



# ASGC Newsletter

## From The President's Desk

Dear Members,

A very happy April to one and all! We're not officially out of the woods yet, but it looks as though Old Man Winter may have given us a break.

First of all, a big thanks to our friends at Integrations Treatment Center in Mentor for a very thoughtful and informative presentation at our March meeting. In case you haven't heard yet, our April meeting will be a gathering at the Great Lakes Brewing Company Tasting Room (2701 Carroll Avenue in Cleveland) for The Greater Cleveland Chili Cook-Off for Autism. The suggested donation is \$15, but we won't mind pulling a few strings for our meeting regulars; everyone's attendance is encouraged and appreciated!

In May, we return to the familiar confines of the parish center at St. Basil's Church in Brecksville for a very special presentation. A nationally-known doctor practicing the DAN protocol here in the Cleveland area, Dr. Philip DeMio, will be

### 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 at St. Basil's will be held May 3.

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.

our featured speaker. Dr. DeMio is also a father of an autistic child. We welcome his insight as a parent and a professional.

In addition to the Dr. DeMio presentation, we welcome our friends from Steps who will provide respite care for anyone who wishes to bring their child to the May meeting. Depending on the level of participation, we may be able to secure the same services for June and July as well. An RSVP in advance is required. For more information, please see the enclosed article.

Thank you so very much for the increasing support we are receiving from all of the parents, professionals and organizations who are sharing our vision to make the Greater Cleveland area the best place to live for those with ASD!

Rory McLean and Gus Gallucci

Respite Care will be offered to those attending the ASGC's May meeting! This service is being made possible by STEPS, an Olmsted Township-based organization which provides consulting and training services to kids diagnosed with autism and related disorders. To reserve a spot, please send an email to support@asgc.org or call (216)556-4937, and let us know how many kids you will be bringing.

Autism Society of Greater Cleveland

April 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

# The Greater Cleveland Chili Cook-Off for Autism

Professional, celebrity and amateur chefs will be cooking up their best chili to benefit The Autism Society of Greater Cleveland on Wednesday, April 5 at 6:00 p.m. at the Great Lakes Brewing Company Tasting Room in Cleveland.

There will be awards for categories including Best Professional Chili, Best Celebrity Chili, Best Amateur Chili, Best Vegetarian Chili and a People's Choice Award.

For information, please contact Jeanne or Joel Hill at:  
hillj3874@adelphia.net or (216)291-3282

If you would like to attend, a \$15 donation is appreciated.

Come and enjoy great chili, great raffle prizes and great fun!

But most of all, come and know in your heart that you are doing something special.



## Advocacy Institute offers new web-based service beginning in April 2006

The special education advocacy network has grown considerably in recent years. It's now time to recognize and respond to the needs of this community of practice with ongoing training and development that will prepare and support individuals who work with families and organizations on behalf of children with disabilities.

The Advocacy Institute is excited to announce the grand opening of the Advocate Academy, a new Webinar service designed to meet the training needs of special education advocates nationwide. Our virtual doors will open in April 2006 with our first training sessions.

Experience each real-time Webinar training session from the comfort of your office or home. Participation requires access to a phone and computer with internet access (preferably high speed).

Purchase Webinar training sessions separately or become an Advocate Academy Subscriber. In addition to savings, subscribers gain access to an exclusive Academy Community of Practice dialogue and receive the quarterly Advocate Academy e-News.

Space is limited! Make your reservations today!

Complete details at:  
<http://www.advocacyinstitute.org/academy/>

## Dr. Grandin to recognize Autism Month in April 6th speech at Landerhaven

Internationally-recognized author and autism advocate, Temple Grandin Ph.D., will be the keynote speaker at the Monarch School's commemoration of National Autism Month.

"Honoring Achievements of People with Autism" will take place on April 6 from 9:30am to 3:00 pm at Landerhaven Center, 6111 Landerhaven Drive, Mayfield Heights.

Following Dr. Grandin's 9:30 am speech, she will greet guests and sign copies of her best selling books, Thinking in Pictures and Animals in Translation.

The cost to attend is \$75 per person or \$35 for students, including lunch.

## Basketball player breaks school record, scoring 20 points in just 4 minutes

GREECE, N.Y. (Feb. 24) - Jason McElwain had done everything he was asked to do for the Greece Athena High School basketball team - keep the stats, run the clock, hand out water bottles.

That all changed last week for the team manager in the final home game of the season. The 17-year-old senior, who is autistic and usually sits on the bench in a white shirt and black tie, put on a uniform and entered the game with his team way ahead.

