



# Down Syndrome Development Council FORUM-January . 2007 volume 16

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



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.

**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](mailto: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!! Babysitting is provided at each meeting.*

**Movie Lover's Club**

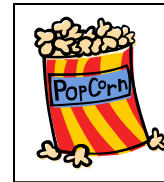
**WHEN: Saturday March 15th (opening weekend!!!)**

**WHAT: Dr. Seuss' Horton Hears a Who**

**WHERE: Liberty Theater (on Milwaukee Ave in downtown Libertyville)**

**TIME: 10:00 am private showing (arrive at 9:45)**

Come and bring the whole family... DDC covers the cost of admission!!! Pop and popcorn will be available for purchase. This is a private showing so we get the place to ourselves. We keep the lights up just a bit and we can adjust the sound as needed so it is fine to let the kids walk around during the film or sit on the floor way in front if they choose....we don't even care if you leave your cell phone on! Our hopes are to encourage families who may otherwise not be able to take their children to a movie due to sensory issues, talking back to the movie, ants in their pants, being afraid of the dark or just needing to avoid the crowds to get out and experience a movie on the big screen. Any questions please contact RaeAnn Collins @ 847.265.8482. Hope to "C" You at the Movies!



**UPCOMING DDC EVENTS:**



- 12/20 Thurs. playgroup, 5:30-7:30pm**
- 1/ 10 Monthly meeting, Legal Issues - Special Education with Charlie Fox 7-9:30pm**
- 1/17 Thurs. playgroup, 5:30-7:30pm**
- 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](http://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 *Prioritization of Urgency of Needs for Service*, 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](mailto: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 [www.dhs.state.il.us/mhdd/dd/forms.asp](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**

February 1\*-2..... Grand Rapids, MI  
March 14\*-15..... Minneapolis, MN  
March 30\*-31..... Chicago, IL\*\*  
April 11\*-12..... Detroit, MI  
April 25\*-26..... Indianapolis, IN  
May 16\*-17..... Milwaukee, WI  
June 6\*-7..... Bloomington, MN  
June 20\*-21..... Chicago, IL

### **The Print Tool**

January 11 .....Detroit, MI  
January 25.....Chicago, IL  
May 16 .....Minneapolis, MN  
June 6,,,,,,St. Louis, MO  
June 20 .....Chicago, IL



\*Pre-K Workshop      \*\*Sunday-Monday

**Handwriting Without Tears<sup>®</sup> 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](mailto:coordinator@hwtears.com).

## Swim across Tahoe raises awareness and expectations for people with Down syndrome

An hour before sunrise Tuesday, with temperatures in the low 30s, **Karen Gaffney** strapped on a bright red swim cap and kid-size turquoise goggles. She tucked a neon glow stick under the goggle strap, took a deep breath, stretched her arms in her full wetsuit and plunged into the 60-degree waters off Dead Man's Point on the East Shore of Lake Tahoe. Gaffney would be swimming into the afternoon in an attempt to make history

Her mission: To be the first person with Down syndrome to cross the lake, swimming nine miles from the East Shore to the West Shore's Sugar Pine Point. **Why? Because she can.** "We're not aware of what these people can do," Gaffney's father, Jim, said confidently before witnessing his daughter plunge into the cold darkness. When asked about his daughter, he simply described her as "determined and disciplined".

Karen, a 29-year-old from Portland Ore., has a college degree, and is a public speaker advocating the abilities of people with Down syndrome with her own non-profit, The Karen Gaffney Foundation. The swim is aimed at raising money for the nonprofit National Down Syndrome Congress. Swimming since she was nine months old, Karen is perhaps more comfortable in water than on land. "She swims much faster than she walks," her mother, Barbara Gaffney said.

Hip dysphasia has made it difficult for Karen to walk. She's had five surgeries in an attempt to correct her gait. She also has poor eyesight, making open water swimming more challenging than being in a pool. Despite all the challenges, Karen continues to break barriers in the sport. She has competed in Donner Lake Swim, Escape From Alcatraz Triathlon. She's even crossed the English Channel on a relay team.

But as the sun rose over the Sierra on Tuesday and with her support team in tow, it was clear Karen would need every bit of the three to six miles a day she trained in the weeks leading up to the swim. The swim taking feeds of Gatorade, bananas and Fig Newtons every 30 to 45 minutes from a support Kayak piloted by her uncle, Bill Gaffney, Karen swam in time with a rotating group of pacers, one of whom was Ken Harmon, from Danville, Calif., the fastest swimmer to cross the length of the lake. But her support team was far from alone Tuesday. An entourage of six boats, mostly camera crews from national and local networks and news services, chronicled Karen's swim from start to finish. Her only brother, Brian, rode near her on a Jet Ski.

"I love her kick!" said Karen's Aunt Katie as she watched her niece's leg rise above the water with the precision of a synchronized swimmer. "They call that the Karen kick," Bri Maier said. Maier helps Gaffney run the non-profit the Karen Gaffney Foundation in Portland. "She dropped me like a brick!" said Phil Summers who swam more than five miles with Karen and also coaches her in Portland.

