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## The RI Autism Spectrum Disorder Evaluation and Treatment Act Signed into law!

In July, the Governor signed into law the *Rhode Island Autism Spectrum Disorder Evaluation and Treatment Act*.

The key components to the legislation include: establishment of an Autism Spectrum Disorder Advisory Committee; outreach and education to physicians for earlier screening; and DOH will establish a system to catalogue each diagnosis.

“This law is important on so many levels,” said Joanne Quinn, executive director. “We’ll be able to get the information on early signs to the pediatricians who will then refer children for evaluations. Early evaluations mean earlier intervention and better long-term results.”

When a diagnosis is made, doctors will then report it to the DOH for total number of individuals with autism. “This is a

huge victory for our families,” commented Joanne. “It means more information will be available to pediatricians and families on early signs and screening methods. We will also have an accurate count to work with when developing programs and asking for funding both locally and nationally.”



*Joanne Quinn and Jessica Burrows at State House*

A special thanks to key supporters of the bill including David Tassoni, APRI Board Member. David helped with the language of the law, but more importantly recruited and kept several key people in good humor while waiting to testify. Thank you too to Drs. Joseph Hallett, Memorial Hospital, and Yvette Yatchmink, Hasbro, CDC, and Sue Constable, RITAP/DOE and Bethany Tassoni for testifying on behalf of our children and families.

The Department of Health is already investigating early screening models and their current systems for cataloguing a diagnosis. The ASD Advisory Committee should convene in the fall.



**Remember, “life is like a box of chocolates”....how? See page 8!**

## From the Executive Director

Dear Friends:

What a day! I just returned from a visit to our camp and I can't stop smiling. The peaceful, yes I did say peaceful, sounds of camp are overwhelming. Forty-five campers are enjoying the beautiful outdoors, making friends, interacting, jumping in the Jump House, meeting up with friends from last year and relaxing. Congratulations to Connie Rinehart, camp director and Deanna Dufficy, assistant camp director for organizing two terrific weeks. Thank you to all the parents for sharing their children with us, some for the fourth year! Thank you too to all our staff who hit the camp running at 8:30 a.m. and don't stop until long after the last camper has left.

It's been a busy summer for us. We rolled out several new programs this summer after receiving our Medicaid Provider status and an important grant from the RI Foundation. We now offer a music-language group, social skills groups and a new Parent to Parent coaching program.

I recently participated in a panel discussion on *Treatment Options for Children with ASD*. Gateway Healthcare hosted the event that was moderated by Representative Jim Langevin.

It was an important event and I felt honored to be a



(L to R) Sue Constable, Rep. Langevin, Joanne Quinn, Dr. Henry Sachs, Dr. Barry Prizant

part of a panel with Dr. Larry Hirshberg, Dr. Barry Prizant, Dr. Sachs from Bradley Hospital, Sue Constable, Bethany Tassoni, Pamela Thompson and Peg Malone from Beacon Health. I hope we can participate in future panel discussions to continue the discussion of treatments and outcomes for our families.

This summer we also saw a shift in the media coverage and discussion of the possible explanation for the rapid increase in the diagnosis of autism. David Kirby, author of *Evidence of Harm*, Robert Kennedy, Don Imus and Tim Russert, moderator for *Meet the Press*, pushed the discussion of the link of Thimerosal (mercury) to increased cases of autism to a national level. The debate continues and as it does, I encourage us all to continue to pay attention to the debate, research all facts and question what's presented on all sides. But most important, I urge us to agree to disagree. Time is too short and our children too precious to waste critical energy that can be directed to furthering the cause of individuals with autism through research and critical support services.

