

PCDS
A Family-
Caring and Sharing



Opening a
World of
Opportunity
For Children With
Down Syndrome

A Little Something Extra

Volume 2, Issue 3

March 2004
Parents of Children With Down Syndrome

Dr. Leichtman To Hold Clinic in Grand Rapids

It is now confirmed that Dr. Lawrence Leichtman will be holding consultations in Grand Rapids on May 21-24, 2004. Appointments are filling quickly. 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 for the metabolic needs of people with Down Syndrome. In November of last year, Dr. Leichtman spoke to the PCDS organization and was very well received. To learn more, visit www.lleichtman.org

4 TO 6 YEAR OLD PARTICIPANTS NEEDED FOR U OF M BRAIN DEVELOPMENT STUDY

The University of Michigan is looking for children ages 4 to 6 years to participate in a child development study investigating links between brain development and children's

understanding of the social world. We use a comfortable hat with external sensors to record children's brain activity while they play a fun interactive computer game.

This study will take place on the University's Central Campus; compensation will include \$25 and a toy prize for the child. For more information call 734-647-1117.

ATTENTION!! PCDS MEN

Would you be interested in joining Alhambra? Alhambra is seeking a Catholic man from PCDS to be a part of their organization. Alhambra is a fraternal order of Catholic men dedicated to assisting people with cognitive challenges. You could be a PCDS representative for Alhambra. The only qualification for the job is to be a Catholic man. For further information about Alhambra and their good works

you can email them at OrderAlhambra.org or visit their website at www.orderalhambra.org

If you are interested in becoming a member, contact Tricia Dewar at (248)554-9191 for further information.

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.

BOARD MEETING

The March board meeting will be held on March 16th at 7:30pm Cross of Christ Lutheran Church 1100Lone Pine Road. Room #7

Just a reminder that all board meetings will be held at 7:30pm on the 2nd Monday of each month in the above location unless notified otherwise. Remember, also, that board meetings are open to **ALL PCDS members. Your presence is welcome and appreciated.

HOLIDAY PARTY 2004

We need a party planner for our 2004 Holiday Party. Yes, you're right, we just had the 2003 party but in a few months it will be time to start planning for the next one. Laurie Whell, who has headed up the committee for the past two years is ready to pass the torch. She will assist in any way she can but wants to take a back seat this year to a new chairperson. If this seems like just the job that you've been looking for to help PCDS and our families, be sure to email or call Paulette.
adoptsunny@aol.com
 248-646-0819

March Birthdays



Happy Birthday to everyone with a March Birthday!

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.

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

BOARD MEMBERS

PRESIDENT

Paulette Duggins
 (248)646-0819 adoptsunny@aol.com

VICE PRESIDENT

Pat Dickson
pmkdbd126@yahoo.com

TREASURER

Melinda Hilborn
mhilborn@detroitdesign.net

SECRETARY

Sue Grigg

CHAIRPERSONS

Buddy Walk

Amy Tyrell
Aetyrrell@cs.com

Calendar Sales

Kathy Davis
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Library/Newsletter

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Playgroup

Annette Liike
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 and
 Julie O'Donovan
odonovanj@comcast.net

Advertising

Tricia Dewar
tdewar2@earthlink.net

Holiday Party

Laurie Whell
whell@email.com
 &
 Annette Liike
aliike@comcast.net

Corresponding Secretary

Directory

Laurie & Mike Whell
whell@email.com

Webserver

Holly Waddell
holly31477@comcast.net

New Parent/Hospital Liaison

Suzanne and Paul O'Leary
suzanneoleary@comcast.net

Home Fellowship

Camille Smith
kdsmith@viafamily.com

Dads of Kids with Down Syndrome

Darrell Williams

Aurelio Stella

David Buckley

At the last board meeting we had set a date to review all materials about the Changing Lives - Medical Model. (January 27th 7-9pm)

I have to be out of town and have rescheduled the meeting for February 17th at 7:00 p.m. at the church. (Cross of Christ Lutheran Church 1100 Lone Pine Road, (NW corner of Telegraph) Bloomfield Hills, Mi,

We would like to have everyone's input, so in my absence, please RSVP your attendance to Laurie Whell (whell@email.com) or 248-473-0894. Thank You for your interest in this National Project. If you have connections in the hospital community, please bring them with you.

December 1, 2003

Dear Parents and Students,

You are cordially invited to attend a series of three informational seminars entitled "CHOICES." The topics of these meetings will provide you with valuable information on future planning for the transition from school to adult life. These programs will be sponsored cooperatively between the Troy, Birmingham, and Bloomfield Hills School Districts. You are invited to attend all three meetings or any of particular interest to you. The following is a list of CHOICES programs that have been scheduled.

Tuesday, February 24, 2004

7:00 * 8:30 p.m.

