REACHING OUT

SPRING 2023

Spotlights:

When to Call the Doctor and When to go to the ER

ON THE COVER

Bryn Clary

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message


Bonnie Royster, CdLS Foundation
Executive Director

It is that time of year again, the sun feels warmer, and everything is in bloom. There is a sense of excitement in the air. We can feel it too here at the Foundation.

After nearly two and a half years of little in-person events, we will be hitting the road for more Family Gatherings, clinics, and fundraisers.

Be sure to check out our calendar of events to see what is happening in your area. Thank you to all who attended the virtual town hall meeting and submitted their thoughts to help us reimage Conference. Awareness Day is on May 13 – an excellent opportunity for all of us to celebrate.

We have been busy creating new materials to help individuals with CdLS thrive. Check out our Helpful Hints section to see what is available.

In this issue, our medical professionals discuss when to visit your primary care doctor vs. going to an Emergency Room. There are great features, specifically on GI and neurology, while Dr. Kline touches on each body system.

Enjoy the spring issue of *Reaching Out*. And remember, we are stronger together.

Bonnie

This issue of *Reaching Out* is dedicated to the memory of Bill Ondr.

Bill had a long and successful career in sales at Madison County Wood Products. He was an avid golfer. If he wasn't playing golf, he was watching it on television. He helped chair the MCWP & PLM Amber Gaines Memorial Golf Classic for 25 years and helped to raise tens of thousands of dollars.

Thank you Bill for your time and talent in providing a future for individuals with CdLS across the United States.

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WHEN TO CALL THE DOCTOR AND WHEN TO GO TO THE EMERGENCY ROOM

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

A trip to the ER will be indicated for a severe accident, difficulty breathing, fainting, or a foreign object put into an ear, a nose or swallowed by accident. And for most, a call to the primary care practitioner (PCP) will be prompted by new onset illness, fever, recurrent vomiting or diarrhea, unusual skin rash, COVID, asthma, and other concerns.

When CdLS is present, there can be additional specific entities needing a call to the PCP or a trip to the ER. These are discussed here by body system:

NEUROLOGIC – People with CdLS (about 20%) can have seizures. These can arise at any age, from infancy through childhood. These can be well managed by a single medication, and parents learn when to give additional medication if needed. The first time a seizure occurs, a trip to the ER should be made. Once seen by pediatric neurology and evaluated, there still will be need for calls to the PCP. Girls with loss of function gene variants in SMC1A have an unusual type of seizure disorder and may need more frequent trips to the PCP or ER.

GASTROINTESTINAL – Most people with CdLS (over 95%) have some GI involvement, particularly gastroesophageal reflux disease. Usually, questions related to vomiting, reflux, medications, back arching, and fussiness can be addressed by the PCP. Everyone with CdLS should undergo a barium swallow study to see if malrotation is present, which could need surgical repair. Questions related to this can be directed to the PCP. Many individuals also have slower-moving bowels and can develop constipation, which the PCP can address, or bowel obstruction, which a GI doctor or surgeon may need to manage. A trip to the ER is likely needed for suspicion of bowel obstruction for any child or adult developing acute abdominal pain with a rigid abdomen. Other signs of a bowel obstruction include a swollen belly and sudden vomiting that is bright yellow.

OPHTHALMOLOGIC – Problems with the eyes usually include droopy eyes, crusted eyes, eye muscle problems, or nearsightedness. These are usually referred by the PCP to the eye doctor. With very severe nearsightedness, there is a risk of a spontaneously detached retina. Someone with self-injury could press their fingers into the eye and cause a detached retina. A nonverbal or less verbal individual may not be able to share symptoms. A visit to the eye doctor or emergency room would be the first step if this is suspected.

PSYCHIATRIC – At times, behavior in CdLS can become "out of control", which should be discussed with the PCP. If the behavior escalates, a referral is indicated to psychiatry for appropriate medications and/or to behavioral psychology to discuss a behavioral plan; both can help enormously. If aggression or self-injury cannot be handled at home and the child or adult is at risk of harming themselves or others, a trip to the ER may be necessary for short-term help.

People with CdLS can have most of their organ systems involved. They have many medical complications, sometimes need surgery, and often might not feel their best. It can be challenging to assess when symptoms are typical for an individual or concerning, and when and whom to call or visit. When in doubt, err on the side of calling the PCP or going to the ER if very concerned.

