

Helping People and Families Affected by Autism

Detachable Monthly Calendar

November 2008

Autism Delaware		(302) 224-6020			www.delautism.org	
Sunday	Monday	Tuesday V	Vednesday	Гhursday	Friday	Saturday
						1
2	3	4	5 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	6	7	8 N.C.C. Roller Skating Party 5:15 –7:15 pm Christiana Skating Center
9	10	11 Parent Coffee Hour 9am Prince on Dela- ware	12 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	13	14	15 10th Annual Auction "The Hidden Treasures of Autism"
16	17	18 N.C.C. Support Group 7pm Autism Delaware Office Kent County Support Group 5:30 pm Posi- tive Outcomes Char- ter School	19 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	20	21	22
23 Autism Friendly Shopping Night Toys R Us 7 –9 pm Newark Store 30	24	25	26 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	27 Office Closed Happy Thanksgiving!	28 Office Closed	29

The Sun

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	1	2	3 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	4	5 Autism Delaware Holiday Open House 11 am—7pm	6	
7 Annual Family Holiday Party Del-Vets 12:30 pm	8	9 Parent Coffee Hour 9am Prince on Delaware	10 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	11	12	13 Family Friendly Holiday Caroling 7pm	
14	15	18 N.C.C. Support Group 7pm Autism Delaware Office Kent County Sup- port Group 5:30 pm Positive Out- comes Charter School	17 N.C.C. Bowling Night 5:30 pm AMF Price Lanes	18	19	20	
21	22	23	24 No Bowling	25 Happy Holidays Office Closed	26 Office Closed	27	
28	29 Office Closed	30 Office Closed	31 Office Closed	January 1 2009 Happy New Year! Office Closed	2	3	

The Sun

BAutism DELAWARE

The Sun

Helping People and Families Affected by Autism

Autism Delaware Newsletter

www.delautism.org

November/December 2008

Inside This Issue...

The Director's Chair			
New Members	3		
Why Autism?	5		
Inside Autism Delaware	6		
Fundraiser Updates	7		
Autism Delaware Social Scene	8		
Fun Fall Photos	9		
Parent 2 Parent	10		
OAR Conference Review	11		
Autism Delaware Announces Re- search Grants	12		
Asperger's News and Activities	13		
Back Cover AD Membership Applica- tion			

Our Mission

Autism Delaware is a community of people with autism, their family members and friends, and professionals who work in the autism field.

Our mission is to improve the lives of people with autism and their families. We will educate, advocate and raise public awareness in order to promote lifelong opportunity and acceptance for people with autism in their communities.

We serve the entire state of Delaware.

What's In A Name?

By: Theda Ellis

It's a new beginning for Autism Delaware. We are moved into our new space with a new name, and soon there will be a new look as well. Our name is simply, *Autism Delaware*.

It seems like an obvious choice, but it was quite a journey getting to this place. With guidance from Tipton Communications, we underwent a process for choosing the new name including a member survey. During this process, we first had to ask: What are the essential parts of the name? This is what we decided.

Autism—it answers the question about why we exist.

Delaware—it answers the question about who we serve. We are committed to serving the entire state, so that's what our name should say. And, it speaks both to people in Delaware and outside Delaware.

But, and this is a big but –we really loved that acronym, **A S D**. It's what we have called ourselves since the beginning –a ten year habit. So we looked for an "S" word. Could we use Service? Support? Spectrum? None of them was quite right. We do services, but we are not all about services. The same is true of support. Our name had to be a big "umbrella" name to reflect all the kinds of things that we do. So, we turned to other words and names. Alliance? We aren't really that. Association? Network? Partnership? Foundation? We aren't any of those things.

In the end, we decided that *Autism Delaware* says it all. It's about autism in Delaware. It's inclusive because it means we can be anything about autism. We are not limited to being just a service, or advocacy, or whatever. We can be any of it, all of it, or somewhere in between. It reflects our mission and it allows us to grow. It's who we are! Autism Delaware, Inc.

Autism Delaware Staff &Volunteers

Autism Delaware is a volunteer organization supported by professional staff. It is the job of the staff to support the board and its initiatives and to support all volunteer and committees with their activities.

The staff gives advice, works in conjunction with the committees and volunteers and helps with all of the administrative duties so that volunteers have more time to do the hands on work out in the community.

(Continued on page 4)





Page 2

The Sun

A publication of Autism Delaware 924 Harmony Road, Suite 201, Newark, DE 19713 302.224.6020-Office 302.224.6017-Fax Email: delautism@delautism.org Website: www.delautism.org

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The Director's Chair

Autism Delaware

By: Theda Ellis, Executive Director

Times of Change

"It is not the strongest of the species that survives, nor the most intelligent, but the one most responsive to change." **Charles Darwin**

Future Shock, about the personal perception of "too much change in too short a period of time" was on everyone's reading list when I was young. Future Shock is what I'm feeling now. In a few short months, we have seen our economy begin to sink. We are facing major national and state political changes that will affect our lives in very profound ways. For most of us, political changes are not obvious or immediate; but when you have a disability or a child with a disability, the impact of change is greater and typically more immediate.

