REACHING OUT

SPRING 2024

Spotlight:
Planning for a Spectacular Summer!

ON THE COVER
Bella Marie

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Greetings Friends,

Spring has arrived, bringing fresh opportunities for engagement with each other and us.

- Enjoy family gatherings in Norfolk, VA and Lincoln, NE.
- Please save the date for our upcoming International CdLS Awareness Day, marking 35 years of raising awareness.
- Join us for our 25th anniversary running in the Chicago Marathon led by team co-captains Marc, Frank, and Peter.
- Hang out with us at the East Regional Retreat in the fall, with an anticipated attendance of nearly 300 individuals. (Check out the calendar on page 8 for all the dates.)

Bonnie Royster, CdLS Foundation Executive Director

We acknowledge the challenging days you face while navigating the CdLS journey, but there are also bright moments. This issue highlights the profound love between siblings and the positive impact a CdLS brother or sister can have on their lives, shaping them into remarkable individuals. Special thanks to Aniya and Danielle for sharing their heartfelt letters brightening our day. (Note: National Siblings Day is on April 10).

The CdLS Foundation is here for you, seeking ways to enhance future support. Gathering data about you and your loved ones is crucial, enabling us to offer relevant opportunities for you to share what matters most as you journey with your loved one with CdLS. Coming soon, the Foundation will initiate an annual survey to gather your input, aiding our collaboration with researchers and clinicians. Keep an eye out for the Voice of the Community Survey.

Looking ahead, we are dedicated to comprehensively understanding our community to better serve you. Through our ongoing listening tour, we learn about your experiences, challenges, and joys, allowing us to develop programs and services that cater to your needs. Our commitment remains unwavering in supporting every individual with CdLS and their families.

Warm regards,

Bonnie

CHECK OUT OUR INSPO WALL ON PAGE 9!

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

Medical Director Spotlight

International Cornelia de Lange Federation World Conference Summary


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

The 2023 International Cornelia de Lange Federation World Conference was held in Zaragoza, Spain at the end of November and start of December. The format included simultaneous World Federation and Scientific Advisory Committee (SAC) meetings, the latter of which held presented abstracts, and then two days of presentations for families that included both clinical and scientific talks. Family consultations with the international clinical specialists occurred on the final day, as well as workshops for the families. Organized by Drs. Feliciano Ramos and Juan Pié Juste, as well as President and Vice President of CdLS-Spain, Ana Mª García and Rosa Gonzalez respectively, the event was attended by 60 families, representatives, and health-related professionals from 12 countries. There were seven members of the Clinical Advisory Board representing the CdLS Foundation USA. There were also 40 volunteer medical students who acted as translators.

Topics during the SAC meeting included new formats for international meetings which should be scheduled in the summer with more science shared and workshops held for more specific age groups. Addressing the limitations of future potential gene therapy was discussed. The international consensus guidelines paper is in the process of being reviewed and updated. Future SAC Board members voted in include Paul Mulder, Ph.D., as Future President and Frank Kaiser, Ph.D. as Scientific Research Expert (new position). Treasurer Armand Bottani, M.D., has retired from the SAC and we thank him for his prior contributions.

Recent discoveries were presented. The way that the *NIPBL* gene interacts with other genes and protein complexes in the body continues to prove how important it is for normal day-to-day functioning, especially during the embryonic period before birth. In CdLS there is widespread up- or down-regulation of general gene expression, affecting other genes in many different tissues and organs of the body. One of the problems in embryos with cohesin gene mutations is that cells stop or slow dividing and can't migrate to help form the organs they are supposed to, and often die sooner than they should. These cells include neurons in the brain, which are both smaller and less abundant. This may also contribute to some of the premature aging signs seen clinically. A number of individuals were described by different speakers with less typical clinical presentations in the cohesin-related genes as well as non-cohesin genes, all still considered part of the CdLS spectrum disorder. Finally, there has been evidence in animal (fruit flies, mice) and human cell line models that treatment with lithium can affect brain formation, and a treatment trial (Italy) using lithium therapy in children with CdLS in Italy will begin soon, assessing cognitive and behavioral outcomes.

From the clinical point of view, there was less new information at this meeting, but children and adults with CdLS continue to teach us about the CdLS spectrum disorder and how to help them day to day, as well as support their families. We always appreciate the generosity of families sharing information with the clinical specialists.

TABLE OF CONTENTS

Planning for a Spectacular SUMMER!

Linda Pierce, M.S.W., Program Director, Family Service

A great way to try and prevent the academic summer slide is by getting kids out into the community and looking for ways to embed learning in everyday routines. This type of enrichment doesn't have to be expensive or require travel. Below are some ideas that may help make your summer interactive, educational, and fun.

ACTIVITIES TO DO AT HOME:

Paint or Sidewalk Chalk

This can be a great outside summertime sensory play activity that can strengthen the muscles in hands, fingers, and arms, improving flexibility and hand-eye coordination. Looking for an easier way to work with paint? Wrap an empty paper towel roll with bubble wrap. Coat the bubble wrap in paint and have your child hold the end of the roll and paint on paper or cardboard. This way of painting also provides a great sound.

Bubbles

Bubbles are a great sensory experience. Almost everyone loves to watch or pop bubbles, from a bubble wand to a small bubble machine. Blowing, watching, and playing with bubbles is a fun way for children to investigate their world with their senses.

Sensory Trays or Tables

Use a plastic chip and dip platter and add different items to each portion of the platter. Handheld soft toys, play dough, shaving cream, or glowsticks. If you want to bring the beach to your sensory tray, put sand in the dip portion and fill the other sections with seashells, animal toys with texture, and smooth pebbles.

Pitch a Tent

Pitching a tent in your yard can be fun, challenging, and creative! If your family isn't quite ready for outdoor camping, put a tent inside, roast marshmallows in an indoor fireplace or over a mini hibachi, make s'mores, cook "camping" food, and use a star projector to make the ceiling look like the night sky. An inside tent can also provide a comforting retreat for some quiet time.

