



pacds

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

265 Saw Mill River Road
Hawthorne NY 10532

Winter 2014-2015

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 (at 40 Saw Mill River Road, Hawthorne), in collaboration with PACDS.

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

September 18, 2014
October 16, 2014
November 13, 2014
December 11, 2014
January 15, 2015
February 12, 2015
March 12, 2015
April 9, 2015
May 14, 2015
June 11, 2015

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

PACDS EVENTS

The annual PACDS pumpkin decorating and playground event took place on October 26, 2014 at Saxon Woods Park – the families that attended had a great time decorating pumpkins, sharing snacks, chatting, and enjoying the playground equipment.

The next PACDS event will be the annual POT LUCK BRUNCH at the home of Ivy and Michael Lewis. The brunch (please RSVP to Ivy at ivylewis@optonline.net if you will be attending, and let her know you'll be coming and what kind of dish you'll bring for the group to enjoy) will be held at 12pm noon on SATURDAY JANUARY 17, 2015. Ivy and Michael's address is 2 Red Maple Ridge in Croton-on-Hudson. Of note, they have a large house and a finished basement so all PACDS family members are invited. Also of note, they have two dogs who will be kept away from the group, but people with allergies should be aware that there are dogs in the house! We hope lots of our group members can join us for this event!

DO YOU REMEMBER READING ABOUT GARRETT HOLEVE IN THIS NEWSLETTER???

Garrett Holeve is a young man with Down syndrome who lives in FL and has long dreamed of being an MMA fighter. The state of Florida refused to allow Holeve to hold a sanctioned MMA fight against David Steffan, a young man with cerebral palsy who has competed in Special Olympics. In fact, the state of Florida even interceded in plans for a non-sanctioned fight between the two. Undaunted, Holeve and Steffan fought on November 8, 2014 in Sullivan, MO at "Cage Championships 50" where Holeve won the match. Holeve is determined to one day participate in an MMA fight in his home state of Florida, but meanwhile he is continuing to train, and pledges to support other adaptive athletes like himself. You can follow Garrett's efforts at www.garrettsfight.org.

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 Ollivero
949-2594

Adult Social Group:

Barbara Albrecht
(845) 628-8972
Debbie Elseman
(718) 884-8496

Family Picnic:

Stephanie Bellantoni
761-3185 and Patty
Conte 654-0238

PACDS Hotline:

739-4085

Spanish Liaison:

Rosa Sanchez
293-0130

MN FAMILY CHANGES HOW PEOPLE ARE TOLD THEIR CHILD HAS DOWN SYNDROME, ONE BASKET AT A TIME

Carissa and Chris Carroll didn't know their son Jack had Down syndrome before he was born, and even though he is 18 months old now, they are still angry about how they were told about his condition. Carissa had difficulties in the delivery so the hospital personnel told Chris about Jack's diagnosis, saying he had Down syndrome, then saying they should "enjoy" their baby. Information about the medical problems and developmental problems associated with Down syndrome came in batches over the next several days, and the Carrolls were confused and upset over the lack of compassion they were shown. To prevent this from happening to others, Carissa and Chris have launched "Jack's Baskets", which they hope to distribute to all hospitals in the Twin City area of Minnesota. The baskets include a note from the Carrolls welcoming the new baby to the family and a recommendation to "take the time to grieve the baby you thought you were getting and to love the baby you've been given". The basket is filled with toys, booties and clothes, as well as resources and information about Down syndrome. The Carrolls "want each family to start their beautiful journey with a Jack's Basket, knowing that their child will change their life for the better". Each basket costs the family about \$60 to make – to learn more about the Carroll's organization or to donate to their efforts in making baskets, go to <http://strengthfortheclimb.blogspot.com/>.

MAN WITH DOWN SYNDROME THRIVES IN CORPORATE AMERICA

Tyler Pence is a member of Best Buddies, an organization that helps people with disabilities thrive. Best Buddies helped Pence land a job with Bank of America, where he is part of a group of 60 people with disabilities. Pence's group organizes large mailings that the Bank is sending out, and they have fun doing it. Pence was bullied in high school, but at Bank of America he is respected. "I am always on time, and I always have a good attitude" says Pence. Coworker Brooks Igo says "he's always bragging to me about how much he gets paid, and his paycheck, and he wants to buy me dinner ... I have definitely seen his confidence grow". Kudos to Bank of America for hiring these folks and helping them live meaningful lives.

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.

FILMMAKERS GET HELP FROM KICKSTARTER

Aspiring filmmakers Sam Suchmann and Mattie Zufelt are teenagers with Down syndrome – they live in Rhode Island and want to make a movie about zombies and, thanks to Kickstarter, they are now doing just that. Suchmann and Zufelt met while participating in Special Olympics track and field events in grade school. Now Zufelt is 19 and Suchmann is 18 and they've turned to Kickstarter for help making a zombie movie. To date they have been able to raise over \$50,000 to make their movie, have story boards all prepared, and are working on a list of celebrities that they want for cameos. On Halloween Kickstarter called Zufelt and Suchmann their "project of the day", and famous filmmakers like the Farrelly brothers (who created hits like "Dumb and Dumber" and "Something About Mary") have shown their support for Zufelt and Suchmann on Twitter. While not sure that they will stick with filmmaking (Zufelt wants to be a DJ and Suchmann wants to be a singer), making this film has given them tremendous confidence. Suchmann says "My whole life, I feel like I never fit in anywhere or had a voice, but some day that will change, I will be somebody, and that day is today". Let's keep an eye out for this movie!