Delaware is facing major leadership changes across the board. Change at the governor's level may bring new directors at state agencies. We know there will be a change at the Division of Developmental Disabilities Services, and it could also bring changes at Medicaid and Vocational Rehabilitation as well - the agencies that most impact individuals with disabilities and their families. Simultaneously, the position of the Statewide Director of the DAP is vacant, so every child in the DAP across the state may be impacted. The autism community needs to be aware of these impending changes and prepare to make their voice heard in decisions about leadership. We need strong and effective leadership at all levels now because the number of people with autism is growing just as our challenged economy has fewer resources for it. School districts are cutting services and programs that we once thought were entrenched forever; the funding structure for Special Education is changing from category to a "needs-based" structure which could have a profound effect on the DAP; DDDS is beginning to require eligibility for Medicaid to receive any service, and Vocational Rehabilitation is going to an order of selection, serving only people with very severe disabilities. This is a lot of change all at once that can have far-reaching consequences. As people with autism and their families and friends, we must be vigilant.

As a community, we must energize ourselves to speak up about filling these vacant positions. We need leaders who are visionarywho can see new possibilities instead of

(Continued on page 5)

A Service of Autism Delaware Productive Opportunities for Work & Recreation

Katina Demetriou Project Director

302.824.2252 (cell) 302.224.6020, ext 207 katina.demetriou@delautism.org

302.824.2253 (cell) Karen Anderson Community Specialist 302.224.6020, ext 207 karen.anderson@delautism.org

eGroup/Listserv On-Line Resources

If there is one thing that having a child with autism brings, it is a lack of free time. There is never enough time to go to all of the meetings, the support groups, the lectures or conferences or even to connect with other parents. That is where a Listserv or eGroup comes in handy. They are free to join and each group has a specific topic or function. Try one out and join today!

- Autism Delaware Main eGroup - This group is for anyone in the autism community in general. This group is not a discussion forum, but a notification system. You cannot post or reply to a message that comes from the group. Only the office staff can post. Posts are usually reminders about social functions, meetings and other important information for the autism community in Delaware. To join, contact Cheryl Frampton at Cheryl.frampton@delautism.org

- Autism Delaware On-Line Support Group - This group is designed for parents or caretakers of individuals with any type of autism spectrum disorder who reside in the state of Delaware. This is an open discussion forum and the only main qualification is that you are a current resident of Delaware. To join, contact Cheryl Frampton (email above.)

The following eGroups/Listservs are not not owned or operated by Autism Delaware and are being provided for your information only. Autism Delaware is not responsible for the content or management of these groups.

- DAP Families eGroup (Brennen School and all DAP satellite locations in the Christina School District) This group is for parents of children attending a DAP Christina School District program. This is an open discussion forum that touches on issues at school, school fundraisers, support and events. Moderators are Deanna Principe and Valerie Wells. To join, contact Deanna at deannap203@comcast.net.

- Alternatives_For_Autism - Contact Person: Jennifer Cornell – fourcornells@verizon.net. Purpose/Mission: We believe that autism is treatable, improvement is tangible, and recovery is possible. Our goal is to provide an atmosphere of support, encouragement, love, and hope that will guide you in your biomedical journey. This group will be a safe environment for you to ask questions, raise concerns, find a supportive shoulder, and discover new treatment options available for your child. Topics we'll be covering in upcoming meetings: The Defeat Autism Now (DAN!) protocol, supplementation and biomedical interventions, dietary interventions, homeopathy, Floortime, Sensory Integration therapy, etc.

New Castle Support Group is Revamping for Parents of Young Children

The next New Castle monthly support group will be on November 18, 2008 at 7 pm with a new focus and a new format. This group will be specifically for parents of young children up to age nine. The meetings will be at the new Autism Delaware office at 924 Old Harmony Road, Suite 201, Newark, DE 19711.

With these new 90 minute sessions, Kathy Hupp, who is both a parent of a son with an ASD and a licensed social worker, will start each session with a presentation of the topic for followed by group discussion. Kathy will be combining her experiences as a mom as well as her skills as a facilitator. Our goal is to assist parents of newly diagnosed children with information and support. Examples of sessions are described below:

Managing Expectations. What will your ASD child's educational and behavioral needs be? What is "normal."

Coping Skills for Parents and Caregivers. Discussion will center on what works and what doesn't work and parents can share their tips for each other.

Dealing with Everybody Else. We all know "the look!" It isn't easy to deal with. Discussion will focus dealing with your ASD child and extended family, friends and community members.