McElwain proceeded to hit six 3-point shots, finished with 20 points and was carried off the court on his teammates' shoulders.

"I ended my career on the right note," he told The Associated Press by phone Thursday. "I was really hotter than a pistol!"

In recent days, McElwain's phone has hardly stopped ringing. When his family went out for a meal, he was mobbed by well-wishers. A neighborhood boy came by to get a basketball autographed.

McElwain, 5-foot-6, was considered too small to make the junior varsity, so he signed on as team manager. He took up the same role with the varsity, doing anything to stay near the sport he loves. Coach Jim Johnson was impressed with his dedication, and thought about suiting up McElwain for the home finale.

His performance was jaw-dropping: 20 points in four minutes, making 6-of-10 3-point shots. The crowd went wild.

"It was as touching as any moment I have ever had in sports," Johnson told the Daily Messenger of Canandaigua.

### Autism rally heads to Statehouse lawn

There will be an Autism Awareness Rally this year! It will be held on Tuesday, April 18 at the Statehouse, South Lawn, from approximately 10:30 a.m. until noon.

We are working on an agenda of great speakers and look forward to sharing new developments on the Ohio Autism Taskforce recommendations. Many thanks to Doug Krinsky for coordinating this effort.

So, please put April 18 on your calendar and plan on coming to Columbus! Be sure to contact your state representative and senator to attend the rally. Also, you can use your visit to Columbus as an opportunity meet with your legislators to make them aware of the issues you face in caring and securing services for your loved one with autism. Their support will be important as legislation that affects autism services comes before them.

ASA Akron chapter Secretary Kelly Shaw is forming a group to go down to the rally. Anyone interested can contact Kelly at [kdshaw5@yahoo.com](mailto:kdshaw5@yahoo.com).

McElwain didn't begin speaking until he was 5. He lacked social skills, but things got easier as he got older. He found many friends and made his way through school in this Rochester suburb, although many of his classes were limited to a half-dozen students. And, he found basketball.

On the varsity, he never misses practice and is a jack-of-all-trades.

"And he is happy to do it," Johnson said. "He is such a great help and is well-liked by everyone on the team."

Even though McElwain was in uniform for the February 15 game, there was no guarantee he would play - Athena was battling for a division title.

The fans, however, came prepared. One section of students held up signs bearing his nickname "J-MAC" and cutouts of his face placed on Popsicle sticks.

The Trojans opened a large lead against the team from the nearby Spencerport. With four minutes left, McElwain took the court to deafening cheers.

The ball came to him almost right away. His 3-point shot sailed completely off course, and the coach wondered if he made the wrong move. McElwain then missed a layup. Yet his father, David, was unruffled.

"The thing about Jason is he isn't afraid of anything," he told the newspaper. "He doesn't care what people think about him. He is his own person."

On the next trip down the floor, McElwain got the ball again. This time he stroked a 3, all net.

He was just warming up.

"As soon as the first shot went in that's when I started to get going," he said.

On the next attempt, he got another 3-pointer. Then another, and another. In fact, he would have made one more 3, but his foot was on the line, so he had to settle for 2 points.

Greece Athena won 79-43, and pandemonium reigned. McElwain signed autographs, posed for pictures and was hoisted by his teammates.

The Trojans began sectional play the following Saturday and McElwain was on the bench again, wearing his usual shirt and tie.

It doesn't bother him. More important, he said, is "trying to win a sectional title for the team."

McElwain will soon be done with high school basketball, then enroll in business management this fall at Monroe Community College.

"I'll go on to college, and I'll try to hoop there," he said. "I just love it, it's one of the greatest sports in the world."

# Students with autism want you to know these 10 things!

By Ellen Notbohm

1. Behavior is communication. All behavior occurs for a reason. It tells you, even when my words can't, how I perceive what is happening around me. Negative behavior interferes with my learning process. But merely interrupting these behaviors is not enough; teach me to exchange these behaviors with a proper alternative so that real learning can flow.

Start by believing this: I truly do want to learn to interact appropriately. No child wants the negative feedback we get from "bad" behavior. Negative behavior usually means I am overwhelmed by disordered sensory systems, cannot communicate my wants or needs or don't understand what is expected of me. Look beyond the behavior to find the source of my resistance. Keep notes as to what happened immediately before the behavior: people involved, time of day, activities, settings. Over time, a pattern may emerge.

