



The Sun

The Voice of Autism in Delaware

Detachable Monthly Calendar
May/June 2007

Autism Society of Delaware

(302) 472-2638

www.delautism.org

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
May		1	2	3	4	5
6	7	8 Parent's Coffee Hour 9 a.m.	9	10	11	12
13	14	15	16	17	18 Teen Night Out 7 p.m.	19 ASD Day with the Blue Rocks
20	21	22	23	24	25	26 Mom's Night Out
27	28 Memorial Day Office Closed	29	30	31 The Drive for Autism Research		
June					1 Office Closed	2
3	4	5	6	7	8	9
10	11	12 Coffee Hour & Dad's Night Out	13	14	15	16
17	18	19 N.C.C. Support Group 7p.m.	20	21	22	23
24	25	26	27	28	29	30



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Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1 July	2	3	4 Holiday Office Closed	5	6	7
8	9	10 Parent's Coffee Hour 9 a.m.	11	12	13	14
15	16	17	18	19	20	21
22	23 Summer Institute for Adults	24 Summer Institute for Adults	25 Summer Institute for Adults	26	27	28 Mom's Night Out
29	30	31				
August			1	2	3	4
5	6	7 Dad's Night Out & Parent's Coffee Hour	8	9	10	11
12	13	14	15	16	17	18
19 ASD Beach Party Picnic	20	21 N.C.C Support Group 7 p.m.	22	23	24	25
26	27	28	29	30	31	



The Sun

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Our Mission

The Autism Society of Delaware is a chapter of the Autism Society of America. We are 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.

Safety and Autism

By: Robin Ireland

On the advice of a friend, I recently subscribed to something called the Schafer Autism Report. SAR is mainly an online repository of articles about autism – from the latest research on mirror neurons to biomedical updates and the latest chapter in the ongoing mercury debate.

It also contains daily news stories from around the world. They are strikingly similar and horrifying to anyone who knows autism. Local boy with autism drowns in lake. Autistic woman victim of police brutality. Asperger's teen beaten on school bus. I try not to look at them but I always do. I can't help myself.

Trying to keep someone with autism safe is a constant challenge. Consider my son. Luke is compelled to run. He is nonverbal. He doesn't respond to his name. He doesn't recognize or fear danger. If a firefighter came inside, he'd probably hide. If he ever got pulled over for speeding (provided he ever became regulated enough to drive a car), I could only hope the cop wouldn't mistake his lack of eye contact for shifty behavior or his fascination with lights for drug use.

In a state with as many children on the spectrum as Delaware, similar fears abound. I have a friend whose high functioning child wandered away from an autism program and tried to walk home. He was found miles away, near an interstate highway, happy but cold and confused.

Another friend lost her daughter during a costume parade – luckily her eagle-eyed sister spotted her before anything terrible happened. Another local boy wanders into neighboring houses and turns on the TV. Another child I know has the treacherous compulsion to walk on the yellow line of the road – and he's bigger and faster than his mother.

The good news is that there have been major advances in safety technology and the awareness of autism within the law enforcement community has grown exponentially in the past few years. What's more, there are simple steps parents can take to minimize hazardous situations.

First, consider calling the Delaware State Police and asking them to enter information about any family member with autism into their database. That way, if you need to call 911, a message will pop up on the dispatcher's screen alerting paramedics, firefighters or police that there is a person at the house with autism. It's called a "premise history" and it might include the name, age and description of the person with ASD. Tell the officer who takes the history if there are any objects that comfort your child, if he prefers to be spoken to in a particular way (perhaps that it's better to simply ask him yes and no questions.) Give the number of an emergency contact or doctor. Address

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5572 Kirkwood Highway, Wilmington, DE 19808
302.472.2638—Office 302.472.2640—Fax
Email: delautism@delautism.org
Website: www.delautism.org

Officers

President: Artie Kempner, 302.777.7273 (h),
artie3boys@aol.com
Vice President: Mike Graci, 302.453.8586 (h),
mjgraci@comcast.net
Treasurer: John Hupp, 302.738.1056 (h),
john96hupp@aol.com
Secretary: Karen Bashkow, 302.453.7411(h),
bashkowk@aol.com

Staff

Executive Director: Theda Ellis, 302.472.2638,
ext 202 (w), 302.388.9798 (c),
theda.ellis@delautism.org
Communications Coordinator: Cheryl Kelley-
Frampton, 302.472.2638, ext 203, (w)
302.998.1466 (h) cheryl.kelley@delautism.org
Development Director: Kim Siegel, 302.472.2638,
ext 204, kim.siegel@delautism.org
Office Manager: Margie Rowles, 302.472.2638,
Margie.Rowles@delautism.org
Asperger's Specialist: Heidi Mizell, 302.472.2638,
ext 205, heidi.mizell@delautism.org

Committee Chairs

Adult Issues: Karen Bashkow, 302.453.7411 (h),
bashkowk@aol.com
Asperger's Committee: Co-chairs: Heidi Mizell,
302.455.9515 (h), toofers2@aol.com
Penny Chelucci, 302.571.8868 (h),
Penny.chelucci@state.de.us
Finance: Michael Graci, 302.453.8586 (h),
mjgraci@comcast.net
New Parent Support: Cheryl Kelley-Frampton
(See Above)
Legislative Issues: Tim Ireland, 302.573.6960 (h),
irelandt@verizon.net
Public Awareness: Dwayne McMahan,
302.235.2101 (h), DMKemps@comcast.net
Social Events: Nicole Curran 302.368.2468 (h),
nicolesmailbox@comcast.net & Robin Delaney,
302.636.0538 (h), katejosh1@verizon.net.
Staff Photographer: Nicole Curran
See Above.

