



# ASGC Newsletter

## From The President's Desk

Dear Members,

Well, what can we say? In what can only be described as a mammoth success, the ASGC extends a lifetime of thanks to Jeanne and Joel Hill, Brian Doyle, Sandy Bender, John Ross, Jan Ross, Nancy Heller, Bob Osterman, Eric Wells, Fred Griffith, the 20+ chili chefs and everyone else who volunteered on April 5. The first annual Chili Cook-Off for Autism brought in over eight thousand dollars for our growing chapter of the ASA, as an estimated two hundred fifty people ate, drank and gave generously at the tasting room of the Great Lakes Brewing Company, who also has our appreciation for their guidance and professionalism.

As caretakers for autistic individuals, we go through the day-to-day struggles and triumphs chasing an elusive and mysterious goal of a happy and productive future for our loved ones with special needs. Many times there is hardly enough energy at the end of the day to give ourselves a much-deserved pat on the back. It's a labor of

### 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 May 3. **CHILD CARE PROVIDED**

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.

love, we think. It's just part of our plan. After all, would God give us any challenge we couldn't handle? We give it our best shot, appreciating any signs of progress and trying to keep things positive.

Then, on those rare occasions, you meet some special individuals. Some that know our situations first-hand and others that don't. Their bond is they want to give of themselves to better understand our situations and help in any way they can. They aren't paid for their efforts. There's no promotional consideration. There's just that feeling when it's all said and done of the highest currency, knowing that you have done a world of good for a whole lot of people. These are the special individuals from the food forum @ Cleveland.com and our own chapter that helped make the first annual Chili Cook-Off for Autism possible. God bless you all and thank you.

We host a very special speaker for our May 3 meeting, Dr. Philip DeMio, a nationally recognized practitioner of the DAN protocol from right here in the Cleveland area. Dr. DeMio is also the father of an autistic child. We look forward to hearing Dr. DeMio's unique perspective and benefiting from his experience. Please join us if you can on our mission, month by month, 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

May 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

## Legislator seeks support for House Bill 431, urges voters to begin letter campaign

It is time to start the letter writing campaign in earnest for House Bill 431. The bill is in the House Education Committee. Here is a link to a listing of committee members.

<http://www.house.state.oh.us/jsp/Committee.jsp?ID=6>

The address for members is 77 South High Street, Columbus, 43215.

Please do not have your parents or your network send a boilerplate message. Individual and personal messages are the best. Handwritten letters are more effective than email but I can understand how time may limit preparation of handwritten letters. I need dozens of letters. Please start now!! If each of you can generate 33 letters, that would be great. Together with the letters I am generating, that will get us over 100 letters, which is more than any legislator receives on any topic!!

Parental choice should be the overriding theme of all of the letters (expressed in personal terms) - parents knowing what is best for their children - not some administrator in a school district. Feel free to add any suggested improvements to the bill (for example, expansion to pre-school) but the dominant theme should still be consistent - one size does not fit all.

You have frequently asked me how to get parents engaged in legislative advocacy. This is how it is done.

The letter campaign should start immediately. I believe this bill could move in May with community support.

### **Greater Akron Chapter**

Serving Summit, Stark, Portage, Wayne and Medina Counties

**Tuesday, May 9**

**7:00 pm**

at Akron Children's Hospital  
William Considine Building - Bowery St. Deck

**How to work effectively with your school** presented by Chris Wnoroski, Special Education Consultant Autism/ Assistive Technology, Akron Public Schools and Gail Love, Parent Mentor, Coventry Local School District

There is no cost for the meeting and no RSVP's needed.

For more information, you can contact us via email at [asagreaterakron@sbcglobal.net](mailto:asagreaterakron@sbcglobal.net), by phone at 330-543-3955 or visit our website at [www.asagreaterakron.com](http://www.asagreaterakron.com).

