

ASA-Net



Autism Society of America's eNewsletter

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ASA Advocacy Update

Legislative Wrap Up on Autism Issues

109th Congress Recesses to Campaign for Re-election

Congress recessed on September 29th so that Members of Congress could return home to campaign for re-election. While Congress was able to complete some of its legislative business in September, much work remains to be done in a lame-duck session. The following is a status update on many of the issues of interest to the autism community.

Defense Appropriations

Prior to recessing, Congress passed the FY 2007 Department of Defense Appropriations bill. This legislation includes funding for a range of biomedical research projects, and for the first time, dedicates \$7.5 million to autism-related research. This program is funded under the Army's Research, Development, Education and Training Center, which supports innovative, cutting-edge research for a range of conditions including cancer, spinal cord injury, diabetes, Parkinson's disease and other diseases and disabilities.

While funding will support research on autism spectrum disorders in the military, breakthroughs in this area -- such as improved diagnosis, early intervention, and treatment -- will have broad application for the larger autism community.

Combating Autism Act

As previously reported in ASA-Net, the Senate unanimously passed S. 843, the Combating Autism Act, in early August. This important legislation would provide an additional \$900 million for autism related research at the NIH. It would bolster efforts to improve diagnosis, early intervention, and treatments for autism spectrum disorders.

Despite the widespread support of the autism community, unanimous support in the U.S. Senate, and broad, bipartisan support in the House, this legislation remains tied up in the House Energy & Commerce Committee. Congressman Joe Barton (R-TX), chairman of the powerful Energy and Commerce Committee, has refused to pass the Combating Autism Act because he has different political priorities.

ASA has not given up the fight on the Combating Autism Act, and is working to convince Chairman Barton, Speaker Hastert, and the House Leadership to move this legislation. ASA advocates have sent tens of thousands of emails, letters, and phone messages to their Members of Congress, urging them to convince Chairman Barton and the House Leadership to pass S. 843. ASA's staff and volunteer leadership have lobbied many Members of Congress and are working with our Congressional champions, the Coalition for Autism Research and Education, to get this bill through the House of Representatives and onto the President's desk.

We will keep up the fight on this important issue until the Combating Autism Act is signed into law. To find out how you can help, visit this link:

http://www.autism-society.org/site/PageServer?pagename=govt_research&autologin=true

Lifespan Respite Care Act

Similar to the Combating Autism Act, the House of Representatives failed to enact H.R. 3248, the Lifespan Respite Care Act. This legislation would establish a program to assist family caregivers in accessing affordable and high-quality respite care. Respite care provides parents, grandparents, siblings and other caregivers the relief they need to cope with providing full-time care for individuals with disabilities. With respite care, family members are better able to maintain their own health, prevent family problems, keep their marriages intact and avoid costly institutional and long-term care.

This legislation was passed unanimously out of the Energy & Commerce Committee, but has not passed the House of Representatives. Unlike the Combating Autism Act, however, the House Leadership has pledged to pass this legislation in the lame duck session (the so-called "lame duck" session cover the period of time after the November elections until Congress is convened in January). ASA has joined with a coalition of other disability related organizations to push for enactment of this important legislation. To find out how you can help, visit this link:

http://www.autism-society.org/site/News2?news_iv_ctrl=-1&page=NewsArticle&id=8973&autologin=true

Family Caregiver Support Act

After months of negotiations and compromise involving the House, Senate, and the Administration, the Older Americans Act has been reauthorized for five years, including the Family Caregiver Support Act. The Act is an improvement over the 2000 reauthorization which authorized caregiver support, such as respite care, for older individuals caring for a child with a disability. Following the 2000 reauthorization, the Administration had defined children with

disabilities as only those up to age 18 despite Congressional intent that older caregivers caring for adult children with disabilities receive the supports. The new law defines children with disabilities to include those over age 18 and reduces the caregiver age to 55. This will be a tremendous support to older caregivers still caring for their adult children with autism at home.

