

AUTISM

ASGC NEWSLETTER

FROM THE PRESIDENT'S DESK

What a night! The second annual Greater Cleveland Chili Cook-Off for Autism was a huge hit! With 26 chefs, live music and well over 500 attendees, we are overwhelmed with gratitude for everyone who helped make this our largest and most successful event ever! Congratulations to **Michael Longo** for successfully defending his "Best Professional Chili" Award. Congrats also to **Rudy Newman**, a teen with autism, who won over the Judges to take the "Best Amateur Chili" prize and the whole crowd as well by taking the coveted "People's Choice Award"! What a great way to cap off a wonderful night that brought in over \$27,000 for the ASGC.

Thanks first to my Co-Chair, ASGC President **Rory McLean**, for his keen leadership and tireless work on the

event and the employees of the Terrace Club at Jacobs Field for their fine hospitality.

The Chili Cook-Off Committee shone bright once again- From last year's Chairs **Joel and Jeanne Hill** to the rest of the gang: Participants coordinator **Sandy Bender**, Judges Coordinator **Brian Doyle**, Printing Coordinator **John Hearn**, Volunteer Coordinator **Nancy Heller, Laurene Sweet, Joe and Sarah Glass, Jim and Jill McIlwee, Shane Scott, Tom Bregar, Diane Sikorski, Bob Osterman, Greg Wolf** and **Barb Rutt**. Thanks also to the friends and spouses of the committee that showed up in big numbers to offer their support that night. I want to also thank my wife, **Janet Gallucci**, for putting up with me for the last eight weeks and for helping register hundreds of patrons on the big night.

Our deep appreciation goes out to all of the sponsors, benefactors, judges and participants, a full list of which can be found on page 2 and 3.

Finally, thanks to all of you who showed up by the hundreds to support the Autism Society of Greater Cleveland! We pledge to continue to raise our efforts to provide the vital assistance needed by you and the many other families of our area affected by autism. God Bless you all.

Sincerely,

Gus Gallucci
ASGC V.P.

Autism Society of
Greater Cleveland

MAY, 2007

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Chapter Meetings

All are welcome to the monthly ASGC meetings!

When: 1st Tuesday of each month

Time: 6:30pm

Where: Cuyahoga Valley Career Center, 8001 Brecksville Rd. in Brecksville.

Your children are welcome, thanks to STEPS Behavioral Consulting!

(Please RSVP the number of children attending)

Info or RSVP (216) 556-4937.

Autism Society of Greater Cleveland Officers:

Rory McLean
President

Gus Gallucci
Vice-President

Laurene Sweet
Secretary

ASGC Dues: \$5 per year.
Dues or donations may be made payable to & sent to:

ASGC
P.O. Box 41066
Brecksville, Ohio 44141

MANY THANKS TO OUR CHILI COOK-OFF SPONSORS!

Windstream Yellow Pages
 Key Bank
 Cleveland magazine
 Crystal traditions
 Cleveland Clinic Children's Hospital
 The Plain Dealer
 Prentke-Romich Company
 Cleveland Indians
 Alpha Business Advisors
 STEPS Behavioral Consulting

The ASGC
 commends these
 fine businesses and
 organizations for
 their extraordinary
 contributions to the
 Chili Cook-Off for
 Autism!

THANK YOU!

Graves Lumber

Cuyahoga County Special Education Service Center
 Gross Builders
 Hickman Lowder
 Carter Jones Lumber
 The Kohl Foundation
 PIRHL Developers
 Alside supply
 Atwell-Hicks
 Monarch Services
 Thermal tech
 World's Fare Culinary

Amazing Chef's, Celebrity Judges, and an Unforgettable Evening!

