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Electronic Newsletter  
March 2011

### **Message from the Chairman:**

As we enter the new legislative cycle, I am energized and buoyed by what AFAM achieved last year. What we accomplished with the passage of ARICA -- the autism insurance legislation -- was proof of what can happen when we band together and advocate with purpose as a community. Because of your hard work -- your phone calls, emails, and visits to legislators -- individuals impacted by an autism spectrum disorder now have access to medical coverage that is supported by one of the most comprehensive insurance laws in the country. Now we look forward to our next cornerstone initiative: adult services. While still advocating for a variety of issues affecting our community, AFAM will work to ensure that all adults with ASD have access to appropriate services. As Chairman, I will work to develop a coordinated long-term strategy with AFAM's Adult Services and Government Affairs Committees to advocate for the needs of the growing numbers of individuals with ASD entering the adult system in Massachusetts.

But we must not ignore the current state of services for children and adults with ASD in Massachusetts. Because of current difficult economic times and proposed cuts in the state's budget, we will face a battle on Beacon Hill in the coming months. It is important for our families to continue to advocate on behalf of their loved one with an autism spectrum disorder. We need your participation in the process. Please come to the Massachusetts State House on Thursday, April 14, 2011 for Autism Awareness Day. If you can't come, please take the time to call your legislators. They are interested in hearing your stories and concerns. Stay in touch with AFAM at [www.afamaction.org](http://www.afamaction.org) for policy and budget updates as well as alerts, and follow us on Facebook and Twitter. I hope to see you on April 14<sup>th</sup>!

Michael J. Borr, Chairman  
AFAM Executive Committee

### **Government Affairs Committee**

**The 2011 Autism Awareness Day at the State House will take place on Thursday, April 14<sup>th</sup>.** April is Autism Awareness Month. Given the current state of the economy, serious budget cuts to human service programs that benefit children and adults with ASD are feared in the coming fiscal

year. We encourage you to come to Autism Awareness Day to learn more about budgetary and legislative issues impacting adults and children with ASD. When the program concludes, you will have the opportunity to meet with your state representative and state senator and share with them the challenges faced by families raising a child with autism. Please plan to join us in the Great Hall of the State House on Thursday, April 14th, beginning at 9:00 a.m. The program includes presentations on the work of AFAM's Government Affairs, Insurance, and Adult Services committees, updates from government officials, and awards to those who have made significant contributions to the ASD community. AFAM will provide you with up-to-date "talking points," so you can speak knowledgeably about pending legislation and budget priorities when you visit your own legislators. Please encourage your friends and family members, too – all our voices are important! And bring photos of your family member, so our elected officials can see that autism isn't just about numbers, it's about people!

Ann Guay, Co-Chair  
Government Affairs Committee

### **Insurance Committee**

ARICA is law! Though the ramp-up appears to be proceeding slowly, early indications are that the implementation in Massachusetts is proceeding at about the same pace as other states have experienced.

We are continuing to hold training sessions for interested groups. A schedule of these is posted on our website ([www.afamaction.org](http://www.afamaction.org)), and we hope you will attend.

As noted on our fact sheet, which is also on our website, ARICA does not affect educational services provided under an IFSP, IEP or ISP. We are expecting additional guidance on this from the Department of Elementary and Secondary Education, and will post this as soon as it is received.

We appreciate the feedback from families about their individual experiences, and are happy to help with specific questions - please feel free to contact us.

Amy Weinstock, Chair  
Insurance Policy Committee

### **Adult Services Committee**

Next month the Adult Services Committee will be asking for your help with a "mission critical" project that will benefit you and others in our community. We will be asking young adults and adults and caregivers in our community to participate in a broad based survey to 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.

Thank you in advance for your participation. We cannot move forward without your help.

In the past couple of months we welcomed a new member to AFAM's Adult Services Committee: Dr. Susan Connors, Assistant Physician/Internist with Lurie Family Autism Center/ LADDERS. Dr. Connors is also the mother of three young adults, including a son on the spectrum. We thank Dr. Connors for her willingness to share her personal and professional perspective with us.

We have been following the work of the Autism Commission and sharing information with the working group/subcommittee on adults on the spectrum, which is chaired by Ann Guay and Dave Harmon. While fiscal and economic times are tough, we are grateful to all the members of the Autism Commission and the volunteers on its subcommittees who are devoting their time and energy to better understanding the needs of the ASD community and developing recommendations for ways in which Massachusetts better meet those needs.

