Reaching Out

The Newsletter of the Cornelia de Lange Syndrome (CdLS) USA Foundation, Inc. Summer 2013

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Director's Message

Looking Ahead to Costa Mesa

It may seem early, but the countdown to the 2014 National Family Conference in Costa Mesa, CA, is well underway here at the Foundation office. The event's tag line, Dream. Explore. Discover. provides us inspiration to plan the schedule and activities, identify speakers, and create a memorable logo.

As we plan the 2014 conference, we are listening to families' past feedback and requests, exploring alternatives and making changes, including Friday night on your own, fewer concurrent workshops and a more structured setup for CdLS childcare.

We also have discovered that many families don't realize the cost to carry out conference or the efforts that are directed towards fundraising for this event. Registration fees only cover a small percentage of the expenses incurred. The Foundation relies on individual donations, corporate sponsors and events organized by our constituency to help raise additional funds.

Your first priority is getting your family to conference (and it's ours too); however, the Foundation also needs your support to make sure your time at conference is everything you hoped for.

Let's *dream, explore, discover* together to raise the funds needed to support this event. Please consider helping the Foundation by responding to a request for support, soliciting local businesses to make a donation or become a sponsor, or by holding a fundraising event (like a wine or beer tasting, walk/run or bake sale).

Together, we can make great things happen.

Thank you,

Marie

Marie Concklin-Malloy
Executive Director

P.S. Conference costs are $200,000 + (about 20 percent of our annual budget) and typically result in a $70,000 loss. Conference is never a moneymaker, nor is that the intention, but the less money we lose, the more we can invest in our services and programs.

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.

In This Issue

Something You Should Know About Conference

Norm Winnerman, Conference Committee Co-Chair

Our conference planning starts first with a review of our last conference in Lincolnshire. As we go through the details, and review the financials, I recall a couple of conversations I had with families about the expense of our conference. One person remarked that, “The Foundation must really make a lot of money from Conference.” **It’s time to set the record straight.**

The Foundation usually supports a deficit for the conference. Try as we might, we’ve never broken even. We provide scholarships, our expenses continually increase and we purposely hold our registration fee to a minimum so that families can attend. We are mindful of the cost of transportation and sleeping rooms and other expenses incurred by our families. We try to make it affordable and we hope that with the two years between conferences, families might start their own “conference fund” to attend the next conference.

Last week, I had my usual Friday breakfast with eight other “old guys” at a local diner. Oatmeal or eggs, bacon and home fried potatoes or a short stack of pancakes or French toast: none cost more than $5. Our 2012 Lincolnshire breakfast buffet is essentially the same menu but the cost was $30 for adults and $15 for children under 12. There was no charge for children with CdLS, regardless of the age, and we had over 100 in attendance.

It hit me: my $8 breakfast at the local diner, cost $30. Wait – it really cost $37.20 because every hotel that ever hosted our conference adds on a service charge that has grown to the current 24 percent.

Hotel economics 101: Any hotel has nothing to sell, but space – meeting space, sleeping space, fitness center space, dining space, etc. To run a first class property, the quality hotels we use require a support staff of hundreds – cooks, dishwashers, wait staff, housekeeping staff, engineering staff, AV staff, front desk staff and all the administrative staff. We contract to sell a certain number of rooms. Our room block rate is contracted at $109 per night (negotiated in 2010) because we guarantee a certain number of rooms to be filled. If families try to get less expensive rooms outside the room block, the hotel can then charge the Foundation for not filling those rooms. Please support all of us in our endeavors.

Our dream, of course, is to be able to host these national conferences regularly, keep our registration fee to a minimum, provide an amazing experience for families, care for your children, and pay the bill as we walk out the door. We appreciate the support and understanding of all of you. At the end of the day, you’re what it’s all about.

Reaching Out
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Birth to Three Services and Preschool to Kindergarten: The Individual Family Service Plan (IFSP)

By Mary Beth Bruder, Ph.D., Professor of Pediatrics and Educational Psychology, Director, University of Connecticut A.J. Pappanikou Center for Excellence in Developmental Disabilities Education, Research and Service

An Individualized Family Service Plan (IFSP) documents and guides the early intervention process for children with disabilities and their families. The IFSP is the vehicle through which effective early intervention is implemented in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate that development.

Through the IFSP process, family members and service providers work as a team to plan, implement and evaluate services tailored to the family's unique concerns, priorities and resources.

According to IDEA, the IFSP shall be in writing and contain statements of:

- the child's present levels of physical development, cognitive development, communication development, social or emotional development, and adaptive development;
- the family's resources, priorities and concerns relating to enhancing the development of the child with a disability;
- the major outcomes to be achieved for the child and the family; the criteria, procedures, and timelines used to determine progress; and whether modifications or revisions of the outcomes or services are necessary;
- specific early intervention services necessary to meet the unique needs of the child and the family, including the frequency, intensity and the method of delivery;
- the natural environments in which services will be provided, including justification of the extent, if any, to which the services will not be provided in a natural environment;
- the projected dates for initiation of services and their anticipated duration;
- the name of the service provider responsible for implementing the plan and coordinating with other agencies and persons; and,
- steps to support the child's transition to preschool or other appropriate services.

U.S. Department of Education rules (1993) require that non-Part C services needed by a child, including medical and other services, are also described in the IFSP, along with the funding sources for those services. The statute allows parents to be charged for some services. If a family will be charged, this should be noted in the IFSP.

