REACHING OUT

FALL 2023

Spotlight:

Augmentative and Alternative Communication (AAC) Devices

ON THE COVER

Joey Riedmiller

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Hello, Glorious CdLS Family and Friends,

We bring you yet another fabulous edition of *Reaching Out* to welcome you in the beautiful Fall season.

We are living in a post-Covid world, and so much has changed. To some degree, we are all experiencing collective grief as we let go of a way of life that doesn't exist anymore. The Japanese term for crisis has a double meaning – one meaning is chaos, and the other is opportunity. Our current crisis/chaos gives us all a chance to refresh and start again but wiser and more experienced.

Working diligently with many of you – our volunteers – we are building toward a new future. Families from all over the world reach out to the US CdLS Foundation. The Language Line™ is a new service offering that allows us to speak to families in any language with medically certified interpreters. This brings up one step closer to enhancing the feeling of belonging, which is the natural result of an organization working toward greater Diversity, Equity, and Inclusivity. (Thank you, Yvonne)

The Research Committee is working with other rare disease groups to create a consortium to solve our community's most pressing problems. The goal of our efforts is to point research toward meaningful therapeutics for you. We are inspired to know that another rare disease foundation (Rhett Syndrome) has achieved just such a noble goal winning FDA approval for Daybue – a drug for repetitive behaviors.

As always, we thank you for continuing to hang in there as we evolve to meet the new challenges we face. Our ability to bring you programs and services is powered by the efforts of dedicated volunteers like the NE Golf Committee – who this year hit 1 million dollars raised for the Foundation!!! Thank you, John, Michele, Ava, Pat, Anders, and Mike.

Mike Feehan has been running and creating obstacle courses for his family and friends, raising over $300K for the Foundation in his backyard.

Contributions of your time, talent, and treasure make a huge difference in allowing us to continue supporting families on their journey of living with CdLS. We can't do it without you.

We came up with a playlist for you to listen to on days when you feel a little low and need some inspiration to keep moving forward. We hope you enjoy this issue and the playlist as much as we did creating it.

Love & Hugs,

Bonnie

Bonnie Royster, CdLS Foundation Executive Director

Staff Playlist

Bonnie K. – TINA TURNER - PROUD MARY
Bonnie R. – DONNY HATHAWAY - SACK FULL OF DREAMS
Deirdre – RACHEL PATTEN - FIGHT SONG
Francesca – BEYONCE - RUN THE WORLD (GIRLS)
Gabrielle – BOB MARLEY AND THE WAILERS - EVERYTHING'S GONNA BE ALRIGHT
Linda – BRUCE SPRINGSTEEN - NO SURRENDER
Maureen – SURVIVOR - EYE OF THE TIGER
Sherry – BILLY JOEL - MY LIFE
Vanessa – PJ MORTON - GOOD MORNING
Whitney – HALSEY - IT COULD HAVE BEEN ME

CHECK IT OUT!

Reaching Out
Published Since 1977
(ISSN 1097-3052)
Cornelia de Lange Syndrome
Foundation, Inc.
Incorporated December 1981
email: outreach@CdLSusa.org
www.CdLSusa.org

CARE COORDINATION AND PERSONAL CARE


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

There are known factors about being a parent. Parents respond naturally to their infant's cries and work to provide nourishment, clean diapers, clothes, and shelter. As children age, they are brought to the pediatrician or family practitioner where immunizations and well child checks are available. Parents enroll their children in a school and maintain contact with the school professionals.

There are many additional factors for parents of children with multiple medical and developmental complications. For children and adults with CdLS, additional preventative visits should include an eye doctor, an audiologist, a pediatric dentist, and early intervention therapists in addition to the primary care doctor. Other specialists may be needed, including cardiology, gastroenterology, urology, neurology, genetics, child psychiatry, and behavioral psychology. Acute care may require visits to Emergency Rooms or Urgent Care.

One significant benefit of your child's insurance (e.g., Medicaid/Medicare/private insurance) or primary care office will likely be a Case Manager (a care coordinator) who can help you navigate the health care system.

