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Electronic Newsletter

September 2011

**Message from the Chairman:**

Many of us still remember that wonderful day in August, 2010, when we proudly witnessed Governor Deval Patrick's signing of the Autism Insurance bill (ARICA) into law in a ceremony at Fenway Park. Short of winning the World Series, it was easily one of the best times we've ever had at Fenway.

Looking back, I'm reminded that the same sort of cooperative effort involved in becoming a world championship baseball team also was essential in taking a bold idea – insurance coverage for medically necessary autism therapies – and working together to make it a reality. So many people played crucial roles in this team effort starting with legislative leaders such as Rep. Barbara L'Italien and Senator Fred Berry and their staffs. This legislative effort was successful because of the hard work of Amy Weinstock and the members of AFAM's Insurance Committee, who were supported by AFAM's member organizations which mobilized the grassroots support of hundreds of AFAM families across the Commonwealth.

While much has been accomplished, much more remains to be done. We are challenged by the knowledge that in the years ahead, waves of young people on the autism spectrum will be reaching adulthood in a society that provides minimal services for them. That is why AFAM's top priority is to push for a significant increase in adult services.

Make no mistake: this is a massive challenge, made especially serious in a still-sluggish economy. But ARICA was similarly a massive challenge, and we achieved success because we worked together! That is why I am calling on all of you – as well as your families, friends and professional contacts – to get involved in a team effort to make Massachusetts a leader in taking care of adults with ASD. In the months ahead, AFAM and its member organizations will be calling on you to contact your legislators to let them know that this is a priority that just can't wait.

Michael J. Borr, Chairman  
AFAM Executive Committee

**Insurance Committee**

August 3 marked the one year anniversary of ARICA! Even though we are still in the implementation phase, we are seeing evidence that the systemic change in how people access

treatment for autism is starting to happen. A well-respected doctor recently commented to me - "I'm usually pretty cynical about how much difference legislation makes, but this is starting to change lives."

On behalf of the committee, we remain tremendously grateful for the autism community's support which helped pass this legislation.

Updates from the Autism Insurance Resource Center ([www.disabilityinfo.org/ARICA](http://www.disabilityinfo.org/ARICA)) :

- Our first webinar was held in July. It was very successful. We will be holding more of these in the Fall, if you are interested in participating, please e-mail us at [info@disabilityinfo.org](mailto:info@disabilityinfo.org)
- Evening training sessions will be resuming in September. Please check our website for locations, times, etc.
- FAQ's on ARICA have been translated into Spanish and Vietnamese. These are available on our website. If you would like a copy e-mailed to you, please contact us. Also, if there are needs for additional language requests, contact us and we will try to help.
- We continue to work with families who are NOT covered under ARICA; specifically self-funded plans, and Mass Health. If you need assistance, please contact us.

Amy Weinstock, Chair  
Insurance Policy Committee

### **Adult Services Committee**

**We need your help!!!** Join the more than 240 young adults and adults with autism spectrum disorders in Massachusetts to date who have completed (or had a family member or guardian complete) the broad based needs survey on AFAM's website ([www.afamaction.org](http://www.afamaction.org)).

If you are a young adult (14 years or older) or an adult with ASD help us:

- document how many individuals over 14 have been diagnosed with ASD in Massachusetts;
- understand what supports young adults may need, especially when they finish school;
- advance understanding of both the similarities and differences of needs within our community;
- increase AFAM's ability to advocate for the most appropriate services; and
- expand awareness and support for ASD among lawmakers, service providers, and affiliated groups within Massachusetts.

The survey just takes about 10 minutes and it will aid us tremendously in our legislative advocacy efforts. You can complete the survey even if you filled out a survey for us in 2009. **Hurry and do it by September 30<sup>th</sup>**. After September 30<sup>th</sup>, we must begin tallying up the survey results so we can present them to legislators this fall.

**Thank you so much!**

The AFAM Adult Services Committee will continue to follow the work of the Autism Commission. In July and August we shared information with the working group/subcommittee on adults on the spectrum, which is chaired by Ann Guay and Dave Harmon, as it shaped recommendations to the Commission about how Massachusetts can better meet the needs of adults with ASDs.

Thanks to a grant from the Danny Foundation we are planning a legislative briefing this fall when we will report the results of our survey and continue to educate state representatives and senators about the needs of adults with ASDs in Massachusetts.

As always, please share your stories, experiences, and ideas with us about the ways in which we can advocate for young people and adults across the spectrum and change the landscape for their futures in our state. We can be reached via email at [office@afamaction.org](mailto:office@afamaction.org). (Please note in the subject line that you would like the email to be directed to the Adult Services Committee.)

