

Reaching Out

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



Winter 2013



Photo by Rick Guidotti

Highlights

Director's Message:

In This Together

Spotlights:

Making Sense of Special
Needs Planning

A Closer Look at
Transition: Learn.
Work. Live.

Super Siblings:

Anne and Ayla



Director's Message



In This Together

When I joined the staff of the Cornelia de Lange Syndrome (CdLS) Foundation in February 2006 as the director of public affairs, I had never heard of CdLS. I had no experience in health care, special education or the nonprofit industry. I was simply looking for a new job.

Seven years later, I find myself in charge of the organization. If you had asked me back then if I thought I would be the executive director in 2013, I'd have said you were crazy. In fact, in my early years with the Foundation, some Foundation leaders asked me if I was interested in the "management track." My mouth said, "sure, maybe, someday," but in my head I was thinking, "no way, I don't know how to do that."

Fast-forward a half-dozen years, several great mentors, amazing colleagues, and here I sit, the executive director.

Life takes you on many paths. I have come to many forks in the road over my 20-year career—all that brought me here. To me, this is not just a job. If it was, I would've left years ago. My heart has been captured by many children with CdLS. I am in awe of the parents who sacrifice so much, of the researchers who work magic in their labs, and of the staff at the CdLS Foundation, who work here because they care, not because they want a big paycheck.

I take very seriously the responsibilities I have been entrusted with. Be assured that I will do all that I can to ensure this organization continues to grow and prosper and be a source of support and education for everyone.

I can't do it alone though. Your support and caring is critical to the success of this organization. I look forward to hearing from you regarding any suggestions and feedback—good or bad—concerning a program or possibly a way you can become more involved.

Simply put, we are in this together.

Marie Concklin-Malloy

Executive Director

The CdLS Foundation wants your thoughts on the *Reaching Out*. Please visit <https://tinyurl.com/RO2013> and take the online survey to give your valued feedback to make the publication even better. The deadline to take the survey is March 15. We appreciate your time and look forward to your responses.



Charity Navigator, a premier national charity evaluator, awarded the Foundation a 4-Star Rating for the second year in a row. This four-out-of-four star rating is awarded to just one quarter of U.S. charities. Charity Navigator bases its ratings on an organization's financial practices and commitment to accountability and transparency.

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Benefits of the Multidisciplinary Aging Clinics



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

Since this Reaching Out concentrates on several of the issues facing older individuals with CdLS, it seemed fitting to talk about the CdLS Multidisciplinary Clinic for Adolescents and Adults, held at the Greater Baltimore Medical Center.

We are in our twelfth year of offering the twice yearly clinic for individuals 12 years of age and older. The clinic is multidisciplinary, which means that providers from many different specialties (gynecology, ophthalmology, behavior, etc.) volunteer their time to see each family and make recommendations. It is also helpful because the professionals can discuss various aspects of care in CdLS with each other to the benefit of the patients.

Each clinic is unique, but the families always have a bond by the end of the day. The clinic held most recently happened to involve only females in their 20s and 30s, so immediately there was a connection. The parents of similarly involved daughters were able to exchange experiences and make recommendations to each other. One of the highlights was that several of the young women interacted, sharing mutual likes, dislikes and complaints.

At another clinic, two families planned to explore part of the Inner Harbor in Baltimore together, and a third family was staying downtown in order to take advantage of the city. Another time two families met ahead of time by staying in the same hotel and were able to dine together and share stories before clinic.

Although the goals of this clinic are primarily for individuals to be evaluated by experts in CdLS, receive recommendations and assess the aging process in CdLS, they include shared experience with other families in similar situations. If these interactions continue after the clinic has passed, all the better.

I constantly marvel at the dedication of the volunteers who have been attending the clinics year after year. They truly go out of their way to help these families. It is always so gratifying to be involved in the whole experience, and I thank all of the participants from the bottom of my heart.

The next clinics are Saturday, April 13 and Saturday, November 9. Contact Deirdre Summa at 800.753.2357 for more information or to sign up.