Garden

If you have the space (even a little raised bed), create a small garden with your child. Starting a garden inside from seeds can be a great way to engage with your child and show them how things grow. Choose local herbs or flowers that flourish in your area. Gardening can help improve motor skills and enhance creativity. Working in the soil can also be a great way to reduce stress and anxiety.

ACTIVITIES TO DO IN THE COMMUNITY:

Explore Local Parks

A picnic in a local park can provide a wonderful afternoon of great snacks, enjoying the scenery, and picking flowers.

Check out Your Local Library or find a Local Playground

Most libraries offer free programs for children of various ages, interests, and abilities. Every child deserves a playground. If you need help finding inclusive and accessible playgrounds, visit **bit.ly/playgroundfinder**.

Visit a Local Farm or Petting Zoo

For those interested in animals, a trip to a local farm or petting zoo can be an excellent experience for children. Many places will allow you to make special arrangements before your visit, allowing you to bypass long lines or arrange for an experience best suited for your child. Petting, feeding, and talking to animals, up close and personal, can provide a great sensory experience and a wonderful learning experience.

We can't wait to hear about your stories, with many fun things to do and places to explore this summer! If you have one that you would like to share – send photos and a write-up to Gabrielle Nadeau at **gnadeau@CdLSusa.org**.

Summer Safety

Linda Pierce, M.S.W., Program Director, Family Service

With its warmth and sunshine enticing us to be outside, summer temperatures and activities can pose some safety hazards. Here are some tips for keeping kids safe.

Keep Hydrated and Cool

Many children with special needs can be more susceptible to heat-related conditions. Certain medications can cause dryness in the mouth, increase sensitivity to the sun, or impair the body's ability to perspire or regulate temperature. Be sure to ask your doctor or pharmacist if the medications you or your child take have warnings about sun exposure.

Avoid Sunburn

Most of us are familiar with sunburn's pain and health risks. Be extra vigilant with children with disabilities, especially those who are non-verbal. Sunburn can also affect your body's ability to cool itself and cause a loss of body fluids.

Seek shade during the hottest parts of the day to protect from UV rays. Remember that cloudy days do not block UV rays, so protection is still needed even when it's cloudy. Cover up with clothing, a hat, and sunglasses, and apply sunscreen early and often. The CDC recommends using sunscreen with at least SPF 15 and labeled "broad-spectrum" to screen out UVB and UVA rays. Remember to protect ears, noses, lips, and the tops of feet.

Babies younger than six months should not be kept in direct sunlight because of their increased risk of heat stroke. The American Academy of Pediatrics advises that sunscreen can be used on small areas of the body, such as the face, when protective clothing and shade are not available.

Be Aware of Surfaces that Can Burn Sensitive Skin

Many children with CdLS have high pain thresholds and may not realize they are being burned. Metal frames on a the wheelchair can cause burns, and when cushions heat up from sun exposure, the plastic covers may cause excessive sweating, leading to dehydration and skin breakdown. Protect your child from contact burns by covering any accessible armrests and metal frame portions of the chairs your child uses. Wheelchair umbrellas are one way to provide added protection.

Be Safe Around Water

Pools, lakes, or other watering holes are great places to swim and for family fun. It's important to ensure everyone follows safety steps in and around the water. Whenever possible, swim near a lifeguard.

Parents and caregivers should still designate an official Water Watcher even when a lifeguard is present. A Water Watcher is an adult who is comfortable in the water, tasked with supervising those in the water. The designated Water Watcher shouldn't read, text, or play games on their phone. The Water Watcher should have a phone with them in case they need to call for help.

Swimming is not only fun but also a lifesaving skill. Enroll children or adults in swimming lessons; many free or reduced-cost options are available from your local YMCA, or Parks and Recreation Department.

Proper fences, barriers, alarms, and covers can be lifesaving devices. A fence of at least four feet in height should surround the pool and not be climbable for children. The water should only be accessible through a self-closing, self-latching gate. install a door alarm from the house to the pool area.

Learning CPR can help save a life. Once you're CPR certified, make sure to keep your certification current. CPR classes are available through many hospitals, community centers, through the American Red Cross at **bit.ly/CPR_RedCross.**

Jasmine Rose

HOW JASMINE INSPIRES MOM

By, Katie

Jasmine Rose is five years old and our first-born princess. She was born weighing 4lbs and 6oz and spent the first 56 days of her life in the NICU. She is now 22lbs and the happiest little big girl you've ever met. Her smile is infectious, and her tiny feet are her best friends, besides her brothers JJ and MJ. We found out about her diagnosis at one day old. Her grandmother, Nanny, did some research on CdLS and found out about the CdLS Foundation.

Jasmine is a happy, sassy girl with two fingers, ten toes, thick hair, and the cutest nose. Almost everybody who comes across her seems to be "scared" in a way where they treat her like she's the most fragile thing. She can't be broken easily and LOVES hugs and snuggles. I wish more people could learn and understand CdLS so they didn't seem so scared by it and love on them!

> "Jasmine is a happy, sassy girl with two fingers, ten toes, thick hair, and the cutest nose."

Jasmine inspires me daily to be more carefree and to smile! Almost everything in my life can be quickly fixed with a Jazzy Smile. As a young mother and my first child, Jasmine has taught me patience, love, advocacy, and humor. Being a momma of a child with special needs is not easy, but it's the biggest blessing and beyond rewarding. It can be so much fun if you don't let the worry, anxiety, and other people in this world affect you so much! Taking every day as it is is another huge thing we have learned. Jasmine has complete control of our days; when she's healthy, yay, but if she isn't, we may get Jazzy snuggles and kisses in bed or even a cozy hospital stay. If plans don't go as planned, it's not the end of the world.

