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Electronic Newsletter  
September 2009

**Message from the Chairman:**

I hope everyone has had an enjoyable and relaxing summer. As we move into September, AFAM is excited about two important items our committees have been working diligently on over the past months. First, our Insurance Committee, headed by Amy Weinstock, has been working on a medical insurance initiative, H3809, an Act Relative to Insurance Coverage for Autism (ARICA). The bill will be heard before the Financial Services Committee this fall. You will hear more from Amy later in this newsletter, but I urge you to stay tuned and help us with your phone calls and support as we reach out to you in the coming weeks.

Our Adult Services Committee has been working hard, under the direction of Chris Hubbard, as they complete a document on the state of adult services in Massachusetts. This paper will be an important tool as we advocate for services for the increasing number of individuals impacted by an autism spectrum disorder entering the adult system in the coming months and years. Just as important is our need to have as many families as possible complete the Adult Needs Survey on the AFAM website. The document and survey are both important tools to support our advocacy, so please -- if you have children ages 14 and older who have an Autism Spectrum Disorder (ASD) and have needs or will have needs for intensive and specialized day, employment, and residential supports when they reach age 22 -- go to the AFAM website ([www.afamaction.org](http://www.afamaction.org)) and take a few minutes to complete our survey.

All of our committee chairpersons and the people who commit time to serve with them on a committee deserve tremendous credit for their time and commitment. The only way AFAM works is through the hard work and commitment of people like this!! Our challenge is to motivate more people to give their time as we work to improve the lives of the people we care about impacted by an autism spectrum disorder. Please help us by getting involved.

Michael J. Borr, Chairman  
AFAM Executive Committee

## **Government Affairs Committee**

Parents of children and adults with Autism Spectrum Disorder face the daily challenge of meeting the needs of their entire family while at the same time trying to maintain some semblance of order in their personal and professional lives. We give new meaning to the term multi-tasking. For some, simple trips to CVs require a great deal of advance work. The idea of trying to make it to the State House to attend a hearing or even staying informed about issues does not always seem plausible but is so important. It is through the political process that parents can effectuate meaningful change.

It was a very difficult budget cycle for the entire Commonwealth and the autism community was not spared deep cuts. While the Children's Autism Waiver was not reduced, family support funding was cut significantly. The DESE/DDS Program, formerly known as DOE/DMR, which enables families with children with disabilities requiring intensive supports to continue to live at home and avoid residential placement, was reduced by DESE. While families currently participating in the program saw steep reductions, families who hope to participate and are on a waiting list may remain on the list for quite some time. As a result, DDS has temporarily closed the program for new applications as of August 17, 2009. DDS will, however, continue to maintain an informal listing of those persons who are interested. Once more funding becomes available, families will be reconsidered. For more information, contact your Regional Family Support Director.

Additional cuts may be proposed again this fall if revenues decline. AFAM will continue to update you on issues that impact all of our families and continue to provide a voice on Beacon Hill for children and adults with ASD. However, I cannot emphasize enough how important it is for AFAM families to remain engaged in the political process. During the coming months there will be hearings on pieces of legislation that will directly impact the Autism community. The ARICA Insurance Bill is an important legislative initiative which can benefit many children and adults with ASD in Massachusetts. However, in order to ensure its passage, parents must continue to contact their legislators, tell their stories and make every effort to attend the hearing which will take place sometime in the fall. Other legislative priorities will also have hearings scheduled. We will keep you informed and let you know what needs to be done.

Thanks for you continued interest and support. Good luck to everyone sending children back to school.

Ann Guay, Chair  
Government Affairs Committee

## Insurance Committee

Here is a summary of House Bill 3809: An Act Relative to Insurance Coverage for Autism (ARICA). We expect hearings to be held this fall. Watch for legislative alerts and visit our website ([www.afamaction.org](http://www.afamaction.org)) for updates.

- Requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorder, which currently affects 1 in every 150 children
- Includes the following care prescribed, provided, or ordered for an individual diagnosed with one of the Autism Spectrum Disorders by a licensed physician or a licensed psychologist who determines the care to be medically necessary:
  - Habilitative or rehabilitative care
  - Pharmacy care
  - Psychiatric care
  - Psychological care
  - Therapeutic care
- Fifteen states, including most recently New Jersey and Connecticut, have passed legislation that requires private health insurers to cover evidence-based treatment of Autism Spectrum Disorder, and more than twenty states are pursuing similar legislation.
- Coverage does not affect educational services provided under an IFSP, IEP or ISP
- Estimated mid-range claim cost per covered person according to Oliver Wyman's independent actuarial analysis prepared May, 2009 would be **\$27.40** annually or approximately **\$2.28** per month. It should be noted that costs would likely phase in over a multi-year period as ARICA is implemented
- Potential savings not only would be realized by families affected by autism, but also by the Commonwealth:
  - Approximately **\$7 million** in reduced Early Intervention costs to DPH. (Note: despite the recent changes to EI legislation increasing insurance reimbursement limits for EI, specialty services are not covered and continue to remain obligations of the State).
  - Reduced Special Education costs. (Studies indicate that 20-50% of the students with ASD who receive appropriate intervention are able to participate in regular education classes, indistinguishable from their peers. 90% show improvement, which also reduces the level of special education support needed.)

- According to a 2007 study conducted by the Harvard School of Public Health, the estimated cost of caring for a person with Autism Spectrum Disorder over their lifetime is **\$3.2 million**. Insurance coverage for evidence-based treatment is the fiscally responsible thing to do.
- Providing access to evidence-based treatment endorsed by the AAP and the U.S. Surgeon General will help improve the quality of life of families in Massachusetts dealing with the extreme challenges related to Autism Spectrum Disorder.

Amy Weinstock, Chair  
Insurance Policy Committee

### **Adult Services Committee**

**Help!!! If you have a family member who is on the spectrum , is 14 years or older and will have needs or will have needs for intensive and specialized day, employment, and residential supports when they reach the age of 22, AFAM needs your help. Actually all we need is 10 minutes of your time to complete a survey for AFAM's Adult Services Committee.**

**AFAM** is compiling information about needs to enable it to advocate for increased and appropriate services for adults on the spectrum. This survey is not targeted to individuals with ASD who are living or expect to be living relatively independently as adults. The Adult Services Committee expects to conduct further surveys in the future targeted to a broader number of adults or young adults on the spectrum and concerning a number of topics. This first survey is directed at a narrower group of individuals as described above.

We know services for adults with ASD in Massachusetts currently are insufficient and, as the number of adults with ASD in Massachusetts grows, the lack of services will be exacerbated. The data generated by this survey will help us make the case to state officials that we need increased services.

You can complete the survey online or download a hard copy and mail it to AFAM. It just takes 10 minutes to complete. All answers will remain confidential. Here is the link to the survey. It's posted on AFAM's website at [www.afamaction.org](http://www.afamaction.org). <http://afamaction.org/adult.html>.

Your participation in this survey will not only help you or your family member but others who have similar needs and who are unable to participate. **Join the many individuals across the state who have already responded to our survey. Results will make a difference in our ability to obtain new services.**

**Thanks for your participation!**

Christine Hubbard, Chair  
Adult Services Committee

## **Your donation supports AFAM's efforts!**

Looking for a way to do something to advance advocacy on behalf of individuals on the autism spectrum in Massachusetts? Your contribution to AFAM makes a difference! Please send you check, payable to The Arc of Massachusetts/AFAM to the following address: AFAM, 217 South Street, Waltham, MA 02453. If you prefer, you may pay by VISA or MasterCard. Just call the office (781-891-6270, ext. 102). Thank you for your support!

## **News and Announcements**

**Autism Speaks New England Chapter** has moved to a new address:  
990 Washington Street, Suite 102 South, Dedham, MA 02026  
Phone: 781-461-8800; Fax: 781-461-8811; Toll free: 888-627-6227

**Community Autism Resources** has moved to a new address:  
33 James Reynolds Rd. Unit C, Swansea, MA 02777. Phone numbers and email addresses remain the same.

