

REACHING OUT

SPRING 2022

A photograph of a baby lying on a white, curly rug. The baby has dark hair and is wearing a headband with white and pink flowers. They are wearing a peach-colored dress with a white lace collar. A clear tracheostomy tube is visible in their neck. The baby's eyes are closed.

Supplemental Security Income ON THE COVER

Avynn Juhnke



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Board President Message



Katherina Terhune, Ph.D., CdLS
Foundation Board President

I am excited and energized to begin my role as the new President of the CdLS Foundation Board of Directors. I first want to thank Mike Christie for the tremendous work he has done for the Foundation with raising awareness and building connections over the past two years. You are an inspiration to all of us, Mike!

As I enter into my term, my efforts will be aligned with the mission of the CdLS Foundation. My involvement with the Foundation over the past seven years has given me the opportunity to be directly immersed in exciting and innovative services to address the needs of the CdLS community. In the year ahead, we will continue with these initiatives while exploring and instituting new ones that capture the dynamics of the changing landscape that we all have been living in for the past couple of years. As a mental and behavioral health professional for nearly two decades, I will be joining the robust efforts of the CdLS Foundation staff, continuing to ensure that the needs of families are heard and recognized, and that corresponding services are readily available. This also includes an opportunity for us to truly understand and examine the emotional impact the global pandemic has had on our community members. The long-term implications of the pandemic are still yet to be seen and fully understood, and it is our priority at the Foundation to make certain that we are at the forefront of providing the necessary services that are needed as individuals and families continue to navigate this new normal.

The past couple of years have also magnified the need for organizations to focus on important efforts centering on diversity, equity, and inclusion (DEI). The benefits of DEI efforts in nonprofit organizations are well documented. Families of children with special needs already experience unique challenges, and these challenges can sometimes be amplified by additional barriers experienced by underrepresented populations. This was my family's experience. My father immigrated from Iran, and experienced challenges as a minority living in the U.S. that compounded the challenges we already faced as a CdLS family. There is much value in the DEI efforts in organizations, which provide opportunities for a variety of backgrounds and perspectives to be represented, and ultimately help inform inclusive decision-making and service delivery. I am excited for the new efforts that are underway at the CdLS Foundation that reflect these principles, and that will shape inclusive practices that meet the needs of our CdLS families.

I am honored to work with the CdLS Foundation staff, Board of Directors and our CdLS community to continue fulfilling our mission of reaching out and providing support. I am incredibly grateful for this opportunity, and I thank you for your support.

Thank You,

Katherina N. Terhune

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COVID-19 SURVEY



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

We hope that everyone has been staying healthy during the pandemic. The CdLS Foundation did a survey about COVID-19, the topic for this editorial.

Following the electronic request for the survey, 175 families responded. The age range of the individuals with CdLS was one to 60 years, with all age groups represented. Over two-thirds of the individuals have been vaccinated and three-quarters had no side effects from the vaccines. Typical side effects from the vaccines occurred in 27%, but some individuals had increased agitation and/or aggression.

Of the individuals with CdLS, 81% live at home and most of the rest live in group homes. Of the group homes, 47% have a closed-door policy and only 27% require staff to wear masks.

Overall, 49% of the individuals with CdLS are willing to keep on a mask. Most of the families whose children refuse to wear a mask have self-isolated at home or distanced outdoors. Ideas for masking include: making a game of it, desensitizing, putting a covering over the stroller or just wearing a face shield (which is not recommended by health care professionals). A small percentage received a mask exemption.

We learned 30 individuals with CdLS had COVID-19. Most had symptoms similar to a cold or flu. Smell and taste were

affected. Two required oxygen and one required intubation, but all did well and recovered. Some had increased behavioral issues while sick. Long-term effects were noted only by those that needed oxygen related to the lungs, although smell and taste did not return in another.

If you would like to report your loved ones' new COVID-19 infection or updates, please fill out this form: bit.ly/CdLSCVD2.

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UPDATE:

Supplemental Security Income

Excerpts Provided by the Social Security Administration

The Supplemental Security Income (SSI) program provides monthly payments to adults and children with a disability or blindness who have income and resources below specific financial limits. SSI payments are also made to people age 65 and older without disabilities who meet the financial qualifications.

You may be eligible to receive SSI monthly payments even if you are already receiving Social Security Disability Insurance or retirement benefits.

HOW SSI WORKS

SSI is a federal program funded by general tax revenues (not Social Security taxes). It provides monthly payments to meet basic needs for food, clothing, and shelter. The base monthly federal amount varies depending on your living arrangement and countable income.

Not everyone gets the same amount. You may get more if you live in a state that adds money to the federal SSI payment. You may get less if you have other income such as wages, pensions, or Social Security benefits. You may also get less if someone pays your household expenses or if you live with a spouse and he or she has income.

You may be able to get SSI if your resources are worth \$2,000 or less. A couple may be able to get SSI if they have resources worth \$3,000 or less.

WHO IS ELIGIBLE FOR SSI?

Anyone may apply for SSI. The SSI program provides monthly payments to people who:

- Are at least age 65 or blind or disabled.
- Have limited income (wages, pensions, etc.).
- Have limited resources (the things you own).
- Are U.S. citizens, nationals of the U.S., or some noncitizens.

- Reside in one of the 50 states, the District of Columbia, or the Northern Mariana Islands. Exception: The children of military parent(s) assigned to permanent duty outside the U.S. and certain students temporarily abroad may receive SSI payments outside the U.S.

