

Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc.  Third Quarter 2015

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Conference is Coming

Spotlights:

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Intervention Plan?

Ensuring Self-Care for
Parents Raising a Child
with CdLS

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CdLS?

Super Siblings

Gabe and Shira





Director's Message



Conference is Coming

Conference is just a year away. A year may seem like a long time, but in terms of putting together an event for 500 to 600 people, the clock is already ticking.

Over the next several months, our National Conference Committee and staff will work together to choose workshop topics and a conference theme; solicit speakers for the sessions and professionals to provide consults; and start planning menus, room setups and much more. We are also already seeking financial support from various sources, from large national corporations to small local business, to help offset the costs. Conference is not a fundraiser

for the Foundation—in fact, registration fees don't cover the true costs, and so finding financial support is key in being able to keep the event viable.

Just as the Foundation is seeking financial support for the event, it's not too early for families to start finding resources to offset their costs. While the Foundation does its best to make conference affordable, it recognizes the financial impact the event has on a family's income. Depending on where you are traveling from, registration fees, hotel and travel can easily run \$3,000 for a family. With 12 months to go, now is the time to start putting money away and to seek funding. To help you get the momentum going, below are some resources for conference support:

- Local town/city government social service departments
- County health and human services agencies
- Charitable foundations at your local or regional hospital(s)
- Church or religious organizations
- Community foundations in your region/ state
- Local sports team foundations
- Service organizations (VFW, Knights of Columbus, Rotary, United Way, etc.)
- State department of education
- Corporations and businesses in your community

As we get closer to conference, be on the lookout for more information and tips. We hope to see as many families as possible at the event. It's truly a highlight for staff to meet families in person.

Marie Concklin-Malloy
Executive Director

2016 National Family Conference

June 23 – 26, 2016, Orlando, FL

Doubletree Orlando at SeaWorld

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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Seeing the “Small But Mighty” in CdLS



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

Many of you may have seen the recent campaign from the CdLS Foundation: “Small But Mighty.” With a cute smiling toddler, who happens to have CdLS, being hoisted into the air with a purple cape flowing behind him, how could you miss it? It encourages us all to “be mighty,” to donate, and to help support individuals with CdLS. It’s a great message in so many ways.

Small is a usual, but not absolute, finding in individuals with CdLS: small size, small head circumference, small nose, small hands and small feet. The old adage “good things come in small packages” is perfectly descriptive of CdLS. Often their appetites are small and there are very small gains on the growth charts, yet they continue to grow on their own curve through and past puberty. Another major finding in CdLS is small, but meaningful, advancements day by day in development. Little by little, individuals with CdLS continue to learn throughout their lives, and it is all by small forward increments of progress. Small is so important from many different points of view.

But let’s not forget the big, too: big smile, big heart, big hair (usually) and big strength (of the muscular type and also in stubbornness). Which brings us to the mighty in CdLS. Truly, these children, young men and women, and adults with CdLS have a lot of the mighty in them. First of all, they are “mighty special” people. Everyone knows this! They leave a special place in any healthcare provider’s heart.

“Mighty” can also refer to strength. I have always said that of all the known syndromes, CdLS stands out in a lot of ways, and one of the clearest ways is strength. Even the tiniest babies have an extra firm grip on your finger when they grasp it. Older children are strong and wiry, can resist almost any grown-up if they have a mind to, and do not seem to get tired even while cruising all over the house all day. Adults with CdLS can be extremely persistent and stubborn, standing firm about an idea or event, which can benefit them in the long run. Finally, the parents, caregivers, relatives, grandparents and siblings who take care of the children with CdLS are mighty in so many ways and accomplish so much on behalf of, and with these children.

Thank you to all who have contributed to the “Small But Mighty” campaign. It is always so worthwhile to support the CdLS Foundation.

For information on the Small But Mighty campaign, go to cdlsusa.org/getinvolved/sbm.htm

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What is a Behavior Intervention Plan?

By Julia O'Connor, Ph.D., Co-Chair, CdLS Foundation Professional Development Committee



A Behavioral Intervention Plan (BIP) is designed for an individual child to address a behavior that is interfering with the child's learning or the learning of other students.

There is a specific, detailed process that is required to develop a BIP. First, the school team conducts a Functional Behavior Assessment (FBA). During an FBA, the team reviews the student's records, completes checklists/questionnaires, and conducts direct observations of the interfering behaviors to determine the function of the behavior. Some potential functions include: getting something (i.e., attention, reward, sensory input) or avoiding something (i.e., difficult work, anxiety, and boredom). Once the function has been determined, the Individual Education Program (IEP) Team develops a BIP.

A BIP incorporates the hypothesis about the function, the definition of the behavior, where the behavior does and does not occur, what happens before and after the behavior, and relevant information about the student (i.e., strengths, health, and medication).

The BIP includes a plan to:

- modify the environment
- teach the child to avoid the behavior "triggers" (i.e., coping skills, noise canceling headphones)
- reinforce the child for using socially acceptable behavior (i.e., toy play, appropriate communication)
- teach the child replacement behaviors
- modify the responses of the adults (i.e., extinction, redirection, blocking)

It may be possible to modify the environment by implementing preventative strategies such as: teachers

stating clear expectations, modifying seating arrangements, adapting instructional pace, avoiding long delays, providing choice, and allowing the student to take breaks.