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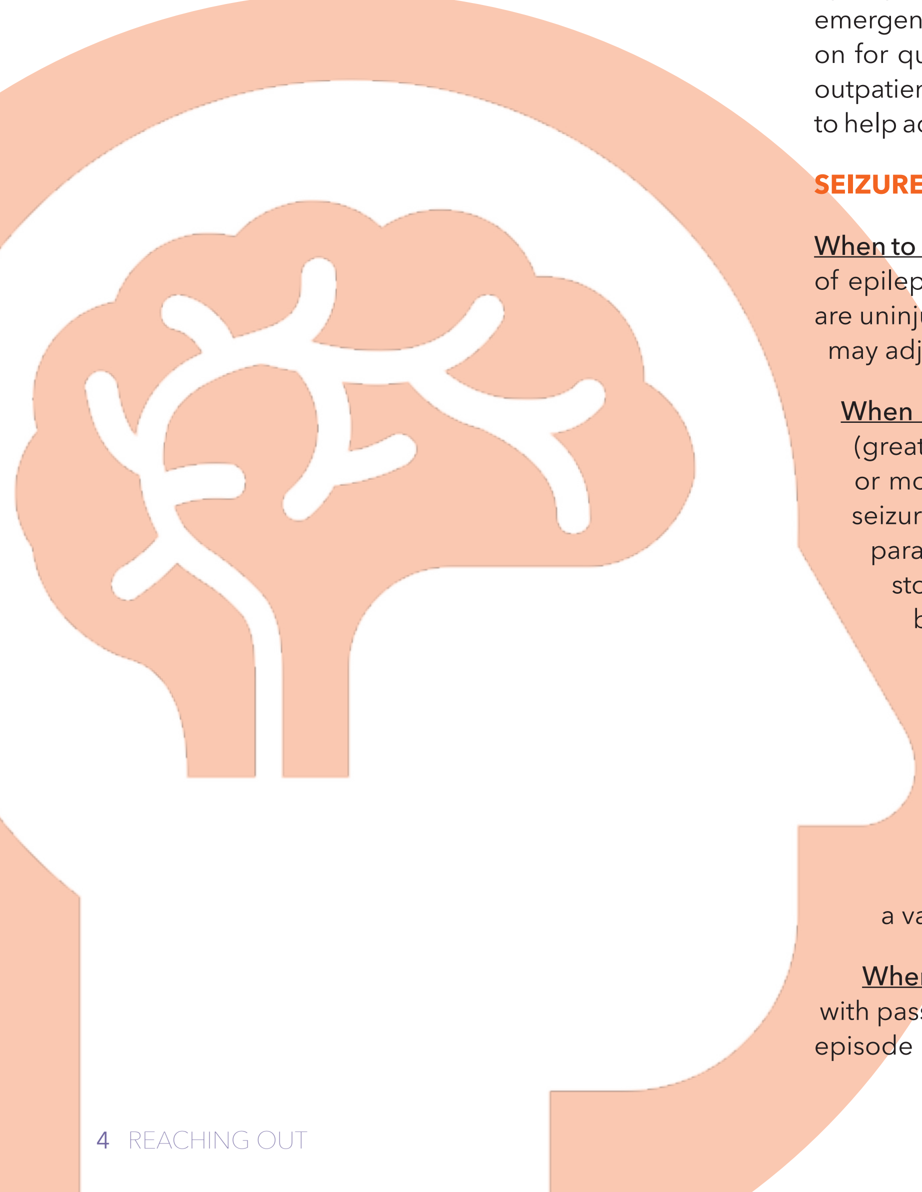
WHEN TO CALL THE DOCTOR AND WHEN TO GO TO THE EMERGENCY DEPARTMENT:

NEUROLOGICA

Kristin W. Barañano, M.D., Ph.D., Assistant Professor, Department of Neurology, Johns Hopkins University School of Medicine, Clinical Advisory Board (CAB) Member



Individuals with CdLS rarely have neurological emergencies or urgencies directly related to their diagnosis of CdLS, other than an increased risk of seizures. However, relatively common neurological issues can also occur when someone happens to have CdLS.

Individuals should go to the Emergency Department (ED) when symptoms can't wait for an outpatient evaluation. Even if neurological symptoms are not life-threatening, going to the ED may help expedite outpatient evaluations and follow up, especially if you go to an ED that has specialists on call for emergencies. However, suppose symptoms have been going on for quite a while, and you are having trouble accessing outpatient care. In that case, your primary doctor may be able to help advocate for you with a specialist to get you in sooner.

SEIZURES

<u>When to call your doctor:</u> If you have a pre-existing diagnosis of epilepsy and your seizure is brief, stops on its own, you are uninjured, and you quickly return to normal. Your doctor may adjust your medication over the phone if appropriate.

<u>When to go to the ED:</u> Call 911 for a prolonged seizure (greater than five minutes) or cluster of seizures (three or more in 20 minutes). Do not drive a person having a seizure to the ED! The emergency medical technicians or paramedics in the ambulance will have medicine to help stop the seizure. If you need to be transported, they will be able to get you medical care in the ED much faster. Emergency Departments should evaluate first-time seizures or seizures associated with fevers.

PASSING OUT (SYNCOPE)

<u>When to call your doctor:</u> When associated with obvious issues like dehydration or a strong stimulus like the sight of blood (which can trigger a vasovagal reaction).

<u>When to go to the ED:</u> If there is an injury associated with passing out, if there is no obvious explanation, or if the episode is associated with exercise.

AL ISSUES

WEAKNESS

When to call your doctor: If weakness develops slowly, over days to weeks.

When to go to the ED: If weakness develops suddenly or over minutes or hours. This could be due to a transient ischemic attack (TIA), stroke, a spinal cord problem, or something like Guillain-Barre syndrome.

VISION LOSS

When to call your doctor: If the vision loss is gradual. You will likely need to see an ophthalmologist.

When to go to the ED: For sudden vision loss. This could be due to a blood clot blocking blood flow to the blood vessel supplying the retina or the part of the brain that processes vision (a stroke). This could also be a retinal detachment that may need urgent surgery.

HEADACHES

When to call your doctor: If you have a history of headaches and the headache is like your typical headache but is not responding to your usual treatment regimen. Your doctor may be able to suggest other options.

When to go to ED: Sudden onset of severe headaches could represent bleeding in the brain, like a ruptured aneurysm. Even if it is your typical migraine headache, if it is not responding to your usual treatments at home and is not tolerable, the ED can offer IV treatment options.

DIZZINESS

When to call your doctor: If the dizziness is brief and associated with a change in position (like going from a seated to a standing position), you may have orthostatic hypotension. Or if the dizziness is brief and associated with a sudden change in a head position like rolling over in bed, that is most likely to be a condition called benign paroxysmal positional vertigo (BPPV) related to a problem in the inner ear.

When to go to the ED: Sudden onset of dizziness, especially if it is ongoing. This could represent nerve inflammation to the inner ear or potentially a stroke affecting the part of the brain responsible for balance and coordination.

HEAD INJURY/CONCUSSION

When to call your doctor: If the injury is minor, there is no loss of consciousness and mild or no residual symptoms.

