



pacds

Parent Assistance Committee on Down Syndrome
A volunteer arm of Westchester Arc

235 Albemarle Avenue
White Plains, NY 10605

Winter 2007

UPCOMING EVENTS

January 13, 2008
Pot luck brunch at the Lewis home in Croton-on-Hudson. See Intro section for details.

January 26, 2008
Special Needs Camp Fair in NYC. See page 4 for details.

April 12, 2008
Pot luck (adult only) get together at the Bellantoni home in White Plains. See Intro section for details.

February 2, 2008
Westchester Arc's Family Resource Day – see page 6 for details.

July 11-13, 2008
NDSC Annual Convention in Boston, MA. See page 4 for details.

COME ONE, COME ALL ... TO ONE OR ALL

Every summer our annual PACDS picnic is a huge success and everyone really seems to enjoy renewing old friendships, talking with other people who are parents of a child with Down Syndrome, etc. We shouldn't have to wait until the summer to get together though, so the Steering Committee has set up several social events (two for families, one for adults only) and we hope that you will all come to at least one of them.

On Sunday January 13 at 12:00pm, Ivy and Michael Lewis will host a brunch for all PACDS members – their address is 2 Red Maple Ridge, Croton-on-Hudson. They have a large finished basement for our kids to play in (including foosball, a pool table, a Ms. Pacman machine, lots of toys, a tv, etc) plus they will make sure their big flatscreen tv is tuned to the NFL playoff games for those that love the pigskin. This is a "pot luck" brunch, so if you are going to come please contact them at 914-827-8277 or ivylewis@optonline.net to arrange for something to bring.

On Saturday April 12 at 7pm, Stephanie and Michael Bellantoni will host an evening of drinks and appetizers for all adult PACDS members – their address is 44 Mt. Morris Avenue, White Plains. This is likewise a "pot luck" event, so please contact them at 914-761-3185 or cervoni246@msn.com to arrange for something to bring there.

Finally, on a date to later be determined, there will be a get together in the fall of 2008 in Westchester Arc's new building in Hawthorne. Look for details in future newsletters.

As you can see, there are LOTS of opportunities to meet and greet our PACDS members – we hope to see you at one or all of these future events in 2008.

PARENT / CHILD
PLAYGROUP

For kids birth to 5
years old.

Run by the
Children's School
for Early
Development in
collaboration with
PACDS

Sessions are held
at the Children's
School
40 Saw Mill River
Road (Route 9A),
Hawthorne

September 19, 2007
October 17, 2007
November 7, 2007
December 19, 2007
January 16, 2008
February 13, 2008
March 12, 2008
April 16, 2008
May 14, 2008
June 11, 2008

Groups meet from
930am-11am

For info contact:
Kathy Higgins at
the Children's
School
347-3227 x107

ELEMENTARY AGE
PLAYGROUP

This group has been
meeting for 3 years
and welcomes new
members. Call
Margaret Lewis at
235-9527 for
details.

SCREENING FOR CELIAC DISEASE IS INEFFECTIVE

Written by Cancer Weekly

Scientists found that screening celiac disease in asymptomatic children with Down syndrome was not cost-effective. "Studies demonstrate an increased prevalence of celiac disease in persons with Down syndrome, leading some organizations and authors to recommend universal screening of children with Down syndrome," scientists in the United States reported.

"However, many children with Down syndrome are asymptomatic, and the long-term implications of screening are unknown. The complication of celiac disease that leads to mortality in the general population is non-Hodgkin's lymphomas. The purpose of this research in asymptomatic children with Down syndrome was to (1) calculate the number needed to screen to prevent a single case of lymphoma and (2) present a cost-effectiveness study of screening," explained N.L. Swigonski and colleagues, Hasbro Children's Hospital.

"We constructed a decision tree using probabilities derived from the published literature for Down syndrome or from the general population where Down syndrome-specific data were not available. Celiac disease was determined by serologic screening and confirmation with intestinal biopsy.

"Sensitivity analysis was used to alter probability estimates affecting the cost of preventing lymphoma. Using our baseline values, the no-screen strategy is dominant; that is, screening not only costs more but also results in fewer quality-adjusted life-years. A screening strategy costs more than \$500,000 per life-year gained," calculated the team.

The researchers concluded, "Screening all asymptomatic children with Down syndrome for celiac disease costs almost \$5 million to prevent a single case of lymphoma. These analyses do not support the cost-effectiveness of screening, and more data are needed before recommendations to screen asymptomatic children with Down syndrome for celiac disease can be made."

