

Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc.  First Quarter 2018

Highlights

Director's Message:

In 2018, help us Build
Bridges Together

Spotlights:

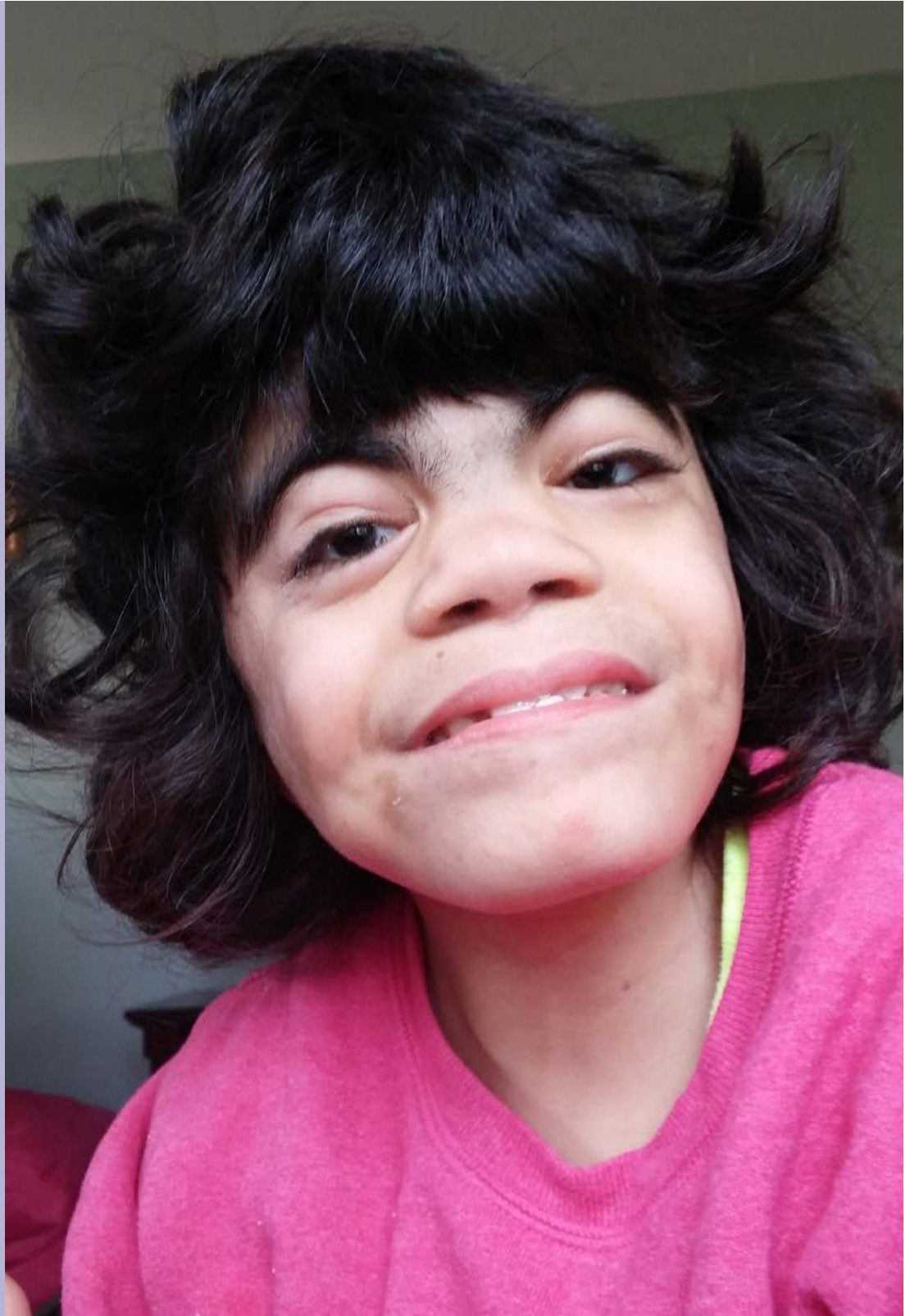
Children with CdLS Inspire
a Woman's Fate in Genetics

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Director's Message



In 2018, help us Build Bridges Together!

I can hardly believe I have my first year as your Executive Director under my belt. I would like to thank everyone from the staff, the board, and our families for their generous support. As I take stock of the last twelve months, I am proud of how far we advanced together. The beginning of a new year is also a natural time to reflect and decide how to advance boldly forward.

The New Year stands before us, like a chapter in a book, waiting to be written. We can help write that story by setting goals. At the Foundation, our goal is to Build Bridges Together – the theme of our National Family conference in 2018. Here are just a few ways we are doing this:

- We are developing even stronger partnerships with the medical community, creating new multidisciplinary clinics and awarding grants to researchers who are discovering important new insights into CdLS every year.
- The Foundation is redesigning our website so it will be easier to navigate and give everyone who comes to our site a more rewarding experience.
- To dramatically raise awareness about CdLS, we aim to partner with the Public Broadcasting System (PBS) to produce a short video that will be broadcasted to the network's 500 media markets nationwide.

We also invite you to help us make 2018 the best ever for the CdLS community. We hope you are planning to attend the National Family Conference in Minneapolis on June 28 - July 1. Over 500 individuals, families, friends, volunteers, and professionals will gather to share stories, information, advances in medical treatment – and lots of support and caring.