HOW TO APPLY FOR SSI

If you plan to apply for SSI, you can begin the application process and complete a large part of your application by visiting our website at www.ssa.gov/applyforbenefits. You can also call us toll-free at 1.800.772.1213 to ask for an appointment with a Social Security representative.

If you're an adult with a disability intending to file for both SSI and Social Security Disability Insurance, you can now apply online for both benefits at the same time if you meet the following requirements:

- Are between the ages of 18 and 65.
- Have never been married.
- Are a U.S. citizen residing in one of the 50 states, District of Columbia, or the Northern Mariana Islands.
- Haven't applied for or received SSI payments in the past.

To apply for Social Security and SSI disability benefits online, visit www.ssa.gov/disability. If you cannot apply for SSI online, you can call us toll-free at 1.800.772.1213 to set up an in-office or telephone appointment with a Social Security representative.

Parents or guardians usually can apply for children who are blind or disabled under age 18. In some cases, other third parties can apply for children.

Dealing with Supplemental Security Income Issues

Carla Leake



Lucas is my 3 ½ year old grandson. Because he and his mom, Lindsey, live with me, I am much more involved in his day-to-day care. Early in Lindsey's pregnancy it was determined that Lucas was not growing as he should be. Once his care was transferred to specialists, he was diagnosed with a congenital heart defect called Tetralogy of Fallot. It was not until after he was born that he was diagnosed with

CdLS. Lucas spent 75 days in the NICU, home for a month, then another 25 days in the hospital for his heart repair. Lucas is hearing impaired, vision impaired, non-verbal, non-ambulatory and tube fed. With so many needs, we are blessed to have members on all sides of Lucas' family that love, accept, and want him to achieve so much.

While Lucas was in NICU, the social workers approached his mom about filing for Supplemental Security Income (SSI) for Lucas. SSI is a needs-based program in addition to eligibility through a qualifying disability or condition. After getting the appropriate documentation, Lucas was eligible for SSI. As part of the ongoing eligibility for SSI, a case manager reviews the file annually, evaluating financial standings and continued disability. In October 2021, Lucas had his annual review. We provided all information and documentation needed for continued eligibility requirements. Two days later, his case manager called saying that a run on his social security number populated a joint account with another grandparent that put his financial status over the allowed \$2,000. In addition, that account had been over the limit since January and Lucas had been ineligible since that time. He would have to repay all of his benefits that he had received for 2021. We've had the same case manager for several years and she was both sympathetic and helpful. Unfortunately, the financial limit is a non-negotiable item

with SSI and even though we were not aware of this account nor had access to this account, Lucas would be responsible for repayment.

Our first order of business was to re-establish his eligibility. The account in question was closed out and information was resubmitted to his case manager. It was only a couple weeks delay in getting Lucas recertified and eligible once again. A repayment plan was established - Lucas will be paying a minimal amount each month for six years to repay the \$6,000 he received during the time period he was ineligible.

The grandparent that had this account, was only doing for Lucas what he does for all of his other grandchildren. Unfortunately, the well-meaning grandparent had forgotten about the \$2,000 limit and after a deposit in January, the account for Lucas exceeded the allowable total resources. Although it is frustrating that saving money penalizes individuals that are on SSI, there are ways to save that don't impact the benefits. For family members that are interested in helping with the financial responsibility of an individual with a disability, there are available options. Our family has discussed and looking at two options, a special needs trust and/or an ABLE account. A Special Needs Trust can be established (this may be a good option if the individual is a beneficiary to a life insurance policy or could receive an inheritance). In our area, there are organizations and lawyers that specialize in this process. Another option we are considering, and will most likely establish regardless, is an ABLE account. ABLE accounts are set up for eligible individuals through the state and must be established by the age of 26. Money is easily transferable from one account to another and SSI benefits are not impacted unless the balance goes over \$100,000 (there are annual deposit limits as well).

Our family is fortunate that this problem was resolved quickly. Although Lucas will have a little money taken out of his benefits each month for years, it will not impact his care. I would advise other families to make sure that any well-meaning family members are aware of the best ways to help save for your loved one with CdLS that will not cause disruptions to services or impact their eligibility for various programs. Do your research and know your options!

HIGHLIGHTED EVENTS

NEW ENGLAND GOLF IS TEEING OFF - MAY 23RD

The popular New England Golf Classic has been moved back to its original long-standing date in spring. If you want to hit the links at the exclusive Ipswich Country Club in Ipswich, MA, then mark your calendars for Monday, May 23, 2022.

This year's outing will be a 9am shotgun scramble, complete with breakfast, 18 holes of fun and competitive golf on one of the region's finest golf courses, as well as contest holes, raffle prizes, silent auction items and an awards luncheon to follow.



The annual New England Golf Classic began 29 years ago when a handful of families, who enjoyed playing golf, decided to make a fundraiser out of it and invite others to join. Since that time, this event has raised approximately \$925,000 to support the work of the CdLS Foundation.

To get a jump on things and take advantage of early bird pricing, golfers who register to play by March 23rd, get a \$25 discount on entry fees. Likewise, any foursome that registers by March 23rd will not only get the discount, but will also be entered into a raffle for a chance to win a free foursome of golf at Ipswich at a later date. What a bargain!



If you, your family or company would like to sponsor the event, we have some great sponsorship packages that will enable you to pay tribute to a loved one and/or to promote your company on the New England Golf website, program, on the course and at the luncheon.