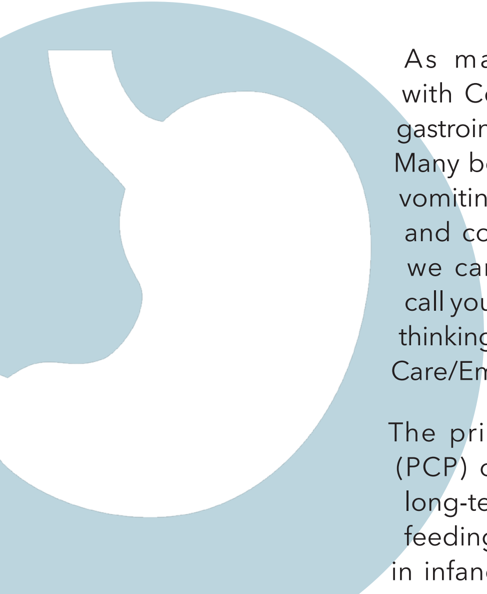
When to go to the ED: If the injury is associated with loss of consciousness or persistent symptoms like confusion, dizziness, headache, or incoordination.

Dear Reader, please note that Emergency Room and Emergency Department are used interchangeably in the Spotlight articles. They both mean the same thing and are used throughout the United States.

When to Visit a Doctor, Urgent Care, or Emergency Room:

GASTROINTESTINAL ISSUES

Raul (Rudy) Sanchez, M.D., Nationwide Children's Hospital – Columbus, OH



As many know, patients with CdLS can have various gastrointestinal (GI) symptoms. Many being feeding troubles, vomiting or reflux, belly pain, and constipation. Hopefully, we can figure out when to call your primary physician vs. thinking of going to the Urgent Care/Emergency Room.

The primary care physician (PCP) or pediatrician is 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 many medical concerns. Presenting to the PCP with a concern about weight loss or poor weight gain is an excellent start, as the PCP can follow growth parameters in the long term over time. Another issue to visit or talk to your doctor about would be 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.

Going to urgent care or an emergency room means there are more concerning issues occurring with your child. Vomiting to the point of not being able to tolerate liquid intake raises the concern for dehydration and warrants presenting to one of these more urgent settings. Signs of dehydration include significant fatigue or tiredness, sunken appearing eyes, higher heart rates, and decreased urine output. It's essential to present to care in these scenarios to have a physician assess if the patient needs intravenous fluids. Also, if the recurrent vomiting has a brighter green color, red color like blood, or a "coffee ground" brown appearance may mean something more serious going on. This will require imaging, such as an x-ray to start. This is another important scenario to present to the Urgent Care or ED. In the clinical setting, constipation can be managed in the long term; however, it can lead to more urgent issues. If your child 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. Going somewhere there are imaging capabilities with at least x-rays would be great.

Realizing these examples cannot encompass every scenario or issue possible. They help highlight what to be looking for. One rule I feel is excellent to follow; if there is a significant concern or your intuition tells you something is not quite right with your child or family member, do not hesitate to call your doctor or go to an Urgent Care/ED for evaluation.

Sharing Information About CdLS with Siblings

Linda Pierce, M.S.W., Program Director, Family Service, CdLS Foundation

Siblings need information for reassurance, to answer their questions and questions of others, as well as to plan for their future.

When siblings lack accurate age-appropriate information, misunderstandings often occur.

Parents want the best for their children. They want them to be happy and remain as unburdened as possible. But even young siblings have a compelling need for age-appropriate information about their brother or sister with CdLS.

For preschool siblings, it may be enough to know:

- √ They cannot catch CdLS
- √ They did not cause CdLS or any of its challenges.

This information may be obvious to an adult, but it may not be as clear to a preschooler who recently caught a cold from a friend. Preschoolers are concrete thinkers, so explanations should be as literal as possible.

One way of explaining CdLS to young children is to describe differences in behavior or routine. For a preschooler, CdLS may mean their brother or sister eats different foods or sees someone who helps them learn to walk. These explanations become the foundation for more information later.

Without information, children can develop theories on why their sibling with CdLS behaves in a certain way. Often the stories they make up can be worse than the truth. Siblings need:

- √ Clear answers to their questions
- √ How to answer questions they may get from peers and even from strangers.

Older siblings have more specific questions. They may ask about behaviors or medications. They may want to know what happens during doctor's visits, a hospital stay, or Physical Therapy. But, siblings are often excluded from the significant sources of information available to adults, including books, websites, and conversations with medical providers. In some families, siblings feel that CdLS is not to be discussed, leaving them alone with their questions and concerns.

Conversations about any disability can be difficult. Here are some suggestions about how to start.

1. Keep CdLS an open topic. Rather than sharing information only during "sit down talks," share information frequently and in small doses. When siblings see adults openly discussing challenges and needs, they learn to do so.
2. Answer direct questions honestly and to the best of your ability. Let your child know you are glad they asked. Address questions with answers that are developmentally appropriate for the sibling.
3. Offer siblings written materials. There are books written primarily for siblings of all ages. We can help you find them.
4. Invite (don't require!) siblings to attend visits with medical providers to be part of the discussion and get their questions answered.

For more information or resources for siblings, contact Family Services at **familyservicesteam@CdLSusa.org**.

HIGHLIGHTED EVENTS

DAD TURNED COMEDIAN RAISES MONEY FOR THE CdLS FOUNDATION

Stephen Hegarty (elf in photo below) is a Clinic Manager by day and a comedian and actor by night. He put his love of entertaining to work to raise money in honor of his ten-year-old daughter Cassidy.

Stephen donated his time to perform a special show at JP's Comedy Club in Gilbert, AZ, called "Twisted Christmas" in December. The show sold out, raising $1,100 for the CdLS Foundation. As a parent of a child with special needs, Stephen and his wife Courtney say humor helps them to cope with many challenges.

