

A Little Something Extra

Volume 3, Issue 2

February 2005

www.pcdsmi.org

Parents of Children with Down Sndrome

Opening a World of Opportunity For Children with Down Syndrome

Membership Round-up

Thanks to the following people for returning the survey. It's NOT too late. Please help us help you find the activities and interests that are most important to you.

Anita Beaman, Terri Bresso, Tim/Carol Brogan, David/Jane Buckley, Theresa Couture, Bob/Kathy Davis, Will/Chris Gottscholing, Sue/Mike Grigg, Nadia Ibrashi, Susan Kelly, Mill/Mary McKee, George/Rachel Nehasil, Patrick/Julie O'Donovan, Ann Sliney, Kathleen Stewart, Darrell/Cheryl Williams and Sandy Young.

Thank You for helping us.

The following have paid their 2005 DUES:

Becky Arwine, Rick/Terry Bresso, David/Jane Buckley, John/Nina Carlesimo, Tom/Paulette Duggins, Douglas/Sandra Holmes, Jim/Mary Jordan, Susan Kelly & David Mahnic, Bill/Mary McKee, Denise/Robert Moore, Paul/Barbara Nagrant, George/Rachel Nehsail, Margie O'Connor, Dave/Jan Popejoy, Mike/Geri Rex, Lisa/Jim Standal, Mike/Laurie Whell, Peggy/David Wilke.

We would like to remind everyone that we are a non-profit organization. Dues paid by our membership mainly covers the printing/mailing of the newsletter and other communications that we send throughout the year, and also indicates that you have an interest in being part of the group. Please keep in mind that we are a support group and it is not our intent to exclude anyone based on their ability to pay/not pay dues. If payment of the dues would be a financial hardship to some families, and we understand some people may be struggling, please, please contact one of our board members to document your situation. As a group we are only as strong as our membership. We need you, and maybe you need us too.

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.

2005 Beautiful Faces Calendars

We still have some calendars left. These beautiful calendars feature the top-notch work of photographer Kendra Dew, made even more beautiful because the models are kids of all ages who have Down Syndrome, many of whom are local and you may know some of them. **The calendars are \$15 each and for a limited time we are selling them 2 for \$25!** Please contact Paulette at 248-646-0819 or email at dugginsp@comcast.net

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 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

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 website for more details and registration information.

February 23, 2005, 6:30-9:00 P.M. Visions of Inclusion, The Jewish Community Center, (see Information on Page 5)

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 for further information

July 29-31, 2005, NDSC National Convention, Hyatt Regency Orange County, Anaheim, CA. See NDSC website at NDSCCenter.org for further information.

August 23-27, 2006, 9th World Down Syndrome Congress, Vancouver BC, Canada. See NADS. Website at NADS.org for additional information.

PCDS Board Meeting

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.

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

Dues are due

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

Bike Camp

PCDS will collaborate with FEDS (Families Exploring Down Syndrome) to sponsor a bike clinic in June 2005 and again in 2006. The camp is being run in Western, MI and in Macomb County. The bike camp is part of a study by Dale Ulrich's Center for Motor Behavior in Down Syndrome, Division of Kinesiology—U of M.

Bike Camp is part of a study and it is being underwritten by a grant at the cost of approximately \$25,000 and is open to boys and girls with Down Syndrome from ages 8 to 18. Participants will be placed in one session or the other by the study team. The success rate for children with disabilities learning to ride a 2-wheeled bike without training wheels is 75 to 85%.

Anyone interested in the Bike Camp should email PCDS at dugginsp@comcast.net. Please use "Bike Camp" in your subject line.

President's Remarks At The Signing of IDEA

(excerpted in part from a press release December 3, 2004, at the signing of the reauthorization of the Individuals with Disabilities Act)

America's schools educate over six million children with disabilities. In the past those students were too often just shuffled through the system with little expectation that they could make significant progress or succeed like their fellow classmates. Children with disabilities deserve high hopes, high expectations and extra help.

In the bill I sign today, we're raising expectations for the students. We're giving schools and parents the tools they need to meet them. We're applying the reforms of the No Child Left Behind Act to the Individuals With Disabilities Education Improvement Act so schools are accountable for teaching every single child. All our students deserve excellent teachers. So this law ensures that students with disabilities will have special education teachers with the skills and training to teach special education and their subject area.

