Reaching Out

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

Highlights

Director's Message:

Conference from a Parent's Point of View

Spotlights:

CdLS Clinics Across the Country

New CdLS Foundation Publication

Super Siblings

Team CdLS Super Siblings Abound

302 West Main Street, #100 | Avon, CT 06001-3681 | 860.676.8166 | toll free: 800.753.2357 | fax: 860.676.8337 | www.CdLSusa.org

Director's Message

Conference from a Parent's Point of View

By Jose Diaz, father to JD, who has CdLS

Hello CdLS family,

I am truly honored to first have been able to attend the 2014 conference, and more so now to share my experience of the conference. My son, JD, was diagnosed with CdLS on July 1, 2012. Naturally, as a parent, you begin searching the Internet for all the information you can find to learn about CdLS, and how to best mitigate the syndrome in your child's life. The most comprehensive information and support came to us from the CdLS Foundation's website and later, the National Family Conference in 2014.

As a father of a child with CdLS, the conference gave me a completely new perspective on the syndrome and how to deal and cope with the emotions I had raising my son. Interacting with parents who were also dealing with the same issues and concerns that I was going through really helped me to feel that I was not alone and could lean on a support group who understood my concerns. The parent group sessions were phenomenal, along with the seminars with the doctors from the CdLS Foundation Clinical Advisory Board (CAB).

Meeting and speaking to the experts in the field, who are the ones making the advancements and discoveries to better comprehend the syndrome, was extremely valuable to me because it allowed me to see just how involved and vested these doctors and the Foundation are to supporting and helping families with loved ones diagnosed with CdLS. My wife, son, and two daughters will be at this year's conference in Orlando, and we are looking forward to meeting new families at the conference, so that we may provide the same support that gave us so much peace in our lives these past two years.

We are very thankful for the Foundation staff and CAB professionals, and look forward to meeting several new families in Orlando as well.

Go Green with *Reaching Out*

We know you love reading the articles here in our *Reaching Out* newsletter, but did you know you could get access to each issue before it hits your doorstep? Many others have already joined the "green movement" and receive this newsletter by email four times each year. It's fast, easy to access, and saves paper in the process.

By requesting to receive this newsletter by email, you can share it with even more family members and friends, because forwarding emails is limitless. You can even share the publication on Facebook and other social media sites too.

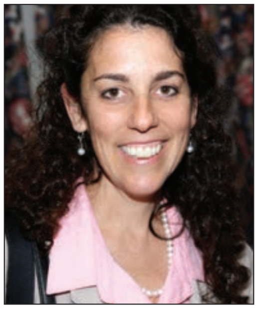
If you'd like to "Go Green" and receive *Reaching Out* via email, contact Brenda Shepard at bshepard@CdLSusa.org today.

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

Calling all CdLS Professionals



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

As you know, our upcoming CdLS Foundation National Family Conference (June 23-26) may prove to be the largest and best one yet! Families will attend from all over the United States and there will likely be several international families as well. One of the privileges of attending conference is the ability for your child to meet with two or more professionals from our Clinical Advisory Board (CAB) or Professional Development Committee (PDC) for one-on-one consultations and specific recommendations. We always encourage all first-time attendees to meet with one of the clinical geneticists, who can then help direct your child for some specific evaluations depending on his or her clinical presentations. Members of the CAB are more medically oriented, involved in a specific body system. Members of the PDC focus more on education, therapies, and behaviors. Both types of meetings can be extremely productive, generating recommendations for your physicians and therapists at home.

Because we have national, and likely world, experts at conference, we always encourage you to mention this to your child's health care providers. Your providers may have many other clients who have CdLS and may be interested in attending the conference in order to learn more about the syndrome. Providers could shadow our professionals for a day, or even half of a day, which would help establish an association, giving your professional the knowleage of the appropriate person on the CAB/PDC to contact if there were questions after conference. This is also a good way for certain professionals to eventually be added to the CAB as an expert. We welcome all such professionals to register for a day or the whole conference! Thank you in advance for inviting them.

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/2016_1stQtr

Reaching Out
Published Since 1977
(ISSN 1097-3052)
Cornelia de Lange Syndrome Foundation, Inc.
Incorporated December 1981
email: info@**CdLS**usa.org
www.**CdLS**usa.org

CdLS Clinics Across the Country

A range of specialists on hand at a new CdLS Clinic at Shriners Hospital

Shriners Hospitals for Children—Salt Lake City, Utah will have their first annual Cornelia de Lange Syndrome clinic Wednesday March 9, 2016 from 8 a.m. – Noon with a range of specialists available just for children with CdLS (age 18 and younger). The specialties will include the following: pediatric orthopeadics, eyes, ears, nose, and throat (ENT), gastrointestinal, pediatrics, neurology, and genetics. The orthotics and prosthetics lab and physical and occupational therapy services will also be available.

