

# WALK NOW FOR AUTISM SPEAKS

## Autism Speaks Long Island Edition

Volume 1, Issue 3

November 2011

### Beautiful Skies for Oct 2nd's Walk Help Us to Surpass Our Goal of \$1,511,000!



Over 30,000 individuals arrived at Jones Beach State Park to show Autism Speaks their support!

Wantagh, NY — The 12th Annual Long Island Walk Now for Autism Speaks took place on a beautiful unseasonably warm fall day on Sunday, October 2nd at Jones Beach State Park.

Over 30,000 participants and 500

teams arrived at the beach to walk in solidarity! The total raised by the end of the day was over one million dollars!

The walk could not have been a success without the passion and dedication of our wonderful Volunteer Committee and the hard work of Jeff Friedman, owner of Verona Productions.

Even though you may have missed the walk, it's still not too late to make a difference! You can still form a team, fundraise, and/or donate to the Long Island Walk Now for Autism Speaks, please visit:

[www.walknowforautismspeaks.org/longisland](http://www.walknowforautismspeaks.org/longisland).

We've successfully surpassed our goal of \$1,511,000 million, which makes us only \$100,000 away from reclaiming our title as the #1 Walk Now for Autism Speaks in the country, as well as in Canada! It's important that we continue to forge forward with our fundraising efforts not only to continue funding important scientific research, Family Services programs, autism advocacy efforts, and autism awareness campaigns, but to surpass Los Angeles and Chicago and secure Long Island's rightful place as Autism Speaks' top walk!

#### Walk Now for Autism Speaks Long Island

- CONGRATS, LONG ISLAND! WE'VE SURPASSED OUR GOAL OF \$1.511 MILLION, BUT THERE'S STILL TIME TO DONATE BEFORE DECEMBER 31ST!
- DONATE ONLINE AT: [WWW.WALKNOWFORAUTISMSPEAKS.ORG/LONGISLAND](http://WWW.WALKNOWFORAUTISMSPEAKS.ORG/LONGISLAND)
- MAIL IN ANY CASH OR CHECK DONATIONS TO THE LONG ISLAND OFFICE AT:  
380 OAKWOOD ROAD  
HUNTINGTON STATION, NY 11746

#### 2011 NATIONAL SPONSORS



### Autism Speaks Awards 10 New Research Grants Funding Nearly \$1.8 Million Over Next 3 Years

On October 12th, Autism Speaks announced that \$1,782,934 in funding to be issued over the next three years was awarded to 10 new research grants that will evaluate the effectiveness of an array of promising behavioral and medical treatments for the core symptoms and associated medical issues in individuals with autism spectrum disorders (ASD).

Three of the pilot projects address the needs of non-verbal individuals with autism by focusing on social engagement and language development. One of these projects is based out of New York at the Albert Einstein College of Medicine. Gottfried Schaug, M.D., Ph.D., will conduct "Auditory Motor Mapping Training," a randomized control

trial of a type of therapy to promote speech. The therapy uses singing, motor activity, and imitation to activate brain regions associated with speech. The other two projects are based out of the University of Kansas and Michigan State University.

New York's Albert Einstein College of Medicine is also piloting one of the two projects focusing on improving quality of life by addressing seizures and sleep, 2 common medical conditions associated with autism. Aristeia Galanopoulou, M.D., Ph.D., is heading up the project that will study the role of mTOR inhibitors (proteins that regulate vital cell growth processes) on the treatment of autism symptoms found in children with infantile

seizures. The other study is based out of the University of Colorado.

Other grants that have been awarded to the New York area since 2007 include Cold Spring Harbor Laboratories, Columbia University, Institute for Basic Research in Developmental Disabilities in Staten Island, Memorial Sloan Kettering Cancer Center, Mount Sinai School of Medicine, New York University, and the Feinstein Institute for Medical Research.

To find more information about all of the grants that are funded by Autism Speaks, please visit the organization's Grant Search page at [grants.autismspeaks.org](http://grants.autismspeaks.org).

#### Recent Local Special Events:

- GAGA Listens When Autism Speaks Family Day (GAGA, Syosset) *September 19*
- Bands Battling Autism (Stuart Thomas Manor) *September 25*
- Lisa Beth Gerstman Foundation Golf Outing (Glen Head Country Club) *October 10*
- New York Islanders Autism Speaks Fundraising Night (Nassau Veterans Coliseum) *October 25*
- Shopping Night for Autism (Sands Point Shop, Entrée, and Dolphin Books) *November 10*

#### Upcoming Local Special Events:

- Cigar Night (J. Barbera Tobacconist) *December 6*
- Bar Night for Autism (Overlook) *December 13*
- LAGOS Holiday Event (Bloomingdales, Walt Whitman Mall) *December 15*
- Long Island Walk 2011 Awards Reception (Crest Hollow Country Club) *January 17*
- Polar Bear Plunge (Bay Shore Marina Beach) *March 3*

# Autism Speaks Long Island Edition

## New York Autism Insurance Bill—A Win Win



Governor Cuomo signing the New York autism insurance reform legislation

New York is now the 29th state to end autism insurance discrimination. Effective November 1, 2012, state-regulated health plans are required to cover the screening, diagnosis, and treatment of autism. The landmark legislation, one of the strongest bills in the nation, imposes no age caps and no visit caps that apply solely to ASD, and provides for applied behavior analysis (ABA) thera-

pies up to \$45,000 per year.

