REACHING OUT

WINTER 2020

COPING CORNER

A Year in Review

ANXIETY

in people with CdLS

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message


Bonnie Royster, CdLS Foundation Executive Director

Two thousand twenty has forever changed the landscape of how we see the world. This year caused us to stop take a breath and look inside ourselves and realize we MUST and CAN rise to the occasion. We have been stronger than we thought possible. In fact, many experts observe that parents of children with special needs tend to be more resilient in moments like these than parents of typical children. Parents who raise children with special needs have learned how to live with unpredictability and not knowing – a skill that has helped many of you weather the storm. You continue to inspire us to stay strong and become ever more resilient no matter what comes.

In this issue, you will learn about the research discussed at the virtual Symposium that was held in October. Dr. Oliver and his group from the United Kingdom put together a great article about anxiety and CdLS. One of our moms wrote a great piece about how she figured out how to help her daughter with her anxiety. Her hope is that perhaps the steps she took can ease the burden from others. You will also hear from a country singer who is bringing awareness about CdLS to his fans. We also have several of helpful hints and resources to help you and your family enjoy the colder months.

As always, we couldn't do what we do without your continued support! Thank you for being there in times of joy and in sorrow. May 2021 bring you nothing but happiness!

Warmly,

Bonnie

Reaching Out
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Cornelia de Lange Syndrome
Foundation, Inc.
Incorporated December 1981
email: info@CdLSusa.org
www.CdLSusa.org

VIRTUAL SYMPOSIUM UPDATE

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

Despite the current pandemic and quarantines, the CdLS Foundation has continued with business as usual. We held a highly appreciated virtual two-day national meeting for families in June, with hundreds of attendees and presenters. Most recently, we hosted our ninth biennial two-day scientific symposium, October 2-3, which was also extremely successful. Presenters who had their abstracts accepted, hailed from the United States and several European countries. There were many international participants with representation from four continents. There were 16 presentations, of which six were given by trainees! All of the talks were illuminating.

Talks the first day were clinically oriented. There were four on behavior. Some research shared included: there is an increased percentage of individuals with CdLS having autism as they get older, but there is more social motivation and better eye contact than in autism seen in other conditions. Individuals with CdLS insisting on the same routines and same procedures, day-to-day, is a way of addressing anxiety, and putting limitations on their world helps them control it, especially in adolescence and adulthood. Applied behavioral analysis is a promising management practice in CdLS. And a future trial assessing treatment for repetitive and self-injurious behaviors is in the works. The other talks addressed medical and health professional needs, insurance and transportation for individuals five years and below with CdLS, speech and feeding interrelationship and communication issues in CdLS including augmentative communication devices.

The second day of the symposium was more basic science-research based. A system of induced pluripotent stem cell lines with mutations in several of the cohesin genes and a related protein CTCF will be used to answer future questions. Another related protein, Med14 in a yeast model, was discussed, which works with cohesin in remodeling chromatin. Information about how sister chromatid cohesion is established, and facilitation of enhancer and promotor locations and communication, was shared. The embryonic origin of the heart is different in *NIPBL* mouse models of CdLS, and left-right patterning in the heart appears abnormal in CdLS, as in other parts of the body, with the right side generally more severe. A study of the placenta in mouse models of CdLS found that cohesin needs to be intact to repair spontaneous DNA damage, and with mutations, the placentas have increased cell aging and the embryos remain small. All of these studies potentially have ultimate implications including towards future treatment.

The next project addressed a group of individuals who appear to have CdLS but are negative on testing for the known genes; many mutations in genes associated with other conditions were identified. Lastly there were three talks on a subgroup of individuals with severe loss of function mutations in the *SMC1A* gene which presents with very severe forms of epilepsy. There was an overview of worldwide cases, and a discussion of locations of mutations and clinical effects, and also an association found between early signs of puberty in this subgroup.

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ANXIETY
in People with Cornelia de Lange Syndrome

Laura Groves, Hayley Crawford, Jo Moss & Chris Oliver

Children and adults with CdLS can experience high levels of anxiety. Anxiety can be shown in response to many different situations, including social interactions, fear of specific objects or events (i.e. phobias) and as a result of hypersensitivity to sensory stimuli, such as noise. Anxiety has three components: how we feel, changes in the body and how we act.

RECOGNISING ANXIETY

It can be difficult to know if someone is experiencing anxiety. Even people who do communicate well can find identifying anxiety and letting others know difficult. For many people, rather than relying on them to tell us when they are feeling worried, watching for changes in behaviour may be more helpful. Behaviours that can indicate anxiety include restlessness, pacing, avoiding events or places, some forms of self-injury, repetitive questions, irritability, loss of appetite, poor sleep or reporting feeling physically unwell. Importantly, some of these behaviours can be indicative of other things as well, such as pain and physical illness, so the key is to look for changes in these across situations based on what is typical for that person.

STRATEGY: EMOTIONAL LITERACY

Emotional literacy is the ability to notice and label what we are feeling, and everyone can find this difficult at times. Developing a person's ability to notice and tell you how they are feeling is really important. This can be as simple as having picture cards of different emotions that you can use to teach the person you care for about emotions, and they can use to tell you how they are feeling. Social stories have also been used to teach people about emotions and there are some great books and films (e.g. "When My Worries Get Too Big!: A relaxation book for children who live with anxiety" by Kari Dunn Buron; Film: "Inside Out") that can be used to support this as well.

