

Reaching Out

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

Highlights

Director's Message:

Corporate Sponsorship
Opportunities

Spotlights:

KISS- Keep it Super
Simple: Techniques
for Making Learning
Meaningful

New Services for the
Adults with CdLS
Network

Super Relatives

Izzy and Kaitlyn





Director's Message



Corporate Sponsorship Opportunities

Your philanthropic contributions to the CdLS Foundation have been providing outreach and awareness to families, friends and professionals, free of charge for 35 years. Your continued generosity enables the Foundation to annually expand free services provided to individuals with CdLS and their family members.

I am pleased to report that in 2016, the following new services were introduced:

- CdLS Clinic at Shriners, Salt Lake City, Utah
- Navigating Healthcare Transitions from Pediatric to Adult Medical Care
- Medical Specialty Treatment Cards
- Additional research funding of \$20,000

We recognize the importance of expanding our revenue stream to support new initiatives. In 2017, the staff and board of directors are striving to diversify revenue sources to lessen the burden on individual donors who currently sustain the Foundation's programs and services. A strategic goal for 2017 is to increase corporate giving. Currently, the Foundation receives approximately \$80,000 annually through corporate partnerships, less than 10% of our annual budget. The Foundation offers multiple avenues for corporations to donate, including, but not limited to:

- Monthly or quarterly giving
- Team CdLS sponsorship
- Golf tournament sponsorships
- Percentage of monthly sales
- *Reaching Out* advertising
- Conference sponsorship

Help the CdLS Foundation build corporate partnerships by identifying businesses in your area that are interested in improving the quality of lives of people with CdLS. Direct them to our web site for more information <http://www.cdlsusa.org/docs/2016-sponsorship-opportunities.pdf> or contact me directly at, kbrown@CdLSUSA.org or 800.753.2357.

Kelly Brown
Acting-Executive Director

Our Mission

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

In This Issue

4 KISS- Keep it Super Simple: Techniques for Making Learning Meaningful

6 New Services for the Adults with CdLS Network

8 Super Relatives- Izzy and Kaitlyn

10 Board Corner

12 Conference Collage

16 Volunteer opportunities at the Foundation



Conditions Similar to Cornelia de Lange Syndrome



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

In 2004 it was welcomed news that “the” Cornelia de Lange syndrome (CdLS) gene (*NIPBL*) had been discovered. By 2015, five genes in total had been discovered; yet there are still 30% of individuals with CdLS who will not be positive on any of the tests in the comprehensive CdLS testing panels.

The CdLS Foundation’s mission statement is directed towards helping those with CdLS “and others with similar characteristics”. We aim to be inclusive, knowing that there are many families who have a child with some, but not all, of the typical findings in CdLS. The list of related conditions to the biologic changes behind CdLS (e.g. the cohesin protein complex) is growing, and many of these conditions are much rarer than CdLS, with no family support group in existence.

There is a small number of other conditions that can resemble CdLS, and occasionally individuals with these conditions arrive at our National Conference, instantly aware that their child seems different. This editorial is a brief summary of some of these other conditions.

The following conditions have overlapping biologic changes similar to CdLS:

Coffin-Siris syndrome includes coarser facial features compared to CdLS, with very full lips, prominent forehead, small size, sparse scalp hair, excessive body hair and low muscle tone, along with finger findings such as absence or small size of the last part of the 5th fingers and/or nail. There can be specific brain changes. This condition is due to changes in six different genes (e.g. *SMARCA4*), all of which have similar roles as the CdLS genes in terms of modifying many other genes.

Nicolaides-Baraitser syndrome can also present coarser facial features, small size with difficulty gaining weight, and there can be sparse scalp hair or excessive body hair. In addition, there can be low muscle tone, seizures that are difficult to manage, prominent joints, and significant intellectual disability. This condition is due to changes in the *SMARCA2* gene, which has similar roles as the CdLS genes in terms of modifying many other genes.

Roberts syndrome was the first condition found to be associated with the cohesin protein complex, and presents with small size, cleft lip and palate, and extremity malformation such as missing forearms and the lower aspects of the legs. Individuals with this condition have severe intellectual disability and often early mortality due to inner organ malformations. Mutations in the *ESCO2* gene, which is part of the cohesin ring complex, are responsible for this condition. This does not resemble CdLS as much, but is directly related.

Continued on page 17

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www.CdLSusa.org

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KISS- Keep It Super Simple: Techniques for Making Learning Meaningful



By Emily Taylor-Snell, M.Ed.,
Project Coordinator

When children have difficulty accessing and processing basic communication and information, it is our job to KISS – Keep It Super Simple! Emily Taylor-Snell's presentation at the 2016 National Family

Conference had participants look at learning from the child's perspective so they can see how to set up activities. This interactive, demonstrated and practiced techniques help children maximize their vision, develop tangible communication systems, and practice hand-under-hand techniques in learning motor tasks.

