

REACHING OUT

WINTER 2021

**Constipation
and CdLS**

ON THE COVER

The Hendricks Family



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

A Look Back at 2021

The past year has been another one for the record books. Along with you, we've been on a shared journey to advance our work together of raising awareness, supporting each other, and improving programs and services for those living with CdLS from coast to coast.

Since January, the Family Services team has held over 800 conversations with parents, grandparents, and professionals looking for information and support. Deirdre and Whitney have worked closely with some of our Regional Coordinators to better understand and give voice to the concerns of parents, and to provide information on local services available on the west coast. We have also been collaborating with Boston Children's Hospital and local parents in the Northeast to open a new CdLS Clinic there.

Other projects include creating a plan to work with parents and the research committee on future patient-centered research projects, as well as collaborating with Jackson Labs.

In 2021, we formally created two new committees - the Grief Advisory Committee and Tele-health committee. The Grief Advisory committee is helping us to create programming and support for families who have experienced the loss of a child. The Tele-health committee is exploring ways to support the health-care experience for caregivers and CdLS patients. We are in the early stages of development and exploration here, but certainly welcome your feedback and any thoughts you'd like to share.

For the past 40 years the CdLS Foundation has weathered many storms. I feel a great sense of pride in what we have all been able to accomplish together. As we prepare to walk boldly into the new year, I want to thank each and every one of you for standing by us over this difficult last year. I hope you will enjoy this issue of **Reaching Out**. Cheers!

Bonnie



Bonnie Royster, CdLS Foundation
Executive Director

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FLU SEASON



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

It is wintertime and, as you know, not only does this bring colder air to much of the country, it also brings “flu” season, or infection due to the influenza viruses, regardless of the weather. Influenza, or the “flu”, can present very suddenly and can cause a mild illness with few symptoms, or a major one with severe complications. It spreads by inhaled droplets which were formed from an infected person coughing, sneezing or talking forcefully. Sometimes it can spread by touching something that has the droplets and then touching an entry point, such as mouth, nose or eyes.

Within 2-4 days of acquiring the droplets, symptoms can begin, although a small percentage of people remain without symptoms. The flu typically presents with respiratory symptoms, such as congestion, cough and difficulty breathing. Some people will require oxygen if it progresses severely. Often, there is a fever, as well as chills. Other symptoms include: sore throat, runny nose, muscle or body aches, and major fatigue. Headaches can develop, and occasionally there can be vomiting and/or diarrhea. It tends to last about two weeks.

People with the highest risk for severe flu infection include those with respiratory complications and immune deficiencies; chronic health problems like asthma, diabetes and heart disease; and those very young or above age 64, but people of all ages are at risk. Individuals with syndromes,

such as CdLS, are not at increased risk to catch the flu unless they have a known risk factor. The “flu shot” is recommended every fall for everyone above 6 months of age and is a vaccine that fights against the influenza virus. The flu can largely be prevented by getting the vaccine, and most years it is very effective. This is for adults and children of all ages, including those with CdLS. There are minimal side effects for this vaccine, other than a sore arm. For those vaccinated people that do catch the flu, the symptoms will be much milder. In addition to the vaccine, there are preventative actions such as frequent hand washing, covering mouth and nose when sneezing and coughing, avoid touching the face, and remaining at home if symptoms develop. More information can be obtained at [cdc.gov/flu/](https://www.cdc.gov/flu/).

This year in addition to the flu, there is a continuation of the COVID pandemic due to SARS-CoV-2. The symptoms of these viral infections can be overlapping, and it may be difficult to tell which infection somebody has. Both infections have preventative vaccines, recommended by the medical community. This winter, it is recommended to be vaccinated against both COVID and influenza.

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Constipation in CdLS

Carol Potter, M.D., Nationwide Children's Hospital and CdLS Foundation Clinical Advisory Board (CAB) Member

Constipation is a common problem in individuals with CdLS. The onset of problems may be subtle, and unfortunately it can lead to trips to the emergency room.

There are a variety of causes for constipation in CdLS. Many with CdLS don't have normal motility of the intestines. This can lead to more time for the colon to extract water from the stool, resulting in hard stools. High pain tolerance can also lead to ignoring the urge to stool. Some with CdLS will have ineffective behaviors when trying to stool where they both hold and push at the same time. They may also have withholding behaviors because they associate the urge to stool with hard painful to pass stools. They may also have a diet which is low in fiber, which also allows the stools to become hard.



With time, chronic constipation, or the infrequent passage of stool can lead to stretching of the colon. The stretching of the colon makes it more difficult for the muscles to push the stool out and makes it more painful to pass. Once the colon is dilated it stays that way unless it can be kept empty for several months. A large stool burden in a dilated colon can lead to a medical emergency called volvulus where the colon is so heavy that it falls over on itself, twisting and cutting off the blood supply to the bowel.

There are many ways to deal with constipation with prevention being the best approach. Careful monitoring to make sure there are daily or every other day stools is important. Aim for stool that is soft and easy to pass in appropriate amounts. Warning signs for constipation include infrequent, very large or hard stools. Once the colon is blocked with hard stool you may see what looks like leaking or diarrhea. This is liquid stool seeping around the edges of a large stool mass.

