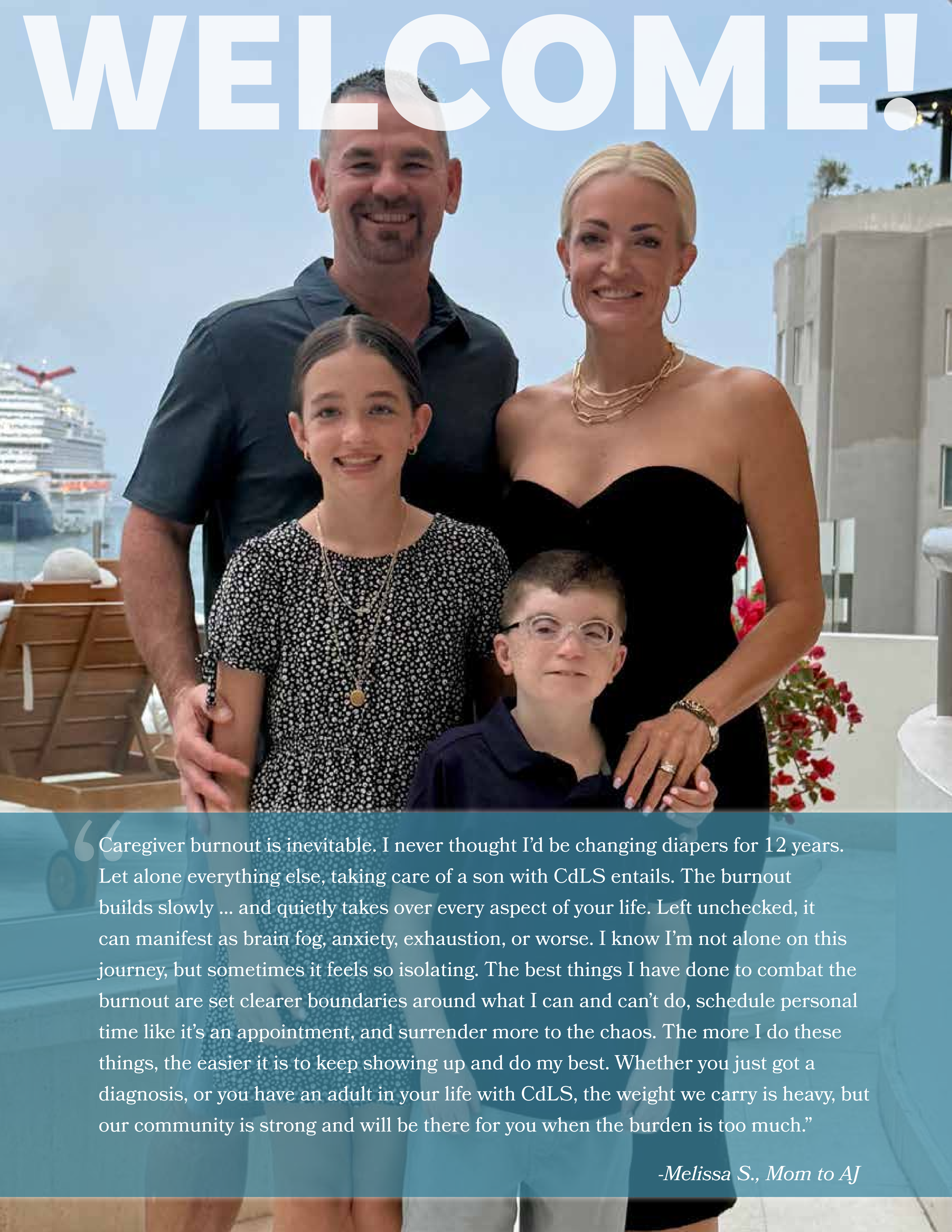
Reaching Out

Spring 2026

WELCOME!



> "Caregiver burnout is inevitable. I never thought I'd be changing diapers for 12 years. Let alone everything else, taking care of a son with CdLS entails. The burnout builds slowly ... and quietly takes over every aspect of your life. Left unchecked, it can manifest as brain fog, anxiety, exhaustion, or worse. I know I'm not alone on this journey, but sometimes it feels so isolating. The best things I have done to combat the burnout are set clearer boundaries around what I can and can't do, schedule personal time like it's an appointment, and surrender more to the chaos. The more I do these things, the easier it is to keep showing up and do my best. Whether you just got a diagnosis, or you have an adult in your life with CdLS, the weight we carry is heavy, but our community is strong and will be there for you when the burden is too much."
>
> *-Melissa S., Mom to AJ*

Inside the Issue

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Resources

Each state is different. Below are a few resources where you can find information specific to the support, services, and organizations available in your state.

CdLS Mental Health Toolkit
Taking care of your mental health is not a weakness; it's part of being human. The CdLS Foundation is proud to share trusted, evidence-based resources to help you find support and prioritize your well-being.