You may have to ask specifically for this benefit, but it should be provided.

Often this care coordinator can help with making/attending appointments and with things like hard-to-find formulas or expensive medications. Each state has a Developmental Disabilities Services office (they all have different names) that helps coordinate targeted case management and provides community (social) services. There may also be a similar coordinator in the school system. Below are some websites that may be useful.

- bit.ly/CdLS_Care_Coordination
- bit.ly/CdLS_Coordination
- bit.ly/CdLS_Care

Throughout all the care needed for your child/adult with CdLS, caregivers have to focus on their own mental health. This involves having a supportive partner in parenting and taking some personal time for errands, appointments, meals, and sleep. Hopefully, this time also involves exercise, pampering, reading, watching tv, gaming, and puttering around – whatever increases happiness and satisfaction. In addition to taking responsibility for others, please take care of yourself!

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Augmentative and Alternative Communication (AAC) Devices

Patti Caudill, M.S., CCC-SLP

Augmentative and Alternative Communication (AAC) describes methods used to support communication with individuals who are non-verbal, have difficulty understanding speech, or with selective mutism. Research on the use of AAC with individuals with CdLS is limited. There are very few studies published, and they consist of individual case studies or small groups. These limited studies, in tandem with studies on the use of AAC with individuals with developmental disabilities, suggest the potential for increased vocabulary, receptive language, speech/speech attempts, and decreased frequency of communication-related behaviors with AAC use.

Types of AAC include:

- Unaided AAC: Methods of communication that do not require voice, speech, or tools. Examples include gestures, facial expressions, sign language, and guiding or leading.
- Low-Tech AAC: Non-electronic tools used to assist with communication. Examples include pictures, communication boards, and object exchange (i.e., grabbing the remote control when wanting to watch tv).
- Mid-Tech AAC: Basic electronic devices that produce limited pre-recorded messages when activated by the individual. The Big Mack is a brightly colored single button. A pre-recorded message (up to two-minutes long) is played when pressed. It is frequently used for requesting an object or activity. It can also be used to share a message, such as "What I did over spring break." with a group. The Quick Talk (and similar devices) have four to 24 pictures with recorded messages, such as "I'm hungry," "I want to play," or "Stop."
- High-Tech AAC: Electronic or digital devices that allow for rapid changes in vocabulary and production of novel, complex language. These devices can grow with the individual as their language develops. High-tech AAC devices can be dedicated or non-dedicated. Dedicated devices are only for speech generation, sometimes called "speech generating devices." Dedicated devices are considered medical devices and are frequently covered by medical insurance. Non-dedicated devices are where AAC software can be uploaded. A quick search in the APP or Google Play store results in many programs with an extensive price range.

Among the interesting developments in AAC over the last 5-10 years is the increasing use of visual scene displays (mid-tech and high-tech). A visual scene display is a picture of a scene in which "hot spots" are programmed to activate speech when selected. Examples of scenes could include photos of the food pantry, a favorite activity like the playground, or pictures associated with routines such as the family room or the classroom. The use of a visual scene depicting the whole concept versus an individual picture/symbol (or series of individual symbols) may be an alternative AAC option for individuals with CdLS who demonstrate increased receptive language skills within familiar routines/environments or gestalt learning and communication (understanding of the whole versus the individual parts) but have not experienced success with AAC to date. Before implementing any AAC device, a comprehensive, functional AAC assessment with an experienced speech pathologist is recommended.

Parents/caregivers of children with CdLS are invited to participate in an online survey as part of a research study about children with CdLS and communication. The purpose of this research study is to gather information on the use of electronic communication devices in children with CdLS. For more information, go to **www.surveymonkey.com/r/CdLSAAC**.

Communication Perspectives

Emily Peterson, Aisley's Mama

Knowing your child will be nonverbal is hard. It has even made me question the teacher in me dictating everything I do and see to model language for Aisley. I thought, "What's the point of modeling language if she will never talk?". Although I know it is still important to model language because Aisley can understand language and has receptive language, those are my honest, hopeless thoughts that have come to mind. (Receptive language is the "input" of language, the ability to understand and comprehend spoken language you hear or read.)

