

# A Little Something Extra

June 2005

www.pcdsmi.org

Volume 3, Issue 6

## Parents of Children with Down Syndrome

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

#### Mark Your Calendars for PCDS Summer/Fall Events

- Golf Outing! Monday August 15, 2005, We are extremely lucky to have the sponsorship and support of Joe and Adele Bologna again this year. They worked extremely hard last year to introduce PCDS and our children to the Oakland County golf community and by doing so made this our biggest fundraiser ever. More important than the money they helped raised they brought an awareness to the community as to how special are children are by inviting them to participate in all aspects of the outing. This Included golf (their nephew Paulie played) as could any of your children, and many other children participated in the raffle & dinner. Along with all the work they do for us it is a known fact to locals and returning customers that theirs is one of the best restaurants in all of Metro Detroit. Not sure... come to one of our golf meetings and stay to enjoy their wonderful cuisine. I guarantee you'll be back. We will post all golf meetings on our website at [www.PCDSMI.org](http://www.PCDSMI.org). Please volunteer to show your support. You will have fun! Contact Anita Beaman at [abeaman02@yahoo.com](mailto:abeaman02@yahoo.com) or (248)393-2736 for additional info.
- We are planning a big end of summer bash for PCDS members and their families on Sunday, August 28, at Walnut Lake in Bloomfield Hills. We are able to reserve a spot on the lake exclusively for our group where we can swim, picnic, play volleyball and other fun family and kid-friendly activities. Like our annual holiday party, this will be an event not to be missed!
- PCDS and Fox Hills are co-sponsoring the Merry Musicmaker, Paula Doak, at Wing Lake Center (corner of Wing Lake and Maple roads—approx 1/2 mile West of Telegraph), on the following dates: June 23, July 21, July 28, and August 4, from 10:00-11:00 AM. Our children and families always enjoy her performances. Siblings are welcome and we will enjoy a picnic at Paulette's afterward.
- **NOTE CHANGE**—Our first Buddy Walk will be held on Saturday, September 19 at the Bower's School Farm in Bloomfield Hills. We are looking forward to the support and participation of our PCDS members and the community to make this a successful event. The Buddy Walk was started to help promote awareness and acceptance of Down Syndrome and we are proud to be a part of it. More details will follow and please note that the date has changed from what we published in our last newsletter.

#### Helping the Out-Of-Sync Child at Home and School

Friday, June 10, 2005

Presented by Carol Stock Kranowitz  
Internationally acclaimed author of  
The Out of Sync Child

This fun, participatory course will explore Sensory Processing Disorder and provide practical techniques for addressing sensory issues at home and school.

Teachers, parents, therapists, early childhood specialists, para-professionals who work with children are welcome to attend this workshop with the following objectives:

- Educate participants in the sensory-motor development of young children.
- Describe how sensory-motor development impacts behavior and learning.
- Learn to recognize and cope with sensory processing disorder.
- Provide developmentally-appropriate activities for children with sensory processing disorder.

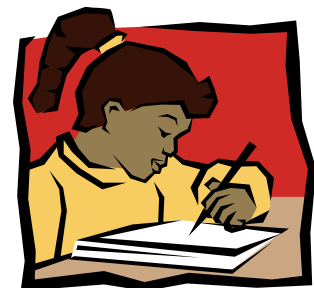
For additional information call the Abilities Center at 248-926-0909, or visit [www.pcdsmi.org](http://www.pcdsmi.org) and click on the link for additional info and to print a registration form.

#### 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.

#### MANY THANKS!

Warmest thanks to the Knights of Columbus for donating \$833 to PCDS from their Tootsie Roll Drive fund. We deeply appreciate the generosity of K of C making this donation to our group. We have all seen K of C members and volunteers with their yellow vests on, sometimes in the rain and the cold, dodging cars, collecting from those who generously donate, and now we understand why they do it and we are forever grateful.



