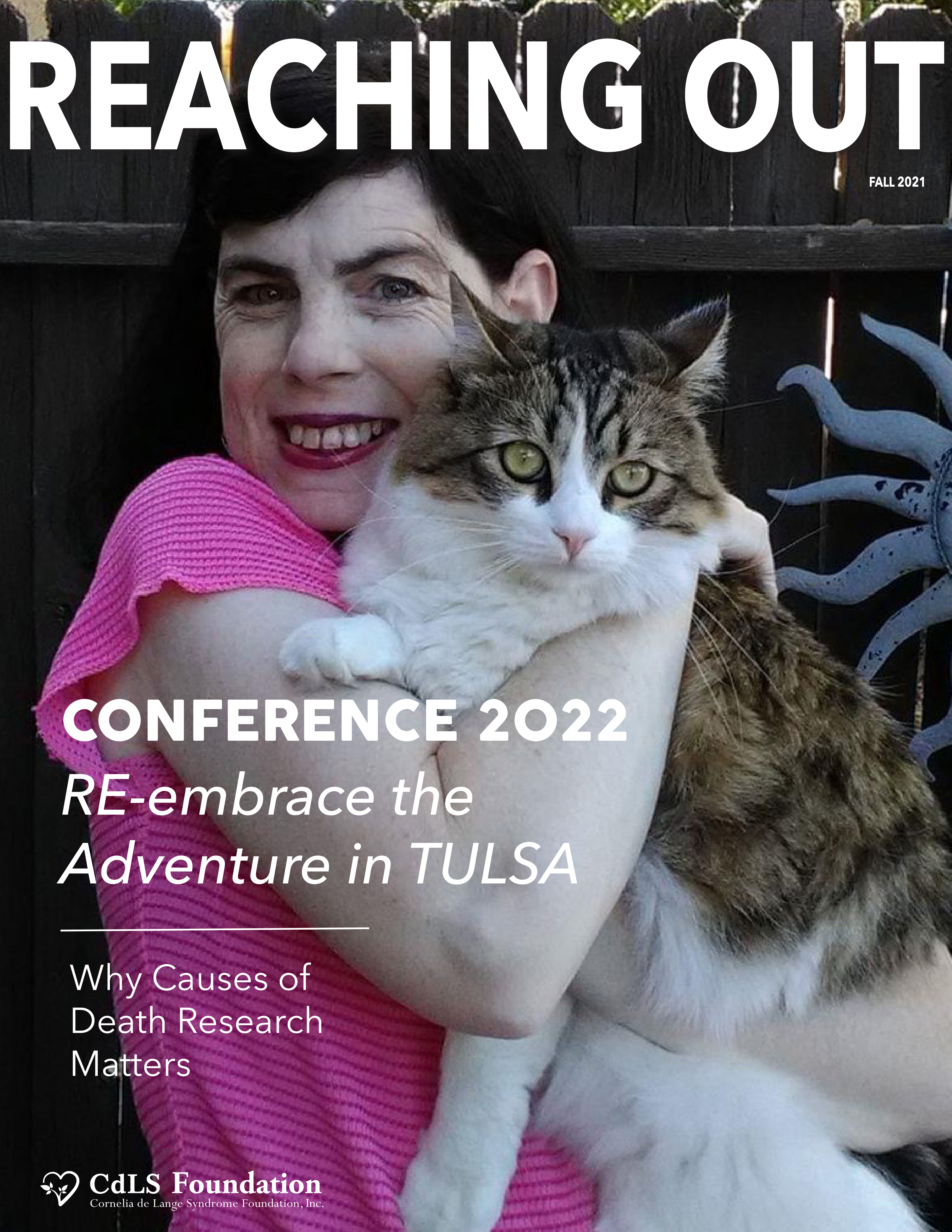
REACHING OUT

FALL 2021



CONFERENCE 2022

RE-embrace the Adventure in TULSA

Why Causes of Death Research Matters

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Celebrating 40 Years

Bonnie Royster, CdLS Foundation
Executive Director

The CdLS Foundation has faced its fair share of adversity since its inception in 1981. However, in those moments of doubt, hope was there too. As the saying goes, "Hope will never be silent".

With the help of our research committee members and their teams, we've learned quite a bit about the genetics of CdLS and how the syndrome is formed early and spontaneously in the development of the fetus. The research group has helped us uncover seven gene mutations so far associated with CdLS. Thanks to our Medical Director and team of dedicated professionals she works with – we've collected important data on the aging process (natural history) for individuals with CdLS. The Missouri Golf Tournament has been a source of financial support for the Foundation for over 30 years and the Chicago Marathon runners under the coaching of Marc Needleman has been going for 21 years – breaking a fundraising record in 2018. In the 40 years since our founding, we have grown from serving 23 families to over 3,600 today.

Our community continues to learn from and support each other – these are the seeds of continued growth that will help us evolve over the next 40 years.

In this issue, we celebrate hope and resilience. Mom, Cindy, lost her beautiful son, David, 9 years ago. She turned her loss into life-giving hope by donating his organs. He now lives on in others. Mom, Rebecca, recalled what it was like in those early days of Ellajean's life in the NICU. The kindness and support she received by other moms who understood, inspired her to pay it forward. Lastly, mom, Lynnette, shares her journey to gratitude on the other side of the Covid-19 Pandemic.

One final thought, as we celebrate 40 years of supporting our beautiful CdLS community; as we continue on this path together, what do we want to accomplish in the next 40?

We are CdLS strong.

Bonnie

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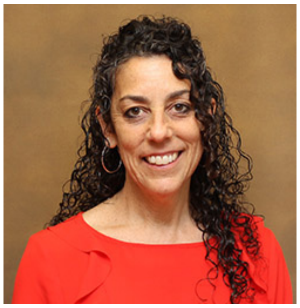
www.CdLSusa.org

THE EVOLUTION OF THE EMPOWERMENT GROUP



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

After experiencing a pandemic and recovery, it is a good time to reflect on changes. When the CdLS Foundation was in its earlier stages, there were many gatherings of families, staff and medical professionals, but there was less opportunity to gather together in very specific groups.

At the national conferences, families were divided by tables related to the state in which they lived, or talks related to age of their child. Several times, workshops were divided into "more severe" and "less severe" involvement. Because less was known overall, and many parents wanted to find out as much as possible during those few short days, they would attend the "older child" or "more severe child" even if they had a newborn or young child. And from the professionals' point of view, we could not be that specific either during the talks we gave, or even while we were meeting with families. We have been aware that smaller divisions within the entire group can lead to the emergence of many positive findings.

More recently, in the last 6-8 years, a group of adults with CdLS who attend the national conferences have gravitated towards each other. They are on the milder end of the CdLS spectrum, and tend to be more verbal and independent. The group started meeting for several hours at each conference with no parents "allowed". One of the family service coordinators and other volunteers (e.g. genetic counselors) helped guide the discussions with this group of older teens and adults. They were able to bring up frustrating moments in their lives at home, or help plan out what to do in the event that something didn't go as planned. They could talk about job interviews or social events. Some were savvy about computers and were able to communicate in between the conferences. At times, members of this group could feel shy or uncertain about approaching others or expressing their views, and the other members were quickly able to reassure them and welcome them.