"We must laugh at the good and bad behaviors of having a child with CdLS and Autism. As well as the frustration involved in dealing with doctors, insurance, uneducated and ignorant people, and everything in between," Stephen explained.

On stage, Stephen tells the crowd, "I make up games to stimulate Cassidy, and she likes to make up games as well … like grabbing random stuff and throwing it … like steak knives!" The crowd laughs. "Sadly, we had to retire that game as my mother-in-law and the dog were not big fans … but they get their stitches out next week, so it all worked out."

For others interested in doing their own fundraisers for the Foundation, Stephen says, "Make it a fun event. Get friends and family to promote it on social media, and be relentless. Also, reach out to local media, restaurants, or anything you can think of to get donations, items to raffle off, or whatever comes to mind."

HIT THE LINKS AT THE 2023 NEW ENGLAND GOLF CLASSIC

Join fellow golfers at the 2023 New England Golf Classic for its 30th year! The event will be held at the exclusive Ipswich Country Club in Ipswich, MA on Monday, May 22, 2023. Don't miss out on this opportunity to play with fellow golf enthusiasts at a true golfer's paradise. Ipswich is an 18-hole championship golf course designed by the legendary Robert Trent Jones Sr. Few golf courses match the beauty and challenge found at Ipswich. Whether you join us for golf, volunteer, and /or sponsor the event, you will not be disappointed.

We have some great sponsorship packages that will enable you to pay tribute to a loved one. As a thank you to all of our Hole Sponsors, you will be listed in our program book. There are also opportunities to promote your company on the New England Golf Classic website, on the golf course, and at the luncheon. Register for golfing or a sponsorship at http://Bitly/NEgolf2023.

SUPPORT TEAM CdLS IN CHICAGO

"I joined the CdLS Team last fall for my first marathon and the experience was so incredible that I knew I needed to come back" was heard by @she a member of Team CdLS Chicago. Last year, Amy and her teammates raised over $70,000 for the Foundation. Veteran runner Richard Flaherty. ran the marathon for the Foundation in honor of Will Smisloff., the son and brother of his great friends. In his seventh year running, each mile he tackled brought to mind a special moment he has shared with this incredible family and the inspiration Will brings to him. Once again, he earned his spot as the largest Team CdLS Chicago individual fundraiser, bringing in over $23,000.

Everyone walked away from the event with a tremendous sense of accomplishment and friendships that will last a lifetime. You can support our runners and the Foundation by visiting: bit.ly/2023ChicagoMarathonDonationPage. Your name will be displayed on the leader board and encourages others to do the same.

CALLING ALL RUNNERS AND WALKERS FOR THE BALTIMORE RUNNING FESTIVAL

Join veteran runners, Tonie Kline M.D., CdLS Foundation's Medical Director, and her co-chair Tasha Howland on October 15 for the Baltimore Running Festival. Tonie, Tasha, and their energetic team join forces each year to raise money for Team CdLS Baltimore. Last year, not only did they surpass their fundraising goal of $12,000, they welcomed many new runners to their crew and were fortunate to have the Foundation's Executive Director, Bonnie Royster, join them for dinner and meaningful conversation.

Come join Tonie, Tasha, and their crew in Baltimore and walk, run, or stroll any length option available – from 5k to the full marathon. The options are up to you!

There are many perks, including pre-race dinner and rally to meet the team and get revved up for race day, race day support (Curb Crew) to cheer you on and provide quick grab-and-go goodies, 18 weeks of virtual coaching from our expert ultramarathoner Marc Needlman, fundraising tools, including your personalized webpage, dedicated staff to provide guidance and a Team CdLS running shirt. Register at bit.ly/TheBaltimoreRunningFestivalCdLS.

If you sign up to participate in the Baltimore Running Fest, you can receive a discount. After you input your information on the sign-up page, there will be an option to "Join or create a group" - select yes. Then choose - Join an existing group, the group name is: Team CdLS Baltimore and the password is: cdls2023.

NOT AN ATHLETE? JOIN OUR FABULOUS CURB CREW!

Openings are available in **Chicago on October 8** or **Baltimore October 14**.

Perks include bonding with other parents/volunteers, and a dinner compliments of the Foundation. **New families are always welcome!**

To join, email to Sherry Waitsman, Special Events Coordinator at swaitsman@cdlsusa.org.

CALENDAR 2023

April 1
Multidisciplinary Clinic for Adolescents and Adults
Baltimore, MD

April 11
CdLS Foundation Webinar: Navigating the Health Care System
Online

May 13
CdLS Awareness Day

May 19
CdLS Foundation Webinar
Speech, Language, and the use of Augmentative and Alternative Communication Systems
Online

May 22
New England Golf Classic
Ipswich, MA

June 25
Family Gathering
Mount Prospect, IL

October 8
Bank of America Chicago
Chicago, IL

October 9
35th Annual Amber Gaines Memorial Golf Classic
St. Louis, MO

October 14
2023 Baltimore Running Festival
Baltimore, MD

November 4
Multidisciplinary Clinic for Adolescents and Adults
Baltimore, MD

Focus on Fundraising

COMING SOON: Online Pop-Up Shops

Would you like to shop for uniquely branded apparel and other items and help the CdLS Foundation simultaneously? Soon you will be able to do both with just a click of your mouse. Periodically, the CdLS Foundation will roll out new online pop-up shops.

"We realize that most of our repeat shoppers are families, and there may only be may only be so many products they want to purchase," explained Development Director Annette Scheidecker. "As a result, we plan to develop new imprint messaging and designs as well as colors for specific times of the year that will be unique and fun."

The online store is through CustomInk and allows the organization to create three unique print designs for ten different products for every pop-up shop. The designs and items will be different each time.

Look for branded items geared specifically for moms, dads, grandparents and more.

For every item you purchase, you receive a good quality product that helps bring awareness. You also help fund the CdLS Foundation, which receives a portion of every purchase.

