



*pacds*

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

235 Albemarle Avenue  
White Plains, NY 10605

Fall 2008

## UPCOMING EVENTS

September 14, 2008  
PACDS Steering  
Committee Meeting  
7pm at Caroline  
Furry's house. See  
pg 2 for contact  
email and tele #s

September 14, 2008  
Romp for Research  
in NYC – see pg 5  
for details

September 21, 2008  
Yorktown Buddy  
Walk – see pg 2 for  
details

Sept 28, 2008  
NDSS Buddy Walk  
in Central Park. See  
pg 2 for details

October 21, 2008  
Westchester Arc's  
Annual "Matter of  
Taste" Event in Rye  
See pg 2 for details

## DISABILITY HISTORY WEEK IS COMING UP

In our continuing struggle to have society accept our children with Down syndrome, the NY Assembly is lending a helping hand. The third week of October will now officially be Disability History Week.

Bill 10801 says "In order to promote a spirit of patriotic and civil service and obligation, and to foster in the children of the state moral and intellectual qualities which are essential in preparing to meet the obligations of citizenship in peace or in war, the regents of the University of the State of New York shall prescribe courses of instruction in patriotism, citizenship, and human rights issues, with particular attention to the study of the inhumanity of genocide, slavery (including the freedom trail and underground railroad), the Holocaust, the mass starvation in Ireland from 1845 to 1850, and the history of people with disabilities, to be concentrated during but not limited to the third week of October, to be maintained and followed in all the schools of the state ... all pupils attending such schools, over the age of eight years, shall attend upon such instruction".

Karen Lazik, who is with the Museum of Disability History, says "It is important that today's youth understand history in order to appreciate how individuals with disabilities were once viewed and treated. During Disability History Week, students will be provided with factual information on disability history leading to invaluable discussions. Students will be given the foundation needed to make decisions in their everyday life on how they view and interact with others of differing abilities. Knowledge of disability history provides a roadmap for the future".

Kudos to our state's Assembly members, and to everyone that fights the daily fight to keep people with disabilities from being discriminated against. Hopefully this new Bill will teach today's youth that everyone has a place in society, so that in the future people with Down syndrome and other disabilities will find a path with less obstacles in front of them.

PARENT / CHILD  
PLAYGROUP

For kids birth to 5yo. This group provides playtime for kids and talk time for parents – it is held at and run by The Children's School for Early Development in Hawthorne, in collaboration with PACDS

Groups meet from 10am-1130am.

Dates are:

Sept 17, 2008  
Oct 15, 2008  
Nov 12, 2008  
Dec 10, 2008  
Jan 14, 2009  
Feb 11, 2009  
Mar 11, 2009  
Apr 15, 2009  
May 13, 2009  
June 10, 2009

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  
Shirley Allen at  
686-0628

**YORKTOWN HEIGHTS BUDDY WALK**

On September 21, 2008 the Yorktown Athletic Club will hold its second annual Yorktown Buddy Walk. The event will be held at FDR Park from 10am -2pm. Last year over \$10,000 was raised and donated to National Down Syndrome Society to further its education, research and advocacy programs and to Westchester Arc to support programs in our area. This year, contributions will be made to our local community's peer play initiative in addition to NDSS and WArc. For details, contact Terri Hunt at 914-243-5874 or [tmhunt@optonline.net](mailto:tmhunt@optonline.net) .

**NATIONAL DOWN SYNDROME SOCIETY BUDDY WALK**

This year is NDSS's 14<sup>th</sup> annual Buddy Walk. It takes place this year on Sunday September 28, starting at noon at the Great Hill in Central Park. The Buddy Walk promotes acceptance and inclusion of individuals with Down syndrome.

Prior to the Walk, starting at 1030am that morning, a video will be shown on the Panasonic News Corporation's Astrovision screen in Times Square.

See [www.buddywalk.org](http://www.buddywalk.org) for details on the Buddy Walk.

**SEEKING NEW MEMBERS**

PACDS needs spirited new committee members. NO EXPERIENCE NECESSARY! We need help to continue to provide support and programming for our families. For our organization to continue to provide assistance, education, and support we need you! Our next meeting is September 14. If you are interested in getting involved and/or joining the steering committee, please contact Caroline Furry at 949-3948 or [dfurrywitt@netzero.com](mailto:dfurrywitt@netzero.com).

**A MATTER OF TASTE**

Westchester Arc hosts "A Matter of Taste" every year - the event allows you to sample signature dishes from the finest restaurants in the area, paired with terrific wines from around the world. The event will be held October 21, 2008 at the Westchester Country Club in Rye, NY. See [www.westchesterarc.org](http://www.westchesterarc.org) for details.

## PACDS CONTACTS

### Co-Chairpersons:

Rosa Sanchez  
293-0130  
Caroline Furry  
949-3948  
Terri Hunt 243-5874

### 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:

Shirley Allen  
686-0628

### 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

### PACDS Hotline:

739-4085

### Spanish Liaison:

Rosa Sanchez  
293-0130

## SAFETY TATTOOS

Many children with Down syndrome would have problems communicating their name, their parents' names, their age, etc if they got lost. SafetyTats™ are temporary tattoos that do the talking for a lost child. They include cell phone numbers, a child's name, etc and they come in stylish designs and cool colors to be kid-friendly. They can not be easily removed by peeling or rubbing and will last 2-3 days, though they can be quickly removed with baby oil. They are made of FDA approved medical material that is durable, yet temporary. They are also available for food allergy alerts. For more information, visit [www.safetytat.com](http://www.safetytat.com)

## CHECK OUT THE MIRACLE LEAGUE:

If you are looking for a way for your child with Down syndrome to play baseball now that school is starting, and your own school district does not have an appropriate program, come check out the Miracle League, at [www.mlwny.org](http://www.mlwny.org) 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 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. And it's free!