Slowly, this group began to support each other in ways that no one else in their families, friends, communities or place of work were able to. They understood each other! They had similar issues! It was something truly rewarding to all involved. They decided to change their name from the "Milder Adults with CdLS" Group to the "Empowerment" Group. Even the name itself is enough to lift your heart and make you smile. This Empowerment Group was even able to meet by zoom during the months of quarantine and isolation, thanks to the facilitation of the Foundation. This in turn alleviated the real risk of boredom, isolation, depression and sadness that COVID-19 caused. I want to thank the members of the Empowerment Group for being an excellent example of perseverance and acceptance, and applaud them for creating a new and important entity within our former traditions.

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Why Causes of Death Research Matters

Sarah Raible, M.S., C.G.C. and Ian Krantz, M.D. (Children's Hospital of Philadelphia)

While our hope is that all individuals with CdLS live long and happy lives, unfortunately many children and adults with CdLS die prematurely. Causes of death (COD) research identifies important etiologies contributing to the morbidity and mortality of specific diagnoses. This ultimately allows for an improved understanding of the potential clinical complications and management for children and adults in certain populations. In 2011 Schrier et al. (Am J Med Genet) reviewed 295 individuals with a clinical diagnosis of CdLS and known COD. Respiratory causes including aspiration/reflux and pneumonias being the most common primary causes of death (31%), followed by gastrointestinal disease, including obstruction/volvulus (19%). Congenital anomalies accounted for 15% of deaths and included congenital diaphragmatic hernia and congenital heart defects. Acquired cardiac disease accounted for 3% of deaths, neurological causes and accidents each accounted for 8%, sepsis for 4%, cancer for 2%, renal disease for 1.7%, and other causes, 9% of deaths.

The use of COD research goes well beyond statistics and can be used to improve medical management guidelines and to avoid morbidity and mortality. Through a detailed understanding of medical issues that lead to illness and death in the CdLS population, we hope to be able to act more proactively to identify these medical issues before they result in significant complications or even presymptomatically. Such findings allow caregivers and physicians to recognize early symptoms, provide appropriate management recommendations and surveillance, and to intervene expediently when needed. An example of this in CdLS is our understanding of the contribution of intestinal malrotation to significant medical complications and even death in individuals with CdLS which has changed our management guidelines to make evaluation for malrotation a recommendation in all children with CdLS as early as possible. If identified, corrective surgery can be undertaken that significantly reduces the risk of medical complications.

As with many rare genetic diagnoses, the ability to identify large numbers of affected individuals is limited. Small numbers have poor statistical power and prior reports focus mainly on observed trends. Much of this prior research was collected from families who submitted clinical records, autopsy reports, and death certificates to research. The data provided by families was invaluable as it made this research possible that would not otherwise be feasible.

In addition to submitting clinical records and autopsy results some families have made the decision to donate post-mortem samples to research. Tissues from organs such as the brain, heart, liver, kidney, intestines, lung, ovaries and skeletal muscle can all be donated to research and used for DNA/RNA extraction. Samples from specific tissues can be important in answering targeted research questions. For example, most recently our team at CHOP has been collaborating with a group in the UK to investigate gene expression in neuronal nuclei isolated from post-mortem cerebral cortex of individuals with CdLS. This type of study is important for addressing mechanisms of neuronal dysfunction in CdLS and is one example of how valuable such donations can be to forward research initiatives and uncover a deeper understanding of certain clinical issues.

The Center for CdLS and Related Diagnoses within the Roberts Individualized Medical Genetics Center (RIMGC) at the Children's Hospital of Philadelphia (CHOP) is continuing to collect information on causes of death in CdLS to expand upon the prior information reported by Schrier et al., as well as banking samples donated from individuals with CdLS who have undergone an autopsy. If you would like to share information with the CHOP research team please contact them at rimgcresearch@email.chop.edu or 267.426.7418.

Why I Chose Organ Donation for My Son

By Cindy Connellan

David was born in 1982. Most doctors hadn't even heard of CdLS. There was no internet to search. No families to get in touch with who had been through this before. David was physically mildly affected, except for reflux. His biggest delay was expressive speech. As he got older his anxiety was through the roof and often resulted in aggressive behavior. Teen years were very difficult. He was hospitalized at 13 on a psychiatric unit. His psychiatrist had no clue what to do.

David loved music, specifically Peter, Paul and Mary. He loved to mow, his family, the staff in his group home and jokes. Life was leveling out for David, until the summer of 2012.

David was admitted to the hospital, again with some behavior issues. After being in the hospital for two weeks he had respiratory arrest that resulted in a nonfunctioning brain stem. It was clear that he would not survive.

As a nurse who has worked in a bone marrow transplant unit, I understand the impact of organ donation. However, I had no idea if David would be able to donate any organs because he was born with CdLS. But I asked – could he? Then next thing that I knew, Midwest Transplant Network had a person come in to talk to us about organ donation and to get our consent.

David donated his corneas, lungs and kidneys. His lung recipients and one of his kidney recipients are still alive and doing well. His liver went to research. Many people didn't realize that David was able to be an organ donor.

Nobody wants to think about death, especially the death of a child. But it is important to think about what our feelings are about organ donation and make that decision before the time comes to make it. Medical research is making huge strides. Something that might not have been possible 5 years ago is now possible. Because of my connection now with Midwest Transplant Network, I have many friends who have received the gift of life through organ donation. I am proud to say that my son, David, lives on in others.

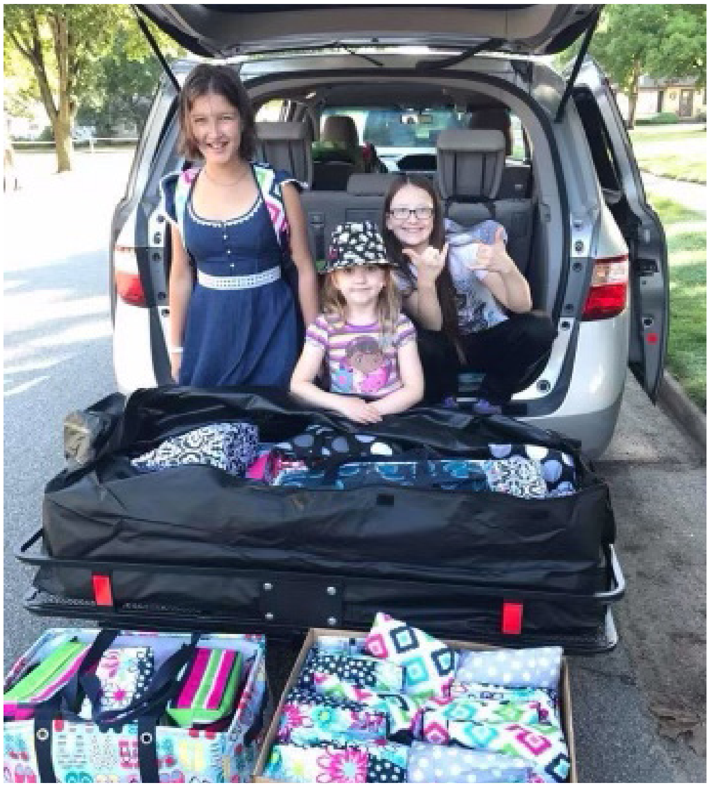
WHY I ALSO CHOSE ORGAN DONATION FOR MY SON

By Corliss Shaw

Our son Corvohn was born 3lbs 8oz. He was a full-term baby but born with CdLS. There was a wide range of complications from health issues to missing or partially grown extremities. Corvohn was healthy but was in full need of care, he thrived with therapy. He was always a joy; he loved eating, dancing and being with his family. He was a very happy person. When the day came to make a decision for Corvohn to donate his organs there wasn't a second thought in our minds to donate. We felt all of his life he was given help; this was the opportunity for him to give back. While in the hospital the nurse and blood donation representative came to us and asked would we consider donating organs and immediately there was no problem. He was able to donate 6 organs. His death is still tragic, but knowing he has been able to help people has been an overwhelmingly feeling of happiness.

