

Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc.  Second Quarter 2016

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Super Siblings –
Levi & Payson



Photo by Avenue Bella Photography



Director's Message



A Message from our New Executive Director

In researching the CdLS Foundation's mission and accomplishments, I knew that the combination of my professional social services background, and my experience of raising a child with a rare genetic syndrome would be a good fit. The more I learned about the Foundation staff, and the board of directors, and their compassion and dedication to families, professionals and community members, the more I felt the Foundation was where my skills and talents could truly make a difference.

There is a strong legacy of the Foundation having an impactful role in the lives of people who care for and about individuals with CdLS. My vision is to build upon this legacy through strategically diversifying and increasing our funding, to expand both current and new services, as well as the number of families we can positively impact. Whether coaching a sport, or leading a professional committee, I find the best outcomes are always accomplished with a strong focused approach. There are a multitude of strengths within all facets of the Foundation upon which to focus and build.

I feel fortunate to join the Foundation at this time, with the 2016 CdLS National Family Conference only months away. As I hear heartwarming stories from previous conferences, the excitement to see the families and professionals rapidly builds. If you are attending conference, please come and say hello. If I don't get the opportunity to meet you in June, I hope we will meet at another event soon. You can also feel free to introduce yourself to me via telephone or email.

In closing, I would like to say a heartfelt thank you to the staff and board of directors for such a warm welcome. I am looking forward to a wonderful journey.

Susan Pribyson
Executive Director

"It is an honor to accept the executive director position and join a well-established team who provides valuable services to those impacted by CdLS"

– Susan Pribyson

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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New Medical Specialty Cards Now Available



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

One of the most difficult aspects of having a child with special needs is the fact that you, as a parent or caregiver, have to become the expert for all of the professionals involved with your child. On occasion you will meet physicians, therapists or allied health providers who will be familiar with Cornelia de Lange Syndrome (CdLS), and understand the issues at hand, particularly

in their fields. But for the most part, they will not know much about it. Better professionals will have searched for relevant information or medical references and likely have found the CdLS Foundation website right before your encounter. The less involved professionals will ask you about the syndrome and what it means from their field's point of view. This can be discouraging and can make you feel concerned that you might not be sharing all of the aspects of the syndrome, or allowing them to see the whole picture.

This is where our Medical Specialty Cards come into play. A sample copy of one of the cards is included in this edition of *Reaching Out* (page 8), and can be removed to be shared! They were intended for you to take them to the appropriate professional when you have appointments, particularly new appointments. Call the Foundation to request a specific specialty, or a full set of cards, and they'll be mailed to you.

The Foundation first published medical treatment guideline cards in 2009 and we have just completed the second version. Now, they are divided by medical topic. Each card was updated by the professionals on the Clinical Advisory Board of the Foundation, in that specific field, and several of us on the staff each proofed and finalized all of the cards. You will see that every card, despite its specific medical area, has some general statements related to CdLS as well. Examples include the need for all individuals with CdLS to seek regular medical care and receive vaccinations, and, on many, the fact that gastroesophageal reflux occurs, can recur and may have complications that need to be addressed. We felt that these were important enough for each family carrying the cards, and each professional receiving the cards, to be aware of and/or understand. The more information that can be shared with professionals, the more thorough their evaluation of your child will be. In addition, you'll have some explanation that could come in handy in emergency situations if the need arose.

Overall, we hope that you will consider using these Medical Specialty Cards and that they will be beneficial in improving the care of your child with CdLS.

Reaching Out
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Educational Testing Approaches for Children with CdLS



*By Shelly Champion, M.Ed,
Co-Chair, CdLS Foundation
Professional Development
Committee*

Before a child can receive special education and related services from the school district for the first time, an individual evaluation of the child must be conducted to see if the child has a disability and is eligible for special education as defined by the Individuals with Disabilities Education Act (IDEA). Parental consent must be obtained in writing before this evaluation can be conducted. The evaluation is done to gather information that will determine the child's educational needs and guide decision-making about appropriate educational programming for the child. The tests and assessments must be valid and reliable, administered by trained examiners and given in the child's primary mode of communication. After the evaluation the school will provide you with a copy of the evaluation report.

Students with CdLS demonstrate a wide range of physical and cognitive manifestations. There are many assessments to choose from and which to use depends on the child's abilities and needs. There are a few things to consider: the child's language ability and mode of communication, the child's physical abilities, and temperament.

The evaluation must assess all areas related to the child's disability, including:

- Health
- Vision and hearing
- Social and emotional status
- General intelligence and learning style
- Communication abilities
- Fine and gross motor abilities
- Strengths, preferences and needs

Tests alone will not give a comprehensive picture of how a child performs or what he/she knows or does not know. Only by collecting data through a variety of formal and informal approaches (observations, interviews with teachers and family) can an adequate picture be obtained of the child's weaknesses and strengths.

