



## NODCC Board of Directors & Staff

### Officers

President: Jennifer Little  
Treasurer: Karen Dineen  
Secretary: Heather Richmond

### Board Members

Kristen Barge	Warren Brown PhD
Angus Cochran	Dan Daly PhD
Karen Dineen	Chad Elseth
Paul Guilbault MD	Guy Harrison
Richard Howell	Matt Levi
Jennifer Little	James Nichols
Lynn K. Paul PhD	Alicia Ramsey
John Ramsey	Heather Richmond
Dave Shirk	Lynn Snyder PhD
Elliott Sherr MD PhD	

### Staff

Business Director: Barbara Fonseca  
Conference Director: Cathleen McCarthy  
Development Director: Tanory Ateek

**Make sure you are getting the NODCC monthly E-Connection. Email [info@nodcc.org](mailto:info@nodcc.org) with your email address.**

## Save the Date!

The 7th Annual NODCC Disorders of the Corpus Callosum Conference 2009 will be in Indianapolis, Indiana, August 14-16. Don't miss this invaluable opportunity for individuals with a DCC and their families to attend professional lectures on living with a DCC and to gather as a community of support for one another.

Registration materials will be mailed in early May, early bird fee is \$185 per person, and \$210 after June 30.

Conference registration includes access to:

- 35 lectures & discussions (medical, therapies, education, behaviors, finances, community life)
- Special presentations by Anne Plassman, a woman with severe disabilities from cerebral palsy, who also earned a masters degree in special education and successfully transitioned to independent living/adulthood
- Workshops especially designed for adults with a DCC
- Exciting Children's and Teens' Camps for kids ages 3-17
- Opportunity to participate in DCC scientific research projects
- Friday evening banquet, Saturday lunch, Sunday lunch banquet
- Fun-filled Saturday evening pizza and dance party for the whole family

The Conference will be held at the Indianapolis Marriott East. Book your rooms as early as possible for the special rate of \$109 per night. Arrange lodging directly with the hotel and use code NODNODA.

Indianapolis Marriott East Phone 317-352-1231 [www.marriott.com](http://www.marriott.com)

For more information, [www.nodcc.org](http://www.nodcc.org)

For sponsorship information and packets, email Tanory at [nodccdevelopment@nodcc.org](mailto:nodccdevelopment@nodcc.org)

## IN THIS ISSUE

### FINANCIAL PLANNING

Ideas for protecting your child's future.

Page 1-2

### SPECIAL MILESTONE

Two mothers join forces to give back.

Page 2

### NEW ADULT MENTOR PROGRAM

New resource for adults with a DCC.

Page 2

### Q&A WITH JOANNE TULLY

Mother speaks about raising daughter to adulthood and beyond.

Page 3

### 2009 CONFERENCE

Check out what's planned for this year's event in Indianapolis.

Page 4

### NODCC MISSION

*To enhance the quality of life and promote opportunities for individuals with disorders of the corpus callosum and raise the profile, understanding and acceptance of these disorders through research, education, advocacy and networking.*

PMB 363 18032-C Lemon Drive  
Yorba Linda, CA 92886 USA  
[info@nodcc.org](mailto:info@nodcc.org) | [www.nodcc.org](http://www.nodcc.org)  
p: 714.747.0063 | f: 714.693.0808

## Saving for the Future When the Future is Uncertain

*By Heather Richmond – mother to Sabine, 3 cACC*

Wherever your child falls on the callosal disorders spectrum, it is almost certain they will need your financial support into adulthood. Some individuals with a DCC may require long-term care, and others may need an occasional financial boost to supplement relatively independent living, but most will require some level of support. For those who meet eligibility requirements, the Supplemental Security Income (SSI) and Medicaid will help provide care into their adulthood. Others may have significant struggles maintaining consistent employment and establishing self-reliance in their adulthood. Fortunately, there is a lot you can do now to prepare for whatever the future holds.

### Show Me The Money

Regardless of income, people everywhere are feeling pinched by this financial crisis. Those that have a child with a disability especially feel the sting. You may want to put savings for your child on hold, but adulthood will be here before you know it, and even the smallest contribution to a savings plan now could yield large benefits for your child in the future.

If the home budget is so tight that all saving must be postponed, consider "finding" funds with a few of the tax breaks you exercised in 2008. If you saved with the Earned Income Tax Credit, or received a belated gift from the federal government in a rebate check that was not utilized in 2007, consider using this money to start or enhance a savings pool for your child.

With wages stagnant or even decreasing, consider changing your employer tax withholding to put a few extra dollars from your regular paycheck into your child's future (see [irs.gov](http://irs.gov)).

