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## Imagine Walk, 2005 Ready To Go...



The 3rd Annual Imagine Walk and Family Fun Day is set for April 10th, 2005 at Goddard State Park. Start time for registration is 9:00AM, walk starts at 10am. The two previous Walks have been tremendous successes both as fundraisers as well as a day of fun enjoyed by the entire family. This year will be no exception. On tap again this year are a host of games and activities for the whole family. Please join us!



**See you there!**

*Many thanks to our Champion Sponsors...*



## From the Executive Director

Dear friends,

**B**uild it and they will come! The energy and activity level of the office the past few months is testament that this is indeed true. It is a good thing that the days are getting longer because there is much to do.

As we recognize Autism Awareness Month, it's time to look back at where we've been and to imagine where we can be.

Three years ago I sat in a very small office with a table, bookshelf, a laptop and the invaluable support of a group of parent volunteers and professionals with tremendous energy, ideas and commitment to our mission. None of us could have imagined where we'd be today. Because of your support, their hard work, vision and dedication we are reaching more friends with autism, their families and the professionals who work with them every day.

One of the best new associations is the RI Autism Coalition. I am so proud to work with so many diverse and energetic organizations with the common denominator of helping people with autism. Please join us for our first event, an **Autism Awareness Rally** on March 31, 11:30 a.m. to 3:00 p.m. at the State House. Come hear many different perspectives and life experiences as our honored guests speak to local and national politicians about our families' struggles and successes.

Also, join us for one of our upcoming fund raising activities, training, camp or a new social opportunity. The 3<sup>rd</sup> annual Imagine Walk and Family Fun Day is April 10 and promises to be the most successful one yet. Our Volunteer Meeting (and light dinner) is scheduled for March 28. If you would like to attend, please RSVP to Roberta at [thezims@gis.net](mailto:thezims@gis.net). Our regularly scheduled programming continues too! Call for information or visit our Website for specifics on any of our programs: A Starting Point; the Parent Resource Center; the Club, Social Skills Groups, Discussion Groups, or a Support Group.

Congratulations to the many parents who worked quickly and effectively to defeat the addition of a \$125 cost share for Katie Beckett recipients' parents. Your voices were heard and because of your courage and conviction the Bill was removed from the Governor's 2006 Budget. Enjoy the Spring!

*Juanno*

**Executive Director**

## Just around the corner...

...the day will come when we all learn to "respect the diagnosis of autism".

**T**he quote comes from Roger Cox of UNC's TEACCH program. I was very fortunate to be in attendance at a workshop in the fall given by Roger when he dropped that pearl of wisdom. I immediately began to do some self-reflection: "Do I respect the diagnosis? Or do I expect to *un-do* the diagnosis?" Expecting to un-do the diagnosis is a pretty arrogant position given the complicated neurological puzzle autism presents.

Roger used the example of deafness to further illustrate what he meant. When we are helping a child with a hearing impairment, do we respect the neurology of *that* diagnosis? Would we ever say to that child: "OK for a certain period of time each day, we expect you *not* to be deaf." Of course not! That would be contrary to the neurology of the diagnosis. Instead, we would insure that the child had all of the supports s/he needed to function *despite* the diagnosis (hearing aids, learning to read lips, learning sign language, etc.). Moreover, we would easily accept the behavioral and social implications associated with deafness when the supports that work for that child were not provided.

And yet, so often, we *do* say to children with autism, "OK for a certain period of time each day we expect you *not* to be autistic!" We say it through our behavioral expectations, through our IEP goals, through our HBTS plans, and through the community experiences we sometimes force our kids into. "No self-stimulatory behaviors." "Increased social interaction with peers." "Meaningful use of language." I am not saying these are inappropriate goals – they are very appropriate. Just like communication goals are very appropriate for a child with a hearing impairment. But do we respect the diagnosis of autism enough to insure that the supports that work for that child are always in place before we expect him/her to function *despite* the diagnosis? And when they are *not* in place, are we accepting of the behavioral and social implications associated with autism in the same way we are accepting of the child who is deaf?

I guess what I hope is that just around the corner, we all learn to respect the diagnosis *and the child* enough to be accepting of behaviors associated with autism when necessary supports are not provided – and that doesn't sound arrogant at all.

