

DOWN SYNDROME DEVELOPMENT COUNCIL

Celebrating 30 years

MISSION STATEMENT:

To promote a greater acceptance and understanding of Down syndrome by enlightening the broader community to recognize the individuality, uniqueness and capabilities.

THE MEETING PLACE:

Community Protestant Church, 418 N. Prairie, Mundelein IL

SECOND THURSDAY OF THE MONTH

Forum Newsletter MARCH-APRIL 2009

Note from the President

THANK YOU...To the founders, past and present Board Members, DDC members and especially those special members who have contributed to 30 years of successfully promoting a greater acceptance and understanding of Down syndrome and for providing support to so many families that have a special member whose uniqueness, capability and individuality enlighten all they touch.

It was in 1978 that several courageous parents started the formation of a Lake County parent support group for families with a child who has Down syndrome. On July 9, 1979, this support group was incorporated as the Down's Development Council. This year the DDC will be celebrating its 30th anniversary and to commemorate this event, we will recognize the founding members at this year's Buddy Walk.

The DDC needs your support to continue to serve greater Lake County for the next 30 years. For more information on how you can get involved, contact a Board Member.

Patrick Collins

THE DDC NEEDS YOU!

Have you ever thought that you would like to become more involved with the DDC? In May, we will be accepting nominations for new board members. As per the bi-laws, the current board cannot remain in office forever...we need to pass the torch. If you think you might be interested or know someone who is, please contact one of the current board members.



UPCOMING EVENTS

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Planning for the Future of
your Child Workshop.....pg 2

PUNS registration.....pg 3
(PUNS registration is in lieu
of the April Meeting)

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DDC Annual Picnic.....pg 6

Movie Lover's Club.....pg 4
(Monsters vs Aliens)

May Annual Board Election
Meeting 5.14.09

In May 2009,
Wrightslaw

will be presenting a workshop on IDEA & NCLB here in Illinois sponsored by Disability Goto (Autism group).

I have attended their workshops before and they are excellent!

This workshop costs \$100 and includes two of their books, which are very goodtoo. If you would like to attend, register soon. **Their workshops fill up fast!**

See you there!

<http://www.disabilitygoto.com/eventsregistration.html>

Gaby Wojciechowski

DDC New Baby Social

Who:

Families of a "new" little one with Down syndrome (ages 18 months or younger)

Where:

Fremont Public Library in Mundelein, 1170 N. Midlothian (right next to Mechanics Grove Elementary School) - Meeting Room A (upstairs)

When:

1 Saturday, every other month, from 9:30-11:30*

What:

An open house for the newest members of our extensive DDC family - a chance to mingle with other babies and their families, to chat with other DDC parents of preschool-age children (we're the hosts that day - our kids stay home, so we can focus on yours!), to share information about Early Intervention and Early Childhood programs, to swap contact info of favorite therapists, to get ideas about what to help your child do next . . . to eat a bagel or a donut, drink some coffee, and generally marvel at how lovely our kids are!

All siblings and grandparents welcome as well - we've got munchies, we've got crayons, we've got a big open space suitable for romping! Feel free to drop in any time during this time - it's an open house, not a "meeting"!

*More information about our upcoming schedule of socials, or to get on our email list - contact Jennifer Jenkins only_connect@msn.com; 847-970-6797

Planning for the Future of Your Child

When: Saturday, May 16th, 10:00am

Where: Protected Tomorrows, 103 Schelter Road, Lincolnshire

Who: You! DDC parents, grandparents, and anyone who would like to learn more about planning for our children's future

Mary Anne Ehler of Protected Tomorrows will present "Bring You Protected Tomorrows(R): Creating the Future Care Plan for Family Members with Special Needs." This presentation is a 90 minute interactive workshop on a comprehensive life planning process which includes the educational, residential, financial, legal, health care, government benefits, employment and recreational needs of the individual with special needs. Her presentation provides a good basic understanding of some important facts, such as how to apply for government benefits such as SSI, SSDI, Medicare, and Medicaid and also reviews in an uncomplicated manner how to prepare financially, and how to have your family's wills and trusts set up so as not to disqualify your loved one for benefits in the future. Finally, and most importantly, the topic of family communication is covered in a fun yet serious manner.