STRATEGY: COMMUNICATION

When someone feels anxious, difficulties communicating this to others and making themselves understood may worsen the feeling of anxiety. Sometimes people find using communication skills more challenging when they are anxious. For example, someone who typically communicates verbally, may find picture cards helpful to say they want to have a break from an anxiety-provoking activity. Improving communication can help clarify the causes of anxiety. For example, we know both social situations and hypersensitivity to some sensory stimuli can underlie anxiety in CdLS. So, if behavioural signs of anxiety are seen at a party for example, it is important to establish whether the cause is the noise, social interaction or something else. This would shape the intervention that would be most appropriate.

> ***"Anxiety has three components: how we feel, changes in the body, and how we act."***

AVOIDANCE

People quickly learn to avoid situations that make them feel anxious. It can be difficult to balance respecting someone's decision to avoid situations and persuading them otherwise. Whilst removing tasks that cause anxiety can be useful in the short term, this may maintain the anxiety or it may worsen over time because people never learn they can cope with the anxiety, or that the situation/object is not to be feared. Sometimes it is possible to gently encourage a person to start with relatively easy situations or only experience these for a short period of time, before working up to situations which cause more anxiety.

STRATEGY: CALMING AND SELF-SOOTHING

When you are encouraging someone to enter a situation that is anxiety provoking, it is important to not send them in empty handed! Ensuring people have effective calming techniques to manage their anxiety such as listening to music, deep breathing or anything that is comforting to them, such as a blanket or favourite object is really important.

Often the person might find initiating the use of these on their own hard so they may need other people to prompt the use of these when they become anxious. It is also helpful for people to 'practice' using these self-soothing techniques at times they don't feel anxious, so they are really effective for them when they need them most.

INTOLERANCE TO UNCERTAINTY

Our research has shown that anxiety linked to an "intolerance of uncertainty" is important in CdLS. Intolerance of uncertainty is where anxiety occurs in response to situations which are unpredictable. Often people who experience intolerance of uncertainty have a strong preference for sameness and routine, (quite common in CdLS), and this might be a coping strategy for unpredictability. This might be why people show behaviours indicative of anxiety when routines or plans are disrupted.

STRATEGY: ROUTINES AND SOCIAL STORIES

If anxiety is experienced when situations and plans are unpredictable, then using visual timetables to show a person's daily routine can be helpful. Social stories can be used to help people navigate new and unfamiliar situations. With either approach, it is important to build in a bit of flexibility. Rigidly following routines means people with CdLS avoid having to manage any unpredictability and so when something inevitably doesn't go to plan that person may experience high levels of anxiety. By having a bit of flexibility or options in routines (remember to make these things the person likes) you are building the ability to tolerate unpredictability.

STRATEGY: CUEING CHANGE

When there are unexpected changes to plans or routines, then using a cue, such as a picture card, to indicate that change is coming can be effective at reducing anxiety. We do know that people with CdLS vary in how well they respond to being told about a change in advance. Sometimes this causes anticipatory anxiety where people may worry more and more until the event happens. Sometimes someone might be really excited about an event and then at the time of the event the excitement turns to anxiety and they may choose not to go. Every person is different and working out what works best can take time but is worth it. Varying when the event is 'cued' to the person and varying the information you give about the event are some ways you can explore what works best for the person you care for.

Our Cerebra anxiety guide has some more information on recognising anxiety and suggestions for strategies to overcome this - cerebra.org.uk/download/anxiety-guide-a-guide-for-parents.

INSIDE LOOK:
Lauren

We recently celebrated Lauren's 40th birthday! It wasn't until she was 3 months old that she was diagnosed and at that time (1980) the information available was minimal and FAR from encouraging. The geneticist literally referred us [Kathy and Erwin Catts, Lauren's parents] to a one-and-a-half-page description in a book of syndromes. It was a tremendous encouragement when we heard about the Cornelia de Lange Syndrome Foundation. Soon after, I contacted the Foundation and began receiving these newsletters. The information provided was like "manna from heaven"! Of all the issues that were addressed, the most vexing for us over these years has been dealing with her anxiety and accompanying behaviors.


Lauren, 40

Early on anxiety manifested in destructive and attention seeking behaviors like writing on walls, flushing items down the toilet, hiding things, dialing 911 and other fixations; none of which were particularly unusual but more persistent and prolonged than one would expect. She'd pick at her fingers and gums until they'd bleed. During that time our focus was on dealing with the SYMPTOMS by avoiding access as much as possible, redirecting, using stress balls, giving her chewing gum and putting gloves and band aids on. Her level of anxiety always increased in severity and duration after being sedated for each of her oral surgeries … that's also when she began having panic attacks in the car. To this day she often becomes anxious when dealing with transition, changes in schedule and many social situations.

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A Year in Review

Over the past year, the CdLS community has faced many unprecedented challenges … massive fires, civil unrest, a global pandemic and fears mounting on what to do next. Through all of the questions, concerns and anxieties, our community has continued to strengthen its bond with one another and hold on to the core beliefs in reaching out, providing help, and giving hope.

As this year closes, many families reflected on what 2020 was like for them, what the past year taught them about being resilient, and what their hopes are for 2021. We hope their words inspire and help if you are struggling to find the strength.

THE BUSK FAMILY …

Needless to say, the start of the year and now its approaching end look vastly different. Each February our family escapes the cold Chicago winter for the land of sunshine and warm temperatures. This year we traveled to the Florida Keys for a few days. We could not be more thankful for that opportunity because it was only a month later the COVID-19 pandemic brought the world to a screeching halt.

