

# A Little Something Extra

Volume 3, Issue 1

January 2005

www.pcdsmi.org

Parents of Children with Down Syndrome

## Opening a World of Opportunity For Children with Down Syndrome

### Calling all girls between the ages of 7 and 13

Some other moms in our group have created a new sub-group of PCDS just for girls as a way to get girls and their moms together with other girls and their moms. Saturday January 22 from 2:30—4:30 P.M. will be our first get-together for Calling All Girls and it will be hosted at the home of Colleen (Elizabeth) Holmes in Bloomfield Hills. We will be doing crafts, cooking, having a ping pong tournament, and outdoor play. Please confirm your attendance to Colleen at (248)891-6291 or email her at [Colleen.Holmes@hur-gsp.com](mailto:Colleen.Holmes@hur-gsp.com)

In the coming year PCDS will be expanding its programs and services. The board will be brainstorming over the next few months. We feel we would like to offer families and the community additional services and programs that will enhance and better the lives of families and individuals with Down syndrome. We believe by reaching out to more families and individuals with Down syndrome we move closer to our vision *that all individuals with Down Syndrome are given the support and information to empower them to live, work and play in the community.*

We would not be able to develop these new services and continue our ongoing programs without the very generous support we receive from families and community members who value and appreciate our work and mission. I thank the many individuals who support PCDS throughout the year by participating in our special events and support the annual giving campaign.

Paulette Duggins, PCDS President

“If you want your children to succeed, teach them how to fail”

#### Who We Are

**Parents of Children With Down Syndrome** was formed in 1982. It is a group of families primarily in Oakland, Macomb and Wayne counties who share common concerns and provide mutual support to parents and their family members.

Norm Kunc will be in the Metro Detroit area February 2nd and 3rd at the Jewish Community Center of Metropolitan Detroit to share his innovative approach to helping people with special needs. For those of you not familiar with Norm, he is a motivational speaker with cerebral palsy who has spent the last 20 years ensuring that people with disabilities are able to take their rightful place in society. His two presentations **The Right to be Disabled** and **Hell Bent on Helping** will be presented on both days at 9:00 am and 7:00 p.m. Call (248)788-7878 ext 209 for more information or to make reservations, or email [BRYNIE@FRIENDSHIPCIRCLE.ORG](mailto:BRYNIE@FRIENDSHIPCIRCLE.ORG). Suggested donation is \$10. Also see additional information posted on the PCDS website at [PCDSMI.org](http://PCDSMI.org)

## PCDS Playgroup News

### Attention all Play Group Participants

Play group dates for the New Year are **February 5**, and **March 12, 2005** at 9:30 a.m. at the Cross of Christ Church, 1100 Lone Pine Road, Bloomfield Hills, MI. If you are planning to attend please RSVP to Annette Liike at [aliike@comcast.net](mailto:aliike@comcast.net) or 248-624-3046 which ever is more convenient for you.

I am going to be bringing my digital camera to take pictures of the players for our website. So if you want your little angel to be a star come to play group.

The group meets at the church because it is somewhat centrally located and it has a great nursery with a lot of toys for the little ones, chairs for us and lots of room. The kids love it and it gives us a chance to get to know each other and for our kids to play.

## Calendar/Important Dates

**January 22, 2:30-4:30**, Calling All Girls get-together. See front page of newsletter for additional info.

**January 27, 2005, 2:00-8:00 P.M.** Healthy Living Fair at Oakland Schools. Contact Michele Harmala ([Michele.harmala@oakland.k12.mi.us](mailto:Michele.harmala@oakland.k12.mi.us)) for additional information.

**February 2nd and 3rd, 9:00 am and 7:00 pm** Norm Kunc speaking at the Jewish Community Center of Metropolitan Detroit "If You Want Your Children to Succeed, Teach Them How to Fail: (see front page of this newsletter or [PCDSMI.org](http://PCDSMI.org) website for additional info)

**February 10, 2005, 6:00-9:00 P.M., Toilet Training for Special Needs Children.** Presented by Early On Oakland County, Great Parents, Great Start Oakland, and Success by 6. Conference Room A at Oakland Schools. See [PCDSMI.org](http://PCDSMI.org) website for more details and registration information.

