



pacds

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

235 Albemarle Avenue  
White Plains, NY 10605

Spring 2008

## UPCOMING EVENTS

March 21, 2008

World Down Syndrome Day – see page 4 for details

April 12, 2008

Pot luck (adult only) get together at the Bellantoni home in White Plains. See page 2 for details.

May 12, 2008

12<sup>th</sup> Annual Golf Outing for the Nat'l Down Syndrome Society at the Montclair Golf Club. Call 212-763-4365 for details

May 18, 2008

Steering Committee meeting at 7pm at Caroline Furry's house in White Plains. Call Caroline at 949-3948 if you would like to attend

July 11-13, 2008

NDSC Annual Convention in Boston, MA. See page 4 for details.

August 10, 2008

Annual picnic at Downing Park in Yorktown Heights

## ANNUAL MEETINGS ARE JUST AROUND THE CORNER

For many families, attending an annual IEP meeting can cause a lot of stress and anxiety. Please consider the following:

Are both my child's strengths and weaknesses both being discussed?

Are the goals for next year attainable, realistic and measurable?

Are we remembering what has worked in the past and what hasn't?

Did all the services on last year's IEP work out? Was my child's schedule realistic in terms of his/her attention span and tolerance?

Is last year's program really the best one for next year?

Do we have long term plans, even for life after high school? Time really does fly and we need to plan accordingly now to make sure our children are being positioned for success down the road.

Have I discussed everything? Before the meeting jot down questions or concerns; also, review last year's IEP before the meeting.

Do I understand everything? Education personnel use lots of 'jargon' - it's ok to ask for clarification if you don't understand something.

Should I go alone? No, if a spouse or family member can't come, bring a friend for support and to be another set of eyes and ears.

I don't have to sign off, right? No, you can take it home to review it and consult with others. If you are ok with part though, agree to that so those services can begin.

The above suggestions should help you have a successful meeting with your school district. Remember that you are an integral part of the CSE team and that no one knows your child better than you do. Good luck to all our families as this difficult time approaches.

PARENT / CHILD  
PLAYGROUP

For kids birth to 5yo. This group is held at and run by the Children's School for Early Development in Hawthorne, in collaboration with PACDS

Future dates are:  
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 at 347-3227 x107

ELEMENTARY AGE  
PLAYGROUP

This group has been meeting monthly for years and welcomes new members.

For details call Margaret Lewis at 235-9527

## PACDS EVENTS

On January 13, Ivy and Michael Lewis hosted a pot luck brunch at their home in Croton-on-Hudson. The crowd of approximately 35 people, evenly split between children and adults, had a terrific time.

PACDS will hold its next social event on Saturday April 12 at 7pm at the home of Stephanie and Michael Bellantoni. The Bellantonis 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 let them know you are coming and to arrange for something to bring.

Our annual picnic will be held on ***August 10 at noon*** in Downing Park in Yorktown Heights. Details will be in the summer newsletter, but in the meantime please note this date on your calendars.

We are still planning a get together in the fall of 2008 in Westchester Arc's new building in Hawthorne. Look for details on page 6 of this newsletter for progress on the new building.

## THE MAGIC TO DO PLAYERS

Westco runs a full theatre arts program for persons between 8 and 20 years old with development disabilities. The group meets from 1pm-4pm on Saturdays, the workshop fee is \$150 and the session culminates in a May 31 performance at Mamaroneck Avenue School. The next session starts March 15 – this link will provide you with the registration form and you can likewise view info about the program:

[http://www.westcoproductions.org/special\\_needs\\_workshops.htm](http://www.westcoproductions.org/special_needs_workshops.htm)

## 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.

Newsletter submissions should be sent via email to Ivy Lewis at [ivylewis@optonline.net](mailto: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. Deadlines are: March 1 (Spring), June 1 (Summer), September 1 (Fall), and December 1 (Winter).

## PACDS CONTACTS

### Co-Chairpersons:

Rosa Sanchez  
293-0130  
Caroline Furry  
949-3948

### New Parent

#### Contacts:

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 Contacts:

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

## 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 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:

- 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. 153<sup>rd</sup> Street:

- 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

## 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 does not have an appropriate program, 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 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.

Plus, it's free!

## WEBSITES OF INTEREST:

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

[www.ndss.org](http://www.ndss.org)  
National Down Syndrome Society

[www.ndsccenter.org](http://www.ndsccenter.org)  
National Down Syndrome Congress

[www.downsed.org](http://www.downsed.org)  
British website with extensive information

[www.ds-health.com](http://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](http://www.metlife.com)  
Metdesk: financial planning for children with special needs.

[www.woodbinehouse.com](http://www.woodbinehouse.com)  
Publishers featuring a special needs collection including many titles specific to Down syndrome.

## 2008 NATIONAL DOWN SYNDROME CONGRESS CONVENTION:

36<sup>TH</sup> Annual National Convention  
July 11-13, 2008  
Boston's Seaport Hotel  
800-385-4000 or [www.seaportboston.com](http://www.seaportboston.com)  
Ask for rooms in the NDSC block

## MARCH 21 IS WORLD DOWN SYNDROME DAY:

If you are in the New York City area, the National Down Syndrome Society is pleased to invite you, your family, and your friends to a special event celebrating World Down Syndrome Day and the paperback release of COUNT US IN: Growing Up with Down Syndrome by Jason Kingsley and Mitchell Levitz.