REBECCA POQUETTE & **CASSIE** SMISKEY

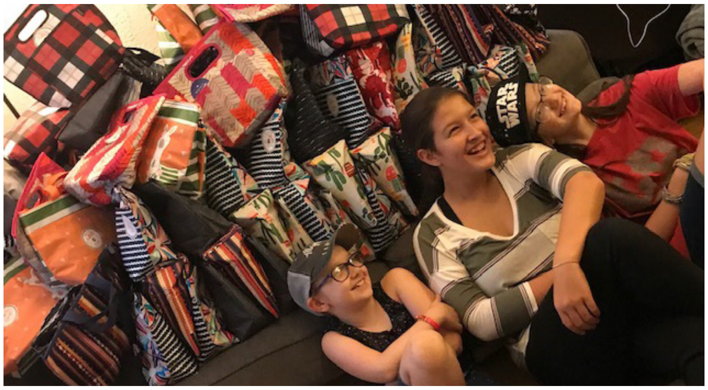
For the past five years, Rebecca and her good friend Cassie have been donating stuffed thermal bags to local NICUs in Eau Claire, WI. The bags are filled with anything a new family could need while being in the hospital for weeks or even months. The inspiration came from when Rebecca and her family were in the NICU for 76 days with her daughter Ellajean.



Ellajean was born with CdLS and Cassie brought Rebecca's family a bag of self-care items to help them get through a tremendously difficult time in their lives. "Knowing people cared was huge, when we were in the NICU," shared Rebecca. "The welcome bags have all the items you don't think of bringing."

To help families going through some of the most challenging days, the friends initially had a goal of packing and delivering 40 welcome bags full of books, and snacks among other essentials. However, they have gone from delivering 40 to over 100 bags to the St Paul, MN Children's NICU each year. This year, they reached their goal of collecting 150 thermal bags.

The project goes hand in hand with Ellajean's birthday and CdLS Awareness Day. This year, a local store, the Chippewa Store in Chippewa Falls, partnered with them in hopes to gather more attention. The store hosted activities to generate more awareness, as well as act as a drop off site for donations.



Rebecca and Cassie work with sponsors to purchase lunch thermals. Then the thermals get stuffed with water bottles, Chapstick, combs, toiletries, chocolates, pens, notebooks, board books to read to their little one and anything else the pair can think of to make families stay at the NICU that much easier.

"We do a thermal as a bag so that if moms pump, they can bring that milk home when they come home … then we also try to fill those gaps when you fly out of the house in an emergency you don't think about hair ties, a journal, tooth brush," said Cassie. "You can't always touch your baby, they are in an incubator, so with books you can at least read to your baby."

Five years in and the friends hope the project continues to grow each year.

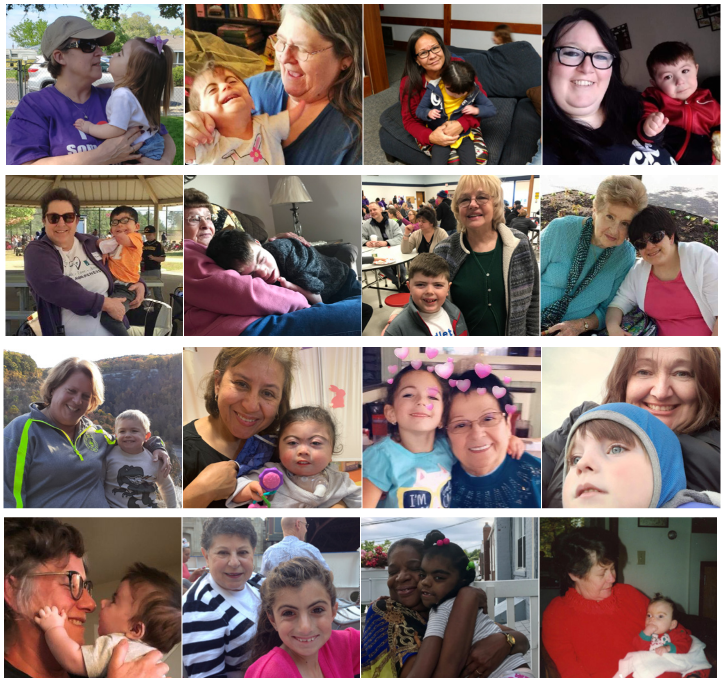
If you have a story you would like to share in *Reaching Out*, email Gabrielle Nadeau at gnadeau@CdLSusa.org.

To Grandma from your Grandchild with Special Needs

Hi Grandma,

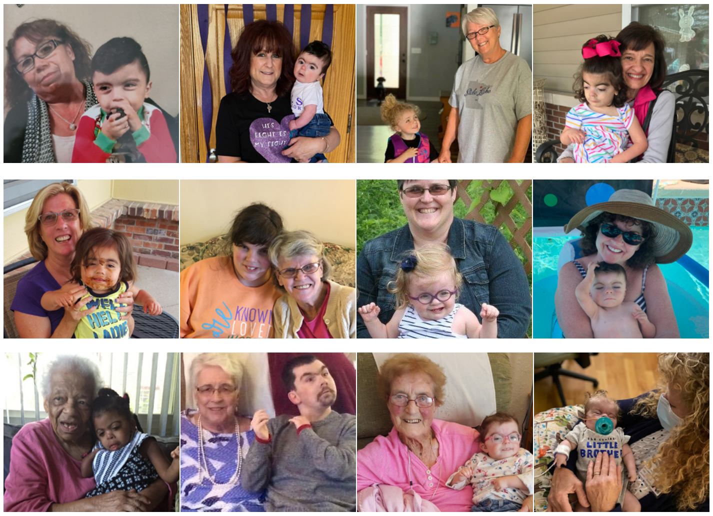
It's hard for me to find the right words, so I decided to write you a letter. Well, Mommy is writing what I say, since it takes a long time for me to write letters.

I like you, Grandma, because you make Mommy and me feel special. You don't make me feel like I'm bad, or make fun of me, or yell at me. Instead of making me play games I don't want to play, you'll join me in what I'm doing. You don't ask me a lot of questions and are okay when I answer yes or no. Somehow you know whether or not I want to talk. Talking is so noisy, but I feel safe having someone just sit in the room with me. Sometimes it calms me down.