Welcome New Members to Board of Directors

Julia O'Connor, Ph.D., is director of Day Treatment Services for the Neurobehavioral Unit at the Kennedy Krieger Institute in Baltimore, MD, and serves as co-chair of the Foundation's Professional Development Committee.

Maegan Lowrey, of Greensboro, NC, is the first person with CdLS to join the Board. Maegan is a self-advocate and an artist and studied visual arts at Barton College.

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Making Sense of Special Needs Planning

By Protected Tomorrows, Inc.



If you are a parent of a child with special needs, government benefits and legal options are often confusing. We often hear families say that their family member

is not eligible for benefits, or that everyone is turned down the first time they apply. We also hear that in order for a person with a disability to receive benefits, the parents must disinherit the child in their will. Both of these statements are not true.

Here is a brief explanation of government benefits that your child may or may not become eligible for, but you may want to investigate:

- **SSI – Supplemental Security Income** – A federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind and disabled who have little or no income. It currently provides a maximum of \$698 per month to be used for basic needs such as food, clothing and shelter. This amount will increase to \$710 per month in 2013. It is generally for people who have little or no work history. An SSI applicant must limit their assets in order to qualify for this benefit. Basically, the allowable assets for a person applying for SSI are a home, one car, a pre-paid funeral, and \$2,000. Of course, understanding what is considered an asset is important, as well as which is the appropriate asset for your family member to own.
- **SSDI – Social Security Disability Insurance** – A federal cash benefit program that may be available if a person is disabled. It pays benefits to the individual and certain members of the individual's family if you are "insured" meaning that you worked long enough and paid Social Security taxes. Each insured individual should receive a statement from Social Security explaining their status of eligibility. Social Security statements can also be obtained from <http://www.ssa.gov/mystatement/>.

- **Medicare** – A federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.
- **Medicaid** – A state run medical assistance program for certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories. Although the Federal government establishes general guidelines for the program, the Medicaid program eligibility requirements are actually established by each State. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops and other programs. This program has asset limitations similar to the SSI limitations.

When planning for your family member, it is important to build a life plan. This involves understanding your dreams for your child's future, and recognizing the fears you have for them as well. The next step is to identify how those dreams can be built upon and the fears can be mitigated as you build a future plan for your child.

It's important to evaluate your child's entire picture and take a few more things into consideration:

- Although you may be dealing with a child at this time, what do you see for him/her in the future? Supported employment? Workshop employment? Residential living?
- Does your existing health insurance remain in effect when your child turns 26?
- What assets are presently in his or her name? Example: savings bonds, life insurance, stocks, mutual funds, homes, etc.
- Is there a possibility of inheriting any money or assets?

Once you've answered these questions, you can then look at what benefits he/she may be eligible to receive and how to best position his/her assets and income.

Often parents ask, is there a way I can leave an inheritance

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A Closer Look at Transition: Learn. Work. Live.



Heading off to College

Preparing for the transition from high school to post-secondary education is a tremendous milestone for anyone. For those with CdLS, as well as their family members, this transition may come with unexpected challenges. It may also be very rewarding and

gratifying experience. Emily (pictured left), a 20-year-old from Alabama, who has finished her first semester in college in December, also has CdLS. Her mother, Sandra, shared her experiences preparing Emily for college and Emily's experiences during the first months in school.

Preparing for Emily's transition:

Exploring college choices was part of Emily's Individualized Education Plan (IEP) transition services goals. Emily initially wanted to attend a larger school, further from home, but we encouraged her to visit other schools. I felt she needed to be in a smaller environment to succeed. Emily ultimately decided where to attend. In most other ways, it was just like preparing my other daughter for college: lots of college visits, applications essays, entrance testing, etc.

Emily had to take the American College Testing (ACT) Exam test three times before she scored high enough for admittance. She scored enough on her first test for conditional acceptance (which meant fewer class hours, monitoring, etc.), but she was determined to score high enough for unconditional acceptance.