Lastly, to continue our many new programs, we must also hold events for you to enjoy while supporting the Autism Project. The next one is a chocolate lover's dream! *Bittersweet* will be the largest Chocolate Buffet ever. Ten of the world's great chefs will visit Providence to create the extravaganza. In addition to the Chocolate Buffet, there will be a live auction, music, wine and hors d'ouvres, and the drawing of our raffle for a custom motorcycle designed by XDream-Cycle worth more than \$100,000! Please consider purchasing a raffle ticket or attending the event. It will be a night to remember. Information is available at [www.BittersweetAPRI.org](http://www.BittersweetAPRI.org)

Sincerely,

*Joanne Quinn*

Executive Director

## From the Development Corner

We would like to express our sincere appreciation to the following businesses and individuals who have recently sponsored fundraising events for the Autism Project of Rhode Island:

Leah Wilson and McFadden's Restaurant and Saloon for hosting an autism awareness night on Thursday, June 9th. Due to their generosity we were able to raise over \$400.00 to support our programs.

South Kingstown Lions Club for donating a camp scholarship for a South Kingstown child to attend Move, Think, Create, Communicate this summer.

Employees of Lincoln Town Hall for hosting a dress down day and raising \$128.00.

Chris Perrotti and the Newport Yachting Center for hosting the 7<sup>th</sup> Annual Snapple Music Festival and raising \$15,000.00.

### Second Annual Drive fore Autism

Once again thanks to the efforts of Michael Andoscia, our annual golf tournament at the Richmond country club was a huge success and we were able to raise \$7,500.00 to support our summer camp. Many thanks to the following individuals who helped make this event possible: Bethany Tassoni, Deb Langevin, Wendy Whitford-Gould, Cathy Easop, Mary Caruso, Lisa Sestito, Brenda Alpaio, Connie Rinehart, Joe Santos, Michael Quinn, Wendy Wagenbach, Adrienne Golden, Jessica Golden and Beth Golden.

### A special thank you to our corporate sponsors:

Inskip Auto Mall for providing hole in one prizes as well as a Volvo!

### Specialty Sponsors:

Maguire Group

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*Flagstick Sponsor:*

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Restivo Monacelli, LLP, CPA

Richard Merola, Esquire

Warwick Mall

**Please mark your calendar**

**4<sup>th</sup> Annual Imagine Walk & Family Fun Day**

**Sunday, April 9, 2006**

**Goddard Memorial State Park, Warwick.**

### School News:

Did you know that your class or school can make a difference? We have many ideas that you can use to fundraise in your classroom and raise funds for some very deserving children. Why not host a Dress

down Day? We would like to acknowledge the following schools for their participation in dress down days which benefited our organization:

Principal Ms. Elizabeth Durfee and all the students and staff at Primrose Hill Elementary School for hosting dress down Fridays and donating \$675.00.

All our friends at St. Joseph of Cluny Sister's School for sponsoring a dress down day and raising \$133.00.

## Come Trick or Treat with us in South County this fall!

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### South County Halloween Stroll

Saturday, Oct. 22, 2005

10 am – 1 pm

South County Commons, South Kingstown, RI

Please join us for a stroll around The Village at South County Commons. Enjoy a raffle and many fun filled activities such as bounce houses, pony rides, face painting, a petting zoo and many more... We will also have a store front available and many vendors will be there to sell items such as Avon, Pampered Chef, Tupperware, Mary Kay etc. If you are interested in setting up a table at our event the cost is \$25.00 per table, (you must provide your own) please contact Deb Langevin at 401-785-2666 or email :

[Deb@theautismproject.org](mailto:Deb@theautismproject.org)

## Music to our ears and smiles too in Newport this summer!

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Many smiles, lots of laughs, and some great songs added up to another great fundraising event for the Autism Project of Rhode Island. It could only be the Snapple Sunset Music Festival and

the Newport Summer Comedy Series.

This summer, thanks to Chris Perrotti, general manager of the Newport Yachting Center, the Autism Project of Rhode Island came out singing a sweet tune with \$15,000 raised for programs and services here at the Autism Project courtesy of the Newport Yachting Center. This year's Snapple Music Festival ran from June 24<sup>th</sup> to July 3<sup>rd</sup>.

Musical acts this summer included Guster, the Temptations, Ben Folds, Dionne Warwick and Livingston Taylor.

## Comedy Series

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Thanks also to Joe Rocco, RocJo Productions for helping make the Newport Summer Comedy Series another great fund raising event for The Autism Project. Joe was kind enough to help us raffle off some great seats for the performances as well as get our banner signed by one of the great comedians on hand and then auctioned off during one of the shows. The Newport Summer Comedy Series began June 18<sup>th</sup> and ran through August 20<sup>th</sup>.

