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Electronic Newsletter
September 2010

Message from the Chairman:

When this legislative session concluded on Saturday, July 31, 2010 three things were certain. A stripped-down budget had been approved, a number of pieces of legislation had been passed, and Advocates for Autism of Massachusetts would be profoundly affected by the results of this past session!

Without a doubt, cuts to the human service budgets will have a significant impact on individuals with an autism spectrum disorder and their families in the upcoming year. It is clear, however -- considering the economic environment -- that those budget cuts, although painful, could have been significantly worse. I want to say thank you to all of our member organizations and their families for their advocacy on Beacon Hill. Because you attended rallies, made phone calls and sent emails when asked, your voices made a difference!

On the legislative side, three of our legislative priorities became law: ARICA, the Augmentative & Alternative Communication Bill and the Anti-Bullying Bill. I want to thank AFAM's Government Affairs and Insurance Committees for all of their hard work the past two years on these pieces of legislation!

I would be remiss if I didn't take note of how special the passage of ARICA was to our families, member organizations and to AFAM as a grassroots advocacy organization. Through the leadership of Representative Barbara L'Italien and Senator Fred Berry, as well as the tremendous support from their staffs, ARICA was AFAM's first successful legislative initiative. As law, ARICA is one of the most comprehensive insurance laws of its kind to be passed in this country to date. Our Insurance Committee, thanks to the leadership of its Chair, Amy Weinstock, wrote the law and was intricately involved as it moved through the legislative process over the past two years. Its passage is proof of what can happen when you, families, participate in the political process. I also want to thank Governor Patrick, Speaker DeLeo, Senate President Murray and the Massachusetts Legislature for their support and vision in passing this legislation.

Having accomplished as much as we did in this session, AFAM will continue its vigorous advocacy when the legislature resumes in January. In the months ahead, we will be developing new legislative priorities and pressing for additional funding for programs that affect our families, and we will continue to urge you to stay involved in the process.

Michael J. Borr, Chairman
AFAM Executive Committee

Insurance Committee

The insurance committee events since the last newsletter can be summed up in one word – WOW!

On August 3, Governor Patrick signed ARICA into law at Fenway Park before hundreds of families. This was one week after ARICA passed both the House and Senate unanimously

We have so much to be proud of and grateful for. Our bill is one of the most comprehensive of its kind; individuals with autism will have coverage for medically necessary treatment with no age caps or dollar limits. ARICA covers people with autism, because they are people with autism, whether they are 2 or 82. And the amount of treatment, just like chemotherapy/radiation for cancer patients, is based on medical necessity, not an arbitrary dollar cap.

I believe another thing we should all be proud of is the collaboration and teamwork that got us to this point. We are a diverse group; we had many different viewpoints and priorities. But we worked together in a coordinated and consistent way which enabled us to effectively get our message across and our mission accomplished. This is a tribute to all of us, and an affirmation of the power of AFAM which was so effective in bringing all the autism organizations in the Commonwealth together to work on ARICA.

This was not an easy piece of legislation and not an ideal environment to try to get ARICA passed. And we were advised by many that it would likely take multiple legislative sessions to pass. But with the strong leadership of Rep. L'Italien and Senator Berry, the strategic support and resources of Judith Ursitti and the Government Relations

Team at Autism Speaks, and the phenomenal advocacy of our community, it passed the first time it was filed.

“Leaders are visionaries with a poorly developed sense of fear and no concept of the odds against them” – Dr. Robert Jarvik

Thank you to our leaders, and to all of you. WE DID IT!

Please visit our website for updates and information on ARICA as the implementation process gets underway.

Amy Weinstock, Chair
Insurance Policy Committee

Government Affairs Committee

Close to two years ago, AFAM adopted three legislative priorities for the legislative session that ended on July 30, 2010: ARICA, the Augmentative & Alternative Communication Bill and the Anti-Bullying Bill. I am pleased to report that these bills, in their amended forms, were all passed by the House and Senate and signed into law by Governor Patrick.

Congratulations to everyone who worked so hard to ensure passage of ARICA. It really is a model piece of legislation. Unlike many other states that have passed autism insurance bills, the Massachusetts bill has no caps and no age limits for coverage. We are so appreciative of the efforts of ARICA's lead sponsors, Representative Barbara L'Italien and Senator Fred Berry, as well as the leadership of Senate President Therese Murray, House Speaker Bob DeLeo, Senator Steven Panagiotakos, Chair of Senate Ways & Means and Representative Charlie Murphy, Chair of House Ways & Means. Their support means that many Massachusetts parents of children with ASD will now be able to obtain the services their children need and have it paid for by their insurer.

