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Electronic Newsletter
December 2010

Message from the Chairman:

Happy Holidays! 2010 has been a groundbreaking year for AFAM. In January of 2008 we filed our first legislative initiative, H3809 - An Act Relative to Insurance Coverage for Autism (ARICA). On August 3, 2010, Governor Deval Patrick signed ARICA into law during a ceremony at Fenway Park. Individuals affected by an Autism Spectrum Disorder in Massachusetts will benefit from one of the most comprehensive autism insurance bills of its kind passed to date in this country. Our thanks go to Representative Barbara L'Italien and Senator Fred Berry, great friends of our community, who sponsored the legislation. Amy Weinstock, chairperson, and her entire Insurance Committee -- all committed volunteer parents and professionals -- deserve tremendous credit for their tireless work throughout this past legislative cycle. ARICA is the perfect example of what can happen when we work in a unified way. As chairman, I intend to make adult services affecting our community our next cornerstone initiative. It will be a immense undertaking! The issues in the world of adult services are vast, complex and vary across the autism community.

As much of an accomplishment ARICA was to our organization and our community, we are still in crisis. Budget cuts and a struggling economy have significantly impacted the ability of our member organizations to serve our families. We need your help. I know this sounds redundant, but in this upcoming New Year I do ask that we all take a moment and think about how we can contribute. Can we give money? Can we volunteer our time? Can we do something as simple as when we see an alert, pick up the phone and call five or ten friends and/or relatives and ask them to help? Please make a commitment to participate and I promise you that good things will result -- we need your experience, input and help!

I wish all of you a happy and safe holiday season.

Michael J. Borr, Chairman
AFAM Executive Committee

Save the Date – Autism Awareness Day 2011

The 2011 Autism Awareness Day at the State House will take place on **Thursday, April 14th**. More details later, of course, but mark the date on your calendar.

Do your holiday shopping at Borders Bookstores during “AFAM Benefit Days!

Thanks to the generosity of Borders Bookstores, AFAM will receive a portion of the money you spend at 4 Borders locations in Massachusetts on Saturday, December 11 and Sunday, December 12 – just in time for your holiday purchases! You will soon receive a coupon that you can use when you shop at any Borders or Waldenbooks locations in Massachusetts on December 11 and 12, and a portion of your purchases will be automatically credited to AFAM. You can reproduce the coupon (which is also available at the AFAM website, www.afamaction.org) and give them to your friends and family members, so they too can help fund AFAM’s advocacy efforts on behalf of individuals on the autism spectrum. **You can also shop online** (www.Borders.com), using the Online Promotional Code: AFAM1211U. Note that the coupon can be used at ANY Borders or Waldenbooks location on December 11 and 12 only, but coupons will not be available in the stores.

AFAM Benefit Days (December 11-12) at the following Borders locations will include book signings by authors of autism-related books:

Burlington, MA
6 Wayside Road
Exit 33A off
Route 95 (next to
L. L. Bean)

Dedham, MA
430 Legacy Place.

Mansfield
280 School St.
Intersection of
Rte. 140 and
I-495

Shrewsbury
476 Boston Turnpike
Route 9 Eastbound

These four participating Borders stores will also host book signings by several authors who have written about ASD. Susan Senator, author of *Making Peace with Autism* and *The Autism Mom’s Survival Guide*, will be at the Dedham location on Sunday, December 12 from 1:00 to 3:00 p.m.. Martha Ziegler, often described as “the mother of Chapter 766” (the landmark Massachusetts special education law) and founder of the Federation for Children with Special Needs, will be at the Borders Store in Burlington on Saturday, December 11 from 1:00 to 3:00 p.m., with her daughter, to sign copies of her recently-published book, *My Daughter, My Teacher: Mary Ann, Autistic in English and Spanish*. Emily Colson, author of *Dancing with Max*, will be at the Mansfield Borders on Saturday, December 11 from 11:30 a.m. to 1:30 p.m. and in Burlington on Sunday, December 12 from Noon to 2:00 p.m.. Photographer Steven Voge, who collaborated with author Ouisie Shapiro to produce *Autism and Me: Sibling Stories* (a book for children) will be at the Borders store in Shrewsbury on Saturday, December 11 from 11:00 a.m. to 1:00 p.m.