Swigonski and colleagues published their study in Pediatrics (Screening for celiac disease in asymptomatic children with Down syndrome: Cost-effectiveness of preventing lymphoma. Pediatrics, 2006; 118(2):594-602).

For additional information, contact N.L. Swigonski, Hasbro Children's Hospital, Brown Medical School, Providence, Rhode Island, USA.

The publisher's contact information for the journal is: American Academy of Pediatrics, 141 North-West Point Blvd., Elk Grove Village, IL 60007-1098, USA.

PACDS CONTACTS

Co-Chairpersons:

Rosa Sanchez
293-0130
Caroline Furry
949-3948

New Parent

Contact:

Terri Hunt 243-5874
Patty Conte
654-0238

Newsletter:

Ivy Lewis
827-8277

Parent/ Child Group:

Terri Hunt
243-5874

Elem. Playgroup:

Margaret Lewis
235-9527

Teenage Contact:

Jean Corvino
693-5392
Magaly Olivero
949-2594

Adult Social Group:

Barbara Albrecht
(845) 628-8972
Debbie Eiseman
(718) 884-8496

Family Picnic:

Stephanie
Bellantoni
761-3185 and Patty
Conte 654-0238

Web Site:

Ken Yudell
723-6568

PACDS Hotline:

739-4085

Spanish Liaison:

Rosa Sanchez
293-0130

PRESCHOOL PARENTS, CHECK THIS OUT

Get Ready to Read! (GRTR!) is a national initiative to build the early literacy skills of preschool-age children. The initiative provides an easy-to-administer, research-based screening tool to early childhood educators, child care providers, and parents in order to help them prepare all children to learn to read and write.

<http://www.getreadytoread.org/content/view/12/285/>

WANT TO SHARE SOME INFORMATION?

We encourage all our members to submit articles or information that MAY be included in upcoming newsletters. Unfortunately, there will be times due to space and/or content that an article may not make it into our newsletter.

E-MAIL NEWSLETTER SUBMISSIONS SHOULD BE SENT TO:
Ivy Lewis at ivylewis@optonline.net

The editors reserve the right to make corrections/edits as appropriate. Original items may be used if properly credited. Copyrighted items must have the permission of the originating author. NEWSLETTER DEADLINES ARE: March 1 (Spring), June 1 (Summer), September 1 (Fall), and December 1 (Winter)

MOVIE FEATURES ACTOR WITH DOWN SYNDROME

A new movie, *The Child King*, is coming out this holiday season. One of the main characters, Jeremy, takes charge of restoring his brother's faith and belief in things that, before their mom died, used to bring him pleasure, overcoming numerous obstacles on their successful journey. Jeremy, played by first-time actor Peter Johnson, is clever, persistent and caring, and has Down Syndrome. The movie portrays a positive message about the abilities of people with Down Syndrome. To watch the trailer, visit www.thechildking.com.

WEBSITES OF INTEREST:

Below are some websites that may be helpful in your search for information.

www.ndss.org
National Down Syndrome Society

www.ndscenter.org
National Down Syndrome Congress

www.downsed.org
British website with extensive information

www.ds-health.com
Dr. Len Leshin, pediatrician and father of a child with DS. Articles and links to other websites. Of particular note: healthcare guidelines and growth charts.

www.metlife.com
Metdesk: financial planning for children with special needs.

www.woodbinehouse.com
Publishers featuring a special needs collection including many titles specific to Down syndrome.

2008 NATIONAL DOWN SYNDROME CONGRESS CONVENTION:

36TH Annual National Convention
July 11-13, 2008
Boston's Seaport Hotel
800-385-4000 or www.seaportboston.com
Ask for rooms in the NDSC block

SPECIAL NEEDS CAMP FAIR

SATURDAY, Jan. 26, 2008 11am-3pm

Presented by Resources for Children with Special Needs, Inc.

Contact: Gary Shulman, 212-677-4650 or
www.resourcesnyc.org

Plan ahead for the summer of 2008 with the wealth of information offered at the 23rd annual FREE Special Camp Fair. The Fair will be held on Saturday January 26, 2008 from 11am-3pm at the Church of St. Paul the Apostle in NYC, the entrance is on Columbus Avenue near West 60th Street.

Representatives from 70 New York City day camps and sleepaway camps in the northeast will be on hand to help parents and professionals plan productive summer experiences for children with disabilities. The Fair will also feature information on travel programs, remedial education programs, volunteer and job opportunities and early childhood programs. Spanish and sign language interpreters will be available.

