

A Little Something Extra

May 2005

www.pcdsmi.org

Volume 3, Issue 5

Parents of Children with Down Syndrome

Opening a World of Opportunity For Children with Down Syndrome

Mark Your Calendars for PCDS Summer/Fall Events

- 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 will sponsor 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. Our children and families always enjoy her performances.
- On Sunday, September 25, we are holding our first Buddy Walk. 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. The location for the Buddy Walk will be announced soon

PCDS Mom's Night Out is a Hit!

April 26 was our second Mom's Night Out and nine of us enjoyed dining at Eastside Mario's restaurant in Troy. Our next Mom's Night outings are scheduled for Tuesday May 24 at Joe's Crab Shack at Orchard Lake and Maple Rd in West Bloomfield. Please RSVP to Sue Grigg at (248)288-6468, by Saturday, May 21 for this month's outing so that we can make the reservation accordingly. We are planning our June outing for Tuesday June 21 at Johnny Carino's Italian at 500 Loop Road (between 14 Mile and Maple) in Commerce Township.

Canine Companions for Independence

We want to let you know about Canine Companions for Independence. CCI is a program that provides dogs to adults and children with disabilities. These are not leader dogs for the blind. They are service dogs, skilled companion dogs, hearing dogs and facility dogs. Each type of dog has different duties, the companion dogs job is to assist children with disabilities and severely disabled adults under the supervision of a facilitator which can be a parent, spouse, or caregiver. Skilled companion dogs are equally valued for their loving companionship, which boosts confidence and alleviates feelings of isolation. The puppies are raised by volunteers for the first 13 to 18 months of life, then they are moved into a six-month training program to master 40 specialized commands. The dogs are then matched with their human partners and go through another two-week training period, then they graduate and live with their human partner. If you are interested in learning more about this program, or becoming a puppy raiser, contact the CCI Regional Center nearest you at 1-800-572-BARK (2275) info@cci.org, website www.cci.org

Thank You!

We would like to thank Dr. Nadia Ibrashi and Angela Comins, the Quixtar representative who came and facilitated our fundraiser at the Cross of Christ church on Friday April 29. It was a wonderful opportunity to come and visit with friends, eat the refreshments and do a little shopping. We thank you for your friendship and your support of PCDS.

Writing Submissions Wanted

Put on your writer's hat! We are interested in your essays, short stories, or other articles of interest related to having a family member with Down Syndrome to include in our newsletter. Please contact Paulette or Sue with any contributions you would like to make to the newsletter.

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.



Happy
Mother's
Day!

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 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, May 7, 9:30 AM

Saturday, June 4, 9:30 AM



Calendar/Important Dates

May 24, 2005, PCDS Mom's Night Out, Joe's Crab Shack at Orchard Lake and Maple Rd in West Bloomfield

June 21, 2005, PCDS Mom's Night Out, Johnny Carino's Italian at 500 Loop Road (between 14 Mile and Maple) in Commerce Township.

June 23, July 21, July 28, and August 4, 2005 (multiple dates) 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

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.

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

September 25, 2005, PCDS Buddy Walk Details TBA

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, 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.

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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.



Mothers Have Spoken: Physicians Need to Do a Better Job in Delivering a Postnatal Diagnosis of Down Syndrome

From Down Syndrome
News

I remember everything about how my husband and I learned that our first-born child, Maren, had Down Syndrome. It had been two hours since her birth and I had only briefly held her—Tim didn't do so at all—and then the hospital staff whisked her away to check her out. Tim had just agreed to go to the nurse's station to ask for the baby to be brought to my room when a man we had never seen before came to the door. He introduced himself as a staff pediatrician and said he was sorry he had something to tell us about our baby. We got the news that our daughter—an intimate stranger—probably had Down Syndrome and likely a serious heart condition. We learned this before we got to see what color her eyes were.

In retrospect, our story could have been far worse. We did get a packet of up-to-date information (provided by our local parent association). The next morning, the doctor did connect us with a family of a two-year-old boy with Down Syndrome. However, the hospital staff seemed to actively avoid us (mind you, I was a patient!) and my husband still resents the fact that everyone in the delivery room knew what had happened—except us.

Brian Skotko is a joint-degree student at Harvard Medical School and the John F. Kennedy School of Government. He has a 23-year-old sister with Down Syndrome and, along with NDSC Board member Cynthia Kidder, has co-authored the book, *Common Threads: Celebrating Life with Down Syndrome*. Brian, a leader of the NDSC's annual Brother/Sister Conference, recently surveyed nearly 3,000 mothers on how they learned that their new baby had Down Syndrome and what support was provided with this diagnosis.