2. Never assume anything. Without factual backup, an assumption is only a guess. I may not know or understand the rules. I may have heard the instructions but not understood them. Maybe I knew it yesterday, but can't retrieve it today. Ask yourself: Are you sure I really know how to do what is being asked of me? If I suddenly need to run to the bathroom every time I'm asked to do a math sheet, maybe I don't know how or fear my effort will not be good enough. Stick with me through enough repetitions of the task to where I feel competent. I may need more practice to master tasks than other kids.

Are you sure I actually know the rules? Do I understand the reason for the rule (safety, economy, health)? Am I breaking the rule because there is an underlying cause? Maybe I pinched a snack out of my lunch bag early because I was worried about finishing my science project, didn't eat breakfast and am now famished.

3. Look for sensory issues first. A lot of my resistant behaviors come from sensory discomfort. One example is fluorescent lighting, which has been shown over and over again to be a major problem for children like me. The hum it produces is very disturbing to my hypersensitive hearing, and the pulsing nature of the light can distort my visual perception, making objects in the room appear to be in constant movement. An incandescent lamp on my desk will reduce the flickering, as will the new, natural light tubes. Or maybe I need to sit closer to you; I don't understand what you are saying because there are too many noises "in between" - that lawnmower outside the window, Jasmine whispering to Tanya, chairs scraping, pencil sharpener grinding.

Ask the school occupational therapist for sensory-friendly ideas for the classroom. It's actually good for all kids, not just me.

4. Provide me a break to allow for self-regulation before I need it. A quiet, carpeted corner of the room with some pillows, books and headphones allows me a place to go to re-group when I feel overwhelmed, but isn't so far physically removed that I won't be able to rejoin the activity flow of the classroom smoothly.

5. Tell me what you want me to do in the positive rather than the imperative. "You left a mess by the sink!" is merely a statement of fact to me. I'm not able to infer that what you really mean is "Please rinse out your paint cup and put the paper towels in the trash." Don't make me guess or have to figure out what I should do.

6. Keep your expectations reasonable. That all-school assembly with hundreds of kids packed into bleachers and some guy droning on about the candy sale is uncomfortable and meaningless to me. Maybe I'd be better off helping the school secretary put together the newsletter.

7. Help me transition between activities. It takes me a little longer to motor plan moving from one activity to the next. Give me a five-minute warning and a two-minute warning before an activity changes - and build a few extra minutes in on your end to compensate. A simple clock face or timer on my desk gives me a visual cue as to the time of the next transition and helps me handle it more independently.

8. Don't make a bad situation worse. I know that even though you are a mature adult, you can sometimes make bad decisions in the heat of the moment. I truly don't need to melt down, show anger or otherwise disrupt your classroom. You can help me get over it more quickly by not responding with inflammatory behavior of your own. Beware of these responses that prolong rather than resolve a crisis:

- Raising pitch or volume of your voice. I hear the yelling and shrieking, but not the words.
- Mocking or mimicking me. Sarcasm, insults or name-calling will not embarrass me out of the behavior.
- Making unsubstantiated accusations
- Invoking a double standard
- Comparing me to a sibling or other student
- Bringing up previous or unrelated events
- Lumping me into a general category ("Kids like you are all the same.")

9. Criticize gently. Be honest - how good are you at accepting "constructive" criticism? The maturity and self-confidence to be able to do that may be light years beyond my abilities right now. Should you never correct me? Of course not. But do it kindly, so that I actually hear you.

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# Students with autism want you to know these 10 things!

From page 4

Please! Never, ever try to impose discipline or correction when I am angry, distraught, overstimulated, shut down, anxious or otherwise emotionally unable to interact with you.

Again, remember that I will react as much, if not more, to the qualities of your voice than to the actual words. I will hear the shouting and the annoyance, but I will not understand the words and therefore will not be able to figure out what I did wrong. Speak in low tones and lower your body as well, so that you are communicating on my level rather than towering over me.

Help me understand the inappropriate behavior in a supportive, problem-solving way rather than punishing or scolding me. Help me pin down the feelings that triggered the behavior. I may say I was angry but maybe I was afraid, frustrated, sad or jealous. Probe beyond my first response.

Practice or role-play - show me a better way to handle the situation next time. A storyboard, photo essay or social story helps. Expect to role-play lots over time. There are no one-time fixes. And when I do get it right "next time," tell me right away. It helps me if you yourself are modeling proper behavior for responding to criticism.

10. Offer real choices - and only real choices. Don't offer me a choice or ask a "Do you want...?" question unless you are willing to accept no for an answer. "No" may be my honest answer to "Do you want to read out loud now?" or "Would you like to share paints with William?" It's hard for me to trust you when choices are not really choices at all.

