



ASBC Express

Serving Boulder & Broomfield Counties

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Special points of interest:

- Conference Corner - Educators Workshop
- Attending Conference Free! Volunteers Needed
- Swedish Study links Autism and Mirror Neurons
- Dems Call for Education Commissioner's Resignation
- ASBC Begins "Ask the Advocate" Series

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Senator Salazar Co-Sponsors Combating Autism Act

On June 12th ASBC was notified by Senator Salazar's office of his co-sponsorship of the Combating Autism Act of 2005. ASBC wishes to thank the parents and professionals who contacted their legislators to ask them to co-sponsor this ground breaking legislation, as well as those signing onto our consensus statement that will be forwarded to Senator Allard in early July. ASBC will continue to seek consent from the community through the summer and forward a final copy of the statement to Colorado's U.S. Representatives before the legislation is heard in the U.S. House of Representatives.

Special thanks to Senator Ken Gordon who contacted Senator

Salazar with his personal request for the Senator's support. Senator Gordon has long been an advocate for the autism community and as recently as May of this year co-sponsored the joint resolution that was passed and requested Colorado's Congressional delegation's support of the Combating Autism Act of 2005. **THANK YOU SENATOR GORDON!**

Background: Currently autism research receives less than 5% of funding of many less prevalent childhood diseases and occurs in 1 out of 166 individuals. It is the fastest-growing developmental disability facing our nation. Senator Salazar, Representatives DeGette, Beauprez and Udall

are co-sponsoring the bill. We need the support of Senator Allard and Representatives Salazar, Tancredo, Musgrave, and Hefley. We are calling upon each and every Coloradoan that loves someone affected by autism, or is concerned about the rising rate of incidence and lack of response from the federal government to sign onto the consensus document that will be forwarded with the a copy of the Colorado resolution to members of our Congressional delegation not currently sponsoring this legislation. **Contact asbc@mho.com, to sign on to the consensus document.**

Manhattan Middle School Donates \$3,600 to ASBC: Raises Awareness

Manhattan Middle School in Boulder kicked off their annual penny pot drive in May with ASBC as this year's beneficiary. With the assistance of parent Stephanie Lynch, ASBC conducted a student body autism awareness demonstration to inform them about the impact Autism has on our society. Autism is more common than childhood cancer, cystic fibrosis, and multiple sclerosis combined and affects 1 in 166 children today.

The drive ended one week later and the student council awarded Autism Society of Boulder County a check in the amount of \$3,600 in front of the entire school body. Boulder Valley Credit Union assisted the stu-

dent council in tallying the funds. ASBC's President and co-founder, Theresa Wrangham, was on hand to accept the check and praise the efforts of the student council and school administration for their fundraising efforts and the opportunity to raise awareness within the student body. ASBC also awarded the school a certificate of appreciation for their efforts and donation.

"In wanting to better understanding a fellow classmate with autism the student council identified ASBC as their beneficiary for the penny pot this year. What is even more important than the funds raised, was the awareness session conducted with the council to act

as ambassadors of autism in spreading information about autism during the drive." said Theresa Wrangham. "Manhattan exemplifies what true diversity in a student body is about. They walk their talk and are informing their students about the diversity that exists in the special needs population to enable students to reach out to this population in the spirit of true inclusion."



REGISTER NOW AND SAVE\$\$\$\$\$

"Pathways to the Future" Sept 9, 2006

Ask the Advocate... by Desiree Vandelac

When parents first begin to deal with the complex process that comprises special education services it is more than overwhelming. Most parents simply do not know where to begin or how to proceed. As such, while this may be remedial for many of you, I would like to start this new column at the beginning.

Special Education is governed by a federal law called IDEA (the Individuals with Disabilities Education Act). Under IDEA parents and children are provided a great deal of rights as well as protection and safeguards. One of the greatest of those rights also holds a great deal of responsibility. It is the recognition that *you* are the expert on *your* child. As such you have an equal position and an equal voice on the IEP team. To be effective in this very important position there are basic steps you need to take.