About Emily's resources:

The university Emily is attending has a disability support office, which has been a great resource. We met with the coordinator at one of Emily's first visits and kept in touch with her throughout the process. I let Emily handle all of the discussions with their office (though I was there if needed) because I thought it was important for Emily

to take ownership of this process. She currently receives extra time for test taking, can take tests in their office, and receives study notes taken by a school-provided note taker.

We started early in Emily's education preparing her to advocate for herself, so she's really good about that. When transition services started at age 14, we made sure Emily knew what her IEP said and prompted her to use her accommodations, but we tried not to let her use her IEP as a crutch. Emily has always been driven by an intrinsic



desire to succeed with as little help as possible.

All public universities and many private schools have some form of disability support. As parents, we don't have many rights once our kids enter college because they are considered adults, so it's important for the kids to know where to go for help, and to be comfortable accessing that help when needed.

About the transition:

The most difficult part of this transition for me was letting go of the control I've always had. Emily had participated in week-long youth camps held at college campuses away from home. These helped prepare her for college life, but she said leaving home was the most difficult part for her. Though she did have some difficulty passing the ACT testing requirements, she could've gone to a junior college first if she had not scored high enough.

About Emily's first semester:

Emily is majoring in education and wants to be a special education teacher. I'm a teacher, her aunt is a teacher, and her grandmother was a teacher, so it made sense to Emily.



Begin the Vocational Journey with the End in Mind

Once school has ended for those with CdLS, a whole new set of adventures awaits. Whether it's volunteering at a local business, attending social events in the community or even working in a bakery, transitioning out of school and into the community can be a wonderful experience if vocational foundations are laid well. Molly, mother of Alex (pictured with his sister below), shares her experience in preparing Alex for this transition.



Transitioning from school age services to adulthood services is an excursion of potholes, bumps and smooth pavement, depending upon any given day, hour or minute.

The process for our son, Alex, who is now 21, began formally around the age of 14, as Pennsylvania law requires families and schools to begin addressing transition age goals in the Individualized Education Program (IEP) at this age. Those goals must address employment, independent living, and post-secondary goals.

Truthfully, we have been planning for a “life” all along. Alex’s educational services could be described as a modified curriculum, based on life skills, with participation in the general education classroom. These

services always allowed him to address as many functional skills as possible in real-life settings, while at the same time permitting interaction with non-disabled peers.

The journey truly began with the end in mind. We have used tools and strategies that helped us dream for our son, from a very young age, and put into words the vision our family has for his future. It allowed us to look at the possibilities, not his disability. We planned, adjusted, and planned again and again. Each change included written documentation of the vision developed by the people who have known and loved him best.

It is important to remember that despite his successes and accomplishments beyond high school, Alex requires one-on-one support to complete his tasks. Despite the level of support required, community inclusion is obtainable.

We continue to surround our family with good people who support our vision. We have chosen paths at times that required some “trailblazing” because they were less traveled. The process over time has included the following:

1. Continuous planning for a future that includes work, recreation and socialization in the community as a driving force, and never losing sight of that end. We would revisit the dream many times throughout Alex’s school years through Person Centered Planning, Making Action Plans (MAPS) and Planning Alternative Tomorrow’s with Hope (PATH) and monthly collaboration meetings from sixth grade through graduation. “A person centered plan can help those involved with the focus person see the total person, recognize his or her desires and interests, and discover completely new ways of thinking about the future of the person.”¹

2. Collaborative team members are necessary and these members have included people who respect our vision or share our vision, including: parents, special education teachers, general education teachers, occupational therapy, physical therapy, Teacher of the Visually Impaired (TVI), speech therapist, hearing consultant, deaf-blind consultant, and local education agency representatives. When the timing was right, Office of Vocational Rehabilitation and Bureau of Blind and Visual Services representatives were invited to join the team. Our school district also hired a vocational consultant to join the team during Alex’s last two years in the school system.

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Home is Where the Heart Is



For people with CdLS, a major transition is one into different housing, and navigating funding for the future. After dealing with a mixture of living models and confronting various financial barriers, Jan and James share their experience with planning this transition for their son, Gregg (pictured left).

