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BUSINESS REWARDS

Please use these business reward numbers to benefit the NODCC when visiting the following retail outlets:

STAPLES #3397024724
OFFICE MAX #1348-26266

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UPCOMING EVENTS

July 18-20, 2008

Disorders of the Corpus Callosum Conference 2008

Cherry Hill, NJ

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Participation Is The Best Gift You Can Give to the NODCC in 2008 and Beyond

Who is the NODCC? You are.

This year, the NODCC will continue to provide resources and networking opportunities for DCC individuals, families and medical professionals. Beyond these very important objectives for the organization, our goal is 100% participation.

This goal is about uniting to create awareness of DCC and to create resources for each other. Every year at our conference, I am stunned once again by the wisdom and expertise of relatives of and individuals with DCC. Somehow, I grew up with the idea that "professionals" and "organizations" were supposed to be all-knowing and provide useful services for any need. But the reality is that when it comes to DCC, YOU are the experts and YOU are the ones who can provide the best resources.

Many of you are probably exhausted and stretched thin by the demands of life, so the last thing you need is another responsibility right? That is why the NODCC is creating multiple avenues for participation that can fit your lifestyle.

1. Join the NODCC – Not sure if you are a current member? Within the next month, you will receive a letter that includes either a membership card (for current members) or forms for joining if your membership is outdated. Like last year, we request a membership contribution of \$3.75 a month (\$45 a year) to help cover operating expenses. However, we will welcome smaller amounts or will grant you a sponsored membership if the suggested amount presents a hardship.

2. Log into NODCC.org – Participate in a discussion board, post your story related to DCC, complete the Family Partnership Program Networking Survey, and post your resource suggestions. Use these tools to find other people and resources that can

help you. The website has been redesigned so that it will be more user friendly and will be reprogrammed once we receive enough donations to cover that expense.

3. Become a Resource Family – Resource families are NODCC members who agree to talk with new members and newly diagnosed people in their region. Just being a listener and sharing your story helps another person or family.

4. Offer your Services – If you have a profession or hobby that might help the NODCC, please notify our staff. If you are interested in serving on a committee or becoming a national board member, please step forward.

5. Be a Fundraiser – As you'll see on page 2, several members have personally become involved in helping raise money for the NODCC in their own creative way.

6. Attend the 2008 Conference – The annual conference continues to provide the best networking and resource opportunity for families and individuals living with DCC.

I encourage you to think about how you can get involved in the organization this year. Maybe it becomes a family affair or a personal mission to make a difference. Your involvement can be tailored to your skills or the time commitment that you can make.

You are the NODCC. Without your participation, the national organization falls short of its potential to advance the mission. I hope you enjoy reading in this issue about NODCC members who made a difference in 2007. Hats off to their commitment to a very personal cause!

– Lynn Paul, NODCC Past President



MEMBER PARTICIPATION

Do-It-Yourself Projects by Our Members

DIY. The popular "Do It Yourself" message on television doesn't just apply to home repair and remodeling.

This past year, a number of NODCC members used their talents to raise money for the organization. In keeping with the theme of "participation" in this newsletter, we wanted to share these stories and recognize the efforts that are ultimately helping fund the mission of the NODCC.

The collection of fundraising stories highlighted have resulted in donations for the NODCC totaling more than

\$5,000.

GRAM'S DISHCLOTHS: When Tamara Davis was caring for her grandmother in the hospital, she began crocheting her grandmother's dishcloths using her own design. The cotton dishcloths are being sold by merchants in Vermont with a percentage of proceeds coming back to the NODCC. Tamara's project helped her pay tribute to her grandmother and raise money for her favorite charity that honors her granddaughter, Donna, who has complete agenesis of the

corpus callosum (C-ACC).

STAMPIN' UP SHOEBOX SWAP: Carrie Ann Poff has been a demonstrator for Stampin' Up for years and enjoys making cards and scrapbooking. In October, Carrie hosted her second annual Shoebox Swap with attendees bringing and making handmade cards to swap. The event featured lunch and a fabulous raffle that benefitted the NODCC. Carrie Ann's son, Andrew, has C-ACC.

ARBONNE PARTY: NODCC Board Member Kristen Barge,

whose son Nathan has C-ACC, hosted an in-home party for Arbonne botanically based products. Fifty percent of the price of the product was donated to the NODCC.

TASHA'S SCRAPBOOKING TREASURES: Tasha Stahl hosted the second annual Survivor Crop with her scrapbooking friends, complete with a silent auction and raffle. There were 45 scrapbookers in attendance, with proceeds from the auction and raffle benefitting the NODCC. Tasha's son, Jaylin,

MEMBER PARTICIPATION

Italian Dinner for a Cause

There is no better way to raise money than filling up your community with delicious Italian food.

Last fall, Helen Yep partnered with Ferrari's Little Italy in Madeira, a close knit community in the Cincinnati area, to host a two-night fundraiser with 20% of proceeds benefitting the NODCC.

Helen sent out email blasts, talked to friends and posted flyers all over town to spread the word about the event.