HOW JASMINE INSPIRES NANNY

By, Jennifer

Jasmine (Jazzy Roo) is my first of three grandchildren. She is now five years old and stole the hearts of her Poppy and me through the weekly high-risk scans and pictures. Her big smile and sweet nature is healing. She is adorable when angry, her laugh is contagious, and her sassiness is loved. Jasmine is the best snuggle buddy and the nosiest gal around when a cell phone is involved! Her favorite stuffed animal and sidekick is a rainbow llama named Charlie, and she loves to kiss and chew his nose. Jasmine is a curious little lady who loves to explore her room. She loves her family. Her parents are her everything.

When Jasmine received her clinical diagnosis, my late husband (Jasmine's Poppy) and I received a phone call from Katie giving us the news. I remember everything about those next few moments. We hung up with Katie and immediately began to google this diagnosis. As we quickly tried to process what we were reading and seeing, we had to take a moment to hold back the panic that seemed to be looming. In that moment, God provided us the peace and comfort to move forward calmly. Within the next scroll, I came across the Foundation's website and began binge-reading the information. Most of Katie's pregnancy seemed to be an exercise in "knowledge is power," within the Foundation's website, we found the information we desperately needed to gain some control. I passed the website on to Katie; it is still our family's top resource.

As cliche as it sounds, Jasmine inspires the people around her to be better people. An example is how it often takes creativity and "thinking out of the box" to get her attention, to play with her, or to make her feel included. Once you have had a chance to interact with her, you want more of her attention and play time, and you so badly want to see her included; therefore, your creativity begins to flourish.

Our family has learned the importance of acknowledging the difficulties and finding the bright side. When sickness and hospital stays happen, concern, anxiety, and sadness will be there, but so should faith, family support, and even joy and humor when they present themselves. We've learned that schedules and routines are essential, but lazy, fun days are just as important. Our kiddos can teach us many things if we are willing to learn.

I want the world to know that the uniqueness of CdLS turns heads and opens hearts. The beauty of these kiddos lies within their fighting spirit, love, determination, and sweet features. There are a lot of medical problems that can accompany a CdLS diagnosis. Managing any medical issue is a chore; however, the proper resources can change the game.

We are very blessed to have such a close family. Jasmine has a network of very involved great-grandparents, grandparents, great-aunts, uncles, cousins, etc. With Jasmine being my first grandchild, I have learned just how much a grandparent can give of themselves to and for their grandchildren. I've seen how vital the grandparent-grandchild relationship is to Jasmine, me, and her parents. Not one moment spent with your grandchild is wasted. The reward is seeing how she lights up when she notices her people. Grandparents are a special part of any child's network, and I know that my grandchildren are the grandest part of mine. I salute all the involved "grands" and hope you are aware of the impact you have.

HIGHLIGHTED EVENTS

JOIN FAMILY AND FRIENDS AT THE CdLS NEW ENGLAND GOLF CLASSIC

The CdLS New England Golf Classic has been a shining light for the CdLS Foundation for more than three decades, raising nearly a million dollars to support their life-changing initiatives. This much-awaited event is driven by parents and supporters who have been affected by the syndrome and it helps the Foundation achieve its many goals, including raising awareness and providing support to families. We invite you to join us and make this year's event the best one yet! The event will take place on Monday, May 20, 2024, at the exclusive Ipswich Country Club in Ipswich, MA.
To register, or sponsor, visit: cdlsnegolfclassic24.com and click register.

CELEBRATE 25 YEARS AT THE CHICAGO MARATHON

We are excited to announce that Team CdLS will participate in the Chicago Marathon this fall, marking their 25th anniversary of running to support the CdLS Foundation and their loved ones. The marathon is scheduled for October 13, 2024.

Many runners have shared that running as part of Team CdLS has had a life-changing impact. This is your chance to set your own pace and join us for an unforgettable experience. By participating, you'll not only gain new friends and a sense of accomplishment, but also the satisfaction of making a difference.

Let's cheer them on for this amazing endeavor.

JOIN OUR CURB CREW TEAM!

Volunteers are needed for **Chicago on October 13** or **Baltimore on October 19**.

Spend time bonding with other parents and volunteers, and cheer on the Team CdLS participants! **New families are always welcome!**

To learn more, email the CdLS Foundation at outreach@CdLSusa.org.

CALENDAR 2024

April 10
National Siblings Day

April 13
Adolescent and Adult
Multidisciplinary Clinic
Baltimore, MD

May 4
Hampton Roads Family Gathering
Norfolk, VA
11:30 a.m. - 3:30 p.m. EST

May 11
35th Anniversary of International
CdLS Awareness Day

May 20
New England Golf Classic
Ipswich, MA

July 6
Nebraska Family Gathering
Lincoln, NE
11:00 – 2:00 p.m. EST

September 13-15
Regional Retreat
Oxford, PA

October 13
Bank of American Chicago Marathon
Chicago, IL

October 19
The Baltimore Running Festival
Baltimore, MD

November 2
Adolescent and Adult
Multidisciplinary Clinic
Baltimore, MD

"YOU GO
GLEN COCO."

90% OF WHAT WE WORRY ABOUT
NEVER HAPPENS.

Next time you're stressed, take a step back, inhale and laugh. Remember who you are and why you're here. You're never given anything in this world that you can't handle. Be strong, be flexible, love yourself, and love others. Always remember, just keep moving forward.

Unknown

"I can't change the direction of the wind, but I can adjust my sails to always reach my destination".

-Jimmy Dean

"The greatest oak was once a little nut who held its GROUND."

- Author Unknown

INSPO WALL

We hope our encouraging words leave a smile on your face. Do you have an encouraging phrase to share with the community? Please send it to the Foundation at outreach@CdLSusa.org.

BE BRAVE

"DON'T BE PUSHED AROUND BY THE FEARS IN YOUR MIND. BE LED BY THE DREAMS IN YOUR HEART."

