

REACHING OUT

A man wearing a yellow beanie with a Boston Bruins logo, a dark green quilted jacket with neon green accents, and black pants is smiling and waving his right hand. He is standing on a snowmobile, with his left hand on the handlebar. The background shows a snowy landscape with trees and a blue sky with light clouds. The snowmobile has a "HONDA" logo on the side.

SPRING 2019

Coping Corner

A Better Day Tomorrow

Making Sense of Government Benefits

Helpful Hints

The IEP Process



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

We are well into 2019. I hope our newsletter finds you bravely facing whatever circumstances life happens to have in front of you. Victory belongs to those who never give up. As stated so beautifully by one of our country's founding fathers, "Patience and perseverance have a magical effect before which difficulties disappear and obstacles vanish."

You Asked - We Listened. In response to the Reaching Out survey, we are addressing topics that seem to resonate with many of you. You asked for features on how parents cope with the challenges of raising a child with special needs. In this issue, you will find a gripping account of a mom who lost her child. You asked for resources to help navigate the journey; this issue provides insight on government benefits, self-care tips and the IEP process. You wanted to meet the new families and we are introducing them to you. In order to provide relevant content - Gifts That Count will be featured in the green version. To go green, call the Foundation at 800.753.2357.

The team is working hard preparing a new webinar series featuring topics that you identified as top concerns. Drs. Julia O'Connor and Marco Grados will discuss behavior and medication. Dr. Sid Srivastava - a pediatric neurologist - will share his insights into Neurogenetics. Series on gastroenterology (GI), genetics and financial planning for individuals with special needs are all in the works.

The 2020 Conference will be held in Tulsa, Oklahoma and we anticipate a Tulsa takeover (#CdLSTakesOverTulsa)! The Local Conference Committee is forming. More information will be shared as the planning unfolds.

We are here to support you in your efforts to be the best caregivers you can. We hope our refreshed design of Reaching Out meets your needs. Thanks for being there for each other and us.



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Executive Director

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How to be Successful in Medically Transitioning Your Child

There is an inevitability that everyone will age. One of the first signs of aging is a change in our senses. Sight and hearing start to decline. Smell and taste seem less distinct. Our ability to touch can be lessened due to numbness or a medical issue, such as arthritis. These are the same changes that happen in individuals with CdLS. Individuals with special needs rely upon these senses to fill in when limitations have been present, and with aging, this can lead to increased difficulties.

When an individual with CdLS ages it is important to know that organ systems can be affected. The GI tract can be impacted, especially with long-term complications of gastroesophageal reflux and abnormal bowel motility causing chronic constipation and an increased risk for bowel obstruction. There is a risk for obesity. Bones become less dense (osteoporosis) over time, compounded by lower testosterone or estrogen that is seen in CdLS. In males the prostate enlarges earlier than expected and this can lead to urination difficulties. Females tend to continue menstrual periods as in unaffected females. Facial features seem to age quicker than the body, and often, individuals with CdLS will look older than their unaffected peers. Kidneys, hormone-producing organs, lungs and other GI organs seem to continue as they have been. In terms of the brain, thinking is not necessarily slower but people with CdLS seem to get a little quieter, and in general prefer to be at home rather than out and about.

There is need for an adult physician to be caring for young adult with CdLS transitioning into adult care. Classically, pediatric providers have maintained care for children with special needs long into adulthood, but as the heart and blood vessels, cholesterol, thyroid hormone and others develop adult-onset conditions, appropriate medical care can be beyond their scope of knowledge. It is best to start the transition process long before it is needed. Identify adult providers in the area who are familiar with individuals with special needs. Ask regional providers in your area if there are some better known and excellent adult providers. Call the offices and ask if the transition can be spread out over a longer period. Bring the CdLS Foundation Adult Guidelines when meeting with the adult care providers. Make sure both you and your child are comfortable with the new provider(s) and able to ask questions. You can always call the Foundation at 800.753.2357 with questions.



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

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Making Sense of Government Benefits

By Mary Anne Ehlert, CFP, Founder of Protected Tomorrows, Inc.

If you're a parent of a child with special needs, or a caregiver of an adult with a disability, government benefits and legal options are often confusing. Here is a brief explanation of government benefits that in the future your loved one may or may not be eligible for, but you may want to investigate:

- **SSI - Supplemental Security Income.**

A Federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind and disabled who have little or no income. It currently provides a maximum of \$750 per month to be used for basic needs. It is generally for people who have little or no work history.

