

A Little Something Extra

Volume 3, Issue 4

April 2005

www.pcdsmi.org

Parents of Children with Down Syndrome

Opening a World of Opportunity For Children with Down Syndrome

PCDS Fundraiser

We will be holding a fundraiser at the Cross of Christ church on Friday April 29, from 7:00-9:00 pm!!!!. A Quixtar representative has offered to come and display some of the high quality items that they have available. Fashion jewelry and other health, beauty and home products will be available with part of the proceeds going to PCDS. Some of the items available are: Personal Accents Jewelry; Designer Jewelry; colored beads and stones, vintage looks; sterling silver; cubic zirconium; Austrian crystals. Also Time Defiance Renewal Lotion; Nighttime Renewal Cream; Daytime Cream. Low-carb EX Energy Drinks and Protein Bars. Many items are available for immediate purchase and credit cards are accepted. There will be fabulous refreshments and we would like everyone to feel free to invite teachers, friends and family members. This would be a great time to stop in and say hello and to do some Mothers' Day shopping in a relaxed atmosphere.

PCDS News

- We are pleased to announce that PCDS will be sponsoring our own Buddy Walk this year. The date for the Buddy Walk is Sunday 9/25. In past years we have joined the FEDS Buddy Walk but determined that our membership can now support having our own Buddy Walk.
- We plan to hold a series of informal coffees to get together. Several of our members have volunteered to host coffees at their homes and we also have one scheduled at the Panera restaurant on Big Beaver, West side of Rochester road on Tuesday, April 26 at 9:30 A.M. Details on the other coffees will follow. Be sure to check our website regularly.
- Thank you to our members who are up-to-date with membership dues! If there is a star on the outside of your newsletter, you have paid your dues. If you don't have a star on the outside of your newsletter, we are still in need of your dues. The following families are up to date with their membership dues: Arwine; Buckley; Carlesimo; Ciagne; Ciszewski; Comfort; Dewar; Dolan; Duggins; Gallagher; Holmes; Jordon; Kelly; Leonard; McKee; Moore; Moon; Nagrant; Nehas; O'Connor; O'Leary; O'Donovan; Popejoy; Reyes; Rex; Richards; Sliney; Smythe; Standal; Stewart; Whell; Wilke; Bresso; Grigg; Hilborn; Jordan; Gibson; Steinberg; Ellwood; Mitchener; Holmes; Wiedelman; Briller.
- PCDS will be sponsoring a summer music program featuring The Merry Musicmaker, Paula Doak, at the Wing Lake Developmental Center in Bloomfield Hills. Watch for dates and details.

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 Update

Tuesday, March 22 was our first PCDS Mom's Night Out. We dined at Papa Vino's restaurant and there were seven of us that had a great time and we were very pleased with our turnout for our first time doing this! Our goal is to continue this on a monthly basis so that our PCDS moms can get to know one another and have a good time. Our next Mom's Night outings are scheduled for Tuesday April 26 at 7:00 P.M. at the Eastside Mario's restaurant at Crooks and I-75, and in May at Joe's Crab Shack at Orchard Lake and Maple Rd in West Bloomfield. Please RSVP to Sue Grigg by Saturday, April 23 for this month's outing so that we can make the reservation accordingly. Our plan is to pick a different restaurant in a different location each month so that it is accessible and convenient for all who would like to participate.

PCDS Playgroup News

Attention all Play Group Participants

The next Play group date is **May 7, 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, May 7, 9:30 AM

Saturday, June 4, 9:30 AM

Calendar/Important Dates

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

April 22-24, 2005, Dr. Leichtman Clinic in Grand Rapids. For an appointment and information call (757)425-1969. Visit www.lleichtman.org for further information

April 26, 2005, 9:30 A.M.—come have coffee with us at the Panera restaurant on Big Beaver road, West of Rochester road in Troy

April 26, 2005, 7:00 PM, PCDS Mom's Night Out at Eastside Mario's restaurant at Crooks and I-75. RSVP to Sue Grigg

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. Please contact Paulette about arranging group transportation for PCDS members who plan to attend the NDSS conference.

July 12-14, 2005, Oakland Schools presents Assistive Technology Core Training Services. (248)209-2262 for more information

July 29-31, 2005, NDSC National Convention, Hyatt Regency Orange County, Anaheim, CA. See NDSC website at NDSCCenter.org for further information. Register for this workshop at (248)209-2500

August 2-3, 2005, Pre-Symbolic Communication and Tangible Symbol Systems: Communication Strategies for Children with Severe and Multiple Disabilities. More info is available at www.designtolearn.com. Register for this workshop at (248)209-2500

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

September 25, 2005, PCDS Buddy Walk at the Bloomfield Hills farm

November 3-5, 2005, Dr. Vincent Carbone workshop. Holiday Inn Fairlane Dearborn, Michigan. To register call 1-888-337-3866

December 11, 2005—Annual PCDS Holiday Party

PCDS Board Meeting

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.