A comprehensive assessment is one that includes tests of intelligence, academic achievement and adaptive behavior (daily living skills, communication skill, and social skills). The evaluation should identify the child's needs in other areas such as speech and language, occupational and physical therapy, and need for assistive technology or transition services.

Intelligence testing can tell you how your child is functioning cognitively. Intelligence tests are important in establishing realistic expectations of your child's abilities. Intelligence tests measure different skills, including:

- Verbal reasoning and vocabulary: thinking with words
- Fluid reasoning: using language to solve unfamiliar problems
- Visual-spatial and visual-motor skills; thinking with pictures, designs, and hands
- Short-term and working memory
- Long term memory and retrieval: recalling factual information and retrieving it from memory
- Processing speed: making small decisions quickly with pencil in hand

Examples of test of intelligence tests are:

- Wechsler Intelligence Scale for Children (WISC-IV) for ages 6 through 16
- Wechsler Preschool and Primary Scale (WPPSI) for ages 2.6 through 7.7
- Wechsler Adult Intelligence Test for ages 16 and up

Intelligence tests should allow the child to demonstrate their abilities and not be penalized for their disabilities. Such intelligence tests may omit expressive language and/or visual-motor skills. The WISC-IV depends on a child's



verbal ability. If a child has weak oral language skills, the test used will not require expressive language skills.

Example of nonverbal tests of intelligence are:

- Comprehension Test of Nonverbal Intelligence (CTONI-2)
- Leiter International Performance Scale (Leiter-3)
- Naglieri Nonverbal Ability (NNAT2)
- Test of Nonverbal Intelligence (TONI-4)

Academic achievement tests measure a child's skills in reading, written language, and mathematics. For children with CdLS it is important to choose appropriate subtests and for the tests to be administered individually, over a period of time to prevent fatigue.

Some routinely used achievement tests are:

- Woodcock Johnson
- Woodcock Munoz
- Kaufman Test of Educational Achievement
- Peabody Individual Achievement Tests
- Wide range Achievement Test (WRAT)
- Brigance Comprehensive Inventory
- Bender Gestalt
- Gray Oral Reading Test
- Key-Math -3 Diagnostic Assessment

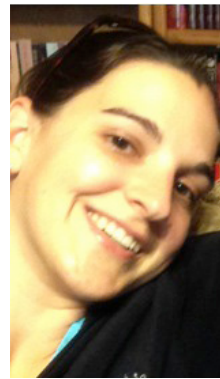
Multiple subject tests:

- Kaufman Test of Educational Achievement (KETA_II)
- Wechsler Individual Achievement (WIAT_III)
- Woodcock-Johnson III Tests of Achievement (WJ III ACH)

Single subject tests:

- Gray Oral Reading Tests (GORT-5)

A Closer Look at Academic Abilities



By Caitlin Wittum, Special Education teacher

I have a student who has CdLS and is currently a junior in high school - I will call her "B." When B started in my classroom freshman year, she was not toilet trained, had no way to communicate, was unable to hold a pencil or make any marks without assistance. She was a "runner," so when she was

upset, she would run out of the classroom and try to escape the building. Slowly but surely, we made progress toward her becoming more independent and able to participate in the community.

The process of getting B to communicate safely, rather than using aggression such as pinching, biting and/or kicking, was a long journey, but well worth it. She is non-verbal. At home her family speaks Spanish, and at school we typically speak English. We introduced B to sign language and a communication device (iPad mini with Proloque2Go). We started by introducing the signs of yes and no. We would ask her if she wanted something we knew she wanted, such as juice, and going to the restroom when it was her scheduled time, then assisted her with hand-over-hand to sign yes. We did the same thing to teach no, but with items we knew she disliked. By teaching her basic signs (yes, no, please, thank you, bathroom, eat, drink, more) she is able to have her basic needs understood. Once she had yes, no and bathroom mastered, we introduced the communication device and worked on saying the same phrases and then branched out once mastered. This journey has taken her three years, but she is much happier now that she can communicate.

Throughout B's time in my classroom, we have worked on minimizing her aggression toward herself and others. As she became more independent in communication her aggression decreased, but there are still times when she can become rather aggressive.



Residential Placement for School



*By Mary E. Levis, M.A., N.C.S.P.,
CdLS Foundation Professional
Development Committee*

Children in the United States are entitled to a public school education at no cost to them or their family. As a parent of a child with a disability, it is most important to work collegially with the Individual

Education Plan (IEP) team at your child's school. Individuals with Disabilities Education Act (IDEA) provide that students with disabilities are delivered a Free Appropriate Public Education (FAPE) in the least restrictive environment (LRE). Disagreement between what is "appropriate" is often the root for disagreement between parents and school systems.

