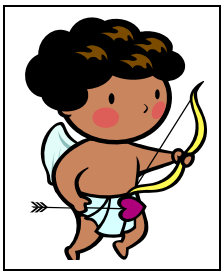
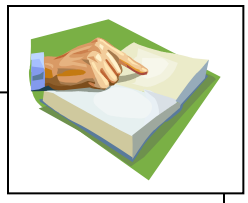


Down Syndrome Development Council

FORUM-February 2008 volume 17



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.**

FEBRUARY MONTHLY MEETING

February 14, 2008 7:00 to 9:30 PM

Pam Labellarte is a trained Parent Advocate who has been supporting parents of students with disabilities in the educational setting for the past 7 years. She has worked as a Parent Advocate at the Lake County Center for Independent Living since October 2003, where she teaches Youth Employment Readiness classes to students in Secondary Transition (ages 14-22) and coordinates Disability Awareness presentations throughout Lake County. Pam will share her knowledge and lead a discussion on:

- **Changes to IDEA (IDEA 2004), including a copy of the new IEP published in July**
- **Common Mistakes parent make regarding their child's IEP**
- **Parent Guides to the IEP, Functional Behavior/Behavior Intervention Plans, etc.**
- **Resources for Secondary Transition Planning**
- **Books for the DDC library (dealing with the IEP process) available for check out that evening**
- **Website Resource Listing for IEPs**

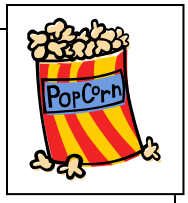
Hope that helps

Pam Labellarte

Parent Advocate

Lake County Center for Independent Living

Parents who are comfortable discussing their child's IEP, can bring it with to discuss a particular concern.



Movie Lover's Club

The families of the DDC are invited to a free showing of the new live action movie **DR. SEUSS' HORTON HEARS A WHO!**
Saturday March 15th at 10 am (please arrive by 9:45am)
at the Liberty Theatre in downtown Libertyville on Milwaukee Ave.
The DDC covers the cost of admission, popcorn and soda pop are available to purchase. This is a private showing just for us; the lights are up a little and the children are free to move around, make noise and have a good time. We encourage the kids to sit together and make new friends.
For more info. Call Rae Ann Collins at **847-265-8482.**

UPCOMING DDC EVENTS:

2/ 14 Monthly meeting, Advocacy - with Pam Labellarte 7-9:30pm
2/21 Thurs. playgroup, 5:30-7:30pm
3/13 monthly meeting, GiGi's coming
3/15 Movie Lovers, 9:45am
4/10 PUNS registration 6-10pm

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.

APRIL 10, 2008 PUNS REGISTRATION

What is PUNS?

PUNS stands for ***P**rioritization of **U**rgency of **N**eeds for **S**ervice*, which is nothing more than a database used by the Illinois Department of Human Services (DHS) to determine unmet needs. That information is used by legislators to make decisions on funding, services, and programs and allows advocates to push for increased funding and services. PUNS is not a guarantee of services or a request for services. It is simply a way to document the needs in Illinois. It is imperative that every single person with a developmental disability to stand up and be counted in the PUNS database!
Representatives from Community Alternatives Unlimited (CAU) will be present to get your child or adult signed up for PUNS. **Sign-ups cannot be done over the phone, so it is important to attend the DDC PUNS Registration night:**

Date: April 10, 2008 **Time: 6 p.m.-10 p.m.**

Location: Pediatric Interactions, 15 Commerce Dr. Ste. 116, Grayslake, IL 60030
Bring: Your child with Ds, a photocopy of their social security card

The process takes about 30 minutes. Call Mary Lou Paff at 847-548-4852 (mlpaff@aol.com) for an appointment.Who qualifies? Persons of all ages with a disability who are anticipating a need for funding in the next 5 years qualify. Services could be respite, behavioral supports, housing. adaptive equipment, etc.
Why should a family with person with Down syndrome do the PUNS survey? Your loved one with Down syndrome must be on the PUNS database in order to be considered for any new services. All future recipients of services will be selected from the PUNS database. If your loved one is not listed in the PUNS database, your need does not exist in the eyes of IL legislators. When funding and policy decisions are made, inaccurate low numbers may result in lower funding and limited service availability. In order to get services and funding to meet our needs, our needs must be recognized and counted in PUNS. Your willingness to complete the survey will support advocacy efforts. Without a need demonstrated by PUNS, the legislature might not increase funding, create new programs, or modify existing programs.