To build these bridges, however, we need your help. If your employer would consider becoming a corporate sponsor or making a corporate donation, we can make Conference more affordable for all families who want to attend. You can help us meet these goal by connecting us with a contact at your company who may be willing to help.

Most of all, I look forward to hearing from you in the year ahead. Your ideas, thoughts and insights are so important and we are always here to listen, learn and support.

So let's Build Bridges – Together!

Bonnie Royster
Executive Director

Our Mission

The Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS, and others with similar characteristics, make informed decisions throughout their lives.

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Why Our National Family Conference is a Great Experience!



As you know, our National CdLS Foundation Conference will be June 28 – July 1 in Minneapolis, Minnesota! This is the Foundation's signature event, that happens every two years. Families who have attended appreciate how much they get out of going and also the efforts the Foundation makes to host it. I hope you consider going!

Families attend from all over the U.S. Each family will get to meet other families from their region, as well as other families with similarly aged children. Each member of your family (mother, father, grandparent, sibling) also will get to interact with similar members of other families. Everyone will be able to choose to attend presentations on clinical, social, and research aspects of CdLS, as well as practical workshops addressing specific issues. Siblings have the opportunity to attend supervised outings with other children.

One of the great benefits of attending Conference is that you and your child can meet with two or more professionals from our Clinical Advisory Board (CAB) and Professional Development Committee (PDC) for a one-on-one interaction. These experts range from medical professionals (physicians, counselors, therapists, etc.) to educational experts (school, early intervention, etc.) and even researchers. This is a consultation in which your child's history will be reviewed and specific recommendations will be made. The consultation can be extremely productive, generating recommendations for your physicians, therapists and care providers at home. **It is helpful to ask all of your child's care providers ahead of time if they would like any specific queries addressed.**

There is also a scientific and educational symposium held the two days before the family conference, to review and share current and new information related to Cornelia de Lange Syndrome and the science behind it. Some families invite their own professionals to attend the symposium, particularly those who are local. Some even request to shadow our "regular" professionals during the one-on-one interactions, to learn more about the complex world of CdLS; some even become so inspired, they become part of the CAB.

The Foundation, in its usual remarkable way, plans in detail all aspects of Conference for families. This includes: how to help with fundraising prior to going; providing scholarships for first time attendees; tailoring the program for everyone with standard and new information to be shared; organizing the CAB professional consults, planning the many meals; helping the conference committee raise funds to help support the conference both ahead of time and during; and making sure everyone is safe, comfortable, socializing, sharing and not stressing! It's a truly wonderful meeting, and I highly recommend that you and your family consider attending!

Reaching Out

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Children with CdLS Inspire a Woman's Fate in Genetics



When Linda Manwaring was in middle school, she had the opportunity to volunteer with her girl scout troop at the CdLS National Family Conference. She still remembers her experience babysitting to this day: CdLS siblings brimming with love and compassion, parents whose strength was palpable, and children with CdLS whose infectious smiles illuminated the room.

This conference was ingrained in Linda's heart and mind as she grew older and chose to attend college as a biology major. She recalls writing one of her first research papers for a human genetics course on CdLS—she even included her conference photos she had preserved for years.

After graduating from college, Linda worked in a lab for many years and quickly realized she missed being with people. “I went to the University of Pittsburgh for my degree in genetic counseling. Most jobs were prenatal and I wanted a position where I got to work with families whose children had genetic conditions. I was really excited to get the job in 1996 working in St. Louis with clinics and families. I'd been at my job for 21 years in the Department of Pediatrics, and I'd worn many hats over the years. When I heard about the new CdLS clinic being organized in St. Louis, I knew I wanted to be a part of it. Part of where I am today is because of the CdLS families I met as a teenager. They helped ignite that passion. I think more than anything, I want to say thank you to these families because I wouldn't be where I am without them,” she said.

In addition to being a genetic counselor, Linda is also a proud mom of a 9 and a 6 year-old. She has their names inscribed on her open circle bracelet made by Lisa Leonard, a jewelry designer she stumbled upon; who just happens to have a child with CdLS. Truly, Linda's destiny has come full circle.

CdLS Sibling & Professional Answers your Question



Katie Nikzad-Terhune understands the gift of knowing a child with CdLS.

One of her nine siblings was a precious little girl named Natalie, who passed away in 1993 from complications due to CdLS. Even though she isn't here today, Natalie's indomitable spirit and legacy live on through Katie's dedication to raising awareness about the syndrome. Today, Katie is an assistant professor at Northern Kentucky University's Social Work Program and has been a therapist for the past 12 years. She has doctoral training in gerontology, which means she specializes in caregiving and aging issues. Katie is also a licensed clinical social worker and has extensive experience in mental health working as an individual, marriage, and family counselor.

Because of her sister, Katie has been compelled to work with families who have a loved one with CdLS. In 2016, she joined the CdLS Foundation's Board of Directors after working on the Family Service Committee. She has regularly contributed articles to *Reaching Out*, has given two presentations at the 2016 National Family Conference and starting in 2018, she will become Secretary for the Board of Directors at the CdLS Foundation. Beginning in February 2018, she will fulfill one of “her life's dreams”—helping others in the CdLS community through her new role as a family support resource.

“I want people to know that they are not alone and there doesn't need to be shame or guilt in acknowledging their struggles. It's more common than they realize and we, as a foundation, will provide that safety and support regardless of what the issues are,” she said. Above all else, Katie wants the CdLS community to feel safe asking her anything.