*Kathy Schleng*

**President, Executive Board**

## Lessons in Learning...

### ASD Parent Resource Center Opens

A new resource is available for parents of children with an autism spectrum disorder. The new ASD Parent Resource Center opened on March 19, 2005 at The Autism Project of RI. "There is so much information a family needs when their child is diagnosed with an autism spectrum disorder," commented Bethany Tassoni, Co-Parent Coordinator of the Center. "Our hope is that the Parent Resource Center can serve as a guidepost for families as the journey through autism."

The Center is designed to allow parents to come in and research, print pictures or just relax and meet other parents. "Hopefully they will learn something here that they can take home with them and help their children and themselves," said Ms. Tassoni

Bethany Tassoni and Melissa Kornasky are the volunteer Parent Coordinators of the new ASD Family Resource Center. They worked for months to collect and sort an amazing amount of information and resources into an organized, user-friendly center. The center is open on Saturdays from 9 to 2:00 p.m. at The Autism Project of RI's office at 51 Sockanosset Crossroad.

The Center offers information on the following topics:

#### *Navigating the System*

Copies of forms needed for SSI/SSDI, Katie Beckett Program, and information on key area agencies are available. A staff member will be available to assist in completing these forms and answer questions that you may have.

#### *Community Phone Book*

We've compiled phone numbers and addresses of relevant agencies and other professionals in the autism community.

#### *Computer Bank with Printer*

Access a computer with Boardmaker® and related ASD programs to create communication and support materials.

#### *Lamination Station*

Laminate materials to create communication pictures, schedules, etc.

#### *Legal Information*

Parents will have access to a rotating list of Attorneys willing to practice pro bono on issues including SSI/

SSDI, Educational Advocacy, and Special Needs Trusts.

#### *Sensory Corner*

Parents can find information regarding sensory issues, learn new sensory activities to do with the children, and look at samples and catalogues of great products geared towards sensory integration.

#### *Swap Corner*

A running list of available items typical to a household of an individual with autism will be accessible. Some of the items will be free, and some for sale or to swap.

#### *Book Look/Library*

A variety of books covering all topics of Autism Spectrum Disorders can be enjoyed in the library. Catalogues are available for parents to look for items that are not available at regular stores. Order forms available for books through the Autism Society of North Carolina Bookstore are available.

#### *Social Story Section*

Parents can learn how to create and view samples of social stories. Carol Gray's Newsletter will be available. Staff members will be available to help with writing social stories.

The ASD Family Resource Center is open to our members. Thanks to the generosity of an anonymous benefactor, there are funds allocated to support memberships for families who may need assistance. Simply email Joanne Quinn at [Joanne@theautismproject.org](mailto:Joanne@theautismproject.org) or ask one of the Parent Coordinators at the ASD Parent Resource Center for assistance.

"Getting involved with the Autism Project has saved my life," commented Melissa. "I have attained the tools necessary to help my child reach his full potential. The Parent Resource Center is designed in that fashion... giving parents the opportunity to become a fundamental part in their child's developmental process."

**Autism Society  
of North Carolina  
Bookstore  
AFFILIATE**



## From the Development Corner

**D**uring the past few months we have been very busy preparing our upcoming **Imagine Walk and Family Fun Day Event** to be held on **April 10, 2005**. Please join us again this year for a fun-filled day for the entire family. We are happy to announce that the brochures were mailed the second week of March. If you do not receive a brochure you can call our office at 401-785-2666 and we will be happy to mail one out to you, or download the information from our website [www.theautismproject.org](http://www.theautismproject.org). We also have posters available for you to display at your place of business, please call 401-785-2666 if you would like one.

The Autism Project of Rhode Island would like to express our heartfelt gratitude to the following Corporate Sponsors of our 3<sup>rd</sup> Annual Imagine Walk and Family Fun Day for their overwhelming support.

### Champion Sponsors:

**Master Card, NBC/10, Gem Plumbing**

### Area Sponsors:

Advanced Financial Services, Citizens Bank, Neighborhood Health Plan of New England, Re/Max, Michael Pinelli, Washington Trust

### T-Shirt/Red Flag Sponsors:

DeWal Industries, Duffy Sweeney & Scott, G&G Technologies, Univar

### T-Shirt Sponsors:

Barrett & Company, Blue Cross Blue Shield, DiPrete Engineering Associates, Global Real Estate, Homestead Bakery, Justice for All, Krispy Kreme Doughnuts, Munroe Dairy, Shaw's Supermarket, Telecompioneers-Providence Life Member Club, George Greer Foods, Zelan Insurance Agency, Meridian, Journey's End Farm, Mei Design.