Shriners Hospitals for Children—Salt Lake City has been helping children with orthopaedic needs regardless of ability to pay since 1925. If you are interested in this clinic please contact Lynn Audette, L.M.S.W., Family Service Coordinator at 1.800.753.2357 or families@CdLSusa.org.

The CdLS Clinic at Santa Clara Valley Medical Center

Debuting in December 2014, this CdLS clinic in San Jose, CA, hosts a core team consisting of a geneticist, genetic counselor, neurologist, gastroenterologist, psychiatrist, nurse, and a social worker. A gynecologist is also available. The clinic is held twice annually and is open to all ages. In addition, 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 1.800.753.2357 or families@CdLSusa.org.

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

The Center for Cornelia de Lange Syndrome and Related Diagnoses at The Children's Hospital of Philadelphia (CHOP)

The Center for Cornelia de Lange Syndrome and Related Diagnoses at The Children's Hospital of Philadelphia (CHOP) provides a setting in which individuals can receive coordinated care, comprehensive services, and the opportunity to translate clinical and laboratory research towards the development of improved management and therapeutics. One major component of the Center's clinical care is the monthly multidisciplinary clinic held every 3rd Thursday of the month. Patients attending this clinic have the opportunity to see specialists from genetics, gastroenterology, child development, and physical therapy in one afternoon. Patients are also scheduled to meet with additional specialists in other areas dependent upon their specific needs. To provide the best medical care possible, the team works together, across many specialties so that every patient has an individualized plan for care that optimizes quality of life.

Beginning in spring 2014, parents from the Philadelphia region who have children with CdLS were trained by the Foundation as volunteer representatives of the Foundation. The trained volunteers attend the monthly multidisciplinary clinics at CHOP, where they serve as a resource for families, providing emotional support and explaining the services available through the CdLS Foundation. Families have the opportunity to attend a pre-clinic lunch to meet the CdLS Foundation volunteers and other families attending clinic that day. The parent volunteers, Beth Patitucci and Liz Geraghty, have become an invaluable resource to clinic families, providing a unique sense of comfort and support to our clinic.

With their tremendous clinical, research and administrative resources, CHOP has embraced the vision of the Center and with their cooperation and support have put into motion the Center's mission and enabled its growth. The Center, in its sixth year of operation, continues in its commitment to providing continued support through managed medical care and scientific research.

If you are interested in this clinic please contact Justyna Wawrzonek, L.M.S.W., Family Service Coordinator at 1.800.753.2357 or familyservice@CdLSusa.org.

"We are so grateful to the wonderful people at the Center for all of their help, support and guidance as we, and so many other families, continue on this journey with our precious children. The Center is an invaluable resource to our children's healthcare team at home and to us and other parents who always have questions or concerns."

- Mother of 19 month old son with CdLS.

GBMC
Greater Baltimore Medical Center

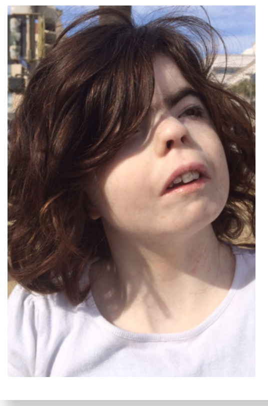
Multidisciplinary Clinic for Adolescents and Adults at Greater Baltimore Medical Center

This CdLS Foundation-managed, free clinic occurs twice yearly at Greater Baltimore Medical Center (GBMC) in Baltimore, MD. Foundation Medical Director Antonie Kline, M.D., director of Pediatric Genetics at the Harvey Institute for Human Genetics at GBMC, has led these free clinics since 2001. Any individual age 12 or older with CdLS can attend with their families. Clinics occur each spring and fall and can accommodate up to eight individuals.

Participants receive one-to-one consultations with specialists from pediatric ophthalmology, gynecology, pediatric dentistry, genetics, gastroenterology and nutrition, psychiatry and behavioral psychology. A Family Service Coordinator from the Foundation always attends to provide support.

If you are interested in this clinic please contact Deirdre Summa, L.M.S.W., Family Service Manager at 1.800.753.2357 or familysupport@CdLSusa.org.

A Closer Look at Clinic – Santa Clara Valley Medical Center: 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 in 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 really a smooth process. We have two kids with special needs, and when we have to take the whole family, doctors visits can be quite the challenge, but it was so pleasant all the way around.