Now seven months later, **we've learned to excel at the art of pivoting**. Quarantine challenged us all. It proved most difficult for both our girls: Abby who has CdLS and thrives on social interaction, and her twin sister, Maddie, a visual learner who truly enjoys the classroom setting and interaction. We've still managed to celebrate the many silver linings, like slowing down and enjoying time as a family.

This year has taught us that we can be agile. It's taught us we can do difficult things. It's also given a new appreciation for things we sometimes take for granted. Long before COVID however, we've had a great model of resiliency within our family: Abby, as with most children with CdLS, academic and other life skills that come naturally to others can take much longer and prove more difficult for Abby to master, yet she never gives up and always preserves with a smile on her face. While the struggles of quarantine sometimes wore on us, Abby is our best reminder that there is still so much for which to be thankful.

From the challenges we've faced in 2020 - COVID and otherwise - has emerged tremendous growth. Globally, I hope we can all carry the lessons from this year and use them to better ourselves and the world. The way we go about our lives is likely to look different for a while, so I hope each of us do our part to make sure it's for the better. Perhaps we can be kinder, more patient, and a lot more forgiving.

THE FERGUSON FAMILY …

2020 has been a very complicated year for me and my family. Dealing with COVID and being in quarantine has brought me and my family closer together and has taught me a lot about family.

This past year has taught me that anything is possible, just because we weren't able to go outside does not mean that we couldn't bring the fun inside. This year was supposed to be the year where Armani practiced walking, eating and bath time. However, without PT/OT being able to come to the house we were devastated. But we used the tools we had inside the home and Armani is taking steps and mini bites of food; which to some may be minor but I am completely warmed hearted about it. When you see a situation, you think that will never happen to me until it does. I appreciate Armani picking me as his mom to continue his life journey.

My hope for 2021 is that we find more information on CdLS that could help more families. I would also love to see more support groups, more gatherings in different states and try to spread more information to those who are not aware of the syndrome.

THE BEAS FAMILY …

For us 2020 at the beginning was a bit more challenging than previous years. With all of the changes Ethan had some minor setbacks with his therapies and school. But once everything began to slowly open back up again, he was able to get back on track. With everything that is going on we were able to focus in on his physical therapy a little bit more at home. He's progressing so much with each passing day and we couldn't be happier.

This past year has taught our family that there is no better way to cope with a situation then to take it day by day. We have learned to be extremely patient and know that we won't always have all of the answers to our many questions. But knowing that we have so many resources available to us through the Foundation makes us feel more confident in knowing that we can get through any situation with the help of the CdLS community

Our hope for our family in 2021 is to be able to meet more families that also have a loved one with CdLS. We would love to be able to share our story with them as well as have them share their story with us. We also can't wait to watch Ethan overcome even more challenges in the upcoming year!

THE DAVIS FAMILY …

2020 started off with basketball season for our youngest and plans for a soccer season in the spring. It started off with preparations for Benjamin and I to attend our third Family Voices of California Health Summit and Legislative Day in Sacramento that was to take place mid-March. Then COVID-19 turned everything upside! It took a few weeks to adjust to remote learning and remote teaching for my husband, but we all settled into a rhythm eventually. We actually enjoyed the flexible schedule in the spring that allowed for some creativity and self-paced learning.

We have tried to make the start of a new virtual school year a celebration. The remote learning has become more challenging and to continue being resilient for the rest of 2020, we may need to figure out how to add more flexibility, choice, and creativity into our days. And I need to revisit the silly, fun things that helped us in the spring to break up the monotony. We are all a bit weary but are also grateful for the opportunity to stay home, for our health, and for technology that allows us to stay connected with family and friends. **I will say that always looking for the silver linings in the situation, sharing gratitude with people in our lives, and creating fun and new experiences have definitely helped keep our spirits up!**

If 2021 is safe, I sure would like to go on a few getaways as a family! Being able to take Benjamin out and about without worrying about all the people not wearing masks would be so great! He misses his outings! And we are hoping for a vaccine and the opportunity to see our family and friends in person again.

HIGHLIGHTED **EVENTS**

MO GOLF TOURNEY BREAKS RECORD IN MEMORY OF AMBER!

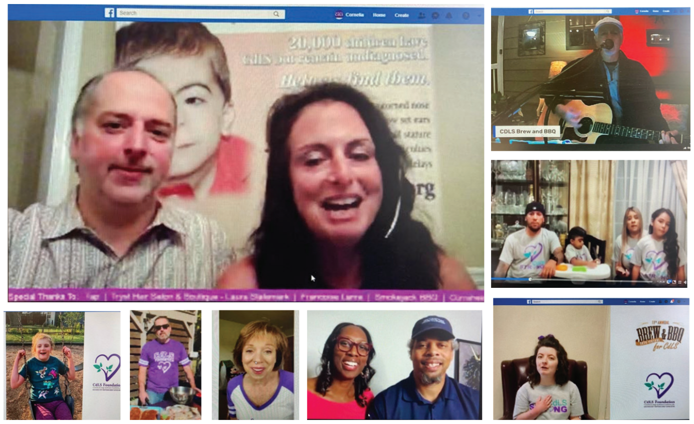
For 31 years the Kesting's Madison County Wood Products (MCWP) and the Snodsmith's Pallet Logistics Management (PLM) have hosted the Missouri Golf Tournament, in honor of Amber Gaines, the beloved daughter of Barbara and Doug Gaines, and an inspiration to hundreds of people across the state. After Amber's sad passing in February, the decision was made to carry on with the golf fundraiser, but now in Amber's memory. The tournament was renamed the Amber Gaines Memorial Golf Classic.