Chris Hubbard, Chair  
Adult Services Committee

### **Government Affairs**

The Massachusetts Autism Commission was created by legislative resolve and approved by Governor Patrick on April 22, 2010. Former Representative Barbara L'Italien was the key sponsor of the legislation authorizing its creation. The Autism Commissioners include government officials, legislators, advocates, educators, self-advocates, physicians and parents of children with ASD.

The Autism Commission began meeting on October 25, 2010 and will continue to meet monthly at One Ashburton Place through December 2011. The meetings are open to the public and minutes of each meeting are posted on the Autism Commission website:  
<http://www.mass.gov/hhs/autismcommission>.

The mission of the Autism Commission is to examine the current services available to children and adults with ASD and make recommendations which will improve the lives of all individuals with ASD across their lifespan.

Four subcommittees were formed to examine the current services and make recommendations for consideration by the Autism Commission: Birth to Five, School Age, Transition and Adults. The Subcommittees submitted their Final Recommendations to the Autism Commission on August 8, 2011 and made their final presentations to the Commissioners on August 29, 2011.

The Autism Commission have taken the Subcommittee Recommendations under advisement and will continue to meet to formulate the Commission's Recommendations for the Governor. We will continue to keep you apprised of Commission developments.

Ann Guay, Co-Chair  
Government Affairs Committee

## Transitioning Back to School: 5 Tips for Parents

Beginning a new school year is exciting and scary for parents and children alike. The transition is especially challenging for families with children on the autism spectrum. While change is difficult, keep these tips in mind to make the transition back to school a success.

### 1. Prepare your child for change.

The beginning of the school year brings many changes at once. Familiarize your child with anything new related to school as much as possible. This may mean bringing your child into their school or classroom, showing your child a picture of their teacher and any classmates, or even meeting the teacher before the first day of school.

### 2. Discuss the unexpected.

Parents cannot anticipate everything that will happen during a school day. Prepare your child for situations that may not go as planned. Talk about a plan of attack for free time, such as lunch and recess. Use social stories to familiarize your child with routines and how to behave when the unexpected happens.

### 3. Reintroduce routines.

Over summer vacation your child's morning and evening routines may have changed. They may be waking up and going to bed at different times. Start adjusting your child to the school year schedule and routine well before the school year actually begins.

### 4. Teach and review school related "hidden curriculum."

While many children may switch easily between the social demands of summer activities and those required in a classroom, children on the autism spectrum may need more explicit reminders. Go over the "dos and don'ts" of acceptable school behavior.

### 5. Prepare yourself for change.

Meet with teachers and administrators to discuss your child's strengths and challenges. Remember, you know and advocate for your child best. Establish communication early to develop positive relationships with your child's teacher and school.

For more information about autism and Asperger Syndrome check out the OAR Life Journey through Autism series at <http://www.researchautism.org/resources/reading/index.asp>  
(Information provided by the Organization for Autism Research.)

## Autism "People" Puzzle Pins Available from AFAM



Looking for a way to help increase autism awareness? We are pleased to offer Autism "People" Puzzle Pins (from Designs by Lucinda.). These attractive pins come in a variety of colors and shapes, each with a group of people (adults and children) and symbols of hope (stars, hearts, etc.). No two are alike, but all are bound to attract attention. They also make terrific gifts for family and friends. You can order pins by calling Judy at the AFAM office (781-891-6270, ext. 102). The cost is just \$15 per pin, plus a modest amount for postage and handling, and a portion of the price will support AFAM's advocacy efforts.

## **Autism Awareness License Plates Are Coming!**

Plans are taking shape for the introduction of Massachusetts license plates with an autism awareness theme. By choosing to have these on your vehicle, you not only help raise public awareness of ASD, you also help support advocacy on behalf of individuals and families. In the coming months, we'll keep you informed of the details of the program and how you can obtain your special autism awareness license plates.

## **News and Announcements**

**Family Autism Center** is expanding their **Explorers Program!** We will now be offering two opportunities a month for adults with autism ages 18-28 to access the community with friends and work on money and social skills! For more information on the Explorers Program, which is run twice a month on a Saturday from 10AM-4PM, please contact Nancy Borr at [nborr@sncarc.org](mailto:nborr@sncarc.org). For information on the **CASS (Community Adventures Social Skills) Program**, which is also a community-based money and social skills program run on one Saturday a month from 10AM-4PM, please contact Betsy Roche at [eroche@sncarc.org](mailto:eroche@sncarc.org).

