



# ASGC Newsletter

## From The President's Desk

First off, a big ASGC thanks to all who attended and generously contributed to our first fundraising effort of 2006! Our Guest Bartending Night at The Mill Road Grill in Brecksville was a rousing success. Rory kept the tunes spinning and Gus only broke one glass bartending in a whirlwind night of raffles, retro and revelry. Our most sincere thanks go out to Gus's wife Janet and our friends Kenny and Shana for all of their help during the night, which brought about \$2,000 to the chapter in a few hours' time.

Thanks also to Glenn Mosham, owner of The Mill Road Grill, for his generosity and vital assistance behind the bar, which was packed with friends enjoying food and drink for most of the evening. Finally, a mention of thanks to The Inn at Brandywine Falls, The Gust Gallucci Co., Wire-dright automotive electronics and the many other local vendors who came through with raffle items at the last minute. All of you have the ASGC's most heartfelt appreciation.

### ASGC Meeting Time & Place

The ASGC meets the first Wednesday of every month at 6:30 pm in room 8 of the St. Basil Parish Center in Brecksville. The next meeting is March 1.

Anyone who is affected by, has a loved one affected by, or just wishes to learn more about autism or autism spectrum disorders is welcome to attend.

In other exciting news, our next fundraiser is already on the books! In what promises to be a huge night for the ASGC, the Cleveland.com Food and Wine Forum just announced that the ASGC has been selected as the sole charity for their 2006 Chili Cook-Off at The Great Lakes Brewing Company on Wednesday, April 5<sup>th</sup>! If that date looks familiar, it is the date of our April meeting. We invite everyone to join us at the Great Lakes Brewing Co. on April 5 from 6-9pm. We will meet again at St. Basil's for our May meeting. We will pass along more information on the Chili Cook-Off as it comes in.

Our featured presenters for the March 1 meeting will be representatives from Integration Treatment Centers in Mentor. Presenters will include ITC founder Lynette Scotese-Wojtila, OTR/L, Michelle Diemer, M.Ed. and Lauren Sweet, PT. The topic will be "Understanding Autism". It will highlight the most recent research available and provide insight to understanding children with autism. This special presentation will be of interest not only to parents and professionals but to their friends and family members as well.

We look forward to seeing you at a chapter meeting soon. Thanks as always for your continued support as we strive to make the Greater Cleveland area the best place to live for those with ASD.

Rory McLean and Gus Gallucci

Autism Society of Greater Cleveland

March 2006

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### Autism Society of Greater Cleveland Officers

Rory McLean  
President

Gus Gallucci  
Vice President

Maureen Ferfolia  
Secretary

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

## Bill would make autism education mandatory for police, prosecutors

A bill that would require police officers and prosecutors throughout the state to learn how to deal with people with disabilities, including autism, is one step closer to reality.

John Rogers, the director the Maine Criminal Justice Academy, signed on to the proposal. If passed, he says the first class of police recruits would undergo the special training at the academy this August.

In 2008, all 3,500 police officers would be required to undergo a two-hour training. Academy officials plan to work with Matt Brown, a federal probation officer, on developing the training program. Brown has an autistic son.

For the past two years, he has trained hundreds of police officers on how to properly deal with an autistic person.

"The nature of autism is such (that) the way that they behave in a stressful situation can cause harm to them and police, so it's critical that they know," said Brown. "It's the fastest growing disability in Maine if you do the math. It's a miracle we haven't had a death. What we want to do is prevent it," Brown said.

The legislature is expected to vote on the proposal in the next few months.