Insurance Committee

We are nearing January 1, 2011 – the date that ARICA goes into effect! The Division of Insurance (DOI) has held five meetings to discuss aspects of ARICA with various stakeholders (consumers, providers, insurers, etc.). The purpose of these meetings was to discuss specific aspects of ARICA and clarify issues, etc. As of this date, it’s not clear whether the DOI will be issuing a bulletin, guidance and/or regulations. We will be keeping you updated as we know more. Training on ARICA is starting to roll out. The first sessions were held at the end of October and more are anticipated for the next few months. If you or your organization is interested in attending, or having us present to your group, please contact us.

For individuals who have self-funded (ERISA) plans – (see the fact sheet on our website: www.afamaction.org/insurance for details), we are gathering information on whether your employer is planning to provide coverage. If you have information, or your company needs more information before deciding, please let us know.

Thank you all again for your tremendous advocacy which helped pass this important legislation!

Amy Weinstock, Chair
Insurance Policy Committee

Government Affairs Committee

As the year comes to an end, I think it is important to remember what was accomplished during this past legislative session. All of AFAM's legislative priorities were enacted into law! This was no small accomplishment. As a result of a lot of hard work, ARICA was passed, the AAC bill became law and the Anti Bullying bill for students with ASD was incorporated into the larger Anti Bullying Law that was enacted as well. Many thanks to parents and professionals who made calls to their legislators, attended Autism Awareness Day and testified at hearings. Your hard work and commitment to meeting the needs of children and adults with ASD helped turn these bills into law. Special thanks to Governor Patrick, Senate President Therese Murray, Speaker Robert DeLeo, Chairman Panagiotakos and Chairman Murphy for their support, as well as the lead sponsors and co sponsors of these bills, especially Rep. Barbara L'Italien. The State House will not be the same without her. We wish her well in her new endeavors.

In the coming months, we will keep you informed about new pieces of legislation that impact the autism community and update you on important issues for our families. Please consider joining the Government Affairs Subcommittee of AFAM. We really could use your help. Should you have any questions or be interested in joining, please contact me at mguay70046@aol.com.

Happy New Year to all of you!

Ann Guay, Co-Chair
Government Affairs Committee

Adult Services Committee

As the calendar year comes to a close and we face the beginning of a new fiscal year, we know that more State budget cuts loom for those adults and young people transitioning to adulthood on the spectrum and in need of services. Despite this tough fiscal and economic climate, we will continue to advocate for a proactive State strategy aimed at developing community, residential and employment supports geared for adults with autism spectrum disorders.

In this past year we have welcomed some new members to AFAM's Adult Services Committee: Robin Slonim, a Framingham parent of a teen age daughter on the spectrum; Carolyn Ferris Gombosi from Newton, the mother of a young man in his early twenties with autism; Nan Leonard, an attorney from Dover and mom to teenage triplets, one of whom is on the spectrum,; and Julie O'Brien, M.Ed., LMHC, Autism Resource Specialist with the Lurie Family Autism Center, MGH/LADDERS, and the Autism Consortium have joined us in our work. We thank them,

together with all of members of our committee, for their willingness to devote time and energy to our advocacy efforts.

In the new year, we will reach out to newly elected legislators to educate them about ASDs and the needs of adults on the spectrum. We plan on tracking the work of the new Autism Commission and sharing information with the commissioners and working groups about innovative practices and models of services which will enable adults with ASDs to continue to grow, work and enjoy life in the community. We will also be asking families with transitioning teens and adults on the spectrum to complete a brief survey that will be tool for demonstrating the numbers and needs of our family members as they become adults and grow older.

Please share your stories, experiences, and ideas with us about the ways in which we can advocate effectively on behalf of 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. (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

Back by popular demand – the AFAM 3rd Annual Wine Sale, just in time for your own holiday needs as well as gift-giving.

To learn how you can purchase private-label wines and benefit Advocates for Autism of Massachusetts at the same time, visit www.BenefitWines.com/afam, where you can order online. Orders placed by December 15 will be delivered by Christmas; orders placed by December 22 will be delivered by New Years. The sale is conducted by Custom Grapes, which has a great track record of working with many charities in Massachusetts and elsewhere. There are six varieties of wine, and you can order individual bottles of multi-bottle gift packs. It's easy to order online, so visit the website now.