Replacement behaviors must serve the same function as the interfering behavior and be equally as effective as the behavior. The amount of physical effort needed, the likelihood that the replacement behavior will produce the desired result, and the delay between the replacement behavior and the desired result must be equivalent or less than that of the interfering behavior. If the replacement behavior is harder to do, does not get reinforced or there is a long delay, the interfering behavior will continue because it is more effective.

Often, a replacement behavior is teaching the student to communicate. As the student begins using the replacement behaviors, school staff should create situations to practice the new skills. Staff persons need to be aware that change occurs slowly.

Because it takes time to see behavior change, it's important that the team decide what will happen when the interfering behavior still occurs. Planned consequences reinforce the replacement skills while decreasing the effectiveness of the interfering behavior. Having planned consequences teaches the student that using the replacement skills is a better way to get the desired result. In some cases, the behavior may be extreme. The team should develop a crisis plan which includes defining what constitutes a crisis, describing the intervention procedures, detailing who will be involved, identifying what resources are required, and describing procedures for documenting the use of the plan. The team also sets up a system to evaluate and modify the plan including a timeline for review as a team and with the family based on the data collected.



A Closer Look at Behavioral Plans: Zachary's Story

We want to thank Jennifer, mother to Zachary, for sharing his story with us.

At Zachary's school, I try to keep communication lines open and work together with teachers and staff, knowing that they care for my child and want to see him succeed as much as I do. I really appreciate all the support we have received.



We do not implement an ABA therapy with Zachary. In terms of an FBA or BIP, Zachary's behavioral needs are addressed throughout his IEP via his behavior goals, as well as through the supplementary aides and services that provide him with additional supports such as repeated directions, small groups environments, adult support, and positive reinforcement to help him learn.

Based on the report from our children's hospital and other reports completed by school staff, Zachary was recommended for Alternative Outcomes Curriculum, which used to be called Fundamental Life Skills. While there was a program that worked on these objectives, it was recommended that he receive the services at his homeschool, due to the hardships involved in bussing him in from so far away.

Some of the recommendations for behavior issues, and some of the things I do at home include:

- Use clear, one-step instructions
- Break down tasks into smaller steps
- Focus on positive reinforcement for positive behaviors

- Ignore disruptive behaviors as much as possible
- Implement a consistent time-out procedure for significantly disruptive behaviors that cannot be ignored
- Focus on providing Zachary with multiple ways of asking for help

Zachary has mild-moderate bilateral hearing loss, so we decided to finally get hearing aids since he is a little more mature now. It was tough at the beginning, just like any other changes for him, but it has been seven months now and he does not complain as much. Zachary loves music. He is a very friendly child who enjoys interacting with school staff and his peers.

I am very happy with the progress he has made this year in writing, reading, and math given direct adult support. He enjoys talking on the phone using "FaceTime" with our family members. He likes to use computers and he uses a tablet that helps him with reading, math and instructional games. He has tried various sports, including soccer, basketball and swimming, but he enjoys riding his bike the most.

I am thankful every single day for being able to raise such a precious miracle. I enjoy every, little advancement he makes and celebrate each milestone. Of course, things are not always easy with him and the support I receive from my family has really made the difference.

Glossary

ABA: Applied Behavior Analysis - The process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree.

FBA: Functional Behavioral Assessment - A problem-solving process for addressing student problem behavior.

BIP: Behavior Intervention Plan - Takes the observations made in a Functional Behavioral Assessment and turns them into a concrete plan of action for managing a student's behavior.

IEP: Individual Education Plan - A document listing, in part, the special educational services that the child will receive. It is developed by a team, including the child's parents and school staff.



Ensuring Self-Care for Parents Raising a Child with CdLS



*Katherina Nikzad-Terhune, Ph.D.,
LCSW, Therapist, Beaumont
Behavioral Health; Affiliate
Faculty University of Kentucky;
CdLS Foundation Family Service
Committee*

Raising a child with special needs produces many joys and challenges for parents, and is often considered one of the most difficult roles one will ever maintain. Even with the most intense demands, parents must learn how to care for themselves as they simultaneously care for their child.

Self-care is an intentional action one takes to ensure physical, mental and emotional health. Quality self-care is often a challenge for parents of children with special needs, albeit advantageous and necessary. Below are useful strategies to ensure quality parental self-care.

Acknowledge Your Grief: Disability is not something we anticipate when having children, and when we are confronted with this reality, negative emotions often ensue. It is necessary to recognize your grief, anger, and other negative emotions that being a parent of a child with special needs sometimes elicits. Do this without feeling guilty. There is nothing wrong with acknowledging these natural emotions. Once you are able to sort through these emotions, you will find yourself more emotionally and physically capable of managing your situation.

Address Basic Physical Needs: Be mindful of how you are treating your body. Try to add an extra 30 to 60 minutes of sleep every night. Increase physical activity in new ways (e.g., taking the stairs instead of the elevator). Find what helps you self-soothe, and try to engage in these activities on a weekly basis.

Practice Gratitude: It is easy to remain focused on the negative components of caring for a child with special needs. Take a few minutes daily to identify something you are grateful for. Perhaps keep a gratitude journal, or express gratitude to someone in your family. Practice more random acts of kindness. When we shift our focus to practicing gratitude and kindness, it reduces negative preoccupations that accompany our caregiving role.