Comedians appearing this summer included Dane Cook, Adam Ferrara, Kevin Meaney and Lewis Black. Charlie Murphy wrapped it all up on Aug 20<sup>th</sup>.

Of course, seeing Chris Perrotti and music legend Livingston Taylor belt out a tune on stage during the Sunset Music Festival was also worth the price of admission!

Thanks also to all the volunteers who made the Music festival and Summer Comedy Series such a fund raising success for the Autism Project of RI, especially Clarke Alexander.

## National Speaker Conference

This year's National Speaker Conference is scheduled for October 27-28 at the Convention Center in Providence, RI. Dr. Pamela Wolfberg, PhD will present: *Promoting Peer Socialization and Imagination in Children with ASD: Integrated Play Groups Model*

This introductory seminar addresses the unique and complex challenges children on the autism spectrum encounter in peer relations and play. Participants will become familiar with the principles and practices comprising Integrated Play Groups, a model designed to support children on the autism spectrum (novice players) in mutually enjoyed play experiences with typical peers/siblings (expert players) within home, school, community and therapy settings. Based on award-winning research, the IPG model has been found to be effective in enhancing reciprocal social interaction, communication, play and imagination in children of diverse ages and abilities with autism, Asperger's and related social-communicative needs.

The conference is a little different this year. Participants may choose to attend one or two days.

The first day is an overview of the Integrated Play Group model. The second day session is arranged in advance to involve a group of participants interested in initiating the practices of the IPG model in home, school, community or therapy settings. Working in teams (professionals and parents), the session focuses on developing action plans to design and implement Integrated Play Groups for selected children. Participants are requested (although not required) to prepare and share brief videotapes of selected children at play.

Two day participants will receive the IPG Field Manual, *Peer Play and the Autism Spectrum: The Art of Guiding Children's Peer Socialization and Play* as part of the registration fee. Professionals and family members are encouraged to attend.

The conference is scheduled for October 27-28 at the Convention Center in Providence. CEUs are anticipated for teachers, paraprofessionals, psychology, counseling, social work and speech and language.

Our presenter, Pamela Wolfberg, Ph.D. is a special education professor at San Francisco State University and co-founder of the AUTISM INSTITUTE ON PEER RELATIONS AND PLAY in California.



Pamela Wolfberg, Ph.D.

As creator of the Integrated Play Groups model, she leads efforts to develop inclusive peer play programs for children at the local, national and international level. She is widely published and the recipient of several distinguished awards for scholarship and research. Her recent books include, *Play and Imagination in Children with Autism* (1999) and *Peer Play and the Autism Spectrum: The Art of Guiding Children's Socialization and Imagination* (2003). She is associate editor for *Autism: International Journal of Research and Practice* for which she recently co-edited a special issue on play.

## A Programming Note

Due to a copy error, some of the times and dates for our Fall Programs here at the Autism Project *were listed incorrectly*. Please follow the updated schedule below when it comes to selecting the program you are interested in.

Thanks.

### APRI

**Rat A Tat Tat**- Tuesday's from 3:30pm to 4:15pm. Runs September 13-October 25. Katie Beckett approved or \$190.00. A preschool music language group that works on the following initiatives:

The Foundation of Communication and socialization to include cause and affect, imitation, (gross motor and speech), relaxation, following a visual schedule, waiting and choice making.

**Leaps and Bounds**-Saturday mornings. Session I (Tadpoles) from 9am-10am. Session II (Frogs) from 10:30am-11:30am. Runs September 10-October 22<sup>nd</sup>. Katie Beckett approved. Call for parent scholarship rates a social group for children 6-14 years old to work on:

Turn taking, functional use of toys, playing games, greetings, sharing, following a schedule, transitions, making choices, waiting, asking for assistance and symbolic and creative play.

**On The Road to Friendship**-A community based social skills group. Any child is eligible.

Goals are made with the family, SLP and APRI workers (bachelor degree). CPR and first aide certified. All goals are community based.