Basis of Content

The tenets of the presentation were drawn from evidence based practice in working with children with dual sensory loss and other complex needs taken from the work of Jan van Dijk, Barbara Miles, Kat Stremel, Charity Rowland and Phil Schweigert.

A few communication techniques presented at the session were:

- Use objects or pictures for communication for choice & requests
- Don't anticipate every need, create need to communicate
- Develop name signs for people and pets
- Make sure activities have a clear beginning, middle and end
- Declutter pictures and areas and use color contrast
- Pause for "more" and turn-taking and transitions between activities hand-under-hand
- Technique vs. hand-over-hand technique

- Routines based learning: Shows HOW activities are done
- Calendar Schedule: Helps anticipate what activity is NEXT
- Include child in daily chores and community activities
- Use fewer commands and have more fun conversations
- Do things together—have two similar items

Ways to engage Early Emergent Literacy, Emily Taylor-Snell suggested:

- Label Objects
- Recipes
- Choice Making
- Logos and Packaging Labels
- Experience Books
- Games that include matching and sorting
- PowerPoint Books

The biggest piece of advice she gave to attendees was, "Be consistent and patient."

WELCOME NEW FAMILIES

Illinois

Elzbieta and daughter Paulina
born May 16, 1995

Nevada

Amira and daughter Amy
born on April 7, 2012

Michigan

Stephanie and son Jacob
born February 24, 2002

Virginia

Emily and Nico and
son Damien
born on December 28, 2015

Nebraska

Lindsay and Matt and
daughter Penelope
born on October 4, 2013



A Closer Look at KISS- Keep It Super Simple



We'd like to thank Kartik's parents, Padmini & Praveen, for sharing their story with us.

At the 26th Biennial National Family Conference in Orlando, Florida, one of the compotent that we took away was the workshop KISS- Keep

It Super Simple: Techniques for Making Learning Meaningful and our interaction at our consultation with Emily Taylor-Snell. We learned about the importance of overall communication and encouragement of all modes of communication, along with making adaptations to lighting, brightness, positioning and contrast.

We have started to encourage Kartik to sit parallel to an object positioned with lighting from behind; we have noticed his eye tracking an object is much better than before. We also noticed that once the lighting and vision is controlled, he seems to balance his body better in that space. See his picture - Kartik is balancing on the couch armrest by himself!

Secondly, we are approaching him with objects then handing them over to him; we use sign language while doing this so he can start making choices. He has sporadic responses, but on the positive side, he is beginning to understand that communication is two-way. He is communicating in other ways, such as asking to be picked up.

Lastly, by playing more "Singing Time with Alex and Leah" videos and rhymes on YouTube that are played by kids (which he loves), he is starting to identify with the child in the videos and responds to the voice of his teachers and therapists.

We feel we have gained immensely with our interaction with Emily Taylor-Snell. The best part about the workshop and consultation was learning easy tips that can be done at home and outside. This information enriches our daily experiences and has shown positive results.

Thank you

Padmini & Praveen

1.800.753.2357



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Development & Early Intervention

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- Developmental assessment in infancy and continuing every one to three years.
- Ongoing developmental services, with school placement and therapy issues individualized. It is likely that most individuals will benefit from physical, occupational and speech therapy.
- The use of sign language is encouraged since this will help facilitate oral communication, as will communication boards and other tools.
- Follow up with appropriate subspecialists as needed.
- Discuss job training or work issues, higher education.
- It is important that individuals with CdLS be evaluated and followed at some regular interval for gastroesophageal reflux (GER). Unexplained pain/discomfort or acting out may be due to an underlying medical condition. Management and treatment guidelines are available www.cdlsusa.org.
- Ensure that the family has the CdLS Medical Alert Card, available from the CdLS Foundation Web site, which would be helpful in an emergency situation (e.g. risk for volvulus).

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



Cut this out and share with your child's doctor.



New Services for the Adults with CdLS Network



*Justyna Wawrzynuk, L.M.S.W.,
CdLS Foundation, Family Service
Coordinator*

The Adults with CdLS Network met at the 2016 CdLS National Conference in Orlando, FL this year. Those in attendance were asked to share their vision for what types of services they would like the CdLS Foundation to provide for adults with CdLS in the future. The group did a wonderful job of brainstorming some very creative and thoughtful responses. Some of these responses included, expanding opportunities for adults with CdLS to connect with one another through the Foundation; creating a “Help Me Explain” card that can be handed out to teachers, employers, etc., explaining CdLS; and a space/forum on the CdLS Foundation web site where adults with CdLS are able to submit personal achievement stories and/or honor important people who have made a difference in their life – just to name a few.