Thinking Problems that Aggravate Stress and Anxiety. Healthy mental functioning will be essential to longterm well-being as a parent of an ASD child. Learn to identify faulty thinking styles which contribute to further stress.

Autism Delaware





Please welcome the following new members to Autism Delaware...

Individual/Family

Hedrick, Judy Tazartu, Caryn and Michael McKelvey, Jane Hawthorne, Jo Eves, William and Audrey Kelly, Chie and James Prettyman, Bob and Maggie Lund, Albert and Dottie Wells, Teresa Ricks, Tracy and Evelyn Planer, Matthew Griswold, Bill Gause, Pattie and Greg Kehr, Charles Ruth, Melody and Richard Gardner, Brock and Dawn Lilly, Pam Flannery, Chris and Betsy Gilligan, Marie and Paul Llaca, Victor and Delia Parida, Prasanta deLeeuw, Gail and Neil McKinney, Russell and Yolanda Garlington, Helen and Bill Casale, Anthony and Kimbery Golfin, Leon & Elaine

Professional

MaryKay Mills Corey Bowen Jane Maroney

<u>Silver</u>

Toomey, Martha & Engard, Ron

Lifetime

Provine, William and Woolard-Provine, Annette

Kempner, Marcy and Artie



Productive Opportunities for Work & Recreation

A Community-Based Service of Autism Delaware for Adults with Autism Spectrum Disorders

We see the World in a Different Way...

We envision the world where all people with autism live fulfilling lives. To do this, POW&R works with adults and their families and friends to create individualized vocational and recreational supports in the community.

POW&R/Autism Delaware 924 Old Harmony Road, Suite 201 - Newark, DE 19713 (302) 224-6020 www.delautism.org

...It's About Life

Autism Delaware Options Policy

All information provided or published by Autism Delaware is for informational purposes only. Reference to any treatment or therapy option or to any program, service or treatment provider is not an endorsement by Autism Delaware.

You should investigate alternatives that may be more appropriate for a specific individual. Autism Delaware assumes no responsibility for the use made of any information published or provided by Autism Delaware.

Get Connected! Join Autism Delaware's On-Line Support eGroup



This group is for parents, guardians or any family member who has a caretaking role of an individual with autism, Asperger's Syndrome or PDD-NOS living in the State of Delaware. This will be a place to safely share your experiences and concerns. This group is set on private and only members can read and post to the group.

To join the group send Cheryl your request with your full name, your child's name, age, diagnosis, day time phone number and email address to:

cheryl.frampton@delautism.org

Next Deadline for Submissions to The Sun: December 1, 2008 Share your family's story, tips or information with everyone! delautism@delautism.org. Or mail it to us (address on page 2). Let Your Voice Be Heard!



From the Director's Chair

(Continued page from page 2

continuing things the way they have always been done. Equally important, those leaders must be managers. They must be able to translate public policy into action. All too often in my career I have seen wonderful advocates move into leadership positions who could not bring about the change they wanted because they did not understand how things work in a bureaucracy. We should never have poor managers in these positions, but it becomes a greater priority to have effective leadership <u>AND</u> management when times are tight.

A group from across the state is gathering to have a voice in these decisions and other legislative initiatives. We have members from all three counties, with leadership from the Lower Delaware Autism Foundation as well as Autism Delaware. Please join with us in this effort to protect the future of those affected by autism.

Charles Darwin was right! It is not the strongest or the most intelligent who survive. I would suggest that it is those who direct the change who survive the best. Please join us in promoting change for all people with autism and their families.



Why Autism?

By: Jen Nardo

Why do people think that it's okay to attack autism? What is it about autism that makes it susceptible to attack? Do people simply pick on autism because they themselves don't really understand it?

This past year has had two widely publicized "critiques" of getting an autism diagnosis and on living with autism. Without naming names and giving these people more publicity, I'll just call them *the radio guy* and *the actor.*

The radio guy used his airwaves to tell people that autism is (I am paraphrasing and using mild language) misdiagnosed more often than not and that those kids just need some swift discipline. The actor wrote in his book that he hates how parents throw money at psychiatrists to get an autism diagnosis in order to explain why their child is lazy thus letting the parents off the hook. Each person went on to defend their positions in the media and also back off what they said/wrote.

When the Centers for Disease Control say that 1 in 150 children in America will be diagnosed with some form of autism, we do need to question why this is happening at such alarming rates. You've probably heard some of the arguments: more environmental causes and better recognition by physicians and educators. I find it impossible to believe that there are parents out there who actually wish their child has autism. My child has autism and I don't, for a millisecond, wish for more members to this "club" to which I was drafted.