Groves High School, 20500 W. 13 Mile Road, Birmingham

"CHOICES" * "Training and Employment"

Topics will include speakers and/or information from Michigan Jobs commission, Oakland Community College * Projects BOLD and PASS, Oakland Advantage and Private Options.

Tuesday, March 9, 2004

7:00 * 8:30 p.m.

Gary Doyle Center, 7275 Wing Lake Road, Bloomfield Hills

"CHOICES" * "Independent Living, Leisure, and Housing"

Topics will include speakers and/or information from Center for Independent Living, On My Own * Michigan, Community Housing Network, MORC, Easter Seals, FAR Conservatory, and SCAMP.

Sincerely,

Mary Ann Kerstein
Transition Coordinator
Lahser and Andover High School
248.341.5715

Information on IDEA and Discussion Topics for Conversations with Policy Makers

Background Information:

This information sheet was developed in response to requests for information about the status of IDEA re-authorization. In early December, the Senate adjourned from the first session of the 108th Congress without taking floor action on the reauthorization of the Individuals with Disabilities Education Act (IDEA). The Senate Health, Education, Labor and Pensions Committee passed the IDEA Reauthorization Bill (S.1248) on June 25, 2003.

Senate leaders have reached an agreement, allowing the bill to move to the floor, while considering a minimum number of amendments. **Senate Majority Leader Frist has released a tentative schedule indicating IDEA may be considered on the floor during the week of March 22, 2004.**

According to the Senate agreement, eight floor amendments will be offered. The most significant appear to be those that deal with limiting reimbursement of attorney fees when parents prevail in due process hearings; funding (2 separate amendments); and giving waivers to some states to reduce paperwork requirements. The Republicans and Democrats will each be given one other slot to offer amendments that are unspecified at this time.

January 26, 2004 (NCPC IDEA Information)

National Coalition of Parent Centers
4676 Larkwood SE
Kentwood, MI 48508
Sue Pratt, Coordinator
Phone: 616.455.5732

HELP WANTED

1. We are looking for someone to take over for the Newsletter Editor starting for the March edition. Some knowledge of Microsoft Publisher would be helpful. Coleen will be glad to give assistance to get you started. If you have any questions before you decide email me @coleenskids@pcdsmi.org.
2. We are looking for someone to fill in (temporarily, from January to June) as our recording secretary for Lauren Bernacki who plans to resume the position in July 2004. This job consists of taking the minutes at board meetings and reading and distributing them at the next meeting.

NEWSLETTER EDITOR WANTED

PCDS is seeking someone to take over for me as the newsletter editor. I'm getting ready to move to another state (Montana) and obviously can no longer do the job. It's a great job and a lot of fun. I've had the opportunity of watching PCDS growing up this past year and been blessed in getting to write about it. I've tried to tell about topics of interest to everyone who has a child or knows of someone with Down syndrome—regardless of age. If you have any knowledge of Microsoft Publisher and would like to give the job a whirl (and you'll be glad you did), contact Paulette at adoptsunny@aol.com

If you would like to fill any of these positions or need further information, please contact Paulette at 248-646-0819 or adoptsunny@aol.com

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

All articles for publication in this newsletter must be submitted by the 3rd Friday of the month to be in the following month's issue.

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

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

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.

*Put It In Writing
And Get It In Writing*

Reed Martin, J.D.

If you only learn one thing from our website, manuals and trainings, you should have learned to communicate in writing!

This is actually the Advocacy Tip of the year. If you have learned nothing else from this website or our manuals, you should have learned that you need to make sure your communications with your school and your state education agency are in writing.

*This writer is often told by school persons "you are a lawyer and you want it in writing so you can sue." Wrong. In more than 35 years experience with school districts it is the **lack of written documentation** that leads to lawsuits. Written documentation usually leads toward compliance with the law.*

If you interact with your school or state education agency, and they respond but will not "put it in writing" then you should create a document, state that this is what was said to you that day (or as soon after as you can put it in writing), send it certified mail, and also direct that it be placed in your child's permanent file. It certainly qualifies as an "educational record" under the Family Educational Rights and Privacy Act and under the IDEA.

Your creation of a written record will usually cause the school district or state education agency to reconsider their response. Your document should say "the special ed director" or "the state education agency complaint investigator" told me something over the phone today but would not put it in writing. And then state as clearly as you can what they said.

TIPS & TIDBITS

DRYMIDS PROTECTIVE UNDERWEAR

What are Drymids?

Drymids are reusable protective undergarments designed solely for children, teenagers, and young adults with special needs between the ages of 3 and 21, and that weigh approximately 30 to 165 pounds. They are discreet, quiet, fashionable, functional, extremely comfortable and most importantly, affordable! Drymids are meant to look and feel like regular underwear, yet work as well as disposable diapers

Drymids contain an absorbent core which is sewn inside a pouch called the "Pocket Sling". This innovative patented design holds the pad very close to the body and prevents leakage. Fabric is used on the sides and portions of the front and back of the garments, giving them the stretch of disposable diapers

without all the bulk and noise. Drymids are also very breathable and cool, which prevent heat rashes.

