

Steps to Success...

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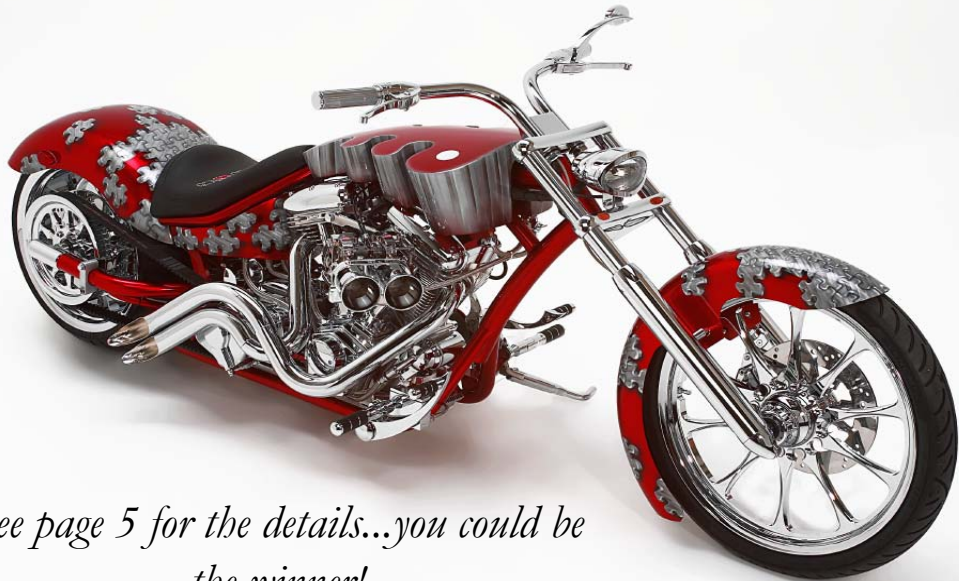
Ms. Beth Pinto

Dr. Anthony Regine

Mr. David Tassoni

Ms. Bernadine Sadwin

Here it is...the Dream Cycle to benefit the Autism Project



*See page 5 for the details...you could be
the winner!*

“This is another challenge for us all to come together to find a solution.” A Katie Beckett Update...

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It's been a busy couple of weeks at the Department of Human Service and the Legislature regarding the Katie Beckett Waiver in general and eligibility requirements in particular. The many families who came and testified at both the House Finance Committee hearing and the DHS public comment hearing got their points across. John Young, Associate Director of Health Care Quality, Financing and Purchasing (Medicaid) commented the “Testimony by parents has been compelling, though difficult at times to hear.”

To bring you all up to date, we are reprinting Mr. Young's letter he sent

following Wednesday, November 2 meeting. The letter is addressed to all stakeholders, including parents and caregivers.

“The public process that began this week will continue: the transcript of last evening's hearing will be distributed to those that have requested it as soon as it is available, comments in response to testimony and answers to questions will follow over the next several weeks. The Department will consider what it has heard to date, and as announced last evening, will continue to accept comments through November 25th. No decisions as to the final disposition of the proposed rules and standards will be made before that time.

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From the Executive Director

Dear friends and colleagues,

In the spirit of Thanksgiving, I'd like to take a moment to reflect on the many organizations and individuals who support the Autism Project. As we move at 100 miles per hour each day, I'm grateful for the season of Thanksgiving that forces us to stop, look around and appreciate the good that surrounds us.

First and foremost, I am thankful for the many children with autism and the families that support them. They are the true teachers in this world. I see so much of the world from an angle I never knew existed. Their strength and courage in the best of times and the worst is inspiring.

I've learned that there is no greater gift than a good teacher. Someone who never stops learning, asks questions, looks for assistance, works as a team member and appreciates the knowledge and insight a parent brings to the table. There are many in RI working to educate our children with autism and warrant a thank you.

Community and national partners are also important to the Autism Project. Without their input, mentoring and experience we could not grow as an agency.

I am so very grateful for the staff, executive and advisory boards at the Autism Project and the many volunteers who keep us going week after week. There is just so much work to be done to support our families and children and teens with autism, and I am grateful to be surrounded by such talented people who come to work every day to help a child and his/her family. It doesn't get any better than this.

