

# Down Syndrome Development Council

## FORUM-March 2008

volume 18



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.

### MARCH MONTHLY MEETING

March 13, 2008 7:00 to 9:30 PM



**Thursday night a representative from GiGi's Playhouse will be joining us to present the new plans for a new playhouse**

**in our area..** GiGi's Playhouse is a not for profit Down syndrome awareness center. With multiple locations, offering activities, resources, educational programs and support for individuals with Down syndrome, their families, and the community. At GiGi's Playhouse they celebrate the lives and showcase the talents and potential of individuals with Down syndrome. GiGi's Playhouse is something different for everyone whether it's a hug, a party, or an educational experience but most importantly GiGi's Playhouse is a place to belong. The minute you walk in the door you can't help but smile and be touched by Down syndrome!

This will be a great resource for our group and for this community. Come and be involved, *Or you could just come for cookies!!* **Babysitting is provided at each meeting.**

### Movie Lover's Club

The families of the DDC are invited to a free showing of **DR. SEUSS' HORTON HEARS A WHO!**

Saturday March 15<sup>th</sup> 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:

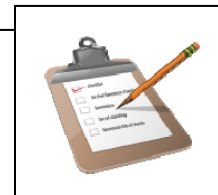
- 3/ 13 Monthly meeting GiGi's coming
- 3/15 Movie Lovers, 9:45am
- 3/15 "Sexuality & Relationships," Workshop, 8:30-3pm
- 3/20 Thurs. playgroup, 5:30-7:30pm
- 3/30 Handwriting w/o Tears
- 4/10 PUNS registration 6-10pm
- 5/8 DDC Board Elections, 7pm

### 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.

**Want to smile? Simply go to [www.youtube.com/watch?v=t\\_0K-gPlyb0](http://www.youtube.com/watch?v=t_0K-gPlyb0) and then send it on to the rest of the world. Let's see what will happen.**

## 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 and medical letter stating that the person has Down syndrome (Trisomy 21)

**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 <http://www.dhs.state.il.us/page.aspx?item=31201> 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.

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

- ◆ 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?

**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.



## DDC NEEDS YOU!

During the May 8th board meeting, **DDC members will elect the new board of directors** for the upcoming year (July 2008 through June 2009). Participation on the DDC board is an exciting and very rewarding opportunity to work with others to continue to accomplish the mission of the DDC: *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 Down syndrome.*

The future of our group depends on parents getting involved! Please consider joining the DDC board, and making a difference in the lives of children with Down syndrome. If you are interested in participating on the DDC board, please call Patrick Collins, DDC President, at 847-265-8482, or e-mail him at [rjohncol@comcast.net](mailto:rjohncol@comcast.net).



**UPS for DownS**  
United Parent Support for Down Syndrome

Support • Information • Community

**Teaching People with  
Developmental  
Disabilities about  
Sexuality and  
Relationships**

**Presenter:**

Terri Couwenhoven, M.S.

**Saturday, March 15, 2008**

**8:30 Registration and Coffee**

**9 a.m. – 3 p.m. Workshop (includes lunch)**

This workshop is designed to help parents and professionals become more comfortable and confident in addressing sexuality issues that commonly surface among individuals with cognitive disabilities. Best practice research for teaching sexuality to individuals with cognitive disabilities will be shared along with resources and ideas for teaching at home or at school.

This workshop **WILL** address a broad range of sexuality and relationship issues, including several delicate, challenging topics.

It is **NOT** about puberty and body changes.

Go to [www.upsfordown.org](http://www.upsfordown.org) for more information and to register.

**Saturday, March 15, 2008**

**8:30 Registration and  
Coffee**

**9:00 a.m. - 3:00 p.m.**

**Workshop (includes lunch)**

**Belvedere Banquets**

**1170 W. Devon Ave.**

**Elk Grove Village, IL 60007**



**DDC New Baby Social**  
**2007-8 Schedule**

Socials occur every other month, on a Saturday,  
from 9:30-11:30 am,  
at the Fremont Public Library in Mundelein  
(1170 Midlothian Road, between Winchester and Route 176).

Our next socials will be:

April 19

June 21

Please **RSVP** to Jennifer Jenkins (847/970-6797 OR [only\\_connect@msn.com](mailto:only_connect@msn.com)) no later than 1 week prior to that month's social – it helps us to arrange food and hosts.

**Looking forward to seeing you there!**

For more info on the DDC's activities, visit our website: [www.theddc.org](http://www.theddc.org)

**Do you know how” Handwriting Without Tears” can help your child? It is time for you to get with it. Sign up for one of the following workshops in your region:**

**Pre-K\* and Printing & Cursive**

- 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**

- May 16 .....Minneapolis, MN
- June 6,,,,,,,,,St. Louis, MO
- June 20 .....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@ hwt tears.com](mailto:coordinator@hwt tears.com) I

**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.**



### JJ GOES TO VOTE.

John Froemke, Jr, "JJ", is 25 so he has voted before. But on January 30, 2006, the two of us went to a Town Hall Meeting in Wheeling where Senator Obama discussed his work in the Senate and took questions from the audience.