First, I encourage parents to take an active role in the IEP process and in advocating for their children. Learn the system, how to write letters, and deal with differences with the members of their IEP team.

Be professional and courteous to IEP team members and other personnel. Treat team members with respect even when disagreeing with them. Always treat people as you wish to be treated. You can disagree with someone and still allow them their dignity.

As I stated above, *YOU* are an equal member of the IEP team! *You* are the recognized expert on *your* child! Your opinion counts!

Speak up! Do not allow yourself to be intimidated or railroaded. **Keep a Communication/phone log.** Keeping a communication log is very simple. I recommend purchasing a basic composition book (you can find these for around a dollar at any store carrying school supplies). Any time you have any verbal communication with anyone from the school, your child's IEP team, or even your own treatment professionals document the date and time of the communication, what was said and by whom. If this conversation happens face-to-face document the circumstances as well. While this may seem "over the top" it is a very handy tool to have when you are trying to recall specific conversations and it can come in very handy as evidence if you need it. Keep your composition book handy (near the phone is a good place for it). One last note on your communication log: do not tear any pages out of it for any reason. You want your logbook complete and intact.

An example of communication logbook entries would be:

January 1, 2001 9:30 a.m. -- I received a telephone message from Mrs. Jones, IEP care Coordinator at ABC Elementary School. Mrs. Jones said that the IEP meeting scheduled for January 5, 2001 at 3:00 p.m. is being re-scheduled for January 10, 2001 at 9:00 a.m.

January 2, 2001 10:05 a.m. -- I returned Mrs. Jones telephone call. I left a message on her voice mail stating that I am not available on January 10, 2001 at 9:00 a.m. but I am available that date after 3:00 p.m.

Set up a file for your child. If you have more than one child be sure to set up a file for each child individually. I recommend purchasing file folders with the prongs at the top. In my experience these work better than three ring binders and you don't run into the problem of punching holes in the text of the document if some-

thing has narrow margins. Wrightslaw provides very good information with regards to setting up your files. Keep copies of everything (letters, memos, IEPs, testing reports, report cards, etc).

Organize your documents in chronological order with the newest documents on top. Write the date of the document lightly in pencil in the bottom right hand corner. Do not write on your documents other than the date in pencil. You want to have a "pristine" copy for your files. I have found it helpful to have a folder for school and a separate folder for medical reports. Many parents make the mistake of having too many folders (one for letters, one for IEP meeting, etc.). This often becomes confusing to navigate when they are trying to find specific documents. The simpler you keep your files, the greater chance you have of being able to retrieve a document when you need it.

Know what you want. What are your goals and desired outcome for your child? This sounds very basic but it really is important. Look short term: Does your child need self-help skills (dressing himself, toileting independently)? Does he need social skills? What about Occupational Therapy? Does your child need to improve his reading? As well as long term: What is my overall goal for my child in life? Independent Living? College? A semi-independent group living situation? When our children are in Elementary school it is very easy to get caught up in short term services (looking only at the current school year). It is important to remember that our children are receiving short-term services in an attempt to improve their long-term lives.

LEARN! LEARN! LEARN! Learn about your child's disability. Learn how the special education system works and the steps to take when it breaks down. Go to conferences, join support groups, read books—lots and lots of books! The more you know the more you can help your child.

A few of my favorite books are: *From Emotions to Advocacy: The Special Education Survival Guide* By Pam and Pete Wright of Wrightslaw *No Child Left Behind* By Pam and Pete Wright *I Need Help With School!* By Rebecca A. Moyes *How Well Does Your IEP Measure UP?* By Diane Twachtman-Cullen and Jennifer Twachtman-Reilly *The Complete IEP Guide* By Lawrence M. Siegel *How to Compromise With Your School District Without Compromising Your Child* By Gary Mayerson

While this list is just the "tip of the iceberg" it is a good place to begin. I have to share with you my absolutely favorite website: www.wrightslaw.com.