While we were 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 many times a day, but we 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.

Continued on page 13

New CdLS Foundation Publication Addresses Pediatric Transition

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

One of my first assigned projects as Family Service Coordinator, since starting with the Foundation in April 2015, was to create the Pediatric to Adult Medical Transition Guide, for both Caregivers and Providers. I was both excited and nervous when I learned about my assignment because I didn't exactly know what I would find.

The first few weeks I found myself drowning in research. I had no idea there were so many moving parts in the medical transition from pediatric to adult healthcare. I found many useful guides, articles and websites but none of them were specifically related to CdLS. The biggest challenge for me was to take all this floating information and synthesize it in a way that encompasses the varied needs of individuals with CdLS in their transitioning process.

My goal was to provide families and professionals with information that can be easily applied to any individual with CdLS, regardless of ability level or involvement. What I've learned through this process is that you can't do it all at once. Just like it took me several months to research, understand and put together the information into a guide, it will take families several years to go through the steps of the transition process. My biggest hope for anyone reading this guide is that you use it just as what it is, a guide. Not all the information may apply to you, your family, or the person with CdLS in your life. However, if there is at least one piece of information that eases your experience of the medical transition process, I will consider this guide a success.

Lastly, I want to thank all the incredible families who shared their medical transitioning stories with me. These stories not only helped in creating this guide, but made this experience more than just a project. This turned out to be a very powerful journey for me that taught me so much about the strength, courage and determination displayed everyday by our amazing CdLS families.

A Closer Look at Pediatric Transition: Grace's Story

We want to thank Grace for sharing her story with us.

At age 18, my pediatrician told me that she would not be able to see me past age 25. I am 19 years old now. Right now, I am not worried about the actual transfer, because I still have a few years left to plan. My pediatric GI doctor told me that she can only see me for one more year, but she told me when the time comes she will help me find an adult GI doctor. This makes me feel better because I trust that she will refer me to someone I will match well with, but I think I may feel somewhat nervous when meeting someone new for the first time. When finding new adult providers I plan on choosing a woman doctor because I feel more comfortable. I think the most important thing for me is to ask questions when I don't understand something. It's important to have your doctor explain things in a way that you understand, especially if you don't have anyone else with you at the time of your visit.

Each pediatric doctor has his or her own policy on how old you can be before you need to transfer so it is important to ask. I will be working with my mom on finding a new adult provider, as I get closer to 25. I plan on meeting with potential adult providers before hand to have a conversation with them in person, as it is easy to be misunderstood on the phone. I also plan on going with my mom when seeing new adult doctors for the first time. Having my mom with me will make me feel more comfortable in case the doctor asks me questions I don't understand or don't know how to answer. Once I feel comfortable with my new adult providers I plan on attending regular check-ups on my own or with a friend. If I will have a problem or an emergency, I will have my mom attend with me, as it's always a good idea to have someone with you for support.

I am pretty sure I will keep the same pharmacy as I use now. I find it helpful to go in and speak to the pharmacy staff in person when refilling a prescription because they sometimes have a difficult time understanding me on the phone. If I am talking to them face to face, there is less room for confusion and misunderstandings.

A Closer Look at Pediatric Transition: Devin's Story

Thank you to Lynnette, Devin's mother, for sharing their story with us.

The very thought of Devin aging out of pediatric care was frightening. In the area that we live, we never really found great pediatric care, other than his pediatrician and dentist. We've always had to go to larger facilities to find quality care, or pediatric specialists, because they either didn't exist in our area, or they were not as comfortable caring for someone as involved as Devin. He is 25 years old now, and is the size of an 8 to 10 year old.

The first transition we had to make caught us off guard because his pediatrician was going to retire. Devin was just about at the age where we had to transition, but we had no idea who our "coach" would be, or who would be the one person to turn to who could refer us to specialists. It was scary to think: "Where are we going to go? What are we going to do? Where do we find competent people who can care for him?"

Luckily, we were able to transition him to our family doctor. We also got lucky because Devin's pediatric dentist has been with him his entire life. He's said since day one, "I will always take care of him – there will never be an age where he'll need to go elsewhere." Most of our specialists are at Children's Hospital of Philadelphia (CHOP), and they are the professionals he was with before he aged out, who allowed him to stay. He continues to see pediatric gastroenterologist, ear, nose and throat, and immunology, because we were able to get in at CHOP before he turned 21, so they'll continue to see him. My suggestion to parents is before your child turns 21, find out what services you are going to be able to continue with, and what services you need to look for elsewhere. Because of these kids' small size, if you go to a regular doctor's office, they will not have blood pressure cuffs, or tips for a scope that are small enough; the right size is important.