As the Senator left he didn't have time to sign autographs, but did for my son. Senator Obama wrote "**To John - Best Wishes Barak Obama**" in his book, **The Dreams from My Father** that JJ handed him. So when JJ went to vote in the Primary, he took the book along so whoever helped him with the ballot would understand who he wanted to vote for. So this is a picture on our way into the polling place in Vernon Hills.

We are proud of our son, he does what he wants to do.

Submitted by JJ's Dad.

[www.specialedmoms.com](http://www.specialedmoms.com) This website provides a great deal of free and valuable information about special education law and children with special needs. Go the BACKPACK for interesting articles like:

- Teaching special-needs students in the regular classroom....
- Home school-ers lose special education aid....
- 'Response to intervention' sparks interest, questions....
- Embracing 'response to intervention'....

To access the articles, simply visit [www.specialedmoms.com](http://www.specialedmoms.com) and click on Backpack.

*Maureen Lowry-Fritz, J.D., M.A.*

### **BREAK DOWN OUT DATED STEREOTYPES AND RAISE EXPECTATIONS AND PROMOTE INCLUSION.**

I am updating my current workshop offering and am intent on making all of my audiences aware of the potential and successes of children with Down syndrome.

My introduction will be dedicated to providing an array of photographs depicting the unbelievable accomplishments of persons with Down syndrome. For instance, my son scuba dives, and I mean scuba not snorkeling. There are so many examples of the beautifully talented persons with Down syndrome. I want to be able to click through myriad pictures depicting the wonderful things are children and adults can do.

I would be very grateful if anyone who has or knows of a person with Down syndrome, that I can openly celebrate his/her accomplishment, would they please provide a note of permission to use your image along with the photo, and Email it to me at [peoples5010@aol.com](mailto:peoples5010@aol.com). I will then select photos for use in my program. We must eliminate outdated, Dark Age references to people who have Down syndrome in order to truly actualize inclusion in the school and community.

Warm regards,  
Sue Peoples

Lecturer for inclusion

## 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

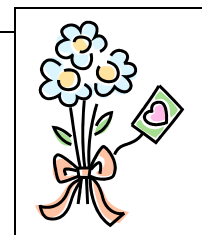
The Down Syndrome Development Council extends a sincere thank you to all of the donors whose contributions have been received in the past month.

Your generosity will allow DDC to continue to offer quality programs and services to our members!

OUR FEBRUARY BENEFACTORS:

**Elizabeth M. Ruffin**

**Attilio and Mary Foresta**



## 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.



JUST WANTED TO LET YOU KNOW SOME INFO I JUST HEARD ABOUT. PLEASE PASS THIS AROUND TO PARENTS THAT HAVE SPECIAL NEEDS KIDS THAT TAKE BUSES TO SCHOOL.

"I JUST STARTED AS AN AIDE ON THE SPECIAL NEEDS BUSES IN OUR DISTRICT GOING TO SEDOL, CIDLASH & THE OTHER SPECIAL SCHOOLS IN GAGES LAKE AREA AT THE END OF NOV. 2007. THE SCHOOLS ARE TRYING TO GET RID OF THE AIDES ON SPECIAL NEEDS BUSES TO SAVE MONEY. I WAS TOLD FROM A SECRET SOURCE, THAT THE PARENTS NEED TO PUT ON THE CHILDS I.E.P.'S THAT THEY WANT AN AIDE ON THE BUSES W/ THEIR KIDS. AN EXTRA PAIR OF EYES IS CAN PREVENT BUS ACCIDENTS BY ALLOWING THE DRIVER TO CONCENTRATE ON THE ROAD." SO YOU CAN'T ASSUME THAT YOUR DISTRICT WILL PROVIDE AN AIDE. PARENTS MUST REQUEST AN AIDE FOR THE BUS BE INCLUDED IN YOUR WRITTEN IEP. (THIS INFORMATION WAS PROVIDED BY DEB POGOSE)

### 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:odonnella@sbcglobal.net">odonnella@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>

### MARCH BIRTHDAYS!!!

ALEX ALLWARDT	1989	
JUSTIN BYCHOWSKI	1995	
JASMINE CARMONA	2000	
DEREK CLARKE	1993	
ELIZABETH FORESTA	1974	
LANCE FRY	1970	
GAVIN LOCHNER	2007	
MAKAYLA OLSON	2001	
CARLIE REUTER	1995	
DOUGLAS ROSTRON-JANSEN	1960	
JACOB SHIMANEK	1996	
CARL STAHL	1999	
GRACE UHWAT	2003	
CARLY ZIESEMER	1986	

"Welcome to our new neighbors".  
 TERESA KEENAN AND HER 2YR. OLD SON FROM GENEVA, IL. AND KIM GALLAGHER AND HER NEW BABY GIRL CHLOE FROM GRAYSLAKE.  
 We are looking forward to meeting them soon.