There are several categories of agents that can be used:

- 1. Softeners:** These agents hydrate the stool helping to keep them soft or hold water in the stool to keep them soft and include Milk of Magnesia and Polyethylene Glycol 3350.
- 2. Stimulants:** These agents are topical stimulants to the colon and can be very helpful with slow motility or holding behaviors. These include senna and bisacodyl.
- 3. Fermentation Agents:** These cause fermentation in the colon which produces gas to make the stool looser. These include, apple juice, other juice, lactulose. Sometimes they are easier to give since they are sweet.

Giving therapy on a regular basis rather than only when there is a problem can prevent the chronic stretching of the colon and repeated impactions. Stools are going to vary from day to day so aim for the middle of what you want. I recommend a soft and easy to pass stool about 5 days a week.

Some patients with constipation will appear to have diarrhea because liquid stool is leaking around a large stool plug. This is more common in kids with chronic constipation with very large stools that clog the toilet.

Ask your doctor about a regular bowel regiment. It is good to have a rescue plan if the constipation gets worse as well as a plan when the constipation is severe. Change in routine such as school and travel may cause more problems so be attentive during those times.

Constipation Issues

Janice Haley

Klara, my daughter, was diagnosed with CdLS a couple of days after birth. She was our first child and like most babies she took some time to figure out. Through information on the CdLS Foundation's website we knew that Klara would have acid reflux for sure and many other things were possible. Klara had many checks and tests run in those early years and we felt blessed that she was a relatively healthy girl.



Klara was orally fed from birth but was vomiting her breastmilk at each feed. We tried several things and settled on a soy-based formula with cereal added in. This seemed to do the trick for her. Once we got the food to stay in, the constipation started.

Constipation was something we were always battling. When she was young, we started with juices; apple and prune, and often still had to use suppositories to get any action. As Klara got a little older, we began using stool softeners prescribed by the doctor. In those early years I was not aware of the slow motility in some of our kids, so I think I worried more than necessary about the lack of bowel movements (BM). I was however aware of the possibility of twisted bowels and total blockages, and that was always a fear.

Klara was not having as many bowel movements as I wanted her to and when she was straining to go it would often cause her to cry as well as vomit through her nose. I did not like that! By the time Klara was two or three, we had switched

back to regular milk because her sister was a toddler and switching to whole milk at that time. Around that same time, we started using MiraLAX. First in small doses and then increasing over the years. I think The MiraLAX caused her some gas and stomach pains that I was attributing to reflux pain for a long time. It's so hard to tell with kids who are non-verbal.

Klara was diagnosed with Eosinophilic Esophagitis (EOE) around the age of 15 when she had her first upper endoscopy. While doing some allergy testing and elimination diets to help with EOE, we discovered that non-dairy really improved her constipation issues. It improved so much so that we decided to stop giving her MiraLAX and eliminate dairy from her diet. After the first couple of months, as the head chef at our house, I decided that small amounts of dairy in the family meals would probably be fine if it wasn't a glass of milk, bowl of ice cream, or cheese sticks. After making that change, I felt it was necessary to start giving her a dose of prebiotic fiber powder in her morning drink.

I think for now we have found the sweet spot for Klara. She has a regular rhythm to her digestion and hopefully this will continue to work for some time. One piece of advice I wish I could go back and give myself would be that it's OK if your child doesn't have a daily BM (or even every other day). And you're doing a good job, don't give up and don't settle into a routine that's not working.



Advice I would give any new family to CdLS would be to go to at least one conference. We went when Klara was just one year old, and it really helped to alleviate some fears I had for my daughter's future. It allowed me to see a range of abilities in our kids with many happy parents and kids at each stage of life. And finally, just a big thanks to everyone at the CdLS Foundation for continuing to do research and improve the information we have that makes all our families' lives a little easier.

BRIAN MONASMITH

I am the owner of A2B Transportation, LLC and has been in the trucking industry for most of my adult life. In July 2014, my granddaughter, Aelycia, was born and at six months was officially diagnosed with CdLS. Like most families, mine had never heard of the syndrome, thus we all took a crash course on CdLS and started "On A Journey Never Planned". We were told Aely would probably never roll over, crawl, stand up or walk. Well, they were wrong. She did all these things although a little later than usual. However, they were right about the walking, she runs everywhere she goes. While Aely is on the lower end of the spectrum she is partially blind in one eye, partially deaf and is classified non-verbal. At age 7, she says few words, but 'Pop-Pop' is one we hear more and more.



From very early on the bond between Aely and me has been phenomenal and taken second place to almost no one else. When she sees my truck in the driveway after a trip, she gets very excited, squeals and dances around while smiling her biggest smile. She then runs to meet me and won't let me out of her sight for the duration of my time at home. She insists on helping me unload my things from the truck. She absolutely loves going for rides with me.

I purchased my first truck in February 2017 and A2B (Aely to Brian) was formed. I became determined to find a way to make the world, or at very least the population of the USA aware of CdLS. On May 13, 2017, Lisa Fisher, owner of Elf Creations, applied the CdLS lettering to my truck. My hope was to raise awareness for CdLS Awareness Day. Also, that year, with a lot of strategic planning, I managed to be in Portland, Oregon for the June 2017 Family Gathering. I took my truck to the event and had pictures with most of the families in attendance.

Ironically, in July 2021 I was on my way to Tulsa, Oklahoma

to trade in my truck when I was spotted in Iowa by a fellow CdLS family member and trucker. Almost immediately a picture of the truck was posted on the CdLS Discussion Board with the statement "who is this guy and I want to meet him". Within hours it was commented on by several other families. Since that posting, I have met up with many families in various locations and hope to meet more in the months and years ahead.