She invites families and loved ones to submit their questions related to family issues, caregiving, and emotional and mental health through the “Ask an Expert” form on the CdLS website, <http://asktheexpert.cdlsusa.org/>.



How to Travel with Less Stress: Parents Share their Tips



As we gear up for Family Conference 2018, many of us will face the inevitable question: how can we prepare more and stress less when it comes to traveling with our loved ones with CdLS?

One way to ease the worry is by tapping into the personal travel stories of two families in the CdLS community.

Jennifer Jo. and her crew are true “travel warriors.”

Last year, she and her husband drove from Florida to Tennessee and back again during Hurricane Irma. In the car were Grace, who has CdLS, her three siblings, and their 90-pound dog. Tips to hold onto their sanity included: lots of stopping, changing Grace in the car, and driving at night so all the kids would be asleep.

“It’s not a walk in the park, but traveling with kids never is,” Jennifer noted.

On a recent flight to Baltimore, she not only spent two weeks pre-planning for the trip, but she also made sure Grace’s nurse was available to accompany them on the plane.

“I couldn’t ask for anyone better to take care of Grace,” Jennifer said. “Elizabeth used blankets and pillows to prop Grace up in the seat and that’s what we were tag-teaming constantly, not letting her sit in one spot too long.”

Since Grace needs several medical items each day such as feeding tubes, diapers, formula, and medications Jennifer also made certain they were easily accessible.

How to Prepare for Behavioral Issues

Another CdLS travel champion is Vanessa S., stay-at-home mom to 12 year-old Isaac, 9 year-old Elijah, and 7 year-old Naomi. She has learned some important lessons when it comes to traveling with Isaac, who has CdLS.

“Isaac is not medically fragile, but his big issues are behavioral, a lot of aggression, self-injury, so for us when it comes to traveling, we have found there’s so little you have control over. But one thing we can control is our time to leave. We always fly out in the morning and make sure it’s a nonstop flight,” Vanessa noted.

Another tip she lives by when it comes to travel: always coordinate Isaac’s medication schedule so they are “at their highest peak of working” during the trip.

She feels “blessed” because Isaac is a child who loves flying and watching planes.

“We try to get to the airport with plenty of time and we let him walk around and be busy, which wears him out for the flight,” she said, with a smile.

A Special Needs Pre-Flight checklist:

Best time of day to travel

- Timing can be very important. Try and book flights when your child is generally the most relaxed and able to handle a change in routine.

Choose your airline wisely

- When flying in the U.S. all airlines are bound by the Nondiscrimination on the Basis of Disability in Air Travel law. However some airlines do better than others when it comes to accommodating individuals with special needs. Visit the link below for more information.

What seat is best for your child?

- It may seem trivial but this could be a game changer. Aisles may not be ideal if your child is active. They may be bumped by beverage carts or constantly brushed against by passerby. On the other hand, window seats may have a claustrophobic feel. You know your child best.

For the full list visit: www.friendshipcircle.org/blog/2012/01/09/a-special-needs-pre-flight-checklist/



Ready, Set, Go!



The 2018 CdLS National Family Conference is Just Months Away

The Biennial National Family Conference is all set for June 28-July 1. We hope you're ready to register and attend this life-changing event.

Every two years, the CdLS Foundation holds its National Family Conference. This unique 4-day event draws over 500 people and provides education and support to individuals with CdLS and their families. Attendees receive free head-to-toe consultations from experts in multiple medical and educational specialties, and can choose from a wide range of workshops designed with their needs in mind.

Above all, the National Family Conference is a place where families — moms, dads, grandparents, siblings — can experience acceptance, support, and connection. Often, first-time families to Conference have never met, in person, another family whose child has CdLS. For others, it's a time for families to reconnect with longtime friends and share stories, insights, encouragement, and hugs.

The theme for this year's Conference – Building Bridges Together – celebrates the invaluable connections and partnerships we build that create better lives for individuals with CdLS and their families. In this spirit of connection, we've made some exciting enhancements to the 2018 Conference that promise to make this event the best yet.

New Technology Will Streamline Registration

When you're registering for Conference, expect the process to be easier and more worry-free than ever. This year, the Foundation will be using Cvent, the latest technology and support system for conferences. Attendees will receive registration packets online, making it easy to store and find information (on a computer/smart phone/tablet, etc.) whenever they need it. Above all, this easy-to-use system will create a world-class experience for our attendees, before and during the Conference including:

- Mobile App that allows families to receive real-time changes as they occur during conference, connect with other registered families, and have access to information about speakers, presentations, etc.
- Medical Consults can be scheduled and updated via your smart phone or other device along with the ability to receive alerts when your appointment is near or gets delayed.
- Streamlined Conference Check-in Process that should make this process easier and less time-consuming!

Register Now Through May 25

Registration launched on February 15, and you can now register online through our website. While registration is open until May 25, the Conference can accommodate up to 150 families and once that number is met, registration is closed.

Early bird registration and the scholarship request deadline is March 29. Scholarships for first-time attending families are offered on a first come, first served basis to U.S. residents only.

