

A Little Something Extra

Volume 3, Issue 3

March 2005

www.pcdsmi.org

Parents of Children with Down Syndrome

Opening a World of Opportunity For Children with Down Syndrome

FREE Fun Family Event!

Tuesday March 22, 2005, 7:00 P.M., McMorran Auditorium, Port Huron MI

See Chris Burke perform with his friends Joe and John DeMasi in EVERY-ONE CAN BE ASINGER WITH THE BAND!

Chris Burke, who has Down Syndrome and is best known for his role as “Corky” from the ABC TV series “Life Goes On,” presents a program/concert that celebrates the many kinds of people who make up our world and the abilities they have. For more information, call St. Clair County Community

Tips and Tidbits—we want to pick your brain!

This will be a new monthly feature in the PCDS newsletter! We would like to hear from other parents or professionals who would be willing to share information about their experiences in raising a child with Down Syndrome and advice that they can offer to resolve particular issues and problems. We want to hear everything from feeding and diapering to dressing and adolescent/growing issues.

Our first Tips and Tidbits is regarding how to help your infant/young child sit independently. For example, while our children are still infants it is very difficult for them to learn to sit up independently without toppling over. Even “prop” sitting them with both of their hands holding them up in front of their bodies doesn’t last long and they soon topple over and become frustrated in the process. Laurie Whell shares that she would sit her daughter Megan on the floor with **TWO** of the **boppy** cushions around her to help hold her up. Thanks Laurie!

To submit your own Tips and Tidbits for future newsletters please call or email Sue Grigg at (248)288-6468/suegrigg@comcast.net

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.

Mom’s Night Out

Tuesday, March 22 will be our first Mom’s Night Out. We will be meeting at the Papa Vino’s restaurant at 3900 Centerpoint Parkway in Pontiac, located near I-75 and Opdyke Rd. Our goal is to have an informal get-together of PCDS moms to get to know one another better and spend a pleasant evening together with conversation and food in a restaurant. Please RSVP to Sue Grigg by Saturday, March 19 so that we can make the reservation accordingly. If this event is well-received we would like to plan it on a regular basis.

A few 2005 Beautiful Faces calendars are still available at \$15 each or 2 for \$25. Don’t miss out, they will be gone soon!

PCDS Playgroup News

Attention all Play Group Participants

The next Play group date is **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.

More Play Group Dates

Saturday, April 2, 9:30 AM

Saturday, May 7, 9:30 AM

Saturday, June 4, 9:30 AM

Calendar/Important Dates

Thursday March 10, 2005, Appetizers/Wines from CA at Joe Bologna Trattoria. \$25/PP Contact Adele@joebologna.com

Thursday March 24, 2005, Foods and Wines from France. \$65.00/PP includes formal 6 course dinner with 5 wines Contact Adele@joebologna.com

Saturday March 12, 2005, Safety in the Kitchen—Children's cooking series at Joe Bologna Trattoria. Contact Adele@joebologna.com

Saturday March 19, 2005, Making a pizza from scratch—Children's cooking series at Joe Bologna Trattoria. Contact Adele@joebologna.com

Saturday March 26, 2005, Easter Desserts—cookies & cakes—Children's cooking series at Joe Bologna Trattoria. Contact Adele@joebologna.com

Tuesday, March 22, 2005, 7:00 PM, Chris Burke with Joe and John DeMasi at McMorran Auditorium in Port Huron

Tuesday, March 22, 2005, PCDS Mom's night out. See front page

Thursday, March 24, 2004, 6:30-8:30 PM, Oakland Mediation Center at Cross of Christ Lutheran Church, Participants will learn how to prepare for special education mediation

Tuesday, April 5, 2005, Ready...Set...Go! Recognizing Family Strengths; Building a Better Future 8:30 AM-2:30 PM., The Hilton Northfield Featuring Keynote Speaker Howard Glasser, MA. Author of Transforming the

Difficult Child. Also featuring workshop sessions designed to educate and provide useful information about children and family mental health services. Sponsored by Oakland County Community Mental Health Authority, Register by Friday March 18, 2005. There will also be providers from Oakland County at this conference.

April 22, 2005, Band of Angels Starry Night Black Tie Gala at the Birmingham Townsend Hotel. RSVP by March 30, 2005. www.bandofangels.com

April 28, 2005, 6:30-8:30 PM, Tools for a Successful Individualized Education Plan (IEP) at Cross of Christ Lutheran Church, Useful info on what parents can do before, during and after and IEPT meeting in order to help assure a successful plan for children getting special education services

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.

December 11, 2005—Annual PCDS Holiday Party

PCDS Board Meeting

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

Newsletter Deadline

The deadline for all submissions to the newsletter is the 25th of each month. Contact Paulette Duggins or Sue Grigg accordingly.