A very frightening thought for me was, in an emergency situation, who can handle his tiny body, when the mandate is that you need to go to an adult facility.

This happened to us just a year ago. Devin's specialists are all from CHOP and they opened an urgent care facility about 10 minutes from where we live. When he fell, and needed stitches, my gut was to take him there. I figured, his records are in the system and we wouldn't need to spend time doing paperwork. Devin can't handle being in an emergency room for many hours, and since stitches are minor and not an emergency, they would typically make us wait a long time. I figured they'd know what to do and care for him.

It was quite an ordeal, however. We found out that they are separate entities, and they were about to refuse treatment because of his age. I argued with them, but they kept refusing because he was 24. The doctor came out and I was almost in tears. She said, "I understand your thinking, but I'm going to have to call my supervisor." We were told, that if the doctor chose to treat him, it was a one-time deal. I didn't do my homework ahead of time.

A Closer Look at Pediatric

Continued on page 13

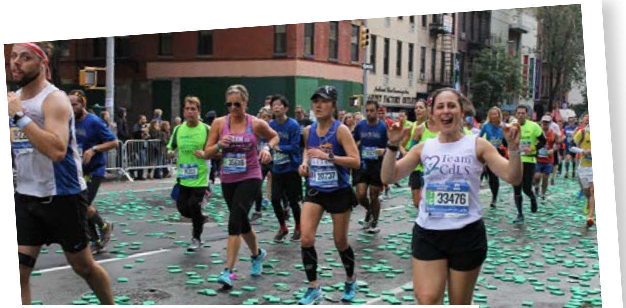
Navigating Healthcare Transitions: Pediatric to Adult Medical Care

Request your copy by contacting the Foundation at 1.800.753.2357, or emailing Justyna Wawrzonek at familyservice@CdLSusa.org.

Currently, professionals may request **Navigating Healthcare Transitions: Pediatric to Adult Medical Care** from the Foundation in PDF format, while print copies are available for parents/caregivers.

Team CdLS 15th Anniversary Year Success

Team CdLS had a banner year accomplishing the goal of 15 races in 2015 to commemorate its 15 year anniversary. Runners crossed finish lines all around the country, in support of the CdLS Foundation and the families we serve. Team CdLS raised over $205,000 in 2015. We plan to expand our team nationwide in 2016 and are looking forward to seeing new and familiar faces.



United Airlines
NYC Half Marathon

Electric Run 2015

Tom King Classic

Dallas Rock
'n' Roll Half
Marathon & 5K

TCS New York
City Marathon

One Love, One
Heart 5K Walk/Run

Bank of America
Chicago Marathon

Highlighted Events

Toyota Fashion Show For CdLS

Regional Coordinator, Karen Miller, and her husband, Jim, worked with Toyota Financial Services near their California home to support the CdLS Foundation through a football-themed fashion show. Each department created a fashion item, and a representative from each department modeled their fashion item. Proceeds from the event raised over $1,000 for the Foundation.

6th Annual Brew & BBQ for CdLS a Success

Through sponsorships, silent auction donations and funds donated, the 6th Annual Brew & BBQ for CdLS raised over $6,000 for the CdLS Foundation. The emotional event, held at Jeckyl Brewing in Alpharetta, GA, was lead by Board member, Fran Rissland, and Public Affairs Committee member, Suzanne Musial.

Walk for Will and Hope

The 7th Walk for Will and Hope took place on October 18, hosting 110 walkers, including a university women's soccer team and a JV cheering squad. The event honors The Feighan-Kurth family's son, Will, who would have been 11 on October 15, and their daughter, Hope who turned eight on October 31. Even with low temperatures, the event, hosted by Maureen Feighan-Kurth and Joel Kurth, raised about $5,000, bringing their event total to more than $30,000 for the Foundation since its inception in 2009.

Maddy's Run

Shortly after the passing of Hunter Jackson and Lynne Kerr's daughter, Maddy, two of Hunter's co-workers approached the couple with the idea for an annual 5K Walk/Run to honor Maddy's life. Each year the event surpasses the previous year's funds raised. Since its inception in 2010, Maddy's Run has raised approximately $140,000, which is split between the CdLS Foundation and the Utah Disability Law Center.

Fighting for CdLS Awareness

The Mischief Mayhem Professional Boxing Event, held on October 30th, promoted CdLS awareness and brought in over $500 to the CdLS Foundation. The event was held in memory of Tia Marie, who passed away in 2015. Her mother, Maryann Santoro, spearheaded this event to honor her daughter and support the Foundation with her family.