CHECK OUT "PRODUCE" (THE MOVIE, NOT THE VEGGIES)

"Produce" is a movie about a retired baseball player in Kentucky who is having a tough time on a daily basis, having difficulties raising his teenaged daughter, and struggling with the "curve balls" that life throws at all of us. He is "awakened" by the most unlikely of sources, a kid with Down syndrome (named Produce) who works in a local grocery store. Family, faith and purpose work their way back into the player's life and Produce becomes intertwined in the player's life in a way that restores meaning and purpose. The film is endorsed by several Down syndrome organizations, and has won several awards at film festivals. The director of one local support group says "Produce is an inspirational film about friendship, community inclusion and a sense of belonging. Attributes of life that individuals with intellectual or developmental disabilities deserve to experience. Changing perceptions to change lives. Way to go Produce" and another local support group director says "We're so proud of our member David [who plays Produce in the film] and for the film that shows people with Down syndrome are people first who can bring gifts into all of our lives". Go to www.iamproduce.com to get more details on the film and where/when it's showing by you.

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

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.

LONDON TEEN GETS CRIMINAL RECORD WIPED CLEAN, THANKS TO AN ONLINE PETITION

19yo Abdul Al-Faisal was arrested for burglary in London after he snuck out of his house, where he lives with his mother, and walked to his school, then broke in through a window, to retrieve a hat he had left in class the day before. Al-Faisal's mother didn't know where he had gone, searched the streets for hours, and ultimately called the police, then later found out he was sitting in jail. The 19yo has a functioning level of a typical 10-12 year old, didn't understand that he had done anything wrong, and signed a "formal caution for burglary" which is a confession in England. Al-Faisal's mother tried to get the formal caution removed from Al-Faisal's record, claiming he didn't understand what the document meant, and that her son was crying and confused in a cell when she got to the police station. The authorities were slow to respond to the mother's request, so she started an online petition in support of her request to get the conviction wiped off his record and more than 120,000 people signed it! The Met Police have now wiped the caution from Al-Faisal's record and have removed his fingerprints and DNA (taken upon his arrest) from their database. The Police has also offered to have Al-Faisal meet with them because he has been "terrified" (says his mother) of them since he was arrested. The mother says "we are grateful to all those who took time out to sign our petition and support us and Adbulkarriem, in other ways. It made a massive difference, we know that for a fact."

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

DISNEY URGED TO INCLUDE CHARACTERS WITH DOWN SYNDROME IN ITS ANIMATED FILMS

Keston Ott-Dahl is a California mother of a 15 month old daughter, Delaney, who has Down syndrome. While she isn't telling animation giant Disney how to make movies, she thinks that Disney should include some characters with disabilities in their movies, so that children like her daughter can relate to the characters they see on the screen. Ott-Dahl is collecting signatures for a petition that she plans to submit to Disney, asking the studio to create animated films that show characters with disabilities. "Disney has done such a great job inspiring children, generation after generation, to be good people," says Ott-Dahl, "and they are in a unique position to directly change the way future generations and societies view people with Down syndrome". Ott-Dahl thinks Disney can create positive change for all youngsters in how they view peers that have disabilities, by encouraging children to be compassionate and accepting of people that are different than they are. Ott-Dahl has collected over 30,000 signatures and hopes that her petition will elicit movies in the future that feature people with disabilities. "The Hunchback of Notre Dame" and "Finding Nemo" are two of the few representations of a character with a disability in a Disney animated film, but those characters had obvious physical disabilities and Ott-Dahl hopes Disney will create characters that also have developmental disabilities.

PAPA JOHN'S IS BEING SUED FOR VIOLATING THE AMERICANS WITH DISABILITIES ACT

The U.S. Equal Employment Opportunity Commission is accusing Papa John's Pizza of discrimination after an employee in the Farmington, Utah restaurant was fired allegedly because he needed the assistance of a job coach. Scott Bonn, a man with Down syndrome, was fired after an operating partner visited the restaurant and saw Bonn working under the supervision of his job coach. The EEOC accuses Papa John's of failing to provide reasonable accommodations to Bonn. MaryJo O'Neill, a regional attorney with the EEOC, says "People with intellectual disabilities are one of the most underemployed segments of the workforce. Many disabled persons are qualified, ready and willing to work. All they need is an equal opportunity. Job coaches are one form of reasonable accommodation that allows employees with intellectual disabilities to be able to work." Papa John's was contacted for a statement by the magazine Disability Scoop, but only said "We are in the process of gathering all the facts, and will then take the appropriate action."

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