## Detachable Monthly Calendar

# November 2007

Autism Society	of Delaware		(302) 472-2638		www.d	lelautism.org
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1	2	3
4	5	6	7	8	9	ASD N.C.C. Skating Party 5:15—7:15 p.m
11	12	13 Parent's Coffee Hour 9:00 a.m.	ASD Chapter Meeting Dover 7 p.m.	15	16	17
18	19	20 ASD N.C. & Kent County Support Groups 7:00 p.m.	21	22 Happy Thanksgiving! ASD Office Closed	23 ASD Office Closed	24
25	26	27	28	29	30	

# The Sun The Voice of Autism in Delaware

Detachable Monthly Calendar

# December 2007

Autism Society of Delaware			(302) 472-2638			www.delautism.org	
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	
						1	
ASD Family Holiday Parties N.C.C. & Kent County		4	5	6	7	8	
9	10	11 Parent's Coffee Hour 9:00 a.m.	12	13	14	15	
16	17	18 N.C.C. Support Group 7:00 p.m.	19	20	21	22	
30	ASD Office Closed  ASD Office Closed	25 ASD Office Closed	26 ASD Office Closed	27 ASD Office Closed	28 ASD Office Closed	29	



# The Voice of Autism in Delaware

# The Sun

The Autism Society of Delaware Newsletter

www.delautism.org

November/December 2007

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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.

# Respite Wrangling—Are You Entitled??

By: Robin Ireland

An envelope falls through the mail slot with your name written in calligraphy on the front. Maybe it's an invitation to your best friend's wedding, or to a black tie dinner benefiting your favorite charity. Either way, it's a chance for you to get out of the house and forget about stimming and PECS and how to hide vegetables inside a chicken nugget.

Can you accept?

If you live in Delaware, the answer is probably yes. Our In-Home Respite program is the envy of parents in surrounding states. Under the terms of this program, which is written into state law and administered by the office of Statewide Director of Autism Dr. Peter Doehring, a DAP affiliated teacher or paraprofessional will come to your house and baby-sit your child with autism – for less money than hiring the teenager down the block.

But because DAP and affiliated state-approved programs for children with autism are growing so quickly, Doehring felt it necessary to spell out the terms of respite and make some minor changes to ensure consistency statewide and resolve any outstanding legal liability issues. He addressed the Brandywine Specialized Autism Program (BSAP) Parent Advisory Committee in September to outline those

changes. It was standing room only. First, the things that won't change: each parent of a child with a primary educational classification of autism and enrolled in a district operating a stateapproved affiliate of DAP is entitled to 24 hours a month of respite care. You also get seven complete days of respite each year, which means you can take your respite provider on vacation or (shocker!) take one yourself. You can choose your respite provider, almost all of whom are teachers and paraprofessionals in your child's school. And there will be a respite coordinator in your school to help you find a provider. The costs range from five to 25 percent of the statewide fee of about \$16 an hour.

Respite still needs to be planned in advance with your school's coordinator. Respite providers need to have undergone safety training, background and medical checks and have a job that provides "ongoing and meaningful" contact with students with autism. They also must not be under a performance review or on a leave of absence from their job. Respite is not guaranteed. Only a small percentage of a school's teachers generally want to provide respite, so early planning is still recommended.

But there are some changes to the

(Continued on page 3)

r provided by:

AstraZeneca

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#### The Sun

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# The Director's Chair

By: Theda Ellis, Executive Director

Writing the director's column is always a challenge. Sometimes it just flows like a stream of consciousness, and sometimes it's like pulling teeth! That's how it feels this month. It's a quiet fall afternoon with only two of us in the office. The quiet is blissful! The days of being mostly alone in the office in the Kempner home are long gone. Now we have 8 staff, office volunteers and POW&R participants coming in and out. It gets very BUSY to say the least!

It's a great busy! It means we have grown and are moving forward. ASD has talked about adult services for the past five years, investigated best practices three years ago, we began to plan services and supports two years ago, and raised money so that we could begin this service over the entire time. It's finally here—POW&R is up and running and there are two young men who are receiving services and supports in the community. Just as important, there are five students in their final year who have chosen POW&R to be their adult provider and their services will begin before you receive this newsletter. You may wonder "What is ASD going to do for students?" These five are part of the Early Start to Employment project –a joint project of the Department of Education, the Division of Vocational Rehabilitation and the schools. It has been a trial for the past three years, and is becoming a permanent part of the service scene in Delaware. POW&R staff will be meeting with these individuals and their families and working with them at school to get to know them. We need to learn what they like to do and what they do well; then we'll be working with them to find jobs. The intent is that these students will be employed by the time they graduate and that POW&R will know these young adults and their support needs very well so that their move to the adult service system is seamless. Our goal is for the day of formal transition to go by unnoticed because the real transition has already occurred.