- **SSDI - Social Security Disability Insurance.**

A Federal cash benefit that may be available if a person is disabled. It pays benefits to the individual and certain members of the individual's family if you worked long enough and paid Social Security taxes.

- **Medicare** - A Federal health insurance program for people 65 years of age or older. Individuals receiving SSDI will be automatically enrolled two years after receiving SSDI payments. Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.

- **Medicaid** - This program provides medical assistance for certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories.

Medicaid program requirements are established by each state. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops and other programs.

It's important to evaluate your loved one's entire picture and take a few more things into consideration:

- Although you may be caring for a child at this time, what do you see for him/her in the future?
- In the case of planning for a child with special needs, does your existing health insurance remain in effect when your child turns 21 and is no longer a full time student?
- What assets are presently in his/her name?
- Is there a possibility of the child inheriting any money or assets?

Once you've answered these questions, you can then look at what benefits he/she may be eligible to receive and how to best position his/her assets and income.

Often parents/caregivers ask, is there a way I can leave an inheritance to my child or loved one with disabilities without negatively impacting their benefits? Yes. An individual may set

up a Special Needs Trust that will permit this. The following are the most common types of Special Needs Trusts:

Discretionary Supplemental Needs Trust or 15.1

- A trust that can hold cash, personal property, or real property, or can be the beneficiary of life insurance proceeds. Simply stated, other people's money or property that they chose to contribute or leave to the child with disabilities.

Discretionary Supplemental Care Trust or d(4)A

- A trust that can hold cash, personal property or real property that is owned by the child with disabilities. This can only be set up by parents, grandparents, legal guardians or the court.

******When thinking about trusts, it is imperative that you speak with an attorney who has extensive experience and knowledge in Special Needs Trusts. ******

Preparing for your loved one's future can often times be confusing. The important thing is to be patient and do your homework so that you are better prepared for the future.

There will be a webinar in the fall to help parents understand this topic. Check the Foundations website to find out more.



Inside Look : The Korbe Family

Quinton enjoying a family vacation.

Twenty-two-year-old Quinton Korbe is the youngest of five children. He was born on March 5, 1997 with typical physical features of individuals with CdLS. He had five heart problems, feeding difficulties and was documented as “failure to thrive”. When he was born, his parents were told Quinton probably had CdLS, and it was later confirmed by Dr. Laird Jackson and Dr. Sechin Cho.

Quinton has severe developmental and cognitive delays. He is incontinent, has severe hearing loss, cannot feed himself and is non-verbal. Quinton had his cleft palate repaired at age three and a feeding tube put in at age six. He has had 15 surgeries ranging from many dental surgeries, hydroceles, throat dilatations, Tympanostomy (ear) tubes, etc.

Having severe cognitive delays Quinton is living life the best he can. At times, he hurts himself when he is in pain. Quinton needs total care. He has a very hard time getting settled and does not sleep well.

Simone, Quinton’s mother, thinks the most important tool the family has

used is faith. They have seen miracle after miracle with Quinton. They have learned patience, try to keep a positive attitude and take it one day at a time. Family and friends have also been an important tool going through life with Quinton. Simone believes that one must ask for help when it is needed and if there is a question, ask the CdLS Foundation and always bring up concerns to their doctor.

Transitioning Quinton has been easy; he was homeschooled and still lives with his parents. They are trying to obtain a limited license in the state of Kansas to be paid providers for Quinton, as this would allow them the funding to hire caregivers, help with additional daily costs and ensure that his care and quality of life remain as high when they are deceased.

Quinton is socialized through outside activities and family vacations. They travel in their motor home during vacations since Quinton has a hard time adjusting to staying in a hotel. He also went through puberty late. Suddenly, he got hair on his legs and began sweating more, which caused a shift in what type of clothing he was wearing.

The major hindrance to Quinton’s transition was his constant dental issues with surgeries for the past 10 years. He would bite his wrist, bang his head on walls or run around in severe pain, at the age of 20, almost all his teeth were removed. It was very painful, but it has made things better. Another issue was a lack of consistency in his schedule. His parents didn’t know how long he would be with them, so a steady routine wasn’t established. He is quite persistent with letting others know exactly what he wants and when he wants it. Aside from his struggles, Quinton is a happy and very healthy small adult.