Registration Fees	before 3/29	after 3/29
Adult (18+)	\$350	\$390
Person providing childcare	\$230	\$260
Children 3-17	\$180	\$205
Children 2 and under	no charge	no charge
Person with CdLS	no charge	no charge
One-day professional	\$110	\$110
Banquet guest (adult)	\$55	\$55
Banquet guest (3-17)	\$35	\$35

The registration fee covers all workshops and sessions, medical and educational consultations, and most meals. It does not cover hotel or travel expenses.

Workshops provide insight and support

This year's roster of workshops covers a far-reaching range of topics that are informative, relevant and timely. Topics include Medical and Research Update: Variations in CdLS Genes; Advocating for Your Child's Needs; and Balancing Family Life While Raising



a Child with Special Needs. Once you check in at the conference, you'll receive a complete schedule of workshops and events that will help you plan each day.

Support Conference and Your Community

Even if you can't come to conference, there are other ways to support the CdLS Foundation as we prepare for this event. The following items are needed for putting together raffle baskets and raising much-needed funds to offset the cost of this event:

- Gift cards (national brand stores, online stores: iTunes, Barnes & Noble, Amazon)
- Entertainment items (new movies, iPods, iPads, etc.)
- Baby/child toys/care items
- Spa/body care items

There are other ways to support the Foundation and other families who are attending:

- Encourage your employer to become a sponsor
- Sponsor another family who may be seeking support through scholarships
- We hope to see you at Conference this June! For more details, as well as registration links and transportation information, visit the Conference web page in our website.

When: June 28 - July 1, 2018

Where: Marriott Minneapolis City Center, Minneapolis, MN (about 30 minutes from Minneapolis-Saint Paul International Airport)

How: Attendees are responsible for booking their own rooms and hotel reservations should be booked after you register for Conference. Once you register, you'll receive a link to book your room for the reduced room rate of \$129/night plus tax.

Rooms are limited.

Missouri Golf Tournament

The 29th Annual CdLS Foundation Charity Golf Tournament took place on Oct. 9, 2017 at Tapawingo National Club in St. Louis, Missouri. The event netted \$60,418! That's a record for the long-standing event. Golfers enjoyed a course that offered rivers, lakes and hardwood forests allowing for players of all skill levels to win prizes.



Madison County Wood Product's (MCWP) team Jim Morton, Bryan Kesting and Jim Kesting along with Pallet Logistic Management's (PLM) team Cheri Colby and Steve Snodsmith hosted the event in honor of Doug Gaines' daughter, Amber, who has CdLS. Gaines is a long-time friend to Jim Kesting and is Vice President of MCWP.

"It was a beautiful day with 132 golfers participating in this event that has become a well-loved tradition here in St. Louis," said Jim.

While this year's event was a resounding "win" Jim is already looking ahead. "In 2018, we will be celebrating the 30th anniversary of the tournament, making it one of the longest running charity events in the St. Louis area," he noted.

Local families attended the event to both play and volunteer, including the parents and grandparents of Charlee Hercules, parents of Charlie K., and aunt to Illinois native, Mikayla N.

Haylee H. shared, "We are so grateful to Madison County Wood Products and Pallet Logistic Management for being active supporters of the CdLS Foundation and helping make things like the new CdLS-specific clinic at St. Louis Children's Hospital possible."



2017 Team CdLS

The 2017 Team CdLS events wrapped up late fall with participants in the Bank of America Chicago Marathon, Baltimore Running Festival, Marine Corps Marathon, and the TCS New York City Marathon. In 2017, over 85 individuals ran, biked, and got muddy to bring awareness about CdLS. They raised nearly \$185,000 in support of the Foundation's program and services.



Runners, pictured above, at the Bank of America Chicago Marathon include: Team CdLS Co-Captain, Frank Mairano; Team CdLS Running Coach Marc Needlman; and teammates Jane Champion, Cynthia Grondsma, Amy Haaland, Colleen McShane-Meyer, Billy Satti, Peter Wagner. These runners ran through 29 neighbors through the city. Members of the team represented different connections to the Foundation including Foundation founders, parents, siblings, and friends of individuals with CdLS. They traveled as close as neighboring suburbs of Chicago and as far away as both U.S. coasts and even the Netherlands! The team enjoyed a pre-race dinner, compliments of Lou Malnati's Restaurant, and supported by curb crew members throughout the course. What was called the "Small, but Mighty Team" of eight raised over \$41,000! Christina Collins participated as a phantom runner, contributing to the funds raised and "running" the Chicago Marathon from the state of Michigan.



The Baltimore Running Festival had over 20 family members and friends take on the streets of the historic Inner Harbor. The Howland, Burrell, and Votcky

families, as well as Foundation Medical Director Tonie Kline's daughter, Julia Clemens, and staff member Kristi Larson participated in the 5K on a crisp autumn morning. Friend of the Foundation, Kelly Hard, took a leap and participated in the Half Marathon. The Baltimore Running Festival's unique event gave participants a variety of events to choose from – a Kid's Fun Run, 5K, Half Marathon, Full Marathon, Relay Race Marathon and a 5K plus Half Marathon event. The team raised approximately \$10,000. Dr. Kline was unable to make the event in 2017, but participated in the Charles Street 12 and helped tremendously in the overall fundraising efforts.

Rich Flaherty has participated in numerous Team CdLS events including the Chicago and New York City Marathons. This year, he beat the heat at the Marine Corps Marathon in Washington, D.C. in support of the CdLS Foundation and his dear friends, Will Smisloff and family. As an independent runner for an event, Rich has once again showed his tremendous dedication and support in raising awareness about CdLS and the Foundation.



