

A Little Something Extra



Volume 2, Issue 5

May/June 2004
Parents of Children with Down Syndrome

Opening a World of Opportunity For Children with Down Syndrome

Important—Please see information regarding the June Board meeting on Page 3

Mark your calendar for Tuesday, June 8

Please join us at the next general membership meeting on Tuesday June 8 when Jean Mellis, a speech therapist, from William Beaumont's speech services will present information about common speech delays in children with Down Syndrome. The meeting will be from 7:00—9:00 pm at Cross of Christ Lutheran Church, 1100 Lone Pine Road Rm. # 7.

In Loving Memory of Stephen Michael Crane August 10, 2000 - April 7, 2004



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.

*When I was There
When I was there with you and lived my life as your son I knew you loved me with all your heart; I felt it from day one.*

I never once regretted having chosen you for my Mom and Dad, and although our time together was short, please don't stay sad. You see, when I was with you I learned so very much, and I took with me to my other life all my memories of your love...

I share it with the other kids I've met since I've arrived, we all have memories of those special times and please never doubt that we're alive...

We are busy helping others and we watch over you with pride as we see you helping others and giving of your time.

I see sometimes when you think of me you are sad that I am gone, but remember that I am still with you, you just can't see me tag along.

I go with you on your travels, and yes that's me in your dreams at night; I still look the same, just maybe a little more handsome in this light...

Here there is no sadness, Mom and Dad, only joy and love and peace, and here is where I'll wait, until you can come and live with me...

In my world now there is no rush, things just happen day by day, so take your time and enjoy life, have a little fun, it really is okay. And when you make your journey to this place where we are all one, remember, I'll be waiting and I'll always be your son...

-Sharon Hauber, Compassionate Friends -

In Loving Memory of Stephen Michael Crane:

*Michael & Marianne Crane
Eugenia Mellis
Nadia Isbrashi
John/Michelle Romig IV
Tonie/Jeffrey Potts
James/Julianne Lilik
Cheryl B Dworman
Patrick/Julie O'Donovan
Stephen/Janet Cheaney
Kleiman, Carney & Greenbaum, P.C.
Briane/Lori Spillane
Ann I Ainslie
Eleanor/Barbara Lakin
Richard/Barbara Lakin
Marilyn S Massaro*

PCDS Playgroup News

Our next playgroup is scheduled for :

Wednesday June 16, 10:00-Noon

Thursday July 8 10:00-Noon

Friday August 13 10:00-Noon at:

Beverly Park (Beverly Road between Southfield and Evergreen), Beverly Hills.

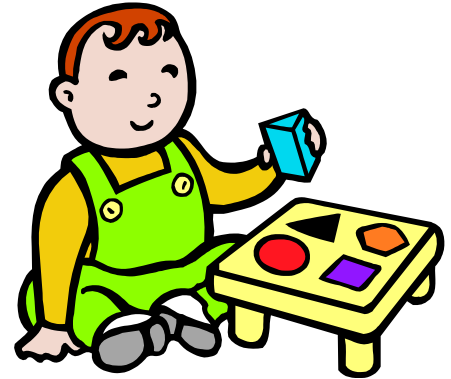
Note: if it rains then the playgroups scheduled for the park will be moved to the nursery at The Cross of Christ Lutheran Church 1100 Lone Pine Road (NW Corner of Telegraph and Lone Pine).

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



Save the dates

July 22-25, 2004

NDSS National Conference

JW Marriott Hotel in Washington, D.C.

August 20-22, 2004

NDSC National Convention

Hyatt Regency Minneapolis on Nicollet Mall

June 17, June 24, July 15 & July

22, 2004 (All dates scheduled are Thursdays) at 10:00 A.M.

Please join us for a special music program at Wing Lake School with The Merry Musicmaker. There is no cost to you and you do not need to call ahead—please just come and have fun!

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

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.

Donations/ Memorials/Grants

We wish to send out a warm thank you to the following:

Kathleen Newman for donating a library cart to store all of our PCDS books/publications which we keep at the Cross of Christ church. Kathleen is a friend of Laurie Whell and graciously donated the cart upon hearing of our need for one.

The employees of West Bloomfield Township who held a casual day on April 2, 2004, to make a donation for our organization

Patricia G Helson for her generous donation of \$50.00

PCDS received a \$500 grant from Wright and Fillipis as part of their 60th year celebration

BOARD MEETING

The June board meeting will be held on Tuesday June 15th at 11:30 am at Paulette's. Children are welcome and please bring your own swimsuits and towels for the pool, and a potluck dish to pass. Please RSVP to Paulette at 248-646-0819 or Dugginsp@comcast.net. Board meetings are open to **ALL** PCDS members. Your presence is welcome and appreciated.