The Professional Chef Participants:

Michael Longo: ML The Restaurant
Don Pesta: Chili's Fire Pit
Jakub Mejstrik: Chef 77
Kris Krieger: Chef's Choice Meats
Anna Harouvis: Good to Go Café
Chad Fuller: Blue Canyon
Nolan Konkoski: Momocho
Dell Stevens: AVI- Cleveland Clinic
Ken Williams: AVI- Medical Mutual
Jim Cox: American Culinary
Ken Kostal: Big Boppers
Karen Lambros: Pzazz
The Scarvelli's: Good Eatz
Pete Dressen: Walden Country Inn
Linda and Randy: Westside Market Café
Matt Mathlage: Light Bistro

The Amateur Chef Participants:

Bill Polewchak
Bob Osterman
Chris Gallucci
Frankie Bruno-Brinkman
Luke Purcell
Matt Cole
Pete Gerome
Josh Contrera
Rudy Newman

The Judges:

Jonathan Bennett: Moxie/Red
Monica Arjev: Food Editor, Cleveland Magazine
Miguel Morales: Bravo Network's Top Chef
Michael Filia: Inn at Turner's Mill
Shawn Monday: Downtown 140 in Hudson
Rick Carson: Vue
Elaine Cicora: Scene Magazine
Eric Wells: SkyeLarae's Culinary Services
Ben Bebenroth: Spice of Life Catering
Nick Kustala: Lure
Brian Doyle: World's Culinary Fare



The 2007 Chili Cook-Off for Autism was a HUGE success, thanks to our fantastic chefs and judges!

The Community Supports the ASGC!

Cleveland Browns
Goodyear Tire and Rubber
IMG
Musca Properties
David Horvath, LPA
WDOK Radio
WXRK Radio
WEWS TV 5
WJW TV 8
WKYC TV 3
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Laube Imaging Products
Woo City Ice Cream
Heather's Heat and Flavor
Fire
Lucy's Sweet Surrender
House of Blues
Super Duper Publications
Beach Club Bistro
Flying Fig Restaurant
Lake County Captains
Society for Rehabilitation
Holiday Pizza
Little Tykes
Cuyahoga Valley Scenic Railroad
Lago Restaurant
Lure Bistro
Carrie Cerino's
Moxie, Jonathan Bennett
Blue Canyon
Lisa's Lil' Nail Shop
Studio 305 hair salon
Danny's Organic Market
Retail Therapy
World's Fare Culinary
May Kay
Malley's Chocolates
Heritage Farms



**THANK YOU TO ALL OF
THE DONORS AND
SUPPORTERS OF THE
2007 CHILI COOK-OFF
FOR AUTISM!**

Santos Pizza
Enzo's Salon
Mill Rd Grill
1100 Club
John Robert's Spa
Eddie's Creekside
Heinen's
Urban Herbs
Austin's Steak House
Penn Station Subs
Hard Rock Cafe
Trader Joes
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River Therapeutic Massage
Hope Educational Consulting
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Tony Miklos' Home Video Studio
CookingClothes.com
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The Rock and Roll Hall of Fame
and Museum
Cleveland Metroparks Golf
Pat Catan's
Western Reserve Bank
Rosie Durr
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Executive Caters
Mr. and Mrs. Anthony Weigand
Santo's Pizza and Pasta
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Frances Wesley
Kelly Burton
Ms. Lindsay Palma
Dr. and Mrs. Robert Schmidt
Mr. and Mrs. Corbin Schmitt
Mr. and Mrs. John Kubek
Mrs. Ann Gallucci
Dr. Philip C. Demio, M.D.
Golubski Deliberato Funeral home
Percision Heating
Florence Sarcyck
Frank Gallucci

**Thank you to all
who supported
the raffle and
silent auction!**

US Senate Appropriations Committee Holds Hearing on Autism Funding ASA Member, Staff and Parent Testifies

On April 17, autism took center stage on Capitol Hill as a new services bill was introduced to the House, and the Senate Appropriations subcommittee, chaired by Senator Harkin, held a hearing on federal coordination and funding for the Combating Autism Act.

