



# ASGC Newsletter

## From The President's Desk

Greetings:

Another year is quickly drawing to a close, and as it does, we believe it is healthy to take a moment in our hectic lives and give thanks for all that we have. Most importantly, for those special individuals on the spectrum that educate us more than we ever imagined, yet with those challenges give us more joy than we ever imagined.

While we spend time with family and those who mean so much to us this season, let us not forget them and all of the neighbors, business associates, teachers, doctors, therapists and community organizations that we value so much and help get us from one day to the next. When you think about all they have done, consider making a list of the positive results their efforts bring.

### Meeting Time and Location for ASGC

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 December 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.

Think too about making a list of areas where support could be better. These lists can help the ASGC target areas in the community that need improvement, using them as programming budget line items needed to complete our 2006 budget. We rely on your feedback to build the most effective strategy for the ASGC programming efforts.

Our next chapter meeting will be on December 7<sup>th</sup> 6:30 PM in the Parish Center behind St Basil's Church in Brecksville. We hope you will be able to join us, holiday treats and beverages will be provided. Please feel free to bring some of your own favorites if you like. This will be a social and support meeting so we invite any questions, ideas, thoughts or stories you may have.

As a chapter, we have been blessed with steady and pronounced growth over the past year. We are very thankful for the wisdom shared by parents and professionals alike. We are encouraged and vitalized by our increased membership, and we are eternally grateful to all of you who gave so generously to the ASGC over the past year. Thanks to all of you and best wishes for a great 2006.

Sincerely,

Rory McLean, President  
Gus Gallucci, Vice President

Autism Society of Greater Cleveland

December 2005

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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

# ASA introduces "In Case of Emergency" decal

As part of the launch of ASA's newly-created "Safe & Sound" campaign, ASA introduced last month its "In Case of Emergency" decal and accompanying Personal Information Record for families affected by autism. All ASA donors and members received these materials. Within the last few weeks, not only are parents ordering additional materials, but the items are being sought after by diverse autism-related organizations as well, with calls coming in from county boards of developmental disabilities, schools, and adult homes to purchase multiple copies.

As those who care for a person with autism will agree, a major area of concern is safety for these individuals. The "In Case of Emergency" decal and accompanying information are very important tools for notifying firemen,

## Voters asked to support long-term care bill in Senate

Waiver services, also known as "Medicaid waivers," are programs offered through the Ohio Department of Job and Family Services (ODJFS), the Ohio Department of Mental Retardation and Developmental Disabilities (ODMRDD), and the Ohio Department of Aging. Waivers provide community services to people who would otherwise be institutionalized. Currently, Ohio has several waivers, and this section offers information about these programs. However, you should contact the agency that administers the waiver to verify the information provided and for more specific information about eligibility and services.

Senators Charles Grassley (R-IA), Evan Bayh (D-IN), and Hillary Clinton (D-NY) recently introduced the Improving Long-Term Care Choices Act of 2005, S. 1602. S. 1602 would give states the ability to add home- and community-based services (HCBS) to its Medicaid plan without the need to apply for a waiver.

The bill is currently in the Senate Finance Committee. Unfortunately, neither Ohio Senators Mike DeWine or George Voinovich are on this committee. But, you can still take action by sending a message to the chair of the committee - Senator Grassley, or the ranking minority member - Senator Baucus. Urge them to send the bill to the Senate for a vote (copying the Ohio senators).

Additional information can be found at:  
<http://thomas.loc.gov/>

police, or paramedics that someone in your home, automobile or facility has autism.

"In Case of Emergency" decals can be placed on the front door of homes, on automobiles, classroom doors, etc., so it is clear to first responders that an individual in the home, car, or classroom has autism and to act accordingly. The "Personal Information Records" can be kept on your refrigerator or in your glove box. Also, be sure to register the child with 911 by calling your local non-emergency number and stating you would like to identify the child as an individual with autism in case of emergency.