We have been "preaching" what needs to be done for quite some time. Now it's time to practice what we preach. Watch in future editions of *The Sun* for more information about what is happening with our adults with autism. And by the way, if you are in a position to hire individuals with autism, please contact us. We will be looking for employment opportunities for our folks!

~ Theda



A Service of the Autism Society of Delaware

Productive Opportunities for Work & Recreation

Katina Demetriou (302) 824-2252 (cell) Project Director (302) 472-2638, ext 207 Karen Anderson (302) 824-2253 (cell) Community Specialist (302) 472-2638, ext 207

katina.demetriou@delautism.org

karen.anderson@delautism.org



## Respite Wrangling

(Continued from Cover)

to the program, too. Respite is intended to provide a short term break for parents. It is not child care. Because teachers generally work an hour or so beyond the school day, it may become harder to get respite care directly after school. The school's principal will need to approve such requests. All respite needs to be arranged either in writing or by email.

In the past, respite workers could agree to baby-sit typical siblings for an additional fee arranged privately between the worker and the parent. Doehring isn't sure whether that policy will continue. Parents at the BSAP meeting expressed concern that respite would be useless unless a typical sibling could also be watched. Also at issue is whether parents of more than one child with autism could use one respite provider. Doehring said he would get feedback from parents, examine the issue further and decide in the coming months.

Respite workers also must fill out a more extensive registration form, especially those who wish to watch children in their own homes. Respite providers who take children into their homes will have to provide information about whether anyone in the house has a criminal record, where and if they keep guns and the extent to which their house is child-proofed. Additional forms also are required if the respite provider intends to take the child for a community outing that might be considered more dangerous, such as a pool.

There is also a new set of forms designed to tell the respite provider about the child with autism. It includes information about how best

to handle a meltdown, what skills the child might have, how he sleeps, if he is potty trained and if he uses communication aids like PECS or signs. There is also detailed information about a respite provider's driving record and a separate permission slip to be used if the provider will be driving a child.

Respite is still overseen by Doehring's office. And a committee from each Parent Advisory Committee will meet yearly to review guidelines. To register for respite, contact the facilitator for your school district. For more general information about In-Home Respite, call Joan French, Assistant Principal for Extended Services at 302-454-2202, extension 103 or email her at frenchj@christina.k12.de.us

Editor's Note: This article talks about DAP families being "entitled" to respite. This is not quite true because the DAP administration cannot force its staff to provide this service. ASD understands that some families, particularly those whose children have medical needs or particularly difficult behaviors, have a difficult time finding a respite worker willing to provide the service.

Looking for a way to help out? Look no further...

The ASD Walk the High Road for Autism
Committee needs you!



Contact: Kim Siegel Kim.siegel@delautism.org (302) 472-2638, ext 204

# ASD New On-Line Support eGroup



This group is for parents, guardians or any family member who has a care-taking 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.

The group is maintained by two parents. Cheryl Frampton is the group manager and will take care of memberships and technical issues. Kathy Hupp, who has a master's in social work, will serve as the moderator for the group. Kathy will be available to help you address your specific needs. If you feel you need more support than the on-line group can provide or feel you need to consult with Kathy privately, you may email her directly with your concerns. You may also contact Kathy about attending one of the live support group meetings.

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





Please welcome the following new members to ASD...

Ayse Kural
Jennifer Rineer
John & Pat Swanson
Valerie Wells
Adymka & Omar Reid
Steven & Becky Hill
Alexandria Hutchinson
Samavia & Douglas El
Joe & Deanna Principe
Yong & Siu Andersen
George L. Johnson, Jr.
Peter C. Vanlandingham

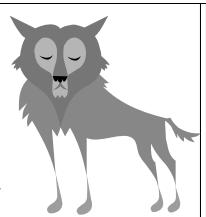
# **ASD Options Policy**

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.

# Wolf is Coming Back!

Two years ago 60 parents and family members came to hear three adults with autism talk about what it's like to have autism. It was a fascinating evening for all of us. We have stayed in touch with Wolf Dunaway from Baltimore. Wolf will be returning to share his experiences at the November chapter meeting in Dover. We shared that he had received a promotion a few months ago. When re-



minded about the upcoming meeting, here is what Wolf had to say.

