent as he'd like to be or like most children his age. He still needs help getting dressed, toileting, bathing, getting in/out vehicles, preparing his food and eating or drinking. And though that may sound like he's totally dependent on me, there are some things that he's worked on or working on, to become more independent. He has a few sensory sensitivities to food textures and sounds.

Elijah is extremely musically inclined, he has fantastic rhythm, and he loves to dance and clap his hands. He loves playing on his piano/keyboard, listening to music and watching song/music videos on YouTube for Kids. Two of his all-time favorite songs are "Wheels on The Bus" and "Hokey Pokey." He also enjoys being outside. As hot as it is here in Texas most of the year, the weather doesn't seem to bother him; he just wants to be outdoors. Elijah likes to play in his rocket-shaped play tent. I call it his house because he has just about everything in there. But it's his space and when he's in there, it's truly "Elijah's World" with his stuffed animals, books, musical toys, pillow and stuff that probably belongs to me.

One challenge for him is that he is often misunderstood because he is nonverbal, and people assume he is a toddler. He understands far more than most people give him credit for. He may not be able to verbalize his thoughts, but he's very aware and for the most part, understands what you're saying and what's going on. He knows some sign language and he uses a communication device to express himself. His doctors may say his biggest challenges are GI-related. It was bumpy for the first five years of his life; but we have most of his GI symptoms/issues under control now.

It's such a joy and peace of mind knowing the CdLS Foundation is here for us. Elijah had just turned one when we went to the National Conference in Orlando in 2016. We were blessed to receive one of the scholarships that year. And oh, what a grand time we had! If I could be around our CdLS family every day, I would be on Cloud 9. To be around other families who shared similar medical histories and stories and be near children like Elijah, without people staring or looking at you because your child is stimming or because your child is beautifully made brought so much relief and "fresh air."

Last year, we attended the Texas CdLS Family Gathering. Though it was just one day, we had a wonderful time. I met people I hadn't met before and saw a few familiar faces from Orlando. I can't speak enough about the phenomenal support from the Foundation.

> "Elijah is my lil' warrior and overcomer"

The Foundation has also assisted Elijah's doctors with inquiries regarding some GI and renal concerns. It's been nice for the Foundation to always keep us "in the know" regarding what's going on in other parts of the country/world regarding CdLS, research opportunities and insights.

Elijah is an exceptional young man and a quick learner. He is an outstanding example of strength, persistence, laughter and wit – nothing (including CdLS) can or will stop him. There's no limits to this fella!

WELCOME
New Families

California
Yancy, Eric, and
daughter Destiny
Born: September 27, 2018

Illinois
Leyla, Zachary,
and son Jake
Born: April 10, 1999

Florida
Mary, Victor, and
daughter Olivia
Born: Jaunary 11, 2020

Megan, William, and
daughter Harper
Born: November 17, 2023

Ohio
Leslie, Ryan, and
daughter Aubrie
Born: September 24, 2021

Tennessee
Gabriella, Raekwon, and
daughter Kalani
Born: July 7, 2023

Utah
Miriam, Allan, and
daughter Harper
Born: June 22, 2011

YOU ROCK!

“The best and most beautiful things in the world cannot be seen or even touched, they must be felt with the heart!”

~Helen Keller

“Always know you're not alone. Someone, somewhere, is praying for you at this moment.”

-The Mountz Family

“IT'S OK TO RELEASE YOURSELF FROM THE EXPECTATION OF OTHERS”

Every survival kit should include a sense of humor.

INSPO WALL

We hope our encouraging words leave a smile on your face. Do you have an encouraging phrase to share with the community? Please send it to the Foundation at outreach@CdLSusa.org.

YOU CAN DO IT!

“Everybody is a genius, but if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.”

~Albert Einstein

“I THINK A HERO IS AN ORDINARY INDIVIDUAL WHO FINDS THE STRENGTH TO PERSEVERE AND ENDURE IN SPITE OF OVERWHELMING OBSTACLES.”