**The Autism Resource Center of Central Massachusetts** has a new website.  
Check it out at [www.autismresourcecentral.org](http://www.autismresourcecentral.org)

Please join **Community Autism Resources** for their annual **Hearts and Hands Walk for Autism and Family Fund Day** on Saturday, September 12 at Bristol Community College in Fall River. All the money raised stays in CAR's region, which includes 85 cities and towns in the South Shore area, the greater Plymouth area, Cape Cod and the Islands, the greater Taunton/Attleboro area, the greater Fall River area, the greater Brockton area and the greater New Bedford area. For a registration form and more information, contact Jan Randall ([janrandall@community-autism-resources.com](mailto:janrandall@community-autism-resources.com) or call 508-379-0371, ext. 16.

**Community Resources for People with Autism** will hold its **2<sup>nd</sup> Annual Family Fun-"Day"-Raiser** on Saturday, September 12 from 11 a.m. to 2 p.m. at Golf Acres in Westfield (315 Union Street). There will be many attractions, including go-carts, a putt-putt course, batting cages and driving range. Admission is based upon pledges. Deadline for registration is September 8<sup>th</sup>. For details, visit their website ([www.communityresourcesforautism.org](http://www.communityresourcesforautism.org)) or call Joe Lavalley (413) 529, 2428, ext. 122.

Join folks in Holliston for a local **Autism Walk** to benefit the **Autism Alliance of Metrowest** on Sunday, September 13 at Pleasure Point. Check-in is from 11 a.m. to noon, and the 1-mile walk begins at noon. Pre-registration is highly encouraged. Walkers are encouraged to raise a minimum of \$25 per walker, and all donations are to be turned in on walk day upon check-in. Once you register you will be sent a packet of additional information. To register online, go to [www.hollistonautismwalk.org](http://www.hollistonautismwalk.org). For more information, contact Mary at 508-893-0677 or at [mkeohane@gmail.com](mailto:mkeohane@gmail.com)

**Asperger's Association of New England** invites you to attend **An Evening with Tim Page** on Tuesday, September 15 at 7:00 p.m. at Regis College (College Hall Foyer) in Weston. The evening celebrates the publication of Tim Page's new book, *Parallel Play: My Life as an Outsider*, based on his 2006 article of the same name published in *The New Yorker*. Page, a Pulitzer-Prize winning music critic for the *Washington Post* will speak about his experience with undiagnosed Asperger Syndrome and will read from his book. The evening includes a dessert and music reception. Tickets are \$35, with proceeds benefiting AANE. For information and reservations, call 617-393-3824.

**Community Resources for People with Autism** will co-host a **Berkshire Munch and Mingle**, in cooperation with Central Berkshire Regional School District SPEC PAC, United Cerebral Palsy of the Berkshires, Berkshire Count Arc, and Berkshire Family and Individual Resources, on Tuesday, September 15 from 6:00 to 9:00 p.m. at Zucco's (451 Dalton Avenue, Pittsfield). Enjoy refreshments while mingling with other parents and care providers. A calendar of the year's upcoming Berkshire Collaborative Workshops and resource information will be distributed. RSVP by September 11 by contacting Megan Sherman (413-443-4780, ext. 15; [shermanm@theassn.org](mailto:shermanm@theassn.org))

**Tee Up for Children With Autism**, the annual golf tournament for the **Autism Resource Center of Central Massachusetts**, will take place at Cyprian Keyes in Boylston on Friday, September 18. You can register to play or to sponsor at [www.firstgiving.com/arccm](http://www.firstgiving.com/arccm). For further information, contact Cheryl at [cchan@hmea.org](mailto:cchan@hmea.org) or visit the Center's website: [www.arccm.org](http://www.arccm.org)

**Support the Family Autism Center through the Rodman Ride for Kids!** The Rodman Ride for Kids -- an all-day cycling event with over 1,200 riders cycling a 24, 50 or 100-mile route through Southeastern Massachusetts -- will be held this year on Saturday, September 26, departing from ride headquarters on Route One in Foxboro, about a mile from Gillette Stadium. Last year the event raised over \$6.3 million for 25 Massachusetts child-welfare agencies. This year the Family Autism Center has set a goal of raising \$50,000 through sponsorships. You can help by joining a Family Autism Center team or by making a donation. For more information on becoming a part of this event, contact Betsy Roche (781-762-4001, ext. 310).