## Researchers investigate immune dysfunction in autism using donated brain tissue

A new paper published in the International Review of Psychiatry from the lab of Carlos Pardo, Diana Vargas and Andrew Zimmerman at Johns Hopkins Medical School summarizes past and current research investigating the role of abnormalities in immune system function, and how these changes affect brain development in autism spectrum disorders. The researchers have found an active and ongoing neuro-inflammatory process in the cerebral cortex, white matter, and notably in the cerebellum of post-mortem tissue obtained from donors with autism compared to tissue from non-affected donors. The authors presented data in this paper that suggests that activation of a specialized brain cell called 'neuroglia' may play a role in the pathology of autism spectrum disorders. These studies were carried out using tissue obtained through the Autism Tissue Program.

The neuroglia play an important role in response to injury or neuronal dysfunction. Currently, scientists are investigating the cause of the neuroglial activation observed in their experiments and changes in neuroglial activation in brain regions affected by autism, including the cerebellum. The causes and changes may include genetic and environmental factors, or a combination of both. In addition, researchers continue to study how these changes are associated with early abnormalities in brain organization and brain cell function associated with autism. The research paper also compares the markers of neuroglia activation in brain tissue to immune system abnormalities found in individuals with autism using blood and cerebrospinal fluid.

Crucial to ongoing studies is donated brain tissue. The authors thank the Autism Tissue Program for access to brain tissue donated for research. Co-author, Andrew Zimmerman, MD, Pediatric Neurologist, Kennedy Krieger

Institute says, "We can make all sorts of guesses about what autism is but the brain stands alone. We can get good ideas and real facts good science from the tissues like we can from nothing else."

More information on the Autism Tissue Program can be found at <http://www.memoriesofhope.org/>. To read one of the original research papers on this topic by these authors, click here:

[www.icdrc.org/pdf/Neuroinflammation.pdf](http://www.icdrc.org/pdf/Neuroinflammation.pdf)

Since our involvement in the ATP in 1999, we have seen some great gains from the research that has been provided utilizing donated brain tissue through ATP's efforts with NAAR and other organizations. It is not a subject that most folks like to discuss, nor really think about. I had started to support the program when I found out more at an ASA/CLN workshop in Texas in 1999. After that I returned home, and due to my criminal forensics background, thought this was something that we needed to support and educate folks on. I gave a presentation at our local ASA chapter in the fall of that year not realizing that within a couple of months my brother would die and our family would make the decision to have him be a donor to the program. Having had both AS and Epilepsy, my brother's life was one of many triumphs and challenges. His story is on the Memories of Hope page under Mark Coriaty. He is one of the reasons why we still continue as a family with our advocacy efforts, so that others do not face the same struggles as our son.

I'd urge folks to consider registering for the ATP. It is something that will assist not only the ASD community, but others as well.

Carolyn Gammicchia

## Doctor Offers Seminar on Relationship Development Intervention in May

"GOING TO THE HEART OF AUTISM":  
RELATIONSHIP DEVELOPMENT  
INTERVENTION THERAPY FOR AUTISM

DR. STEVEN GUTSTEIN

MAY 3 & 4, 2006  
RADISSON HOTEL  
INDIANAPOLIS AIRPORT  
INDIANAPOLIS, INDIANA

PRESENTED BY  
THE INDIANA RESOURCE CENTER FOR  
AUTISM

INDIANA INSTITUTE ON  
DISABILITY AND COMMUNITY  
INDIANA'S UNIVERSITY CENTER FOR  
EXCELLENCE ON DISABILITY

### Overview of "Going to the Heart of Autism"

#### Research & the Core Deficits of Autism

Some of the latest scientific research, including results on the quality of life for people on the autism spectrum.

The developmental path unique to people on the spectrum, including the concepts of dynamic mental engagement, absolute vs. relative thinking, imperative vs. declarative communication, etc.

#### Principles of the RDI Program

Basic principles. Determining developmental readiness, choosing simple settings, creating an experience-sharing communication environment, guiding and pacing, capturing episodic memories, developing

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## PECS Training Comes to Cleveland

Pyramid Educational Consultants, Inc. is the source for services designed to enhance the lives of children and adults with autism and related developmental disabilities. We are sponsoring **The Two-Day Picture Exchange Communication System (PECS)** training workshop in **Cleveland, Ohio** during the month of **April 2006**. Pyramid's training workshops are appropriate for all educators, speech/language pathologists, OTs, PTs, social workers, parents and caregivers of individuals with autism and related developmental disabilities.