We would like to thank everyone who contributed to sharing these ideas and giving us a fresh point of view. For the majority of the time of the Foundation’s existence, services were focused towards family members or professionals. It is really exciting for us (the staff) to be able to hear from individuals with CdLS and to take their ideas and turn them into reality.

Currently we are in the planning stages of revamping our web site in order to encompass some of the ideas shared by the Adults with CdLS Network. The first web site features (available in January 2017) will be the “Connect

with Peers” and “Cornelia’s Corkboard.” The “Connect with Peers” feature is an online form that will allow adults with CdLS to request to be matched with other adults with CdLS in their state, region, age group or by hobbies. Once the electronic form is submitted through the web site, Family Service Coordinators will facilitate the initial connection and be available for any additional support as needed. “Cornelia’s Corkboard” will provide adults with CdLS who wish to share their experiences with the world; a space to display a collection of stories, photos and updates.

We extend the opportunity for all teens and adults with CdLS to share their ideas and feedback, even if they were unable to participate at the Adults with CdLS Network group at Conference. We want to know what all teens and adults with CdLS would find helpful in terms of support and services offered by the CdLS Foundation moving forward. Please contact Family Service Coordinator, Justyna Wawrzynuk, at 800.753.2357 or email at familyservice@CdLSUSA.org to share all of your great ideas. No idea is too big or too small, and we want to hear them all!

2016 - 2017 CALENDAR

November 12, 2016
Southeastern Family
Gathering
Mt Pleasant, SC

December 3, 2016
Western Region Family
Gathering
Sebastopol, CA

November 29, 2016
Giving Tuesday

March 19, 2017
United Airlines NYC Half
Marathon
New York, NY

December 3, 2016
One Love One Heart 5k
Decatur, GA

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/M35LJY5>



A Closer Look at the Adults with CdLS Network



It's been a while since I last attended a CdLS Foundation event (the last one being a family gathering in Salt Lake City, UT), so I was really excited to attend the CdLS National Family Conference in Orlando, FL this year. It was a fun experience for me to meet others with CdLS, and it

was fun seeing friends again and talking with them and just being around others with the same syndrome that I have. It feels good to be able to just hang out and talk to others who understand me, and talk about ideas we have for new services for our group- The Adults with CdLS Network. I have to say that the conference was the most exciting thing I did all summer, and of course cookouts with my family.

It can be hard staying connected with the CdLS Adult Network because we don't get to see each other that often, as conference happens every two years and not everyone can always attend. There aren't too many CdLS families or CdLS events in Idaho, so it's hard to meet with my CdLS friends often. I try to stay connected with my CdLS friends through Facebook and email and this helps me feel connected. Sometimes it can be hard to communicate or get the right words out, but it's nice to know I am not alone.

I am excited to hear that the CdLS Foundation is working on new services for the adults with CdLS. I would love to see a website or Facebook Group for "Adults with CdLS". I would also like to see the Foundation start an "Adults with CdLS" get together or a gathering every six or 10 months where we could do something fun. I can't wait to see the new services for the Adults with CdLS that the Foundation is working on and start using them soon.

CdLS Registry

CoRDS, or the Coordination of Rare Diseases at Sanford, is based at Sanford Research in Sioux Falls, South Dakota. It provides researchers with a centralized, international patient registry for all rare diseases. This program allows patients and researchers to connect as easily as possible to help advance treatments and cures for rare diseases. The CoRDS team works with patient advocacy groups, individuals and researchers to help in the advancement of research in over 7,000 rare diseases. The registry is free for patients to enroll and researchers to access.



Enrolling is easy:

1. Complete the screening form.
2. Review the informed consent.
3. Answer the permission and data sharing questions.

After these steps, the enrollment process is complete. All other questions are voluntary. However, these questions are important to patients and their families to create awareness as well as to researchers to study rare diseases. This is why we ask our participants to update their information annually or anytime changes to their information occur.

Researchers can contact CoRDS to determine if the registry contains participants with the rare disease they are researching. If the researcher determines there is a sufficient number of participants or data on the rare disease of interest within the registry, the researcher can apply for access. Upon approval from the CoRDS Scientific Advisory Board, CoRDS staff will reach out to participants on behalf of the researcher. It is then up to the participant to determine if they would like to join the study.

Visit sanfordresearch.org/CoRDS to enroll.



Super Relatives - Izzy and Kaitlyn



In 2011, Izzy and I married into the Fischer family. My husband is one of eight children, and they are a close-knit group. They are crazy, loud, kind, sarcastic, and most of all, they are loving. I will never forget the first time Izzy and I met his family.

