



# ASGC Newsletter

## From The President's Desk

"It is the month of June,  
The month of leaves and roses,  
When pleasant sights salute the eyes,  
And pleasant scents the noses."

Given the special challenges we often face, I suppose I could have gotten by with a simple "stop and smell the roses". What can I say, it's a sunny day. Welcome to June.

After months of deliberations and conversations, we are proud to announce that the ASGC now has an operating board comprised of a variety of experienced and committed parents from a wide range of backgrounds. Along with Rory, Maureen and myself, please join us in welcoming Tom Bregar, Jim Mcilwee, Shane M.D. Scott, Shayna Jackson, Deborah Zelinski, Donald Patterson and Barbara Rutt to the ASGC Board.

We are currently engaged in a strategic planning process that will help guide the

### 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 June 7.

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.

ASGC well into the future. This is your chapter, so we welcome your input as well. Contact us at [support@asgc.org](mailto:support@asgc.org) anytime with your thoughts or feedback.

The ASGC wishes to extend its sincere thanks to Dr. Philip DeMio for a very interesting and informative presentation at our May meeting. We appreciate Dr. DeMio's perspective as both a professional and parent.

Please join us at our June meeting as we welcome Jordye Joyce, O.T., President and founder of Whole Child Therapy in Stow. Jordye and her team of occupational and speech therapists work with autistic children in individual and group therapy settings. Their work has been featured recently in a special report by Monica Robbins on WKYC-TV3 as well. We look forward to having Jordye present and answer your questions at our next meeting on June 7. Once again, child care will be provided by STEPS.

Thank you all for your continued support as we continue to grow in pursuit of our mission to make the greater Cleveland area the best place to live for those with ASD.

Sincerely,

Rory McLean  
Gus Gallucci

Autism Society of  
Greater Cleveland

June 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:  
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## There is an understanding among parents of kids with autism, one mom says

SEVEN YEARS AGO, a doctor looked at my toddler son and immediately recognized autism.

Since then, I've seen it countless times in the halls of the mall, in grocery stores and restaurants. I will notice a child who seems a little bit different. Perhaps, he's spinning in circles or avoiding eye contact, flapping his hands or repeating phrases from a movie. Right away, I'll sneak a glance at the mom, recognizing her even though we've never met.

But Miss Manners hasn't come up with a delicate way to ask, "Is your kid autistic too?"

And so we pass each other without a word, just a small nod to show our solidarity.

But, I want to walk up to that mom and talk to her, because even though she looks nothing like me, somewhere inside we're the same: Mothers who know what it's like to lose a child who's sitting right next to you.

I want to ask her if she ever thought she'd shop for diapers for a 9-year-old. To know if she's ever sobbed as she scrubbed poop out of a carpet, wondering just how her life turned out this way.

I want to know if she too lies awake at night wondering what it would be like to hold a conversation with her first-born child. I would ask when she stopped speculating about which college her son would attend.

I want to know how she handles the dirty looks and even reprimands from strangers, because her child doesn't behave like the other kids.

We could almost speak another language to each other, using jargon like IEP, EEG, ESY and FAPE. After a while, the letters roll off your tongue so easily that you forget the rest of the world has no idea what you mean.

But, this mom would know. She would know that single word with six letters can change your entire life.

I want to tell her that I too go years in between dates with my husband, because it's too hard to find a babysitter. That I've been a mother for nine years, but my family has taken only one vacation. Our time, energy and money all go elsewhere.

I want to talk about how my husband and I decided not to have any more kids, not because we don't want a bigger

family, but because after having two kids with autism, the genetic odds just don't seem to be in our favor.

Mostly, I want to know if she ever noticed the moment autism stopped being a tragedy and simply became a fact of life.

Of course, this mom and I are not exactly alike. In fact, besides autism, we might have nothing else in common.

That's the reality of autism: It can strike in just about any family.

As parents of children with autism, we cross all races and nationalities. We're rich and poor, single parents and married couples, conservatives and liberals. Some of us are shy; others are loud.

Just about anyone can be inducted into our club. In 20 minutes, there will be a new initiation. That's how often a parent hears "Your child has autism." This year, doctors will say that 24,000 times.

That's a lot of parents who know just what I'm talking about!

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**This is** not only a Cleveland landmark for over 50 years, but a great place to take your child, especially one with ASD that you want to introduce to the amusement park experience. It's a frequent summer event for our family!

Memphis Kiddie Park  
Memphis Road (W. 117)  
less than 2 miles off I-480 or Brookpark Road  
(Take Ridge Road or Tiedeman Road off 480)  
Brooklyn, Ohio.

