

A Little Something Extra

Opening a World of
Opportunity For
Children with Down
Syndrome

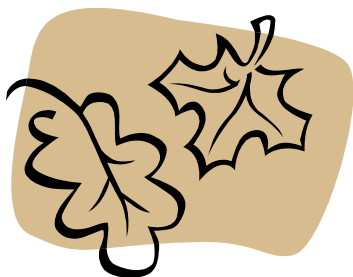
Volume 2, Issue 8

October 2004

www.pcdsmi.org
Parents of Children with Down Syndrome

How do you like your PCDS?

We are considering a slight change to the format of our group and how we provide education and support to our members. We have been having monthly general membership meetings in which we try to schedule a speaker to present topics of interest to our membership. At times there is only a small turnout at these gatherings and we sometimes have to compensate the professionals we have scheduled to speak and it is our goal to have more attendance at these meetings. We know it is difficult for families to attend weeknight meetings and we are wondering if it would make it easier to attend if we scheduled two semi-annual conference-type events which we would hold locally on a weekend day and have several scheduled speakers or workshops, and provide entertainment and space for children, and some fun things as well. We want to ensure that we continue to make information and support accessible to all of our members. **Please email either Paulette Duggins at dugginsp@comcast.net, or Sue Grigg at suegrigg@comcast.net to let us know if such a change would make it easier for you to attend and participate and please let us know of any ideas you have as well.** We will continue to have regular board meetings and of course the fun events like our annual holiday party and **we have a PCDS-sponsored pizza party scheduled for Saturday, October 23, 5:00 P.M. at Caesarland In Clawson!**



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.

Down Syndrome specialist to hold clinic in Bingham Farms.....

Dr. Lawrence Leichtman will be holding consultations on October 23 & 24. If those two dates become filled, he may also hold appointments on the 22nd. Consultations will be held at the Southfield Pain Clinic at 30400 Telegraph Road, Suite 351, between 12 and 13 Mile in Bingham Farms. If you are interested, please call 757-425-1969. Dr. Leichtman is a board certified pediatrician, clinical geneticist and President of the board of directors of Trisomy-21 Research Foundation, Inc. He has treated over 2,000 individuals with Down Syndrome and has helped to design a nutritional supplement specifically formulated for the metabolic needs of people with Down Syndrome. In November of last year Dr. Leichtman spoke to the PCDS membership and was very well received. To learn more, visit www.lleichtman.org

Respiratory Syncytial Virus (RSV)

The Respiratory Syncytial Virus is a major cause of respiratory illness in all ages. In adults, it tends to cause mild cold symptoms; In school-aged children, it can cause a cold and bronchial cough; in infants and toddlers it can cause bronchiolitis (inflammation of the smaller airways of the lungs) or pneumonia. It has also been found to be a frequent cause of middle ear infections (otitis media) in pre-school children. Reinfection throughout life is common. There is concern also that RSV infection in the first year of life may increase the risk of the baby developing asthma later in childhood.

RSV epidemics are common in late fall to early spring, and the spread among households, day care and schools is rampant. The time from exposure to infection is 4 to 6 days; after an infection the person may be contagious for a week. RSV is especially dangerous in infants less than one year old, children with asthma or other lung disorders, or heart disease.

-- continued on page 6--

PCDS Playgroup News

Our next playgroups are scheduled for :

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 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.

Wednesday October 20, 2004, 6:30 P.M.-8:30 P.M., Inclusion: "The Art of Possibility", Farmington Training Center, 33000 Thomas, Farmington, MI presented by Everyone Together Oakland County. For additional info email etoakland@yahoo.com, or call (248)888-4111

Saturday October 23, 2004, 5:00 P.M.—PCDS-sponsored Pizza Party at Caesarland, 1241 W. 14 Mile Road, Clawson (248)435-3770.

Saturday October 23, 2004, the Down Syndrome Association of Western Michigan Semi-Annual Conference 8:30 A.M.-1:00 P.M. Kent Intermediate School District

Note NADS conference at the Congress Plaza Hotel in Chicago, IL on 10/23/04 has been canceled.

Saturday November 6, 2004 8:30 A.M.-3:00 P.M. 5th Annual Michigan Fathers Conference, at Birmingham Covington School, 1525 Covington Rd.(corner of Quarton and Covington), Bloomfield Hills.

www.dadsempowered.org for additional info,

Note: we think this would be a very worthwhile conference for all dads

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:

December 5 Holiday Party (details to follow)

January 11

February 8

March 8

April 12

May 19

PCDS Board Meeting

Tuesday, October 26 9:00 A.M.-11:00 A.M. at Paulette's house 3805 Quarton Road in Bloomfield Hills. 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.