**The Autism Resource Center of Central Massachusetts** and Summit Academy announce **Motivating our Children to Excellence: Therapeutic Martial Arts**. The 8-week program, for children with ASD and siblings ages 6-12, will begin on September 13 and will end on November 1. Classes are held at Summit Academy (15 Jamesbury Drive, Worcester) from 6:00 to 7:30 p.m. Cost is \$320 for 8 sessions. For families registered with the Autism Resource Center of Central Massachusetts, scholarships of \$250 are available. Call 508-298-1605 for details. Note: teens and adults (age 13 and up) will be offered a separate class when interest is expressed.

The **Autism Insurance Resource Center** will offer a **Webinar** on Tuesday, September 13 from 10:00 to 11:30 a.m. The topic is "**We Got Insurance! What Happens Next?**" and will focus on the new Autism Insurance Law in Massachusetts (ARICA) and the Autism Insurance Resource Center at New England INDEX. Space is limited, so be sure to reserve your space by emailing [Angie.Aguirre@neindex.org](mailto:Angie.Aguirre@neindex.org) After registering you will receive a confirmation email containing information about joining the Webinar.

**Family Autism Center** will be starting its **Young Adult/Adult Bowling Program** on Monday, September 19. The program will run for 12 weeks throughout the fall. Cost is \$150 for the 12-week session and includes expenses related to bowling, T-shirts, and an end-of-the-session celebration the last week. For more information, please contact Nancy Borr at [nborr@sncarc.org](mailto:nborr@sncarc.org).

**The Autism Resource Center of Central Massachusetts** will hold a golf tournament, **Tee Up for Children with Autism 2011**, on Tuesday, September 20 at the Blackstone National Golf Club

in Sutton, MA. The shotgun start is at 1:30 p.m. Cost is \$125 per player. To register online, visit [www.autismresourcecentral.org/golf.html](http://www.autismresourcecentral.org/golf.html)

**The Autism Resource Center of Central Massachusetts**, in cooperation with Seven Hills Family Services, is offering a six-part series, **Autism 101** on six Tuesday mornings beginning Tuesday, September 20. All sessions will take place at the Family Support Center – South Valley (128 Main Street, Sturbridge) from 10 a.m. to Noon. The program is offered to parents of diagnosed children and others interested and will cover an overview of ASD, an overview of supports offered by state agencies, educational rights workshops, an introduction to behavioral methods, biological interventions and an organizational workshop. Families may opt to attend all sessions or a single session, but registration is required. Contact the Family Support Center at 508-796-1950.

**Family Autism Center** will be participating in **The Rodman Ride for Kids** on Saturday, September 24 in Foxboro, MA. All proceeds from the event will benefit the many programs run by Family Autism Center. FAC would like to thank the many riders they have taking on the 25, 50 and 100-mile tours on behalf of their event on organization! You can see who is riding on behalf of FAC at <http://fac.kintera.org/sncarc> as well as make a donation to their cause! Thank you for your support!

**Community Autism Resources** will hold its annual **Hearts & Hands Walk for Autism** (as well as a **Family Fun Day**) on Saturday, September 24 from 9:30 a.m. to 2:30 p.m. at Bristol Community College. The event raises funds to help support families in the everyday challenges of living with ASD. Community Autism Resources provides FREE services to children and adults with ASD and their families in the South Shore, Cape Cod and Islands, and most of the southeastern region of Massachusetts. For more information, visit their website: [www.community-autism-resources.com](http://www.community-autism-resources.com)

Join the fun at the **12<sup>th</sup> Annual Eastern Bank Flutie 5K** on Sunday, September 25. You can walk, run or just support your favorite runner/walker for this terrific family event that has become a fixture in the Metrowest community and beyond. The race begins at the Metrowest Medical Center (Leonard Morse Hospital) in Natick at 11:05 a.m., and will take place rain or shine. For complete information and registration, visit the Flutie Foundation's website ([www.dougflutiejrfoundation.org](http://www.dougflutiejrfoundation.org)) or call 1-866-3AUTISM.

The **Autism Alliance of Metrowest** will host a program on **Basic Rights in Spanish** on Wednesday, October 12 at 7:00 p.m. at the Framingham Public Library (49 Lexington Street, Framingham). The program is presented by the Federation for Children with Special Needs.

