



pacds

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

265 Saw Mill River Road
Hawthorne NY 10532

Summer 2014

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.

The group meets from 10am-1130am on the following days:

September 19, 2013
October 17, 2013
November 14, 2013
December 12, 2013
January 16, 2014
February 13, 2014
March 13, 2014
April 10, 2014
May 15, 2014
June 12, 2014

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

PACDS EVENTS

THE ANNUAL PACDS PICNIC WILL BE HELD ON AUGUST 3 this year. As usual, the picnic will start at 12pm and will take place at Downing Park in Yorktown Heights on Rts 35/202. There is a suggested contribution of \$10 per family to cover the cost of the pavilion rental and the BBQ foods. Families should also bring something to share with the group (a main dish, a side dish, beverages, dessert, paper goods, etc). All PACDS families are welcome. Please RSVP to Stephanie Bellantoni at 914-424-3860 so we can get an accurate expected headcount, and to let us know what you will be bringing to share with the group. Please also bring a picture of your child(ren) for our annual poster board. We hope to see everyone there.

At the April 26 pot-luck dinner at the home of Stephanie and Michael Bellantoni in White Plains, NY many parents had a great time – thanks to Stephanie and Michael for hosting.

FLORIDA MAN WITH DOWN SYNDROME CLASHES WITH POLICE

In April, Gilberto Powell, who has Down syndrome and is 22, clashed with Miami-Dade police because the officers allegedly saw a bulge in the waistband of Powell's pants and they thought he was concealing a weapon. The police started to give Powell a pat-down, but he panicked and ran; after a struggle, which resulted in Powell's head hitting the sidewalk and one of the officers being hit in the chest by Powell, the officers handcuffed Powell and started to question him. It turns out the bulge in the waistband was Powell's colostomy bag! Powell's family is outraged; their attorney says it's immediately obvious that Powell has Down syndrome, and that the officers' actions were completely unacceptable. The police department says only that they are still investigating the matter.

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
831-5868

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

KEEP YOUR EYES OUT FOR A SURVEY TO BE DISTRIBUTED BY ONE OF PACDS'S OWN

Marissa Lewis is finishing 10th grade at Croton-Harmon High School, here in Westchester County. Her brother, Benjamin, has Down syndrome and her mother, Ivy, is the editor/author of the PACDS newsletter. Marissa is taking part in a three year Independent Science Study Class at her school that allows students to focus on an area of study that interests them, develop a hypothesis, work with mentors in their chosen field, conduct research to prove their hypothesis, and ultimately they submit their findings to the Intel Science Talent Search and other national science competitions.

After news broke in the summer of 2013 that a University of Massachusetts at Worcester team had silenced the extra 21st chromosome of a cell with Down syndrome by injecting a compound including protein XIST into the cell, Marissa became interested in the topic. She met with the lead researcher on the UMass team, Dr. Lisa Hall, and learned they would be testing their developed compound on genetically engineered mice within 1-2 years; and 7-8 years from now, they plan to test it on humans with Down syndrome. Marissa wondered whether her brother Ben would be able to participate in a chromosomal trial like this, and how other families would feel about their children participating. The UMass team does not yet know what the practical effects will be when their compound is used on people with Down syndrome ... will the person's intellectual capacity improve?, will some of the physical problems associated with Down syndrome no longer be present (ie hypothyroidism, low muscle tone, the early onset of Alzheimer's, etc)?, will some of the character traits associated with Down syndrome (ie an easy going and trusting nature, a happy and smiling personality?) be changed? There's lots of excitement about what the research team at UMass is accomplishing, but also a lot of questions. It's these questions that Marissa is interested in, and have prompted her to focus on, for her three year project.

Dr. Hall agreed to serve as a mentor for the technical material, and additionally Marissa has enlisted renowned bio-ethicist Dr. Arthur Caplan (at NYU) to serve as a mentor to assist her in wording her survey questions, and Dr. Kathryn Berrier Sheets (at Duke University) as a mentor regarding the statistical analysis of the survey responses. Once her survey is complete (in the spring of 2015), Marissa will be sending it to PACDS families and to several national Down syndrome organizations. We will be sure to publish her results once her project is completed.

WEBSITES OF INTEREST

Here are some sites 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 note: healthcare guidelines and growth charts.

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

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

SEEKING NEW COMMITTEE MEMBERS

PACDS needs spirited new committee members. NO EXPERIENCE IS NECESSARY! If you are interested in getting more involved with PACDS, please contact Terri Hunt at tmhunt@optonline.net 243-5874, Patty Conte at ebean37@hotmail.com 654-0238, or Stephanie Bellantoni at cervoni246@msn.com 761-3185.

MARYLAND PASSES DOWN SYNDROME PRO-INFORMATION LAW

In May, Maryland Governor Martin O'Malley signed the Down Syndrome Pro-Information Bill (also called Senate Bill 654) into law. The bill changes how parents are given information about Down syndrome after giving birth to a child with the condition. The bill came about after years of people complaining that doctors provided them with inadequate, incorrect, and antiquated information.

