

A Little Something Extra

Opening a World of
Opportunity For
Children with Down
Syndrome

Volume 2, Issue 7

August/September 2004

www.pcdsmi.org

Parents of Children with Down Syndrome

Thanks to the Duffers !

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The 10th annual Joe Bologna golf outing raised \$15,000 for PCDS!! A nice time was had by all who participated in the event which included a beautiful day on the green at the Paint Creek Country Club, lunch and dinner as well as live entertainment by pianist Vladimir Kalmsky, and magician Dave J. Castle, and other events such as a silent auction and 50/50 raffle. We would like to convey our deepest gratitude to Castello Di Bologna, and the other sponsors for this very generous gift which will help us continue to reach out to, and network with, other families learning about Down Syndrome. We would also like to thank Wendy Larkin and Mary Rosales of Sam's Club for their donation of a \$1,000 Sam's Club gift card which we plan to raffle off at the PCDS holiday party. Many thanks also to The Paint Creek Country Club and General Manager, Pete Reyburn, and Club Pro, Steve Vickery. The following volunteers and sponsors worked to make the Joe Bologna Down Syndrome golf outing the success that it was: Adele Bologna; Anita Beaman; Bill Trombley; Bridgit Chayt; Bruce Valentine; Patty Abate; Paulette Duggins; Ron Godlewski; Stephanie Valentine; Adam; Ambrose; Andrea; Chase; Danny; Diane; Giordana; Joellyn; Marge; Marshall; Matt; Nathan; Pete and Wayne. We send endless thanks to all of you that gave of your time and to those of you that golfed! Last but not least we would like to point out that **Castillo Di Bologna** is not only a generous benefactor to our organization, but is a wonderful dining and banquet facility located at **Olde World Canterbury Village** in Lake Orion. They also have more a more casual dining atmosphere at their **Wildwood Tavern**, and scrumptious deserts, fine wines and breads available for take out at **Cannoli's Bakery and Market** located on the premises. You and your family and friends might enjoy an outing to explore and taste all that they have to offer. Call (248)391-5780 for additional information or check it out at www.canterburyvillage.com

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.

Key Sponsors:

Tech Induction
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PCDS Playgroup News

Our next playgroups are scheduled for :

Saturday September 11 10:00-11:30

Saturday October 9 10:00-11:30

Saturday November 6 10:00-11:30

at:

The nursery at The Cross of Christ Lutheran Church 1100 Lone Pine Road (NW Corner of

Telegraph and Lone Pine).

All mothers with new/young infant/toddler children are welcome to come with their siblings or friend they would like to bring.

For additional information contact:

Julie O'Donovan (248)649-5725/
odonovanj@comcast.net or

Annette Liike (248)624-3046/
aliike@comcast.net



Calendar/Important Dates

Saturday September 11, 2004 11:00 A.M. – 4:00 P.M. Oakland County Special Olympics Family Fun Day at Hess-Hathaway Park in Waterford

Thursday September 16, 2004 at 6:30 P.M. "Supporting Inclusion in the Classroom" featuring Dr. Michael Peterson, Wayne State University. Meeting will be held at the Bloomfield Hills Library, Bloomfield Hills, MI

Friday September 17, 2004 1:00 P.M.-3:30 P.M. the Michigan Developmental Disabilities Council is meeting with families, advocates, et. al, at the Sacred Heart Seminary, 2701 W. Chicago Blvd, in Detroit

Friday September 17, 2004 10:00 A.M.-12:30 P.M., training session for people with disabilities who would like to register to vote and get involved. Call Chris Horstman at (248)858-7821 to register

September 17-19, 2004, ABILITIES EXPO, at the Novi Expo Center. Will show an assortment of assisted living products/equipment and services. Call 1-800-385-3085 or visit www.abilitiesexpo.com

September 24, 2004 12:00-7:00 P.M. Community Connections/Oakland County Resources at Oakland Community College Auburn Hills Campus (Building H) **PCDS has a table at this.**

Saturday September 25, 2004 "Making it on Our Own". Classes include: crafts, dancing, cooking, safety. The cost is \$15 per person. Hosted by the Interdependent Living Council. For more information call Barb Maklin at 248-263-8937

September 28 & 29, 2004 9:00 A.M.-4:00 P.M., Case Management/Supports Coordination and Public Benefits: FIA, Section 8, SSA

Advocacy in your own agency justice system: How to assure equity preventing guardianship self determination (at WISD through the Washtenaw Association for Community Advocacy)

Saturday October 16, 2004, 8:00 A.M.-12:00 P.M. "Developing Social-Emotional Intelligence in Young Children" presented by Dr. Ira Glovinsky at EMU's McKenny Ballroom.