Goodbye AmazonSmile, and Hello iGive.com

Earlier this year AmazonSmile ended their charitable giving program. Thank you to those of you who used that program to make online purchases, which included a donation of a percentage of sales to the CdLS Foundation.

Since 2015, your purchases through AmazonSmile have provided the Foundation with more than $22,000. Last year you raised $5,600 that went toward the organization's mission.

You can continue to make a difference for the CdLS Foundation and have a more significant impact by signing up to shop at www.iGive.com.

iGive.com™
Change online shopping for good.

There are 2,000 stores affiliated with iGive.com. On average those stores donate 3% of the funds from your sales to the charity of your choice - compared to AmazonSmiles which only donated half-a-percent. There are also multiple coupons and deals available on the iGive.com site.

Signing up is simple. Go to www.iGive.com and create an account. Then follow the prompts to select your charity of choice. After that, you can shop the stores and use the coupons available, knowing that with every purchase you make, you help the Foundation and the precious ones living with the challenges of CdLS.

SPRING APPEAL HEADING TO HOMES IN MAY

The CdLS Foundation staff works hard to innovate, serve, and streamline care and support to the thousands of community members they encounter.

This year, the compassionate team will travel more to meet with you at clinics and family gatherings nationwide. Meanwhile, the Ask the Expert medical, clinical, and educational volunteers are responding to increasing inquiries.

As resources and services expand, so do the organization's financial needs. As a result, you will receive a spring appeal letter asking you to donate what you can to help sustain the crucial work for the first six months of the year.

You will have the opportunity to donate by check using the return envelope or online by using the link that will be provided. No gift is too small.

Thank you for believing in the work the staff is committed to.

What Tax Strategies can be used for Charitable Contributions

Source: Fidelity.com

Many people know they can deduct donations to charity from their income taxes but increasing your knowledge of tax planning strategies can maximize your giving impact. Check out these easy tips.

1. **Long-term appreciated assets –** If you donate long-term appreciated assets like bonds, stocks or real estate to charity, you generally don't have to pay capital gains, and you can take an income tax deduction for the full fair-market value. It can be up to 30 percent of your adjusted gross income.
2. **Combine multi – ear deductions into one year -** Many taxpayers won't qualify for the necessary deductions to surpass the standard deduction threshold established by tax reform in 2017. However, you can still receive a tax benefit by "bunching" multiple years' worth of charitable giving in one year to surpass the itemization threshold. In off-years, you take the standard deduction. Use our Charitable Giving Tax Savings Calculator to estimate your savings.
3. **Estate Planning –** By naming a charitable organization in your will or as a beneficiary of a qualified insurance policy, retirement plan or trust, you reduce or even eliminate the burden of estate tax for your heirs. Your Giving Account continues to support the charities you love and your legacy lives on. (It is important to consult your tax and estate planning advisors regarding modifications to your estate plans.)
4. **Donor-advised fund –** A donor-advised fund is a dedicated account for charitable giving. When you contribute to a charity that sponsors a donor-advised fund program, you are eligible for an immediate tax deduction. You can then recommend grants over time to any IRS-qualified public charity and invest the funds for tax-free growth. Donor-advised funds provide many benefits for organizing and planning giving, but they also offer advantages in terms of income, capital gains and estate taxes. In some cases, these benefits are more advantageous than those from contributing to a private foundation.

By using the proper tax planning strategies, charitable contributions can reduce three kinds of federal taxes: income, capital gains and estate taxes.

1. **Income tax strategies –** Donations to 501(c)(3) public charities qualify for an itemized deduction from income. Because the tax rate is then applied to a reduced income, this can minimize your overall tax liability. Many donors don't realize that there are many ways to maximize this seemingly straightforward deduction. For instance, you can "bunch" your charitable contributions in a single tax year, using a donor-advised fund, to increase the amount you donate in a high-income year, and then the funds can be used to support charities over time. Or you can make a combined gift of appreciated assets and cash to maximize your benefits.

   Capital gains tax strategies – You can use charitable contributions to reduce your capital gains tax liability by donating long-term appreciated assets. Not only can you deduct the fair market value of what you give from your income taxes, you can also minimize capital gains tax of up to 20 percent. Assets subject to capital gains taxes can include investments like stocks or mutual funds, or hard assets like real estate. They can include assets that are both publicly traded or nonpublicly traded. For example, some givers donate shares of a private business before it is sold to dramatically increase their charitable impact.
2. **Estate tax strategies –**The federal estate tax is a tax on the transfer of your property at your death. In 2023 the estate and gift tax exemption is $12.92M per individual, so fewer estates will be subject to this tax.

   By making properly structured gifts and donations, you can remove assets from your estate before the total is tallied and taxed. In fact, you have an unlimited charitable deduction if your estate plan makes gifts to charities.

   Charitable tax strategies for estate planning purposes can be among the most complex, and it typically makes sense to consult a professional.

Bryn Clary

Kirsten Halstead

Bryn was born on December 25, 2000, with tons of curly hair, a sweet, upturned nose, and the funniest little cry I had ever heard. She weighed 6 lbs., 8 oz, a normal weight, but she was a full two pounds smaller than her big brother so she seemed tiny to me. She was the ultimate Christmas gift. Even so, my joy at my baby girl's birth was tempered with concern when I was informed that her head circumference was abnormally small, she had a soft heart murmur, and her right eyelid was droopy (known as ptosis). Being a NICU nurse I spent that first day with her trying to keep my anxiety at bay as I knew the potential meaning of each of those characteristics.

For most of her life, Bryn suffered most from neurologic issues. In her early months Bryn developed periodic head tilts and was diagnosed with benign paroxysmal torticollis - a pediatric migraine variant. The head tilts lasted until she was around a year of age. When she was two, she had her first generalized seizure. At first her doctor's felt that the seizure may have been a one-off, but at the age of three she started having strange startle like movements as she was drifting off to sleep. Her EEG showed that she was having myoclonic seizures and she was started on an anti-seizure medication.