SCAN CODE

To learn more about our sponsorship opportunities or to register, please visit: bit.ly/NEgolf2022, or use your smart device to scan the QR code.

Questions? Contact Sherry at swaitsman@cldsusa.org or 800.753.2357, ext.1227.

CREATE YOUR OWN HIT THE TRAILS FUNRAISER FOR CdLS



Here is a fun and easy way for you and your local community to enjoy a pleasant time together while raising awareness and money for the CdLS Foundation.

Pick a date, time, distance, and location near you and let your supporters know that you intend to Hit the Trails for CdLS and ask them to support your campaign.

We will help you create your online fundraising site. All you need to do is send your fundraiser link to your friends and watch as their donations come into the CdLS Foundation prior to your event day.

Those raising \$1,000 or more will receive a "I Hit the Trails for CdLS" t-shirt and will be mentioned in *Reaching Out*. For more information, contact Annette Scheidecker at events@cldsusa.org or 800.753.2357, ext. 1391.

GOING WHOLE HOG FOR CHARLIE AND OTHERS WITH CdLS

Rob and Alana Donald of Kentucky were determined to make their annual pig roast the most memorable one yet. The couple has held their Whole Hog event for the past four years, but this one had a bit of a twist. The Donald's made the event a fundraiser in honor of someone very special to their hearts, their darling playful six-year-old son Charlie, who has CdLS.



The Donald's invited family and friends, who attended the yummy affair, to consider making a donation to the CdLS Foundation.

"The CdLS Foundation has been a great support to us since Charlie's diagnosis," explained Alana Donald. "Through them, and especially through the biennial CdLS National Conference, we have been given access to experts, gotten essential information on how to best care for Charlie, and have been able to meet and connect with many other CdLS families".

Wanting to ensure that the Foundation can continue serving others like Charlie, the Donald's impassioned plea was heard by those who love them. The Whole Hog pig roast raised close to \$3,000! Thank you to the Donald family and all of their family and friends.

THANK YOU TO OUR \$40 FOR 40 DONORS!



Last year the CdLS Foundation celebrated our 40th anniversary. As a special fundraiser to mark the occasion we started a \$40 for 40 Campaign,

encouraging those who were able, to donate a dollar for every year that the Foundation has served our families in honor of the special milestone year.

We say thank you to our wonderful \$40 for 40 Donors:

Valerie Barnes	Richard & Martha Jane Moreland
Rick & Vicki Boehman	Jana Mountz
Elizabeth Delaney	Melinda Muenzberg
Marilyn Eberle	Gabrielle Nadeau
Nichole Elcano	Mary Nicholls
Maricela Flores	Karla & Michael Postell
Richard & Dianne Haaland	Karen & Larry Prada
Earl Hosterman	Morrisette Royster
Paula Jarratt	Annette Scheidecker
Shelley Jensen	Paul & Maureen Schuler
Matinel Kahn	James & Tori Stephens
Myrna & Wendy Kaplan	Luann Webster
Judith Kotanchik	

Thanks to our generous donors, we exceeded our goal of \$2,000 and raised \$2,760.

CALENDAR 2022

April 2

Virtual Forum for Adolescents and Adults with CdLS

May 14

CdLS Awareness Day

May 23

New England Golf Tournament
Ipswich, MA

October 9

Chicago Marathon
Chicago, IL

October 10

Missouri Golf
Sunset Hills, MO

October 15

Baltimore Running Festival
Baltimore, MD

Four Easy Ways You Can Help

We are so grateful to all of our incredible donors and fundraisers, who are the lifeblood of the CdLS Foundation. You ensure that the organization has the funding it needs to continue our important mission of serving our families across the nation.

We realize that most of you want to give back to the organization, but not everyone is able to volunteer, make a donation or participate in an event. After all, you are already dealing with the challenges of caring for someone with CdLS, which can be exhausting and at times expensive. We recognize that fundraising is not a one-size fits all endeavor.

To provide some options you may find helpful, here are some easy ways that won't hurt your wallet or your busy schedule:



- **Amazon Smiles** - This program donates 0.5% of your eligible purchases on Amazon to a charity of your choice. All you need to do is select the Cornelia de Lange Syndrome Foundation as your charity and start your shopping at [smile.amazon.com](#). The donation will be made at no extra cost to you.



- **Bertucci's Fundraiser** - Have a Bertucci's restaurant near you, or another place of business that offers charitable contributions for business you send their way? Fill out their easy charity donation form (via the link below), and pick a date. Then notify your family and friends to dine at the restaurant that day/evening, and to mention the CdLS Foundation. Bertucci's will donate 15% of the sales from your supporters that day to the CdLS Foundation. [bit.ly/cdlsbert](#)



- **Facebook/Meta Fundraiser** - Use Facebook to celebrate special milestones by starting a Facebook fundraiser and selecting the CdLS Foundation as your charity. Many of you already do this and have had great success.



- **iGive.com** - Select the CdLS Foundation as your charity of choice and shop with any of the 2,000 participating stores online. A donation ranging from 4% - 25% of your purchase will go to the Foundation - at no additional cost to you. [bit.ly/cdlsigive](#)

Whether by raising funds or awareness or by trusting us to help you navigate through your CdLS journey, your dedication to the CdLS Foundation means the world to us. Thank you.

Connecting with Families Local to You

Did you know the CdLS Foundation has a program where you can be connected with families in your local community? Living life with someone who has CdLS has both its rewards and challenges. The families that make up our community have seen it all. Making connections with others who have lived through something similar is a vital part of what we do here at the Foundation. This service, Connect with a Family, allows Family Service Coordinators to connect you with another CdLS friend. To participate, visit: cdlsusa.org/connect-family.