I like what you do for Mommy too. When you hug and laugh with her, she has a smile on her face. Mommy doesn't show her smile very often. It's pretty. I like when you bring food over even when I don't like it. I'm a picky eater, but it's Mommy's favorite. Mommy likes when you talk about when she was little or ask her about books instead of talking about me. And boy does she love white daisies. That's probably why you bring them to her sometimes. You're nice to help Mommy with all her jobs around the house. When you help, she gets done faster and doesn't seem so tired.

I like it when you come over and then Mommy leaves, too. Because sometimes Mommy and I just need to be apart for a while. Besides when it's just you and me at home, we have fun. When mommy comes back it's like she took a nap. I don't want mommy to be tired all the time.



Mommy told me that you are her mommy. Mommy doesn't lie so I know it's true. Thank you for being her mommy.

I'm out of words and Mommy's crying a little. Even though she's smiling, too.

I love you, Grandma!

Your Special Grandchild

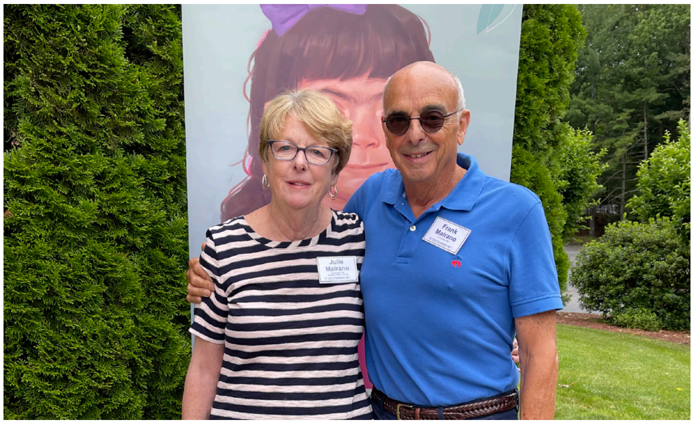
If you would like to share a piece of encouragement to the CdLS community, email Gabrielle Nadeau at gnadeau@CdLSusa.org.

HIGHLIGHTED **EVENTS**

HITTING THE TRAILS FOR CdLS

Families from New England joined CdLS Foundation co-founders, Julie and Frank Mairano, board members and staff for a fun afternoon of walking, talking and celebrating at the Hit the Trails for CdLS event held in June.

Hit the Trails for CdLS is a brand-new event, and was used to kick off the Foundation's 40th anniversary. Held in the Foundation's hometown of Avon, participants came together to enjoy a leisurely two-mile stroll down the scenic Farmington Valley Rail Trail. The trail was lined with timeline signs showing photos and information about the Foundation's progression over the past four decades.



The event began with a special presentation to Julie and Frank, of a dedication plaque in memory of their daughter Lisa, who was the inspiration that led them to work with other families to establish the Foundation in 1981. A similar dedication plaque also hangs on the wall inside the CdLS Foundation office.

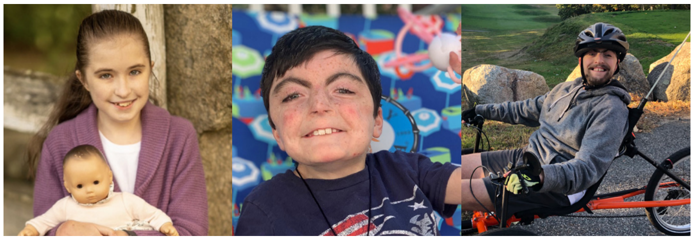
Following the walk, participants were treated to delicious 40th anniversary cake pops, raffle prizes and a chance to write their favorite memory on the Foundation mobile memory wall.

To make the event even more special, participants helped to beat the first-year goal of $2,000 by bringing in more than $7,300! A huge thank you to all who participated and contributed to the success of this event.

If you were not able to attend the event, you can create your own Hit the Trails for CdLS fundraiser wherever you are, and invite your friends, family, classmates, colleagues and other trail enthusiasts to join you for a walk/bike event at a trail or park near you. For more information just go to this link: bit.ly/VirtualHittheTrails or contact Annette Scheidecker at events@cdlsusa.org or 800.753.2357.

WALGREENS RAISES AWARENESS AND FUNDS FOR CdLS

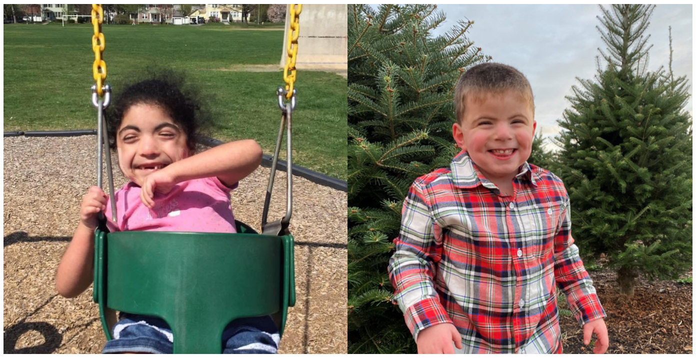
Thanks to CdLS Foundation Board President, Mike Christie (Taryn's dad), and his commitment to raise awareness and funding for CdLS. His employer, Walgreens, wrote a check for more than $24,000 for the Foundation this summer.



During the last two weeks of June, Walgreens held a special event in 73 stores in the Southeastern region of Massachusetts, where customers were urged to donate to the CdLS Foundation while checking out at the register. As part of the event, signs featuring five CdLS Foundation ambassadors from the region were posted in all of the stores, helping to raise awareness. In just 14 days the event raised $19, 097!

On top of that wonderful show of support from Walgreens and their patrons, the pharmacy chain also agreed to partner with the CdLS Foundation as a Gold Sponsor by making an additional $5,000 donation through the Walgreens Corporate Social Responsibility Program.

"Walgreens is committed to the health and wellbeing of all the people in the communities in which we serve and we are thrilled to be able to support those in the CdLS community with these funds," commented Mike Christie, Walgreens Area Director of Southeastern MA.



"We couldn't be more grateful to Mike and Walgreens for keeping CdLS and the Foundation top of mind," explained Bonnie Royster, Executive Director of the CdLS Foundation. "The support from Walgreens and their customers means so much to us, and will go a long way in helping us to provide the much-needed care that is crucial to the health and well-being of our families."

Thank you, Mike, Walgreens and Walgreens patrons from the families and staff at the CdLS Foundation!

GET IN ON THE 40TH CELEBRATION

This is a special year of celebration for the CdLS Foundation as we take a look back at all that the Foundation has accomplished by way of outreach and support for our families over the past 40 years.

Now as we look ahead to the challenges going forward of serving a growing CdLS population, and the funding required to support more than 3,600 families across the nation, we look to you, our faithful and wonderful readers, for support.

For the remainder of the year, we are encouraging you to celebrate with us by participating. If you are able, please make a one-time $40 donation. To be included in this special celebratory fundraiser, simply make your donation online through this link: bit.ly/CdLS40for40 or fill out the coupon on page 19.

Donations that come in through this campaign will get special recognition in the first edition of *Reaching Out* in 2022 (unless you note otherwise).