- ROY T. BENNETT, THE LIGHT IN THE HEART

"Do the best you can until you know better. Then when you know better, do better."

- Maya Angelou

Take a deep *breath;*
it *calms* the mind.

You've got THIS.
Trust yourself TRULY.

CREATING A FAMILY ADVENTURE AT SLEEPAWAY CAMP … OR IN YOUR OWN BACKYARD

Linda Pierce, M.S.W., Program Director, Family Service

Exploring the great outdoors as a family can be a fabulous adventure and a welcome contrast to other times that may seem filled with medical appointments. Below are some tips to keep in mind whether you choose a family sleepaway camp, a family camping trip, or have your child attend a day or sleepaway camp.

1. Identify your child's interests and what they can handle. Then plan your adventure around them. Resist the urge to overschedule.
2. Consider whether your child has ever been away from home, for the weekend or even longer, and what experiences might help prepare him or her for camp.
3. Decide if you are more comfortable being somewhere provided with scheduled activities or if you want to plan your own activities.
4. Decide if it is important for you to be somewhere close to a medical facility. Travel with important medical information. You can do this electronically by using the CdLS Health Care Notebook.
5. Research and choose a family sleepaway camp, campground, or youth camp carefully. Make sure the camp or campground has all the amenities your family needs.
6. Practice and prepare at home first.

Finding a camp that is a good fit for your child can be a challenge. You will want to make sure your child will get the attention he or she needs and can fully participate in the camp's activities. You may worry if your child will fit in and make friends and if the camp staff will understand your child's special needs.

Many mainstream camps include children with special needs within their camp groups. There are also camps specifically for children with special needs. There are also choices to consider based on the camp's length, philosophy, location, and cost.

Whatever type of camp you're leaning toward, it's important to explore your options. The American Camp Association (ACA) has an online listing of camps broken down by the types of camps, cost, length of stay, state/region, and campers' ages. You can find it here: find.acacamps.org. The site is also loaded with information for parents of would-be campers, including what to look for and how to plan for camp.

Whatever you choose, these experiences can help broaden everyone's experiences, and help children grow by providing a supervised positive environment.

Family Sleepaway Camps or Planning Your Own Camping Adventure … Where to Begin

Family Sleepaway Camps allow your family to attend camp together and often include all activities, food, and lodging. Family sleepaway camp vacations offer fun, adventure, and family bonding.

If this sounds like a great idea for your family check out these resources for more information.

- Top 10 Family Camps: bit.ly/topcamps
- Camp Jellystone: bit.ly/CJellystone
- Camp Get-A-Way: bit.ly/CGetaway

Planning your own camping adventure with children with disabilities can be challenging but it also has many rewards. Before you hit the road, consider these tips from others you may find helpful.

- Download the Access Pass from the National Parks System: on.doi.gov/3SYD7i0
- Campgrounds that have the amenities your family needs: bit.ly/Camp-accessible
- Camp at a KOA or similar campground: koa.com

CALLING ALL SIBLINGS – Celebrate National Siblings Day

Linda Pierce, M.S.W., Program Director, Family Service

We know how special you are! Siblings can be best friends and worst enemies on the same day! Siblings can encourage us to be our best but can also frustrate and embarrass us. Siblings are an enormous part of almost every family. Did you know more than 80% of Americans grow up with at least one sibling? For many people, sibling relationships can be the longest-lasting relationships they ever have.

All sibling relationships can be bumpy at times! Having a sibling with a disability can bring unique challenges. You may have questions about CdLS or about what your brother or sister needs. Sometimes, you may get embarrassed, sad, or angry about your sibling's appearance or behavior or if someone at school says something mean about your brother or sister.

Other times, you might feel proud when your sibling learns to do something on their own or make them laugh. You might feel happy when your sibling with CdLS makes you laugh when you're having a bad day. Maybe you've thought you are the only person who has these feelings. But most siblings have these feelings sometimes. Always remember you are part of a community of siblings, and this day celebrates you!

Siblings Day's message of love has reached beyond the United States. It is celebrated in Australia, Brazil, Canada, Ghana, India, Ireland, Japan, New Zealand, Nigeria, Philippines, Singapore, South Africa, Sweden, and the United Kingdom.

We Hope You Enjoyed National Siblings Day:

1. Did you post a Picture on Social Media? It can be a recent picture or a long-ago memory, a posed formal picture, or a silly picture that will make everyone smile! If so,be sure to use #CdLSsiblings and tag the CdLS Foundation.

2. Do you want to share your story? Write your story and send it to **gnadeau@CdLSusa.org**. Share your wisdom, share your jokes, and share your story. Tell us something about your life with your sibling with CdLS. Feel free to include the good, not-so-good, and everything in between. What do you want the world to know most about your life as a sibling of someone with CdLS?

3. Learn About Books, Podcasts, and Groups Just for Siblings. There is an entire organization for siblings of people with developmental, health, and mental health concerns. To find the books, newsletters, online and in-person events for siblings of all ages of individuals with disabilities, visit **siblingsupport.org**. For additional information, email Family Service at **familyservicesteam@CdLSusa.org**.

Bella

Ginny, Bella's Mom

Bella Marie is an outdoor-loving curious 10-year-old who stands 41 inches tall and weighs 29 pounds. She has an oversized personality in a tiny package. She is goofy and has recently found her need for independence. Using a "nubby" on her left arm and one finger on her right hand, Bella has learned many ways to manipulate things we never knew she could.

Bella loves to travel and has seen all the southern states from coast to coast. We plan on starting the northern states this year. Bella's all-time favorite thing is to be outside, preferably camping. She has her hammock chair and loves to go off-road in the mountains and have the wind blowing all around her. Her go-to toy is her piano. She loves to be loud and have people notice her.