Nurture Your Marriage: Raising a child with special needs can certainly add strain on any marriage, but it does not have to destroy your marriage. Make sure you are taking time for you and your spouse to stay emotionally connected to one another, and make sure you are communicating your needs and feelings to your spouse regularly.

Ask For Help: Asking for help is difficult, but is often a necessity when raising a child with special needs. Make the choice to ask for more help, even if you do not want to. Know who in your circle is willing to help, and try to identify what types of help are most beneficial.

Protect Your Time: Get creative with generating new increments of time for yourself. Take the longer drive home from work or take an extra ten minutes in the shower. If you create more time for yourself, use it to engage in healthy self-care activities. Do not fill extra time with more work and do not commit to new obligations.

Remove Toxic People: Having a strong and healthy support system is crucial. Take a moment to reevaluate your current social support system. Are there family members or friends who are causing undue stress, being unsupportive, or creating unnecessary conflict in your lives? If so, consider setting new boundaries, or removing these people from your lives altogether.

Utilize Respite Care: Take advantage of respite care programs offered in your area. It is essential to have time away from your caregiving role to replenish and reenergize.

Educate Family: Family members do not always possess the depth of understanding that parents of a child with special needs have. Consider educating your family members and friends about CdLS, and how it manifests itself in your child. Educate them about physical, emotional, and behavioral issues that your child may be struggling with, and provide suggestions for how they can be helpful when these issues arise. This can reduce frustrations with family members who simply do not know any better.

Befriend Those Who Have Children with Special Needs: Connect with those who “get it.” Parents benefit from finding someone they can talk to who truly understands the magnitude of their situation. Developing these connections allows you to share stories, gain insight,



provide mentorship, and share humor. Consider the possibility of a parent support group as well.

Reevaluate Your Expectations: Having unrealistic expectations and standards for yourself, your child, and your situation can cause heightened stress and disappointment. Make sure your expectations are realistic and aligned with your current reality.

Seek Therapy When Needed: Never hesitate to speak with a therapist to help you navigate your role as a parent of a child with special needs. Having an objective viewpoint and someone to help you cope effectively with emotions, anxiety, and conflict is a healthy and proactive decision.

*More valuable information on parental self-care can be found in the book, *Thrive Now Blueprint: Self-Care & Success Strategies for Parents of Special Needs Children* (2014) by Siobhan Wilcox.

A Closer Look at Self-Care: Kathy's Story

We want to thank Kathy for sharing her story with us.

You cannot give to others at the level needed as a special needs parent if you don't first take care of yourself. The old adage of putting your own oxygen mask on before your child's is really true! What is a good idea for "typical" parents tends to be essential for those of us who are parents of individuals with special needs. Without good self-care, burnout is guaranteed. My adult daughter, Molly, [who has CdLS] still lives at home with us, and I've found that self-care gets even more important as you age.

Each person is very different as to what fulfills and refuels him or her. I think we should be careful to not make our lives "all special needs all the time." Personally, I burned out doing just that. I needed something totally separate from that part of my life. I looked back and thought about what had brought me happiness in my past, and it was being creative, which led to my development as an artist. For my husband, Peter, it has become running marathons.



Kathy, top, second from the left, and her family.

Exercise is truly a magic bullet. It reduces stress, is a natural antidepressant, and keeps you in shape for the very physical work we do moving our kids around. It is my number one self-care routine. I go to the gym twice a week and walk on as many other days as possible. It is a very high priority for me. While exercise is really important, it doesn't really fuel my creative nature. I took a drawing class many years ago, which led to painting. I now have my own studio, and paint with a group of other artists once a week. I also take workshops frequently. This has become easier to do as my other two children are grown.

Share your self-care techniques with the CdLS Foundation and we will continue to share them with others. The way you care for yourself may work well for another parent or caregiver. Email Brenda Shepard at bshepard@CdLSusa.org or call 800.753.2357.



Is a Blenderized Diet Right for My Child with CdLS?



By Joni Rampolla, RDN, LDN, Registered Dietitian, Nutritionist; CdLS Foundation Clinical Advisory Board

Many individuals with Cornelia de Lange Syndrome (CdLS) are unable to eat by mouth and therefore require

long-term home tube feedings. While most families use standard commercial formulas for meals, a growing number of patients want fresh unprocessed whole foods instead of, or in addition to, the typical commercial formula. Talk to your medical team before making any changes to your child's feeding plan.

Blenderized feeding is creating a meal with whole foods that are liquefied in a blender with broth, water, juice, or various types of milk, and given directly via syringe bolus in feeding tubes. This practice is flexible, ranging from adding one small blended food per day with a standard commercial tube-feeding regimen to consuming a diet consisting solely of blenderized foods. To achieve balanced nutrition, blend ordinary meals in quantities similar to what they'd normally eat orally, using the government's "ChooseMyPlate" system. The nutrient content of more than 8,000 foods can be found on the USDA National Nutrient Database for Standard Reference at <http://ndb.nal.usda.gov/ndb/foods>.

Pros

If done properly, blenderized foods through a feeding tube can be safe, healthful and often cost less than commercial formulas. Children and their caregivers report that blenderized food is more appealing than commercial formula because of the family aspect, the variety of diet, the sight and aroma of foods which may allow a taste of real food again through smelling (and burping). This "tasting" is especially beneficial if you are planning to introduce table food to a child that has never eaten before. There are many nutrients, phytochemicals and fibers present in fruits, vegetables, whole grains and other foods that are not present in commercial formula. These may help with reflux, constipation, and diarrhea. Another

benefit is that processed ingredients such as corn syrup, maltodextrin, sucrose, casein and whey proteins and oils found in formulas are not present. Lastly, blenderized food allows you the joy of cooking your own food again and it is a benefit to children with intolerances or who are allergic to certain ingredients in standard formulas.