Happy Thanksgiving!

Sincerely,

Juanno Quinn

Executive Director

Katie Beckett

continued. from Pg 1

However, it is clear that there is considerable opposition to the proposed changes. Regardless of DHS' motivation or intent in proposing these changes, we need to deal with the substance of that opposition, and be prepared to make additional changes to accommodate legitimate concern within the constraints of federal Medicaid rules. That said, DHS is of necessity an organization of rules and standards, and we need to move this to a discussion of alternatives: if NOT these rules and these standards, what others can be considered? The examination by the ad hoc sub-committee being formed by the House Finance Committee to study the role of commercial insurance in providing services to these children will offer valuable insight to this discussion.

I am therefore suggesting that we convene a workgroup open to all interested parties to discuss alternatives to what the Department has proposed. The workgroup will meet on a regular schedule to identify options and alternatives in moving towards regulations upon which we may all agree, and more information about meeting times and dates will follow. Please join us, circulate the invitation to others, or suggest additions to the open invitation list.

I am struck that we have been faced with similar controversies and disagreements over the years, and they have all led to a stronger and better system for children with special health care needs: CEDARR Family Centers, development of additional CEDARR direct service options, a more accountable and responsive HBTS network, enrollment of children with special health care needs in RIte Care, and the continued evolution of Early Intervention. This is another challenge for us all to come together to find a solution."

The Autism Community was well represented by parents and professionals at the meetings last week. Staff and members of The Autism Project of RI are committed to taking a lead role on both the DHS workgroup and the Task Force being considered by the House Finance Committee.

The DHS workgroup began November 18 and will continue to meet weekly through December (no meeting on the Friday after Thanksgiving) from 12:30p.m. to 2:00 p.m. The meetings will be at the EDS Office that is located at 171 Service Ave., Warwick RI. The purpose of the workgroup will be to discuss alternatives to the policies and criteria for Katie Beckett eligibility proposed by DHS.

If you would like to be on the committee please RSVP to Susan Buontempo at sbuontempo@dhs.ri.gov. Or, if you have comments or concerns, email them to info@theautismproject.org and we will bring your comments to the next meeting. We will continue to keep you updated via email.

So. County Stroll Is A Success

Many thanks to Alexis Skeffington and South County Commons for hosting the first South County Halloween Stroll on Saturday, October 22, 2005. The children and families had a wonderful day trick-or-treating, decorating bags, eating popcorn and cotton candy and shopping at all the vendor tables. No one noticed the “slight drizzle”!

Thank You to the vendors who participated:

Frerichs Farm, Accents by Jen, Avon, Home Interiors, Kangaroo Kids, Mary Kay, Newport Yachting Center, Pampered Chef, The Sensational Child, Southern Living at Home, Stampin’ Up, Traveling Scrapper and Wild Tree Herbs



Colorful costumes ruled

Thanks also to those vendors who donated items for our raffle:

Applebee’s, Anne Dansicker, Deb Langevin, Adventure Land, Blithewold Mansion, BJ’s, The Children’s Museum, McDonalds, Blockbuster Video, Bowling Academy, Bickford’s, Black & Decker Outlet, Broadway Pizza, Cheeky Monkey, Chili’s, Domino’s of Narragansett, Frerichs Farm, Gob Shops, Hasbro, Krystal Shoes, Landing Restaurant, Mona Coldwell, Mystic Institute for Exploration, New England Dough, Newport Playhouse, Ocean State Gymnastics, Only a Dollar, Patriot Cinemas, Roger Williams Zoo, RI Rock Gym, Rose Mia, Shaws Supermarket, Starbucks, Southwick Animal Farm, T&J Nail Design, Up with Learning, Wal-Mart and Whale Watch.



The “Great Pumpkin” brought lots of smiles

And thanks to the volunteers who donated their time to work with the children and raise awareness. All the children and their families who attended had a Spooktacular time!

Congratulations to Deb Langevin who did a great job with her 1st event! Thanks also to our committee members whose hard work and effort made this event possible: Melissa Voccio, Barbara Frerichs, Trish DiRaimo, Anne Babineau and Alexis Skeffington.



