Director’s Message
Conference 2010

Spotlight
Communication
Back to School

A Closer Look
In the Classroom

Awareness
Tear-out flier

Super Siblings
Michael & Jessica
**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.

A key part of the CdLS Foundation’s mission is to help people with CdLS and their families make informed decisions throughout their lives. That’s a core component of our next national biennial conference, taking place June 24 – 27, 2010, in Dallas, TX. The conference’s theme is *Living & learning for a lifetime* and it focuses on medical, behavioral and educational issues throughout a person’s life.

Thanks to the many volunteers on our National Conference Planning Committee, especially Chair Norm Winnerman and Co-Chair Angie Young, planning for next summer’s event is well underway. The conference will provide updates on medical and research advances, as well as general sessions and workshops covering such topics as behavior, legal concerns, educational issues, and transitioning children into adulthood. There will also be free medical consultations and expanded educational consultations.

For professionals interested in CdLS, we have two offerings. In addition to our fourth CdLS Scientific Symposium, we are introducing an Educational Symposium. This opportunity to bring together professionals with expertise in educating individuals with special needs will only improve the quality of care provided to all children affected by the syndrome.

So, mark your calendar and don’t miss out on the opportunity to live, learn and laugh with other families. I hope to see you in Dallas.

Sincerely,

Liana Garcia-Fresher, R.D., M.S.
Executive Director
director@CdLSusa.org

PS – Please join us in our effort to continue the tradition of providing outstanding national conferences. I’m asking all of the Foundation’s families and friends to donate at least $25 each to help reach $100,000 and make conference a reality. Donate online at [www.CdLSusa.org/give](http://www.CdLSusa.org/give); RSVP to your “invitation to make a difference” (arriving in your mailbox soon); or request your letter-writing fundraising kit at 800-753-2357 or info@CdLSusa.org.
It’s my honor to introduce the CdLS Foundation’s new Educational Advisory Group (EAG). EAG consists of educational professionals from many specialties who volunteer their time to share knowledge about educating children with CdLS. The group is chaired by Shelly Champion, M.Ed., a longtime Foundation volunteer and mother of an adult with CdLS. Shelly also brings 25 years of experience as a special education teacher.

From principals and school nurses to gym teachers and speech therapists, there are many professionals working with children with CdLS in the school setting. Almost daily, the Foundation staff hears from families and professionals looking for advice and best practices for working with students who have CdLS.

Members of the EAG are now available to answer questions about education issues from both parents and professionals. Questions can be submitted online at www.CdLSusa.org by following these steps: Go to the “Be Informed” tab, then select “Ask the Doctor.” A form will appear. Type your question, being sure to select Education in the “Select Topics” menu. (Don’t have access to a computer? Don’t worry. Call in your questions at 800-753-2357.)

Future goals of the EAG include establishing guidelines and recommendations for professionals and families to use when planning educational programs for students with CdLS. The group also plans on creating education-based workshops and regional family gatherings for parents and professionals.

If you know an exceptional teacher or therapist you would like to recommend to join the Educational Advisory Group, call or email Janette Peracchio at 800-753-2357 or familyservice@CdLSusa.org.

GO GREEN

Help the Foundation save money and “go green” by receiving your issue of Reaching Out electronically. Each time Reaching Out is published, you’ll receive an email with a link to the latest issue. The Foundation saves printing and mailing costs while being more environmentally friendly.

To subscribe to Reaching Out electronically, contact Barbara at info@CdLSusa.org or 800-753-2357 and let her know you’re “going green.”
Children with CdLS use many methods to communicate. My daughter brings me a cup or a bottle of juice from the refrigerator when she is thirsty. She will take a person’s hand, lead them to the couch and put her feet on his or her lap when she wants her feet massaged. A child in school will fall out of his seat or throw himself on the floor when he needs a break from work, or if the work is too challenging. Another child will push children in line when he wants their attention. These are all forms of functional communication, in which the child directs a behavior toward another person in order to receive a direct reward or response.

