
ASCG Newsletter

From The President's Desk

Dear ASGC Members:

I know how difficult it is getting the children squared away for the start of another school year. As a parent, I worry about more things than I did as a child. It seems that we never can be sure what the new school year is going to hold for our children. Will they adapt to their new teacher? Are the children going to accept my son or daughter? Will they have any new friends? Is this school year going to be a happy memory for my child?

I watched an excerpt from an interview of a college professor of psychology who attended college where she taught. She did this as an experiment. Her colleges felt she would have no problems acing the quarter.

Time and Location for ASGC Meeting

The ASGC meets the first Wednesday of every month at 6:30 p.m. in room 8 of the St. Basil parish Center in Brecksville. Meetings will be held September 7 and October 5. Anyone who is affected by, has a loved one affected by or just wishes to learn more about autism is welcome to attend. Please call (216)556-4937 for more info.

She found it very difficult because every thing was new and disjointed. Everyone moves in different directions with no opportunities for developing friendships. Expectations of teachers, bosses, volunteer organizations, resident assistants, parents and room-mates are all different. This confusion lead to frustration, anxiety and depression. This professor was at a master's or doctorate level. She got thru the quarter with a "C".

I can't help but think if this is how people who aren't on the spectrum feel and act than our children that are not socially or emotionally mature yet must be angels. So, when your child is crying, kicking and screaming because he or she can't take his or her favorite video to watch in school, this might be one of those little bursts of aggression. Remember it too shall soon pass.

Our next meeting is Wednesday, September 7, at 6:30 p.m. at St. Basil on Brecksville Rd. in Brecksville. We have Stacey CianCilol of Monarch Services coming to speak with us about their program. We will have an open discussion following with opportunities to ask other parents how they deal with IEP issues. See you there!

Sincerely,
Rory McLean, President

Autism Society of Greater Cleveland

September Issue, 2005

Special Points of Interest

"Fittin' In"	2
Do Vaccines Cause Autism?	3
No. of Autism Cases Declines	4
Fragile WHAT?	6
Upcoming Conference	8

ASGC Officers

Rory Mclean
President

Gus Gallucci
Vice President

Maureen Ferfolia
Secretary

We can be reached at:
(216)556-4937

Fittin' In

Autism can feel like a fortress,
Protected from humanity.
Living in this place of seclusion,
I don't fit in with what I see.

Structure keeps my chaos in order.
Routines can organize my mind.
Knowledge holds the truth that I strive for
I cope with useful facts I find.

Chorus:

Talk to me with your heart
Even if my eyes look away.

You will know how to start
When you feel the right words to say.
Show the world from your view.
I get lost again and again.
Help me live like you do.
I'm fittin' in the best I can.
My world contains puzzles and patterns.
I'm mesmerized by what I see.
Social rules are too complicated.
Their meanings are a mystery.

Words are like a language I don't know.
Your facial cues are hard to read.
Feelings tend to hide from awareness.
I don't always know what I need.

Chorus

Why do I get everything wrong?
What can I do to belong?

Chorus

by Julie Herndon

Autism Association Asks for Voters' Support of Senate Bill; Wants Hearings

As you may know, State Senator Teresa Fedor is sponsoring a bill (SB49) that would significantly reduce the amounts of mercury in vaccines given to children and pregnant women. SB49 has been referred to the Senate Committee on Health, Human Resources and Aging, where it awaits a hearing. We are asking people to contact the chairman of the health committee to ask that he schedule hearings on SB49 as soon as possible. Please contact Senator Kevin Coughlin at:

Senator Kevin Coughlin
Senate Building
Room #137, First Floor
Columbus, Ohio 43215
Telephone: 614/466-4823
Email: kcoughli@mailr.sen.state.oh.us

Sample letter

Dear Senator Coughlin,

My name is _____ (name). I am contacting you to ask that you schedule hearings on SB49 as soon as possible. SB49 would significantly reduce the amounts of the mercury-based preservative, thimerosal, used in vaccines. Mercury is a known neurotoxin and should not be present in something we inject into young children and pregnant women. In order not to compromise immunization rates in our state, we must ensure safe vaccines for the most vulnerable in our community. On behalf of all the children and pregnant women in Ohio, I ask that you take action on SB49. Sincerely,

(name & contact info)

Please feel free to contact the Ohio chapter of the National Autism Association, should you have any questions or concerns at jtm@naa-ohio.org. **Website: www.naa-ohio.org**

“What if vaccines really do cause autism?”

by Julie Deardorff

I held my son and cried when he received his first vaccinations. But my tears weren't over his pain. Instead, I was thinking, “What if vaccines really do cause autism?”