Sponsors and golfers alike turned out to make this tournament one of the best ever. For the first time in the event's 32-year history, they had a full course of golfers, hosting 37 teams! Golfers were joined by spouses afterwards for an awards dinner featuring photos of Amber, and the reading of a very special letter written by Barbara. Since its inception in 1988, this event has raised approximately $784,000 for the CdLS Foundation. We are forever grateful!

TEAM CdLS RUNS ON TO VICTORY

The streets of Chicago and Baltimore may not have been lined up with spectators or filled with runners this year for their respective marathons, but that didn't stop our Team CdLS runners from hitting the pavement to raise funds for our families.

The Chicago Marathon virtual runners exceeded their goal raising close to $50,000. A big thanks to team captains Frank Mairano, Bruce Brockstein, Dominick Curalli, Tera Larson, Paul Lambert, and Ava Frank. Meanwhile, their counterparts running the virtual Baltimore Running Festival also did quite well, thanks to the efforts of team captains Tonie Kline, Tasha Howland, Sarah Burrell, Julie Kaplan and Michaela Whitelaw. Way to keep the spirit alive, Team CdLS runners! We thank you!



BREW & BBQ GOES LIVE IN GA

Fran and Karl Rissland, (Riley's parents), weren't going to let COVID-19 halt their 11th Annual Brew & BBQ in Alpharetta, GA, this year. With Karl's experience in techonology and Fran's expertise in marketing and event planning, they make quite a team. This formidable pair put their heads together, and created an entertaining and informative live streaming, that not only helped to raise funds for the CdLS Foundation, but also worked as a wonderful CdLS awareness event.

Folks from around the country were able to join the live stream and bid on auction items from the comfort of their own home. To view a recorded version, visit: **bit.ly/cdlsbbq**.

Our thanks go out to the Rissland's for all of their hard work and dedication to the CdLS Foundation!

WALK FOR WILL & HOPE TAKES PLACE IN MICHIGAN

On a chilly rainy day in Michigan in October, the Feighan-Kurth family set out for a 2-mile walk to raise money for the CdLS Foundation as part of their annual Walk for Will & Hope. At the same time friends and supporters were also walking for the same cause in different locations and even in different states.

The cause is something near and dear to the Feighan-Kurth family. Mom Maureen started the event 12 years ago in honor of 12-year-old daughter Hope, who has CdLS, and in memory of son Will, who died from complications related to CdLS when he was just 3-months old. As a tribute to both Will and Hope, and all the CdLS Foundation families, the The Feighan-Kirth family and their friends beat their goal for this virutal year, raising close to $4,000. Thank you, from the CdLS Foundation!

CALENDAR 2021

January 8 - 10th
One Love One Heart
Virtual 5K

October 10
Bank of America Chicago Marathon
Chicago, IL

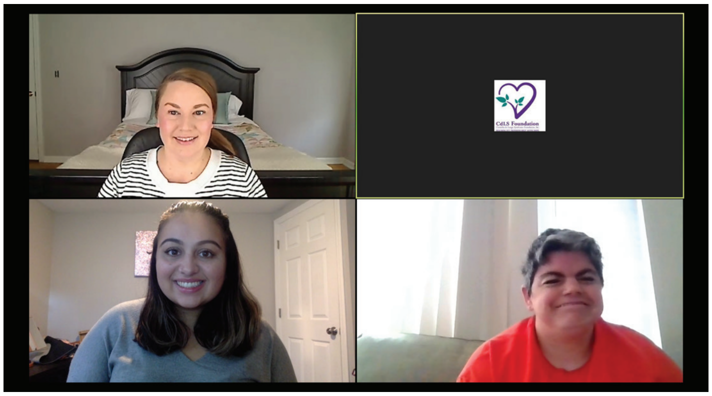
October 11
Amber Gaines Memorial Golf Classic
St. Louis, MO

November 7
TCS New York City Marathon
New York, NY

EMPOWERMENT TEAM UPDATE

The CdLS Empowerment Team is a group of individuals with CdLS who are 18 and older. The group was developed by the Foundation to create a place where adults can come together to support one other. The Empowerment Team motivates members to socialize and develop relationships across the country through different opportunities. Team members are encouraged to participate in a group of their peers to assist in the development of resources specific to the needs identified by the adults with CdLS.

COVID-19 has changed the way we are able to interact and socialize with others. Most of our adult community are not able to attend day programs; return back to work or go out into the community. It has caused a major disruption to their daily routines which can cause an increase in feeling lonely, isolated and depressed. The Foundation wanted to create a place where members could come together for an hour a month and be able to see and interact with one another. This interactive platform is a safe space where everything that is discussed is kept confidential and group's members are respectful towards one another.



We believe in providing a platform where adults can share their struggles and victories, ask questions, and participate in topic discussions in a safe space. The Zoom calls are held once a month for one hour. Staff tries their best to accommodate members activities, appointments and work schedules. Dates and times are chosen by what works best for the majority of the group. For more information on how to join, contact Family Services at **familyservice@CdLSusa.org**.

MEDICAL DIRECTOR SPOTLIGHT CONT.

