

# REACHING OUT

FALL 2020

## Remote Learning...

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COPING CORNER

Caring for a Loved One  
with Behavior Issues

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**COVID-19** and CdLS



**CdLS Foundation**  
Cornelia de Lange Syndrome Foundation, Inc.

# Director's Message

As we all adapt to the ever-changing world around us, let us all take a collective breath. Whatever the format, the CdLS Foundation and our precious community will continue to find innovative ways to be here for each other. The staff is continuing to work remotely with a skeleton crew in the office. Although, we've had to evolve the way we do business, our intention remains constant: continue to provide support and services to our families for whom CdLS is part of life.

This year in spite of COVID-19 forcing us to cancel our in-person conference, we've forged ahead and created a new way to come together for our National Conference. The virtual conference format allowed us to include families who normally wouldn't be able to attend and to invite our friends from around the world. The staff worked very hard to create this on very short notice to ensure we didn't skip a beat. Please do send them a note of thanks when you can. (Conference is available on demand for anyone who may have missed it - [www.cdlsusa.org/virtual-conf](http://www.cdlsusa.org/virtual-conf)).

Over 50% of our families now have an adult with CdLS over the age of 18. As a result, we've created a special edition of *Reaching Out* focused on adults living with CdLS called *The Path Forward* as well as creating new webpages specifically designed to tackle the reality of our children with CdLS growing into adults. For more information, please visit [www.cdlsusa.org/transition](http://www.cdlsusa.org/transition) to learn more.

In the pages of this edition of *Reaching Out*, you will find more helpful insights from professionals on how to better manage during our new normal of life during the pandemic. You will hear from parents on what has worked for distance learning and how some inspiring moms are teaching inclusion in the classroom and online.

Times may be challenging, but in our own way let's keep pressing forward. Don't let up #CdLSstrong.



Bonnie Royster, CdLS Foundation  
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## COVID-19 and CdLS



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

Hello everyone - writing to you amidst the coronavirus pandemic of 2020, with all families in voluntary stay-at-home or quarantine. I certainly hope you and your loved one with CdLS are doing well. Many families whose children/adults live separately have not been able to get together with that child/adult in person for many months or have only been able to have a reunion recently. We were all sad not to have our national meeting in person this year.

COVID-19, or coronavirus disease 2019, is from a new type of coronavirus (called SARS-CoV-2), circulating the world since last year. Dr. Jyonouchi and I addressed concerns earlier this year on a live webinar [<https://bit.ly/COVIDCdLS>]. Although there have been many severe cases, there have been more instances in which people have had few or no symptoms. Studies have shown that children are less severely affected than adults and are more likely to have no symptoms, however, infants below 12 months can be more involved than older children.

Because CdLS does not typically cause immune compromise, or serious lung/respiratory involvement, there should be no increased risk for children/adults with CdLS to get COVID-19. We have heard of only a few individuals with CdLS who have been affected with COVID-19, some needed hospitalization, but most have done well. Medically, the most important measure is to wear a mask; this protects not only yourself but others in case you are affected without symptoms. If

symptoms develop, contact your doctor. Testing is important to confirm an infection and for the health of the public. Self-isolate, keep hydrated and in touch with your doctor. Numbers have spiked in recent weeks and there may be a second wave in the fall, so continue to wear a mask, maintain six feet distance from others and wash your hands well.

Children with CdLS during this isolation period still need to have access to school, as well as continued involvement in early intervention therapy. Even if therapy occurs online, it should be ongoing or resume with school. Some adults with CdLS may have gone back to work as an essential worker, putting themselves and their families at risk for exposure to COVID-19. They need to be able to have appropriate transportation and support. It is of utmost importance that they wear well-fitting masks, wash their hands frequently and be encouraged not to get too close to others or touch their face. We applaud their bravery and appreciate their dedication.

Separation from loved ones is one of the greatest secondary casualties of this pandemic. Anyone with any inability to understand everything fully will not understand this separation, especially the length of time needed to be apart. It is difficult not to have contact in person, not only for the individual with CdLS, but also for you as parents/caregivers. Facetime cannot substitute for touching, hugging, or hearing the voice in person, but are still very important. Please try to bear with it, have a hopeful attitude, maintain good mental health, and know that at some point we should be able to return to our former regular lives (although possibly with masks). Stay healthy and please take care of yourselves and your children with CdLS. We miss them too!

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# Remote Learning for Children with Disabilities

By Patti Caudill, M.S., CCC-SLP, Greater Baltimore Medical Center

Remote learning offers new challenges for children with disabilities and their families. Here are a few tips to help your child move forward in the new school year.