In August 2021, I contracted Thunder Graphix in Joplin, Missouri to design and install the graphics package for the new truck. This is just the beginning as I hope to upgrade the graphics and include the trailer.

In my travels, someone will approach me and ask about CdLS, so I have information on hand for them as well as verbally give them an overview of CdLS. My inspiration for doing this is my granddaughter, Aelycia, and the families everywhere who have a loved one affected by CdLS. The ultimate goal is to raise awareness about CdLS. I hope that every day I am on the road someone will see my truck and take the time to educate themselves. This idea has been further advanced by the CdLS heart logo on the back doors of my trailer along with the QR code to guide anyone interested to the CdLS website. My theory is if my truck is going to be out there anyway, what better way to spread the word about CdLS.



I can be found on Facebook and Instagram. I can also be reached on messenger or by email at Brian@A2btransportationllc.com. I hope to add Facebook and Instagram pages for the CdLS Truck and A2B Transportation LLC in the future.

Do you know any Inspiring Individuals? Tell us their story by emailing Gabrielle at gnaudeau@CdLSusa.org.

An Open Letter to My Best Friend with A Disability

Everyone learns something from their best friend.

Dear Best Friend,

We have known each other ever since Pre-K. We started talking in 4th grade, and ever since then we have been inseparable! I have had your back for as long as I can remember, and I know you always have had mine. You always talk so nicely about me, and it makes me feel amazing to know I have an amazing best friend like you! Remember we would meet weekly with a teacher in elementary school? We would have group meetings and we would play these fun games and always talk.

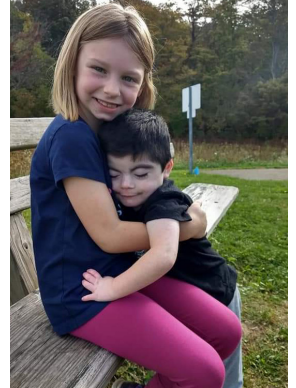


I have learned so much from you! Everything about your disability makes me more curious every day. It has opened my mind about kids/ adults with disabilities. Everyone is not the same, and

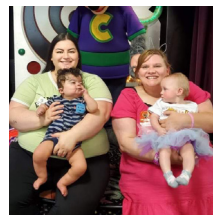
no one will be the same! We are all different, and you my wonderful best friend are not different, or "normal"; no, you are none of those! In my book you are unique! You have opened my eyes, and I can't thank you enough!

Your disability never stopped you. You are a positive, and wonderful young lady! I have seen you grown from a little girl with a walker to a wonderful young lady who can walk faster than me! You smile all the time, with that smile you light up the whole room, with that smile you will never be put down! No one will shove you around and no one will

make you fall with that smile. Your laugh is very contagious, when you laugh, I will always laugh! You laugh at the smallest things! if I say the word "booty" you would laugh. Your jokes are very hilarious, sometimes they don't make sense, but I laugh anyway because you are my best friend and I love you.



Now I am in college, and it's the first time we have been a far distance away from each other. You call me every day, and whenever I can't pick up you will leave me the most amazing voicemail's that make me cry sometimes.



Being with you ever since Pre-K has been life changing! You have taught me everything that I never knew before I had met you!

XOXO



HIGHLIGHTED EVENTS

TEAM CdLS RUNS ON TO VICTORY IN CHICAGO & BALTIMORE

Both the Chicago Marathon and Baltimore Running Festival were held in-person this year. Team CdLS runners chose to run either in the in-person events or virtually on their own in October. This group of athletes showed great fortitude as they determined to push their bodies and raise money for the CdLS Foundation and the wonderful families whom we serve.



Runners in Chicago really pushed through some unprecedented heat and humidity to cross the finish line. At one point, race officials announced a Code Red Threat Level, telling runners to walk and stop running because humidity levels had become too high to run safely. Despite the weather, the runners pressed on. Meanwhile, in Baltimore, runners celebrated the Running Festival's 20th anniversary by competing in either the full marathon, half-marathon, 10K or 5K races.

Because of their perseverance and with the help of their supporters, as well as an incredibly generous anonymous benefactor, who matched every donation dollar for dollar up to \$40,000...Team CdLS runners blew past their fundraising goals. The team's effort in both Chicago and Baltimore grossed more than \$92,000 for the CdLS Foundation!

Our thanks to our amazing Team CdLS marathoners. Team CdLS Chicago: Luisa Borges, Jane Champion,

Bree Cunningham, Ashley Doody, Robert Doody, Rich Flaherty, Ava Frank, Jennifer Kelly, Frank Mairano and Bree McDermott. In Baltimore: Team Peyton with captain Tasha Howland, and runners Christal Harris, Juanita Greene, Verita Mason-Frempong and Kofi Frempong. Running for Baltimore with team captain Tonie Kline and runners Alex Levin, Kelly Hardy, Doug Clemens, Eli Clemens, Paul Kruzka, Alison Eaton, Patti Caudill, Beatriz Kolher, David Roberts, Shirly Vojtecky, and Aimee Holleb.



And a very special thank you to our anonymous donor, who chose to match donations made to this year's runs as a way of inspiring our Team CdLS runners and to help support the important mission of the CdLS Foundation.

GOLFERS SHOW THE LOVE FOR THOSE WITH CdLS

Despite another challenging year fraught with lingering Covid concerns, the CdLS Foundation's two signature golf fundraisers managed to raise more than \$123,000 for the organization collectively in 2021!