Next Month: Basic IEP meeting and Advocacy Strategies. If you have Advocacy questions you would like answered please email "Ask the Advocate" at advocate@autismboulder.org

Desiree Vandelac, Special Education Advocate and Legal Assistant, for the Law Offices of Louise Bouzari, a law firm specializing in serving the families of children with special needs. In addition to being a Special Education Advocate, I am the mother of two wonderful boys. My oldest son, who will be turning 10 years old this summer, has Asperger's Syndrome.

Infant Study Links Autism & Mirror Neurons

A group of Swedish scientists from Uppsala University did a study with infants at 6 months of age, 12 months of age and adults. For example, they had each group watch video of an actor placing objects in a bucket. At 12 months and adulthood the groups could anticipate the placement of the objects in the bucket, but the 6 month old group could not.

This is shown through activity of the mirror neurons in the brain that aide people in understanding the intentions of others. "We think that this indicates that infants are endowed with a neural system that facilitates the acquisition of social understanding (the mirror neuron system)," said Prof Hofsten. "This has indeed important implications for the understanding of autism.

A recent study at The University of California in Los Angeles has shown that those with autism has almost no activity in the section of the brain which possess the mirror neurons. [Dr. Mirella Dapretto](#) believes this deficit is what disables autistics socially.

To read the Daily Telegraph UK article about the Swedish study go [here](#).

Special Education Ruling: Virginia Family Wins Legal Decision For Private Schooling

A family from Virginia has been fighting their county school system on behalf of their autistic son. At stake are not only the educational rights of this one child, but the future of special needs children throughout the country. The decision could lead to the payment of some \$500,000 in tuition, legal costs and interest to the family whose Federal educational needs weren't met. Go to The Richmond Times Dispatch [article](#) to learn more about the most recent ruling.

PARENT CORNER: Acupuncture & Autism

When our son Kanta, age, 6, was diagnosed with Autism, we began a gluten-free and casein-free diet. We noticed that the diet helped him achieve better eye contact and bouts of hyperactivity became less frequent. Prior to the diet, he would have a severe cough at night and that was gone. We noticed his symptoms returned if he ate foods containing gluten and/or casein

At the ASBC conference, I was fascinated by Dr. Billica's talk, especially the correlation of glutamate/GABA balance, inflammation, immune reaction, etc. But I have been wondering if there was any other way than using medication to regulate the balance. I have researched several alternatives, and ended up with Traditional Chinese Medicine (TCM). I had known several people that explored

this method to be cured of food allergies, psychiatric disorders and migraines.

One thing I found in my research is that results directly depend on the ability of an acupuncturist. I searched online and called some acupuncturists. When I saw Pao-Chin Huang's website, I felt something. When I called him, I could talk directly with him. He even told me to take Kanta to his clinic any time rather than making an appointment.

Kanta liked Pao-Chin very much. He started massaging Kanta's body and a tried a couple of acupuncture points. His wife prescribed a completely individualized mixture of Chinese herbs. Pao-Chin also taught me some exercises to improve his performance. Pao-Chin gave Kanta pieces of

chocolate when we left his clinic. I was worried the symptoms would show. That night he was just fine. So we gradually increase the amount of regular foods and confirmed his problem with gluten or casein was gone.

I do not know if Kanta's improvement in arm strength and interaction with other kids were coincidence. I cannot say Kanta's autism will be cured, but Pao-Chin helped him a lot. He has treated several children and adults with various disabilities. I believe it is worth trying his TCM. You can find him online at (www.ruseto.us).

Ken Emoto is a Polymer scientist working in the field of biotech with experience in drug delivery systems (not drug synthesis). Moved to Broomfield 2 years ago just after

INFLUENZA VACCINES

WHAT YOU SHOULD KNOW



ASK YOUR PHYSICIAN FOR VACCINES THAT MEET FEDERAL SAFETY GUIDELINES

Download your free brochure at autismboulder.org



Calling All Parents & Professionals

Please share your expertise. Submit informative articles of 500 words or less for our newsletter. Topics can include anything related to Autism treatment or research, therapy, family fun or anything that could benefit our members.