As for the child needing more discipline, I can only sit slack-jawed at the idea of punishing my child for behaviors that are beyond his control. I know what sets my son off: unexpected changes in routine, loud and crowded stores, too many transitions at once, and currently, changing one's clothing from season to season. The meltdowns that ensue are just the outward sign to the emotions which he cannot express verbally.

I offer the radio guy and the actor the chance to live in my shoes for a day. That's all they would need – one day. I offer them the opportunity to learn what it means to live with autism 24/7/365. I offer them the chance to attend my son's school during that day. They will be in a place where all of the students are living with autism – their autism. They could see and hear the emotional meltdowns that occur all day long. They could see the anguish on these children's faces as they try to fit into a world that does not make sense to them; that makes them hurt; that makes them angry/sad or any long list of emotions; a world that takes all of their energy to maintain composure as they try to learn something new.

So, why attack autism? The attack I want to see is in the research laboratories as they whittle away at the causes of autism. I want to see attacks from therapists and special education teachers as they show my son how to tie his shoes and write his name. Let's forget about the radio guy and the actor. They can spit out their hateful words, but let's show them the only attacks that matter are those that make the future better for people living with autism.

Autism Delaware

Page 6



Open House

You probably know by now that Autism Delaware has moved to 924 Old Harmony Road, Suite 201, Newark, DE 19713. Now that we have all the boxes put away, we would like to invite you to visit us on December 5, anytime from 11 am until 7 pm. See our new digs, learn about projects that we are working on, meet the staff and perhaps some of our POW&R guys, and have some refreshments. This is your organization. We work hard to make you proud of us, so please join us to celebrate the season, the office, and the many good things we have in Delaware.

Light refreshments will be served and kids are always welcome!

Insurance Committee

The insurance committee is moving forward with our goal to get insurance coverage for therapies for children with autism. By therapies, we are talking about the traditional occupational, physical, and speech therapies, but most important, we will be pushing hard to include ABA. The committee has determined key components of what we need in a bill. and we have had a conference call with the Autism Speaks attorney, Stuart Spielman, for guidance. Stuart put us in touch with Judith Ursitti, the grassroots organizer for Autism Speaks. Judith will be assisting us through this process. Once the election is over and we know who will be in the legislature, we will be looking for sponsors. In the meantime, you should be speaking with your legislators about the need for insurance coverage. Autism is a disability and as such, should have therapies

covered by insurance just as they are for other children with disabilities.

We also want to welcome Dena Brown and Lisa Poytko to the committee. If others are interested in joining us, please send an e-mail to Theda.Ellis@delautism.org. We can use our conference line for people who cannot join in meetings.

Membership

It's time to renew your membership. Autism Delaware's strength has always been our members. It is members who come to us to request new support groups, to look at insurance issues, to help provide social events for families, to expand downstate, and even to start adult services. Over the past year with the separation from the Autism Society of America, we have downplayed membership, but with that issue behind us and a bright future ahead, we will once again be recruiting members.

Membership allows us to bring in national speakers at lower cost. It provides eligibility for conference stipends, scholarships for students, lower cost participation in family events, and most important, it gives you a voice in the statewide autism community. Autism Delaware is increasingly active at the local and state level, working to ensure that children get the best education possible, that adult services are in place, and that parents have access to the information and education they need in order to make treatment decisions for their children.

It's a great deal at \$20 for a family membership. Join today.

Membership application on back page of newsletter.

Autism Delaware Bowling Night



Bowling nights are held on every Wednesday at the AMF Price Lanes at Prices Corner on Kirkwood Highway in Wilmington. This is the BEST part; there is only ONE rule....**Please email or call Mark or Cher the Monday before bowling to RSVP.** The size of the group keeps growing and we need to let the bowling alley know how many lanes to reserve. After that, NO rules!

Here is the breakdown:

-You call or email us by Monday night. <u>markdelautism@yahoo.com</u> or 302.998.1466 -You arrive at the bowling alley between 5:30-6:30 p.m. -Parents and siblings are welcome to bowl. Autism, Asperger's, PDD-NOS, Group Homes...whomever! -There is no age limit. -You can come once a month or four times a month, no commitments!

-You can bowl one game, half a game, 10 games. It is entirely up to you.

-You pay for your games and shoe rentals. We do get a discount.

- -The snack bar is open.
- -No winner, no losers.

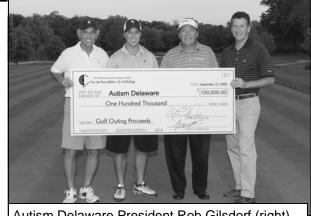
-Bumpers for whoever wants them. -No worries if the weather is too hot, cold or wet!

-We are usually located on the far end in the 40's and 50's. So we have a side door exit and bathrooms right behind us.

-There is also a game room for those who need to take a break or want something a little different to do.

So that's it! Just give us a call and come out to have some fun!