## PCDS Playgroup News

### Attention all Play Group Participants

The next Play group date is **June 4, 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 [aliiike@comcast.net](mailto:aliiike@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.

I hope to see the usual faces and some new faces. Jon and Josh will love the company. Everyone is welcome! Annette Liike—Playgroup Chairperson PCDS

### More Play Group Dates

**Saturday, June 4, 9:30 AM**



## Calendar/Important Dates

**June 10, 2005, 8:30-4:00 P.M.** Helping the Out of Sync Child at Home and at School. Judson Center in Royal Oak. Call the Abilities Center at 248-926-0909, or visit [www.pcdsmi.org](http://www.pcdsmi.org) and click on the link for additional info and to print a registration form.

**June 21, 2005, 7:00 P.M.** PCDS Mom's Night Out, Johnny Carino's Italian at 500 Loop Road (btwn 14 Mile and Maple) in Commerce Twp

**June 23, July 21, July 28, and August 4, 2005** (multiple dates) **10:00—11:00 A.M.** Merry Musicmaker, Paula Doak, at Wing Lake Center (corner of Wing Lake and Maple roads—approx 1/2 mile West of Telegraph),

**June 27—July 1, 2005**, Bike Camp (details provided to registered participants)

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

**August 28, 2005**, PCDS Summer Picnic at Walnut Lake.

**September 19, 2005, PCDS Buddy Walk**. Bower's School Farm in Bloomfield Hills.

**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** Details TBA

### PCDS Board Meeting

**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).

#### Membership Update

If there is a red STAR on the outside of your newsletter it means that your PCDS dues payment is up to date. We make every effort to keep our membership informed and get current information out to you. Please advise our newsletter editor, Sue Grigg, If you do not wish to remain on our mailing list to receive our newsletter.

## **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**

#### **Need Volunteer**

#### **Newsletter**

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

#### **Playgroup**

Annette Liike  
alike@comcast.net

#### **Advertising**

Tricia Dewar  
tdewar2@comcast.net

#### **Holiday Party**

Annette Liike  
aliike@comcast.net

#### **Corresponding Secretary**

Sue Grigg  
suegrigg@comcast.net

#### **Directory**

Laurie & Mike Whell  
whell@email.com

#### **Webserver**

Anita Beaman  
abeaman02@yahoo.com

#### **New Parent/Hospital Liaison**

Caryn Gallagher  
cciange@yahoo.com/248-865-9850

## **Newsletter Deadline**

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

### New Postsecondary Scholarship Opportunity!

NDSS is excited to announce a new postsecondary scholarship program, The Joshua O'Neill and Zeshan Tabani Enrichment Fund. This fund was established by Zeshan Tabani to honor his friend, Joshua O'Neill. Joshua was fortunate to participate in a postsecondary education experience and he benefited greatly from this opportunity. Financial aid for postsecondary education is rarely available to individuals with Down syndrome, and while many young adults want to continue to enrich their lives through further education after high school, they frequently do not have the financial means to do so. The Joshua O'Neill and Zeshan Tabani Enrichment Fund will offer financial assistance to young adults with Down syndrome who wish to continue to enrich their lives by taking postsecondary enrichment courses to obtain employment and other important life skills.

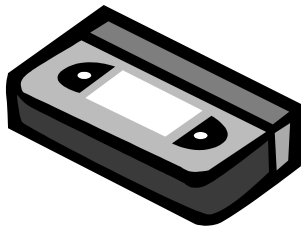
The fund will award five (5) grants of up to \$1,000 to individuals with Down syndrome who wish to take a postsecondary enrichment course at their local community college or other educational institution. We encourage all individuals who meet the eligibility criteria to apply for this grant. The applicants must meet the following eligibility criteria: the individual has Down syndrome; is 18 years old or older; demonstrates a desire to continue their education; and should intend to enroll in a postsecondary class that will enrich their life, through employment, independent living skills, life skills or another way. Applications will be available on Tuesday, March 15, 2005. Completed application packages must be returned to NDSS by June 10, 2005. The grants will be awarded no later than July 1, 2005. If there are any questions, please feel free to contact Erin Geller at [egeller@ndss.org](mailto:egeller@ndss.org). Please visit the website at [www.NDSS.org](http://www.NDSS.org) to download the Scholarship Application.