First, look to your child's IEP to see if measureable progress has been made on their annual goals and benchmark objectives. If minimal progress or no progress has been made on some or all of their goals, it is the IEP team's responsibility to meet and discuss needed changes to the IEP. What additional supports, instruction, accommodations, modifications, change in LRE, etc., may be needed to ensure that your child receives FAPE and makes academic, functional, and behavioral gains that are reasonable and measureable? Decisions to change a student's IEP to a more restrictive placement must be data driven.

If an IEP is formulated that requires a more restrictive placement, such as a separate day program within a private school (Private Separate Day) or a full time special education program within a private residential setting (Private Residential Facility), it is the local school system's responsibility to pay for that educational placement as well as the required transportation. The local school system (LSS) is the school system where your child currently attends school. Sometimes, if there are other agencies involved with your child, they may share some of the costs of placement, however, the LSS is required to pick up the educational costs incurred in such a placement if they cannot meet your child's needs in their system. With regard to transportation, sometimes school systems will

provide transportation or some have reimbursed families who transport their children for their travel expenses.

This makes it sound like a straightforward process that will occur when and if your child has needs that are more than what their school can provide. Unfortunately, it doesn't always go that way. The following are some suggestions on how to best advocate for your child so they are provided with an appropriate education:

- Make sure that you carefully review the goals and objectives on their IEP. You want to be sure that the goals are measureable, as well as the objectives that document progress to each of their goals. The data supports the decision-making.
- Be aware of the differences between related services, such as occupational therapy, physical therapy, speech therapy, etc., that are provided in the educational setting versus those that are provided in a clinical setting. In school, these related services are to facilitate educational performance. They are not habilitative or rehabilitative.
- Research other educational facilities, programs, and resources in your area. Many school systems have a parent resource center as part of their system, which can offer a variety of support services, including things such as advocacy, providing information on other educational programs, and family support groups.



A Closer Look at Educational Placement Alternatives: Shannon's Story



We'd like to thank Shannon's mother, Sherri, for sharing her story with us.

Shannon can be so loving and bond with people (very selectively, of course) which makes it hard to wrap your head around the extreme behaviors of aggression, reaction or random usage of profanity that comes from her without warning.

As Shannon (now 18) became a young adult, the talk of transition to potential work environments was not one I could possibly envision, especially in the school system she was in and her behavior. She was in a special needs program in her public high school. I attended transition workshops with local company sponsors that have work programs for those with special needs. I asked if behavior issues should occur, how would they handle that situation? The answer was always the same: "this may not be the right program for your daughter."

I knew I could no longer do everything on my own without having help. We were working with a school system that has a special needs program, which conforms to the regular school hours. I knew I needed far more structure and care for her during the day. Being past the age for "day care," trying to find in-home support with someone who was able to handle the extreme behaviors of my daughter was beyond "challenging." It was not an easy realization, but I learned after many years, that asking for help was not a sign of weakness but strength.

My sister told me of a school that a family friend's daughter had attended. I learned that the school district had to refer her because they were no longer able to sufficiently educate her in their setting. Our school system didn't help, and didn't want to talk about alternatives, insisting they were handling everything sufficiently. I also finally learned that the IEP and associated meetings were my chance to be heard and documented, so I continued to bring up alternatives. I felt they were not educating or handling Shannon's behaviors adequately. They were doing the best they could, but she needed more.

When she had to be removed from the rest of the class and brought into a 2 to 1 setting, due to her spontaneous acts of aggression, the school started to talk about alternatives. It was a year and half of challenging them before any action took place, but I had the documentation, and my next step would have been to have an attorney push the school district. Once the new special needs principal engaged the inter-collaborative team (made of representatives from the school district and social services), they went through the process of going before the board of education for a referral.

The help, services and environment I had been fighting for had now been achieved. Thinking about Shannon no longer living with me, with it being just us for so many years, was very sad. It was also freeing; releasing the hopeless feelings I was having of when and how help would ever come. I knew that I was at the end of my rope of how much I could personally handle. I had to find peace and acceptance of the support. I helped Shannon to understand the transition that she was growing up.

This change "saved" both of us in many ways. Shannon is now learning independence. There are many things she still needs help with, but she is doing more, and has help from trained, educated professionals who care very much about and for her. As a parent, there are things you cannot teach your child that they have to experience. It is not easy to ask for or find help, but you have to stay healthy for you, your future and your loved one. A residential home does not mean you are leaving them or they are leaving you; it gives help and hope to you both.



Shannon's school holds a family picnic day so we can meet other families. They had a theme for the girls and they made their outfits. They dressed in unison, but each had a unique flare. She was beautiful! They also hold a Prom every year, which is something I thought she would never be able to attend, but in her school, she can!