Super Siblings – Team CdLS Super Siblings Abound

Team CdLS is full of inspiring stories of family members running for their loved ones who have CdLS. In this issue of Reaching Out, we focus on one set of siblings on our team who choose to show their support for their brothers in their own special way.

Rich & Amy – Brother and Sister to Joseph

"I'm proud to be a part of supporting the CdLS Foundation and helping other families. It's a way for us to honor Joe's memory while raising awareness and support for the Foundation. I think Joe would be really proud of us running a marathon together to help other families affected by CdLS," said Rich. "In a way it feels a bit like all three of us are spending time together since we didn't get much time together before he passed away," he said.

"Joe changed our family forever and so running with Rich for CdLS feels like another bonding experience to bring us closer with each other and with the memory of Joe," said Amy. "Being able to do something to help other families who are affected by CdLS and being able to inform my friends a little more about CdLS through the fundraising is very important to me. I was very young when Joe passed away but I know we would have been the best of friends if we would have had more time together," she continued.

The L.A. Marathon will be the third time the brother/sister duo is running with Team CdLS (past races include the NYC Marathon, and Baltimore Running Festival).

"My favorite part of running with Team CdLS is seeing the other runners, curb crews and supporters of Team CdLS," said Rich. "It's a constant reminder that it's not just about me running a race… plus, it's nice to spend time with my sister, at least until she decides to leave me in the dust."

Mailbag

– Stephen –

It took six years before we received a diagnosis for Stephen. I knew something was not right when he was born. Those first six years were the toughest. He was home very little, either in the hospital bed or the operating room. He could not suck or swallow, so feeding was a big issue.

Pre-school was awesome, but then came public school, which was not so great. He could not get the extra help he needed in public school because he scored too high on the IQ test. We decided to home school instead. This worked out well, as Stephen continued to be in the hospital a lot, so we could go at our own pace. During the fourth grade, he was in the spelling bee, and throughout school, he did chorus, played baseball and joined Boy Scouts. He also took dance lessons to help with physical therapy. He graduated with two diplomas, one being of high honors.

He is now almost 32 years old, and he goes to Day-hab four days a week. On his day off, he takes a taxi by himself to get allergy shots, which is just about an hour each way. It is also "errand day" and his first stop is always the bank. The drugstore is always next, and we plan on being there a while, because everybody needs to speak with him. Stephen loves to go into the stores by himself if we only need a couple items.

You will never get lost with him in your car, because he's a walking GPS unit. He became an eagle scout in 2002. He still sings in a chorus group, and belongs to a bowling league. He participates in the Exceptional Art program every year, and he takes a photography class when available. In 2012, one of his photos was displayed in a museum, and then traveled around the country. He also loves to do theater when it's available. He played the king in *Aladdin*, and Gaston in *Beauty and the Beast*. In *Peter Pan*, he played one of the Peters, and the father.

He belongs to a family support service program and they go out two or three times a month and do many activities. I can't take all the credit for Stephen's success. The staff at Day-hab and his service coordinator needs credit too. One of Stephen's favorite sayings is, "being disabled does not mean I'm unable."

Our biggest issue now is keeping track of all his medical equipment and medications. He takes 20 pills a day, has two inhalers and one nasal spray. Stephen thinks the greatest things ever invented are the microwave and cell phones. The most important thing I need to remember is to make sure Stephen never sees the bottom of the cookie jar.

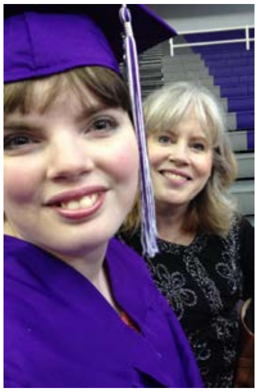
I've been asked many times, if there were an operation to fix Stephen, would I have done it. I say, of course not, he isn't broken.

-Robin, Mother of Stephen, New York

Share your Mailbag or Super Sibling Story!

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

On the Cover: Katie



Katie graduated from high school in 2015. She is 21 years old and I hope to look into some social programs for Katie. I love having her home with me, as she is a great buddy and loves to cook with Mom in the kitchen and help. She loves helping with her nephew as well. He's almost 17 months old. I plan to continue working with her education-wise at home. Her teacher gave me a wealth of educational materials so I can keep working with her. Katie's high school had a wonderful mentor program… they have a huge heart for people with special needs and we've become such great friends with them. It really made our hearts smile.