**Walk Now for Autism.** Save the date for one of the annual walks organized by **Autism Speaks, Inc. New England Chapter**. The **Southern New England Walk** will be on Sunday, September 13 at Colt State Park in Bristol, RI, with registration at 9:30 a.m. and the walk at 11 a.m. To register, go to [www.walknowforautism.org/sne](http://www.walknowforautism.org/sne) The **Western New England Walk** will take place on Saturday, September 26 at Stanley Park in Westfield, MA, with registration at 9:00 a.m. and the walk at 10:00 a.m. To register, go to [www.walknowforautism.org/wne](http://www.walknowforautism.org/wne) The **New Hampshire Walk** is on Sunday,

October 4 at Greeley Park in Nashua, NH. Registration will be at 10:00 a.m. with the walk at 11:00 a.m. See [www.walknowforautism.org/nh](http://www.walknowforautism.org/nh) The **Greater Boston Walk** will be held this year on Sunday, October 18 at Suffolk Downs Race Track in East Boston. Registration begins at 9:00 a.m.; the walk begins at 10:00 a.m. For further information, visit [www.walknowforautism.org/greaterboston](http://www.walknowforautism.org/greaterboston)

**The Doug Flutie, Jr. Foundation for Autism** will hold a “**An Evolution of Style**” (a fashion Show, Raffle, Silent Auction & After Party) at the Langham Hotel in Boston on Sunday, September 27 from 6:00 to 9:00 p.m. For tickets, please contact I Soci Salon (617-867-9464)

The **Gottschall Autism Center** presents “**When the Belly is the Beast: How Intestinal Health Impacts Brain and Behavior,**” on Friday, October 2 from 9:00 a.m. to 2:00 p.m. at Rachel’s Lakeside (950 State Road, Dartmouth, MA), featuring Dr. Martha Herbert and Pamela Ferro, RN. Hear how intestinal function plays a pivotal role in behavior, communication, socialization and cognition in people with Autism Spectrum Disorders. \$30 per person includes lunch, instructional DVD, and conference syllabus. Register online at [www.gottschallcenter.com](http://www.gottschallcenter.com)

**The Asperger’s Association of New England** will hold its **annual conference** for adults with AS, parents, educators and professionals on October 2-3 at the John Hancock Hall in Boston. Keynote speakers are Kari Dunn Buron (October 2) and Dr. Tony Attwood (October 3). For more information, contact AANE (617-393-3824) or visit their website: [www.aane.org](http://www.aane.org)

The **Doug Flutie, Jr. Foundation for Autism’s** 10<sup>th</sup> Annual Eastern Bank **Flutie 5K Road Race** will take place on Sunday, October 4, beginning around 11:00 a.m. The starting point is the MetroWest Medical Center (Leonard Morse Hospital) in Natick. Pre-registration is \$20; race day registration is \$25. For more information, visit the Flutie Foundation website: [www.flutiefoundation.org](http://www.flutiefoundation.org) or contact Kerri Blume at [kerri@flutiefoundation.org](mailto:kerri@flutiefoundation.org) or 508-270-8855.

The **Autism Support Center** will hold its **Annual Family Picnic** on Sunday, October 4 from 1 to 3 p.m. at Endicott Park in Danvers. Contact ASC for details: 978-624-2301.