Two of the professionals announced their retirement, and this may have been one of their last professional appearances. We heard from both Chris Oliver, behavioral psychologist and long-term Scientific Advisory Board member for CdLS World from the United Kingdom and Dale Dorsett, developmental biologist and long-term Clinical Advisory Board member for the CdLS Foundation USA from St. Louis, now relocated to Rochester, New York. Both talks were excellent and we thank them for participating during symposium and over the years. Hopefully they will continue to participate in CdLS meetings!

Fundraising for the Future

While we are so very thankful for the hard work and dedication of our fabulous fundraisers and donors, there is no question that the CdLS Foundation, like most non-profit organizations today, is facing some financial challenges. As a result of the pandemic, some of our large fundraising events were cancelled in 2020, including the New England Golf Tournament as well as a large major donors' reception that was to have taken place in California this past spring. Meanwhile, 2021 is still an unknown, as we attempt to plan ahead.

We will continue to be creative and develop new ways of holding events, however, we understand now more than ever, that relying too heavily on event fundraising is not in the Foundation's best interest going forward.

We recognize the need and are expanding our giving opportunities:

PLANNED GIVING – LEAVING A LEGACY

For the first time ever, during Estate Planning Awareness Month (Oct. 17-23), a mailing was sent out to major donors encouraging them to consider making a "planned gift", which could be in the form of a bequest, living trust, IRA, Charitable Gift Annuity or a gift from a life insurance policy. It is as simple as filling out the form at **bit.ly/CdLSlegacy** and contacting your accountant, attorney or estate planner to include the CdLS Foundation as a beneficiary of your chosen gift.

GRANT APPLICATIONS

This year alone we have applied for 17 grants to cover a multitude of expenses ranging from costs associated with our Ask the Expert and helplines to publication printing costs, to name a few. For 2020 we have received $32,083.48 in grant funding, and are hopeful for another $50,000 for 2021.

EMPLOYER MATCHING GIFTS

We are encouraging donors to contact us if they would like some help finding out if their employer has a matching gifts program. Email us at: **MatchingGifts@cdlsusa.org**

We thank all of you for your devotion to the CdLS Foundation. With your generous support, you become a part of something bigger than yourself, and you enable us to continue to reach out, provide help and give hope.

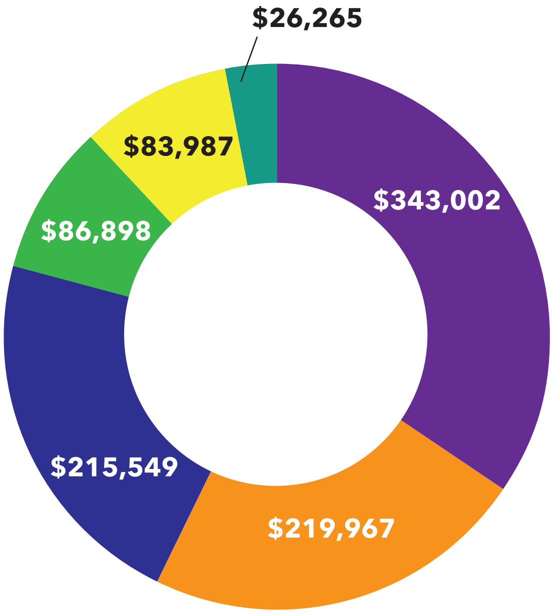
Finance Corner

Your contributions allow us to sustain and enrich our efforts in supporting the families and individuals affected by the syndrome, increase awareness, connect families, print informational materials, and fund research.

We sincerely appreciate your kindness and continued support.

Your donations make a difference!

In 2019, the organization had operating expenditures of $975,668:



PAT POLLIFRONE

Pat and Kensley laughing together. Pat is a proud advocate for his younger cousin and is happy he can use his platform spread awareness.

I first heard about CdLS from my cousin Nicole, whose daughter, Kensley, was diagnosed with CdLS. Once I realized how expensive each doctor's visit was and how much care Kensley needed, I wanted to get involved. I wanted be able to help not only raise awareness, but also raise funding for families with similar expenses.

We were able to play the 2020 CdLS virtual Conference, which was an honor to be included in. Closer to home, we were able to perform at my cousins' "Rolling for Kensley" bocce tournament fundraiser, where partial funds went straight to the CdLS Foundation.

> ***"...Kensley powers through, full steam ahead. No matter what each day brings..."***

Kensley has inspired my day to day life, as well as my music. Kensley is no stranger to perseverance and overcoming obstacles. Whether it's unexpected trips to the doctor's office, or learning a different way to communicate, Kensley powers through, full steam ahead. No matter what each day brings, Kensley finishes each day with a smile. I have tried to take that same perspective and "Kensley spirit" with the many obstacles my music career has thrown me. Like Kensley, I have the support of an awesome family.

It was an honor and a pleasure performing for families during the virtual Conference during a time when there was so much uncertainty in the world. Our band had not been able to perform in a few months. This was our first performance since COVID-19. We were excited to be able to play for CdLS community and we want to thank the CdLS Foundation for allowing us to share our passion and be a small part of this incredible group.

I have been able to educate others about CdLS and talk about it with the influence that I do have. Word of mouth is one of best education opportunities we have. I wear my "small but mighty" CdLS t-shirt and use it as a conversation starter.

Pat and his family gathering to raise funds and awareness at the annual "Rolling for Kensley" bocce tournament.