Some students with disabilities will need intensive, individualized help. So, this law, for the first time, will support tutoring programs to help children in schools that need improvement. When schools are so busy trying to deal with unnecessary and costly lawsuits, they have less time to spend with students. So we're creating opportunities for parents and teachers to resolve problems early. We're making the system less litigious, so it can focus on the children and their parents.

The people who care most about the students are of course the teachers, and especially the parents, who know their needs and know their names. So we're giving more flexibility and control over the students' education to parents and teachers and principals. We'll make sure that parents and schools can change a student's educational program to better meet their needs, without having to attend unnecessary meetings or complete unnecessary paperwork. We trust the local folks to meet high standards for all our kids, and this bill gives them the freedom and flexibility to meet our goals.

All students in America can learn. That's what all of us up here believe. All of us understand we have an obligation to make sure no child is left behind in America. So I'm honored to sign the Individuals With Disabilities Education Improvement Act of 2004.

Make a date with your browser....

We want to share with you that there are many helpful websites on the Internet. One that we like is www.bridges4kids.org. Remember that the National Down Syndrome Society and National Down Syndrome Congress have websites, www.ndss.org and www.ndscenter.org, respectively. Some of the information that we post in the newsletter and on the website is obtained from other reading done on the internet. And don't forget our own website at www.pcdsmi.org. Our webserver, Anita Beaman, has done a fabulous job of redesigning the website and getting the latest information posted. And we even have working links to these and other websites! And Please ensure PCDS has your E-Mail address.

Kaufman Children's Center for Speech, Language, Sensory-Motor and Learning Potential, Inc.

5793 West Maple Road, Suite 150, West Bloomfield, Michigan, 48322

Phone (248) 737-3430 • Fax (248) 737-3433 • www.kidspeech.com**Upcoming Parent Education & Support Groups:****Sensory Integration: An Introduction For Parents, March 14, 2005**

Marjorie Deschner, OTR and Michelle Cody, OTR

Understanding The Handwriting Without Tears Programs, April 11, 2005

Emma Lee Zamm, OTR

Functional Communication Interventions For Children With Autistic Spectrum Disorders, April 19, 05

Carol Afflerbaugh, M.A., CCC/SLP, BCBA

Therapeutic Listening: Questions & Answers, May 2, 2005

Cari Cooke, M.S., OTR and Jennifer Howison, OTR

Apraxia of Speech: Parent Education and Support, May 4, 2005

Nancy Kaufman, M.A., CCC/SLP

Social Skills Development, June 6, 2005

Diane Nancarrow, M.A., CCC/SLP and Sally Bloch, Ph.D.

Everyone Together Oakland County

Presents

VISIONS of INCLUSION*A sense of belonging... A feeling of happiness... The satisfaction of being accepted just the way you are...*

These are the feelings of *inclusion*. When we feel included, we feel welcomed and valued. We have friends. We feel good about ourselves, and good about the community in which we belong. Sadly, through lack of forethought or perhaps sometimes simply out of habit, people with disabilities are often *excluded from* rather than *included in* their communities.

Is it possible to create a community that includes **all** of its members? A community that does not exclude even one person? Yes! We can start the process in the first community in which we all learn to live, work and play together: **our schools**.

It *is possible* for all children, even those with the most significant of disabilities, to be included in the school community. And it *is possible* to make that happen in a way that actually supports the learning of all children, all together, all the time: via Universal Education. Join us in a conversation about how educational environments that are Universal (that is, inherently flexible and designed to support a variety of learning styles) are good for **all** our kids!

Jill England, Ph.D.

Inclusive Education Consultant

Dr. England is nationally known for her practical work to include students with disabilities in general education settings. You will walk away from this evening wondering why every child is **not** included!

When: **Wednesday February 23, 2005**
6:30 p.m. □ 9:00 p.m. (Sign-in at 6:00 p.m.)