The season ended with a very cold and rainy day in New York City. Ten brave runners ran through the five boroughs of New York City, 26.2 miles, in what at times became torrential downpours. The team who raised over \$32,000 consisted of Tanaya's mother (Ava Frank), sisters to Sofia and Jessica (Isabel Teixeira and Anna Smith, respectively), father, sister and brother-in-law to Tyler (Stephen Nelson and Tessa and Justin Rose), friend of Logan (Corey Grever) and friends of Will Smisloff (Anmari Hanrahan and Erin O'Connor). They collectively raised over \$32,000. Katie Giberson (Emma's sister) participated as a Phantom Runner and assisted in overall fundraising efforts.

What's up for 2018? How about you tell us? Contact Kristi Larson at Klarson@CdLSusa.org and let her know about the Team CdLS event you would like to join!



2018 CALENDAR

March 14

CdLS Clinic at
Shriner's Hospital
Salt Lake City, Utah

March 18

United Airlines NYC
Half Marathon
New York, NY

April 7

Multidisciplinary Clinic
for Adolescents and
Adults
Baltimore, MD

May 6

2018 TD Five Boro
Bike Tour
New York, NY

May 21

New England
Golf Tournament
Ipswich, MA

June 2

Southwest Region
Family Gathering
Salt Lake City, Utah

June 27-28

8th National CdLS
Scientific & Educational
Symposium
Minneapolis, MN

June 28 - July 1

2018 CdLS National
Family Conference
Minneapolis, MN

October 7

2018 Bank of America
Chicago Marathon
Chicago, IL

October 8

MO Golf Tournament
Tapawingo National
Golf Course
Sunset Hills, MO

October 20

Baltimore Running
Festival
Baltimore, MD

November 4

TCS New York
City Marathon
New York, NY

WELCOME NEW FAMILIES

California

Tiffany and Michael and
son Tristan, born
February 20, 2016

Kentucky

Cierra and daughter
Maddison, born
March 7, 2014

Massachusetts

Catherine and Matt and
daughter Alexis
born 2006

Minnesota

Daniel and son Ryan,
born 2012

Annie and Scot and son
Barrett, born
July 28, 2016

Missouri

Susan and Karl and son
Joshua, born 2010

Janene and Joe and
daughter Janelle, born
July 15, 2008

Deanna and Joel and son
Leo, born 2005

New York

Heather and daughter
Ava Rose, born
October 19, 2017

New York

Maria and Peter and
daughter Hannah, born
May 17, 2016

North Carolina

Amber and daughter
Mattie, born
October 31, 2014

Nevada

Gavin and Leeanne and
daughter Olivia, born
March 3, 2012 and
son Noah, born
February 24, 2016

Texas

Staci and Adam and
daughter Naomi, born
June 15, 2011



Welcome New Foundation Board President, Pat Lyons

Pat Lyons lives in Portsmouth, New Hampshire with his wife Karen and their three children, Delaney (12), Luke (CdLS, 10) and Owen (8). Pat is a channel sales manager at Hewlett Packard Enterprises and has served as Secretary of the Board for the past year. As a passionate advocate for individuals with CdLS, Pat is excited by this new opportunity to serve the CdLS community.



Q: When was Luke diagnosed with CdLS and how did you get involved with the CdLS Foundation?

A: Luke was born full term and was a healthy 7lbs., 4oz. We didn't know or suspect anything was wrong until the nurses noticed he had trouble breathing, and his Apgar scores were low. His pediatrician immediately suspected CdLS just a few hours after his birth. (He had recognized Luke's characteristics right away because another child with CdLS was also under his care.) Then, about six weeks later, a geneticist confirmed via clinical diagnosis that Luke did indeed have CdLS, and he directed us to the CdLS Foundation. We were lucky that we knew about CdLS almost immediately and could make sure that Luke received the right medical care and early intervention services right from the start.

Q: How did finding the CdLS Foundation make a difference for your family?

A: For me, the turning point was attending a local Family Gathering when Luke was just a baby. I felt less alone knowing that there were other families who were going through the same struggles we were facing. Seeing everyone learning from each other at the family gathering was inspiring, and my wife and I later hosted one ourselves

in our area. Since then, the Foundation has been with us every step of the way. Family Services helped us connect with resources we were unaware of, guided us to medical experts, and most of all, understood our challenges, as these have changed over time.

Q: What impact has the National Family Conference had on your family?

A: The first Family Conference I attended was in Dallas in 2010, when Luke was 3 years old. Walking into the Family Conference that first day, I could feel the energy of all these people who were in the same boat. It's almost impossible to describe the experience of being with so many other families that have children with CdLS. Every elevator ride you took was with another family... We had meals together... the hotel lobby was packed with people going through the same thing we were going through. While at the National Family Conference in Florida, we were all hanging out by the pool, we shared stories and watched over each other's kids. To say the Family Conference feels like one big family sounds like a cliché, but it's true! I also learned so much from the speakers and experts who were there to help and support us through complicated issues.

Q: Did anything surprise you about attending the Family Conference?

A: When I first attended the Family Conference, I was astounded by all the friendships I made and the impact these people have had in my life over time. Above all, I left knowing there's a place for me and my family where we're always welcome, in this sometimes crazy world we live in. That's why I've been going to the Family Conference since 2010.

Q: You've been the Secretary of the CdLS Foundation. What motivated you to serve as President now?