Through social media, I have been able to post pictures focusing on CdLS, whether it be wearing the t-shirt in our YouTube videos, or on mine (and my dogs') social media accounts to help spread awareness.

Again, I would like to thank the CdLS Foundation for allowing me to be a part of such a special cause that is near and dear to my heart. Also, a special shoutout to my little cousin, Kensley ... I love you so much my little peanut!

INSIDE LOOK:
Lauren cont.

Lauren was prescribed everything from Ritalin (age 8-10) to a variety of antidepressants and anti-psychotics beginning at age 21. Two years ago, we recognized that both the behaviors and anxiety were symptoms and made a decision to deal with the real SOURCE and the first step was tapering her off all these drugs. She was suffering with so many side effects like increased aggression, lethargy, nausea, very dark ideations, weight gain in addition to the anxiety that had never totally went away.

> "Two years ago, we made a decision to deal with the real SOURCE of the anxiety and behavior issues."

We began by healing her gut ... first cutting back gluten, dairy, sugar, and adding probiotics along with amino acids; GABA, Tryptophan, inositol, and others to her vitamin regime. After more research, we began neuro feedback and chiropractic treatments to balance her nervous system. She is now off all medications and a much happier person overall. She's lost 50 pounds (she had become obese). We're still struggling with some anxiety during transitions and trips in the car but find that she has become more content, focused and expressive in a positive way.

As parents and caregivers; we all want the best life for our children. I recognize that may look different for each individual and their family. For us, going the more holistic route was one of the most difficult decisions to follow through particularly in the face of well-meaning friends and professionals.

In the future, I would like to see the Foundation explore and hopefully even support research to more holistic approaches for GI and behavior as well as other issues both in the newsletters at conferences.

If your loved one is experiencing challenging behaviors and you would like to speak to someone, please contact the CdLS Foundation at 1.800.753.2357 or **familysupport@CdLSusa.org**.

WELCOME
New Families

GRIMALDI FAMILY

We are the Grimaldi family, Rich, Ashley and Marco. Marco was born in April 2020 and diagnosed with CdLS. We are new to the CdLS community and are proud to share our little Marco with you. We hope to gain great knowledge and support through this wonderful community!

Massachusetts
Natalie and Jeff Galarneau and daughter Ella born January 14, 2008

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

Fermina Lopez

Fermina is passionate about advocating for people with disabilities.

I am from Bakersfield California, now I live in Nashville TN. I was born February 2, 1999. I live with my dad and 2 sisters. I also have an older brother and sister living in California. I enjoy traveling with my family and attending concerts. Some of my favorite singers are Ariana Grande, Prince Royce and Becky G.

I was diagnosed at age 5, my dad kept telling the doctors that he was concerned about my cognitive development stages and there were some physical appearances that were different than my siblings, but the doctors said I was just a late bloomer. But when I started kindergarten, I was not communicating like the rest of my peers, so my dad requested tests. After several tests, visiting specialist and taking a lot of bloodwork the doctors at Children's Hospital in Fresno diagnosed me with CdLS.

My intellectual disability caused by my CdLS makes it hard for me to be completely independent. My family helps me make decisions when balancing my money and paying bills. I also need help with understanding important documents and medical issues. I must watch the foods I eat because of gastroesophageal reflux. I also have small hands and fingers with Swan Neck finger deformity which makes it hard for me to do certain household chores and can make my hands hurt. I also have limited use of my left arm and it is weak due to my radial head dislocation.

I have faced challenges in school because of my condition and people not being familiar with CdLS. There were many times I was sick at school because of my reflux problems and the staff didn't believe me and would ignore my symptoms. I also had problems with agencies that were supposed to help me with transition into a career or post-secondary education; telling me I couldn't go to college because of my disability. I had to fight for my rights and challenge my vocational rehab counselor to allow me to go to college. I do understand that most of my struggles I have faced were due to people not understanding my disability, but I have a strong family support that helps me stand up for my rights.

While in college Fermina planned off campus events, sponsored by private donors, to assist her follow classmates to gain social skills.

I am part of the Empowerment Team* (CdLS Foundation's group for individuals with CdLS, 18+). It has been great being a part of this group because we discuss issues that we experience and how our peers have dealt with similar issues. The team gives me great information about my condition, challenges I might face and how to deal the issues.

The Foundation has helped me by connecting me with resources and other people that can help me succeed. Even though CdLS has put many tests in my life, the syndrome has made me a strong person because I am always learning from my challenges caused by my condition.

*For more information visit page 10.

To the Father of Kids with Special Needs

By, Alethea Mshar

Pictured: Dad Frank and son Landon

On that day we promised "for better or worse, in sickness and in health," I don't know about you, but I figured on more better, more health. A couple of decades later, and we've had more than our share of sickness and worse. Neither of us had the first inkling of what our lives together would be like.

Parenting our son with disabilities and multiple medical conditions wasn't what we anticipated so many years ago, but you've stepped right up to the plate, and been exactly the father our children need.

Sometimes I wonder if you see your friends coaching soccer teams and playing hoops in the driveway with their kids while we're busy running to doctors and therapists, and wonder if you feel left out or sad. If so, you hide it well.

Your friend's wives have all returned to work, they bring in a pretty nice income, and can buy and do things we can't because I'm not able to work outside the home. I wonder if you wish it could be that way. If you would like that extra income instead of a wife who is a full-time mother and caregiver. If so, you never let on.