The bride, the bunny and the baker?

Lessons in Learning...Gifts for Children with ASD

The holidays are upon us and for families raising a child with an autism spectrum disorder this can be a time of joy, triumphs and struggles. Many friends and relatives will be asking for gift ideas for children with ASD in their lives and it is often difficult to select something appropriate.

Here are some pointers to help guide your relatives in their selection of a gift. First, do your homework. Before you head to the mall, take time to investigate some key areas of development and interest for the gift's recipient. Ask her parents what type of play is she doing? (Parallel, Pretend, Imaginative, Arts & Crafts) How concrete, or black and white do the toys need to be? What is the child's developmental age? Is there a toy that meets her development level that is also age appropriate? An example of this would be a lava lamp. It meets the child's young development age and her love of watching things float, but it's also age appropriate since she's 12 years old.

Another consideration is durability and longevity of a toy. Toys made of heavy plastic, rubber, wood or metal will last longer. Many times children with autism don't play with the toys in the traditional manner they were designed. A more durable toy will last longer. Consider the child's strong interests. Finding a toy that has the child's favorite character associated with it may be the "in" to teaching a child to play with a new and novel toy and be successful at it.

Videos and computer games are another great gift for children and parents alike. They are portable and can be brought along for holiday visits. The video provides something familiar in a different environment and can be calming for the child as well as give the adults a chance to visit.

Memberships are a great gift and something that can be used year round. A membership to the Zoo, YMCA or Children's Museum truly is a gift that keeps on giving year round. Of course all children are different and there is not one kind or type of toy

that will fit every child's needs.

Lastly, consider something that will satisfy the child's sensory needs such as play dough, foldable tents and tunnels, a large exercise ball, an inexpensive (or used) stationary bike, a small indoor trampoline or a sit and spin. A great local resource is *The Sensational Child*. Located in North Kingstown, RI, the store offers a wide choice of products for children of all abilities that are loved by both children and parents. Below are some web sites to explore different possibilities. Happy Shopping!!

The Sensational Child , www.thesensationalchild.org

Super Duper Publications, www.superduperinc.com

Adapt Net , www.adaptnet-tech.com

Come Play With Me , www.comeplaytoys.com

Enabling Devices , www.enablingdevices.com

TFH (US) Limited , www.tfhusa.com/us_home.html

The Center for Creative Play ,

www.center4creativeplay.org/shop.htm

Rehab Toys.com , www.rehabtoys.com/

Indoor Swing, www.indoorswing.com

In Memoriam:

The staff and consultants of The Autism Project of Rhode Island extend their sympathies to the family and friends of Margaret "Miss Maggie" Duffy Stephenson who died unexpectedly last week. Miss Maggie worked as a paraprofessional in East Greenwich, Rhode Island. She dedicated her career to working with children with special needs. She will be missed by both fellow staff members and the families she worked with.

From the Development Corner

Perrotti/Hutchinson Challenge: Thanks to Hutch Hutchinson who ran and completed the Mystic Places Marathon in 4 hours and 37 minutes on October 22nd and to Chris Perrotti who has lost 60 pounds to date. Their efforts have raised over \$2000.00 to date with the culmination of the challenge to be announced on December 2, 2005 at the tree lighting ceremony at the Newport Yachting Center. Please join us to unveil the new, improved Chris Perrotti. There is still time to donate to this cause visit www.hutchhutchinson.net

We would also like to thank the Snow family for asking for donations to the Autism Project of Rhode Island in lieu of gifts for their son's birthday. These gifts were most appreciated and will be used for our camp scholarship fund.

Charity Shopping Is A Success

Close to 100 people donated \$5.00 to shop for the benefit of The Autism Project of RI at the Real Simple *Festival of Giving* at the Providence Place Mall on Sunday, November 20th. Shoppers received one-time discounts, gift cards, a chance to win fantastic door prizes, and samples of great food. The festive mood was provided by local dance companies and Carolers from Trinity Rep. 100% of the ticket proceeds sold by our volunteers benefited our organization. Thanks to all who participated.

