



*pacds*

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

265 Saw Mill River Road  
Hawthorne NY 10532

Fall 2009

## UPCOMING EVENTS

PARC's Sunset & Fireworks Cruise – Sept 12, 2009 – see page 2 for details

NDSS Annual Buddy Walk at the Great Hill in Central Park – Sunday – Sept 26 at noon – see page 4 for details

A Matter of Taste – October 7, 2009 – see this page for details

Pumpkin Madness – October 25 at Saxon Woods Playground Park in White Plains. See this page for details

Yorktown Buddy Walk – April 25, 2010 – check future newsletters for details

## PACDS EVENTS

Pouring rain couldn't ruin the PACDS annual picnic at Downing Park on August 2. About a dozen families came out in the horrible weather to eat hot dogs and burgers (a special shout-out goes to our grillmasters who cooked in the rain while holding umbrellas), catch up on what's going on in their lives, do arts & crafts, have fun with Zooky the Clown, and spend a rainy afternoon together.

The next PACDS event will be our pumpkin decorating get together at Saxon Woods Park in White Plains. This year PACDS Pumpkin Madness will be held on Sunday October 25, 2009 from 2pm-4pm. Everyone needs to bring their own pumpkins and a snack to share with the other PACDS families. We'll supply all the decorating stuff! The Saxon Woods Playground Park is on Mamaroneck Avenue in White Plains, off the Hutchinson River Parkway. Please join us!

## NEW/SAFER PRENATAL TEST FOR DS EXPLORED

The National Academy of Sciences reports that researchers from Stanford University, the Howard Hughes Medical Institute, and Lucile Packard Children's Hospital have developed a new technique to test for chromosomal abnormalities. This new test, which uses fetal DNA in a pregnant woman's blood, improves on previous research in this area. The blood is scanned for fetal abnormal chromosome numbers that indicate various conditions, like Down syndrome. This test should be safer than the currently available testing methods, like amniocentesis, that carry a miscarriage risk of about half a percent. This test, done by a simple blood draw, could lead to earlier diagnosis since fetal DNA shows up early in pregnancy.

## A MATTER OF TASTE

On Wednesday October 7, 2009 Westchester Arc will be holding it's 6<sup>th</sup> annual Matter of Taste event. This year it will be held at the Westchester Country Club in Rye, NY – check [www.westchesterarc.org](http://www.westchesterarc.org) for details.

PARENT / CHILD  
PLAYGROUP

For kids 0 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. on

Sept 16, 2009  
Oct 14, 2009  
Nov 18, 2009  
Dec 9, 2009  
Jan 20, 2010  
Feb 10, 2010  
March 10, 2010  
April 14, 2010  
May 12, 2010  
June 9, 2010

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

**PARC’S 4<sup>th</sup> ANNUAL SUNSET & FIREWORKS CRUISE**

On Saturday September 12, 2009 Partners with PARC, which is based in Brewster, NY and benefits children and adults with disabilities, is holding its 4<sup>th</sup> annual Sunset & Fireworks Cruise. The cruise leaves from the Cold Spring Boat Club and runs from 8pm - 11pm. There will be a gourmet dinner buffet, three hours of open bar, a silent auction and raffles, dancing, and quadricentennial fireworks display. Tickets are \$100 each. For details go to [www.partnerswithparc.org](http://www.partnerswithparc.org) or call 845-278-7272.

**PEOPLE MAGAZINE’S ALL-STARS AMONG US WINNER**

Cherry Hill, NJ resident Bob Hennefer was watching a Philadelphia Phillies game some months ago when he learned about a People magazine contest that recognizes individuals who have served their communities in their “All-Stars Among Us” campaign that is jointly run with Major League Baseball – he immediately decided “I’m going to nominate my brother”.