We went to his sister's house after his niece's first communion. I was very nervous because I had no idea how they were going to react to Izzy. However, within two minutes, one of his sisters came over and scooped her out of her infant seat, grabbed her feeding tube and machine and off they went. Everyone circled around her, greeting her and loving on her. Within a couple of minutes, my nerves turned into happiness. Everyone was so accepting and anxious to get his or her turn to hold and play with her.

Kaitlyn, the oldest of the Fischer-grandchildren has always set a good example for the younger kids. She is one of the most kind hearted young ladies I have ever met, and I get the pleasure to call her my niece. Kaitlyn has always approached Izzy as a little person rather than someone with a disability. Currently, Kaitlyn is a junior at Iowa State University. Last fall, she had to do a group project for one of her classes. As a team, they had to create a product to sell, and donate the profit to a charity, they had to make at least \$100 profit to successfully complete the project.

Kaitlyn proposed creating a Christmas-themed Iowa State sweatshirt, and donating the proceeds to the CdLS Foundation. Kaitlyn not only took the lead role in the project, but she also took the time to educate her peers and professor about CdLS. In the end, Kaitlyn and her team raised over \$600, which was donated to the CdLS Foundation.

I don't think that Kaitlyn could possibly understand how much it meant to me that she took the time to fundraise, educate, and advocate for Izzy and the other children with CdLS. She is an exemplary young lady who lights up any room with her beautiful smile and kind heart. Izzy is so extremely lucky to have her as a cousin and advocate.

Mailbag – Brian



My name is Nancy Drach, and my husband Dave and I have three sons: Aaron, 28; Alex, 24, and Brian, 22, who has Cornelia de Lange Syndrome (CdLS).

When Brian was born in February 1994, the doctors knew something was wrong, but did not know what. They

immediately did a chromosome test, but that did not show anything. Throughout Brian's first year, he had so many issues that we now know are tied to CdLS: reflux; very little weight gain or growth; sinus, ear, and dental infections; undescended testes; minor heart defect; goopy eyes; tight torso and heel cord muscles, etc. Since Brian's hair was not black, and he had his fingers and toes, it was not something that could be easily diagnosed. However, we kept pushing forward, and kept asking questions.

When Brian was a year old, my neighbor told me about a dentist/geneticist at the University of Minnesota. We called him, he asked us to send a photo of Brian, then immediately diagnosed Brian through that photo. We then went back to Brian's pediatric geneticist who confirmed the diagnosis.

While we likely would have had Brian's medical needs addressed even without a diagnosis, we were able to get a much stronger starting point for Brian's "race" in life, with a diagnosis. We were able to get connected to the CdLS Foundation, and through there, were able to get a much larger support network of friends and family.

The diagnosis and support from my network has also allowed me to have more courage and confidence in advocating for Brian, as he is nonverbal. It is difficult to get him to use any sign language, and he just takes apart talk machines (along with everything else!). Whether it was when I spoke up to the experts when Brian had severe medication side effects after spinal surgery, or when I felt his self-induced vomiting, then head banging seemed to become learned behaviors during puberty, I realized my best asset as Brian's advocate was to be observant and



tuned in to him. My confidence and the resources have also allowed me to work more effectively with medical, behavioral, and educational professionals. I understand experts have a lot of education and experience, and I easily respect the vast majority, but what I can do is help them understand Brian better.

Although Brian is now a young man, we still struggle with some of his behaviors, and continue to make shifts with medications. It's also harder to find medical and behavioral experts who are also "special needs" experts for adult children with CdLS, especially when they are nonverbal. But, Brian's worth the effort.

The best advice I can give to parents is the advice I continue to follow myself: ask questions from reliable sources, listen, talk, communicate, and connect. Also, remember to laugh, cry, have fun with your loved one with CdLS but also have fun with friends. Go ahead and fall apart while planning when and how to put yourself back together. Persist, persist, persist. Remember, our loved ones with CdLS have to do most of this each and every day, so why not us?

Share your Mailbag or Super Sibling Story!

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

On the Cover: Sarah



Sarah is a 19-year-old young woman who attends a special program at her local high school where she is learning life skills. She is non-verbal, but uses the LAMP app on her iPad, as well as sign language to communicate. A highlight for her last year was the opportunity to attend homecoming. She had fun

dancing the night away with her cousins!

Sarah is very social and has a magnetic personality. She makes friends wherever she goes and is happiest when surrounded by family and friends. She is also a greeter at her church.

Sarah's wish for her own swimming pool was granted last year through the "Make a Wish" program. She used it almost every day throughout summer! Sarah loves balloons, riding her bike and doing puzzles. She enjoys playing on the Miracle League Baseball team, where her brother, Noah, is her buddy. She also attends music therapy with friends.