Most parents fall into two camps when it comes to the complex issue of childhood immunizations. One group has no idea a controversy is raging over the mercury-based preservative thimerosal still found in some vaccines. They dutifully give their babies 21 jabs in the first 18 months of life.

Others have heard just enough to be terrified. We're moms and dads who know disease prevention must be a collective effort. We never want to see a child with polio or diphtheria.

Yet we also wonder whether thimerosal, containing about 50 percent ethyl mercury, is linked to autism, an unproven theory. We wonder why mercury, a neurotoxin, is still in vaccines, even though government agencies asked that it be removed several years ago.

But most of all, we wonder: How do I best protect my child?

Mercury exposure from childhood vaccinations more than doubled between 1988 and 1992 as more vaccines were introduced. But no one bothered to calculate cumulative exposure. When a government researcher finally did in 1999, he found it exceeded the federal limits.

During the same time period, there was a corresponding spike in reported cases of autism spectrum disorders, according to David Kirby, author of “Evidence of Harm” (St. Martin's Press, \$26.95), who cites a peer-reviewed study published in the journal *Pediatrics*.

Despite no conclusive evidence that thimerosal was harmful, the American Academy of Pediatrics and the Public Health Service in 1999 called for its removal.

Today, as a preventive measure, most - but not all - vaccines are thimerosal-free. Regardless, the government says our children will be safe.

In what was to be the final word on the contentious issue, the prestigious Institute of Medicine issued a report last May that found no connection between vaccines and autism.

But the finding only further enraged parents of autistic children. Moms Against Mercury and nearly a dozen other advocacy groups have planned a rally for anti-thimerosal legislation in Washington, D.C. Three states have banned it, and more than 30 others have pending legislation.

Illinois' sweeping Mercury-Free Vaccine Act, currently sitting on Gov. Rod Blagojevich's desk, would phase out vaccines with mercury by 2008. It's a logical start there's no reason to be injecting mercury into babies and toddlers. But what can parents of low-risk infants do in the meantime?

Ask for thimerosal-free vaccines. “Look at the package insert,” said Dr. Anju Usman, a family practice physician, who treats autism spectrum disorders using alternative methods. Her Naperville, Ill., practice is booked through August 2006.

Time it right. Don't vaccinate your child when he's sick or on antibiotics. “Don't use acetaminophen after a vaccination, because some studies suggest it inhibits a key detoxification pathway,” Usman said.

Consider delaying Hepatitis B vaccine. Your infant probably isn't an IV drug user or engaging in promiscuous sex. Hep B is given at birth for convenience.

Skip the flu vaccine. For the first time last year, the government recommended flu vaccine for children as young as 6 months. The pediatrics academy expects a shortage of the thimerosal-free flu vaccine for several years.

Pay attention. Watch your child closely after vaccination and call your doctor if you suspect a reaction. If your doctor isn't concerned and you are, go to the emergency room.

Get educated. Learn about the state vaccine requirements, your rights and legal exemption. You can find a copy of mandatory vaccination laws at the National Vaccine Information Center (www.nvic.org).

Forum on Planned Changes To Be Held by State Departments Ohio Home Care Consumers Invited

Forums will be held for Ohio Home Care Consumers to discuss planned changes to the Ohio Home Care Waiver and the Core Plus Benefit Package.

These forums will present important information about planned changes that may affect services and benefits. You will have a chance to hear about program changes, ask questions and give us your feedback.

All forum sites are wheelchair accessible.

Identical afternoon and early evening sessions will be held at each location beginning promptly at 2:00 p.m. and 5:00 p.m. Sessions are scheduled to be two hours long. Forums are provided by the Ohio Department of Job and Family Services, Bureau of Home and Community Services (BHCS).

Space at the forums is limited. Advance registration is required

You may register by sending an email message to: BHCS@odjfs.state.oh.us. Type "Consumer Forum Registration" in the subject line, and in the text of the email message, indicate your name, address, phone number, the number of people (including yourself) in your party, your county of residence, and your choice of session.