Saturday October 23, 2004, the National Association for Down Syndrome conference at the Congress Plaza Hotel in Chicago, IL (Anyone interested in taking the train, a bus, or drive contact Paulette at (248)646-0819)

Wednesday November 10, 2004 at 6:30 P.M. "How Special Education Law Supports Inclusion" featuring Laura Athens, Special Education Attorney. Meeting will be held at the Bloomfield Hills Library, Bloomfield Hills, MI.

November 12 & 13, 2004 Las Vegas Night at the Waterford Elks club. Proceeds will benefit Oakland County Special Olympics

November 16, 2004 9:00 A.M. - 4:00 P.M. Self-Advocacy, Self Employment, ADA (Location TBA through the Washtenaw Association for Community Advocacy)

Sunday December 5, 2004, PCDS Holiday Party (details to follow)

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

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

PCDS General Membership Meetings on Tuesdays

in classroom #7 at the Cross of Christ Church from 7:00-9:00 pm on the following dates:

September 14 - Parent Panel 15 things you wish you knew about Down Syndrome

October 12 (There will be a welcome party/member reception)

November 9 (Information about "On Our Own" will be presented)

December 5 Holiday Party (details to follow)

January 11

February 8

March 8

April 12

May 19

PCDS Board Meeting

Tuesday, September 28 9:30 A.M.-11:30 A.M. in classroom #7 at the Cross of Christ Church will be our first meeting. 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 Dugginsp@comcast.net.

Help Wanted

We need a volunteer coordinator for the Buddy Walk and we are in need of a website administrator immediately. Please contact Paulette if you can help.

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**

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VICE PRESIDENT

Pat Dickson
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TREASURER

Melinda Hilborn
mhilborn@detroitdesign.net

SECRETARY

CHAIRPERSONS**Buddy Walk**

Vacant—Need a volunteer

Calendar Sales

Kathy Davis
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Library

Newsletter

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Corresponding Secretary

Sue Grigg
suegrigg@comcast.net

Directory

Laurie & Mike Whell
whell@email.com

Webserver

Vacant—need a volunteer

New Parent/Hospital Liaison

Suzanne and Paul O'Leary
suzanneoleary@comcast.net

Home Fellowship

Camille Smith
kdsmith@viafamily.com

Dads of Kids with Down Syndrome

Darrell Williams

Aurelio Stella

David Buckley

Reading Resources

Classroom Language Skills for Children with Down Syndrome, A Guide for Parents and Teachers, Libby Kumin, Ph.D., CCC-SLP

Fine Motor Skills in Children with Down Syndrome, A guide for Parents and Professionals, Maryanne Bruni, BSc OT ©

Communication Skills in Children with Down Syndrome, A Guide for Parents, Libby Kumin, Ph.D., CCC-SLP

Gross Motor Skills in Children with Down Syndrome, A Guide for Parents and Professionals, Patricia C. Winders, P.T.

Teaching Reading to Children with Down Syndrome, A Guide for Parents and Teachers, Patricia Oelwein, M.Ed.

Medical and Surgical Care for Children with Down Syndrome, A Guide for Parents, Edited by D.C. Van Dyke, M.D., Philip Mattheis, M.D., Susan Schoon Eberly, M.A., and Janet Williams, R.N., Ph.D.

Differences in Common, Straight Talk on Mental Retardation, Down Syndrome, and Life, Marilyn Trainer

Second Edition **Babies with Down Syndrome**, A New Parents' Guide, Edited by Karen Stray-Gundersen

Delicate Threads, Friendships Between Children with and without Special Needs in Inclusive Settings, Debbie Staub, Ph.D.