Sarah has not missed a CdLS conference since she was born and some of her favorite memories include her CdLS family.

Family Gathering Hosts Needed

In 2017 we are looking to coordinate family gatherings in RI, IL, TX, MN, OR, AR and FL. Gatherings are a great way to meet other families, share stories and meet with professionals familiar with CdLS. Contact Deirdre Summa at familysupport@CdLSusa.org for more information.





Board Corner



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

It's easy to think of the CdLS Foundation as an office in Avon, CT with people there for the families and friends of those with CdLS. In addition to the office staff in Avon, the

CdLS Foundation consists of over 20 organized groups with a network of well over 100 volunteers that work to ensure the CdLS Foundation is the primary source of information and support for every person who has or knows someone with CdLS. These groups of parents, friends, professionals and people with CdLS give their time and energy to connect others to the resources each person needs. Board Member Mary Opitz shares, "I have always been impressed with and grateful to the Foundation staff for their love of our children and their dedication to our vision and mission. I have also been impressed with our families and how much they give of their time and talent in support of the Foundation and the families it serves."

The Board of Directors are a group of volunteers who work to help provide direction towards the future for the Foundation so it continues striving to improve the lives of all individuals with CdLS. This December the seven extraordinary individuals below will step down from the Board after providing their insight and voice to the Foundation for six years; although each of them has been involved with the Foundation for much, much longer. Each member is appreciative of the opportunity to serve on the Board, and we are extremely grateful for their efforts.

- Shelly Champion, mother of Julie (Massachusetts)
- Michele Churchman, mother of Josh (Delaware)
- Dianne Lessa, mother of Valerie (Massachusetts)
- Charlie Madrid, brother of Vanessa (Texas)
- Mary Opitz, mother of Katie (Texas)

- Fran Rissland, mother of Riley (Georgia)
- Beth Smisloff, mother of Will (New York)

The efforts of this group of dedicated volunteers can't easily be summarized in this column, as they're often operating behind the scenes in many efforts you may recognize, all while caring for themselves and their own families. They've worked tirelessly behind the scenes to ensure the CdLS National Family Conference, Family Gatherings, Brew and BBQs, the New England Golf Tournament and Team CdLS are growing, connecting people and raising awareness for CdLS. They've also used their own experiences to develop materials that provide the most up to date information for professionals and families who strive to care for each person with CdLS.

In the midst of those efforts, they also call out to each of us to use our skills to become more involved in growing the CdLS Foundation. Shelly Champion shares, "I'm thankful to have been on the Board. I have seen and experienced so much growth in this exceptional organization. I will continue to be part of the CdLS community, meeting and helping individuals with CdLS and their families. I know from experience how valuable connections are when one has a child with a disability."

Dianne Lessa shares, "As part of the Board and also the many committees that I am on or have been on, I have learned so much about the Foundation and also about the syndrome. The Foundation staff is made up of a wonderful group of caring and knowledgeable people, but it is also made up of a huge group of people who volunteer in one way or another. It is so fulfilling to be part of this wonderful organization. I would recommend that if you are not involved, join a committee, help out at a fundraiser, or become an awareness or regional coordinator. You will not be sorry – it is so rewarding."

Fran Rissland says, "Anyone can fundraise! Whether on the Board or not, I encourage everyone to do something – whether it be a bake sale at school or a lemonade stand on the street. Every little bit counts! Those efforts, no matter how big or small not only raise funds to grow the Foundation, but also awareness of CdLS and the important efforts of the CdLS Foundation to support the needs of everyone with CdLS."

Take the time to call or email the Foundation and find out ways that you can become more involved in shaping



the CdLS Foundation of the future. It is only through our combined efforts that we are able to reach our goals. As Beth Smisloff reminds us all, “The Foundation isn’t just an office filled with hardworking and dedicated people. The Foundation is a collection of each person who participates; parents, caregivers, family members, teachers, doctors and scientists. The more we all participate in research studies, fundraising and awareness events, the more we can grow our understanding of CdLS, which will help us all reach our collective goal: to improve the lives of individuals with CdLS.”

de Lange Society Class of 2016 Inducted

The de Lange Society induction was held on Saturday, June 25 at the 26th Biennial National Family Conference dinner banquet in Orlando, Florida. The 9 inductees (6 in attendance) received recognition for 20 years or more of service, volunteerism and support to the CdLS Foundation.



Acting Executive Director, Kelly Brown, congratulates the class of 2016 de Lange Society members (listed left to right): Kelly Brown, Kari Cunningham-Rosvik, APRN, and her Daughter Iselen, Lynn Audette, L.M.S.W., Michele Churchman, Mary Opitz, Ron Berger, M.D., FACS, and Linda Berger. Not in attendance Luanna Fielder, Elizabeth Fouts, Ph.D., and Brian Luyt.