**April 22, 2005**, Band of Angels Starry Night Gala at the Birmingham Townsend Hotel (details to follow)

**July 7-10, 2005**, NDSS National Conference, The Fairmont Hotel, Chicago. See NDSS website at [NDSS.org](http://NDSS.org) for further information

**July 29-31, 2005**, NDSC National Convention, Hyatt Regency Orange County, Anaheim, CA. See NDSC website at [NDSCCenter.org](http://NDSCCenter.org) for further information.

**August 23-27, 2006**, 9th World Down Syndrome Congress, Vancouver BC, Canada. See NADS. Website at [NADS.org](http://NADS.org) for additional information.

### PCDS Board Meeting

**Tuesday, January 18 7 –9 P.M.**

**Tuesday, February 15 7-9 P.M.**

**Tuesday, March 15 7-9 P.M.**

**Tuesday, April 12 7-9 P.M.**

**Tuesday, May 10 7-9 P.M.**

**Tuesday, June 21 7-9 P.M.**

Board meetings are held at the Cross of Christ Church. Please RSVP attendance to Paulette

#### BOARD MEETING

Board meetings are open to **ALL** PCDS members. Your presence is welcome and appreciated. Please contact Paulette with any questions you may have at 248-646-0819 or email Paulette at [Dugginsp@comcast.net](mailto:Dugginsp@comcast.net).

**Beautiful Faces Calendar**

We have our supply of the 2005 calendars featuring beautiful pictures of many local children who have Down Syndrome. The calendars are \$15.00 and make a great gift as well as providing an opportunity to support PCDS from the sales of the calendars. Please contact Paulette for the Beautiful Faces calendars.

**Who We Are**

Parents of Children With Down Syndrome was formed in 1982. It is a group of families primarily in Oakland, Macomb and Wayne counties who share common concerns and provide mutual support to parents and their family members.

**What We Do**

Our group meets regularly throughout the year, both formally and informally, socially and informational including:

- Sharing and parent social gatherings
- We provide a library containing a wide range of materials on Down syndrome and community group services and programs
- A newsletter that covers current legislation, articles on education, health, child development, estate planning, and a calendar of upcoming events, seminars and conferences.
- Occasional expert speakers who present topics of vital interest and concern to parents of children with Down syndrome.
- A website (pcdsmi.org) with up-to-date information on articles of interest to our members

**PCDS**  
**MISSION STATEMENT**

*Parents of Children with Down Syndrome*

is a parent and family support group. Our goal is to share information about available services and programs in the areas of health, education, guidance counseling, advocacy, and other related matters.

PCDS is a 501 ©(3) non-profit organization. All donations are tax deductible. If you would like to help us in our mission of serving people with Down syndrome and their families, we welcome your contributions.

PCDS is an affiliate of the National Down Syndrome Society.

To reach NDSS write:  
666 Broadway  
New York, NY 10012-2317  
or call 1-800-221-4606

**DISCLAIMER POLICY:**  
The editor of this newsletter writes as a non-professional. This newsletter reports items of interest about Down syndrome in an effort to educate and to promote awareness and positive attitude. PCDS does not support or endorse any particular regimen, treatment or religious view, Inclusion of items does not necessarily imply promotion or recommendation of its sponsors. Articles from this newsletter may be reprinted but proper credit must be given to its source.

**BOARD MEMBERS**

**PRESIDENT**

Paulette Duggins  
(248)646-0819 dugginsp@comcast.net

**VICE PRESIDENT**

Pat Dickson  
pmkbd126@yahoo.com

**TREASURER**

Melinda Hilborn  
mhilborn@detroitdesign.net

**SECRETARY**

Lauren Bernacki

**CHAIRPERSONS**

**Buddy Walk**

Suzanne O'Leary/suzanneoleary@comcast.net

**Calendar Sales**

Paulette Duggins/dugginsp@comcast.net

**Library**

Margie Wheelock

**Newsletter**

Sue Grigg  
(248)288-6468 suegrigg@comcast.net

**Playgroup**

Annette Liike  
alike@comcast.net

**Advertising**

Tricia Dewar  
tdewar2@comcast.net

**Holiday Party**

Laurie Whell  
whell@email.com  
&

Annette Liike  
alike@comcast.net

Colleen Holmes

**Corresponding Secretary**

Sue Grigg  
suegrigg@comcast.net

**Directory**

Laurie & Mike Whell  
whell@email.com

**Webserver**

Anita Beaman  
abeaman02@yahoo.com

**New Parent/Hospital Liaison**

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**You (and your beautiful children) ought to be in pictures.....**

We would love to have pictures to post on the PCDSMI.org website. Please email them to abeaman02@yahoo.com, or use the "contact us" link on the PCDSMI.org homepage.