Visitors to the Fair will receive a free copy of the Camps 2008 Guide. If you are interested in getting a copy of the Guide but can't make it to the Fair, the Guide is also available by sending a check for \$25 plus \$8 for postage and handling to the following address:

Resources for Children with Special Needs, Inc.
Department PR1
116 East 16th Street, 5th Floor
New York NY 10003

(websites cont'd)

www.hwtears.com
Tips, materials and seminars focusing on pre-printing, printing and cursive writing as per the Handwriting Without Tears Program.

www.talktoolstm.com
Sara Rosenfeld-Johnson site for seminars and speech tools (e.g. straw hierarchy, horns)

CHECK OUT THIS CLIP FROM CBS NEWS:

October was Down Syndrome awareness month – click on this link to see a clip about it by CBS news:

<http://wcbstv.com/video/?id=104770@wcbstv.com>

FREE WORKSHOPS IN THE BRONX

Resources for Children with Special Needs, Inc. is holding FREE workshops for families with children, youth and young adults with disabilities throughout the winter of 2007 and the spring of 2008. All programs run from 10am-1pm. Refreshments will be served, but there is NO child care available. Gary Shulman is the Training Coordinator for this group and can be reached at 212-677-4650 x20 if you have questions about any of these programs.

At the Jewish Child Care Association, 555 Bergen Avenue:
- February 6, 2008 - Getting Appropriate Educational Services
- March 5, 2008 - Early Childhood Services: Birth to 5
- April 9, 2008 - Community Resources

At the Visiting Nurse Service of New York, 489-493 E. 153rd Street:
- December 7, 2007 - Turning 5: Transition to School Age
- February 29, 2008 - Transition from School to Adult Life
- March 7, 2008 - Turning 5: Transition to School Age
- April 4, 2008 - Getting Appropriate Educational Services
- May 2, 2008 - Early Childhood Services: Birth to 5
- June 6, 2008 - Early Childhood Services: Birth to 5
- June 20, 2008 - Getting Appropriate Educational Services

DIFFERENTLY ABLED CATALOG

Still looking for holiday gift ideas for your child? Does a grandparent live far away and like to order gifts online for your kids? Check out this site for terrific toys specifically designed for kids with disabilities:

<http://www.toysrus.com/category/index.jsp?categoryId=2257808>

HEAR YE!

HEAR YE!

Get all the news as fast as it's out!
Send your email address to Anne Majsak to be included in the PACDS email chain amajsak@verizon.net

RESEARCH STUDY

PACDS has been contacted by Elyssa Sperber, a Doctor of Psychology candidate at Pace University. Her doctoral dissertation assesses the experience of individuals (ages 18-35) who have a sibling diagnosed with a disability, specifically she is studying the acceptance levels for others with disabilities based on having a sibling diagnosed with a disability.

All information is being collected through the use of questionnaires and will be kept strictly confidential; the questionnaires take about 15 minutes to complete, and all participants will be entered in a free raffle for a Best Buy gift certificate.

If you are interested in participating in this research, please contact her at elyssa.sperber@gmail.com or by phone at 516-312-7548.

CHECK OUT THE MIRACLE LEAGUE:

If you are looking for a way for your child with Down Syndrome to play baseball, and your own school district is not meeting his/her needs, come check out the Miracle League, <http://eteamz.active.com/mlwny/> or 914-960-6391.

The Miracle League is a national organization founded in Atlanta in the mid-1990s, which believes "every child deserves a chance to play baseball". There are more than 140 Miracle League fields throughout the US, including one in Hartsdale, NY at Ridge Road Park. Miracle League participants play on a specially designed rubberized field which is completely flat (the lines and markings are painted on), allowing for both ambulatory and non-ambulatory children to play without restrictions. The Miracle League plays several games on Saturdays and several games on Sundays, in both the spring and the fall, so it's easy to pick a convenient time, and each player is matched with a buddy who is either a teenager or an adult. Each game lasts about two hours, but there is no scoring, resulting in only winners with a tied score in each game.

Several of our PACDS members play with the Miracle League and agree it's a wonderful organization that goes out of its way to make sure every child, whether they are high functioning, low functioning or anywhere between, has a great time playing baseball. It's free!

WESTCHESTER ARC'S FAMILY RESOURCE DAY

Come to White Plains High School on February 2, 2008 for Family Resource Day, a fair and workshops for families of people with developmental disabilities. Lunch and child care will be available. 9am-230pm

PACDS
c/o Westchester Arc
121 Westmoreland
Ave
White Plains, NY
10606