Communication, as defined by Merriam-Webster’s dictionary, is “a process by which information is exchanged between individuals through a common system of symbols, signs or behavior.” This system is referred to as language, which is the code we use to communicate ideas and express our wants and needs. Language is made up of spoken and written words, pictures, gestures, symbols, or other codes.

We communicate for two reasons: (1) to make a request in order to get what we want and (2) for social interaction, such as praise or attention we may receive from commenting on the world around us. It’s important to remember that we can communicate without using speech and its various modifications. Even though speech would be an ultimate goal, for some that isn’t possible.

If a child has limited or no speech ability, this doesn’t mean he has nothing to say. Many children with CdLS understand spoken language, but need alternative techniques to communicate with others. Some children with CdLS benefit from an individualized augmentative and alternative communication (AAC) system. I stress the word individualized because one AAC technique won’t meet all children’s communications needs.

AAC techniques are interventions designed to compensate for the expressive impairments of individuals. These interventions are used to improve the effectiveness of communication through existing means (including speech), as well as alternative systems that temporarily or permanently replace speech. Under the Individuals with Disabilities Education Act (IDEA), AAC systems are considered a type of “assistive technology.” When children are determined to need assistive technology, including AAC, the public school is obliged to provide the necessary devices or adaptations.

AAC includes all forms of communication (other than oral speech) used to express thoughts, needs, wants, and ideas. We all use AAC when we make facial expressions or gestures, use symbols and pictures, or write. People with severe speech or language problems rely on AAC to supplement existing speech or replace speech that is not functional. Special augmentative aids, such as picture and symbol communication boards and electronic devices, help people express themselves. This may increase social interaction, school performance, and feelings of self-worth. AAC techniques do not interfere with the development of speech; in fact, AAC may promote speech development in some children.

Communicating without speech requires the use of alternative symbols. There are two main types of AAC symbols: unaided and aided. Unaided symbols do not require any equipment to produce and include gestures,
body language, vocalizations, and manual signs, such as sign language. Aided symbols require devices, such as communication books, voice output communications devices, and computers. The easiest type of aided symbol is a real object. For example, presenting a cup for a drink is a symbol for being thirsty. Actual photos of the object would be the next step up in symbol representation, followed by line drawings.

It’s important to start the communication at the child’s right stage of development. Not all children can interpret pictures at first and must use objects. As children learn to communicate with individual symbols, these can be put on communication boards or into books. There are also many electronic devices that can generate speech, thereby allowing the user to construct messages. The best AAC system for an individual may include both aided and unaided systems to accommodate a variety of situations.

Teaching a child with CdLS a system of communication is important. Whatever method of communication is decided upon must be geared towards the child’s strengths and needs. Teaching communication alternatives is one way to reduce or prevent behavior problems that stem from frustration. When children acquire functional communication skills and are able to make their needs known, their lives and those of their families and teachers become greatly enriched.

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### Will you go the distance for children with CdLS?

**Become a Team CdLS Phantom Runner**

(No sneakers required)

Don’t be left behind at the starting line.

**Register today by contacting events@CdLSusa.org.**

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### Calendar

<table>
<thead>
<tr>
<th>September 12</th>
<th>October 11</th>
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<tbody>
<tr>
<td>Family Gathering</td>
<td>Team CdLS runs the</td>
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<tr>
<td>Lodi, CA</td>
<td>Bank of America</td>
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<td>September 26</td>
<td>Chicago Marathon</td>
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<td>21st Annual Madison</td>
<td>Chicago, IL</td>
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<td>County Wood Products Golf</td>
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<td>Tournament</td>
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<td>Wood River, IL</td>
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<td>October 3</td>
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<tr>
<td>Team CdLS runs the</td>
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<td>Manhattan Beach 10K</td>
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<td>Manhattan Beach, CA</td>
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<tr>
<td>November 6-7</td>
<td>Board of Directors Meeting</td>
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### Get ready to leap

It’s not too early to gear up for the second annual *Leaps of Love* pledge event next February.

The Valentine’s Day-inspired program—suitable for children in preschool through grade two—raised nearly $7,000 for the Foundation earlier this year.