- 1** Understand federal special education law. Due to the pandemic, greater flexibility has been extended to school systems in provision of special education services. School may not be required to provide the same level of service during the pandemic.
- 2** Reach out to your child's teachers/counselors/therapists (team) prior to starting school. Proactively discuss prioritizing goals, daily schedule, format of instruction and barriers to remote learning (sensory/motor impairments, technological needs, behavioral concerns, family issues such as work schedules or multiple learners in the home). Ask what resources are available to help. Many school systems are providing computers/AAC devices for home use; internet access (through local internet companies); written materials; loans of hands on learning tools used in the classroom; or assistive technology consults to help the child assess remote learning.
- 3** Establish a consistent and open communication system with your child's team. This may be via email or brief weekly video check-ins. Discuss your child's successes and challenges with remote learning. Work together to adapt the plan as needed.
- 4** Find an optimal learning area for your child in the home. Use this area for learning every day. This area should be distraction free. Your child will need a sturdy table or tray, supportive seating optimally with arm rests and feet on floor or a footstool if safe for use with your child. Many children benefit from a quiet environment, but others may learn better with a quiet noise level in the background. Consider use of headphones to assist with hearing and focus (if tolerated). For children with difficult to understand speech, use of a head set with a microphone or an attached collar microphone will help their understandability over video conferencing platforms.
- 5** Establish daily routine and structure from day 1. Start and end the remote learning school day at the same time each day, just like in school learning. Use a schedule or a daily list of activities (like what was used at school). Your child may benefit from a visual (digital or paper), tactile or auditory (such as a bell or kitchen timer) schedule. Include breaks for movement, play, sensory time, snacks and meals. Your child's teacher and/or therapist can assist you in developing a similar schedule to the in-school schedule used with your child.
- 6** Relax and take movement/sensory breaks. Discuss with your child's team movement and sensory strategies and materials were built into your child's school day and add these into your child's schedule. These may have included: quiet/nap time, sensory play/fidget toy time and active movement time. If you don't have these materials at home, ask your child's team for recommendations on how to adapt what is available at home. For example, if you don't have a bouncy ball, your child could bounce on the edge of the bed or on a stack of big pillows with supervision.
- 7** Give yourself permission to be creative. Close the laptop, put away the tablet and engage in experiential learning experiences with your child. Look at your child's learning goals and get creative about incorporating those into everyday activities. For example, make a new sensory toy by using food coloring to paint rice and place in a clear bottle (colors, motor movement, verbs "shake, fall down," exclamation "oh-no, uh-oh", sound /sh/) or match socks (matching, counting 1-2, motor movement - roll, toss into sock drawer/laundry basket, vocabulary "sock, push, match, 1-2, in") or correctly sequence the steps in making a snack. Discuss ideas with your child's team.
- 8** Be good to yourself. It's a stressful time for all of us. Give your child, yourself and your child's team permission to have a bad day, learn from it and move forward. Find some time for yourself to rejuvenate and recharge. Identify a support group of friends or other parents in the CdLS community.

# INSIDE LOOK:

## Benjamin

Benjamin is 14 years old and lives in Santa Barbara California with his dad, myself (mom - Dena), and little brother. He received most of his instruction in a special day class until March and was fully included in art and P.E. classes with his typically developing peers. Benjamin uses a speech app (SnapCore) to communicate along with gestures and has been walking independently for the past four years.

Before COVID-19 Benjamin had a full schedule. After school he had either OT, PT, ABA, or horseback riding and was about to start Challengers Little League again. He loves seeing all the people in his life as well as greeting strangers. He had a lot of fun watching his brother play sports and was looking forward to the spring soccer season.

When COVID-19 first hit, it was rough for the first few weeks. Quarantine started a week before our spring break, so we just told Benjamin that everyone went on vacation early. He really did not understand what was happening and was perseverating daily about his teachers, therapists, the bus, riding horses, going to the park, seeing grandparents. Like everyone else, his world had been turned upside down.

When I first began remote learning with Benjamin the repetitiveness was overwhelming, so I reached out to our ABA agency for support. Our supervisor helped me create additional icons for our daily schedule that we had started using to show when therapies would take place. Pre-COVID Benjamin would wake up asking to see his ABA therapists right away, so we were working on concepts like "before" and "after" and days of the week.

When school began remotely, I created a daily schedule for all the home activities and another for People I See This Week. I asked all his paras, teachers, specialists, and therapists to send me selfies, and our ABA supervisor created sheets of faces for me to cut out and laminate, as well as additional icons for the daily schedule.

It took him a little while to settle into the routine. Before school restarted, his teacher stopped by the house and dropped off some reading and math packets and visited for a bit from a distance. That made Benjamin's day! Once school started it required my full assistance for him to participate in remote learning. His teacher had a class meeting every Monday morning. The students had a chance to interact and after a few weeks they included speech or adapted PE for the group in these sessions. Then Benjamin met with a para educator (under the teacher's supervision) for reading



Benjamin working on his AAC device.

and math once a week. I taught him these subjects the other days of the week. He also had a speech session as well as adapted P.E. and met again with his teacher during his office hours on Friday. We opted out of general ed Art and P.E. as I was also trying to support my other son and we had P.T. (from a therapist at school and outside school) and O.T. exercises to complete. We did our own art and sent in photos to his art teacher.

Benjamin's biggest struggle was not understanding why he couldn't see everyone in person. He especially missed riding horses. At one point one of the teachers at the equestrian center sent him a personalized video from the horse he used to ride. Having his dad at home working but not available to play with was pretty challenging, as well. We turned the playroom into an office and had to add a lock to the door to keep Benjamin from interrupting my husband's classes. We were so grateful to have the space for each teacher and student to work in peace. We know not everyone had that privilege.