**Autism Speaks** has announced the dates and locations of its annual **Walk Now for Autism Speaks** events for 2011. The **Northern New England Walk** will take place on Saturday, September 10 at the NH Hospital Grounds in Concord, NH. The **Southern New England Walk** will take place on Sunday, September 18 at Colt State Park in Bristol, RI. The **Western New England Walk** will take place on Saturday, September 24 at Stanley Park in Westfield, MA. The

**Greater Boston Walk** will take place on Sunday, October 2 at Suffolk Downs in East Boston. For more information, visit [www.walknowforautismspeaks.org](http://www.walknowforautismspeaks.org).

South Norfolk County Arc's **Family Autism Center** and Family Support Programs will be sponsoring a **transition series of workshops** for families and caregivers this fall. All workshops will be held on the second Thursday of the month from October-December at 789 Clapboardtree Street in Westwood from 6:30PM-8:30PM. In October, representatives from the Newton/South Norfolk Department of Developmental Services Area Office will be coming to discuss the adult eligibility process and adult services through the Department. In November, we will be having representatives from various adult residential programs. In December, we will have representatives from various adult day programs.

**The Asperger's Association of New England** will hold its **Annual Fall Conference** on October 14-15 at the Best Western Royal Plaza Hotel in Marlborough, MA. The conference is designed for teens and adults with AS, parents, friends, spouses, educators and other professionals. There will be 57 workshops and panels on a wide range of topics over the two days. Continuing education credits are available. For detailed information and registration, visit [www.aane.org](http://www.aane.org).

**The Autism Resource Center of Central Massachusetts** will hold an **Anti-Bullying Workshop** from 7:00 to 9:00 p.m. on Wednesday, October 19. Parents, professionals, and teens with disabilities will learn specific legal requirements that will assist them in advocating for educational services to meet the needs of students related to bullying. For further information, contact the Autism Resource Center (508-835-4278) or visit their website: [www.autismresourcecenter.org](http://www.autismresourcecenter.org).

**Family Autism Center** will be hosting an **evening with Kim Stagliano** on Wednesday, October 26th from 6:30PM-8:00PM at their facilities located at 789 Clapboardtree Street, Westwood, MA. Kim Stagliano is the mother of three daughters who have autism, the managing editor of *Age of Autism* (the nation's first daily web newspaper about the autism epidemic), a contributor for *The Huffington Post*, *The Debutante Ball*, *The Dallas Morning News Moms Blog* and has appeared on Good Morning America (with her kids!), ABC News, Fox News, in *The Chicago Tribune*, *The National Catholic Register*, and on blogs around the world. Most recently, she is the author of *All I Can Handle: I'm No Mother Theresa (A Life Raising Three Daughters with Autism)*. Please join us for a night of stories, both Kim's and yours- we would love for you to come and share your own thoughts on living with autism! Kim's book will be available for purchase. If you are interested in attending, please contact Betsy Roche at [eroche@sncarc.org](mailto:eroche@sncarc.org).

**The Autism Support Center** will host a program on **The New Anti-bullying Law: IEP and School-wide Strategies to Prevent Bullying of Students with Disabilities** on Wednesday, October 26 from 6:30 to 8:30 p.m. at the ASC office (6 Southside Road, Danvers), presented by

Johanne Pino of Mass. Advocates for Children. Please RSVP to [asc@ne-arc.org](mailto:asc@ne-arc.org) or call 978-777-9135.

**The Autism Resource Center of Central Massachusetts** presents **Wrightslaw: Special Education Law and Advocacy Conference** on Thursday, October 27 from 8:00 a.m. to 4:30 p.m. at the Four Points Sheraton (99 Erdman Way, Leominster, MA). The presenter is Peter W.d. Wright, Esq. Space is limited, so early registration is strongly encouraged. Contact the Autism Resource Center by phone (508-835-4278) or visit their website: [www.autismresourcecenter.org](http://www.autismresourcecenter.org) .

**Melmark New England** is offering **Incredible Years: A Parent Training Series**, on Tuesday evenings from 6:00 to 8:00 p.m., beginning September 13<sup>th</sup> and going through December. Topics to be covered include play, praise, appropriate discipline, and strengthening social skills. The program is designed for parents of children with developmental delay, ages 3-6 years. The classes will be held at Bournedale Elementary School in Bourne, MA. There is no cost to parents, and complimentary dinner and childcare will be provided. Advance registration is required and space is limited. Contact either Jessica Everett at [jeverett@malmarkne.org](mailto:jeverett@malmarkne.org) or 978-806-1910 or Mary Kaminski at [mkaminski@melmarkne.org](mailto:mkaminski@melmarkne.org) or 781-413-4628.