Children learn about CdLS through a story booklet about Emma, a little girl with CdLS. They also make heart-shaped cards for Emma or another child with CdLS in their community. Participants then collect pledges for each leap they make during one minute. The school or daycare that raises the most money receives a $250 gift card to Barnes & Noble. Children raising more than a set amount also receive prizes.

Email outreach@CdLSusa.org or call 800-753-2357 for an informational sheet you can share with your school’s director or principal. Most schools plan their charitable programs for the academic year in the fall, so don’t wait.

If your school or daycare won’t participate, consider holding a *Leaps of Love* event yourself, recruiting siblings and your friends’ children.
With the new school year right around the corner, it’s time to prepare your child for the transition back to the classroom. Parents and children may feel both joy and dread about starting a new academic year, and there are ways to make the return to school less stressful.

Start transitioning your child back to school towards the end of summer break by talking about school and looking at pictures of her classroom and friends from the previous year. Let her help choose a book bag, school clothes and supplies. Begin wake-up and bedtime routines a few weeks before school starts. Avoid any negative conversations about school or the staff, and don’t talk about missing your child when she is in school. Focus on the positive school experiences that she enjoys.

To prepare teachers and therapists, especially if they are new to your child, it’s important to have a meeting prior to the first day of school. Be sure to provide information about CdLS and let them know about the Foundation and its resources.

Ideally, this introduction would’ve taken place at the end of the previous school year or during summer school (if your child attends), allowing the professionals to see your child in class and become familiar with her level of functioning. The new teacher and therapists should receive reports from the previous year’s staff that shares your child’s preferences and skills.

It’s also helpful if you visit the classroom a day or two before school starts in order to bring any special equipment or supplies your child needs in the classroom. Be sure to call the school office to make an appointment with the teacher at a convenient time. Relationship building begins right away, and it’s helpful if the teacher knows you want to be an active participant in your child’s success at school.

Parents also need time to prepare for back to school. Choosing supplemental child care and shopping for supplies and clothes takes time, but these tasks are important for a smooth start to the new school year. Purchase a notebook to keep a written record of all phone calls and correspondence with the school. Once school starts, ask questions about anything that you don’t understand. Let staff know when you think they’re doing a good job and when you feel that things aren’t going well. Remember, although the teachers are the ones teaching, they’re also learning a great deal from you and your child. It’s rare for teachers to have a student with CdLS during their careers, so you’ll be an important resource to them.

Be an equal, contributing member of the educational team that works with your child. Attend team meetings and open houses, visit the classroom, and participate in special activities. Know what the teacher is doing at school so you can reinforce the skills at home. Find opportunities for your child to continue to learn in school-like settings during school breaks. Sports, music, art, crafts, camps, parks, and community programs can help you and your child discover new interests.

Most important, remember that if your child has a positive attitude towards school, success follows.

Support the Foundation in Style

The CdLS Foundation's online store offers a variety of logo apparel and gifts. From t-shirts and hats to coffee mugs and greeting cards, the store has everything you need to sport the CdLS Foundation, Team CdLS and Leaps of Love logos.

A portion of all proceeds directly benefit the CdLS Foundation and support its efforts to reach out and help families. There's nothing better than supporting a great cause and looking good while doing it.

A CLOSER LOOK: IN THE CLASSROOM

By Jennifer Sangeloty, CdLS Foundation Communications Coordinator

Education is the foundation of life, and regardless of a person’s mental or physical limitations, she or he has the ability to learn. For children with CdLS, like five-year-old Emily, a structured learning environment is essential to development. And throughout the learning process, teachers, like Emily’s teacher, Janet, find themselves learning valuable lessons from their students with special needs.

Emily has been Janet’s student at Newtown Preschool in Newtown, CT, since she was three. Although she teaches a variety of students with special needs, Janet had no prior experience with, or even knowledge of, CdLS. Throughout their years together, Janet learned about the cognitive effects of CdLS, along with how best to help Emily succeed educationally amidst her many inherent challenges.

During the 2008-09 school year, Emily attended school two full days and two half days each week. While there, she participated in physical and occupational therapy twice a week, along with daily speech therapy.