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

May/June Birthdays

Happy Birthday to everyone with a birthday in May and June!

**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.

Beautiful Faces 2004

The 2004 Beautiful Faces Calendar from the Band of Angels Press is available at all PCDS meetings, conferences, etc. or

contact
Kathy Davis at
bdavis210706@comcast.net
The cost is **\$14.00**

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:

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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kdsmith@viafamily.com

Dads of Kids with Down Syndrome

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Aurelio Stella

David Buckley

Recommended Reading and Library Additions

A copy of **Down Syndrome: The First 18 Months** (video) Woodbine House has recently been added to the PCDS library—Thirteen leading medical and developmental experts on Down Syndrome, experienced parents, and infants and toddlers with Down Syndrome are brought together in this heartwarming production to inform, inspire, guide, and support. A must-have for families with a young child with Down Syndrome and the professionals who support them.

Recommended (PCDS does not currently have)—**Oral-Motor Exercises For Speech Clarity & The HOMEWORK Book** by Sara Rosenfeld Johnson, Innovative Therapists International, www.talktoolstm.com. Sara's step-by-step task analysis approach insures success for clients of all ages and ability levels who evidence muscle-based speech clarity disorders. The HOMEWORK books takes each of Sara's exercises and puts them into easy-to-follow homework sheets.

Please remember that PCDS member-families are welcome to borrow the publications and videos, etc., that are part of the PCDS library.



Get Kids Into Special Olympics

Special Olympics recently released SO Get Into It. A free service learning curriculum developed to introduce Special Olympics and explain intellectual disability to youth and encourage them to become involved in the movement.

The overall goal of SO Get Into It is to increase the participation of children and youth with and without intellectual disabilities in Special Olympics by establishing school-based Special Olympics programs and activities.

SO Get Into It is made up of four lesson plans compatible with curriculum standards in areas of language arts, social studies, history, health and physical education and other areas. The curriculum, tailored for grade levels K-2, 3-5, 6-8 and 9-12, highlights Special Olympics athletes and their compelling stories of overcoming odds and living their dreams. It is designed to achieve several closely related student learning goals:

- **To understand**, accept, and celebrate individual differences
- **To learn** about becoming involved in Special Olympics
- **To become involved** in a service-learning project or activity related to Special Olympics

For more information, visit: www.specialolympics.org/getintoit or call 1-800-700-8585.

Individualized Education Plan (IEP) Information—Transition Specialist

A transition specialist should be part of your teenage child's IEP team. The transition process in local communities varies but the transition process for all students with disabilities should encompass employment, post-secondary schooling or additional training, and community integration. IDEA requires that all students with disabilities (age 14-1/2 and older) have needed transition services outlined in their IEP and this plan must be reviewed annually. Career and vocational training should be a part of a student's high school career.

The ORS (Office of Rehabilitation Services) transition specialist can assist school personnel in providing and developing such experiences. The transition specialist activities include:

- Linkages to adult service agencies
- Diagnostic services
- Guidance and counseling
- Direct job placement
- Supported employment
- Advocacy
- Job coaching
- Job shadow services

- Job seeking skills
- Referrals to vocational training program

The ORS transition specialist also assists in educating parents about the transition process and the adjustment to adult services. Additionally, they work with students to help them become accustomed to and understand how the service system works, including what is expected of them once they graduate from high school.

(from NADS News, March 2004. Reprinted from NCSSED Transition Times, Vol. 2, Issue December 2003)

*OUR SHEPHERD LUTHERAN SCHOOL
PROUDLY PRESENTS*

*MOMS TO MOMS
RESALE
AND
KIDS' GARAGE SALE*

*SATURDAY, JUNE 12TH
9:00 AM – 1:00 PM*

*Our Shepherd Lutheran Church
2225 East 14 Mile Road
Between Coolidge and Woodward*

Over 40 tables in gym to include large item area!!

*Concessions with bake sale
Face painting*

*Kids Garage Sale
Reserve your own spaces... bring a blanket and sell.*

*\$1 Admission for adults only
Strollers welcome!*

*All proceeds to benefit
Our Shepherd Lutheran School Site Improvement*

*Table or Blanket Reservations – Call (248)649-2053
Email – chriscgottschling@mom2momlist.com*

News you can use



Help Wanted

We are looking for someone to be the librarian for PCDS. PCDS has many publications and books which many families may find useful on this journey in raising a child with Down Syndrome. If you are interested in helping out please contact Paulette at 248-646-0819 or email at Dugginsp@comcast.net