### Buddy Walk Times Square Video Contest

Celebrate the Buddy Walk's 10th anniversary by entering the Times Square Video Contest. The video, which showcases the contributions that individuals with Down syndrome make to their communities, will air on the Panasonic Astrovision screen in Times Square on September 25 at 10:30 a.m. The New York City Buddy Walk will follow the video.

NDSS will be accepting photos of individuals with Down syndrome of all ages from May 1 through July 15. Please limit photos to no more than three per family.

To enter, please visit the "Times Square Video" section of [www.BuddyWalk.org](http://www.BuddyWalk.org) to upload photos and submit a consent form through the Web site. You also have the option of downloading a consent form and mailing it in with your photos to NDSS Call For Photos, 666 Broadway, New York, NY 10012. The deadline for submitting photos is July 15, 2005. They will notify you ONLY if we accept your photograph for the video, and they are unable to return any photos.



### Open Study of Rivastigmine in Children with Down Syndrome Who Are Between the Ages of 10 and 18



Dr. Priya Kishnani of Duke University Medical Center's Department of Medical Genetics is investigating the effects of rivastigmine on individuals with Down syndrome who are between the ages 10 and 18. This medication is FDA-approved for the treatment of Alzheimer's disease but is not

approved for use in children or in people with Down syndrome. Dr. Kishnani is examining whether or not this medication is safe and if it can improve memory, mood, speech, language and activities of daily living in children with Down syndrome.

This study requires the participant and his or her primary caregiver to complete four outpatient visits to Duke University Medical Center in Durham, NC. Psychological, speech and language and medical assessments will take place during the visits. The assessments, medication and medical care related to the study are provided free of charge, and a travel stipend is available for families requiring an overnight stay. For more information about this project, please contact the study coordinator, Blythe Crissman, by telephone at (919) 684-2036 or by e-mail at [criss004@mc.duke.edu](mailto:criss004@mc.duke.edu).

### NATIONAL POLICY CENTER UPDATES

On April 8, 2005, NDSS issued an informational bulletin about a new policy for students with disabilities under NCLB. Announced on April 7 by the Secretary of Education, the new guidelines permit the creation of a new category of students whose advanced and proficient scores on non-grade level assessments could count towards Adequate Yearly Progress (AYP).

Currently, only students with the most significant cognitive disabilities can have their proficient and advanced scores from alternate assessments counted towards their schools' AYP, and the number of these scores that can be used toward AYP is capped at 1%. The new policy calls for the creation of a category called "students with persistent academic difficulties" and raises the cap to 2%. NDSS is concerned that with the creation of the new category, many students with disabilities will fall victim to low expectations and, as a result, never attain grade-level achievement.

You can read the full Information Alert, which explains changes in detail, at <http://capwiz.com/ndss/issues/alert/?alertid=7619491>. To read NDSS's position on the new guidelines, visit <http://www.ndss.org/content.cfm?fuseaction=NwsEvt.PressPSArticle&article=1217>.

**Tips and Tidbits**

This month's tips and tidbits comes from Kathy Gibson of Southgate who has a 20-year-old daughter with Down Syndrome. Kathy attributes her daughter's excellent speech and diction to the fact that she was breastfed until she was ten months old. There are many benefits of breastfeeding and increasing the muscle tone of the oral muscles may be particularly beneficial to our children with Down Syndrome. Breastfeeding is difficult for any new baby, especially our children with Down Syndrome, but Kathy would encourage mothers of infants with Down Syndrome to stick with it as long as possible and to seek help and support from the La Leche League or your local hospital. Another option is using special bottle nipples for bottle-fed babies that are more like natural nipples and require infants to work harder at their feedings and may provide similar benefits to breastfeeding. To submit your own Tips and Tidbits for future newsletters, please call or email Sue Grigg at (248)288-6468 /suegrigg@comcast.net . We need your tips and tidbits for future newsletters.