At school, Emily received one-on-one attention, which helped her focus on the task at hand and learn at her own pace. During this time, Janet used Applied Behavior Analysis (ABA) techniques, which provide structured activities designed to reach a variety of learning goals. With a little help from her teachers, Emily has learned how to spell and write her name, understands and communicates more than 70 signs, counts, and colors. She also took on independent tasks, such as feeding herself and washing her hands. Towards the end of the school year, her teachers and speech therapist introduced a new “Go Talk” augmentative communication device to supplement and enhance her communication skills (see page four for more information about communication devices).

Emily’s classroom has always been integrated, with about half of the students having special needs. This integration allows Emily to grow socially and learn to communicate with her peers while promoting acceptance among all classmates. Playtime focused around different play stations, in which Emily interacted with other classmates for a specific amount of time. And at “circle time” Janet led Emily and her classmates in reading, singing and dancing, all of which were accompanied by basic sign language.

Communication between Emily’s teachers and her parents was key. Throughout the year, teachers sent home daily reports of Emily’s activities, behavior and accomplishments. “Communication with Emily’s teachers was very important to us because we wanted to know what she was learning so we could build upon it at home,” said Lori, Emily’s mom.

Emily has made great strides, literally. “When she first went to school, she couldn’t even walk,” says Lori. “Now, she’s running.”

This fall, she’ll be running right to kindergarten.
What do these children have in common?

These children have Cornelia de Lange Syndrome (CdLS), a little-known genetic condition that causes a range of medical and developmental challenges. CdLS is not a one-size-fits-all condition. While many children have the classic signs—small size, eyebrows that meet, thin upper lip, long eyelashes, missing arms or fingers—others are so mildly affected, they go undiagnosed. When these children slip through the cracks, they miss out on critical services that can improve the quality of their lives.

If you think you know someone with CdLS, contact the CdLS Foundation to learn how we can help, 800-753-2357 or info@CdLSusa.org.


Photos by Rick Guidotti, Positive Exposure

a) Happy, smiling faces
b) A zest for life
c) A rare genetic condition

Answer: ALL OF THE ABOVE

Tear out our new awareness flier and post it in your community
Super Siblings: Michael and Jessica

Even before his eighteenth birthday, Michael was working with top-notch scientists and doctors studying Cornelia de Lange Syndrome (CdLS).

Two years ago, the New York City teen spent a summer working in the Children’s Hospital of Philadelphia (CHOP) lab of Dr. Ian Krantz, who led the team that discovered two of the three gene changes responsible for CdLS. The work is close to Michael’s heart because his twin sister, Jessica, has CdLS.

“Being an unaffected twin caused me to ponder some very philosophical things at a very early age. Some of my earliest memories are of thinking, ‘Why her and not me?’,” says Michael, who enters his sophomore year at the University of Chicago this fall.

“I think that my not having CdLS makes it a little bit harder for both Jessica and myself. I knew very early on that she was pretty different from me, and I imagine she could see the same thing.”

Michael got answers to ‘why her and not me?’ and more during his time at CHOP—where he did not spend his time doing intern-like jobs like washing test tubes and running errands. Rather, he built a faster method to query gene sequences.

“About 65 percent of the cases of CdLS are due to known gene changes. CHOP is working to find genes involved in the other 35 percent of the time, but the process to find a gene involved querying a database for five minutes per DNA sequence, and there were 500 sequences. So I decided to build a faster method,” the mathematics major explains.

His work bore fruit. He developed a method that cleanly speeds up the data-mining process. “The parts were available, so I built the wheel.”

Michael says he’s not sure if he wants to be a scientist when he’s older, but he enjoyed the lab environment.

“While a random misfortune played a role in bringing me there, collaborating with smart people to ignite sparks that will light the way to further research taught me a lot about what the sciences can be. And, as I had hoped, some of my longstanding questions were answered.”

