Reaching Out

Winter 2025

WELCOME!

> “Abel loves being around his family (mom, dad, and younger brother Beckett). He feels so much joy when he’s playing piano, listening to music, and swinging in his sensory swings at home. Abel’s love for his family and caregivers in the home is exceptional to be a part of. His smile lights up a room, peppered in with his spice (using all of the household light switches for a light show, and dumping out all of his favorite snack bags all over the floor). Just him being at home in his safe space wraps him up with happiness.”
>
> *- Deana Taylor*

Scan the QR code
to watch Abel’s Joy

Inside the Issue

Winter 2025

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 Health Care Notebook
The CdLS Health Care Notebook from the CdLS Foundation is a convenient, real-time, electronic tool that helps you easily track, access, and share important care information whenever needed.

Financial Health During Difficult Times
NDI's Financial Resilience Center (FRC) is an online hub offering trusted information and support to help people with disabilities and chronic health conditions strengthen their financial resilience and manage their finances during difficult times. bit.ly/finarescenter

Regional Resource Center Program (RRCP)
The RRC Program supports all states and territories in enhancing education for children with disabilities, funded by the federal Office of Special Education Programs while facilitating networking among jurisdictions. bit.ly/rrcp-cdls

QUICK FACTS ON GI CONCERNS:

What Families and Providers Should Know

CdLS Foundation

Children and adults with CdLS often face a range of medical challenges, and gastrointestinal (GI) problems are among the most common. Understanding the signs, diagnosis, and treatment options can help parents, caregivers, and healthcare providers recognize symptoms early and provide the best care possible. Below are some of the GI conditions most frequently associated with CdLS.

GI problems are not just uncomfortable; they can lead to serious health complications if left untreated. In CdLS, where communication challenges may make it difficult for individuals to describe their pain or discomfort, caregivers and clinicians must closely monitor physical signs, such as changes in feeding, weight, or breathing.

While GI complications can feel overwhelming, knowledge is empowering. By understanding the risks, recognizing the signs, and advocating for timely medical care, families and providers can help children and adults with CdLS live healthier, more comfortable lives.

Key Takeaways

- Trust your instincts. Persistent vomiting, weight loss, breathing issues, or unexplained irritability should always be taken seriously.
- Early diagnosis and intervention significantly improve outcomes.
- A team approach, including pediatricians, gastroenterologists, surgeons, and CdLS specialists, ensures comprehensive care.

GI CONDITIONS	COMMON SYMPTOMS	DIAGNOSIS AND TREATMENT
Gastroesophageal Reflux Disease (GERD) is when stomach contents flow back into the esophagus. In CdLS, reflux can be persistent and severe, sometimes causing long-term damage to the esophagus, throat, or even the lungs.	• Chest pain (non-burning, radiating to the back) • Difficulty swallowing (dysphagia) • Sore throat and chronic cough • Increased salivation • Shortness of breath	Doctors may use tests such as an upper endoscopy, pH monitoring, manometry, or barium swallow to confirm GERD. Treatments typically begin with lifestyle and dietary modifications, as well as the use of medications. In some cases, endoscopic procedures or surgery may be necessary, especially if other therapies don't bring relief.
Pyloric Stenosis is a condition that occurs when the muscular valve between the stomach and small intestine becomes abnormally thick, narrowing the passage and preventing food from moving forward.	• Forceful vomiting after feeding • Constant hunger • Dehydration • Weight loss • Visible stomach contractions	An ultrasound is the standard diagnostic test. Pyloric stenosis requires surgery (pyloromyotomy) to loosen the muscle and allow food to pass normally. Before surgery, fluids and electrolytes are carefully replaced to prevent complications.
Diaphragmatic Hernia is an abnormal opening in the diaphragm that allows abdominal organs to move into the chest, crowding the lungs. This condition may be identified at birth or even before, through a prenatal ultrasound.	• Severe breathing problems soon after birth • Bluish skin (low oxygen) • Rapid breathing and heart rate	X-rays and physical exams can confirm the condition. Surgical repair is required to reposition the organs and close the diaphragm opening. Infants usually need breathing support during recovery.
Intestinal Malrotation is a birth defect where the intestines don't rotate properly during fetal development. Volvulus is a twisting of the intestine, often associated with malrotation, which blocks the intestine and can cut off its blood supply.	• Vomiting bile (green fluid) • Abdominal pain and swelling • Constipation or diarrhea • Bloody stools • Poor growth (failure to thrive) • Rapid breathing or heart rate	Tests may include abdominal X-rays, CT scans, barium swallow or enema, and sometimes flexible sigmoidoscopy. Treatment often requires IV fluids, antibiotics, and the insertion of a nasogastric tube. Surgery to untwist the intestine is urgent and often lifesaving.