Until our son, Gregg, turned 18, there were few changes in his life with us, except for different school situations. Once he turned 18, we filed for legal guardianship and were able to enroll him in our state (New Mexico) Medicaid waiver. He continued in school until age 22, while still living with us. Gregg is now 47 years old.

A new group home opened around the same time that he could no longer go to school. We wanted to be sure he could be independent of us, so he moved to the group home with the Medicaid waiver funding. At the time, we felt group homes were the best answer to assure his care and independence, while still having the ability to monitor him.

After six years, New Mexico stopped funding group homes and institutions, and placed the people in independent living situations within the community. Most people lived in rentals, with staff there on a full-time basis to care for them. Generally, the rentals were paid by the residents from their Social Security income and were at the low-cost end of the rental market. This meant they were not always the best houses or landlords, so changes of residence were common. We did not want this to happen, so we purchased a home in 1996, where Gregg and one other client live and pay rent still today.

It was initially a supported living model, staffed by people working eight-hour shifts. While we monitored the situation and caregiver staff carefully, there were always problems having different people providing care at different times. The pay for caregivers was not high, so the turnover in personnel was frequent as well.

We changed to a home-based care model, where the caregiver does not change and lives in Gregg's home. Many clients live in homes owned by the caregiver. In our case, the caregiver resides in Gregg's house full time and receives a salary. We do not charge the caregiver rent or utilities, and she has 700 to 1,000 hours of respite time off.

Gregg gets out of the house daily through a "day-hab" program three days per week or doing volunteer work. He volunteers at our church every Saturday for five hours as well. He also goes to the gym three days per week to work on flexibility, which has become a problem as he ages.

Planning Ahead

At one point, we funded a Supplemental Needs Trust to provide money for Gregg's brother to obtain the extra things Gregg might need that are not funded under the Medicaid waiver. We didn't spend any of the funds in the trust, but found the tax filings and reports were more effort than it was worth.

A Special Needs Trust wasn't too expensive in our case, though it could be for some families. The problem is that agencies that monitored Gregg's program really didn't understand what it was. Gregg had no access to this money, only we did. They would hear the word "trust" and think he had money stashed away. It took a lot of explaining so we stopped bothering to mention it.

We now have a Family Trust, of which Gregg's brother is the recipient and executor. Gregg has no access to this trust, but we've included a letter of intent, which is updated periodically concerning Gregg. In this letter, we describe Gregg, his medical information, his personal needs, his likes and dislikes, his living arrangements, and our concern for his welfare in the future. As Gregg ages, care giving and living arrangements change and therefore information has to be updated as well.

For now Gregg's situation is stable, with his care assured when we are gone. However, programs change, and certainly budgets and funding change. His caregivers change from time to time and finding the right person to live with him is not always easy. At one point we took over his care for a few months until we found the right person to live in the house and care for him. As parents and legal guardians, whether it is us or Gregg's brother, we must always monitor and guide his programs.



Super Siblings: Anne and Ayla

For 21-year-old, Anne, and her 22-year-old sister, Ayla, who has CdLS, being so close in age has brought both challenges and also great joy to them both. As part of a documentary photography project through the University



of Missouri, Columbia, Anne had the opportunity to photograph people with CdLS (example shown below), in hopes of bringing the rare syndrome into the spotlight. The resulting project will be seen around the country, including one of the most famous museums in the world, the Smithsonian in Washington, D.C.

“With the photography project I’m working on, there are just three classes in the United States that are being taught using the same syllabus. We could pick any topic we wanted, so I chose Cornelia de Lange Syndrome because it’s a big part of my life and I felt it was something a lot of people would know nothing about.”



The photography projects from these three classes will travel to Columbia, MO, Pittsburg, PA, and Austin, TX, then the Smithsonian in 2013.

“Ayla and I were born 15 months apart, so we were always

really close,” said Anne. “We shared a room until we were 16 years old, much to our disappointment. Mostly we play games together, but now instead of playing with Barbie’s, we play games on our Wii.”