News and Announcements

Community Autism Resources will hold its **Holiday Gift Sale & Open House** on Saturday December 4th from 9:00 a.m. to 1:00 p.m. at their office, 33 James Reynolds Road Swansea, MA (directly off exit 2, Rte. 195, across the street from the entrance to Cardi's Furniture). We'll have an assortment of Autism awareness necklaces, pins, key chains, books, DVDs and other unique items for sale. Donna Procopio designer and creator of the Glimmers of Hope Autism Awareness bracelets will be there with a wide variety of her eye-catching bracelets that promote awareness about Autism. Along with the bracelets, Donna has also has matching earrings for some of her designs. There will also be some fun stocking-stuffers for the kids and we some terrific gift ideas for teachers, therapists, caregiver's, and staff! There will be free refreshments, door prizes and a chance to meet some of the CAR staff. All proceeds will go towards supporting the free services that Community Autism Resources provides to families of children and adults who are on the Autism Spectrum.

The Lurie Center LADDERS of MGH Program is offering its **Annual Roger A. Bauman Parent Lecture Series** on Thursday evenings, once a month until June, at the 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 www.charlesrivercenter.org All sessions are scheduled fro 6:30pm – 8:30pm

Thursday December 9, 2010 “ARICA Massachusetts insurance coverage overview/training for parents,” presented by: Judith Ursitti (Autism Speaks) and Amy Weinstock, (Chair, Advocates for Autism Massachusetts Insurance Committee (www.afamaction.org))

Thursday January 27, 2011 “Transition Planning Program: What You Need to Know for Legal and Financial Planning for your child who has Special Needs,” presened by Jack Raycroft and Annette Hines, Esq.

Thursday February 17, 2011 'Talking with your children about sexuality, social skills and safety: A discussion for parents, ” Presented by Sally Fogel, M.Ed.,

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 Childcare MAY be available by preregistration only

The **Autism Support Center** is going on the road! Come visit us ...at the Lowell DDS Area Office (325 Chelmsford St., Lowell). To accommodate our many families in the Lowell area, we are offering 2 options to help families get connected to the Autism Support Center: (1) A **Support Group** will be held on the 1st Tuesday of the month. The first support group will be held on Tuesday, December 7 at 10 a.m.. Please join us to get tips and network with other local families. (2) The Autism Support Center will hold **Office Hours** on the 3rd Tuesday of each month, beginning on Tuesday, November 16, from 10 a.m to 12 noon. This will give families a chance to meet one-on-one with a staff member who will help provide information and resources. For more information, contact: Whitney Ryan at 978-624-2305 or by email wryan@ne-arc.org

The **Family Autism Center** has new autism awareness items for sale at our on-line store. Most new items are less than \$10. each, so they make perfect teacher/holiday gifts! Please check them out at www.sncarc.org/1store/index.htm

The **Family Autism Center** is offering a **Future Planning Training Series for parents of children ages 14-22**. This once per month training series will provide you with the information you will need as your child becomes an adult, and what options exist thereafter. All trainings are on Thursdays and will take place at SNCARC, 789 Clapboardtree Street, Westwood, MA from 6:30-8:30PM. Schedule of Sessions:

December 9 - Adult Day Program Options- Presentations on a variety of day program options, including dayhab program, supported employment and job training, and a program that is suitable for individuals with more challenging behaviors.

January 13 - Residential Services and Alternatives to State-Funded Placements- This training will begin with a presentation on state-funded adult residential placement. However, due to the fiscal climate and the scarcity of these types of placements, we will provide you with some alternatives, including Adult Family Care and the Katydid Foundation.

February 10 - Guardianship at Age 18- A step-by-step look at the entire guardianship process will be addressed, starting with the Clinical Team Report and the various paperwork that needs to be completed, ending with instructions on how to file that paperwork in court.

March 10 - Financial Planning- 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 any or all of these trainings, please contact Tessa Cannata at 781-762-4001 ext. 303, or tcannata@sncarc.org

Autism Alliance of MetroWest, A Program of Advocates, Inc. is offering the following programs, all of which will be held at the Morse Institute Library, Natick at 7:00 pm

Starfish Summer Camp – January 12, 2011 Guest Speaker: Emily Golinsky

New Autism Insurance Laws – February 9 Guest Speakers: Amy Weinstock and Judith Ursitti

Home Modification Loan Program – March 9 Guest Speaker: Christina Cutting-SMOC

For more information on these speakers, please call Nannette or Allison at (508) 652-9900.