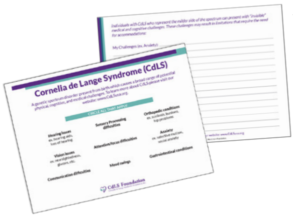
~CHRISTOPHER REEVE

NOTHING IS IMPOSSIBLE.

YOU DON'T HAVE TO BE PERFECT TO BE AMAZING!

Request Your Education and Advocacy Materials

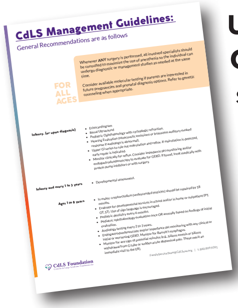
Family Service has a variety of education and advocacy materials for the whole family. If you would like to receive any of these items, contact Family Service at **familyservicesteam@CdLSusa.org**.


Cornelia de Lange Syndrome (CdLS)

Self-Advocacy Cards are fillable and an excellent tool for any individual with CdLS who attends extracurricular activities, employment, or volunteer opportunities in the community, regardless of their communication level. It is currently available in English.

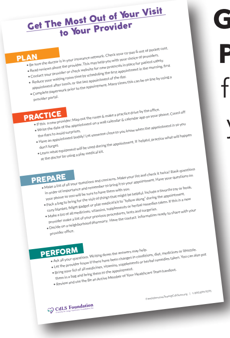

KNOW YOUR CdLS GENE

Gene Brochure gives an overview of the body systems affected and findings you may see. It reviews management guidelines, CdLS' genetics, and individual gene change prevalence. It is currently available in English and Spanish.

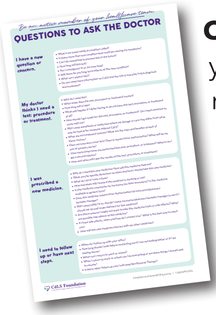

CdLS Management Guidelines:

Updated Management Guidelines highlight routine screenings and care for people with CdLS by specific age groups, including infancy, early childhood, adolescence, and adulthood. These guidelines are in English and Spanish.

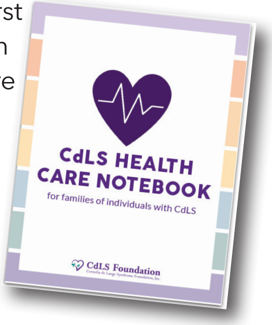
Provider Letter helps educate any medical or therapeutic professionals about the diagnosis of CdLS, the genetics behind it, the prognosis, and where to go if they have any questions. Educating new professionals about CdLS is vital to encourage more understanding in the medical, educational, and therapeutic fields. This letter is available in English.


Get The Most Out of Your Visit to Your Provider

Get the Most Out of Your Visit to Your Provider document helps you prepare for medical appointments and maximize your time with providers during a medical appointment. It is available in English and Spanish.


QUESTIONS TO ASK THE DOCTOR

Questions to Ask the Doctor guide helps you and your loved one with CdLS feel more confident going to the doctor and asking questions. Knowing what to ask can help you and your loved one with CdLS become more active members of your healthcare team. This is available in English and Spanish


CdLS HEALTH CARE NOTEBOOK
for families of individuals with CdLS

The CdLS Health Care Notebook is the first of multiple tools from the CdLS Foundation that makes accessing and coordinating care more manageable. It provides an easy way to keep track of important information so you can find it and share it any time you need. You can update the notebook in real-time, with the ease of a smartphone or any electronic device. It is currently available in English.

Government Benefits Informational Sheets are available from the Family Service team, which review SSI and Medicaid benefits. Each state has different regulations with regarding benefits, and the team has created easy-to-understand guides to help you with the process.

UPDATE YOUR CONTACT INFORMATION WITH US

The CdLS Foundation wants to inform you of the latest information about CdLS or events you can attend. Be sure your contact information is up to date. Please send updated contact information to **familyservicesteam@CdLSusa.org.**

A drawing of the Noah's Landing community design via the project's Facebook page.