Bella was given her clinical diagnosis at just a few hours old and genetic diagnosis at two weeks. She was born with classic physical features, from eyebrows to arms. At birth, she weighed one lb., 12 oz, and was 12 inches long. After 53 days in the NICU, Bella came home weighing three lb. 2 oz.

CdLS does affect our family's day-to-day life. Bella gets up in the morning, cleans up, and needs medicine administered through her feeding tube. She needs help with just about everything. Bella is home-schooled but, does go to therapy weekly; we call her therapy sessions her school.

Bella has challenges with her feeding and digestion. She has gastroparesis, a growth hormone deficiency, and a Specific Antibody Deficiency, each requiring specific medications. Her immune deficiency delayed her walking and we have been working towards that goal ever since. Another challenge is Bella's desire to "fit in" with her peers. She does not understand when they are able to do things she cannot, or when other children do not want her to join in. Most 10-year-olds find it difficult to play with her using their games or toys.

One of the most significant challenges we face is how people react to us in public. Since she was a baby, we have gotten comments, some rude, from strangers who wanted to see her and ask about her. As she has gotten older, we ask people if there is something they want to know. We encourage kids to ask questions and talk with her. We hope this increases awareness and kindness.

Having a child with CdLS has been an emotional roller coaster. At first, we wondered, "what did we do wrong to cause this?" Thankfully, we quickly moved on to "what can we do to make her life better?" It has made us better parents. We have become well-versed in every aspect of her care so that we can advocate for her. There is never a dull moment, and we do our best to take it in stride and not let any of it define us.

The CdLS Foundation has helped us, giving us a central group of people to email, call, and to look for help. They have connected us with the Children's Hospital of Philadelphia (CHOP) and other families. We stay in touch with multiple people from the Foundation.

CdLS may be Bella's syndrome, but that does NOT define who she is! Look deeper and get to know kids for who they are, not their label. We have chosen to live our lives out in the world. While we take precautions for Bella's health, we rarely stay home and have made it our goal to give her the best life possible. Having a child with special needs does not mean you stop living; it means you find new ways, adventures, and experiences. It means you learn to cope with everything to give us all a life worth having! Do not back down because of comments and stares; smile because you know you have a uniquely amazing child, and most people will never know what that is like.

Annie, Aniya, and Danielle

Aniya and Danielle, sisters of Annie

Aniya and Annie

I'm Aniya and I'm a younger sister to Annie. I am 11 years old and in 6th grade

The coolest thing about having Annie as my sister would definitely be telling people about Annie and our life story. It's also fun that, with Annie, I get to learn about something not a lot of people can learn. Growing up with Annie, I had to understand some sign language and how Annie herself signs them. Learning sign language is really fun!

The hardest thing about having a sister with special needs would be the dirty looks we get in public. It just upsets me. My family is very different from other families. First, we have Annie who has special needs. Then there is me. I am Hispanic and African American, and I have a family with all people that have different hair and skin color than me. We get a lot of stares from all different people. Sometimes it's little children and other times it's grown men and women.

When I explain CdLS to my friends, their reactions can be kind of different. Some of my friends love Annie and always say hi to her and some of them get scared when she has tantrums or hits people. If it's one of my close friends and they're scared of Annie, that kind of disappoints me. But they have a learning experience to see what special needs kids are like and how they act, so it's cool that my friends get to learn about CdLS.

I'm honestly grateful that I grew up with a sister with special needs because I know what it's like and I would never judge somebody that looks or acts differently. I would say that my life has only been impacted a little by having a sister with special needs. If I could go back in time, I wouldn't change a thing. I think it's so cool that I have grown up to learn about people who have disabilities. Sometimes, my family and I wonder how different it would be if Annie didn't have CdLS. I could imagine how different our lifestyle would be, but I have adapted to how we live life and, honestly, I love it!

Danielle and Annie

"I am sorry." Those three words are the worst thing anyone has ever said to me when I tell them I have a twin sister with CdLS. My twin sister, Annie, is the biggest blessing in my life. When the question is asked, "who is the biggest role model in your life?" most people would respond with a celebrity or an actor. My response has always been the same since day one. Without any hesitation, it's Annie because she has shown me more than any celebrity could ever. She is my rock, my number one supporter, and the reason I am the person I am today.

My name is Danielle, and I am a Junior at Illinois State University studying to become a Child Life Specialist. If you ask students my age what their dream job is, most of them would respond with an influencer, an actress, a celebrity, you name it. But I am different. My dream job is to be a Child Life Specialist. A Child Life Specialist is a healthcare worker who helps children cope emotionally with being in the hospital. People always ask me, "Out of all the occupations in the world, why a Child Life Specialist? The pay is terrible, the hours are long, and it will be so mentally draining." The statement I receive that hits me every single time is "It takes a very special person to do that." That statement is why I continue to put in countless hours to pursue my dream career. The reason for this goes back to January 27, 2003. The day that Annie and I were born. Annie's courage, strength, and resilience is what has continued to inspire me each day. These qualities are what make up a special person. Annie IS a special person. Without Annie, I truly don't know what I would be studying on this day. I have spent countless hours doing respite work, volunteering in special ed classrooms, being inclusion aids, and above all, just being a friend. I see so much potential and light in children with special needs that many people in this world fail to see.

So yes, when people say, "I am sorry" to me, I get upset and angry. I am proud to say I have a twin sister with CdLS. Through my eyes, she is the light in this world, and we need so many more people like her.

Join us at Camp Saginaw from September 13-15, 2024 for a tranquil weekend retreat with friends who share your unique journey. Nestled in peaceful surroundings, this will be a delightful opportunity to unwind, learn, and be inspired.

Our hope is that you will leave Camp Saginaw feeling recharged and empowered. Check out our all-inclusive pricing and join us at Camp Saginaw for an unforgettable experience.

When and Where Will the Regional Retreat be held?