This workshop is being offered free of cost to DDC members (adults only) and guests. You might consider bringing family members or others who may be interested in helping to plan for your child's future. Childcare will be available, but you must reserve a spot by Wednesday May 13, to help us provide for the appropriate number of sitters.

If you plan to attend, please RSVP by Wednesday, May 13, to Janis Kern, at 847-548-4417, or by e-mail at janiskern@comcast.net.

APRIL 9, 2009

PUNS REGISTRATION

What is PUNS?

PUNS stands for **P**rioritization of **U**rgency of **N**eeds for **S**ervice, which is 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 9, 2009

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) 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. You cannot complete the survey online. However, you can review the questions and think about your answers in advance.

How do I prepare for my appointment?

- ◆ 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.

FIND OUT MORE ABOUT BLUEPRINT

THE DDC BUDDY WALK

The Buddy Walk is not only a wonderful family event that promotes Down syndrome awareness, but it is also our biggest fundraising event of the year. The funds raised allow the DDC to continue to offer quality programs and services.

We need your help to make the Buddy Walk successful.

If you would like to help, please contact a board member for more information.

MOVIE LOVER'S CLUB

Join us for a private showing of **Monsters VS Aliens!** DDC covers the cost of admission * pop and popcorn will be available for purchase.

Bring the whole family!
Saturday April 4th
10:00am
Libertyville Theater
located on Milwaukee
in downtown
Libertyville.

My name is Helen Kauffman and I am a member of the Illinois Council on Developmental Disabilities. The Council is a federally funded state entity, comprised of self-advocates, family members of people with developmental disabilities and provider and governmental representatives. The mission statement of the Illinois Council expresses its goals: We help lead change in Illinois so all people with developmental disabilities exercise their right to equal opportunity and freedom.

I am the mother of a 29 year old woman with Down syndrome who inspires my continued efforts to improve the system which serves her and her many peers. I am contacting you to seek support for a recent initiative of the Council, The Blueprint for System Redesign, which is, essentially, a long term plan for rebalancing the system, identifying goals and methods to reduce reliance on large congregate care facilities to serve our individuals and increase access to quality supports in the community.

You have been identified as a key contact in Illinois in the disabilities world.

I don't suppose any of us would disagree that as parents and advocates for individuals with disabilities, Illinois has fallen short of meeting the need. The number of individuals waiting for community based supports and services is growing and the resources are shrinking. We were already behind most other states in providing community based supports and services and there is no doubt, we will stay behind if we don't do something.

The Blueprint is a plan to "do something," and we are asking that you endorse the plan and have your membership do so also.

Attached you will find a copy of the Blueprint for System Redesign, the Executive Summary and a document of endorsement. In addition, I am providing you with links to the petition and other information on the Blueprint.

http://www.state.il.us/agency/icdd/includes/Blueprint/ICDD_petition072508_FINAL.pdf

<http://gettoknowtheblue.org/>

<http://www.familysupportnetwork.orgNewsletter%202008%20%20June.pdf>

We would like to name your organization as a supporter in future campaigns with our legislators and state decision makers to promote and implement the plan.

I think, when you have had the chance to sit down and review the plan, you will agree that it is well crafted and designed to promote community inclusion for all, in a safe and respectful way.

Please sign on so that we can be united with one voice to ensure that all individuals with developmental disabilities are able to live a full life among family and friends in their own communities. We would like to name your organization as a supporter in future campaigns with our legislators and state decision makers to promote and implement the plan.

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Feel free to contact me if you have any questions.

Thank you.

Helen Kauffman 847.948.8262
847-948-8262

Playgroup

Our monthly playgroup meets on the 3rd Thursday evening of the month. 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 playgroup includes a light 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 (belinda.hidalgo@alere.com). If you would be interested in attending a Saturday morning playgroup, please contact Belinda.

Dominicks “eScrip” Fundraising

DDC has earned a total of \$556

from the eScrip program through January 2009. Our monthly earnings continue to grow! This is an easy way for DDC to fundraise, and all you have to do is register your Dominick’s Fresh Values Card! To find out more about the program, and how to register, please go to “TheDDC.org”.