These Communities Could Reduce the Affordable Housing Problem for Adults With Special Needs

By, Rachel Kassenbrock , The Mighty

Two housing communities in Florida are currently in the works as part of a larger movement to provide more housing opportunities for adults with special needs.

The Villages at Noah's Landing is a housing development undergoing construction in Lakeland, Florida. It's designed to provide a sense of community as well as living assistance for people with physical or intellectual disabilities such as cerebral palsy, autism and Down syndrome. Expected to be fully operational by this time next year, the 56-acre gated community will include 132 apartment units, a recreation center with a pool, a community garden, a farm yard and a commercial kitchen with an optional dining room. Residents will be able to walk or ride their bikes within the community and will have access to public transportation, according to the project's website. Staff, volunteers and parents will provide individually-tailored oversight as well as help to foster a sense of community among residents, Disability Scoop reported.

The Arc Village, a 97-acre community design similar to Noah's Landing, will soon begin construction just outside Jacksonville, Florida. In addition to fostering a social environment within the community, the Arc aims to enable residents to interact with the greater Jacksonville community in ways they could not have before, according to the project's website.

Once completed, both communities will hopefully reduce the waiting list for affordable housing for people with intellectual and physical disabilities in Florida. Noah's Landing and the Arc Village are among the first housing developments of their kind in Florida, but comparable communities exist throughout the United States and beyond. Residences such as Pathfinder Village in New York, the Baddour Center in Mississippi and Annendale Village in Georgia provide a similar combination of independent and assisted living for people with special needs. The Camphill Association of North America founded more than 100 living communities for people with special needs worldwide, 11 of which are in the U.S., according to its website. In Europe, both Switzerland and the Netherlands have designed housing communities for people living with dementia and Alzheimer's disease.

Hopefully, the movement will continue to grow. "We believe we're starting a tsunami," Jack Kosik, a Noah's Landing founder told Disability Scoop. "If we do it right, this will be a national model."

Our Deepest Sympathy

Blair Behan
October 6, 1988 -
February 13, 2024
Daughter of Deborah and
David Behan
54 Bobbin Hill Road
Tiverton, RI 02878

Maria Burney
March 7, 2018 -
February 2, 2024
Daughter of Novaya Burney
2504 Spring Brook Trail Apt 2504
Smyrna, GA 30082

Alicia Ekholm
October 27, 1979 -
February 16, 2023
Daughter of Diana Ekholm
75 Frontier Road
Windom, KS 67491

Delany Espinoza
April 20, 1994 –
October 31, 2024
Kelly and Joe Espinoza
P.O. Box 842
Manhattan, MT 59741

Noah Henry
July 22, 2022 – July 3, 2023
Son of Francesca Flores
130 Brown Street
Hartford, CT 06114

Jacob Jones
April 11, 2001-
February 14, 2024
Son to Tracey Jones
4008 Harley Trail
LaGrange, NC 28551

Nicole Lewis
November 11, 1986 -
March 3, 2024
Daughter of Jewel and
Donald Haines
3304 Marne Ave.
Norfolk, VA 23509

Jonathan Parisi
November 2, 1995 -
October 25, 2023
Son to Jeannette and
Vincent Parisi
43 Lemon Drive
Saylorsburg, PA 18353

Brody Rocco
September 8, 1997 -
June 21, 2024
Son of Donna Gath and
John Marsh
2 Colleen Dr.
Salem, NH 03079
and
Bob Rocco and Beth Rocco
10 Mac Dr.
Tewksbury, MA 01876

Erika Templer
December 5, 1985 -
February 10, 2024
Daughter to Peter and
Wendy Templer
610 Fernwood Drive
Oxnard, CA 93030

Isaac Vanden Toorn
March 14, 1994 –
February 16, 2024
Son of Melissa and Michael
Vanden Toorn
3637 Loveland Road
Youngstown, OH 44502