Newsletter Circulation

Please feel free to share your copy of the PCDS newsletter with your child's Special Education teacher, and/or notify us if your child's teacher would like to receive their own copy. There is always information in the newsletter that teachers may find helpful, as well as the possibility for us to reach out to other families who may not know about our group.

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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Reading Resources

The following reading selections have been added to the PCDS library:

Teaching Math to People with Down Syndrome and Other Hands-On Learners, Book 1: Basic Survival Skills, DeAnna Horstmeier, Ph.D

Kids with Celiac Disease, A Family Guide to Raising Happy, Healthy, Gluten-Free Children, Danna Korn

Incredible Edible Gluten-Free Food for Kids, 150 Family-Tested Recipes, Sheri L. Sanderson

I Can, Can You?, Written and Photographed by Marjorie W. Pitzer, M.Ed.

My Friend Isabelle, Elizabeth Woloson, Illustrated by Bryan Gough

My Friend Isabelle TEACHER'S GUIDE, Amy Thrasher

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

Parents of Children has these and other books and publications that PCDS members are welcome to borrow.

These and other books are available from Woodbine House, 1-800-843-7323. Woodbine House is offering a 20% discount on purchases through the end of October. Books are also available at Amazon.com at a savings off the list price.

Therapy and Enrichment

Music Therapy Encourages Development—By Kay Luedtke-Smith, MT-BC, Minneapolis MN, reprinted from Down Syndrome News, newsletter of the National Down Syndrome Congress

What is music therapy?

Music therapy uses music as a powerful tool to create positive behavior changes. A music therapist's main goal when working with a child with special needs is to assist the child in reaching his or her greatest potential. Music therapy can enhance development in areas such as social/emotional, cognitive/academic and fine/gross motor skills. Music interventions are chosen specifically to meet individual goals such as improving hand/eye coordination or increasing verbal skills.

Although therapy participants can learn music skills, therapy goals do not focus on developing musical skills. Music therapists focus on the process of making music in contrast to a music educator whose main interest is on the final product. Focusing on the process means that there is no right or wrong response. This positive atmosphere allows children's self-esteem to grow along with their skills.

Music therapy can be provided in one-to-one, small or large group settings. Group sessions provide children with

the opportunity to participate in sing-alongs, partner dances, passing games and structured settings for them to share creative ideas.

Is music therapy new?

No, during World War I, music therapy was used to assist war veterans with their rehabilitation goals. The American Music Therapy Association (AMTA) was founded in 1950 and now has nearly 3,400 registered members from across the country. The AMTA accreditation board assists the public in identifying qualified, professional therapists.

The organization that I work for, Fraser, was founded in the 1930s when Louise Whitbeck Fraser began using music to teach children with special needs. Seventy years later, music therapy is an integral part of our work with thousands of families each year.

Where do music therapists work?

Music therapists work in a wide variety of clinical and educational settings including: public and private schools, hospitals, rehabilitation clinics, psychiatric facilities, nursing homes, community mental health centers, prisons and hospice programs.

Continued on Page 5

Participation in Studies

The Center for Motor Behavior at the University of Michigan is studying the effects of an early kicking intervention and early reaching intervention on the motor development of infants with Down Syndrome. If you have a very young or infant child and are interested in participating in these studies please contact Meghann Lloyd at (734)936-2607 or email at meghann@umich.edu.

The Center for Motor Behavior at the U of M is looking for participants for a study investigating the effects of foot orthoses on the gait of new walkers with Down Syndrome. Participants should be able to take 8-10 independent steps and should have three months or less of independent walking experience. The study will assist in determining the usefulness of using foot orthoses in young children with Down Syndrome. Interested families can contact Julia Looper at (734)936-2607 or email jlooper@umich.edu.

October Birthdays

Happy Birthday
to everyone
with a birthday
in October !

Therapy and enrichment—continued

Music Therapy—Continued from Page 4

How can music therapy help a child who has Down Syndrome?