On a crisp fall morning in late September in Ipswich, MA, golfers lined-up at check-in for the **28th Annual New England Golf Classic**. The excitement had been building for a little over a year in part because the event was postponed due to the pandemic.



Eighty-four golfers were treated to an exciting day of golf, prizes, delicious meals, a silent auction and several contests.

"We had an absolutely beautiful day!" remarked Committee Chairman Pat Lyons. "It was so nice to be able to build awareness, raise money, and enjoy being with friends and family."

Thanks to the dedicated volunteer golf committee and the generous support of people near and far, the event grossed close to \$50,000.

As the New England golfers were winding down, organizers of MCWP & PLM's **Amber Gaines Memorial Golf Classic** in St. Louis, MO, were gearing up in mid-October to host more than 100 golfers at their 38th annual golf fundraiser.

This event is one of the CdLS Foundation's largest annual fundraisers, bringing in over **\$76,000** this year, and raising more than **\$900,000** for the Foundation and our families in over three decades!



Named after Amber Gaines, the daughter of MCWP Vice President, Doug Gaines and his wife Barbara, this golf event has become a memorial tribute to Amber, who sadly passed away last year, at the age of 38. Amber had been diagnosed with CdLS when she was a baby.

"Our goal is to bring hope and love to families who struggle with CdLS. It's a rare disease that many are unfamiliar with," explained Bryan Kesting, MO Golf Co-Chair. "The more awareness and support we can bring, the more resources we have to help these families."

Thank you to all of the committee members, volunteers and supporters of both of these incredible events. The Foundation couldn't do what it does without you!

MOMS RAISING FUNDS & AWARENESS

Two annual fundraising events produced by two moms in two different parts of the country continue to raise funds for the CdLS Foundation both in honor and in memory of their children with CdLS.

In Michigan, Maureen Feighan-Kurth reached out to her friends and family and asked them to rally together in October and walk two miles to raise money for her **Walk for Will and Hope** fundraiser. Maureen began this annual event after her son Will, who had CdLS sadly passed away in 2005. Her daughter Hope, who is now 13 years old, also has CdLS. The walk is in memory of Will and in celebration of Hope. It was another successful event for Maureen and her family, as thanks to their generous supporters they raised more than their goal to bring in over \$6,000 for the CdLS Foundation.



Meanwhile, more than a thousand miles away in Georgia, Fran Rissland was glad to hold her **12th Annual Brew & BBQ** also in October, in-person once again, after holding a virtual event last year due to the pandemic.

Friends and family purchased tickets to attend a fun-filled evening complete with delicious barbeque, local brews, live music and auction items.

The Brew & BBQ not only puts the fun in "fun"draiser, but it also is a great opportunity to raise awareness about CdLS and the Foundation. Fran's 17-year-old son Riley, who has CdLS, is the inspiration behind the event.

It is thanks to families like the Feighan-Kurth's and the Rissland's that the CdLS Foundation receives funding to help ensure that we can continue the important work that we do to help our Foundation community. We are so very grateful.

If you would like to start your own third-party fundraiser for the CdLS Foundation, please contact the Development office at events@cdlsusa.org or 800.753.2357.

CALENDAR2022

February 12

CdLS
Remembrance Day

February 28

Rare Disease Day

April 2

Multidisciplinary
Clinic for Adolescents
and Adults
Baltimore, MD

May 14

CdLS Awareness Day

May 23

New England Golf
Tournament
Massachusetts

June 11

Hit the Trails
Avon, CT

ANGIE'S JOURNEY FOR SIBLINGS

In Memory of Aaron

It takes a special and brave heart to set out on a journey to raise money for others after having lost your beloved son just four months earlier... and that is just the kind of heart that CdLS Foundation Board Member Angie Young has.



While she and her family continue to grapple with the terrible loss of her 41-year-old son Aaron, who had CdLS and passed away in May, Angie decided this summer to channel her pain into something exquisite.

On September 21st, Angie and her sister Dee Dee flew from Florida to Arizona to take on a 21-mile fundraising hike from the South Rim of the Grand Canyon to the North Rim all in one day.

Their goal? To raise \$10,000 in scholarship money to enable siblings of those with CdLS to attend the sibling program at the next National Family Conference. As the CdLS Foundation's Conference Co-Chair since 2010, Angie is very well versed on its programs and their effectiveness.

The name of the sibling program is *Kids Explore*. The program consists of two days of planned outings just for siblings. It offers them an opportunity to form new friendships with others who also have a brother or sister with CdLS. It gives siblings a chance to open up to one another regarding CdLS if they choose.

"I have always known that Aaron's siblings, Chris, Justin, and Kendal, loved Aaron, and he impacted their lives considerably," explained Angie. "However, I was not

prepared for his death's impact on them or us as a family."

It is that sensitivity to the impact that Aaron's life is having on his siblings, that inspired Angie and Dee Dee to take their journey for siblings in memory of Aaron.

"As much support as I have received from the Foundation and other parents over the years, and now with Aaron's passing, I realize his siblings and other siblings need the connection too from their peers and the Foundation," Angie commented further.



Aaron with little sister Kendal

You can help Angie reach her goal and help siblings of those with CdLS attend the *Kids Explore* program at National Conference by making a donation to her fundraising link: bit.ly/HikingForSiblings.