You can register at “escrip.com”. The DDC is listed as Down Syndrome Development Council, Mundelein, IL 60060. If you have any questions, please contact Janis Kern, DDC Treasurer, at (847) 548-4417.

The Arc of Illinois

February 20, 2009

What Happens to the Federal Medicaid Money for the 50% Match when the State does not Match It?

Looking at this decision from the perspective of state government, the 50% federal reimbursement in many ways looks like a 50% off sale at a local department store. If it is something you could use and you have the money, you take advantage of the bargain. But, if it is something you don't need or you don't have the money, you simply reject the notion of buying it. You have not lost or given up anything.

However, if you consider the same issue from the perspective of the average citizen, which is of course the role and responsibility of elected politicians, it looks quite different. From this perspective, it appears to be something we both want and need, because more than 15,000 Illinois citizens with DD are currently not receiving any services. Furthermore, as federal taxpaying citizens; we have already paid a 50% deposit using federal funds to hold those services until we return to pay the balance of 50% using state funds. When the state fails to do so, we lose our 50% federal deposit and receive nothing, even though we paid for half of it.

This makes no sense to Illinois citizens who realize what our elected politicians are doing in Springfield. Undoubtedly those politicians are hoping no one is watching how they are mishandling our finances.

The same logic applies to all the waiver eligible services that Illinois does not currently provide. The latest data shows that Illinois ranks dead last, 51st of the 50 states and D.C., for allowing citizens with DD to live in a home in a community rather than to live in a large facility. Current estimates are that Illinois must spend an additional \$500 million annually to reach just the countrywide average for DD services. Nearly half of that money, \$250 million, has already been paid, like a deposit for these services, through the federal taxes we all pay. The state of Illinois is leaving that money on the Medicaid table.

The state government, as directed by our politicians who are elected to look out for our interests, are walking away from that deal saying we cannot afford it. This is simply not true. Illinois ranks in the top ten states for personal income and wealth. Our own elected officials are at fault for not making responsible decisions to protect our interests and achieve these benefits for the citizens, when we have already paid half the costs. We, the people, must expect more from our government and hold them accountable for their decisions at election time.

Is it possible they really don't understand what they are doing?

Tony Paulauski * The Arc of Illinois * 815-464-1830

**SPREAD THE WORD
TO END THE WORD**

03.31.09

www.r-word.org

On 31 March 2009 the Special Olympics is calling for a national day of awareness for America to stop and think about their use of the R-word

DDC PICNIC

save the date

Come join us for an afternoon of fun activities, fishing, good food and good friends. Everyone is welcome to attend.

August 2, 2009 from 12-4
Half Day Forest Preserve
Lincolnshire

i Have a Voice

Nancy Gianni, founder of GiGi's Playhouse, an awareness center for children with Down syndrome and their parents, teamed up with Barrington photographer Thomas Balsamo to create a traveling exhibit of black and white portraits of individuals with Down syndrome.

The exhibit, "i have a voice," will be on display at the Ela Area Public Library in Lake Zurich March 1-30.

For more information, call the Ela Area Public Library, (847)438-3433.

Achieving a Better Life Experience Act (ABLE)

The Achieving a Better Life Experience Act (ABLE) of 2009 (S 493/HR 1205) was introduced last week in both the Senate and House. The ABLE Act will give individuals with Down syndrome and their families the ability to save for their child's future just like every other American family, and help people with disabilities live full, productive lives in their communities.

The ABLE Act will allow individuals with Down syndrome to create a disability savings account that would accrue interest tax-free. The account could fund a variety of essential expenses for the individual, including medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation. The legislation prohibits amounts held by, or paid or distributed from any ABLE accounts from being treated as income or assets when determining eligibility for benefits provide by any Federal benefits program.

Asset development is one step towards improved economic self-sufficiency, and the legislation's focus on encouraging asset development will greatly incentivize people with disabilities to live more productive lives through earning and saving assets.

Talking Points to Call Your Senators and Representative:

I am calling to ask my [Senator/Representative] to cosponsor the Achieving a Better Life Experience Act (ABLE) of 2009 (S 493/HR 1205) led by Senators Casey (D-PA), Hatch (R-UT), Dodd (D-CT), Kennedy (D-MA), Brownback (R-KS), and Burr (R-NC) and Representatives Crenshaw (R-FL), Meek (D-FL), Kennedy (D-RI), and McMorris Rodgers (R-WA).