On the eve of the final day of the legislative session, an amended version of the Augmentative & Alternative Communication bill passed the House and the Senate. The new law ensures that teachers of students with moderate disabilities and teachers of students with severe disabilities receive instruction on the appropriate use of augmentative and alternative communication devices. This law will make a huge difference in the lives of children with autism and other types of disabilities and is an important first step. Thanks to our lead sponsors, Senator Cynthia Creem and Representative Garrett Bradley for their hard work and dedication.

Special thanks also to all of the parents who took time to make calls and visits to their legislators. Your voices were heard!

Ann Guay, Co-Chair
Government Affairs Committee

Adult Services Committee

The Adult Services Committee of AFAM looks forward to a busy year of advocacy around the needs of adults with Autism Spectrum Disorders. Visit our pages on the AFAM website in October as we create a clearinghouse of links to resources for adults with autism and send us any links to resources that you come across that you believe might be helpful to share with others.

We are also looking into families' experiences with guardianship and Roger's monitors since changes in the guardianship laws were adopted in July 2009. Your input would be helpful. Have you run into concerning situations in the administration of guardianship for your family member with an ASD who is 18 or older? Have you had any concerns in dealing with a court-appointed Roger's monitor? We are trying to assess whether we might want to facilitate some training for Roger's monitors about Autism Spectrum Disorders and issues related to antipsychotic medications. Please email us at office@afamaction.org. Any information you provide will be treated with confidentiality.

As we look to a new year and a new legislative session, we will be working toward legislative briefings for new State Representatives and Senators and following the work of the newly constituted Autism Commission as it relates to services for adults with ASDs.

Chris Hubbard, Chair
Adult Services Committee

AFAM supporters "rock" at fundraiser

AFAM hosted another great fundraiser at the C-Note Music Club at Nantasket Beach on August 8, with music by four terrific bands: J Place; State of Mind; The Groove Doctors; and Blues Revival. The event also included caricatures by John Doherty, book-signing by author Martha Ziegler, and a silent auction. Thanks to AFAM's Development Committee for planning this great event: Marcy Wenning (Chair), Michael Borr, Lisa Borges, Sue Linehan, Laura Osborne and Christine Delany. Special thanks to C-note owner Charlie Fruzzetti for his generous assistance.

SEPTEMBER 20-OCTOBER 1, 2010
New Application Period for Massachusetts
Children's Autism Medicaid Waiver

For a short and limited time period, the Department of Developmental Service's (DDS) Autism Division will be conducting a new application process for parents of young children with autism to apply for the Children's Autism Waiver Program.

PLEASE NOTE, DDS HAS NOW DECIDED TO PLAN THE OPEN APPLICATION PERIOD FROM SEPTEMBER 20-OCTOBER 1, 2010, in order to provide sufficient time for outreach to families throughout the Commonwealth. The Autism Division anticipates that approximately 60 additional children will be eligible for the Waiver program during this initial application period that will last for approximately 12-18 months.

The Children's Autism Medicaid Waiver program provides up to \$25,000 worth of services per year of intensive in-home services (such as ABA and DIR/Floor Time) for children with autism spectrum disorder (ASD) and other services that will support children who are from low-income families in their homes and communities. The program is limited to children between the ages of 0-8 who are Medicaid eligible and at risk of institutionalization now or at some point in the future. The one page application for families to submit should be available soon on the DDS website (translated into different languages) www.mass.gov/dds

Remember even families that are on the current wait list for the Waiver need to re-apply, Note: application forms **MUST** be postmarked September 20-October 1 (applications postmarked earlier or later are not eligible).

News and Announcements

Autism Speaks New England Chapter has announced the dates and locations for the 2010 **Walk Now for Autism** walks:

Western New England, Sunday, September 19, Stanley Park, Westfield, MA
Greater Boston, Sunday, September 26, Suffolk Downs, East Boston, MA
Southern New England, Sunday, October 2, Colt State Park, Bristol, RI
Northern New England, Saturday, October 3, Fisher Cats Stadium, Manchester, NH

For information, visit the website: www.walknowforautismspeaks.org.

The Asperger's Association of New England will hold its annual conference for teens and adults with AS, parents, educators and professionals – **Connections 2010** – on September 24-25 at the Best Western Royal Plaza Hotel and Trade Center in Marlborough. Registration deadline is September 15th. For details, visit the AANE website (www.aane.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 25, departing from ride headquarters on Route One in Foxboro, about a mile from Gillette Stadium. Last year the event raised over \$7.2 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 Michele Kehling 781-762-4001, ext. 395.