Parents Helping Parents Empowers Parents Like YOU



Parents Helping Parents provides support and information to families raising children with special needs. They offer webinars, online learning, assistive technology exploration, 1:1 help, and more.

Most of their staff are parents of children with special needs. They understand how complex and sometimes overwhelming it is to find the help you need for you and your child. To learn more, visit: www.php.com.

WELCOME New Families



THE BUSKEY FAMILY

We are the Buskey family! Our daughter Aubrey was diagnosed with CdLS at 2 1/2 years old. Aubrey is a happy little girl who loves dancing/listening to music, watching Raya and Zootopia, playing with her toys, snuggling with her mommy and daddy and spending time with her extended family, who are an incredible support system for our little girl. We are very excited to connect with other families through the CdLS community to help us continue to learn about CdLS so that we are able to give Aubrey all the support she needs/deserves!

Arizona

Jennifer and Chris Ravare
and son Noah, born
February 7, 2018

Texas

Samantha and Daniel
Clanton and daughter
Blake, born
October 12, 2021

Texas

Leah and Brian Markle and
daughter Noelle, born
January 21, 2020

Texas

Rachel and Greg
Williamson and
son Stephen,
born March 4, 2018

Nevada

Dawn Yaeger and Josh
Dunn and son Braxton,
born August 25, 2021

Director's Message

Welcome to 2022 – a year that numerologically speaking represents love, family and partnerships. This is a good omen for us and the work we do. First, the staff and I would like to thank you all for the incredible financial support in these trying times and the continued acknowledgement of our efforts to serve you. We received your many letters, cards and emails during the year sharing your beautiful children with us and thanking us for being a ‘friend’.

Over the last year, we’ve once again weathered the storm thanks in no small part to your continued support of our efforts here at the Foundation.

We’ve welcome 97 new families to our community. Many of the newer families joining our community have younger children between the ages of newborn and 3-years-old as they are being diagnosed earlier.

Requests for support come in from all over the country from as far away as Alaska, or vast landscapes as North Dakota to New York, California and Florida. We also receive many calls from support from our international community handled in partnership with our peers at the World CdLS Foundation ... (many thanks Dave Axtell & Company).

The Foundation is always listening and adapting to meet the needs of our families. New and expanded programming in 2021 includes a pilot support group led by Eileen Ahern for parents managing extreme behavior issues. Feedback from the group has been very positive. Learnings there will fuel future programs and services for parents living with that experience.

The Empowerment Team is a monthly support group of mildly-affected young adults with CdLS expertly facilitated by Whitney Rinaldi. The group discuss topics relative to living with and navigating CdLS as young adults. The members have shared that they feel more supported knowing they are not alone and have given us insights on how to make them feel – well more empowered! More to come there.

Lastly, a new health sub-committee of the board was formed to investigate how the Foundation might better assist our families with navigating the healthcare system ultimately improving the quality of care. The group is very early in formulating our thinking, but will continue to reach out to you in focus groups to help guide our answers. If you would like to give your feedback directly on your healthcare journey please reach out to us at Outreach@CdLSusa.org.

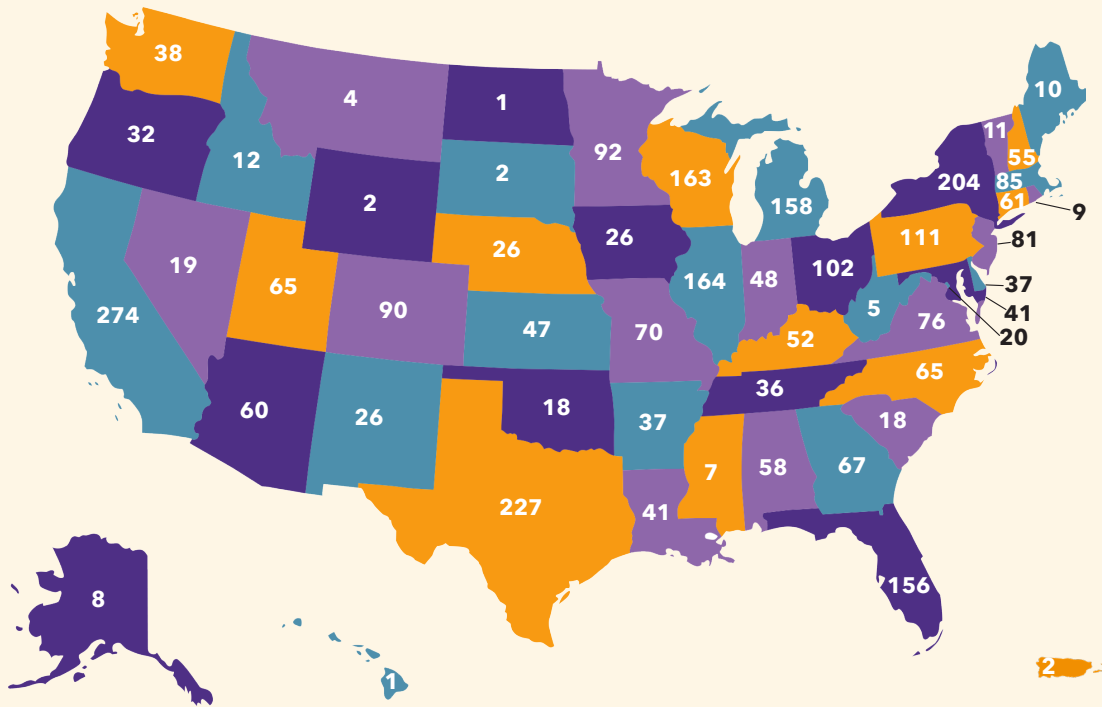
We continue to evolve in an effort to meet you where you are. We hope we have understood the assignment and feel determined to deliver in spite of the many adversities we all face.