THE GRIEF SUPPORT ADVISORY GROUP IS HERE TO HELP

If a parent experiences the heartbreaking loss of a child, the Foundation is here to provide support in many ways. Our team of Family Service Professionals is available to listen, guide and offer assistance. We can also connect parents with others who have gone through a similar experience. Our dedicated team of Grief Support volunteers can offer invaluable support and understanding during this difficult time. Additionally, we have a Bereavement page on our website where parents can find helpful and inspirational resources, and an In-Memoriam page where families can share cherished 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****.*

Tribute Gifts 02.01.24 - 07.30.24

In Honor/ Celebration

The many ways the Foundation staff provide help and hope to families worldwide
The Mairano Family Giving Fund

Carolina Amor
Fernando & Priscila Amor

Zackery Arrowood
Theta Mu Sorority

Adrian Illyana Bajema
Melissa Appleton
Rebecca Runge

Antoinette Beaumont
Rita Deck

Blair Behan
Lynn B Wells

Aubrey Bender
Brooke and Travis Bender

Sheila Bengston
Jeannine Bengtson

Robin R Berman
Robert Berman

Aisley Birrer
Alice Eshom Andrus
Shenaya Muniz

Brianne's 33rd Birthday
Karen and Larry Prada
Douglas Canning
Pamela or Thomas Harrington

Robert Carter
William Carter

Dane Curalli
Tanya Shane
Pauline and Byron Anderson

Mason Dahl
Jennifer Robins

Mason and Charlie Dahl
Jem Med Spa
Gustavo Galante

Carlie de Sibour
Charles de Sibour

Chase Duff
Barbara Robinson

Joy Eicher
Ronald P Jagner

Lyle Farley
Kevin Parker

Kellie Feehan's 50th Birthday
Carrie Keeley

Richie Flaherty
Michael Lee

Nathan Frischmeyer
Allen M. Stickfort

Aryanna Gage
Sarah E Griffith

Aubrey Garrigan
Mallory Luparello
Western New York Oldsmobile /GM Club

Matinel Holleb
Rob Levinson

Caitlin Igoe
MaryAnne and Stephen Igoe

Adam Jackson
Dorothy and Daniel Steimke

Tayvion Joyner
Theresa Joyner-Lewis

Janet and Russ's First Anniversary Of 50 Years
Aimee Holleb
Kate O`toole

Daniel Kliewer
Kathleen Rulka and Brian Ewert

Antonie Kline, MD
James L & Carole D Frankenfield

Charlotte Lawrence
Diane Smith

Noelle Markle
Barbara Markle

Valerie Lessa
Dianne Lessa

Lisa and Mike Lewin
Mary Mammarella

Little Miss Sparkles 9th Birthday
Ms. Joy Durae Eicher

Eric Loftus
Annie Fetzer
Karen Szukalski

Sam Luce
Tim Luce
Karen Szukalski

Katie Luyt
Robbin and Bruce Bailey
Lynette and Clifford LePiane

Sydney Marks
Chris Evans

Payton McDonald
Karen and Bill McDonald

Paige Olson
Susan and Timothy Baker

Stacey Overcast 40th Birthday
Judith Brewster
Jane Frye
Larry D Mayland
Kathi Morrison
Laurie Wendling
Tracy and John Worrall

Kaylee Parris
Theta Mu Sorority

Deion Parrish
Sonya and Tyronne Snow

Andrew Patitucci
Nancy E. Tossona

Naya Patterson
Maria Luna

Aisley Peterson
Julie Gross
Andrea Jahns
Patricia Lehan
Connie Petereit
Jenna Peterson
Mother Emily Peterson
Carol Temple
Julie Walters

Maya Pomfret
Susan and Jay Lilien

Alexander Protasov
Seyedehzahra Hosseini

Rare Disease Day
Wendy and Andrew Miller

Sasha
Luis Pelayo Zepeda

Sierra Ritch
Linda Wilcox

Wilson Simmons
Dewayne & Teresa England
Kathy Hackel
Kathryn and Ward Miller
Niki and Chuck Gray
Jennifer Stephenson

AJ Staggs
Kathy and Todd Ackerman
Trent Ackerman Lone Pine Livestock
Jackie Cooper
Dutton Estate Winery-Sebastopol Vineyard & Winery Corp
Carol and Paul Every
Frances and Gregory Guerinoni
Jina and David Homan
Sanchietti Farming Inc.
Sierra Pipeline Inc.