I was interested in learning American Sign Language (ASL) from the beginning. Aisley and I would watch "Signing Time" together and practice our new signs. The most repeated sign we would try was "mom," "dad," and "more." I know for a fact Aisley has intentionally signed Mom and Dad at least once; then, it never happened again. We are holding our breath until we see it once more.

Aisley finally started to wave after her fourth birthday.

We are so thrilled when she does it!

In the spring, at the end of Aisley's first year in preschool, she received an AAC device through S.E.L.P.A. I asked for it, hoping for more engagement and success to assist Aisley's communication. After participating in the CdLS Foundation's webinar on AAC devices, I felt validated for advocating for this early in her education. One of Aisley's speech therapists gave me a sense of relief when she told me to use the device to model language rather than the pressure for Aisley to engage and press the correct word/image. This advice has made navigating the new app (she's using Go Talk Now on an iPad) and device a lot less stressful.

I do not know if Aisley will learn sign language or how to communicate with her AAC device. I want to try all the tools available in hopes something clicks. Having a four ½-year-old who cannot tell us how she feels is heartbreaking. It makes you feel helpless at times. We will hold on to hope that Aisley will learn to use signs or her AAC device. Until then, we will listen to Aisley's vocalizations, cries, laughs, smiles, and body language as her way of communicating.

WELCOME
New Families

Oklahoma
Cassidy and Joey Pfaff and daughter Jovie born January 8, 2022

Idaho
Hailey and Andrew Luckman and son Brok born April 12, 2017

New Medication Approved for Repetitive Behaviors in Rett Syndrome

Lynne Kerr, M.D.; Antonie Kline, M.D.; and Kristin Baranano , M.D., Ph.D.
Approval by Marco Grados, M.D., M.P.H.

We wanted families to be aware of this medication as it may eventually be helpful in individuals with Cornelia de Lange Syndrome (CdLS). However, please note that because there are not yet any studies in CdLS patients, it is not FDA-approved for CdLS, and it is unlikely that it will be covered by insurance. This may change in the future and families should follow news about this drug as it may become an option.

Daybue, or trofinitide, is a medication approved in March 2023 for individuals 2-65 years old with Rett Syndrome only. In the US, Daybue is being distributed by Acadia Pharmaceuticals, but it was developed by Neuren Pharmaceuticals in Australia. The Foundation has not been able to obtain more information.

In individuals with Rett Syndrome, caregivers using the Rett Syndrome Behavior Questionnaire and physicians using the Clinical Global Impression-Improvement Scale found a significant decrease in repetitive behaviors including hand movements, stereotypical breathing patterns, repetitive vocalizations and other repetitive behaviors in individuals receiving the medication instead of placebo. One recent study of children with CdLS [Srivastava S, et al., J Autism Dev Disord, 2021;51:1748-58] found that all 50 children in the study had at least one type of repetitive behavior, including motor movements and/or self-injury. Daybue's mechanism of action is not specific for Rett Syndrome, but the drug seems to increase neuronal plasticity in a mouse model of Rett. Daybue may eventually be shown to improve some behaviors in individuals with CdLS.

Daybue is available by prescription only and the dosing is weight based. Its cost may be prohibitive to many families. The main side effects of trofinitide are diarrhea and vomiting, which may be lessened by starting slowly and increasing gradually, and possibly weight loss.

As we learn more about the drug and its availability for patients outside of Rhett Syndrome we will keep you posted.

PLEASE NOTE, this article is for information purposes only.

The CdLS Foundation does not recommend individuals with CdLS take this medication.

Alice McClanahan

Samantha Reed

"A person is a person no matter how small." Alice was born prematurely at 34 weeks, weighing in at 4 lbs., she was the most beautiful gift given to me in just the palm of my hand. While I was pregnant with Alice, I knew she had something different about her, but we didn't know what nor care because we loved her already, no matter what the road ahead. It was after birth that my daughter made it to the NICU. I was so lucky to have had her pediatrician there, and to have a child of her own, just like my beautiful daughter. They both shared what is called Cornelia de Lange Syndrome. This was when I knew Alice's life would be a full-time job, but a job that I would learn to be so rewarding. Alice had a smile and sass to her that you couldn't help but laugh and smile along with. As she grew, the more the hospital stays and the more equipment she required.