Benjamin did a great job with remote speech therapy from school. Adapted P.E. (AEP) group sessions were more challenging since he needs assistance from me to do the group exercises. The APE teacher provided some activity choices and videos related to different goals, and I preferred the option to choose some and record them each day in an APE log. Our P.T. at school gave the option of Zoom sessions or receiving activities to do with Benjamin. We opted for the activities and a weekly check in with the P.T.



# Caring for a Loved One with Behavior Issues



My daughter's name is Kaitlyn. She is 24 years old and lives at home with her dad and me. She is not non-verbal, but is not completely verbal either. She has a very hard time expressing feelings and pain. She was born at 38 weeks (due to weak to non-existent fetal kicks/movement). While the doctor thought I was going to give birth to just under an 8 lb. baby, she was only 6 lbs. 9 oz. and 19" long. The doctor knew she had a syndrome at birth, but it took six days to get an appointment with a geneticist to obtain a clinical diagnosis of CdLS. She was in the school system from age 3 (early intervention) to graduating at 22. The school experience, I for one, am glad is over.

For Kaity, behaviors started in earnest, around age 12. We worked with her and a school appointed behaviorist to help her. This just did not work and I was fighting to keep her from being medicated. By the time she was 15, I realized we needed more help and turned to the Foundation. They got us into the next session of the Multi-Disciplinary Clinic for Adolescents and Adults in Baltimore. What an experience!! This provided us with a lot of information to take back to our primary care. A year ago, we started working with Dr. T. Gaultieri and Amy Boison at NC Neuropsychiatry in Chapel

Hill, NC, when Kaity's medical needs out grew her GP's ability. They are currently working with Kaity on a cocktail of serotonin increasing medications to help keep her at an even keel and we are just adding a med to assist with the dopamine to see if we can even out what I call the "witching hours". Kaity seems to be at her worst between 4-4:30pm until about 7pm, each and every day. And it feels like we have tried EVERYTHING to help her during this time by the way of: naps, snacks, going for walks, quiet time with music or reading stories. Nothing seems to help.

Over the last 12+/- years, EVERYONE has tried to figure out what "triggers" the outbursts. They are so random and no one (including us) has been able to pin point one item, experience, activity, etc. that sets her off. I take that back... crying babies and sirens are an immediate meltdown. But those are few and far between, as we usually hear them before her and are able to control the situation. We did try taking Kaity to a therapist one summer about 5 years ago as it was highly "suggested" by the school system that we do it. This only lasted a few sessions since there was not any dialog with Kaity and it was all just her dad and I regurgitating what had happened in the past week, etc. The only piece of advice that he gave, that has stuck with us, is that she basically holds on to negative feelings, actions, words, etc. If her brother scolded the dogs, a week ago, to stop barking, this may set her off again because she thought about it again. If she wet the bed two days ago, which makes her very angry, she can think about that and get angry all over again. We also feel that sometimes it is just her acting out because we are not giving her our undivided attention 24/7. She was tested for autism in the late fall of 2019 and has been given a diagnosis of autism with the mentality of a 3y 8m child. This was hard to accept at first because she does do a lot at a much higher level. But thinking about her behaviors and attention span, they truly are at the level of a 3 or 4-year-old.

Kaity directs her outbursts/meltdowns/behaviors towards objects first (house plants, TV, anything sitting on tables, tossing her plate of food and windows), then she will turn on the nearest person (hitting, pinching, spitting, and kicking and destroying glasses). Then on to her room where she will knock over a dresser that is as big as she is. Everything comes out of the other dressers and curtains come off the wall. You get the picture.

After all is said and done, Kaity is always remorseful. Repeating sorry, sorry, sorry, over and over again. At this point we usually hug it out. Sometimes she has to cry it out. Then, as if a switch has been flipped, she goes about cleaning up the mess that she has made in her room, without any prompting and works at it until she is done.



Dealing with the behaviors is very difficult for me. I take them personally, so I react before I think, which does not help the episodes. Sometimes we just have to put her in her room and walk away. One time we secured her in her stroller and covered her with a weighted blanket. We will be doing this more! You could see her physically relax. Sometimes, a timer is set and she has to be still and quiet for an amount of time before we will allow her to get up. If she is unable, we talk, and the timer is set again. Episodes can be as short as 10 - 15 minutes, but she has had one that lasted four hours (I really think that one was a delayed drug interaction from a dentist appointment).

I want to be honest, there are days that I really think I can't take care of her anymore. That I should let Kaity "grow up" and move out to go live her best life, by placing her in an adult assisted living home. It would then enable my husband

and me, to live out the rest of our years as most other parents do. But it chokes me up and brings tears to my cheeks to think about it. She has been abused, physically and verbally, by staff, in her own home and at school. She has been lost by staff. She has been denied medical care by staff. And if that is happening in her own home, what is going to happen to her in a different setting, where there is not someone to see what is going on daily and hold the staff accountable? And I decided that would not be the best life for Kaity. Mentally she is 3 - 4. She still sleeps with dolls and night-nights (security blankets). She is not going to understand why mommy and daddy are not there every night to tuck her in and give her kisses. Or why we can't come to her when she calls out for us during the night. And that gets me through until the next time. It is my goal to keep her with me as long as I am physical and mentally able.