## Letter from our PCDS President

WOW! Another year has gone by. I think we say every year, "Where did the year go?" As I start my fourth year as President, I am excited about the programs that will be implemented in 2005 as a result of our strategic planning process.

We plan to do more training with teachers of our school age children to assist with their knowledge of Down Syndrome, health issues, etc. We plan to increase the number of books, audio and video tape information in our library. And we want to become much more proactive in public policy issues. We are excited that volunteers have come forward to chair the Buddy Walk, Road Rally and Summer Picnic.

I would like to take this opportunity to thank the PCDS Board who will serve in 2005.

Holiday Party: Thanks to Annette Liike and her family as well as Laurie Whell and Mary McKee who came on Saturday evening to set-up the Annual Holiday Party. (next year we welcome many more helpmates). The food was irresistible and a special thanks to Toni of the Original Roman's for the chicken, salad and mostaccioli. A special thank you to the Best Mr. & Mrs. Claus ever- their patience is incredible! It was great to see so many families at this event.

A special Thanks to Sams Club of Lake Orion for their generous \$1000 cash donation which was won by our own Sue Grigg, newsletter editor. We hope to be able to share this cash donation again next year.

We would also like to again thank, Joe & Adelle Bologna for all the monies raised in August 2004 from the Joe Bologna Golf Outing. Without their support many of the new programs would not be able to be funded.

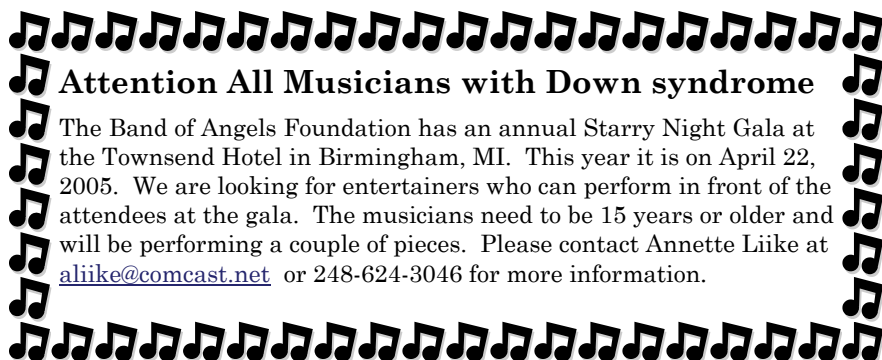
### Volunteer corner

The mission of PCDS is strongly supported by the commitment of our volunteers. We anticipate an increase in the need for volunteers in 2005, not only for our special events, but for our programs and services as well.

I ask that you consider becoming a unique part of this organization by taking the opportunity to give the gift of time by becoming a volunteer. Whether you choose to volunteer one evening at a special event or on an ongoing basis, you will find that volunteering can be personally rewarding while you are providing a valuable service to PCDS and your community.

Please take a few moments to complete the 2005 survey or visit our website at [www.pcdsmi-org](http://www.pcdsmi-org) and click on Volunteer. We will match your current interests as a volunteer to our programs and special events. You will be contacted as we plan each event or as needed for ongoing programs.

HAPPY NEW YEAR from PCDS



### Attention All Musicians with Down syndrome

The Band of Angels Foundation has an annual Starry Night Gala at the Townsend Hotel in Birmingham, MI. This year it is on April 22, 2005. We are looking for entertainers who can perform in front of the attendees at the gala. The musicians need to be 15 years or older and will be performing a couple of pieces. Please contact Annette Liike at [alike@comcast.net](mailto:alike@comcast.net) or 248-624-3046 for more information.

### Dues are due

2005 Membership dues are now payable. **If the front of your newsletter has a star, you do NOT need to pay**

PCDS has purchased a 9' x 9' inflatable Deluxe Castle Bounce 'Round. We plan to use it for PCDS functions and will allow PCDS members in good standing to borrow it pursuant to a standard agreement for the care and return of the bouncer and a deposit. To arrange to use the bouncer please contact Paulette.