Risks

While many patients report positive experiences with the use of blenderized foods in tube feedings, there are some risks involved, such as inadequate or unbalanced nutritional intake, microbial contamination and tube clogging.

Caregivers need to make safe and appropriate food choices. Without knowledge and guidance, caregivers can unintentionally cause harm. I recall a family adding table sugar or excessive un-measured amounts of protein powder to a child's formula to help him gain weight. There are many recipes for blenderized food on the Internet, but that doesn't mean they're well balanced, healthy or appropriate to go through a tube. Also think about the quantity in the recipe: If this quantity of food were on a plate, is it enough or too much for the person you are feeding?

Food safety is a huge concern because unlike standard prepackaged tube feeding products, freshly blenderized foods don't undergo the canning process. Blenderized foods need to be refrigerated to prevent spoilage. Wash all produce before use and ensure routine cleaning of blenders, utensils, and syringes to prevent microbial contamination. For continuous tube feeding via a feeding pump blenderized foods should be completed in less than two hours to minimize the risk of spoilage.

Tube clogging is a risk, but with proper care it can be avoided. Choose a modern high-speed blender to liquefy foods, and then strain mixtures if necessary. Use sufficient amounts of liquid in blends and frequently flush tubes with water.

Continued on page 17



A Closer Look at Blenderized Diets: Andrew's Story



We want to thank Beth, mother to Andrew, for sharing his story with us.

Andrew was born in June of 2001. He was diagnosed with CdLS almost immediately, and it was quickly evident that he was suffering from severe gastroesophageal reflux (GERD). With the increased risk of aspiration, we decided to do the Nissen fundoplication

and began feeding through a gastric feeding tube (G-tube) at two months of age.

Andrew was fed formula through his G-tube for the next eight years of his life. During that time, he suffered from constipation, loose stools, reflux (even with the fundoplication), gagging, retching, and volume issues. It was always a challenge to get enough calories into him. Behavior wise, he was generally happy, but often sluggish and distracted. He had discomfort throughout the day and was often ill with whatever was going around at the time. Mornings were difficult after an overnight feeding that left him grumpy and often very uncomfortable. He also suffered from very severe pain episodes often multiple times a day. These pain episodes were accompanied by aggression and self-injurious behaviors. The sheer terror in his eyes during these episodes, and the complete helplessness we felt as his parents (who are supposed to protect him), were unbearable and tore through our hearts.

After trying everything we could think of to help Andrew and never finding any answers regarding the intense pain he suffered, we decided to try real food when he was eight. It was a very scary step. The only support we had was a group of parents and individuals online who were tube feeding themselves or their loved ones a diet of real food blended in a high-speed blender. After a lot of trial and error and tweaking, along with the continuous education of food and health, the results are nothing short of miraculous.

Today, Andrew is fed a diet that consists of 100 percent real food through his G-tube. There are no more pain episodes. There are no more signs of reflux and no need for reflux meds. Constipation is controlled by diet. His health has improved dramatically and he has had very few illnesses. He is happy and active, and his attention span at school improved dramatically. Now, he wakes up happy and ready to start his day with a smile, and it's the best feeling to see him pain free.



Formula has its place. Andrew wouldn't be here without it, and we're extremely grateful that it was available to us. Some individuals do just fine on formula and that's great. Some do not. His quality of life has improved so dramatically that formula will never again be an option for him. My goal now is just to spread awareness and make

sure that families know there is another option. It's a personal choice—and if formula is working for you, then go with it. If your child is suffering as Andrew did, then maybe real food is something to consider.

Below is a lunch/dinner recipe Beth makes that will make about 1,800 ml's of food and is nearly 2,800 calories. It will last us up to three days and can be frozen.

Raw – Organic Baby Spinach, 2 cups
Walmart – Canned Yams, 0.8 cup
Nuts – Walnuts, English, 1 cup
Any Brand – Cooked Quinoa, 1 cup cooked
Extra Virgin Olive Oil – 6 Tbsp
Carrots – Raw, 1 medium
Bush's Black Beans, Canned, 0.3 cup
All Brands – Himalayan Pink Salk, 0.3 Tsp (1g)
Nature's Way – Alive Whole Food Energizer Multi-vitamin Max potency, 4 Tablets
Woodstock – Organic – Tahini – Unsalted, 1 tbsp (15g)
Fruits – Prunes, 8 prunes
Avocados – Raw, 0.5 avocado, NS as to Florida or California
Rice Dream – Rice Drink – Organic Rice Milk, 2.5 cups
Market Pantry – Minced Garlic, 1 tsp



New Federal Program Provides Savings Account for People with Disabilities

Signed into law by President Obama last December, the Achieving a Better Life Experience Act of 2014 (ABLE Act) was created to help families set up a tax-deferred account to pay for expenses.

What is an ABLE account?

ABLE Accounts are tax-advantaged savings accounts for individuals with disabilities and their families. Income earned by the accounts would not be taxed. Contributions to the account made by any person are not tax deductible.

Why the need for ABLE accounts?

