

The CIDSO News

VOLUME 3, ISSUE 8

NOVEMBER 15, 2007

"A Brighter Tomorrow"

President:

Jean Bates
452-2555

Vice President:

Rick Bauersfeld
874-2038

Secretary:

Brenda Harms
378-2388

Treasurer:

Steve Newbold
668-0928

Newsletter:

Dawn Mattia
750-9164

CIDSO Open:

Bill Crutcher
452-5556

Buddy Walk:

Jean Bates
Dawn Mattia

Social Chair:

Judy Bates
726-1145

Holiday Gatherings

Amid all the fun and love when relatives gather, there sometimes can be tension when a child with disabilities is part of the clan. Some family members may not understand your child's special needs and what kinds of accommodations are needed. Others may have questions about the disability but be uncomfortable asking them. Still others may even be afraid. The result can be unintentional hurtfulness.

Carolyn Anderson, Virginia Richardson, and Dao Xiong know firsthand what it's like. All three PACER advocates have grown children with disabilities and remember well the challenges they faced in the early years when family would gather. If you would like a three-step plan for creating an inclusive family environment for your child, take a CUE from

them: Communicate, Understand, Educate.

Communicate

No matter how much they love you and your child, relatives are not mind readers. They need you to share information about your child's skills and interests, his or her disability, accommodations you may need, realistic expectations for what your child can do, and your expectations for the family. They also need to know whether it's okay to ask questions about your child's disability.

Virginia puts it this way: expect my family to be supportive. But I have to give them enough information to be supportive in the way I want them to be." For her, that meant letting people know that her daughter Deborah's seizures weren't life threatening. "I didn't want them to be afraid of her or to think that

she was so fragile that every seizure was a Code Blue," she recalls.

She also made sure that they knew who Deborah was as a person. "I let people know what she was doing in school, that Deborah was participating in gymnastics," she says.

"I was still crying my way through the world at that time," she adds, so she enlisted her sister, Jessie, to be her spokesperson. "I wanted to give factual information about Deborah's disability, and I wanted people to know what we were working on at the moment so they could ask," she explains. "I was interested in the right information being conveyed. I wanted them to ask the family and not be afraid they were going to hurt anyone's feelings."

Dao, whose daughter Tsai has cognitive delays, notes that when

Holiday Gatherings Continued

it comes to talking about a child's disability, keep in mind that there may be cultural differences in how and when such communication occurs. In the Hmong community, for example, even though the parent is open to discussion, people aren't likely to come forward publicly and ask a direct question about the child," Dao says. "Instead, they might indirectly ask how the child is doing. That might lead to a more direct private conversation."

Understand

Even in the most loving, well-intentioned families, there are bound to be times when someone does or says something insensitive to your child. Carolyn remembers family gatherings where no one communicated with her son Matthew, who is deaf. If people learned any sign language, it was for words like "no" or "stop—negative things.

"You do the best you can," she says, noting that she tried to teach family members some sign language and show them how to speak to Matthew so he could read their lips. "Just try not to be judgmental," she says. "Remember, if it wasn't your child, you might be acting the same way. You have the opportunity to know better."

Educate

Family members won't automatically know the right ways to interact with your child with a disability. You, however, can help them learn skills and attitudes by modeling them your-self.

"We talked about Matthew's deafness openly," Carolyn explains. "We had a positive attitude toward the disability. We also modeled good communication rather than just telling people what to do. For example, we would tap Matthew on the shoulder to catch his attention before we talked with him. We also tried to teach some sign language to the people who were open to it."

Dao encourages parents to help other family members to find ways for the child with disabilities to participate. "Parents may need to say, 'I want my child to play. Let her join.' They might need to point out specific things the child needs in order to participate, like asking the other children not to chase her too last in a running game."

At the heart of all these CUEs is a philosophy of belonging. As Dao says with a smile, "Any family gathering is a time to include the children."

New Holiday Party Plans

We will be having our annual Christmas Party on Sunday, December 2nd at Calvary United Methodist Church on the corner of Towanda and Raab in Normal, IL starting at 4 pm. **We will begin eating dinner promptly at 5 pm.** Please RSVP to Judy Bates by November 26th if you wish to attend so she can plan for food accordingly.

The evening will also include our annual meeting and election of officers. Please notify Brenda Harms if you are interested in running for office or would like to nominate someone.

The party will also include singing Christmas carols and a fun-filled activity.

Something new this year:

While Santa will make an appearance at this year's party, he will not be bringing gifts to CIDSO members. Instead, we ask each family give Santa an unwrapped toy that he will distribute through the Toys for Tots program. We thought this would be a nice opportunity for our children to experience the joy of giving and will help out those in the community who are less fortunate. In addition, Santa's elves are really busy this time of year and this will give them a bit of a break.

Interested in Supplements?

Mitchell Hahn is on a supplement called Ambrotose Complex by Mannatech. It is a mixture of complex sugars that are necessary for cell-to-cell communication. I believe Ambrotose is one of the only supplements available that contains so many of the glyconutrients in one supplement. It is available as a powder that can be mixed into food or drink (that's how we give it to Mitchell) or in a capsule. There is information about it and other supplements at Mannatech's website www.mannatech.com or more specifically for product information <https://www.mannatech.com/Shopping/StandardProducts.aspx>

There is a book about glyconutrients called [Sugars that Heal](#) that we found very helpful in understanding this supplement. *submitted by Rebecca*

Mark the Date:

November 26:

RSVP for Christmas Party

December 2:

*Christmas Party & Annual Meeting
4pm to 7pm*

January 14:

CIDSO Board Meeting

CIDSO Resources: You Can Check Them Out!

The Bloomington Public Library houses CIDSO's collection of resources. There is a list available at the library which includes the books and videos that CIDSO has donated to library. Materials are donated yearly and intended to be used by CIDSO members along with other members of community who are interested in learning about Down syndrome.

Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote any therapy, treatment, institution or professional system, etc. Please discuss specific concerns with a professional.