### Investment Considerations

In these days of Ponzi schemes and toxic assets, the mattress often looks like a better investment tool than a money market, stock or mutual fund. There are, however, some less risky investments such as high-yield savings accounts, or long-term certificate of deposits, assuming they do not exceed \$250,000 per person.

**Trusts:** Special needs and other trusts should not be overlooked. Financial planning, in the event of your death, will assure that your child's best interest is taken into account and that she will be cared for regardless of the money she inherits. A trust gives someone – a family member, friend or attorney – the authority to act in your child's best interest to assure that any money left to her is used to support her care and lifestyle. A special needs trust has eligibility requirements but works to maintain the SSI and Medicaid support, regardless of monies inherited. For children who do not qualify for the special needs trust, an attorney can draft a similar type of trust that also dictates how money should be used to support your child. It is critical to work with an attorney who specializes in this area. Check out [www.specialneedsplanners.com](http://www.specialneedsplanners.com).

**Education Accounts:** Many children with a DCC will not attend college so the famed 529 or college savings option may not be the best investment tool. However, some states allow more flexibility in their 529 by including technical programs instead of college. The website, [www.collegeadvantage.com](http://www.collegeadvantage.com), gives long and short-term savings options for children who may want to continue some type of education beyond high school. The Coverdell Education Savings Account is another investment tool that allows parents to save money for education but is broader in scope and allows funds to be used for grades K-12. Both options provide tax incentives for savings and may be options for your child's future.

With all the challenges of living and the financial turmoil reported in the news, saving for the uncertain future is, well, uncertain. But what is certain is that our children with a DCC need help now and into adulthood. Planning for the future and saving now are things we cannot afford to ignore.

A new bill in Congress will allow the creation of tax-deferred savings accounts for individuals who qualify for SSI and Medicaid. Up to \$500,000 of funds can be placed into an "ABLE" (Achieving a Better Life Experience) account that functions like an IRA or 529. (Senate 493, House of Representatives 1205).





## MEMBER PARTICIPATION

### Brooke and Ian's Run: Turning Hardship into Positive Action

By Tanary Ateek, NODCC Development

"Brooke and Ian are achieving amazing things despite what life has put before them," says Brooke's mother, Kadie.

Brooke and Ian were born only a month apart in Northern California and both have a disorder of the corpus callosum (DCC). In their unending search for answers, Brooke's mother Kadie, and Ian's mother Colleen, stumbled across the NODCC, through a connection to a neurologist in their area who specializes in DCC, and eventually they found each other.

Since they live in the same community, Colleen and Kadie became friends,

sharing the ups and downs of the first year of life with special needs children. As Brooke and Ian's first birthdays approached, their mothers wanted to mark the milestone in a special

way. However, "all the typical first year birthday visions one normally has just didn't fit for our children" says Kadie. "We wanted to give back," says Colleen, "and to express our gratitude for

all the support we received from so many over the last year." They decided to organize "Brooke and Ian's Run for the Families" to benefit the NODCC. Their expectations were small, but the event quickly turned into something larger than they ever imagined, involving hundreds of members of their community, raising so much awareness about DCC, as well as over \$10,000 for the NODCC.

The NODCC thanks Kadie Demar, Colleen Deidrich and their community in Northern California for making a difference in the lives of so many affected by a DCC.



### "Adulthood" from the Perspective of an Adult with a DCC

By Kyle

When it comes to raising a child with a DCC, parents must focus their attention on the present moment in their child's life, rather than their future. The future has an infinite number of scenarios. Concentrate yourself on the positive achievements rather than the negatives that result from your child. The functioning level for your child depends on your child, not from statistics of other DCC children or from the medical field. When a person wins a race, he does not achieve it by winning the actual race. The person achieves the win by training for it. It is the preparation that parents must focus on for their child. Weight lifters do not stop lifting weights that are too heavy for them at that precise moment. Weight lifters work and train themselves to surpass their previous weight level, even when the pain is unbearable for them. Each step that a DCC child takes in his or her life is one step closer to winning the race, even if they come in last place. Life is filled with brick walls that we occasionally hit. Every single person encounters their own personal brick wall(s). We can break down those walls and go through them or we could find an alternate route.

As an adult living with DCC, my diagnosis was a turning point in my life. I encountered many brick walls. Every time I felt I was taking a step forward in my life, I would encounter a brick wall that kept pushing me back two steps. I know many parents are very interested in hearing my story.

Anyone can read my story and other thoughts by visiting: <http://breakingdownthebrickwalls.blogspot.com>

## MEMBER PARTICIPATION

### Adult Mentor Program Launch

By Becky and James Nichols, Parents of Jacob, aged 4, C-ACC

The NODCC was founded in part by parents of children with a DCC, so it has focused mainly on the needs of families and children affected by a DCC. However, those children are quickly becoming adults, and with the increase of MRI's and other neuroimaging, more and more adults are being diagnosed and seeking out the NODCC for resources and support. In response to these individuals, the NODCC is pleased to launch the Adult Mentor Program.