GASTROINTESTINAL (GI) ISSUES in Individuals with CdLS

Raul (Rudy) Sanchez, M.D., Clinical Advisory Board Member at the CdLS Foundation and Pediatric Gastroenterologist at Nationwide Children's Hospital

Many individuals with CdLS experience gastrointestinal (GI) issues at some point, and parents often find themselves navigating feeding challenges from an early age. Some of the most common concerns include feeding difficulties, acid reflux, and constipation. The reassuring news is that these issues are treatable, and numerous tools are available to support a child's comfort and growth.

Sorting out what is typical for CdLS versus what may signal something more serious can feel confusing. Everyday symptoms, such as reflux or slow digestion, are common in the CdLS community. However, when an anatomical difference is present, such as intestinal malrotation or a diaphragmatic hernia, symptoms often look more intense. Persistent vomiting, signs of breathing trouble, or vomit that appears bright green (due to bile) can be important clues that further testing is necessary.

Some conditions, like volvulus, develop suddenly and require emergency care. While there's no way to predict a volvulus, parents can look out for severe belly pain, a swollen or hard abdomen, and ongoing vomiting that may also be bilious. Other complications, like aspiration pneumonia, can occur if food or stomach contents accidentally enter the lungs. Persistent cough, low oxygen levels, fever, or shortness of breath after vomiting are reasons to seek medical attention.

The connection between CdLS genetics and gut motility is still being studied; however, several medications can help keep digestion moving more smoothly.

The best approach depends on a child's specific symptoms, which is something families can explore with their GI team.

Looking long-term, the outlook for GI health is often positive. As children grow into adulthood, reflux is the symptom that most commonly continues. Long-standing reflux can irritate the esophagus; therefore, adults with CdLS may occasionally require an endoscopy to assess for inflammation or early changes that necessitate treatment.

Feeding difficulties are highly individual; there's no single cause in CdLS. Some children require additional time to develop the coordination necessary for chewing and swallowing. For others, discomfort from reflux or inflammation makes meals stressful. One condition seen more frequently is eosinophilic esophagitis (EoE), where food-related inflammation affects the esophagus without causing typical allergic reactions. Identifying the root cause allows care teams to tailor therapies in a way that feels achievable for families.

Therapy and behavioral support can also help when food aversions or mealtime anxiety become barriers to nutrition. For some families, working with a feeding psychologist, alongside therapists, provides the right mix of strategies and understanding.

Supportive therapies can also make a meaningful difference. **Speech therapy** is helpful for children who are working on oral-motor coordination or have both feeding and speech delays. **Occupational therapy** can help when sensory challenges, like food textures or fine motor skills, make eating difficult. Many children benefit from a combination of both.

Sometimes, despite therapy and medication, growth still doesn't progress as expected. In those moments, a **feeding tube may become part of the plan**. Tubes can ensure reliable nutrition and facilitate easier medication administration when swallowing is difficult or stressful. While placement does involve a procedure and a small risk of infection, many families find that the benefits — more energy and steady growth — far outweigh the challenges.

To ensure a child is getting enough nutrition and hydration, regular check-ins with a pediatrician or a GI specialist are crucial. Growth charts, urine output, and guidance from a dietitian can help confirm whether a child's intake meets their needs, even when food choices feel limited.

Reflux can cause further irritation over time, which is why symptoms like chest discomfort, feeding refusal, or frequent vomiting shouldn't be ignored. An endoscopy may be recommended to evaluate for inflammation, and acid-blocking medication can protect the esophagus and maintain comfort.

Constipation is another frequent concern. A combination of stool-softening and stimulating medications often helps, along with simple routines such as sitting on the toilet after waking up or after a meal when the gut naturally wants to move. A small footstool during toilet time can make pushing easier. In rare or stubborn cases, doctors may consider treatments such as botulinum toxin (Botox) injections to relax the anal sphincter, allowing stool to pass more easily.