One thing Anne said that she has learned having a sister with CdLS is patience.

“We were in the same grade in school, so we had to study all the same things, only she wouldn’t learn them as fast as I would,” she said. “I would have to try and teach her something we had learned together and that could be frustrating at times.”

Ayla and Anne have such a strong bond and Anne is proud of how Ayla has overcome struggles she faces.

“I’m happy that she doesn’t use having CdLS as an excuse. She drives and goes to work even though it may be harder than it would be for others. She may complain about it, but she still goes every day.”

One of Anne’s favorite memories with Ayla is when they would play together and be silly.

“We used to play dress-up in our storage room and look as crazy as possible while dancing around. I remember dancing to music by the Spice Girls. We would have so much fun!”

WELCOME NEW FAMILIES

Arizona

Jenni and Kevin and son Declan,
born June 28, 2012

Utah

Joanne and Garrett and son
Samuel, born April 19, 2012

Florida

Maria and son Adam,
born January 4, 2012

Washington

Bobby-Jo and Richard and
daughter Zepplyn,
born September 19, 2012

Illinois

Gloria and daughter Lylah,
born November 2, 2010

Mandy and daughter Khloe,
born December 16, 2009

North Carolina

Stephanie and son Amari,
born October 14, 2012

Virginia

Melanie and daughter Jolieanna,
born March 27, 2012

Texas

Crystal and son Damion,
born May 18, 2009



Mailbag - Becky -



Becky is 30 years of age and enjoys working with children. She has a volunteer position working as a teacher's aide in the preschool of the YMCA. She works the morning session as well as the afternoon session. Becky has become an

important addition to the classroom. Last summer Becky worked in the preschool day camp. This summer, Becky was asked if she would like to do it again.

Becky participates in many of the programs offered by Seaspar, an organization that provides recreation for people with special needs. Becky has taken piano lessons and has participated in the recitals. She goes to the theater and attends dances throughout the year. She has gone to the Special Olympics for swimming and now she participates in classes preparing for the Special Olympics for Rhythmic Gymnastics. Locally, she won in her division in all four categories of Rhythmic Gymnastics and is going to the State level in Bloomington, IL.

Becky has a lot of common sense and uses it. When I fell and broke my wrist she and I were the only ones home. I told her to call her father to come home from work. She immediately reacted, but she did not call her father, she did something even more wonderful – she called 9-1-1 instead. What great thinking in a stressful situation, much better than my thinking.

This December, Becky participated in a Christmas pageant, and sang a song, "When You Wish Upon a Star." This was amazing, as she had been mute for a long time. Attending the CdLS Foundation National Conference in Lincolnshire, IL, and being able to visit with a psychologist and a psychiatrist (and continuing to see a psychologist since conference) has helped Becky understand her needs, and clearly it is helping her because

she agreed to do the play. Her friends were so excited when she sang!

Roberta,
Becky's mom, IL

Submit your Mailbag or
Super Siblings Story!
Send your story and photo to
bshepard@CdLSusa.org.

2013 CALENDAR

- | | |
|--|--|
| March 9
Family Gathering
Baton Rouge, LA | July 13
Lapel Village Fair CdLS
Benefit 5k
Lapel, IN |
| March 16
Southwest Region Family
Gathering
Mary Jo Peckham Park
Katy, TX | July 14
Merrell Down & Dirty
National Mud Run Series
Philadelphia, PA |
| April 5-6
Board of Directors Meeting
Avon, CT | September
Southeast Region Family
Gathering
New Orleans, LA |
| April 6
de Lange Society Luncheon
Avon, CT | September 15
Saratoga Palio 5k and half
marathon
Saratoga Springs, NY |
| April 13
CdLS Multidisciplinary Clinic
Baltimore, MD | September 28
4th Annual Brew & BBQ to
benefit CdLS
Sweetwater Brewery
Atlanta, GA |
| May 11
CdLS Awareness Day | September 28
Maddy's Run 5k walk/run
Salt Lake City, UT |
| May 11
Northeast Region Family
Gathering
Baltimore, MD | October 5
Manhattan Beach 10k
Manhattan Beach, CA |
| May 20
21st Annual New England
Golf Tournament
Ipswich Country Club
Ipswich, MA | October 12
2013 Baltimore Running
Festival
Baltimore, MD |