Kiddie park with many, fun amusement rides. Also has a train ride for parents to ride with children. This is a great little place for young children who enjoy amusement park rides.

Free admission, pay for tickets for the rides, good for kids ages 2 - 7 years.

**For the** latest U.S. government report on autism and autism diagnosis rates, please visit:

[http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5517a3.htm?s\\_cid=mm5517a3\\_e#tab1](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5517a3.htm?s_cid=mm5517a3_e#tab1)

## Hollywood provides glimpse of autism in movies, TV and books

The entertainment world's take on autism has long been Dustin Hoffman's RainMan, a savant who's a whiz with numbers but can't connect with people. Now a range of movies, TV series and books promises to shed light on the biological condition's varied guises.

Hollywood's awareness reflects autism's increasing prevalence: As many as 1 in 166 children under 10 have autism, says the National Centers for Disease Control and Prevention.

"These days, even if you don't have a child who is autistic, you're bound to either be related to or know someone who does," says Jim Ball of the Autism Society of America, the advocacy group that promotes April as Autism Awareness Month. "Any exposure is good. People need to see the big picture."

### The cultural snapshot includes:

**Movies.** Columbia Pictures just bought the rights to the story of Jason McElwain, an autistic teen from Rochester, New York, who went from basketball team manager to scoring phenomenon when he nailed six three-point shots in his first and only appearance on court.

"As (executive producer) Magic Johnson says, 'You have to be ready when your moment comes,' and Jason showed he was as ready as anyone could be," says producer Laura Ziskin, who is aiming for a 2008 release.

Warner Bros. plans this year to release its version of Mark Haddon's 2003 *The Curious Incident of the Dog in the Night-Time*, about an autistic teen who investigates the death of a neighbor's dog. Also on track is a big-screen version of Marti Leimbach's new novel, *Daniel Isn't Talking*. Julia Roberts is in talks to play the lead, a mother battling for her autistic son to defy doctors' grim predictions.

Opening now after a limited European run is Josh Hartnett's *Mozart and the Whale*. Hartnett plays a taxi driver with Asperger's syndrome, a high-functioning form of autism; the script is by Rain Man screenwriter Ron Bass.

**Television.** Up for a Daytime Emmy is Leven Rambin, 15, who plays an autistic teen on the ABC soap *All My Children*. "One girl wrote me saying that she was doing well with the outside world by copying the way my character copes," Rambin says.

On ABC's *Boston Legal*, Christian Clemenson's recurring lawyer character recently pulled a knife on a

coworker after being passed over for promotion. Charges are dropped when it's revealed he has Asperger's.

**Books.** Due June 1 is Cammie McGovern's *Eye Contact*, a thriller that finds a mom parsing through her autistic son's fractured memories of a killing.

Leimbach, whose 9-year-old son, Nicholas, is autistic, says there's a universality about autism that makes it ripe for exploration.

"It dramatizes the fact that none of us have perfect children," she says. "And that's something we all can relate to."

- Marco R. della Cava, USA Today

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I just wanted to share some additional information about the new film "Normal People Scare Me" that Taylor Cross, a young man with ASD directed and had produced by Joey Travolta's production company. The film opened the other night in New York, and I was contacted by a mom of one of the folks featured in the film. She said the film was well accepted, and Taylor Dane was on hand to sing the film's title track. Her daughter also was thrilled at how she and other individuals with ASD are portrayed in the final cut of the film. It's said to be very insightful and empowering.

Additionally, *People* magazine has an article about this young man, the film, and four other stories of individuals on the spectrum. One mom featured has two sons with ASD and she recently obtained a diagnosis as well. The article titled "Would I Trade In My Autism? NO" is a very nice piece and also is wonderful for Autism Awareness.

For more information on this film, you can visit the website at [www.normalfilms.com](http://www.normalfilms.com) and view a clip.

We are also lucky in Michigan because Jack's Place for Autism will be hosting a film camp with Joey Travolta's production company this summer for kids with ASD. Thirty individuals with ASD and twenty siblings will attend a two week camp to make their own films. It's a very exciting opportunity for folks, and I'd urge folks to contact the production company to see about hosting a camp locally.

- From ASGC Friend Carolyn Gammicchia

# Lack of brain activity in people with autism may be clue to disorder

By Jennifer Warner

People with autism may not daydream like most people do.

A new study suggests that the brain activity found in most people while at rest or "daydreaming" is absent in people with autism.

Researchers say the brain regions normally active while at rest or daydreaming are important for processing emotional and social issues. The lack of this activity in the brains of people with autism may help explain some of the antisocial behavior and emotional problems found in people with the disorder.