When presented with the question..."Do you feel distant when your child attacks you?" Parents responded with great insight, including:

"Keeping it real- yes, sometimes. He's only 3, but sometimes it really hurts. I cry and need some space to regroup. I worry all the time about what it will look like when he gets older and stronger!" - Kristin W., mother to Connor.

"Yes, sometimes. As well as anger. But we also feel a similar, temporary distance from our typical child too at times, even if it looks different because of different communication styles. My son is still young and we have recently been trying to remember that it's not him against us, but it's all of us together working to figure things out. It's hard. Sending love." Molly H., mother to Ollie.



Julia O'Connor, Ph.D., Clinical Psychology and Professional Development Committee Member at the CdLS Foundation offers this advice to families. "My first feedback for parents experiencing physical attacks from their child is to remind them that they MUST take care of

themselves since this is such a significant stressor. Parenting is hard enough, let alone when the demands of a child with special needs and challenging behaviors are added into the mix. Find strategies to improve their own sleep, resilience and ability to remain calm and nourished. Classes in yoga, mindfulness and other stress reducers might be helpful. Talk to friends and family and find some time for fun. Seek out local supports for respite from community agencies, your place of worship or friends and family. Spend time with your other children and your spouse. Ask for help. Breathe."



# HIGHLIGHTED Events



## AWARENESS DAY 2020

The 2020 CdLS Awareness Day was like none we have seen before. However, that didn't stop the passionate community from doing its best to raise awareness about their loved ones. Each of you took a creative approach on how to tell your community about something that is so important to you. We cannot thank you enough for continuing to be one unified voice. 2021 is right around the corner so get those ideas ready!

Also, in spite of COVID-19, many of our families still forged ahead and not only raised awareness for CdLS but raised funds for the Foundation. These much needed funds will help us continue to provide support to individuals with CdLS and their families, offer virtual tools to cope with the new normal we live in and so much more. Because of your strong support, virtual Awareness Day fundraisers raised over \$12,000! With you, #hopestartshere.

## BACKYARD "MUD RUN"

The Feehan family showed us not only how to get it done, but how get it done in spades...even amidst a quarantine! Mike Feehan, Connor's dad and CdLS Foundation Board Treasurer, was determined to do his annual mud run in June, and was not going to let the pandemic stop him.

Instead, Mike got creative and turned his backyard into an obstacle course. Even soliciting his children's help for obstacle ideas. The Feehan's impromptu backyard "mud run" was a wonderful success, raising over \$31,000 for the Foundation! The icing on the cake was that Mike was able to compete with Connor right alongside him.

Mike is encouraging other families to do the same, and is working with the Foundation to create a "Backyard Mud Run How To" kit. Stay tuned for details in our next edition!

Mike - we are grateful to you and your family for continuing to be a part of the CdLS community, and for providing such inspiration to us all! Thank you! #CdLSstrong

## CALENDAR

### October 1-15

Virtual Baltimore Running Festival

### October 5-11

Virtual Chicago Marathon

### October 12

Missouri Golf  
Sunset Hills, MO

### October 17

Virtual Brew & BBQ  
GA

### October 18

Virtual Walk for Will  
and Hope

### December 1

Giving Tuesday



## The Future of the Foundation

These days of quarantine and social distancing due to COVID-19 have certainly created some unusual challenges for the Foundation. However, we are excited to announce some new initiatives and twists on old initiatives that we believe are going to make a positive difference for us in 2020, a year like none other!

### Your Employer Matching Gifts

We so appreciate the many financial contributions that you make to the CdLS Foundation, but do you know whether or not your employer will match your gift? There are many benevolent companies that do. If you want to know if your employer will match your donation to the CdLS Foundation, please reach out to our Development Department, and we will find out for you. Email us at: [MatchingGifts@cdlsusa.org](mailto:MatchingGifts@cdlsusa.org)

### Corporate Giving - Recognition

We are ramping up our efforts to make connections with corporations, being sure to recognize their contributions with enhanced marketing and logo visibility as well as shared corporate website and video links. We understand that businesses are bombarded with donation requests, so we want to make sure that the companies that choose to partner with the CdLS Foundation receive the visibility and recognition they deserve.

### Special Events

As you can imagine many of our fundraising events have been cancelled due to social distancing concerns, however, several of our fabulous event chairs and committees are still operating full steam ahead, either with virtual events, or by carrying on using safe distancing practices. Here are just a few of the events that we are working on now:

- **Chicago Marathon & Baltimore Running Festival**  
Whether you're a runner, a walker or a dog walker, you can participate virtually by picking your own distance, your own pace and your own "course" over the span of several days. Join other participants for a fun pre-race Zoom Party to pump you up!
- **32nd MO Golf Tournament - Oct 12** Now renamed the Amber Gaines Memorial Golf Classic, this event will be held as usual with social distancing inside for the lunch and dinner portion.
- **11th Annual Brew & BBQ - Oct. 17** Participants in this year's virtual event, will pick up their delicious BBQ and brew and return home for a Zoom Party with live music and speakers.