Sometimes constipation leads to what looks like diarrhea. A hard stool can act like a "cork," allowing only liquid stool to leak around it. In those cases, clean-outs or rectal treatments, such as suppositories, can help reset the system.

A colonoscopy is typically not necessary for constipation alone. It becomes more critical if a child is struggling with very slow growth, ongoing diarrhea, or blood in the stool—symptoms that may indicate inflammation.

Because many children with CdLS communicate discomfort through behavior, it's not always clear whether a change in eating or self-injury stems from pain or from a behavioral challenge. An upper endoscopy can help determine whether the issue originates from reflux, stomach irritation, or another underlying medical cause. More specialized tests, such as gastric emptying studies or esophageal manometry, are available when needed, however they are rarely the first step.

Diagnostic testing is always tailored to the child. One of the most common studies for CdLS is an upper GI series, which checks for intestinal malrotation. Abdominal X-rays are sometimes used when a physical exam is difficult, or when it's unclear whether diarrhea is tied to constipation.

Families play a powerful role. You're often the first to notice when something shifts, whether that's a change in appetite, mood, sleep, or bowel habits. Trust those observations. When you share your observations with the care team, it helps ensure that your child receives the support they need to grow, explore, and enjoy food in ways that feel safe and comfortable.

When to Visit a Doctor, Urgent Care, or Emergency Department when Faced with GI Issues

Raul (Rudy) Sanchez, M.D., Clinical Advisory Board Member at the CdLS Foundation and Pediatric Gastroenterologist at Nationwide Children's Hospital

Patients with CdLS can have various gastrointestinal (GI) symptoms. Many symptoms include feeding troubles, vomiting or reflux, belly pain, and constipation. Hopefully, we can determine when to contact your primary physician versus when to consider a visit to the Urgent Care/Emergency Room.

PRIMARY CARE PHYSICIAN

A primary care physician (PCP) or pediatrician is often consulted for long-term care issues, such as feeding difficulties, especially in infancy. Some pediatrician offices have lactation consultants on staff to help with feeding issues in infants with all medical problems. Discussing concerns about weight loss or poor weight gain with the PCP is an excellent start, as the PCP can monitor growth parameters over time. Another issue to discuss with your doctor is constipation or difficulty passing regular bowel movements. The PCP can follow and initiate treatment for simple or common constipation issues. The PCP can also evaluate whether a referral to a Gastroenterologist (GI) is needed for more specialized evaluation and treatment. If you have an established GI doctor, you can also relay these questions to them, and they can assist with the assessment and management of many of these issues.

URGENT CARE/ EMERGENCY DEPARTMENT

Visiting an urgent care facility (UC) or an emergency department (ED) indicates that more concerning issues are occurring with your loved one. Vomiting to the point of not being able to tolerate liquid intake raises the concern for dehydration and warrants visiting one of these more urgent settings. Signs of dehydration include significant fatigue or tiredness, sunken eyes, higher heart rates, and decreased urine output. In such scenarios, it is essential to have a physician assess whether the patient requires intravenous fluids. Additionally, if the recurrent vomiting has a brighter green color, a red color-like blood, or a "coffee ground" brown appearance, it may indicate a more serious underlying issue. This will require imaging, such as an X-ray, to start. This is another crucial scenario to present to the UC or ED.

FLIP TO THE BACK OF THIS ISSUE FOR HELPFUL TEAR OUTS IF YOU NEED TO GO TO THE HOSPITAL.

CLINICAL SETTING

In the clinical setting, constipation can be managed in the long term; however, it can lead to more urgent issues. If your loved one has not had a bowel movement in 3-4 days or longer AND has other symptoms such as vomiting, visible abdominal distention, or significant abdominal pain, this should be evaluated immediately. Visiting a facility with imaging capabilities, such as those offering X-rays, would be ideal.

These examples cannot encompass every possible scenario or issue. They help highlight what to be looking for. One rule I believe is excellent to follow: if you have significant concern or your intuition tells you something is not quite right with your loved one, do not hesitate to call your doctor or visit a UC/ED for evaluation.