Caring for a Caregiver
Caregivers carry many unseen roles, from medical care and appointments to finances, home life, and relationships. The weight of caregiving can be constant and overwhelming. The CdLS Foundation's Caregiver Toolkit offers support and practical resources to help families cope and care for themselves, too.

Finding Respite Care Support
ARCH can help you find local respite options through State Respite Coalitions, Lifespan Respite Programs, and national directories. If options are limited, the National Respite Locator Service (NRLS) can connect you to respite care that fits your needs. bit.ly/arch-respite

Caregiver Burnout in Medically Complex Families

Katherina Nikzad-Terhune, Ph.D., LCSW-S, College of Health and Human Services
Northern Kentucky University and Clinical Advisory Board (CAB) Member

Caregiver burnout is often described as being “exhausted” or “overwhelmed,” but for families caring for a medically complex child or loved one with a rare or chronic condition, that language barely scratches the surface. Burnout in these families is not a temporary depletion that can be fixed with a nap or a weekend away. It is a sustained physiological, emotional, and cognitive state shaped by years of vigilance, responsibility, grief, and love all happening at once. If you are burned out, it is not because you failed to cope well enough. It is because you have been doing something extraordinarily difficult for a very long time.

WHAT BURNOUT REALLY LOOKS LIKE

Caregiver burnout does not always look dramatic. Often it appears quiet and functional. You still show up to appointments, administer medications correctly, and advocate fiercely for your loved one. And yet inside, something feels hollowed out. Burnout can look like emotional numbness, irritability that feels out of character, difficulty concentrating, forgetfulness, or a sense of dread that starts the moment you wake up. It can look like resentment followed immediately by guilt. It can feel like your body is moving through the day while your mind is braced for impact. Many of the caregivers I have worked with describe feeling “on edge” all the time, unable to relax even when nothing is actively going wrong, and never feeling rested even if they are getting enough sleep. This is not a personal flaw. It is a nervous system that has learned that safety is temporary.

CHRONIC VIGILANCE AND MEDICAL PTSD

In medically complex families, vigilance is not optional. You monitor symptoms, equipment, labs, behaviors, subtle changes in breathing, tone, or mood. Over time, this constant scanning becomes automatic. The problem is that chronic vigilance keeps the nervous system in a prolonged state of threat response. For many caregivers, this leads to symptoms similar to post-traumatic stress, including intrusive memories of medical crises, hyperreactivity to alarms or hospital smells, difficulty sleeping, and a persistent sense that catastrophe is imminent. Medical trauma often accumulates quietly. Each hospitalization or emergency decision layers onto the last. Caregivers may minimize their own trauma because “we got through it” or “others have it worse.” But the body remembers, even when the mind tries to move on.

WHY RARE DISEASE CAREGIVING IS DIFFERENT

Caregiving is challenging in any form, but rare disease and medically complex caregiving carry unique burdens. There is often diagnostic uncertainty, limited treatment options, and a lack of providers who truly understand the condition. Caregivers frequently become the experts, coordinators, and educators, often correcting professionals who have more formal credentials but less lived knowledge. Isolation is also common. Friends and family may not understand the condition or may disengage over time. There may be no roadmap, no peer support group nearby, and no reassurance that things will stabilize. The future can feel both urgent and undefined. This combination of high responsibility with low external support or validation is a recipe for burnout.

COMPASSION FATIGUE

Caregivers are asked to provide sustained empathy in the face of ongoing stress or crises. Over time, this can lead to compassion fatigue, which is a reduced capacity to feel empathy or joy, even though you still care deeply. This does not mean you love your family member less. It means your emotional reserves have been stretched beyond what they were designed to hold. Compassion fatigue is not a moral failing; it is a signal that the demand has exceeded the supply.

GRIEF AND ENDURANCE AT THE SAME TIME

One of the most painful aspects of medically complex caregiving is holding grief and endurance simultaneously. You may grieve the life you imagined, the ease others seem to have, or the version of yourself that existed before caregiving became all-encompassing. At the same time, you solve problems, advocate, and protect daily. There is often no clean space to process grief because the work continues. This “dual load” is emotionally exhausting and rarely acknowledged.

NERVOUS SYSTEM OVERLOAD

Burnout is emotional and physiological. Prolonged stress dysregulates the nervous system, leading to chronic tension, digestive issues, headaches, sleep disruption, and increased susceptibility to illness. When the body is constantly preparing for crisis, it has little capacity for repair. This is why advice that focuses solely on mindset or positivity often falls flat. Burnout lives in the body as much as the mind.

WHY SELF-CARE OFTEN FEELS IMPOSSIBLE

Caregivers are frequently told to “take care of yourself,” yet the structural realities of caregiving make this extraordinarily difficult. Time is scarce, and trusting others with complex care may not be realistic. Financial constraints, guilt, and sheer exhaustion can make self-care feel like another task you are failing to complete. When self-care is framed as an individual responsibility rather than a systemic need, caregivers are set up to feel inadequate instead of supported.