This research study asked mothers to reflect on a central question: How could medical support have been better when you received the diagnosis of Down Syndrome for your child? The results have been published in the January 2005 issue of *Pediatrics*, the journal of the American Academy of Pediatrics. A copy of the published study is available on the NDSC Web Site, www.ndsccenter.org. Included below is a summary of the recommendations.

Skotko reports that through more than 1,200 collective responses, mothers have called upon physicians to adopt 10 recommendations when delivering a postnatal diagnosis of Down Syndrome:

1 The person to deliver the news should be a physician.

Mothers in this study received the diagnosis from a variety of health care providers: pediatricians, neonatologists, obstetricians, genetic counselors, nurses, and in two cases, the lactation specialist and the candy-striper volunteer. Mothers felt that a physician was the person most knowledgeable to present the diagnosis.

2 Obstetricians need to coordinate their messages with neonatologists and pediatricians.

In many hospitals, mothers suggested that there was confusion and, at times, disagreement over which physician was responsible for delivering the news. Physicians from various specialties need to work collaboratively.

3 The news should be delivered once the mother is settled and as soon as a physician suspects the diagnosis.

Some mothers were upset that they received the news immediately, particularly while episiotomies were still being sutured. Most mothers, however, were worried during what was described as a silence period, where no health care professional would give them an honest answer about what was going on. A physician should not wait until a diagnosis is confirmed through karyotyping; mothers prefer to be aware of the physicians' thought process, no matter how difficult the news might be.

4 Whenever possible, the physician should make the announcement with both parents present, in a private setting.

As the diagnosis of Down Syndrome is just as novel to the father as it is to the mothers, physicians should not expect that fathers should be the ones to share the news with the mothers.

5 When delivering the news about Down Syndrome, the physician should first congratulate the parents on the birth of their child.

Mothers have recommended that physicians include the positive aspects of Down Syndrome in their first descriptions of the condition. Many mothers mentioned that the best words used by their physician during this initial explanation were, "Love your child like any other child."

6 Health care professionals should keep their personal opinions to themselves.

Mothers have asked physicians to offer sound medical advice based on up-to-date information, but not personal opinion.

7 Mothers should be provided with up-to-date printed materials.

Most new parents were frustrated at either receiving outdated information or no information at all. Mothers requested receiving complimentary copies of books on Down Syndrome that included positive imagery; or, in the cases where hospitals were financially unable to do so, a bibliography listing the most current resources for new parents.

8 Parents should be provided access to other families who have children with Down Syndrome.

First call programs—that is, support programs in which a parent of a child with Down Syndrome visits or phones one of the new mothers—were mentioned as invaluable sources of help to the new parents. Hospitals and parent support groups should work collaboratively to provide this requested outreach to new parents.

9 After the initial diagnosis or suspicion is shared with parents, they should be offered a private hospital room.

As mothers respond to the diagnosis with a variety of emotions, many requested that they have a private space to express those emotions. **Physicians should be cognizant of the realities and possibilities of growing up with Down Syndrome.**

Simply put, Down Syndrome is not just what was taught in medical school. Mothers considered it the responsibility of doctors to stay informed about the educational and social potentials of children with Down Syndrome.

The time for change is long overdue. These recommendations offered by mothers are by no means revolutionary and could be easily implemented by all physicians responsible for delivering diagnoses of Down Syndrome. You can continue to effect change by sharing the full study with the hospitals in your surrounding area.

Other Resources



Don't forget that there are numerous resources and organizations to help parents and families who have kids with Down Syndrome or other special needs. One that we like is Bridges 4 Kids. You can visit their website at www.bridges4kids.org. Where there are links to many helpful topics that include how to contact legislators, how to handle parenting stress, education, legal, and other issues too numerous to list here.

Protecting Children from Dangerous People

Two new resources can teach your children how to avoid people who want to harm them.

Kidsmartz. One resource is KidSmartz, a 30-minute program that shows parents and caregivers exactly what to say to their children to help prevent child abduction. The DVD was produced by actor Bryan Cranston, who plays the hapless father of five sons in the hit TV show *Malcolm in the Middle*. It is currently available at Amazon.com, Sam's Club online, and at www.bryancranston.com.