As state budget cuts loom for adults and young people transitioning to adulthood on the spectrum and in need of services, we ask you to join us in advocating on Beacon Hill this Spring-- on April; 14<sup>th</sup>, Autism Awareness Day at the State House, and throughout the budget season. 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

### **News and Announcements**

**Family Autism Center and SNCARC Family Support** will be hosting a **Financial Planning seminar** on Thursday, March 10 from 6:30 -8:30 p.m. at 789 Clapboardtree Street in Westwood.

A Financial Planner/Special Needs Advisor will present on estate and financial planning for special needs families. Learn what unique steps often have to be taken in order to protect your child's entitlement to adult benefits. If you are interested in attending, please contact Tessa at 781-762-4001 ext. 303 or [tcannata@sncarc.org](mailto:tcannata@sncarc.org).

**Community Autism Resources** and **Barry Prizant, Ph.D.** will hold their **16th Annual ASD Symposium** on Thursday, March 10 & Friday, March 11, 2011 at Rhodes on the Pawtuxet in Cranston, RI. Speakers include Jed Baker, Ph. D., "No More Meltdowns: Handling Challenging Behaviors & Teaching Social Skills;" Carol Gray, "Gray's Guide to Bullying Children with ASD: The Real World;" and Ros Blackburn, "Logically Illogical: Information and Insight Into Autism." Continuing Education credits are available for clinical psychologists, social workers, speech

pathologists, occupational therapists, MA Department of Education, RI Department of Education, and CT Department of Education. Everyone receives a certificate of attendance for each day they attend. Lunch and complimentary parking are included! . For more information, contact [www.community-autismresources.com](http://www.community-autismresources.com), or [www.ccseminars.com](http://www.ccseminars.com).

The **Asperger's Association of New England** is offering a two-day program, **Asperger Academy for High School Educators and College Personnel: Success After High School for College Bound Students with Asperger Syndrome** on Friday and Saturday, March 18-19. Location: UMass Lowell Inn and Conference Center. Day One will focus on Transition; Day Two will focus on post-secondary. Continuing Education credits are available for social workers. Registration deadline is March 10. For registration information, visit the website [www.aane.org](http://www.aane.org) or call 617-393-3824.

**The Autism Alliance of Metrowest** is hosting a **Children's Resource Fair**, sponsored by The 200 Foundation, for newly diagnosed families with Autism Spectrum Disorder and or parents of children 10 and under on the autism spectrum, on Saturday, April 2<sup>nd</sup> from 11:00 a.m. to 3:00 p.m. at the Morse Institute Library, Natick. This resource fair will give you access to the best of the best. Come spend an hour or two and learn which therapist in your area will provide the most for your child. Learn what doctors and dentists are available, who you should call and where you should visit to find the right services for your child on the autism spectrum. There will be loads of information on local resources, and there will be free demonstrations and **free** sensory-based tools for your children. Light refreshments will be served.

\* On Site Child Care      \* Spanish Translator      \* Transportation  
\* Child Care, Translator & Transportation –require pre-registration –call (508) 652-9900

**The Doug Flutie, Jr. Foundation** and **Children Making Strides** will present **Autism Update 2011** on Thursday, April 7 at the Sheraton Four Points in Norwood. The featured speaker is Shonda Schilling, wife of former Red Sox pitcher Curt Schilling and author of The Best Kind of Different: Our Family's Journey with Asperger's Syndrome. Other topics include "Raising a More Independent Teen: How Your School Can Help," Evidence Based Practices in the Classroom and Community Settings," "No More Bullying Around," and "How to Bill Health Insurance Companies for ABA Services." For full descriptions and registration information, visit [www.flutiefoundation.org](http://www.flutiefoundation.org)

**Family Autism Center** will be hosting their very own "**Autism Awareness Night**" at their center on April 26, 2011 from 6:30 to 8:30 p.m. at 789 Clapboardtree Street in Westwood. We will be inviting legislators who represent Norfolk County to come and hear from representatives of AFAM as well as from families impacted by Autism Spectrum Disorders. The agenda will cover an update on ARICA (insurance coverage related to Autism Spectrum Disorder), an update from AFAM's government affairs committee in which they will address their current legislative and budget priorities, an update on the ALEC Program (Autism and Law Enforcement Education Coalition) and the progress it has made over the past 7 years throughout Massachusetts and New England, and a time where we will open up the floor for to families to speak to legislators about how Autism impacts their lives. Please RSVP to Betsy Roche at 781-762-4001 ext. 310 or [eroche@sncarc.org](mailto:eroche@sncarc.org).

