

# FOCUS

Foundation

Winter 2015

**CdLS Foundation**  
Cornelia de Lange Syndrome Foundation, Inc.



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A publication for donors and friends of the Cornelia de Lange Syndrome (CdLS) Foundation

## Foundation Focus

Published Since 2010  
Cornelia de Lange Syndrome  
Foundation, Inc.

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# DIRECTOR'S MESSAGE

## Building On Success

As the Foundation wraps up its 2013-15 strategic plan, I'm happy to report successful completion of our goals and objectives. As we transition into a new strategic plan for 2016-18, we also say goodbye to Marie, who was integral in accomplishing our goals, including the creation of a CdLS clinic on the west coast in San Jose, CA, creation of a CdLS Registry, and an increase in Foundation-sponsored family gatherings. I am extremely grateful for her leadership and guidance, and will continue to build on her success.

The 2016-18 plan, approved by the Board of Directors in July, calls for continued increase in research funding, establishment of CdLS clinics in the Midwest and Southwest, expansion of our biggest fundraiser—Team CdLS—into new regions, and creation of publications covering important social and family issues.

- This new plan, just like the previous one, was created from input from participants in a strategic planning survey last fall and personal interviews earlier this year. Some program goals of the 2016-18 plan are:
- Ensure high quality medical care that reflects our most current evidence-based diagnostic and treatment procedures for common medical issues in CdLS.
- Equip and empower families to make informed decisions about their child's health, development, education, and future.
- Cultivate an environment that sustains and grows quality and relevant clinical and molecular research.

On the operations side, our goals—which are determined by the Board and staff and support the program goals above—include increasing revenue by 20 percent over three years, and partnering with like syndrome groups in an effort to share resources and create alliances to solicit funding/grant support. If you have questions or comments about the Foundation's strategic plan or its process, don't hesitate to contact me at 800.753.2357 or [kbrown@CdLSusa.org](mailto:kbrown@CdLSusa.org).



Kelly Brown  
Acting-Executive Director



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## 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.

## Thank You 2015 Team CdLS Sponsors

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### 2016 Partners Needed

With many new initiatives planned for 2016 and beyond, the CdLS Foundation is looking to expand its partnerships with our friends, sponsors and anyone else who understands the importance of the services we provide to families.

In 2016, we will continue to offer our staple programs; regional family gatherings, multi-disciplinary clinics, free publications and National Family Conference. We are also expanding our goals to grow the care options for families around the country. The spring issue of our family newsletter, *Reaching Out*, will be devoted to treatment and management guidelines to help families advocate for proper care.

New initiatives in 2016 include: a webinar presentation welcoming new families, conference vignettes, a publication for Fathers, online learning modules for professionals, online resources for adults with CdLS, increased research funding, and expansion of our outreach to professionals.

Funding is critical to provide these programs and services free of charge. The 2016 budgeted expenses are nearly one million dollars of which \$900,000 is spent directly on family support programs, professional outreach and awareness, research, and public information and education.

Whether it's a small monthly gift, or a larger corporate donation, we need your help in financially supporting these initiatives in order to serve as many families, professionals and individuals with CdLS as possible.

### Foundation Honored as 2015 Top-Rate Nonprofit



The CdLS Foundation has been honored with a prestigious 2015 Top-Rated Award by GreatNonprofits, the leading provider of user reviews about nonprofit organizations.

"We are excited to be named a Top-Rated 2015 Nonprofit," says Kelly Brown, Acting Executive Director at the CdLS Foundation. "We are proud of our accomplishments this year. The Top-Rated Nonprofit award was based on the large number of positive reviews that the CdLS Foundation received – reviews written by volunteers, donors and constituents. People posted their personal experience with the nonprofit, and they've found their experiences to be positive over the years."

One reviewer wrote: "We could not have survived the last 30 years without the friendship, support, advice so generously and compassionately offered from the staff at the CdLS Foundation. Even with director and employee changes through the years the CdLS Foundation employees are dedicated, caring and top notch! I'd give them 10 stars!"

Being on the Top-Rated list gives donors and volunteers more confidence that this is a credible organization. The reviews by volunteers, donors and constituents show first-hand testimonials of the impact of the CdLS Foundation. This award is a form of recognition by the community.

"Savvy donors want to see the impact of their donations more than ever," said Perla Ni, CEO of GreatNonprofits. "People with direct experience with the CdLS Foundation have voted that the organization is making a real difference."

# MEET OUR NEW BOARD MEMBERS

It is our pleasure to introduce our newest members of our Board of Directors, starting in January 2016.