The **Asperger's Association of New England** is offering a full-day seminar for parents of older teens and adults and for adults with Asperger's Syndrome, **Asperger Syndrome and Adult Life: Navigating the Massachusetts Public and Private Supports & Service Systems**, on Saturday, January 8 (snow date: January 16), at Mass. Bay Community College (50 Oakland Street, Wellesley). Topics to be covered include Financial Support (SSI and SSDI); Public Housing Options; Alternative Housing/Independent Living Options; Employment Supports; Healthcare Options and What Healthcare reforms means for those with AS; and Financial and Legal Planning. For registration information, visit the website www.aane.org or call 617-393-3824.

The **Autism Support Center** is presenting **ARICA Update for Parents** on Wednesday, January 19 from 11:30 a.m. to 1:30 p.m. at 6 Southside Road, Danvers. Guest speaker is Amy Weinstock, who chairs AFAM's Insurance Committee. Beginning January 1, 2011, the new ARICA law requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of autism spectrum disorder. Join ASC to learn how to determine if your health insurance plan falls under ARICA, what treatments may be covered, and how education services are affected. Seating is limited, so please RSVP (email: asc@ne-arc.org; phone 978-777-9135).

Community Autism Resources will hold its **2011 Parent's Retreat** on January 15th & 16th at Whispering Pines Conference Center in West Greenwich, RI. The program is designed to provide a relaxing and supportive environment for parents or caregivers to reflect on, explore, and share the rewards and challenges of raising a child with ASD. There will be opportunities for relaxation, discussion, networking, making new friends and learning from other parents, in a beautiful country setting with terrific food. Although there will be opportunities to learn, the format is that of a retreat, different from a conference. The atmosphere is relaxed and casual. The retreat is scheduled from Saturday AM, to Sunday after lunch. Participants must commit to the full time of the retreat (attendance for one day is not permitted), but how you choose to use the time is very flexible. A nominal fee is requested for the weekend. Funds raised from the annual ASD symposium subsidize the retreat, so scholarships are available if finances are a

factor. To receive an application to attend the retreat please contact Community Autism Resources at 508-379-0371 ext 22

Community Resources for People with Autism will hold its **Second Annual Stepping Out for Autism** on Saturday, January 22 from 6:00 to 11:00 p.m. at The Delaney House in Holyoke, MA. Hors d'oeuvres and dinner will be served, plus dancing to the music of Union Jack. There will also be a Silent Auction and raffle prizes. Ticket price is \$40 (early bird ticket @ \$35 must be purchased by December 15). Table of 10 is \$350. For more information and to purchase tickets, visit www.communityresourcesforautism.org or call 413-529-2428.

The **Family Autism Center** will be holding their **Annual Bowling Tournament** on Saturday, February 5, 2011 at Norwood Sports Center at 7PM. Cost is \$150 for a team of 6 people.

Registration includes bowling costs and shoe rental. To sign up to be a part of the event, please contact Nancy Borr at 781-762-4001 ext. 412 or nborr@sncarc.org as soon as possible. Space is limited to 16 teams. Get your friends together, make a team and support a worth while cause while having fun with your family and friends!

Save the Date! 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." For more information, contact www.community-autismresources.com, or www.ccseminars.com. NOTE: Early Bird Savings on registrations received through December 31, 2010.

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. For registration information, visit the website www.aane.org or call 617-393-3824.

Family Autism Center's ALEC (Autism and Law Enforcement Education Coalition) Program has expanded throughout New England over the past 12 months due to funding we received from The Doug Flutie, Jr. Foundation for Autism. Close to 1,000 First Responders have been trained in Maine, New Hampshire, Rhode Island, New York and Massachusetts on Autism Spectrum Disorders. The intent of the ALEC Program is to train First Responders on ASDs so they are able to recognize situations involving children and adults with ASD. Training is available for Police Officers, Firefighters, EMTs, Paramedics, Hospital Emergency Room Personnel and Court/Judicial System Personnel. In December, ALEC will present to First Responders at a state-wide conference for Fire and EMS professionals in Connecticut. Thank you to The Doug Flutie, Jr. Foundation for Autism for their support in bringing this essential curriculum throughout New England and New York!