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Dentistry

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- A pediatric dentist, or family dentist familiar with patients with special needs, should provide an evaluation every six months, starting at 12 months of age or when the first primary (baby) tooth erupts into the mouth.
- For adults, dental evaluation should be every four to six months, depending upon specific oral health issues, such as, oral hygiene and caries risk. Ideally, this should take place with a pediatric dentist or family dentist familiar with patients with special needs.
- Standard of care includes routine examination, cleanings, periodic X-rays and sealants on all posterior teeth.
- If cleanings and procedures are unable to be done in the office, because of limited compliance, sedation or general anesthesia is recommended in an appropriate clinical or hospital setting.
- Follow up with appropriate subspecialists as needed.
- When surgery or treatment under general anesthesia is recommended, it is advantageous to inform other involved specialists in order to coordinate as much treatment and diagnostic studies as possible under one anesthetic experience.

Support organization information should be given to the family whenever a diagnosis is made:
 The CdLS Foundation
 1-800-753-2357
www.CdLSusa.org

New Medical Specialty Cards Available

We are pleased to announce we now have CdLS Medical Specialty Cards. These new cards provide valuable care information in the following specialties: behavior, cardiology, dentistry, development, gastroenterology, gynecology, neurology, ophthalmology, orthopaedic, and otolaryngology. Contact Lynn Audette at families@CdLSusa.org to request your own Medical Specialty Card(s), which you can also share with your child's care team members.

"I want to thank the Foundation for the Medical Specialty Cards you sent for FREE to our family. This is a valuable, simple and quick reference of the issues that may effect our 15 year old daughter Kenzie. I quickly discovered information about some issues that she may be dealing with that we have not had checked by a doctor. The dental card was much needed at this time to explain and discuss the special care needed for her upcoming major dental work."

-Kinisha, mom to Kenzie

2016 CALENDAR

April 29-30
 Board of Director's Meeting
 Hartford, CT

May 23
 24th Annual CdLS Charity
 Golf Tournament
 Ipswich, MA

June 22-23
 CdLS Scientific and
 Educational Symposium
 Orlando, FL

June 23-26
 2016 CdLS National
 Family Conference
 Orlando, FL

October 9
 Bank of America
 Chicago Marathon
 Chicago, IL

October 10
 28th Annual CdLS Charity
 Golf Tournament
 Sunset Hills, MO

October 15
 Baltimore Running Festival
 Baltimore, MD

November 6
 2016 TCS New York
 City Marathon
 New York, NY

 Cut this out and share with your child's dentist!



Get Ready for Fun in the Sun at the 2016 CdLS Foundation National Family Conference June 23-26, 2016



This year's conference theme -- *Stronger Together* -- is inspired by the community families find when they connect with the CdLS Foundation. Join us June 23-26, 2016, in Orlando, FL, where attendees have an opportunity to gain knowledge on how to best care for their child and meet other families facing similar challenges. Individuals with CdLS receive free head-to-toe consultations with experts from a range of health and educational fields.



Registration closes May 27.

The registration packet includes information on the hotel, childcare and sibling programs, the event schedule and consultations. If you need a copy mailed to you, call the Foundation at 800.753.2357. Register online, or download the forms by visiting www.cdlsusa.org/what-we-do/biennial-cdls-conference.htm.

The room block at the DoubleTree by Hilton is sold out!

Anyone who wishes to cancel their hotel reservations for conference, please contact the Foundation prior to calling the hotel. (The room will go back into their inventory, not to our master account.)

Special accommodations, registration, or hotel questions? Contact Kelly at kbrown@CdLSusa.org or call the CdLS Foundation at 1.800.753.2357 with any inquiries.

CdLS Foundation National Family Conference Wish List

National Family Conference is a hallmark event that the CdLS Foundation puts together, and we need your help to make it a success. 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, cds, iPods, iPads, etc.)
- Small electronics
- 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
- Place an ad in our Scientific Symposium Booklet
- Sponsor another family who may be seeking support
- Purchase a dolphin with your loved one's name on it

For information on how to support conference or the CdLS Scientific and Educational Symposium contact Kelly Brown at kbrown@CdLSusa.org or call 800-753-2357.



Mailbag

– Steven & Arlene –



Steven has worked at the same job, at the Columbus Community Center, since 1968, taking apart X-Ray medical equipment so that O-rings can be repaired. He works every day, and a couple years ago

Steven received the “Dignity at Work” recognition for his strong work ethic as one of the best employees at the company.

My husband and I were two of the 10 or so parents who started the Columbus Community Center many years ago, and it has flourished into a big, beautiful building. The company employs young people, and then helps get them working in the real world.

Steven never learned to read or write, however, he likes to have the paper read to him every day. He’s interested in world events, and wants to know what’s happening. His hobbies include buying new videos and watching them after work. He loves Indian Culture and collecting Indian statues. He loves people, and everyone is his friend. He enjoys talking to people, and speaks very fluently.