COMING SOON!

New publications covering topics such as Single Parenting, Marriage Survival and Advice from Other Dads and more!

Taking Care of Me and From One Dad to Another: Raising a Child With Special Needs.

Award Recipients Honored at 2016 Conference

The CdLS Foundation relies on volunteers around the country to successfully implement many services and ideas. The following individuals were recognized for their years of dedication and efforts to create new programs, enhance scientific endeavors and provide a significant impact on the Foundation and the families served.

Sue Anthony Award: Angie Young

The Sue Anthony Award is the Foundation’s highest award and is named for our primary Founder and the co-ordinator of Reaching Out. Sue Anthony represented innovation, commitment, integrity, and enduring contributions to families living with CdLS.

President’s Award: Bob Boneberg

The President’s Award is presented to an individual whose considerable, long-term efforts on behalf of the Foundation have made a notable impact and advanced its mission.

Special Recognition Award: David Cataline & Julia Clemens

Special Recognition Awards are presented to individuals or organizations whose efforts on behalf of the Foundation have made a specific impact. This award may be given to a nominee for a single, significant and notable contribution to the Foundation.

Dr. Laird Jackson Award: Ian Krantz, MD

The Dr. Laird Jackson Award, inspired by the Foundation’s first medical director, recognizes an individual’s significant medical or scientific contributions toward understanding CdLS and improving the lives of people affected by the syndrome.

Outstanding Philanthropy Award: Dena & Daniel Borgia

The Outstanding Philanthropy Award recognizes outstanding individuals or organizations whose long-term contributions of financial support, time and talent have made a significant impact for individuals with CdLS.



2016 CdLS Foundation National Family Conference

Stronger Together

In June of 2016, 146 families attended the 26th biennial National Family Conference in Orlando, FL. Families spent three days becoming stronger together.







CdLS Symposium Recap

The Seventh Biennial CdLS Foundation Scientific and Education Symposium brought together 55 individuals from across the country and around the world. The event was a huge success, not only in the quality of the abstracts and presentations, but also in the discussions, and supporting sponsorships.

Over 30 presentations were given during this two day event, including the following 2015 Small Grants Program recipients:

- Communication Intervention for Nonverbal and Minimally Verbal Individuals with CdLS, Siddharth Srivastava, M.D., Kennedy Krieger/Johns Hopkins Medical Institute
- Role of NIPBL in Neocortex Organoid Development, Jason Mills, Ph.D., Children's Hospital of Philadelphia
- An Evaluation of Autonomic Dysfunction in Individuals with CdLS, Lynne Kerr, Ph.D., M.D., University of Utah Medical Center
- Use of Blenderized Diets for Gastronomy Feeding in Patients with CdLS, Sarah Noon, M.S., Children's Hospital of Philadelphia



"We all had fun...I was very taken with the high level of organization and the amazing amount of love and caring in the organization."

-Barry C.

2016 Research Grant Recipients Announced

As part of its 2016 research grants program, the Cornelia de Lange Syndrome (CdLS) Foundation awarded a total of \$45,000 to researchers studying various aspects of CdLS. The following projects were funded:

Phenotypic evaluation of patients with SMC1A mutations and intractable epilepsy, Kristin Baranano, M.D., Ph.D., Johns Hopkins University

This study will explore the question of whether there is a distinct syndrome associated with SMC1A mutations and intractable epilepsy. Thorough phenotypic analysis will help better delineate the spectrum of CdLS and identify issues specific to this group of patients, which may lead to insight as to appropriate medications or therapies.

Genetic analysis of a new Cornelia de Lange-like Syndrome (CdLS), involving TAF1, Gholson J. Lyon, M.D., Ph.D., Cold Spring Harbor Laboratory

This study explores a recently discovered X-linked intellectual disability syndrome associated with sequence variants in *TAF1* (which the researchers are currently calling *TAF1* Syndrome). Finding shared and non-shared transcriptional signatures between the various conditions will further uncover basic mechanistic insights into disease formation, thus setting the stage for potential treatment developments in the future.

Somatic Mosaicism in Cornelia de Lange Syndrome, Sarah Noon, M.S., The Children's Hospital of Philadelphia

This study aims to further investigate the role of somatic mosaicism in CdLS and determine its prevalence. The ultimate goal is to use information gained from this study to help develop guidelines for a comprehensive testing strategy that is efficient and effective in obtaining molecular confirmation of a CdLS diagnosis, thus allowing for a more timely diagnosis with early intervention to better optimize outcomes.

Researchers are required to present their findings at the next CdLS Scientific and Educational Symposium (June 27-28, 2018, in Minneapolis, MN), and write an article about their study results for the CdLS Foundation newsletter, *Reaching Out*.