Update to Donating Your Loved Ones Organs

There were many questions asking about the process of donating your loved one's organs after their passing. Although this can be an overwhelming time, we hope these steps provided by Sarah Raible, M.S., LCGC, from Children's Hospital of Philadelphia (CHOP) and unos.org can help you better understand the steps. Even though cases vary, the following describes the basic steps in donation:

- 1. Brain death declared:** Brain death is diagnosed as an irreversible loss of blood flow to the whole brain, causing the brain to die. After brain death, the donor's body is supported by artificial means, such as a ventilator.
- 2. Evaluation:** Specially-trained medical practitioners from the organ procurement organization (OPO) go to the hospital to see if the patient is medically suitable for organ donation.
- 3. Authorization:** The doctor talks to the family about the patient's death. Then, someone from the OPO, or specially-trained hospital staff, talks to the family about donation. If the patient signed up to be a donor in his/her state or national registry, that information is shared with the family and the OPO family counselor talks to the family to explain the donation process and answer all of the family's questions. The OPO and hospital work together as a team to support the family and honor the patient's wishes.
- 4. Placement:** The donor's data are entered into a national computer system to begin the organ allocation process. Appropriate candidates are found. Timing is especially important at this step and during recovery.
- 5. Organ recovery:** The donor is taken to an operating room, where organs are surgically removed. After that, the organs are sent to the transplant hospitals where candidates are waiting for them. The donor is treated with honor and respect throughout the donation.
- 6. Funeral:** After donation, the donor is taken to a funeral home, and the OPO works with the funeral director to honor the donor and donor family's funeral wishes. An open casket funeral is possible after organ donation.

- 7. Follow-up:** A few weeks later, the OPO sends a letter to the donor's family, letting them know which organs were transplanted while keeping the names of the recipients confidential. Most OPOs continue to provide support to donor families, such as bereavement counseling and later, memorial events.

If you are donating tissue for research, CHOP has families sign a consent form. They would then work with the medical experts where your loved one is to collect and ship the samples as soon as possible.

Six Accessible Clothing Lines for Teens and Young Adults with Special Needs

- 1. Silvert's** offers affordable styles for a variety of special needs, such as jeans and pants, shoes, tops, comfortable and easily removable undergarments, cute adaptive sleepwear, dress shirts, slip resistant socks, and so much more.
- 2. Rackety's** is a UK-based brand (which ships internationally) offers a selection of outerwear, shirts, pants, vests, pajamas, and more that are accessible and colorful. You can also find wheelchair capes, accessories, and underwear.
- 3. Able2Wear** is another UK-based company which also ships internationally. It offers a wide variety of clothing for teens and young adults in wheelchairs. Working men and women can also find clip-on ties for the office.
- 4. Ross Daniel Adaptive Apparel** offers resistant socks, waterproof bandana scarves, and ProtecTees clothing protectors that come in cool prints and colors.
- 5. Patti & Ricky** is an inclusive marketplace consists of more than 65 designers making functional, adaptive, stylish designs for adults and kids with disabilities.
- 6. Adaptations by Adrian** specializes in individualized adaptive clothing since 1993. You can find almost anything you need on the website, from arm and leg warmers, to bags, to footwear, to capes and jackets, to shirts and pants, to suits and more.

A Guide to Navigating the Hospital

Adapted from Courageous Parents Network

If your loved one with CdLS is seriously ill, you may find yourself spending quite a bit of time at your local hospital. Hospitals are good places to be, as your loved one will be safe and cared for by experts. But hospitals can also be challenging. Understanding and anticipating this new environment will help you feel more in control, better able to support your child and advocate when it matters.



You May Feel Disoriented – Initially

No matter what the road to diagnosis looks like, you will likely approach the hospital in a state of confusion and shock. Two things are going on at once: first, trying to get to a diagnosis. Then, learning a new system that most of us who aren't medical providers know very little about. No doubt you really don't want to be here, in this strange place, because it means that your child is unwell. Stress and anxiety are natural responses.

The Hospital is Like a Foreign Land – Ask for Directions

The hospital may feel like a different world to you. Everyone else is moving quickly and seems to know where they are going. The clinicians are using terms that may not be familiar. And no matter how warm and comfortable the hospital staff tries to make the space; you are not home.

During the hospital stay it is important to know the medical team you will be working with and their schedules. As the team and then the specialists come and go, you may notice that they ask similar questions. They do this so they can make sure they hear and understand everything themselves, but it can get tiring to repeat yourself. Understanding their intention, and knowing that you are helping them help your child, may help you feel more empowered—and more in control.

Work as a Team

Your loved ones' medical team probably includes multiple physicians with different specialties. Each of the specialists will give you lots of information and will have suggestions for how to proceed with your child's care. You may have questions about how their plans fit together, or about how to decide between different options they offer. This can all be very stressful.



Advocate for Your Child

It is appropriate for you to ask questions whenever you have them, and to share your feelings

with the providers. It is totally acceptable to say to any member of the team, at any time, "Please help me out,

because I am getting mixed messages from all of the doctors. I am confused. Can you please communicate with each other and then come back to me to explain the plan?"

If the providers don't address a topic that concerns you, you can say, "This is what we understand is going on. Are we correct? This is our major concern. Should we be worried about this?"

You can also request a family meeting, which is an opportunity for you to sit down for a discussion with your child's health care providers. You can ask questions about your child's care plan and request updates and recommendations from the various members of the team.