## Measuring Brain Activity

In the study, which appears in the *Proceedings of the National Academy of Sciences*, researchers used functional magnetic resonance imaging (MRI) scans to compare brain activity while at rest in a group of 15 people with autism spectrum disorders (including autism and related conditions such as Asperger's syndrome) and 14 people without autism or related disorders.

Researchers say activity in certain areas of the brain is suppressed while performing mentally demanding tasks, like solving a puzzle. But when a person is at rest or

## Amazon.com offers Autism Manual

The Official Autism 101 Manual is released and available at Amazon.com.

This is your ultimate resource for understanding and responding to autism as a parent or professional.

This is a high-quality collection at absolutely no additional charge, all being donated by authors who are concerned with our common goal of curing autism.

Take a look at <http://www.autism101manual.com/>

## 2006 Autism Institute will be August 8-10

The 2006 Autism Institute will be held in Columbus August 8-10. Please disseminate to anyone who might have an interest in attending. It is possible to register online at [http://www.ocali.org/au\\_profdev.html](http://www.ocali.org/au_profdev.html). The Team Application should be available now.

performing nonstimulating tasks, these areas become very active, triggering daydreams and other introspective thoughts.

The scans showed that this type of daydreaming brain activity found in nonautistic participants was missing in those with autism.

Researchers say these self-directed thoughts are important for processing emotional and social issues. In fact, they found that the more socially impaired the autistic individuals were, the less of this brain activity they had.

The researchers say the results of the study suggest that although some of the emotional and social symptoms found in people with autism seem to be associated with inability of this network to function properly, they cannot say that autism is caused by a neurological abnormality or vice versa.

## Kit to help assess kids with disabilities

OSERS Assistant Secretary John Hager and OESE Assistant Secretary Henry Johnson released on Tuesday, April 25, 2006, a "tool kit" designed to assist states in raising the achievement of all students with disabilities.

The Tool Kit on teaching and assessing students with disabilities will support districts and schools in appropriately assessing and instructing students with disabilities to meet the goals of both NCLB and IDEA.

The tool kit provides guidance for assessing the achievement and progress of students with disabilities and includes a set of technical assistance products produced by OSERS grantees in the areas of assessment, instruction, behavioral interventions and accommodations for students with disabilities. Additionally, the tool kit includes a set of six papers offering research and ideas on including students with disabilities in large-scale assessments. The papers were commissioned by OSERS, and cover such topics such as IEP team decision-making, professional development for educators, standards and assessment approaches, and the validity and reliability of alternate assessments.

As part of the U.S. Department of Education's distribution plans, each State Commissioner of Education and State Director of Special Education will receive a tool kit. CD versions of the tool kit will be available within the next two weeks. They will be mailed to State Assessment Coordinators and also will be widely disseminated across the nation. The tool kit can be downloaded from an earmarked website at: <http://www.ed.gov/about/offices/list/osers/reports.html>



### Inside the Autistic Mind

A wealth of new brain research-- and poignant testimony from people who have autism--is lifting the veil on this mysterious condition

Please see the May 15 issue of Time for this cover story. A must read!

**Dr. Tom Fish** at The Ohio State University's Nisonger Center has focused on the needs and concerns of siblings of children and adults with disabilities. For several years, he has sponsored a Sibling Conference.

The 2006 conference will be held on November 5 and 6 at The Columbus Airport Marriott Hotel. Registration will be \$85. Financial aid may be available through the County Board of MR/DD, or by accessing the Ohio Developmental Disabilities Empowerment Fund by calling Mary Smithson at 614.466.5205. For more information, call Dr. Fish at 614.292.7550, or send an email to [fish.1@osu.edu](mailto:fish.1@osu.edu).

Our featured speaker is Rachel Simon, author of *Riding the Bus with my Sister*.

### Hattie Larlham offers Autism Day Camp in July

Two week Autism Day Camp  
July 17-21 and July 24-28

Hattie Larlham Center for Children with Disabilities  
Mantua, Ohio 800-233-8611

If interested in more information please call:  
Karen Stoltzfus 1-800-233-8611 ext 3102

#### Topics in child development: Transition through the lifespan for individuals with autism spectrum disorders.

Thursday and Friday, June 22-23, 2006  
Kent Student Center

Transitions frame our lives. For individuals with ASD daily, developmental, and life changing transformations can pose a particular challenge. This year's conference will explore a variety of transition challenges and propose solutions for individuals with autism, their families, and collaborating professionals from earliest diagnosis to adulthood.

Please contact Kathy Brown at 330.672.0537 or [kbrown5@kent.edu](mailto:kbrown5@kent.edu) for further information.