We hope you know just how much each of you mean to us. You make the CdLS Foundation what it is, and we are forever grateful to you.

Do you have any upcoming events that are raising funds for the Foundation? If so, contact Annette Scheidecker at events@CdLSusa.org.

CALENDAR

September 12
Grandparent's Day

September 27
New England Golf Classic
Ipswich, MA

October 9
Baltimore Running Festival
Baltimore, MD

October 10
Bank of America
Chicago Marathon
Chicago, IL

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

November 6
Multidisciplinary Clinic for
Adolescents and Adults
Baltimore, MD

November 7
TCS New York City
Marathon
New York, NY

November 30
Giving Tuesday

CHANGING OF THE GUARD

JIM KESTING TO RETIRE

Anyone involved in the Amber Gaines Memorial Golf Classic, formerly known as the Missouri Charity Golf Tournament in MO, knows that founding father, Jim Kesting, is all-in when it comes to raising money to help children and adults with CdLS and their families. Now after more than three decades at the helm of this incredible fundraiser, Jim has decided it's time to hand the reins over to son Bryan, who is equally passionate about the CdLS Foundation and our families.

Jim started the tournament after learning that his business partner and his wife, Doug and Barbara Gaines, had a daughter named Amber, who was born with CdLS.

"Learning about the degrees of severity these children are born with along with the joy that they bring to their families, my goal has been to help families cope with all of the unknowns that they will face," Jim explained. "The CdLS Foundation is the best resource for those needs, and they need the monetary support for that to happen."

The golf event that Jim started so many years ago is now one of the Foundation's largest annual fundraisers, raising approximately $775,000 since its inception.

"I am grateful for all the support of Steve Snodsmith at PLM, along with the employees at PLM and MCWP, our friends and our business associates. It takes a cooperative group of team members for an event like ours to be successful and to last this long," reflected Jim.

Following in his father's footsteps, son Bryan says he hopes future golf tournaments will shine a spotlight on CdLS.

"I want all CdLS families to feel they have hope and know that they are not alone. There is much love and support for them, and of course we want to raise more money each and every year to keep that support alive," Bryan added.

The next Amber Gaines Memorial Golf Classic is scheduled for October 11, 2021. While Jim won't be leading the way anymore, he says "I know that I'm leaving it in very good hands."

> *"Learning about the degrees of severity these children are born with along with the joy that they bring to their families, my goal has been to help families cope with all of the unknowns that they will face…"*

ALL ABOUT BACK TO SCHOOL

SPECIAL EDUCATION (IEP/504) INFORMATION

The Pacer Center, located in Minnesota, has a section of their website dedicated to Special Education. In the section, you will learn the Individualized Education Program (IEP) and the importance of your participation in developing your child's IEP Plan. You are a required member of your loved one's IEP team, and your ideas must always be considered in any decisions the IEP team makes. The development of the IEP is required in the federal Individuals with Disabilities Education Improvement Act (IDEA 2004), its regulations.
To review all of the resources they have available, visit: www.pacer.org/parent/.

IEP PREP WEBINAR

Learning Essentials created a webinar series called IEP Essentials which is hosted by Wendy Taylor, M.Ed., Executive Director of Learning Essentials. The series explores six core topics that guide views through the IEP process. Attendees get educational and professional insight they need to advocate with confidence for your loved one. To watch the first webinar and to stay up-to-date when the news ones are released, visit: learningessentialsedu.com/webinars/.

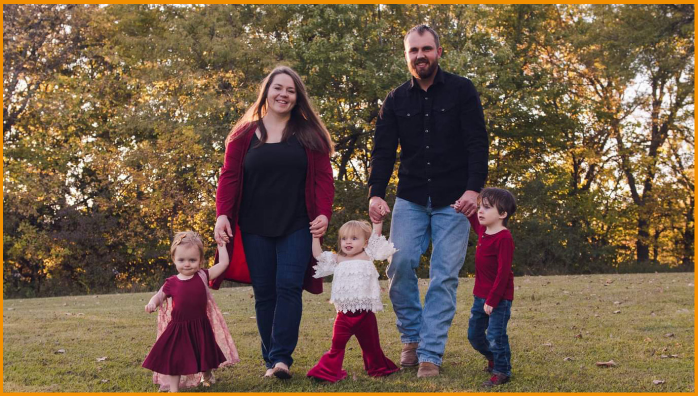
ADAPTED PHYSICAL EDUCATION

Students with special needs are required to receive at least the same amount of Physical Education (PE) as students who are typically developing. Federal law defines PE as the development of physical and motor fitness, fundamental motor skills and patterns, and skills in aquatics, dance and individual and group sports (including intramural and lifetime sports).

Some students with disabilities are able to participate in regular PE activities. Adapted Physical Education (APE) is PE that is customized and modified to address the needs of the individual.

To learn more about each core principles, visit: bit.ly/APE_CdLS.

WELCOME New Families



THE FARLEYS

We are the Farleys. Lyle was diagnosed at 4.5 years of age. One of our greatest joys, as Lyle's parents, is getting to watch him light up when he sees his sisters. Lyle loves going to school, Oreo cereal, slides, water play and toys that make noise.

California
Diana and Zachary, and daughter Eliana, born September 9, 2018

Florida
Melanie and Tyler, and daughter Makena, born March 1, 2021

Illinois
Cindy and Nick, and son Zachary, born April 12, 2021

Illinois
Brad and Maria, and daughter Maryelle, born May 14, 2019

Louisiana
Cassaundra and daughter Amari, born May 5,2018

Massachusetts
Emily and Andy, and daughter Delany, born August 2018

Missouri
Emily and Jared, and son Callum, born March 26,2020

New York
Christiana and Jared, and daughter Eden, born November 4, 2020

Ohio
Noelly and Robert, and daughter Allison, born 2017

Texas
Charlotte and Frank, and daughter Malia, born September 22, 1991

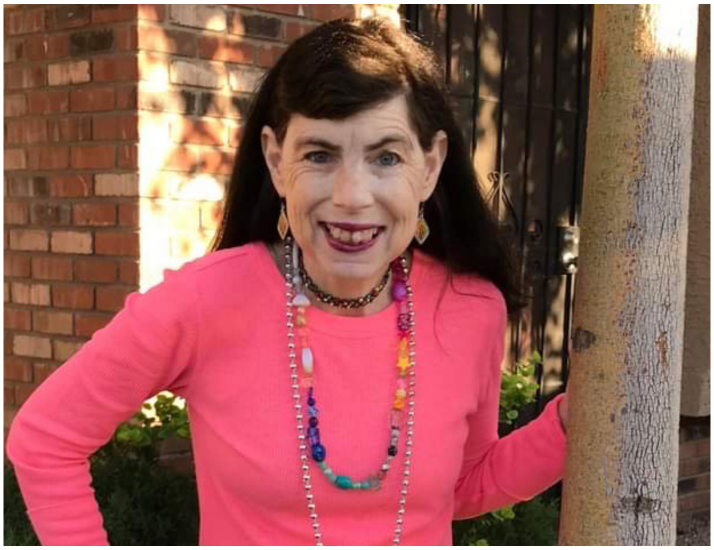
Virginia
Melissa and Adam, and daughter Harper, born January 15, 2012

Stephanie Fox

Stephanie is a fabulous 50-year-old who lives in California. Her favorite foods are Alfredo Fettuccine with angel hair pasta, with salad and ranch. Her favorite beverage is ginger ale, cherry Pepsi or Shirley Temples. At breakfast, Stephanie enjoys grape and apple juice. In the winter, she enjoys making her hot tea with her favorite tea pot.