Throughout her school years Bryn was plagued with neurologic issues. While we were able to take Bryn off her seizure meds when she was 5 years old, she continued to have periodic episodes where she would lose consciousness and look like she was having a seizure. When she was a Junior in high school she had several instances of extreme abdominal pain, followed by passing out and having a seizure. She sustained a concussion with one of these episodes. An EEG this time showed seizure waveforms and she was put back on seizure medication.

Right after Bryn graduated high school we moved from the Bay Area in California to Colorado, to be closer to family. Within a few months of moving, Bryn started to have very concerning episodes where she would become very dizzy, confused, and her vital signs would become unstable. She was diagnosed with POTS and then later an adult neurologist diagnosed her with insular seizures. She was hospitalized 6 times in two and a half years and had everyone puzzled because all her EEGs were negative for seizure activity. Her quality of life was terrible as she couldn't tolerate being upright for very long and she felt terribly ill. This occurred during the early days of Covid and because her doctors couldn't find a clear medical reason for her symptoms, they suggested that these "spells" were anxiety related. However, as a mother and an experienced nurse, I knew in my heart and my head that anxiety was a by-product of her episodes, not the cause.

As we were navigating this medical journey, I started working at Children's Hospital Colorado. I felt strongly that Bryn had a syndrome and knew that pediatric subspecialty care was what would help us get to the bottom of what making her so ill. With the help of some wonderful coworkers at Children's, we were able to get her admitted to the Epilepsy Monitoring Unit and after a few more admissions, were able to get a referral to Genetics. In September 2021, at nearly 21 years of age, we got the answer - Bryn has Cornelia de Lange Syndrome (*NIPBL* variant)!

From there we discovered that she had complete intestinal malrotation with significant adhesions and she had her repair in February 2022. Almost immediately after the surgery, Bryn's episodes lessened significantly. After one of her first full meals after surgery she said "Mommy, I never knew that when you eat, you should feel the food go down and not up".

Today, one year after her Ladd's procedure, Bryn is doing so much better. Her neurologist believes strongly that her seizure-like episodes most likely were from her vagus nerve being stimulated and causing her to pass out and have seizure like movements. Bryn has been weaned off all her seizure meds which has made a world of difference in her ability to think clearly. Though she has been diagnosed with hemiplegic migraines, she is working hard on finding out what her triggers are to decrease the number and severity.

The Foundation has been so incredibly helpful to our family as we have sought answers to a million questions and navigated all the testing that needed to be done upon diagnosis. Knowing that we can reach out anytime and get expert support and answers is such a comfort. Bryn attended the clinic in Baltimore this past October. It was so wonderful to make connections with other families and to meet in person everyone who has helped us so much in one short year. Knowing that there are so many other families navigating these waters has helped us to feel not so alone and that is priceless.

Despite this long tale about Bryn's medical journey, it's important to know that she is so much more than her diagnoses. She is a funny, persistent, intelligent, sweet, and loving young woman. Instead of taking what others tell her at face value, she will research the subject and come to her own conclusions. She loves to watch movies and television shows (she loves slapstick comedy), to spend time with her family, and to read about living a healthy life. Right now, she is reading about healthy sleep habits! Her goal is to become a certified nursing assistant (CNA) so that she can work with ill children. Her quiet, sweet demeanor and the fact that she knows what it is to be a child with a chronic and serious health condition makes her perfect for this line of work.

Bryn is the most resilient person I know.

To read Kristen's full story, visit: www.cdlsusa.org/on-the-cover-bryn-clary

To watch Bryn's story, scan the QR code.

WELCOME
New Families

California
Douglas Bodger and daughter Penelope, born 12/17/2018

Connecticut
Francesca Torres and son Noah, born 7/22/2022

Illinois
Samantha Brown and Edward Patterson and daughter Naya, born 2/22/2022

Minnesota
Tiffani and Taylor Hoffbeck and son Riggins, born 12/11/2020

Ohio
Leslie and Ryan Schilling, daughter Aubrie born 9/24/2021

Tennessee
Carrie and Zach Willmore daughter Letty, born 8/12/2018

The Schilling Family

My sweet daughter Aubrie was recently diagnosed with CdLS. It has been tough adjusting to this diagnosis and all my daughter's recent medical appointments. I reached out to the CdLS Foundation, and Linda has been excellent and helpful. She has given us resources and checks in often. I am thankful to her and this organization for helping us navigate this life change. Aubrie is a happy girl and loves playing with her sister Zoey. They are the best of friends, along with our two dogs

Our Deepest Sympathy

Blake Clanton
October 12, 2001-
October 29, 2022
Daughter of Samantha and
Daniel Clanton
127 Lake View Circle
Montgomery, TX 78626

Alice McClanahan
August 2, 2016 –
December 6, 2022
Daughter of Samantha and
Jake McClanahan
1035 Massachusetts Street
Lawrence, KS 66044

James Whitlach
September 4, 1989 –
November 20, 2022
Son of Kiperly and
Eric Whitlach
387 Bridge Street
Waynesburg, PA 15370

THE GRIEF SUPPORT ADVISORY GROUP IS HERE TO HELP

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

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

ADVICE FROM A LITTLE BOOK ABOUT GRIEF

New grief publication by the CdLS Foundation

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

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

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

The Rauscher Family

Every journey through the world of CdLS is different. Unfortunately, some journeys are shorter than others. When the live of an individual with CdLS ends, their families often continue to lean on the Foundation for support services and guidance. In the past, there were no offerings, however, over the last few years, staff members with a group of committed parents, have created a safe and caring world for families who have lost of a loved one with CdLS. Below is one of their stories, from both perspectives, mom and dad.