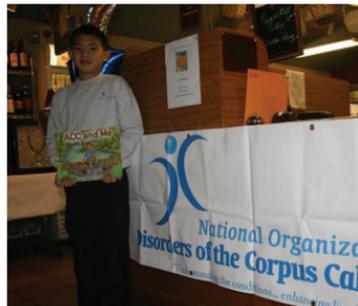
On both nights, the parking lot of the restaurant was full and the donations for the NODCC were rolling in.

Helen's 11-year-old son Timothy, who has C-ACC, attended the event and

helped raise awareness for disorders of the corpus callosum.

The event was a huge success in the community and even garnered a front page story in the local paper, complete with color photos and an article about ACC.

Helen hopes to make this an annual event for NODCC.



Timothy Yep proudly displays the ACC and Me book at the fundraiser at Ferrari's Little Italy.

MEMBER PARTICIPATION

Alley Cats Holiday Event

In 2006 at the NODCC Conference in Irvine, the Alley Cats, a popular a cappella and doo-wop group, entertained our children and adult attendees with a fun, musical show.

In December, the Alley Cats hosted a holiday fundraiser for the NODCC in Brea, California. The performance, titled Christmas with the Alley Cats, was a wonderful blend of Christmas classics sung in beautiful harmonies, touching solo performances and playful humor.

Organized by Irene Imhof and Barbara Fonseca, the theatre was filled to capacity with 200 attendees, among them family and friends of Nathan Fonseca, who was born with hypoplasia of the corpus callosum.

Irene and Barbara sold tickets to the concert with a percentage of the ticket price donated to the NODCC. Gift baskets were also donated by local businesses and sold at a Chinese auction, in which attendees purchased raffle tickets. The tickets, which were dropped in the gift baskets that attendees hoped to win. Winners were drawn and announced at the conclusion of the concert.

The lively holiday fundraiser helped raise money for the NODCC and helped raise awareness of disorders of the corpus callosum.

The Alley Cats, Irene and Barbara are looking forward to a repeat performance in 2008.

eNewsletter Coming Soon!

Later this year, the NODCC plans to launch an electronic version of our newsletter that will supplement (not replace) our existing printed NODCC News.

The new eNewsletters will increase the amount of information we can disseminate as well as save trees and postage. We also can take advantage of the unique features of the eNewsletter format. An article on Special Needs Trusts, for example, could include URL links to other Web resources so you would only have to click on the link rather than type the entire address. In addition, many people find it much easier to retrieve a past eNewsletter in their computer than locate a printed document.

To make sure you don't miss the first edition, send your email address to info@nodcc.org with "Send Newsletter" as the subject. We'll take care of the rest.

We would also like to hear from our members about stories and topics that you would like to read about related to disorders of the corpus callosum. Please email us your thoughts and ideas. And, if you want to join the Communications Committee and help us with the newsletter or write stories, we would appreciate your help!

EMAIL US TODAY!

info@nodcc.org

From the Heart Of A Parent: Tomorrow Is Only A Day Away

Recently, our four-and-half-year-old son went through a battery of neuropsych-testing by a noted specialist in our area. We had the testing done to find out if kindergarten was appropriate for our son for next year, and what sort of learning environment would suit him best.

At 13 months, he was diagnosed with P-ACC, an enlarged third ventricle (whatever that means!), and hypoplasia. You know the drill: floppy, poor reflexes, delayed gross and fine motor skills, began walking at two, speaking at three. . . . And as his parents, we sat poised between trying to be optimistic and not limiting our child's horizons, and wanting to confront the brutal facts to really address what he needed.

After he was diagnosed I remember feeling so numb some mornings, it was like I was sitting in front of the VCR with three video tapes, blindly groping for one to play that day. The doom tape—that was the one in which we were the bravely suffering parents of a disabled child. The perky hero tape—that was mostly me making wry quips and being matter-of-fact about how my son was different, impervious to others insensitive questions or pity. And the most frequently played tape of all—the one where I managed to convince myself that my son was no different than other kids, and that the diagnosis didn't really mean anything.

A story I thought about a lot back than was one my best friend told me years before, when she was in medical school. The parents of a young girl with Prader-Willi Syndrome had come with their daughter to talk to medical students about parenting a disabled child. The girl looked typical

for children with her disease: She was very short, overweight, and retarded. One inquisitive medical student wanted to hear what the symptoms were like directly from the child. After taking a moment to collect herself, the girl came to the front of the class and cleared her throat. Smiling, she told them, "I'm not really prepared to talk, but I do have a song." She took a deep breath and with every ounce of herself began to sing, "Tomorrow" from the musical Annie. She stood in front of that big and imposing class and sang every single verse.

So when we sat down in the neuropsychologist's office to hear her findings about our son, I thought again about that strong little girl. And then I waited quietly to hear what the specialist would say.

Our son, she said, has the requisite skills to be placed in a mainstream kindergarten class as long as he has sufficient one-on-one support, and continues intensive speech and occupational therapy. That is what she said. In fact, she said it several times.

Our son tested in the 94th percentile for vocabulary. Ninety-fourth percentile! Oh sure, on all sorts of other tests his scores were lower, and some significantly. But our little guy—our smiling, warm, goofy, loving little guy—will be going to kindergarten. Who knows what accomplishments tomorrow will bring! And that, as Annie sings in "Tomorrow," is only a day away.

— Ann Eisenberg is a NODCC Board Member and a mother of two boys.