What does the form look like? Go to http://www.dhs.state.il.us/mhdd/dd/forms.asp and click on "Appendix 2- Illinois PUNS Form (English Version, pdf)" to review the form before your appointment. Remember that you cannot complete the survey online. However, you can review the questions and think about your answers in advance. The PUNS form first categorizes need by three levels of urgency:

- Emergency: the individual or caregiver needs support immediately;
- Critical: the individual or caregiver needs support within one year;
- Planning: the individual or caregiver needs support within 1-5 years or their caregiver is aged 60+.

Then it asks you to identify supports and services you or your loved one with a disability needs or will need in the future.

- Think about what your loved one needs to be successful, either in your home or his home in the community.
- Don't limit yourself. If you could ask for anything at all, what would you need?
- Think hard about the life changes you expect in the next 5 years.
- Does your child need respite or after school care?

What happens after I complete the PUNS survey?
Completing PUNS does not guarantee services. But you will know that your data is helping to move the system forward. You will know that you are being considered in critical funding, program, and policy decisions. You will know that you will be considered for enrollment when there is new funding for services that meet your needs and qualifications. Each year you will receive a reminder to update your PUNS data. Annual updates are mandatory, but changes can be made at any time.

How do I prepare for my appointment? Be prepared to provide a photocopy of:

- Child's social security card
- Trisomy 21 karyotype or medical letter stating that the person has Down syndrome
- It may be challenging to anticipate the needs of the next 5 years. Talk to others with loved ones older than yours to find out what you can expect. Talk to the therapists and care providers working with your loved one to see what they suggest or anticipate. Here are some things to think about:
- Don't ignore some needs because you assume they will never be met. This is not the time to be proud.
- Think of all the things you do that would have to be done by someone else if you were gone.
- Think of what you need help with in order to live a more typical life.
- Think about what your loved one needs to be successful, either in your home or his home in the community.
- Don't limit yourself. If you could ask for anything at all, what would you need?
- Think hard about the life changes you expect in the next 5 years.
- Does your child need respite or after school care?

This important topic will be discussed again in the March newsletter.

Now is the time to get training and make the most of the New Year! "Handwriting Without Tears" is offering the following workshops in your region:

Pre-K* and Printing & Cursive	**The Print Tool**
February 1*-2..... Grand Rapids, MI	January 11 ……Detroit, MI
March 14*-15..... Minneapolis, MN	January 25……Chicago, IL
March 30*-31..... Chicago, IL**	May 16 …….Minneapolis, MN
April 11*-12..... Detroit, MI	June 6,,,,,,,…,St. Louis, MO
April 25*-26..... Indianapolis, IN	June 20 …….Chicago, IL
May 16*-17..... Milwaukee, WI	
June 6*-7..... Bloomington, MN	
June 20*-21..... Chicago, IL	*Pre-K Workshop **Sunday-Monday

Handwriting Without Tears® is excited to introduce new editions and new products for the 2008 workshops! Our 2008 workbooks and teachers' guides are the culmination of successes from previous editions plus many new ideas from our collaborations with educators throughout the country. In our workshops, we have added new music for K-2, new multi-sensory activities for all grades, and more strategies and ideas for teaching throughout the year.