A: We have a new Executive Director, and the Board has a great vision for growing the CdLS Foundation. Our goal is to create more awareness of CdLS, so that people who are undiagnosed, and the medical community, can be better informed of this rare syndrome. Our family was fortunate in that we received an accurate diagnosis, the right information, and support right away. But we think that there may be thousands of children who are not diagnosed properly, and we are determined to help change that.



We are also actively funding multiple research grants to understand more about the syndrome so that doctors, therapists, and teachers can develop better treatment options and educational opportunities.

And we always want people to know that the CdLS Foundation is here for them for medical, emotional and social support. The CdLS Foundation has more than 30 years of experience with individuals with CdLS and their families, and we are committed to building that awareness across our CdLS and professional community—to corporate sponsors and the general public.

Q: At the Family Conference, there is a “Dads Meet-and Greet”—What would you like to say to the other dads out there?

A: Let your guard down. Show your heart. Ask for help when you need it. Take care of yourself when you need a break. There are plenty of dads (and moms) out here to support you!

Q: What’s the best advice any parent has ever given you?

A: That’s tough, because as a parent, I get advice all the time! But my favorite is: there’s no right or wrong way to be involved. As soon as I started making connections, going to Family Conferences, planning a Family Gathering myself—it helped me cope and gave me hope that I could make it through the challenging times. I felt I had a community that understood me and my unique family.

CdLS Foundation Now Accepting Research Grant Requests

The 2018 Research Grants Program is now open. Funding is available to researchers at academic and research institutions in the U.S. Fellows and graduate students are encouraged to apply. Overhead or indirect costs are not supported by these grants. The maximum funding request per application in 2018 is \$12,500. A Letter of Intent is required by February 28, 2018. Final applications are due March 30, 2018 with funding distributed the first week of September. Grantees will present their papers at the Foundation’s Scientific and Educational Symposium in June 2020.

For more information, email director@CdLSusa.org or go to www.CdLSusa.org/research/grants.htm to review the guidelines and download the application.

CdLS Registry: Enroll Today!

There are so many questions that accompany a diagnosis of CdLS. Questions you have are probably the same as many other families across the country, and world. To get answers, medical professionals rely on information from families to guide their hypotheses and research. This is why the CdLS Foundation has established a CdLS Registry at the Coordination of Rare Diseases at Sanford (CoRDS).



CoRDS Registry
Coordination of
Rare Diseases at Sanford

You can help researchers progress forward into determining more about the causes and manifestations of CdLS. For those of you interested in participating in this registry, visit <http://bit.ly/CdLSReg> to begin the process.



Super Sibling - Zachary & Nirel



One of the first things Zachary does when he comes home from high school is scoop up his 15 year-old sister, Nirel, in his arms.

Nirel, who has CdLS, is only 18 months apart from her brother. The two siblings have a very special relationship. "Nirel doesn't really have the social interactions that children who are higher functioning do, so having a brother who has always been looking out for her has really made their relationship very special," said their mother, Gayle. "He helps take care of her, literally. He feeds her if she's hungry and sometimes he even changes her diapers. He's done everything that other brothers who don't have a sibling with special needs would never imagine having to do. Despite it all though, he has a great attitude about it. It's shaped the kind of person he is and taught him to be a better person, a very mature teenager."

"My special sister has changed my life for the better," said zachary

Zachary has become very appreciative of people with disabilities.

"They're important as people and they should be cared for by society and not taken for granted," he said, noting he regularly volunteers at races and camps to raise money for children with disabilities.

A 17 year-old junior in high school, Zachary plans to pursue science and engineering in college. No matter what field he goes into, he intends to continue volunteering his time to help children with special needs.

"Whenever I play with Nirel or simply interact with her, it puts a smile on her face and that to me is what's really important. I like to see her happy," Zachary said.

His mother added, "She gets this huge smile that takes over her entire face, to the point where her eyes are squinting, she giggles and laughs and it's contagious." Nirel's younger sister, 8 year-old Eden, agrees, "What I love most about Nirel is her smile and laugh."

One of Zachary and Nirel's favorite past times is watching crime shows together. "Nirel has actually figured out how to change the channels manually," big brother Zachary said with laugh.

On the Cover: Nirel:



Nirel is affected by complex medical and developmental issues. She weighs about 50 pounds and cannot speak or walk, so she gets around by walking on her knees. If she stands up fully, she's about 3 and a half feet tall. Like most

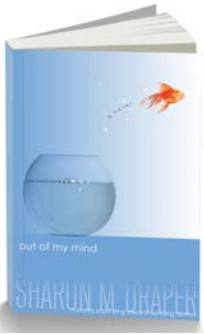
15 year-olds, she has hit puberty. Her favorite activity is looking at photos of her family, relatives, and classmates. She is a whiz with electronic devices. She loves to eat, and has a sweet tooth for cakes and cookies. Her favorite holiday is Thanksgiving because she loves to eat all the fixings.

**Share your Mailbag or
Super Sibling Story!**

Send your story and photo to
outreach@CdLSusa.org.



Mailbag –



Julie Comeaux recently read the book, *Out of My Mind*, about a child with special need. Below, she shares the positive impact it had on her life.

Dear Sharon Draper,

Your book *Out of My Mind* has made a big impact on how I view children with special needs. After reading *Out of My Mind* and the point of view of the character Melody, I realize that children with special needs face great challenges that we don't often think about because we are so wrapped up in our own lives. Children with special needs struggle every day.