Autism Delaware



Autism Delaware President Rob Gilsdorf (right) accepts a check for \$100,000 from Louis Capano, Jr., Louis Capano III, and Joey Sindelar Family on September 15, 2008.

Louis J. Capano, Jr. & III Family Foundation Golf Outing

Louis J. Capano, Jr. & III Family Foundation was pleased to announce that it would donate all proceeds from its Third Annual Charity Golf Outing to Autism Delaware. Nearly 200 golfers came out to play on Monday, September 15, 2008, which was a record turnout and the beautiful fall weather certainly didn't hurt. The event had two special celebrity guests, Joey Sindelar of the PGA and winner of the 2004 Wachovia Championship and Cindy Rarick of the LPGA, winner of five titles. When all was said and done, Louis J. Capano, Jr. and his son, Louis Capano III were thrilled to present a check in the amount of \$100,000 to Autism Delaware. They thank all of their sponsors for their support.

Autism Delaware wishes to extend a heartfelt Thank You to the Capano Family for their generous contribution.



Autism Delaware Social Scene

Autism Delaware Open House

Come join us on December 5th from 11 am to 7pm to Celebrate Autism Delaware's Grand Open House and 10 Years of Serving the Autism Community!

Check out our new office & meet the staff. Snacks and beverages will be provided. No RSVP required. 924 Old Harmony Road, Suite 201 Newark, DE 19713

Roller Skating Party

November 8, 2008 Christiana Skating Center, (Route 273), Newark 5:15—7:15 p.m.

Admission is Free! \$2-3 Skate Rentals. Snack Bar is Open. Autism Friendly Lights and Music. Bring Friends and Family. All are Welcome. Facility is Closed to the Public. No RSVP needed.

Autism Friendly Holiday Shopping Event at Toys R Us

November 23, 2008 From 7-9pm Low lights and low/no music Givzaways & Snacks! NO RSVP Needed!

Don't miss this chance to get a head start on your shopping in a autism family friendly environment!

December 7, 2008 - Autism Delaware's Annual Family Holiday Party Del Vets off of Naamans Road, Wilmington, DE.

Bring a covered dish to share (Please call Social Chair Robin Delaney and let her know what you plan on bringing (302) 636-0538.)

12:30 - 3 pm.

We will provide drinks, desserts, entertainment, crafts and a special surprise visitor!

Please RSVP no later than December 4th so that we may have supplies for everyone. Call the office at (302) 226-6020 or email delautism@delautism.org. We need your full name, day time phone, number of adults and the number of children attending and an email if available.

Family Holiday Caroling Hosted by Elizabeth and Rob Scheinberg Saturday, December 13 7—9 p.m. Pleasant Valley Estates, Newark Please RSVP by December 6, 2008 and/or to get directions contact Elizabeth at 302.494.8076 or email montagnebeau@aol.com Bring a plate of cookies to share. Beverages to be provided.