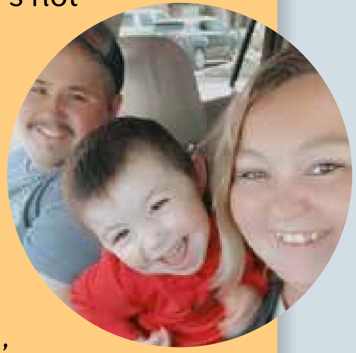
Voices Unscripted

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

"To other parents walking a similar path, our advice would be to never lose hope, even when the journey feels overwhelming. Trust your instincts and advocate for your child, even when the answers don't come easily. It's okay to feel uncertain or afraid or feel whatever emotions you feel. Every child is unique, and their progress, no matter how different it may seem, is worth celebrating. Embrace the small victories and focus on what your child can do, rather than what they struggle with."

– Cassie B.

"No Mommy wants to hear the words that something is wrong with their baby. The news can shatter you, but don't let the diagnosis define your child. Yes, my son has "CdLS," but it's not who he IS. He is a loving, funny, special kinda kid. My advice: don't hold back. Push your child to be who they are, not what they have. Life is crazy and hectic and can be scary. But you got this, Mama!"



– Jamie C.

"The hardest thing about having a sister with CdLS is that she can't tell me what is wrong when she is sad. I don't like it when she is sick and has to stay in the hospital."

– Hunter H.

"The one thing I would tell the world about my sister is that she has the most beautiful, crooked smile ever. I have never in my life seen a happier, joyful, and loving smile than hers. It truly lights up the room, and you can't help but smile either."

– Maya R.

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!*

ALEXANDER

EWAN

SHARP FAMILY

ARKANSAS
Holly, Kaleb, and daughter Annora
Born in 2019

COLORADO
Melissa, John, and son Milo
Born: April 24, 2016

CONNECTICUT
Cera, Brian, and son Maverick
Born: February 9, 2016

FLORIDA
Selina and daughter Valeria
Born: June 20, 2024

LOUISIANA
Janelle, Noah, and son Manoah “Manny”
Born in 2024

MINNESOTA
Jenn, Tommy, and daughter Julia
Born: August 6, 2023

MONTANA
Kasey and son Jeremy
Born: January 15, 2004

NEW YORK
Tina and son Alexander
Born: February 14, 2011

NORTH CAROLINA
Jayne, Vladimir, and son Caleb
Born: July 11, 2008

OHIO
Chelsea, Richard, and son Ewan
Born: September 18, 2019

Elizabeth, Mark, and daughter Isla
Born: May 17, 2023

OREGON
Sarah and daughter Remie
Born: March 28, 2012

PENNSYLVANIA
Brandon, Megan, and daughter Rosalyn
Born: December 11, 2014

Emily, Albert, and son Theo
Born: August 3, 2021

TEXAS
Trina, Brandon, and son Elijah
Born: April 28, 2024

UTAH
Iris and Francisco and son Franciris
Born: December 6, 2007

WYOMING
Kayla and daughter Annaliese
Born: February 1, 2024

CAMBRIAN

PERFECTLY MADE

Cambrian is a smart, sweet boy full of personality! He craves undivided attention, loves to be held, and enjoys snuggling. With three lively siblings, life is never dull as he fills our home with laughter through his silly antics, like his "fake sleeping" and "fake crying." He especially loves cheering on his big brothers at the baseball field.

Though he is nonverbal, Cambrian communicates beautifully through his unique cues and gestures. He is G-tube fed but is working on his oral feeding skills with a speech therapist.

Our journey began with a heartbreaking 20-week anatomy scan that revealed complications. Initially, doctors suspected the pregnancy might not be viable, leading us to specialists at Winnie Palmer Hospital. After extensive testing, we received the diagnosis: CdLS.

Despite the uncertain prognosis, what mattered most was that our baby was viable. Researching CdLS was daunting, but we found peace, trusting that God was in control. Cambrian has taught us patience, faith, and strength, guiding us through 75 days in the NICU and multiple surgeries.

> *Our best advice for families facing challenges is simple: trust that you can handle what comes your way and accept help from others. It truly takes a village.*

Cambrian's routine is comforting. His feeding pump runs overnight, stopping at 7 a.m. He often scoots to the bottom of his crib, kicking the side to be let out. Most mornings start with big smiles and hugs.

Four days a week, Mrs. Kelly, his wonderful nurse, helps care for him. His feeding schedule is every two hours, using a pediatric peptide formula due to his dairy allergy, along with probiotics to manage his chronic constipation.

He receives in-home therapy twice a week, speech and feeding one day, and physical therapy another day. We also balance appointments with playtime.