Warmly,



Bonnie Royster, CdLS Foundation
Executive Director

Our Service Numbers in 2021



In 2021, there were 2,294 services provided to families across the United States. We were in contact with 937 individuals and welcomed 97 new families to the CdLS community. The top five states that had the highest number of families connecting with the Foundation were: California, Florida, New York, Texas, and Wisconsin.

Our Volunteers Support Our Efforts

Last year, the Foundation worked on a new initiative with Regional Coordinators in California. Regional Coordinators (RCs) are volunteers who are parents/caregivers of individuals who have CdLS. They are generally who we turn to to help parents locally facing problems or looking for support in caring for their loved one with CdLS. In 2021, the staff wanted to see how to better partner with these passionate and highly experienced parent experts. Long-time Regional Coordinator, Karen Prada, shared the importance of feeling connected and especially having a mentor to help navigate the many services available. Family Service Coordinators met with families virtually and will be engaging more RCs in other states in 2022.

Another great group of volunteers are the Spanish-speaking volunteers. This small group of Spanish-speaking Coordinators have been identified to talk to, translate questions and provide support to other Spanish-speaking families.



Post cards sent to families in CA introducing them to their RCs.

Support Groups Helping Families Near and Far

The CdLS Foundation is proud to offer important and empowering support groups to all members of the CdLS community. Three main groups are the Grief Advisory Task Force, The Empowerment Team and the Peer-to-Peer Support Group.

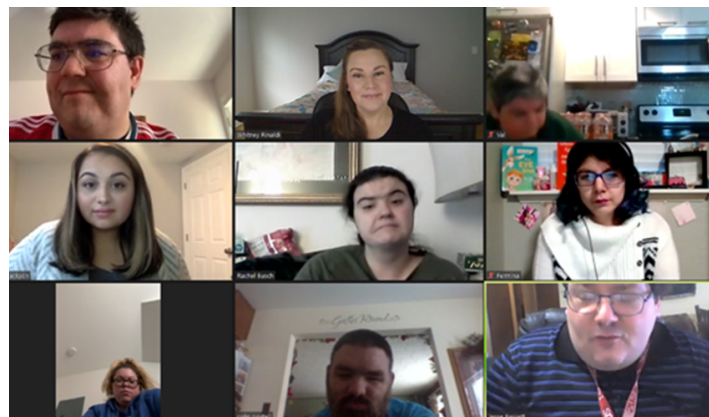


The Grief Advisory Task Force (GATF) is a group of passionate parents who have lost a child with CdLS. This group serves two purposes: 1. they act in an advisory capacity to help the Foundation create programs and services that resonate with those who have lost a child, and 2. they serve as a volunteer corps that makes outreach calls and cards to those who have lost a child.

The CdLS Empowerment Team is a group of high functioning individuals with CdLS, 18 years old and older. This group was formed because adults with CdLS face special challenges as the structure and supports often in place in high school end. The Family Service Team addresses these needs by providing information and resources to families with youth transitioning out of the school environment and into adult life.

Whitney Rinaldi, BSW one of our Family Service Coordinators originated and facilitates the monthly Empowerment Team meeting. Whitney has been an amazing resource for our adults. The group allows its members to come together to support and encourage each other.

During 2020, the Team went from a small group of adults



who looked forward to seeing each other every other year at Conference to an active, participatory one that now meets

monthly. The pandemic changed the way we are all able to interact and socialize. Some members were not able to attend day programs or work as sites closed. The group met a need for these adults with CdLS that felt increasingly isolated during this time.

The Empowerment Team now provides an ongoing opportunity to socialize and develop relationships across the country as it provides a caring and safe environment. This virtual social and support group, helps participants hone social skills, identify interests, navigate challenging situations at home, school, or work and in the world of social media. The Empowerment Team also helps participants develop self-advocacy skills as they learn to manage their own health care and navigate the health care system. The group is currently creating resources helpful for themselves as well as other families.

The Empowerment Team is an interactive and confidential space to share struggles, questions, concerns, and victories. If you would like more information about The Empowerment Team or any of the Family Service Department initiatives, please contact the Foundation at FamilyServiceTeam@CdLSusa.org or at 1.860.676.8166

The Peer-to-Peer Support Group is a pilot program the Foundation started in 2021 headed up by mother and professional, Eileen Ahearn. This is a parent-facilitated support group that talks about behaviors parents are experiencing with their child while supporting each other through the difficulty of managing it all and offering strategies to cope. We are working with Eileen to create a model with best practices to scale this out to a local community near you.

If you have questions or suggestions about this group, please email outreach@CdLSusa.org.

Healthcare Sub Committee

In 2021, The Foundation formed a board sub-committee focused on exploring how we could improve the healthcare experience for families and CdLS patients. The committee is led by board member Paul Villani. Under his guidance and leadership, we have convened a wonderful team of experts to help guide our thinking. Additionally, we continue to do outreach to parent groups to understand the key challenges are you all face. So far, the most common themes we heard are:

Medical Advocacy: How can I get my child's medical provider to hear me? How can I get appropriate referrals, tests, and procedures for my child?