How the IFSP Differs from the IEP

The IFSP differs from the Individual Education Plan (IEP) in several ways:

- It revolves around the family, as it is the family that is the constant in a child's life.
- It includes outcomes targeted for the family, as opposed to focusing only on the child.
- It includes the notion of natural environments, which encompass home or community settings such as parks, child care and gym classes. This focus creates opportunities for learning interventions in everyday routines and activities, rather than just formal, contrived environments.
- It includes activities undertaken with multiple agencies beyond the scope of Part C. These are included to integrate all services into one plan.
- It names a service coordinator to help the family during the development, implementation, and evaluation of the IFSP.

Steps that Lead to Effective IFSPs

Conduct a Functional Assessment

An effective assessment process:

- addresses the family's questions about enhancing their child's development, focusing on each family member's concerns and priorities;
- collects information for a specific purpose. For example, the evaluation conducted by the early interventionist at the beginning of the IFSP process determines if the child is eligible for services;
- reflects a complete and accurate picture of the child's strengths, needs, preferences for activities, materials, and environments; and,
- has a person familiar to the child conduct observations and other assessments in settings familiar to the child (e.g., home, outdoor play area, child care program).

Identify Strategies to Implement the Plan

This step involves working closely as a team to increase learning opportunities,

- to use the child's surroundings to facilitate learning,
- to select the most effective strategies to bring about the desired outcomes, and,
- identify reinforcers that best support the child's learning.

Implementation may involve a toddler participating in a library story hour one afternoon a week; a physical therapist showing family members how to use adaptive equipment; or a service coordinator completing the paperwork to pay for a child's transportation from his/her home to needed services.

Intervention strategies should help promote generalization of outcomes—i.e., the child performs new skills in a variety of environments after intervention has ended. Intervention strategies might involve offering physical assistance during mealtimes, prompting the correct response during a self-care routine, or providing simple pull-on clothing to enable a child to dress without assistance.

Interventions provided within natural environments should look like a "typical activity." A child learning to develop fine motor skills should be encouraged to color, draw pictures, play with puzzles, build with blocks, pick up toys, use eating utensils, play finger games, etc. Interventions should:

- be embedded in everyday natural environments;
- emphasize the acquisition of functional competencies;
- make it possible to increase a child's participation within the environments; and,
- include both social and non-social activities.

Evaluate Early Intervention to Ensure Quality

An evaluation may focus on a child's progress toward obtaining desired outcomes and upon the quality of the intervention program itself. Ongoing monitoring of the child's progress requires keeping records in a systematic manner in order to answer critical questions.

Part C of IDEA requires that the IFSP be evaluated and revised annually and that periodic reviews be conducted at least every six months (or sooner if requested by the family).

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The full article can be found in the CdLS Foundation's Education Handbook, which is available in PDF format by contacting Deirdre at 880.753.2357, familysupport@CdLSusa.org.

A Closer Look: Early Intervention Services

Mason's Story

We want to thank Mason's mother, Maria, for sharing Mason's story and experiences with us.

At first, my husband and I were not only overwhelmed with the diagnosis, but with the constant traffic of people in our home. As time went on and Mason started doing things and interacting with us more, we realized just how valuable early intervention is. Mason was approximately five weeks old when he started receiving services. While in the neonatal intensive care unit (NICU), a social worker had explained early intervention services (EIS) to support us and offered a couple of agencies in our area.

We chose Easter Seals for Mason because they helped my late sister (who had Spina Bifida) throughout most of her younger years, so we were familiar with them. The EIS coordinator came to our home the week after Mason came home from the NICU. Shortly after the initial meeting, a group of therapists came over to evaluate him and start a plan.

Mason receives many therapies through EIS: physical therapy, speech therapy, occupational therapy, swim physical therapy, and music therapy. A hearing therapist also sees him. Mason has received equipment to assist him with everyday activities such as a gait trainer, bath chair, exercise balls, an anti-roll bar and pictures to communicate. Most of the therapists come to our home weekly for one-hour sessions, and we also do swim therapy at our local university's therapy pool.

We have seen tremendous progress over the last eight months with Mason. He is combat crawling, rolling everywhere, and cruising at the back of the couch. He's become more vocal and is starting to point to pictures or items that he wants. He most recently started pointing to his eyes, nose and mouth when asked. We will be starting the transition process shortly as Mason will be three in March and out of the program. We are very pleased with the programs and services offered for Mason. We just wish that the cut-off age was five.

The therapists, service coordinator and parent consultant with Easter Seals have been extremely supportive not only to Mason, but to us as parents as well. They have downloaded the growth charts and have read all the information on the Foundation's Web site to better serve Mason. They are constantly looking for ways to help him move forward and reach goals that we have set. They also helped us obtain an iPad for Mason through our local Lions Club. When they asked if Mason could represent Easter Seals as their child ambassador, we jumped at the chance to help them. Mason has been to two events as an ambassador: a University of Rhode Island basketball game and an Easter Seals event in May.

Research Grants Awarded

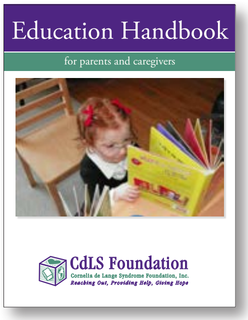
The Foundation awarded more than $20,000 in grants as part of its 2013 Small Grants program.