You may register by calling the Ohio Medicaid Consumer Hotline at (800) 324-8680. The Hotline is available to take calls Monday through Friday from 7:00 a.m. to 8:00 p.m., and Saturday and Sunday from 8:00 a.m. to 5:00 p.m.

Or, you may register by calling BHCS directly at (614) 466-6742 between the hours of 8:00 a.m. and 5:00 p.m. Monday through Friday.

You will be notified ONLY if we are unable to give you your choice of session, or if the forum sites you selected are already full.

AKRON/CANTON/CLEVELAND AREA (Registration Deadline: Friday, 9/2/05)

Wednesday, 9/7/05:	2:00 pm to 4:00 pm
Wednesday, 9/7/05:	5:00 pm to 7:00 pm
Thursday, 9/8/05:	2:00 pm to 4:00 pm
Thursday, 9/8/05:	5:00 pm to 7:00 pm

**Akron Area Agency on Aging
1550 Corporate Woods Parkway, #100
Uniontown, Ohio 44685-7840**

(No food or beverages are permitted in any of the rooms where the forums will be held. We apologize for any inconvenience this causes.)

Canadian School Trains Service Dogs To Work with Autistic Children

Since 1996, National Service Dogs has been training Labrador and Golden Retrievers to assist children and families living with autism. We are proud to be the first school in Canada to provide such dogs to families with children who are autistic.

Criteria For Families

- * A CHILD with Autism between the ages of 2 and 10 at the time of application
- * POSITIVELY exposed and socialized the child to large dogs in the past
- * NO other family dog in the house at the time of Team Training
- * TIME to devote to the learning curve of adding a Service Dog to their lives
- * A WILLINGNESS to have one or both parents travel without the child to our facility for an one day seminar, and for 5 days during Team Training when you receive the dog
- * A FENCED yard or plan to contain the dog when in the yard
- * ONE dedicated parent that stays home during the weekdays if the child is not yet in school. This project will be more successful if the dog bonds with the child and one parent, not a selection of different caregivers

For complete website: <http://www.nsd.on.ca/autism.htm>

New Autism Cases May be Dropping in California

by Thomas H. Maugh II

The number of newly diagnosed cases of autism in California, which had been skyrocketing for more than a decade, has leveled off and may even be declining, according to new data compiled by the state Department of Developmental Services.

Although the total number of autistic children receiving special education services from the state continues to grow — bringing the current total to 28,046 — the rate of increase peaked in 2002 and has dropped slightly since then.

The findings are important because California has the best reporting system for autism in the United States and is generally considered a bellwether for the rest of the country.

Experts do not have a good explanation for the slowdown in new cases.

“Perhaps whatever caused [the number of cases] to go up — environmental insult, or whatever — is no longer present,” said Dr. Robert Hendren, executive director of the UC Davis MIND Institute, which researches neurodevelopmental disorders. “It’s all speculation. I wish we had good studies.”

Parent activist Rick Rollens of Sacramento, who played a key role in the creation of the MIND Institute, said that the trend roughly corresponds to the removal of mercury preservatives from pediatric vaccines. Many activist groups say that the use of mercury in the vaccines caused the sudden increase in autism cases. Federal scientists, however, have continually said that the evidence does not support such a link.

The state data do not include children under the age of 3. According to the department, about 90% of all autistic children are entered into the system before the age of 6.

That means, Rollens said, that children born since 1999, about the time that mercury was phased out of vaccines, are just now entering the system. The slowdown could thus reflect the change in vaccination practices.

“We can argue till the cows come home about what

caused the increase,” Rollens said, “but the bottom line is that the increase is slowing.”

California guarantees access to special education for all children diagnosed with autism and other developmental problems. Thus, the state’s data are considered particularly reliable.

According to the state data, 2002 was a record year for new autism diagnoses, with 3,259 cases. In 2003, the number of new cases slipped to 3,125. In 2004, the number was 3,074.

For the first half of 2005, there were 1,470 new cases, compared to 1,518 in the same period in 2004.

“The interesting thing is that, before 2002, every quarterly report had shown an increase over the previous year,” Rollens said. “Now, that is no longer the case.”

CDC Holds Secret Autism Conference

This article was originally printed on July 19.