**Family Autism Center** hosted a **Bike Club** this past summer where teenagers and young adults came to our offices in Westwood and worked on basic bike safety skills. By the end of the session, we had several participants biking without their training wheels! All of the participants gained confidence and the necessary skills needed to ensure safety while biking in the community. We would like to say a special thanks to Bob Smith of Norwood, MA and Mary Wallan of Sharon for all of their hard work and dedication to this group! We hope to offer and expand this program next summer.

**Family Autism Center** has been awarded a \$52,780 **Fire Prevention and Safety Grant** from FEMA (Federal Emergency Management Agency). Under the leadership of Captain Bill Cannata, the Statewide Coordinator for the ALEC (Autism & Law Enforcement Education Coalition) Program at SNCARC Family Autism Center, we will be hosting trainings for Fire Fighters on autism spectrum disorders and the best way to handle crisis situations involving someone with autism in 14 states throughout the U.S. The states we will be bringing the training to are: Oklahoma, Minnesota, Virginia, Alabama, Maine, West Virginia, Texas, South Carolina, North Carolina, Rhode Island, Massachusetts, New Hampshire, Connecticut, New York.

The **Lurie Center LADDERS of MGH Program** is proud to offer the **Annual Roger A. Bauman Parent Lecture Series**

When: One Thursday Evening per month, September - June

Where: Charles River Center, Needham, Ma (59 E. Militia Heights Rd, located at the top of Dwight Rd, off of Central Street), in the Paul D. Merritt Building, basement conference room Website: [www.charlesrivercenter.org](http://www.charlesrivercenter.org)

Time: 6:30pm – 8:30pm FREE!

September 22 : Pamela Milman, Special Education Attorney & Gretchen Timmel, Special Education Consultant, “Educational Collaboration: How do Parents, Education Consultants and Special Education Attorneys Work Together?”

October 27: Dr. Joseph Moldover, Developmental Neuropsychologist, “Navigating The Transition to Adulthood for Students with High Functioning Autism or Aspergers Syndrome”

To register, Please contact Julie O’Brien, Family Support Clinician, Lurie Center of MGH for Children at 781-860-1726 or jobrien20@partners.org

\*Limited childcare slots may be available by preregistration and confirmation in advance

The **Institute for Behavioral Studies at Endicott College** has announced two new programs focusing on Autism and Applied Behavioral Analysis: a **Master of Education in Autism**, fulfilling the educational requirements to sit for the BCBA certification examination and a **Certificate in Autism**. Both programs are presented in a hybrid online format, including summer courses taken in a Face-2-Face format on the oceanfront Endicott campus, located in Beverly (20 miles north of Boston). For information, contact Michael Dorsey (mdorsey@endicott.edu) or Mary Jane Weiss (mweiss@endicott.edu).

**The TRANSCEND Research Program** (a collaboration of Massachusetts General Hospital and Harvard Medical School), is looking for Healthy children & Children on the Autism Spectrum, ages 7 to 13, to participate in a **research study** of how the brain works and how it develops; how the brain and body affect each other; and why some children have developmental disorders such as autism. The research team is trained to work with children of all ages and abilities to make the experience fun, comfortable and informative for your child. They use the latest, safest and non-invasive technologies to compare the brains of healthy children and children with developmental disorders. The goal of the research is to determine the causes of autism and language problems and find ways to detect autism and language problems earlier in childhood. Participants will be compensated for their time (\$20-\$50/hour), parking and travel expenses. Your child will be given the opportunity to pick a prize at the end of each visit. The research team will provide participants with a summary report of their child’s cognitive test score. If you are interested, please contact the TRANSCEND Research Program at (617) 966-9766 or email them transcend@partners.org

**For additional announcements, please visit the websites of our Founding Organizations**

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Danvers, MA 01923  
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[www.ne-arc.org/autism](http://www.ne-arc.org/autism)

Autism Resource Center of Central Massachusetts  
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[Sloring@HMEA.org](mailto:Sloring@HMEA.org)

[www.arccm.org](http://www.arccm.org)

Community Autism Resources, Inc.  
33 James Reynolds Road, Unit C  
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508-379-0371 or 1-800-588-9239  
[car@community-autism-resources.com](mailto:car@community-autism-resources.com) [www.community-autism-resources.org](http://www.community-autism-resources.org)

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Community Resources for People with Autism  
116 Pleasant Street  
Easthampton, MA 01027  
413-529-2428  
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Asperger's Association of New England  
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**Visit our website: [www.afamaction.org](http://www.afamaction.org)**