WHAT CAN HELP

There is no single fix for caregiver burnout, but some supports are more realistic and compassionate than others.

- **Support your nervous system.** Small, regular practices that signal safety (e.g., gentle movement, paced breathing, grounding activities) are often more helpful than intensive self-care routines.

- **Trauma-informed therapy.** EMDR (Eye Movement Desensitization and Reprocessing) and Accelerated Resolution Therapy (ART) are evidence-based trauma-informed therapies designed to work directly with how the nervous system holds stress and medical trauma. Instead of requiring caregivers to retell every detail, these therapies use guided bilateral stimulation (such as eye movements) to help the brain reprocess distressing medical experiences (e.g., emergencies) so they no longer activate the same intense emotional or physical response. For caregivers, this can mean reduced hypervigilance, fewer intrusive memories, and a greater ability to feel calm even while continuing to provide care. To learn more about EDMR, visit: bit.ly/EDMRcdls
- **Peer Support.** Connecting with others who have lived similar medical, emotional, and system navigation experiences provides validation that cannot always be found in professional settings. Peer support normalizes reactions such as exhaustion, grief, and hypervigilance, helping caregivers understand that these responses are natural outcomes of sustained caregiving.
- **Permission to grieve.** Naming and honoring loss without needing to "fix" it can be profoundly relieving. When grief is unacknowledged or postponed, it can intensify stress, contribute to burnout, and become stored in the body as chronic tension or emotional numbness. Allowing space for grief lets you process loss without carrying it alone, making it more sustainable to continue caregiving with compassion for both your loved one and yourself.

Caregiver burnout in medically complex families is not a sign of weakness. It is the outcome of sustained love under pressure. At the CdLS Foundation, we see and hear our caregivers, and we are here to walk beside you every step of the way.

For additional resources that support mental health and wellness, visit the Mental Health Toolkit page on the CdLS Foundation website. Mental Health Toolkit | CdLS Foundation

WHEN YOU'RE RUNNING ON EMPTY A NERVOUS SYSTEM PERSPECTIVE ON BURNOUT

Justyna Wawrzonek, DSW, LCSW, Founder of Embodied Truth + Power

Burnout doesn't usually arrive at once. It builds quietly, in the middle of appointments, school meetings, insurance calls, therapies, work deadlines, and late-night worry. If you are parenting a child with special needs, the demands may be layered and ongoing. The nervous system rarely gets a full exhale.

Burnout is not a personality flaw. It is not a lack of resilience. It is what happens when stress remains high, and recovery remains low for too long.

When the body is under prolonged strain, the stress response adapts. Sleep becomes lighter or disrupted. Patience shortens. Concentration slips. Energy fluctuates. Over time, chronic stress can reduce the nervous system's flexibility, its ability to shift smoothly between activation and rest. In burnout, the system begins to lose range.

Each of us has a range where we function best in a zone where we can think clearly, feel emotions without being overwhelmed, and respond rather than react. This is sometimes called the *Window of Tolerance*.

Inside this window, stress is manageable. Outside it, the body shifts into survival patterns.

With chronic caregiving stress, workplace demands, or ongoing uncertainty, that window can narrow. You may find yourself outside it more often, sometimes in overdrive, sometimes in shutdown. Burnout often involves moving between both.

HOW BURNOUT SHOWS UP IN THE BODY

HIGH ACTIVATION	LOW ACTIVATION
Irritable, reactive	*Numb, flat*
Racing thoughts	*Brain fog*
Muscle tension	*Heavy fatigue*
Trouble sleeping	*Trouble starting*
Always "on"	*Low appetite or overeating*
Bracing for the next thing	*Emotionally withdrawn*
Restlessness or difficulty relaxing	*Feeling hopeless or unmotivated*
Digestive upset	*Feeling disconnected from loved ones*

High activation feels like being stuck in "go." The body remains braced. Even when exhausted, it struggles to power down.

Low activation feels like hitting a wall. Motivation drops. Everything feels heavier. Research consistently identifies both emotional exhaustion and cognitive slowing as central components of burnout. Neither state is weakness. Both are stress physiology. The goal is not to eliminate activation. Activation is necessary for functioning. The goal is flexibility, the ability to move between effort and recovery without getting stuck.

Why Movement and Rhythm Matter

The nervous system is built for oscillation, activation followed by settling. When stress becomes chronic, that rhythm gets disrupted. Research shows that moderate physical activity improves markers of stress regulation, including heart rate variability. Even short walks can improve mood and mental clarity. Movement helps complete stress cycles that might otherwise remain internally activated.

Practices that combine breath and movement, such as yoga, have been shown to reduce perceived stress and support autonomic balance. Slower breathing patterns, particularly those that emphasize a longer exhale, influence systems involved in emotional regulation. Emerging research on rhythmic auditory practices, including sound meditation, suggests repetitive, predictable sound may support physiological settling and mood stabilization. Rhythm appears to help regulate internal rhythms. These practices do not remove stress. They restore range.