County Liaisons

Kent County: Yolanda Flanigan, 302.284.2499,
LY1998@netzero.com
Sussex County: Barry Sipple, 302.684.0725 (h),
laurelmc@verizon.net

The Sun Editorial Committee

Marcy Kempner	Judy Hedrick
Theda Ellis	Robin Ireland
Brenda Holsey	Jen Nardo

Desktop Publishing: Cheryl Kelley



The Director's Chair

By: Theda Ellis, Executive Director

I'm sitting at my desk on a rainy Friday afternoon in March, thinking about what to write. In a more typical time, I would write about a new initiative or summer coming or perhaps recognize a volunteer. This hasn't been a typical month at ASD however, and my mind can't go to those places right now.

ASD has had two major losses over the past few weeks. Our volunteer Mary, who comes in twice every week and has for more than two years, is in intensive care fighting for her life. Her son with autism was home alone with her for more than 48 hours before her sister found her in a coma. Mary's small family consists of her 13-year-old son, her aging parents, and her sister and her family. Over the past winter, Mary's father had a major heart attack. He had been Mary's key support person as well as the primary caretaker for her mother, who herself has a disability and uses a wheelchair. Now they are living with her sister – a household of 4 adults and 3 teens. Her son with autism—a great kid, has been in respite with Brennan school staff. His future is unclear now because Mary's future is unclear.

Just as we were adjusting to Mary's health problems, we learned about Liam Bradley, who died so suddenly at age 12. Although I didn't know Liam personally, I learned a lot about him at his memorial service. It painted a beautiful portrait of his life, the person who he was, the love within the Bradley family, and his great impact on the people who knew him, including his priest.

These are keen reminders to me that life can be short. Those bright moments at the summer picnic or a spring night at the Blue Rocks become more important. That quick phone call or e-mail from a friend is more valued. I am thankful that the DAP has a respite program that kept Mary's son safe and in familiar hands during this hard time. I am grateful that Pete Bradley was able to speak about how welcoming Delaware was to Liam and the family when they moved here. We are lucky in Delaware to be a small state with people who care about each other. If ASD does nothing else, our first responsibility to our members is to create a welcoming community that supports each other—to share the happy times and to be a support in the sad times. As we grow larger because the community grows larger, this becomes a greater challenge. Join with us in creating this community. Our world will be a better place.

*Things which matter most must never
be at the mercy of things which
matter least.*

- Johann Wolfgang von Goethe



Safety and Autism

(Continued from Cover)

echolalia if necessary. Include any sensory concerns, dietary restrictions and de-escalation techniques.

And don't forget to tell officers if your child is nonverbal or can't follow simple commands. If he has a communication book or keyboard, let the officer know where it can be found.

Several safety web sites offer window decals for houses and cars, so that police or fire officials are alerted to the situation in the event that you can't speak. Many parents circulate letters to neighbors introducing their child with autism. Often, people are afraid to get involved with a stranger's child for fear of being perceived as nosy or overbearing. Giving neighbors permission to call police if they see your child walking down the sidewalk unattended might just save his life. And police will have your information on file and know how to react.

If your child wanders frequently, consider investing in a locator device. This type of equipment comes in two parts – a transmitter that can be attached to your keychain and a locator that can be affixed to a child's belt or shoe. Press the button and it beeps. These devices can be a godsend in very crowded places like amusement parks or parades. Other devices come equipped with global positioning devices.

Identification bracelets also can let people know that your child has autism. It should include contact information and allergy alerts. Consider buying a fire safe box for your child's medical, SSI and IEP infor-

mation, including phone numbers and probate instructions. Put a detailed map of your child's program in the box, too. If something should happen to you, you'll want your child's program and care to continue as uninterrupted as possible. No one likes to think about this stuff—but the alternative is far worse.

On the bus, speak to the driver about autism and make sure he understands your child's unique needs. Ask how behavior issues are handled. And make sure you are comfortable before you let your child onto that bus.

Recently, a Buffalo woman became concerned when her happy and outgoing son began crying when the bus came. She put a microrecorder in his backpack and pushed record when he got on. Captured on it were the aide and the driver taunting her child with comments like, "I love to aggravate him" and "I'm going to punch his lights out." The tape lead to the firing of both people. Many communities are currently pushing for cameras to be installed on buses used by special needs students.

In addition, make sure someone responsible is there to physically pick up your child at school and that the driver knows not to pull away from your house at the end of the day until he sees your face. State your needs in simple, plain language. Now is not

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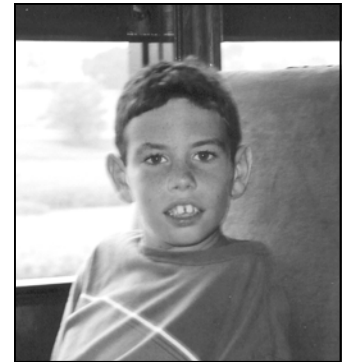
Safety Tip 911 Registration

You can register your household with 911 and let them know that you have someone in your home with special needs by filling out a form on line at:

<http://ddc.delaware.gov/911Registration.shtml>

or by calling: (302) 659-2349

Never Forgotten



Sadly, we lost a young and vibrant member of our community this month. Liam Bradley, age 12, son of Denise and Pete Bradley and brother of Alana and Connor Bradley passed away suddenly on March 12th. Liam will be missed by all who knew him. His life was full of love and attention from a very special family who devoted their lives to his treatment and happiness. While Liam has left us here on earth, he will never be forgotten by all of us who knew him. Many of you have met Denise Bradley through her work with ASD. Denise has been very active with ASD Legislative Committee over the past several years and has been a true advocate for our community in so many ways. Please keep the Bradleys and Liam in your prayers and help to ease their grief and great feeling of loss. Letters of support and condolences may be sent to, "The Bradley Family, 1002 Sugartown Circle, Middletown, DE 19709".

- Rob Gilsdorf

*To live in hearts
we leave behind is
not to die.
-Thomas Campbell*



Welcome!

Please welcome the following new members to ASD...