Stephanie has a creative spirit. She loves making jewelry, keychains and colored pencil artwork. Her favorite things are dreamcatchers, butterflies and most of all peace signs. She enjoys shopping and going places with her family, especially eating at the Cheesecake Factory and Olive Garden. In her spare time, she loves watching the Hallmark Channel.

She babysits her nieces and nephews, and likes spending quality time with them. Stephanie has seven nephews, one great-nephew, nine nieces and two great-nieces. She also has a blended family that includes four sisters and three brothers. She loves her amazing 6-year-old cat, Angel, who is the love of her life. Stephanie loves to cook and bake.



She was born full term and weighed 3 ½ pounds at birth. She stayed in the NICU for two months and gained enough weight to go home, but she was never diagnosed (this was 1971) with anything except low birth weight, failure to thrive and was classified as being small at the time of birth. It was difficult for her to gain weight. When she was four, she was diagnosed at Children's Hospital of Orange County in California. Up until then, it was very scary and frustrating not knowing why is she was delayed in walking and speech, was behind on the growth chart for her age. Her younger sister was surpassing her in many traditional milestones set for her age.

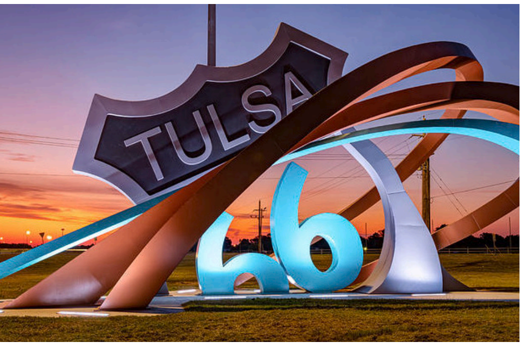
> *"Finding the Foundation years ago really was a blessing... We have made many friends and lasting friendships along the way which has been very important."*

One main challenge that Stephanie has dealt with is food intake. Her family maintains a soft food menu so she can swallow and digest. Also, dental appointments in the past have been challenging. Another obstacle is buying clothes and shoes that are age appropriate. She wears 10/12 size in kids, and wears a 1 ½ -2 in children's shoes.

Stephanie has a huge and caring heart, and has kindness and love for all people. She truly does not have bitterness or hate anywhere in her soul. She sees only the best in everyone she meets.

Do you want your loved one or you to be featured on the cover of *Reaching Out*? Learn more about the process by emailing Gabrielle Nadeau at gnadeau@CdLSusa.org.

RE-embrace the Adventure in Tulsa



Brighter days ahead and the world is finding safer ways for loved ones to be together again. We are excited to announce that we will be embracing the adventure in Tulsa in June of 2022!

The CdLS Foundation National Family Conference is scheduled for **June 23 - 26, 2022**, in Tulsa, OK. The goal remains the same – provide education and support to individuals with CdLS and their families.

As we get closer to the conference, be on the lookout for more information and tips. We hope to see as many families as possible at the event. It's truly a highlight for staff to see families in person, so we'll see you in Tulsa!

FAQS

WHEN CAN I REGISTER FOR CONFERENCE?

Registration for conference is scheduled to open Tuesday, March 8, 2022. The early bird registration deadline is April 8; the final deadline is May 20. Registration is available online through the CdLS website, visit www.cdlsusa.org/conference/. Conference can accommodate up to 150 families. Once that number is met, registration is closed.

WHAT DOES REGISTRATION COVER?

Registration Fees		
	Before 4/8	After 4/8
Adult 18+	$370	$410
Person Providing Childcare	$250	$280
Children 3-17	$190	$215
Children 2 and Under	No cost	No cost
Person with CdLS	No cost	No cost
One-day Professional	$150	$150

The registration fee covers all workshops and sessions, medical and educational consultations, and the following meals: Thursday night ice cream social; Friday breakfast, lunch and dinner; Saturday breakfast, lunch and dinner and Sunday continental breakfast. It does not cover hotel or travel expenses.

WHERE ARE WE STAYING, AND WHEN CAN I BOOK MY ROOM?

The conference takes place at the Marriott Tulsa Hotel, Southern Hills (bit.ly/marriottsouthernhills). Access to booking hotel rooms is through online registration. The reduced room rate is $125/night plus tax. The reduced room rate is only for people registered for conference. All non-registered guests using the conference room rate will be removed from the room block and be required to pay the regular room rate.

WHAT IS THE HOTEL'S POLICY FOR COVID-19?

Marriott has implemented a variety of new protocols and elevated practices, in response to the COVID-19 pandemic, including social distancing measures & contactless experience, and enhanced cleaning protocols. They have also made other adjustments to services, amenities, and facilities. To read all of their updates, visit: bit.ly/CdLSHotelCon22.

WHAT ARE MY CHILDCARE OPTIONS?

Children with CdLS (any age) can attend **Jindi's Place** at no cost. Activities include arts and crafts, movies, games, toys, reading, and a quiet room. Arrangements can be made for tube and bottle feedings. More details regarding child care options will be available soon.

WILL THERE BE A VIRTUAL COMPONENT?

The Foundation is looking into potential options for families who are not comfortable or unable to attend in-person. There will be more information in the winter issue of *Reaching Out* as well on the website.

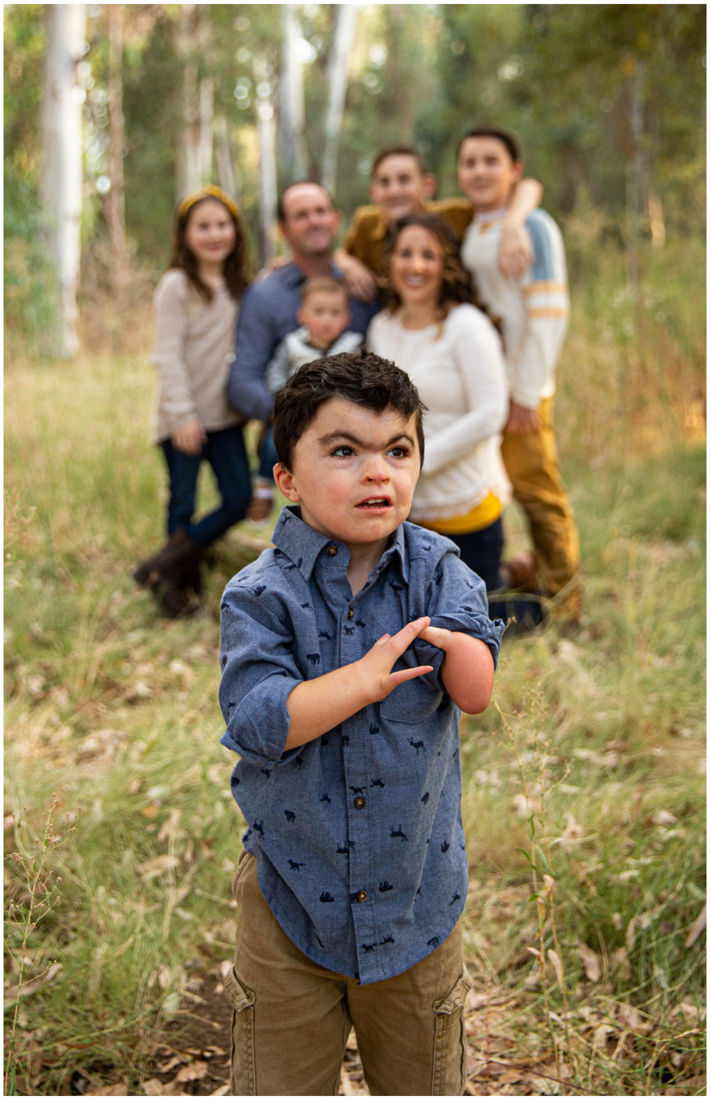
More details on conference, as well as registration links, amusement park discounts, and transportation information will be on the conference web page.

