



pacds

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

235 Albemarle Avenue
White Plains, NY 10605

Fall 2007

UPCOMING EVENTS

Sept 16 - Romp for Research ... see annasamigos.org for information

Sept 15 - Elem age playgroup meets in Eastchester - call 235-9527 for info

Sept 17 - the 23rd Annual MBIA Golf and Tennis Invitational

Sept 30 - NYC Buddy Walk for NDSS
www.ndss.org

Oct 17 - Arc's "A Matter of Taste" Fundraiser ... call 428-8330 for info

Oct 21 - Yorktown Athletic Club Buddy Walk - call 243-5874 for info

Oct 24, 25, -26 Nat'l Assoc for the Dually Diagnosed Conference ... see www.thenadd.org

Nov 14 - NDSS Annual Gala & Auction at Chelsea Piers 212-763-4365

It's Fall ... Again

Summer always goes by so quickly, and this year was no different. The hectic school year is now upon us and memories of camp, swimming, and the hot weather will soon be just that, memories.

Is your school district still able to meet all of your child's educational needs? Has your child outgrown the dance class they've been taking for years? Maybe it's time to try that martial arts class you've heard about? How about starting to think about a sleepaway camp for next summer? You've been avoiding a sleep study for your child, but maybe now it's time to have it done? Did you check your IEP for errors?

No matter how old your child is, PACDS continues to be a great resource for us all. Our children with Down syndrome present unusual challenges and using our network of friends is a great way to gain information, advice and recommendations. Please don't hesitate to contact any of the folks listed on the left side of page 3 - we're happy to help in whatever way we can.

Down Syndrome Myths & Truths

- **Myth: Down syndrome is a rare genetic disorder. Truth:** Down syndrome is the most commonly occurring genetic condition. 1 in every 733 live births is a child with Down syndrome, representing approximately 5,000 births per year in the U.S. alone. Today, Down syndrome affects more than 350,000 people in the U.S.
- **Myth: Most children with Down syndrome are born to older parents. Truth:** Eighty percent of children born with Down syndrome are born to women younger than 35-years-old. It is true that the incidence of births of children with Down syndrome increases with the age of the mother, but more children are born to women younger than 35 vs those over 35.
- **Myth: People with Down syndrome are severely retarded. Truth:** Most people with Down syndrome have IQs that fall in the mild to moderate range of retardation. People with Down syndrome are definitely educable and educators and researchers are still discovering the full potential of people with Down syndrome.
- **Myth: Most people with Down syndrome are institutionalized. Truth:** Today people with Down syndrome live at home with their families and are active participants in the educational, vocational, social

PARENT / CHILD
PLAYGROUP

For kids birth to 5
years old.

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

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 is looking for
new members. Ages
5-12. All are
welcome 9/15 at
the home of
Margaret Lewis
1 Columbus Circle
Eastchester
Call 235-9527

Down Syndrome Myths & Truths (cont'd)

and recreational activities of the community. They are integrated into the regular education system, and take part in sports, camping, music, art programs and all the other activities of their areas. In addition, they are socializing with people with and without disabilities, and as adults are obtaining employment and living in group homes and other independent housing arrangements.

- **Myth: Parents will not find community support in bringing up their child with Down syndrome. Truth:** In almost every community of the United States there are parent support groups and other community organizations directly involved in providing services to families of individuals with Down syndrome.
- **Myth: Children with Down syndrome must be placed in segregated special education programs. Truth:** Children with Down syndrome are included in regular academic classrooms in schools across the country. In some instances they are integrated into specific courses, while in other situations students are fully included in the regular classroom. The degree of mainstreaming is based in the abilities of the individual; but the trend is for full inclusion in the social and educational life of the community.
- **Myth: Adults with Down syndrome are unemployable. Truth:** Businesses are seeking young adults with Down syndrome for a variety of positions. They are being employed in small and medium sized offices: by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industry, in clerical positions and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.
- **Myth: People with Down syndrome are always happy. Truth:** People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship and they are hurt and upset by inconsiderate behavior.
- **Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage. Truth:** People with Down syndrome date, socialize and form ongoing relationships. Some are beginning to marry. Women with Down syndrome can and do have children, but there is a 50 percent chance that their child will have Down syndrome. Men with Down syndrome are believed to be sterile, with only one documented instance of a male with Down syndrome who has fathered a child.
- **Myth: Down syndrome can never be cured. Truth:** Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with DS in the future.