WELCOME NEW FAMILIES

California
Enith and Sergio and daughter Esme Faith,
born June 28, 2015

Florida
Rebecca and BJ and daughter Nina, born March 31, 2006

Florida
Constance and Karen and daughter Calleigh,
born February 5, 2014

Illinois
Shruti and Ian and son Ethan,
born June 16, 2014

Indiana
Jasmine and daughter Brynnlee, born July 10, 2013

Kentucky
Alana and Robert and son Charlie, born February 8, 2015

Michigan
Andrea and son Aiden,
born September 26, 2011

Missouri
Kayla and daughter Raegan,
born November 14, 2013

New York
Gisel and Matthew and son Niko, born July 2015

Pennsylvania
Mindy and Todd and son Todd, born October 21, 2008

Pennsylvania
Kimberly and daughter Audrey, born
December 24, 2007

Texas
Matylda and daughter Maya,
Born July 1, 2008

Texas
Diane and Tony and daughter Olivia, born April 14, 2013

Texas
Sharonza and son Elijah,
born June 18, 2015

Board Corner

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

On behalf of the Board of Directors for the CdLS Foundation, I want to thank our "retiring" Board members, Marc Needlman, Bob Boneberg, Dave Harvey and Maegan Lowrey. They have all worked tirelessly to help the CdLS Foundation transition from being a grassroots non-profit group, to a true national organization serving the people and families affected by CdLS. Their insight will be greatly missed as we move forward.

We're also lucky to welcome two excellent new additions to the Board of Directors: Jim Kesting from Missouri and Katie Nikzad-Terhune from Kentucky. Jim serves on the Development Committee, is a member of the de Lange Society Class of 2013, and has been instrumental in establishing and continuing the annual Missouri golf event to benefit CdLS. Katie is a Licensed Clinical Social Worker with a doctorate in gerontology, who serves on the Family Services Committee and has authored articles for *Reaching Out*. We're excited to have them join the Board and look forward to their expertise as the CdLS Foundation continues to grow.

If you have ideas that you think would assist the Foundation enhance their services for people and families affected by CdLS, please drop us a note in the Suggestion Box on the Foundation's website at www.cdlsusa.org.

CdLS Registry: Enroll Today!

There are so many questions that accompany a diagnosis of CdLS. Questions you have are probably the same as many other families across the country, and world. To get answers, medical professionals rely on information from families to guide their hypotheses and research. This is why the CdLS Foundation has established a CdLS Registry at the Coordination of Rare Diseases at Sanford (CoRDS).

Patient registries are designed to collect, store and curate data on individuals to be used for a specified purpose. They can be tools to establish natural history studies, establish prevalence, and connect patients with researchers who study their conditions. The CoRDS registry specifically houses basic contact and clinical information on any individual who chooses to enroll and who has been diagnosed with a rare condition.

Please help the Foundation, and researchers move progress forward into determining more about the causes and manifestations of CdLS. For those of you interested in participating in this registry, visit http://bit.ly/CdLSReg to begin the process.

A Closer Look at Clinic – Santa Clara Valley Medical Center: Caitlynn's Story cont.

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.

2016 CALENDAR

February 14
Skechers Performance
Los Angeles Marathon
Los Angeles, CA

March 9
NEW CdLS Clinic
Salt Lake City, Utah

March 12
Midwest Region
Family Gathering
Cedar Springs, MI

March 20
United Airlines
NYC Half Marathon
New York, NY

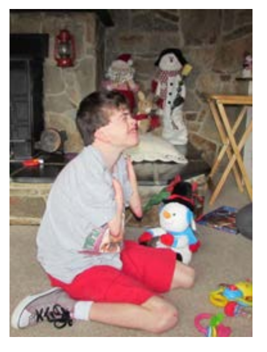
April 9
Multidisciplinary Adolescent
and Adult Clinic
Greater Baltimore Medical
Center (GBMC)
Baltimore, MD

April 11
CdLS Clinic
San Jose, CA

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

Transition: Devin's Story cont.

Another big deal in transitioning was that we could only get labs drawn for Devin through our connection with CHOP. He goes to Children's Seashore House, where kids get specially cared for by nurses who are great with veins. The only other way we've been able to successfully get blood drawn is under sedation.



Insurance is another nightmare. In transition from pediatric to adult care, when the child turns 18, they can qualify for Social Security Insurance (SSI), independent from their parent's income. Generally, it's not an issue, if they're covered under the parent's insurance, but if you transition from pediatric care with Medicaid, there aren't a lot of doctors out there who accept Medicaid. Devin's under our heath plan with Medicaid as a secondary coverage, but at age 26, he'll be out of our coverage. I'm not sure what happens then.