As evenings get busy with his siblings' activities, Cambrian loves to tag along. Bedtime is consistent: medication, pajamas, and winding down with Daddy by 8:30, followed by sleep by 9 p.m., for over 10 hours.

We're blessed with a fantastic support system: family, friends, our nurse, and an amazing team at Arnold Palmer Hospital. When Cambrian is hospitalized, his family steps in to care for his siblings, allowing us to stay by his side.

Cambrian adores adventures! He loves being outdoors, as long as it's not too hot. This summer, he received his passport and visited Nashville, Virginia, Niagara Falls, and Vermont.

We strive to include him in all family experiences, from concerts to the beach. When people stare, we respond with openness, educating others about CdLS. His siblings proudly share his story as his biggest cheerleaders.

Life looks different now, slower and more intentional. Feeding pumps, oxygen machines, and medical supplies are part of daily life. Therapies come to us, and we focus on love, laughter, and gratitude.

Cambrian is becoming more mobile, scooting around or cruising in his walker, and his upper limb difference doesn't slow him down. He loves exploring, especially buttons and balls.

As his birthday approaches, we reflect on how far he's come. Cambrian is strong, determined, and full of light. Our hearts overflow with pride and love for our perfectly made little boy.

To read more about Cambrian, scan the QR code.

Paisley’s Smile, Paisley’s Way

Submitted by: Lillian, Paisley’s Mom

Paisley Mei is five and is a bundle of inspiration and joy, and we could not be more grateful for her.

She was in the hospital for the first 371 days of her life, where she endured many surgeries and treatments. She has been diagnosed with CdLS and 14q.23.1 microduplication, both chromosomal abnormalities. Both seem to display some of the same diagnoses that Paisley displays.

Paisley has had heart surgery for TOF and VSD, cleft palate surgery, and tubes replaced in her ears four times, to name a few. She is a very happy, mischievous little girl who is currently working hard on learning how to sign and walk with her gait trainer. She wears hearing aids or a Baha headband hearing aid and glasses.

She is a very precious child; regardless of the day, she always tries to be happy. She is the most inspirational little girl I have ever met.

Her smile can make anyone’s day.

Her mischievous ways never go unnoticed, and Paisley does what she wants on her timeline ... and we are totally ok with it! She has been through so much in her short life and takes it like a champ!

Submit your mailbag story to Ashley at akus@CdLSusa.org

Our Daughter's Final Act of Heroism as an Organ Donor

Vivian Comeau's Family

When the doctors told us there was nothing more they could do for our 25-year-old daughter Vivian, we were devastated. But in that moment of heartbreak, we remembered her state ID had the organ donor option checked, so we began to explore the possibility of organ donation. It became a way to transform unimaginable sorrow into something meaningful. It was a chance for Vivian's life to continue making a difference.

It was one of the hardest decisions we've ever made. We were caught in a storm of emotions: grief, disbelief, love, and a deep yearning to hold on. Letting Vivian go felt impossible. But in the midst of that pain, we searched for a way to bring light into the darkness.

Vivian was a believer in Christ, who gave Himself so that others might live. We saw organ donation as a reflection of that same spirit, an act of selflessness and grace. We believe her life, like her faith, could be used to help others in need.

Organ donation became a way to honor her life, her kindness, and her quiet strength. It was a way to say her story doesn't end here. We later learned that less than 1% of people can donate, which made her gift mean even more to us.

A close family friend had once needed a lung transplant but never received one. We knew how critical timing and compatibility could be, and Vivian's uncommon blood type and size would not be limiting factors. We also followed the story of a boy with special needs who became a hero through organ donation. His story stayed with us, reminding us of the profound impact a life can have.

The NJ Sharing Network played a vital role in helping us navigate the path of organ donation. While in the hospital, they organized a flag-raising ceremony that marked Vivian's legacy in a visible, lasting way. They also arranged an honor walk, allowing hospital staff to line the halls and pay their respects. It was deeply moving to see strangers stand in quiet tribute, recognizing Vivian not just as a donor, but as a person whose life had meaning.

Afterward, we held a Celebration of Life to extend those memories to the many circles Vivian would call family. Over 300 attendees from various circles considered family, including Church, Girl Scouts, Special Olympics, Day programs, Night to Shine, respite, Marching Band, neighbors, and many others, came together to share stories, laughter, and tears. It was a mosaic of love, a testament to the communities she helped build and the joy she brought to others.