Post-Katrina Emergency Management Reform

Before leaving for their districts, the Congress passed the FY 2007 Department of Homeland Security appropriations bill (HR 5441), which includes the Post-Katrina Emergency Management Reform bill. The disability community, including ASA, supported the establishment of a Disability Coordinator to ensure that the needs of individuals with disabilities are being properly addressed in emergency preparedness and disaster relief. Responsibilities of the Coordinator include: providing guidance and coordination on matters related to individuals with disabilities in emergency planning requirements and relief efforts; consulting with organizations that represent the interests and rights of individuals with disabilities about the needs of individuals with disabilities; ensuring the coordination and dissemination of best practices and model evacuation plans for individuals with disabilities; ensuring the development of training materials and a curriculum for training of emergency response providers, and providing guidance and implementing policies to ensure that the rights and wishes of individuals with disabilities regarding post-evacuation residency and relocation are respected. The Act also amends the Robert T. Stafford Disaster Relief and Emergency Assistance Act by inserting "disability" into its nondiscrimination clause.

Other Autism Funding Issues

Another issue on the agenda for the lame duck session is completion of the FY 2007 Labor, Health and Human Services and Education Appropriations legislation. Both the House and the Senate have reported their versions of this important spending bill out of committee. However, due to funding shortfalls, neither the House or the Senate has passed their versions on the floor. It is possible that this bill will be included in an end-of-year omnibus appropriations bill, or that it may be pushed off until next year.

Currently, both the House and the Senate bill provide funding for the CDC's autism program, which funds autism surveillance (counting the number of individuals with autism), early diagnosis and treatment programs and professional education programs. Despite the growing need for these types of activities, the House provided only \$15.5 million for this critical program, the same as the funding level for FY 2006. The Senate also provides continuation funding, but does not provide funding to expand this important program.

Autism research at the National Institutes of Health was similarly shortchanged. Funding for the entire agency was cut by approximately \$300,000, but funding at the leading autism institutes - - the National Institute of Child Health and Human Development and the National Institute of Deafness and Other Communication Disorders -- was cut by almost \$10 million. While the Senate bill provided some additional funding for these activities, autism research continues to be underfunded.

With control of the House and Senate hanging in the balance, it is unclear whether Congress will enact appropriations bills in the lame duck Congress or will defer these hard decisions until January. ASA will certainly continue its efforts to secure additional funding for these critical autism related programs, and will alert our advocates about any progress on these important bills.

ASA's New Advocacy Page Now Live
Get Up to Date on ASA's Government Relations Activities

ASA has been the leading organization representing the autism community in the nation's capital for more than 30 years. The efforts of ASA's leaders and staff over this time have resulted in the successful launch of a number of pieces of legislation affecting the autism community. Our work not only increases public awareness about autism, but has also resulted in millions of dollars devoted to autism research and services.

Now, we have updated our advocacy page, which is live on our Web site. Get informed on the latest developments on Capitol Hill by clicking "Get Involved" on the tool bar above, then clicking "Advocacy." Here, you will see a brief introduction about ASA's advocacy efforts, along with links to the five core areas of our legislative agenda, recently approved by the ASA Board of Directors.

ASA is continuously monitoring the activities of Congress and the federal government, educating these groups about the unique needs of those with autism and pushing for increased attention and programs. We are dedicated to this now and into the future. As always, we will keep you informed about our activities through ASA's Web site; our magazine, *The Autism Advocate*; and through our "Action Alerts," which are often included as action items in our bi-weekly, free electronic newsletter, *ASA-Net*.