When Maryland resident Heather Sachs gave birth to a daughter with Down syndrome in 2006, she was handed a pamphlet entitled "So You've Had a Mongoloid: Now What?" even though the term "Mongoloidism" was dropped by the World Health Organization in 1965. When Maryland resident Kathleen Wachter gave birth to her son that same year, none of the doctors in the hospital said anything to her about their concerns that her son had Down syndrome until after a DNA test was completed days later. Both Sachs and Wachter lobbied hard to get this bill signed into law; it says that "health care providers caring for families may provide information when a child is diagnosed with Down syndrome". While parents are pleased that the issue has gotten lots of attention, many feel the bill should have included the word "shall" or "must" instead of "may", as "shall" and "must" would make the dissemination of information a legal requirement versus an option. Hopefully this Maryland bill, the first of its kind in the country, will prompt other states to take up the issue, and hopefully with more stress on what SHOULD be done, rather than what MIGHT be done.

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)

ELEMENTARY AGE PLAYGROUP

This group has been meeting monthly for years and welcomes new families that have children with Down syndrome between the ages of 5 and 15. For details call Shirley Allen at 831-5868

BOSTON FAN WITH DOWN SYNDROME SINGS NATIONAL ANTHEM BEFORE RED SOX GAME

Michael Mullins, a 38 year old die-hard Boston Red Sox fan, has Down syndrome. For many years Mullins has been dreaming about singing the "The Star Spangled Banner" at Fenway Park. Mullins has sung the national anthem for more than 10 years for a minor league team, and has been lobbying for a long time for the Red Sox to let him sing at Fenway. Well he finally got his chance to do so on May 1, and did a great job belting it out before a capacity crowd waiting to watch the Sox play. Here's a link to Mullins' performance: http://www.huffingtonpost.com/2014/05/06/down-syndrome-national-anthem-fenway-video_n_5269626.html .

2015 SPECIAL OLYMPICS GAMES TO BE BROADCAST ON ESPN

The 2015 Special Olympics Games will take place in Los Angeles, California (kicking off July 25, 2015), and the opening ceremonies will be broadcast live by ESPN on it's television networks and online. ESPN will also air a nightly "highlights" segment on it's networks. While ESPN previously streamed coverage online for the 2013 games (the Special Olympics Games are held every two years and alternate between summer and winter), this is the first time the Games will be broadcast live on television. The Games draw about 7,000 participants, and more than 500,000 spectators from around the globe are expected to tune in to watch. The National Down Syndrome Congress gave ESPN its National Media Award in 2013 for their use of respectful language when telling stories about people with Down syndrome, so surely they will do a great job with the 2015 Games.

TRYING TO GET "THE ABLE ACT" PASSED

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

Many families plan for their typical children to go to college, and open a "529 account" to afford them the chance to do so; a 529 account is a special type of savings account (created by the federal government) allowing money to grow tax free when used for higher education. Those of us with children with special needs, for whom college is a less likely option, often use a supplemental needs trust as a vehicle to put aside money for those children's needs. Supplemental needs trusts allow monies to be saved for a disabled child's use while still maintaining that child's eligibility for services under the supplemental security income program and Medicaid. However, those monies do not grow tax free ... yet! PA Senator Bob Casey has sponsored the Achieving a Better Life Experience Act (or ABLE Act) which would allow tax-free savings accounts, similar to how 529 accounts are structured for educational use, to pay for special need services. There is strong bipartisan support in both the House and Senate, and Casey is hoping to bring it to the floor for a vote soon. The bill would cost \$1.2 billion over the first ten years (according to a report from the congressional Joint Committee on Taxation). The ABLE Act proposes that families could contribute up to \$13,000 a year (529 accounts allow \$10,000 per year to be invested) and that monies withdrawn from the accounts would remain tax-free as long as it is spent on a qualifying expense such as housing, transportation, education, occupational training, assistive technology, and health and wellness. If it becomes law, the ABLE Act will provide another tool for parents to help their children with disabilities thrive.

THE NEWEST GIGI'S PLAYHOUSE LOCATION IS OPENING IN WESTCHESTER

Gigi's Playhouse is a ten year old organization that creates achievement centers for people with Down syndrome, giving them a chance to grow their confidence, skills and beliefs while advocating a global message of acceptance. There are currently 16 centers throughout the US and one in Mexico. Gigi's Playhouse offers FREE educational and therapeutic programming to individuals of all ages with Down syndrome, their families, and the community. Gigi's Playhouse is coming to Westchester, NY and they are hosting an informational OPEN HOUSE at Village Lutheran Church & Chapel School at 172 White Plains Road in Bronxville) on June 21 from 10am-12pm and there will be food, fun and raffles. Come find out what Gigi's Playhouse can do for your family. For more information on the open house, send an email to westchester@gigisplayhouse.org – for more information on the organization itself, go to www.gigisplayhouse.org.

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c/o Westchester Arc
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