The festivities are being held at Barnes & Noble by Lincoln Center, specifically 1972 Broadway, New York, NY on Wednesday March 21 at 7:30 p.m.

**About the book:** At ages nineteen and twenty-two, respectively, Jason Kingsley and Mitchell Levitz shared their innermost thoughts, feelings, hopes, and dreams, their lifelong friendship, and their experiences growing up with Down syndrome. Their frank discussion of what mattered most in their lives—careers, friendships, school, sex, marriage, finances, politics, and independence—earned Count Us In numerous national awards, including the EDI Award from the National Easter Seal Society. On March 21 the authors will discuss their lives since then—milestones and challenges, developments both expected and unexpected—in a new afterword.

**About the authors:** JASON KINGSLEY graduated from high school in 1994 and in 1997 from Maplebrook School, a postsecondary transitional program. He has received the Joseph P. Kennedy Jr. Foundation Families Award, among many others recognizing his contribution toward better understanding and acceptance of people with developmental disabilities. He lives in Hartsdale, New York.

MITCHELL LEVITZ graduated from high school in 1991 and is now a consumer issues specialist at the Westchester Institute for Human Development. He also serves on the board of directors of the National Down Syndrome Society. In 2004 Mitchell received the Daniel Piper Self-Advocacy Award. He lives in Cortlandt Manor, NY.

(websites cont'd)

[www.hwtears.com](http://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](http://www.talktoolstm.com)  
Sara Rosenfeld-Johnson site for seminars and speech tools (e.g. straw hierarchy, horns)

## [NEW RECOMMENDATIONS FOR PRENATAL TESTING](#)

In December 2007, the American College of Obstetricians and Gynecologists (ACOG) recommended that invasive prenatal testing, including amniocentesis and chorionic villus sampling, be offered to all pregnant women regardless of age. Previously, amniocentesis and chorionic villus sampling were routinely offered only to women who would be over the age of 35 at the date of delivery, or who had a family history, or an adverse result on their blood tests. However, ACOG has now dramatically expanded access to prenatal testing, suggesting that all pregnant women undergo invasive testing.

ACOG has not provided support for its new recommendation, and some organizations are concerned that the new recommendation carries an implication that individuals with genetic conditions are a bad outcome that should be avoided. When told their babies have a higher chance of having Down, nine out of 10 pregnant women terminate the pregnancy, national studies have estimated.

The National Down Syndrome Congress (NDSC) issued a statement in January 2008 that urged doctors to provide up-to-date and accurate information about the lives of people with Down syndrome to women who are undergoing prenatal testing. Specifically the NDSC's statement says that "individuals with Down syndrome have innate worth and should be treated with dignity and respect. Our goal is not to limit a woman's access to prenatal screening, nor to limit her reproductive choices. Rather it is to ensure that the screening and diagnostic process is done in the context of an informed personal conversation with the woman's doctor, during which current, balanced information is given about the reality of Down syndrome today".

A 2006 poll by the National Opinion Research Center found that 70% of Americans felt that women should be able to obtain a legal abortion if there is a strong chance of a serious defect in the baby. But there does not appear to be a national consensus on what exactly a "serious defect" might be, and the NDSC maintains that OB/GYNs have largely failed to inform prospective parents of medical and educational advances that have dramatically improved the lives of people with Down syndrome and more than doubled their life expectancies in recent years.

The NDSC further wrote in its statement that "if prenatal testing can take place in an atmosphere of informed consent, based on accurate and balanced information, we hope decisions can be made based on knowledge and not fear".

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

## [DOWN SYNDROME MAY PREVENT CANCER](#)

Reported in the January issue of Nature, new research shows that the genetic roots of Down syndrome may protect against intestinal cancer.

A recent study at Johns Hopkins University School of Medicine that used genetically altered mice found that a gene called Ets2, which sits on chromosome 21, represses tumor formation. Researcher Roger H. Reeves, PhD, a professor at Johns Hopkins, says that the Ets2 gene had previously been suspected of causing – not curbing – cancer. But in Down Syndrome, the extra copy of that gene may tip the balance in favor of cancer prevention.

The study determined that mice with the extra Ets2 gene were less likely to develop intestinal cancer and had smaller tumors than other mice. Reeves says that he and his colleagues want to develop a potential drug that would boost Ets2 in people without Down syndrome to curb cancer. It will take work to see if it can be done safely, but the study “offers an explanation for why having three, rather than the normal two, copies of chromosome 21 ... provides some protection from solid tumors”.

## [MOVIN' IN](#)

Westchester Arc plans to move into its new Hawthorne NY digs, called the Gateway To The Community, in late March/early April.

Westchester Arc's board has approved up to \$15.5 million for the project, which will include funds from the sale of its current Herbert Katzenberg Center building in White Plains, and its first capital campaign.

Ric Swierat, Arc's executive director, says the capital campaign's theme is “Envision Possibilities” because it will “support individuals with developmental disabilities in their efforts to eradicate stereotypes and to promote recognition of both their personal talents and their right to participate in community life”.

See highlights from their groundbreaking ceremony and photos of the construction progress to date on the following website:

[http://www.westchesterarc.org/about/Capital\\_Campaign\\_2007/WestchesterArc-Construction\\_Progress.htm](http://www.westchesterarc.org/about/Capital_Campaign_2007/WestchesterArc-Construction_Progress.htm)

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