**Family Autism Center** will be hosting **April Vacation Week programs and family events** during the school vacation week. Please visit their website at [www.sncarc.org/fac.htm](http://www.sncarc.org/fac.htm) for more details.

**May Institute** has partnered with the Hockomock Area YMCA for this year's "**Experts on Autism**" series. This free series will explore a variety of topics related to autism. The content is especially relevant for families, but educators, advocates and pediatricians are also encouraged to attend. To register online or find out more information regarding the dates and topics, please visit the website [www.mayinstitute.org](http://www.mayinstitute.org) or contact them by phone (781-437-1248) or email [jcharron@mayinstitute.org](mailto:jcharron@mayinstitute.org). The registration deadline is 3 days prior to the date of the presentation you wish to attend. All presentations begin at 6:30 p.m. and will be hosted at the Hockomock Area YMCA, 67 Mechanic Street, Foxboro.

March 9: "All He wants Are French Fries! -- How to Address the Often-Challenging Feeding Issues of a Child with Autism:

April 21: "Let Me Hear YOUR Voice!" Helping Schools Learn to Value Parent Input

**Community Resources for People with Autism** will hold its **21<sup>st</sup> Annual Conference** on Tuesday, April 12 at the Log Cabin Banquet and Meetinghouse (500 Easthampton Road, Holyoke), from 8:00 a.m. to 3:30 p.m. Barry Prizant, Ph.D. will conduct a session on the basics of the SCERTS Model for children who have or are at risk for social communicative difficulties. Roy Richard Grinker, Ph.D. will speak about how individuals, communities and businesses can create environments that help people with disabilities lead personally and economically fulfilling lives, and how changes in our society and our workplaces can enrich the lives of people with autism and the environments in which they live and work. For registration information, visit their website: [www.communityresourcesforautism.org](http://www.communityresourcesforautism.org) or contact Karen Greaney at 413-529-2428, ext. 118; email [greaneyk@theassn.org](mailto:greaneyk@theassn.org)

**The Doug Flutie, Jr. Foundation for Autism** will hold its **2<sup>nd</sup> Annual Rock N' Hoops** event at the Basketball Hall of Fame in Springfield on Friday, April 15 from 6:00 to 10:00 p.m. Here's your chance to compete in a one-of-a-kind speed free throw contest, meet Doug Flutie and players from our beloved sports teams. To register for the contest or purchase spectator tickets, visit [www.flutiefoundation.org](http://www.flutiefoundation.org) today!

The **Autism Alliance of Metrowest** will hold its **Annual Kite Day** on Sunday, May 1 from Noon to 4:00 p.m. at Bose Mountain in Framingham. Sponsored by: Autism Alliance of MetroWest along with the Doug Flutie Jr. Foundation for Autism, Inc. Free kites, face painting, balloon twisting, and lots more! A Fun, Free Family Event- Rain Date May 8<sup>th</sup> Noon -4:00 pm  
Call 508 652-9900 for more details for visit [www.autismalliance.org](http://www.autismalliance.org)

The **Lurie Center/LADDERS of MGH Program** is again offering its **Annual Roger A. Bauman Parent Lecture Series** once a month on Thursday evenings. All lectures are held from 6:30 to 8:30 p.m. in the Paul D. Merritt Building at the Charles River Center (59 E. Militia Heights Road, Needham (located at the top of Dwight Road, off Central Street).

Thursday, March 24 "Early Screening/Diagnosis/Treatment/Supporting Families and providing Resources for children with Autism Spectrum Disorders" Presenters: Dr. Roula Choueiri,

Neurodevelopmental Pediatrician, Tufts Medical Center Floating Hospital/CCSN; Dr. Sheldon Wagner, Behavioral Psychologist; Bernadette Bentley, Autism Resource Specialist, Autism Consortium/Tufts Medical Center Floating Hospital/CCSN.