The Adult Mentor Program is designed to help adults with a DCC gain a better understanding of their diagnosis and create a network of support for them. Since the program is in the early stages we are reaching out to adults with a DCC to find out what their interests are and how we can help them through

this program. Our goal is to connect adults to each other through the NODCC conferences and website, so that they can share their experiences, difficulties, successes and ultimately develop a network of friendships and supportive relationships to enhance their lives.

We are so excited to serve as volunteer coordinators to help grow this program. Although Jacob, our son with a DCC, is only 4, we feel that we can learn so much from the adults who participate. Hopefully, by the time Jacob reaches adulthood, he will be able to plug right into a vibrant network of people who understand what he experiences and can offer support and encouragement.

If you are interested in the Adult Mentor Program, please email [info@nodcc.org](mailto:info@nodcc.org).

### We Are All Navigating This Road Together

An Interview with JoAnne Tully, mother to Kathleen, 21, p-ACC

#### 1) Can you share a little about Kathleen?

Kathleen will be 21 in May of this year. She's a delightful, happy, friendly girl who loves people and animals. She has complete ACC as well as chromosome microdeletion 1q44.

The chromosome anomaly causes most of her delays, both physical and cognitive (she does not walk and has very delayed speech skills). She had seizures until age 5 and still takes medicine for seizures due to irregular brain

waves during sleep. She is small in stature (about 4 foot 10) and looks much younger than her age.

#### 2) You and your husband helped start the NODCC, so can you talk a little about that, and how the NODCC has been helpful to you?

Yes, I was on the founding board of NODCC. The organization has helped us form networks and friendships with others affected by DCC. We found the conferences we attended to be wonderful experiences, and we plan to continue attending as often as we can. Our other children (Kathleen's siblings) have benefited from sibling workshops and discussions about the disorder. Professionally (I'm a Speech/Language Pathologist), the NODCC has given me an opportunity to broaden the scope of my work (answering inquiries about speech/language and ACC, presenting at conferences several years ago, being part of a Q/A section of the NODCC website).

#### 3) Can you share a little about your "highs and lows" with DCC? What has been the most challenging part and when have you felt most encouraged?

Our highs have been much more

numerous than our lows because Kathleen has been such a happy, funny individual all her life. At birth, she had severe medical problems, and we were told that she might not live to be one year old. After her condition stabilized

and we realized she would survive, our overriding view of her was as a wonderful gift. Any problems she had, physically or cognitively, were just part of the package.

The most challenging times with her were in the years from about age 7 to 17 when she would become very

loud and upset in public places. She was known to scream (blood curdling, horror-movie quality screams) in shopping malls and restaurants. We weren't able to take her many places during those years. Her behavior has improved tremendously in the past few years, and we are able to take her out more than we did. The biggest improvement came after we got contact lenses for her. Before that she was extremely nearsighted but wouldn't wear glasses; public places were a confusing, noisy, blur for her.

#### 4) As Kathleen entered legal adulthood, did you expect a major transition? What kinds of things have you been thinking about her independence, her long-term care, her provision, etc? When did you start thinking about and start preparing for this transition?

We are still navigating those transitions into adulthood. Most of the legal/ bureaucratic things went smoothly, such as registering her for social security disability benefits at age 18 and obtaining legal guardianship. One big challenge is the fact that while there is a lot of information available about the transition into adulthood, there is no

surefire way to know if we are doing everything we need to do. We have learned most of our information from communicating with other parents, attending workshops and searching the internet. I still have a fear that one day I'll find out we were supposed to do something years ago that we never did. As for Kathleen's independence, she will not be able to live independently at any time. We plan to keep her with us as long as we are able to care for her, but the years after that are still unclear... and too easy to avoid thinking about.

#### 5) Does Kathleen see herself or you differently as a result of becoming an adult?

Kathleen is more mellow than she was as a younger child, but I think it has more to do with her vision and some medicine changes than with her perception of herself as an adult. I have seen a few changes since she became an adult, though. For example, she has a nephew who is 2 years old, and she doesn't just treat him like any little child -- she seems much more proprietary, like a true "proud aunt." She watches the news and seems to understand some of it, and she laughs at more mature things than she used to. She even... ahem... occasionally uses some off-color language. It's hard not to laugh when she does.

#### 6) Any other advice or wisdom you'd like to share for parents who may be dealing with similar situations to yours?

My biggest advice is to stay in contact with as many people as you can who have children or family members with DCC. Attend the NODCC conferences and collect all the information you can, including contact information for people you can stay in touch with. Don't be afraid of the future, because we are all navigating this road together. As you face and overcome challenges, share that information with others who are just starting the journey.