## University of Alabama conducts research on siblings of special needs children

The University of Alabama Psychology Department is beginning a new study of siblings of children with developmental disabilities, specifically autism spectrum disorders (ASD) and Down syndrome (DS). This project is being conducted as part of a graduate student dissertation. We are interested in families with children between the ages of 4 and 16 years of age.

This study examines strengths and weaknesses observed in children as they cope with having a sibling with special needs and will provide valuable information for future research and clinical interventions with families of children with developmental disabilities.

Information for this study will be collected in two stages. First a parent will complete a brief, 15-minute interview by telephone. Next, parents will be mailed a survey packet of questionnaires regarding their children and family, which will take approximately 1 hour and 15 minutes to complete. The survey packet may be completed at the participant's convenience and returned to the researchers in a stamped envelope at no cost to the participant.

Following completion of the survey, participants will receive a \$5 gift certificate to a major bookstore. Each family that participates will also be entered into a drawing to receive one year's membership to a local parent support group.

If you are interested in participating in this study, please contact Sarah O'Kelley, a graduate student supervised by Dr. Laura Klingler, at (205) 348-9312 or by email at [crump002@bama.ua.edu](mailto:crump002@bama.ua.edu).

Study Explores How Children With Disabilities Make Friends: How Can Parents and School Personnel Help? by Pamela Thomas, Sunny Roller, Ann Scharnhorst, Sean Cunningham, and Seth Warschausky

Printable version:

<http://www.cenmi.org/focus/downloads/march06/GATA06-01.pdf>

This FOCUS on Results document offers information for parents and school personnel working to facilitate the friendship-making process in children with disabilities. The document provides suggestions to help children with disabilities become more socially integrated.

# Children who have siblings with disabilities face challenges too!

by Steve Ruark for The New York Times

"I knew there was something wrong with my place," he recalled. "But I didn't know how to explain what that was."

He knew that he would have to tell his friends why they could play only in his bedroom - and only with the door locked. And that, ultimately, he would have to explain what was "wrong" with his older brother Burleigh, who is profoundly autistic.

"I just didn't have the words," he said.

Now 30, Mr. Seaton said he realized that as a child, he felt he could not ask his parents for those words.

"I was so aware I couldn't make a big deal with my family," he said. "My parents already had enough on their hands."

An estimated seven million "typically developing" American children have siblings with disabilities, according to the Arc of the United States, a leading advocacy group for the mentally retarded. Those children face many of the same challenges - and joys - as their parents, but they also face other problems. Some resent the extra demands placed on them at an early age by their disabled siblings, and many feel neglected by their often overburdened parents.

Some children say they fear "catching" their siblings' disabilities. Others may wish that they, too, were disabled, so that they could get all the attention their siblings do. And many suffer embarrassment about their siblings' inappropriate behavior or abnormal appearance, and then feel guilty about it.

These are difficult emotions for children to struggle with, and Don Meyer, director of the Arc's sibling support project, says the needs of siblings like Mr. Seaton are often overlooked. Most assistance organizations and support groups are intended for disabled children themselves or for their parents.

"These brothers and sisters will likely have the longest-lasting relationships of anyone, relationships easily in excess of 65 years," Mr. Meyer said. "They should be remembered at every turn."

Still, many siblings welcome the early maturity and responsibility that come with having a disabled brother or sister. They are often well versed in the details of their siblings' disabilities, and they take pride in being able to explain them in sophisticated ways. For example,

Hannah, 16, of Dearborn, Mich., who did not want her last name used out of concerns for her privacy, said she related better to adults than to children her age because of having to cope with her brother Ian's autism.

But that maturity does not inoculate her from embarrassment about Ian's outbursts, particularly during church services.

"Sometimes he'll kind of start making noises, and then sometimes he'll kick and flail his arms, or he'll start rocking and crying," Hannah said. "My mother will take him outside, but it's still, like, okayyyyy...."