Community Autism Resources will hold its **Hearts & Hands Walk for Autism and Family Fun Day** on Saturday, September 25 from 9:30 to 1:30 p.m. As always, it will be held at Bristol Community College in Fall River. The Hearts & Hands Walk for Autism and Family Fun Day is the MAIN fund raising event of the year for Community Autism Resources. It is an absolutely fantastic day full of fun and games for all ages, an amazing Autism Awareness Store, giant raffle, team and family photos, free sno-cones, popcorn, pizza and other snacks and of course the 2 mile Autism Awareness Walk. We will also pay tribute to our 2010 Volunteer of the year and our Sponsor of the Year. ALL OF THE MONEY RAISED helps Community Autism Resources continue to provide FREE services throughout our region. To register your school team or family for the walk, go to www.community-autism-resources.org

The 11th Annual Eastern Bank Flutie 5k Race will be held on Sunday, October 3, 2010 at the MetroWest Medical Center, Natick, MA. Post-race festivities include refreshments, music, kids' activities and ceremony. For more information, contact the **Doug Flutie, Jr. Foundation for Autism** (phone 1-866-3-AUTISM; email info@flutiefoundation.org)

Community Resources for People with Autism and The Doug Flutie, Jr. Foundation, together with the University of Massachusetts, Amherst, are co-sponsoring a **24 Hour Relay for Autism** on Saturday and Sunday, October 23-24 at the UMass Track. The Relay, which runs from 3 p.m. on Saturday to 3 p.m. on Sunday, will have 40 teams competing. For information about teams, sponsorships and donations, contact Nancy Farnsworth (413) 529-2428, ext. 113.

The Lurie Family Autism LADDERS program is proud to announce the 3rd Annual Roger A. Bauman M.D. Parent Lecture Series for September – December 2010

Thursday September 23 Susan Senator, parent and author of Making Peace with Autism and Mom's Survival Guide

Thursday, October 21 *The (Mass) Schools obligation to Meet the Unique Needs of Children with Autism Spectrum Disorders, parent training by Massachusetts Advocates for Children www.massadvocates.org*

Thursday, November 18 *Home Based ABA Program Overview,*
Barbara Natoli, LMHC, BCBA, Applied Behavioral Associates, Inc, Framingham
www.aba4kids.org

December TBA

When: (NEW NIGHT!) Once per month on *THURSDAY evenings*
Time: 6:30 p.m. – 8:30 p.m.

Where: *CHARLES RIVER CENTER 59 E. Militia Heights Rd, Needham, MA*
(located at the top of Dwight Rd, off of Central Street) in the Paul D. Merritt
Center For directions, please visit www.charlesrivercenter.org

YOU MUST RSVP/REGISTER Please contact Julie O'Brien, Resource
Specialist, Autism Consortium , LFAC/ LADDERS at 781-860-1726,
jobrien20@partners.org *For updates on the schedule visit: www.ladders.org
and www.autismconsortium.org events page

LIMITED CHILDCARE MAY BE AVAILABLE BY PRE-REGISTRATION ONLY
Contact Julie O'Brien at 781-860-1726

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

www.ne-arc.org/autism

Autism Resource Center of Central Massachusetts
71 Sterling Street
West Boylston, MA 01583
508-835-4278
Sloring@HMEA.org

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

www.community-autism-resources.org

Autism Society of America, Massachusetts Chapter
47 Walnut Street
Wellesley, MA 02481
781-237-0272
asamasschapter@hotmail.com

www.geocities.com/asamasschapter

Community Resources for People with Autism
116 Pleasant Street
Easthampton, MA 01027
413-529-2428
info@communityresourcesforautism.org

www.communityresourcesforautism.org

Asperger's Association of New England
85 Main Street, Suite 101
Watertown, MA 02472
617-393-3824
info@aane.org

www.aane.org

Family Autism Center
789 Clapboardtree Street
Westwood, MA 02090
eroche@sncarc.org
781-762-4001

www.sncarc.org/FAC.htm

TILL/BFA Autism Services
20 Eastbrook Road, Suite 201
Dedham, MA 02026
781-302-4600
elizabeth.waters@tillinc.org

www.tillinc.autismservicesprovided.htm

Autism Alliance of MetroWest
P. O. Box 2118
Natick, MA 01760
508-652-9900
Autismalliance@earthlink.net

www.autismalliance.org

Doug Flutie, Jr. Foundation
615 Concord Street
Framingham, MA 01702
1-866-3-AUTISM
info@flutiefoundation.org

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Massachusetts Advocates for Children
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