The Centers for Disease Control and Prevention (CDC) is holding a secret press conference in Washington, D.C. today on autism and thiomerosal in childhood vaccines. Curiously, the invitation-only meeting is taking place the day before an autism rally in the Capital which will focus on connections between thiomerosal in vaccines and autism. Not one of the 13 organizations involved in the rally was notified of the CDC press conference

The meeting is open only to a select, handpicked group of reporters. Despite repeated demands for open communication with the autism community, the CDC did not invite any of the national autism groups to speak, nor did they share any copies of what will be presented with these groups. The Director of the CDC, Dr. Julie Gerberding, is the lead speaker.

Many representatives from different autism organizations plan to be at HHS during the conference today as a showing of solid force and to communicate that the government cannot continue to conduct these studies or hold such press conferences and expect the community to not be involved. The 13 organizations that were not invited or notified about the CDC press conference include Moms Against Mercury, the National Autism Association, Safeminds, CoMed, A-Champ, Dads Against Mercury, Generation Rescue, NoMercury, NVIC, Unlocking Autism, and Educate Before You Vaccinate.

Fragile WHAT?

by Mary Beth Langan and Sally Nantais

Although Fragile X Syndrome is the most common known cause of inherited cognitive impairment, the up-to-date name for mental retardation, the average person has not heard of Fragile X Syndrome. The average health professional has very little knowledge, or dated knowledge, of Fragile X Syndrome. Until our children were diagnosed, we were average people asking, "Fragile what?"

Cognitive impairment related to Fragile X Syndrome affects probably one in 4,000. However, because more milder learning difficulties are probably much more common, it is estimated that one in 2,000 are affected.

Approximately 1 in 250 women and 1 in 800 men are carriers of Fragile X Syndrome.

It's critical to remember these numbers are only estimates because it is also estimated that 80-90% of people with FXS are not yet correctly diagnosed.

Fragile X Syndrome is a genetic condition caused by a mutation of the FMR1 gene on the X chromosome. The mutation can differ from person to person, typically a boy with a full-mutation's genetic material does not produce FMR1 protein, or not enough of it. Through research, it has been determined that the FMR1 protein is critical for typical brain development. Boys only have one X chromosome, therefore they are typically more affected than girls. Girls have an advantage because they have two X chromosomes; an unaffected chromosome may produce enough FMR1 limiting the affect.

What does this really mean?

Unless a parent already knew they were a carrier of Fragile X Syndrome (FXS), they wouldn't know their child might have FXS until they began to see developmental delays. There are minor physical traits noted in many persons with FXS, but not in all. These are traits which may also be present within the typical population, nothing unique which would necessarily indicate FXS testing is necessary for your child.

Fragile X Syndrome may cause:

Mild learning problems to severe cognitive impairment

Behavior issues such as ADHD and ADD

Autistic-like features such as poor social skills, poor eye contact, hand-biting and hand-flapping

Shyness and social anxiety

The majority of persons with FXS have autistic-like features (estimated at 50-90%); a smaller percentage (approximately 30%) have a true dual diagnosis of autism.

Within the first few years in the life of a child with undiagnosed FXS, two of the most common things parents often notice are language delays and sensory issues. Even after a diagnosis of FXS, many parents believe working on these issues are the most important methods to help their child be the best they can be.

In recent years, research has also discovered that Fragile X Syndrome (FXS) not only affects children with a full mutation, but also male and female carriers of FXS.

Fragile X-associated Tremor/Ataxia Syndrome (FXTAS), discovered in 2003, is a neurological disorder that can involve tremors, balance irregularities, difficulty walking and dementia which sadly is often misdiagnosed as Parkinson's and/or Alzheimer's. This condition is present in some older FXS carriers (typically after the age of fifty), usually in males but FXTAS can also affect female carriers.

Premature Ovarian Failure, more commonly known as early menopause, is a condition that affects 20-28% of the female FXS carrier population.

"Spotlight Autism" Available on the Web

New York Families for Autistic Children are proud to announce that their Television series "Spotlight Autism" has come to the the web! You can view the first two installments of this series - episode "Siblings" or episode "Behavior Analysis" - by visiting the site <http://www.nyfac.org/spotlightau.html>. Each show is about 30 minutes in length.