**Community Resources for People with Autism** will host a 2-day workshop, **Integrated Play Groups for Children with Autism Spectrum Disorders** on Friday, October 16 and Saturday, October 17 at the Castle of Knights in Chicopee, MA (1599 Memorial Drive) from 9 a.m. to 4 p.m. on each day. The instructor is Pamela Wolfberg, Ph.D. The deadline for registration is September 25, but you are encouraged to register early as space is limited. For a detailed description of the workshop and other information concerning registration, see the website [www.communityresourcesforautism.org](http://www.communityresourcesforautism.org) .

**Community Resources for People with Autism** invites you to attend its **1<sup>st</sup> Annual Stepping Up and Stepping Out for Autism**, an evening of food, drink, music and silent auction, on Friday, October 23 from 6:00 p.m. to 11:00 p.m. at Rivers Memorial Hall, Western New England College in Springfield. For further information, visit their website [www.communityresourcesforautism.org](http://www.communityresourcesforautism.org)

**Save the Date!** The **Autism Support Center** will offer a conference, **Overwhelmed No More**, a conference for parents featuring Joan Celebi, Special Needs Parent Coach, on Saturday, October 24 from 8:30 a.m. to 2:00 p.m. The conference will take place at the Autism Support Center, 6 Southside Road, Danvers. There will be a morning workshop, "Overwhelmed No More!" and an afternoon workshop, "Surviving and Thriving Through Crisis Times." In addition to the workshops, there will be a boxed lunch – and a complimentary chair massage. Simultaneous Spanish interpretation will be available. Conference fee is \$30. Registration is required. For further information, contact ASC (978-777-9135 or [asc@nsarc.org](mailto:asc@nsarc.org)).

The **Ford Hall Forum** presents **Autism: Looking Beyond Cause and Cure**, at C. Walsh Theatre, Suffolk University (55 Temple Street, Boston), on Thursday, October 29 from 6:30 to 8:00 p.m. Speakers are Dr. Susan Wilczynski (National Autism Center), Dr. Brenda Smith Myles (Ziggurat Group) and James Brett (current chair of the Governor's Commission on Developmental Disabilities and President of the New England Council). There is no charge for this program

**Plan Ahead** – for the **Autism Resource Center of Central Massachusetts' Fall Conference**, to be held at the Hogan Center at Holy Cross in Worcester on Saturday, October 31 This year's theme is "Not in Polite Company: Autism and Religion, Sex and Politics." Speakers include Sally Patton, Sally Fogel and Ann Guay. For more information, visit their website: [www.arccm.org](http://www.arccm.org)

The **Current Trends in Autism 2009 Conference** (CTIA 2009) will be held on November 6-7 at the Crowne Plaza Hotel in Natick. The annual conference delivers up-to-date, scientifically sound information on Autism and PDD to parents and professionals concerned about children, adolescents and adults whose diagnosis falls along the Autism Spectrum. Distinguished faculty will report on what is now known, how what we know can be applied to the education and care of those with autism, and what direction future research needs to take in order to advance our knowledge and understanding. Please visit the website [www.ladders.org/eventsfol.php](http://www.ladders.org/eventsfol.php) for conference information.

The **Asperger's Association of New England** has now posted its **2009-2010 Schedule of Workshops for Parents of Children and Teens** on their website ([www.aane.org](http://www.aane.org)). You can now register online at any time, day or night.

The **National Autism Center** announces a **year-round Autism Spectrum Diagnostic Clinic** (an affiliation between NAC and May Institute) for individuals up to the age of 21 years. The expanded clinic, in addition to ASD diagnostic

assessments, now provides testing for a broad array of clinical disorders, as well as therapeutic and support services for children, adolescents, adults and families. The clinic accepts most forms of insurance and services are provided by highly trained clinicians. The Center is open Monday through Friday from 8 a.m. to 6 p.m. For more information on all of our services, or to schedule an appointment please call Jennifer Papagno (877-313-3833, ext. 375) or visit our website at [www.nationalautismcenter.org](http://www.nationalautismcenter.org).