Liam Sundstrom
Colebrookdale Faculty Fund

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Etiony Aldarondo
Luis Chiappy
Felix Martinez
Mr. Victor M Torres

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Susan and Lyle Tryba

The Van Burens
Raymond C. and Susan J. Carlton

Maya Wardrip
Rachel Medley

Tyler Weissman
Buffalo Bills Backers
Jacquelyn and Frederic Vezina

Norm and Barbara Winnerman's Birthdays
Anne Cahn

In Memory Of

Carolina Amor
Janet Berner

Michael L. Austin
Ms. Judith G. Stilwell

Adrian Illyana Bajema
Melissa Appleton
Rebecca Runge

Jack Barnes
Valerie Barnes

Elizabeth Bernhardt
Custom Hair Studio
Lisa M. and Otto W. Kraenzle

John II and Michael Cataline
John Cataline

James Cole
Christine Miller
Thomas Redick

Kamren Coleman
Ramona Cox

Shaylin Hope Cubeta
Gail Louise Hitchcock

Susan Curalli
Merrilee Curalli

Elaine Davis
Molly M Frantz

Daniel Eriksson
JoAnn and Eric Eriksson

Arnold Domenic Etcheberry
Thomas Reviglio

Marci Fisher, Vicki Fisher
John Fisher

Donna Fotopoulos
Kelsy Addington
Jessica Charpentier
Liz Cozad
Barbara and Thomas Gregory
Frances and Neale Johnson
Ernestine Lyons
Lauren Maroudas
Linda and Arvel McElroy
James McLaughlin, MD
Patricia Perahoritis
Piper J Price

Paula Hauffe's 72nd Birthday
Georgia Hauffe

Mary Anne Igoe
Linda C. and George W. Barnet Jr
Jonathan Bork
Martha and William Brunelle
Jean Connor
Joanne M. M. Corliss
Larry & Lori Cuoco
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Stephen Kahn
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Stephen Kahn

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Maria Isabel Madrid
Mary Opitz

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Dr. Ann Perkins

Stewart O. Manthey, Jr
Kimberly Foreman
Lawrence Holt
Marcie Romberger
Phyllis Setta

Garry Markle
Kathleen and Michael Desloover
Barbara and Stanley Emerick
Amanda Filbrun
Cheryl Harnica
Nancy and Bryan Harwood
Brian Hutchinson
Nancy Hutchinson
Nancy Johnson
Olga and Wasyl Karpenko
Lisa Khoury
Douglas and Sharon King
Yvonne Kovacevich
Susan Krieger
Jeff La Roux
Rebecca and Mark Leach
Ken and Sherry Locke
James Majka
Michelle and James Mello
Chase Moore
Barbara Markle
Angeline Mazurek
Mark Nelson
Pennine Industrial Equipment Limited
Trina and Troy Peschke
Donna Renner
Cindy and Dennis Reuther
Kyle Rhodes
Ashleigh Rippee
James Rivet
Brittany Robbins
Robin Schmidt
Janice Schnorberger
Kelly and Matthew Smith
Sandy Sobieralski
Angela Sujek
Paul Swanberg
Bobby Sweeney
Colleen Sweeney
Sallie & Pat Sweeney
Mary Beth Thomas
Barbara Whitney

Emily Gayle Marston
Gayle and Dr. Samuel Marston

Michele McDonald
Karna F. and Mark O. Herron
Robert J Soltess

Connor Myrthel
Robert G. Myrthel

James M. O'Keefe
John and Shelly Champion
Elsie and George Jacobson
Martha-Jane and Richard Moreland
Charlotte and Dennis O'Keefe