WELCOME NEW FAMILIES

<table>
<thead>
<tr>
<th>State</th>
<th>Family</th>
<th>Child</th>
<th>Date of Birth</th>
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<tbody>
<tr>
<td>Alabama</td>
<td>Kristen and Chris and foster child Amber</td>
<td>born August 15, 1994</td>
<td></td>
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<tr>
<td>California</td>
<td>Elvia and Rafael and son Rafael</td>
<td>born June 20, 1994</td>
<td></td>
</tr>
<tr>
<td>Georgia</td>
<td>Audri and son Jacob</td>
<td>born February 3, 2009</td>
<td></td>
</tr>
<tr>
<td>Illinois</td>
<td>Maria and Jerico and daughter Jasmine</td>
<td>born February 5, 2009</td>
<td></td>
</tr>
<tr>
<td>Kansas</td>
<td>Jaci and Devin and daughter Madison</td>
<td>born September 25, 2008</td>
<td></td>
</tr>
<tr>
<td>Kentucky</td>
<td>Elisha and Nathan and son Vance</td>
<td>born June 3, 2009</td>
<td></td>
</tr>
<tr>
<td>Michigan</td>
<td>Linda and daughter Ericka</td>
<td>born May 11, 2007</td>
<td></td>
</tr>
<tr>
<td>Minnesota</td>
<td>Christine and William and daughter Payton</td>
<td>born July 10, 2008</td>
<td></td>
</tr>
<tr>
<td>Missouri</td>
<td>Heather and son Luke</td>
<td>born November 12, 2007</td>
<td></td>
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<tr>
<td>North Carolina</td>
<td>Shannon and Jason and daughter Melissa</td>
<td>born April 24, 2008</td>
<td></td>
</tr>
<tr>
<td>New York</td>
<td>Marta and daughter Mia</td>
<td>born January 30, 2009</td>
<td></td>
</tr>
<tr>
<td>Texas</td>
<td>Beatriz and Domingo and daughter Grace</td>
<td>born September 20, 2007</td>
<td></td>
</tr>
<tr>
<td>Washington</td>
<td>Kelly and daughter Drea</td>
<td>born January 29, 2002</td>
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</tbody>
</table>

Only new families who have given us permission to print their information as of June 18, 2009 are listed above.
**Awareness Around the Country**

**Awareness Day Roundup**
A big thanks to everyone who helped ring in the 20th annual CdLS Awareness Day on May 9. Governors and community leaders around the country issued proclamations; parents handed out information at work and made CdLS goodie baskets for therapists and doctors; and several newspapers ran feature articles about the syndrome (which you can read at our online Media Room).

**Way to go!**
Valerie of Massachusetts was part of a team of 26 adults with developmental disabilities that was honored for its successful advocacy work to change the name of the state’s Department of Mental Retardation to the Department of Development Services. According to the state’s Web site, the new name “reflects the positive changes in language and expectations about the people with disabilities.”

**Awareness by Month program kicks off**
The 2009-10 Awareness by Month program gets underway this fall. Through the program, we ask our 100-plus volunteer Awareness Coordinators (ACs) to perform one awareness-raising activity a month over 10 months. Activities range from speaking at a child’s school to hanging awareness fliers around the community. The Foundation provides a list of activities and the supplies, when needed.

ACs receive their 2009-10 packages this fall, and it’s not too late if you want to get involved. If you are a parent or relative interested in becoming an AC, contact Marie Malloy at outreach@CdLSusa.org or 800-753-2357.

**Paging Dr. de Lange**
As part of her fourth-grade Living Museum project, Natalie of Missouri was Dr. Cornelia de Lange. Natalie provided information about CdLS and a picture of the real Dr. de Lange for students and teachers to see. Since Natalie is non-verbal, her teachers recorded historical information about Dr. de Lange and Natalie played back the recording for people to hear when they stopped by her table.

**Thank you very much**
One family took the opportunity to spread awareness of CdLS by writing the Foundation web site on the wall at Graceland, Elvis’ home in Memphis, TN. “I am a huge Elvis fan. We had a blast and were excited to spread the word about CdLS,” said Angie, mom to Addison, shown here by the wall with her big brother.

