
ASCG Newsletter

From The President's Desk

Dear ASGC Members:

Things are moving in a very positive direction for the ASGC. I want to thank all of those in attendance for last month's meeting. It was encouraging to see the number of new members and old members alike. We thank all of you that have offered your support over the last few weeks. A special thanks goes out to our Webmaster, Greg Wolf, for keeping www.asgc.org polished and updated.

I also welcome Maureen Ferfolia to the board, filling the position of Secretary. She has a writing background and a degree in journalism. She is also mother to a six-year-old son on the spectrum and a four-year-old daughter. A big ASGC thanks and welcome goes out to Maureen, we look forward to working with her.

New Time and Location for ASGC Meeting

The ASGC meets the first Wednesday of every month at 6:30 p.m. in room 8 of the St. Basil parish Center in Brecksville. The next meeting is July 6. Anyone who is affected by, has a loved one affected by or just wishes to learn more about autism is welcome to attend. (216)556-4937

For this month's meeting on July 6th, we have two presenters who will each provide valuable information to the membership.

Janet Gallucci attended the Milestones Conference on June 20th. She will provide a summary on several topics that were offered there. Ed Bosse of MetDESK will be speaking on the vital issue of Estate Planning for those with children on the spectrum. Both speakers are appearing at the memberships' request. I thank them for their time and effort, and I also thank the membership for their feedback in helping us provide speakers they consider most important.

Coming up in August we look forward to hosting representatives from the law office of Hickman Lowder. They will be giving us an update on the reauthorization of IDEA, and how its implications can affect us all. We look forward to seeing you at an ASGC meeting soon, and thank you for your continued support as we forge ahead together to make the Greater Cleveland area the best place to live for those with ASD.

With Sincere Thanks-

Rory McLean, President

Autism Society of Greater Cleveland

July Issue, 2005

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ASGC Officers

Rory Mclean
President

Gus Gallucci
Vice President

Maureen Ferfolia
Secretary

We can be reached at:
(216)556-4937

Congressional Staffers Get Info on Incidence of Autism

ASA President, Committee Chair and NYFAC President lead address

ASA President & CEO Lee Grossman, together with New York Families for Autistic Children (NYFAC) President & CEO and ASA Government Relations Committee Chair Andrew Baumann, briefed Congressional staffers on June 7, 2005, on the startling statistics in the incidence of autism, and the desperate need for services, and increased funding for such services, individuals on the spectrum require.

Baumann opened the session by noting the drastic increase in individuals being diagnosed with autism today. "When my son Anthony was diagnosed 8 years ago, autism occurred in 1 in 2,500 births; now it's 1 in 166 births," he said. "The disorder has reached epidemic proportions. We don't know what causes it, and we don't know how to cure it. But we do know we must provide respite for families."

Grossman concurred, stating that "today, 60 families' lives will change. We're seeing a tsunami effect of children being diagnosed. This is a national emergency. And those are not just ASA's words; those are the words of the National Institutes of Health and the Centers for Disease Control." He added that the far-reaching effects of autism go well beyond the diagnosis of the child.

"When autism presents itself in a family, it dominates the family's lives. All aspects of the family are centered on the child with autism. That child's needs are so intense, the family cannot conduct themselves in a 'normal' manner," he said.

Grossman then outlined the dollar figures of providing adequate services for individuals with autism, citing decades of neglect for this disorder. "To service this population adequately, we're looking at \$60-90 billion in funding annually; in 10 years, we project that estimate to go up to \$300-400 billion," he said. "Currently, autism is receiving \$6 billion, so the balance is coming out of families' pockets. And unfortunately, those with autism do not outgrow it. Ninety-percent of costs for autism are in the adult sector."

Grossman and Baumann did not, however, want meeting attendees to walk away with the notion that an autism diagnosis is hopeless. Both pointed out that although autism is a complex developmental spectrum disorder that knows no ethnic or social boundaries and has no known cause or cure, "we do know it's treatable," said Grossman. "We know if we apply intensive and appropriate services to these kids, they will improve."

Global Autism Project To Visit Cleveland State University

Global Autism Project is traveling the world empowering families with knowledge about autism. Our vision is to provide parents with the same knowledge and skills that their child's providers have. We strive to provide this service using the most cost-effective means, so that this powerful information is accessible to as many families as possible.

Fortunately we are able to provide 10 full scholarships for each workshop and 20 partial scholarships for each workshop.

