



Down Syndrome Development Council FORUM-December 2007

volume 15

JANUARY MONTHLY MEETING January 10, 2008 7:00 PM to 9:30 PM

Attorney Charlie Fox Presentation on Legal Issues and Special Education

- 1) Parent Advocacy Training..
- 2) Overview of IDEA 2004 and How to make it work for you.
- 3) Transition Planning as a Crucial Part of your Child's IEP.
- 4) Developing Strategies and Documentation to Develop Better IEP's.

Charlie Fox is a parent of a child with special needs who has become an experienced special education attorney. His presentation will be approximately an hour and half with time after to answer specific questions. If you have any specific questions or issues that you would like address, please email them to

Patrick Collins at rjohncol@comcast.net. Mr. Fox is looking forward to having an interesting and informative discussion with the DDC members. *Or you could just come for cookies!!*

Please contact us at:

DDC
PO Box 906
Mundelein, IL
60060

Our Meeting Place:
Community Protestant Church
418N. Prairie Mundelein,
Second
Thursday of the month.

Our Mission:
To promote a greater acceptance and understanding of Down syndrome, by enlightening the broader community to recognize the individuality, uniqueness and capabilities of individuals with DS.

Our wonderful Christmas party will be held

December 9 from 1-5pm at the Community Protestant Church, 418 N. Prairie in Mundelein.

Main Dishes and beverages will be provided by the DDC.

We ask our families to bring food to share. If your last name begins with **A-I please bring an appetizer, J-R a dessert, and S-Z please bring a salad or side dish.** Santa will be arriving at 2:30pm with gifts for the children.

Please RSVP and volunteer to **Deb Pogose (847)973-1622** or email beauvp@sbcglobal.net no later than Nov.30th

Share the joy of the season with your DDC family.



THERE WILL BE NO DECEMBER MONTHLY MEETING.

UPCOMING DDC EVENTS:



- 12/8 New Baby Social, 9:30-11:30am**
- 12/9 DDC Christmas Party, 1-5pm**
- 12/20 Thurs. playgroup, 5:30-7:30pm**
- 1/ 10 Monthly meeting, Legal Issues - Special Education with Charlie Fox 7-9:30pm**

For a current listing of the books available in the DDC library, go to our website:

www.TheDDC.org Our library is located at the Center for Independent Living. If you are interested in checking out a book please call Pam at 949-4440, ext.15. The office is open Monday-Friday, 8:30-5:00pm.



Welcome!

What: DDC New Baby Social

We'll have light breakfast food (coffee, juice, bagels, etc.) for people to munch as they talk, a video viewing/play area (at one end of the same room) for any older kids in your family, and 2-3 DDC parents on hand (parents of kids age 5 and under) to answer any questions we can about Early Intervention, preschool, or recreation programs in our area. All members of your family are, of course, welcome to attend (though we will leave the rest of ours at home - it's a working day for us!) - they can eat, bring their own favorite toys to play with, or watch the "movie of the week"!

Who: Families new to the DDC, with a "new arrival" 18 months or younger

When: Every other month on a given Saturday morning, from 9:30-11:30

Next social - December 8

(feel free to come and go as you can!)

Where: Fremont Public Library

1170 N. Middlethian Road, Mundelein

****Questions? Please contact Jennifer Jenkins to receive the year's "social schedule" ****

(847/970-6797 only_connect@msn.com)



Dominick's "eScrip" Fundraising

Dominick's has an exciting new fund raising program called **eScrip**. Once an individual enrolls, up to 4% of your qualifying purchases are credited to our group every time you shop with your Dominick's Fresh Values Card. I shop all the time at Dominick's and just my grocery bill alone should generate a nice donation to DDC. The advantage of this program over some of the previous "grocery store" type fundraisers is that once you enroll, you do not have to do anything different or special when you shop and use your Fresh Values Card. It does not involve a credit card, or remembering any coupons or receipts. Once enrolled with DDC as your recipient organization, you just shop! The eScrip program automatically tallies all benefits and forwards the funds to DDC. Just think how much income this program could generate for DDC if all of our DDC members signed up!

All you have to do is go to escrip.com to register. It takes less than 5 minutes. All you will need is your Dominick's' Fresh Values card. When asked to select the organization that you will donate to, you can search by zip code, or by name. We are listed as Down Syndrome Development Council, Mundelein, IL, 60060. Thank you for your participation. The income from this program will allow DDC to continue to offer quality programs and social events! If you have any questions, please contact Janis Kern, DDC Treasurer, at (847) 548-4417.