Kent County Support Group

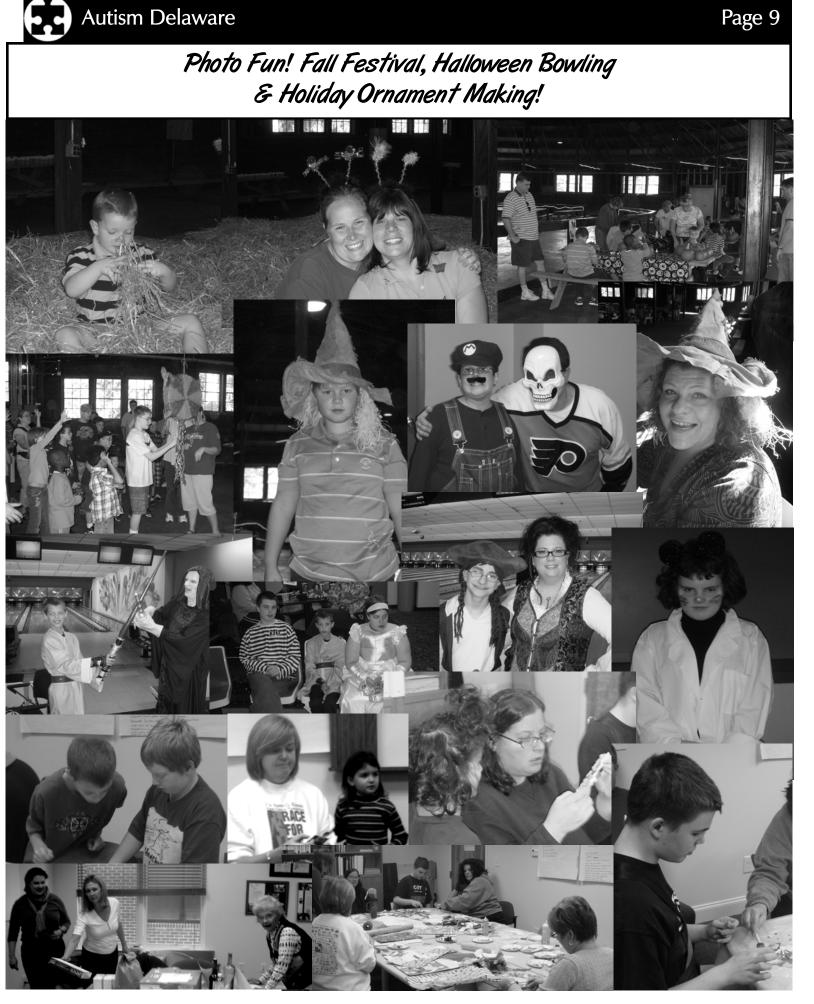
November 19, 2008 5:30 - 7:00 p.m

Location: Positive Outcomes Charter School

Contact: Kate Stomerioski at beazelbeak@juno.com for more information







Page 9

Parent 2 Parent

Aesop and Autism

By: Melanie Matusheski

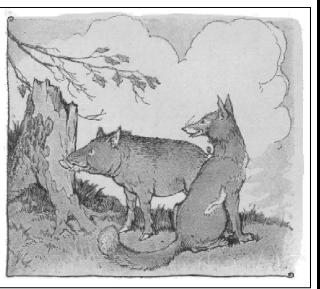
Ever hear the Aesop's fable about the boar and the fox? A boar was standing next to a tree, sharpening his tusks on the trunk. A fox came by, looked strangely at the boar, and asked the boar why he was sharpening his tusks when there was no hunter or other danger nearby. The boar answers, "It's simple, if something were to attack me I wouldn't have time to sharpen

my tusks, but if I have them ready, I'll be ready for whatever comes along."

That's good advice for anybody, but especially for parents of children with autism. We may not actually have someone shooting bullets at us, but it sure feels like it sometimes. And I know, you're saying, "I'm too busy 'dodging bullets' and living minute-to-minute to prepare for future problems." But if you can take five minutes here and there a few times a week, you can be ready for whatever might come along. Here are some suggestions for keeping your tusks sharp:

Medical – Try to stay up-to-date with your child's checkups and medical records. Discuss with your doctor all your concerns and possible treatments. Have a neurologist evaluate your child, even if you're not having any major problems right now, so that you establish a baseline of behaviors. You don't want to wait (like I did) until your child has serious behavior issues before you phone the neurologist, only to be told that the first available appointment is in six months

School – How many times have you looked at all the handouts, newsletters, schoolwork, and permission slips that your child brings home everyday, put them aside somewhere thinking that you'll take care of them later, but when later comes you can't find the paper you need? I've discovered that different colored folders, labeled *Artwork*, *Information*, *Sign and Return*, and *Urgent* (or whatever labels work for



you) can really help keep all the paperwork organized. Also, keep in close daily contact with your child's teacher so that you'll both be informed about what's going on at school and home.

Social – When taking your child on an outing, take along things that will make the trip easier: extra clothes, cleaning products, snacks, bottles of water, toys. Taking your child out in the community can seem daunting and exhausting, but the more you do

for parents by parents

it, the more comfortable your family becomes with different situations. Most important, take advantage of the social events that Autism Delaware sponsors. We have a lot of fun and nothing your child does will faze us (as a group, we've seen it all!).

If you have any suggestions for keeping tusks sharpened, please send them to me at melaniematusheski@comcast.net and help us add to this list!





Second Tuesday of every month 9:00 a.m.



Prince on Delaware 124 Delaware Street Historic New Castle Coffee is on us. Little ones not in school welcome. Invite family and friends.

No RSVP required.





OAR Conference Report By: Theda Ellis

The Organization for Autism Research offers a small two-day jewel of a conference every October in Arlington, Virginia. Organized by Dr. Peter Gerhardt, it highlights the *best-of-the-best* to talk about research to practice. Each session was fascinating, only to be followed by another session that was better

yet. Big conferences are wonderful, but they can also be overwhelming with the number of sessions to choose from. Who is the best speaker? Who do you choose? Because it's small, the OAR conference has a more human face. Dr. Gerhardt personally chooses all the speakers from his 30 years of experience, and offers two sessions to choose from with opportunities to meet the speakers for follow-up conversations. Here are a few highlights:

Dr. Ami Klin, Yale Child Study Center on Social Engagement in the First Two Years. Evidence is beginning to mount that problems with social engagement of children with autism are present in infancy. Typically developing newborns give preferential attention to people, preferring the sound of a human voice over silence. By 3 months old, typical infants look more at a person's eyes than any other part of the face. Yale researchers conducted studies comparing typical children, children with non-autistic developmental delays, and toddlers with autism to look at this attention to the eye. They found that by age 2, children with autism not only did not look at the eyes, but looked much more at the mouth - a

phenomena already established on older individuals with autism. In a related study using light point figures doing pat-a-cake, they found that toddlers with autism do not see the relationship of the figure to a human, nor do they respond to the social interaction of the figure until the point of the clap-when the sound and the action are at the same time. In fact, our kids prefer this audio-vision synchrony 90% of the time. Combined with the studies showing the preference for looking at the mouth, the thought is that children with autism look at the mouth because they are seeking