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.

For an updated workshop listing, please visit our website at [www.pecs.com](http://www.pecs.com).

## NIH releases new autism Web site

The National Institutes of Health (NIH) is pleased to announce the release of the Autism Research Network (ARN) Web site: [www.autismresearchnetwork.org](http://www.autismresearchnetwork.org)

The NIH supports two major research networks dedicated to understanding and treating autism: The Collaborative Programs of Excellence in Autism (CPEA) Network and the Studies to Advance Autism Research and Treatment (STAART) Network. This Web site provides a single source of information about these networks and the research they conduct.

## Preview autism book on Amazon.com

*Autism and the God Connection: Redefining the Autistic Experience Through Extraordinary Accounts of Spiritual Giftedness* (Sourcebooks, Inc.) will publish April 1, 2006, but is now available for pre-order on Amazon.com at the discounted price of \$10.17.

To learn more about the book, view its cover art, and read the advance praise it's garnered from nationally-noted authors, researchers and others, please visit <http://www.williamstillman.com/> and click on the "Bill's Books" section.

## Web site helps children avoid bullying

Children in second through sixth grades now have an entertaining, safe way to learn how to respond to bullying. PACER's new Kids Against Bullying Web site includes a cast of 12 animated characters, celebrity videos, kid videos, Webisodes, games, contests, stories, artwork, poems, information, and much more. The site is for all children. Children with disabilities are integrated throughout the Web site.

Visit [www.pacerkidsagainstabullying.org](http://www.pacerkidsagainstabullying.org).

## **An open letter to CBS President and CEO Leslie Moonves, The Dr. Phil Show, Executive Producer Carla Pennington Stewart and host Dr. Phil McGraw**

Dear President Moonves, Ms. Pennington Stewart, and Dr. McGraw:

We are representatives of eight Autism organizations who watched the episode of "Dr. Phil" that co-featured Asperger Syndrome (AS) as its topic. The January 17 airing of this CBS daytime talk show shared subject material with another diagnosis, Tourette's Syndrome, that we are unqualified to judge. But, from both a medical and ethical view, we found the portrayal of AS to be disturbing. Your show reaches a huge audience. We recognize that in the past, the non-threatening demeanor and natural charm of the host, Dr. Phil himself, has allowed for much relevant change and information to reach an audience that otherwise might not have been influenced. And, it is within this context of the show's proven potential for good, that we are driven to write.

At one point in his remarks to the audience, Dr. Phil mentioned that it was the exception, not the rule, for people diagnosed with AS to display violent behavior. This is quite true. And yet, everything else intimated by the show contradictorily depicted otherwise. The episode opened with the tragic Los Angeles incident in which a young man with AS killed two neighbors before killing himself. Camera angles on the episode's young man in question (Alex) were implemented to suggest psychosis. And the parents' fears for their safety were given great respect.

What was especially troubling was that at no time in the show was it suggested that Alex's violent potential might be heavily, even overbearingly caused by having two parents that constantly seemed to be yelling at him. Also, Alex's mother admitted to having said to her teenage son that she hated him. Teenagers are bound to say they hate their parents every once in a while. Yet, parents that say that to their children must be held accountable for the damage they have caused, and not get to blame the problems on their child's diagnosis.

The parents' needs were also unmet by Dr. Phil. In a situation where parents have spun so out of control that they can become so abusive to their child, usually the problem is that they are not getting the help they need.

A requisite step to this is admitting they need help themselves, and oddly enough, these parents seemed to be doing that. They seemed to be reaching out. But, instead of being steered toward the serious counseling and support they clearly need, all the blame was thrown their son's way, for a diagnosis that he was born with. And the son, Alex, by contrast, seemed much more capable of improvement.