Global Autism Project is coming to Cleveland State University (Main Classroom 101) from 9 am -2 pm on the following dates:

July 2: How to Elicit Communication in the Home and Community

July 16: Generalization and the Natural Environment

The format is an intensive lecture, small group exercises, individual exercises and practical homework application aimed at parents. Each of the lectures is comprehensive and includes a carry-over from the previous workshop.

For scholarship information and brochures please contact:

1.877.731.5600 ext 2 or 3
info@globalautismproject.net

Workshop to Highlight Communication System

General Description: The Picture Exchange Communication System (PECS) is a language training package that is used to teach communication skills rapidly to those with limited functional speech. PECS promotes communication within a social context, without lengthy prerequisite training. Training in PECS begins by teaching spontaneous request, and goes on to teach additional communicative functions such as responding to questions and commenting. An added attraction for pre-school children with autism and related disabilities is the high proportion of children who acquire independent speech. Participants will learn how to implement the six Phases of PECS, including attributes, through presenter demonstrations, video examples and role-play opportunities. Participants will leave the workshop with an understanding of how to implement PECS with individuals with autism, related developmental disabilities, and/or limited communication skills.

Workshop Date and Location

Columbus, Ohio

July 25 & 26, 2005

Presented by:
Diane Black, M.Ed. & Anthony Castrogiovanni, Ph.D.

Holiday Inn & Suites

If you know anyone who might benefit from our training workshops, feel free to pass along this information. If you are interested in sending a group of five or more, please contact us regarding group discounts. We look forward to seeing you and/or your staff at our upcoming workshop.

For an updated workshop listing and information about registration, please visit our website at www.pecs.com.

Informational Web Sites

The Department of Aging, recipient of the CMS Real Choice System Change Grant recently unveiled a new web site called ConnectMeOhio.org. "Although Connect Me Ohio will continue to expand in the months ahead with new information, its features include a database to locate information and resources of services for persons with a disability, regardless of age. It has information about a lot of different topics, legislative updates, a live chat feature, and a discussion board.

This site is a national model that is currently being used in 10 states and was customized specifically for Ohio.

Look for additional information about ConnectMeOhio.org in the upcoming months and encourage any groups or organizations that you are aware to be sure to list their services there." Please consider posting your group's information there.

Visit the site at www.connectmeohio.org.

While designed to assist people over 55, the following website may also be of assistance to adults with disabilities in determining what medical benefits they may be eligible for.

<https://ssl2.benefitscheckup.org>

Generation Rescue is an organization with more than 150 parents who are successfully treating their own autistic children using a variety of biomedical interventions individualized for each child. For more information, see the organizations Web site at www.GenerationRescue.org.

Legislative Update

The Combating Autism Act of 2005 has now been introduced into both the US House and Senate. This update from www.autismbill.org provides great information, a bill summary, and links on what to do to help NOW and how to contact your federal legislators. Please make your voice heard and contact your legislators today!

CMS Implements Prescription Drug Coverage

The Centers for Medicare & Medicaid Services (CMS) is beginning to implement Medicare prescription drug coverage, under the Medicare Modernization Act of 2003, in which all Medicare beneficiaries will be eligible for drug coverage. The plans will cover both brand name and generic drugs, and, most noteworthy for families of individuals with autism, there will be extra help to pay for prescription drug coverage provided for those in need.

According to CMS, almost 8 million people will automatically qualify for this extra help, and beginning in late May through June, those with Medicare and Medicaid, those in a Medicare Savings Program, and those who receive Supplemental Security Income, will receive a notice from Medicare telling them they will receive the extra help automatically, so they do not have to apply for it. To view the notice, visit: www.cms.hhs.gov/medicarerereform/lir.asp.

Extra help is also available to those who do not automatically qualify, but have limited income and resources. The Social Security Administration (SSA) and CMS are working together to help these people apply for extra help and get pre-qualified before the enrollment period begins in the fall. SSA will be mailing a letter and an application to almost 19 million people beginning in late May through August, so they, too, can benefit from the extra help. To view the letter, visit: www.ssa.gov/organizations/medicareoutreach2/.

Medicare and Social Security will be conducting nationwide outreach events in the next six months to inform people about the availability of extra assistance for drug coverage and ensure that those who qualify complete the application, so that in November they can enroll in a prescription drug plan that meets their needs.

Senators and Representatives Introduce Combating Autism Act

On April 19th, U.S. Senators Rick Santorum (R-PA) and Christopher Dodd (D-CT) introduced the Combating Autism Act of 2005 (S.843), a bipartisan bill that could significantly expand the federal government's response to the autism epidemic. The bill (H.R.2421) was also introduced in the House of Representatives by Congresswomen Mary Bono (R-CA) and Diana DeGette (D-CO) on May 18th. The Combating Autism Act commits an unprecedented \$860 million in federal funds to combat autism through research, screening, intervention and education efforts, in effect doubling the current federal autism funding level.