10 Things You Should Know About Fragile X Syndrome

1. It's genetic.
2. 1 in 250 women is a carrier. If a woman is a carrier, each time she has a child, she has a 50% chance that the child will be affected by Fragile X (they may be a carrier or have Fragile X Syndrome).
3. 1 in 800 men is a carrier. If a man is a carrier, his sons will not be affected by Fragile X Syndrome, but all of his daughters will be carriers.
4. Fragile X Syndrome does not discriminate; it is present in all ethnic and socioeconomic groups.
5. Fragile X Syndrome is a spectrum disorder. Symptoms may vary from mild learning disabilities (including shyness and social anxiety) to severe cognitive impairment (mental retardation). Symptoms can include autistic-like tendencies or a dual diagnosis of autism.
6. Premature Ovarian Failure, more commonly known as early menopause, is a condition that affects 20-28% of the female FXS carrier population.
7. Fragile X-associated Tremor/Ataxia Syndrome (FXTAS), discovered in 2003, is a neurological disorder that can involve tremors, balance irregularities, difficulty walking and dementia which sadly is often misdiagnosed as Parkinson's and/or Alzheimer's. This condition is present in some older FXS carriers (typically after the age of fifty), usually in males but FXTAS can also affect female carriers.
8. There are minor physical traits noted in many persons with Fragile X Syndrome, but not in all. These are traits which may also be present within the typical population, nothing unique which would necessarily indicate FXS testing is necessary for your child.
9. When testing for Fragile X Syndrome (FXS), it is critical that the correct blood test is ordered - the Fragile X DNA (Southern Blot) test. Inaccurate results occur far too often with the generic chromosomal panel. Test for FXS to obtain a diagnosis or to rule it out. If you don't have what may be the correct diagnosis of FXS, then you will never be aware of improved treatments or the cure when it's found.
10. Where to go for the most accurate and up-to-date information on fragile X syndrome: www.fragileX.org, the National Fragile X Foundation and www.fraxa.org, Fraxa Research Foundation.

ASA Members Offered Savings on Child Monitoring Device

The Autism Society of America (ASA) and Bluespan®, Inc., an emerging company in the research and production of wireless applications for consumer purposes, established a partnership to provide the company's state-of-the-art monitoring equipment to ASA's membership at a significant discount. The device is being offered to members for \$165.

The company's first product, ionKids®, is an easy-to-use system designed to assist parents and guardians in keeping tabs on children and other dependents. ionKids' short-range monitoring equipment consists of a wristband, or Wristag™, worn by the child or dependent (a tamper- and water-resistant bracelet that requires no interaction on the part of the child and contains a strong locking mechanism that can not be easily opened without a key), and a handheld device, or base unit (a small, device used by the parent or guardian to monitor the location of the Wristag wearer, which also allows parents to monitor up to four Wristags simultaneously).

Go to the shopping cart section of ASA's Web site, www.autism-society.org, and order now!

Columbus Conference Highlights Housing Options for People with Disabilities

Keys to Housing Options will be held in Columbus on October 19 and 20. The conference will provide information, resources, and supports for people with disabilities, their families and communities sponsored by the Ohio Developmental Disabilities Council and co-sponsor the Ohio Department of Job & Family Services, the Governor's Council on People with Disabilities, and the Ohio Olmstead Task Force.

Conference highlights include: nationally recognized keynote speakers; 12-15 diverse workshops about housing for people with disabilities and their families; and displays.

The \$100 registration fee includes meals. A limited number of waivers and scholarships will be available for people with disabilities and family members. CEUs pending for MRDD and Social Work...For more information or registration materials, contact: AXIS Center for Public Awareness at (800) 231-2947.

Autism Society of Greater Cleveland

P.O. Box 41409
Brecksville, OH 44141
Phone: (216)556-4937
Email: support@asgc.org

From Diagnosis through Adulthood

The ASGC is a volunteer organization

Find us on the
Web!
www.asgc.org

Upcoming Autism Conference

Autism Society of Ohio
Bi-Annual State Conference

**“Reaching beyond the horizon...Challenging the
Autism Spectrum”**

October 14-15, 2005
Marriott Kingsgate
Conference Hotel
University of Cincinnati
Cincinnati, Ohio

Keynote Speakers:
Dr. Vince Carbone
&
Dr. Teresa Grossi

www.autismohio.org