You take for granted the amazing number of choices you have on a daily basis. You constantly choose one option over others knowing that both having choices and being able to choose provides you control over your life and future. For me, choices are much more limited, which is why it can be harder to feel confident about myself. Providing me with frequent choices helps me become more actively engaged in everyday life.

Whenever possible, offer a choice within a 'have-to'. Rather than saying: "Write your name and the date on the top of the page," say: "Would you like to write your name first, or would you like to write the date first?" or "Which would you like to write first, letters or numbers?" Follow by showing me: "See how Jason is writing his name on his paper?"

Giving me choices helps me learn appropriate behavior,

but I also need to understand that there will be times when you can't. When this happens, I won't get as frustrated if I understand why:

"I can't give you a choice in this situation because it is dangerous. You might get hurt."

"I can't give you that choice because it would be bad for Danny" (have negative effect on another child).

"I give you lots of choices but this time it needs to be an adult choice."

The last word: believe. That car guy Henry Ford said, "Whether you think you can or whether you think you can't, you are usually right." Believe that you can make a difference for me. It requires accommodation and adaptation, but autism is an open-ended disability. There are no inherent upper limits on achievement. I can sense far more than I can communicate, and the number one thing I can sense is whether or not you think I "can do it." Expect more and you will get more. Encourage me to be everything I can be, so that I can stay the course long after I've left your classroom.

## Computer program made for autistic kids

A math flash card computer program is available for children with autism. Please contact Marian at: [DMHelmick1@wmconnect.com](mailto:DMHelmick1@wmconnect.com).

## Library releases new knowledge path

The MCH Library released a new knowledge path about autism spectrum disorders (ASD) identification and intervention.

It is available at [www.mchlibrary.info](http://www.mchlibrary.info).

## Alert! IDEA rights may be in danger

The Feds are proposing requirements for multi-year IEPs and paperwork reduction.

Download the full text of this Alert at [www.wrightslaw.com](http://www.wrightslaw.com).

## New service matches parents, tutors

There's a matching service now available for parents who have children with autism. The service provides a directory of tutors for parents and a directory for tutors to find parents. This list covers the entire nation. There's a decent list of people in our area too. See the site for more info. Also, they have a free seminar for registered parents coming up. See [www.autismtutors.com](http://www.autismtutors.com).

# News Briefs

## Autism Spectrum Quotient Quiz

Visit the link below to take the Autism-Spectrum Quotient Quiz!

Rate your response to the 50 statements from Strongly Agree to Strongly Disagree. When you are finished, the quiz will reveal your Quotient and give a range of average responses.

[http://www.msnbc.com/modules/newsweek/autism\\_quotient/default.asp](http://www.msnbc.com/modules/newsweek/autism_quotient/default.asp)

## The Generations Club

ASA recently launched The Generations Club, a unique membership program that addresses the special interests of grandparents of individuals with autism and parents of adults with autism, and provides an exciting new forum for networking and sharing.

## 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

For more information on this exciting new program or to join, visit: [www.autism-society.org/generations](http://www.autism-society.org/generations).

## Understanding Autism Spectrum Disorders booklet

The American Academy of Pediatrics offers a new 44-page booklet, Understanding Autism Spectrum Disorders (ASD) that is written in straightforward language and based on sound medicine and commonsense advice from the nation's top pediatricians. This booklet was developed for families of children suspected of or already diagnosed with a condition on the autism spectrum. It provides introductory information, associated issues, management strategies, family and community supports, and issues on adolescence and adulthood. Booklets can be purchased from the AAP online bookstore at [www.aap.org/bookstore](http://www.aap.org/bookstore) and are sold individually or in packs of 10 for \$35.

## Free skate lessons at Brookpark Skateland

Free skate lessons are being offered for special needs children at Brookpark Skateland every other week on Saturday mornings from 9:00am to 9:30am.

Special Olympics Cleveland Chapter offers free roller skating lessons for special needs children of all ages. Skating lessons are a 1/2 hour, and there are instructors for individualized coaching. There is a regular skating session for children from 10:00am to noon. The regular admission fee applies for that session.

Brookpark Skateland is located off of I-480 at Brookpark Rd and 130th street in Brookpark, Ohio. Take the 130th street exit to Brookpark Rd. The next free skate date is April 8th.

## Developmental Therapeutic Listening

Studies have show that listening programs can aid in developing: communication skills, vocal quality, articulation, auditory comprehension, balance, sleep, attention, mood regulation, readiness to learn and reduced sound sensitivity.

You are invited to attend a free information meeting for Developmental Therapeutic Listening, introducing "EnListen".