Third Edition **Negotiating the Special Education Maze**, A Guide for Parents and Teachers, Winifred Anderson, Stephen Chitwood, and Deidre Hayden

From the Heart, On Being the Mother of a Child with Special Needs, Edited by Jayne D.B. Marsh

Uncommon Fathers, Reflections on Raising a Child with a Disability, Edited by Donald J. Meyer

Books for Children/Siblings

A Day with Russ, children's book series, Janet Elizabeth Rickert, Photographs by Pete McGahan

We'll Paint the Octopus Red, Stephanie Stuve-Bodeen/Illustrated by Pam DeVito

My Brother, Matthew, Written and illustrated by Mary Thompson

Views from our Shoes, Growing Up with a Brother or Sister with Special Needs, Edited by Donald J. Meyer/ Illustrated by Cary Pillo

My Money; Banking for Beginners, Book One: Keeping Records, Natalie Hale, 1-866-553-2042, www.specialreads.com

The New Language of Toys, 3rd edition, Teaching Communication Skills to Children with Special Needs, a Guide for Parents and Teachers, Sue Schwartz, 1-800-843-7323, www.woodbinehouse.com

Down Syndrome and Vitamin Therapy, Unlocking the Secrets of Improved Health, Behavior and Intelligence, Kent MacLeod BSc.PhM, 1-888-384-7855, www.nutrichem.com, also available through amazon.com

Say It With a Sign, vol. 1, Early Communication Through Basic Sign Language, 30-minute video, ages 6 mos.-up, (512)349-9436, www.sayitvideos.com

Oh Brother! Growing Up with a Special Needs Sibling, Natalie Hale, 800-374-2721, www.specialreads.com

Please remember that Parents of Children does have a collection of books and publications that PCDS members are welcome to borrow. We are still looking for a librarian to keep track of the books. If you are interested in helping out please contact Paulette at 248-646-0819 or Dugginsp@comcast.net

The book titles referenced in the first two columns above are available from Woodbine House, 1-800-843-7323 or at www.woodbinehouse.com

Donations/ Memorials/Grants

We wish to thank the Monaghan Council 2690 of the Knights of Columbus in Livonia for their generous donation of \$1,223.03 to PCDS from their 2004 Fund Drive for Mental Retardation Project.

Please note that the Knights of Columbus is changing the name of this fund (from the Tootsie Roll drive) to the Mental Impairment Fund (in Michigan). While it has always been called the Mental Retardation Fund, and some may dislike or be offended by this description, the K of C feels it is outdated and in an effort to be more sensitive is pro-actively making the change to Mental Impairment Fund which you will see from now on (in Michigan).

August/September Birthdays

Happy Birthday to everyone with a birthday in August and September!



Hearing/Speech Information

Language Enrichment at Home

Talk to your child often from birth on. A lot of language learning is going on even before she can talk. Turn pleasurable daily routines (mealtime, bath time, etc.) into language learning opportunities. Repeat special phrases that go with the routine often (Here comes the spoon!) Later, pause for your child to fill in the blank. ("Here comes the _____.")

- Imitate your child's sounds. Always leave a pause for him to take a turn.
- Share your child's level and focus of attention. Get down on the floor with her and interact face to face. Listen and wait more; talk less. Watch to see what captures her interest. Let her take the lead.
- Interpret all your child's sounds and words as attempts to communicate. Let him know that what he says is important to you.
- Sing songs to your child. Play simple children's music. Make up silly songs.
- Have fun with animal noises, car sounds and other noises from the environment.
- Read to your child from birth. Talk about the pictures. When he's older, pause to let him finish sentences in familiar stories.
- Accept some mistakes as she is learning to talk. Model the correct pronunciation rather than correcting her.
- Play interactive games, such as rolling a ball back and forth, in which you and your child take turns.

From NADS News, July, 2004, Reprinted from Community Times, Vol. V, number 3, published by Community Therapy Services, PC, Geneva, IL, (630)208-8880

Songs of Love

Songs of Love Foundation is a non-profit organization which creates personalized songs for children with serious illnesses or disabilities. As part of the program each patient receives a CD or cassette of their own song, free of charge, with original lyrics based on profiles submitted by hospitals and families. The song includes the child's name and all of his or her favorite people and things.

Since its inception, the foundation has produced over 5000 songs for more than 300 hospitals across the United States.

Over 350 songwriters and singers have used their abilities to create the "Medicine of Music."

Individuals with special needs up to age 21 are eligible for the service. The usual turnaround time is 30 days. Songs can be performed in any style or language and are created to highlight the individual and what they would most enjoy hearing.