Steven wears glasses, and gets the occasional headache, but is otherwise in very good health. He is totally capable, but lazy sometimes – he thinks if he works all day he should get the evening off. He can run, play, swim and talk. Steven is quite intelligent and has accomplished much more than what the doctor said he would. Now he’s making \$300 a month, and has done really well in his life.

We have a good routine together: I help him wash his hair and shave, and he keeps me in good company at my age. We lost his father six years ago, and since I’m 95 years old, we’re doing well together. Steven has five brothers and sisters, who will take good care of him while I’m gone. He’s been a joy in my life, and we’ll be together to the end.

Arlene, Steven’s Mom, Utah

Mailbag – Essential Oils

Success for Isabelle –

Alternative therapies may be a tool to aide in the relief of various symptoms in a child with CdLS. The Foundation recommends consulting your doctor before beginning any therapies for your child, even in conjunction with existing care.

Isabelle has terrible anxiety issues. Triggers for her are changes in her routine, unexpected things happening, and anytime she’s sick. When her anxiety is bad, she will spend hours crying, pick at her fingers and toes to the point of pulling off nails, and has a very difficult time falling asleep. Before starting medication solutions for her anxiety and behavior, we decided to pursue essential oils as an option.



At the very start of school this year we decided to try using essential oils to help Isabelle’s sleep and ease her anxiety. The results have been amazing. She is having many less crying spells and is picking at her fingers and toes much less. We were using melatonin for sleep, and have been able to stop that since starting with oils.

We apply the oils to either the back of the neck, wrists, or feet depending on the oil and what we’re using it for. We’ve used them on the belly and sternum, if needed, for reflux or stomach problems. We also diffuse the oils, which disperses them into the air.

If you’d like to discuss what exactly we’re using, please feel free to reach out to me, at sixsdairy@gmail.com. It’s very important to do your research before starting, and to be sure that you are using very high quality oils as not all brands are created with equal quality standards. You should, of course, always consult with your child’s doctor before starting alternative therapies.

Jenny, mom to Isabelle, Michigan



Super Siblings – Levi & Payson

Levi, 6, loves his little brother, Payson, 5, who has CdLS. So much so, that he took a special opportunity at his school to teach his classmates about CdLS and special needs.

“The students go to classes like music and gym together,” said Christie, Levi and Payson’s mom. “Levi came home and shared that the students in the special education class all sat on one side of the room in those classes, and no one really talked to them. Some of the special education students make noise, or look a little different, and the other students were unsure of them.”



“Levi was concerned about the separation in class, knowing that if Payson was in school with him, he’d want to talk to everyone,” said Christie. “On his own, he planned to save up his ‘good behavior tickets,’ and use them to bring Payson into his class for show and tell.”

Students can use “good behavior tickets” they earn for treats, like wearing a hat in school for a day, sitting in the teacher’s chair, or getting a pass on homework. Instead of using them to skip a homework assignment, Levi saved up his tickets for months, and chose to educate his classmates about how being different is no reason to be scared.

Levi’s classmates quickly took to Payson, and enjoyed hearing about how he and Levi were just like their siblings in many ways.

“The class waved at Payson, admired his new leg braces, and kept saying how cute he was,” said Christie. “Levi told them about how Payson likes to play with cars, and how he copies him all the time. He shared how Payson loves to play outside. The teacher asked the class, ‘how many of you like to play outside?’ and most of their hands

went up. Levi explained that sometimes Payson can be annoying, and again, the teacher asked, ‘how many of you have siblings who can bother you sometimes?’ with many little hands going up again.”



It was a special moment for Christie, seeing maturity in Levi, who had typically struggled with sharing attention, and being the sibling of someone with special needs.

“Saying I was proud puts it lightly,” said Christie. “I was really surprised that it was Levi wanting to do this. Seeing a six year old who saw a problem in his class, and taking the initiative to solve it, was a special moment as a mom.”

Share your Mailbag or Super Sibling Story!

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



Coopervision Corporate Donation Surprise



Coopervision, founded in 1980, is a soft contact lens manufacturer. In December 2015, Coopervision chose the CdLS Foundation to be its charity beneficiary for the year, thanks to the awareness efforts of Courtney Hegarty, mom to Cassidy, 3, who has CdLS.

It began in May 2015, when colleagues of Courtney learned it was CdLS Awareness Day, and decided to do an internal fundraiser in their department, as a surprise to Courtney.

“For awareness day, my colleagues raised around \$2,500 for the CdLS Foundation,” said Courtney, “and one of my bosses flew in and did an awareness walk with us as well. Little did I know, that my boss went on to suggest the CdLS Foundation for the 2015 corporate charity designation, and they agreed, keeping to their donation within the Coopervision family.”