## Research Opportunity

The research team at the University of Michigan Autism and Communication Disorders Center is interested in the social and communication behavior of children with a range of developmental delays. Currently, they are being funded to learn more about the effectiveness of their diagnostic instruments in differentiating children with autistic spectrum disorders from those with other developmental delays or disorders unrelated to autism. Children with Down syndrome are of special interest in this research since they may share some language difficulties, but generally have a different pattern of social strengths than do children with autism. They would like to evaluate children with Down syndrome between 12 months and 16 years of age, using a social observation measure commonly used in diagnosing autism as well as standardized measures of mental age and language development. Participation in this study requires approximately 6 hours of your family's time (ideally, they would like to conduct a parent interview as a first appointment and the child assessment as a second appointment). The center is located at the University of Michigan in Ann Arbor. Participating parents will receive a written report providing feedback on their child's language and cognitive functioning, as well as a \$100 gift card for full participation. If you are interested in participating or would like more information, please contact Kaite Gotham at 734-936-8774 or toll-free 866-968-6222 Ext. 4, or email kog@umich.edu.

## Drug May Improve Learning in Children with Down Syndrome

Aricept, a drug used to treat Alzheimer's disease, may also help increase the language skills of children with Down Syndrome, according to Duke University Medical Center researchers.

They conducted a 22-week preliminary clinical trial that included seven children, ages 8 to 13, with Down Syndrome. After 16 weeks of taking Aricept (donepezil hydrochloride) the children showed improvements in their ability to communicate thoughts and feelings.

A larger, randomized trial is necessary to confirm the results, the researchers said.

While both studies showed promise, this kind of treatment would likely have the most benefit in children with Down Syndrome, the researchers said.

"A therapy that could change the lives of people with Down Syndrome early in childhood, making them more active learners, could really maximize their benefit and quality of life," lead research Dr. Priya Kishnani, a medical geneticist and co-director of the Down Syndrome clinic at Duke, said in a prepared statement. (the study appears in the October 15 issue of the **American Journal of Medical Genetics Part A**). From the DSA Press, De-

**PCDS will sponsor a week-long bike clinic in June 2005 and again in 2006 designed to teach individuals with Down Syndrome age 8 and older how to ride a 2-wheel "standard" bicycle. Each student will receive instruction by trained therapists from U of M and volunteers. Watch future newsletters for the details on this program.**

## Fluency: Helping Your Child Read and Understand

In order to be a good reader, your child must be able to do two things at the same time:

- 1) decode the words on the page and 2) understand what the words mean.

Early reading instruction focuses on teaching a child how to read single words. But being good at reading single words is not the only skill your child needs. Once your child has become good at decoding single words, he or she needs to learn to read easily, becoming a fluent reader.

Fluent readers have moved beyond decoding single words well. Fluent readers read quickly and accurately. They can read with expression. They tend to separate sentences into groups of words based on the meaning. They also tend to read many individual words automatically. They can understand what they are reading. This is the ultimate goal for reading.

It is hard to understand what you are reading when you are not a fluent reader. Researchers believe that everyone has a limited ability to pay attention when learning a new task. So, if your child needs to use a lot of attention to decode single words, there is little left over to use understanding what he or she has read. Once decoding single words becomes automatic, attention can then be turned to meaning. Fluent readers can begin to enjoy the meaning of what they read. They can move beyond learning to read. Then can now read to learn.

Ask your child's teacher about your child's reading level. Your child will be ready to work on becoming a fluent reader when he or she is reading on the 2nd or 3rd grade level. If your child is working to become a fluent reader, there are some things that you can do to help.

### Encourage your child to do more reading

Research tells us that the best way to become a better reader is to spend more time reading. Anything you do to encourage your child to spend more time with print will help make him or her a better reader. Reading aloud to your child while he or she watches the page is also helpful. On occasion, turn on the captioning while your child is watching TV. Write simple notes to your child. The more your child reads, the more automatic reading will become. Try to be

creative with reading material. Keep in mind that ANY reading is better than no reading.

### Reading new materials or rereading familiar materials both help improve fluency

Researchers have tried to figure out what types of reading material are best for improving fluency in reading. Fluency seems to improve based on the amount of time spent reading. It does not matter whether this time is spent reading new things or re-reading favorite selections. If he wants to, allow your child to re-read his favorite book one more time. It may not be interesting to you, but it is helping your child become fluent.

### Read aloud not only to your child, but WITH your child

Research has shown that you, as the parent, can serve as a good model of a fluent reader for your child. Read out loud together with your child. This is sometimes called choral, paired or assisted reading.