Care Coordination: My child's specialists don't always talk to each other or to my child's PCP. I worry that this lack of communication may result in something being missed or interaction of medicines not being paid attention to.

Lack of Confidence: I wonder if my child's diagnosis or symptoms should be treated as part of CdLS or something else. Should these symptoms or diagnosis be treated differently because my child has CdLS? I need a second opinion.

Transition to Adult-Care: I'm having a hard time finding an adult provider. I must re-educate my new provider on the nuances of CdLS.

We hope we have those concerns right, but feel free to email us at Outreach@cdlsusa.org to let us know. Stay tuned as we hope to share some enhancements that could make navigating healthcare a bit easier.

Research Efforts Ongoing in the CdLS Community

In the last two and a half years, the CdLS Foundation has teamed up with eight research professionals to further the knowledge of CdLS. Below is a list of the efforts since 2020:

YEAR	RESEARCHER	ORGANIZATION	RESEARCH PROJECT
2020	John Michael Falligant, Ph.D.	John Hopkins Medicine	Behavioral Assessment and Treatment of Problem Behavior in Children with CdLS
2020	Justin Chung, Doctoral Researcher	University of Birmingham	The Stay Calm Project
2020	Sarah Fitzpatrick	Cincinnati Children's Hospital Medical Center	Characterize sleep patterns in people with Cornelia de Lange Syndrome.
2021	Dr. Tracy Dudding-Byth	NSW Health	Face Match Research Project
2021	Marco Grados, M.D., M.P.H.	The Johns Hopkins Hospital	Self-Injurious Behavior in CdLS
2022	Asmita Mistry	Keane University	Service delivery for selective mutism in adolescents and young adults with Cornelia de Lange Syndrome
2022	Philip Boone M.D.	Massachusetts General Hospital	CdLS and Related Disorders Research at Massachusetts General Hospital
2022	Kamli Faour	Boston Children's Hospital	Cornelia de Lange Syndrome and Related Disorders: From Gene to Disease, A Boston Children's Hospital Study

To learn more about these projects, visit: bit.ly/CdLSresearch.

Avynn Juhnke

Hannah Juhnke

Avynn was one-year-old and had a smile that lit up her whole face. She loved music, people watching, and all the attention on her. She had an unrepaired heart defect and cleft palate. Avynn also used a feeding tube and a trach.

Avynn was suspected to have CdLS after birth because of her facial features and birth defects. She had a confirmed diagnosis at a month old after we received results from genetic testing. She had the classic form of CdLS which affects the *NIPBL* gene.



Avynn experienced a lot of time in and out of the hospital in her first year of life. She had 5 surgeries over the course of several months which caused setbacks in her physical development. We worked daily on sitting and her motor skills. I could see how frustrated she felt when her body wouldn't do what her mind wanted it to, for example, being able to grip a toy. Another ongoing issue was her severe reflux. We did all we could to keep it under control, but sometimes that was still not enough. She struggled with it daily.

She loved when someone read books, sang, and/or talked to her. Avynn was very observant and enjoyed taking in the world around her. Her favorite toys were the ones that played music and lit up.

When Avynn was 8-months-old she stopped breathing in our home due to reflux aspiration while she was sleeping. An ambulance rushed her to the ER where they revived her. The ER team had difficulty getting a good IV line in her, so they wanted to intubate her to put in a central line IV. She

coded during their efforts to intubate and went through an emergency tracheostomy surgery. We never had time to process the trach and it was a big adjustment for us as a family. Avynn spent 52 days in the PICU to recover her lungs and recover from surgery. While at first, I was angry about the trach, the trach saved her life and I am grateful that the technology exists. We had decided to keep it for her upcoming heart surgery since she had a difficult airway.

Having a child with CdLS will open your eyes to a whole new world. You learn to appreciate the small things and live life to its fullest. CdLS has allowed me to become an ally within the disability community. I am passionate about sharing Avynn's story with others and helping parents who may be at the beginning of their journey. I am grateful for the CdLS family that helped me process and navigate through the diagnosis.

The CdLS Foundation was the first website we went to after Avynn's diagnosis. Their research and resources have been helpful in answering questions for Avynn's medical team. When Avynn was in the hospital for aspiration pneumonia, we contacted the Foundation to get more information on the Nissen fundoplication surgery for individuals with CdLS. It was our last option to help alleviate her severe reflux. We were hesitant to move forward with surgery because we weren't sure if it would help her. The Foundation took down our questions and sent them to their CdLS specialty team of doctors. They helped answer our questions and gave us confidence in our decision to do the surgery for Avynn.

A diagnosis can prepare you for a lot of things, but it doesn't prepare you for the unique love and joy you will experience with a child with a disability. Love is the foundation that made all that Avynn went through worth it. The love we had for her was unconditional. Avynn has taught us to see joy in the mists of heartache. No matter what happened, her life still had purpose and meaning. I know she lived a rewarding one that was full of love, laughter and light.

Avynn passed away 1/15/22, I shared Avynn's journey with CdLS on her Instagram page, @amazing_avynnmae if you're interested in seeing how her story unfolded.