We have to tag team to care for children who still need constant adult supervision well into their tweens and teens instead of enjoying nights out and vacations like our peers. I know you wish we could have fun like that, but you don't waste time feeling sorry for yourself.

You cheerfully build whatever adaptive equipment I suggest, you invest in specialized bicycles, toys, beds, toilets, you name it, and you never seem put out. In fact, I sense that you're proud to provide for your kids in this way.

I hear you brag about your children and tell their stories. You are raising awareness about their abilities and disabilities just by being a proud dad.

I know we didn't plan for this, but you have risen to the occasion and then some, and in so doing, you have stolen my heart. Again.

I fell in love with you as a young man, carefree and unfettered. I fell in love with you again as a father, responsible and conscientious. As a special needs dad, you have swept me off my feet yet again, but this time, not in that charming way of youth, but in your reliability, your teamwork, your solid strength that is the perfect accompaniment to my own. You have dazzled me with your patience and resourcefulness and this bond we have goes deeper than whatever naïve vision I had as that pastor officiated our vows.

No, this isn't what we had in mind. It is infinitely more complex, intimate, and vulnerable and real than I ever could have dreamed.

Five Fun Winter Activities for Individuals with Special Needs

Darla Davis, SLP, Kids Who Count

1. **USE SNOW FOR SENSORY EXPERIENCES** – Winter is the perfect time to take advantage of some frosty, sensory playtime. Make a point of experiencing the cold and lightness of snow by making snowballs, tiny snowmen, or snow angels. You can help your child practice their vocabulary during the activity by naming the winter words: cold, white, snow, snowball, frozen, etc.

2. **PUT TOGETHER A FORT-BUILDING KIT** - Gather some old sheets, blankets, pillows, cardboard, clothespins and yarn in a big laundry basket. Let the kids use their imaginations to build forts between chairs or behind couches. Don't be afraid to get involved with the fort building, especially if your child is small or has special needs. Having a flashlight or battery powered candle will make the fort cozy.

3. **CREATE A DISCOVERY BAG** - Find a few items at your local dollar store, or around your house, to fit in a box, bag, or pillowcase. Try to find quiet time items that your child can use with less supervision like puzzles, fidgets, books, or sensory toys with a distinct shape (ball, blocks, car, shoe, cup, or spoon).

4. **MAKE A WINTER SENSORY BAG** - Making a bag filled with sensory items is a fun way to experience winter without a lot of mess. Fill a large zip close bag with about a cup of inexpensive clear hair gel. Then add small marshmallows, glitter, tapioca balls, and little cotton balls.

5. **SET UP AN INDOOR OBSTACLE COURSE** - Set up an obstacle course over stools and under tables, around chairs and through tunnels made with blankets. Use towels as free spaces or islands and pillows for resting spots. You can also set up rows of blocks to navigate around or a path with rags for jumping.

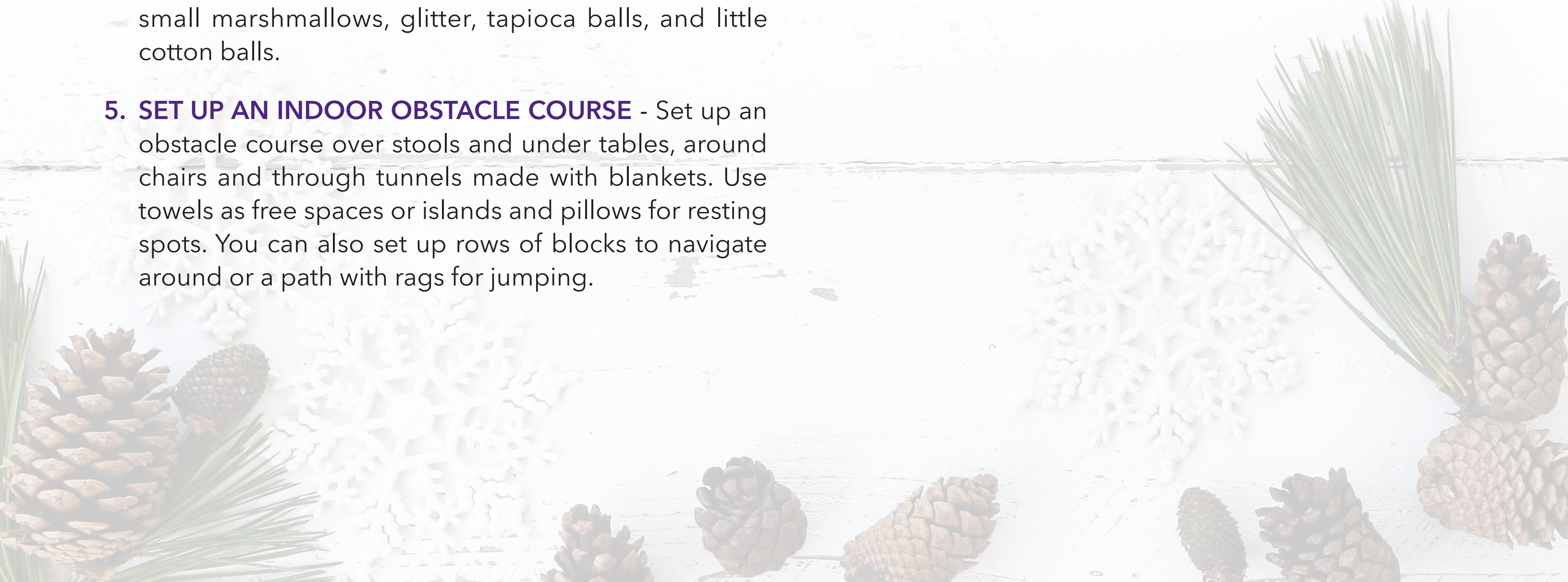
Mommies of Miracles

The mission of Mommies of Miracles is to eliminate the isolation mothers of children with complex medical needs experience daily by providing an extended network of resources, grief support, and hope.