“On the last day of our annual sales meeting, that’s when they reveal who they’ve designated as the charity,” said Courtney. “We were sitting there as the president of the company stood up to announce the charity, and when they showed the CdLS awareness video on this massive screen, I realized they had chosen the CdLS Foundation. I just stood up and started crying. Then, as if I wasn’t already emotional, I turned around and there were my parents and Cassidy, who had been hiding.”

“I had no clue,” said Courtney, “but everyone in my office knew it was happening, my husband knew, and even my parents knew. I felt pure excitement and amazement. I was so shocked I became speechless. I held Cassidy, and we went up on stage to accept the check together. It speaks volumes on the type of company Coopervision is. This meant the world to us.”

How your company can help

The CdLS Foundation actively seeks support from corporations—big and small—that are committed to improving the lives of people with CdLS. Your sponsorship of the CdLS Foundation helps us provide programs and services—like family gatherings, help lines staffed by licensed social workers, free publications, and funding of relevant research.

The following programs and services provide opportunities for corporate sponsorships and support:

- Family support and services
- National biennial family conference
- Professional education and outreach
- Research
- National biennial Scientific and Educational Symposium
- Team CdLS
- *Reaching Out* Quarterly newsletter

Opportunities can be custom-made to suit a company’s interest and budget. To discuss opportunities or learn more, contact the Foundation at events@cdlsusa.org.



The Importance of CdLS Foundation Research

By Brenda Shepard, Communications Coordinator, CdLS Foundation

Research had not always been a main focus of the Cornelia de Lange Syndrome (CdLS) Foundation, because we were mainly dedicated to family support services, as was appropriate. We began to see more and more of a need for us to be an advocate for research into CdLS. We knew we needed to push CdLS research forward, and increase funding given on a regular basis, making it one of the priorities in our multi-year strategic plan.

Since 2005, we've gone from providing research funding of \$15,000 every other year to providing funding every year and increasing the amount to \$50,000. By changing the format and increasing funds to support multiple projects, we are allowing for the opportunity to better serve families down the road from a care and treatment perspective.

The Foundation's research grant process is set up to allow professionals to perform various studies, whether lab-based, survey, or any sort of a clinical study. The process begins by soliciting submissions from investigators (some may be familiar with CdLS, and some may not). An appealing part of supporting research, is that we're able to encourage young investigators who may not have a lot of exposure to CdLS to become intrigued and focus their interest in researching CdLS in the future.

Each spring, applicants send in letters of intent, followed by proposals. The Foundation's Research Committee recruits reviewers who have expertise in the various content fields being covered. Once the review process is complete, those applicants with the best reviews and highest scores receive funding. Currently, proposals are limited to requests of up to \$15,000. This is done with the intent that the Foundation has the resources to fund at least three projects each year.

The Research Committee is made up of individuals who are invested in the Foundation and research success. Soon, discussions will begin to determine what research funding will look like as we ask for funding from outside sources that will directly support research.

The committee is tasked with developing a plan to use future larger funding amounts. Funds may result in multi-year research projects, funding research fellows, or allowing for increased funding allotment per project.

Research coordinated through the Foundation is important because we're able to ensure that these smaller-scale projects are targeted to be applicable to families or people with CdLS. One criteria projects are judged on, is how likely the project is to have an effect on the way we treat or care for people with CdLS. They may not necessarily be immediately applicable, but our hope is that down the road, they will be.

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 and researchers move 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.

Register for your chance to win \$500!

What would you do with \$500 cash? We are sponsoring a lottery drawing of \$500 for three winning families who complete their registration with the CdLS Patient Registry by June 25, 2016. The drawing will take place at this year's Family Conference* in Orlando, FL. CoRDS will be facilitating the raffle and informing the Foundation of the \$500 prize winners, because the CdLS Foundation doesn't know who is enrolled in the registry. Good luck!

*Need not be present to win.



Educational Testing Approaches for Children with CdLS cont.

- Comprehensive Test of Phonological Processing (CTOPP2)
- Oral and Written Language Scales (OWLS_II)
- Tests of Written Language (TOWL_4)
- Key-Math-3 Diagnostic Assessment

Speech and Language Skills:

A speech and language assessment will assess a child's receptive and expressive skills which include listening, oral expression, vocabulary, syntax, semantics, nonliteral and abstract language, and speech articulation. Speech and language evaluations should be administered by a Speech and Language Pathologist (SLP). Some examples of tests are Clinical Evaluation of Language Fundamentals (CELF-5), Oral and Written Language Scales (OWLS-II), Peabody Picture Vocabulary Test (PPVT-5), and Goldman-Fristoe Test of Articulation (GFTA-2).

Auditory, Visual, Visual-Motor, and Sensory Processing Assessments can determine a processing disorder in any one or combination of the senses. These evaluations should be conducted by an occupational and/or physical therapist trained in sensory integrative disorders. Examples of these evaluations are The Berry Buktencia Developmental Test of Visual Motor Integration, The Motor Free Visual Perception Test, and The Developmental Test of Visual Perception.