Governor Cuomo, through his leadership on this issue, did even more than provide access to autism treatments through insurance for the estimated 1 in 110 children living with autism, he brought tax relief to New York State. An expected cost savings of an estimated \$13 million dollars is expected in special education, Medicaid, and social service

costs, an amount expected to only increase. Our state government worked in a true bi-partisan effort to provide for the most vulnerable in our communities, while being fiscally responsible, and they should be commended.

*-written by Diane Cahill, President, Autism Coalition of Long Island & New York State Advocacy Chair, Autism Speaks*



Young Edward Nitkewicz throws the ceremonial first pitch to former New York Mets player, Buddy Harrelson

## Long Island Ducks Hold Autism Awareness Night

Islip, NY— August 8th was Autism Awareness Night at Bethpage Ballpark. The Long Island Ducks took on the Lancaster Barnstormers. As part of Autism Awareness Night, the Ducks set aside a section of seats at a discounted price with a portion of

the sales benefiting Autism Speaks! The first 1,500 fans received an Autism Speaks-branded fun-sized puzzle of the field at Bethpage Ballpark.

Thirteen-year old Edward Nitkewicz of Melville, the inspiration for Ed-

ward's Army, one of Long Island's top Walk Now for Autism Speaks teams, threw out the ceremonial first pitch to former New York Mets player and current manager for the Long Island Ducks, Buddy Harrelson.

## 3rd Annual Bands Battling Autism a Success!

Farmingdale, NY— The Autism Speaks Long Island Youth Leadership Council held their signature fundraising event, the 3rd Annual Bands Battling Autism, on Sunday, September 25th at the Stuart Thomas Manor in Farmingdale!

The event raised over \$3,000 for the Long Island Walk Now for Autism Speaks through event ticket sales, raffle ticket sales, and event t-shirt sales. T-shirts were created by Spectrum Designs and promoted the names of the bands participating in the event on the backs of them. Performing acts included The Seaweed Takos, Last Great Hero, Char-

lie Dane, Homebound, and Runnin' on Empty.

Raffle prizes were generously donated by Ambiance Hair Salon, Barnes & Noble, California Pizza Kitchen, Denny's, Edward Alan Big & Tall, Howard Rosenthal Photography, IHOP, New Jersey Devils, New York Giants, New York Islanders, New York Jets, New York Rangers, Panera Bread, Robert Bodian, Spectrum Designs Foundation, Target, and the Brain Balance Center. Jet-Blue Airways and Sam Ash Music Corp donated the event's amazing grand prize raffle prizes: a voucher for 2 roundtrip tickets to anywhere,

anytime and a Fender Strat Pack. The raffle ticket sales alone raised \$550!

Sam Ash Music Corp also donated a Samson Q3HD to be used as a prize for the winning act. Winning band, Last Great Hero, consisted of students hailing from Plainedge and Bethpage High Schools and rounded out the stage show at the Long Island Walk Now for Autism Speaks at Jones Beach on October 2nd! Congratulations and much thanks to all of our participating bands!

Stay tuned for future events hosted by the Youth Leadership Council!



2011 Bands Battling Autism winners, Last Great Hero

## Take the Polar Bear Plunge!

The Long Island Autism Speaks office has partnered with AHRC Suffolk to host the 2012 Polar Bear Plunge at the Bay Shore Marina Beach in the Town of Islip on March 3rd at 10:00 am (Registration will start at 9:00 am).

Everyone is encouraged to take the plunge for this great cause. Participants under the age of 18 are required to get a parent or legal guardian signature. Proceeds from the event will be split between AHRC Suffolk and Autism Speaks.

Additional details of the event will be forthcoming. Stay tuned to the Long Island Walk Now for Autism Speaks website

([www.walknowforautismspeaks.org/longisland](http://www.walknowforautismspeaks.org/longisland)) for more information on how to get involved as it becomes available.



Proceeds of the 2012 Polar Bear Plunge will benefit Autism Speaks and AHRC Suffolk

## **Spectrum Designs Foundation Opens New Nicholas Center for Autism!**

In October, Spectrum Designs Foundation held a ribbon-cutting ceremony for their brand new location for the Nicholas Center for Autism in Port Washington. The facility boasts enough space to accommodate the Spectrum Designs workshop (an apparel decorating company that employs individuals with autism and similar conditions), office space, as well as a state-of-the-art kitchen and several bathrooms to be used in order to teach important life skills, such as meal preparation, personal hygiene, grooming, dressing, household chores, etc., and three

bedrooms. The Center also has plans to offer an Overnight and Weekend Respite program for families of individuals with autism in the near future.