PACDS thanks the National Down Syndrome Society for contributing text to this publication. The mission of NDSS is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. For more information call (800) 221-4602 or visit www.ndss.org.

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:

Caroline Furry
949-3948

Teenage Social Group:

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

Web Site:

Ken Yudell
723-6568

PACDS Hotline:

739-4085

Spanish Liaison:

Rosa Sanchez
293-0130

Special Needs Sports Programs at SUNY Purchase

The **Backyard Sports Plus** program will offer special needs children (ages 5-15) a safe and appropriately competitive program to learn and enjoy athletics. The program will focus on basic coordination and movement development skills while also creating the right setting for an enjoyable social experience.

The program is staffed with trained teacher/coaches to handle the needs of your children. The activities are professionally designed to build confidence and self esteem.

Group sizes in each class will be small and determined by age/ability so all kids can participate in a comfortable environment.

Classes run for 10 weeks and the fee is \$400. Info at www.byardsports.com

Program Information

Session #1 Mondays (5:00-6:00 pm)

Dates: Sept. 10, 17, 24 / Oct. 1, 15, 22, 29 / Nov. 5, 12, 19

Session #2 Thursdays (5:00-6:00 pm)

Dates: Sept. 6, 20, 27 / Oct. 4, 11, 18, 25 / Nov. 1, 8, 15

Session #3 Sundays (10:00 am- 11:00 am)

Dates: Sept. 9, 16, 23, 30 / Oct. 14, 21, 28 / Nov. 4, 11, 18

For more information call Danny at 914-304-4052 or send an email to:
danny@byardsports.com

We have reprinted the following article because of the unusual issues it brings up, and we know that not everyone has seen it ...

Prenatal Test Puts Down Syndrome Into Focus

Printed May 5, 2007 in the New York Times

Sarah Itoh, a self-described "almost-eleven-and-a-half," betrayed no trace of nervousness as she told a roomful of genetic counselors and obstetricians about herself one recent afternoon.

She likes to read, she said. Math used to be hard, but it is getting easier. She plays clarinet in her school band. She is a junior girl scout and an aunt, and she likes to organize, so her room is very clean. Last year, she won three medals in the Special Olympics. "I am so lucky I get to do so many things," she concluded. "I just want you to know, even though I have Down syndrome, it is O.K."

Sarah's appearance at Henry Ford Hospital here is part of an unusual campaign being undertaken by parents of children with Down syndrome who worry about their future in the face of broader prenatal testing that could sharply reduce the number of those born with the genetic condition.

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.

Prenatal Test (cont'd)

Until this year, only pregnant women 35 and older were routinely tested to see if their fetuses had the extra chromosome that causes Down syndrome. As a result many couples were given the diagnosis only at birth. But under a new recommendation from the American College of Obstetricians and Gynecologists, doctors have begun to offer a new, safer screening procedure to all pregnant women, regardless of age.

About 90 percent of pregnant women who are given a Down syndrome diagnosis have chosen to have an abortion. Convinced that more couples would choose to continue their pregnancies if they better appreciated what it meant to raise a child with Down syndrome, a growing group of parents is seeking to insert their own positive perspectives into a decision often dominated by daunting medical statistics and doctors who feel obligated to describe the difficulties of life with a disabled child.

They are pressing obstetricians to send them couples who have been given a prenatal diagnosis and inviting prospective parents into their homes to meet their children. In Massachusetts, for example, volunteers in a "first call" network linking veteran parents to new ones are now offering support to couples deciding whether to continue a pregnancy.

The parent evangelists are driven by a deep-seated fear for their children's well-being in a world where there are fewer people like them. But as prenatal tests become available for a range of other perceived genetic imperfections, they may also be heralding a broader cultural skirmish over where to draw the line between preventing disability and accepting human diversity. "We want people who make this decision to know our kids," said Lucy Talbot, the president of a support group here who prevailed on the hospital to give Sarah and two teenage friends an audience. "We want them to talk to us."

The focus on the unborn is new for most parent advocates, who have traditionally directed their energy toward support for the born. But after broader testing was recommended in January, the subject began to hijack agendas at local support group meetings. A dwindling Down syndrome population, which now stands at about 350,000, could mean less institutional support and reduced funds for medical research. It could also mean a lonelier world for those who remain.

"The impact of these changes on the Down syndrome community is going to be huge," said Dani Archer, a mother in Omaha who has set aside other Down syndrome volunteer work to strategize about how to reach prospective parents.