Bike Camp

Bike Camp 2005 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 8 to 18 during June 2005 and 2006. Participants will be placed in one session of 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%. We need approximately 75 children for the 2005 and 2006 camps. These camps are being run in Western, MI and in Macomb County. The bike camp is part of a study by Dale Ulrich's and the Center for Motor Behavior in Down Syndrome Division of Kinesiology—U of M.

For your child to be considered for Bike Camp, please email PCDS at dugginsp@comcast.net. Please use "Bike Camp" in your subject line. An application will be forwarded to you with the details of the camp when they are finalized. Bike camp 2005 will take place the week of June 27, 2005

American Sign Language Browser

The following website is fun and informative. There is a person on it who will sign thousands of signs over and over until you tell her to stop! Signs like "MORE", "BABY", "EAT" etc. Take a look and start learning so that you can teach your little one. Remember our children are late talkers but they have something to say. Many parents start teaching a sign or two before the child is 18 months. These children are less frustrated and will drop the signs as they learn to speak. Typical babies benefit from learning sign too.

<http://commtechlab.msu.edu/sites/aslweb/browser.htm>

The ASL Browser is dedicated to the memory and work of Dr. David Stewart (1954-2004). David was a top national scholar in Deaf Education, working as a professor and Coordinator of the Deaf Education Program at Michigan State University, authoring several renowned books on sign language and Deaf education, and working on several interactive media projects including the [Personal Communicator](#), [ASL Browser](#), and [Signing Online](#). His passion for Deaf Education and American Sign Language lives on through his work.

Speechercise

Developed by a Speech-Language Pathologist (SLP), is an all-new musical resource designed to make daily speech practice fun and easy while making lasting changes in a child's overall speech production ability. It is developed to help children who may:

- Mispronounce a sound in certain words, yet pronounce it clearly in other words
- Leave out entire syllables from longer words
- Leave off the beginning or ending sounds of words? Make the /T/ or /K/ sounds incorrectly
- Pronounce words differently from situation to situation
- Have difficulty combining sounds into words, and
- Struggle to move the tongue, lips, and jaw consistently

At home, school, or even in the car, follow the Speechercise workout leaders through the musical workout. Visit www.twinsisters.com to order and read more about this program.

Sign Babies

Sign Babies flash cards introduce the most useful ASL signs for babies and children. The flash card pictures help baby learn to recognize common objects, actions, and emotions. Use the cards individually as you learn the signs. Or, make your own personalized book by placing cards in a photo album. The ASL sign and hint on the back side helps you remember the sign.

These custom laminated 4x6 flash cards can be used to create a custom "book" in a photo album or can be used individually to teach concepts and words. Visit www.signbabies to order and to read more about this product.

Calling for volunteers....Our PCDS Holiday Party is scheduled for Sunday, December 11, 2005. Please volunteer if you can. If we could get 2 or 3 people to chair/co-chair this event it's not a lot of work. Planning early helps to lighten the load. This is a wonderful event that is looked forward to and enjoyed by our members and you will find it very gratifying to be a part of it and add your own special touches. Contact Paulette or Annette Liike.

New PCDS Library Resources:

Inclusion: Educating Students With Down Syndrome With Their Non-Disabled Peers.

Transition Planning: Helping Students with Down Syndrome Prepare for Life After High School

Both are publications of the National Down Syndrome Society and can be downloaded from their website at www.ndss.org

Interactive Reading Books:

These are books that come with pictures that Velcro on to the pages to help children learn to associate pictures with words. Children learn the skills to match, identify, label and sequence. To check out the books for yourself or to obtain your own copy go to www.greenhousepub.com. Additionally, the books are assembled by Special Olympics Nebraska Area 6 athletes.

Research Opportunities

Calling all 8 to 10 year olds**Treadmill Study**, Children between the ages of 7-10 (must be 8 by beginning of study) are needed for a research study. Faculty and students in the Center for Motor Behavior in Down Syndrome at the University of Michigan are studying how children with Down Syndrome use their muscles when they walk on a treadmill and how this changes with practice. There is compensation of \$20 for each visit, a U Of M Kinesiology t-shirt, and photos of the participant to keep. For more information or to volunteer, please call 734-615-1494 and ask for Cheryl Drenning or email csdren@umich.edu.

U of M Communication Study & 100 Gift Card for Participation, Our 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, we are being funded to learn more about the effectiveness of our diagnostic instruments in differentiating children with autistic spectrum disorders from those with other developmental delays of 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. We 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, we would like to conduct a parent interview as a first appointment and the child assessment as a second appointment). Our 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.

No Child Left Behind (NCLB) Myths and Facts

Published March 1, 2004

Myth: NCLB punishes “failing Schools.”