The East Coast Regional Retreat will be held September 13-15, 2024, at Camp Saginaw (740 Saginaw Road, Oxford, PA 19363). The camp is just over an hour away from Baltimore and less than 1.5 hours from Philadelphia. We will be the only group on-site for the weekend enjoying the beautiful landscape. The camp is nestled in peaceful surroundings, and the weekend will be a delightful opportunity to unwind, learn, and be inspired.

What are the Pricing and Registration Details?

East Coast Regional Retreat Selection	Price per person
Early Bird – East Coast Only	$299
Early Bird – Caregiver (non-parent)	$225
Individual with CdLS	No Cost
Regular Registration	$375
Caregiver (non-parent)	$300

- Early Bird Registration opens on June 18, 2024 for East Coast Region
- Regular Registration opens for ALL on July 23, 2024 for All Regions
- Registration closes on August 16, 2024.
- The registration cost is an all-inclusive per-person rate that will include programming, sibling camp, all meals, and lodging, which we hope all families interested in attending will find manageable.

The states that make up the East Coast Region include Maine; New Hampshire; Vermont: Massachusetts; Connecticut; Rhode Island; New York; Delaware; Maryland; New Jersey; Pennsylvania; Washington D.C.; Virginia; North Carolina; South Carolina; Georgia; Florida; West Virginia; Ohio; Kentucky; Tennessee; Alabama; and Mississippi.

There will be scholarships available to US families on a first-come, first-serve basis. The CdLS Foundation has a limited amount of funding to provide scholarships on an as-needed basis.

Families in the East Coast Region will receive an email notifying them it is time to register for the Retreat. Don't forget to set a reminder for your registration block so that you don't miss out.

What Should I Bring?

A packing list is being created and will be available soon. It will be posted on the Foundation's website and sent to attendees.

What Will Happen During the Weekend?

On Friday, families are welcome to start arriving for early check-in at 3:00 p.m., there will also be a welcome event for first-time families. That evening, we will begin the festivities with a welcome dinner for all attendees! After dinner, there will be multiple firepits with some surprises as we socialize together under the stars.

Once the sun rises on Saturday, get ready for a full day starting with breakfast and the chance to tune into nature. The day's workshops will include a medical and research update, GI session, and a behavior workshop. Everyone will have a chance to speak with Clinical Advisory Board members in the informal Meet the Expert small groups. You can ask questions, share experiences, and collaborate with professionals on the next steps to best meet your family's needs. Saturday afternoon begins with Moms and Dads groups then take some time with your families to enjoy many of the camp's fall activities. The evening will kick off with a delicious mocktail hour and special dinner, followed by a caregiver/grandparent group, and capped off with more campfire social time.

Sunday will be the final day of the event. We will enjoy breakfast together. Before we say our goodbyes, seasoned parents and guardians will share their hard-won wisdom to help you take on the challenges of raising your special child.

What is the Sibling Camp?

We know having a child with special needs impacts everyone in young and growing families. While siblings share many of the same concerns as their parents, they also have concerns and challenges that are uniquely theirs.

At our East Coast Regional Retreat, siblings aged 5 and above can spend a fun-filled day participating in various activities like go-karting, canoeing, kayaking, ATV riding, arts and crafts, and more. The Camp Saginaw staff will lead the activities, giving siblings the opportunity to bond with others in their age group.

Although we don't have a daycare program for individuals with CdLS or children under the age of 5, caregivers will have the opportunity to do camp-related activities with the person they are chaperoning. All meals, lodging, and activities are included in the pricing for the caregiver.

The Board of Directors and staff at the CdLS Foundation look forward to the upcoming East Coast Regional Retreat and cannot wait to see you there.

For more updates, please visit: cdlsusa.org/regional-retreat, follow the CdLS Foundation on social media, or subscribe to our email list. Not sure if you receive our emails? Contact Family Service at familyservices@CdLSusa.org to update your contact information.

WELCOME
New Families

Arkansas
Crystal and son Kayden
Born: August 17, 2022

Colorado
Kenna and daughter Ruth
Born: January 1, 2024

Florida
Megan, William, and daughter Harper
Born: November 17, 2023

Texas
Grayson, Christina, and daughter Coravieve
Born: October 1, 2021

Our Deepest Sympathy

Elizabeth Bernhardt
August 22, 1991-
January 3, 2024
Daughter of Randy and Mona
Bernhardt
9278B Dickson Rd
Bristol, IL 60512

Jim Cole
November 10, 1971-
December 13, 2023
Son of Judi and Michael Cole
1850 Clearwater Harbor Drive
Largo, FL 33770

Danielle Dale
June 28, 1985 - July 27, 2023
Daughter of Deborah Dale
2202 Mayflower Drive
Lynchburg, VA 24523

THE GRIEF SUPPORT ADVISORY GROUP IS HERE TO HELP

If a parent experiences the heartbreaking loss of a child, the Foundation is here to provide support in many ways. Our team of Family Service Professionals is available to listen, guide and offer assistance. We can also connect parents with others who have gone through a similar experience. Our dedicated team of Grief Support volunteers can offer invaluable support and understanding during this difficult time. Additionally, we have a Bereavement page on our website where parents can find helpful and inspirational resources, and an In-Memoriam page where families can share cherished 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.