Charles Olson
Gail Mastio
Helen McLaughlin

Ayzic Allen Murray
Christpher A Lubic

Steve Olson
Susan and Timothy Baker
Jamie and Paul Faber

Victoria Patisaul
Dr Charles and Kimberly Patisaul

Princess
Robert Berman

Kip Reaves
Valerie Benson
Victoria Moenaert
Diane Phillips

Tia Marie Rivera
Angelei Rivera

Paul Rocco
Donna Gath

Camille Rodriguez
Rob and Clara Rodriguez

Sandy
Ellen Braverman
Stephanie Sophia Smith
Crystal and Jerry Smith

Leroy Stublaski's 80th Birthday
Susan and Lyle Tryba

Erica Templer
Illona Aguayo
Elya Braden
Aunrey and Morey Bubis
John Burchett
Karen Clark
Virginia Camarillo
Nancy Cole
Dorothy Elchoness
Marlene Gilbert
Myrna Golden
Elizabeth Gollner
Lexi Kendall
Barbara Libby
Nicole Miller
Ellen Posard
Karen and Larry Prada
Eleanor/Mark Richman
Carrie Rothstein-Fisch
Ruth Schwartz
Jessica Templer
Nancy Tillman
Paul Tousignant
Christine Weber

Allison Sue Tryba
Miriam and John Braun
Thomas E. Fugate
Judith and Peter M Stockton

Molly Wagner
Frank Richmond

Ethan Walters
Ms. Penelope Mary Keating

Tim Young
John Cataline
Joanne and Stephen Gersuk

Tim and Aaron Young
Kathy and Gene Van Buren

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

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

☐ Check (payable to the CdLS Foundation)

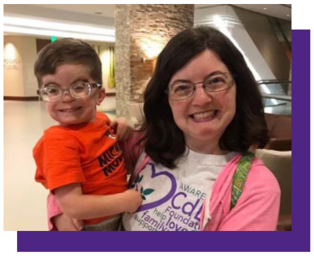
☐ Credit Card

☐ Visa ☐ MasterCard ☐ American Express ☐ Discover

CC#:________________________________ CV:_____ Exp. (MM/YY):_______

Signature:____

Email:____



Scan this QR code to **Donate online.**

ROFALL24

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

Hmm, How can I help?

PULL-OUT THIS SECTION ON HOW TO ASK FRIENDS AND FAMILY FOR HELP

1

HOME

- ☐ Leave dinner at the door
- ☐ Plant flowers in my flower pots
- ☐ Fold laundry
- ☐ Put away monthly supplies
- ☐ Grocery shop
- ☐ Take my car for a wash

2

SUPPORT

- ☐ Sleep over for a night
- ☐ Come to my house and send me on a walk
- ☐ Get to know my kid, like really know him/her
- ☐ Come sit with me during a procedure
- ☐ Bring me lunch in the hospital and visit with me for 1hr
- ☐ Bring over yoga mats and stretch with me

3 ACTIVATE

- ☐ Ask for books & podcasts to learn more
- ☐ Talk about rare diseases and educate others
- ☐ Volunteer & engage at my events
- ☐ Be a point person during hospital stays & home

4 HANG IN

- ☐ Continue to invite me
- ☐ Understand I am living in crisis mode
- ☐ Check In regularly- send a text and be ok without a response
- ☐ Pick me up and take me to the movies
- ☐ Treat me the way you did before

Once Upon A GENE

www.EffieParks.com

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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Be a Phantom Runner

JOIN TEAM CdLS

This fall, two teams of CdLS athletes from across the country are hitting the pavement in Chicago and Baltimore to raise awareness and funds for the CdLS community.

We want YOU to be part of the team!

Challenge yourself to raise $250 or more without breaking a sweat, stretching a muscle, or icing a knee. All you need to do is create an online fundraising page by scanning the QR code below, and BAM! Share the link with friends and family to donate!

Participants will receive a certificate of appreciation, a thank you letter, and the top fundraiser will receive a branded gift from the CdLS Foundation.

Questions? Contact Lisa Schroeder, Events Manager, at lschroeder@CdLSusa.org.