Congressmen Mike Doyle, Christopher Smith, Eliot Engel, and Chip Pickering introduced at a press conference the Expanding the Promise for Individuals with Autism Act of 2007. ASA President and CEO Lee

Grossman, Jon Sheshtack (Autism Speaks), and Bradley Whitford were the featured speakers. Later in the day, ASA Director of Communications Marguerite Colston--who is also the mother of a 6-1/2 year old son with autism spectrum disorder-- participated as a panelist to testify in front of the U.S. Senate's Appropriations Committee's Subcommittee on Labor, Health and Human Services, Education and Related Agencies, about her experience as

the parent of a child with autism on service needs in the autism community, calling for federal funding and leadership. The testimonies can be viewed at <http://appropriations.senate.gov/hearings.cfm>.



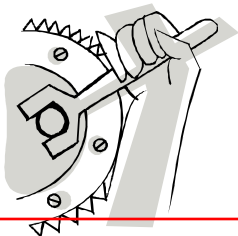
Institute on Rehabilitation Issues Publishes "Rehabilitation of Individuals with Autism Spectrum Disorders"

ASA Contributes Expertise on Vocational Rehabilitation Solutions

The 32nd Institute on Rehabilitation Issues has published its document

on "Rehabilitation of Individuals with Autism Spectrum Disorders." ASA President and CEO Lee Grossman, ASA Board Chair Cathy Pratt, Ph.D., ASA Board Member Stephen Shore, and Panel of Professional Advisors Members David Holmes, Ed.D. and Ruth Christ Sullivan--along with other experts in the field--were primary study group members on this project and wrote several chapters.

Statistical information generated



by the Rehabilitation Services Administration (RSA) for fiscal years (FY) 2003 to 2005 indicates that people with autism are severely underserved in terms of achieving employment outcomes by the state/federal vocational rehabilitation (VR) program. The primary study group was brought together create a document that would:

- * Outline the state of the science on autism spectrum disorders (ASD)
- * Understand the continuum of the disorders and strategies for increasing awareness
- * Enhance the implementation of informed choice throughout the VR process
- * Identify issues and conditions

for effective transition from school to work, training, or postsecondary education

- * Build effective partnerships between academic, training, health, housing, and other community-based social programs and agencies
- * Improve employers' understanding of ASD
- * Promote holistic VR: integrating family, community, and social supports to improve employment outcomes
- * Improve VR counselors' and employers' skills, competencies, and knowledge for increasing accessibility and employment opportunities
- * Describe evidence-based strategies for effective job development, placement, and retention

2007 ASA National Conference: Together a Brighter Tomorrow

2007 ASA National Conference: Together a Brighter Tomorrow, will be held in Scottsdale, AZ July 11 - 14 at the Westin Kierland Resort & Spa. Join thousands of professionals and families dedicated to autism at the nation's largest conference on autism spectrum disorders. Over 110 concurrent sessions and pre-conferences will be held.

NEW this year: The ASA has



Together a Brighter Tomorrow
PHOENIX, AZ ~ JULY, 11-14, 2007

partnered with UC Davis & the MIND institute to add a CME track at the conference

for medical professionals on Saturday, July 14!

Sign up now online at

www.autismohio.org

You can see the schedule of the presentations and speakers online. We have over 200 speakers for you to choose from. There is something for everyone! Many professional continuing education credits are available.

A simple keystroke could help a child with autism

As a parent with a child with autism, imagine your keyboard as a gateway to researchers searching for answers about autism. For the first time, you can share information online with researchers who in return, can share those results with you. You could be helping your child and many others with Autism Spectrum Disorders.

It's a bold new move, but one that can be easily achieved using the Internet. What we need is your commitment to sharing the most valuable of all assets... your own personal knowledge and experience.

Share today. And tell others about IAN so research can flourish, uncovering and unweaving the many mysteries surrounding this puzzling disorder. It's an exciting new way to become part of the solution.