**The LADDERS Program** announces the **2<sup>nd</sup> Annual Roger A. Bauman M.D. Parent Lecture Series 2009**. All programs will take place on Wednesday evenings at the Charles River Center (59 E. Militia Road, Needham) from 6:30 to 8:30 p.m. (except for the November 18 session which will run from 6:30 to 9:30 p.m. **REGISTRATION IS REQUIRED**. Fee is \$5 per person at the door. To register contact Julie O'Brien at 781-860-1726 or [jobrien20@partners.org](mailto:jobrien20@partners.org)

The schedule through the end of 2009 follows:

September 16: "Transitions 101": High school (age 14) – Adulthood (age 22)", Terri McLaughlin, mother/trainer, Federation for Children with Special Needs

October 21: "Special Education Law: Children with Autism Spectrum Disorder" Joanne Pino, Trainer, Massachusetts Advocates For Children

November 18: "Communication Needs Now and in the Future." A presentation of the film "*Voice Colors--Billy's Story*," a documentary film that explores the lifetime historical challenges and strategies that enable Billy, who is now 19 and on the autism spectrum, to become an independent communicator. This film is unique in that it presents footage from ages 3 to 16, showing Billy learning and wrestling with all that is entailed in understanding the elements involved in a social interaction. The question and answer period will include how the development of communication scripts over a lifetime. The film was produced by Eve Megargel and Susan Sutherland.

December: program to be advised.

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

Autism Support Center  
6 Southside Road  
Danvers, MA 01923  
978-777-9135  
[asc@nsarc.org](mailto:asc@nsarc.org)

[www.nsarc.org/autism](http://www.nsarc.org/autism)

Autism Resource Center of Central Massachusetts  
71 Sterling Street  
West Boylston, MA 01583  
508-835-4278  
[Sloring@HMEA.org](mailto:Sloring@HMEA.org)

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

Community Autism Resources, Inc.  
33 James Reynolds Road, Unit C

Swansea, MA 02777  
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)

Autism Society of America, Massachusetts Chapter  
47 Walnut Street  
Wellesley, MA 02481  
781-237-0272  
[asamasschapter@hotmail.com](mailto:asamasschapter@hotmail.com) [www.geocities.com/asamasschapter](http://www.geocities.com/asamasschapter)

Community Resources for People with Autism  
116 Pleasant Street  
Easthampton, MA 01027  
413-529-2428  
[info@communityresourcesforautism.org](mailto:info@communityresourcesforautism.org) [www.communityresourcesforautism.org](http://www.communityresourcesforautism.org)

Asperger's Association of New England  
85 Main Street, Suite 101  
Watertown, MA 02472  
617-393-3824  
[info@aane.org](mailto:info@aane.org) [www.aane.org](http://www.aane.org)

Family Autism Center  
789 Clapboardtree Street  
Westwood, MA 02090  
[eroche@sncarc.org](mailto:eroche@sncarc.org) [www.sncarc.org/FAC.htm](http://www.sncarc.org/FAC.htm)  
781-762-4001

TILL/BFA Autism Services  
20 Eastbrook Road, Suite 201  
Dedham, MA 02026  
781-302-4600  
[elizabeth.waters@tillinc.org](mailto:elizabeth.waters@tillinc.org) [www.tillinc.autismservicesprovided.htm](http://www.tillinc.autismservicesprovided.htm)

Autism Alliance of MetroWest  
P. O. Box 2118  
Natick, MA 01760  
508-652-9900  
[Autismalliance@earthlink.net](mailto:Autismalliance@earthlink.net) [www.autismalliance.org](http://www.autismalliance.org)

Doug Flutie, Jr. Foundation  
615 Concord Street  
Framingham, MA 01702  
1-866-3-AUTISM  
[info@flutiefoundation.org](mailto:info@flutiefoundation.org) [www.dougflutiejrfoundation.org](http://www.dougflutiejrfoundation.org)

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Massachusetts Advocates for Children  
25 Kingston Street. 2<sup>nd</sup> Floor

Boston, MA 02111  
617-357-8431  
[Jlandau@massadvocates.org](mailto:Jlandau@massadvocates.org)

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

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**Visit our website: [www.afamaction.org](http://www.afamaction.org)**