My Life Post COVID with a Child with CdLS

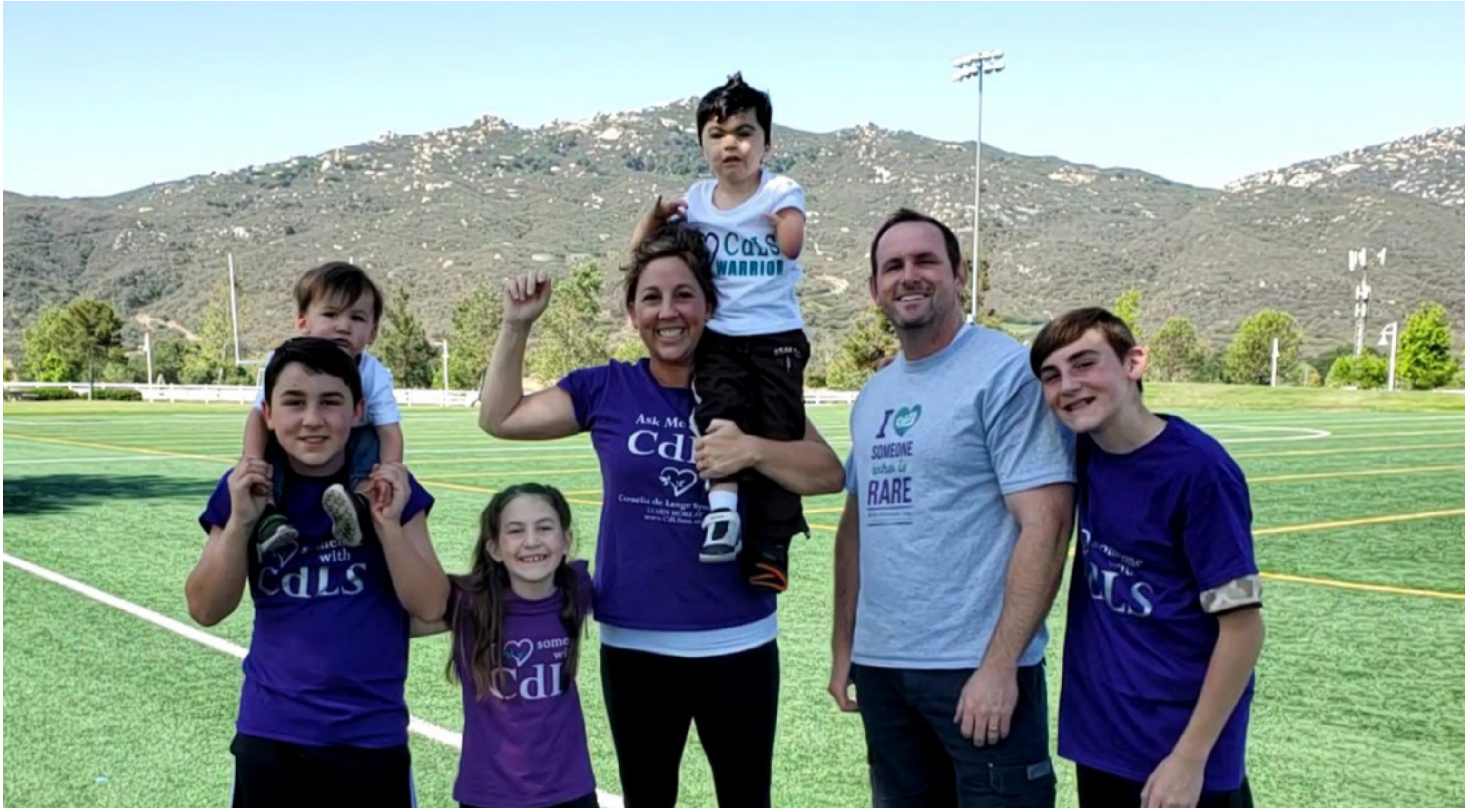
LYNNETTE STEVENS

When the pandemic hit California, our lives were turned upside down. Not only did everything in our area shut down, but we also lost our LVN (Licensed practical nurse) help, schools were canceled, outside therapy stopped and doctor checkup appointments were canceled. We went from busy full days to doing nothing. The worst part was seeing my son Conner (age 6, CdLS), who enjoys having a set schedule, upset and frustrated without a voice to express himself and not knowing what was going on. He didn't understand that when we walked by the park we normally played at, he couldn't go and play. His frustration levels rose even higher when we tried to zoom in with his teachers and aides at home for school. All he wanted was to be in person with them and not look at a screen image. We experienced temper tantrums like never before and even full defiance of refusing to do tasks which he had normally enjoyed. This was such a disaster and difficult for me, at times I was ready to tell the school we were done! But through consistent effort and a lot of patience, Conner was able to transition into a new groove. By small and simple acts, taking things day by day and working together, we were able to see huge blessings for our family, especially for Conner.

The first blessing I received was a personal reconnection with my son. I became not only Conner's mom, but also his full-time caretaker, therapist, teacher, nurse and play buddy. The beginning of the pandemic was rough for me with 100 % of Conner's care, medically and emotionally, falling on me 24/7 when I had been used to having LVN care support for help. In addition, I was caring for his 4 other siblings as well. During this stressful stage, I realized I had mom guilt. I had relied on my nurse too much and was used to a certain amount of freedom. This freedom however, had put the tiniest amount of distance between me and my son and the rest of the family. Now that it was fully removed, I was able to reconnect more fully through his education and care. Doing these small and simple everyday things together made my love for him grow.



My family was also dramatically impacted by these changes. I had always thought we spent good family quality time together before, but it was nothing compared to the time we spent together now. We all came to see that there were so many outside activities that took away from our time together and when they disappeared, we as a family became stronger together. The family also came together to take care of Conner. Everyone had a hand in his care. The kids worked with Conner on communicating with his AAC, they played more with him, and we all became more aware of



his educational goals. As time progressed, we saw Conner improve both academically and socially. A favorite memory was a night while we were all lying down watching a movie. Usually, Conner will 'do his own thing'. This time, Conner came over to the kids, looked at them watching the show and then scooted in between two of his siblings and lied down with them. That was one of the first times I could remember him actually coming and initiating a social interaction with his siblings. From then on, he would go to his siblings, grab their hands and take them to an activity or show them what he wanted to do. It was so wonderful to see my children growing closer together.