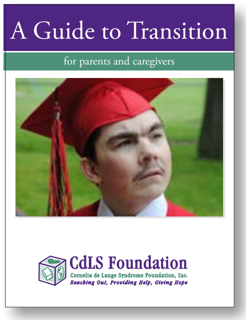
Awardees are:

- Jennifer Gerton, PhD (Stowers Institute for Medical Research): *Treatment of Zebrafish Models for CdLS with L-leucine.*
- Yvon Bryan, MD (Wake Forest Baptist Medical Center): *Airway and Anesthetic Telephone Survey for Children and Adults with CdLS.*
- Clair Francomano, MD (Greater Baltimore Medical Center): *Mitochondrial Dysfunction in CdLS.*
- Yaning Wu, PhD (Children's Hospital of Philadelphia): *Heterozygous Drosophila Models for CdLS.*
- Grantees will report their findings at the Foundation's 2014 Scientific Symposia and in a forthcoming issue of *Reaching Out.*

New Education and Transition Resources Available

The Foundation is excited to announce that it has published a new Education Handbook and Guide to Transition. These are great resources for families as well as education and medical professionals who work with your child. You can request either booklet by contacting Deirdre at familysupport@CdLSusa.org or 800.753.2357.





Clinic for Adolescents & Adults: November 9

The next CdLS Multidisciplinary Clinic for Adolescents and Adults is Saturday, November 9, at Greater Baltimore Medical Center (GBMC) in Baltimore, MD.

The free daylong clinic is led by Foundation Medical Director Antonie Kline, M.D., director of Pediatric Genetics at the Harvey Institute for Human Genetics at GBMC.

The twice-yearly clinic brings together individuals ages 12 and over with specialists from a range of fields, including ophthalmology, gynecology, dentistry, otolaryngology (ear-nose-throat), gastroenterology, nutrition, and behavior.

A Family Service Coordinator from the Foundation attends to provide support.

For more information or to sign up for the November clinic, contact Deirdre at 800.753.2357 or familysupport@CdLSusa.org.

CHOP Offers Monthly Clinic

The Center for Cornelia de Lange Syndrome and Related Diagnoses at the Children's Hospital of Philadelphia offers monthly comprehensive evaluations to address common medical and developmental issues and concerns.

The center offers "virtual consults" as well for those who may be unable to visit from out of state.

Families should verify with their insurance provider whether or not their visit is covered.

If you have questions or would like more information, call Sarah Noon at 215.590.4248 or email NoonS@email.chop.edu.

Choosing an Educational Placement for Your Child

Shelly Champion, M.Ed.; CdLS Foundation Professional Development Committee, co-chair

Regardless of a person's mental or physical limitations, all children with Cornelia de Lange Syndrome (CdLS) have the ability to learn. The goal of education should be to educate the child to develop their full potential. The federal law known as Individuals with Disabilities Education Act (IDEA) mandates that every child is entitled to a Free Appropriate Public Education (FAPE) including an Individual Educational Program (IEP) and in the Least Restrictive Environment (LRE). There are many options available for a child's education. Deciding what is best for your child can be confusing and overwhelming, but with a few suggestions, it is manageable.

The first step is to have the school system evaluate your child - determine the areas of strengths and challenges (what is their best learning style, how to handle behaviors if present, and determine the type of environment that is best for him or her). At the IEP meeting you will talk about your child's strengths and challenges, set measurable goals, look for a setting that fits and that will help your child achieve his/her goals whether it involves communication, academics, social skills, physical skills, getting ready for college, post graduate study, and /or learning work skills.

Once evaluations have been completed and the education team meets, options for the child's education will be discussed. **There are many options available:**

- Inclusion or mainstream class is a placement where your child will be in a regular education class with their age peers. Your child will have a regular education teacher and a special education teacher whose job it is to adjust the curriculum to your child's abilities.
- A resource room is a setting where a child receives instruction outside of the regular education setting with a special education teacher in a small group setting using techniques that are effective for your child. The student is usually with his/her regular education peers for most or some of the day.
- In a self-contained classroom your child is removed from the general school population for all academic subjects and works in a controlled environment with a special education teacher. Self-contained classes provide structure, routine, and appropriate expectations. Students work at their own level.
- While some self-contained classrooms are in the local public school, others are considered out-of-district when the school is outside of your neighborhood. Out-of-district placements do provide specialized instruction to address special learning or behavioral needs. These schools provide a high degree of structure, routine, and consistency throughout the school day. However, they remove any possibility of interacting with regular education students and are costly to school districts.
- Sometimes a private setting is considered and is paid for by the school district if there is no other placement in which the child will receive an education designed to meet any unique educational needs. Some parents may opt to pay for a private school.
- Some children with CdLS require a residential setting in which they live at the school they are attending and receive around the clock care. For some children with severe medical needs, their education may be in a hospital setting.

Deciding which is right for your child is based on his/her individualized needs. Ask yourself what kind of setting your child learns best in. Parents have a lot of input into their child's education since they know if they respond best to rigid schedules and strict discipline or if they blossom with hands-on projects and move at their own pace. You know whether your child has friends that they want to socialize with or whether the mainstream has been unfriendly or dangerous. Does your child enjoy different teachers or prefer the consistency of the same teacher? Research shows that children learn best in the LRE. For some that would be close to home with their general education peers. For others it might be a self-contained setting.