KidSmartz includes tips on how kids can recognize potential danger and how they can avoid it before it happens. The program presents the material in a way that does not disturb or scare the viewers.

"The media has given tremendous exposure to child abductions in recent years," Cranston explained one day at the AARP office in Washington, DC. "I knew that my young daughter, like kids everywhere, would see these TV reports and have questions about them. I realized that I needed to find out exactly what I should say."

Cranston and his partners researched the topic at the National Center for Missing & Exploited Children, and at the FBI's Crimes Against Children unit. They spoke with educators, social workers, law enforcement experts, parents and grandparents.

"We learned some amazing information," Cranston recalls, "like why we should never tell a child 'don't talk to strangers.' Young kids equate the word 'stranger' with strange looking, acting, or smelling. So if an abductor approaches a child dressed just like the child's parent—or driving a similar car—the child won't think it's strange to go with that person."

A Good Knight Story. A second set of resources on child safety comes from the Good Knight Child Empowerment Network Inc. The network was established in 1985 by a group of retired law enforcement and military officers. An award-winning, bilingual activity book, *A Good Knight Story*, inspires children to become Knights Champions and protectors of those they care about, including themselves. A DVD *ABC's of Safety*—teaches children how to recognize and avoid the approaches used by criminals. Order your free copy of the book and DVD at www.goodknight.org or call 301-595-8989.

Book and Video Reviews

Eating Gluten-Free with Emily: A Story for Children with Celiac Disease

by Bonnie J. Kruszka
(Woodbine House, 6510 Bells Mills Rd., Bethesda, MD 20817,
www.woodbinehouse.com 1-800-843-7323), 2004, (32 pp), hard-cover, \$14.95. This book is written



for three-to-seven-year-olds and uses simple language and colorful illustrations to explain a complex condition, celiac disease. The main character, Emily, is five-years-old and likes to laugh and has a dog named Max. She also has celiac disease and then tells about how she felt before she was diagnosed, how she was diagnosed and what she needs to do to stay healthy (avoid gluten). Emily talks about how she feels when she goes to a friend's house or has an event at school where she can't eat the same things that everyone else does. In the end, Emily says that celiac disease is only part of who she is and that eating gluten-free makes her special. A nice way to help kids understand celiac disease and another way that people can be different.

A Teacher's Guide to My Friend Isabelle: Classroom Activities that Foster Acceptance of Differences

by Amy Thrasher, M.A., CCC-SLP. This is a companion guide to *My Friend Isabelle* by Eliza Woloson (Woodbine House). Download a free copy of the guide from the Woodbine House website, www.woodbinehouse.com. It goes through each page of *Isabelle* and offers classroom activities and lessons that help reinforce the message of accepting differences and promote interactions between children.

Signing Time!®: There are now six videos (\$16.99 each or DVDs for \$21.99 each) that teach children basic ASL (American Sign Language) signs in an entertaining and captivating format. The signs are clearly demonstrated by an adult and then a montage of shots of children using the signs help reinforce the idea. It's a fun way to learn a new language, whether your child is verbal or not. The engaging songs are also on two music CDs (\$13.99 each) and give kids more chances to practice their signing to music. Check out a clip of the video on their website at www.signingtime.com.

Editor Note: Most of the books that we include in the newsletter are always available from Woodbine House, or at Amazon.com.

Tips and Tidbits

This month's tips and tidbits comes from newsletter editor Sue Grigg; Since some of our kids do not learn to handle buttons and zippers on clothing until much later, a friend who has a niece with Down Syndrome recently shared with me that her niece's mom removes the buttons and zippers and sews in Velcro. 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.

Teaming Up On Bullies, By Dan Coulter (From DSA Press)



When I was little, playing with some neighborhood kids, I let them roll me up in a rug. Or I rolled myself up, I can't remember. I do remember the felling of being totally helpless. Someone sat on me and didn't let me unroll for an eternity of probably a minute or so. I struggled, realizing that no matter what I did, I couldn't free myself. I was absolutely at the

other kids' mercy until they let me go.

That's something like the sense of desperation I now realize my college-age son, Drew (who has Asperger Syndrome), felt when he was bullied in high school. He talked about it at the dinner table last night. I didn't understand until that moment how deeply it affected him.

My wife and I knew he had to deal with bullies in high school. We worked with him, teaching him to ignore taunts so he didn't get into fights. We urged him to tell us about any problems. We made sure key people at Drew's school knew his situation and that Drew knew who to go to when he was being tormented.