Suzanne Ripley, who has two sons with cerebral palsy says that a child's disability can embarrass parents, too, but that embarrassment can be more acute for siblings, especially those in the throes of adolescent conformity. Young siblings are also prone to teasing from other children, who do not have the social inhibitions of adults.

But Ms. Ripley, the director of the National Dissemination Center for Children With Disabilities, based in Washington, notes that adults can often be just as rude.

"People tend to be uncomfortable with anyone who's different, so they look for a second and then look away," Ms. Ripley said. "Imagine how that would make you feel" as a child.

Parents like Ms. Ripley are likely to seek comfort through talking with others about their conflicting emotions. But children may not have the sophistication to do so or they may feel guilty about acknowledging any negative feelings they have.

Hannah, for example, says she loves her 13-year-old brother and feels terrible about her reactions to his outbursts.

"I know it's not his fault and that's the way he is, and so I shouldn't really be embarrassed, but sometimes I am," she said.

But she said she did not discuss those feelings with her parents.

"They'd get that, 'Oh well, you can deal with it' kind of attitude," she said. "I know they would listen, but they would get defensive."

Ally Cirelli, a 9-year-old in Towson, Md., whose sister is

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# Over 120 experts to converge in Chicago for 2006 Autism One Conference

**AUTISM ONE 2006 CONFERENCE**  
**Wednesday, May 24 – Sunday, May 28**  
**Chicago Westin O'Hare Hotel**  
<http://AutismOne.org>

## **Hope is Real. Healing is Real. Our Children Get Better.**

The most comprehensive conference on autism ever assembled is proud to bring together over a 120 of the world's leading authorities. Meet, learn, and be inspired by experts such as David Kirby, Dr. Richard Deth, Dr. Andrew Wakefield, Dr. Arthur Krigsman, Dan Olmsted, and over a hundred others.

Because questions and answers do not stop at the boundary of a discipline, Autism One brings together all disciplines. Multivariate in presentation and cure autism bows to the collective weight of scientists working with practitioners working with therapists working with educators working with parents working to recover their children.

Autism One offers five tracks to help you make the best decisions and most informed choices.

1. The Science of Autism & Biomedical Treatments
2. Behavior / Education / Communication Therapies
3. Complementary and Alternative Medicine
4. Adolescence and Adulthood
5. Government/Legal/Personal Issues

Choose the presentations which best meet your needs.

## **A Celebration**

The hopes of a mother and dreams of a father are real. Given the proper treatments and therapies many of our children recover or improve tremendously.

In addition, to the five tracks two pre-conference days are devoted to helping families thrive and also to quickly get you up to speed on special diets.

If you would like individual attention please sign up for a Mentor Parent. Mentor Parents are extremely knowledgeable in biomedical treatments, behavioral therapies, and dealing with school districts. Your mentor is a year-round resource.

## **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 by April 24, 2006.

## **About Us**

Autism One is a 501(3)(c), non-profit, charity organization started by a small group of parents of children with autism. Parents are and must remain the driving force of our community, the stakes are too high and the issues too sacred to delegate to outside interests.

Become your child's most effective healer and advocate.

## **Contact**

Contact Edmund Arranga at 714.680.0792 or [ear-ranga@autismone.org](mailto:ear-ranga@autismone.org) for more information or visit <http://AutismOne.org>.

## **Autism and the God Connection draws attention of documentary filmmaker, available on Amazon .com**

The first review of *Autism and the God Connection* is in, this from the publishing trade journal *Booklist* (see below). Much momentum is accruing for the book, and it's already attracted the attention of a filmmaker who rendered a beautiful documentary about a man with Lou Gehrig's in addition to other media interest.

*Autism and the God Connection* is **now shipping** on Amazon.com for the reduced rate of \$9.72 per copy. If you are pleased with it, kindly share your support by posting a review on Amazon.