When Simone was asked what she wanted the public to know about Quinton, she responded, “Please don’t ignore or turn away from Quinton. At least look at him and smile...accept Quinton and others with differences. Be patient with individuals with CdLS because it is a tough syndrome and always think of how difficult it IS to THEM.”

Natalie playing
with her dolls.

A Better Day Tomorrow

By: Jane Leonard-Hathaway

As the 25th anniversary of the death of my daughter, Natalie, approached this past November, my eldest daughter Katie suggested that I write about the ever-changing look of my grief and what, if anything, I would have done differently.

My first experience with grief was as a child right after the death of my Grandfather. During a family visit I overheard my Grandmother crying over the fact that no one cared enough to take her anywhere and that she was always alone. My mother objected by reminding Grandma that people did offer to get her out of the house, but that she never wanted to leave. I understood that my Grandma was sad, which made me sad, and as a young child I came to the conclusion that when people are really sad they

just do not make any sense. The incident eventually faded from my memory, and the grief that I felt for my Grandmother's sake loosened its grip.

Our fifth child, Natalie, was born in June of 1988. At 12 days old Natalie was diagnosed with CdLS and we were advised to prepare for her death due to "failure to thrive." My husband and I were devastated and the thought of losing our child completely overshadowed the CdLS diagnosis. I found it impossible to make sense of a grief that came before the loss had occurred. Over the course of the next four weeks all I could do was hold my daughter, feed my daughter, and all she could do was sleep. At the end of that month Natalie began to gain weight, wake more often and respond to her surroundings. The crisis had

passed and the sorrow of almost losing my daughter faded from my memory and the grief that I felt loosened its grip. Natalie continued to thrive, but her petite, doll-like features took some people by surprise. She never learned to walk independently, so it became the norm for all of us to carry her and that created a bond that was both physical and spiritual. Over the next five years Natalie grew and reached the size of a two-year-old and the maturity of a one-year-old. As an infant she received home-based therapies and eventually preschool services. The help that we received, plus the support and information from the CdLS newsletter, *Reaching Out*, was amazing. Life was good and life made sense.

That sense was shattered on November 8, 1993, when Natalie unexpectedly

died of flu-like symptoms. I found myself and my family entering a realm that was frightening and impossible to navigate. My grief morphed into many faces, and sometimes so rapidly that at times it was difficult to breathe. Weeks after Natalie died, I found myself standing in a checkout line, fighting back tears and the urge to shout to everyone in the store to stop what they were doing, and by a show of hands declare themselves if they had ever lost a child. I needed to know that I was not alone. I did not yell in public that day, instead, I gripped the shopping cart until the agonizing moment passed, and my grief became quiet. It was like drowning. Many people imagine a drowning victim as flailing their arms and calling for help, but it often times is a very quiet event, which is why someone can drown in a crowded pool surrounded by people who are completely unaware. During that time, none of the adults in my life, seemed aware of my anguish and turmoil, and if they were, they never spoke of it. My husband and I seemed incapable of sharing our grief with each other. We only knew that we were both in a tremendous amount of pain because each of us understood how much we had loved Natalie.

I knew how much my children loved Natalie and how much they had to be hurting, but beyond the everyday routine of nurturing them, I know I failed to help them with their own grief. There was a stillness that descended on our family that was frequently interrupted by our 2-year-old daughter, Olivia, asking for her sister. I would console her until she fell asleep in my arms. Grief spares no one. It was piercing moments like that when I felt my sorrow becoming irrational. My grief became frantic and I was desperate to calm myself. Winter had come which only contributed to new feelings of isolation. Evenings were the most difficult time for me. After the dishes were cleaned, children bathed and homework done, we would gather in the living room. It was then that I found myself counting the heads of my children and willing the number to be seven, but it was always six. It finally drove me out of the house, and I fled into the darkness of night.

I quickly came to discover a peace outdoors, even in the brutal cold. I could cry in solitude, free of the worry that I felt when my children saw me cry. I could walk for miles and it was enough to help me sleep. When that was no longer enough of a challenge, I began running. In no time I was averaging nine miles every other night. For the next decade I relied on running as a coping mechanism. I can honestly say that those runs saved my life. They

were a tremendous help, but over the years I have come to recognize that what would have been an even greater help was grief counseling. At the time of Natalie's death, I had never heard of grief counseling. I have to assume that no one in my family or circle of friends had heard of it either, because it was never mentioned. I do believe that it would have helped my whole family, especially our children, who not only had to cope with their own sorrow, but who were also attempting to process my sorrow. I wanted to remain composed in front of my children, it just was not always possible, and one episode stands out in my memory and probably in their memories as well. It all started in the kitchen.