To view the advocacy page, go to: www.autism-society.org/advocacy

Federal Legislation to Limit Discrimination on Access to Mental Health Services for Individuals with Autism
Contact Your Representatives to Support the Paul Wellstone Mental Health Equitable Treatment Act

The Paul Wellstone Mental Health Equitable Treatment Act of 2005 (HR 1402), introduced by Representatives Patrick Kennedy (D-RI) and Jim Ramstad (R-MN), would expand the Mental Health Parity Act of 1996 and address discrimination in group health plans against persons with mental or substance use disorders. This would be accomplished by amending the Employee Retirement Income Security Act of 1974 (ERISA) and the Public Health Service Act to prohibit a group health plan or group health coverage that provides both medical and surgical benefits and mental health benefits from imposing treatment limitations or financial requirements on mental health benefits, unless comparable limitations or requirements are imposed on medical and surgical benefits.

The legislation defines "mental health benefits" as benefits with respect to services for all categories of mental health conditions listed in the Diagnostic and Statistical Manual of Mental Disorders, including autism spectrum disorders. Some states have passed insurance mandates regarding coverage of mental health treatments, however ERISA plans have been exempt from such mandates, too often leaving children and adults with autism without needed mental health and behavioral services. The legislation closes the loopholes that allow discrimination in the co-payment, co-insurance, deductible, maximum out-of-pocket limit and day and visit limits. It applies only to group health plans already providing mental health benefits, and excludes (as does current law) health plans sponsored by employers of fewer than 50 people.

The bill has 230 cosponsors and just before the House recessed, Representatives Kennedy and Ramstad filed a "discharge petition" that, if approved by the House, would compel a November vote on the bill. Individuals with autism, families and professionals concerned with the

availability of mental health services should contact the bill cosponsors (to see if your representative is a cosponsor, go to <http://thomas.loc.gov/> and type in bill number "H.R. 1402") and ask them to sign discharge petition #18 for immediate passage of the Paul Wellstone Mental Health Equitable Treatment Act. Take the time to tell them how much you appreciate his/her having cosponsored the bill, but that families struggling with autism spectrum and mental health disorders need this additional help now.

To see a list of representatives that have already signed the discharge petition, go to: <http://clerk.house.gov/109/lrc/pd/petitions/Dis18.htm>. You can use the toll-free Parity Hotline, 1-866-parity4 (1-866-727-4894) to call your representative to urge him/her to sign the petition to bring mental health parity to a vote. (The Parity Hotline reaches the Capitol switchboard, which can connect callers to their Members of Congress.)

ASA Research Update

CDC Funds Largest Study of Autism's Cause

The largest federal study to date into the causes of autism was announced Friday -- a multi-state investigation that will involve 2,700 young children. The U.S. Centers for Disease Control and Prevention and five other research centers will study the children over five years. The research is designed to investigate any genetic and environmental factors that may contribute to autism.

To find out more, go to: <http://www.cnn.com/2006/HEALTH/10/06/cdc.autism.ap/index.html>

UC Davis M.I.N.D. Institute's Clinical Implications of Environmental Toxicology for Children's Neurodevelopment in Autism Conference, Co-sponsored by ASA

November 2-3, 2006

Concern is increasing that environmental toxins may play a significant role in abnormal neurodevelopment and may be associated with mental disorders in children. This course will describe evidence for this association, describe potential interventions to treat and protect children and discuss effective interventions to help remove neurotoxins from our environment. The target audience includes physicians and other health care providers who work with children who have or are at risk for neurodevelopmental disorders.

Tuition: \$210 for physicians, \$160 for all others; the fee will increase to \$260/\$200 after October 12, 2006.

For more information and an enrollment form, use the link below:

http://www.ucdmc.ucdavis.edu/cme/conferences/pdfs/ENVTX007_11-2-06.pdf

ASA Education Update

The *Autism Advocate*: ASA's Premier Magazine on Autism Spectrum Disorders

The 4th edition of the *Autism Advocate* is in homes now, and we are hard at work on our exciting 5th edition, which is a special issue on environmental health and autism. The first publication of its kind, this issue convenes pre-eminent researchers and professionals to discuss

the spectrum of environmental impacts on autism.