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> this sound/action synchrony. They do not look at the face or eyes for social context as other children do, but for physical action. Klin's suggestion is that "At age 2, the less the child looks at the eyes, the more severe the autism is." His goal is to develop charts for social engagement that would be used like growth charts – to follow social development over time.

> Dr. Roy Richard Grinker is a parent of a teen with autism, an anthropologist at George Washinton University, and author of <u>Unstrange Minds</u>, called one of the "30 Best Books of 2007" by the Library Journal. Dr.Grinker, who is currently conducting prevalence research on autism in Korea for NAAR/Autism Speaks offered a message of hope. "As a society," he says, "we are beginning to get it right and we are having an impact

on the world in that way." He highlighted the latter with a funny story. He met a Zulu couple in South Africa with a child on the spectrum. Forced by family to see the local witch doctor to "exorcise" their child, after the two-day experience, the witch doctor advised them their child did not have a demon, but instead he had autism. How did he know? He used the only village computer and read about it on the internet – an example of how the world is learning about autism.

More than ever before, younger children are getting the services

they need. Dr. Grinker's view is that that rising prevalence rates are not to be feared, but are instead the result of seeing people in a different way. He looked at New Jersey's prevalence rates compared to Alabama's, then at New Jersey's number of programs and services compared to Alabama's. He believes that Alabama's lower

rate of autism is not real, but the result of less education, less diagnostic ability and fewer services and thus fewer cases of autism are reported. He spoke about his recent experience in South Korea, a country that reports that they have no autism. The currently conducted prevalence studies are showing their rates are in fact, about the same as the U.S. Grinker believes that the focus is really on us as a society, and how we can rearrange society to better support individuals with disabilities.

And finally, I want to share a bit about what Dr. Joanne Gerenser, Executive Director of Eden II, had to say about speech language issues in autism. We all hear about functional language, and in Delaware, there is a good understanding of behavior

OAR Conference

(Continued from page 11)

as communication. Dr. Gerenser emphasized "the stranger test." Can everyone understand the child, not just the family in the home? If not, she supports using augmentative communication in any form. In fact, Dr. Gerenser thinks a child with a good use of PECS may have more functional language than a verbal child. She sees "noncompliant" behavior as really a way of saying "I don't know what you want me to do."

Part of this problem is that our folks can understand words, but they need to know how words go together and understand what that means. Then they need to understand the change of meaning when the tone of voice changes, or the setting changes. She highlighted this with a discussion of inclusion. According to her, children with autism -particularly verbal children-often do fairly well in the first and second grade. Problems typically arise in third grade because learning moves from the concrete to the abstract. Now the child can't just do something - s/he must also be able to explain why and how he did itsomething that is often beyond their ability.

Because people with autism don't use language as much or in the same way as the rest of us, they don't have the same opportunity to practice and learn from frequency. This means their processing takes longer. Even our kids who have language and who may talk a lot don't have fluent use of vocabulary or good flexible language. She cited the mom who was talking to her son about the concepts of singular and plural. His reaction –"but Mom, Cingular is a phone company!" Her advice and challenge to parents and teachers is to stress vocabulary, and not just words, but their relationships to each other and how they can be used differently. Fluency and flexibility are the key. A star is not just something up in the sky. It's also someone named Brad Pitt—something a teen may need to know more than that thing in the sky.

In summary, conferences always excite me. Sometimes I learn new things. Sometimes things are re-framed for me, and sometimes I just have fun. Join me next year at OAR. We can have some fun and learn together at the same time.

Autism Delaware Announces Research Grants

Autism Delaware is very happy to announce its research awards for 2008. There are two components to research. The first is pure science – looking at the cause of and cure for autism as well as medical treatment. In past years we gave those funds to NAAR (National Alliance for Autism Research) and CAN (Cure Autism Now). Since both organizations have merged with Autism Speaks, we have started awarding research monies to Autism Speaks.

In 2008 Autism Delaware is awarding Autism Speaks \$16,500. Autism Speaks is looking at research in four basic areas: <u>What</u> <u>causes it? (Etiology) What is it?</u> (Biology) How do you know if <u>someone has it? (Diagnosis) How</u> <u>do we make it better? (Treatment)</u>. Examples of their initiatives include the Autism Genome Project, Environmental Factors, and Innovative Technology for Autism and many others. In addition to these funds, board members Artie Kempner and Mark Rossi, and member Pete Bradley arranged a fundraiser at Dover Downs over race weekend that helped both organizations, so Autism Delaware has really assisted Autism Speaks to raise more than \$100,000 during the past year.