I have a neighbor named Riley. He is a teenager with a genetic condition named CdLS that affects 1 in every 10,000 children. He is probably one of the sweetest boys I know. Before reading *Out of My Mind*, I just thought of him as a brother of one of my friends. I was always nice to him, but I did not ever focus much attention on his disability and struggles. But after I read your book, I realized that he may sometimes feel trapped. Riley has a talking device similar to Melody's. Although he has a device to help him talk, it does not always work. It seems to have a mind of its own. Riley really embraces his differences as if he is just a typical child. I now know that he has just as many, if not more, feelings than we do. I now think much more about Riley and consider him like my brother. I would not trade him for anybody else in the world.

I recently read your book for a third time. I found out that some of my other neighbors were going to have a baby girl. Months later, they found out that she was going to have Down Syndrome. While Down Syndrome is a different genetic disease than CdLS, I understand that she will face many more hardships as a child with special needs than I will ever face. I have not gotten to hold her or meet her face to face yet, but I know that I will. This baby is going to face hardships in her life, but I also know that she will be able to handle them.

I want to thank you for writing *Out of My Mind* because I now realize how lucky I am. Some children with special needs may never be able to learn certain life skills that

many of us will learn such as cooking. I now realize that children with special needs may sometimes feel trapped in their heads, but it doesn't mean they don't have feelings. Thank you so much for changing my view of children with special needs. I can never thank you enough for this lesson.

Regards,

Julie Comeaux

CdLS Empowerment Team

The Empowerment Team creates a setting where adults with CdLS can come together as a group to support and empower one other in their communities. The team encourages members to socialize, and develop relationships across the country through a variety of opportunities.

Interested in joining the CdLS Empowerment Team? For further information, please contact Whitney Rinaldi at familyservices@cdlsusa.org or call 800.753.2357.





3rd Party Event Highlights:

Walgreens Scannable Coupon Event in New England



During the first two weeks of October, 95 Walgreens stores throughout Massachusetts and Rhode Island encouraged customers to purchase a scannable icon in donation amounts of \$1, \$3, or \$5.

After two weeks of fundraising, over \$37,000 was raised for the CdLS Foundation.

Mike Christie, father to Taryn who has CdLS and Director of Pharmacy and Retail Operations at Walgreens, commented, “Most people have not heard of CdLS, so we knew it was important to not only raise money, but awareness of the syndrome. The folks at our stores were so proud that because of their efforts, families will get services they need, such as going to medical clinics that specialize in treating children with CdLS. The health and happiness of our community is what Walgreens is all about and we are so glad to make a difference.”

Thank you to the following individuals who were Ambassadors for the two-week long event, with their pictures and stories being featured at one of the 95 stores: Jaxon Alarie, Taryn Christie, Mason King, Luke Lyons, Amerah Sanchez, and Jack Yadisernia.

Brew and BBQ



Fran Rissland and Suzanne Musial hosted the 8th Annual Brew and BBQ at the North River Tavern in Sandy Springs, GA, raising a record breaking \$9,000! Over the past 8 years, the event has raised nearly \$40,000 for the programs and services provided by the CdLS Foundation.

More than 90 people were in attendance, many coming from as far away as Wisconsin for this very special event. The evening featured 85 silent auction items, including four Katy Perry tickets, a waterproof GoPro HERO

Session, and a Westin Hotel weekend getaway.

Fran Rissland shares her experience with coordinating the annual Brew and BBQ, “The first year is always the hardest because you have to find your way, but once you organize one, it literally goes into auto pilot thereafter. Suzanne and I used to meet to plan to the event each year, now we do it all through messages.” Rissland continues, “And at the end of the event, the sense of accomplishment is overwhelming and knowing that we are helping other families is the reason why Suzanne and I continue to coordinate this event.”

Walk for Will and Hope

Local family and friends of the Kurth Family joined together in the Shelby Township of Michigan on October 15 to celebrate the 9th Annual Walk for Will and Hope. The leisurely 2-mile walk took place at the Stony Creek Metropark, which is situated close to Romeo and Rochester Hills.

Maureen Feighan-Kurth and her husband Joel continue to be amazed by the outpouring of support from their friends, family and community. The event raised over \$4,600 in 2017; \$40,000 since its 2009 inaugural event.

The annual event is in honor of Maureen and Joel’s two children with CdLS: daughter, Hope and late son, Will.

“It really was a Walk for Will & Hope miracle,” stated Maureen, “After endless rain, the clouds parted early morning, the sun came out just a little bit and we walked to raise money for the CdLS Foundation before the rain started again. I was convinced it was going to be a wet one and it wasn’t. Maybe Will was keeping an eye out for us on his birthday. An especially big thank you to the Smith, Swanson and Collins families. Thanks all!”

Sarah’s Bowl



On November 12th the Suttman family hosted the 12th Annual Sarah’s Bowl for CdLS in the town of Batesville, the heart of southeastern Indiana.

Nearly 100 friends and family members of the Suttman family made the event the most successful one yet by raising over \$16,000! Participants at the event enjoyed a



fun day of bowling and amazing variety of silent auction prizes.

Anne shares, “I am very lucky for the support of my family and friends leading up to the event. Everyone has been volunteering for so long that we each know what we need to do in order to make the event happen.”