Event Highlight: Thank you Reception

It wasn't the panoramic views from the Charlotte City Club or the NASCAR Hall of Fame that attracted families, friends and the CdLS Foundation board of directors to gather in Charlotte, NC, in November 2012. It was an opportunity for the Foundation to personally thank guests for their support, share experiences, information and communicate that we are always here for them.



The Foundation's gracious hosts were David and Christine Fry, parents of Gracie (shown above with her dad).

"We were blessed by the CdLS Foundation Web site from the second that we found it," said David. "We have been blessed by the staff the second they picked up the phones and we were blessed by the gatherings, friends, and other patients with CdLS and doctors the minute we opened up to them."

The reception was an extension of the Frys' past experience of being welcomed to the CdLS Foundation organization. In 2010, David, Gracie and his mother, Linda, attended their first National CdLS Foundation Family Conference in Dallas. The Fry's appreciation for the Foundation's services is apparent.

"The Foundation only wants to give. To us they are the most loving and giving organization we have ever encountered. They expect nothing in return. They just give and smile and ask if they can give some more."

Ornament Fundraiser



In December, Denise Ray held a holiday fundraiser in Springfield, TN, to raise money for the CdLS Foundation in honor of her niece, Haven (shown above). Denise made handmade CdLS Foundation ornaments and displayed them on a tree at a local business.

de Lange Society to Honor Leaders and Volunteers

The de Lange Society will publicly recognize 39 individuals and volunteer groups, who, like Dr. Cornelia de Lange, led the way for others. These volunteers bring creative vision, innovative ideas, vital assistance and leadership to the Foundation. They will be honored April 6 at a luncheon in Avon, CT. Tickets and sponsorship opportunities are available by calling 800.753.2357.



Cornelia de Lange Syndrome Foundation



Giving through your workplace

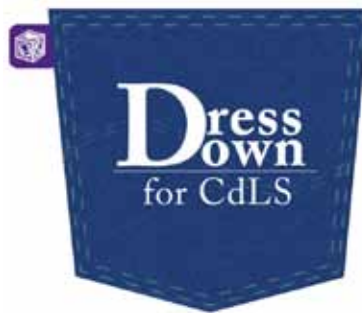
Many companies offer workplace giving. Workplace giving is a means by which employees donate to the charities they care about, primarily through payroll pledges. Donors decide which issues are most important to them and contribute a set amount from each paycheck. If your employer has a program like this, you can use the opportunity to support the CdLS Foundation.

Many employers will also match charitable donations made by their employees throughout the year. For example, some employers match each dollar. That means, if you give \$100, the Foundation receives \$200. Once you understand your employer's matching plan, you can make the most of your workplace giving campaign and maximize the level of funding the Foundation receives.

For more information on how to give to the CdLS Foundation through workplace giving, contact your human resources or payroll department.

Dress Down for CdLS

Get comfy for a good cause. It's simple to raise funds and awareness for the CdLS Foundation by organizing a Dress Down Day in your workplace. It's fun, easy and gets everyone involved. The Foundation provides everything you need to make this day a success. All you need to do is schedule the date and publicize your event. Everyone who makes a donation receives a special gift. All proceeds benefit the CdLS Foundation. It's that simple!



For more information contact specialevents@CdLSusa.org or call Kellie Santiago at 800.753.2357.

Celebrate CdLS Awareness Day on May 11

National Cornelia de Lange Syndrome Awareness Day is Saturday May 11. This is a day to spread the word about CdLS, how it was affected your family and what others may need to know about the syndrome. Now's a great time to start planning your events for that day, or the days leading up to it.