The latter is true because AS does not have to be the curse that your show portrayed it as. Not only are individuals with AS able to lead happy, productive, and often amazing lives providing they have the right supports, but also because from a medical standpoint AS is not a "mental illness" or a "disease" as the show implied. Mental illness is different than a neurological condition, and for something to be a disease it has to be something acquired, not something you're born with. Most of the enlightened world knows that Autism is at its root, genetic, and therefore by definition it is not something that can be considered "curable" or a "disease".

We were also concerned with the highly questionable "Brain Matters, Inc.", the company represented by Dr. Hixster (sp?) that received airtime in the episode. From our standpoint, these are most certainly not known people in the Autism/Asperger world. Now, just being known to us obviously does not imply good quality. But, contrary to the show's suggestions, educational and therapy-based interventions are the best hope that people diagnosed on the Autism spectrum have for leading happy lives. The after-scan treatments that this company was offering to the family were vaguely presented, perhaps with good reason. Using phrases like "brain-based" and "we go directly to the brain," Dr. Hixster suggested to that poor family that there was great hope for their outcome. We know of no such therapy that is of any proven worth. Please understand that you are dealing with a very vulnerable parent audience. You might consequently deprive them of appropriate and effective interventions. Ones we can help lead you to.

After the Los Angeles incident last year, there was a

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# An open letter to top figures of The Dr. Phil Show and CBS

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great and inspiring effort amongst the world's media to refrain from using the tragedy to demonize people living with Aspergers. To say from a journalism standpoint that the aftermath was "responsible" would be an understatement. The burdens of running a daily television show are those we can only imagine, but the January 17 episode of "Dr. Phil" did much to nullify the good work attempted by the majority of media giving airtime to AS and Autism-related issues. In the future, we hope you will contact one or all of our signing organizations to help guide you through what can be a very complicated world. We would be more than happy to help as your show is indeed capable of enormous good.

Sincerely,

**Michael John Carley**

Executive Director  
GRASP, the Global and Regional Asperger Syndrome Partnership, Inc.

**Lee Grossman**

President & CEO  
Autism Society of America

**Dania Jekel**

Co-Founder and Executive Director  
Asperger Association of New England

**Valerie Paradiz, Ph.D.**

Executive Director  
The School for Autistic Strength Purpose and Independence in Education

**Cathy Pratt, Ph.D.**

Chair of the Board  
Autism Society of America

**Lois Rosenwald**

Co-Director  
The Connecticut Autism Spectrum Resource Center

**Pat Schissel**

President  
AHA/AS/PDD (Advocates for Individuals with High Functioning Autism, Asperger's Syndrome and other Pervasive Developmental Disorders)

**Lori Shery**

President and Co-Founder  
ASPEN (Asperger Syndrome Education Network)

**Liane Holliday Willey, Ed.D.**

Founding Board Member  
Asperger Society of Michigan

Yours,

**Michael John Carley**

Executive Director  
GRASP  
The Global and Regional Asperger Syndrome Partnership, Inc.

## Disability Summit 2006 Raising Expectations!

CSESC presents in collaboration with Center for Mental Retardation, East Shore SERRC, Ohio Coalition for the Education of Children with Disabilities, and The Ohio Developmental Disability Council

Guest Speaker:

Sue Swenson, Executive Director  
The Arc of the United States

## ***Autism taskforce posts finance report***

The final report for the Ohio Autism Taskforce Finance Workgroup is now on the Taskforce Web site. Please click this link to access the report. [www.ohioautismlegislation.org/index.php?option=com\\_content&task=view&id=62&Itemid=1](http://www.ohioautismlegislation.org/index.php?option=com_content&task=view&id=62&Itemid=1)

# Autistic senior scores 20 points in basketball debut

by Jim Aroune

They may never stop talking about what they witnessed at Greece Athena's final home boys varsity basketball game of the season.