The 5,500 children born with Down syndrome each year in the United States suffer from mild to moderate mental retardation, are at high risk for congenital heart defects and a variety of other medical problems, and have an average life expectancy of 49. As adults, some hold jobs, but many have difficulty living independently.

"There are many couples who do not want to have a baby with Down syndrome," said Deborah A. Driscoll, chief of the obstetrics department at the University of Pennsylvania and a lead author of the new recommendation from the obstetricians' group. "They don't have the resources, don't have the emotional stamina, don't have the family support. We are recommending this

(websites cont'd)

www.hwtears.com
Tips, materials and seminars focusing on pre-printing, printing and cursive writing.

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

Prenatal Test (cont'd)

testing be offered so that parents have a choice."

But the richness of their children's lives, parent advocates say, is poorly understood. Early medical intervention and new expertise in infant heart surgery stave off many health problems; legally mandated inclusion in public schools has created opportunities for friendship and fostered broader social awareness of the condition.

With no formal financing or organization, parents are arranging to meet with local obstetricians, rewriting dated literature and pleading with health care workers to give out their phone numbers along with test results. Medical professionals have for the most part responded with caution. Genetic counselors, who often give test results to prospective parents, say they need to respect patients who may have already made up their minds to terminate their pregnancy. Suggesting that they read a flyer or spend a day with a family, they say, can unnecessarily complicate what is for many a painful and time-pressured decision. Their goal, parents say, is not to force anyone to take on the task of parenting a child with disabilities. Many participants in the ad-hoc movement describe themselves as pro-choice. Yet some see themselves as society's first line of defense against a use of genetic technology that can border on eugenics. "For me, it's just faces disappearing," said Nancy Iannone, of Turnersville, N.J., mother to four daughters, including one with Down syndrome. "It isn't about abortion politics or religion, it's a pure ethical question."

Others admit freely to a selfish motive for their new activism. "If all these people terminate babies with Down syndrome, there won't be programs, there won't be acceptance or tolerance," said Tracy Brown, 37, of Seattle, whose 2-year-old son, Maxford, has the condition. "I want opportunities for my son. I don't know if that's right or wrong, but I do."

Ms. Brown has taken it upon herself to serve as a community resource on Down syndrome for prospective parents. She was encouraged when a counselor at the University of Washington Medical Center sent her an e-mail message recently with a question from a patient. What developmental age equivalent, the patient wanted to know, do most people with Down syndrome reach? For parents on an e-mail list where Ms. Brown solicited answers, the question underscored the difficulty in conveying the pleasure of parenting a child with Down syndrome to someone who has the option to reject it. "Verbally," wrote one mother of her teenager, "she's at a 6-month level, but what 6-month-old do you know who can climb out a window and dance on a roof?!?!? We joke that she could climb Mt. Everest." Another wrote "If someone had told me Sam would still be in diapers at age 5 — ugh — I probably would have died. Living through it, not such a big deal. Because you don't give birth to a 5-year-old, you grow with and love this kid for five years."

Doctors have long recommended an amniocentesis test for pregnant women 35 and over, whose age puts them at greater risk for chromosomal defects. But because it carries a small risk of miscarriage, it has not been routinely offered to younger women, who give birth to the majority of children with Down syndrome. Now, with a first-trimester sonogram and two blood tests, doctors can gauge whether a fetus has the extra 21st chromosome that causes Down syndrome with a high degree of accuracy and without endangering the pregnancy.

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

Prenatal Test (cont'd)

But many parents see expanded testing as a step toward a society where children like theirs would be unwelcome. The Newsweek columnist George F. Will labeled it a "search and destroy mission" for a category of citizens that includes his adult son, Jon Will.

Dr. Brian Skotko, a medical resident who has studied how mothers were told of prenatal diagnoses, found a high level of dissatisfaction. He said that most doctors have little or no training on how to relay a prenatal diagnosis of Down syndrome. When he talked to obstetricians, geneticists and medical students at Massachusetts General Hospital in Boston about the subject last month, though, he was questioned sharply.

One doctor asked about studies suggesting there is a higher risk of early-onset Alzheimer's disease in people with Down syndrome, potentially saddling parents with another caretaking burden as they themselves age. Others take issue with the notion that they do not give parents a balanced portrayal of the condition.