The ABLE Act recognizes the extra and significant costs of living with a disability. These include costs related to raising a child with significant disabilities, or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare.

Who is eligible for an ABLE account?

The final version of the ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet these criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you would still be eligible to open an ABLE account if you meet SSI criteria regarding significant functional limitations.

You need not be under the age of 26 to be eligible for an ABLE account. You could be over the age of 26, but must have the documentation of disability that indicates age of onset before the age of 26.

How is an ABLE account different than a special needs or pooled trust?

An ABLE Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will be considerably less than either a Special

Needs Trust (SNT) or Pooled Income Trust. With an ABLE account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABLE account will be a significant and viable option in addition to, rather than instead of, a Trust program.

Thank you to the National Down Syndrome Society for sharing information about the ABLE Act with us.

Ask the Expert



For parents, caregivers, health care providers, and teachers, concerns and questions often arise in regards to the care and well-being of individuals with CdLS. Our Ask the Expert service allows users to email their questions for response from members of our Clinical Advisory Board, or Professional Development Committee. Whether you are seeking assurance about development, have concerns about medical issues or have questions about best practices for communication, no question is too big or small to ask. Visit www.asktheexpert.cdlsusa.org to get your questions answered by our volunteer professionals in various areas of focus.



Board Corner



*Bob Boneberg Esq., President,
Board of Directors*

By the time this issue of *Reaching Out* reaches you, I will have completed a 5K to support the CdLS Foundation. Although I have supported the Foundation in different ways over the years, this is the first time that I have engaged in a Team CdLS

running event. Because this is my last year on the Foundation's Board of Directors, I have called this effort "Bob Runs off the Board."

My running has made me think once again about the many people who support the Foundation in many ways. Some folks run in one or more races a year to raise money for the Foundation, and some do this year after year. Others not only run in races they help organize Team CdLS events, teams of runners, or both.

Some folks organize golf tournaments. Others put together garage sales, or bake sales, or dress down days in their office. Others may host or help to support a family gathering. In short, many creative and talented people are

supporting the Foundation in many creative and talented ways. Our Foundation could not continue as it is without this support and encouragement.

So, thank you to all those volunteers who, in one way or another, support the Foundation.

If you are not a volunteer, perhaps this is the year that you can do so. As a parent myself, I am very well aware that the needs of our children can be all-encompassing, but perhaps there is some time when you can assist the Foundation in some way. And if you cannot, the next time you come across a person who is volunteering for the Foundation, maybe at a family gathering, or perhaps somewhere else, please take a moment to say thank you.

All the best,
Bob Boneberg

PS. Bob and his son Alex completed the race and raised more than \$3,000.

CdLS Foundation Store is now open

Mugs, t-shirts and tote bags
- oh my! Get your CdLS Foundation gear by visiting
www.cdlsusastore.org.



Super Siblings: Gabe and Shira



Shira is the author of a recent article, "How my Brother Flirted with Nuns and Taught us All About Religion." The article can be found at: <http://newvoices.org/2015/02/25/cdls/>

I am very close to my brother, Gabe, or as I call him sometimes, Gabie. We did a lot of things together growing up and I still see him when I come home, even

though he's in a group home. I used to play with Gabie a lot and do things to keep him entertained, like dance with him or sing with him.

Some of my favorite memories with Gabe are those when we used to watch "Kidsongs" videos together, and he would play along on his piano and I would sing and dance with him. I also loved the few times I got to visit Gabe at his day program through my high school's community service day and we would hang out together and he would give me one of his amazing smiles.

I decided to write about Gabe for *New Voices* online magazine because I knew they were having a disabilities week and I wanted to share my story about Gabe and how much he has changed my life for the better. I also thought it would be interesting since we're a Jewish family and this is a Jewish magazine, but Gabe went to a Christian residential school.

I hope that because of this article that people will want to learn more about CdLS, but that they will also come to somewhat know, love, and understand Gabe like I do. I am actually writing my senior thesis (creative writing capstone) on growing up with Gabe and have received positive feedback from both the professor and my class. I am in the final editing stages of the capstone now, but it will be done by April 28. I have loved the opportunities that I've had to write about Gabe and what life was like growing up with him.

Mailbag – Kenzie –



Kenzie is a big University of Alabama fan, so when we knew she'd have surgery on both legs/feet in November 2014, I began brainstorming who I knew that might know an Alabama Cheerleader that would give some time to teach her a cheer when she was healed. The ball started rolling and Kenzie met two

"Crimsonette" cheerleaders before her surgeries.

Kenzie then had her two major reconstructive surgeries to repair both her feet. She was in casts above her knees until January, and on different weeks she had the cast changed and lowered to below her knees. At that point she had a lot of knee pain since they had been stuck in the same position for so many weeks. Despite the pain, she began working on standing and walking again as soon as the lower casts were on.

She worked hard on her own all during the day to stand on her feet and began walking again. Her determination was an inspiration to me. Before I knew it she was walking around the house holding on to things, going up and down stairs and back to her favorite past-time: training herself to be a cheerleader. She would watch her "Bella Bella cheer-a-rela" DVD and do all the moves she could.

Today, Kenzie walks like a champ. As a family we have enjoyed many things that would not be possible before her surgeries, and of course, her dream of being an Alabama Cheerleader came true! She was able to cheer on the sidelines with the team in April.