They didn’t hear anything for a while, but ultimately People magazine called and told them that Bob’s brother Brad, age 20, was one of the 90 finalists in the country. Nearly 300,000 applications had been received and People had narrowed it down to three people for each of the 30 teams in the major leagues – the three remaining for each team were then to be chosen from an online vote. Bob says “we got the entire Down syndrome community to get online and vote” because Brad had started the Golf for Life Foundation in 2006 in Newfield NJ, where he is the director for golf at White Oaks Country Club. The foundation’s goal is to “provide a golf developmental process for individuals with Down syndrome to introduce the game of golf, provide a level of consistency, maintain involvement and participation, provide opportunities for competition regardless of skill level and physical abilities, with support for education and special assistance that will ultimately lead to employment and productive citizenship”.

After Brad was selected as the winner on behalf of the Phillies, Major League Baseball coordinated a press conference with MLB Commissioner Bud Selig, the Phillies gave Brad a jersey that he wore and also gave him a second jersey that was signed by all the Phillies players and he was honored at a Phillies home game against the Tampa Bay Rays. Brad also got to participate in a parade and go to the Home Run Derby that was part of the All Star Game in St. Louis.

Now that his baseball thrills are done, Brad is back at work at White Oaks and he’s also taking classes at Camden County Community College, including a public speaking course that will help him with the many speaking engagements he is now signed up to do. Congrats to Brad on his All Star win!

## PACDS CONTACTS

### Co-Chairpersons:

Patty Conte  
654-0238  
Stephanie  
Bellantoni  
761-3185  
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

## **BUDDY CRUISE BOOKING IS IN FULL SWING**

Don't miss the boat! Reserve your cabin today! Only the deposit is needed at this time to reserve your cabin. This year, Buddy Cruise Inc is setting sail October 17 for a 5 night voyage to Cozumel and Grand Cayman! There will be two days at sea filled with wonderful workshops and events especially designed for our Buddy Cruise. Join families from across the nation as we celebrate our amazing children! Visit [www.buddycruise.com](http://www.buddycruise.com) for details; the website has just been updated with pre-night hotel info and more.

Buddy Cruise Inc. is a not for profit organization serving families and friends of individuals with Down syndrome. It is their purpose to provide educational opportunities and resources for families, while promoting awareness, acceptance, inclusion and advancement for individuals with Down syndrome. Their events are a forum for prominent educational speakers addressing a wide range of Down syndrome and disability related topics.

## **COME JOIN THE MIRACLE LEAGUE**

With fall's arrival, the Miracle League of Westchester is about to embark on its 3<sup>rd</sup> season of baseball. Many PACDS members play with the Miracle League, a group that fully embraces their motto that "everyone plays". The games are not competitive and players need not be ambulatory to participate, plus each player is paired with a "buddy" and there is no charge to be in the league.

For the fall session, there are general games on both Saturdays and Sundays, plus there are separate sessions for the "Spectrum group" (a program run in conjunction with Westchester Jewish Community Services) and the "skills group" (for more advanced players). This season runs from September 12 through October 18. Games are at the Miracle Field at Ridge Road Park in Hartsdale, NY. Information, game times, and registration links can be found at [www.mlwny.org](http://www.mlwny.org).

## **SEEKING NEW COMMITTEE MEMBERS**

PACDS needs spirited new committee members. NO EXPERIENCE IS NECESSARY! We need help to continue to provide support and programming for our families. If you are interested in getting more involved, please contact Terri Hunt at [tmhunt@optonline.net](mailto:tmhunt@optonline.net) 243-5874, Patty Conte at [ebean37@hotmail.com](mailto:ebean37@hotmail.com) 654-0238, or Stephanie Bellantoni at [cervoni246@msn.com](mailto:cervoni246@msn.com) 761-3185

## 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.

## **A POTENTIAL NEW DRUG FOR HIGH-RISK LEUKEMIA**

Dr. Shai Izraeli of Tel Aviv University's Sackler School of Medicine and Sheba Medical Center reports in the medical journal "The Lancet" that a mutation of the JAK2 protein in patients with Down syndrome may provide a path to new life-saving medication options for people with leukemia.