Milady Santos

Justin Gordon

Sharon Davis

Anto Abrefa

Jacqueline V. Smith

Marlene C. Nilsen

Robert & Melanie

Matusheski

Frances Ryl

ASD Options Policy

All information provided or published by the Autism Society of Delaware (ASD) 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 ASD.

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



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

ASA's 2007 National Conference theme, *Together a Brighter Tomorrow*, reflects our mission that it takes the perspectives of all those affected by autism — individuals, families, professionals and friends—to achieve success. During this conference, ASA will bring together experts from various disciplines with the creative ideas and energy to address the diverse challenges individual with autism and their families face. Our goal is to provide conference attendees with the opportunity to learn from innovators and access critical information to improve their lives and those of the people they love, treat and inspire. In collaboration and armed with knowledge, ASA is sure that there will be a brighter tomorrow for the autism community.

For more information or to register go to:
www.autism-society.org.

Next Deadline for Submissions to The Sun:
August 1, 2007

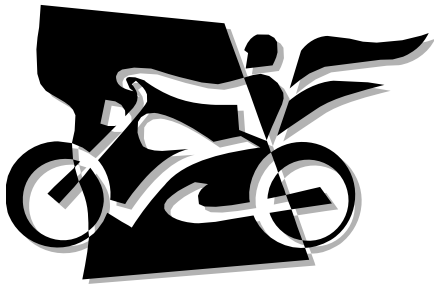
Want to share a story? Have an idea for an article? Send it to ASD today!
delautism@delautism.org. Or mail it to us,
(address on page 2)
Let Your Voice Be Heard!



ASD reserves the right to edit for space and content.



The Motorcycle Run to Cure Fragile X



On Sunday, July 22, 2007, join ASD member Jen Nardo and friends at Mike's Famous Harley Davidson in New Castle for a motorcycle run fundraiser for FRAXA the Fragile X Research Foundation.

FRAXA is dedicated to funding research into treatments and hopefully a cure for Fragile X Syndrome. Just recently, the FDA granted orphan drug status to a compound called Fenobam that is showing success in blocking glutamate receptors in the brain. These receptors are overactive in the brain of someone with Fragile X as well as someone with autism. Fenobam was created in the 70's for people with anxiety disorders. The way it worked was unknown until current research explained it. Hopes are high that this drug will help with the cognitive deficits of those with both diagnoses.

The run will begin with registration at 10am at Mike's and a kick-off at 11am. After the run, which will go to the Eastern Shore of Maryland, a BBQ will take place at the DuPont Chestnut Run Pavilion off of Lancaster Pike and Route 141. Non-riders are also welcome to attend the BBQ. There will be a silent auction along with the hot dogs, Tastykakes and Green's Ice Cream. The local band, Dayjob, will be performing classic rock favorites throughout the event.

For more information or to find out how to help, contact Jen Nardo at 234-7854 or email jen9612@aol.com.

Valero Surprises ASD with a Gift



This winter the office received a phone call from Valero announcing that ASD would be the recipient of a contribution. We thought it was quite nice and thanked them appropriately. We were astounded when the letter arrived a few days later, notifying us that the contribution would be for \$5,000. Board member Rob Gilsdorf, Theda Ellis, and Kim Siegel attended a breakfast in March to accept the check.

Valero and its partners have an annual golf tournament as part of the PGA tour in Texas that raised \$7 million and provided almost \$300,000 to 20 Delaware non-profits. The non profits are nominated by local employees. ASD is very fortunate to have been nominated and we want to thank those employees of Valero who nominated us. We don't know who you are, but we deeply appreciate what you have done.

These funds are specifically to be used for children; ASD will be using them to sponsor social skills training for children and teens.

Thank You!!

Family Support Waiver Alert!

Guided by board member Rob Gilsdorf, ASD with support from the Arc of Delaware, CERTS, and LDAF held a Legislative Meet & Greet on April 5th in Dover to represent the families of the nine member organizations of the Delaware Advocacy Coalition for the Family Support Waiver. Members of the coalition organizations were invited to come with their families to meet our representatives and senators. We also created a new, shorter fact sheet about the Family Support Waiver that is posted on our website at www.delautism.org.

This is critical funding for families and hard to get in a year when funds are tight and competing with other priorities in the disability field. **This is important!!!** Call your local legislators and ask them to support the funding of \$1,200,000 for this year. Remind them:

- It will serve 1378 families. At minimum, that means 2,756 people will benefit even if everyone only had a 2-person family.
- It will help families keep their children at home longer, saving the state money.
- It will give individuals and their families more control of resources and services.
- Autism group homes can cost up to \$180,000 per year. Half of that is state money.



Safety and Autism

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the time to mince words. The same goes for teaching your child – either with words or pictures – about who is permitted to touch their private parts. The “good touch, bad touch” conversation is frequently too subtle for children with ASD. Difficult though it may be, spell it out in direct terms so there is no confusion. Ask your child’s doctor or teacher to help, if necessary.

At home, take advantage of the warm weather to get outside and scan your neighborhood. Without distractions, try looking at your surroundings the way your child might. Are there unsecured dogs? Pools with broken fences? Railroad crossings? Wooded areas? Major highways? Retention ponds? Many children with ASD are often drawn to water and, with no fear of danger, feel free to jump right in. If your child wanders compulsively, consider installing locks up high on the door or equipping doors and windows with an alarm that will chirp when the door is opened.

Stow chemicals and fire starters out of reach. Turn down the temperature on the water heater to avoid scalding and strap unstable furniture to the walls to avoid toppling. If necessary, install safety guards on upper floor windows. If your child breaks glass, windows are now available with safety glass or Plexiglas.

At school, tell officials to call 911 immediately if your child goes missing from the building or playground. And get that policy in writing. Bad things can happen while they sit around developing a plan. Insist on security measures at entrances and fully contained play areas.