As part of that celebration, we shared miniature toy pigs, a playful nod to Vivian's love of bringing her own pig on family trips. Friends and family have continued to take those pigs on adventures, snapping photos and posting them to the Team Vivian Facebook page. Through these celebrations and reflections, we found a way to carry our grief with grace. Organ donation didn't take away the pain, but it gave it purpose. It allowed us to transform loss into legacy and sorrow into service. And in that, we found comfort, not just in what was lost, but in all that Vivian continues to give.

Are you struggling with the loss of your loved one with CdLS? Contact the Family Service team at familyservicesteam@CdLSusa.org.

Deepest Sympathies

Erin Aponte
April 9, 1977 – August 16, 2025
Daughter of Linda and Angelo Aponte
99 Trotters Lane
Allendale, NJ 07401

Branden Bowden
January 31, 1997 – September 7, 2025
Son of Brandi Davis
258 Wimberly Rd
Hawkinsville, GA 31036

Johnny Burchett
October 8, 1962 – March 29, 2025
Son of Fay Burchett
P.O. Box 306
Thomasville, NC 27361

Teshon Crawford
August 6, 1988 - April 19, 2025
Son of Lenore Crawford
5643 Westhill Circle
College Park, GA 30349

Vivian Comeau
March 27, 2000 – June 10, 2025
Daughter of Debbie Comeau
54 Klein Drive
Yardville, NJ 08620

Becky Lee Dittmer
May 10, 1980 – June 17, 2025
Daughter of Terry and Genie Dittmer
11011 W Martell Rd
Crete, NE 68333

Chad Dyrdahl
October 27, 1981 – September 7, 2025
Son of Paul and Gayle Dyrdahl
9448 Giffort Ct
Monticello, MN 55362

James Lee Jr.
Dates Unavailable
Son of Sabine and James Lee
8102 Saylynn Lane
Houston, TX 77075

Ty Morgan
October 10, 1988 – May 18, 2025
Son of Sheilena and James Smith
1080 Estate Drive
Dalton, GA 30720

Tara Pace
August 24, 1998 – January 16, 2025
Daughter of Tarina and Kevin Pace
17836 S Meadowpark Dr.
Walton Hills, OH 44146

Thomas Russo
January 4, 2010 – May 24, 2025
Son of Tracey and Thomas Russo
38 Summer Street
Foxborough, MA 02035

Corrine Stone
August 20, 1964 – August 13, 2024
Daughter of Barbara Stone
18 River Road #1
Peppermill, MA 01463

Alyssa Turner
March 25, 1994 – April 9, 2025
Daughter of Leila and Allen Turner
1303 West 425 South
Layton, UT 84041

Directors Message

As we close out the year, I'm reminded once again of the extraordinary strength within our CdLS community. This Winter 2025 Edition is especially meaningful because we've dedicated it to one of the most common and challenging aspects of CdLS — gastrointestinal (GI) issues, which affect nearly every child and adult living with the syndrome.

By focusing on this topic, we want our families to know: we see you, we hear you, and we are walking beside you. The guidance shared by Dr. Rudy Sanchez and others offers not only clarity, but comfort — helping transform knowledge into hope.

The stories of love, resilience, and generosity help remind us of the deep humanity at the very heart of our community - from siblings finding strength in one another, to families turning loss into life through organ donation.

As you turn this final page, may you feel uplifted by the collective compassion and courage that unite us. Together, we continue building a future of understanding, care, and possibility for all those touched by CdLS.

With gratitude and hope,

Bonnie

In Memory of Eric Johnson
Longtime Treasurer of the CdLS Foundation

Eric Johnson, who recently passed away after a brief but valiant illness, served the CdLS Foundation for many years with quiet strength, integrity, and deep commitment. His thoughtful stewardship guided the organization with care and clarity, ensuring families remained at the heart of every decision.

We honor Eric's dedicated service and the meaningful role he played in strengthening the Foundation. His legacy endures in the work he helped shape, and he will be truly missed.