Welcome New Staff to the CdLS Foundation



Linda Pierce joined the Foundation in 2021 as Program Director of Family Services. Her social work career began working with families as an oncology social worker in Baltimore, Maryland. Over the years Linda has worked in both medical and behavioral health managed

care setting, serving families with both commercial and Medicare or Medicaid. She has held management positions in clinical care and operations departments. For the past 11 years, Linda was the Director of Member Engagement for an administrative services organization managing medical benefits for her state's medical population. Linda brings a wealth of experience and dedication to meeting the needs of families. One fun, and often heartbreaking fact about Linda is that she grew up in Buffalo, NY and has been Buffalo Bills fan through thick and thin. #GoBills.

Volunteer with Us



The Foundation relies on volunteers from all over the country to help raise awareness and support, reach out to other families, and help caregivers make informed decisions. Volunteers sit on committees that plan and implement Foundation services and events.

We are currently looking for volunteers for a variety of different areas including, but not limited to: Spanish-speaking Coordinators, Awareness Coordinators, Committee Members for our Family Service, Public Affairs and Professional Development Committees. Each role has its own set of responsibilities, which are available to view here: www.cdlsusa.org/volunteer. If you are interested, email us at outreach@CdLSusa.org.

NATIONAL FAMILY CONFERENCE

Great news! The **National Virtual Family Conference will be held on June 25 - June 26, 2022**, from the comfort of your own homes! The best part is the week leading up to the big event will be filled with pre-conference workshops that discuss important topics including being a newly diagnosed CdLS family, transitioning from high school to adulthood, psychiatric medication, siblings support and so much more!

There will also be social "after hour" time for moms, dads and grandparents. This will be a great time to kick back, relax and spend time with your CdLS family.

Conference workshops will host cross-section of experts and families to ensure that there is something for everyone.

REGISTRATION WILL OPEN ON MAY 16, 2022.

To be up to date about Conference, visit: www.CdLSusa.org/conference.

SCIENTIFIC & EDUCATIONAL SYMPOSIUM

The upcoming **Virtual Scientific & Educational Symposium** will feature talks by leading researchers on the molecular and cellular functions of cohesin, and the clinical and educational aspects of CdLS. It encourages interactions between basic scientists and clinicians.

If your local medical, educational, or therapeutic professionals are interested in attending symposium, registration opens May 16, 2022.

Overcoming My Disability is Something I've Never Done

Chloe Tear, chloetear.co.uk

"Disabled people can overcome their disability if they try hard enough". I hear this type of phrase all too often. It also comes with a few variations: overcoming disability, defying disability and disability did not stop them from achieving. Just to name a few.

However, I have never overcome my disability and I don't intend to do so.

I found myself really examining how this statement is used, what it implies, and if it's even accurate. Overcoming my disability leads me to believe I have beaten it in some way. As a result, I have now accomplished a goal that I previously was unable to achieve. Yet my disability doesn't magically disappear with my willingness to overcome it. I am disabled, both with or without a certain achievement.

Having a disability is an integral part of who I am. To overcome such a deep-rooted part of me is saying it shouldn't be there in the first place. Not to mention the fact that certain achievements are just off limits when you have a disability, regardless of your actual ability.

"They achieved so and so despite their disability."

I appreciate that sometimes things are harder for us. We may face more hurdles than non-disabled people, but that also devalues the things that everyone achieve. If you achieve something and have a disability that obviously means you have won against the odds or defied expectations. Don't get me wrong, we're a determined group of people and we probably do sometimes exceed more than medically expected. However, that is down to our abilities and hard work, rather than overcoming a part of ourselves.

What do I need to overcome? When people use the word overcome in reference to disability, they are more accurately describing the barriers that society puts in our way. I need to defy the notion that having a disability is bad thing.

I also need to overcome the mindset that trying harder to accomplish a goal will lead to always achieving on par

with non-disabled people. It doesn't matter how hard I try; I will not be able-bodied and that's okay. We live in a society that strives for perfection, with the idea that we just need to work that extra bit harder. Yes, working harder than most will enable me to achieve some things. Yet I will always have limitations. I could try my hardest to read a menu, no amount of squinting will make the words appear!

I regularly need to overcome social barriers and attitudes, but I know I'm not alone in this. The misconceptions can slowly grind you down with every (very often) innocent comment. I know people normally mean no harm, yet this is why it's important to have these conversations. You've been sold the lie that disability is negative and that we need to get rid of it if possible. Surely, we want future generations to not have these misconceptions?

My disability is here to stay. If I did choose to dismiss my disability in an attempt to overcome challenges, I'm not giving myself the best chance possible. Whether I like it or not, I am disabled – even if this means society sees me as less.

People might see the achievements as something amazing. Yet this might not show the full story. Today I walked two miles to raise money for CP Teens UK, the fact I completed it is a really good achievement for me. Yet what about the things that happen behind the scenes. The fact it was split into many sections so I could rest a lot, or the fact that pain levels now resemble running 17 marathons in one go! Not to mention the fact I did it with my brother because of my sight. I also know the physical impact of that walk will stick around for a while. Knowing my own limits, like having breaks and expecting the payback, is what allowed to complete the walk.

I don't want to overcome my disability. To truly achieve I have to embrace and acknowledge any limitation and work around it. It also is knowing when you need support or understanding you can't do something. Knowing my disability actually allows me to succeed. I do not need to change or overcome. I am not giving up if I say no.

Making the decision to not overcome my disability doesn't make me less capable.