Submit your article to newsletter@autismboulder.org for consideration.

New Studies Searching for Subjects

Dr. Ann Reynolds, MD, at The Children's Hospital in Denver is beginning a new research study to evaluate intestinal permeability and gastrointestinal symptoms in children.

Commonly known as "**Leaky Gut**" **Syndrome**, the study will include Autistic and typically developing children from 2 to 18 years old. For children with **autism**, study participation involves: Developmental assessments, Questionnaires

7-day stool diary, drinking sugars and collecting urine for 6 hours, and Blood collection. For children with **typical** development, study participation involves: Questionnaires and drinking sugars and collecting urine for 6 hours. Compensation will be provided. If you would like more information on how to join the study, please call: Kristina Kaparich at 303-315-0066

A Caregiver Study: You are invited to participate in a research study looking at the short-and long-term effects of receiving a diagnosis of an autism spectrum disorder (ASD) in one's child. With your help, we can learn more about the process families go through to get a diagnosis of an Autism Spectrum Disorder. If you choose to participate, you will complete a survey packet now and again one year from now. The packet should take approximately 40 minutes to complete. You will receive a \$10 Wal-Mart gift card after completing each survey packet. All personal information will be kept confidential. You are eligible to participate if:

- Your child has been formally diagnosed with an Autism Spectrum Disorder (autism, Asperger's disorder, Pervasive Developmental

Disorder, Not Otherwise Specified [PDD-NOS]) by a licensed clinical psychologist or medical doctor

- This is your first child to be diagnosed with an ASD
- Your child was diagnosed less than 6 months ago

You can complete the survey packet online at: <http://mypage.iu.edu/~mlstuart>
Or request a paper copy from Melissa Maynard at (317) 274-1091, mlstuart@iupui.edu



July Events

July 15 10am. Family Fun Day. Six Flags/ Elitch Gardens. From I-25, go south on Speer Boulevard (Exit Speer South, 212A) then turn right onto Elitch Circle. We need a group of 10 people for a discounted group rate of \$21.00 (Gate fee is \$44.99). RSVP with check to Brenda Tuttle 1445 Wakerobin Ct., Fort Collins, CO 80526 by **June 27th**.

RDI: Going to the Heart of Autism 2-Day Workshop - Dr. Steve Gutstein dramatically illustrates the Relationship Development Intervention Program (RDI) via audience participation & hours of video taken from actual intervention sessions.

Jul 28 - Jul 29 Denver 9am-4pm; \$275 by Jul 14 TBA - Kristin Adiska
www.rdiconnect.com
adiska@rdiconnect.com 866-378-6405 x 119

Democrats Call for Resignation of Education Commissioner

Democrats who lead the House and Senate education committees called for the resignation of Education Commissioner William Moloney in early June. Rep. Michael Merrifield, D-Manitou Springs, and Sen. Sue Windels, D-Arvada, were leading the charge against Moloney based on his lack of leadership and ability to institute change.

Republicans on the state Board of Education continue to support Moloney. This leaves the Board of Education Panel in a deadlock vote 4-4, the panel of 8 is equally divided among Democrats and Republicans.

While Democrats are urging Moloney to step down now so a new commissioner can be appointed, the board fears it will need to wait for elections on November 7th before any action can be taken,

There is concern that after the elections, the board will add more Republicans and could appoint a partisan replacement.

To support this initiative contact Progress Now at www.progressnow.org. They are taking petition signatures at <http://MoloneyResign.com>.

Memorable Quote...

“How is it that mercury is not safe for food additives and over the counter drug products, but it is safe in our vaccines and dental amalgams?”