Another blessing from the pandemic was that Conner's health actually improved. We went almost a year without him being sick. Doctor appointments were virtual. I wasn't taking him to outside therapies and his exposure to other people was limited. My husband and I also decided to increase and become more consistent with feeding him home blends after attending the Virtual CdLS Conference. Previously, I had found it easier just to pop open a new carton of formula. Now, having more time and being motivated by the reports that kids with home blends were hospitalized less, we jumped into creating our own more nutritious meals. Once we got into the groove of blending, we found so many upsides to it. Conner was able to digest the food better, faster and we even found that his GI issues became less. Conner seemed happier and healthier and it has been one of my favorite changes from COVID. Over the last six months Conner has also had a nice little growth spurt, by not only growing 2 inches but also gaining 3 pounds. This is the most he has ever grown in that amount of time and we love seeing the extra little bit of chunk on his body!

We know that the pandemic is not over, but things have already started getting back to normal. Conner and the other kids have started going back to school. Conner has resumed going back to outside therapies and we have learned that some doctor appointments can continue being telehealth while others need to be conducted in person. My Husband and I chose to be vaccinated after much thought and consideration, but in the end, we thought it would be another way to help protect Conner's health. We are still wiping surfaces, cleaning hands and trying to stay as safe as possible, but we feel it important for Conner to have as normal a life as possible. Going to parks, the beach and family trips again has been so good for everyone's mental health! The family has chosen to not resume LVN help for the time being. We have enjoyed it and don't feel so overburdened any more with his care. Caring for Conner's medical needs has become a part of our "New Normal" and we all love having Conner look to us for play and entertainment.

With the return to normalcy, we want to remember and keep those things that we learned. Our goal as a family and especially for Conner is to continue giving each other our attention, to not let the busy things that really aren't as important take over our life and to continue to be there for one another. We have chosen to put family first and find joy in what comes our way. The last year has taught us that we are stronger together than apart and that we are strong enough to overcome any trial or struggle.

Our Deepest Sympathy

Devin Abeyesundere
February 24, 1991 – February 13, 2021
Son of Shahn and Schani Abeyesundere
11611 Remington St
Lake View Terrace, CA 91342-6137

Jocelyne Sharrard
February 27, 1978- February 25, 2021
Daughter of John and Beverley Sharrard
41372 Ladybug Court
Aldie, VA 20105

John Belliard
January 18, 1992 – May 23, 2021
Son of Glenda Belliard
15476 SW 8 Way
Miami, FL 33194

Aaron Aicardi Young
February 11, 1980 – May 28, 2021
Son of Angela and Tim Young
14195 Danpark Loop
Fort Myers, FL 33912

THE GRIEF SUPPORT ADVISORY GROUP IS HERE TO HELP

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

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

In Honor/ Celebration

Gregg N. Abbott
Jan and Jim Abbott

Carolina Amor
Priscilla and Fernando Amor

Brandt Anderson
Fran and Wayne Shull

Zackery Arrowood
Theta Mu Sorority

Hunter Barrett
Gary Hartman

Annie Beaumont
Rita Deck

Colin A. Bell
Cheryl La Roe

Elizabeth A. Bernhardt
Ramona and Randal Bernhardt
Rita Linert

Katie E. Bettendorf
Nancy and Roland Bettendorf

Aisley Birrer
DeAnna Paulding

Ashley Calamaco
Amy Wilson

Douglas R. Canning
Ann Moore
Maria and Maury Paslick

Robert W. Carter
William Carter

Barbara Cimino
Paula Ceder

Nicholas D'Angelo
Korissa Pierce
Connor Willey

Kristian L. Daly
Leeann Howe

Alyssa M. Delgado
Gricelda Contreras

Delaney DeMaria
Vincent Berardini

Hugh Devlin
Diva Dance Competition

Kevin Devlin
Breda and Kevin Devlin

Samuel Diehl
Karen and Jeff Diehl

Diva Dance Competition
Heather Luxenberg

Halston Dorow
Doni Hamann

Brian J. Drach
TD Ameritrade Institutional

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Susan and William Elphingstone

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Barbara Falls

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Caitlyn Martin

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Carolyn and Ted Williams

Ruby Fjeldsted
Courtney and Paul Fjeldsted

Logan Fowler
Jane Arai
Christl Schambach
Betsy and James Wilson

Lindsay Franco
Susan and Scott Coleridge
Amy and Don Franco

H. G. Fry
Linda Chatham

Leonard Furman
Jasmin Furman

Aryanna N. Gage
Sarah Griffith

Manuel J. Garcia
Liana Davila & Michael Garcia

Aubrey Garigen
Nicholas Garigen

Mason Gilbert
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Marlene and Wesley Harris

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Linda and David Hendrickson

Jade Holmberg
Claudia Strelow

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Moneta Howland
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Geralynn and Don Huffman

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Sara and Rodney Lair
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George Jacobsen

Avynn Juhnke
Judy Donnell

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Jessica and Neil Bernanke Ewachiw
Barbara Kahn
Amanda Katz
Randi Kieffer
Alisa Kotler-Berkowitz
Brent Newton
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Gwen Stokols

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Oswego Oil Service Corp.

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Kathy and Andy Wood

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Christy and David Whetstone

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Penny Ketchem

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Anne Cahn

Jack Yadisernia
Diva Dance Competition

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Andy Win

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Lisa and Thomas Alicata

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Melissa Appleton
Rebecca Runge and Tyler Bajema
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Yolanda Schneider

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Sherry Brick

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Margaret Lawler
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Mildred and Charles Wollborg

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Phyllis Zinner

Myrna Kaplan

Please note there was an error in our previous lists. Rylie J. Kohn, Katherine Lutz, Trey Green were listed in memory and were meant to be listed in the in-honor section. We apologize for the confusion.

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Yes, I want to help the Foundation **CELEBRATE** 40 years.

40th Anniversary
Celebrating forty years of support

Enclosed is my tax-deductible gift of:

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Cornelia de Lange Syndrome Foundation, Inc.

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Avon, Connecticut, USA 06001
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IT'S TIME TO GOLF FOR CdLS!

Golfers mark your calendars for some fantastic golf during the prime autumn season at the gorgeous Ipswich Country Club in Massachusetts or the fabulous Tapawingo National Golf Club in Missouri!

The New England Golf Classic is set for **Monday, September 27th in Ipswich, MA.** Registration and breakfast begin at 7:45am with a 9am shotgun start, followed by cocktails, lunch, awards and prizes at 1:30pm.

The Amber Gaines Memorial Golf Classic is scheduled for **Monday, October 11th in St. Louis, MO.** Registration and lunch begin at 11am with a 12:30pm shotgun start, followed by cocktails, dinner and prizes at 5:30pm.

For more information, including sponsorship opportunities and registration details, contact Annette Scheidecker at 800.753.2357 or events@CdLSusa.org.