~ Chloe x

In Honor/ Celebration

Jesse R. Bassett
Geraldine Maness

Elizabeth A. Bernhardt
Rita Linert

Hannah Boehman
Neil Boehman

Rachel Busch
Mary Ann Randall

Michael Cataline
Carol and John Cataline

Taryn Christie
Kim and William Carroll

Bryn Clary
Patricia and David Clary

Shaylin H. Cubeta
Alice Hoke

Charles A. Dahl
Kelly Oneill

Chase J. Duff
Barbara Robinson

Logan Fowler
Christl Schambach

William L. Fowler
Alexandra and Seth Miller

Gage
Nanci Bell

Mason Gilbert
Kelly Oneill

Vincent Hackenberg
Keane Vintage

Gretchen E. Heinrich
Ellen and Daniel Smock

Colt Highberger
Susan Barker

Caitlynn Jacobsen
George Jacobsen

Anders Johnson
Nancy Kear-Johnson and
Eric Johnson

Nancy Kear-Johnson
Nancy Kear

Matinel H. Kahn
Mark Hecker

Robert T. Kelliher
Christina and Patrick Tighe

Antonie Kline
Miriam Kline

Kaitlyn A. Kuepferle
David Eberle

Hope Kurth
Carla and Todd Vollmer-Bills

Charlotte Lawrence
William Paredes

Sam Luce
Michelle and Timothy Luce

Luke Lyons
Kumiko Shortill

Zachary Markowitz
Susan and Arthur Markowitz

Payton G. McDonald
Lorraine and Dennis Koss

Leah Michaud
Susan and David Michaud

Andrew D. Miller
Diane Miller

Devin Miller
Kevin Walters

Henry Miller
Diane Miller

Samuel D. Miller
Diane Miller
Elizabeth and Mark Burnett

Mikayla Needlman
David and Pam Kahn

Bianca M. Pradlik
Joyce Masongsong-Ray

Siena M. Renteria
Teresa and Frank Mandella
Francie Barber and
Craig Cheney

Review of the 2022 Budget

We are grateful for the support of our families and donors that allowed us to make 2021 feel more "normal" than the last. We were able to have some in-person gatherings and regular events. We were able to carry our services and respond to any new emerged concerns within the community due to Covid.



At the end of every year, we plan for the next and we create our budget based on our expectations for the following year. For the past years as well as our budget for 2022 we've had budgets with expected deficit. There is inflation every year, we want to do more for the families, but we do not have government or state grants to rely on. The projected deficit for 2022 is \$90,000. We were fortunate to have your dedicated support through the years and during the really challenging past two years due to covid. We were also able to mitigate the deficit by applying for grants available by the government to support businesses and organizations through the pandemic.

We are grateful to all of you for continuing to support the CdLS Foundation and strengthening our community as the years go by and we overcome challenges together. We would like to ask you to consider using your social media to raise awareness, to ponder ways to introduce your workplace, your local stores, restaurants, networks to CdLS, to the need and importance of our mission, to build better and solid foundation for what we are to face tomorrow.

We are making a difference together!

Riley A. Rissland

Allison and Patrick Liu

Wilson SimmonsBrandi Diamond
Sierra Hammock
Anne Putt
Nissa White
Elliott Wood**William E. Smisloff**

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Thomas and Ellen Heile

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Christian Thomas

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Earl Hosterman

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Linda and C. Edwin Martin

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Isabelle Rastler-Cross

Jaime Timm

Andrea Vanzant

Aaron Zimmerman

Samuel Fiorentino

Elizabeth and Philip Contant

Michael Jennings

Dylan K. Fuller

Duane Fuller

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Susan and Raymond Molinari

Philip Schneider

Jupiter Gunter

Phyllis Marfo

Gabrielle and Tim Nadeau

Joseph F. Haaland

Dianne and Richard Haaland

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Larry and Barb Hall

Brenda J. Heltne

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Wiladene E. Heaston

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Paul Jacobs

Mary L. Horsey

Vicki and Brad Haneberg

Mary Manning

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Ann Murray Johnson

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Eric Johnson

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Tara M. Joyce

Patricia Joyce

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Winona Woods

Molly Wagner

Judy and Joel Fisher

Debra Wenger

Robert C. Wenger

Aaron A. Young

Carol and John Cataline

Angela and Tim Young

Our Deepest Sympathy

Karen Prestwich

December 23, 1983 - October 9, 2021
Daughter of Susan Prestwich
700 S 800 E
Springville, UT 84663
And
Kent Heger
11842 Hidden Valley Club Drive
Sandy, UT 84092

Cathleen "Cathy Pooh" Banks

August 18, 1972- January 14, 2022
Daughter to Pat and Charles Banks
1950 SW Regency Parkway Dr
Topeka, KS 66604

Avynn Juhnke

November 18, 2020 - January 15, 2022
Daughter of Hannah and Gabe Juhnke
923 N Mission Road
Wichita, KS 67206

Mathew Rodgers

January 30, 1992- December 24, 2021
Son to Donna and Todd Rodgers
811 Flexer Ave
Allentown, PA 18103

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.



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

Yes, I want to **SUPPORT** the CdLS Foundation!

Enclosed is my tax-deductible gift of:

☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 ☐ \$40 ☐ Other \$____

Payments may be made by check or credit card.

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Donate online at www.CdLSusa.org



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Join Families Across the World to Celebrate CdLS Awareness Day

CdLS Awareness Day will be held on May 14th this year. We are encouraging every family to celebrate. Whether it is an in-person get together or a social media post, let's spread awareness about CdLS. Need inspiration or ideas? Connect with Gabrielle Nadeau at the CdLS Foundation 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.



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