**Did you see the Foundation’s new awareness flier on page eight?** Want more copies? If so, call us or download the flier from our Web site. Go to www.CdLSusa.org, then click on “Get Involved,” then “Article and Publications.”
CAROLYN AND RICHARD HOST A YARD SALE IN PENNSYLVANIA IN HONOR OF THEIR GRANDSON, JONAH

This summer, volunteers in 34 states made the commitment to “Tag the Day” for CdLS by organizing a yard sale to benefit the CdLS Foundation. The first annual Yard Sale Across America raised more than $9,500 to help provide vital programs and services to families.

Neighbors, friends and family donated unwanted items, and countless hours were devoted to preparing for the yard sales. This nationwide event allowed hundreds of ardent bargain shoppers to leave each yard sale with both treasures and the knowledge that CdLS exists.

The generosity of Yard Sale Across America participants far extended the CdLS family. All unsold items were donated to other charities.
MAILBAG

— GRACIE —

Hello All,

We would like you to know Gracie graduated from Hillwood High School on Tuesday, May 19th. She has progressed through Metro schools with her class since kindergarten. Although she has primarily been in Special Ed, Gracie is well known and somewhat of a celebrity in her community.

She had a great year – most especially serving as wheelchair chauffeur for her classmate, Michael. He apparently enjoys her occasional “locker bumps” and likes it when she lets go of the chair as they are rolling down the concrete ramps around school. Although these are not happy moments for the teacher, Michael responds with a huge grin and asks her to “do it again!”

Many classmates greet her at the grocery store or restaurants. They smile and interact with genuine fondness and kindness toward her. She has become an expert at faking out her teachers while escaping the classroom. She enjoyed better health this year after fairly extensive dental surgery last fall.

Over the years, many have noted how difficult it must be to live with Gracie’s special circumstances. It is true that life is different and does seem harder at times. But those of you who know us best know, in fact, we are fortunate. Because we are her parents and we love our child as much as any parent, we do not see any choice but to travel this road with our daughter. Along the way, we have been humbled and gratified to serve her. Many times (and more significantly) in spiritual and psychologically beneficial ways, she serves us. She makes us better.

Gracie triumphs in the face of daunting obstacles. Her feet are severely misshapen, making it painful to walk. She is unable to verbally communicate with anyone in this world and she never has a moment’s choice of where she wants to go or who she wants to be with. However, she gets up every morning with a smile on her face and embraces whatever the day brings. She maintains a determined and positive demeanor. Gracie finds humor in most anything, forgives quickly and loves unconditionally.

She may not understand the significance of the occasion, but we and her classmates did. We simply wish to share our happiness with you. For anyone who would like to celebrate in spirit and honor Gracie, we ask you to reach out to someone with a disability, see them as equal and valuable and let them know it.

Thank you for your love and support over these many years.

Therese and Mike, Gracie’s parents, Nashville, TN

— BOZENA —

Dear Reaching Out,

Just a quick note to let the Foundation know that our daughter, Bo, is finally moving into a long term residence program at Matheny Hospital in Peapack-Gladstone, New Jersey. She had been on the wait list for two years and the call finally came. She was officially admitted on Monday, June 1. It will be a major transition for all of us.

When she was born, she lived in the hospital for 3½ years. She came home and has been with us for 15 yrs. Now at age 18½, she is moving on. It comes with many years of decision making but, in doing so, we are not only securing her future but also her two older brother’s future. We felt all deserve the opportunity to see if this would work.

I remain open to correspond with any families facing similar decisions. It does not come easy but, if there was an emergency, I did not want my sons to be forced into facing the burden of this. As a parent, I felt it is my responsibility. I do not know how it is in other states, but the wait lists for services in New Jersey are incredibly long. We were extremely lucky to only have to wait two years for placement. It only came this quick because she was placed on the list while still a child. If I had waited till adulthood, the wait is well over six years.

Liz, Bo’s mom, Cranford, NJ
**Workplace Giving: A Few Dollars a Week Goes a Long Way**

Donating money to the Foundation through your paycheck is an easy way to make a difference in the lives of families affected by CdLS.

If your employer offers a workplace giving program, consider contributing to the CdLS Foundation. If you work for the federal government, you can set up the donation through the Combined Federal Campaign. Our number is 11777.