Adaptive Behavior Assessment tests the skills that a child needs to live safely and independently in the community. Appropriate adaptive behavior scales should be selected with the individual child in mind. One useful assessment is the Vineland Adaptive Behavior Scales test.

A Functional Behavior Assessment (FBA) is used to understand a child's behaviors and the purpose they serve and develop a Behavior Intervention Plan.

Transition assessments for ages 14 and older are a necessary step in helping young adult with CdLS set goals for their future. These include:

- Street Survival Skills Questionnaire (SSSQ)
- BRIGANCE Transition Skills Inventory (TSI)
- Enderle-Severson Transition Rating Scales (ESTR)
- COPS Picture Interest Inventory (COPS-PIC)
- Reading Free Vocational Interest Inventory (R-FVII)

Additionally, a good resource for parents is *All About Tests and Assessments*, by Melissa Lee Farrell, Ph.D., SAIF, Pamela Darr Wright, MA, MSW, and Peter W.D. Wright, Esq. (WrightsLaw)

In summary, children with CdLS can be challenging to test because of their wide range of abilities and physical, cognitive and developmental disabilities. It is important to look at the individual child, the needs of the child, and what the goal of testing is - assessment, evaluation, or progress monitoring.

A Closer Look at Academic Abilities cont.

I reached out to the CdLS Foundation and they were able to give me tips and advice that I could implement into her BIP (Behavior Intervention Plan), such as actively ignoring behaviors, such as hitting her chin or biting her hand. If she displays aggressive behaviors towards others (ex: kicking, biting) we block the behavior, and ignore her. When she has stopped the behavior, then we give her attention and try to help her communicate what she needs/wants. The behaviors have not completely eliminated, but it has been reduced dramatically.

I have told many of my colleagues and friends that I have re-defined Special Education (SPED) as "Students Proving they can Excel beyond their Disabilities." My journey with B is far from over, but I am excited about the progress we've made, and that she is now able to be more independent than she was when she first entered my classroom. Consistency has been the key to interacting and setting expectations. This journey has had many ups and downs. I counted on the research I found on the CdLS Foundation's website and the help of the staff. You are not alone in this journey; rely on others in similar situations for tips, ideas and suggestions.



Board Corner



*By Richard Haaland, Ph.D.,
President, Board of Directors;
CdLS Foundation Research
Committee Chair*

The CdLS Foundation Board of Directors is excited to welcome Susan Pribyson as the new executive director for the CdLS Foundation, and is perhaps even more excited about the opportunity to work with her to craft a special future for the Foundation. As we begin a new chapter for the CdLS Foundation, it's important to remember the excellent position we are currently in and begin building the Foundation into a nationally recognized organization meeting the needs of everyone who routinely faces CdLS.

It's abundantly clear to the board of directors that this Foundation has worked diligently over the past 35 years to establish the roots necessary to grow upward and outward. The efforts of dedicated staff and selfless volunteers have developed a large number of very successful programs to help support everyone with CdLS. Yet the question continues to remain: what does the future of the CdLS Foundation look like?

As we start thinking about a future for the Foundation, it's difficult to imagine what we should be doing to best meet the needs of the families and people affected by CdLS on a daily basis. Now is the time to start building the Foundation to meet the needs of each and every person who encounters CdLS at some point in their life, which can mean different things to different people. To the general public, it may mean CdLS has a nationally recognizable Foundation, where people in the streets are aware of CdLS and the challenges it poses. To the clinical or laboratory researcher, it might mean the Foundation provides funding and connections for new studies to improve care and treatment. To the physician, it might mean the Foundation is a trusted source for the most current information on how to provide the best possible care to each person with CdLS. To the families of those affected, it may mean connecting with other families who fully understand your struggles. To the person with CdLS, it may mean knowing there are people who love and support you in all you aspire to be.

As we begin carving out the CdLS Foundation of the future, we can start to see how the Foundation becomes the primary resource for each and every person who has CdLS, cares for someone with CdLS, performs research on CdLS and sees someone with CdLS in their school. It is this type of future that we are looking to take steps towards in the coming years, and it is only through the input of the people who are intimately connected to CdLS that we can truly become the Foundation of the future. Please take a few moments to participate in the various avenues we have for you to express your experiences, needs and desires for CdLS, such as the registry, the variety of research surveys and the suggestion box located on the CdLS website. The CdLS Foundation of the future can't be built without your insight.

On the Cover: Gavin



Gavin is a twin; he and brother, Jace, turned three in March. Gavin also has a big sister, Skylar, who is six, and a dog named, Weaver. They all keep mom and dad very busy.