**The Club**-Fridays. Social skills group for High Functioning Autism and Aspergers Syndrome. Katie Beckett approved or \$275.00 Requirements: September 9-October 21.

**A Starting Point**- A 9 week training series for parents and professionals working with children with Autism Spectrum Disorders. Fall session runs from September 22-November 17. Classes are held Thursday nights at our training center. \$299.00 for professionals, \$75.00 for parents. Space is limited.

**Aspire**- A 5 week Asperger training session for parents and professionals who are raising and educating children with Aspergers. Classes begin September 20 and end October 18 and our held Tuesday evenings from 6:30pm to 8:30pm at the Autism Project of Rhode Island office in Cranston.

**Parent to Parent**- A course created to support families as they begin their journey

with a child diagnosed on the Autism spectrum. Course includes two home visits and 5 classes at the Autism Project of Rhode Island in Cranston. Classes begin September 21<sup>st</sup> and are free to eligible parents. Please call for information.

**For more information on our programs or if you are interested in a news feature story, please contact Tim Gray, Director of Community Outreach, the Autism Project of Rhode Island. 401.785.2666**

## LESSONS IN LEARNING...

While there are many difficult concepts to teach a child with autism, one of the more difficult concepts is “wait.” Waiting is difficult for all children, but because children with autism often struggle with the concept of time, it’s even more difficult for them. But, we want our children to know that wait simply means some time may have to pass before we continue on to the next thing.

So, how do we teach, “wait?” Well, in natural occurrences, we can begin by labeling “wait.” To label, you need to identify waiting as often as possible. If you’re standing in line at McDonald’s, you can say, “Wow, you are doing a great job waiting.” Every opportunity you can label waiting as it’s happening; do it.

There are some key tools to help you teach your child to wait and to help them actually do it. We learned about the wait card when my older daughter, Julia would ask for a grilled cheese sandwich and then tantrum while it took time to cook. I presented her with a wait card and had her stand by the stove while it was cooking so she could see.

When the grilled cheese was done, I took the wait card back and praised her for waiting. It took about a week for the tantrums to finally dissipate. Now,



**WAIT**

when she is handed a wait card, she knows that some time will have to pass before she gets what she wants, but that eventually she will get it.

Some parents find it helpful to put pictures of a child’s favorite thing on the back of a wait card. The child can look at their toy or numbers while waiting and the time will pass quicker.

Another great tool is a timer. A popular one is the Time Timer®, but a watch or oven timer works well

for the children when the concept is learned. The Time Timer® offers a great visual for our children to watch as the big red triangle disappears they understand time is going by and the waiting will be over soon. Go to [TimeTimer.com](http://TimeTimer.com) for information



on purchasing a timer.

By Susan Sposato, Parent Support Liaison

## Grand Rounds at Rhode Island Hospital



On June 24, Connie Rinehart, Program Administrator, and Joanne Quinn, executive director presented a presentation on Autism Spectrum Disorders titled, *What I Learned in Summer Camp*. They presented with Dr. Regina Gargus, a Fellow at Hasbro at the Pediatric Grand Rounds at RI Hospital. Dr. Gargus volunteered for two weeks at summer camp in 2004 to learn firsthand about our children and the interventions we use to support them in a community setting.

## One Sweet Weekend

The Autism Project of Rhode Island along with the Ocean State Collaborative are set to host a one of a kind fundraising effort that will definitely leave a great taste in your mouth and could also rev up your engine!

On **September 25<sup>th</sup>**, ten of the top chocolate and pastry chefs in the USA will visit Providence to put on a mouth watering buffet of award winning chocolate, all to benefit the Autism Project of Rhode Island. The event is called **“Bittersweet”**. All proceeds from this magical day go directly back into programs and services at the Autism Project of Rhode Island.

Autism is a severe developmental disorder that now affects 1 in every 166 children across the nation. In Rhode Island alone, autism rates have increased a **19 hundred percent** over the past thirteen years.

A one of a kind chopper, custom built by X-Dream Cycle in Warwick, is our major raffle item. The stylish street motorcycle is valued at over **\$100,000**.