Make sure the school or caregivers have a detailed list of emergency numbers – including doctors and people who are authorized to make decisions of your behalf. Carry a picture of your child in your wallet. Police also offer fingerprint and identification kits that can be kept on file at your home. It takes five minutes and could aid emergency workers immeasurably in the event that your child gets lost.

If possible, teach your child to call 911. Better to have him call the number by mistake than to have him unable to use the phone in case of emergency. Remember, police will have your information on file. If no one answers the dispatchers, an officer will be sent to your house. You can inform officers, by way of the premise history, that they are permitted to break down the door if no one answers. The teaching of telephone numbers also can be considered an I.E.P goal. It is, after all, a domestic skill. If you can’t do it, enlist the school.

If first responders are called for your child, remind them immediately that your child has autism and include the following information: if he is nonverbal, if he cannot follow simple commands, and how to calm him. Paramedics don’t need a saga. Just the facts. And make sure to let them know if your child has an unusually high pain threshold, as many children with ASD do.

“When it comes to dealing with someone with any type of learning difference or medical issue, it’s important that we have as much

information as possible,” said Corporal Jeff Whitmarsh of the Delaware State Police. “Our job is to help you. Don’t be afraid to let us know something that helps us to that job better.”

For more information on obtaining premise history forms from the Delaware State Police, call Terry Whitham at 302-744-2682

Safety and Emergency Preparedness

By: Theda Ellis

Safety isn’t just about locked doors, hot stoves, and strangers. It’s also about being prepared for emergencies. That is not something that most of us like to think about or plan for. It’s complicated, it’s unknown and it’s unforeseen. In the days of Y2K, my household armed itself with water, food, and cash. That’s about as much of an emergency plan as we’ve ever had. Then came 9/11; then came Katrina. Suddenly we are all faced with the understanding that we need an emergency plan. That need came home to roost in early February when one of our members fell into a coma. Her 13 year-old son with autism was alone with her for two, and possibly three days, before she was discovered. Although verbal and pretty capable, he only understood that Mom was asleep, and didn’t answer the telephone or know to call 911. Fortunately, her sister knew she had a sprained ankle and wasn’t able to leave the house, so became worried when she didn’t answer the phone and drove 30 miles to check on her. The DAP was also calling and sending e-mails, but the absence wasn’t long enough to kick in “truancy” guidelines or a visit to the home.

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Inside The



POW&R; Adults and Autism

We hope you all saw the lengthy article in the *News Journal* about adults with autism, complete with photographs. ASD would particularly like to thank Barney Vincelette, David Lerner, Patrick & Lynne Murphy for agreeing to meet with the *News Journal* and allow photographs to be taken. Hiran Ratnayake, the *News Journal* reporter, contacted many, many people and worked hard to write a good article that captured so many issues. It was good to see local coverage of this important topic.

Looking at numbers of students with autism is not so surprising after having learned the new CDC number of one in 150 with an autism spectrum disorder among 8-year olds. Did you know that there are 714 students in Delaware public schools with autism? Here's where they are according to the Department of Education.

Kent County	129
New Castle County	403
Sussex County	<u>182</u>
Total	714

Of all of these students, 559 students are in the statewide DAP, and 155 are in their local school districts. Currently 55 students are between the ages of 18 and 21, up from 16 in the same age group ten years ago. We don't know if all 55 will require services, but we know most of them will.

ASD will be starting services in August. This effort will be under the guidance of Katina Demetriou.

Katina is coming to us from Chimes Delaware, where she was in charge of Community Employment. She wowed our search committee of Karen Bashkow, Lucy Graham, Dom Squittere and Ron Engard with her understanding of our vision for recreation as well as for employment, and her creative ideas. We are very excited about what we can accomplish under her guidance. Katina will join staff on June 4, and we will be hiring a second person shortly. This is a big thank you to the search committee for their time and assistance during this process.

If you are a parent or a person with autism who would like to consider getting services from POW&R, please contact Theda Ellis at 472-2638 prior to June 4, and contact Katina Demetriou at the same number after June 4.

Volunteer Recognition

ASD has had another amazing year and we are moving forward in many arenas. As a small organization, we could not do this without the hard work of our volunteer board of directors and dedicated members. It is our combined effort that allows us to move forward and to maintain the many activities that we have become known for. Every year ASD recognizes key volunteers who have made a difference for this organization or for the autism community in general. This year we are acknowledging these recipients at the *Walk the High Road for Autism*, as well as at a special dinner with the board in June. We want to thank all of these four individuals, and recognize that ASD would not be the great organization it is without their efforts. Let's all give our thanks to these individuals who have helped us so much over the past several years.

Dr. Maricar Belicena-Badillo: Maricar was an active part of the Physician's Awareness Project for more

than 18 months. She participated in this project from the beginning, serving on its planning and oversight committee and giving presentations in more than 15 offices or conferences in New Castle County. This project was the first of its kind in Delaware to bring information to the medical community about the effectiveness of using parent screening tools.

Jeff Curran: Jeff has spent many hours "behind the scenes" working for ASD by creating the PSA we used in 2006 and highlighted at the Drive for Autism Research. Additionally, Jeff makes multiple copies of videos and CDs that we use in media kits for our fundraisers and other events. He has also assisted us with editing.

Robin Delaney: Robin is our "all around volunteer!" She volunteers for every major ASD event including the Autumn Auction and the Drive for Autism Research. She has been an integral team member for the walk committee and is one of the current social committee "butterflies." This year the social committee added the Fall Festival which was a huge success.

Camille Miller, Esq.: Camille is an attorney who provided pro bono legal work for ASD, securing trademarks with the United States Patent and Trademark Office of the ASD Logo and the Golf Outing Logo that ASD uses. This process took two years of patient work, and has protected our established logos.