The JAK2 mutation has already been linked to Polycythemia Vera, a disease common in adults that leads to the overproduction of blood, and Dr. Izraeli recently discovered that the JAK2 mutations also exist in children who initially suffered from Down syndrome and subsequently developed leukemia. A drug that is already in clinical trials for a blood disease common in adults may be relevant for children with leukemia also. "Those children at the highest risk for leukemia may be treated with inhibitors of JAK2" says Dr. Izraeli, adding that the discovery offers "potential hope" because the JAK2 inhibitors are not based on chemotherapy, and there are very few side effects.

## **COME JOIN THE 15<sup>TH</sup> ANNUAL NDSS BUDDY WALK**

The 15<sup>th</sup> Annual New York City Buddy Walk®, sponsored by the National Down Syndrome Society, will be held on September 26, 2009 at noon. The Buddy Walk begins at the Great Hill in Central Park and is a flat one mile walk that returns back to the Great Hill.

You can also celebrate the 15<sup>th</sup> Anniversary of the Buddy Walk® by entering the Times Square Video Contest. The video, which showcases individuals with Down syndrome from all over the world, will air on a jumbo screen in the heart of Times Square at 10:30 a.m. on the day of the Walk. Each year, NDSS receives thousands of photo submissions for the Times Square Video Contest. Because the Buddy Walk promotes acceptance and inclusion of individuals with Down syndrome, the winning photographs feature children, teens and adults with Down syndrome working, playing and learning with friends and family. Only ONE photo per individual can be submitted to the contest (NDSS will only use the first submission if more than one photo is sent in). For more information, or to submit a photo go to [www.ndss.org](http://www.ndss.org).

Winners will be contacted by a representative from NDSS via email.  
**You will not be contacted if your photo is not selected.**  
**Photographs will not be returned.**

## 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)

[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)

## **SHRIVER LEAVES LEGACY WITH SPECIAL OLYMPICS**

Eunice Kennedy Shriver died August 11, 2009 – the Kennedy family has long been connected to public service, but it was Eunice that started the Special Olympics organization in 1962 as a sports camp in her backyard, for the most part because her sister, Rosemary, had an intellectual disability. The first Special Olympics Games were held at Chicago's Soldier Field in 1958. The estimated 200 million people in the world that live with intellectual disabilities were largely unseen and voiceless at that time. Shriver told the 1,000 athletes that had gathered in the stadium "In ancient Rome, the gladiators went into the arena with these words on their lips ... let me win, but if I cannot win, let me be brave in the attempt" and brave they have all been ever since. David Tolleson, executive director of the NDSC says "Special Olympics emphasizes what folks can do, and it does it in a manner that's fun and exciting and it offers a sense of community both within the family of those with developmental disabilities, as well as with the greater community at large. Eunice Kennedy Shriver will surely be missed by her friends and family, but the legacy she leaves behind reaches throughout the world.

## **20 YEAR OLD BECOMES AN EAGLE**

20 year old Adam Townsend of Mesquite, TX has Down syndrome – he recently earned the rank of Eagle Scout, the highest honor bestowed by the Boy Scouts of America. Adam started scouting when he was 6 and has completed years of requirements, culminating in his Eagle project in which he managed and supervised the renovation of a church parking lot. Adam's mother Barbara Townsend says "for parents with children with disabilities, your child can do it ... you just have to believe".

## **BAND OF ANGELS**

Band of Angels is a foundation that provides support for families of individuals with Down syndrome, autism and other disabilities. Started in 1994, they produce high-end stationery, jewelry, cards, calendars, and apparel that celebrate children with special needs.

Founder Cynthia Kidder began Band of Angels after she discovered how her son Jordan, who has Down syndrome, was more the same than different. She refers to Jordan as her "1 in 800" baby and this foundation has lots of products that espouse that phrase.

Band of Angels is based in Detroit, Michigan but their products are available online at [www.bandofangels.com](http://www.bandofangels.com) – check out their wonderful stuff; they even have a scholarship program for post-high school education for people with Down syndrome.

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