For other workplace giving programs, simply write in Cornelia de Lange Syndrome Foundation. The Foundation does not have an assigned number from the United Way, but it participates in the Children’s Medical Charities of America, which works with the United Way on the Foundation’s behalf.

For more information, call 800-753-2357 or email info@CdLSusa.org.

**Committee Corner**

*Ordinary People Accomplishing Extraordinary Things*

This issue celebrates the Special Events Committee, chaired by Jay Franciscus (pictured). The committee oversees dozens of fundraising events, from golf tournaments to bowl-a-thons to runs/walks, carried out by volunteers across the country. These events raise more than $250,000 annually for the Foundation.

The committee is charged with creating event manuals and other materials that make managing a fundraising event as effortless as possible for volunteers. These elements also provide consistency and uniformity among events, strengthening the CdLS Foundation “brand.”

If you’d like to share your skills and interest on one of the many new CdLS Foundation committees, email director@CdLSusa.org or call 800-753-2357.

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**Our Deepest Sympathy**

- **Justin Sample**
  December 22, 1980 – February 7, 2009
  Son of Jamie and Sam D. Sample
  4019 Hwy. 14
  Pickens, MS 39146-9801

- **Sean C. Brisbane**
  March 12, 1985 – April 21, 2009
  Son of Nancy and Mike Brisbane
  28 Shannon Crescent
  Spencerport, NY 14559-9757

- **Amaria Moore**
  October 10, 2002 – April 27, 2009
  Daughter of Candace Moore and Marvin Williams
  10210 Mount Arburn
  Cleveland, OH 44104

- **Tara Brown**
  December 17, 1971 – February 17, 2009
  Daughter of Vivian and Frank Brown
  1683 Gold Hill Road
  Independence, VA 24348

- **Madisyn Elizabeth Warner**
  Daughter of James and Jenna Warner
  491 Deering Avenue, Apt. 3
  Portland, ME 04103

- **Lorelati Doria**
  February 19, 2009 – April 10, 2009
  Daughter of Erica-Marie Doria and Mark Schmidt
  PO Box 492
  Liberty, NY 12754

- **Alan T. Jones**
  October 24, 1982 – May 22, 2009
  Jeanette and Alan Jones
  28364 Three Mile Point Road
  Chaumont, NY 13622

- **April Michelle Wilson**
  September 1, 1974 – June 2, 2009
  Daughter of Alice Johnson
  323 Woodside Drive
  Hampton, VA 23669

- **Daniel Krueger**
  August 30, 1988 – May 26, 2009
  Son of Theresa and Kurt Krueger
  7118 Silvermill Drive
  Tampa, FL 33635
If you know of a club or membership organization with a commitment to community service, we have just the program. The Foundation is launching *Pennies for Jessica*, a national coin-drive event aimed at clubs and organizations. The event gives groups like the Kiwanis, Knights of Columbus and others the chance to support a meaningful cause while demonstrating a commitment to children with special needs.

This new program was inspired by Jessica (pictured), a young girl with CdLS from Mississippi, who began collecting pennies for the CdLS Foundation more than a decade ago.

For more information, contact events@CdLSusa.org or 800-753-2357.

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**WISHLIST**

- 100 memory sticks
- Coil or comb binding machine
- Printer ink cartridges
- Digital camera (minimum 10 mega pixels)
- New or refurbished computers
- Phone cards for volunteers
- Postage stamps
- Blank CDs
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*Providing Hope Through Change*
Join us next summer in Dallas for the CdLS Foundation’s biennial conference, where parents, relatives, caregivers, and individuals with CdLS have the opportunity to learn, laugh and love. Part clinic, part classroom and part reunion, the conference offers:

- Free medical consultations with doctor and allied health professionals who have expertise in caring for people with CdLS;
- Information from experts in the fields of genetics, education, law, and others;
- Support in an environment where families’ stories and struggles are the norm, not the exception; and
- New friendships that lasts a lifetime.

For your conference letter-writing fundraising kit or to donate to the Conference 2010 Fund, contact info@CdLSusa.org or 800-753-2357.