Let your child pick something interesting to read. At first, you will take the lead and your child will follow you. Point to the words as you pronounce them. Read clearly and with expression. Go at a pace that is comfortable to your child. Let him or her follow along with your voice and point to the words that you are both saying. If your child wants to read a bit alone, let him. Step in when he struggles over a word. Pronounce the word correctly and begin reading aloud together at the start of that sentence.

This method is multisensory: it combines your child's senses of vision and hearing with the motor activities of speaking and pointing. Done on a regular basis, this activity can help your child make big gains in fluency. While it is not always as effective as reading with a person, some children will be able to benefit from the multisensory activity of reading out loud with a recorded book-on-tape. Books-on-tape are available in many neighborhoods at the local library.

### Good fluency instruction includes learning about the rhythm and expression of our language

You or the voice of the speaker on a book-on-tape is a role model for reading and expression. By listening to expressive reading at a good pace, your child

is learning how to group words into meaningful phrases. Good skill at rhythm and expression help readers understand and enjoy what they are reading.

As a parent, you can help your child become a better reader. You can do this by making reading fun and surrounding your child with text. Remember, as a developing reader, your child must do more than learn to decode the words on the page. Your child must also learn how to understand what he or she is reading.

(this article is from FAPE. Funding for the FAPE project comes from the U.S. Dept. of Education, Office of Special Education Programs (Cooperative Agreement no. H326A980004). See website at [www.fape.org](http://www.fape.org)

### Preventing Dental Disease in Children with Disabilities

By The Arc, Johnson & Johnson Dental Care Co., the American Dental Hygienists' Association and The Academy of Dentistry for the Handicapped

Preventing Dental Disease in Children with Disabilities is a 10 page pamphlet of information on helping children with disabilities have healthy teeth and gums. [Pamphlet 10-8](#) can be downloaded from the Arc's website at [www.thearc.org](http://www.thearc.org) and includes such information as:

- Prevention
- Adapting a toothbrush
- Step-by-step brushing and flossing
- Making visits to the dentist easier
- Common pediatric dental problems
- Growth and development checklist for children
- Checklist for finding the right dental office
- Tips for planning a successful dental visit, and
- A listing of support groups.

Advertising



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 ★ Happy Birthday to ★  
 ★ everyone with a birth- ★  
 ★ day in January! ★  
 ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★ ★

**DID YOU KNOW?**

The Department of Treasury says that when you pledge to give to United Way this year, you can designate your contribution to PCDS.

 Please pledge to direct your gift to PCDS by writing this name and number on your pledge card:

**“Parents of Children with Down Syndrome”**

or “PCDS” and the number **“121194”**

Cut out and save this information to put in your purse or wallet for when you sign up and be sure to pass the word to your friends and family who are giving to the United Way.

**ADVERTISE WITH US**

This newsletter goes out to over 250 families each month. Would you like to advertise your business with us? The monthly rate for a business card size ad is only \$20.00. If you would like to advertise for 6 months the cost is only \$100.00—for a year \$200.00. Think about it. Many people read this and may be able to use your services. Call Tricia Dewar for further information. (248)554-9191

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Opportunity For Children**

PCDS  
PO Box 522  
Royal Oak, MI  
48068-0522  
  
Phone: 248-827-9135  
Fax: 248-683-1698  
E-mail: www.pcdsmi.org

PCDS Opening A World Of Opportunity  
For Children With Down Syndrome



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Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email Address \_\_\_\_\_

Would you like to be on our email alert list? Yes \_\_\_\_\_ No \_\_\_\_\_  
\$15.00 (1 Year) Renewal? \_\_\_\_\_

Child's Name \_\_\_\_\_ and birthdate \_\_\_\_/\_\_\_\_/\_\_\_\_

Make checks payable to:

**Parents of Children with Down Syndrome** or  
**PCDS** and send to:

PO Box 522,  
Royal Oak, MI 48068-0522

Would you like to give a gift to some-  
one else; grandparents, aunts, un-  
cles—what about your child's teacher?  
A PCDS gift membership would make  
the perfect gift...

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Address: \_\_\_\_\_

From: \_\_\_\_\_

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Relationship: \_\_\_\_\_

This form and \$15.00 per gift should  
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**PCDS**

**PO Box 522**

**Royal Oak, MI 48068-0522**