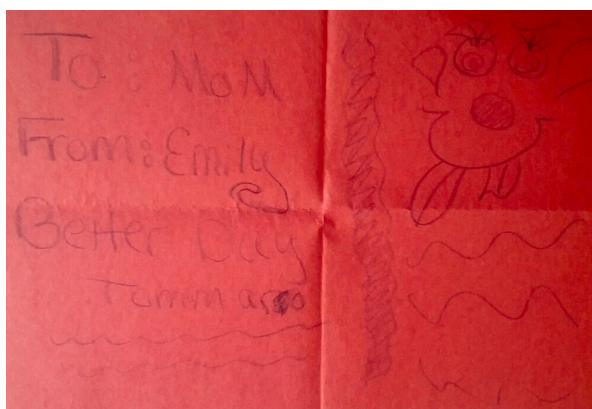
Natalie enjoyed being in the kitchen whenever I was cooking. She could crawl and she knew her way around the first floor of our house. Natalie would pull herself up and hold onto the counter with her fingertips and keep me company while I prepared meals. She enjoyed food and I was in the habit of letting her taste everything that I made. Her absence in the kitchen was very difficult for me, but one night, without warning, I found it to be unbearable.

The simple task of making sloppy joes became overwhelming, and I flung the frying pan across the kitchen, sending meat and sauce everywhere. I ran, wailing, to my bedroom, leaving the children to fend for themselves that night. My eldest daughter, Katie, who was only 12 years old, cleaned up the mess and helped her siblings find something to eat. The next day our eight year old daughter, Emily, came to me with a message that she had drawn on a large sheet of construction

paper. In her 3rd grade hand she had written BETTER DAY TOMORROW along with a smiley face. I clung to that hopeful message, and I still have that drawing.

That picture, along with mementos and keepsakes from all my children sits in a large treasure chest in the living room. I have three granddaughters whose middle names are in honor of their Aunt Natalie. Several of my children have been involved in fundraising and awareness efforts for the Foundation. My eldest daughter currently serves on the Board of Directors. I have wept at the love my children will always feel for their sister. I have wept remembering the profound grief we all endured after her death, but mercifully, profound grief is temporary, and eventually, it will loosen its grip. There came a time when I realized that I could awaken in the morning, feeling calm, and that I was no longer being tormented by irrational thoughts, fear, and frenetic activity.

Continued on page 13





HIGHLIGHTED Events

Fueled by the momentum of the start of the event fundraising season, the CdLS Foundation celebrated record-setting fundraising and milestone events.

The fall event season kicked off with 17 Team CdLS Bank of America Chicago Marathon runners toeing the line. The charity partner program goal was to raise \$30,000. The team crushed it with a record-breaking \$104,000! This is the highest amount a single event has raised for the Foundation.

In St. Louis, golfers and volunteers celebrated the 30th Anniversary CdLS Foundation Charity Golf Tournament. This fundraiser was created by Board Member, Jim Kesting, to honor his friends', Doug and Barbara, daughter, Amber. It has transpired into an event that raised nearly \$700,000 since its inception to support the programs and services provided by the CdLS Foundation.

Over 55 runners and walkers participated in the Baltimore Running Festival and raised over \$16,000! The extraordinary attendance and fundraising was largely led by the dedication of Dr. Tonie Kline, Tasha H., Sarah B. and Rachel T.

Team CdLS events wrapped up in November at the New York City Marathon. The dynamic team represented returning team member Anna S. who runs in honor of her

twin sister, Jessica; first time marathon runner, Katie G. who was honoring sister, Emma. Tabitha M. was honoring friend, Luke L. and the Team CdLS running coach and dad of Mikayla N., Marc.