Happy Mother's Day –A Tribute to Mothers of Children with Autism Everywhere

Mythology is full of stories of the *heroic* journey. That journey is

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Safety and Emergency Preparedness

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We are a mobile society with many single parent households. We cannot predict the future, so the next best thing to do is to be prepared. What if something happens? What will happen to your child? The Center for Disabilities in the Health Professions (CDHP) of Western University of Health Sciences has an excellent website (<http://www.cdihp.org/products.html#eeguide>) that publishes guides to planning and what to do to be prepared in times of disaster emergencies, and the South Carolina chapter of ASA has a great website dedicated to protecting individuals with autism (<http://www.scautism.org/protect.html>).

Suggestions from the CDHP to prepare are:

- Establish support relationships with several individuals
- Notify each other when you are going out of town and when you will return
- Place a quarterly reminder on your calendar to check the status of your personal support network
- Conduct practice sessions to ensure that the individuals you choose are capable of offering the assistance you need (i.e. strong enough, can communicate clearly, or can guide you safely).
- Know how you will instantly create a personal support team

A question that is not asked is "What if something happens to the caregiver?" In addition, we might add these suggestions:

- Make arrangements for someone to check on you if you don't

show up at work or your child has an unexcused absence from school. This doesn't necessarily mean that school staff comes to your home, but perhaps they could notify a neighbor or relative and ask them to check on you if you don't respond to school efforts.

- If your child has the capacity, teach them to answer the telephone.
- Again, if your child has the capacity, teach them to call 911 if you are "sleeping" and don't wake up. Another approach might be to teach them a speed dial to a relative or friend. Not every child can do this, but some children can.
- Make advance arrangements for who can care for your child in the case that you are incapacitated. Make sure your child knows this person and is comfortable in their home.

We almost lost our friend Mary. She has a long road to recovery, and her son will be in foster care until she's able to return home and care for him. ASD wants to ensure that other parents don't face this same situation. We cannot ensure we will always be healthy and able, but we can think ahead and plan for unexpected events. By staying connected and supporting each other we not only help keep our loved ones with autism safe, but also promote peace of mind for us all.

Safety Tip Window Blind Safety

Most Americans are not aware of the 8 ways a child can strangle on a window blind, mini blind or Venetian blinds.

Get informed!

www.windowblindskillchildren.org

Inside the ASD Happy Mother's Day

(Continued from page 7)

a road of tests which ultimately transform us and define us as fully human. Best known as a journey for the Golden Fleece or to kill the Minotaur, it is really the pattern of life and growth through experience. What greater heroic journey is there than that of being the mother of a child with autism? It is full of trials, of twists and turns with an unknown outcome, of courage, of fear and despair, and hopefully, at the end it is the story of triumph! That triumph is the child who grows up with a quality life full of things that make it meaningful. This life is the result of many people, an education, and well-chosen supports; but most of all, it is the result of the efforts of a determined and loving mother who guided the journey to adulthood and through life.

This year, as in past years, ASD has recognized mothers as outstanding volunteers, who in their devotion to their child have made significant contributions to us. Some of these mothers over the years have declined to be recognized. One of our unsung heroes wrote these words:

"Each day, this special breed of moms perseveres against great odds to not only get through the day but to also make life better for their children. Given the manifold challenges of caring for a child with autism, it is doubly remarkable that many moms also are able to make the time to treat, research, accommodate, plan, and advocate on behalf of their children on numerous fronts. With Mother's Day approaching, what better way to recognize these people whose efforts are nothing short of heroic."

Happy Mother's Day to all mothers of children with autism. We hope that we are a help to you on your own *heroic* journey! And a special thank you to those women who have helped ASD become the organization that it is through your many and diversified efforts—whether you helped with fundraising and public awareness, program and social events or office infrastructure. We are stronger because of you. Thank you so much!



Girls Just Wanna Have Fun... Mom's Night Out!!

The next Mom's Night Out will be held on May 26th and July 28th. For details on each date please contact Monica McMahan at (302) 235-2101 or email m.mcmahan28@comcast.net.



Updates on both Mom and Dad's Nights out will be posted on the ASD website at www.delautism.org, the ASD eGroup and the ASD monthly update sent home through school.

Dad's Night Out

June 12 & August 7, 2007
Time and Location TBA
(They always wait till the last minute to plan things!)
Who can go? Dads, Uncles, Grandfathers or Friends of those living with autism.
Interested? Of course you are!



Contact:
Artie Kempner
(302) 983-6621
artie3boys@aol.com

Fast breaking NEWS!!!

Vince Meconi, Secretary of Health and Social Services, advised ASD that the eligibility criteria for the Division of Developmental Disabilities will be revised in the coming year through the regulatory process. This is great news, because it means that folks with Asperger Syndrome that also have functional skills will be eligible for their services, including things like a case manager and long term supports.

DDDS Director Marianne Smith advises that the agency will be coming to organizations such as ours to receive public input. There will be opportunities for anyone to comment on this issue as DDDS begins to go through the regulatory process. We want to make sure that a limited IQ is not part of the criteria, but adaptive behavior is. Stay tuned—we will keep you informed!!!

PARENT'S COFFEE HOUR

The Second Tuesday of Every Month

Crossroads Restaurant, Route 7 & Kirkwood Hwy, Wilmington.



Moms, Dads, Grandparents or anyone with a connection to autism is welcome to attend. Little ones not in school? No problem, bring them along, too.

Just Show Up at 9 a.m. and Ask for the Autism Table. Coffee is on US!

Club Phred Fundraiser

A Big Thank You to Club Phred for kicking off Autism Awareness month with their April 2nd fundraiser for ASD at Shaggy's on Main Street in Newark.

The band raised \$500 for ASD!!



Plan on seeing more of Club Phred as they are scheduled to perform at the 9th Annual Autumn Auction for Autism "Smoke and Mirrors" to be held on October 20, 2007 at the Greenville Country Club. Thanks again!!