For more information on the **“Bittersweet”** event in Providence, please log on to

[www.theautismproject.org](http://www.theautismproject.org) and click on the **“Bittersweet”** link.

We look forward to seeing you on September 25<sup>th</sup> for an event in Providence that promises to be very **“sweet”**.

### Event Information

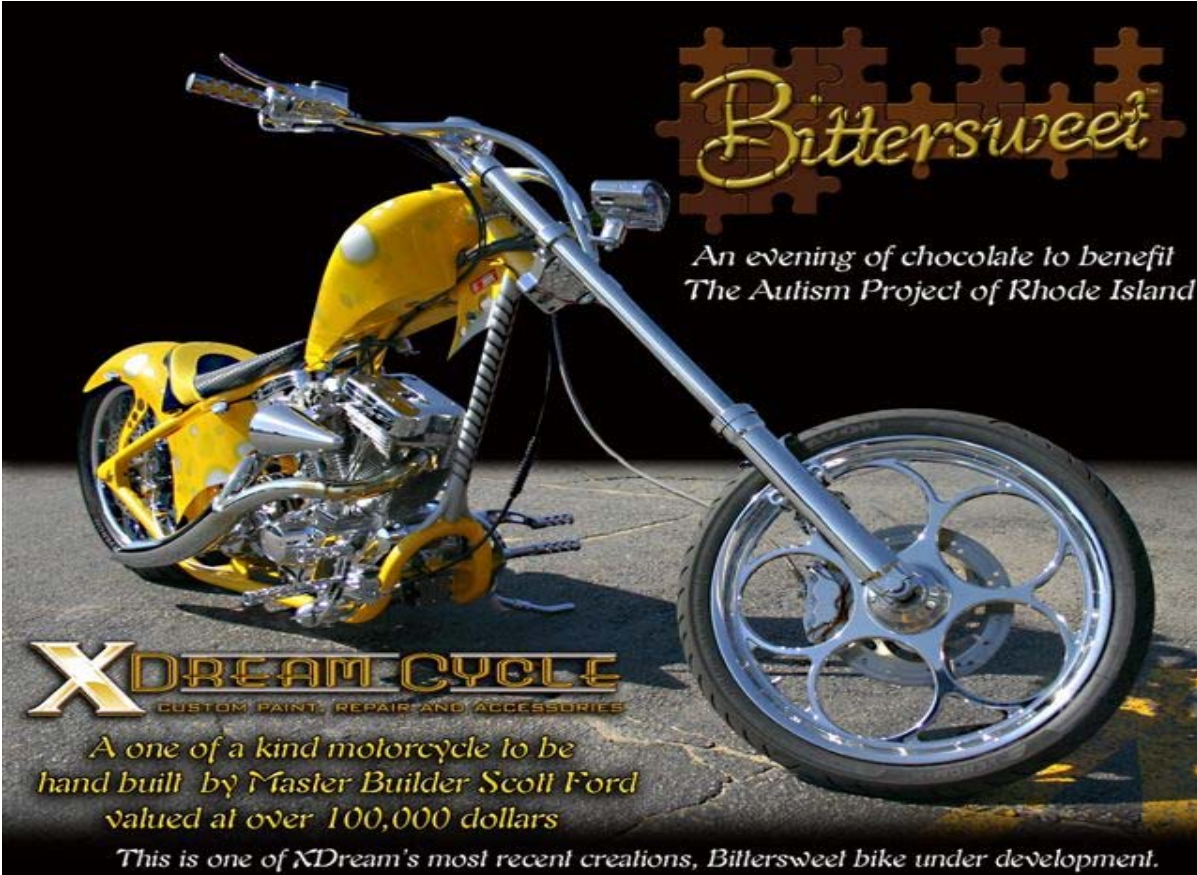
**What:** *“Bittersweet”*

**Where:** *Peerless Building at Westminster Lofts, 150 Union Street, Providence.*

**When:** *September 25<sup>th</sup>, 2005*

**Time:** *4pm to 8pm*

**Contact:** *the Autism Project of Rhode Island. 401.785.2666*



**Bittersweet**

*An evening of chocolate to benefit  
The Autism Project of Rhode Island*

**X DREAM CYCLE**  
CUSTOM PAINT, REPAIR AND ACCESSORIES

*A one of a kind motorcycle to be  
hand built by Master Builder Scott Ford  
valued at over 100,000 dollars*