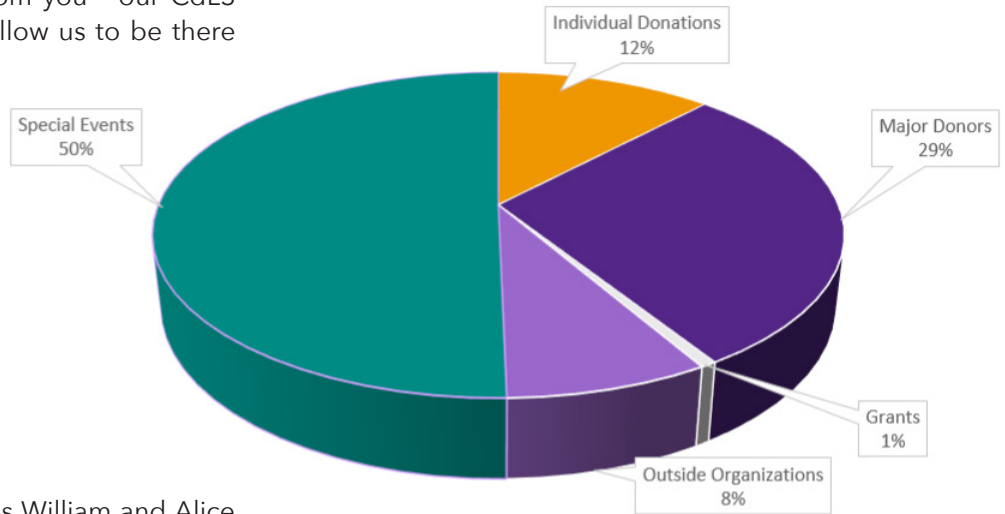
Team CdLS not only broke a fundraising record in one event, but also broke the record for the number of participants in a year with 120 runners.

Throughout the fall and winter season, several events were hosted by members of the CdLS community including Brew and BBQ in Georgia hosted by Fran Rissland; Walk for Will and Hope in Michigan hosted by the Kurth Family; One Love, One Heart in Georgia hosted by the Pomfret Family; and an annual wine tasting in New Jersey hosted by Connie Kelly and the Carr Family.

The remarkable achievement for the 2018 events and fundraising season is a testament to the dedication of volunteers and supporters who are ensuring that individuals with CdLS, their families and support systems have the resources needed to make informed medical, educational and therapeutic decisions.

FOUNDATION FUNDING IN 2018

There were many ways the Foundation was funded in 2018. However the largest support came from you - our CdLS Community. Your contributions truly allow us to be there for you.



GRANT FUNDING UPDATE

We received \$7,800 from the generous William and Alice Mortensen Foundation to support the printing of Reaching Out during 2019. THANK YOU!

The Rotary Club of Avon-Canton kindly funded \$800 to professionally translate and print eight educational articles, which will be distributed to our Spanish speaking families and made available on our website.

CALENDAR

May 18

Northeast Region
Family Gathering
Maplewood, NJ

May 20

New England Charity
Golf Tournament
Ipswich, MA

August 17

Missouri Family
Gathering
Rocky Mount, MO

October 13

2019 Bank of America
Chicago Marathon
Chicago, IL

October 19

2019 Baltimore
Running Festival
Baltimore, MD

November 2

Multidisciplinary Clinic
for Adolescents and
Adults
Baltimore, MD

November 3

TCS New York City
Marathon
New York, NY



Jordan proudly showing off her new diploma.

Jordan Fischer

My name is Jordan Fischer. I am 21 years old and was diagnosed with CdLS when I was born.

I live in Long Island in New York State. I am writing so you can see how I am doing. My big news is that I got my diploma from high school on June 24, 2018.

I liked high school, but I like my life now better. I am lucky because I work two great jobs. During the week I assist in the billing department of a radiology business. I have a mentor named Patti. She is really nice. My favorite part is seeing my coworkers, but sometimes I don't like doing the same thing over and over.

I also work on Saturdays at a burger place where I clean tables and deliver food to tables. I have worked there for two years and I know all the rules and always complete my work assignments.

I have an awesome group of friends. Some of them I've known since preschool, but some of them I met this past

year at a social group. When we can't hang out we text each other. We are always there for each other.

I keep busy. I go to the gym in my town to make sure I stay strong and in shape. On Wednesdays I volunteer at the local animal shelter. I clean the cages and help feed the cats.

I worked very hard to graduate high school and learn my jobs. Even if something takes longer I can still learn it. I think it is important that everyone tries to reach their goals.

WELCOME

New Families



THE BRUNDAGE FAMILY

Melany and David are first time parents to Liam who is currently 6 months old and was born with the *SMC3* gene mutation. Liam is a very happy boy who loves going for walks in his stroller and putting everything he can into his mouth. Melany is currently on extended leave at her job as a teacher due to Liam's medical issues, and David is an entrepreneur.