## For Your Information...

In Ohio, one can keep their child from being immunized on "philosophical" grounds. No doctor's order is needed. Ohio is one of only eight states that has the philosophical objection which must be honored by any party to whom it is given. A letter stating your objection is sufficient, and immunization cannot be forced. The only thing the school or agency can do is ban a student from attending classes for two weeks following an "outbreak" of one of the immunized diseases.

- as blogged by Lyn in a recent Yahoo forum

The following site may help with an IEP:

[www.hopementoring.com/services](http://www.hopementoring.com/services)

Integrations Treatment Center in Mentor is currently accepting applications for the Fall 2006 Day Treatment Program for children with Autism Spectrum Disorders. There may also be a few openings available for the Summer 2006 program.

The following programs may be available to your child:

- PRESCHOOL GROUP  
(9:30-2:30 Monday through Thursday\*)
  - KINDERGARTEN GROUP  
(9:30-2:30 Monday through Thursday\*)
  - SCHOOL-AGE GROUPS  
(9:30-2:30 Monday through Friday\*)
- \*Program times are subject to change.

Integrations Treatment Center is a provider for the Ohio Department of Education Autism Scholarship program.

The program is high quality, intense, and individualized. Group sizes are small (3-6 children each). Treatment is based on the child's needs and may include speech therapy, occupational therapy, physical therapy, nutrition therapy, special education, and music therapy. Staff members are extensively trained in autism spectrum disorders. The program features a Typical Peer Program where typically developing children participate during social activity periods to improve social, language, and play skills. Treatment approaches include sensory integration programming, play based therapy, ABA programming, social skills training, academic instruction, and language based intervention.

Please call Yashila Crowell at (440) 578-1100 or email her at [yashilac@itc-autism.com](mailto:yashilac@itc-autism.com) with any questions. We look forward to meeting you!

# Program makes discounted prescription drugs available to those eligible

by John Baer

THIS MIGHT be the most significant thing I write in 2006, because it could result in helping someone getting or staying healthy.

There's a private-industry program, Together Rx Access (<http://www.togetherrx.com/>, scroll down to "Together Rx Access" in the center section) providing free cards for discounted prescription drugs to folks without health insurance who don't qualify for Medicare. It's for the working poor and working not-all-that-poor; a family of five making \$70,000 is eligible.

It covers more than 275 commonly prescribed brand-name drugs with savings of 25 to 40 percent. It covers generics too. There is no fee, not now, not ever, to use the card.

There's nothing else like it. Yet, it's not well-known.

A dozen pharmaceutical firms, including local big gun GlaxoSmithKline, are sponsors. I don't care why - whether to push product, get tax breaks or buy goodwill - doesn't matter to me. What matters is somebody is offering working families something other than talk on the issue of health care.

What's needed to get a card? Be a legal U.S. citizen with no prescription-drug coverage who's not eligible for Medicare.

Income levels are \$30,000 for a single person, \$40,000 for a family of two, \$50,000 for a family of three, \$60,000 for a family of four, up to \$70,000 for a family of five.

In a state where the average worker's annual pay is \$36,995, I gotta think it's worth looking at.

The application form is five lines and can be filled out online at [togetherrxaccess.com](http://togetherrxaccess.com) or over the phone at 1-800-444-4106.

The program's a year old but fewer than 400,000 people nationwide are enrolled.

Now, I know every drug manufacturer offers patient assistance - some even offer free drugs. But most require long forms, detailed data, a doctor's signature, written proof of income eligibility and/or call-backs seeking the source of one's income - in other words an aggravating, labor-intensive process.

Community health professionals familiar with such programs say it's easy to understand why many who might qualify don't ever apply.

So what's the catch?

"There's nothing wrong with it," says Tom Snedden, Pennsylvania's veteran and widely respected prescription-drug czar, director of the state's PACE/PACENET.

## **Legislative Advocacy Training** A Self Advocacy Training Opportunity

This is a cognitively adapted training session designed for adults and young adults who are eligible for County Board of MR/DD services.

**When:** June 12, 2006; 10:00 AM to 2:30 PM

**Where:** Ohio State House Atrium, Columbus

**This training will help self-advocates to understand:**

- **issues that are handled by the State Legislature**
- **talking to legislators about how issues will impact you**
- **tour of the state house, finding the offices of your legislators**
- **presenting issues to the public, getting attention for your issues**

There is no cost for this training session.

Lunch is provided for persons who are county board of MR/DD eligible and the persons who attend to support them.