U.S. Congressman Dan Burton

Coping With Autism: Going to War Against “Fake Therapy”

A recent article by Linda Seebach of the Rocky Mountain News stating that parents of autistic children need to hear that autistics can't be cured, that they must “cope”, declaring them “desperate” enough to try a “fake therapy” like chelation and calling doctors and researchers “quacks” for investigating mercury’s role in autism require close examination and setting the record straight.

One has only to watch the video “Autism Every Day” to understand that many of our children are more than just “different” and parents’ ability to “cope” is stretched unbelievably. Colorado’s legislature passed a resolution requesting Colorado’s Congressional delegation to support the Combating Autism Act of 2005. This legislation doubles NIH spending on autism research and creates a nation wide screening program for the early identification of children with autism. Limits on a cure or treatments remain unknown and research continues.

With regard to mercury, most Americans don't realize that in 1999 and 2000 the American Academy of Pediatrics (AAP) and U.S. Public Health Service (PHS), issued a joint statement advising removal of mercury, a known neurotoxin. In 2001 the Institutes of Medicine (IOM) and 2003 Mercury in Medicine reports found the mercury/autism link **plausible** and recommended additional epidemiological, clinical and biological study. While the IOM 2004 report fell short of these recommendations, since the 1999 recommendation independent biomedical research continues to mount and documents mercury’s dangers. 2006 developments include the Centers for Disease Control announcing a new probe on mercury and autism while

Congressional leaders have requested the National Institutes of Environmental Health Sciences study mercury in vaccines and autism. Bottom line – investigation of this neurotoxin continues and questions remain. Is there a link in the rise of neurodevelopmental disorders and mercury in vaccines? Why continue to use mercury when investigation continues and mercury free/trace amount vaccines are available?

Regarding chelation, it is not a fake therapy. Chelation is an approved therapy for heavy metal poisoning - mercury is a heavy metal. Its use in the treatment of autism is new and was recommended for study by the 2001 IOM and 2003 Congressional reports due to toxic levels of mercury exposure via vaccines. Chelation, like any medical procedure, has risks and it is important to consult an experienced physician like Dr. Roger Billica of Fort Collins, who specializes in functional, nutritional and environmental medicine and is a former Chief of Medical Operations for NASA charged with all health and medical aspects of space flight and astronaut health care. Do these credentials reek of quackery? If so, it is hard to see the average doctor escaping such a label. Impressive too are the credentials of the researchers conducting independent biomedical research on mercury; they hail from places like University of California – Davis’ MIND Institute, Tulane University Medical Center, Utah State University Biotechnology Center and University of Michigan Department of Pharmacology.

While unbalanced media coverage of mercury continues, perhaps poor coverage may be expected. The Columbia Journalism Review (11/05) in reviewing the

issue and interviewing journalists reported, “Some reporters who have portrayed this as an ongoing scientific controversy have been discouraged by colleagues and their superiors....covering the thimerosal controversy had been nearly career-ending...For some reason giving any sort of credence to the side that says there’s a legitimate question here I don’t know how it becomes this untouchable story, I mean that’s what we do, so I don’t understand why this story is more touchy than any story I’ve ever done.” Journalists like Dan Olstead of UPI, Mryon Levin of the LA Times, David Kirby, author of “Evidence of Harm” and NBC’s Dateline are to be applauded for covering the issue.

In the past, parents of autistic children have successfully questioned and pushed science to disprove “medical theories” such as mothers/bad parenting causes autism; autism is a mental health issue and autism is not regressive. The autism community will continue to push science to perform the studies necessary to answer what are legitimate questions.

Parents of autistic children are not “desperate” and have proven they are resourceful, loving, and tenacious and continue to fund and advocate for research towards a cure and treatments.

Theresa K. Wrantham
President & Co-Founder,
Autism Society of Boulder
County
Parent of an autistic child



“What it boils down to is that parenting a child with autism is a difficult job; writing about it is far easier.”

**Elizabeth Moon,
Author and Parent of an Autistic Child**