As a mother, you want the best for your child, so each stay was a lesson and study to where I almost felt like a doctor. Even though her life seemed to revolve around appointments and the hospital, we could still give her the normal life we all so badly wanted for her. She was able to go to school and make friends. Alice was, let's say, everyone's best friend! There wasn't a kid who didn't know her that wouldn't stop to say hello to her as we passed them every morning to Alice's class. Not only did Alice experience all these new things, but I got to do it alongside her. I was so blessed to have seen children treat my daughter the same even though she didn't eat the same and couldn't do some of the things they could. The teachers would say how kids would give up recess to hang out with just her. Alice's life was full of difficult times, but she never let it get her down. She was so strong. I have never seen someone fight as hard as she did to be here with us. I remind myself how lucky I am to have her as my daughter daily.

December 6, 2022, was the day Alice left this world, and I learned what true grief meant.

No pain compares to the loss of a child. You find yourself missing all the small things like the sound of her machine going off from her hanging her pump upside down just so I'd come running into her room to where she'd just be giggling, to all the foot rubs she insisted she had after every bath, and the way she'd go crazy baby and laugh and shake her head back and forth. She only ever learned one word. That word she knew she'd get what she wanted no matter what was Momma. I got the joy of hearing that word at six months to her next six years of life. She was truly my sidekick and my best friend. She was the world's best big sister and just played the role. She'd pick on her little brothers just like any big sister would. The bond she had with her siblings is still so strong now. Not a thing stood in the way of what she wanted when she wanted it, and why would you say no to her cute little face? I sure didn't. She got the true princess treatment.

Alice made me a mom and showed me what it was like to love in a way that I never knew I could. We took every step together, and we took every single struggle together. Her little hand was in mine every step of the way. It's hard not to want to believe you're not dreaming. I have to remind myself every day it's not goodbye, it's see you later.

HIGHLIGHTED EVENTS

NEW ENGLAND GOLF SUCCESS

The 2023 New England Golf Classic celebrated its 30th year at the exclusive Ipswich Country Club in Ipswich, MA, on Monday, May 22, 2023. The tournament raised $35,000 to help precious children and families affected by CdLS. Over 120 golfers, volunteers, and sponsors enjoyed a great day on the course. After finishing the 18 holes, golfers were treated to a southern-style barbeque luncheon and awards ceremony. Shelly Champion, mom to Julie, was honored for her dedication and service to the CdLS Foundation. The New England Golf Committee thanks Title Sponsor – ePlus for their generous donation of $10,000.

A special thank you to the fabulous volunteers and additional sponsors that made this event possible.

NOT AN ATHLETE? JOIN OUR FABULOUS CURB CREW!

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

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

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

GEARING UP FOR GIVING TUESDAY – NOVEMBER 28

Giving Tuesday – a movement started in 2012 to "unleash the power of radical generosity around the world." The CdLS Foundation is so grateful to all of you who choose us as your charity of choice on this annual day of giving.

This year's goal is $15,000.

Help us beat that goal and put Giving Tuesday, November 28, on your calendar.

Spread the word to encourage your family, friends, and the local community to donate to the CdLS Foundation on Giving Tuesday.

Posting photos and sharing stories about your loved one with CdLS on your social media sites will help to raise funds for the CdLS Foundation. It will also help spread awareness about CdLS – both are equally important for the organization's future.

Thank you for being so supportive and choosing to make a difference in the lives of all individuals living with CdLS and their families.

To start donating or spreading the word, visit: **bit.ly/CdLS-GT2023**.