Feeling Judged by the Team

All parents want to feel that they are doing the very best they can for their child. At the hospital, surrounded by "experts," you may feel like you are being watched and judged. It is natural to want the medical team to like you and respect you.

Know that providers are not there to judge you; they are there to provide the best possible care for your child. They know that you are your child's #1 advocate and they want to hear what you have to say. It helps if you tell them how you are feeling: "I'm having a tough time. Can we talk later?"

How Palliative Care Can Help

Many hospitals—and the number is growing—offer families support from a palliative care team. The members of this team are physicians, nurses and nurse practitioners, social workers and others who can act as a sounding board to help you discuss and share your goals for your child and family. The palliative care team can also help coordinate your child's care which can be especially helpful if you have many different specialists on your child's team.

Palliative care may sound scary, because many people confuse it with hospice. They are very different things. Palliative care focuses on quality of life and what matters most to you and your child, not prognosis. A team can work with a patient or patient family at any point in the illness journey—for many, the earlier, the better. If a team is not assigned to you, you may wish to ask about it.

Take Care of Yourself and Other Family Members

No parent wants to leave their child alone in a hospital room, but it is really important to get out at least once a day. Taking care of yourself will help you take the best possible care of your child. Over time, you will find the people who you trust to be with your child so that you can take a break. If you need someone to come into the room so you can leave, ask the

nurse. If you know when rounds will occur, you can schedule your break around the team's visit so that you don't miss it. This may help you feel less anxious about leaving your child.



Stay Connected

Many hospitals have special programs to help family members take care of themselves. Ask your social worker or nurse what is available for you. Everything that helps you feel part of a bigger world will help you cope.

Get Rest

When you are with your child in the room you may still want quiet time. Here is a suggestion from a family: "We put a little sign on the door that said, 'Hi, my name is Jack. There are so many people who are helping take care of me. But if you don't really, really need to see me today, can I ask you to please come back tomorrow so I can have some quiet in my room.'" The providers will respect this as much as they possibly can. And then, sleep.

Conclusion

The more you communicate your ideas, observations, questions, concerns, worries and hopes, the better prepared the other members of the team will be to work with you. you can take a break. If you need someone to come into the room so you can leave, ask the nurse. If you know when rounds will occur, you can schedule your break around the team's visit so that you don't miss it. This may help you feel less anxious about leaving your child. To read the whole article, visit bit.ly/NTHCdLS.

The Hendricks Family

Tiffany Hendricks

We're the Hendricks family! Tristan (5.5), Ollie (almost 3) and I (37) have the *SMC3* gene. Tristan was diagnosed before his 2nd birthday. At that time, my husband and I were tested and I found out that I also have CdLS. When I was pregnant with Ollie, I was told there's a 50% chance of me passing it along. She was diagnosed at 1 month old.



Tristan is a very smart, sweet and energetic little boy. He loves Disney Cars and Paw Patrol. He just started Kindergarten and can already read. Around the same time that he was diagnosed with CdLS, he was also diagnosed with autism. He struggles with regulating his emotions, sensory issues and has some behavioral difficulties but has improved so much. ABA, OT, PT and speech have helped out a lot. He does see specialists because he has congenital heart defects, hearing loss and difficulty gaining weight. He had moderate hearing loss at a year and a half old, which caused speech delay. He then had speech regression before his 2nd birthday and was nonverbal until he was 3.5 years old. His hearing still fluctuates. He has thrived so much in spite of the obstacles that have been put in his path.

Ollie is a very caring, intelligent and active little girl. She loves playing with her babies and wearing tutus. She is always wanting to do "homework" and loves to learn. She also struggles with regulating her emotions and some sensory issues. She doesn't have as many medical issues as her brother. She did have mild hearing loss as a baby but after getting tubes in, her hearing has been in the normal range. She used to do ABA, OT, PT and speech, but now only does OT. She also thrives with what life throws at her.

I had no idea that I had CdLS until I was 33. Since I was unaware most of my life, CdLS didn't affect me. I don't have any developmental or physical delays. I was diagnosed with ADHD at 6 years old so I have struggled with that. Even though I have CdLS, I still got married and started a family. I went to college and graduated with an AA and plan on going back someday soon to work on my bachelor's. I put school on hold to start a family; my amazing family, which took me awhile to finally get. I struggled with infertility and had three miscarriages so my beautiful kids are my miracles.

Even though my kids have CdLS, I don't let that stop them. I tell them that they can do anything and I challenge them. I found resources to help them when needed and also let them figure things out on their own. The diagnosis doesn't define them but it is a part of them and they should be proud of who they are. I'm extremely proud of them and everything that they have accomplished.

The CdLS Foundation has been incredible. They have provided me with support, information, advice and an extended family with all the other CdLS individuals and their families. Having a support system with people who know exactly what you are going through and are with you for every tear and milestone, means everything.



So, thank you to the CdLS Foundation and thank you to my CdLS family for always being there.

Welcome New Staff to the CdLS Foundation



Silvia Goldman joined the CdLS Foundation as a Chief Financial and Operational Officer. She brings 20 years of progressive and diverse experience in finance management combined with Administration, Compliance, HR, IT, Acquisitions and Capital projects management, aligning strategy and sustainability. She worked in various nonprofit organizations building a deep understanding and passion working towards longstanding and impactful difference in the lives of those who need support. Silvia has a Masters in Accounting, HR Management and MBA in Finance.