**Where:** The Galvin Center, 3800 Park East Drive, Suite 150, Beachwood, Ohio.

**When:** Thursday, May 2 from 7:00 pm to 9:30 pm

**Presented by:** Dr. Billie Thompson, PhD.  
Sound Listening Corp., Phoenix, AZ

Known for her extensive consulting, training, speaking and writing in the field of sound listening training.

To RSVP call 216-514-1600, please register early, if possible.

## Parents, therapist touts Chelation for treatment of young boy's autism

There is a treatment that has been around for decades and it's commonly used to treat lead poisoning, but now some are using it to treat autism.

Parents and therapists claim Chelation causes dramatic changes in autistic children's behavior. Others say there is some controversy surrounding the drug.

Now almost 4-years-old, Josh Shoemaker is not his old self; his parents are happy to say. "It's just not even comparable, he's just not the same child," says Angie Shoemaker, Josh's mother.

Josh was diagnosed with autism a year ago. His parents say Josh barely spoke, rarely responded, and had slid into his own world.

Scott Shoemaker, Josh's father says, "He used to spin himself in circles constantly, we were losing him daily." But, within five months, Josh was talking and responsive. The Shoemakers credit a treatment called Chelation outlined in this edition of *Mothering Magazine*.

Josh's parents spread a sulfur-based cream on his skin, a compound they and doctors who prescribe it, say roots out toxins like mercury from the body, toxins they blame for Josh's autism.

Dr. Phil Demio prescribes Chelation for autism.

"The sulfur grabs onto the mercury like a magnet so our body can excrete it where it would never have the ability to do that on its own without something like this," Dr. Demio says.

Authorities are far from consensus about what causes autism, and most doctors see no place for Chelation in dealing with it. Two years ago, the Centers for Disease Control commissioned a report that found no evidence of a mercury-autism link.

Mercury's effects on children, though, are a concern of the FDA. It warns pregnant women to avoid certain fish and have had a mercury ingredient removed from most vaccines.

But, can Chelation, a treatment big insurers cover for mercury poisoning, help against autism?

One pediatrician cautions that Josh's progress, though dramatic, isn't proof.

Pediatrician, Dr. Bill Goldman says, "Why he improved?"

I don't know. Would he have improved on his own? I don't know, but as of now mercury is not a cause of autism and

Chelation is not an acceptable form of treatment for autism."

Josh's parents and his speech therapist say it's proof to them.

"Josh is the only child I've ever worked with that I can say 'he's going to kindergarten being a perfectly normal kindergarten' and he was not a perfectly normal 2-year-old. It's Chelation that did it," says Nancy McCloskey, Josh's speech language therapist.

"It's like he went from his world, into ours," Angie Shoemaker says.

A joyful relief for Josh's parents, who are convinced that they found the solution for him.

The drug is FDA approved, but only to treat lead poisoning. Federal researchers are also looking into whether Chelation can help heart patients by draining calcium from clogged arteries.

### Treatment center offers daylong seminar

Integrations Treatment Center, 8671 Tyler Blvd., Unit F, Mentor, Ohio is offering a course titled "Autism: Effective Parenting Strategies" on Saturday, May 20, from 8:00-4:30. Parents will experience lab and lecture sessions to gain information about specific treatment techniques. Topics include Sensory Integration, Play skills, Behavior, Learning (Information Processing), and Socialization. The fee is \$100. Parents can call Integrations Treatment Center for a brochure at (440) 578-1100.

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

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.

### ARC of Ohio to visit Cedar Point May 25

The Arc of Ohio day at Cedar Point has been scheduled for Thursday, May 25th. The brochure with details on prices and deadlines will be mailed out in the next couple weeks. Please contact the Arc of Ohio at [arcoho@rroho.com](mailto:arcoho@rroho.com) if you would like added to the invitation list.

## 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

**Facilitated Communication: A  
Lifeline for Those Who Struggle  
with Verbal Communication**

**Friday, April 7  
7:00 pm to 9:00 pm**

**Featuring: Speech Language  
Pathologist Marilyn Chadwick &  
Jamie Burke, co-producer of a  
documentary on one person's  
journey with autism**

**Case Western Reserve University  
Cleveland, Ohio**

**For more information, visit  
www.autismtutors.com or call  
(216)258-6337**

**Milestones Annual Autism  
Conference**

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

**Autism Awareness Forum**

**Tuesday, April 4  
7:30 am to 4:00 pm**

**Sponsored by:  
The ARC of Stark County &  
Akron Children's Hospital**

**The Barrette Business and  
Community Center  
Walsh University, N. Canton**

**For additional information  
please call:  
1-866-676-0053**

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