These are just some of the initiatives that the Development department is excited to be working on along with some fun ways for you to get involved. Be sure to check out our website for information on current and upcoming events. As always, thank you for your continued support of the CdLS Foundation.

## PURCHASE YOUR CdLS HEART NECKLACE TODAY!



The CdLS Foundation has partnered with Lisa Leonard Designs to create a one-of-a-kind design that captures the heart and soul of the CdLS community. The necklace is hand-crafted in sterling silver and strung from a sterling silver chain. You can add up to 5 tags with special names

to make it even more unique! Purchase here: [bit.ly/CdLSnecklace](https://bit.ly/CdLSnecklace)

## GET READY FOR GIVINGTUESDAY

# #GIVING TUESDAY

In this time of uncertainty, there's a fundamental truth that gives us hope - that together we can do extraordinary things. Over the past few weeks and months, the entire world

has been coming together to stand up, help out, give back and heal. Whether that's through donations to community organizations, celebrating doctors and nurses at shift changes, or reaching out to a neighbor to help with groceries, generosity has been helping the entire world get through this global pandemic. Together. Join the CdLS Foundation on December 1st as we celebrate GivingTuesday, the global day of unity and giving. For ideas on how to join, contact Annette Scheidecker at [ascheidecker@CdLSusa.org](mailto:ascheidecker@CdLSusa.org).

# Melissa Staggs

*"I believe if you have an opportunity to educate people in a meaningful way, I think we have an obligation to try."*

Just Two Moms (JTM's), today is actually 4 moms who all take turns leading presentations that talk about the importance of acceptance and inclusion of individuals with special needs. We talk a little bit about our diagnosis journey, we read one or two books aloud to the kids that highlights individuals with varying abilities, but more importantly we discuss ways that students can include those with a variety of abilities. We try to take the taboo out of disabilities by creating a safe and vulnerable place to discuss our lives and give students an opportunity to share their experiences and ask us questions.

I learned about JTM's through my friend Larkin O'Leary, who started JTM's with a friend of hers. Both women have a child with Down Syndrome, and they started by putting together a little presentation for their kids' pre-school class to teach the kids about acceptance and inclusion. The presentation was such a hit, the preschool asked them to come back. Other local schools heard about Just Two Moms, and the booking requests started pouring in. The group now has presentations targeting all age ranges from preschool to college. We do community events and host meet-ups with other families who have children with special needs.

Larkin's son James and AJ (my son) became fast friends, as they were on the same little league team and soccer class. Larkin knew about my volunteer work with other organizations, as well as my advocacy and awareness work for CdLS. She asked if I was comfortable sharing my story and speaking in front of crowds. I said yes, and yes!

While I was initially devastated by our CdLS diagnosis, it became clear to me pretty quickly that I had an obligation to make AJ's life as full and amazing as possible. That meant taking one foot in front of the other - no matter what. It meant learning everything I could, and then sharing our experiences with our loved ones. Even before JTM's, I knew the only way to overcome the sorrow was to understand it, and then use it to my advantage - I knew that if I could do that than others would follow my lead as it related to AJ. His diagnosis in some ways faded into the background because we were simply focused on being a family. Now that we're solidly in our groove, JTM's has given me the opportunity to share what I've learned over the last 6 and a half years with kids who may not have any other exposure to someone with a disability or special needs.



Melissa and friend Larkin O'Leary



Melissa and Larkin's kids, AJ and James

## Inside Look: Benjamin cont.

This worked well for Benjamin and our family, as my husband could help me when he was finished teaching. Our P.T. and O.T. outside school also sent exercises, which we incorporated into the daily schedule.

In the classroom setting Benjamin is extremely distracted and wants to attend to everything and everybody. He is extremely social. So, having his para educators on a screen helped him focus his attention, and then having me as his 1:1 physical support really worked well for him. It was exhausting for me at times, but it was also a great opportunity to see how others worked with him and to be able to collaborate with them on curriculum. Benjamin loved being able to see all his friends and the adults in his school life, which made him happy. He also liked the predictable routine of school even though it was remote. I appreciated the teacher's flexibility and willingness to work with our family's schedule and needs since we had one person teaching and two students learning remotely. The master schedule I created and had on the refrigerator to keep track of everyone's activities was quite something. Benjamin also enjoyed participating in some of his brother's remote learning assignments such as observing animals via webcams at zoos and aquariums. On the days that I taught reading, I would add in other activities to go along with the stories including videos, art activities, songs, games, and puzzles. During math time we tried to do hands-on activities like counting, matching, and sorting coins to make things more engaging and to work on OT skills.