Music therapy can be powerful in the life of a child who has Down Syndrome. The music therapist evaluates the child to assess his or her strengths and areas of concern. Music therapy goals often overlap and reinforce skill areas which are being addressed during the child's other therapies. When possible, the music therapist collaborates with other professionals who are working with the child. For example, music therapy activities could complement occupational therapy sessions for a child working on increasing hand strength. The music therapist would use a variety of instruments, beginning with tapping a drum or tambourine with the palm of the hand, then grasping the handle of a maraca or set of rhythm sticks. The weight of the instrument used would increase as the child's strength improved. Eventually, pushing piano keys or strumming guitar strings could strengthen individual fingers.

Through research we know that speech and language development originate in the left hemisphere of the brain and musical stimuli is generally processed in the right hemisphere (Love & Webb, 1992). This helps to explain why many children with speech and language difficulties respond to language more quickly when displayed through music. For these children, vocalization could be increased through a variety of activities. Therapy could begin with singing syllables to familiar tunes. The therapist would sing the words leaving out the last word of the phrase and the child would attempt to fill in the missing words. For example: "Twinkle, twinkle, little ____." First attempts may be by gesture, a nod of the head, a clap of the hands, but soon a vocalization will replace the gesture.

One reason this approach is so successful is because the expectations are clear. The lyrics in the song remain the same so the child understands exactly what is expected.

In physical therapy, a child works on improving muscle tone, coordination, and balance. Movement activities would be incorporated into music therapy to encourage the child to bend, stretch, jump, march, balance, tip toe, etc. To enhance the movement, props such as scarves, pom poms, and parachutes might be used.

The use of music and rhythm can energize and organize a child's environment and encourage the child to participate. Music may also be used to relax a child when an environment becomes over stimulating.

Bret

As a toddler, Bret attended Fraser school and participated in group music therapy sessions with his class once a week. Following his second birthday, Bret's parents enrolled him in individual music therapy sessions so he could work on goals tailored for his development. Initially, Bret's music therapy goals focused on increasing his vocalizations. He enjoyed songs about animals and quickly attempted to imitate animal sounds while singing "Old McDonald" and "Down on Grandpa's Farm." To help Bret learn how to control his tongue, singing games were done in front of the mirror. This allowed him to see the frequency his tongue was protruding from his mouth and how closely he was mimicking the therapist's actions.

A year later, as Bret's attention span increased, his weekly 15-minute therapy session was increased to 30 minutes. His therapy was expanded to include songs with actions, allowing him to learn how to identify body parts, how to follow directions and additional imitation skills.

The following year, Bret's goals centered on strength. A variety of hand-held rhythm instruments were introduced to increase his hand strength. Bret was also developing his hand-eye coordination as he manipulated these instruments to make music. His gross motor skills also began emerging at this time, so dance activities incorporating marching, jumping and balance became part of his weekly sessions.

As Bret's language continued to blossom, focus turned toward fostering expressive language. Singing short phrases and increasing his articulation became key points addressed during therapy. Songs with repetitive lyrics provided lots of practice opportunities. In addition, slide whistles and harmonicas were played to enhance breath support. Academic concepts such as shapes, colors and the ABCs also were highlighted to encourage development.

Today, as Bret prepares to enter kindergarten, his music therapy consists of learning tools to broaden his social skills and encourage additional spontaneous speech. He also will be given the opportunity to invite a peer to join him in his music therapy sessions. Bret always greets the therapist with a warm smile and "Let's play!" The only resistance is when it's time to sing "Goodbye."

Visit www.musictherapy.org to learn more about music therapy and finding a therapist.

Additionally, you can find more information on Art and Music Therapy by visiting the National Down Syndrome Society website at www.NDSS.org and clicking on the "Information & Resources" tab at the top of the page, then click on the bar for "Education & Schooling" then click on the list on the left side of the page for "Down Syndrome and the Arts"

News and resources you can use

Respiratory Syncytial Virus (RSV) (continued from Page 1)

It is a major cause of hospitalizations of children in the winter months. The symptoms of bronchiolitis include a hacky cough and a wheeze on exhalation (a high pitched noise from the chest). There is typically fever and a cloudy nasal drainage. The infant is irritable and oral intake decreases. Danger signs include a respiratory rate over 40 breaths per minute, a bluish discoloration of the skin around the mouth, retractions of the skin between the ribs (this indicates the infant is working so hard to breathe that he is using the muscles between the ribs to help), and/or decreased fluid intake to the point of dehydration. RSV is diagnosed by checking for signs of the virus (antigens) in nasal washings, or growing the virus from nasal swabbings.