Tribute Gifts 07.01.23 - 09.30.23

In Honor/ Celebration

Gregg Abbott
Jan and Jim Abbott

Brandt Anderson
Wayne M. Shull

Max Balthazar
Ryan Shuwarger

Hunter Barrett
Gary Hartman

Hannah Mae Boehman
Neil Boehman
Rick and Victoria Boehman
Schwab Charitable

Luca Borgia
Karen Galasso

Hazel Burchardt
Dana and Joe Mussatto

Micah Burrell
Judy Adrianson

Jennifer Busk
Ann Arnott

Douglas Canning
Judith Caires

Leia Caudle
Mrs. Margaret Caudle

Julie Champion
Lori Macleod

James Cole
Judy Cole

Shaylin Cubeta
Tianna Sandoval

Alyssa Delgado
Gricelda Contreras

Ajit Dhillon
Tracey Maguire
Maheshinder and Rana Jit Sandhar

Luke Domeny
Jami Domeny

Brian Drach
Marjorie Drach

Chase Duff
Barbara Robinson

Joy Eicher
Cam Vossen
Ronald P Jagner

Connor Feehan
Robert Feehan

Barrett Ferguson
Kathleen Oresky

Lindsey Fernandez
Jeffrey Arps

Don Finck
Emma Weidig

Richie Flaherty
Robert Shea Jr

Lindsay Franco
James A Franco
M Susan Coleridge

Gracie Fry
Linda G. Chatham
Gigi Fry
Mrs. Rebecca Hoog

Manuel "Manny" J. García
Liana Davila

Julie and Roy Gonella
Wendy Carson
Cheryll Lynn
Carole and Richard Lee
Debra Richard

David Harrison
Carol E. Smith

Oliver Hesse
Deborah Anderson-Phillips

Colt Highberger
Connie and Robert Colbenson
Spencer Kotas

Adam Jackson
Sara Lair

George "Jake" Jacobson
Teddi and Brian O'Keefe

Jaiya
Pali Nahal

Joy Jensen
Mary Bartels
Shelley Jensen

Jenna K
Tracey Viola M.D.

Mati Kahn
Amanda Katz

Katie and Emma
Lesa Rader-Giberson

Antonie Kline, M.D.
Tess Kline

Jared Koelling
Rachel Condelli
Jerry Koelling

Hope Kurth
Sharon K. Blomme

Sammy Kirshner
Patty Buccilli

Kutz Family
Muriel Barlow

Charlotte Lawrence
Barbara Lawrence
Diane Smith
William Paredes

Lizzie's Memorial
Michelle Kazak

Luke Lyons
Kumiko Shortill

Katie Luyt
Nancy Gorski

Tyler D. Macy
Dorothy McAfee
Tim and Barbara Macy

Julie and Frank Mairano
Gene and Kathy Van Buren

Whitman Mamayek
Janis and Joe Mamayek

Jake Marcus
Best Lawns, Inc.
Carrie and Scott Radomsky

Noelle Markle
Heather Warnick

Zachary Markowitz
Fidelity Charitable Gift Fund

Henry P. McKenna
Michael and Linda McKenna

Hugh McLaughlin
Krista Quackenbush

Devin Miller
Kevin M. Walters
Muriel Walters

Henry Miller's Birthday
Myrna Kaplan

Sam, Henry & Andrew Miller's Birthdays
Diane Miller

Sam Miller's Birthday
Myrna Kaplan
Susan Miyake-Terhune

Wendy Kaplan Miller's Birthday
Betsy Caswell

Tanaya Molzan
Richard Friedman

Hannah Moore
Patty and Brian Moore

Kelly Noyes
Jennifer Noyes

Mary Sophia Parker
Kristine McFadden

Jonathon Parisi
Laura Bush
Joan Samra
Maria Spence

Andrew Patitucci
Nancy E. Tossona

Alice Perkins
Mary Weiler

Aisley Peterson
Mary J Vitkovich

Maya Pomfret
Penelope and James Pomfret
Richard Pomfret

Elizabeth and Kevin Poplawski's Wedding
Brian Vasquez

Bianca Pradlik
Schwab Charitable

Siena Renteria
Alicia Perry
Nancy Merrill
Francie Barber and Craig Cheney
Mary Kaye and Jim Micallef

Shana Reidy
Merrilee Curalli

Matthew Rodgers
Maura Nitka

Daniel Ruiz
Charlene Ruiz

Brynn Scheidegger
Ashley Huibregtse

Bill Schiller
Gay M. Tompkins

Aubrie Schilling
Schwab Charitable

Jessica and Alexis Schnaderbeck
Remix Therapeutics

Anthony Seipts
Jeffrey Boulanger

Will Smisloff
Diane and Randall Rushin
Thomas J. Whalen
Timothy Whalen

Sarah Suttmann
Ellen and Thomas Heile
Fidelity Charitable Gift Fund

Jonathan Swanson
Julia and Peter Swanson
Suzanne W. Soltess

Sofia Teixeira
Oswego Oil Service Corp.

Wilder Thompson
Michael Korber

Olivia C. Torres
Victor M. Torres

Harper Turman
Marvin L. Bertsch

Stephanie Vojtecky
Dan & Pat Grim

Jacob Vu
Megan Vu

Caleb Wherry
Kathy and Andy Wood

Jacob Weber
Keiko and Daniel Nishiyama

Garrett Wise
Kay Benton
Krista Martin

In Memory Of

Joshua Ackles
Barry W. Pugh

Caitlin Suzanne Alicata
Tom & Lisa Alicata

Alyssa Auld
Janice and Thomas Auld

Ella Ault
Sue Keefer

Aidan Bard
Meredith and Scott Wanamaker
Sherron M. Brick

Jack Barnes
David H. Barnes
Judy and Joel Fisher
Seth Barnes
Valerie Barnes

Elizabeth "Lizzie" Bernhardt
Amber Asbury
Mary and Rob Becker
Jennifer A. Bernhardt
Randy and Mona Bernhardt
Marge Czop
Laura, Dave & Elsie Elkins
Karen Lee
Matthew Levinson
Daniel Linert
Norma E. and Patrick A. Lucansky
Dawn Olson
Mary and Robert Oplawski
Oun Miller Platt
Jeremy Putman
Kelsey Redger
Barbara Schwarzentraub
Carrie Shields
Bill Slater
Donna Sisler
Mike Terry
Lisa Topel
The Board and Staff at the CdLS Foundation

Denise A. Carman
Coleen Bistor
Tina Keplinger
Oshp Benefit Fund
Lynne Robinson
Bonnie and David Trouten