## Jim Kesting, Missouri



Jim is the president (soon to retire) of Madison County Wood Products (MCWP). His business partner has a daughter with CdLS, and this has inspired Jim to invest a strong stake in the Foundation. He and his colleagues at MCWP, have helped in hosting a CdLS golf tournament for 27 years. A graduate of Saint Louis University, he currently serves on the Development Committee and is a member of the de Lange Society class of 2013.

“My wife, Joyce, and I have been involved with CdLS since our first gathering at the old

Walmart in Fredericktown, MO. My business partner’s daughter, Amber, was born in 1981, and we attended that first fundraiser in her honor. I was so moved by these children and the struggles that their parents go through, I wanted to somehow make a difference in their lives. With the help of many, I started the Madison County Wood Products Golf Tournament for CdLS, and just celebrated its 27th year, raising nearly \$600,000 dollars. I am also proud of the research being done by Dr. Dorsett at the St. Louis University Research center, just down the street from our corporate headquarters. It will be my privilege to serve on the board, build and continue the great works of the past.”

## Katherina (Katie) Nikzad-Terhune, Ph.D., LCSW, Kentucky

Katie is a Licensed Clinical Social Worker with a doctorate in gerontology. She currently works in private mental health, and has ten years of experience as a therapist. Her primary focus is working with adults, couples, and families in the treatment of a variety of mental health issues, caregiving stress, and relational matters. Katie is a graduate of the University of Kentucky, where she received her Ph.D. in Gerontology. She is an adjunct professor at the University of Kentucky, and has published in the fields of social work, gerontology, and nursing. She is an appointed member of the Ethics Committee for the National Association of Social Workers (Kentucky Chapter), a member of the Gerontological Society of America, and has served as a board member for a non-profit organization for the past six years.



“I am very honored to become a member of the board of directors. Although my sister is no longer with us, I can help continue her legacy by being part of an organization of visionary leaders who strive to enhance our knowledge of CdLS through advancements in research, medicine, genetics, and the ways in which we serve CdLS families. I cannot think of a better way to honor my sister’s life and memory.”

Katie currently serves on the Family Services Committee and has written articles for *Reaching Out*. Her sister, Natalie (who passed away in 1993) had CdLS.

Bob  
Boneberg

## Bob's Farewell

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

I am writing my last message as president with great appreciation and profound humility. CdLS Foundation Board members serve a maximum of two consecutive three-year terms and, as my six years end in December, it is appropriate to thank those who have made my Board service so very special to me. It has been a privilege to have been associated with the CdLS Foundation for many years.

During the time that I have been privileged to serve on the Board, I have been helped and guided and inspired by many, many people beginning, of course, with all the past and present members of the Board who volunteer to serve. I have tried to learn from, and be guided by, each of you. Also, I thank the Foundation staff who helps the Board as they help so many others, with skill, insight and patience. Thank you also to the many doctors, scientists, social workers, and other professionals who not only address the problems of today, but also help the Board think about the best way to meet the challenges of tomorrow. Thank you very much also to the friends and supporters who help the Foundation in many ways, seen and unseen. Truly, without your efforts, the Foundation would not be what it is today.

And, most especially, thank you to all those who have been diagnosed with CdLS and their families and friends. I have met and spoken with you at family gatherings and conferences and at places in between. Thank you for your advice, suggestions, your good humor and your support. You are our Foundation.

As a parent, I have been grateful for the support of an outstanding staff and appreciative of all those who made the Foundation what it is. As a Board member, I have been permitted to serve with selfless people who are dedicated to the improvement of the Foundation. Now, as the Foundation is developing a Vision Statement, I am excited to see what the Foundation and all its stakeholders plan for the future. I know that you all will continue to guide and support the Foundation and its Board, and I look forward to seeing how the Foundation grows and thrives in the years to come.

I look forward to seeing you again just around the next corner.

All the best,  
Bob Boneberg



Bob with his son, Alex, and wife, Karen.

## FINDING HOPE THROUGH SUPPORT (AND MUD)

*By Shawn Carr, father to Layla Ann*

My wife, Kim, and I were expecting a baby, Layla, in May of 2014. During Kim's 20 week ultrasound we were informed that Layla was not developing properly and that we had cause for concern. We spent the next five months back and forth to The Children's Hospital of Philadelphia (CHOP) and our local doctor conducting test after test in order to determine why Layla was not developing accordingly. Despite the advanced testing, physicians were unable to diagnose Layla in utero, however we were aware that when she arrived she would be coping with heart disease as well as multiple other problems associated with some sort of syndrome. Layla was born on May 22 and placed in the Cardiac Intensive Care Unit at CHOP. The following day we learned from the national expert that she had Cornelia de Lange Syndrome (CdLS) and that she was on the severe end of the spectrum. Layla was with us for a few short, beautiful days before sadly passing away in our arms from a heart condition associated with the syndrome.