*This is one of XDream's most recent creations, Bittersweet bike under development.*

## In Memory Of...

The Autism Project of Rhode Island gratefully acknowledges the very generous gifts we received on behalf of the family of Mrs. Helen Wright:

Ms. Hannah Siener  
 Mr. & Mrs. Roland & Cynthia White  
 Mr. & Mrs. Richard & Helen Reid  
 Mr. & Mrs. Richard & Janet White  
 Mr. & Mrs. Gregory Underwood  
 Mahlon Wright  
 Mr. & Mrs. David & Jane Hall  
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 C. Pallatroni  
 Mr. & Mrs. Peter & Karen Pizzarusso  
 Mr. & Mrs. Robert & Barbara Vennerbeck

## Let's Go Camping

The Autism Project of Rhode Island's 4<sup>th</sup> Annual Camp for children ages 5 to 19 with an Autism Spectrum Disorder is being held the last two weeks of August.

**"Move, Think, Create, Communicate"** is a two week summer camp for children with an ASD or related communication disorder. The program is rich with visual supports, structured teaching methods, sensory based activities and traditional camp activities like swimming, arts & crafts, and nature walks.

This year's camp is being held at Camp Champlin in Cranston. The first session is **August 15-19**. Session two is **August 22-26**. The camp runs from 9:00am to 2:30pm Monday through Friday.

Almost **100 children** were enrolled this year with many more on a waiting list. The Autism Project had just **7 campers** in the first year camp was offered in 2002.

This year's camp also received some great media coverage from NBC 10 and the Providence Journal who interviewed kids and took some great video and pictures.

Congratulations once again to the Autism Project of Rhode Island's Program Administrator Connie Rinehart and her staff who put together our most successful camp ever.

For information on next years camp, please call the Autism Project at 785-2666.

**Volunteers needed for this years CVS 5K run. You don't have to run...just walk to the nearest phone and call Mary at 785-2666 for details.**

## A Day without Autism (Asperger Syndrome)

*Written by Jessica Burrows*

*February, 13, 2005*

If I could have a day  
 Where I can be “normal”  
 Myself without Autism  
 Would I be thankful God heard (answered) my prayer?  
 Or would I be sorrowful and wish he never heard me?  
 Would I like who I am, and would I stay awake for as  
 long as I can, dreading midnight  
 And wishing that the end of the day would never  
 come?  
 Or would I hate myself, and go to bed early, thankful  
 it was just a day, knowing that when I wake up this  
 day of hell would end, coming as quickly as possible?  
 Would I be smarter?  
 Or would I lose the unusual wisdom?  
 Would I still be good at music?  
 Or would (listening to) it become a bane of existence?  
 Would I be as kind as they say?  
 Or would my heart freeze and kindness go away?  
 Will I be glad to be free of my “quirks”?  
 Or will I embrace them when they return?  
 Though I may wish it would happen  
 Or not  
 Until it comes I’ll never know  
 Maybe I never will  
 Maybe I’ll live my life without it (the day)  
 The question following me to my grave.



The Autism Project of Rhode Island has joined this non-profit organization , Mission Fish, to enhance our fund raising capability. This organization operates through e-bay and essentially facilitates sellers in giving a portion of their sale proceeds to a charity of their choice.

How it works...

- 1) Nonprofits sign up with Mission Fish.
- 2) e-bay sellers pick a non-profit and a percentage to share for each sale.
- 3) Once the item is listed bidding begins on e-bay.
- 4) If the item sells, the seller gets paid by the buyer and ships the item-same as always.
- 5) Mission Fish collects the donation from the seller, pays the non-profit and provides a tax receipt to the seller.

Next time you go online, check out their site at [www.missionfish.org](http://www.missionfish.org)

Next time you sell on e-bay we hope you will think of the Autism Project of Rhode Island.