Some in attendance at Athena's game against Spencerport will say it played out like a Hollywood script; like "Rudy," or "Radio;" stories about a long-shot and a waterboy who inspired their teams by not letting their shortcomings stop them from giving their all.

In what Jason McElwain did during the waning moments of the "Senior Night" at Athena, there may be much more.

Jason is the trainer for the Athena varsity team. So dedicated is Jason, he has not missed a game or practice in the three years he's served the team.

Wednesday for "Senior Night," Athena coach Jim Johnson had Jason suit up for the game. He sat excitedly on the bench in his school colors, number 52; an acknowledgement of Jason's commitment to the program.

Athena moved to a comfortable 20-point lead against Spencerport. With the home crowd calling and classmates waving signs of support, Johnson called down the bench to number 52. Jason, headband and all, headed out onto the court.

"I just wanted to score a basket," McElwain said.

"I'm just sitting there saying 'Let him score just one point,'" his mom, Deb said.

With the help of his teammates, Jason stared down a shot from the corner. The entire Athena bench, and every person in the gym rose.

Jason missed.. by six feet.

Moments later, Jason grabbed another pass and let it rain. The shot, from beyond the three-point arc, swished straight through. In unison, those in the gym screamed.

In the game's final four minutes, Jason shot five more times from behind the three-point arc. He made them all. Each time, teammates on the bench would hold their heads and scream, fans would stomp, tears would flow.

Jason scored 20 points. He set an Athena record with a half-dozen three-pointers. His teammates and friends stormed the court. They raised him on their shoulders... wide-eyed and in awe of what they had seen. They asked Jason for his autograph.

"I was focused on the game. You gotta be focused on the game. Not anything else," Jason said.

What made Jason being "in the zone" Wednesday not just another shooting streak is that he is autistic.

What his example will do for others with autism is a story yet to be told. Justin's mother believes it will mean great things for her son.

"Once the severe autistic child can break through, they can live in this world. Just like anyone else," Deb McElwain said.

## Area Special Needs Doctors

Cara E. Marker, Ph.D.  
Pediatric Psychologist  
Executive Director, Inner Health Ministries  
17730 Lorain Road, Suite 7  
Cleveland, Ohio 44111  
Phone: 216-252-1399

### Pediatric Dentist for special needs children:

Arlene J. Coloma DDS. MS.  
Phone: 440-526-2350  
Brecksville, Ohio 44141

### DAN Doctors:

DeMio, Philip M.D.  
320 Orchardview Ave. Suite Two  
Seven Hills, Ohio 44131  
216-901-0441

Lonsdale, Derrick M.D.  
Preventive Medicine Group  
24700 Center Ridge Rd., Suite 317  
Westlake, OH 44145  
Tel: 440-835-0104  
Fax: 440-871-1404

# Doctor Offers Seminar on Relationship Development Intervention in May

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competence, modifying and evolving frameworks, and teaching functions before skills.

## RDI with teenagers

## RDI Program implementation in school settings

Dramatic video clips showing RDI in action.

## How-To Strategies & Activities

Changing the communication environment to bring about dramatic changes in relating.

Developing a new type of memory to create motivation for genuine relationships.

Adapting everyday activities to use RDI program concepts as a regular part of daily life.

Identifying obstacles to RDI implementation, and much more.

## Who Should Attend

This workshop is geared for general and special education teachers, administrators, early intervention providers, family members, and those interested in learning more about educating students on the autism spectrum.

## Training Funds

For information on training funds for family members or individuals with disabilities in Indiana, contact the Indiana Governor's Planning Council for Person's with Disabilities at (317) 232-7770 or IN \*SOURCE at (800) 332-4433.