To register, get more information, or see a list of all the other scheduled HWT workshops, go to the Workshop page or contact our National Workshop Coordinators at 402-492-2766 or coordinator@hwtears.com. I

Last Month at the DDC . . . – Speaker: Charlie Fox (Attorney)

In January we welcomed attorney Charlie Fox to our monthly gathering to share his experiences of working as a child/family advocate in special education law; it's a role that he has developed as a result of being a parent of a child (now teenager!) with special needs (in his case, cerebral palsy). Charlie spoke to us in particular about strategies for making IEP meetings run as smoothly, effectively, and favorably to your child's educational needs as possible. He reminded us that ultimately an IEP needs to live up to its acronym – it needs to be individualized, educational, and planned! In his work on behalf of children with Down syndrome, he noted that the most common obstacle is the history of a given school, teacher, social worker, etc., such that one's child is forever having to battle against stereotypical assumptions about what "kids with Ds" can or cannot do; the result is frequently a bar being set too low and a surprise at any evaluations that reveal unexpected "normalcy." Too often, expectations of evaluators are based on generalizations about "the diagnosis," rather than a close examination of the specific child's place along the vast spectrum of achievement. Charlie reminded us of the importance of monitoring the language used in IEP discussions to make sure that everyone is working with your child's specific needs as much as possible (as opposed to dealing in "here's what we typically do with kids who have _____"). In general, his advice to parents falls under a two-pronged approach: VISION and VIGILANCE. The former changes with your child's achievements, and it's important to always consider both the long- and short-term goals of your child's educational process; goals may shift around (you learn as you go what needs to happen in what order for your particular child), but one must always be clearly moving towards something! The latter requires parents to always ask the difficult questions, ones that aim for specific responses that are tailored to the needs of your child ("how will you teach my child this particular skill?"); it demands that parents question categorical statements made by the evaluators/educators (things like "we don't do that with kids with Ds," "kids with Ds don't . . .," etc.) and reminds them that "norms" CAN be challenged and exceeded. Resist the pull towards "it's always been done that way," always make sure that you ask about the hierarchy of authority in matters of disagreement ("what is the written policy on this particular point?"), and don't accept the frequently heard calls for parents to "be realistic" about a child's potential; this tact may simply be the result of no previous attempts to change the status quo at a given school or program.

Finally, Charlie reminded us of the vital role that assistive technologies can play in a child's educational plan; it's an area that often gets overlooked unless parents ask for an evaluation, yet the vast range of tools available can significantly alter a child's experience in the classroom. For many kids, as Charlie quips, AT is not "the icing on the cake" – it's the cake! He referred us to a number of websites that describe the array of technologies, the means of applying and qualifying for such assistance through state programs, etc. – for information on this area, as well as related areas of special ed law and family advocacy, see Charlie's own website: **specialedlawblogs.com.**

- Jennifer R. Jenkins, Secretary

UPS for DOWNS
PRESENTS

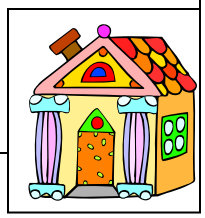
THE JIM GILL FAMILY MUSIC SHOW

Sunday February 10th
2: 15 pm

Join in the singing at the Mount Prospect Public Library/ room A.
10 South Emerson
Mt. Prospect, IL (847)253-5675.
Refreshments will be served following the show.
Parking is available in the garage under the library. Enter the parking garage and follow the yellow library parking signs. Take the elevator to the first floor to room A.

GiGi's Playhouse is coming to a county near you!!

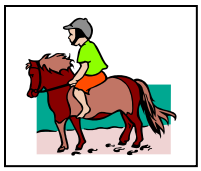
A representative from the McHenry GiGi's Playhouse will be outlining their mission and programs, and where they are currently in their progress. Join us at our March monthly meeting, questions will be answered and information will be available. Please feel free to contact Susan DuBois at 815-955-4202.



Therapeutic Horseback Riding Scholarships

Great news! Partners For Progress therapeutic riding program is currently accepting applications for scholarships through the Leroy Mathison Scholarship Fund. Applications must be turned in by February 1, 2008. Partners For Progress is a premier therapy program specializing in equine intervention to assist riders to learn and develop the skills they need to reach their fullest potential in life. The program is located at Fields and Fences riding stables, in Gurnee, Illinois. Scholarships will be awarded for one year to those who cannot afford to pay the weekly charge to participate in the program. There are multiple scholarships still available, but hurry, the deadline is approaching quickly!