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

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



Team CdLS Off to a Strong Start

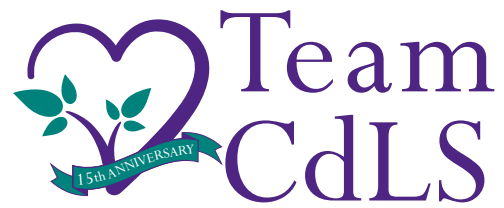
Team CdLS typically picks up speed in the second half of the year, but 2015 has gotten off to a phenomenal start with races in Dallas, Nashville and New York City leading the way.



Rock n' Roll Dallas Half Marathon, the Luyt Family



Dena Borgia with Kelly Brown, New York City Half Marathon



Cornelia de Lange Syndrome Foundation

Family Album

Thank you to the families and caregivers who have shared pictures, memories and the wisdom they have gained from their loved ones with CdLS on our Online Family Album. If you wish to share your child's story, visit familyalbum.cdlsusa.org.



2015 CALENDAR

July 25

Indiana Family Gathering
St. John, IN

August 24

27th Annual Golf Tournament
for CdLS
Sunset Hills, MO

September 9-12

CdLS World Conference
Lisbon, Portugal

September 12

Northeast Region Family
Gathering
Fort Washington, PA

September 20

Team CdLS
Saratoga Palio
Saratoga Springs, NY

October 3

Midwest Region Family
Gathering
St. Paul, MO

October 11

Team CdLS
Bank of America Chicago
Marathon
Chicago, IL

October 17

Team CdLS
Baltimore Running Festival
Baltimore, MD

October 23-24

Board of Directors Meeting
Orlando, FL

October 24

Southeast Region Family
Gathering
Orlando, FL

November 1

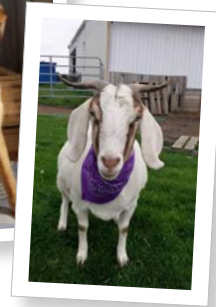
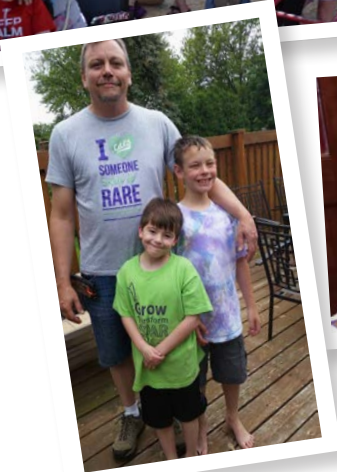
Team CdLS
TCS New York City
Marathon
New York, NY



CdLS Awareness Day Recap

National CdLS Awareness Day was celebrated around the country with activities and family support. Some families gathered together for a meal, others shared information on social media to raise awareness. Some schools educated students the day prior and encouraged them to wear purple to show their support.

Walks and other special events were held as well, bringing communities together. Kudos to volunteers who obtained National CdLS Awareness Day proclamations in the states of Illinois, Massachusetts, Oklahoma, and the city of Statesville, NC.