## NEW YORK ARC CONVENTION

October 15 – 18, 2008 New York State Arc will hold its annual convention in Albany, NY. Check [www.westchesterarc.org](http://www.westchesterarc.org) for details if you are interested in attending.

## WEBSITES OF INTEREST:

Here are some sites that may be helpful in your search for information.

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

[www.ndscenter.org](http://www.ndscenter.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 note: healthcare guidelines and growth charts.

[www.metlife.com](http://www.metlife.com)  
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.

## COME SAIL ON THE BUDDY CRUISE

FRIENDS-Support, Inc is presenting an exclusive Down syndrome awareness cruise on board Royal Caribbean' "Sovereign of the Seas". This 3 night Bahamian cruise departs Port Canaveral, FL on October 17, 2008. FRIENDS-Support, Inc is using this Buddy Cruise as a way for families from all across America to come together and bring awareness to Down syndrome.

Sujeet Desai is a 26 year old musician with Down syndrome who will be on the cruise. He and his wife Carrie have been featured on The View, 20/20 and Oprah. Sujeet will share his musical talents with his fellow cruisers and will also share his story from birth to marriage, including his graduation from the music academy and the NY State funded program that helps he and his wife remain independent. PACDS member Emily Kingsley will be presenting the Keynote Presentation "Thirty Four Years with Down Syndrome. The 'ups', the 'downs' and what I've learned from life with Jason". Emily has received 17 Emmy Awards and 13 Emmy nominations for her work on Sesame Street, specifically her efforts to include people with disabilities in the cast. Her son Jason will present a workshop also. Nikole Whitehead, co-founder of STAND ([www.STANDAdvocates.org](http://www.STANDAdvocates.org)) will also be giving a presentation on the Buddy Cruise called "Cruising Through Your Child's Special Education".

Call Cruise Planners at 1-888-464-1827 for details.

## EYEGASSES FOR KIDS WITH DOWN SYNDROME

Maria Dellapina's nine year old daughter Erin has Down syndrome. "Erin was always looking over the glasses or tipping her head way back to see through the center of them" says Dellapina, an optician by trade. Four years ago Dellapina did lots of research and learned that 87 percent of preschool children with Down syndrome needed glasses, so she set out to create a design that would fit right on those children. Her company, SPECS4US, sold its first set of frames in June 2008. "Erin is now wearing a pair of glasses that I rarely see her pushing back up on her face, and she is no longer hiding them from me" says Dellapina, and she gets emails daily from parents about how the glasses have helped their children see correctly and how they have heightened the quality of their lives overall. For information on SPECS4US check out their web site: [www.specs4us.com](http://www.specs4us.com)

[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)

[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](mailto:amajsak@verizon.net)

## [WESTCHESTER ARC GETS NEW DIGS](#)

Westchester Arc is moving into a brand new building, called "Gateway to the Community" on September 12, 2008. "The capital campaign's theme is 'Envision Possibilities'", explains Ric Swierat, executive director, "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 fully in community life". Arc's staff is busy packing up all their belongings and readying for their move – the ribbon cutting ceremony will be September 18, 2008.

## [PACDS TO MEET at ARC'S NEW BUILDING](#)

This fall, PACDS will hold a get together at Arc's new building in Hawthorne. The date and details of this event are still being worked out, but please stay tuned for future information.

## [ROMP FOR RESEARCH](#)

On September 14, 2008 the second annual "Rompage for Research" will be held in support of The Down Syndrome Research and Treatment Foundation. The event will be held at Asphalt Green, between 90<sup>th</sup> and 92<sup>nd</sup> Streets at York Avenue in NYC (enter on 90<sup>th</sup> Street). The DSRTF's mission is to stimulate biomedical research that will accelerate the development of treatments to significantly improve cognition for individuals with Down syndrome. The 2007 "Rompage" was attended by more than 800 people and more than \$175,000 was raised for DSRTF. The "Rompage" is an event featuring music, food and beverages, games, a silent auction, arts and crafts, prizes, entertainment, fire trucks provided by NY's Bravest, and many friends and supporters of the Down syndrome community. See [www.rompageforresearch.com](http://www.rompageforresearch.com) for more information.

## [A LOCAL SUCCESS STORY](#)

On June 19, 2008 Carissa Cerrato graduated Pinesbridge School in Yorktown, she is 21 years old. PACDS member Loretta Cerrato, Carissa's mom, says it seems like "only yesterday" when Carissa and 3 other babies started the first infant program offered at WArc. Carissa went to WArc, St Agnes CRC and Boces, meeting many wonderful professionals along the way, and making terrific friends, including those in PACDS. Loretta says "We have had good times and bad times, good days and bad days. But I wouldn't trade my 'trip to Holland' for anything in the world." Carissa is now at the Richmond Children's Center in Mt. Kisco, enjoying cooking, music, art and lots of other wonderful activities.

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