## About the Speaker

### Dr. Steven Gutstein

Dr. Steven Gutstein serves as the director of The Connections Center and the Relationship Development Research Institute (RDRI), both located in Houston, Texas. He is internationally recognized as the developer of Relationship Development Intervention (RDI), an innovative new program designed to improve the quality of life for individuals with Autism Spectrum Disorders. RDI has grown at an incredible rate since its formal inception in 2001, with more than 2,000 families participating in RDI around the world. Currently, 33 professionals in the

U.S., Canada, and Australia are Certified Consultants in RDI, having completed an intensive training process. Additionally, over 100 professionals currently are in certification training. Dr. Gutstein has conducted clinical research and published papers in diverse areas. For the last 16 years, he has worked to develop a research-based intervention program addressing the core defects shared by all people on the autism spectrum. The program is called Relationship Development Intervention (RDI). He and his partner and wife Dr. Rachelle Sheely, have published three books and numerous articles related to RDI. They travel internationally conducting workshops and training programs. Dr. Gutstein's preliminary evaluation study of RDI recently was accepted for publication by the Journal of Autism and Developmental Disorders (JADD).

Dr. Gutstein, received his Ph.D. in Clinical Psychology from Case Western Reserve University and interned and did post-doctoral work at Rutgers Medical School. From 1979-1987, Dr. Gutstein was assistant professor of psychology and pediatrics at Baylor Medical School and the University of Texas Medical School. During this period, he also was director of psychology at Texas Children's Hospital and director of research at the Houston Child Guidance Center.

If you have questions about the seminar content, please contact Cathy Pratt at (812) 855- 6508.

Registration questions should be directed to Diana Stille or Donna Beasley at (812) 855- 6508.

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## ASA's National Conference to be held in July 2006

The Autism Society of America's 37th National Conference on Autism Spectrum Disorders, "Lighting the Way to Hope, Navigating to Success & Solutions," will be held in Providence, Rhode Island, July 12-15, 2006. The Workshops will be day-long sessions on July 12, with the Opening General Session on Thursday morning, July 13. The exhibits also open on July 13.

## Autism resource available in Spanish

It is my pleasure to let your ASA Chapter know about a new resource on autism available in Spanish, **Los Trastornos del Espectro de Autismo de la A a la Z**. A comprehensive book of over 500 pages, **Los TEA** explains the essential information parents and professionals need to understand and to help their child, student or client. Please share the news with those who would like to know.

## Autism Society of Greater Cleveland

P. O. Box 41409  
Brecksville, Ohio 44141

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

From Diagnosis through Adulthood.

The ASGC is a volunteer organization



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## Upcoming Ohio Autism Conferences

**Two-Day Picture Exchange Communication System (PECS)**  
training workshop in **Cleveland, Ohio** during the month of **April 2006**.

Judy Barrett  
Marketing Coordinator  
Pyramid Educational Consultants, Inc.  
226 West Park Place, Suite One  
Newark, DE 19711  
Tel (302) 368-2515  
Toll Free (888) 732-7462  
[jbarrett@pecs.com](mailto:jbarrett@pecs.com)

**Milestones Annual Autism Conference**

**June 19, 2006**  
**8:00 am to 5:00 pm**  
**Landerhaven**

*Promoting the Independent Learner*

**Keynote speaker:**  
**Dr. Patricia Krantz**

Princeton Child Development Institute

**Milestones Annual Meeting and Dinner**

**June 19, 2006**  
**5:45 pm to 7:30 pm**  
**Landerhaven**

**: 2006 Autism Institute: Comprehensive Programming for Individuals with Autism Spectrum Disorders through the Lifespan**

**Presented by:**

Ohio Center for Autism and Low Incidence (OCALI)

and

Ohio Department of Education,  
Office for Exceptional Children

**Save the Dates:** August 8 – 10, 2006

**Location:**

The Columbus Athenaeum  
32 North Fourth Street  
Columbus, Ohio 43215  
Phone: 614.222.8609

<http://www.columbusmeetings.com>

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