Benjamin would have loved more social time with his friends and other students even if remote. I am hopeful that with more time to plan for remote learning, his high school teacher will incorporate some group lessons and fun interactions. Benjamin misses riding horses so much! Watching videos of horses just isn't the same as being in the saddle. Some of the curriculum was a bit advanced for him and needed to be adapted. As a former teacher I was able to find appropriate activities, use them, and share what we were working.

The most important things were building on relationships we had already established with teachers and therapists and giving them grace in a very new situation for all. Along with that empathy, though, came the clarity and motivation to ask for what we needed to support Benjamin. Whether it was schedule icons or the flexibility to participate in therapies in real time or on our own, we needed to create a plan that worked for our family and that especially worked for Benjamin. I have already reached out to Benjamin's new teacher at the high school and look forward to sharing with her what worked and didn't work in the spring and hearing what she has planned.

1.800.753.2357

# WELCOME

## New Families



### THE JACKSON FAMILY

Hi my name is Berklie, I am 8 years old, I live with my parents. I have an older sister and younger brother. We just moved to Minnesota and I'm really excited to be closer to my Pops. My whole family can't wait to see snow and try sledding for the first time. I love playing outside and listening to music, we have lots of impromptu dance parties. Thanks for welcoming us!

#### California

Bianca, Miguel and son Miguel born February 17, 2019

#### Ohio

Karrie, Justin and son Wallace born, 2016

#### New York

Ashley, Rich Grimaldi and son Marco, born April 22, 2020

#### Texas

Gayla, Clay and daughter Berklie born September 8, 2011





Riley and his family all smiles in their Hope Starts Here shirts.

## Riley Rissland

Riley is the oldest of four. He is 16 years old and a freshman in high school. He loves going to the movies, especially to see anything Marvel or the newest kid movie. He is very fond of super-hero figures that he calls his 'guys' and builds the most interesting LEGO creations. Riley loves school especially being social with his friends. He enjoys saying hello to everyone he meets and makes friends quickly.

He has a very laid-back personality. When he is not building Legos or watching a movie in his room, he hangs out with his mom, Fran, while she is working, visits his brothers playing video games or hangs with his sister. In the summer, Riley's family goes to their lake house on the weekends; he enjoys swimming in the lake, riding in the boat and will sometimes get on the tube.

He loves his family! As his siblings have gotten older, they all have such a great relationship and 'get' it now. They have always treated Riley with respect and understand he needs more assistance. They understand CdLS a lot better now and are very empathetic not just toward Riley but other people with disabilities which make their parents very proud. Riley's family is very involved with the Foundation. His mom, along with another mother, created Brew & BBQ 10 years ago to give back for all that the Foundation has done.

*"When he was born, we were told he may not walk, he may not talk, enjoy life, live at home, or go to school... but Riley fooled them all." Fran has stated when describing Riley. "He walks, he talks, he's enjoys life, lives at home with his loving family... I have learned so much from him. He has taught me to never give up, to be strong, and patient. He has taught me to always look for the silver lining in any bad situation."*







# An Open Letter to the Special Needs Sibling

By Lauren Cootes

Dear Special Needs Sibling,

**It's not easy being you. Period.**

I know it feels as if your needs are never put first. As your parent, it's gut-wrenching to have to make decisions that are vital to your sibling's health and well-being, but may leave you feeling like you don't matter as much. Sometimes you cry, occasionally you are angry, and at times you protest, yet when all is said and done, you handle it with a grace that far exceeds your years. I admire you.

You know nothing else in this life other than being a helper. It's likely you don't remember a time when you weren't a special needs sibling. Offering to lend a hand just comes second nature to you. While still a child yourself, you know: how to operate a feeding pump, just how to orient a nurse who's new to our home, the perfect distraction to calm your sibling amidst a meltdown, and where all the medical/emergency supplies are located. This has created a servant's heart in you which is beautiful to behold. YOU are special, too.

Having a sibling with a disability has ingrained in you a bit more patience and kindness than most of your peers possess. Not only are you a wonderful sibling, you're also a fantastic friend. Taking up for the underdog and making

sure everyone gets a turn are just things you do naturally. Witnessing how loving and inclusive you are when at play with other children is enough to make me burst with pride. I am in awe of you.

Our family life is rarely predictable. One minute we are enjoying a family dinner, and the next I could be headed to the hospital with your sibling. You are shuttled off to spend the night (or two or three) with friends. When this happens, we all miss each other terribly. You take it in stride because you have no other choice. You display a strength that no child should have to. You amaze me.

Oftentimes I feel unworthy of being your parent, and like I may be failing you. There's simply not enough of me to go around, I'm afraid. However, I see who you are now and who you are becoming, and I could not be prouder. Being your parent is an incredible honor.

My darling child, words cannot express just how much you mean to me. I can't imagine a life without you. You are so important and valued!

You complete us.