Gavin received a clinical diagnosis of CdLS from NIH's Undiagnosed Disease Program in June 2015. He recently started sitting up on his own and has started to scoot around in his own way. He is fascinated with exploring his new environment. He enjoys music and songs and is a big fan of Mickey Mouse. He has a love of books and loves it when we read to him.



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Our Deepest Sympathy



Maribeth Markowski
August 19, 1965 - November 14, 2015
Daughter of Mary Markowski
5739 S 113th St
Hales Corners, WI 53130-1805

Keel Christian Salmons
March 14, 1980 - October 16, 2015
Son of Sue Salmons
5902 San Souci Cir
Huntington Beach, CA 92647

David Lindholm
October 14, 1989 - July 30, 2015
Son of George Lindholm, MD
PO Box 39570
Ninilchik, AK 99639
and Rhonda Leach PO Box 1414
Homer, AK 99603

Meredith Joan Clark
September 9, 2007 - December 23, 2015
Daughter of Abby and Craig Clark
23 Hills Farm Drive
Cherry Hills Village, CO 80113

Tanner Gabriel Jencik
December 9, 2013 - October 13, 2015
Son of Brittany and Barry Jencik
15 Cassidy Court
Penfield, NY 14526

Emma Lynn Kissock
April 7, 2007 - January 21, 2016
Daughter of Robin and John Kissock
8519 15th Ave S.
Bloomington, MN 55425

Annabelle Schwindler
December 8, 2013 - February 17, 2016
Daughter of Michelle and Andrew Schwindler
4755 W. State Road
Delphi, IN 46923

Spring has sprung in Cornelia's Garden!

Get a head start on your summer garden and fill it with wildflowers that signify the hope that CdLS Foundation gives to people with CdLS and their families.

Contact Kristi Larson at Klarson@CdLSUSA.org or 800.753.2357 to request your Cornelia's Garden kit. Your kit will include seeds and materials for you to share with 10 people so they, too, can plant wildflowers in honor of a person with CdLS.

planting hope for CdLS





WELCOME NEW FAMILIES

California

Youmna and Ahmad and son Yousuf, born May 5, 2015

California

Katrina and foster daughter Michella, born February 12, 1986

California

Vicky and son Kevin, born January 11, 1993

Florida

Cintia and son Kevin, born May 5, 2008

Florida

Anna and great-grandson Jeremiah, born March 22, 2012

Illinois

Janet and son Nicholas, born September 2, 2011

Indiana

Hannah and David and son Sorin, born August 17, 2012

Maryland

Annetta and Donald and daughter Rosie, born November 23, 2015

North Carolina

Nina and John and daughter Madelyn, born June 27, 2015

New Mexico

Rita and daughter Cecilia, born October 8, 2002

New York

Agnieszka and Wojciech and daughter Lillian, born August 9, 2015

Ohio

Chanel and daughter Mila, born February 27, 2013

Oklahoma

Angie and son Daniel, born January 8, 2004

Rhode Island

Erika and Jason and son Jaxon, born December 31, 2015

South Carolina

Tara and Chris and daughter Nola, born September 17, 2015

Texas

Julie and Trevor and daughter Kimber, born May 24, 2013

Vermont

Brigid and daughter Rachel, born February 2, 2015

Love something in this issue?

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
<https://www.surveymonkey.com/r/2ndRO2016>



Select a dolphin to be displayed at the CdLS Foundation National Family Conference:

 **\$25.00**
Finn (Small)

 **\$50.00**
Sandy (Medium)

 **\$100.00**
Splash (Large)

(Please indicate how you wish the name to appear on the dolphin)

To: _____ From: _____ ☐  Finn ☐  Sandy ☐  Splash

To: _____ From: _____ ☐  Finn ☐  Sandy ☐  Splash

To: _____ From: _____ ☐  Finn ☐  Sandy ☐  Splash

To: _____ From: _____ ☐  Finn ☐  Sandy ☐  Splash



CdLS Foundation

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 Avon, CT 06001-3681
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Enclosed is my check for \$ _____

You may also dedicate your dolphin online at www.CdLSusa.org or by contacting us at 800.753.2357.

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When you run, swim, bike, walk or tough mud this year, make your miles count for more than just distance. Join Team CdLS and help provide programs, services and support to families across the country at no charge to them.

Participate in an event in your community, start your own Team CdLS event, or join our established teams throughout the country. For a full schedule visit: <http://www.cdlsusa.org/events/team-cdls.htm>.

Email TeamCdLS@CdLSUSA.org or call 800.753.2357 to learn more.



SCHEDULE

The Saratoga Palio
September 18, 2016,
Saratoga Springs, NY

Bank of America Chicago Marathon
October 9, 2016,
Chicago, IL

Baltimore Running Festival
October 15, 2016,
Baltimore, MD

2016 TCS New York City Marathon
November 6, 2016,
New York, NY