CALENDAR 2023

October 7
Wisconsin Family Gathering
Reedsburg, WI

October 8
Bank of America Chicago Marathon
Chicago, IL

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

October 14
2023 Baltimore Running Festival
Baltimore, MD

October 14
Texas Family Gathering
Plano, TX

October 22
Iowa Family Gathering
Spirit Lake, IA

November 4
Multidisciplinary Clinic for Adolescents and Adults
Baltimore, MD

November 28
Giving Tuesday
Online

Doctor Carol Potter

Deirdre Summa, LMSW, Family Service Manager, CdLS Foundation
Gabrielle Nadeau, MA, Communications Director, CdLS Foundation

The CdLS Foundation and community have had the privilege of having Dr. Carol Potter as part of our family for over 20 years. Her insight, knowledge, and compassion have enhanced our mission of ensuring individuals living with CdLS and their families are cared for and heard.

With her abundance of medical knowledge, she has been a powerful influence in the world of CdLS. She has been a part of the Clinical Advisory Board (CAB), addressing questions from families, providing guidance, and addressing Ask the Expert submissions in her area of expertise.

Over her 20+ years with the Foundation, she has participated in conferences by providing consultations and presenting workshops. She has traveled to many states to attend family gatherings and support families as they navigate learning about CdLS and sharing her insights and expertise.

Whenever she doesn't travel for the Foundation, she often has provided articles for *Reaching Out*, participated in creating new documents for families to get the best care for their children, such as, the Treatment Guidelines, critical care info, etc., and executed webinars when the Foundation was early providing these to families.

She has also recruited Raul (Rudy) Sanchez to take her place on the Clinical Advisory Board when she retires.

Thank you, Dr. Potter, for your many years of Reaching Out, Providing Help, and Giving Hope to the thousands of lives you've helped.

On The Cover

JOEY RIEDMILLER

Rachelle Riedmiller, Joey's Mom

Joey was born full-term on April 26, 2004. He weighed 7 lbs–1 oz. We had no indication anything was going on throughout the pregnancy. We were shocked the next day when the doctors started to tell us they suspected Joey had Cornelia de Lange Syndrome – that day started our CdLS journey with Joey.

Joey is currently 19 years old. He has three brothers and two sisters. One thing Joey loves to do is go to school. He thrives on structure and schedule. Joey also loves taking pictures on his iPad. If he gets ahold of someone's phone, he will scroll to the camera app. He also knows right where to find the photos on any device. Joey also enjoys playing his keyboard (volume on high, of course), taking people's keys to try to open EVERY door at school, and looking for clocks. His dad is a golf course superintendent, and he has loved going to "work" with him in the evenings this summer. They ride in a golf cart around the golf course doing various things or walking around. When we ask Joey if he's ready to go to "work" with Dad, he claps his hands and heads for the door!

Joey faces daily challenges due to having CdLS. He is nonverbal, which makes communication difficult. Another challenge we face is Joey is "busy" all the time, never wanting to sit down or take a break from his active ways. He needs constant supervision. Joey also wants food all the time. He doesn't seem to understand being full. Joey would eat all day long if we'd let him. He struggles with daily gas/stomach pain. We have medications to help control that, but it is still a problem. He had emergency surgery in June 2020 for a bowel obstruction. It remains a significant concern that he will have another one in the future, so we try to stay vigilant in watching for symptoms. Safety is also an issue. If he gets a chance, he will take off. He's pretty fast! I'm sure Joey feels frustrated daily when we establish boundaries for him. Unfortunately, that comes out in the form of self-injurious behavior. It breaks our hearts to see him hurt himself. It's such a powerless feeling.

The CdLS Foundation has been a great help to our family over the years. I hate to admit it, but I spent the better part of Joey's first year of life trying to deny there was anything wrong. Once I finally reached out, they had so much information available. We were connected with a family in our area who also had a child with CdLS. Things got so much better after that. We were empowered with knowledge, and it wasn't as scary anymore. For that, I am forever grateful.

For our family, CdLS not only stands for Cornelia de Lange Syndrome but also for Courage, determination, Love, and Strength.

"What lies before us and what lies behind us are small matters compared to what lies within us." Emerson
Rachelle Riedmiller.