Facts: Schools that do not make AYP for two consecutive years are identified as “needing improvement” and are given help, not punishment. NCLB never labels schools as “failing.” A school may have a great reputation because most of its students are achieving at a high level. However, if one subgroup at the school does not make AYP it is fair to say that even a great school “needs improvement.” These schools do not lose federal funding; in fact they are eligible for additional support. If a school continuously does not meet AYP there eventually is a possibility that the state will take over the operation of the school, but that is only one of a number of possible alternatives.

Myth: Students with disabilities can’t be expected to attain proficiency.

Facts: This myth represents the low expectations that NCLB is trying to extinguish. Most students with disabilities are on diploma track and with appropriate accommodations and instruction should be able to attain proficiency on grade level assessments. In addition, students with the most significant cognitive disabilities can take alternate assessments based on alternate achievement standards and should be able to attain proficiency as measured in this manner. In order to help more students reach proficiency there will need to be greater access to the general education curriculum in the least restrictive environment. The teachers must be qualified in the subject areas they are expected to teach. It will also be important to develop universally designed assessments that are not invalidated by accommodations and are appropriate for widest possible range of students.

Myth: NCLB requires proficiency on a “one size fits all assessment.”

Facts: Under NCLB, students with disabilities can take the regular assessments, with or without accommodations, or they can take an alternate assessment based on grade level achievement standards or alternate achievement standards. States have the flexibility to have a number of different alternate assessments and a number of different alternate achievement standards. This is not a “one size fits all” situation.

Myth: High performing schools are not making AYP because of the scores of a few students with disabilities.

Facts: It takes more than the scores of a few students with disabilities to cause a school not to make AYP. In fact, the accommodations on the grade-level assessments and the availability of alternate assessments based on alternate achievement standards for students with the most significant cognitive disabilities level the playing field so many of these students receive proficient scores. Even if students with disabilities are doing poorly the “n” factor and the safe harbor will often prevent these scores from affecting AYP. If a large subgroup of students with disabilities does not meet AYP it may mean the school will be identified as needing improvement, even if all the other students are proficient. That is the point of NO Child Left Behind; a school has to help all its students get an education.

Myth: All students with cognitive disabilities should take an alternate assessment based on alternate achievement standards.

Facts: The regulation permitting proficient and advanced scores from these alternate assessments to be used to calculate AYP refers to students with the most significant cognitive disabilities. This clearly doesn’t mean all students with cognitive disabilities. With the appropriate accommodations, many students with cognitive disabilities should be able to take a universally designed grade-level assessment or a grade-level alternate assessment. Since the 1% rule is generous enough to allow most states to place all students with cognitive disabilities in an assessment based on an alternate standard, it is left up to parents to ensure that the IEP team places their child in the appropriate assessment.

Myth: NCLB causes excessive federal intrusion into state education policy.

Facts: There is a tremendous amount of state flexibility built into NCLB. Except for the general requirement of a state accountability plan that measures AYP and the requirement for highly qualified teachers, most of NCLB applies only to schools receiving Title I funds. Otherwise, the provisions in state plans define accountability requirements. The diversity among the approved state plans is evidence of state flexibility. AT <http://www.ed.gov/news/pressreleases/2004/01/01142004.html> there is a ten page document discussing the many options each state can choose under NCLB. To learn more about the No Child Left Behind Act and take action on this issue visit the NCLBNDSS.org’s Advocacy Alert.

Advertising



It's all about helping kids succeed!

The Abilities Center, Inc. specializes in providing exceptional and caring therapy services for special needs children.

Physical Therapy Occupational Therapy Speech-Language Therapy

- We also offer... Enrichment Classes Summer Camp Programs Birthday Parties Psychology Educational Tutoring School Visits / Home Visits Parent Training and Support P.L.A.Y. Project Therapy Books, Toys and Products

248-926-0909

www.abilitiescenter.com

Kaufman Children's Center

For Speech, Language, Sensory-Motor, and Learning Potential, Inc.



Speech/Language Therapy Occupational Therapy

Social Skills Groups Literacy Psychology Special Apraxia of Speech Treatment For Down Syndrome kids!

West Bloomfield Michigan (248) 737-3430

Happy Birthday to everyone with a birthday in March!



Castello di Bologna

2336 Joslyn Ct. Lake Orion MI 48360 (248) 391-5780

See Children's cooking classes and wine tasting events on page 2 of Newsletter. Also, call and book early for Easter Family Style Dinners. Call for details.

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.

We 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 _____

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...

PCDS GIFT MEMBERSHIP

Please send a gift membership to:

Name: _____

Address: _____

From: _____

Phone: _____

Relationship: _____

This form and \$15.00 per gift should
be sent to:

PCDS

PO Box 522

Royal Oak, MI 48068-0522