The day’s event concluded with recognition to teams bringing in the most donations for the CdLS Foundation.

One Love, One Heart 5K

On December 2, Jim and Jen Pomfret coordinated the 12th Annual “hottest 5K of December” in Decatur, GA. As the One Love, One Heart 5k slogan reads, “One love” and refers to the universal love and respect expressed by all people for all people. At the event, this love is directed towards those with CdLS. This includes their daughter,



Maya.

Over 70 participants and several community members and businesses helped contribute to the \$11,000 raised to benefit the CdLS Foundation. The beautiful sunny day with family, friends, and children’s laughter created a sense of community, while raising funds.

Jen says, “I would love to spend a day in Maya’s mind. We don’t know fully what goes on in the minds of many children with CdLS, although most days seem filled with joy and the capacity to share that joy with those around them. CdLS is not a disease you get over, neither the child nor the caretaker, but you learn to embrace it and have the strength and determination to persist every day. It is events like this that make your heart feel good and you just forget about it all for a little while.”

Wine, Beer and Coffee!

During the first weekend of December, Connie Kelly, owner of CK Pilates, hosted her fourth annual Wine

Tasting event in memory of her granddaughter, Layla Carr. This year, the annual wine event included handcrafted beer and home roasted coffee made by Layla’s father, Shawn.

“We are excited to present the Foundation with our most successful Wine Tasting event with raising over \$6,000,” says Connie. “It is always so wonderful to have our friends and family over for this event. The gatherings we host are a way that we can honor our sweet granddaughter, Layla, and bring awareness to the community about CdLS.”

Layla’s family has made fundraising for the CdLS Foundation a family affair by participating in different events so that they can raise funds, awareness and challenge themselves physically and mentally. Connie’s daughter designates a portion of her company’s sales to the Foundation; Connie has hosted wine events; and Shawn and Kim challenge their friends and family to an endurance event, such as Spartan Races, in the summer. Since 2014, the family has collectively raised nearly \$39,000 in memory of Layla Ann.



Guest Bartender

David Fowler, brother to Logan, was guest bartender in early December at a bar in New York City. In David’s second annual bartending event for the CdLS Foundation, he raised

approximately \$3,000 in just over 4 hours! What’s up next for David? He will be running the streets of Chicago for Team CdLS in October!

Interested in starting an event like the Brew and BBQ, being a guest bartender or coordinating a local walk, run or bowling event? Contact Susan Salina at susan@CdLSusa.org who is happy to help you start the process.



Planned Giving: Why Start Now

When Michael G. was born in 1988, parents Julie and Roy immediately became involved with the CdLS Foundation after a recommendation from their geneticist. The family attended their first CdLS National Family Conference when Michael was just six weeks old.

Their relationship with the Foundation flourished. Both served on the Board of Directors for many years, and Roy joined as President through the late 1990s. They also served as Regional Coordinators in Southern California, welcoming new families and holding events.

Michael passed away in 2006 at the age of 18. His family honored their son through revised estate planning and named the CdLS Foundation as a beneficiary of their legacy through the Circle of Caring program.

“It is a smart idea to do estate planning in general, and it allows you to think about how you want to help certain organizations in the long term,” Roy revealed. “This way, you will be able to help the organizations and leave a legacy.”

Planned giving is a growing interest for families and friends of the CdLS Foundation. There are many gifts that can honor your charitable intentions, while meeting your financial and tax planning goals. Common types include: bequest by will, living trusts, retirement plans, and more.



CIRCLE of CARING
CdLS Foundation

Participating in the Circle of Caring not only demonstrates your commitment to the mission of the CdLS Foundation, it ensures the long-term strength of the organization. Long after they are given, planned gifts positively impact the lives of children and adults with CdLS and those who care for them. The family hopes the Foundation grows and develops for years to come, and believes that their legacy contribution will help it progress.

“I trust our contribution will allow the Foundation to be able to continue the good work they are already doing, and to find even more families who may not be aware of the great help the Foundation can be,” Roy said.

Giving begins at the heart, and we are so thankful for what you have already done to further the CdLS Foundation. We kindly ask you to consider the next step to be forever-connected to our mission and explore planned giving.

Roy’s best advice? “Do it now! Don’t wait.”

Plan your future today to leave a legacy of giving for tomorrow. To learn more about planned giving options, or to let us know that the CdLS Foundation is already in your estate plans, please contact Kati at kati@CdLSusa.org. You can also view the Circle of Caring brochure online at donate.CdLSusa.org/docs/circle-of-caring-web.pdf.

Our Deepest Sympathy

Declan Presmyk

June 28, 2012-December 25, 2017

Son of Jennifer and Kevin Presmyk

26253 North 72nd DR

Peoria, AZ 85383





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Help us build a special Bridge as we honor the individuals with CdLS at our CdLS Foundation National Family Conference this summer. Inspire your loved ones to celebrate the milestones they have reached and the friendships and connections they will make at Conference—many that will span a lifetime!

All money raised supports Conference taking place on June 28-July 1 in Minneapolis, MN.

Choose from three different “brick” sizes (one name per brick, please):

Keystone \$100 (large), **Flagstone** \$60 (medium), **Paver** \$30 (small)

To purchase your brick, go to www.CdLSusa.org and look for the Bridge “button” on the homepage. Or, use the coupon inside this issue or call Bonnie Royster at 800.753.2357.