In collaboration with Dennis Debbaudt, leading expert in autism and risk management, ASA will be expanding the reach of "Safe & Sound" over the coming months, including a massive awareness campaign with first responders to introduce them to this critical product.

Decals may be purchased on the ASA Web site, [www.autism-society.org/store](http://www.autism-society.org/store) for \$2.50. Personal Information Records are \$2. For more information, contact Tiffany Gill, 301-657-0881 x124.

## Toilet training help offered for children with autism

If you are planning to toilet train your child or have tried to teach your child to use the toilet but have not been successful, come and learn how to evaluate why your child is having difficulties and specific strategies to make your child successful.

**Instructed by Kim Renner**

**at:**

The Croxton Memorial Auditorium

The Toledo Hospital

2142 N. Cove Blvd., Toledo, Ohio 43606

Free parking is available in the front parking garage.

You must pre-register for these workshops. Cost is \$10 per workshop per family. Scholarships are available. Please remit payment to: Autism Society of Northwest Ohio, 4848 Dorr Street Ste 1, Toledo, OH, 43615. Questions? Call Linell at 419-578-2766.

# Click, Click, Click

by Pauline Fraser

We ducked into the dimly lit thrift shop to get out of the rain. Like so many things since our daughter's birth, I hadn't planned on a trip to this place. But, I figured we'd see what they had since we were there.

"Hi, today is stuff a bag day. Would you like one?" the clerk asked.

"What is stuff a bag day?" I said.

"You take a bag and stuff it with what ever you want and it's only \$3. Best deal in town," the clerk said.

"Okay, sounds great," I said, despite the fact I hadn't planned on buying anything. I took my six-year-old daughter's hand and we started to wander around. Suddenly, there was a tug on my hand and my attention was being directed to the shoe section. She shares my weakness for shoes, so we stopped for a minute to look. I let go of her hand and she reached out to touch a pair of shiny black shoes with a strap and silver buckle.

"Buy me?" she inquires.

"Oh, Sweetie, they are tap shoes. You aren't taking tap."

"Buy me?" she repeats.

"Well, let's try them on," I said.

She sits on the floor and removes her bright pink rain boots, with Barbie on the sides, and easily slides the new shoes on. A perfect fit. When she stands up she hears "click."

She takes a step. Click, click.

Slowly recognition dawns, as she makes the connection between the shoes and her moving feet. Click, click, click.

"Buy me?" she says with a hopeful look in her eyes. Again, "Buy me, peas?"

"Okay Sweetie, take them off and put them in the bag."

We look around some more and get a few t-shirts, pants, books and games and a naked baby doll. Well, it's stuff a bag day -- might as well get my money's worth, I think to myself.

The sun has come back out as we emerge from our little side trip, and we continue on our way. As we near the car, Amara reaches for the bag. As she climbs into the back seat, I give her the bag wondering what treasure she is looking for. The shoes, of course. She is my daughter after all.

"My wear," she said.

It's not a question, so I took the tag off and helped her with the buckle. Our next stop was the grocery store and these shoes were made to make noise, especially on my little girl's feet. This could be interesting...

Click, click, click -- people turn to look as we enter the store.

Click, click, click. I can feel the disapproving stares of the proper people. People who would never allow their daughter to wear tap shoes to the grocery store. I hold my head up with pride. The click, click, click is music to my ears.

"Excuse me dear. Is your daughter in tap this year?" a shopper asked.

"No," I said.

"Well, why on Earth would you allow her to wear tap shoes, here, of all places? They make such a noise," the shopper said.

"Yes, isn't it wonderful?" I said.

"Wonderful? My dear, this is not the place to wear those shoes," the shopper said.

"Oh, I think this is the perfect place to wear them," I said. "You see she asked for them."

"Just because she asked for them, doesn't mean you have to get them for her," the shopper remarked.