The home treatment of RSV has typically been to relieve the symptoms: cough and cold medicines (variable in their efficacy) and bronchodilators such as metaproterenol or albuterol to help relieve chest congestion and wheezing. Humidity may also help. When hospitalized, oxygen is given by mask, nasal tubing or tent. In the late 1980's, a medication called ribavirin was developed to be given by aerosol to hospitalized children. It has been shown to greatly improve oxygenation in arterial blood; effects on killing of the virus are mixed at best. Due to its high cost and selective efficacy, it is only given to those hospitalized infants who are at greatest risk from the virus.

In 1996, the FDA approved a preventative treatment for RSV called RespiGam® (RSV-IGIV). RespiGam® is made from plasma taken from large numbers of normal, healthy individuals, and contains a high concentration of protective antibodies against RSV. These antibodies do not prevent RSV infections, but do help protect children against the most serious conse-

quences of the virus. In a large, multi-center study, the use of RespiGam® decreased the need for hospitalization by 38% from the non-treated group. At the present time, it is indicated for children under two years of age who are considered to be at "high risk" for RSV infections: Being born premature (5 or more weeks before the due date), or having a chronic lung condition such as bronchopulmonary dysplasia. Children with cyanotic heart defects should not get RespiGam® due to side effects involving the circulation.

RespiGam® is only available presently as monthly intravenous infusions, each requiring 6 hours to perform. Treatment with RespiGam® begins in the Fall before the first outbreaks of RSV normally occur. The treatment regimen involves an intravenous dose once a month through March or April (regional differences in the RSV season may occur). The monthly doses are required as the antibodies only fight off the RSV for about 4 weeks.

In 1998, the FDA approved an intramuscular version of RSV monoclonal antibodies called palivizumab (Synagis®). The indications for its use are the same as with RespiGam®: under 2 years of age and prematurity and/or chronic lung disease. (Having a heart defect is not an indication for the use of Synagis®). This prophylactic treatment consists of monthly injections in the thigh during the course of RSV season; since this is not as invasive as intravenous therapy, Synagis® is now prescribed much more often than RespiGam®. Palivizumab does not interfere with normal immunizations.

The American Academy of Pediatrics has made the following recommendations on the use of palivizumab:

1. Palivizumab or RSV-IGIV prophylaxis should be considered for infants and children younger than 2 years of age

with chronic lung disease who have required medical therapy for their lung disease within 6 months before the anticipated RSV season. Palivizumab is preferred for most high-risk children because of its ease of administration, safety, and effectiveness. Patients with more severe lung disease may benefit from prophylaxis for two RSV seasons, especially those who require medical therapy.

2. Infants born at 32 weeks of gestation or earlier without chronic lung disease or who do not meet the criteria in recommendation 1 also may benefit from RSV prophylaxis. Infants born at 29 to 32 weeks of gestation may benefit most from prophylaxis up to 6 months of age.
3. Given the large number of patients born between 32 to 35 weeks and the cost of the drug, the use of palivizumab in this population should be reserved for those infants with additional risk factors (day-care attendance, school-aged siblings, four or more people living in the home with the infant, exposure to passive smoke, being a member of a multiple birth).
4. Palivizumab has not been evaluated in randomized trials in immunocompromised children. Although specific recommendations for immunocompromised patients cannot be made, children with severe immunodeficiencies (e.g., severe combined immunodeficiency or severe acquired immunodeficiency syndrome) may benefit from prophylaxis.

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Also see:

www.rsvprotection.com

www.aap.org/policy/re9839

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

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Financial and Web Resources

www.GovBenefits.gov, a valuable and innovative website, is managed by the U.S. Department of Labor. This free and confidential site helps citizens determine their potential eligibility for hundreds of government-funded benefit and assistance programs. This comprehensive resource features information on more than 400 federally and 100 state administered programs. www.GovBenefits.gov

offers diverse and extensive benefit program information for people in all walks of life: veterans, seniors, teachers, children, people with disabilities, disaster victims, farmers, caregivers, job seekers, prospective homeowners and more. This site has attracted more than 11 million visitors to date, increasing citizens' access to benefit programs and information that they may have not known existed.

Is the high cost of diapers and disposable training pants draining your wallet? Some insurance plans will cover the cost of having these items delivered directly to you if your child is not toilet trained by age three. A Dr. prescription is required and you should review your individual health insurance plan to see if it would be a covered benefit for you.

**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**



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Would you like to be on our email alert list? Yes _____ No _____
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Child's Name _____ and birthdate ____/____/____

Make checks payable to:

Parents of Children with Down Syndrome or
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Royal Oak, MI 48068-0522

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the perfect gift...

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