"It's a mistake to say 'your baby is going to be mentally retarded, you should have a pregnancy termination,' " said Dr. Allan Nadel, director of prenatal diagnosis at the hospital. "By the same token, I don't think it's quite fair to say 'these are wonderful lovely human beings, you can deal with all of their problems and it's not that big of a deal.' We strive to have the proper balance." Parent advocates have some advice: don't begin with "I'm sorry," or "I have bad news," as many of their own doctors did.

Weeks after Patricia Lanter decided to continue her pregnancy, having learned that Down syndrome had been diagnosed in her fetus, her doctor reminded her that she could still get an abortion in Kansas if an ultrasound indicated the baby would need heart surgery. Ms. Lanter, an emergency physician from Norwich, Vt., has secured an invitation to lecture the obstetricians in her hospital this summer.

In Wilmington, Del., Kristin Pidgeon recalled her doctor's gloomy forecast for a local hospital audience: "She may be able to count change for the bus," he had said of her as-yet-unborn daughter. "But what's going to happen when the bus doesn't come?" (Her daughter Aliza, now 5, does not yet take the bus, Ms. Pidgeon said, but she does ride horses as part of her therapy.)

In the Detroit suburbs, Ms. Talbot is still working out the best strategy to drive her points home to medical professionals. When one doctor suggested she had chosen to show them only "high-functioning kids" like Sarah and her own daughter, Megan, she asked Trevor Taylor, who lacks the ability to communicate verbally, to join the lineup. At the Henry Ford visit, Mr. Taylor, 19, a natural ham, acted out his speech as Megan, 18, read it, before hitting the music and signing along to "What a Wonderful World."

At the end, he blew a kiss to the audience. Then he hugged his mother.

Copyright © 2007 by The New York Times Co. Reprinted with permission.

DO YOU HAVE SOMETHING FOR THE NEWSLETTER?

We encourage all our members to submit articles or information that **MAY** be included in future newsletters. There may be times due to space and/or content that an article may not make it into our newsletter.

EMAIL YOUR NEWSLETTER SUBMISSIONS 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), Sept 1 (Fall), and Dec 1 (Winter)

Special Education Training & Resource Links

- Vocational and Educational Services for Individuals with Disabilities (the VESID website contains information and answers to many of your questions and is also a source of all State Education Department publications) www.nysed.gov
- New York State Office of Mental Retardation and Developmental Disabilities. www.omr.state.ny.us
- Special Education Quality Assurance (SEQA). www.vesid.nysed.gov/specialed/quality/qaoffices
- National Down Syndrome Society. www.ndss.org
- National Down Syndrome Congress. www.ndsccenter.org
- National. Information Center for Children & Youth with Disabilities. www.nichcy.org
- The Special Ed Advocate. www.wrightslaw.com
- Consortium for Appropriate Dispute Resolution in Special Education. www.directionservice.org
- Westchester Institute for Human Development(WIHD). www.wihd.org

(PACDS does not promote or recommend any therapy, treatment, institution, etc., and does not espouse any particular political, educational or religious view. Inclusion of an item does not necessarily imply promotion or recommendation)

USEFUL WEB PAGES FOR TRANSITION

SED VESID Life Long Services Network. www.vesid.nysed.gov/lsn/home

Cornell University Employment and Disability Institute. www.ilr.cornell.edu/edj

Social Security Online. www.ssa.gov

New York State Independent Living Council. www.nysilc.org

Westchester Independent Living Council. www.wilc.org

Putnam Independent Living Center. www.putnamils.org

A Matter of Taste 4

October 17, 2007
at the Westchester Country Club
Rye, New York

This is Westchester Arc's big fundraiser for the year. Please join other PACDS families in a journal ad thanking W. Arc for their continued support and good work. The deadline for the journal is September 19, 2007, so please respond promptly by filling out and mailing the tear-off below.

We also hope you will attend the fundraiser itself, which gives everyone the opportunity to sample foods from some of Westchester's finest restaurants. The details are below:

- Attire - Business to Best
- Silent auction
- Raffle
- VIP Reception 6:00pm-7:00pm
- Event: 7:00pm-9:00pm
- Ticket Cost: \$175 for event, \$300 for VIP reception and event

Thank you !!

Please include my name in PACDS's journal ad for Westchester Arc's
A Matter of Taste 4

Name (as you wish it to appear) _____

Address _____

Amount \$ _____

Make your tax-deductible check out to "Westchester Arc Foundation"
And mail it, with this form, to *A Matter of Taste 4*, Westchester Arc,
121 Westmoreland Ave, White Plains, NY 10606

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