Unique Custom Built Bike auction to benefit the Autism Project of RI



RI Bike Designer Donates Time to Create \$100,000 Bike

Warwick- A one-of-a-kind custom built Pro Street bike valued at \$100,000 will be raffled off March 10, 2006 at Rosecliff Mansion to benefit the Autism Project of Rhode Island. Scott Ford, a Warwick resident and bike shop owner has put together this custom bike, with top of the line components. Raffle tickets for this unique bike are on sale for \$100.00 at www.bittersweetapri.org and X Dream Cycle. Ford's hand crafted custom gas tank is sure to set it apart. Dual carburetors give an extra boost to the 125 hp V-Twin engine. A massive 330 rear tire and a custom built frame with a 5" backbone stretch and minus 2" down tube compliment the 19" seat height. Custom paint and airbrush design by Scott Ford and Anthony Osario and custom embroidered seat by Valley Auto Top add to this unique design. Other features include one of kind Cycle Control handlebars, Baker 6 speed right side drive transmission, right side inboard rear brake and much more! Photos and details of the bike are seen at www.bittersweet.org, or www.xdreamcycle.com.

Scott Ford has been building his own motorcycles from the ground up for many years. Many of his bikes take hundreds of hours of work. Scott's web site, www.xdreamcycle.com is a great place to see some of his recent work. The shop is located at 1620 Post Road in Warwick and the phone number is 401-734-9500.

The winner of the bike will be announced at the "Bittersweet" Dinner Dance, open to the public, on March 10, 2006 at Rosecliff Mansion in Newport to commemorate eight years of service and support to individuals with autism and their families. To purchase tickets please contact Mary at the Autism Project of Rhode Island at 401-785-2666.

The Autism Project of RI is a non-profit dedicated to offering the community educational services and programs. These programs help not only children diagnosed with autism, but also their families, Rhode Island Educators and the local medical community.

Bittersweet Event Rescheduled

New Date: March 10, 2006

**New Place: Rosecliff-548 Bellevue Ave,
Newport Rhode Island**

New Ticket Price: \$75.00 per person

The Ocean State Collaborative and the Autism Project of Rhode Island are sponsoring a one of a kind fundraising event that will definitely leave a great taste in your mouth and could also rev up your engine. Please join us for a light dinner, experience award winning chocolate delicacies by renowned pastry chef Andrew Shotz and dance the night away at Rosecliff. Tickets for the event are \$75.00. To order please call Mary at the Autism Project at 401-785-2666 or email mary@theautismproject.org

Sponsored by: Autism Speaks, CVS, Hasbro, Neighborhood Health Plan of New England, The Providence Journal and WJAR/10.

The Walk:

New Date: April 30, 2006

Please join us on April 30, 2006 at 10AM for our 4th Annual Imagine Walk and Family Fun Day in celebration of National Autism Awareness Month. The

walk will take place at Goddard Memorial State Park. Registration begins at 9:00AM. It will be an interactive walk utilizing red flags designed to communicate awareness of autism. A family fun day will follow the walk designed with activities for all children and featuring events appropriate for autism and special needs children. The URI football team will also be there again this year thanks to Coach Tim Stowers.

Volunteers are needed for all aspects of the walk. If you or your group would like to volunteer please contact mary@theautismproject.org or call 401-785-2666.

Join the Imagine Walk and Family Fun Day Committee

It's that time of year again... we are forming our committee for the fourth annual *Imagine Walk and Family Fun Day*. The *Walk* is only five months away and we can use your help. Please consider working or chairing one of the committees that make this a terrific day. Time commitment is a monthly meeting until the middle of March when we begin to meet more frequently.

We are also looking for Team Captains. It's so moving to look down the line of walkers and see the different team banners, shirts and even balloons! Information for this role will be on the website in early 2006.

If you would like to be a part of a dynamic team that creates a memorable day for children and teens with autism spectrum disorders and their families, call Mary at The Autism Project of RI at 785-2666, ext. 102.

National Speaker Conference Held

Dr. Pamela Wolfberg presented at our National Speaker Conference that took place at the Convention Center on October 27 and 28. More than 150 parents and professionals attended.



Dr. Pamela Wolfberg

New this year, RESOURCE ALLEY introduced attendees to area agencies and resources. These were very well represented and a great deal of interest was shown on the part of the attendees.