**Stillman, William.** *Autism and the God Connection: Redefining the Autistic Experience through Extraordinary Accounts of Spiritual Giftedness.* Apr. 2006. 272p. Sourcebooks, paper, \$14.95.

In certain cultures, people with illnesses affecting the ability to communicate are thought to be visited by spirits. The sufferer may be regarded as a messenger for a deity, an anointed one to be revered and honored. Sadly, Western culture often relegates those diagnosed with autism and related disorders to the ranks of the incurably crippled. Worse, almost everyone, from family members to friends to primary caregivers, too easily writes off the intelligence of a person who has difficulty speaking. So written off, the sufferer is discounted and ignored. Stillman, who has Asperger's syndrome, a high-functioning form of autism, speaks out on behalf of the wisdom of considering people with autism as not just intelligent but also highly spiritual. Drawing on testimony from dozens of parents, teachers, and autistic individuals, he builds a solid case in favor of not just his mantra —“always presume intelligence” - but also of thinking that God's most challenged people possess a deep, abiding spirituality. —*Donna Chavez*

## Children who have siblings with disabilities face challenges too!

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developmentally disabled, says the biggest complaint she hears from her peers is that the disabled siblings get all the attention.

Some are so jealous of their siblings that they wish they had their own disability, and the special treatment that comes with it, she said. But Ally, too, avoids talking to her parents about her feelings. And she is quick to back-pedal when she does talk about it, insisting that her sister, Katie, 8, does not embarrass her "all that often," and that she is "really fun" to play with.

Mr. Meyer, of the Arc, says children need a place where they can openly discuss these concerns and emotions. To fill this gap, he started the sibling support project, which is based in Seattle and provides information and holds discussion groups for children around the country. In 2005, Mr. Meyer also published "The Sibling Slam Book: What It's Really Like to Have a Brother or Sister With Special Needs," a collection of candid remarks by 80 children.

Mr. Meyer said that when asked about the most embarrassing moment of their lives, few of the children cited anything having to do with their disabled siblings. Instead, most recounted the usual teenage humiliations: problems in romantic relationships or dealing with parents.

And that, Mr. Meyer says, underscores an important point: "When I talk to parents about embarrassment (about disabled siblings), I ask them to keep in mind that it's an age-related condition," he said. "That's the good news, that a lot of that seems to be resolved by even their late teens."

Please consider joining us for Kent State University's Early Childhood Intervention Program's first annual **Summer Institute**. The mission of the ECIS program continues to be to increase the number of qualified personnel to serve young children with disabilities and their families. In particular, the program seeks to prepare personnel with the skills necessary to be effective members of *interdisciplinary teams* that operate from a *developmental framework* and incorporate a *family-guided approach* to service delivery.

**When:** June 26th through June 30th

**Where:** Moulton Hall Ball Room - Kent State University, Kent, OH

**Who:** Anyone who works with young children with and/or without disabilities and their families.

**How Much:** The cost for each of the institute strands is \$75.00 (total of \$150.00 for the whole institute)

[http://fpsrv.dl.kent.edu/ecis/Web/Inservice/SummerInstitute/summer\\_institute.asp](http://fpsrv.dl.kent.edu/ecis/Web/Inservice/SummerInstitute/summer_institute.asp)

The work of disability advocates and the mainstreaming of children with special needs in schools and in the wider society has fostered more awareness of - and less discomfort with - disabilities.

Ms. Ripley, for her part, says she has noticed a change in public attitudes, especially when she is struggling to maneuver with her sons in public places.

## NEA offers new resource for teachers with autistic students

To assist educators in their daily work with children who have autism, NEA has produced a new resource in collaboration with the Autism Society of America, the American Speech-Language-Hearing Association and the National Association of School Psychologists.

Teachers and related service providers need this resource. "The Puzzle of Autism" is a succinct informational guide for all education personnel who work with students with Autism Spectrum Disorders (ASD). This 38-page guide explains common autistic characteristics and suggests effective classroom strategies for improving communication, sensory, social, and behavioral skills.