Some ideas for events include (but are not limited to):

- Request your governor, to proclaim May 11, "Cornelia de Lange Syndrome Awareness Day"
- Plan a fun walk or 5k "Race for CdLS Awareness" fundraiser or a field day with games that teach people about CdLS.
- Plan a CdLS Awareness Day Block Party and invite your neighbors to join you and learn about CdLS.
- Offer to speak about CdLS at a local library, town hall meeting or other community gathering.
- Write about your family's experience with CdLS and submit it to your local newspapers, radio and television stations.

We love to get pictures from these events, so take pictures and video to share with us.

If you need materials or assistance with your ideas, contact us at 800.753.2357 or email bshepard@CdLSusa.org. Be sure to check the Foundation's Web site for templates and information.

Connect the Foundation with Corporate Funds

Many companies provide charitable grants to nonprofits as part of philanthropic objectives each year. If you work for a company that has a charitable giving arm, the Foundation would love to hear more about it. Contact Marie Concklin-Malloy at 800.753.2357 or by email at director@CdLSusa.org.



Making Sense of Special Needs Planning con't.

to my child with disabilities without negatively impacting my child's benefits? YES. An individual may set up a Special Needs Trust that will permit this. The following are the most common types of Special Needs Trusts:

Third Party Discretionary Supplemental Needs Trust

– A trust that can hold cash, personal property, or real property, or can be the beneficiary of life insurance proceeds. Simply stated, other people's money or property that they choose to contribute or leave to the child with disabilities can be set aside safely to provide for the supplemental care for your child's future. There are some very specific rules for this type of trust, such as that it must be irrevocable, the funds must be used for supplemental care only, and that the assets of the trust cannot be made payable directly TO the individual with a disability.

First Party Discretionary Supplemental Care Trust or Payback Trust

– A trust that can hold cash, personal property or real property that is owned by the person with disabilities. This can only be set up by parents, grandparents, or legal guardians of the person with disabilities, or the court. This trust also has very specific rules that must be followed, and it differs from the Third Party trust in that it must have a payback provision, so that the state is paid back for medical expenses paid, at the death of the beneficiary.

When thinking about trusts, it is imperative that you speak with an attorney who has extensive experience and knowledge in the Special Needs Trust arena.

Another area to be discussed is the area of future guardians, or Future Care People™ as we call them. Who will be there to step into your shoes if something were to happen to you? Who will handle the medical, school, employment, residential, and recreation decisions? Many parents postpone the planning process, as they find this decision so difficult. However, it is one of the most important areas to document.

Last but not least, one step that we find very important is to document your child's life. Think of all of the things you have filed away in your head that are specific to your

child – all things from the very small minute details to those things that may be very complex. Who else knows what you know? If something should happen to you, who will have the “instruction book” of care? Would they know never to try a certain medication, or would they know a certain shampoo gives your child a horrible rash even though it smells so good? Would they know your child's everyday routines that may seem inconsequential, but are of major importance to your child's every day functioning? Pass this information along in some written form. Keep a journal, a notebook, or whatever works for you. While this task may appear to be just one more thing to do, in the long run, it's well worth the effort.

To many families these issues are often confusing and just plain daunting. The important thing is to be patient and do your homework so that you are better prepared for the future.

Can you do this yourself? Of course! There are many resources available on the Internet, such as: www.protectedtomorrows.com, www.ssa.gov, and www.statehealthfacts.org among many others. Additionally, Protected Tomorrows has a cost effective program to provide families with tools and resources for planning for their loved ones' future. The Protected Tomorrows Family Membership offers webinars covering many of the topics discussed in this article, exclusive access to extensive resources, as well as an interactive planning tool to guide you through the Process for Protected Tomorrows – a holistic, step-by-step approach to creating a Future Care Plan™ for your loved one with special needs. Go to www.ProtectedTomorrows.com for more information.