Check out our blog! www.joeyswalk.blogspot.com

Request Your Education and Advocacy Materials

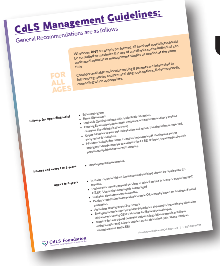
Family Service has a variety of education and advocacy materials for the whole family. If you would like to receive any of these items, contact Family Service at **familyservicesteam@CdLSusa.org**.

Cornelia de Lange Syndrome (CdLS)

Self-Advocacy Cards are fillable and an excellent tool for any individual with CdLS who attends extracurricular activities, employment, or volunteer opportunities in the community, regardless of their communication level. It is currently available in English.

KNOW YOUR CdLS GENE

Gene Brochure gives an overview of the body systems affected and findings you may see. It reviews management guidelines, CdLS' genetics, and individual gene change prevalence. It is currently available in English and Spanish.



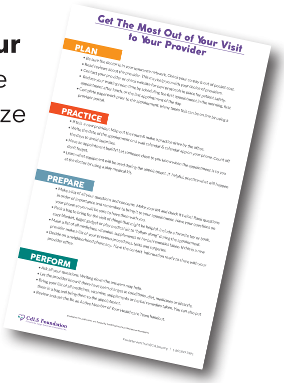
CdLS Management Guidelines:

General Recommendations are as follows

Updated Management Guidelines highlight routine screenings and care for people with CdLS by specific age groups, including infancy, early childhood, adolescence, and adulthood. These guidelines are in English and Spanish.

Provider Letter helps educate any medical or therapeutic professionals about the diagnosis of CdLS, the genetics behind it, the prognosis, and where to go if they have any questions. Educating new professionals about CdLS is vital to encourage more understanding in the medical, educational, and therapeutic fields. This letter is available in English.

Get the Most Out of Your Visit to Your Provider document helps you prepare for medical appointments and maximize your time with providers during a medical appointment. It is available in English and Spanish.



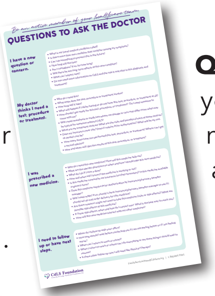
Get The Most Out of Your Visit to Your Provider

PLAN

PRACTICE

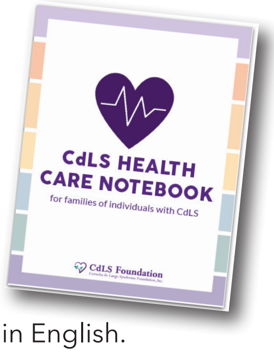
PREPARE

PERFORM



QUESTIONS TO ASK THE DOCTOR

Questions to Ask the Doctor guide helps you and your loved one with CdLS feel more confident going to the doctor and asking questions. Knowing what to ask can help you and your loved one with CdLS become more active members of your healthcare team. This is available in English and Spanish



CdLS HEALTH CARE NOTEBOOK

for families of individuals with CdLS

The CdLS Health Care Notebook is the first of multiple tools from the CdLS Foundation that makes accessing and coordinating care more manageable. It provides an easy way to keep track of important information so you can find it and share it any time you need. You can update the notebook in real-time, with the ease of a smartphone or any electronic device. It is currently available in English.

Government Benefits Informational Sheets are available from the Family Service team, which review SSI and Medicaid benefits. Each state has different regulations with regarding benefits, and the team has created easy-to-understand guides to help you with the process.

UPDATE YOUR CONTACT INFORMATION WITH US

The CdLS Foundation wants to inform you of the latest information about CdLS or events you can attend. Be sure your contact information is up to date. Please send updated contact information to **familyservicesteam@CdLSusa.org.**

Our Deepest Sympathy

Avery Grace Cavanaugh
February 22, 2023 -
February 25, 2023
Daughter of Noelle Cavanaugh
2355 Horsley Drive
Henrico, VA 23233

Mary Fiori
January 4, 1994 -
February 28, 2023
Granddaughter of Carolyn
and Ted Williams
3004 Melville Court
Spring Hill, TN 37174

Matthew Matheson
March 13, 1970 - May 3, 2023
Son of Pam and
John Matheson
12233 Carroll Mill Road
Ellicott City, MD 21042

THE GRIEF SUPPORT ADVISORY GROUP IS HERE TO HELP

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

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

ADVICE FROM A LITTLE BOOK ABOUT GRIEF

New grief publication by the CdLS Foundation

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

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

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

New Language Line to Help You

Exciting news! We're thrilled to announce a new partnership between the CdLS Foundation and leading language-access provider LanguageLine Solutions.