The Riverbend Down Syndrome Parent Support Group of Edwardsville, IL has published their newsletter "Moonlight". It is posted on the web and here is a sample of what you may want to check out:

Puttin For Down Syndrome by Tim Nienhaus.

PUNS Is No Joke: What Is It? Why Should the Down Syndrome Community Care? By Michele Westmaas.

Making the grade by Michael Bérubé.

I Can't Talk With My Mouth Full Or... "The Confessions of a Home-Schooling Mom Who Eats Her

Words" by Gigi McLaughlin. Down Syndrome Community Newsletter. February 2007. p. 1, 3-4. These articles

and more can be found at <http://www.altonweb.com/cs/downsyndrome/> ph# (618) 208-1659

Last Month at the DDC . – November 2007



For our guest speaker this month, we welcomed Sarah Kozak, a speech/language pathologist and clinical director of Pediatric Interactions in Grayslake, a clinic with five full-time therapists and numerous therapy aides who assist in the group setting. She walked us through a number of handouts on a variety of speech and feeding issues that often arise in kids with Down syndrome (copies available from board members), then opened up the floor for questions. The majority of the kids she sees at her clinic have diagnoses on the autism spectrum, but there are a lot of similar oral-motor and language therapies that can be used in treating kids with Down syndrome. The overall focus of speech therapy is to help the child “get organized” in such a way that learning and communication are more enjoyable, and the best therapists have a whole-body, developmental approach, one that searches for ways to “activate” the child’s whole body and to create a general sense of stability that is more conducive to speech production. She noted that speech therapists in particular work “from hips to lips,” first strengthening posture and airway capacity, then refining the motions of the jaw, lips and tongue (with facial and oral massage, taste/temperature stimulation, etc.) to make oral-motor work more facile. In the service of these general goals, Sarah answered questions about the various systems that we often employ with our kids as pre-speech “bridges” of communication (sign language, PECS); she reminded us that sign language is a great tool to use early on with your child, as it builds on the natural tendency to use gestures of all kinds in our first efforts to talk to our kids. Most of all, communication should occur in a variety of settings, whenever and wherever possible and NOT just in a therapy session – we should encourage our kids to use language (of all levels and stages) in as many meaningful ways as possible! - Jennifer R. Jenkins, Secretary



GiGi's Playhouse Wants YOU!

GiGi's Playhouse is excited to announce the opening of a new chapter. The location has not been finalized but will be located to conveniently serve families in Northern Illinois and Southern Wisconsin.

Our mission is to increase awareness of Down syndrome by providing programming, education and support to individuals with Down syndrome, their families, and the community.

We need YOUR help to make this dream a reality. We are having a “town meeting” on January 18th, 6:30 to 8:30 pm at the Kensington Manor Club House.
8400 Cunat Blvd, Richmond IL. 60071

All are welcome to come and learn more about GiGi's Playhouse. We would love to hear YOUR ideas for activities, education and community programs.

This is your chance to make a difference!!!

For more information call Susan DuBois @ 1-815-955-4202

Or email Carol AnCel @ ps1272000@yahoo.com

**RSVP is appreciated as
Limited space is allocated**



FROM: Susan Goodman, Director Governmental Affairs

DATE: November 2, 2007

ACT NOW TO STOP BILL THAT VIOLATES RIGHTS OF PEOPLE WITH DISABILITIES

As you may know, the federal Developmental Disabilities Act has funded Protection and Advocacy (P&A) agencies in each state to act as a legal representative on behalf of persons with disabilities and their families. Because of the work of P & A lawyers and advocates, individuals with disabilities are able to live in the community outside of large institutional settings, included in schools, jobs and the community. This has been accomplished through legal action which resulted in favorable court rulings, settlements and representation for many people with disabilities and families in education, employment and community living. Congressman Barney Frank (D.MA) has introduced a bill that would severely restrict the ability of P & A agencies to represent individuals with disabilities. This bill is being pushed by groups that favor large institutional living. Below are talking points and other information from the National Disability Rights Network to familiarize you with this issue. a.. Members will make many decisions on whether to cosponsor legislation based on the input they have heard from back home. If all they have heard from people is to cosponsor a piece of legislation, it is likely they will choose to cosponsor a bill b.. However, if they hear from people opposing the legislation it can cause them to consider the issue more, providing valuable time to make the full case on why H.R. 3995 is a bad piece of legislation. In fact, we have already heard from some offices that if a call had not been received they were going to cosponsor the legislation! c.. Even if you simply convey the message that your Representative should not cosponsor or support H.R. 3995 because it is a bad piece of legislation for their constituents with developmental disabilities, that is enough for now. d.. While it is best to ask to speak to the staff member that handles disability issues, it also helpful to just leave a message for the Representative with the person that answers the phones. e.. The following link will get you to a list of the Representatives where you can find the phone number for their Washington, DC office:

<http://www.house.gov/house/MemberWWW.shtml>

Advocates are urged to call their House of Representative member today and urge them not to co-sponsor H.R. 3995. It is the calls from family members and other advocates that are keeping members from co-signing, because many House members do not understand the significance of this bill.