The following are some tips in searching for an appropriate school:

Look at the overall environment. Is the school doing what they say they will? If they are practicing inclusion, are the supports in place for the child in the classroom with the necessary curriculum adjustments. If your child needs a quiet space to calm down, will it be provided, and how? Do teachers use a variety of instructional methods? Are there school-wide projects that can include the needs of your child?

Ask about the principals background and experience with special education (they are largely responsible for the special education programs in the school) and ask the same about the staff, teachers and paraprofessionals. If your child needs close supervision, ask who will be responsible. How are teachers trained and tracked? If your child has both a regular education teacher and a special education teacher, how do they communicate? Do they team teach or is your child taken out of the classroom? Do they meet often to discuss your child's progress?

Ask your child's teacher about assessment, instruction, and evaluation regarding your child's learning needs. What are the assessments and what do they do with the results? Are the results used to determine instructional needs? Are evaluations informative and ongoing or just at the end of units?

It is important for family and school staff to be working together. Does the school have open communication between the family and school outside report card times, either through a notebook, phone calls, email or text? Does the school staff ask for input from the family? Most importantly, does the school feel inviting to you and your child and do you see a happy developing child come home from school every day?

In conclusion, you need to advocate for your child. You know him/her best and can gauge what setting would be the most productive, beneficial and stimulating place for your child to learn in. Not every school can provide services equally, which is why it's important to interview more than one placement. Public and private schools both have services to offer. There is not one best solution. The placement should be monitored closely to determine what is or isn't working. Remember that your child's placement is not permanent. If the placement is not working, your child's behavior is increasing, or he/she is not making progress, you can request that the educational team meet and revaluate the placement. All children are constantly developing: what placement works this year may not be beneficial the next year.

A Closer Look: Educational Placement

Ben's Story

We want to thank Ben's mother, Dena, for sharing Ben's story and experiences with us.

Initially, Ben went to preschool at a parent cooperative preschool one morning each week with me. He was also getting support at home through Child Development Services (CDS) which is Maine's version of early intervention serivces. The development therapist would sometimes come into the preschool to show us techniques on how to work with the other children, or how to share, etc. We then found another preschool through CDS that was entirely children with special needs. Ben received speech therapy, phycial and occupational therapies at that school for about a year.

Then a speech teacher from that preschool started her own private preschool with mostly children with special needs but not all. They focused a great deal on speech and language.

Ben is in public school currently and will be going into 2nd grade in the fall. He's so social and he loves going to school.

I was nervous at first, but that's just like any kindergarten parent would be. He rides the school bus, which was one challenge because we had to fight to get proper seating for Ben. We have an amazing bus driver though and it makes me feel comfortable sending him on there each morning. The principal and school district have been flexible with transportation and giving us the options for Ben to stay in school half the day, or having to leave early for therapy during the school week.

Before Ben started going to public school, we looked into two alternative schools, but the traditional school environment is good for Ben because it's more structured. In our school, they have a Life Skills class from kindergarten to 4th grade. There are multiple aides and they rotate students. We like this model because Ben doesn't get too attached or dependent on one person, but can get to work with different people. He is mainstreamed for some subjects as well. I went into the classroom and talked to the kids about CdLS so they understand it too.

My suggestion for other parents is to keep communication lines as open as possible between you and the school. Think of it as you and the school working together as a team, rather than on opposite ends of the road. We asked for inclusion as much as possible and don't have to fight them on much. Know that there are people out there who do care for your child and want to see him/her succeed.

Alexander's Story

We want to thank Alexander's mother, Christina, for sharing Alexander's story and experiences with us.

Alexander is mildly affected and we felt fine putting him in public school. We have an excellent school system, which is actually why we moved here. He's been in public school since kindergarten.

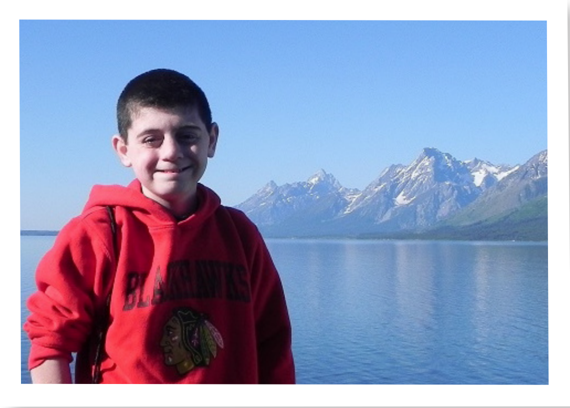
Right away, we knew he had speech problems and so he's been receiving speech therapy since he was two. His teacher suggested he get tested to see if there were services he could qualify for. We didn't even know that was an option, but we were glad his teacher recommended it. We were nervous at first, we didn't know what he would qualify for, or what the school could offer, but we found that they offered many services that we didn't even need to argue or push for.

He's received speech therapy (which he still does for an hour each week) and occupational therapy (OT) which he doesn't receive anymore. He's also qualified for extended school year (ESY) and receives speech therapy in the summer.

continued on next page

He goes to a resource room in school for a little while each week and has an aide with him in the general classroom. She helps him and reminds him to get his pencil out or to take notes. Sometimes she will help him write things down since he has trouble taking notes very quickly.