Learn more in the IAN network at <http://www.ianresearch.org>

A Web Project of Kennedy Krieger Institute, sponsored by Autism Speaks, is looking for volunteers to participate in an online research study. To participate, parents of children with an Autism Spectrum Disorder will answer questions online about themselves, their affected child, and other family members. The study's purpose is to increase knowledge about Autism Spectrum Disorders (ASDs) and help find effective treatments. IAN will also match willing families affected by ASDs with other research studies locally or in the United States.

Who Can Participate?

The following people and their immediate family members can participate in this study:

Anyone who is living in the USA and who is less than 18 years of age, who has ever been told by a professional that they have any of the following Autism Spectrum Disorder (ASD)

Autism

Asperger Syndrome

Autistic Disorder

Pervasive Developmental Disorder

Pervasive Developmental Disorder-

Not Otherwise Specified (PDD-NOS)

Childhood Disintegrative Disorder

By "immediate family members" we mean biological or adoptive parents and full or half siblings.

Principal Investigator: Paul Law, M.D., M.P.H.

Contact: ResearchTeam@IANproject.org

JHM IRB#: NA_00002750

Research is a powerful tool for change!

Medigenesis Library Data Base

Imagine visiting a library where instead of books there are the anonymously shared experiences of children like yours. Where the children are similar to yours not only because of a diagnostic label, such as autism, PDD, asthma, or colitis - but with a likeness portrayed in a fully-remembered, detailed description that defines each child as an individual.

This description consists of signs, symptoms, environmental exposures, laboratory results and life events, as well as good, bad or neutral responses to various treatments. What if you could easily find those who are *most like* your child, not only in major or severe symptoms but with respect to minor or odd issues that may have puzzled you and your doctors? Would you not be interested in considering data that talks to you about what worked for children who closely match your own?

I invite you to join a free beta-trial

of such a 'library' and to help build a community of mutual support and information-sharing. This system was created for empowering people to make informed decisions about their own health. It has become a reality with the support of Dr. Bernard Rimland and Dr. Stephen M. Edelson whose surveys of parent feedback have been the model for a new way of listening to parents.

www.medigenesis.com collects your child's data and offers the immediate benefit of well-organized reports that you can share with professionals to efficiently present a full picture of your child. As our database grows you will also gain near-term feedback from clusters of children who match yours. In addition, you will reap the long term benefits of a system that uses information technology as a 'macroscope' to see otherwise invisibly large or hidden patterns.

To get access to the free, private beta, please visit [http://](http://www.autism.com/medigenesis/)

www.autism.com/medigenesis/ and enter your email address.

You will then be sent a special code (ticket) that you can use to get access to the site at medigenesis.com. The number of special codes available is strictly limited and available on a first come, first served basis until the end of May 2007.

www.medigenesis.com is very careful about your data privacy, and in any event does not collect data permitting identification of individuals. The privacy and security policy is available at <http://medigenesis.com/privacy.jsp>.

Sidney MacDonald Baker, MD
Co-founder and Emeritus Medical Director of Defeat Autism Now!



Local Father Featured New Book About Autism

Patrick Link of Bellefontaine is featured and shares insights on being a father of a child with an autism spectrum disorder in the new book, Autism Heartfelt Thoughts From Fathers.

Families Touched by Autism, a local support group,

will be donating a copy to the Logan County Library in honor of autism awareness month.



This book can be purchased at Amazon.com:

http://www.amazon.com/gp/offer-listing/1883175127/ref=dp_olp_2/103-7007635-0974269?ie=UTF8&qid=1177978453&sr=1-7

THOUGHTFUL RESPONSE TO AGITATION, ESCALATION AND MELTDOWNS IN INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

With nearly two hours of training, this DVD presents a way of understanding individuals with Autism Spectrum Disorders (ASD) that helps guide both proactive and, when necessary, reactive responses to escalating agitation. The premise of this presentation is that consequences don't always, or even often, work with individuals with ASD who are, by the nature of their diagnosis, easily frustrated and often inflexible.