WELCOME NEW FAMILIES

Colorado

Lauricia and Jose
and son Zacchaeus,
born March 26, 2015

Kentucky

Rachel and Bruce and
daughter Maya Grace,
born September 5, 2014

North Carolina

Priscilla and son Kane,
born December 16, 2014

Washington

Destiny and daughter,
born on August 8, 2014

Iowa

Trista and daughter Skyler,
born December 14, 2011

Michigan

Darcy and Eric and son Owen,
born August 7, 2013

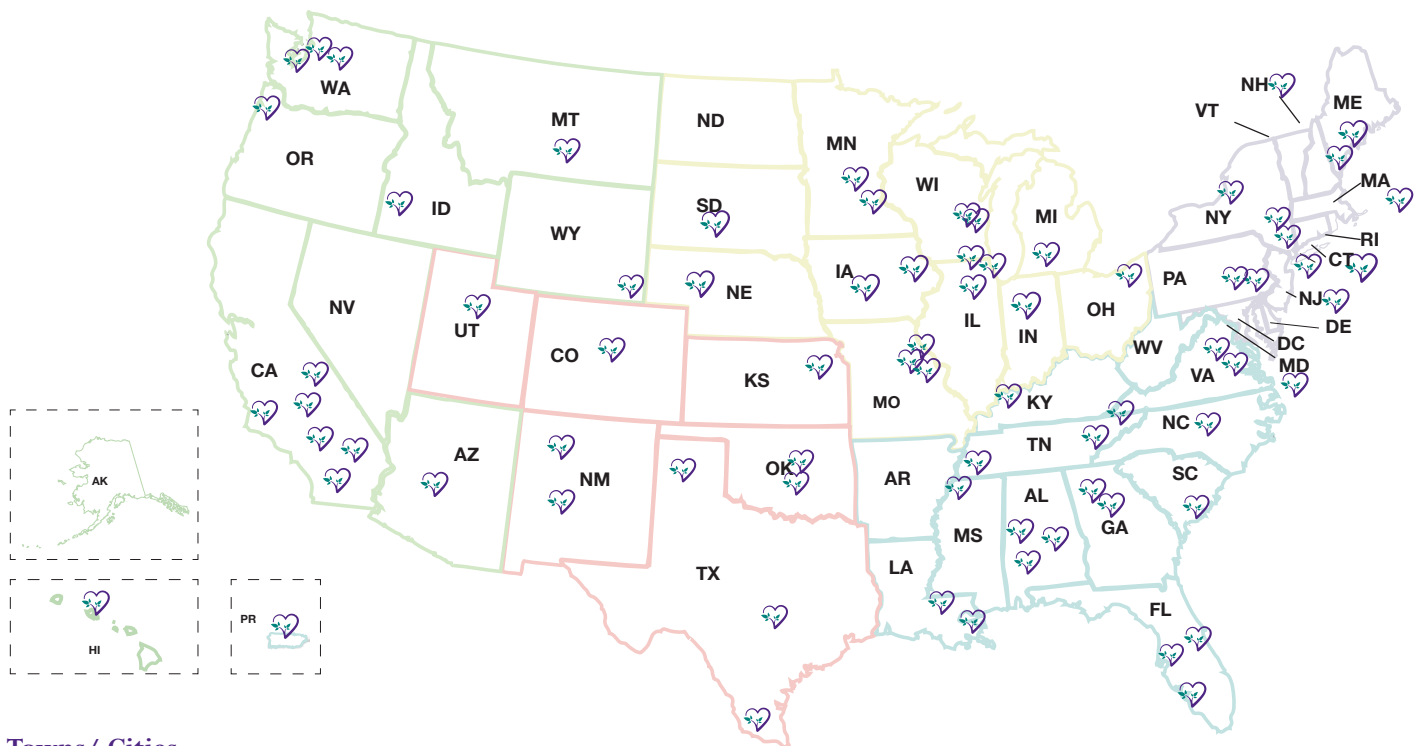
Pennsylvania

Christina and daughter
Katherine, born July 25, 2000

Connecting Families

If you want to connect with other families in your state, let us know. We have the ability to connect families who may have children of similar age, or are close to you geographically. Our Regional Coordinators (RCs) can help facilitate connections as well, and are great resources for you to reach out to in your state. The map below show the locations of our RCs.

FIND YOUR REGIONAL COORDINATOR*



Towns/ Cities

ALABAMA Luverne Pelham Dothan	COLORADO Colorado Springs	HAWAII Honolulu	IOWA Dubuque Waukee	MARYLAND Pikesville Ellicott City	MISSOURI O'Fallen Florissant Fredericktown	NEW JERSEY Maxwell	OHIO Hudson	SOUTH CAROLINA James Island	UTAH Layton	WYOMING Cheyenne
ARIZONA Peoria Mesa	CONNECTICUT Hartford	IDAHO Boise	KANSAS Gardner	MASSACHUSETTS Grafton	MONTANA Billings	NEW MEXICO Albuquerque Almogordo	OKLAHOMA Bethany Newalla	SOUTH DAKOTA Martin	VIRGINIA Fredericksburg Annandale	
CALIFORNIA San Luis Obispo Riverdale Turlock Escondido Torrance Irvine	FLORIDA Viera Port Charlotte Deland	ILLINOIS Lincolnshire Gurnee Burbank	KENTUCKY Henderson	MICHIGAN Portage	NEBRASKA Maxwell	NEW YORK East Setauket Brockport Hawthorne Saratoga Springs	OREGON Hillsboro	TENNESSEE Memphis Sweetwater Bristol	WASHINGTON Seattle Redmond Bothell	
	GEORGIA Alpharetta Decatur	INDIANA Lapel St. John	LOUISIANA Harvey Baton Rouge	MINNESOTA Coon Rapids Bethel	NEW HAMPSHIRE Gilsum	NORTH CAROLINA Greensboro	PENNSYLVANIA Dresher Allentown	TEXAS San Antonio Amarillo Mercedes	WISCONSIN Mequon Menasha	
			MAINE Thomaston Yarmouth	MISSISSIPPI Horn Lake			PUERTO RICO Guaynabo			

* As of June 2015



Meet the Staff

In 2015, the CdLS Foundation has welcomed three new staff members to the team:



Justyna

Justyna joined the Foundation in 2015 as Family Service Coordinator. She earned her Master's Degree in Social Work from the University of Connecticut. She also holds a Public Health Certificate

in Interdisciplinary Disability Studies. Justyna enjoys spending her free time with her two dogs, Blake and Teddy. Interesting fact: Justyna was born and raised in Poland and immigrated to the U.S. in 1997.



Nicole

Nicole joined the staff as Development Coordinator in 2015 and is the key lead for Team CdLS. She holds a B.A. in Communications from Roger Williams

University. After graduating from college, Nicole worked in the Development Office at the Stamford Hospital Foundation then at a church directing programs and special events for youth and young adults. Interesting fact: Nicole is a huge Harry Potter fan and the highlight of her 2015 honeymoon was visiting the Harry Potter attractions at Universal Studios, Orlando.



Susan

Susan joined the Foundation in 2015 as Office Coordinator. She earned her associates degree in accounting while raising her four children. Susan initially

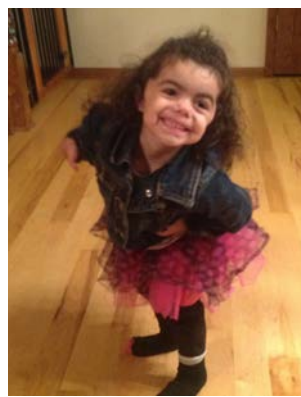
worked in Manhattan in the 1980s for a commodities trading group and rejoined the workforce in 2010 at a small employee communications company keeping the books and managing the office. Interesting fact: On her daughter's 18th birthday, Susan accompanied her on a tandem parachute jump from 13,500 feet.