Between the five months of gut wrenching unknowns and the birth and death of Layla, Kim and I were distraught. We were lucky to have immense support from family and friends throughout the entire ordeal. We discovered the Cornelia de Lange Syndrome Foundation after Layla's diagnosis. In order to help cope with the loss of our daughter, we felt that we needed to get involved with the Foundation. What better way to get involved than a mud run! My brother, Ryan, and his girlfriend Bailey, along with my sister-in-law, Suz, some

other friends and myself participated in our first 10k mud run in Warminster, PA. With the help of many generous people we were able to raise over \$14,000 for the CdLS Foundation. Kim joined us this past summer for another mud run where we continued our fundraising efforts, and we plan to do so for many years to come.

We have also had additional family members become involved with the Foundation. My mom, Connie Kelly, owns CK Pilates, a pilates studio in Marmora, NJ, and my sister, Kristy Holt, owns Eco Chic Blossoms, a floral design shop in Wilmington, NC. Both Connie and Kristy donate a portion of their profits to the CdLS Foundation throughout the year. During one of Connie's Pilates fundraising events, we were able to meet a few families with children who have CdLS and it touched our hearts to know how much the Foundation has helped them through the years.

Becoming part of the Cornelia de Lange Syndrome Foundation family has meant the world to us. We see it as a way to honor the memory of Layla. By assisting families that are affected by this syndrome and creating awareness, it helps to provide a vehicle for our healing. Before Layla, we had never even heard of CdLS. Our hope is to continue to administer support and awareness in whatever means possible.



### The CdLS Clinic at Santa Clara Valley Medical Center

Debuting in December 2014, this CdLS clinic in San Jose, CA, has a core team consisting of a geneticist, genetic counselor, neurologist, gastroenterologist, psychiatrist, nurse, and a social worker. A gynecologist will also be available. The clinic will be held twice annually and is open to all ages. A Foundation-trained volunteer attends. Insurance authorization is required. If you are interested in this clinic please contact Lynn Audette, L.M.S.W., Family Service Coordinator at 1-800-223-8355 or [families@CdLSusa.org](mailto:families@CdLSusa.org).

The next clinic will be held Monday April 11, 2016.



#### Caitlynn's Story

*We want to thank Caitlynn's mom, Tracey, for sharing their experience with us.*

We live about five hours away from San Jose, CA, just north of L.A., and even though it was a long drive, we figured it was worth it to see all different kinds of specialists, all on one day, one right after the other. It's been pretty rare to find even one CdLS specialist, so this trip to see many specialists at once made it worth it.

We had a great experience, and everything went really smoothly. Right from the start, while we were filling out paperwork during the registration process, we were seen right away. We didn't have to wait at all and when you have a child with special needs, it makes it a really smooth process. We have two kids with special needs, and when we have to take the whole family, doctor visits can be quite the challenge, but it was so pleasant all the way around.

While we were waiting in the waiting room – we talked with another family who had an infant. Their child was

born at the same hospital, taken care of in the ICU by the same doctor. It was special for us to connect, because Caitlynn is 18 and grown up, and I can only imagine their thoughts about their child growing up.

We saw a gynecologist who addressed some concerns about Caitlynn's cycle. She goes to school, and can get a heavy cycle, so we asked about birth control. Most doctors shy away from it all, but the woman here made us so comfortable about the whole thing. The GI specialist gave us some really great ideas. Caitlynn pulls out her G-Tube a million times a day, but got some ideas on how to get her to leave it alone. Caitlynn's also had a hard time having a large volume of formula, but the nutritionist was able to adjust her formula so that she would be getting the proper amount of nutrition; and more calories per ounce.

The level of expertise and advice specific to CdLS they were able to give us far surpassed any doctors we've taken Caitlynn to. All six of the professionals we saw were in the room with us at the same time, which was fantastic. We didn't have to keep repeating ourselves, and when they were making suggestions, others would chime in with new ideas as well. I found it even more valuable than going to conference – they were all with us at the same time. It was so much more personal and they spent so much time with us. We're planning on going back, most likely every other year, per their suggestion, to check in.



You share the joy and struggles of your child's life with others who care for, and want to see success in their future. At the Cornelia de Lange Syndrome (CdLS) Foundation, we have become a part of your team as well. We share in your joys and triumphs, and we share in your hardship and sadness.

You've supported us in the past, but we're asking you to give once more this year. This 2015 Annual Appeal, with a goal of \$25,000, will support new projects in 2016, including increased research grant funding, additional online resources and publications.

We know there is strength in numbers, and we need your family to help us now. You and your loved ones can also make a donation online, by visiting [donate.cdlsusa.org](http://donate.cdlsusa.org), or can donate by mail, or by phone to 800.753.2357.

## Help make a difference in the lives of children with CdLS!

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