To receive your complimentary copy email:

[gapsinfo@nea.org](mailto:gapsinfo@nea.org)

You can also download the PDF at:

[www.nea.org/specialed/images/autismpuzzle.pdf](http://www.nea.org/specialed/images/autismpuzzle.pdf)

Opening lines:

### **The Puzzle of Autism: What Educators Need to Know**

Mr. Davidson begins his signature tennis ball game for reviewing and locating geographical formations, rivers, and towns in his Westward Movement unit. The students clamor for the ball and the chance to go to the map. Michael's hands go over his ears as the noise level rises. His body shrinks into his chair with each scream. When the noise level becomes intolerable, Michael leaves his chair with a book and enters the hallway. He paces the hallway with his nose in a book.

At the end of the game, the door opens to signal Michael that the game is over and class will begin. As Mr. Davidson begins his lecture on the Westward Movement, Michael raises his hand. When called on, he asks, "Did you know that General Custer kept a live lynx in his basement?"

## Web site outlines upcoming changes

Helpful link from the Ohio Department of Job and Family Services regarding pending changes to the Ohio Home Care Wavier and Core Plus Services:

<http://jfs.ohio.gov/Ohp/ohc/ohc.stm>

Thanks to the ARC of Ohio for sharing this information.

## OSERS releases information on IDEA and special needs students placed in private schools

Troy R. Justesen, deputy assistant secretary of the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education, is pleased to share news of the release of some helpful information about students with disabilities placed by their parents in private schools.

A useful online resource for school districts and parents about how the reauthorized Individuals with Disabilities Education Act (IDEA) provides for students with disabilities enrolled by their parents in private elementary schools and secondary schools is now available on the Department's Web site. Titled Questions and Answers on Serving Children with Disabilities Placed by Their Parents at Private Schools, this resource was developed in response to queries from state officials, elected representatives and parents since a change to IDEA became effective on July 1, 2005. This resource is posted to the IDEA 2004 Resources Web page at [www.ed.gov/policy/speced/guid/idea/idea2004.html](http://www.ed.gov/policy/speced/guid/idea/idea2004.html).

The statutory revisions to the IDEA in 2004 significantly changed the obligation of states and local education agencies (LEAs) to children with disabilities enrolled by their parents in private elementary and secondary schools. While previously it was the responsibility of the LEAs in which the parents resided to conduct child find and provide equitable services to these students, that responsibility has now shifted to the LEAs in which the private schools are located.

Questions and Answers address such topics as child find and individual evaluations for parentally placed private school children, the provision of equitable services, and preschool and out-of-state parentally placed private school children with disabilities.

Questions and Answers is the latest resource added to the IDEA 2004 Resources Web page, intended to assist educators, students and families.

## Adults with Autism - The Upward Spiral Thursday, September 14

**Dana Conference Center  
3110 Glendale Avenue  
Toledo, OH 43614**

**sponsored by:  
Bittersweet Farms  
Medical University of Ohio  
Ohio Department of Mental Health**

Topics to include:

*"Co-Morbidities in Autism - Chronic Implications  
And Medical Management"*

*Max Wiznitzer, M.D.*

*Associate Professor of Pediatrics and Neurology  
Case Western Reserve University  
Director, Rainbow Babies and Children's Hospital  
Autism Center*

*"Life Span Aging Issues in Adults with Autism"  
"Staff and Family: Developing Cooperative Support"*

*David Holmes, Ed.D.*

*Chairman/CEO, Lifespan Services, LLC*

*"Clinical Aspects of Autism"*

*John Pierce, M.D., ABFP*

*Private Practice, Portage Valley Medical Group  
Medical Director, Bittersweet*

*"Vocational Strengths"*

*Ellen Williams, Ph.D.*

*School of Intervention Studies  
Bowling Green State University*

*"Research Findings Regarding Early Interventions  
with Autistic Children and Adult Outcomes"*

*Luke Y. Tsai, M.D.*

*Professor of Psychiatry and Pediatrics  
University of Michigan Medical School  
Director, Developmental Disorders Clinic  
University of Michigan Health System*

## Providence to host the Autism Society of America's 37th Conference

Online registration has begun for ASA's 37th National Conference and Exposition to be held in Providence, Rhode Island, July 12-15, 2006.