And he listened. When kids who knew that Drew didn't like rapper Eminem's lyrics and that Drew was sensitive to noise sat behind him on the bus with a boom box and blasted an Eminem CD into Drew's hears—he kept himself in check.

He got off the bus and went to the coach who was the school disciplinarian, as we'd told him to. The coach found out who was on the bus and read them the riot act.

We appreciated this. It helped. But I'm realizing now that we only got the tip of the iceberg. Drew got good grades and overcame multiple Asperger Syndrome challenges to make a number of friends his senior year. But he didn't tell us the full extent of the daily attempts other kids made to tear him down. As Drew describes it now, I have a better understanding that lots of the taunting was routine and subtle and omnipresent. And Drew felt it was inescapable and often unreportable. While the coach dealt with the highly visible bus incident, Drew says that when he did report being harassed, often teachers didn't do anything.

There's no shortage of approaches to dealing with bullying, teasing and insults. Most of us have "ignore them" in our advice kit. I know of a father who felt his son's karate classes could help him deal with bullies. I hope it's helpful, but my experience is that a kid with special needs who gets into a physical confrontation is frequently assumed to be in the wrong. And only a fraction of bullying is physical.

Even if your kid is big and strong or knows martial arts. How does he deal with the continual, subtle, non-physical stuff that the teachers never see? Having conditions such as AS puts some kids at a natural disadvantage and makes them a magnet for the worst in some other kids.

So what do you do? The best advice I've heard about came from a panel of people with Asperger Syndrome in a seminar on bullying. They said, "What are you talking with us for? Talk to the bullies! They're the ones causing the problem!"

I think you can take this to the bank. No matter what you do to prepare your child to deal with a range of bullying behavior, you've also got to hit the problem at its source.

Fortunately, there's a growing wave of information, programs and resources that can help you and your child's school address the source of the problem. Schools can help prevent bullying by making all their students and staff aware of what it looks like, that it's serious—and that it won't be tolerated. More and more schools are starting formal awareness training on bullying. The state of North Carolina, where I live, has initiated a "Bullies Don't Belong" campaign supported by the state's attorney general.

If you have a child in school being harassed, banding together with other parents to support bullying awareness training for students and staff is one of the best investments you can make in your child's education. And if you're frustrated at trying to access limited school resources to support a relatively small number of students with special needs, this time you're pushing for something that benefits kids throughout the school. I've seen estimates that one-third of school kids have been bullied.

It's terrible that the new bullying awareness programs were sparked by a series of school shootings, but maybe these programs can help prevent future violence—and make daily life at school dramatically better for many, many kids who would never consider violence.

These programs can help those teachers and school officials who need to better understand the problem. An administrator at one of my son's schools told us that kids learning to deal with bullies on their own was just a part of growing up. But what good does it do to tell our kids not to get into fights over taunting and cruelty and to tell a teacher instead, if the teachers don't take action? This just makes kids feel helpless and trains them to suffer in silence.

Your PTA is a good place to get the ball rolling. In fact, the national PTA organization has information about dealing with bullying on its website at: www.PTA.org, and click on the Parent Involvement link, then click on the Help Your Child Succeed link, and click on Know What a Bully Looks Like under Resources to bring up a series of articles on bullying. This information includes signs to watch for that your child is being bullied (or that your child is a bully.)

I don't believe in looking back and beating yourself up for what you might have done, but I do think we need to learn from the past. I had to wait until my son was in college (where his experience is light-years better than high school) to learn just how tough high school really was for him socially. Luckily, you can tap into resources that weren't available to me just a few years ago.

Here's hoping you find them and use them. Nothing is going to totally eliminate bullying. But if you prepare your child AND support awareness programs to reduce the problem, you're taking out a huge insurance policy in his happiness. You don't want your child felling helpless, like he's rolled in a rug. You want him felling free to learn in a safe, positive atmosphere.

About the author: Dan Coulter is the writer/producer of the video: "ASPERGER SYNDROME DAD: Becoming An Even Better Father To Your Child With AS." You can find additional articles on his website at: www.coultervideo.com.

**Opening a World of
Opportunity For Children**

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PCDS Opening A World Of Opportunity
For Children With Down Syndrome



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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:
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Would you like to give a gift to some-
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A PCDS gift membership would make
the perfect gift...

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