3 cups gluten-free flour mix*
 2 eggs
 1 teaspoon soda
 1 cup sugar
 1 teaspoon cream of tartar
 1 teaspoon almond (or flavoring of your choice)
 1 cup gluten-free margarine

*Four Flour Mix:	
Garfava Bean Flour	(2/3 part)
Sorghum Flour	(1/3 part)
Cornstarch	(1 part)
Tapioca Flour	(1 part)

Sift flour, soda & cream of tartar – cut in margarine or butter (I find that margarine is easier when rolling out the cookies). Beat eggs, add sugar & almond – mix well. Pour egg mixture into flour mixture and mix well by hand. Chill at least 15 min (several days is also ok). Roll out to desired thickness on floured surface and cut into shapes. Decorate with colored sugar, or if you prefer, after baked & cooled frost and then sprinkle with colored sugar, etc. 2 cups powdered sugar mixed with some melted butter & lemon juice frosts one batch. Bake at 350F for 9 minutes.

A Special Needs Parent's Wish List

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So you'd like to give me a gift? That's nice. But the things I really need don't wrap so well. Put away that paper, keep your card, and give me one of these.

All I really want is:

Babysitting: A few nights out this year will do me a lot more good than another sweater or DVD.

House Cleaning: Oh, yeah. Come clean my house. Anytime. Do you do windows?

Homework Help: Teach my kid math. Help her write a paper. Drill him with flashcards. Give me a break.

Sounding Board: Therapy? Expensive. Someone like you, who I can call and gripe to for hours? Priceless. *

Back-Up: Come to IEP meetings and doctor's appointments with me. Bring tissues. And maybe a baseball bat. *

Child's Play: My child wants to play with me, needs to play with me, all the darn time. You take a few shifts, okay? *

Sleep: Offer to take my kids to school one morning. Also wake them up, and get them dressed and fed. I'm sleeping in.

Playgroups

Our monthly playgroups meet on two different days each month, one on Saturday morning, the other on Thursday evening. In each case, families are encouraged to bring all of their children for an interactive group play therapy session, led by our developmental therapist Kris Murray and hosted by various DDC parents. The Thursday evening group meets in early evening (the third Thursday of the month) and includes dinner. Spanish language interpreters are available with advance notice. These playgroups are completely free of charge and open to all DDC member families! For more information about the upcoming playgroup schedule and locations, please contact Kris Murray (847-630-4991) or Belinda Hidalgo (hidalgob@comcast.net). **If you would be interested in attending a Saturday morning playgroup, please contact Belinda.**

MAKING FAMILY GATHERINGS GOOD, NOT GHASTLY

Family get-togethers are the worst. Too many people. Too much noise. Too much food. Too many opinions on the ways you're raising your children. Never mind the fact that kids with special needs often go crazy during big family events -- they're often not exactly a shining hour for us as parents, either. How can you make it through the meal without chewing someone out, putting your foot in your mouth, or eating your words? If a quiet dinner at McDonald's is out of the question, here are some ways to get through these gatherings without going crazy.

1. Make an escape plan. Better to leave before things go bad than stick it out and live to regret it. If you're spending the holiday at a home other than your own, arrange a time limit or a signal ahead of time and observe it - even if it means missing the pumpkin pie. If your child seems to be coping better than expected, you can always extend the deadline, but be ready to split at a moment's notice. If at all possible, when your holiday travels involve such a distance that you'll have to stay overnight, get a hotel room. Your child (and you) will need someplace quiet and chaos-free to decompress after so much family exposure. Then again, if everybody's coming over to your house for dinner, make your child's room off-limits to everybody but him or her, and encourage your child to use it as a refuge when things get overwhelming.