**Dust off those golf clubs!!!**

We would be thrilled to have participation in this year's golf outing from as many as possible of our members, friends and family. The outing is not until August 15 so you've got eleven weeks to brush up on your game and we know you'll enjoy the practice! Contact Anita Beaman at [abeaman02@yahoo.com](mailto:abeaman02@yahoo.com) or (248)393-2736 for additional info



PCDS would like to thank the following members for renewing their membership for 2005:

Arwine	O'Leary	Ellwood
Buckley	O'Donovan	Mitchener
Carlesimo	Popejoy	Holmes
Ciagne	Reyes	Wiedelman
Ciszewski	Rex	Briller
Comfort	Richards	Ayers
Dewar	Sliney	Bernacki
Dolan	Smythe	Deland
Duggins	Standal	Williams
Gallagher	Stewart	Brinker
Holmes	Whell	Gier
Jordon	Wilke	Liike
Kelly	Bresso	Wasenko
Leonard	Grigg	Couture
McKee	Hilborn	Holmes
Moore	Jordan	MacLean
Nagrant	Gibson	Tessmar
Nehas	Ibrashi-Cosovic	Wheelock
O'Connor	Steinberg	

**Help! Canopy Tents needed for Buddy Walk**

Please contact Suzanne O'Leary if you have a canopy tent that you can loan us for the Buddy Walk on Saturday September 19. Suzanne can be reached at 248-988-8464 or [suzanneoleary@comcast.net](mailto:suzanneoleary@comcast.net). We need several of the canopies for things such as refreshments, etc., and would appreciate the loan.

**The Michigan Yellow Pages for Kids with Disabilities**

Is an online resource for families. The publisher, Wrightslaw, lists educational consultants, psychologists, diagnosticians, health care specialists, speech language therapists, and more. The address is: [www.yellowpagesforkids.com/help/mi.htm](http://www.yellowpagesforkids.com/help/mi.htm).

**A two-day Sibshop Training** is set for Sept. 9-10 in Detroit. It is part of Children's Hospital of Michigan's 8th annual *Issues and Challenges* conference. Featured speaker is Don Meyer, director of the Sibling Support Project of the Arc of the United States. "Tuition assistance" is available to families. Babysitting is available for a limited number of pre-registered children. For details, phone (313)745-5458 or email to [sboyd2@dmc.org](mailto:sboyd2@dmc.org)

**The Youthhood** ([www.youthhood.org](http://www.youthhood.org)) is an interactive, dynamic new site that young adults with special needs and their parents can use to plan for life after high school. "Youthhood offers a unique and extensive blend of content, interactive activities, links to related Web sites, and planning tools," states the host, the *National Center on Secondary Education and Transition*. "The site provides a progressive learning experience...the more activities that are tried and planning that is done, the more youth will learn and be able to apply the information to their own lives."

Youthhood is organized like a neighborhood. Among seven locations, **The Health Clinic** addresses managing care and preventing problems. It also covers disabilities and chronic illness, insurance, relationships, and sexuality.

**Oakland County Early On Summer Resource Directory**
  
 Visit the on-line guide at [http://www.oakland.k12.mi.us/resources/earlychildhood/pdf/Summer\\_Resource\\_Directory\\_2005.pdf](http://www.oakland.k12.mi.us/resources/earlychildhood/pdf/Summer_Resource_Directory_2005.pdf) for a comprehensive listing of area programs this summer. The directory includes everything you need to know from available recreation programs to respite care and how to get help with fees and funding.