Where: **The Jewish Community Center**
6600 W. Maple Rd. West Bloomfield 48322

RSVP by February 21, etoakland@yahoo.com Voice Mail 248-888-4111

Research Opportunity

The University of Michigan is recruiting new walkers with Down syndrome for a study entitled, "The effect of foot orthoses on new walkers with Down syndrome." If you would like to participate or have Questions about the study please contact Julia Looper, PT at (734) 936-2607, at the Center for Motor Behavior and Pediatric Disabilities University of Michigan

Assistive Technology Act of 2004

Passed by both the House of Representatives and the U.S. Senate, the President signed the Assistive Technology Act of 2004 on October 15, 2004.

The House and Senate worked in a bi-cameral, bi-partisan fashion to move assistive technology reauthorization along a fast track, without the need for going into a conference committee before the bill is signed.

The act primarily funds state programs that provide assistive technology (AT) devices and services to individuals with disabilities. Some features of this legislation include:

- The 60/40 and 70/30 split in funding for state activities;
- A minimum state grant of \$410,000; and
- A sunset provision is waived, so the AT will now be regularly re-authorized.

Authored by 21st Century Competitiveness subcommittee Chairman Howard “Buck” McKeon (R-CA), it expands access to technology for individuals with disabilities. This bill shifts the focus of the program to provide greater benefit to individuals with disabilities. “Our goal is to help states get more assistive technology into the hands of individuals with disabilities,” said McKeon. “I know this will help states continue to make progress in their efforts to expand access to technology and that increasing numbers of individuals with disabilities will be able to participate in society more fully everyday.”

This bill strengthens assistive technology programs by refocusing resources to provide more direct aid to individuals with disabilities. By requiring states to spend the majority of their AT grants on activities that directly benefit individuals with disabilities, the Assistive Technology Act of 2004 will help guarantee great access and encourages states to invest in programs that have been shown most effective in providing AT devices.

Representative John Boehner (R-OH), chairperson of the Education & Workforce Committee, praised the bill’s reforms. “This bill is a milestone for Americans with Disabilities who depend on AT to improve their quality of life,” said Boehner. “By devoting fewer resources to building bureaucracy, this bill will expand access to needed technology for Americans of all ages living with disabilities.” A summary of the Assistive Technology Act of 2004 can be accessed at: <http://edworkforce.house.gov/issues/108th/education/at/billsummary.htm>

It’s Tax time.....

The Arc of Oakland County has a Tax Guide available for persons supporting children and/or adults with developmental disabilities. You may obtain a copy from the Arc of Oakland County, 1641 West Big Beaver Road, Troy, MI 48084-3501, (248)816-1900. The cost for the copyrighted tax guide is \$11.00 per copy.

Books of Interest to Review for Bridges4Kids

Available now:

Bubbles, Rainbows and Worms: Science Experiments for Preschool Children

(<http://www.gryphonhouse.com/showbook.cfm?code=10243>)

The Learning Power of Laughter

(contains over 300 playful games, activities, and ideas that promote learning with children)

(<http://www.gryphonhouse.com/showbook.cfm?code=16238>)

Do You Know the Muffin Man? Literacy Activities using Favorite Rhymes & Songs

(<http://www.gryphonhouse.com/showbook.cfm?code=19624>)

The Giant Encyclopedia of Preschool Activities for Four-Year-Olds (contains over 600 activities)

(<http://www.gryphonhouse.com/showbook.dfm?code=14964>)

Coming Soon:

Alex: The Fathering of a Preemie

(<http://amazon.com/exec/obidos/tg/detail/-/0897335287/102-70489537784935?v=glance>)

The Bilingual Book of Rhymes, Songs, Stories and Fingerplays

(<http://www.gryphonhouse.com/showbook.cfm?code+12874>)

Note: If you would be interested in reviewing any of these books please contact Jackie@bridges4kids.org) Bridges4kids is seeking volunteers to do book reviews. If you are selected to review a book (based on number of responses received) you must review the book within 45 days and the book is yours to keep. This may be of special interest to teachers and other professionals. The hyperlinks beside the book titles lead to a description/photo of the books.

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

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.



Encourage you 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

**Opening a World of
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



MEMBERSHIP APPLICATION

Name _____

Address _____

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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 ____/____/____

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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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