He has language arts in a special education environment for two hours each day and also attends science and social studies in a general classroom. He also has both a math lab, which is a special education, small group setting, as well as a general math class each day. He's offered a modified curriculum, so instead of four choices on a multiple choice test, he may only have two.



Alexander will be in 8th grade in the fall. This next year, when we review his IEP, a representative from the high school will attend that meeting to make sure he's ready to attend next year. We'll verify the services he'll receive in high school and how we can prepare him best. We hope that he will be able to get his diploma, but in our school system he has to pass algebra to get it, so we'll see how things go. We want him to have the best opportunities for the future.

Learn at Our New Online Module: What is a Medical Home?

The University of Utah developed a Medical Home Portal, which is now available for parents and professionals. What is a Medical Home? A Medical Home is a place where parents and medical care providers come together in a partnership to assure that the medical and non-medical needs of the patient are met. It allows medical professionals from various fields to communicate with one another and the family seamlessly.

One goal of the Medical Home is to help you learn how to better care for your child with chronic and complex conditions, and become a more effective partner in your child's care. The American Academy of Pediatrics (AAP) describes the ideal Medical Home as one that provides, "accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective care."

We encourage parents to share the module their child's care providers. Continuing Medical Education (CME) credits are available. Learn about the Medical Home Portal by visiting the CdLS Foundation Web site at www.cdlsusa.org/professional-education/online-learning.htm. We'd like to thank Dr. Lynne Kerr, for spearheading this project.

Our Deepest Sympathy

Sharon Ortega
August 20, 1973 – April 9, 2013
Daughter of Hester and Merrill McCarty
822 E De La Guerra St
Santa Barbara, CA 93103

Natasha Gail Thomas
October 9, 1973 – March 21, 2013
Daughter of Victoria and Ernest Owens
317 W. High St
Winnsboro, SC 29180

Kathleen Oller
May 25, 1963 – April 27, 2013
Daughter of Anne Oller
PO Box 625
Georgetown, CT 06829-0625

Adam George Steer
May 18, 1971 – June 9, 2013
Son of Patricia and George Steer
62 Paradise Boulevard
Toms River, NJ 08757

Sarah Beltran
August 25, 1978 – May 11, 2013
Daughter of Hila Beltran
3833 N. Braeswood Blvd Apt 427
Houston, TX 77205

Super Siblings: Kathleen and Maegan

For 39-year-old Maegan, email and social media networks are the preferred methods of communication over speaking on the telephone. But a little bit of shyness hasn't stopped her from becoming a lively spokesperson for CdLS. Diagnosed with a mild form of CdLS in adulthood, Maegan has since become a member of the Board of Directors for the Foundation, making her the first Board member with CdLS.

Her sister, Kathleen, an associate professor of anthropology at the University of Alberta, says that having a sister with CdLS has taught her many powerful lessons.

"She's not as judgmental as I am…working as an academic, there is a lot of emphasis on being competitively brainy. Maegan makes me so aware that all of that is just a tiny sliver of the human story. That system of competition (and others like it) doesn't have any categories for 'who is a really good and kind and consistently brave person.' In fact most of the people who are real stars in those categories don't get many worldly rewards at all," says Kathleen.

For Maegan and Kathleen, being a part of the CdLS Foundation has been a rewarding experience. Maegan especially loves the family support network and connecting with other adults with CdLS.

"CdLS is a spectrum, and not everybody is at the same place on it – but just connecting with people who know about that variety of life experience, even if it is not exactly the same, is a big deal. I think the same is true for the connections Maegan has made with self-advocacy organizations for people with disabilities," says Kathleen.

Prior to speaking at the June 2012 CdLS Foundation National Family Conference, Maegan graduated from Partners in Policy Making in 2005. "Before 'Partners' I was terrified of public speaking and phones! Now, it's just phones. 'Partners' gave me the confidence to get up there and present myself to others, to tell my story," says Maegan.

Kathleen was the person who figured out that Maegan had CdLS, so her watching Maegan speak at the conference was a powerful and moving experience.

"I was crying by the end of the first speaker and Maegan was the third! A lot of it was what they said, and a lot of it was the feeling of sharing how proud you are of this person with other people – not just family members, but people you don't even know – and knowing they get it and feel it too," says Kathleen.

Kathleen says that Maegan has introduced her to a lot of comedy and music and art that she wouldn't have otherwise heard about. The sisters enjoy laughing together and watching British comedy television, and in the summer time they go on vacation with Kathleen's two-year-old daughter, Rose.

Kathleen says that one favorite memory she has is riding the bus with Maegan and her daughter.

"Maegan knows all the routes and planned a great one for Rose. She was over the moon and it was all because her 'Auntie Em' was so thoughtful and created such a perfect adventure for her!"

Mailbag

– Paula Jane –

Hello there,

My name is Paula Jane. When I was born, back in the 1950s, I had many problems which made me the mystery gal of the family. My parents took me to several doctors, all of whom came up with different diagnoses.

From the beginning, at five pounds, three ounces, I was born with a dislocated hip. For quite a while I wore a splint that made me look and feel like a frog. The left side of my body was smaller than my right. I even had a dent on the left side of my small head, different from my soft spot. That was just on the outside of me.

On the inside, I had tummy troubles. My digestive system was working overtime, and I cried a lot. At last my mother found a doctor who came up with the correct formula and I became a much happier baby. My broken hip mended itself and my whole body began to heal. It took me a year to learn to roll over, sit up and stand by myself and another year to walk. I began to grow a little and I developed a sweet personality, becoming more aware of my surroundings. I received much love and attention from my mom, dad, sister and family.