Love, Your Parent

## COVID-19 RESOURCES

**NORD COVID-19 Critical Relief Program** provides eligible individuals with financial assistance for non-medical, essential expenses such as, but not limited to, the following:

- Unexpected utility expenses
- Communication expenses (e.g. phone, cell phone, internet)
- Emergency repairs to car, furnace, home or major appliances
- Assistance with travel and/or lodging logistics and expenses
- Rent or mortgage payment assistance
- Support for adaptive learning during school closures

**COVID-19 Rare Disease Premium and Medical Assistance Program** provides financial assistance for certain out-of-pocket costs associated with patient's health insurance premiums. It also provides eligible uninsured and under-insured patients (for whom insurance has declined coverage for this expense) with financial support for out-of-pocket medical expenses limited to:

- Medical visits and telehealth consults
- Laboratory and diagnostic testing
- Physical and/or occupational therapy and/or other physician prescribed therapy
- Durable medical equipment
- Medical supplies (tube feeding supplies, dressing kits, personal protective equipment)

For more information on either program and to apply, please contact NORD at 203.242.0497 or [COVID19assistance@rarediseases.org](mailto:COVID19assistance@rarediseases.org).

**Weareteachers.com** has developed a list of resources that is suitable for students of any age range for the upcoming school year. With teachers figuring out how to deliver lesson plans and classroom activities as part of distance learning. This tool will be helpful to parents keep their loved ones on track with their studies and educational growth. Visit, [bit.ly/COVID20resources](https://bit.ly/COVID20resources) to review the list.

## ONLINE RESOURCES TO CHECK OUT

Explore this website, and discover user-friendly ways to schedule your child's day, record your child's meals, track games and activities, log medications, and share emergency contact information. Visit: [planner.thecplawyer.com](https://planner.thecplawyer.com)

**DisaboomJobs** is the leading online resource for jobs for people with disabilities. These aren't "disability" jobs, they're ability, skill set and professional-expertise jobs. The companies represented here are, however, actively seeking to recruit and provide employment for people with disabilities as part of their inclusive workforce. Search among more than 600,000 jobs and/or career opportunities, create your profile, upload your resume, and showcase your skills to potential employers today. Jobs for people with disabilities is the goal for these employers – but they're looking for your abilities, so here's the place to showcase them. Visit: [ww3.disaboomjobs.com/?&](https://ww3.disaboomjobs.com/?&)

**Innovative Housing for Adults with Additional Needs.** Specialized Housing Inc. developed the first housing program in the US to enable adults with special needs to own their own homes while receiving professional support. Creative use of home ownership with condominiums and co-operative housing models. This is an excellent special needs resource. Visit: [www.specializedhousing.org/](https://www.specializedhousing.org/)





## WELCOME NEW CdLS FOUNDATION STAFF



Annette joined the Foundation in August 2020 as the Development Director. She is thrilled to be able to put her years of experience in marketing, event planning and development to work helping to bring about greater awareness and support for individuals with CdLS. A native of Virginia, with a

BA in Communications from Allegheny College in Meadville, PA, Annette has lived in New England for more than 20-years. She has spent most of those years as a Marketing Director working in-part with non-profit organizations on special events, fundraising and brand building. Before moving to New England with her family, she was the District Director for the American Cancer Society for the Northeast Region of Indiana. Prior to that, Annette enjoyed an award-winning ten-year career as a broadcast news anchor/reporter. She currently resides with her two sons and two dogs in Longmeadow, MA.

## SIBLING CREATES PROGRAM TO HELP WITH QUARANTINE BLUES



Sara, sister to Rachel who has CdLS, created Simple Needs to help individuals like her sister to entertain themselves during quarantine. She was inspired to start this program because Rachel one day during quarantine received a package in the mail filled with fun items and was excited about it.

Her goal is to make this stay at home quarantine more entertaining. "If I put one smile on one kid's face, I would feel accomplished. I just want them to feel special and happy when they open the packages." Sara has said.

If you are interested in receiving a package, you can contact Sara at [simpleneedsbox@gmail.com](mailto:simpleneedsbox@gmail.com).

## CONFERENCE HIGHLIGHT

Even though this is our first virtual Conference, the 2020 Conference marks the 30th conference held by the United States CdLS Foundation. There were over 200 individuals attending the 2020 CdLS Foundation Virtual Conference. We were joined by families from around the world including: USA; United Kingdom; Australia; Canada; Costa Rica; Greece; Mexico; Spain; Colombia; and Israel. We were fortunate to be able to collaborate with experts in CdLS from around the world who brought knowledge and insight to this very special event. We hope you plan to join us in 2022 as we plan to have our 31st Conference in Tulsa, OK from June 23-26. For more information and to learn ways to start planning now, visit [www.cdlsusa.org/conference](http://www.cdlsusa.org/conference).



Have the chance to watch the 2020 Virtual Conference on-demand.

Didn't have time to attend for the Conference? Want to hear from leading experts in the field of CdLS?

Now is your chance to be able to purchase a subscription to the conference recordings. One or two-day recording available. Visit: [www.cdlsusa.org/virtual-conf/](http://www.cdlsusa.org/virtual-conf/) to purchase your copy of Conference today. Please note that if you attended Conference you are able to log back in at any time to watch the conference at your leisure.