Drymids are made in the United States of America (North Carolina). Each and every garment is hand stitched by our own team of highly trained and experienced seamstresses who strive for perfection in all that they do. We offer a basic pull-on, boxer shorts, double front, and two new products: "Overnighters" and "Swim Undergarments".

Who Are Drymids?

The story of Drymids began when someone approached the company about the possibility of using our patented stretch fabric in protective underwear for children. This person was frustrated by what was being offered at the time.

We are constantly in touch with the children and their families through various trade shows, hospital visits and feedback through our website and toll-free telephone number. We firmly believe that this constant form of communication will help us all be winners.

See the Drymids website : <http://www.drymids.com> for questions, further information and testimonials of satisfied customers.

The goal of Drymids is simply to make a difference in the lives of children with special needs, so they can focus more on living and less on feeling "different" than everyone else.

Have You Been Wanting to Get Involved in a Worthwhile Project?

PCDS may have a **volunteer** job opening for you! Great benefits, such as:

The opportunity to be a valued part of a caring group,

The opportunity to enrich the lives of the children, adolescents and adults that we serve,

The satisfaction and pride of knowing that you've contributed to the health and well-being of others.

****Remember, we are only successful as an organization if each of us does our part to strengthen it and ultimately provide positive impact for our children and families. ******

Your abilities are being wasted in just

CONTACT THE NETWORKS

Several television shows will feature actors with Down syndrome over the next several weeks. If you appreciate seeing characters with disabilities in television shows and believe that casting them encourages overall inclusion, please contact the networks and tell them you support what they're doing.

The Guardian

CBS, Tuesday, February 10th

"All is Mended"

Guest star Blair Williamson as Mark Barlow

To contact CBS: www.cbs.com

Click on "Feedback" at the bottom of the home page, then select the show THE GUARDIAN.

ER

NBC, Thursday, February 26th

"Forgive and Forget"

Co-Star Christine Young as Janie

To contact NBC: www.nbc.com

Click on "Contact Us" at the bottom of the home page, then select the show ER.

Kingdom Hospital

ABC, Wednesday, March 3rd

Series regulars Brandon Bauer as Able and Jennifer Cunningham as Christa

To contact ABC: www.abc.com

Click on "Contact ABC" at the bottom of the home page, then click on the e-mail address at "ABC Primetime and Daytime Shows".

(continued from page 5)

Your creation of a written record will usually cause the school district or state education agency to reconsider their response. Your document should say "the special ed director" or "the state education agency complaint investigator" told me something over the phone today but would not put it in writing. And then state as clearly as you can what they said.

That not only creates a record that they will have to respond to, but it also creates a document that might make all the difference later. We hope you do not end up in court, but this writer has been in many situations where three years later the most important issue in the trial turns out to be the conversation between the parent and the school official. What actually did the parent ask and what actually did the school person tell them? The school person prepares to testify about their recollection (refreshed, of course, by a recent session with the school board attorney) but their testimony is then blocked by one or more of several court rules that the "best evidence" of that conversation is the parent's written memorandum, made contemporaneously at the time of that conversation three years ago. Your document becomes the sole record.

We assume you contract to purchase a number of things for which you keep the receipts, warranty, rebate card, return policy and so forth. You make the seller "put it in writing." Make sure you keep a written record of your interactions with your school over their contract to provide your child a free appropriate public education. Your child is certainly worth it.

This information is educational and not intended to be legal advice.

Reed Martin is an attorney with over 35 years experience in special education law and recognized as one of the nation's leading experts.

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.

**AUTISM SOCIETY OF AMERICA
OAKLAND COUNTY CHAPTER
PRESENTS**

**WRIGHT'S LAW
SPECIAL EDUCATION
LAW
CONFERENCE**

FEATURING

Peter W.D. Wright, esq. Nationally acclaimed special education attorney and Pamela Darr Wright, M.A.,MSW.

www.wrightslaw.com

February 28th, 2004

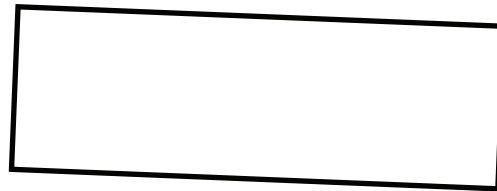
9:00 A.M. TO 4:30 P.M.

**MSU Management Education Center
Troy Michigan 48098**

Registration Information available after September 1st, 2003 at www.asaokland.org or by phoning

PCDS
Opening A World Of
Opportunity For Children
With Down Syndrome

PCDS
PO Box 522
Royal Oak, MI
48068-0522
Phone: 248-827-9135
Fax: 248-683-1698
email: www.pcdsmi.org



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 ____/____/____

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, uncles,
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**