2. Clothes don't make the kid. If your child has sensitivities to certain types of clothes, or just stubbornly insists on wearing something you (or, you suspect, your mother) will find inappropriate, don't pick a battle today. Eyebrows may rise if your kid's in sweats while every other little cousin is dressed to the nines, but you want to start your child out with as low a stress level as possible. Fussing over clothes, or putting him or her in clothes that you know will cause anxiety, is a bad way to start. And this way, when the inevitable spills occur, you'll be the only parent at the table who's not worrying about ruined outfits.

3. Augment the menu. Whether you're bringing a little something to somebody else's party or planning your own repast, make sure there's something your child will enjoy eating. And then don't comment if that's all he or she will eat. The goal of the day isn't cleaning your plate or trying new foods or pleasing the cook. It's getting through the meal with a minimum of trauma. And, more importantly, it's about giving thanks for the good things in our lives. If your child only wants to give thanks for macaroni and cheese, so be it.

4. Be the one who watches the kids. Keeping a close personal eye on your little one has a number of benefits. You can intervene in inter-child squabbles. You can assess your child's level of over stimulation and act accordingly. You can play with your child if no one else will, or lead the other children in a game your child can participate in. And, perhaps most importantly during these events when you feel every judgmental eye is on you and your family, you can avoid conversations with grown-ups. You'd sure like to discuss your child-rearing flaws with Aunt Gertrude, but -- oh, honey, do you need some help with that? Why don't we sit down here on the floor and do it together.

5. Bring supplies. Fill a backpack with things your child finds reliably comforting or fun to play with- toy cars, a stuffed animal, a tape and tape player, a few books. Having them available, even if he or she doesn't actually play with them much, may give your child a sense of familiarity that will be relaxing. If he or she gets over stimulated, find a quiet corner or a back room in which to spend a little time with the toys. If nothing else, toting the toy bag around and making it available when necessary gives you something to do that does not involve long conversations with unpleasant relatives.

6. Beware of bribes. You may be tempted to offer some big reward for your child's good behavior at a family get-together, but that can backfire. The fear of losing that much-wanted thing may add to your child's stress overload and actually bring on even worse behavior. Some kids may talk themselves out of wanting the reward because they feel so incapable of providing the required self-discipline. And once you've lost that incentive, things can go downhill very quickly. Small spontaneous rewards during the course of the event are often more effective, because they reduce stress and improve mood. Then, if your child does pull it off, you can always give the big reward later with much praise and encouragement.

Continued from last page:

7. Remain calm. Memorize this phrase, and repeat it over and over in your head whenever you feel yourself losing your cool: I do not have to apologize for being a good parent to my child. We may struggle under the weight of "advice" or disapproval from family members, but our kids don't care about that: They need what they need. You know best what your child needs, and providing it is your most important responsibility, no arguments. Since most children with special needs react badly to stress in their environment, particularly stressed-out parents, staying relaxed and low-key is one of the best things you can do to keep your child's behavior in line. You can always throw a tantrum when you get home.

8. Don't overbook. Hold the festivities down to one event per holiday. Don't hop from house to house, or plan a big outing the night before a family event. Give your child (and yourself) the maximum amount of de-stressing time surrounding the minimum amount of stressful activity. This may be a disappointment to friends and family members who feel you are sheltering your child too much or rewarding difficult behavior, but you know best –
Happy Holidays

Donate to DDC!

The Down Syndrome Development Council (DDC) provides support, educational programs, social events and monthly newsletters to families of individuals with Down syndrome as well as Down syndrome awareness in our communities. The DDC no longer charges membership dues, or fees for most of our programs. Our costs are covered entirely by donations and various fund raising events. If you would like to contribute to DDC to help us cover the costs of our programs and newsletters, please mail your tax deductible check (payable to Down Syndrome Development Council) to:

DDC, P.O. Box 906, Mundelein, IL 60060. Please call our treasurer Janis at 847-548-4417 if you have any questions about your donation or our program.

DECEMBER BIRTHDAYS!!!

KIMBERLY NISKANEN	1993
MICHELLE LABELLARTE	1993
MATTHEW TEITZ	1999
PETER RYBACK	1977
NICHOLAS AUSTIN	1999
BROGAN HORA	2004
SAM COLLINS	2002
TARA DIEDRICH	1988
REBECCA WITT	1993
MADISYN ROSS	1999
ZACHARY WILLIAMS	1996
ZACHARY JEWITT	2002
SARAH LOCKHART	2003
GIADA RASMUSSEN	2006
HALEY SCOTT	2000
LUPITA ORDUNO	2004



DDC Board Members 2006-2007

President	Patrick Collins	847-265-8482	rjohncol@comcast.net
Vice Pres	Mary Lou Paff	847-548-4852	mlpaff@aol.com
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