Rolfe's Story

The year 1996 changed our lives forever. We were blessed with a spunky little girl, Nikki. Shortly after birth, she was diagnosed with CdLS, something we were not ready for. We soon connected with the CdLS Foundation and learned of the many challenges she would be facing. However, Nikki seemed to surpass expectations of her. I was a stay-at-home dad, so I was the primary caregiver for Nikki. Nikki and I went everywhere together.

Nikki passed away in 2015 and is in my heart and mind daily. When that happened, I lost my daughter and my primary purpose in life. My grieving process was to shut people out. I would hermit gently and to varying degrees. Interacting and being involved with others CdLS families as Team Nikki helped me open up. Approximately two years ago, I lost my eldest son, who had Spina Bifida, and compounded with the loss of Nikki, it caused me to go into almost total seclusion for about two months. I slowly opened up with the help of family, friends, medical professionals, and CdLS families on social media. Opening up to them, I realized I did have a purpose in life and wanted to carry on with Nikki's legacy.

Dawn's Story

Grief is a part of my daily life. There's not a moment in any day that I'm not reminded of her. Nikki was only a few weeks old when the doctors told us she had a grave prognosis. So, the grieving started then – fear of her unknown future was heartbreaking for any parent to hear. But I couldn't stop asking, "how do you know what she is capable of? "I told my husband she could grow up and be famous for all we know.

Reflecting on that statement, I see Nikki exceeded all that! She touched an abundance of hearts throughout her lifetime and through social media at the end of her journey. It wasn't long after her death, I walked into the store and caught a glimpse of girl's clothing, and the tears just started – no more clothes for her – we were always told she would win the award for best-dressed child. Over time it does become a little easier, but I know she is always with me in spirit and often reminds leaving her pennies – we have quite the collection.

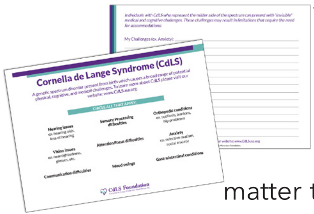
Eight years later, grief still lives in my heart, and every so often, it will leak out through my tears, and I take a moment to reflect and be grateful for the 18 years we had together.

At the CdLS Foundation, we are striving to ensure our stories are capturing what you want to hear about. Do you have questions for the Rauscher family or suggestions for staff? Email outreach@CdLSusa.org.

New Materials for YOU

Family Service and Communication teamed up and created a variety of awareness materials for the whole family. If you are interested in receiving any of these collateral items, contact Family Service at familyservicesteam@CdLSusa.org.

ADULT AWARENESS CARDS



Individuals with CdLS who represent the milder side of the spectrum can present with "invisible" medical and cognitive challenges. These challenges may result in limitations that require the need for accommodations:

My Challenges (ex. Anxiety):

Cornelia de Lange Syndrome (CdLS)

A genetic spectrum disorder present from birth which causes a broad range of potential physical, cognitive, and medical challenges. To learn more about CdLS please visit our website: www.CdLSusa.org.

CIRCLE ALL THAT APPLY:

Hearing issues ex. hearing aids, loss of hearing

Vision issues ex. nearsightedness, glasses, etc.

Communication difficulties

Sensory Processing difficulties

Attention/focus difficulties

Mood swings

Orthopedic conditions ex. scoliosis, bunions, hip problems

Anxiety ex. selective mutism, social anxiety

Gastrointestinal conditions

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These fillable cards would be a great self-advocacy tool for any individual with CdLS who attends extracurricular activities, employment, or volunteer opportunities in the community, no matter their communication level. It currently is available in English.

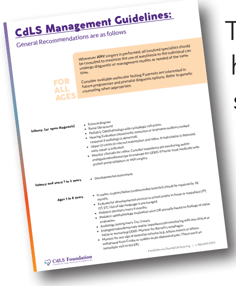
GENE BROCHURE

KNOW YOUR CdLS GENE

CdLS Foundation

This new brochure gives an overview of body systems affected, findings you may see. It reviews management guidelines, the genetics of CdLS, and the prevalence of individual gene changes. It currently is available in English.

UPDATED MANAGEMENT GUIDELINES



CdLS Management Guidelines:

General Recommendations are as follows

FOR ALL AGES

Whenever **ANY** surgery is performed, all involved specialists should be consulted to maximize the use of anesthesia so the individual can undergo diagnostic or management studies as needed at the same time.

Consider available molecular testing if parents are interested in future pregnancies and prenatal diagnosis options. Refer to genetic counseling when appropriate.

Infancy. (or upon diagnosis)	Echocardiogram Renal Ultrasound Pediatric Ophthalmology with cycloplegic refraction. Hearing Evaluation (otoacoustic emissions or brainstem auditory evoked response if audiology is abnormal). Upper GI series to rule out malrotation and reflux. If malrotation is detected, early repair is indicated. Monitor clinically for reflux. Consider impedance pH monitoring and/or endogastroduodenoscopy to evaluate for GERD. If found, treat medically with protein pump inhibitors or with surgery.
Infancy and every 1 to 3 years	Developmental assessment.
Ages 1 to 8 years	In males: cryptorchidism (undescended testicles) should be repaired by 18 months. Evaluate for developmental services in school and/or in home or outpatient (PT, OT, ST). Use of sign language is encouraged. Pediatric dentistry every 6 months. Pediatric ophthalmology evaluation once OR annually based on findings of initial evaluation. Audiology testing every 2 to 3 years. Endogastroduodenoscopy and/or impedance pH monitoring with any clinical or initial or worsening GERD. Monitor for Barrett's esophagus. Monitor for any sign of potential volvulus (e.g., bilious emesis or bilious withdrawal from G tube or sudden acute abdominal pain. These merit an immediate visit to the ER).