Protected Tomorrows, Inc. is the leader in enhancing the lives of families with members who have special needs. By guiding families through its comprehensive, proprietary planning process, Protected Tomorrows helps ensure the well-being of a loved one by creating a Future Care Plan™. Through their work with clients and the family's advisors, and alongside of other advocates and legislators, Protected Tomorrows addresses many concerns of families with special needs such as: future care funding, government benefits, legal considerations, residential options, employment opportunities, recreational choices, education options and family communication. For questions, contact info@protectedtomorrows.com or visit www.protectedtomorrows.com.



Begin the Vocational Journey with the End in Mind con't.

3. Vocational exploration was derived from what interests and motivates Alex. It was important that the vocational goals extended from these interests and were then embedded as functional goals within his IEP. Any skill practiced in real life settings of the school building were mimicked in the community. For example, working in the school library scanning the returned books and straightening the shelves led to a volunteer position in one of our local libraries doing similar activities.

Delivering teacher supplies on a pushed cart led to a position at a local nursing home delivering mail from a pushed cart. Folding towels in the consumer science class carried over to folding towels at the YMCA, with the added bonus of recreational swimming afterward. Quality Vocational Assessments should be conducted. Alex had three vocational assessments completed by three separate agencies during his middle/high school years.

4. Monitoring progress through a formal transition checklist. This can be obtained through your Department of Education or other organizations such as your Regional Deaf-Blind Project (if the student qualifies) or perhaps a parent training and information center. Documentation of the transition process and progress is very helpful to be certain that steps for a smooth transition are not forgotten.

Examples of success:

- Alex owns his own vending machine, and he purchases items, stocks soda and snacks, and banks.
- He volunteers at a nursing home delivering mail twice a week and removing activity calendars monthly. He is working toward more days which could lead to paid employment.
- He volunteers at the YMCA folding towels. He has his own membership and swims.
- Alex volunteers at a local library where he straightens shelves and chairs and checking in books.
- He bakes dog treats at a local dog grooming business.

He purchases ingredients, then mixes, bakes and packages the items.

- Alex delivers shredded paper to a local farmer for animal bedding and then enjoys the atmosphere of the farm.

Never stop dreaming! The next step for Alex is a home of his own, and we have always included this dream in the transition plan too. To sum it up, the work may be in the details, but the proof is in a happy young man, with jobs to do, people to meet and places to go.

Molly Black is a Family Liaison, Pennsylvania Training and Technical Assistance Network (PaTTAN) Deaf-Blind Initiative.

¹Mount, Beth, and Kay Zwernik. *It's Never Too Early, It's Never Too Late: A Booklet about Personal Futures Planning for Persons with Developmental Disabilities, Their Families and Friends, Case Managers, Service Providers and Advocates.* St. Paul, MN: Metropolitan Council, 1988. Print

Heading off to College con't.

She loves kids and relates well to children with special needs. Emily says she likes that her classes only last one semester, so she isn't stuck in any one class for too long."

She mostly likes her classes, but did feel a little overwhelmed during finals. She loves the social aspect, but is having a little trouble adjusting to fewer academic supports (such as having projects broken down into incremental due dates). She joined Phi Lambda, which is a social club (similar to a sorority). She's also a member of W.IN.G.S. (Women in Godly Service), which is a group of female students that participate in church-sponsored youth events.

Advice:

My biggest advice for those thinking about college: start saving now! Emily doesn't qualify for Social Security Income (SSI) because she's so mildly affected, so we are funding it on our own. Also, start early working toward independence if you hope for your child to be independent. In college, students get accommodations but not modifications, so start removing modifications from your child's IEP early in high school. A good school system will help you do this as part of their transition efforts, but parents need to be aware of this, and understand that it's designed to help prepare students for higher education.



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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.

Our Deepest Sympathy

Matthew Aydn Brown
May 15, 2006 – November 3, 2012
Son of Brandi and Max Brown
6752 South County Rd 800 West
Reelsville, IN 46171

Katie Richard
February 16, 1990 – December 4, 2012
Daughter of Lora and Daniel Richard
632 Conner Drive
Mishawaka, IN 46544

Kyle Christopher Wilson
July 19, 1991 – October 26, 2012
Son of Cindy and Chris Wilson



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Deadline: May 1, 2013