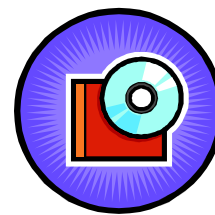
The presentation is divided into three sections:

Part 1: Understanding the inflexible-explosive individual

Part 2: Understanding the stages of crisis leading to meltdowns

Part 3: Reacting to agitation, escalation and outburst

In each of these sections, Rebecca Klaw emphasizes the need to understand the characteristics of the inflexible, explosive and autistic individual, and how these characteristics are determined and driven by neurological difference. Once you fully recognize this, Rebecca contends that it is possible to come up with a range of effective strategies, designed specifically for individuals with the characteristics



**NEW DVD
AVAILABLE!**

associated with ASD, for those difficult and sometimes explosive moments.

The cost of the DVD is \$65 plus \$5 shipping and handling.

For more information and to purchase, go to www.rebeccaklaw.com

Public Hearings on Proposed Special Education Rule Changes

The Office for Exceptional Children-OEC (State Dept of Special Education-Columbus) is proposing changes to our current State Operating Standards For Ohio's Schools Serving Children with Disabilities. The rumor mill is that the changes and the language is mirroring the Federal Changes in our Federal Regs of IDEA 2004. There is no rumor about the State maybe going "above and beyond" what the Federal law requires. Federal law guides our States on what they must do minimally, States are allowed and can offer more (above and beyond) what the Federal

Law (IDEA 2004) requires. This is why **PARENT INPUT** is so important at these meetings. So please review the following list, if any of these meetings are within your area and you are able to attend please do so. A copy of the proposed rules **are** on ODE's website at:

<http://www.ode.state.oh.us/GD/Templates/Pages/ODE/ODEDetail.aspx?page=3&TopicRelationID=840&ContentID=28143&Content=28357>

Please, try to attend on of the following meetings:

May 10, 2007
SESERRC, 507 Richland Avenue
Athens, Oh 45701
2:30 - 4:45pm or 6:30-8:45pm
(seats 40)
Director: Dave Roach 740-594-4235 91_droach@seovec.org

May 11, 2007
SWOSERRC
Southwestern Ohio SERRC
1301 Bonnel, 3rd Floor
Cincinnati, Oh 45215
12:30-2:45 or 4:00-6:30 pm
Director: Bill Bogdan 513-563-0045 x12 bill.bogdan@hcesc.org

For the latest updates on legislative action alerts, visit the Autism Society of Ohio at www.autismohio.org

SCHOOLS COLLABORATING WITH PARENTS = PARENTS COLLABORATING WITH SCHOOLS

After reading the January/February newsletter article titled "When Bad Things Happen at School", we felt compelled to respond in a manner which we hope will give both parents and school personnel ideas on how to work together to support children with ASD. We are both parents and professionals associated with the education of students with ASD. As a parent we bring many things to the table. We know our children inside and out. We know their strengths and their shortcomings. We know uncertainty triggers anxiety. We know that predictability keeps order. We want our children challenged but not frustrated. From the school, we expect understanding, assessments of our children's abilities and evidenced-based practices implemented in their specifically designed instruction.

As professionals, we continue with ongoing assessments. We continue to research and implement evidenced-based practices to support the ongoing communication, social and academic needs of students with ASD. When problems occur we look at their biological/sensory needs. We examine and re-examine reinforcements. We address environmental settings and adjust structure and visual supports accordingly. We adjust task demands as we continue to identify skills to teach and maintain. Evaluation of programs is ongoing and includes all members of the IEP team.

Open dialogue between members of the team promotes trust. Parents trust that the school provides the Least Restrictive Environment while adding supports when needed. Parents rely on the communication from school regarding progress and concerns. Schools trust that the parents communicate changes that occur outside of the school setting in order to help meet their students' needs.