May Institutes Speaker Series: Experts on Autism The May Institute has partnered with the Hockomock Area YMCA for this year's Experts on Autism Speaker Series. This free series will explore a variety of topics related to autism. While content is especially relevant for families, we encourage educators, advocates and pediatricians to attend.

To register online or find out more information regarding the dates and topics, please visit www.mayinstitute.org/events/calendar. Or you may contact us at 781-437-1248 or 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, MA 02035.

December 15, 2010: "Going to Grandma's House for the Holidays!" - How to Prepare to Travel with a Child with Autism. Traveling with a child with autism can sometimes be more stressful than relaxing. As the holiday season approaches and travel increases, take some time to learn new strategies to prepare your child for these transitions. Also hear how you can structure the time with your child during the holiday breaks. Presenter: Marisa Petruccelli, Psy.D., Director of Home-Based Services, May Institute

January 12, 2011: "Want to Schedule a Play Date?" - Developing Social Skills with Children with Autism

February 16, 2011: Parenting a Child with Asperger's Disorder

March 9, 2011: "All He Wants Are French Fries!" - How to Address the Often-Challenging Feeding Issues of a Child with Autism

April 21, 2011: "Let Me Hear YOUR Voice!" - Helping Schools Learn to Value Parent Input

Participants sought for research studies at BU and Harvard

Boston University: Are you a parent or guardian of a child, teen, or young adult with an Autism Spectrum Disorder? We need your help to develop a new way of assessing your child's strengths and needs!

The adaptive behavior of children, teenagers, and young adults with Autism Spectrum Disorder (ASD) is measured in a lot of different ways.

Some assessments of adaptive behavior take a long time for parents to complete, only ask questions about specific behaviors associated with ASD, or are targeted to children in one age group. This makes it hard to track your child's progress and development over time.

The purpose of this project is to develop an efficient and comprehensive assessment of adaptive behavior of children and youth with autism spectrum disorders (ASD) ages 3-21 years.

Adaptive behavior is the performance of everyday activities that help children and youth be active members in their family, school, & community. These activities include self care (bathing & dressing), getting around, taking care of personal belongings, making friends, communicating needs and feelings, and managing health & wellness.

We are looking for parents/guardians of children who are diagnosed with an Autism Spectrum Disorder (ASD) and are 3-21 years old. We are especially interested in hearing from parents of:

Teenagers with an ASD, ages 13-17 years.

Young adults with an ASD, ages 18-21, who are transitioning to adulthood & independent living.

Children and youth with ASD who use alternative methods of communication and/or are non-verbal.

You will complete a series of questionnaires and the PEDI adaptive behavior survey on-line, at a time and location that is most convenient for you. Questions will be about your child's past and current abilities and level of functioning. The on-line survey will take about 90 minutes to complete. Parents who complete the full on-line survey will receive a \$25 gift card to Amazon.com, and be entered into a drawing to win an i-pod touch! Three parents will be selected at random to receive an i-pod touch. Parents of children 5 years or older will also have an opportunity to enter to win a Flip Video SlideHD by completing one additional survey.

If you are interested in learning more about this project, email us at asdcat@bu.edu, or visit <http://www.bu.edu/kidsincontext/>. This study is funded by the Eunice Kennedy Shriver National Institute Of Child Health & Human Development, Award Number R21HD065281 to Boston University, Dr. Wendy Coster, Principal Investigator. This text has been approved by the Boston University IRB: 9/10/10-9/9/11.

Harvard University: Researchers at Harvard University and Mass General Hospital are conducting a study to better understand the health and financial impact of autism spectrum disorder. As part of this study, the researchers would like to interview parents of children between the ages of 3-18 years who have been diagnosed with autism, Asperger's disorder, or pervasive developmental disorder-not otherwise specified.

In 90 minute group interview sessions, parents will be asked questions about their child's current wellbeing, as well as characteristics of their child that influence his or her wellbeing. They will also be asked about their own wellbeing, both physically and emotionally, and the financial costs that their family has had to bear because of their child's autism spectrum disorder.

If you would like to participate in this study, please contact Tara Lavelle at (617) 858-1738 or via email at tlavelle@partners.org. More information can be found at:

<http://www.autismconsortium.org/images/stories/pdfs/MGH%20Lavelle.pdf>

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

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car@community-autism-resources.com www.community-autism-resources.org

Autism Society of America, Massachusetts Chapter
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