Register online at [www.autismsociety.org/site/R?i=bQ3YcVYj0EEwCF3lwWP3kg](http://www.autismsociety.org/site/R?i=bQ3YcVYj0EEwCF3lwWP3kg).

This July, the Autism Society of America arrives in Providence, a city that seamlessly blends urban sophistication with graceful small-town charm.

Attendees, when not in session, can experience a leisurely glide in gondolas on the Providence River past gleaming office buildings. Cobblestone streets lead to some of the finest restaurants in the country. This unique mix adds to the excitement of participating in the largest national conference focusing on autism spectrum disorders in the United States.

With a thriving arts district, a commitment to historical preservation and a sophisticated nightlife, Providence offers a variety of entertainment options. The Tony® award-winning Trinity Repertory Company draws throngs of theatergoers into the city. Children and adults will delight in the sights and spectacles at the Roger Williams Park Zoo and the Providence Children's Museum.

Providence is home to the world's largest culinary educator, Johnson & Wales University, and many students stay in the city after graduation. Providence has more degreed chefs per capita than any other city in the U.S. From authentic ethnic foods to seafood fresh from Narragansett Bay, the city offers a dazzling array of restaurants that will delight even the most discerning palate.

And shoppers beware! Connected to the Rhode Island Convention Center and the Westin Providence, Providence Place offers visitors a mall with more than 100 shopping, dining and entertainment options. Funky urban chic can be found at one of the many boutiques on Thayer and Wickenden streets, both on the city's east side. For those seeking one-of-a-kind items, RISD/Works is an innovative hybrid of retail store, gallery and design showroom featuring works from Rhode Island School of Design alumni and faculty.

### Keynote Sessions

ASA has confirmed Sally J. Rogers, Ph.D., (Program Director) Professor, Department of Psychiatry and Behavioral Sciences, UC Davis School of Medicine the UC Davis Mind Institute, as ASA's opening keynote

speaker. Martha Herbert, M.D., Ph.D. from the Pediatric Neurology Department at Massachusetts General Hospital will join ASA on Friday morning and V. Mark Durand, Ph.D. from the University of South Florida St. Petersburg will closeout what is shaping up to be one of, if not the finest, conferences ever.

More online at: [www.autismsociety.org/site/R?i=7VgoJB\\_tSSDHLsOxUQhK4A](http://www.autismsociety.org/site/R?i=7VgoJB_tSSDHLsOxUQhK4A)

Online registration and other information: [www.autismsociety.org/site/R?i=GVlaD9ZRM9FbVRSNo2bg3A](http://www.autismsociety.org/site/R?i=GVlaD9ZRM9FbVRSNo2bg3A).

ASA National Conference advance marketing and pre-registration is proudly supported in part by: [www.autismsociety.org/site/R?i=CRAIxHU9WA3mEo3bZFF5Aw](http://www.autismsociety.org/site/R?i=CRAIxHU9WA3mEo3bZFF5Aw)

### 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.

### Participants encouraged to complete survey

In February, I posted a survey I am developing with colleagues designed to increase parent-professional collaboration. I would like to thank each person who completed the survey and provided input regarding the clarity and importance of each item. At this time, I would like to encourage those who are interested to contact me to obtain a survey and/or to complete the survey you received.

Should you like to participate or have questions, please contact me at [laudet@kent.edu](mailto:laudet@kent.edu) or the phone number in my signature line.

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

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

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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**

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