It's a tangled web. Ages 18 to 21 are such a challenging time. You're dealing with school transitions, medical transitions, and guardianship. It's nerve wracking, and worrisome. In school, they prepare you for this transition with IEP meetings. There has never been a meeting with doctors that compares to an IEP meeting at school, with a plan for moving forward.

Donations from 9/11/15 - 12/1/2015

Gifts that Count - In Honor/Celebration

Abigail Busk
Kathryn Galley

Adam Jackson
Dorothy and Daniel Steimke
Marilyn and Emerson Prange

Anjuli Roy
Urbi Ghosh and Hemant Roy

Anya Janoski
Beth Stern

Benjamin Miller
Mindy and Jeffrey Miller

Beth Patitucci
Luann and Jim Webster

Bradley Winter
Elaine Reed

Brandt Anderson
Fran and Wayne Shull

Brenda Shepard
Stephen Ligda

Christopher Carioscia
Janine Premo
Susan Scheibenreif

Cole Simsarian
Peggy Hauck

Delaney DeMaria
Vincent Berardini

Devin Miller
Lynnette and Dean Miller

Dylan Fuller
Jean Houser

Dylan Taggart
Carol and Juergen Gustowarow

Ella G. Musial
Farrah Kennedy and Timothy Peterson

Esme F. Gomez
Enith Vallin and Sergio Gomez

Frank Leone
Rose and Vincenzo Sperandio

Gabriel Sloan
Fawn Combs

Gary Melchiano
Jacalyn and Gary Melchiano

Gracie Fry
Corinthia and Paul Greenway
Linda and Bruce Fry
Linda Chatham

Harley Anne Butler
Jane Fenske

Henry McKenna
Stephanie and Benino McKenna

Hope Kurth
Mary Bailey

Hunter Barrett
Carolyn and James Fulks

Izabelle Schon
Kaitlyn Vorthmann

Jane Schiek
Cynthia Van Es
Donna Ritke
Felipe Moreno
Jacquelyn Edwardson
Kathlryn and Alan Wolkenstein
Lori Falk
Lynn Welk
Marianna and Michael Bruch
Patricia Godsell
Sheila Pospichal

Janinne Dall'Orto
Liana Davila and Michael Garcia

Jeremy T. Picazio
Kelly and Douglas Henke

Jess R. Soltess
Bernard Bigley
Jo and Jim McDonald
Judith and Michael Runk
Margaret Gibson

Jesse Sosa
Mary Caggiano

Jessica Ward
Jane and Robert Mason

Jonathan Swanson
Judith and Ross Soltess
Julia and Peter Swanson
Suzanne and Jess Soltess

Julie Champion
Shannon and Thomas Noonan

Katie Luyt
Lynette and Clifford Lepiane

Katherine Harvey
Alberto Alvarado
Marilyn Foshee

Kyla Francis
Krista Francis

Lillian Choong
Chapel Hill Family Medicine

Lindsey Fernandez
Jeffrey Arps

Lucas Hoen
Joyce and David Veterane
Marcia and Gary Lagerloef

Marissa A. Salas
Miriam and Adolfo Salas

Mary Fiori
Carolyn and Ted Williams

Mason Linehan
Valerie and Jay Lienhard

Mikayla Needlman
Sally and David Bowers

Nicole Miller
Sharon Flynn

Nicole Cardona
Migdalia and Juan Rivera

Peyton Howland
Ann Wonneberger
Ernestine Shearin
Evangelyn S. Davis
Florence and Edison Jackson
Janet and John Garzia
Nathan Mugala
Patricia and Donnell Slater
Patricia Barile
Vickie Presley

Sam Miller
Diane Miller
Eleanor Lipson

Sandra Kaufman
Diane and Michael Friedman

Sarah Suttmann
Marie Clark
Anne and Mike Suttmann
Carolyn and Rita Ungruhe
Chris Werner
Dorothy Werner
Edith and Raymond Simmermeyer
Ellen and Thomas Heile
Jennifer and Dennis Lents
Jill Weber
Johanna and Robb Painter
Judith and Joseph Luhring
Mary Helen's Bed and Breakfast
Obermeyer Chiropractic, P.C.
Rebecca and Dwayne Hornberger
Thomas Konnersman
Victoria and John Roelker

Siena Renteria
Mary Micallef

Stelianos Bardis
Carol Hoffman

Taryn Christie
Cathleen O'Brien
Rosemary Christie

Tyler Macy
Barbara and Timothy Macy

Will Smisloff
Elaine and Thomas Whalen
Laurie and Michael Nelson
Lorrie and Michael Patenaude