Because of a different committee agenda in the House, H.R.2421 does not include provisions of the Senate bill relating to the National Institutes of Health. Those issues will be considered separately in the House. In every other respect, H.R.2421 is identical to S.843, including vital provisions relating to autism surveillance, public awareness, and--most importantly--early identification and treatment.

How can you help?

We urge you to join concerned families and all major autism organizations in supporting the Combating Autism Act of 2005. Both Houses of Congress must successfully secure the sponsorship required to enact this legislation. You can help by contacting your representatives in Washington D.C. and asking them to co-sponsor the Combating Autism Act of 2005, known as S.843 in the Senate and H.R.2421 in the House. This is the most important and comprehensive autism-related legislation since the Children's Health Act of 2000, which expires this year. If we join our voices through this organized effort, we can get the Combating Autism Act enacted this year.

On His Mind: Autism Inflation

Jerome Kagan and Robert Pozen, *Forbes Magazine*, June 6, 2005

Doctors should use biology, not only behavior, to evaluate children.

The bad news is that the reported incidence of autism has tripled over the last decade. The good news is that this figure is probably exaggerated.

Autism's sharp rise is, in large part, a matter of definitions. Is a child with severe learning problems autistic? What about a child who is insensitive in social situations? What about children who have trouble communicating or seem to retreat into their own shells? These days a large number of children who fit any of those descriptions are likely to be tagged with the autism label, or their parents will be told that they have a disorder (like Asperger's syndrome) that falls somewhere in the autism spectrum.

This looseness of definition is getting in the way of medical progress. We will not find effective cures for autism until we add biological markers to behavioral symptoms in diagnosing children.

Three different types of biological features can help to distinguish among the children currently labeled as autistic by behavioral symptoms.

A larger brain, as revealed in MRI scans, is one sign. The larger brains of some autistic children could be due to an excess of myelin, the sheath of white matter around the nerve cells. This could mean that the neurons are overly active, since neuron activity stimulates the production of myelin. Other autistic children have abnormally small neurons in the prefrontal and temporal cortex. These parts of the brain play a major role in language development and behavioral control--key challenges for many autistic children.

A second set of biological markers involves the responses of neurons to external stimuli as measured by the timing and magnitude of brain waves. Some autistics do not show the expected wave form when they hear a change in a spoken syllable (e.g., from "pa" to "ba"). This suggests that there is something deficient in language perception.

The biochemistry of the brain supplies a third differentiating feature. A set of the relevant molecules can be measured by examining the cerebrospinal fluid, which bathes the spinal cord and extends upward to the brain. Some autistic children show abnormally high concentrations of molecules called gangliosides. Other biochemical features, which can be measured by brain-scanning techniques, show that certain autistic children have abnormally high amounts of serotonin, a critical molecule for regulating mood.

If children with autistic behaviors were evaluated for these biological features, physicians would likely find several distinct profiles among the children, despite the similarities of their behavior. In other words, what we call autism today is likely to constitute two, three or even more quite different disorders.

Continued on Page 7

State Rep Wants Autism Awareness License Plate

On June 14, 2005, Rep. Jon Peterson (R-Delaware) introduced legislation - HB 298 - to create an autism awareness license plate! This was one of the recommendations of the Ohio Autism Taskforce and we are very pleased that progress continues on the recommendations.

Rep. Peterson has asked for additional sponsors for the legislation. Please contact your State Representative and encourage them to co-sponsor the Autism Awareness License Plate bill (HB 298). Potential co-sponsors should contact Rep. Peterson's office - a list of the current sponsors follows my signature. There are currently over 25 co-sponsors for the bill, which is great - but more would be even better. Not sure how to find your state Representative? Visit www.house.state.oh.us, click on "Your Representatives" and enter your zipcode. The process of creating the Autism Awareness

the legislation has now been introduced. The second part is collecting signatures to support the license plate. Over one thousand (1,000) signatures must be collected for a new license plate to be created!

Here is where we need your help. Please download the file, sign the petition and encourage your friends, neighbors and relatives to sign. Visit www.autismo-hio.org, click on "ASO License Plate" from the list of choices on the left, then scroll down to the bottom of the page and click on "DOWNLOAD the License Plate Petition". By signing the petition, people are not "technically" obligated to purchase an Autism Awareness License plate, but we would hope that people would show their intent to buy by signing. In order to keep the license plate "active", at least 1000 must be purchased each year.