ODMR/DD CEUs are available for staff attending to support self advocates. To register, visit [www.thearcofohio.org](http://www.thearcofohio.org) or contact Jodi Murray at [jmurray1@rrcol.com](mailto:jmurray1@rrcol.com).

For more information, contact The Arc of Ohio at [info@thearcofohio.org](mailto:info@thearcofohio.org).

## MUO Department of Psychiatry presents several summer lectures

The MUO Department of Psychiatry, in cooperation with NAMI of Greater Toledo, presents a series of lectures:

### **Mental Illness in Children and Adolescents: Medication and Non-Medication Treatments**

**June 14**

#### **The Impact of Mental Illness on the Family**

- Identification of healthy coping styles for family members
- Non-medication treatment choices: conventional treatments (behavior, family therapies), Non-traditional treatments
- Treatment team approach and roles

**Speakers:** Nancy B. Carroll, M.D. and a panel of parents

**July 19**

#### **Alternative Treatments for Children and Adolescents (Part 1)**

- Nutrition, diet, and biomedical issues for children with autism spectrum disorders

**Speaker:** Mary Walters, R.D., L.D.

- Nutrition, diet, and biomedical issues for children with mental illness and neurobiological disorders

**Speaker:** Nancy B. Carroll, M.D.

**August 16**

#### **The Role of the Educator and the Schools on the Treatment Team**

- Educators, parents, and mental health professionals working together

**Speaker:** Susan Zake, Ph.D.

**Audience:** Social workers, counselors, therapists, educators, parents/children

**Location:** MUO Campus – Health Education Building – Room 105

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**This week** the U.S. Supreme Court heard arguments in its second IDEA case this term; *Arlington v. Murphy*. Despite the serious and far reaching implications of this case, little media coverage was received.

We invite you to learn more about this case through first hand accounts posted to our website at [www.picofnj.org](http://www.picofnj.org).

Those of you who are interested in learning more may contact us through our website at: [http://www.ndrn.org/amicus/briefs/0603edu\\_Murphy.pdf](http://www.ndrn.org/amicus/briefs/0603edu_Murphy.pdf)

All workshops will be held from 7:00 pm to 9:00 pm.

To register or to request more information, call 419.243.1119. There will be no charge for attending these presentations.

## **STEPS serves area children with autism**

STEPS Behavioral Consulting Services specializes in the treatment and education of persons diagnosed with autism and related developmental disabilities. STEPS consultants utilize treatment modalities that are based on principles of ABA, including Applied Verbal Behavior and Discrete Trial Therapy. Treatment consists of two main components; clinical programming to increase skill development and behavior modification to decrease maladaptive behaviors and increase desired behaviors. Research has suggested that early and intensive intervention, utilizing ABA methodology has had the greatest impact on helping children diagnosed with autism and related developmental disabilities. STEPS consultants are data driven and look at the needs of each child individually when developing clinical programs and behavior management programs. The goal of STEPS is to help each individual serviced to reach their full potential for happiness and independence.

See website for more information at:  
[www.stepsconsulting.org](http://www.stepsconsulting.org)

## **Websites may prove to be valuable resource**

Here are links to two resources that, while not autism specific, may be of value to families. Thanks to the Ohio Coalition for the Education of Children with Disabilities for sharing these.

**Service Coordination - A Guide for Families**  
developed by Ohio Legal Rights and NAMI Ohio  
[http://www.namiohio.org/Service\\_Coordination\\_080905.pdf](http://www.namiohio.org/Service_Coordination_080905.pdf)

**Family Guide to Systems of Care for Children with Mental Health Needs**  
developed by the US Department of Health and Human Services  
<http://nmhic-dev.shs.net/media/ken/pdf/SMA-4054/SMA4054.pdf>

We will be posting both of these links to our website -- [www.autismohio.org](http://www.autismohio.org). And speaking of our website, we are in the process of completely revising it. Please visit and let us know what you think.

## 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

#### **Milestones Annual Autism Conference**

**June 19, 2006**

**8:45 am to 4:45 pm**

**Landerhaven**

*Promoting the Independent  
Learner*

**Keynote speaker:  
William Heward, Ph.D.**

Professor Emeritus  
Ohio State University

**Milestones Annual  
Meeting and Dinner**

**June 19, 2006**

**5:45 pm to 7:30 pm**

**Landerhaven**

**"Socially Speaking: A Window  
on the World of Autism"**

**August 1-2, 2006**

**Featuring:**

**Dr. Temple Grandin, Sean Bar-  
ron, Rebecca Moyes**

**Duquesne University campus  
Pittsburgh, PA**

**For more information:**

[www.autismlink.com](http://www.autismlink.com)  
[info@autismlink.com](mailto:info@autismlink.com)

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