In Memory

Alexander J. Flores
Genevieve Rohn

Allison Tryba
Marcia and Tom Kiepczynski
Peter and Judy Stockton

Angela Thompson
Margo and William Wilkins

Anne Herlihy
Board and Staff of the CdLS Foundation
Michele Andolina

Archie Eugene Gaddy
Mary Opitz and Brian Luyt

Barbara Goodenow
Sandra Crisenberry

Brenda Heltne
Tracie and Gregory Maloney

Daniel Krimpenfort
Jo Ann and Robert Hanekamp
Mary and Jim Krimpenfort

Eric Molzan
Susan and Chuck Rankin

Ethan Walters
Penelope Keating
Candace and Shane Kelly

Ethel Taylor
Barbara Wilson
Juanita Tate
Kathleen and Louie Barletta
Laurie Hayn
Norma Clark
Patricia and Julian Bordona
Susan Tandy
Theresa Stroud

Jack Brigham
Jack and Patty Brigham

James Fenske
Harley Anne Butler
Jane Fenske

Jeremiah Caudillo
Barbara and James Galyean

John Viola
Salvatore and Margaret Napolitano

Katherine L. O'Grady
Elise and Frederick Ahearn
Eileen Ahearn and Mark Kliewer
Daniel Logue
Ming Kai Tam
Susan Bardhi

Kerry Myrthel
Willing Workers of Paradise Valley

Kevin J. Meaney
Gerry and Thomas Meaney

Layla Carr
Connie Kelly
Eco Chic Blossoms
Kristy Holt

Lisa Mairano
Barbara and Regis Koontz
Case's Lawn Service
Deborah and Jeffrey Schneider
Pepin Steel and Ironworks LLC
Richard Kenyon

Maribeth Markowski
Dana Henning

Liddy Horsey
Jill and Andrew Stefanovich
Karen Manning and Thom Horsey
Patricia Horsey

Matthew Jones
Phoenix Pediatrics, LTD.

Michael Gonella
Susan and Raymond Molinari

Ryan O'Connell
Board and Staff of the CdLS Foundation
Shari and Maurice Drake
Shailyn O'Connell

Sara Peracchio
Rina and John Bigotto

Stephanie Smith
Crystal and Jerry Smith

Tara Joyce
Patricia and Gerard Joyce

Tia Marie Rivera
Hard Hitting Promotions, LLC
Lisa and Mike Lewin

Our Deepest Sympathy

Ryan O'Connell
September 11, 1985 – September 9, 2015
Son of Shari and Maury Drake
20 Jack Henry Drive
Windham, CT 06281
and
James O'Connell
210 Bundy Hill Rd, Lot #25
Lisbon, CT 06351

Anne Herlihy
March 9, 1978 to September 20, 2015
Daughter of Toni Herlihy
8889 Sandusky Ave S
Jacksonville, FL 32216

Tropical LAGOON

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

$25.00 **Finn (Small)**
$50.00 **Sandy (Medium)**
$100.00 **Splash (Large)**

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

To: _______________**From:**________________ ☐ Finn ☐ Sandy ☐ Splash
To: _______________**From:**________________ ☐ Finn ☐ Sandy ☐ Splash
To: _______________**From:**________________ ☐ Finn ☐ Sandy ☐ Splash
To: _______________**From:**________________ ☐ Finn ☐ Sandy ☐ Splash

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street #100
Avon, CT 06001-3681
800.753.2357 • www.CdLSusa.org

Enclosed is my check for $ _____________

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

Charge my gift to: ☐ VISA ☐ MC ☐ AMEX
Card #: ________________________________
Expiration: ________ Security Code: ___________
Print name on card: ____________________________
Signature: ____________________________________
Email address(es): _____________________________

Cornelia de Lange Syndrome Foundation, Inc.
302 West Main Street, #100
Avon, Connecticut, USA 06001

Return Service Requested

Tropical LAGOON

Swim with us in our Tropical Lagoon as we honor individuals at our CdLS Foundation National Family Conference this summer. Inspire your loved ones to find joy in the milestones they have reached, navigate the open water and find strength in the community they're a part of here at the CdLS Foundation.

Choose from three different dolphin sizes:

Splash, $100 (large), Sandy, $50 (medium) or Finn, $25 (small).

Your dolphin will safely be swimming in our lagoon, named in honor of your loved one (one name per dolphin please) encouraging them to dream bigger and work together within our larger CdLS Foundation family to succeed in the future. All money raised supports conference, taking place June 23-26 in Orlando, FL.

To purchase your dolphin: go to www.CdLSusa.org and look for the Tropical Lagoon "button" on the home page, use the coupon inside this issue, or call Kelly Brown at 800.753.2357.