"You don't understand," I said. "When she was a baby, we were told she would never walk or talk. It has taken a lot of hard work and patience, but she ASKED for the shoes and the click, click, click says that she CAN walk."

My daughter, the one who never stays still, or quiet, will graduate from grade twelve next year. It has not always been easy, but it has all been worthwhile. She has taught me that it doesn't matter what others think. They don't walk in your shoes. And, just like the ladies in the purple hats, sometimes you simply have to wear tap shoes to the grocery store -- if for nothing else, just for the sheer joy of hearing the click, click, click.

## OSU researchers looking for participants for drug study

Researchers at Ohio State University Nisonger Center are working with a pharmaceutical company to test the safety and effectiveness of an investigational drug known as Oralgam. Oralgam, or oral human immunoglobulin, is a natural product that contains human antibodies. Antibodies are particles that the body forms to fight illnesses. Examples of these illnesses include measles, chickenpox, the flu, and colds. These antibodies also help fight infections in the stomach and intestines. As many as 40% of children with autism experience regular stomach problems, including chronic diarrhea or constipation, bloating, gas, or abdominal pain. It is possible that the stomach problems may lead to behavior difficulties in such children. The O.S.U. investigators are also hoping that the investigational medication will improve problem behaviors in these youngsters.

Investigators at O.S.U. are looking for participants to be in the present research study. **To be eligible for the study, participants must:**

- be between the ages of 2 and 17 years, inclusive,
- meet diagnostic criteria for autism,
- experience regular stomach or bowel problems (chronic diarrhea or constipation, bloating, gas, abdominal pain)
- **not** have a significant medical condition (e.g. heart disease, liver or kidney failure, unstable seizure disorder),
- have no plans for medication changes in the next 4½ months

The study takes 4 ½ months for each participant. There is a 75% chance of receiving Oralgam, and a 25% chance of receiving placebo. Each participant takes six capsules a day: three in the morning and three in the evening. The capsules can be opened and sprinkled on food if the child is unable to swallow them. Parents complete an electronic diary every day and send results by phone for the duration of the study.

If the child has not been diagnosed with autism, a study clinician can do an evaluation. All evaluations and medication are free. Families who participate will receive small payments for lost work time or sitter costs, and the child will receive a small token for participating. If your child has autistic symptoms **and** stomach or bowel problems, and the idea of an investigational medication interests you, please contact Lindsay Crowl at (614)688-8214 or [crowl.15@osu.edu](mailto:crowl.15@osu.edu) for more information.

## Disability website developed

The President's New Freedom Initiative has developed a user friendly disability website that has links to more than a dozen governmental agencies and many non-profit organizations. People with disabilities, their advocates, and professionals can search by topic and need not know which organization to look for. The general topics are employment, health, transportation, housing, civil rights, benefits, technology, and community life. The web site can be found at: [www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=137](http://www.disabilityinfo.gov/digov-public/public/DisplayPage.do?parentFolderId=137)

## APRAIS Offers Parent's Guide

APRAIS, a coalition of disability-related groups, including TASH and ARC, has created "IN THE NAME OF TREATMENT: A Parent's Guide to Protecting Your Child From the Use of Restraint, Aversive Interventions, and Seclusion". The guide provides suggestions for parents if their kids' schools are using abusive behavioral treatments and techniques, including physical restraints, time out rooms and aversives. It is a very good publication and should be in the hands of every parent of a kid w/a disability who attends a private special ed school or publicly-operated school, class or program.

For more information, visit [www.tash.org/publications/parentguide](http://www.tash.org/publications/parentguide)

## Book gives teaching suggestions

**Tasks Galore** is a delightful series of "how to" books filled with full color photographs and creative ideas for teachers, therapists, and parents working with exceptional learners. Our goal is to provide assistance in creating a fun, satisfying, and meaningful collection of tasks that will aid in the successful educational careers of your students and children.

