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Electronic Newsletter
December 2016

Message from the Chairman:

It's been 4 weeks since the presidential election and the furor is yet to die down. As the parent of a son with ASD, I am certainly concerned with a lot of what I've heard from our new President-elect during the campaign. But years of experience as a political junkie have taught me not to hit the panic button. Often a candidate's rhetoric changes when faced with the realities of actually holding office and governing. I urge all in our community to remain calm and wait to see the actual policies he and his administration put in place.

Having said that, I also realize that since much of the supports and services for individuals with ASD are in part funded by federal monies, it's more important than ever for us – AFAM -- to be vigilant and prepared to advocate for those policies that will support the people we love and who are in most need of help. We need *your* help to do that! The fact is, the success of our advocacy on behalf of those with ASD requires not only dedicated volunteers and committed grass-roots advocates, but funding as well. We are dependent on the generosity of individuals and families – people like you and me -- to enable us to continue our vital work.

Please support us! Your contribution of time or dollars, both equally important, are vital to making sure the voices and interests of individuals diagnosed with an autism spectrum disorder are considered by those in government.

With best wishes to you and your family a happy and safe holiday season!

Michael J. Borr, AFAM Chairman

Government Affairs Update

2017 Budget Concerns for People with Autism

AFAM is concerned about budget shortfalls, specifically in the area of Turning 22 and Adult Autism. These budget line items are underfunded in terms of the numbers of individuals that are eligible and in need of services and supports.

This past year, over 600 individuals were found eligible for services through the Autism Omnibus legislation. This legislation allows individuals with autism who do not have an intellectual disability to apply for DDS supports. More individuals are applying for eligibility every day, yet funding is unavailable. Massachusetts has over 900 individuals with autism or intellectual and developmental disabilities who are Turning 22 this year and many of them are now facing uncertainty in their future.

If you have a story to share about your experience with funding for services related to autism, please contact Maura Sullivan at sullivan@arcmass.org. AFAM shares these real life stories with legislators and DDS leadership as the most effective way to advocate.

Adult Services Update:

As we head into the holiday season the AFAM Adult Services Task Forces are focused on the advocacy that will be needed in 2017 to ensure that supports and services for adults with autism are implemented as the numbers of people in need of assistance with healthcare and LTSS, housing, and employment increase .

We are particularly concerned with the funding in Massachusetts of the Turning 22 account and day and residential services account which were underfunded this fiscal year and will be under pressure again next fiscal year as the number of those in next year's T22 class is expected to grow. We are also tracking the restructuring of MassHealth in Massachusetts and the implications this complete overhaul has for people with autism, offering comments to regulators as this process evolves.

We will be participating in legislative efforts to increase opportunities for the creation of affordable housing and paid employment as bills are filed in the new two-year legislative cycle that kicks off next month. And we will do our best to track the potentially dramatic changes that may occur at the federal level in the next few months, including proposals to block grant Medicaid, and provide information to you about advocacy efforts focused on those changes.

At this time of year we want to thank all of our volunteers on the Adult Services Task Forces for their input and actions throughout the year. They are truly dedicated to our mission of improving the lives of people with autism in Massachusetts! Would you consider joining us in the New Year? We are in need of some additional volunteers for our Employment Task Force, in particular. The task force meets a handful of times a year, mostly by conference call. This is a great opportunity to learn more about employment issues and opportunities, and make your voice heard as we work to increase employment opportunities for folks with autism. If you are interested, please email us at AFAMoffice@yahoo.com.

Best wishes to all for a joyous holiday season!

Insurance Update:

Health Connector open enrollment began on November 1, 2016. Open enrollment continues through January 31, 2017.

To obtain more information or for families interested in enrolling in a child-only health plan with autism benefits, call the Autism Insurance Resource Center at 774-455-4056.

News and Announcements

SAVE THE DATE! Join us for AFAM's Annual **Autism Awareness and Acceptance Day** at the State House on **Monday morning, April 10**. Watch for details after the new year.

Community Resources for People with Autism has changed its name and is now known as **Autism Connections**. Their address and phone numbers remain unchanged.

The American Repertory Theater (ART) is presenting a **Sensory Friendly performance of "James and the Giant Peach"** on Friday, December 30 at 2:00 p.m. The sensory friendly performance is welcoming to all students, teachers, families, and community members living with or supporting those with autism or other sensory sensitivities. All families will be provided a Social Story specific to the production to help in preparation for visiting the theater. To learn more and to purchase tickets for this performance, visit www.americanrepertorytheater.org Tickets for this performance can also be purchased in person or by calling (617) 547-8300 during box office hours (Tuesday - Sunday, 12-5 p.m). A.R.T. Ticket Services staff will walk you through the alterations to the performance, as well as answer any questions you might have. When ordering tickets, use Discount Code "PEACH5" to waive all ticketing fees and take an additional \$5 off of every ticket purchased

The Massachusetts General Hospital Lurie Center is offering a series of small-group informational workshops for parents, caregivers and families about **Understanding the Guardianship Process in Massachusetts**. All sessions will take place at the Lurie Center (1 Maguire Road, Lexington). Please Note: These workshops are provided by a parent/professional, are ***not*** intended to provide legal assistance or advice, rather they are informational only. Referrals to legal experts are provided as needed.