Continued on Page 7

Job Openings

Ardmore Inc.

Ardmore Inc. is on a Fast Track to open up a home for children with autism by July 2005.

Ardmore inc. will have available 13 openings for employment

- 1 Full time manager
- 9 Full time positions
- 3 Part time positions

Contact: Mike Noe
Coordinator of Autism Services
Ardmore Inc.
Center for Autism
981 East Market Street
Akron, OH 44305
(330)535-2601 ext 3333

Autism in the News

Check newsstands for the latest issue of RollingStone magazine featuring an article authored by Robert F. Kennedy Jr. on the preservative thimerosal, which will simultaneously run today on <http://www.salon.com/>.

Bellefaire JCB

Job Position: Outreach and Admission Specialist

Contact: Simone McNitt
216-320-8442
mcnitts@bellefairejcb.org
www.bellefairejcb.org

The Outreach & Admission Specialist will play a key role in Bellefaire JCB's growth by marketing mental health and autism services to a diverse audience in Ohio. Responsibilities include managing an expanding portfolio of clients; representing Bellefaire in the public arena; extensive in-state travel. The ideal candidate will possess strategic thinking skills with an ability to find creative and compelling ways to market Bellefaire services; excellent communication skills; and will be exceptionally organized and self-motivated. Sales and marketing background preferred.

On His Mind

From Page 5

The currently preferred treatment for children exhibiting early signs of autism is enrollment in intensive behavioral programs. These programs involve one-on-one interactions between the child and the therapist from 20 to 40 hours per week. Scientific studies of the most popular of these programs have shown modest results. Although intensive behavioral therapy can reduce the frequency of certain autistic behaviors for certain children, it does not cure the basic language and emotional deficiencies of most autistic children.

To find new cures, we need more research into the biological bases of the various types of autism. Over the last few years the National Institutes of Health has greatly increased funding for such research, but it must continue to coordinate the studies at various laboratories to ensure systematic conclusions on these biological markers. Once these conclusions are established, we'll be well on our way to prescribing new therapies that target each child's particular biological disorder, rather than general therapies aimed at all children labeled as autistic.

Perhaps in a few decades, when a young child begins to exhibit autistic symptoms, a physician will order blood tests and brain scans. These will lead to a targeted set of therapies that will be far better than the uniform response we offer today.

Jerome Kagan, professor of psychology at Harvard, and Robert Pozen, chairman, MFS

Autism Awareness Plate

From Page 6

The purchase of a plate does two things - increases awareness of autism and represents a \$15 donation to the Autism Society of Ohio. People have to purchase plates each year anyway - if they are committed to improving services for persons with autism and their families in Ohio then this is an easy way to show it! And for those who are unable to do anything else - it is a major help!

Even if you are able to only collect one signature - every signature helps! If every advocate collects just two (2) signatures, we will have over two thousand!

Please note that persons can sign with a social security number OR their current license plate number. Only petitions with original signatures can be submitted to the BMV, so please snail mail any petitions with signatures to the ASO License Plate Chair:

Ann Hagerstrand
11739 Grandstone Lane
Cincinnati, OH 45249

Proceeds from the License plate will be used by ASO to continue our work of advocating for more and better services for persons with autism and their families in Ohio. Additionally, we hope to provide grants and assistance to ASA Chapters in Ohio.

Musical Tells Real-Life Story of Autistic Girl

Artistic Director David Esbjornson's is featured in his inaugural season at Seattle Repertory Theatre. The slate will also include Tuesdays with Morrie, Nine Parts of Desire, and a new musical based on the life and growth of an autistic girl, Temple Grandin.

Based on the real life of a girl who did not speak until she was three but grew up - despite her autism - to achieve success, a doctorate and more, "this world premiere musical celebrates the determined ingenuity of a miraculous spirit through the true story of Temple Grandin."

Temple music by Norman Durkee, book and Lyrics by Silvia Peto (March 2- April 1, 2006).
By Ernio Hernandez

Autism Society of Greater Cleveland

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Phone: (216)556-4937
Email: support@asgc.org

From Diagnosis through Adulthood

The ASGC is a volunteer organization

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Web!
www.asgc.org

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Jerry Newport and
Mary Wrobel

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www.futurehorizonsautism.com

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Cincinnati, Ohio

Keynote Speakers:
Dr. Vince Carbone
&
Dr. Teresa Grossi

www.autismohio.org

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