Parents, educators and leading authorities in the field have welcomed **Tasks Galore**. Written by teachers and therapists who are highly experienced in structured teaching methodology, this series offers a compilation of tasks and strategies which were used by the authors in North Carolina TEACCH-affiliated classrooms and in the University of North Carolina Division TEACCH treatment sessions and trainings.

Visit [www.tasksgalore.com](http://www.tasksgalore.com) for ordering information.

# Companies are offering assistance to parents of kids with disabilities

By Sue Shellenbarger

From The Wall Street Journal Online

For years, David Bruesehoff hesitated to tell anyone at work about his daughter, Karissa, who has autism and Down syndrome.

At his company and many others, "it's the 'culture of the smart,' " the Dallas father says. "It can be hard when another parent is talking about his child getting into prep school, and your child's big accomplishment is getting on the bus to go to school."

A code of silence has long kept parents of children with disabilities, from autism and Down syndrome to cerebral palsy and depression, from talking about their kids at work. Now, driven by growth in their numbers and in the cost of raising special-needs children, some of these parents are starting to "come out" at work. And a handful of employers are stepping up to help, with support groups, informational meetings and insurance benefits.

The incidence of U.S. children and teenagers with a disabling condition has tripled to 7% from 2% in 1960, based on data published in 2000 in the Archives of Pediatric and Adolescent Medicine, reflecting increased survival rates and a rise in the diagnosis of conditions such as autism. Today, an estimated one in 12 U.S. workers has a child with a disability or special need, says MassGeneral Hospital for Children, Boston, which is conducting a five-year, federally funded project to examine workplace supports for these parents.

"Stigma and fear of reprisal" have kept many workers from disclosing their family situations, says Chris Fluet, director of the MassGeneral project.

The risks of speaking up are real: Soon after Kevin McGarry, Hyde Park, N.Y., started asking questions about insurance coverage for his disabled daughter on a previous job as a paralegal in the mid-1990s, his supervisor got upset and told him to stop asking for benefits. "They didn't want my health insurance company to get wind" of the rare syndrome his daughter had from birth. Although his performance previously had drawn praise, he says he soon started getting negative feedback. Eventually he was laid off.

Having a child with a disability also requires time and effort to find and manage treatment, forcing 30% of these parents to quit or cut back at work, says a 2001 survey by the federal Maternal and Child Health Bureau.

Few parents can afford to cut back. More than 40% of families with special-needs kids have financial problems because of care costs, says a study published in June in Maternal and Child Health Journal. And, 60% of children with special needs rely on their parents' employers for health insurance, MassGeneral says.

Now, some parents are taking the opposite tack -- turning to the workplace for support. After her autistic son was born 11 years ago, Kathy Gonzalez, a technology manager at Toyota Motor Sales USA, Torrance, Calif., was overwhelmed trying to find treatment for him. Seeing her co-workers networking on other topics, she helped start a support group last year at Toyota that draws up to 40 parents of special-needs kids to its monthly meetings. "If I could help even one parent get on track for whatever service they need for their kid, it would be worth it," Ms. Gonzalez says. At Microsoft, employees with autistic children have formed a similar network.

Jack Harris, whose 11-year-old son is autistic, was startled to learn during on-site meetings of a father's network at PricewaterhouseCoopers's Tampa, Fla., office, that 10 of the 50 other men there also had children with disabilities. With PricewaterhouseCoopers's blessing, Mr. Harris, a practice support manager, is planning an on-site special-needs resource fair early next year. The firm is looking for other ways to support such parents, a spokeswoman says.

In recent years, Mr. Bruesehoff gradually began talking about his daughter on his job in Los Angeles for accounting firm Ernst & Young. Then, when he was offered a transfer to Dallas in 2002, "I decided I was just going to come clean" and explain that the availability of programs in Dallas for Karissa, now 17, would be pivotal. Co-workers responded warmly, helping his family forge new ties in Dallas, where he now works as a human-resource manager, he says.