Sherry Waitsman joined the CdLS Foundation as the Special Events Coordinator in August 2021. She holds a Bachelor of Science in Elementary Education from Bridgewater State University and a certificate in Relational Database Design from Worcester Polytechnic Institute. After a brief period in technology, it was clear that her passion was working in the nonprofit sector to help improve the lives of those less fortunate. She specializes in event and volunteer management, relationship development, and social media marketing.

Welcome Our Newest de Lange Society Members



The Cornelia de Lange Syndrome Foundation (CdLS) staff and Board of Directors are pleased to announce the newest members to de Lange Society, class of 2021. The de Lange Society honors the Foundation's most exemplary and inspiring volunteers, their achievements and their leadership.

- Dale Dorsett, Ph.D.
- Barbara and Doug Gaines
- Eric Johnson
- Elizabeth Poplawski, M.D.
- Dawn and Rolfe Rauscher



2022 CdLS Foundation National Family Conference Update

Thank you for your patience regarding the 2022 CdLS Foundation National Family Conference.

Survey Says: the 2022 conference will be virtual!

CdLS Foundation will work to increase staff & CdLS expertise at regional gatherings throughout the country. Questions or concerns? We're listening at **outreach@CdLSusa.org**.

Be on the look out for updates about the 2022 Virtual National Family Conference in the coming months!

How We Transitioned Our Sons with CdLS to Adult Life

Mike and Karla Postell



We have now gone through the transition process two times. One for our son, Colin, and the second for our son, Samuel.

Our oldest son, Colin, is not as physically impacted by CdLS, he was not diagnosed until he was 10 years old. However, he has had to deal with cognitive issues his entire life and we knew early on that we would have to be his legal guardian when he turned 18.

He was 15 years old when we found out about the Foundation. They were very helpful as we learned more about CdLS. It also took us a while to hook up with the support provided by our county's Department of Human Services. They were able to help us as we worked through the process of transition.

Here in Wisconsin, they helped us to meet with a court appointed lawyer to work out the details of his guardianship. When it came time to go to court, the judge asked Colin several questions to verify the results of the lawyer's different recommendations. In the end, Mike was appointed as his guardian and Karla takes care of his finances.

Colin is now 33. He still lives with us and works in a sheltered workshop 5 days a week (when he doesn't have any health issues). We have looked at the option of finding a group home for him but have not found anything we are comfortable with yet. He has liked doing Zoom meeting

this past year with others who have CdLS and he is also a member of the local Kiwanis Club, and he enjoys working with them.

Our other son, Samuel, just turned 18 and we just finished his guardianship paperwork. He was diagnosed with CdLS at birth and has some obvious physical issues. Samuel also does not communicate verbally and is at a much lower cognitive level. Seeing Samuel, there was no question he needed someone to be his guardian.

Even though there were many years between the two trips to court to become their guardian, the process was very similar, except this time we had to pay part of the lawyer's fees. And because Samuel is non-verbal (and due to COVID-19 restrictions) he was not required to be in court. Mike was again appointed as guardian, and Karla handles his finances. Being a little bit older now, one other change was we had our daughters also listed in the guardianship paperwork. We did not think about that option when we were working on Colin's situation. That would be one thing we would highly recommend; give some thought to who might need to serve in a back-up or future guardian situation.

Samuel also lives with us, and we are in no hurry to look for a group home for him. He will stay in school until he's 21, and we're not sure about what he'll be able to do after that, as he does face physical and cognitive issues.

Over the years, we have appreciated the work the Foundation does. It has been a good source for information. We have also attended several conferences and Mike found one workshop hosted by Mary Anne Ehler, from Protected Tomorrows, to be a great help. He attended it at two different conferences to make sure he was not missing anything.

The advice we always give to parents is to not only use the Foundation but to check to see what government resources are available in your community, county and state. With Colin, he was 16 before we found out about what was out there, and there were several ways they could have helped had we known leading up to his 18th birthday. With Samuel, we were able to get help over the years to take care of various things.

Overall, doing the transitions for both Colin and Samuel

Finance Corner

Last year was the beginning of a challenging period for all of us. Thanks to your support we were able to continue our work and find new ways to continue making a difference.

We closed 2020 with a \$51,449 surplus, which included the PPP Loan of \$122,197 that we applied for and subsequently was forgiven and turned into a grant.

2020 AUDITED FINANCIAL



\$368,291 Family Support Program
\$208,851 Outreach and Awareness
\$195,609 Public Information and Education
\$95,226 Fundraising
\$85,215 Management and General

We rely on supporters like you to help carry our mission and continue making a difference. There are many ways you can support us.*

One that we have not mentioned recently is donating a long-term capital-gain property. You can usually deduct the full fair market value of appreciated long-term assets you've held for more than one year, such as stocks, bonds or mutual funds. In addition, if you donate stocks or other investments, you pay no capital gains tax. Donating investments, especially highly appreciated securities, instead of cash can be a very effective and tax-efficient way.

Another donation option to consider, if you've turned 70.5 years old, is a qualified charitable distribution (QCD) from your tax-deferred retirement account, such as a traditional IRA.

Also, under the CARES Relief Act cash donations for 2021 up to \$300 for individuals and up to \$600 for joint filers are an above-the-line tax deduction. The above-the-line deduction lets even people that are not using the itemized deduction to take a charitable deduction too.

Your support allows us to keep our community connected.