After six hours of being in the water Karen was numb head to toe, but could see the shore of Sugar Pine Point lined with supporters, media and on-lookers. With a final stroke and kick, she swam into the arms of her uncle Bill, who helped her walk to shore. "I feel great!" Karen said as her water-wrinkled face cracked a smile.

Amongst the crowd were several children with Down syndrome who see Karen as a role model. As she watched from the boat Gaffney's Aunt Katie Lynch got the chills as she watched reached Sugar Pine Point. "We have a poster of Karen and it's a great thing to aspire to," said Alex Silverman of Tahoe City whose two-year-old son, Finley, was born with Down syndrome. Finley's father, Ralph Silverman's also provided Chris-Craft boats for the support crew. Nancy Muir came to Tahoe, from Rocklin, to watch Karen swim with her daughter MacKenzie, a six-year-old with Down syndrome. "I've been looking forward to this day for months," Muir said. "We're constantly being told our kids can't do these kinds of things. She's opening doors for my daughter."

(Continued on the next page)

As for Karen, she couldn't be happier, but it will be a while before she gets in water again. "It was a new experience," Karen said. "I really hit a homerun on the swim and I really made a lot of people proud." Karen's family could not be more pleased — and relieved — seeing her back on land. "It's awesome," her father said. "It's been a long-time dream. There are so many things that can go wrong." As she watched from the boat Gaffney's Aunt Katie Lynch got the chills as she watched reached Sugar Pine Point.

Why Tahoe? The Gaffney's chose Tahoe for the historic swim because it has been a favorite of the family for generations. Karen Gaffney said remembers playing on the beaches as child. Father Jim Gaffney said he was looking for a good spot to complete a "solo" swim "to demonstrate on her own how strong she is in the water." The only concerns the Gaffney family expressed prior to Karen's early morning swim was starting on time: "You're just racing against the wind. You got to get started before it picks up," Barbara Gaffney said.

Her pace was strong and consistent as she glided, and the waters of Big Blue cooperated with a classic fall calm." It's one of the most beautiful lakes in the world," mother Barbara Gaffney said.

While taking a well-deserved break, Karen and her family said swimming shore-to-shore in Tahoe will not be her final triumph. "(I want her to) swim Napali off the north coast of Kauai," Phil Summers, one of Gaffney's coaches said. "The other is a secret; I have to do some research to see if it's even possible." Chances are, for Gaffney, it will be. *For more information go to [www.karengaffneyfoundation.com](http://www.karengaffneyfoundation.com)*

**“What an inspiration; don't you think?”**



Karen Gaffney

## **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](mailto:hidalgob@comcast.net)). **If you would be interested in attending a Saturday morning playgroup, please contact Belinda.**

## 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

Allstate Giving Campaign

Anonymous donor

Joanne Bairstow in honor of Erich Smith

Kristine Pierre in honor of Max Kern

Cheryl Russell in memory of Robert Francis Connors

Ellen O'Donnell in memory of Robert Francis Connors

Kathy Murray in memory of Robert Francis Connors

Henry Pierce in memory of Robert Francis Connors

**Buddy Walk matching grants were received from the following corporate donors:**

Walmart of East Dundee (Buddy Walk matching grant), Walmart of Gurnee (Buddy Walk matching grant)

Sams Club of Vernon Hills (Buddy Walk matching grant)

**Check out these Down Syndrome Articles in Dec issue of Moonlight**

**What is the Home-Based Support Waiver for Children?**

**Theology and Down Syndrome:** Re-imagining Disability in Late Modernity by Amos Yong. *Excerpt:*

**Complicating salvation:** *Intellectual disability and Down syndrome.*

**An All Inclusive Debate — Whether Academic Inclusion Best Serves Students' Social Development.**

*Update, newsletter of NDSS, Spring 2006, Vol. 22, No. 1.*

**Stubborn Is... As Stubborn Does** by Carol Johnson. *CDSS Quarterly 11(1): 5-6 (1998 Spring).*

**Web Wanderings: Obesity-Related Hormone is Higher in Children with Down Syndrome**

<http://www.altonweb.com/cs/downsyndrome/dec07.html>



## 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](http://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.

### JANUARY BIRTHDAYS!!!

JACK DEVINE	1992
EMILY MAATMAN	1987
MADLINE PADULA	1990
JACK MORY	1998
LANIE HAYSKAR	2002
NELLIE OVERTON	1995
ALYSSA SANCHEZ	1990
DANIELMAGERS	1984
KAILYN SCHWEDE	2003
ANDREW ZEMAITIS	1991
P.J. BRANKIN	1981
CONRAD GRAEF	1996
CLAIRE TURON	1995
ANDREW JACOBSEN	2004
TREVOR BRAHM	



Welcome to our new members:  
Andrea Weadick of Wauconda and  
her new baby Theodore (Sept)

Thanks to all the families who made the DDC Christmas party such a wonderful event. It is great to see all the children with Santa each year, how they have grown and all of their progress. What a terrific group of people we are. Happy New Year!!!

## DDC Board Members 2007-2008

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