The legislation encourages persons with disabilities to save in order to live an independent and meaningful life while reducing their dependency on public benefits. This legislation allows for the establishment of tax-exempt financial security accounts for individuals with disabilities to pay certain expenses, including: medical and dental care, education, community based supports, employment training, assistive technology, housing, and transportation. The legislation prohibits amounts held by, or paid or distributed from any ABLE accounts from being treated as income or assets when determining eligibility for benefits provide by any Federal benefits program. If your boss is interested in signing on as a cosponsor, please contact:

* Bryn McDonough (202-224-6324) in Senator Robert Casey's office
* Dustin Krasny (202-225-2501) in Representative Ander Crenshaw's office

NDSS National Policy Center
5505 Connecticut Avenue, N.W. # 239
Washington, DC 20015-2601
Phone: (800) 743-5657
e-mail: advocacy@ndss.org

(Thank You Sheila Hebein at NADS)

DDC Board Members 2008-2009 (**voting board members)

**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
**Board	RaeAnn Collins	847-265-8482	rjohncol@comcast.net
Playgroups	Belinda Hidalgo	847-838-4398	belinda.hidalgo@alere.com
FORO Newsletter (Spanish Issue)	Anna Roeser	847-362-0980	roeser1984@yahoo.com
Dir. of Fundraising	Deb Pogose	847-973-1622	beauvp@sbcglobal.net
Newsletter Editor	PennySue McKenzie		pennyontheverge@gmail.com

March Birthdays

*Alex Allwardt
Justin Bycowski
Jasmine Carmona
Derek Clarke
Elizabeth Foresta
Lance Fry
Charlie Halperin
Gavin Lochner
Tempest McKenzie
Carlie Reuter
Douglas Rostron-
Janse
Jacob Shimanek
Carl Stahl*

(continued March Birthdays)

*Grace Uhwat
Carty Zieseemer*

April Birthdays

*Faith Brown
Julianna cerda
Jeremiah Hendricks
Kevin Kinder
Anthony Lopez
Serenity Parker
Megan Witt*

Contributions

Anonymous (individual)
Abbott Laboratories Employee Giving Campaign
AIG - Michael Roeser
Allstate Employee Contributions
Hospira Employee Giving Campaign
Diane Chapin
Laurel Jacobus
Joe and Pam Labellarte
Jerry and Helen Jenkins
Raymond and Ann Johnson in honor of Sam Collins
Takeda Pharmaceuticals Employee Giving Campaign

The Down Syndrome Development Council extends a sincere **thank you** to all of the above donors whose contributions were received since last September. Your generosity will allow DDC to continue to offer quality programs and services to our members!

We would like to extend a very warm welcome to **PennySue McKenzie** as she becomes our new Newsletter Editor. She will begin with the May-June 2009 Newsletter. Thank you PennySue!

Please keep the **Brahm Family**

in your thoughts and prayers as Trevor, 16,
begins leukemia treatments.
Visit Trevor's web page

<http://www.caringbridge.org>

name: **trevorb**
password: **Arizona1**

Cards sent to the family are welcome.
Contact Janis Kern for more info.

SPECIAL NOTE

The DDC will begin sending out newsletters every other month with special mailings as needed for special events & updates.

In order for the DDC to serve you better,
please contact RaeAnn Collins at rjohncol@comcast.net
or 847.265.8482 to update your contact information.

For every newsletter we email, the DDC saves money. If you would like to receive your DDC newsletter electronically, please contact RaeAnn Collins to update your information

Please note: The Forum newsletter is written on a volunteer, non-professional basis. Information presented should not be construed to be objective or definitive, but represents the opinions and understanding of the editor and its contributors. **Your contributions are welcome.** Please contact RaeAnn at rjohncol@comcast.net or PennySue at pennyontheverge@gmail.com

Downs (Down Syndrome) Development Council, DDC, is a not-for-profit 501(c) (3) organization and volunteer support group established in 1978 by parents of children with Down Syndrome.



Down Syndrome Development Council
P.O. Box 906
Mundelein IL 60060