Back then it was believed that mystery kids like me didn't live beyond 25 years. CdLS wasn't heard of in our neighborhood then, but there were other mystery kids. Special facilities were built for them. Our doctors urged my folks to look for a good, healthy placement for me. I was full-time care so after much looking and many decisions, I started a whole new life-style in a different situation. It seemed like I have lived at college all my life. Dorms, classrooms, work and play activities, music and dances, festivals, vacations at the beach and Special Olympics. The University of Florida Medical School is where I learned about CdLS and my short leg. I have wonderful, caring people looking after my best interests. My family has lived near me most of the time. We visit, go on outings and attend meetings with staff. My communication skills are limited. Few words, but facial expressions and emotions help me get to know you and you to know me.

My reason for having my mom write this was to let you know that I, this mystery lady, have fooled everyone. They said 25 would be the magic age for me to leave this world. Ha, ha, I turned 61 on my last birthday. I am doing quite well…my latest gift given to me is a rocking chair. It helps to keep me calm and at my age, I deserve it, don't you think?

-Paula Jane and mom Jackie, FL

Submit your Mailbag or Super Siblings Story!

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

WELCOME NEW FAMILIES

California
Amy and Andrew and daughter Marissa, born April 24, 2013

Maria and Daniel and daughter, Dariele born May 11, 2013

Colorado
Katie and Bryan and son Hayes, born July 17, 2012

Florida
Tina and daughter Payton, born December 9, 2009

New Hampshire
Elizabeth and Ryan and son Jake, born October 4, 2009

New York
Nicole and Nic and daughter Aubrey, born April 29, 2013

Nicole and Robert and son Landon, born April 3, 2013

Ohio
Becky and David and son Monte, born April 12, 2013

Event Highlight:

Dress Down Day at Fielder Electric

The Fielder family and its office staff hosted a Dress Down Day for CdLS on May 10, 2013, in conjunction with National CdLS awareness Day and in honor of their daughter, Jaclyn. Photos from the event prove that it was a creative way for this group to celebrate CdLS awareness and raise funds for the Foundation. The group was able to raise $6,500. This year's theme was sports teams. The staff has already chosen next year's theme: superheros.

Share a cup of hope

3rd Annual Grandparents Tea
September 8
RSVP by August 15

Join other grandparents by inviting your most treasured friends (they need not be grandparents) to share a cup of hope in honor of your grandchild on Grandparent's Day.

Invitations, teabags, envelopes and RSVP/donation cards are included in your Grandparent's Tea packet.

Contact events@CdLSusa.org to request your invitations.

2013 CALENDAR

August 24
Northeast Region Family Gathering
Owls Head, ME

September 7
West Region Family Gathering
Oakley, CA

September 15
The Saratoga Palio
Saratoga, NY

September 16
25th Annual Madison County Wood Products Golf Tournament
Pevely Farms Golf Club,
St. Louis, MO

September 28
Maddy's Run 5K walk/run
Salt Lake City, UT

4th Annual Brew and BBQ
Sweetwater Brewery,
Atlanta, GA

Southwest Region Family Gathering
Harvey, LA

October 5
Manhattan Beach 10K
Manhattan Beach, CA

October 12
Baltimore Running Festival
Baltimore, MD

ING Hartford Marathon
Hartford, CT

Midwest Regional Gathering
Menesha, WI

October 13
Chicago Marathon
Chicago, IL

October 19-20
3rd Annual Arzillo Industries Softball Tournament
Virginia Beach, VA

November 3
ING New York City Marathon
New York, NY

November 9
CdLS Multidisciplinary Clinic
Baltimore, MD

November 10
Sarah's Bowl
East Bowl Family Fun Center
Batesville, IN

For more scheduled events visit calendar.cdlsusa.org

Donor Spotlight: JD Carpets

John Marken, CEO of JD Carpets, in Parkville, MD, and his daughter Kim Canatella, president of the business, have committed to send a monthly contribution of five percent of their sales to the Foundation.

"CdLS has been a very important part of our lives since the birth of our angel Lindsey in 1987," said Kim, Lindsey's aunt. "When we were in need and lost, they helped us find our way. They gave us the love and support that we needed to understand what challenges we would face. Our customers at JD Carpets. have also been loyal and supportive since 1969. We have been blessed to have many good people, businesses and religious organizations help us to build a strong and healthy business."

Though Lindsey passed away at age 20, John, Kim and their family have remained active in fundraising for the CdLS Foundation, through various efforts, including the "Tootise Roll Benefit" with John's Knights of Columbus group, bake sales and other volunteer opportunities.

"We felt that it was time for us to step up to the plate and give back to the people that supported us for so many years. In memory of our angel in heaven coupled with the generous support of our customers, we decided to donate a portion of our monetary sales to the CdLS Foundation. We wanted to give back to an organization that gave us so much."

5K Club – A Story of Inspiration

5Ks are a great way to get active, get healthy and give back to the CdLS Foundation. They provide a fun and unique way to fundraise. The Foundation is starting a **5K Club** so that individuals and groups who want to take on the goal of a 5K can do so easily.

Read about 13-year-old Shay, who decided to run in honor of her cousin, Michael, who has CdLS.