Parent 2 Parent

written by parents
for parents

Cynque's Journey

By: Jenn Webb

I am writing about the road that I am traveling with my six-year-old son, Cynque', who has severe autism and seizure disorders.

Our neurologist diagnosed Cynque' with severe atypical (absent) and akinetic seizures in 2004, and immediately put him on Depakote, an anti-seizure medication. When his seizures did not improve in two months, we increased his medication. This became a common theme for Cynque'. Within six months Cynque' started suddenly dropping to the floor; then came another diagnosis of atonic (drop) seizures. With this new type of seizure came yet another new medication, Lamictal. Cynque's medications were consistently adjusted or changed, yet nothing is controlling his seizures.

After many hospitalizations and trips to the emergency room combined with the daily trials of dealing with Cynque's seizures, I decided that we needed a second opinion and requested a consultation with Kennedy Krieger Institute (KKI). It took two years of fighting with Medicaid to get there, but we finally got to KKI this winter, where we met Dr. Zimmerman, a neurologist at KKI. Within 20 minutes of meeting with Cynque', Dr. Zimmerman diagnosed yet more types of seizures. As he listed the seizures that Cynque has, he mentioned myoclonic, a subtle type of seizure that is very hard to see.

At this point, Dr. Zimmerman

suggested that Cynque' might benefit from the Ketogenic Diet, a diet that is very high in fat and has little to no carbohydrates. The portions are generally smaller than typical as well. If we try this diet, Cynque' must be on it for two to three years. We decided that it's worth the effort because there have been reports of total seizure control when correctly maintained. Dr. Zimmerman warned us that Cynque' will have to be hospitalized for the first week to two depending on how he takes to the diet. It will also

require a dietitian to follow Cynque' to ensure that he stays on the diet. If all goes well in that two-to-three-year period on the diet and he is seizure free, Cynque' will be weaned off of the diet and reintroduced to regular foods.

For a parent, this is all very overwhelming. Not only are we dealing with all of Cynque's seizures but a dramatic lifestyle change with this diet. Why are we considering this drastic lifestyle change? Because if Cynque' does not take to the diet, he will have to stay on medications. That means the only alternative may be brain surgery to stop the seizures. That's not an option we want to have to take!

So, we take life day by day to make sure that Cynque' is safe. He enters the hospital on April 23, 2007 to start the diet. Our dream is that he will accept it, and become seizure free so that he can live a better life. And so can we.

**For more information on
seizure disorders visit the**

Epilepsy Foundation

**www.epilepsy
foundation.org**

**or call at
(800) 332-1000**

Team Conor's Lemonade Stand

Sisters Maura and Tara Grier raised \$91 at their lemonade stand for their brother Conor's walk team for the "Walk the High Road for Autism Walk" which was held on April 28th at Bellevue State Park.





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Childcare is available at all regular ASD chapter meetings. Please contact the office at 302.472.2638 or delautism@delautism.org two days in advance.

ASD Chapter Meetings

- ▶ **May 2007** — There is no chapter meeting in May.
- ▶ **June 2007** — There is no chapter meeting in June
- ▶ **July 2007** — There is no chapter meeting in July.
- ▶ **August 2007** — There is no chapter meeting in August.
- ▶ **September 2007**— ASD Chapter Meeting, 7:00 p.m. Exact date and location TBA. Pivotal Response Training, Kennedy Krieger.

Social Events, Public Awareness & Fundraisers

- ▶ **May 8, 2007** — Parent’s Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9:00 a.m. More information on page 9.
- ▶ **May 12, 2007** — ASD Kent County Skating Party—Milford Skating Center, 1 Park Ave., Milford, 5:30 –7:30 p.m. Autism friendly lights and music. Closed to the general public. Free admission. \$2-3 skate rentals, snack bar open. No RSVP needed. Bring friends and family!
- ▶ **May 18, 2007**—Teen Game Night. For information contact Heidi Mizell, (302) 472-2638 or heidi.mizell@delautism.org.
- ▶ **May 19, 2007** — ASD Day at the Wilmington Blue Rocks
- ▶ **May 26, 2007** — Mom’s Night Out, 7 p.m., Location TBA. More information on page 9.
- ▶ **May 31, 2007**— Drive for Autism Research Celebrity-Am Golf Outing. DuPont Country Club, Wilmington.
- ▶ **June 12, 2007** — Parent Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9:00 a.m. More information on page 9.
- ▶ **June 12, 2007** — Dad’s Night Out. Time and location TBA. More information on page 9.
- ▶ **July 10, 2007** — Parent’s Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9:00 a.m. More information on page 9.
- ▶ **July 23-25, 2007** — Summer Institute on Adults on the Spectrum. More information on page 14.
- ▶ **July 28, 2007** — Mom’s Night Out, 7 p.m., Location TBA. More information on page 9.
- ▶ **August 7, 2007** — Parent’s Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9:00 a.m. More information on page 9.
- ▶ **August 7, 2007** — Dad’s Night Out. Time and location TBA. More information on page 9.
- ▶ **August 19, 2007** — ASD Day at the Beach Picnic, Cape Henlopen, Lewes. More information on page 12.

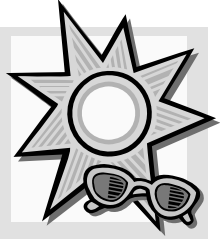
Support Groups

Parents/caregivers of an individual with an autism spectrum disorder are welcome. (Autism, Asperger’s Syndrome, PDD-NOS). The New Castle County evening support group meetings are held on the third Tuesday of every other month.

- ▶ **June 19, 2007** — ASD’s N.C.C. Support Group — South Wilmington. Meetings are held on the 3rd Tuesday of every other month and are facilitated by Kathy Hupp. Meetings are held at 7:00 p.m. at the ASD office, 5572 Kirkwood Highway, Orchard Commons. The next support group is schedule for August 21, 2007.