Event highlight: Brew & BBQ for CdLS

We are very excited to announce that the 7th Annual Brew and BBQ for CdLS in Georgia, raised more than \$6,300, bringing the event's lifetime total to over \$30,000 raised over the past seven years.



Hosted at the North River Tavern in Sandy Springs, GA, the event was also sponsored by Kiddos' Clubhouse. Long-time event hosts Francesca Rissland and Suzanne Musial, pictured left, continue to put forth great effort in making this event a success year after year, in support of the Foundation and in honor of their children, Riley and Ella Grace.

"The CdLS Foundation is very near and dear to our family," said Rissland, pictured right. "After Riley was diagnosed at 17 months old we were beyond devastated. I found the CdLS Foundation and was greeted by Lynn, one of the family service coordinators; I knew we had found the right place. Fast forward and I found myself a proud member on the Foundation's Board of Directors and a Regional Coordinator for the state of Georgia."



Thank you to Francesca, Suzanne, and all those who supported this event through charitable gifts, raffle donations, or sponsorship. Cheers!

24th Annual CdLS Charity Golf Tournament

Family and friends within the New England region raised \$60,000 for the CdLS Foundation at the 24th annual New England Golf Tournament held on Monday, May 23rd at the elite Ipswich Country Club in Ipswich, MA.

The New England Golf Tournament was established 24 years ago by families who lived within the New England area. Many of the committee members still serve on the committee and volunteer. As the event continues to grow, the committee is seeking to expand and encourages families within the New England region to participate.

The event included a dinner and auction for 110 golfers and 35 dinner guests. Evercore, Inc. of Boston, MA (pictured below) earned the 2016 Sponsor Cup Champions and Overall winners. Contest prize winners in the women's division were: Denise Teixeira (longest drive) and Linda O'Keefe (closest to the pin). In the men's division, Rich Bohane earned the spot for closest to the pin and Matt Bradley had the longest drive.



The CdLS Foundation New England Golf Committee recognized the Eagle Sponsor: KeyBanc Capital Markets; the Birdie Sponsors, BMO Capital Markets, RenMac, Donald A. Sadoski, DMD, the Teixeira Family, Evercore ISI, Craig-Hallum Capital Group & DA Davidson Companies; Hole-in-One Sponsor, Acura Peabody. The committee also recognized Cart Sponsor IRG Focus and Beverage Sponsor Striker Partners.

Interested in being a part of the New England Golf Tournament Committee?

Contact: Kristi Larson, Development Manager,
800.753.2357 or Klarson@CdLSUSA.org.

New England Golf Committee Members:

Shelly Champion
Ava Frank
Dianne Lessa
Pat Lyons
David Moltzan
Brian O'Keefe
Denise Teixeira
Frank Teixeira



Volunteer opportunities at the Foundation

You've got the skills we need. We have no doubt that out in the world are individuals who have just a few extra hours each month they can put to use here at the CdLS Foundation. We're looking for additional volunteers to help serve on various committees, and initiatives we hope to pursue. If you want to get involved, we have a space for you. Here are just a few ways you can give back to the CdLS Foundation without opening your checkbook:

Bilingual families

Our goals include providing better resources and support for the Spanish-speaking families we hear from. If you are bilingual in Spanish and English, you can be a life-saving resource for families across the country. Let us know if you're interested in learning more about becoming a Spanish-Speaking Coordinator volunteer for the CdLS Foundation. Email Justyna Wawrzonek at familyservice@CdLSusa.org for more information.

Graphic designers

With so many initiatives taking place, we're always looking for help creating new materials, from social media graphics to design and layout of booklets. If you have experience in graphic design, we'd love to have you assist us in these efforts. Email Francesca Scognamiglio at communications@CdLSusa.org to get started.

Committees

The Public Affairs Committee guides the Foundation in its public outreach efforts, including media relations, legislative advocacy, and the Awareness Coordinator program. Contact Kristi Larson, klarson@CdLSusa.org, for more information on joining this committee.

The Family Services Committee guides the Foundation in development, implementation and evaluation of information, resources and support services to families whose children have CdLS throughout the lifespan. Contact Lynn Audette, families@CdLSusa.org, for more information on joining this committee.

The Research Committee keeps the board apprised of scientific developments related to CdLS, and its members possess the appropriate research/medical background to

make recommendations related to research. Contact Kelly Brown, kbrown@CdLSusa.org, for more information on joining this committee.

The Conference Planning Committee oversees, coordinates and evaluates the Foundation's biennial national conference; assuring that the conference addresses identified needs of the families of children with CdLS. Contact Kelly Brown, kbrown@CdLSusa.org, for more information on joining this committee.