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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.

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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.

In Memoriam

We would like to take this opportunity to remember Stephen Crane who passed away unexpectedly April 7, 2004 at the age of three. Stephen is survived by his parents Jean and Bruce Crane and his sister, Christina. We want the Crane family to know that they are in our thoughts and prayers and we will not forget Stephen.

IDEA 2004: A new law

There were many changes made to the Individuals with Disabilities Education Improvement Act (IDEA 2004). The changes include Funding; IEPs; Dispute Resolution; Early Intervention; Discipline; and changes to eligibility due to learning disabilities. For additional information please visit www.ndss.org and click on the link for Summary of IDEA 2004.

Bike Camp

Remember that PCDS is sponsoring the Bike Camp for 8-15 year-olds with DS the week of June 27, 2005. If you have signed up for this you should have received a form to be completed and returned to U of M and you should have received an additional packet with an informed consent form to be returned to U of M. Please do not delay responding to the Dept. of Kinesiology at U of M if you would like for your child to participate in the bike camp. The bike campers listed below are scheduled participants: Anthony K.; Braden A.; Peter J.; Jake B.; Michelle G.; Jaymie B.; Andrew K.; Tony L.; Philip C.; and Katie K.

Aricept® trial

Widely reported results of a preliminary clinical trial at Duke University Medical Center are that Aricept, a drug already approved for treating patients with Alzheimer's disease, might also boost the expressive language skills of children with DS. Results of this small study of seven children with DS between the ages of eight and 13 would need to be confirmed in a larger trial before researchers would recommend prescribing the drug to children with DS. For details, visit www.dukemednews.duke.edu for a copy of the Sept. 29, 2004 news release.

New products

PCDS is not paid to endorse any products or brands, however, we do like to let our membership know about products that might make your life easier and healthier. Two new products that we want to tell you about are Nordic Naturals® Omega oil supplements and Squigle® Enamel Saver Toothpaste...

Nordic Naturals has omega oils available in a fruit-flavored liquid and chewable capsules for children. We have all heard and read about the benefits of having a diet rich in Omega-3 fatty acids, now families who do not consume fish regularly, or are concerned about the possible contaminants in fish products can now benefit from the Omega-3 fatty acids. Nordic Naturals are available at health food stores and Whole Foods Market,. For samples call 1-800-662-2544 or visit their website at nordicnaturals.com.

Squigle Enamel Saver toothpaste is a product that does not contain the harsh detergents and strong flavoring found in most other mass-marketed toothpaste brands. Upon reading about Squigle we learned that the sometimes burning sensation and strong flavors associated with the use of other toothpastes is what many of our children object to. Additionally, if they don't rinse too well afterward it is not a problem with Squigle because of its gentler ingredients. Squigle toothpaste is available from several online retailers found by doing a Google search for "Squigle Toothpaste" on your internet browser.

Tips and Tidbits

This month's tips and tidbits comes from Anita Beaman...

Anita said that she felt some reassurance after attaching a heart-shaped dog tag to her son's shoelace with their last name and cell phone number engraved on it. Anita said that some pet stores have the service where you pick out the tag and complete the engraving yourself and suggested that older children might be willing to wear an engraved ID bracelet, etc. We all know that if our children wandered off or became separated from us while on an outing that they would not necessarily be able to communicate their address and phone number to someone who is able to help. Thanks Anita!

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

The Sports page.....

The Miracle League: Children can play baseball on a special "Miracle Field" in Southfield, MI., that can accommodate wheelchairs and other walking assistance devices while helping to prevent injuries. Miracle League team members are assigned "buddies" who assist them in hitting the ball and "running" the bases. The Miracle Fields cost \$535,000 to build and The Miracle League has been featured in several local and national newspapers across America, televised on NBC and FOX affiliates as well as a segment of HBO's "Real Sports" and PAX TV's "It's a Miracle" and has appeared in People and Family Circle magazines. For additional information contact the Miracle League of Michigan at (248)506-4604 or www.MichiganMiracle.org

TOPSoccer: TOPSoccer is an amazing SOCCER program for any child under the age of 19 who has mental or physical disability. This program is geared toward development and not necessarily competition. Players will be placed on a team by ability, not by age. TOPSoccer will be adapted in ways that will ensure that your child learns at his/her own pace and has a good time doing it. It will also help improve the overall fitness and self-esteem of your child and, at the same time, give them a sense of belonging to a team.