CdLS Foundation staff (front row, left to right): Tonie, Marie, Deirdre, Justyna, Brenda, (back row, left to right) Kelly, Lynn, Francesca, Nicole, and Susan.

The CdLS Foundation staff thanks you for all of your support and looks forward to serving you and your families in the future.

On the Cover



Annika is four years old, but has a passion for life of someone much older. She came home from the hospital at one month old as our foster daughter. We were able to finalize her adoption for her second birthday. Despite the challenges she has faced, never once has she let them hold her back.

Whether it's playing with her siblings or working on school projects, she always displays the drive and determination that most people envy. She enjoys riding her bike, playing on her iPad, swimming, riding the bus to preschool and having fun with her 10 brothers and sisters (one of which is her biological sibling, who also has CdLS). We are truly blessed to have Annika in our family. She keeps us on our toes, but has also taught us how to stay positive when facing adversity.



Is a Blenderized Diet Right for My Child with CdLS? cont.

Conclusion

While the use of blenderized foods for tube feeding is uncommon, it's becoming more popular among home tube feeding patients. However, it isn't for everyone, so discuss it with the patient's physician and medical team before switching nutritional regimens. For example, blenderized foods are medically inappropriate for people with severe maldigestion or malabsorption disorders who require elemental nutrition formulas. They're also unsuitable for those who lack the skills and motivation to prepare them.

Yet, for many people who have the desire, skills, and nutrition knowledge or a dietitian's guidance, and the ability to purchase the right foods and equipment, blenderized foods are a healthful alternative to tube feeding. As with any type of feeding, monitor your child's progress and ensure he or she is tolerating the blenderized foods well and meeting weight goals. For individuals with CdLS, adequate growth is important.

Se buscan coordinadores bilingües voluntarios

Una de nuestras metas para el año 2015 es la provisión de mejores recursos y apoyo para las familias hispanohablantes que se ponen en contacto con nosotros. Si usted es bilingüe en español e inglés, podrá ser un recurso fundamental para esas familias en todo el país. Si desea obtener más información sobre cómo convertirse en Coordinador hispanohablante voluntario para la Fundación SCdL, póngase en contacto con Deirdre Summa enviando un correo electrónico a familysupport@CdLSusa.org.

Got clinic?

Don't miss out on the opportunity to meet with specialists from a range of medical disciplines. The current schedule for CdLS Clinics is as follows:

- **The CdLS Clinic at Santa Clara Valley Medical Center (San Jose, CA)**
August 10, 2015
Insurance authorization required.
- **Multidisciplinary Clinic for Adolescents and Adults at Greater Baltimore Medical Center Clinic (ages 12 and up)**
November 7, 2015
- **Center for CdLS and Related Diagnoses at Children's Hospital of Philadelphia**
Meets once monthly.
Insurance authorization required.



The CdLS Foundation offers one-time travel reimbursement up to \$250 to assist families with travel.

For more information on CdLS clinics, contact Deirdre at familysupport@CdLSusa.org or 800-753-2357.



Donations from 03/06/2015- 05/15/2015

Gifts that Count - In Honor/Celebration

Jack D. Barnes

Mary Waldo

Jillian M. Billings

Wee Bears Preschool

Howard Braverman

Michael and Diane Friedman

Andrea and Marc Needlman

CdLS Foundation

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Lillian M. Choong

Marjorie and Mark George

J.D. Cook

Jane and James Cook

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Michael Savicki

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Andrew Welborn

Allison Wells
Joseph Santopolo

Keiwan Williams
Board and Staff of the CdLS Foundation



Our Deepest Sympathy



Keiwan Williams
September 2, 1983 - March 5, 2015
Son of Letisha Williams
2812 Deerfield Rd. 1st Floor
Far Rockaway, NY 11691

Blake Johnson
February 5, 1985 - March 26, 2015
Son of Ruth and Finlay Johnson
159 Virginia Dr
Trussville, AL 35173

Tia Marie Rivera
November 21, 2013 - March 11, 2015
Daughter of Maryann Santoro
and Manny Rivera
824 Wilder St
Philadelphia, PA 19147

Aiden Bard
December 25, 2006 - April 20, 2015
Son of Stacy Bard
9000 La Crosse Ave Apt 1A
Skokie, IL 60077-1731

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Want to see **something else** in here?

Let us know your thoughts about this issue
of *Reaching Out*, and what you'd like to see in
future issues, by visiting
<http://bit.ly/RO3rdQtr2015>.



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CoRDS Registry

Coordination of Rare Diseases
at Sanford



The CdLS Registry at CoRDS: Working Toward Understanding

How many individuals with CdLS have immunodeficiency? How many have sleep apnea? How many take medication for reflux? These are just some of questions the CdLS Foundation is trying to get answers to through its Registry.

Launched last fall and hosted by the Coordination of Rare Diseases at Sanford (CoRDS), the registry aims to collect, store and curate data that can then be used for a variety of reasons—including establishing prevalence of certain aspects of the syndrome and connecting families with researchers. As investigation into the syndrome continues to move forward, the CdLS Registry is just another way the Foundation plays an important role in helping advance understanding of the syndrome and improving the quality of care for those affected by it.

To learn more about the CdLS Registry at CoRDS, www.sanfordresearch.org/cords.