Micro-Rest in Real Life

Recovery does not require large blocks of time. Short, repeatable shifts are often more sustainable. Micro-rest might look like closing your eyes in the car before walking into an appointment, stepping outside for two minutes of fresh air, taking five slower breaths with longer exhales, or simply sitting upright and noticing your feet on the floor. These brief pauses interrupt prolonged activation. Over time, they widen the window again.

What Respite Actually Looks Like

Respite is often imagined as a full weekend off or a real vacation. In reality, it is more often brief, imperfect, and woven into daily life.

It can be ten quiet minutes alone.

It can be someone else making one phone call.

It can be declining one optional commitment.

It can be leaving a hospital room to walk the hallway.

Even brief reductions in demand lower physiological strain. The nervous system does not require luxury. It requires the interruption of a constant load.

If You Feel...	Try This	Why It Helps
Wired or reactive	Slow breathing (longer exhale)	Reduces stress activation
Overstimulated	Reduce light and noise	Lowers sensory load
Stuck in your head	Orient: name five visible objects	Signals present safety
Heavy or foggy	Brief brisk walk	Gently increases activation
Disconnected	Cold water on face	Stimulates alertness pathways
Emotionally flooded	Ground: feel feet pressing into floor	Anchors body awareness

Practical Tools to Widen the Window

Regulation is not about forcing calm. It is about increasing the range.

Grounding, orienting, breathwork, sensory awareness, and mindfulness interrupt automatic stress loops and reintroduce choice. The more often the nervous system experiences safe activation followed by settling, the more flexible it becomes. Flexibility is resilience.

Boundaries as Nervous System Protection

Chronic stress accumulates what researchers call allostatic load — the wear and tear from prolonged activation. When demand remains unpredictable, recovery becomes harder. Boundaries reduce unpredictability. Limiting after-hours communication, consolidating updates, sharing decision-making, or scheduling structured breaks are not acts of selfishness. They are physiological regulation tools. For parents navigating complex systems, boundaries are often necessary for sustainability.

Grief, Guilt, and Anger

Burnout rarely arrives alone. It often carries grief for what has changed, guilt for not doing more, and anger at systems that feel relentless. These emotions are not signs of failure. Suppressing emotional experience can increase stress activation. Allowing space for feeling, gradually and safely, reduces internal strain. You can love deeply and still feel overwhelmed. Both can exist in the same nervous system. You Are Not Failing. If you are running on empty, it does not mean you are failing. It means your nervous system has been working continuously, often without relief. It means you have been carrying more than most people can see.

You may not be able to change the demands overnight. But you can begin to change the rhythm, a pause before the next appointment, a boundary around one conversation, a short walk, a moment of naming the grief instead of swallowing it. These are not small acts. They are how range returns. The nervous system heals through repetition, repeated signals of safety, and repeated experiences of settling after activation. Over time, those moments accumulate. You are not weak for feeling tired. You are not ungrateful for feeling grief. You are not failing for needing rest. You are a human nervous system under sustained demand. And flexibility can be rebuilt gradually, gently, and in ways that fit your real life.

Voices Unscripted

Authentic stories, feelings, and advice shared by our community members.

“When we got Aubrie’s diagnosis, 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.” – Leslie S.

“I experienced extreme fatigue and anxiety most mornings when I have to wake him up and get him ready for the transition program. He does not cooperate. When we arrived at school, he would start crying and grab my clothes or anything he could, so I had to trust the teachers and let go. It really gives me anxiety as if he were a little boy starting school.” -Jennifer R.

“One of the hardest things about having a sibling with special needs is carrying a love so deep it sometimes hurts. You feel this constant mix of emotions—joy, pride, frustration, and guilt. There are times you wish things were easier for them, and it’s hard when so much attention has to go toward their care. But the hardest part, deep down, is fear. The fear that their syndrome could one day cause something really bad to happen. That quiet worry never fully goes away. You learn to live with it, to be strong, to smile for them—but it’s always through it all, the love you have for them unshakable. It teaches you how powerful can really be.” -Natalie C.

“In those early days, the most significant challenge we encountered was her health. Each hospital visit and feeding time felt overwhelming, and it was truly heartbreaking to witness her endure pain, even for something as simple as having a bottle of milk. I focused on taking it one day at a time. With Jo, tomorrow is filled with uncertainty, so I’ve learned to embrace each moment in the present as fully as I can.” -Sergio D.

When Letting Go Feels Like Failing

The following reflection was shared by a father in our CdLS parent community. His words capture a moment many caregivers quietly face—but rarely say out loud.

Paul P., Andrew's Dad

As many of you know, I have been Andrew's 100% caregiver for quite a while. I finally realized that if something happened to me, he would have no one to take care of him, so I found a great place for him.