TOPSoccer Guidelines:

- *PLAYERS: Boys and girls ages 4-19 who have a mental or physical disability.
- * PARENTS: Each player must be accompanied by an adult who must remain for the entire practice session or game. Input is welcome regarding your child's needs.
- * BUDDIES: A TOPSoccer goal is to have "Player Pals" with your child during practices and games. Volunteers will come from the Lakes Area Youth Soccer League.
- *Coaches: Coaches will oversee the soccer practices and games. They will assist the players and player pals in small sided games as well as help teach the game of soccer, teamwork and fun.
- * FORMS: Each player will be required to fill out an application and a Medical Health Form that will be verified by the player's physician.
- * FEE: There will be a small fee for registration that will include insurance, uniforms, and equipment.

TOPSoccer is sponsored by Lakes Area Youth Soccer League. To register, please call Franci Silver at 248-505-9007 or Jeff Raben at 248-539-4866: or on your computer by typing in Lakes Area Youth Soccer League and going down to TOPSoccer.

My Chance to Dance: Weekly My Chance to Dance fitness classes for children and adults with special needs are running in several cities on Oakland and Macomb counties. Get details at www.ccplusdance.com or call 586-412-8454

Free Stuff and Other Perks, By Celia Taylor

When you walk out the front door in the morning, you just never know what can happen. Life with a disability, like any life, can bring about the most pleasant and serendipitous occurrences. One thing is for sure; it's never boring.

Proving Ann Frank's belief that people are good at heart, the humanity that we see in the faces and in the actions of people around us is truly heartening. Strangers especially knock me out with the sometimes silent and always generous gestures they give from somewhere deep in their hearts. I call them "free stuff and other perks:", what happens when someone's disability brings out the best in others.

In *Babyface: A Story of Heart and Bones*, Jeanne McDermott writes about the day her son, Nate, received an unexpected give at Fenway Park. Nate has Apert syndrome, a rare genetic condition that causes craniofacial abnormalities and webbed fingers and toes. Nate, his parents and brother sat together until Nate changed his seat to get a better view of Mo Vaughn. He sat between two middle-aged men intent on getting a bat boy to throw them a ball. When he did, they acted like a couple of 12-year olds, dancing in place and making lots of noise. Each of the men caressed the ball and held it up like a jewel. Then they turned to Nate and gently gave it to him. His mother couldn't tell who was happier—the men or the boy.

These kinds of occurrences are not at all uncommon. Over the years, it's happened countless times to my son and me. At the store, the amusement park, in the mall, at concerts, almost anywhere lots of people gather. These perks aren't always tangible things like a cool major league baseball. But each one is as precious and as appreciated as the next.

As I see it, there are three levels to free stuff and other perks. The first level is the benevolent smile. When it happens, it lasts only seconds, but its impact is felt for a long time afterwards. It starts as a glance. Whatever the person was thinking about is momentarily forgotten as he/she looks over at my son and me. The head tilts

slightly, the face softens and a smile spreads across the face. Our eyes meet as we pass each other in an aisle, on a sidewalk, at the park. A smile is a perk we never tire of.

The second level is a gradual shifting from the smile to actual words. In the grocery store recently, a woman says hello to my son, who has Down Syndrome. She asks him, "How are you? Are you helping your mom shop today?" She wants to know how old he is, where he goes to school. Her questions aren't intrusive, just a way of connecting. When she leaves, I wonder about what the impetus was for her, what, in that moment, led her to take that leap in making the connection with my son and me. It must be someone whose own life is intertwined with disability in some capacity I think. Either that or she was an angel.

The final level is free stuff. We are always getting things and experiences without trying. In Florida last week, we got front row seats to shows at Disney, and extra Easy Passes to the rides with the longest lines at Islands of Adventure. The best was, when at Sea World, a woman working near the Dolphin Cove approached us, asking if Cliff would like to feed the dolphins. We all watched from a prime spot around the cove as Cliff threw small fish into the dolphin's mouth and petted his smooth, wet head. While everyone else stood in line in the hot sun to buy fish snacks, there was Cliff, having his very own (free) dolphin encounter!

Free stuff and perks are some of the bonuses in a life with challenges. Just when I'm at my most pessimistic, my most misanthropic, when I've lost faith in people, someone tosses a major league baseball our way. Perks have a way of restoring faith, reminding me that kindness abounds, and the world has a heart after all.

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Happy Birthday to everyone with a birthday in April! Ryder Ciszewski



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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
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48068-0522

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Fax: 248-683-1698
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For Children With Down Syndrome**



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