The service offers immediate access to medically certified interpreters in over 240 languages, so you can get the support and information you need.

We understand language barriers can be challenging, and the CdLS Foundation is committed to helping your family overcome them and obtain information and support no matter what language you speak!

Call us at 1.800.753.2357 (Monday- Friday 8:30 - 5:00 PM ET) to get started. We look forward to hearing from you!

Reaching Out to be Translated into Spanish

As the CdLS community grows, there is a need to share crucial information with families in different languages. At the CdLS Foundation, language barriers are among families' most significant challenges in understanding medical information and getting appropriate care and services.

In the United States, almost 1 in 5 families speak a language other than English at home, and nearly 62% speak Spanish. To better serve our families, the CdLS Foundation continues expanding our library of Spanish material. We are excited to have the first issue of Reaching Out fully translated into Spanish and available electronically!

If you OR you have friends and family members that would like to receive the Spring 2023 issue of *Reaching Out* emailed to you in Spanish, email **gnadeau@CdLSusa.org**.

REACHING OUT

PRIMAVERA 2023

En el foco:
Cuando llamar al médico y cuándo acudir a urgencias

EN LA PORTADA
Bryn Clary

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Nuevo servicio de interpretación con LanguageLine Solutions

¡Tenemos novedades! Estamos encantados de anunciar una nueva colaboración entre la Fundación CdLS y LanguageLine Solutions, un proveedor líder de acceso a servicios de interpretación.

Este servicio brinda acceso inmediato a intérpretes médicos certificados en más de 240 idiomas, para que pueda acceder al apoyo y la información que necesita.

Entendemos que una barrera lingüística puede ser un desafío importante y la Fundación CdLS se compromete a ayudar a que su familia y usted puedan superar esa barrera y obtener información y apoyo, sea cual sea su idioma.

Llámenos al 1.800.753.2357 (de lunes a viernes de 8:30 AM a 5:00 PM ET) para empezar. ¡No dude en ponerse en contacto con nosotros!

La edición de primavera de 2023 de *Reaching Out* está en español

A medida que crece la comunidad CdLS, existe la necesidad de compartir información crucial con las familias en varios idiomas. En la Fundación CdLS, sabemos que la barrera lingüística es uno de los desafíos más importantes a los que se enfrentan las familias para la comprensión de información médica y para conseguir los cuidados y los servicios adecuados.

En Estados Unidos, casi 1 de cada 5 familias habla un idioma en el hogar que no es el inglés y casi un 62% de esas familias habla español en el hogar. Con el fin de brindar un mejor servicio a nuestras familias, la Fundación CdLS sigue expandiendo su oferta de materiales en español. ¡Nos complace anunciar que ya tenemos la primera edición de Reaching Out traducida al español y disponible en formato digital!

Si usted, algún familiar o un conocido suyo desea obtener una copia de la edición de primavera de 2023 de *Reaching Out* en español por email, solo tiene que escribirnos a: **gnadeau@CdLSusa.org**.

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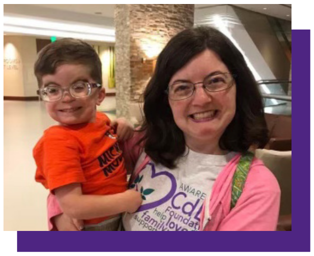

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Have you planned an event, hosted a family gathering, or have a story to share?
WE WANT TO HEAR ABOUT IT!

Reaching Out represents the voices of the CdLS community, so let yours be heard.

Email outreach@CdLSusa.org with your story submission with photos/video and see yourself in a future edition of this publication.