He has 24/7 care and has been placed for about a year. It was rocky at first, but things are going very well, and he's very happy these days. His transaction went very easily for him. He never had a problem being there.

But what I'm dealing with after a year is unbelievable guilt. I built my entire life around him and basically had none of my own. I still see him frequently. I love spending time with him, but when I drop him off or even when I'm home thinking of him, I'm a wreck.

I've started to date a little, but it is just a distraction. Can anyone who has gone through this tell me how they've dealt with it? I know I did the right thing and that he is safe and happy, but I still feel like I failed him. I know I am overly empathetic, but this is killing me.

> ***"…but I still feel like I failed him."***

Shared with permission by Paul, originally posted on the discussion board.

You're Not the Only One Who Feels This Way

What followed was an outpouring of honesty, reassurance, and lived experience from parents walking this same path—some just beginning to consider it, others many years beyond it.

"It was the hardest thing I've ever done. There is so much guilt—and while it lessens, it never fully goes away. But he is happy, well cared for, and loved."
- Beth

"Placement broke me... the guilt is something we carry throughout our children's lives. It just changes form."
- Rosemary

"I can only imagine how heavy that grief is... but there is no failure in preparing a future for your child."
- Jamie

"You have not failed him at all. You have expanded his life."
- Jenny

"We still feel it when we drop him off... but we also have more time to rest and be present. You've expanded his village."
- Nancy

"I reached a point where I could no longer meet her needs. She now has care I couldn't provide—and while the guilt still comes, it was the right decision."
- Anne

"I'm going through this too. The question I wrestle with is—who am I if I'm not her caregiver?"
- Kim

"Guilt is something we put ourselves through—even when we've made the best decision. Burnout helps no one."
- Ann Marie

More Parents Shared...

"Emergency placements are much harder. Planning ahead—while difficult—is actually the best thing you can do."
- Cindy

"You ensured his future care. That is love, not failure. Now try to allow yourself to live, too."
- Mary

"Guilt is normal, but sometimes placement allows our children to thrive in ways we simply can't provide alone."
- Misty

"I am exhausted physically and emotionally... and facing this decision has been incredibly painful, but necessary."
- Lilia

"I still feel it when I drop him off—but I also know he is safe, supported, and part of a larger circle of care."
- Nancy

"We felt lost at first—but also proud. He had outgrown us in a way, and now he is thriving."
- Karen

"You have built not just care—but a whole team around your child. That is something to be proud of."
- Jess

"It's not giving up—it's making sure they are cared for, no matter what happens."
- Mary

Some parents are experiencing a mix of emotions regarding caregiving. While some find their loved ones thriving with broader support, others feel exhausted and fearful of losing their ability to provide care. Guilt persists, and for those not yet facing these circumstances, the fear of future decisions remains significant.

Why This Conversation Matters

For many families, this is one of the hardest transitions they will ever face—and one of the least talked about.

As caregivers, we spend years—often decades—building our lives around the needs of our children. The idea of stepping back, even when it is the right decision, can feel like a betrayal of that love.

And yet, what we hear again and again from families is this: planning ahead is not giving up—it is protecting the future.

Within this community, there is space for both truths to exist at the same time. The certainty that you are doing what is right… and the grief that comes with letting go.

This conversation is not about choosing one feeling over the other. It is about acknowledging that both can live side by side—and that no one has to carry that weight alone.

A Professional Perspective: Planning for the Future

What Paul shared—and what so many parents echoed—is something we hear often in the disability community.

At the heart of it is a question many caregivers carry quietly:

"What will happen to my child when I'm no longer able to care for them?"

According to Mary Anne Elhert, a long-time advocate and Board member of the CdLS Foundation, this fear is not only common—it is one of the most important conversations families can begin to have.

"No one will ever care for your child exactly the way you do. But planning for the future is not about replacing you—it's about protecting your child when you can no longer be the one providing that care."

For many families, the idea of planning ahead—especially when it involves residential care or support outside the home—can feel overwhelming, or even unimaginable.

But waiting until a crisis occurs often makes the transition much harder—for both parent and child.

Steps That Can Help Ease the Transition

- **Start building relationships early**
  Connecting with care providers, support staff, or care management agencies now allows you to build trust over time.
- **Explore options—even when it feels uncomfortable**
  Visiting group homes, host homes, or supported living environments helps ensure your child's needs are understood and met.
- **Document everything**
  Write down routines, preferences, medical needs, and behaviors to support continuity of care.
- **Build a "team" around your child**
  A network of caregivers, professionals, and community supports can create a stable system of care.

Planning for the future is not about letting go of your role as a parent.

It is about expanding the circle of care—so that your child is supported not just today, but for years to come.

And perhaps most importantly...

It allows you to remain present—not just as a caregiver, but as a parent.