The first series, **Guardianship 101: Learn the Basics of the Guardianship Process**, provides an overview of what guardianship is and how it is determined in Massachusetts; the types of guardianships (including limited, Rogers); how to decide if your child needs a guardian and alternatives to consider; a review of how to begin the process and what the Massachusetts probate court requires; the steps you need to follow and a suggested timeline to prepare for your child turning age 18. Guardianship 101 is offered on the first and third Friday of most months, from Noon to 1:00 p.m. The fee: is \$20 per person/family. Registration is required: phone 781-860-1700.

The second series, **Guardianship 102: Learn the Step-by-Step Process for court required Paperwork**, offers a more hand-on group tutorial and will include: where you are in the process and moving forward; a review of relevant checklists for each attendee; guidance with probate court processes and referral to legal resources as needed; guidance on filling out required

documentation (petition, bond, citation/giving notice, care plan); and a question and answer session. Guardianship 102 is offered on the second and fourth Thursday of most months from 11:00 a.m. to 12:30 p.m. The fee is \$35 per person/family. Registration is required: phone 781-860-1700.

Research

SPARK : Simons Foundation Powering Autism Research for Knowledge

Boston Children's Hospital would like to invite individuals diagnosed with autism as well as their biological family members to join **SPARK!** SPARK, sponsored by the Simons Foundation Autism Research Initiative, has the mission of advancing understanding of autism by building the nation's largest autism study. Together we can improve lives by helping to accelerate research!

What is the study about?

SPARK is an online study with a simple mission: to speed up research and advance the understanding of autism. By increasing the number of research participants, SPARK aims to help facilitate research that has not yet been possible.

How much time does it take?

Registration takes about 20-30 minutes. As part of your participation in SPARK, we ask that you register and complete a few questionnaires online, and provide a DNA sample using a saliva collection kit that will be shipped directly to your home.

Who can be in the study?

Any individual diagnosed with autism as well as their biological family members.

Who do I contact if I am interested in hearing more about the study?

Registration and information can be found here: www.SPARKforAutism.org/BCH

Questions? Contact Emily Matthews at SPARK@childrens.harvard.edu or (617) 355-8300.

enTRAIN parent-child research study at Northeastern University for 2-5 year old children with autism: \$75 compensation

New opportunity for you and your child to be involved in a **fun, play-based study** using a new toy developed by researchers at MIT along with cutting-edge wearable technology that can measure heart beats and stress levels. We're looking for *(mothers, fathers, parents, as appropriate)* of children who have a diagnosis of an **autism spectrum disorder aged 2-5 years** old to take part in a 1.5-2 hour study in our Northeastern University lab; you'll be with your child the entire time. We will pay you \$50 plus \$25 toward travel costs as well as a small toy/gift for your child; parking is available. If you're interested in learning more, please visit www.cbslab.org/entrain or email entrain@cbslab.org.

The **Lab for Infant & Toddler Language at Emerson** is currently seeking participants for a study looking at how overhearing others' conversations supports language development. The goal of this study is to explore this question in children with autism spectrum disorder. The study is enrolling children ages 2-5 years who have a diagnosis of Autism Spectrum Disorder and both normal vision and hearing. It involves one two-hour visit to the lab with free parking, free childcare for siblings, and a small toy for your child. For more information, please contact us at (617) 824-3511 or email CSDResearch@emerson.edu.

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

Autism Support Center
6 Southside Road
Danvers, MA 01923
978-777-9135

www.ne-arcautismsupportcenter.org/

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

www.autismresourcecentral.org

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

www.massautism.org

Autism Connections
116 Pleasant Street, Suite 366
Easthampton, MA 01027
413-529-2428
iris.scott@pathlightgroup.org

www.autismconnectionsma.org

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

www.arcsouthnorfolk.org/family-autism-center.html

TILL's Autism Support Center
20 Eastbrook Road, Suite 201
Dedham, MA 02026
781-302-4600
Lisa.Connor@tillinc.org

www.tillinc.autism_support.html

Autism Alliance of MetroWest
1881 Worcester Road
Framingham, MA 01701
508-652-9900
ADaigle@advocates.org
PMcKillop@advocates.org

www.autismalliance.org

Doug Flutie, Jr. Foundation
P. O. Box 767
Framingham, MA 01701
508-270-8855
info@flutiefoundation.org

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Massachusetts Advocates for Children
25 Kingston Street. 2nd Floor
Boston, MA 02111
617-357-8431
Jlandau@massadvocates.org

www.massadvocates.org

Autism Speaks, Inc. - New England Chapter
85 Devonshire Street, 9th Floor
Boston, MA 02109
617-726-1515
Russ.Kenn@autismspeaks.org

www.autismspeaks.org

Charles River Center
59 E. Militia Heights Road
Needham, MA 02492
781-872-1000
ekilicarslan@charlesrivercenter.org

www.charlesrivercenter.org

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