The second, larger award of \$27,500 is to the Organization for Autism Research (OAR). OAR is a much smaller organization that specializes in applied research, translating the pure research done by Autism Speaks into practice. The goal of OAR is to fund studies that will produce practical results to help parents, families, professionals and people with autism to make more fully informed choices that will lead to healthier and happier lives. Recent research includes work on sleep disturbance and daytime functioning in children; supports for success of college students, and joint attention intervention in young children.

We believe it is our responsibility to support research at both the level of pure science and at the applied science level in order to meet all the needs of this community. Prevention, cure, and treatment are all critically needed and all must be addressed.

There are

no impossible dreams...

Just our limited perception of what is possible.







Speech Therapy Recommendations

Wordplay For Kids Ages: 6-12

Quick, what's a beverage that has the letters "J" and "Q" in the name? You've got 60 seconds. Wordplay for Kids is fast, fun and challenging. The spinner provides 2 letters that must appear in the word. A die roll selects the word category. *Working on: word finding, categorization, turn taking*

Paired Up Jr.

Ages: 7 and up

Players get randomly "Paired Up®" with other players and take turns acting out or describing the pairs on the game cards, using their own words or actions.

Working on: association skills, word finding, creative thinking

Wordxchange Junior Ages: 5 and up

Try to make, steal and keep words to win.

Winner of The National Parenting Center's Seal of Approval and Parents' Choice Honors Award. *Working on: phonemic awareness, spelling, reading, abstract thinking*

Don't Make Me Laugh, Jr. Ages: 5 and up

Laughter cards prompt players, partners and sometimes the whole group to perform various improvisations such as: pretend you're a sprinkler, imitate your favorite teacher. *Working on: using body language, interpreting body language, turn taking*

Guess Who Ages: 6 and up

There's a mystery person on your opponent's card. Can you find that

It is the holiday season! What can I get my child that is both fun and therapeutic? By: Heidi Mizell

matching face in the crowd? Start with a gameboard full of funnylooking suspects. Then ask the right questions to eliminate the wrong faces! Once you're down to a face or two...solve the case by guessing who! *Working on: asking questions, categorizing, turn taking*

Taboo Ages: 12 and up

Try to get your team to guess the word on the card without using the five most popular descriptions *Working on: word finding, describing, categorizing, using attributes, listening skills*

Hullabaloo Ages: 4 and up

Get kids bouncing, twisting, spinning and dancing to the commands of Hullabaloo. As they do, they hone their problem-solving skills and are rewarded for quick thinking and cooperation.

Working on: problem solving skills, following directions, critical thinking skills, cooperating with others, body awareness, motor planning

I Spy Memory Game Ages: 4-7

This game features word games and group challenges that are fun and rewarding for the entire family. Have fun while helping young players develop memory, reading, thinking and language skills. *Working on: social skills like taking turns, following rules and sharing*

Moods

Ages: 12 and up

Players test verbal and acting skills by portraying one of 60 moods as they read a humorous, but often unrelated, phrase drawn from a stack of cards.

Working on: interpreting body language, using appropriate body language, tone of voice

Excerpt from Orchard Friends School gift guide. Used with permission.

What's going on??

(Sponsored by Pike Creek Psychological Center)

PEER Program

PEER Program is an informal way to help your child improve social skills, make new friends, and spend time with trained counselors so you can have a break too!

Sibling Support

Our Sibling Support Program is designed with the emotionally and behaviorally disordered children in mind. Siblings sometimes feel overlooked because of the demands of raising a special needs child.

Hey! Adults with Asperger's! How about attending a group to hang out with other people who have interests and challenges similar to yours?

For information on the above programs, please call 302.738.6859

Kent County Game Night November 11 and December 9 Registration is required Contact: Heidi Mizell at 302.224.6020 or Heidi.mizell@delautism.org

Autism Delaware Formerly known as the Autism Society of Delaware Annual Membership Application						
Please enroll me in the followir [] Individual/Family \$20 []	Please enroll me in the following category: [] Individual/Family \$20 [] Professional \$50 [] Silver \$100 [] Platinum \$300 [] Lifetime \$500					
[] am a new member []	I am renewing my membership					
Name(s):						
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Email: (1)	Email	: (2)				
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My membership fee is I would also like to contribute th Total amount enclosed (add bo	his amount directly to Autism Delaware \$ oth amounts)\$_	\$ \$				
demonstrated special leadersh	more beyond your membership fee will m nip and a deep commitment to making a s our newsletter and annual report as a lead	significant difference in	the fight against autism. You will			
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Helping People and Families Affected by Autism