Layla Carr
Connie Kelly
Aimee Kirsch

Michael Cataline
Maura & Frank Cook
Erin Maney

Jim Cole
Jack Callahan
Cindy, Randy, Hunter & Hudson Mitchell
Irene K Ratner
James Roble
The Board and Staff at the CdLS Foundation

Frances and Francis Colosi
Robyn Rothman and John Stevenson

Gina Cotta
Kathleen and Louie Barletta
Karen and Larry Prada

Shaylin Hope Cubeta
Alice Hoke
Jim and Tara Hoke

Susan Curalli
Merrilee Curalli

Trey Den Boer
Dawn E Meiklejohn

Danielle Dale
The Board and Staff at the CdLS Foundation

Delaney Demaria
Manuela Winter

Edith Diyanno
Claire Whalen

Jessica Doherty
Timothy Doherty

Elizabeth Donovan
Christina Donovan

Libby Donovan
Paul and Melissa Long

Chloe Duckworth
Sharon and Donald Wiens

Alicia Ekholm
Erin Ekholm

Austin Erdman
Pamela Erdman

Corinne Fitch
Andrea Korber

Dee Frazier
Dorothy and Greg Laumann

David E. Fry
Linda Fry

Dylan Fuller
Duane Fuller

Amber Gaines
Donald and Elizabeth P. Doherty
Moneta Group

Michael Gonella
Kathy Barron
Patricia Daniels
Ray and Susan L. Molinari
Frank J. Olivadoti
Philip Schneider
Joseph Salzillo
Mary Young
Schwab Charitable

Elisabeth Gustowarow
Elisabeth Conboy
Carol Gustowarow

Frank Hanson
Dana and Jim Clayton

Adam Hasecke
Martha Robertson

Skyler Hauck
Synneva and Terry Meldahl

Brenda Heltne
Jean & Dennis Eich

Liddy Horsey
Mary and Robert Geis
Vicki Haneberg
Mary Grace Manning

Steven Knapp
Paul Sustersic

Fran Lamdanski
Stephen and Kim Lee Hoffman and Sim
Caryn Solomon

Isabel Eva Calof Lander
Arthur Lander and Anne Calof

Brian Leung
Sid & Allison Leung

Amy Lester
Give Lively Foundation, Inc

Maria Isabel Madrid
Carol Hartman

Lisa Mairano
Norman & Barbara Winnerman

Alice Manthey
Andrea Brassard
Deborah Crowley
John Dorval
Lawrence Holt
Marcie Romberger
Phyllis Setta
Katherine B and Gunter Siemsen
Mary Ann Smith

Garry Arthur Markle
Asti Powell
Connie Matteson
Gary & Nancy Reese
Karen Pavao
Maria White
Melanie Campbell
Paul Wildt

Matthew Matheson
Julie and Frank Mairano

Patricia Murray
Karen C Murray

Charles Newcomb
Joyce Newcomb

Natalie Nikzad
Marion Leonard
Mrs. Margaret M. Keller

Noah
Jeremiah Combs

James O'Connell
Shari and Maurice Drake

Briana Paganetti
Karen L Balchunas

Michael Pagani
Don and Amy Franco

Robert E Patterson
Eddie Slaughter

Rachel Penedos
Sheila E Steele

Sara Peracchio
Give Lively Foundation, Inc

Audrey Erin Sherga
Karen Sherga

Stephanie Sophia Smith
Crystal H. and Jerry T. Smith

Karl Stenerson
Donna and Richard Stenerson
Derik Stenerson

Christian Thomas
Jacqueline Hudson

Claudia Tioagson
Robert J. Schoen

Allison Sue Tryba
Jane and Paul Shebeneck
Marcia and Tom Kiepczynski

Molly Wagner
Frank Richmond
Beth Goduti

Ethan Walters
Ms. Penelope Mary Keating

Alison Wells
Norman & Barbara Winnerman

Debra Wenger
Schwab Charitable

Julia Rose Wickness
David and Barbara Wickness

Chase Magdeline-Anne Winnen
Carmen Lee Smith

Garrett Samuel Wise
Billie F. and James J. Thomy
Lauren & Sarah Juncal
Randall Wise
Rick Wise

Matthew Zipp
Amy and John Zipp

YES! I want to continue to support the CdLS Foundation.

☐ **$150** ☐ **$100** ☐ **$75** ☐ **$50** ☐ **$25** ☐ **$**____________

☐ Check (payable to the CdLS Foundation)

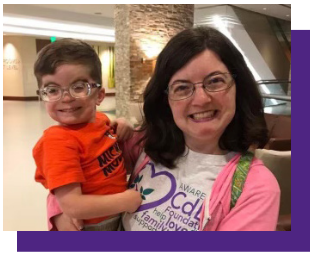
☐ Credit Card

☐ Visa ☐ MasterCard ☐ American Express ☐ Discover

CC#:________________________________ CV:_____ Exp. (MM/YY):_______

Signature:____

Email:____



Scan this QR code to **Donate online.**

ROSP24

CdLS Foundation | 30 Tower Lane, Suite 400, Avon, CT 06001

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

30 Tower Lane, #400
Avon, Connecticut, USA 06001
800.753.2357
www.CdLSusa.org

NON-PROFIT
U.S. POSTAGE
PAID
HARTFORD, CT
PERMIT NO. 751

Join Families Across the World to Celebrate the 35th Anniversary of International CdLS Awareness Day

International CdLS Awareness Day will be held on **SATURDAY, MAY 11** this year. We are encouraging every family to celebrate. Let's spread awareness about CdLS, whether it is a get-together or a social media post.

NEED INSPIRATION OR IDEAS?

Connect with Gabrielle at gnadeau@CdLSusa.org. Interested in becoming an Awareness Coordinator? Gabrielle can show you how. Together, we can educate the world about your loved ones.

McPhee Foundation

Printing of this publication is supported by the McPhee Foundation.