The Autism Project of Rhode Island would also like to thank the following businesses and individuals for their recent donations:

St. Mary's Church, Newport RI for their recent stewardship award of \$1000.00 to our organization, and the Newport Yachting Center for their recent donation of \$4490.00 from "A Taste of Rhode Island".

### Upcoming Events:

Our 2<sup>nd</sup> **Annual Wine, Dine & Help Autism** wine tasting event will be held on **May 4<sup>th</sup>** at Gian Carlo's Ristorante, 153 Hamlet Ave., Woonsocket RI. Tickets are \$65.00 and include a four course meal with wine tasting and a

small raffle. Cocktail hour begins at 6:00PM. For tickets please call Mary at 401-785-2666. Advanced registration is required due to the limited number of seating. All proceeds from this event support a camp scholarship fund for children with autism. Last year twelve children were able to enjoy our camp, **Move, Think, Create, Communicate** due to your generosity.

On **June 9, 2005, McFadden's Restaurant** is hosting a special evening to benefit the Autism Project from 5-8PM. Tickets are \$8.00 and include appetizers. Drinks are half price. Please join us after work and help us support our programs designed exclusively for children with Autism.

We are hosting our 2<sup>nd</sup> Annual Golf Tournament, **"Drive for Autism"** on Monday, July 18th at the Richmond Country Club. The cost per golfer is \$125.00 and includes greens fees, cart and steak dinner. We also have some great prizes which include a \$10,000 money hole. If you would like to register to play, please contact Michael Andoscia at (401) 265-2882.

We are happy to announce that **Frerichs Farm**, 43 Kinnicut Ave, Warren, RI is going to donate a percentage of their greenhouse and gift shop sales for the month of April to the Autism Project of Rhode Island. If you are getting your garden ready, what better place to shop...we thank the Frerich family for their generosity and support of our organization.

The Autism Project of RI is happy to welcome Mrs. Jackie Brosco to our organization. Jackie will serve as the Chairperson of our Fundraising Board, joining existing members, Michael Andoscia, and Bethany Tassoni. Jackie is busy planning our annual silent auction event to be held later this year. If you would like to help with this committee or donate a silent auction item, please contact Mary at 401-785-2666.

### *In Memory Of...*

The Autism Project of RI gratefully acknowledges the very generous gifts we received on behalf of the family of **Pauline LaFauci**:

Mr. & Mrs. Walter Benson, Ms. Elisabeth Bestwick, Leslie and Gerrit Brouwer, Mr. & Mrs. Donald Cotter, Mr. & Mrs. David Day, Ms. Anne Fornaro, Mr. & Mrs. Kevin Hodgson, Ms. Mildred Crabb, Ms. Judith Taylor, Mr. & Mrs. Henry Kandzinski, Mr. & Mrs. Norman Nelson, Mr. & Mrs. Albert Plate, Mr. & Mrs. Fred Schofield, The Honorable Bruce Selya, Mr. & Mrs. Allan Taylor.

You can also help our organization by hosting an event on your own or in conjunction with your business. Contact our Development Director, Mary Farhoumand at (401) 785-2666 or e-mail her at [mary@theautismproject.org](mailto:mary@theautismproject.org) if you can help. **We are proud to report that 94% of your donation goes directly to our programs!**

### Merchandise

We now have the **Autism Car Ribbon Magnets** available. You can pick them up at our office at 51 Sockanoset Crossroad in Cranston or order them directly from our website. For every \$5.00 donation you will receive a free magnet for your car. We also have the **Autism silicone bracelet** as well as the **Autism label pin** available for a donation of \$5.00 each, shipping is free.



## Camp Program Set For 2005

**M***ove, Think, Create, Communicate* is a two-week summer camp program for children with an autism spectrum disorder (ASD) or related communication disorders sponsored by the Autism Project of Rhode Island. The program is rich with visual supports, structured teaching methods, sensory based activities and traditional camp activities like swimming, arts and crafts, and nature walks. It will be held at the Boy Scouts of America Champlin Scout Reservation, a beautifully wooded rustic campsite complete with a pond and a swimming pool, located in Cranston, RI.