Scholarship forms are available by contacting Janis Kern at (847) 548-4417, or at janiskern@comcast.net, or by calling Diane Helgeland , Executive Director of Partners for Progress at (847) 226-1300.



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.**

BATTER'S UP!

The Libertyville Little League is looking for more players for the Challengers team. What, you don't know what the Challengers are? Well, the Challengers is a Little League sanctioned special needs baseball team available to kids as young as 6 years old. We Practice once a week starting in late April and have games on Saturday mornings. We play against other special needs teams. Our home games are played at the Little League fields at Butler Park in Libertyville. The away games will also be on Saturdays. Each player receives a uniform and hat. The players are responsible for their own baseball mitt and shoes. Each player needs to have a sibling or parent at every practice and game. We need each "buddy" to help out the player, not play for them, but to be there to assure the player does not get hurt. Our coaches run the practices like regular baseball. There are warm ups, hitting practice (using both pitching and a batting tee), and fielding practice. If you are interested in joining our team or need more information call the Libertyville Little League 847-367-1448 or visit their site www.libertyvillebaseball.org. Register on–line before February 29th.

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 complete the following form and mail it, along with your check (payable to Down Syndrome Development Council) to: DDC, P.O. Box 906, Mundelein, IL 60060

Name _____

Address _____

City _____ State _____ ZIP _____

Phone _____e-mail address_____

Amount: $_____

I would like my donation to be acknowledged in the next newsletter (no amounts will be published)

_____yes _____no

My donation is in honor of: _____

or in memory of: _____

If you have any questions, please contact any of the board members by phone or e-mail.

Contributions

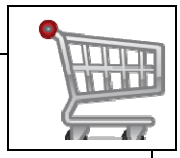
The Down Syndrome Development Council extends a sincere thank you to all of the donors whose contributions have been received in the past month. Your generosity will allow DDC to continue to offer quality programs and services to our members!

Abbott Laboratories Employee Giving Campaign
TAP Employee Giving Campaign

Buddy Walk matching grants were received from the following corporate donors:
Walmart – East Dundee (Buddy Walk matching grant).

DDC Board Members 2007-2008

President	Patrick Collins	**847-265-8482**	rjohncol@comcast.net
Vice Pres	Mary Lou Paff	**847-548-4852**	mlpaff@aol.com
Secretary	Jennifer Jenkins	**847-970-6797**	only_connect@msn.com
Treasurer	Janis Kern	**847-548-4417**	Janiskern@comcast.net
Past Pres	Andrea O'Donnell	**847-949-1975**	odonnela@sbcglobal.net
Playgroups	Belinda Hidalgo	**847-838-4398**	Hidalgob@comcast.net
Board	RaeAnn Collins	**847-265-8482**	rjohncol@comcast.net
Newsletter	Terri Christolini	**847-267-1169**	Christolin@aol.com
Foro (Spanish Issue)	Anna Roeser	**847-362-0980**	roeser1984@yahoo.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.

"Welcome to our new neighbors".
Cherie Clark and her 1 year old son Jack will be relocating from Nashville Tenn. to Green Oaks. We are looking forward to meeting them soon.

FEBRUARY BIRTHDAYS!!!

Thomas Aguirre	1997
Michael Asher	1988
Darrell Bermas	2001
Michael Campbell	1992
Michael Doetsch	1999
Sara Marie Echles	1997
Michael Holm	1983
Mary Elizabeth Kloss	1987
Helen Liapis	2000
Samuel Lenihan	2001
Sophia Mannino	2003
Valerie Ann Pajerski	1997
Lindsey Pazerunas	1995

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:! Please contact Jennifer Jenkins to receive the year's "social schedule" (847/970-6797 only_connect@msn

Where: Fremont Public Library 1170 N. Midlothian Road, Mundelein

**Questions? Please contact Jennifer