"I had to decide on a mitzvah project, which involves giving back to others. I felt that I wanted to raise money for the CdLS Foundation. I decided to find a 5K and run for the Foundation. I felt that this would be a great way to honor my cousin. I went online to find a 5K race that was not too far from where I live.

The race was a great experience for me and enjoyable too because I ran with my uncle and cousin. As I was running, I felt good inside, since I was doing something to help others. That feeling helped me complete the race.

I felt a sense of accomplishment as family members cheered. I had done it; I completed my goal of running in a 5K while raising money for CdLS. It was an experience I will never forget and one I will keep close to my heart forever."

Team CdLS
5K
CLUB
www.CdLSusa.org

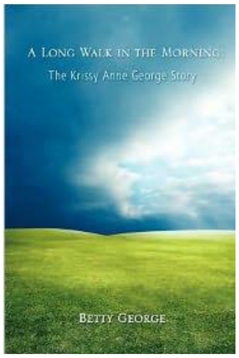
If you would like to take part in a 5K in your area, and join the 5K Club, please contact Brenda at bshepard@CdLSusa.org.

When You "Shop CdLS," You Give Back

Donating to the CdLS Foundation is made easy when you shop for these products!

iGive: At more than 700 online stores, when you shop through iGive, the CdLS Foundation automatically receives a donated portion of the purchase price. There are no codes and no need to notify us—all you have to do is shop. When iGive members shop via special links (starting at the iGive.com web site or having installed the iGive Button), tracking enables us to identify the purchases of each individual iGive member with a member ID number. The Foundation will then receive 100 percent of the donation amount, which is advertised on the iGive Web site. Check it out by visiting www.iGive.com, and get started today.

A Long Walk in the Morning: The Krissy Anne George Story by Betty George. Buy a copy of this book, a non-fiction work about the joys and frustrations of raising a child with CdLS and a portion of proceeds will go to the CdLS Foundation. Learn more at BettyGeorge.net



Katie Luyt Inspired Charity: Purchasing ViSalus Science Body by Vi and Rodan + Fields Dermatology products through this charity will provide contributions back to the CdLS Foundation. For more information, or to register, visit http://supportotherkaties.com.

Federal Employee Giving Campaign

The CdLS Foundation is a confirmed charity by the U.S. Office of Personnel Management for inclusion in the Fall 2013 Combined Federal Campaign (CFC). Federal employees donating through a CFC should provide the Foundation's CFC number to identify the Foundation as a recipient of their gifts. The CdLS Foundation's CFC number is: 11777. This code is only for federal employees and is only applicable for CFC donors. Therefore, if you participate in other state campaigns, local public sector campaigns and/or corporate campaigns they will have different codes. It is recommended that donors confirm the Foundation's code in their own workplace campaign giving guide. If you would like more information or have questions regarding employee giving, please contact the Foundation at 800.753.2357.

¡Buscamos voluntarios!

Nos gustaría empezar a ofrecer un boletín de noticias trimestral traducido para nuestras familias hispanohablantes y buscamos voluntarios que estén dispuestos a traducir su contenido. Si le interesa ayudarnos a hacer llegar información valiosa a las familias hispanohablantes de todo el país, email Deirdre en familysupport@CdLSusa.org.

Además, muchas familias hispanohablantes se ponen en contacto con nosotros para comunicarnos que les gustaría entablar relación con otras familias. Si ser un "Coordinador hispanohablante" le parece una buena manera de ofrecerse como voluntario para nosotros, email Deirdre en familysupport@CdLSusa.org.

Al convertirse en un recurso para la Fundación CdLS y para otras familias en cualquiera de estas capacidades, usted ayudará a transmitir información valiosa, recursos y tranquilidad a las familias que buscan respuestas a sus dudas.

Cornelia de Lange Syndrome Centers of Excellence Renewed

The Greater Baltimore Medical Center, Saint Louis University School of Medicine, Children's Hospital of Philadelphia, and the University of California, Irvine, have been distinguished by the CdLS Foundation as Cornelia de Lange Syndrome Centers of Excellence for a second five-year period. These designations recognize the named institutions' continued excellence and outstanding achievement in research and/or clinical work related to CdLS. "The work done by these professionals and facilities continues to mold the future of CdLS research and care and how it applies to the CdLS community as a whole," said CdLS Foundation Executive Director Marie Concklin-Malloy.

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On the Cover

Henry, cover boy, is 19 months old and is a super happy, smiley little guy. He loves to cruise around the house and play hide-and-seek. For a year now, he has been army crawling and just last week he finally started doing a real crawl. A lot of the time he likes to tuck his head under and check out what his legs are doing, so he looks like a little charging rhinoceros. It's adorable!

Henry is a very vocal little guy and likes to make lots of noise when he's excited about something. He only has one consonant sound and one vowel sound, but is learning American Sign Language (ASL) and has three words: more, eat/food, and mom. Henry makes friends everywhere he goes. We don't know if it's his amazing hair and killer eyelashes, or the fact that he's a shameless flirt, but he has his therapists and doctors wrapped around his tiny baby finger.

We could never express just how thankful we are for all of Henry's medical providers, interventionists, special education teachers, and therapists.