*Move, Think, Create, Communicate* is designed to fill the gap often created when Extended School Year (ESY) programs finish and there is a break before the new school year

Children from age 5 (and entering kindergarten) to 17 with an ASD diagnosis or related communication disorder may attend *Move, Think, Create, Communicate*.

Our summer camp runs from 9:00 AM to 2:30 PM. Session I will run from August 15<sup>th</sup> to 19<sup>th</sup>, Session II will run from August 22<sup>rd</sup> to August 26<sup>th</sup>.

The tuition for camp is \$375.00 per week. Camperships are available on a limited basis. Tuition may be paid by personal check, VISA, MasterCard or checks from other funding sources.

## ASD Bills Introduced at State House

*Rhode Island Autism Spectrum Disorder Evaluation and Treatment Act* and the second bill H5729 have been introduced to the house and will be placed on the calendar for hearings soon. H5729 is a bill to remove mercury from vaccines in Rhode Island for good.

Here's a link to both bills: RI ASD Evaluation and Treatment Act: [www.rilin.state.ri.us/Billtext/BillText05/SenateText05/S0740.pdf](http://www.rilin.state.ri.us/Billtext/BillText05/SenateText05/S0740.pdf)

Mercury Removal: <http://www.rilin.state.ri.us/Billtext/BillText05/HouseText05/H5729.pdf>

## Welcome New Staff Members

**W**e welcome two part-time staff members to our organization. Susan Baylis Sposato recently joined our staff as our part-time Parent Liaison Coordinator. Her primary responsibilities focus on our parents' needs for support and access to information. Sue will answer parent phone calls, oversee the A Starting Point series, offer support for Picture Exchange Communication consultations, and be responsible for Community Outreach.

Many of you already know Sue from her recent position as the Parent Coordinator for the A Starting Point series. A parent of two young girls with autism, Sue brings a wealth of knowledge to our organization and parents from her life experiences and extensive training in many areas related to autism spectrum disorders.

Deb Langevin is our new Project Support person. Her remarkable bulk mailing skills and office/program support will be a great help as we continue to grow programs and events. Welcome to both Sue and Deb!

## Social Skills Group Plans

**W**e're finishing our Pilot program for our new social skills groups. The next round of a seven-week series will begin the last week of April. We will introduce a new 6 to 9 year old play group for children with PDD. There will also be a 9 to 12 year old and 13 to 18 year old Clubs that include one day of Karate at the Kent County YMCA and one day of social skills at The Club in our Cranston location. Call Connie Rinehart for updates on our new Club Social Groups.

The Rhode Island Autism Coalition  
Invites you to

**Autism Awareness Day**  
**At the State House**

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**Join people with autism spectrum disorders, family members, advocates, education professionals and legislators for this very important event!**

**Thursday, March 31, 2005**

*[Autism Awareness Month begins April 1<sup>st</sup>!]*

**Rhode Island State House – Providence, RI**

**11:30 a.m. Exhibitors**

*[Refreshments will be served. \*]*

**12:00 – 1:30 Program**

**1:30 – 2:30 Visits to Legislators**

\* Sponsored by ASD Support Center [RITAP], Autism Project of Rhode Island & Families for Effective Autism Treatment

**After the program, please plan to visit your legislators to discuss issues of importance to people with ASD and their families. Please take advantage of this very important opportunity and tell your story!**

**For more information please contact Sue Constable of the ASD Support Center at (401) 222-4600, ext. 2014.**

*Please be prepared to show identification at the State House.*

**GROUP MEMBERS OF THE COALITION REPRESENTED INCLUDE:**

Asperger's Association of New England [Rhode Island Chapter]

ASD Support Center [Rhode Island Technical Assistance Project]

Autism Project of Rhode Island

Families for Effective Autism Treatment

Island Community Autism Resource Exchange [Newport Area Support Group]

Moms for Options to Treat and Heal Autism and Related Syndromes

National Alliance for Autism Research

Rhode Island Department of Education

**Communication/Access Requests** Individuals who need a sign language interpreter or other auxiliary devices for effective participation are asked to make the needs and preferences known to Sue Constable at (401) 222-4600, ext. 2014 by March 21, 2005. Individuals using TDD may call Relay RI at 1-800-745-5555