# Our Deepest Sympathy

## **Bonnie Costello**

June 13, 2007 - January 25, 2020  
Daughter of Gloria and Tom Costello  
11 E William St.  
Bayshore, NY 11706-6804

## **Grace Alexandra Quigley**

September 13, 2008- September 4, 2019  
Daughter of James and Alicia Quigley  
612 S. Willard Peak Road  
Manuta, Utah 84324  
Beloved by Clay and Krystle Cook  
And Brooke Yarbrough

## **Daniel Dunn**

September 28, 1975 - February 6, 2020  
Son of Janice and Robert Dunn  
30 Aldie St  
Allston, MA 02134  
Beloved by his brother Robert Dunn

## **Amber Nichole Gaines**

July 2, 1981 - February 5, 2020  
Daughter of Barbara and Doug Gaines  
4841 Highway C  
Fredericktown, MO 63645-7090

## **Lori Etlicher**

July 21, 1961 - February 22, 2020  
Daughter of Paul and Barbara Etlicher  
Sister of Susan Busse and Barbara Huss.  
Kenosha, Wisconsin 53142

## **Kenneth John Rowe (KJ)**

March 16, 1996 - January 21, 2019  
Son of Mary and David Rowe  
Brother of Sara Rowe  
Dollar Bay, Michigan 49922

## **Charles J. Keithley**

April 25, 2001 - May 29, 2020  
Son of Christine Keithley  
18021 Treeborough Ct  
Wildwood, MO 63038-1511  
And  
David and Stephanie Keithley  
199 Gilla Drive  
Ballwin, MO 63011

## **Karl Stenerson**

September 30, 1998 - June 7, 2020  
Son of Julie and Derik Stenerson  
15111 NE 110th Pl  
Redmond, WA 98052-2521

“Cherish the good memories of your child and  
remember: hold on to hope, rest when you're weary,  
take time to grieve, and let your heart mend.”

-Excerpt from “When Angels Take Flight: the Loss of a Loved One with Cornelia de Lange Syndrome”

If you would like to speak with Foundation staff or connect with other  
families who have lost a child with CdLS, please call 800.753.2357.



# New Grief Support Advisory Group Aiming to Enhance Connection

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-Memorial page where families can share loving memories and stories about their loved one. Visit: [www.cdlsusa.org/in-memorial](http://www.cdlsusa.org/in-memorial).

Being acutely aware that every family grieves in its own way, the Foundation is looking to further expand our support, outreach services and capabilities. This is why, this summer many parents, such as Rolfe and Dawn Rauscher, joined the Grief Support Advisory Group. This nationwide task force is exploring new ways the CdLS Foundation can provide even greater support to parents and families who are grieving the loss of their child.

In 2015, the Rauschers lost their daughter Nikki to complications from CdLS. Dawn and Rolfe recall that, "After Nikki died, we didn't know what our involvement or role would continue to be in the Foundation. For instance, should we still go the National Family Conference? We have so many CdLS families that are great longtime friends, but we weren't sure where we would fit into their lives or the community anymore. We want to be sure that all parents know they are a forever a treasured part of the CdLS community.

*"Everyone is unique in their grief and the road ahead can be long," the Rauschers observe. "The mission of the Grief Support Advisory Group is to offer as much connection and support as possible, in new and even more meaningful ways, every step of the way."*

## In Honor/Celebration

Aaron Bailey  
Mary and Donald Caisley

Addison I. Brown  
Ellen and Gary Rooze

Aisley Birrer  
Alice Eshom Andrus  
Austin C. Cadena  
Maria Bobadilla

Allan Rudnick  
Myrna Kaplan

Amerah Sanchez  
Esther Garcia

Andrew Patitucci  
Joan and David Hanisco  
Nancy Tossone

Ann J. Rees  
Helen Thompson

Annie Beaumont  
Sharon and Frederick Brill

Aryanna N. Gage  
Sarah Griffith

Austin J. Staggs  
Ann and Rocky Harris

Benny W. Fromhartz  
Diane Fromhartz

Brady Kelton  
Mary and Mark Kelton

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Janet and George Eckerson

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Karen and Larry Prada

Brynnlee Beekman  
Bonita Boxell

Caitlin Igoo  
MaryAnne and Stephen Igoo  
Nina and Jeffrey Kellogg

Caleb A. Wherry  
Kathy and Andy Wood

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Catherine Belcher

Carolina Amor  
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Janice and Eric Duff  
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Cheryl La Roe

Colm A. Toman  
Diana Stewart

Colt Highberger  
Connie and Robert Colbenson

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Mary Ann and Pat Feehan  
Barbara and Terrence Longe

Connor Willey  
Jennifer and Scott Crawford

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Kathleen Rulka & Brian Ewert

Devin Miller  
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Stephanie & Edmund  
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## A Guide to Adult Transition

**NOW AVAILABLE**



We are excited to announce that we have updated our Transition Guide. The refreshed guide offers updated insights to the world of transitioning into adulthood. In the guide some things you learn include, planning for your child's future, reviewing healthcare transition planning and learning about special needs planning.

To receive your copy, contact Family Service at [familyservice@CdLSusa.org](mailto:familyservice@CdLSusa.org) or call 800.753.2357.



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