Gifts that Count

07.30.2024 - 01.31.2025

In Honor/ Celebration

Aunt Jo & Uncle Bill
Owen 's family cousins

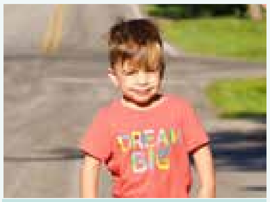
Brianne's 34th Birthday
Karen and Larry Prada

Mati's 6th Birthday
Sivan Kotler-Berkowitz

Gentry
Dalton Fuchs

Mason
Ralph Milillo

Olivia
Rick Boylan



Ollie
Heartwarming smile
Molly Hesse
Kate O'Connell

PAIGE
Correy & Crystal

Rose Ann and Steve
Susan Hartman

Sai
Sahayra Carbajal

Helen Alfirevich
Lori and Joe

Jenna Allen
Brenda Patrick

Cristina Arsuaga's 60th Birthday
Liana Davila and Mike Garcia

Shirley Bacon
Pamela Wisel

Adrian Illyana Bajema
Melissa Appleton
Stacey Bajema

Max Balthazar
Uncle Mike and Aunt Anne

Hunter Barrett
Gary Hartman

Danielle, Annie and Teagan Beaumont
Andrea & Marc Needleman

Colin Andrew Bell's Birthday
Cheryl La Roe

Aubrey Bender
Brooke & Travis Bender

Mary Ann Bieze
Siddharth Sethy

Jillian Billings
Sandra Beickert

Hannah Boehman
Sara Boehman
Victoria and Rick Boehman

Hazel Burchardt
Joe Mussatto

The Carr Family
Robin and Frank Gatto

Robert Carter
William R Carter

Julie Champion
Adam Champion
Michele Champion
Tom & Ginny Clayton

Kamren Coleman
Joyful spirit, shining always
Ramona Cox

Mason and Charlie Dahl
Sherry L Gonzalez
Jennifer Robins

Alyssa Delgado
Gricelda Contreras

Jessica Doherty
Timothy Doherty

Chase Duff
Barbara Robinson

Joy Eicher
Cam Vossen

Nancy Erdmann
Carlene Hansen

Connor Feehan
Ashley Evans
Mary Ann and Pat Feehan
Monika and Jerry Glenn
Sam & Joyce Nolt
Elizabeth Pinizzotto

Lindsey Fernandez
Ashley Fernandez

Milton and Sophie Fields
Jason Karlin

Rich Flaherty
Michael Lee

Sage Franck
Tammy Gardner

Lindsey Franco
M Susan and Scott Coleridge

Tanaya Frank
Heather Gittings
Prashant Pandey

Heather Gittings
Prashant Pandey

Nathan Frischmeyer
Allen Stickfort

Gracie Fry
Linda Chatham

Aryanna Gage
Sarah Griffith

Aubrey Elizabeth Garigen
Western New York Oldsmobile /GM Club

Caleb George-Guidry
Jackie and David Guidry

Michael Gonella
Loved deeply by his family
Julie and Roy Gonella

Kolten Griffen
Belinda and John Waller

Emily Griffin
James Ranieri

Mika Hallenbeck
Jill Hallenbeck

Ray Halverson
Bobbi Halverson

Janet Herald Hedrick
Marianne Frank Curtis

Lucas Hoen
Weber Hoen and Hein Nguyen

Sydney Hoffman
Deborah Marks

Aimee Holleb
Heidi Kaplan
Sharon Langlois

Holleb family
Kim Sigle

Charli Howe
Courtney Hauer

Caleb Huang
Ching-Shu Jing and Shih-Che Fang

Grant Hutton
Dorothy Maki-Green

Marshall James
Steven Siegel

Molly & Keris
Janet Sherman

Daniel Kliewer
Kathleen Rulka and Brian Ewert

Charlotte Lawrence
Barbara J Lawrence
Diane Smith

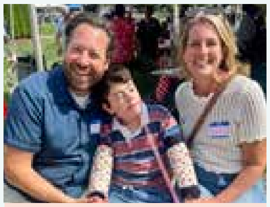
Josh Levis
Mary Levis

Beth Lively

Elaine Garyantes

Eric Loftus

Karen Szukalski



Luke Lyons

Full of love and laughter

Brantley Family

Elizabeth Marant

Sinclair Family

Smith Family

Janis Mamayek

Kelly & Don @ CHA

Maria Meza

Javier Meza

Devin Miller

Lynnette Miller

Muriel and William Walters

Nicole Miller's 32nd Birthday

Susan Miyake-Terhune and Allen Terhune

Inez's Mom

Keren Yairi

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Blair

Debbie

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Larry

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Noah

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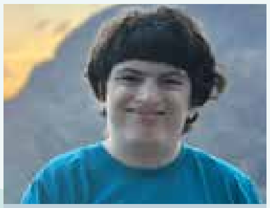

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The Grief Support Advisory Group Is Here to Help

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.