Mr. Bruesehoff is among 64 parents of special-needs kids who have joined a parent network formed last January by New York-based Ernst & Young. Sandra Turner, a human-resource manager, says parents on the network's informational conference calls are slowly opening up to each other. While fewer than one-fifth were willing to give their names on the first call, about half now feel comfortable identifying themselves.

Raytheon, an aerospace and defense contractor, has hosted several speaker dinners for employees with special-needs children at its Tucson, Ariz., and Woburn, Mass., facilities.

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## Survey aims to improve services for kids with special needs

Are you the parent of a young child with special needs (IEP) who is 3, 4 or 5 years old?

Has your child received itinerant preschool services at any time in 2002, 2003, 2004 or 2005? If so, we'd like you to help us by completing a short internet survey. Before completing the survey, please read the short policy brief available at <http://homepages.utoledo.edu/kwolodk/Executive%20Summary.htm>.

The Ohio Department of Education is recommending that itinerant (visiting) early childhood special education services move toward a consultative approach in which the itinerant teacher serves primarily as a consultant or 'teaching partner' to preschool teachers or parents who work (and live, in the case of parents) with the child very day. We're asking parents of young children who

have received itinerant early childhood special education services their opinion about this move.

Your comments about this 'new' policy is very important and will help school districts and the Ohio Department of Education improve itinerant services for young children with special needs. To complete the survey, please go to the following website: <http://www.zoomerang.com/survey.zgi?p=WEB224JZMK77TU>.

Questions? Please contact Keith Wolodko at [keith.wolodko@utoledo.edu](mailto:keith.wolodko@utoledo.edu) or (419)530-5390 if you have questions about completing the survey. If you have questions about the policy or comments you'd like to share, please contact Dr. Laurie Dinnebeil at [laurie.dinnebeil@utoledo.edu](mailto:laurie.dinnebeil@utoledo.edu) or (419)530-4330 or Dr. Bill McInerney at [william.mcinerney@utoledo.edu](mailto:william.mcinerney@utoledo.edu) or (419)530-2284.

### Area Special Needs Doctors

Here is a brief list of doctors and other practices that may help you find needed care.

If you know of a good physician or other service, please send your comments to Marian at: [DMHelmick1@wmconnect.com](mailto:DMHelmick1@wmconnect.com)

#### 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

## Largest ever study to help determine causes of many common diseases

By Maggie Fox

WASHINGTON (Reuters) - Researchers hoping to determine the causes of many common diseases like autism and diabetes will follow 100,000 U.S. children from birth through adulthood in the largest ever study of its kind.

"We're looking to find the root causes of many common diseases and disorders. When we do, we'll be in a position to prevent them from ever occurring," said U.S. Surgeon-General Dr. Richard Carmona.

In particular, scientists will try to find out whether there is a link between environment and diseases.

Most studies used now to link environment and disease are retrospective, meaning they rely on a patient's or a parent's recall of events, food eaten, and behaviors. Scientists place much greater faith in studies that look at actual behaviors in real time to more accurately link them to consequences.

Researchers will also take samples from the children and their parents to see what chemicals they have actually absorbed into their bodies.

The six centers where the research will begin include the University of California in Irvine, the University of North Carolina in Chapel Hill, the Mount Sinai School of Medicine in New York, Children's Hospital of Philadelphia, the University of Utah in Salt Lake City and the University of Wisconsin-Madison.

## Companies Offer Assistance

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Jeff Stolz, whose son Joseph, 10, has autism and bipolar disorder, was among those attending. Heartened to learn many of his co-workers also had special-needs kids, Mr. Stolz for the first time took Joseph in April to the annual "Take Your Child to Work" day festivities at Raytheon. He was apprehensive; Joseph verged on a tantrum during an introductory session. But as the day wore on and supportive adults reached out to him, Joseph calmed down, and even introduced himself by microphone at the closing session.