John Beltzer
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Songs of Love Foundation
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Forest Hills, NY 11375
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718-441-5422
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www.songsoflove.org

From NADS News, July 2004

High Frequency Hearing Loss

High frequency hearing loss is probably more common in people with Down Syndrome. It is also seen frequently in older people who do not have Down Syndrome. One aspect of this loss is the reduced ability to distinguish different consonant sounds. Therefore, the person with Down Syndrome may be hearing the sounds but may have difficulty discriminating what is being said. Therefore, what may appear to be defiance or oppositional behavior or even a decline in intellectual skills may actually be impaired hearing. It is important to speak clearly to a person with high frequency hearing loss. It is also beneficial for the person with the hearing loss to be able to see the person that is speaking to him or her. Crowded or noisy rooms are places where the person may find it particularly difficult to discriminate what is being said.

Hearing aids may also be indicated for some people with high frequency hearing loss.

From NADS News, July 2004

News and resources you can use—continued

Read your school's report card—The Michigan School Report Cards provide information about the performance of schools in Michigan. You can search or browse for a school to view its report card. The report card provides a comprehensive grade for the school. Then you can view the details on each report card to understand the basis for each grade. Visit <http://ayp.mde.state.mi.us/ayp/> to learn about how your school is doing. This site also provides a Guide to Reading School Report Cards, a glossary and the Adequate Yearly Progress/Education YES! State Status Report.

IDEA Update—New OSEP Information Center Offers In-Depth IDEA Updates—the National Center for Children and Youth with Disabilities (NICHCY) is now operating a new dissemination center funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). The new center, called the National Dissemination Center for Children with Disabilities, will be serving as a central source of information on the Individuals with Disabilities Act (IDEA) and No Child Left Behind (NCLB) as it relates to children with disabilities, and research-based information on effective educational practices. The new center will continue to offer the information and services established through NICHCY with an emphasis on improving the results for children with disabilities and their families. For more information visit: www.nichcy.org/reauth/scoop.htm

The Key to Homeownership Program—The Michigan State Housing Development Authority's (MSHDA) Office of Existing Housing has designed a new program called the HCV "Key to Own" Homeownership Program. This program will offer a homeownership option for families that hold a MSHDA Housing Choice Voucher (HCV). Qualified tenants will be able to use their voucher subsidy toward a mortgage on a home rather than towards rent. The purpose of this program is to provide the HCV participant with pre-purchase counseling and training through MSHDA's LINKS counseling network and other local partners to accomplish the goal of successful homeownership.

What are the Eligibility Requirements? To qualify for the HCV Homeownership program the participant(s) must be:

- A current participant in MSHDA's HCV tenant-based rental assistance program for a minimum of one year; and
- A first-time homeowner or you have not owned a home in the last three years; and
- Enrolled and actively participating in the Family Self-Sufficiency Program (except elderly persons or persons with a disability); and
- Employed full-time continuously for the last year (except elderly persons or persons with a disability); and
- Within the household income eligibility guidelines of the program.

To receive a pre-application or receive additional information, contact Sandy Pearson (517)335-7291, pearsonsa@michigan.gov; or Lisa Lehman (517)241-4474, lehmanl1@michigan.gov

Web Resources

Waisman Center News for Families, University of Wisconsin-Madison. www.waisman.wisc.edu/rpc.

Waisman Center conducts several research participation studies, and are looking for subjects. Some that may be of interest to you are

Language Learning Disabilities: Cognitive Problem Solving. Your child may be eligible to participate if he or she has difficulty remembering things you tell him or her; following directions or explaining things, and

understanding school assignments. Participants need to be between ages 7-9 and have either language learning disabilities or typically developing language. See www.childlang@waisman.wisc.edu, or Beth Simon at (608)265-2642

Structure and Function of the Brain

A study using MRI-magnetic resonance imaging. Looking for participants between ages 10-12 years and not have any known brain disorders. Participants will be paid. The study will be used as a comparative template for imaging studies of children with developmental disorders. Contact David Levy at (608)262-8772 or davidlevy@wisc.edu

Free Online Advocacy Course for Parents For more information about the course send an email to advocacy@exchange.tc.columbia.edu and tell them you heard about the course from Wrightslaw and the Special Ed Advocate newsletter. The course includes surveys, readings, self-study questions, and a short-answer assignment. You also receive an extensive resource list and course certificate that you can print.

**Opening a World of
Opportunity For Children**

PCDS
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Royal Oak, MI
48068-0522

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Fax: 248-683-1698
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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:

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Would you like to give a gift to someone else; grandparents, aunts, uncles—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:

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