*Each vehicle and strategy offer different benefits, including tax deductibility, AGI% limit and administrative costs. Speak with your financial planner for the best alternative for your situation.

WELCOME New Families



THE HALSTEAD-CLARY

Hello! We are the Halstead-Clary family. Bryn, who is the baby of the family was diagnosed a couple months ago, at the age of 20, and we are so glad to finally have some answers! Bryn is a brave, funny, insightful, smart and spunky girl who inspires me every day. Bryn loves animals, spending time with family and friends, working on puzzles, dancing and watching TV and movies.

Arizona

Alejandra and Eduardo Arenas and daughter Emma born December 12, 2018

Ohio

Armando Gonzalez and daughter Natalia, born January 15, 2017

California

Carole Detherage and daughter Sydney born February 10, 1992

Texas

Prasanna Ramavarapu and son Raghav, born December 9, 2009

Colorado

Kristen Halstead and daughter Bryn, born December 25, 2000

Wisconsin

Sarah Nelson and daughter Anna, born June 14, 2014

In Honor/ Celebration

Hunter Barrett
Gary Hartman

Brynnlee Beekman
Bonita Boxell
Mary and Glen Dehaven

Julie Champion
Shannon and Thomas Noonan

Norman Chevette
Karen and Mark Sepe

Dottie Colonia
Patricia Bergen
Charlene Cavanaugh
Michelle Langsam

Dane Curalli
Pauline and Byron Anderson

Chase J. Duff
Barbara Robinson

Lyle Farley
Rachel Farley

Connor M. Feehan
Mary Ann and Pat Feehan
Barbara and Terrence Longe

George A. Flores
Maricela and George Flores

Zalman Gagerman
Sharon and Mitchell Weiss

Manuel J. Garcia
Laura Garcia

Aubrey Garigen
Western New York
Oldsmobile /GM Club

Colt Highberger
Connie and Robert Colbenson

Landon Hollner
Nicole and Robert Hollner

Dustin J. Jones
Model Cleaners LLC
Local Union #725, I.B.E.W.

Ryan Kaplan
Ann and Michael Swartz

Brady Kelton
Mary and Mark Kelton

Valerie Lessa
Mrs. Dianne Lessa

Eric M. Loftus
Karen Szukalski

Frank J. Mairano
Linda and Ron Berger

Diane Miller
Myrna Kaplan

Jeanne Miville
Bonnie Miville

Andrew Patitucci
Joan and David Hanisco

Brianne N. Prada
Karen and Larry Prada

Sheila Shemud
Katrina Swank

William E. Smisloff
Laurie and Michael Nelson
Thomas J. Whalen

In Memory Of

Rick Armbruster
Katherine Fisher
Joann Allen

Ella Ault
Michael Powers
Madeline Starzec

Adrian Bajema
Rachel Morgenstern-Clarren

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Kamisha and Robert Coleman

Chloe P. Duckworth
Sharon and Donald Wiens

Samuel Fiorentino
Mary Spadaro
Joanne and Charles Bongiovi
Judith Fiorentino Swanson
Susan and George Alvord
Joanne and James Hickey
Marlene and William Pepin
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Yacovone
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Lavelle Dover
Susan Kelly
Beth and Gary Noll

Michael Gonella
Patricia and Aldon Daniels

Allan Grossman
Mr. Arleigh Grossman

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Emily Lamberson

Claudia R. Tionson
Dolores and Robert Schoen
Michele MacIntyre

Ethan Walters
Penelope Keating

James D. Walters
Dorothy and Gene Barkley



Jack Barnes

February 28, 1988 –
March 23, 2021
Son of Valery and David Barnes

Valery Barnes
PO Box 247
Woods Hole, MA 02543

David Barnes
2 Adams Circle
Durham, NH 03824

Sydnee Foreman-Baugh

Daughter of Teala Foreman
and Robert Webster
7865 Canyon Drive Spc 34
Amarilla, TX 79110

Daughter of Samuel Baugh
947 E Riverdale PK Lane
Winamac, IN 46996

Dylan Fuller

December 13, 1990-
July 26, 2021
Son of Barbara and Karl Fuller
214 Longleaf Ct.
Canton, GA 30114

**Jupiter Roman "Pooh"
Gunter**

Son of Shaunita Garrett and
Christian Gunter
13614 Summit Ridge Drive
Houston, TX 77085

Benjamin Miller

April 26, 1985- July 21, 2021
Son of Jeff and Mindy Miller
3218 Sandy Ridge Rd
Clearwater, FL 33761



Yes, I want to **SUPPORT** the CdLS Foundation!

Enclosed is my tax-deductible gift of:

☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 ☐ \$40 ☐ Other \$____

Payments may be made by check or credit card.

☐ Check enclosed

☐ Charge my credit card

☐ VISA ☐ MC ☐ AMEX

Card Number: _____

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Donate online at www.CdLSusa.org



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WHY YOUR DONATIONS ARE SO IMPORTANT

The CdLS Foundation is the only organization in the United States dedicated to children and adults with CdLS as well as the world-leader in research, development and support. This award-winning nonprofit organization with a small staff of eleven has impacted the lives of more than 3,600 families. As more families desperate for help and information discover the Foundation and rely on our programs and resources, our expenses increase. Your support is needed in order for the Foundation to fulfill its mission. Your tax-deductible donations sustain this organization. Without you, we could not exist. Thank you, on behalf of everyone with CdLS and their families, for all that you do to for the Foundation.