If You're Facing This Transition

- Talk with a therapist or counselor experienced in caregiving transitions
- Begin exploring options early (group homes, host homes, supported living)
- Connect with other parents who have walked this path
- Stay involved—your role shifts, but it doesn't disappear
- Take small steps to rediscover your own identity and well-being

The Foundation is exploring additional support opportunities for families navigating this transition.

You Are Not Alone

If you are holding this same tension—
knowing something is right, but feeling like it's wrong—
you are not alone.
Within this community, there is space for all of it—
the love, the grief, the doubt, and the hope.

Welcome to Holland

We are thrilled to welcome new families to the CdLS Foundation! Upon joining, they receive our inspiring publication, *Facing the Challenges*, which opens with the uplifting piece, *Welcome to Holland*. This message beautifully conveys that, although you may find yourself in unexpected circumstances, you are in a truly wonderful place. Our vibrant community is here to embrace you with open arms and warm hearts as you embark on this journey together!

Scan the QR code to read *Welcome to Holland!*

HAMMMEN FAMILY

MILLIE

SAMANTHA

FLORIDA
Emma, Justin, and their daughter Millie
Born: October 15, 2024

INDIANA
Kylee, Hector, and their son Kenzo
Born: October 19, 2025

IOWA
Katelyn, Jared, and their daughter Mamie
Born: September 17, 2025

TEXAS
Christi, Rick, and their daughter Samantha
Born: January 7, 2012

VIRGINA
Brandi and Travis, and their son Reuben
Born: August 24, 2015

OUR JOURNEY WITH ZAYLA

Written by Irene W. and Armando P., Zayla's Parents

Although Zayla is nonverbal, she is very smart and sometimes sneaky. She gives this cute little sideways look when she knows she is being talked about. She listens, takes it all in, and sometimes giggles. Zayla is the boss in the house. What Zayla wants, Zayla gets. She knows how to warm your heart. Zayla loves monkeys. She has to sleep with her favorite stuffed monkey. Zayla's favorite foods are green beans, salad, pizza, and pretty much any pasta. Zayla loves looking out the window while we travel on the road. She doesn't like it when the vehicle stops moving. She is the 3rd-oldest of 4 girls. She is a little princess at school. Everyone knows Miss Zayla. She has attended Monte Vista school since she was three years old. Zayla can fake-cry one minute and laugh the next. She loves to relax on her special spot on the couch in the living room, where we spend family time.

Zayla was born on March 26, 2009. When she was born, a few specialists were in the room because I had been monitored since Zayla was smaller than usual, and the doctor never knew why during my pregnancy. As soon as she came out, the team immediately recognized 5-6 symptoms and features of CdLS. I must have been in denial because I saw Zayla as a perfect baby. Our perfect baby. It wasn't until the genetic testing later that year that they confirmed everything they thought about Zayla's condition. We were told that Zayla has a missing chromosome, which is the reason she has CdLS. They tested us, but we did not carry the gene. The geneticist told us it was simply spontaneous. Zayla stayed in the NICU for her first month.

Her doctor at the Children's Hospital advised me to research CdLS to understand it better. I did my best, but soon after, I realized that you have to be careful about what you read online because there is a wide range of information, and not all of it is pertinent. I decided not to continue and to put it in God's hands. Some of the information I read about other people's experiences made me feel depressed. And little did I know, I was actually suffering from postpartum depression. Once I controlled that, I could better care for Zayla. It really took a village to help raise Zayla. My husband and I were blessed to have help from my parents and my Grandma Lala. At night, we rotated shifts every two days to try to get some rest. It took me a few years to embrace motherhood. By this time, I had another daughter named Zeonna. Zayla and Zeonna are 15 months apart. Zeonna was diagnosed with Intellectual Disabilities. Raising two children with special needs has been challenging, but with the help of Early Head Start and Central Valley Regional Center, it has been a lot easier. I thank God for putting the right people in front of us. And having the CdLS Foundation connect with other parents going through the same sort of stuff helps as well.

When we first found out that she had CdLS, we were scared. We knew nothing about the syndrome. We started researching and realized there were many variations, and some cases were severe. We soon saw how blessed we truly were because Zayla had all ten fingers and ten toes. All organs were normal. Her eyesight was perfect. The only issue was a slight hearing loss due to tiny ear canals. She has been pretty healthy for most of her life.

A typical day with Zayla looks a lot like any other, but she needs support with nearly everything, from getting dressed and bathed to her daily routines. On school days, we wake her at 6:15 a.m. to get ready and onto the bus with her favorite driver, Lisa. This year, she rides with Zeonna, which feels like a real blessing. After school, Zayla enjoys her PediaSure and a short nap. She can feed herself when food is prepared in small pieces, and evenings are spent together as a family - walking, watching TV, or listening to the instrumental music she loves. Then we wind down and get ready for bed.