Other Events

- ▶ **July 11-14, 2007** Autism Society of America 38th National Conference & Exposition, “Together a Brighter Tomorrow.” Phoenix, Arizona. Together a Brighter Tomorrow reflects our mission that it takes perspectives of all those affected by autism — individuals, families, professionals and friends—to achieve success. For more information or to register: www.autism-society.org or call (800) 3AUTISM.
- ▶ **October 22-23, 2007**— Kennedy Krieger Institute’s Center for Autism and Related Disorders Annual Conference, “Autism: Early Detection and Intervention in Infants and Young Children— From Neuroscience to Intervention.” The Conference Center at Sheppard Pratt, Baltimore, MD. For more information, please call (443) 923-7680 or (877) 850-3372, email schmidtk@kennedykrieger.org or visit www.kennedykrieger.org.



Summer Fun in the Sun



ASD will be holding it's 9th Annual Summer Picnic at Cape Henlopen State Park, Lewes, DE.

August 19th, 10 AM to 4 PM, Rain or Shine.

Lots of Food, Games, **food**, swimming, **food**, **sand**, and did we mention, **FOOD?** We'll provide hot dogs, hamburgers, rolls, and drinks. You bring a side dish, dessert, (or maybe both!) to share, beach towels, chairs, OH...and the kids, too! There will be a train ride and an obstacle course. This is one of our most popular events so don't miss out on a great day of fun at the beach!

Please RSVP by August 15th, so we can have enough food. Email: delautism@delautism.org or (302) 472-2638.

Reminder!!!

Don't forget about all of the summer recreational resources that ASD published in the last issue of *The Sun*. You can find the complete list on line at: www.delautism.org/recreation_resources.htm or you can call the ASD office at (302) 472-2638 to request a copy.

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Elkton, MD 21921
(410) 395-6900

High Road School of Baltimore County
7707 German Hill Road
Baltimore, MD 21222



Thank you to the following sponsors of ASD's first annual walk –Walk the High Road for Autism, held on April 28, 2007. Photos from the walk can be found on the ASD website at: www.delautism.org

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Friend Sponsors



Supporter Sponsors

Neurology Associates Delmarva Power Bestfield Properties
McConnell Development, Inc. Alliance Personnel Pyramid Educational Consultants, Inc.

Step Sponsors

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Delaware Academy of Family Physicians Samantha Balick Sun Trust Mortgage

Water Sponsors

Linda Felicetti of Patterson Schwartz Glazar Brothers
High Road School of Cecil County Sun Trust Mortgage

Thank You and See You Next Year!!



Summer Institute on Adults on the Spectrum



We are excited to announce that ASD will be sponsoring a major training session on adults with spectrum disorders with the Division of Vocational Rehabilitation, the Department of Education, and the Division of Developmental Disabilities Services. This will be for a 2 ½ day session of the Summer Institute of the Division of Substance Abuse and Mental Health.

Adults on the Autism Spectrum—Success in the Community and the Workplace

When: July 23-25
 Where: DSAMH Summer Institute at Clayton Hall
 Trainers: Dr. Peter Gerhardt, President, Organization of Autism Research
 Dr. Jed Baker, Social Skills Training Project

Adults with Autism Spectrum Disorders such as Asperger Syndrome, PDD-NOS, non-verbal learning disorders, and high functioning autism are often misdiagnosed and misunderstood. This workshop highlights what these disorders are; common mental health issues; how to recognize their particular attributes; why social and communication issues are so important, and provide important tools about how to address the unique issues of adults on the spectrum.

Individuals with ASD's often struggle in personal, sexual, work and social situations due to their lack of understanding of the unspoken or hidden rules of social interaction. Managing anxiety, frustration, and anger are critical to success. This course will highlight critical social skills needed for an individual to be successful in personal and work arenas, and provide insight into teaching these highly needed social skills.

Dr. Gerhardt will address the issues of those with dual diagnoses and how they manifest themselves in the three areas of employment, sexuality, and the criminal justice system. He'll talk about potential interventions, and planning for the future.

Dr. Baker will identify key social skills needs and the typical skills that are missing. He'll address the skills that students who are transitioning to adult life, college, and work need to be successful. Keys to his presentation include:

- Motivation – does the person buy into the need for learning these skills?
- Skill acquisition – does the person know what to do
- Generalization – can they use it when they need to
- Acceptance by the community—are these folks accepted by the community?

For more information about registration, contact Chris Knox at DSAMH, telephone (302) 255-4450, or christopher.knox@state.de.us.



*ASD Spring Egg Hunt—March 31, 2007
Carousel Park, Pike Creek*

On your mark...

Get set...

GO!!!



Thank you to the ASD Social Butterflies,
Nicole Curran and Robin Delany for putting
together yet another great social event and experience for our families!



Who We Are



Who am I?

My name is Jennifer Nardo. I have two sons: Frankie (10 ½) attends St. Edmond's and Jake (9) attends the Brennen School. Jake was diagnosed with Fragile X Syndrome shortly before his second birthday, and he was diagnosed with autism 1 ½ years ago. My husband, Frank, and I have been married for over 15 years.

What do you do?

I am a stay-at-home mom. Besides my home and family responsibilities, I volunteer with ASD, at St. Edmond's serving lunch, and with FRAXA; the Fragile X Research Foundation. In my "spare" time, I like to read and am active with a local book club.

How long have you been with ASD?

Shortly after Jake started attending Brennen, I started attending the Parent Coffee Hour sponsored by ASD at Crossroads Restaurant. It was a great experience to meet other parents and make connections. As I got to know more about

about what ASD does, I saw that I might be able to help out. I am now active with the Public Awareness Committee by writing articles and just being part of the brainstorming efforts by the committee.

Why do you do this?

I think that the only way to make a difference is to be involved. I'd like to see greater strides in Fragile X research so I raise money for it. I want the world to know how stressful and scary it can be to raise a child with autism so I spread the word trying to get people to take notice and get involved. I hope the phrase; "the squeaky wheel gets the grease" is true.