## Pediatric Summer Safety Questions & Answers Source: keepkidshealthy.com

**Important Disclaimer:** This information is for educational purposes only and should not be considered to be medical advice. It is not meant to replace the advice of the physician who cares for your child. All medical advice and information should be considered to be incomplete without a physical exam, which is not possible without a visit to your doctor.

**Q. Are swimming lessons for younger children beneficial?**

A. The American Academy of Pediatrics recommends against formal swimming lessons for children under age 4. Lessons or aquatic programs for infants and toddlers can be fun, but don't decrease your child's risk of drowning. Young children should not be left unsupervised around water, even if they know how to swim.

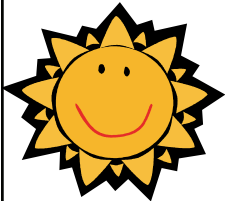


**Q. When should you reapply sunscreen on your children?**

A. You should usually reapply sunscreen every 2 hours and after your child has been swimming or playing hard.

**Q. Could my child burn if he is outside all day when it is cloudy, he is sitting in shade, or he is wearing a hat, long pants, and a long sleeve shirt?**

A. UV rays can reflect off things into the shade and reach you through clouds, so you may still burn if you aren't wearing sunscreen. Also, clothing usually only has a SPF of 5-9, so you can still get a sun burn.



**Q. What is the best way for my child to avoid a sunburn?**

A. To avoid sunburn, you should use a sunscreen with a SPF of 15 or above, even if it is cloudy, and avoid peak times of the day when the sun is most intense (usually 10 am to 4 pm).

**Q. What SPF should I put on my child if he burns easily and is going to be outside for a few hours?**

A. The SPF determines how long you can stay in the sun without burning, so if your child typically burns after he is in the sun 12 minutes, you would need a sunscreen with SPF 15 (15x12 minutes +180 Minutes or 3 hours).

**Q. Are there alternatives to insect repellents with DEET?**

A. Insect repellents that don't have DEET include those with citronella (Avon's Skin-So-Soft), soybean oil (Bite Blocker) and other plant based materials (OFF botanicals).

**Q. What percentage of DEET in insect repellent provides the best protection?**

A. The concentration of DEET that an insect repellent has does not relate to its strength (or safety), but instead to how long it will last. So a repellent with 10% DEET might last 2 hours, while 24% DEET can last 5 hours. You should select the lowest concentration of DEET that will last for the amount of time that your kids will be outside.

**Q. At what age can you start using an insect repellent with DEET?**

A. According to the American Academy of Pediatrics DEET containing insect repellents can be used once an infant is 2 months old.

**Q. Insect repellents list different percentages of DEET. How do I know which will provide the best insect repellent?**

A. The benefits of DEET reach a peak at a concentration of 30%, so concentrations above this aren't stronger.



**Q. How can my children avoid food poisoning at a picnic or barbeque?**

A. To avoid food poisoning, your children should wash their hands frequently, avoid foods left out for more than 2 hours and avoid undercooked foods.

**Q. What should I do if my child touches a hot barbeque and I think he has a first degree burn?**

A. For a first degree burn, you should usually run cool water over the burned area or place a cold compress on the area. Call your pediatrician unless the burn is very minor.

**Q. What should I do if I am outside gardening and accidentally spray my child with an insect killer?**

A. Many types of insect killers and other products used in the garden can be poisonous, even if your child hasn't swallowed it. In this case you should wash off the chemicals, remove contaminated clothing and call Poison Control (1-800-222-1222) for further help.

**Q. What infections are more common in the summer?**

A. Lyme disease and other tick-borne and mosquito-borne illnesses (like West Nile) are more common in the summer than other times of year..



**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

**Together We Can  
Be Strong**



**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 \_\_\_\_/\_\_\_\_/\_\_\_\_

Please include our information in PCDS membership directory Yes \_\_\_ No \_\_\_

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**