Abigail, Henry's mom, CA

Donations from 3/31/2013-6/30/2013

Gifts that Count - In Honor/Celebration

Aaron Birdwell
Newcastle Public Schools

Adam Jackson
Dorothy and Daniel Steimke

Adrienne Patterson
The Gifted Wedding

Ajit S. Dhillon
Puneet and Yuvraj Dhillon

Alexander Nicolazzo
Gretchen and Kenneth Bates
Rare and Associates

Alexys Spencer
Christine Thode

Alyssa Larson
Linda Starr

Amy M. Stead
Jean Stead

Angela S. Latham
Latham's Hardware

Aubrey Garigen
Mary Beth Saba

Barbara Edwards
Luanna and William Fielder

Barbara Winnerman
Anne Cahn

Brian Drach
Alice Hultmann

Brian Kahn
Andrea and Marc Needlman

Camden Robbins
Jean and Keith Beach
Debbie Lark

Christie Rouse
Kim and Rick Pataky

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Rilette and Jerry Hugo
Cheryl and James La Roe

Corinne Canning
Maria and Maury Paslick

Cristian J. Reza
Julissa and Jesus Reza

Daniel Lopez
Maria Rodriguez
Sonia Ayon-Diaz
Lucia Rodriguez
Alicia Rodriguez

Dean B. Light
Jeanne and Marc Kniedler

Declan Presmyk
Cassandra Northup

Delaney Green
Lori and John Green

Devon Webster
April and Kevin Clark
Judith and Donald Schroeder
Rosemary Webster
Michele and John Birtch
Luann and Jim Webster

Diane Friedman
Lois Braverman

Dylan K. Fuller
Gail and William Baxley

Elisha Massey
David Chapter #21 O E S

Ella G. Musial
Elizabeth Musial-Martey
Kay Love
Peggy and Lonnie Harrington

Emma Perez and in memory of her Great Grandfather Robert Thompson
Barbara Herochik
Beverly and Gary Gessner

Eric M. Loftus
Karen Szukalski
Amy and Chris Loftus

Eric Solomonson
Gordon Gnasdoskey

Ethan Fischbein
Andrea and Marc Needlman

Ethan Walters
Penelope Keating
Candace and Shane Kelly

Finn Thomson
Lorraine Derby

Gracey Belle Hampton
Legence Bank

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Gary Hartman
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Andrea and Marc Needlman

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Sandra and Stuart Kaufman
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Tom Nugent
NCCECE Staff

Trinity Malone
Sandra McCalla

Winifred Connor
Layne and Bill Benedict
Connie and Phalen Schuler
Joan and Dwaine Thill

In Memory

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Durkin Family
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Cheryle Campbell
Sally and Ronald Donald
Karen Gallagher
Rebecca Curtis

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Judy Wendell
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Christopher Bennett
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Lee Lund
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Linda and Leonard Donofrio
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Ethel Kochiss
Mary and John Eckert
Milford Pediatric Group, P.C.

Samantha Sorvino-McGowan
Barbara Lucaci

Sarah Beltran
Board and Staff of the CdLS Founfation

Sharon Ortega
Board and Staff of the CdLS Founfation

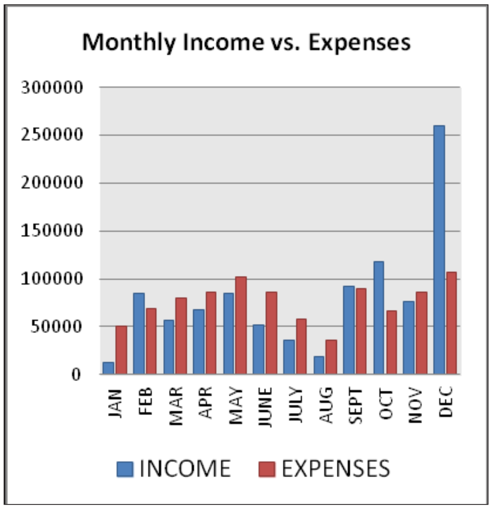
Help us Take the Lead

Come-from-behind wins are always exciting to watch, but are stressful to manage.That's what it's like here at the CdLS Foundation, as we operate at a loss eight to ten months out of the year, and then hit a homerun in the last inning. In fact:

- 60 percent of annual revenue is received in the last quarter
- 25 percent of that revenue is received in December (see chart for a visual)

Most people make their charitable gifts at the end of the year. We need donors to change their mindsets and give earlier.

Giving a year-end gift early, or in monthly installments, increases cash flow during slow months and helps the Foundation take the lead earlier. To discuss your giving for 2013, contact Gail at 800.753.2357 or events@CdLSusa.org.



2011

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street #100
Avon, CT 06001-3681
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Yes, I want to be an all-star for people with CdLS.

Enclosed is my tax-deductible gift of:
☐ Other $_______ ☐ $500 ☐ $250
☐ $100 ☐ $50 ☐ $35

☐ I have included the CdLS Foundation in my will or trust

☐ Please Charge $ _________ to my credit card
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Donate online at www.CdLSusa.org.

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Kindness begins with you.

A small gesture of kindness can mean the world to someone, especially if that someone is dealing with the challenges of Cornelia de Lange Syndrome (CdLS). A caring smile or encouraging words are often all that are needed to brighten their day.

You can help inspire others to pass on that kindness by asking them to support the CdLS Foundation in honor of your child with CdLS. We provide everything you need to invite 10 friends and family members to pass on kindness. The kit even includes a Kindness Coin for them to give to someone who has been especially kind to them.

Ready to pass on kindness?
Contact events@CdLSusa.org or 800.753.235.