CdLS Foundation

FamilyServiceTeam@CdLSusa.org | t. 860.899.9391

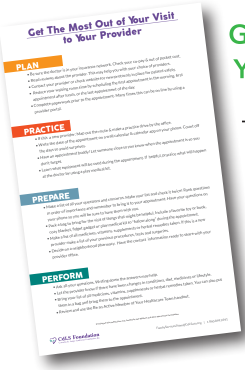
The revised Management Guidelines highlight routine care for people with CdLS by specific age groups, including infancy, early childhood, adolescence, and adulthood. At each age, individuals with CdLS will have particular healthcare needs. These guidelines are in English and Spanish.

PROVIDER LETTER

Family Service Coordinators, along with Dr. Kline, have updated the CdLS Foundation's provider letter.

The purpose of this letter is to educate any new medical or therapeutic professionals about the diagnosis of CdLS, the genetics behind it, the prognosis, and where to go if they have any questions. It is so important to educate new professionals about CdLS to encourage more understanding in the medical, educational, and therapeutic fields. This letter comes in English and Spanish.

GET THE MOST OUT OF YOUR VISIT TO YOUR PROVIDER



Get The Most Out of Your Visit to Your Provider

PLAN
- Be sure the doctor is in your insurance network. Check your co-pay & out of pocket cost.
- Read reviews about the provider. This may help you with your choice of providers.
- Contact your provider or check website for new protocols in place for patient safety.
- Reduce your waiting room time by scheduling the first appointment in the morning, first appointment after lunch, or the last appointment of the day.
- Complete paperwork prior to the appointment. Many times this can be on line by using a provider portal.

PRACTICE
- If this a new provider: Map out the route & make a practice drive by the office.
- Write the date of the appointment on a wall calendar & calendar app on your phone. Count off the days to avoid surprises.
- Have an appointment buddy! Let someone close to you know when the appointment is so you don't forget.
- Learn what equipment will be used during the appointment. If helpful, practice what will happen at the doctor by using a play medical kit.

PREPARE
- Make a list of all your questions and concerns. Make your list and check it twice! Rank questions in order of importance and remember to bring it to your appointment. Have your questions on your phone so you will be sure to have them with you.
- Pack a bag to bring for the visit of things that might be helpful. Include a favorite toy or book, cozy blanket, fidget gadget or play medical kit to "follow along" during the appointment.
- Make a list of all medicines, vitamins, supplements or herbal remedies taken. If this is a new provider make a list of your previous procedures, tests and surgeries.
- Decide on a neighborhood pharmacy. Have the contact information ready to share with your provider office.

PERFORM
- Ask all your questions. Writing down the answers may help.
- Let the provider know if there have been changes in conditions, diet, medicines or lifestyle.
- Bring your list of all medicines, vitamins, supplements or herbal remedies taken. You can also put them in a bag and bring them to the appointment.
- Review and use the Be an Active Member of Your Healthcare Team handout.

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CdLS Foundation

This document, developed with the Empowerment Team, is to help you prepare for medical appointments and get the most out your time with providers during a medical appointment. It is available is English and Spanish all in one document.

UPDATE YOUR CONTACT INFORMATION WITH US

The CdLS Foundation wants to keep you informed with the latest information about CdLS or events you can attend. Be sure your contact information is up to date. Send updated contact information to familyservicesteam@cdlsusa.org.

In Honor/ Celebration

Gregg Abbott
Jan and Jim Abbott

Eva Aykut
Dhaval Patel

Brandt Anderson
Wayne Shull

Audra Andrus
Peggy Wingo

Max Balthazar
Elizabeth Balthazar
Ryan Shuwarger

Hunter Barrett
Gary Hartman

Jesse R Bassett
Robyn Dietzinger

Landa Beard
Mark Ferguson

Aubrey Bender
Brooke and Travis Bender

Lizzie Bernhardt
Nancy A. and Michael D. Bernhardt
Daniel Linert
Rita Linert

Jillian Billings
Sandra Beickert

Angel Bock
Scott Figari

Hannah Boehman
Neil Boehman

Aisley Ross Birrer
Jenna Peterson

Sara Bumgardner
Janie and Larry Bumgardner

Leia Caudle
Margaret Caudle

Julie Champion
Andrew and Lori MacLeod
Mason Gilbert and Charles Dahl
Jennifer Robins

Matthew Chevrette
Lori and Michael Chevrette

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Pam Powers

Dane Curalli
Tanya Shane

The Curalli Family
Pauline and Byron Anderson

Mason & Charlie Dahl
Kelly Oneill

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Gricelda Contreras

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Edward Hoen

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Joseph Delisi
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Ken and Lucille Hicks

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George Jacobsen

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Liana and Michael McKenna

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Jennifer Blakeslee

Devin Miller At Christmas
Lynnette and Dean Miller
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Margaret Walters

Henry Miller's Birthday
Myrna Kaplan

Nicole Miller's 30th Birthday!
Susan and Chip Terhune

Sam Miller's Birthday
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Deb Hood

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Barry Pugh

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Mary Ahearn
Elise and Rick Ahearn

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Lisa and Thomas Alicata

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Janice and Thomas Auld

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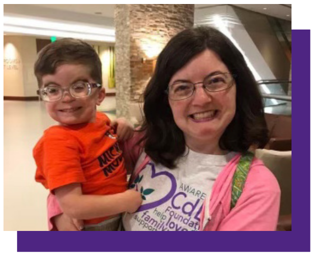

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Join Families Across the World to Celebrate International CdLS Awareness Day

International CdLS Awareness Day will be held on May 13 this year. We are encouraging every family to celebrate. Let's spread awareness about CdLS. Need inspiration or ideas? Connect with Gabrielle Nadeau at the CdLS Foundation at gnadeau@CdLSusa.org. Interested in becoming an Awareness Coordinator? Gabrielle can show you how. Together we can educate the world about your loved ones.

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