The Finance/Investment/Audit Committee oversees, evaluates and directs the Foundation's activities to achieve the financial health of the Foundation; oversees finances through regular financial reporting; and creates and reviews financial policies and procedures. Contact Kelly Brown, kbrown@CdLSusa.org, for more information on joining this committee.

The Planning Committee assists the board with its responsibilities for the organization's mission, vision and strategic direction. Contact Kelly Brown, kbrown@CdLSusa.org, for more information on joining this committee.

The Development Committee oversees efforts to seek external funding as it relates to such external programs as corporate donations, foundations/grants, clubs and organizations, special events, national conference, and federated campaigns. Contact Kristi Larson, klarson@CdLSusa.org, for more information on joining this committee.

The Team CdLS Committee leads the way to new initiatives for our charity race team, including marathons, walks, 5Ks, phantom runners, and so many more sporting events. Contact Kristi Larson, klarson@CdLSusa.org, for more information on joining this committee.

The Professional Development Committee is responsible for planning, developing, and coordinating the Foundation's professional programs and services. Including, answering Ask the Expert questions, reviewing IEP's and providing consults at clinics and conferences. Contact Justyna Wawrzonek, familyservice@CdLSusa.org, for more information on joining this committee.

Want to give back in another way? Call us at 800.753.2357 or email info@CdLSusa.org for more information on how to get started.



Conditions Similar to Cornelia de Lange Syndrome cont.

Other conditions which appear similar to CdLS are:

Chromosome disorders can have similar features, particularly duplications of the short arm of chromosome 3, with facial resemblance to CdLS, excessive hair, intellectual disability and small size. The mouth appears different and there are no thin arched joined eyebrows as seen in many individuals with CdLS. Brain changes can be much more severe and there can be more limb findings, including extra fingers or shortening of the limbs. Most individuals with CdLS will have had a SNP microarray, which should pick these changes up.

Fetal alcohol spectrum disorder is when a fetus has been exposed to alcohol consumption by the mother and is a difficult condition to diagnose. The disorder has some facial features seen in CdLS; including small size and head circumference, intellectual disability and significant behavioral issues, particularly ADHD and oppositional defiant disorder. These individuals do not tend to have small hands and feet, or significant speech and language delays, as we primarily see in CdLS. There is no test available; diagnosis is made based on maternal history.

Floating Harbor syndrome presents with small size, some similar facial features; including, small chin but often a wide mouth, and usually normal head circumference. Skeletal findings can include very prominent joints and wide tips of the fingers. There can be intellectual disability,

behavioral issues and organ system involvement which can overlap with CdLS. Some individuals will have changes in the *SRCAP* gene, but most are negative on testing.

Fryns syndrome involves having excessive hair and some similar facial features, but also some overlapping internal organ malformations such as cleft palate and diaphragmatic hernia. The mouth tends to be much wider and usually size is normal at birth. This condition is generally more severe than CdLS and can lead to early death. No specific gene change has been associated.

Rubenstein-Taybi syndrome includes small size and head circumference, excessive hair on body and sometimes face, and intellectual disability. There are some similar facial features such as small chin, but the shape of the nose is very different. The thumbs and great toes are very broad. These noted different facial features and digit differences are usually helpful in differentiating the syndromes. Individuals with Rubenstein-Taybi syndrome have less internal organ malformations, as well. Two genes (*CREBBP* and *EP300*) are associated with this condition.

There are many more conditions that could potentially overlap with or appear similar to CdLS. We are always willing to try and help direct families to other support organizations, or provide advice if the findings overlap clinically.



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
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PO Box 20383
Sarasota, FL 34276

Regan Lee
June 17, 2011 – February 23, 2016
Son of Sarah and Brian Lee
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Sawyer, ND 58781

Nylah Cherry
August 29, 2014 – February 24, 2016
Daughter of Kendra Cherry
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Pineville, LA 71360

Abby Dawn French
April 24, 2004 – March 14, 2016
Daughter of April and Mike Pemberton
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And Derek French

Jenna Kraemer
September 1, 1984 – April 7, 2016
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Grand Blanc, MI 48439

Emery Raye-Ann Vinson
May 4, 2010 – May 18, 2016
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Richard Veal
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Son of Nancy Veal
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Jayden Vera
January 11, 2016 – June 28, 2016
Son of Arcelys and Bryan Vera
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Nola Ricci
September 17, 2015 – July 18, 2016
Daughter of Tara and Christopher Ricci
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Travelers Rest, SC 29690

Paula Hauffe
February 27, 1952 – August 22, 2016
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Visit the CdLS Foundation **#GivingTuesday** Donation page to support the CdLS Foundation as part of **#GivingTuesday!** This is a fast and secure way to support the Foundation during this special time of year.

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