THE HENDRICKS FAMILY

My son, Tristan (3 yrs old), my daughter, Olivia (3 mos old) and I have CdLS with the *SMC3* gene. We may be one of the first families to pass the *SMC3* gene from parent to child. We discovered that my son and I had the gene in December 2017. I was unaware my whole life that I had CdLS.

Alabama

Brianne and son Zedekiah, born September 16, 2018

California

Betty and son Julio, born June 5, 1996

Tiffany and Michael and daughter Olivia, born November 8, 2018

Melany and David and son Liam, born August 22, 2018

Colorado

Amber and Nathan and daughter Laney, born April 24, 2014

Katrina and son Hezekiah, born November 19, 2015

Florida

Christina and Alex and son Liam, born September 14, 2017

Indiana

Deanne and Paul and son Levi, born June 26, 2017

Kansas

Ryan and Scottee and son Benjamin, born March 21, 2018

Maine

Regina and son Quinn, born June 18, 2010

Minnesota

Angie and Joe and daughter Claire, born November 2, 2016

Mississippi

Lauren and James and daughter Emory, born February 9, 2017

Jhamesha and Gavin and daughter Gia, born July 14 2018

Nevada

Katie and AJ and daughter Riley, born September 3, 2018

New Hampshire

Katie and Batiste and daughter Éveline, born October 26, 2018

Ohio

Jamie and son Bransen, born July 7, 2016

Oklahoma

Karli and Joe and son Colvin, born July 5, 2016

Pennsylvania

Sheralynn and son Michael, born October 24, 2009

Tennessee

Lakisha and daughter Keely Harper, born July 22, 2003

Texas

Meredith and daughter Emrie, born August 5, 2017

Joyce and daughter Jenelle, born August 21, 2018

Christy and Andrew and daughter Kylee, born November 4, 2016

Liz and daughter Morgan, born November 27, 2016

Kiley and Dusty and daughter Macy, born November 21, 2011

Virginia

Tyesh and daughter Aaliyah, born February 21, 2005

Wisconsin

Kelly and Gary and daughter Veda, born January 31, 2018



Whitman on his recumbent bike before a joy ride.

On the Cover

Whitman is 23 years old and an avid New England sports fan. He lives with his parents and younger sister. Whitman attends a day program for community-based services and supported employment - he's diligent at his tasks and a hard worker.

In his spare time, he loves the freedom his bicycle offers and rides his loop through the neighborhood making all his social stops along the way. Whitman rides both a mountain and recumbent bike. He loves playing basketball with his buddies, he has played on the same unified Special Olympics team for the past 10 years. He enjoys riding around on his ATV in Maine. Whitman is manipulating the technology of his iPad to work for him from the years spent on various augmentative devices.

Since Conference last June, Whitman has maintained contact with folks he met. He enjoys Facetiming with a young man from across the country so they can watch the same basketball game; he also will send a few text messages and 'like' different things on Facebook.

"We thank Conference for making the contact and technology for maintaining the connection for our non-verbal young man!! We really are one big CdLS family."

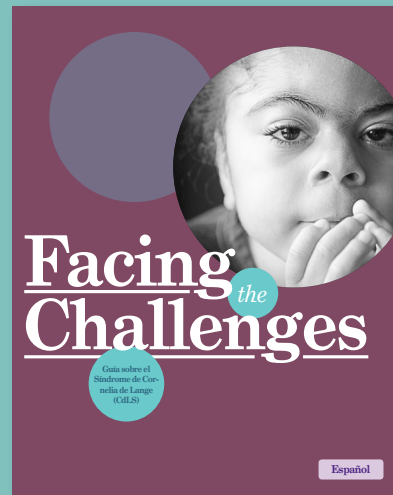


Better Day Tomorrow continued...

Perhaps it was a calm that was born from sheer fatigue, because profound grief is exhausting. Whatever the cause, I welcomed it. The sensation of drowning was over and I felt myself slowly emerging from a grief that was lonely.

I did not choose to remain alone in my sorrow. I simply did not know to whom I could turn for help. As universal as grief is to the human condition, it is also unique and intimate to each individual. There are people who understand this and respond to the call of helping others during times of profound loss. At the time of Natalie's death, if I had it to do again, I would have entrusted my grief to a professional counselor. I would encourage any parent who has lost a child to seek professional services, whether it be counseling, support groups, or family services from the CdLS Foundation.