Spectrum Designs Foundation and the Nicholas Center for Autism was founded by CEO Stella L. Spanakos, Director of Development & Community Liaison, Nicole Sugrue, and Program Director, Patrick Bardsley due to the discouraging lack of resources for young adults living with autism and other similar conditions.

Spectrum Designs has designed and

created artistic and high-quality t-shirts for many local events such as the Long Island Autism Speaks' Youth Leadership Council's 3rd Annual Bands Battling Autism as well as many of the t-shirts worn by walk teams at this year's Walk Now for Autism Speaks, including Bill's Team, Eric's Swim Team, and Team Super Matt.

For more information regarding the Nicholas Center for Autism, please visit [www.ncafastism.org](http://www.ncafastism.org). For more information regarding Spectrum Designs, please visit [www.spectrumdesigns.org](http://www.spectrumdesigns.org).



*NCA and Spectrum Designs co-founders, Stella L. Spanakos, Patrick Bardsley, and Nicole Sugrue pictured with Town Clerk of North Hempstead, Leslie Gross, at the Nicholas Center for Autism ribbon cutting ceremony*

## **Stay Involved & Informed!**

**11/15 People First Waiver**—Major changes on the horizon! On November 15th, New York State Office for People with Developmental Disabilities (OPWDD) announced the availability of a Request for Information (RFI) that will gather input regarding the developmental reforms recommended by the People First Waiver design teams and summarized within OPWDD's 2011-2015 statewide comprehensive plan.

We strongly encourage parents to visit the OPWDD website (<http://www.opwdd.ny.gov/>) and familiarize themselves with the People First Waiver as the manner in which you'll be receiving services may change over the course of the implementation time period. Any input to the RFI needs to be submitted by November 30th. The submitted questions and answers will be posted to the website on December 13, 2011.

## **Pollari Fulfillment Center Offers Hope for Future Adults**

With our focus shifting to the greatly underserved population of young adults with autism soon to be leaving the classroom for the real world, the Pollari Fulfillment Center in Deer Park may have found a way to prepare our youth for a promising future following academia.

At the close of the summer, Pollari initiated a program in conjunction with the Developmental Disabilities Institute (DDI) of Smithtown to provide vocational training for kids with special needs in hopes that they can one day join the workforce. The goal of the program is for these kids to gradually become accustomed to working an entire shift that includes repetitive motion type of work, such as hand assembly and packaging. The participants are paired with a "shadow" (on some occasions, one "shadow" is assigned to two individuals) that helps guide them to remain focused on the task at hand. Occasionally, the participants take some of the materials they work with

back to DDI in order to continue their training.

There is already a process in place for assimilating these kids into "typical" schools. Why can't the same be done for the workplace? Zach Tesch is one of the few young individuals piloting the Pollari program. Zach's family has been joining us for the Long Island Walk Now for Autism Speaks for several years now as "Zach Pack." In addition to the walk, the Tesch family has remained an integral part of the Long Island Autism Speaks community. Both of Zach's parents, Larry and Stacey, hold positions on the Volunteer Committee while his siblings, Jake and Morgan, serve on the Youth Leadership Council. Jake, in particular, has been the Council's Co-Chair for over 2 years. Every Wednesday, Zach spends a few hours at the Fulfillment Center with his "shadow," working on hand assembly and packaging skills. According to Larry, "[Zachary's] employment has meant a great deal to us and Zach-

ary. He is provided with transportation and aided by a staff member from DDI. The job signifies the beginning of Zachary's transition from full-time student to a productive member in the workplace. It also places Zachary in an environment where he can live up to his capabilities in a professional, yet nurturing atmosphere. Like any job, there are expectations of how proficient Zachary is to be at the tasks assigned to him, but the staff at Pollari Fulfillment Center are alert to the requirements of their special needs employees."

At the start of the school year, Pollari took this idea one step further and partnered with South Oaks to bus high-functioning special needs high school students into the Fulfillment Center several hours a week to be trained on repetitive motion type of work.

It's the innovation and progressiveness of companies like Pollari Fulfillment Center that brings the autism community hope that there will be a brighter future for our children.

**"THERE IS ALREADY A PROCESS IN PLACE FOR ASSIMILATING THESE KIDS INTO 'TYPICAL' SCHOOLS. WHY CAN'T THE SAME BE DONE FOR THE WORKFORCE?"**



*Zach Tesch, pictured here in his element at the Pollari Fulfillment Center*



Autism Speaks  
 Long Island Office  
 380 Oakwood Road  
 Huntington Station, NY 11746  
 Phone (631) 521-7853  
 Fax (631) 424-3404  
 longisland@autismspeaks.org

Meet the Long Island Office Staff:

Rich Mallow  
 Walk/Event Director, Long Island

Rose Ann Walsh  
 Walk/Event Manager

Serena Ahne  
 Walk/Event Coordinator

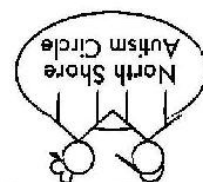
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