Caregiver burnout occurred during COVID. When Zayla started her menstrual cycle, the pain was unfortunately unbearable, causing her to pull her hair near her ears or sometimes scratch her face. I believe this was a form of communication because Zayla is nonverbal. Zayla also had her days and nights mixed up during the next 5 years. We averaged 2-3 hours of sleep per night. During this time, Zayla's poor appetite led to fluctuations in her weight. On some nights, I would cry and pray; it was all I could do. But God always gave us enough strength to keep on going and not give up, even when we wanted to.

In January of 2025, we were referred to a gynecologist for help. Zayla was on the Depo shot for about 9 months before we realized it wasn't working at all for her. The doctor then decides that Zayla should try the Xulane patch. She has been on the patch since November 2025, and it has worked wonders. Zayla is happier and eating more. She is almost back to her normal weight. We finally found what works to keep Zayla's menstrual cycle and cramps under control.

There have been times when Zayla stays up for days at a time or when she gets sick and doesn't want to eat. She requires 24/7 care, and even when we help each other out, we can still get burned out.

We started hosting a Bible study life group at our home through our church, and we realized that having friends who were like family, supporting and lifting us spiritually and emotionally, was everything. I lost my mother and best friend to cancer back in September of 2018. So, my father really stepped in to help us when we needed it. Zayla and her PaPa were inseparable. If we needed to run an errand, he was right there to help and never once complained. Honestly, they adored each other. They walked to the park, and sometimes my dad would run and push the stroller when training for a road race or marathon. Unfortunately, he passed away in August 2024. We once again had to make a huge adjustment. We have always been blessed with a good support system, but things became a little tough after losing my mother-in-law and father-in-law. We finally got help with a respite care program through CVRC.

> *This journey has really shaped me. I am much stronger, braver, and more confident about motherhood. Zayla has taught me so much, but mostly how to love and be patient.*

I am very grateful to her and her sister. I love that we have a working system. My husband and I are a team. We know that our testimony is meant to help other parents going through the same thing. Zayla has taught me patience and unconditional love. Because of her, I work with other special needs kids at her school.

I would tell other parents awake at 3 a.m., wondering how they'll get through another day, "Don't give up. Keep going." One day, you will look back, and it will all be a memory. We have to remember that with God, all things are possible. Also, it is perfectly okay to cry. And something my brother Daniel would always tell me when our mom was going through her cancer battle, which I started to believe was, "You are stronger than you know."

Faith in the Center

Submitted by: Elma E., Elia's Sister

I am Elma Espinoza (47), and my sister, Elia Espinoza (51), was born with CdLS. We live in Mendota, California, with our parents. My mother, Teresa (71), and I are the caregivers for my sister, Elia. We are also caregivers for my dad, Ramon (81), who is a disabled Vietnam Veteran. However, I am the only official caregiver for both because my mom does not want to deal with any paperwork, especially since she cannot read or write in English. My mother was born in Mexico and became a U.S. citizen, as did my dad. Even though she understands quite a bit of English, she prefers to speak Spanish. My parents found out that Elia was born with CdLS when she was attending school. Her symptoms are mild to moderate.

Although it can be a challenge to help my sister out in different situations. For example, she gets her mood swings as my mother and I call it. This is when she gets upset over something, such as not being able to find something that belongs to her, like her hairbrush or a sock. Elia likes to keep things in a specific place. In addition, she likes to keep the television on a specific channel before turning it off. A surprising reaction from my sister happened last year. Elia allowed me to get the remote of our television in the room to change the channel, but then, in an instant, she changed her mind. She got upset fast and hit me on my chest. For the first time in 47 years, my sister hit me, and that was a shocker. She got punished by my mother, and she realized what she had done wrong. My mother's punishment was that she would not be able to watch television or listen to music for a week, as well as not be able to go with me to mass for three weeks. My poor sister kept apologizing to me, since she likes to repeat things over and over again.

> ***"Having someone to share responsibility is extremely important because whenever we need a break or a mini-vacation, we can take one."***

Elia and I have more siblings in our family because, in addition to us, our parents have four more adult children, who have their own family responsibilities. My mother and I are fortunate to have each other to care for my dad and sister, because this is one factor that helps us to prevent burnout. Having someone to share responsibility is extremely important because

whenever we need a break or a mini-vacation, we can take one. I lean on God for help because without Him I cannot do anything. I attend mass about five times a week, and this gives me spiritual strength to carry on with daily trials and tribulations. I love my sister, and I am thankful to God for creating her as she is. We have grown up together, shared so many wonderful moments, and continue to be in each other's lives; therefore, I have had the opportunity to practice patience, kindness, self-control, generosity, and faithfulness.

If you are a sibling caring for a loved one with CdLS, never give up and seek help. Seek God if you do not yet have a personal relationship with Him. I highly recommend getting someone to share the responsibility of caring for your loved one. Make sure you get time off. I personally try to take two mini-vacations a year to be with God, pray more, and be filled with His love, because the more I am filled, the more I can give. Remember that with God, anything is possible. Always trust in God, no matter what may come your way. God knows what is best for us and our salvation. Always remember that God loves you because we are all His children!