Thursday, April 14 “Making Sense of Healthcare Financing” Presented by the Massachusetts Family-to-Family Health Information Center. An overview of MassHealth programs for families with children with special health care needs; eligibility and application; explanation of MassHealth Programs, Waivers and Relief Fund; Advocacy Strategies for working with private health insurers.

Thursday, May 12 “Anti Bullying Special Education Laws in Massachusetts” – a new presentation by the Federation for Children with Special Needs

June “Psychopharmacology in ASD’s updates” -- details TBA

To register, Please contact Julie O’Brien, Family Support Clinician, LURIE CENTER LADDERS of MGH for Children at 781-860-1726 or [jobrien20@partners.org](mailto:jobrien20@partners.org)

The **Lurie Institute for Disability Policy** will present a lecture, **Understanding the Increased Prevalence of Autism**, by Dr. Peter Bearman (Columbia University) on Thursday, March 24 at 12:30 p.m. in the Schneider Room G3 at the Heller School for Social Policy and Management, Brandeis University. For further information, contact the Lurie Institute (781-736-3928).

**The Gottschall Autism Center** presents the Second Annual conference, **When the Belly is the Beast: How Intestinal Health Impacts Brain and Behavior**” on Friday April 1 from 8:00 a.m. to 4:30 p.m. at Rachel’s Lakeside (950 State Road, Dartmouth, MA). Featured speakers are Dr. Martha Herbert (Mass. General Hospital and Harvard Medical School; Dr. Alessio Fasano (University of Maryland) and Pamela Ferro, RN (Hopewell Associates). For more information and registration details, visit [www.gotSCD.org](http://www.gotSCD.org)

**Friends of LADDERS** will hold a conference, **Current Trends in Autism 2011 (CTIA 2011)**, on April 29-30 at the Crowne Plaza Hotel on Route 9 in Natick.

CTIA 2011 will deliver the most up to date, scientifically sound information in the field of Autism and Pervasive Developmental Disorders 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 of this disorder.

Speakers include: Margaret L. Bauman, MD; Timothy M. Buie, MD; Katarzyna Chawarska, PhD; Ann Densmore, EdD; Marie Duggan; Peter Gerhardt, EdD; Charles Henry, MD; Dorothea Iannuzzi, LICSW; Michael Mancusi, LICSW; James McPartland, PhD; Marvin Natowicz, MD, PhD; Carlos Pardo, MD; Mary Elizabeth Parker, PT, MSPT, PCS, NCS; Jerry Newport; Stephen Shore, PhD et al; Sheldon Wagner, PhD; Michael Weiss, PhD; Rosemary White, OTR/L; Timothy Yu, MD; Andy Zimmerman, MD.

Visit <http://www.ladders.org/pages/Conference.html> for conference information. Online registration will be available in early March. Mail-in registration forms can be obtained by contacting Kay Murray at [kmurray8@partners.org](mailto:kmurray8@partners.org).

## **Participants sought for research study at Harvard Medical School**

**The Wall Lab at Harvard Medical School** is a group of dedicated researchers working towards a complete understanding of autism. They are launching a study aimed at finding diagnostic markers for autism. Since the early 90s, there has been a broadening of the definition of autism and dramatic increases incidence, but little gains in our understanding of the genetic roots of the disorder. We believe that adults with autism, namely those diagnosed before the big rises in incidence, will be more helpful to the search for genetic causes than recently diagnosed individuals. We plan to sequence the entire genome of more than 500 autistic adults, a first for the field, in an effort to identify genetic causes that will result in diagnostic markers, earlier therapy for newly diagnosed children, and information vital for therapeutic intervention.

We are currently recruiting for this project and could use your help. If you're interested, please contact Dr. Dennis Wall at [Dennis\\_Wall@hms.harvard.edu](mailto:Dennis_Wall@hms.harvard.edu).

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

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

[www.ne-arc.org/autism](http://www.ne-arc.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  
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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)

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

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

Community Resources for People with Autism  
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[www.sncarc.org/FAC.htm](http://www.sncarc.org/FAC.htm)

[www.tillinc.autismservicesprovided.htm](http://www.tillinc.autismservicesprovided.htm)

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Autism Speaks, Inc. - New England Chapter  
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