Don't let your friends and family miss this great issue! Forward the link below and get them informed!

Already a member? Go to www.autism-society.org/magazine to read the *Autism Advocate* online.

**Department of Health and Human Services to Host Celebrating Persons with Disabilities
Event to Celebrate the Abilities of Persons with Disabilities**

To celebrate the abilities of persons with disabilities and those making a difference in the lives of persons of all ages with disabilities, the Office on Disability within the U.S. Department of Health and Human Services will host Celebrating Persons with Disabilities, on Wednesday, October 25, 2006, from 2:00 to 3:30 p.m., in the Great Hall of the Hubert H. Humphrey Building, 200 Independence Avenue, SW, Washington, D.C.

To assure appropriate seating arrangements and recognition, please RSVP by October 13, 2006, to Brian Bergmark at (202) 260-5017 (Voice), (202) 205-8280 (TTY) or Brian.Bergmark@hhs.gov.

ASA Conferences Update

ASA October 2006 Regional Training

October 21: Nashville, TN
"You're Going to Love This Kid"
Teaching Students with Autism in Inclusive Classrooms

If you thought that only having 90 minutes with Paula Kluth, Ph.D., was not enough at ASA's 2005 National Conference in Nashville, TN, well, you are in luck. ASA and the Autism Society of Middle Tennessee (ASMT) are bringing her back for a full day!

Dr. Kluth's interactive presentation focuses on strategies, techniques, plans and methods, which have facilitated the successful inclusion of students with autism in general education classrooms.

Use the link below for more information and to register:
<http://www.autism-society.org/site/Calendar?view=Detail&id=4481&autologin=true>

Special event during the weekend with Paula Kluth and ASMT: "Rockin' in Nashville," an evening with friends, food and fun, as well as a silent auction, with proceeds to benefit ASMT. For more information: <http://www.autism-society.org/site/Calendar?view=Detail&id=4481#fnse>

"Having a Ball on the Beach" and Regional Chapter Leader Development Workshop in Virginia Beach Well Received

ASA chapter leaders, special educators and parents from the Mid-Atlantic came together last weekend at the Founders' Inn in Virginia Beach to learn about positive behavioral supports for

children with autism. The workshop, lead by ASA Board Member and Panel of Professional Advisor Co-Chair Jim Ball, gave important strategies for communicating with children all across the spectrum, optimizing their education programs in the classroom, and classroom tips for immediate use. ASA staff Jeff Sell, Ed Shipley and Marguerite Colston led a regional chapter leader development workshop that gave chapter leaders tools and information on advocacy, message development, handling the media and governance.

2007 National Conference Call for Papers Now Open

ASA's 2007 National Conference theme, "Together a Brighter Tomorrow," reflects our belief that success will be achieved with all affected by autism -- individuals, families, professionals and friends -- working together. During this conference, to be held in Phoenix, AZ, July 11-14, 2007, ASA will bring together experts from various disciplines with the creative ideas and energy to address the diverse challenges individuals with autism and their families face. Our goal is to provide conference attendees with the opportunity to learn from innovators and access critical information to improve their lives and those of the people they love, treat and inspire. With collaboration and armed with knowledge, ASA is sure that there will be a "brighter tomorrow" for the autism community.

Submit your abstract/paper for consideration to speak at ASA's 38th National Conference:
<http://asa.confex.com/asa/2007/cfp.cgi>

ASA in the Media

Metin Bereketli to feature his work and support for autism awareness on Los Angeles public awareness show

Renowned Los Angeles-based painter and long-time ASA supporter Metin Bereketli will appear on "Eclectic Moments" on Time Warner (formerly Comcast) public access cable television. The show, hosted by producer Terry Scott-Mitchell, explores the problem of autism, the mission of ASA and Metin's valued efforts at bringing inspiration through art to individuals with ASD. The show will air in the Los Angeles media market on October 24 and 25, 2006. For information in your region, please contact your cable representative.