We recognize that parents and schools are not always in agreement. However it can and does work when both sides share and identify solutions to concerns. Parents should remain advocates of their children. Parents are encouraged to ask questions about their child's program. Parents should keep good records about their child's program. Parents should observe the various school settings. Schools are also advocates for children. Schools should also ask questions about their students. Schools should institute best prac-



tices when designing programs for children with ASD.

When a situation gets to the point of the student in the letter, no one wins. It is conveyed that the family does not trust the school and that the school is affected by the family's fear and anger as well. As bad as this situation appeared to be that it could be worse elsewhere. This family and school both obviously care about the student but are not using that focus to work together. As a parent of a student with ASD many hours were spent observing and working with teachers to share ideas, teach one another and develop trust. We are surrounded by so many methods of instruction which are all advertised as the best and private professionals make recommendations of specific interventions that we don't totally understand as parents it is hard to know what to do. When your child with ASD comes home from school upset, call and ask questions and work with the teacher to figure out the situation. Any parent who is that fearful needs to spend more time observing, questioning and getting to know the educators working with their child to lessen that fear. These children are amazing to get to know and work with. Every opportunity you have to teach just one more person whether an educator, someone who sits by you at church or someone in line at the bank about ASD, do it. Cherish the opportunity to share the great gifts of your ASD child. It's not easy, it may take 10 times more effort at each step of the way, but the end result is incredible. Don't feel alone; make your child's teacher(s) your child's allies and teachers become allies to your students' parents. Take advantage of any and all consultants and supports to help. If both sides continue to work at collaboration the student comes out the winner.

Barbara Baley, M.A.
School Psychologist
Mother of Childs with ASD

Vicki Koller, M.Ed.
PEP Assist Consultant

Autism Society of Greater Cleveland

P. O. Box 41066
Brecksville, Ohio 44141

Phone: 216-556-4937

"The mission of ASGC is to serve the autism community by providing information, coordinating support services, and facilitating communication for the benefit of those with Autism Spectrum Disorder from diagnosis through adulthood."

The ASGC is a 501(c)3 non-profit, all volunteer organization.

Your donations are tax deductible and we welcome your support!

To learn more, call us or log on to:
www.asgc.org

The information in this newsletter is for educational purposes only. The Autism Society of Greater Cleveland does not endorse any specific product, method of therapy or organization. Our aim is to provide information that assists our membership in making educated decisions.

Thank you for your support!

Autism Conferences and Events in the Area

ECIS Summer Institute at Kent State University

<http://www.ehhs.kent.edu/ecis07>

2nd annual ECIS (Early Childhood Intervention) Summer Institute will be held June 25 to June 29, 2007. It is designed for anyone who is interested in and/or working with young children with disabilities (birth to five) and their families.

The online registration form includes brief descriptions of each session. <http://www.ehhs.kent.edu/ecis07>

Questions: Mary Shumar at mjshumar@kent.edu or Sandy Robbins at srobbin4@kent.edu.

The 5th Annual Milestones Organization Autism Conference Life-Long Strategies for Success: School, Home, Community & Work

Monday, June 18, 2007

8:45 a.m. - 5:00 p.m.

At [Executive Caterers at Landerhaven](#) in Mayfield Heights, Ohio.

The keynote speaker is [Gregory S. MacDuff](#), Ph.D., Director of Adult and Community-Living Programs at the Princeton Child Development Institute. Please, register online at www.milestones.org.

Questions: (216) 371-4765 or email at infomilestones@yahoo.com.

Week long teacher training available June 18-22 through Milestones.

Two-Day PECS (Picture Exchange Communication System) Training Workshop,

July 23-24 from 8:00-4:00 at the Holiday Inn Cleveland South in Independence. The presenter is Anthony Castrogiovanni, Ph.D.
Course Fee: \$425

For more information, please email at pyramid@pecs.com or call Toll Free 1-888-732-7462 or visit www.pecs.com