ADVOCATING DURING A HOSPITAL STAY

Hospitals can be challenging to navigate. Having an advocate to clarify information, describe how your family member typically behaves and share information about what care provided at home is always helpful.

A strong advocate can make a difference in what care is received, when and how care is provided, how informed you feel, and how well care after the hospital is planned.

Speak with your primary care nurse, hospital care manager, or patient advocate to identify key individuals on your care team and your primary contact for updated information.

Whenever possible, have someone else with you. Another set of ears is often helpful.

1 If English is not your primary language, request an interpreter.

Hospitals are required to provide them at no cost to you.

2 Identify your primary contact for updated information.

There is usually one person on the medical team reviewing information and making treatment decisions. Learn who this is and how and when to contact them for updates.

3 Ask if the hospital has a Palliative Care or Complex Care team

These teams guide and coordinate care in the hospital and after discharge. Focusing on enhancing the quality of life for individuals facing serious illness. Palliative care helps patients navigate the complexities of their conditions with dignity and grace.

4 Identify who helps coordinate discharge planning and how to contact them.

5 Request a Patient Care Conference.

Within 24 hours of admission, set up a Patient Care Conference. The primary hospital physician, specialist(s), case manager, or discharge planner should be involved. Use this meeting to discuss current issues and treatment, any concerns you have, and plans for a safe discharge from this unit or hospital

6 Request a Patient Advocate

Plays a crucial role in the hospital by ensuring that a patient's needs, preferences, and concerns are communicated effectively to the healthcare team. Their support helps to empower patients, navigate complex medical decisions, and ensure a compassionate and personalized approach to care.

7 Access the online patient portal.

Many hospitals offer a patient portal you access from an app. You can view laboratory, pathology, and radiology reports in this portal. If you have not already downloaded this app on your smartphone, consider doing so now.

8 Ask Questions Until You Understand:

When asking questions, write down the answers and all the information you hear. When possible, have someone else with you for another set of ears.

9 Contact your health plan or program.

Confirm that any procedures or procedures that require prior authorization have been approved. Speak with a care coordinator or care manager to see how they can assist in discharge planning or in obtaining services after the hospital stay.

10 Ask how to obtain a second opinion during this hospital stay.

CHECK LIST FOR HOSPITAL GO BAG

If your loved one with CdLS requires frequent hospitalization, consider keeping a Go Bag ready. Here are some things to keep handy.

- ☐ **Items or toys that calm or entertain your family member with CdLS**
- ☐ **Pens and notebook for keeping track of information and appointments**
- ☐ **Extra-long phone charging cord (the outlet is always far away!)**
- ☐ **Paper copies of these pages from the Health Care Notebook:**
  - ☐ Who Am I?
  - ☐ Important Contact Information
  - ☐ My Providers
  - ☐ Medical Equipment and Supplies
  - ☐ Medications
  - ☐ Hospital Note Forms
- ☐ **Copies of critical medical and legal forms such as:**
  - ☐ Power of Attorney
  - ☐ Guardianship
  - ☐ Advanced Directives
  - ☐ Attorney Contact Information
- ☐ **A set of comfortable clothes — you may be staying**
- ☐ **Personal hygiene items like hand sanitizer, lip balm, toothpaste/toothbrush, face wipes**
- ☐ **Reusable water bottle and snacks**
- ☐ **A copy of your health insurance card. Keep the original in your wallet**
- ☐ **Cash or credit card for snacks and incidentals**
- ☐ **Passwords for online patient portals to access prior discharge summaries and current orders for equipment or medication**

CdLS Foundation
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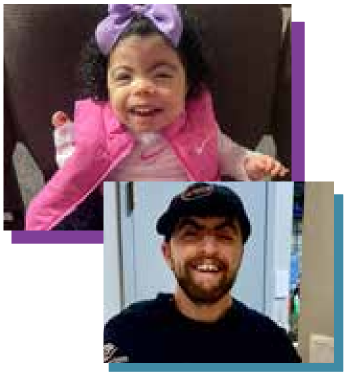

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