Who am I?

My name is Judy Hedrick and the grandmother of James Cipolla, who is 7 years old. James was diagnosed with autism in 2003 and is in the Brandywine Specialized Autism Program at Darley Road Elementary School.

What do you do?

I retired from DuPont in 2002 after 32 years of service. Retirement gave me the opportunity to spend more time with my grandson and allow my daughter and son-in-law to work full time.

How long have you been with ASD?

I've been with ASD almost 4 years. I volunteer 2 days a week in the office and am involved in the golf outing, autumn auction, Newsletter editing, and Walk the High Road for Autism. I assist with large mailings, filing, or whatever is needed. No job is too insignificant!

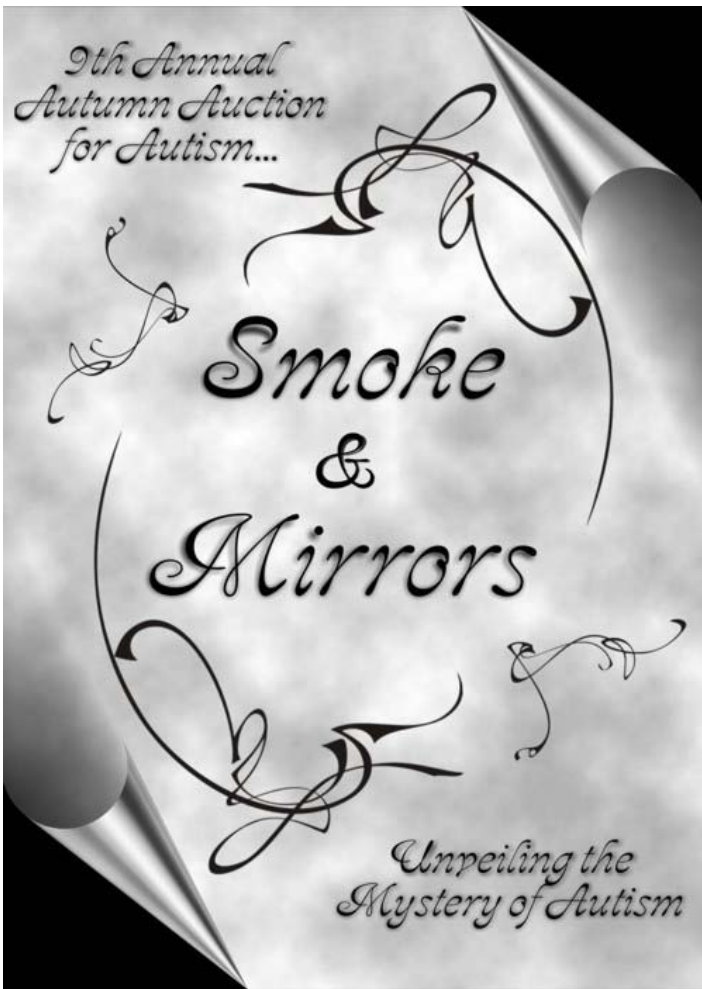
Why do you do this?

When my grandson was diagnosed with autism, I went through all of the inescapable emotions. My feelings of helplessness and despair turned into a positive factor when I talked to Alison Kortanek. I wanted to volunteer my time, energy and skills to do anything to MAKE A DIFFERENCE. Alison talked to Theda, and the rest is history. Volunteering is my way of saying thank you to ASD for their support. I know my grandson will have a richer quality of life because of the ASD family. I KNOW I DO.

Safety Tip

Emergency Evacuation
Planning Guide for
People with Disabilities

[http://www.nfpa.org/
evacuationguide](http://www.nfpa.org/evacuationguide)



October 20, 2007 Greenville Country Club

Honorary Chairs

FOX News Co-Anchor Dawn Stensland &
CBS 3's Eyewitness News Anchor
Larry Mendte

Featuring Music by:

Club Phred
www.clubphred.com

Magic by:

Chad Juros
www.magicalchad.com

Dinner, Dancing, Live and
Silent Auction, a fun evening for a great
cause!

Help out ASD over the summer...

Get involved with collecting auction items.

It's easy! Just contact ASD for an information packet with a guide on how to get items. Some of the categories of items we are looking for are: Wine, Jewelry, Artwork, Holiday Fun, In the Kitchen, Home Décor, plus the always popular Gift Certificates to Restaurants, Spas, Hotels, Shopping and other services. Also popular is Sports Memorabilia and Tickets to Events, and Children's Toys and Games. And don't forget those one of a kind items...they are always a hit!

Auction sponsorships opportunities are available.

Interested in sponsoring the auction? We have many levels of sponsorship available! Call ASD at (302) 472-2638 for sponsorship information. Invitations for seats and tables will be sent out in September.

Autism Society of America Membership Application

Please enroll me in the following category:

Student \$15 Individual \$30 Family \$40 Outside USA \$50 Professional \$100 Agency \$500
 Life \$1,500

I am a new member I am renewing membership

Name (s): _____

Address: _____

Phone: (h) _____ (w) _____ Email: _____

Employer or professional background: _____

I am joining through ASA's local chapter named the Autism Society of Delaware.

I am a: Parent Family Member Service Provider Educator Medical Professional
 Individual with Autism Other (please describe): _____

Yes! Please add my name to the mailing list to receive ASD's newsletter *The Sun*. **(This is for families who do not receive *The Sun* through DAP Distribution only please.)**

My membership fee is..... \$ _____ Date: _____
I would also like to contribute this amount directly to ASD \$ _____
Total amount enclosed (add both amounts)..... \$ _____

Please make your check payable to the Autism Society of Delaware (ASD) and send the check and application to ASD, 5572 Kirkwood Highway Wilmington, DE 19808. All membership fees and contributions are tax deductible.

The Autism Society of Delaware
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Wilmington, DE 19808

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