Losing a child is the most devastating passage parents will experience in their lifetime, but we do not have to endure it alone. We can support, love, and learn from one another, and eventually, tomorrow will be a better day.



Facing The Challenges in Spanish

Facing the Challenges translated in Spanish is available by request! Families within the United States can contact familyservice@CdLSusa.org to request their copy of the newly translated publication.

Families living outside the United States can contact familyservice@CdLSusa.org to request their digital copy of the newly translated publication. Please provide your updated contact information when submitting your request by email.

SELF-CARE TIPS

Being the parent of a child with a disability carries with it unique responsibilities. It requires an extra dose of emotional resilience, perseverance and resourcefulness. Invisible obstacles can be all the more agonizing when they are unacknowledged. The Global Partnership for Education notes, "children with disabilities remain the most excluded group [when it comes to educational opportunities], discriminated not only because of their disability but also because of lack of understanding and knowledge about its causes, implications, and stigma." More and more parents are becoming burnt out. It is so important to keep yourself healthy as well as keeping your child healthy. Self-care is becoming a priority in many peoples lives.

Here are some key ways for you to make it important in your life:

Get support

Spend time with friends and family

Seek and take advantage of respite care services

Meditate

Eat healthy

Get a massage or go to a spa

Get enough exercise

Say no to extra responsibilities

Give yourself quiet time

Put the devices down

Spend time outdoors

Tips from www.scanva.org and www.goodtherapy.org

Easterseals offers respite services that allow both caregivers and individuals with CdLS to relax and recharge. Their respite services are offered nationwide and designed to give caregivers a much needed break from the stress of caregiving. Visit their website to find services in your area: www.easterseals.com/explore-resources/for-caregivers/respite-care.html

IEP PROCESS

The formation of an individualized program involves six steps:

Pre-referral: Prior to developing an IEP, the school will implement various interventions depending on the kind of problem a child is exhibiting.

Referral: Parents or school professional(s) may request an evaluation to determine if a child has a disability. Parents must consent to an evaluation. This evaluation must be completed within a reasonable time after consent is provided.

Identification and Eligibility: A group of qualified professionals and the parents look at the child's evaluation results. Together they decide if the child has a disability as defined by IDEA. If parents disagree with the evaluation, they have the right to take their child for an Independent Educational Evaluation (IEE) and ask the school to pay for it.

Development of an IEP: The IEP team gathers to talk about the child's needs and write the IEP. Parents and the student (when appropriate) are part of the team. If a different group decides the child's placement, the parents must be part of that group as well.

Implementation of the IEP: The school makes sure that the child's IEP is being carried out as written. Parents are given a copy of the IEP. Each of the child's teachers and service providers has access to the IEP and knows his/her specific responsibilities for carrying it out.

Reviews and reevaluation: The child's IEP is reviewed by the IEP team annually, or more often if the parents or school asks for a review. If necessary, the IEP is revised.

The CdLS Foundation's Professional Development Committee can review your child's IEP free of charge. Please contact Family Services at 800.753.2357 or familyservice@CdLSusa.org for more information.

Our Deepest Sympathy

Justin Michael Roesler

December 16, 1993 – February 15, 2018
Son of Janette and Michael Roesler
123 Pine Hollow Lane
Huntsville, TX 77320

Jimmy Goodbreak

July 3, 2003 – May 16, 2018
Son of Trish Earl
1209 Lincoln St.
Eldorado, IL 62930

Roland “Rodie” Owen

February 2, 1974 – October 29, 2018
Son of Melissa and Roland Owen
14080 Gregg Neck Rd
Galena, MD 21635

Mia Mannino

August 10, 1989 – December 26, 2018
Daughter of Pauline and Tanino Mannino
36421 Payne St
Clinton Township, MI 48035

Molly Wagner

April 12, 1988 – February 22, 2019
Daughter of Kathryn and Peter Wagner
335 Clay Hill Rd
Cape Neddick, ME 03902

“Cherish the good memories of your child and remember: hold on to hope, rest when you’re weary, take time to grieve, and let your heart mend.”

–Excerpt from *“When Angels Take Flight: the Loss of a Loved One with Cornelia de Lange Syndrome”*

If you would like to speak with Foundation staff or connect with other families who have lost a child with CdLS, please call 800.753.2357.



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