Their organization is a growing, international, peer-driven support group of mothers who have children of all ages, with complex care needs, many with rare or undiagnosed conditions and developmental disabilities. For more information, visit: **bit.ly/MommiesofMiracles.**

Different Dream

Different Dream defines themselves as "a gathering place for parents of special needs children." Their website provides resources and literature, with a blog that addresses what parents of special needs children often encounter. Learn more by visiting: **differentdream.com.**



8 Sensory-Friendly New Year’s Eve Ideas for Kids

By Dylan Robson

If you are looking for some sensory-friendly New Year’s Eve ideas for kids and would prefer to stay home to celebrate, then try out one (or all!) of these simple ideas.

01 CELEBRATE AT NOON INSTEAD OF MIDNIGHT

Many kids with autism have sleep issues. So, if staying up until midnight would disrupt your child’s bedtime routine, then try celebrating at noon instead of midnight. Or try celebrating midnight in a different time zone! You could even try ringing in the new year multiple times by hopping through the different time zones.

02 MAKE A NEW YEAR’S THEMED SENSORY BIN OR SENSORY BOTTLE

Playing with a sensory bin can be calming for kids who get overwhelmed by sensory input, so try making a New Year’s Eve themed sensory bin filled with confetti, party streamers, balloons, party blowers, glow sticks or whatever else your kids might enjoy. Or make a calm-down sensory bottle using water mixed with glitter or confetti.

03 SET UP A BALLOON OR CONFETTI DROP

Create your own balloon or confetti drop version of the ball drop to celebrate the new year. For a quick and simple idea, fill a drawstring garbage bag with balloons or confetti and pull the drawstrings closed. I personally would cut up large pieces of party streamers to make my own confetti instead of using regular confetti. Or save the ribbons, bows, and tissue paper from Christmas morning to fill the bag.

Next, hang the bag upside down from the ceiling and then start your countdown. When you reach the end of your countdown, open up the bag and let the balloons or confetti fall down on your kids.

04 MAKE OR DECORATE PARTY HATS

Celebrate New Year’s Eve by making and/or decorating your own party hats. They’re a much quieter alternative to celebrating with party blowers.

05 WATCH VIDEOS OF FIREWORKS

Instead of watching real fireworks on New Year’s Eve, watch videos of fireworks. That way you can control the volume of the fireworks.

06 CUDDLE UP WITH A WEIGHTED BLANKET FOR A FAMILY MOVIE NIGHT

Weighted blankets provide calming deep pressure and proprioceptive sensory input. So, cuddle up and watch your kids’ favorite movie as a simple way to ring in the new year. Be sure to pair it with some popcorn to sneak in some oral motor sensory input as well!

07 PLAN A FAMILY BOARD GAME NIGHT

Playing board games together is a perfect way to work on social skills, so spend New Year’s Eve playing your kids’ favorite board games.

08 DRESS UP AND HAVE A DANCE PARTY

If you have active kids that need to move and wiggle, then have a dance party! Dance until it’s midnight (or noon if you are celebrating it at noon instead)! If your kids like dressing up, then try getting dressed up in fancy party attire!

Our Deepest Sympathy

Frank Eugene Hanson
March 24, 1962 - August 28, 2020
Son of Gene and Joyce Hanson
Brother to Dana (Jim Ed) Clayton
Uncle to Drew (Joanna), Kevin (Courtney) Clayton
Great Uncle to Anjali, Sanjana, Caleb, and Rohen Clayton

> "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.

HELPFUL RESOURCES PROVIDED BY THE GRIEF SUPPORT ADVISORY GROUP

The Grief Support Advisory Group has been hard at work compiling a list of resources that will help families who are going through the lost of a loved one with CdLS.

SPEAKING GRIEF: This resource is a public media initiative aimed at creating a more grief-aware society by validating the experience of grievers and helping to guide those who wish to support them. **Visit: speakinggrief.org**

THE COMPASSIONATE FRIENDS: A nationwide non-profit designed to provide resources to families who are coping with the death of a child. **Visit: www.compassionatefriends.org**

BEARING THE UNBEARABLE: Love, Loss, and the Heartbreaking Path of Grief Book: Dr. Joanne Cacciatore–bereavement educator, researcher, Zen priest, and leading counselor in the field–accompanies us along the heartbreaking path of love, loss, and grief. Through moving stories of her encounters with grief over decades of supporting individuals, families, and communities–as well as her own experience with loss–Cacciatore opens a space to process, integrate, and deeply honor our grief. **Visit: amzn.to/35Te7k5**

HEALING AFTER LOSS: Daily Meditations For Working Through Grief Book: For those who have suffered the loss of a loved one, here are thoughtful words to strengthen, inspire and comfort. **Visit: amzn.to/3fgDYVY**

8.1.2020 - 10.15.2020

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With your generous support, you become a part of something bigger than yourself, and you enable us to continue to reach out, provide help and give hope.

Visit: **bit.ly/CdLS20** to make your gift today.

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