Deepest Sympathies

Chance Bowden
January 31, 1997 - September 7, 2025
Son to Brandi Davis
258 Wimberly Road
Hawkinsville, GA 31036

Samuel Diehl
August 12, 1977 – June 20, 2025
Son of Karen and Jeffery Diehl, brother to Jessica and Kjerstin
45200 W Layton Ave
Greenfield, WI 53220

Vanessa Huerta
May 19, 1970 - January 5, 2026
Daughter of Antoinette Chavez
1441 Mustang Court
Turlock, CA 95380

James Wayne Lee
March 1, 1993 - June 4, 2024
Son of Sabine Lee and James A. Lee
8102 Saylynn Lane
Hourson, TX 77075

Trey McCarthy
October 23, 2023 - April 9, 2025
Son of Keisha Walker
4409 Donerail Run Drive #104
Louisville, KY 40299

Laura Mycock
February 11, 1984 - January 11, 2026
Daughter of Debbie Mycock
111 E Main Street
Wrighstown, NJ 08562

Annalisa Patton
December 31, 1981 – November 30, 2025
Daughter of Carol Patton
2927 Southeast Village Loop #t414
Vancouver, WA 98684

Adam Rutherford
December 25, 1981- July 13, 2020
Son of Eileen Thill
706 Lyman St.
Gaffney, SC 29340

Matthew Schrum
March 4, 1985 – December 30, 2025
Son to Robert and Lynn Schrum
66593 Glencoe Road
Saint Clairsville, OH 43960

Trinity White
November 19, 2004 – December 2, 2025
Daughter of Rhonda and Robert White
315 Virginia Ave SE
Washington, DC 20003

Consider sending a sympathy card to a family in our community. Your words of care can bring comfort during a difficult time.

Directors Message

Dear CdLS Family & Friends,

As you reach the final pages of this edition of Reaching Out, I hope the stories, expert perspectives, and voices from our community have reminded you of something deeply important: you are not alone on this journey.

Caring for someone with complex medical needs requires a level of strength and endurance that most people outside this community rarely see. The love, vigilance, and advocacy you bring to your loved one every day are extraordinary. At the same time, the emotional and physical demands of caregiving can be overwhelming. Feelings of exhaustion, frustration, or burnout are not failures. They are very human responses to an extraordinary level of responsibility.

At the CdLS Foundation, we want you to know that we see you, we hear you, and we are working hard to strengthen the ways we support families walking this path.

Recently, we have expanded opportunities for families to connect with one another through virtual support groups, creating spaces where parents and caregivers can speak openly with others who truly understand the realities of medically complex caregiving. Looking ahead to 2026, we are planning more family gatherings across the country, including several larger ones where families will have the opportunity to meet directly with clinicians and specialists who understand CdLS. These moments of connection with other families and knowledgeable professionals are an important part of building a community that surrounds you with support.

At the same time, we are working behind the scenes to strengthen the Foundation's internal infrastructure so we can partner more effectively with researchers and clinicians. Our goal is to help accelerate the knowledge, resources, and medical understanding that families need, not only today but also for the future of every individual living with CdLS.

The strength of this community has always been one of its most remarkable qualities. Families support one another in ways that are honest, compassionate, and deeply human. When one parent reaches out at a difficult moment, others step forward with understanding, empathy, and encouragement. That spirit of connection is one of the greatest sources of resilience within the CdLS community.

Thank you for the love, courage, and persistence you bring to your families each day. Your strength is the heart of this community, and it is an honor for all of us at the CdLS Foundation to walk alongside you.

A special thank you to Katherina Nikzad-Terhune and Justyna Wawrzonek for their contrubution to this issue.

Warmly,

Bonnie

Gifts that Count

10.1.25 -1.31.26

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Kristin Mangilit-Pradlik and Anthony Pradlik

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Ajay Dholakia

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Schani Abeyesundere

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Rebecca Runge & Tyler Bajema

Max Balthazar
Compassionate & inspiring presence.
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AT&T
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joy, resilience, and love.
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Paula Jarratt

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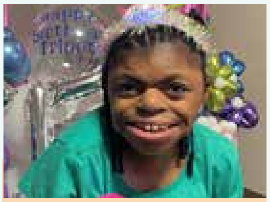

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Radiant, Resilient, and Determined
Charlotte Escalon
Nestle Corporate Security Team
The Board and Staff at the CdLS Foundation

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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.

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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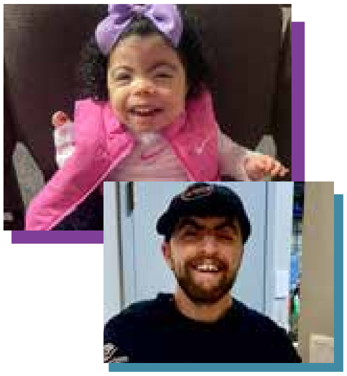

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