In a surprising move in today's cost-cutting climate, a few employers are even expanding insurance coverage for special-needs kids. Microsoft, oil-industry supplier Halliburton, and insurer Progressive Group have begun covering some of the cost of applied behavior analysis, or ABA therapy, intensive early training for autistic kids that can cost \$20,000 or more.

These employers, of course, are the exception. If you have a child with a disability, only you can size up your corporate culture. A MassGeneral manual offers tips and resources, available online at [www.massgeneral.org/ebs](http://www.massgeneral.org/ebs) by clicking on "Resources for Employees," then opening "workplace benefits."

## Children's books on autism published

Many parents can tell you that it is very difficult to answer complex and often emotional questions children pose about why their autistic sister, brother or friend who behaves a certain way.

Marvie Ellis, a pediatric speech-language pathologist, has written two children's illustrated bilingual autism books to help families with these questions. "Keisha's Doors" and "Tacos Anyone" are published by Speech Kids Texas Press and are available for \$16.95 each via the publisher's website at [www.speechkidstexaspress.com](http://www.speechkidstexaspress.com).

The books received nominations for the 2006 Dolly Gray Children's Developmental Disabilities Literature Award.

## Family launches autism-related website

A new website [www.AutismConcepts.com](http://www.AutismConcepts.com) created by an African American family raising an adolescent child with autism, shares credible and relevant information with other families. [AutismConcepts.com](http://AutismConcepts.com) shares information, research and resources related to African Americans.

## Youth Leadership Forum is seeking 2006 Candidates

The Governor's Council on People with Disabilities is now accepting applications for its 2006 Youth Leadership Forum (YLF) for high school juniors and seniors who are students with disabilities. To be eligible for this forum, students must: (a) have a disability; (b) be a junior or senior by December 31, 2005; (c) have demonstrated leadership potential in the school and community; and (d) reside in Ohio. YLF is a cross-disability forum, so please consider all students with disabilities, from learning disabilities through severe physical impairments. It is our intention to have a forum that reflects the racial, ethnic and disability diversity of Ohio. There is no cost to the students or parents for attending YLF; all lodging, meals, personal care assistance and other costs are paid by the program. While we do ask that students provide their own transportation to and from Columbus, if this is a problem, we usually can work something out. We have volunteer staff and delegates coming from all over Ohio, so carpooling is usually one possibility.

The deadline for applications is January 31, 2006. If you have any questions about the program, please contact Leslie Alloway at (614)438-1392 or [leslie.alloway@rsc.state.oh.us](mailto:leslie.alloway@rsc.state.oh.us). She will be happy to answer any questions or provide additional information. If you are interested in having a speaker come and talk with a group of students about YLF, call or e-mail. We often can arrange for a former delegate who lives or is attending college in a particular area of the state to come and speak.

You can find additional information about YLF, including photos of past YLFs, at the Governor's Council website, <http://gcpd.ohio.gov>.

### **Greater Akron Chapter of the Autism Society of America**

serving Summit, Stark, Portage, Wayne and Medina Counties

#### **January 24, 2006 at 7pm**

Get the "Poop" on Training Your "Whiz" Kid with  
Autism Spectrum Disorder  
Beth Anne Martin - Cleveland Clinic

#### **February 21, 2006 at 7pm**

Met Desk / Met Life  
Estate and Trust Planning for your child with Special Needs

Meetings at Akron Children's Hospital Considine Building  
[www.asagreaterakron.com](http://www.asagreaterakron.com) or 330-543-3955

## 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 Autism Conferences in Ohio

**"Behavioral and Inclusion  
Strategies for Home,  
School and Community"**

**Featuring:  
Maria Bird-West Wheeler  
and Dr. Paula Kluth**

**February 1-2, 2006  
Cleveland, OH  
Holiday Inn West**

**[www.spectrumtrainingsystemsinc.com](http://www.spectrumtrainingsystemsinc.com)**

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