"I have done a lot of personal growing since you all saw me last. I have a lot of really awesome insights to share with you on many levels so I hope everyone comes armed with awesome questions because I will likely have great answers. My book is almost finished and that has me happy. The book is going to be a blast at helping others with autism and those who know or care about us. I am looking forward to your event and 60 minutes 90 minutes 120 minutes— I am autistic you can't wear me down so do not worry about that at all. I enjoy helping others so time is not an issue with me. You are spending a LOT of money to bring me there and I want everyone who attends to feel they got more than their money's worth from my visit so tell everyone come armed with there best questions, because I am ready willing and able to discuss anything on their minds."

#### This is a MUST see for any parent!!!

When: 7 p.m. November 14, 2007
Where: Charlton School Cafeteria
278 Sorghum Mill Rd
Camden, DE 11934

Child care is available. You must call the office at (302) 472-2638 seven days prior to the meeting for childcare. Please provide your name, day-time phone number, your child's name and age. We cannot guarantee childcare to anyone who calls after the deadline. If you called to request childcare and are unable to attend, please call the office and let us know.

Next Deadline for Submissions to The Sun: December 3, 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,

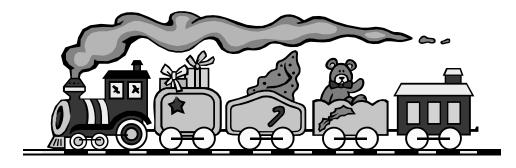
(address on page 2) Let Your Voice Be Heard!

ASD reserves the right to edit for space and content.



# ASD Family Holiday Parties

One Day + Two Parties = Lots of FUN! Sunday, December 2, 2007



# **New Castle County**

Del Vets—North Wilmington from 1-4 p.m.
RSVP by November 29 at (302) 472-2638 or delautism@delautism.org
Bring an appetizer or snack to share...
Door Prizes, Arts & Crafts,
Pictures with Santa, Crafts and Entertainment by Miss Vicki!

**Kent County** 

Wyoming United Methodist Church, Broad Street, Wyoming from 2-4 p.m. RSVP by November 29 with Kate Stomieroski at beazelbeak@juno.com or (302) 734-4884.

Mr. & Mrs. Claus, Ronald McDonald to perform magic and juggling, Music and Games...Be ready to Limbo and Chicken Dance!

Please bring a snack to share.

Volunteers are needed at the Kent County Party for set up and clean up. If you are available to help, please give Kate a call and a hand!

**Happy Holidays From Everyone At ASD!** 



# Inside The

#### Support Group Happenings

It is time to re-think what a support group means. Around the country parents are not using support groups like they used to. We do not know if this is because parents are busier than they used to be: if the internet has met that need; if time of day or child care are issues, but we know that organizations around the nation face the same challenge. We also know that parents need support, so ASD is going to try some new approaches in New Castle and Kent counties. For the first time, ASD is charging a \$10 co-pay for each session, and require participants to register for each series of the first three sessions.

# Kent County Support Group Is Beginning

ASD is contracting with Dr. Janet Asay of Perspectives in Counseling in Dover to offer three sessions to start. If we have enough interest, we will continue to support this group. If not, we'll consider it a trial and try something else. If you are interested, please contact the office and send your checks. The sessions will be held on October 23 and November 20 in her office at Treadway Towers, 9 E. Loockerman St. Dover, DE. The January date will be set later. Kate Stomieroski will be the local contact person. You can reach Kate at (302) 734-4884 or via e-mail at beazelbeak@juno.com.

# New Castle County Support Group is Revamped

In New Castle we are taking a different approach. Kathy Hupp, MSW, will continue to lead the group, but we are changing the location so that we can offer child care. The new group will be held at the Special Olympics Office, 619 South College Ave, Newark, DE. Kathy is also interested in using a conference call approach so that participants could call in and speak with her. We set this up to begin at the regular October meeting. Like the Dover project, we will try this approach for three months to see how well it works.

# Volunteers and Volunteer Coordinator

Organizations like ASD are only as strong as our volunteers. We have been lucky to have a great volunteer base, and we are currently working to strengthen it with good support from our membership.

Long time volunteer Judy Hedrick has taken the role of Volunteer Coordinator and you can look for a call from Judy to help with various ASD events. She is currently recruiting volunteers to man community events and conferences with the ASD board, and she also will be recruiting volunteers to assist with our many mailings, social events, and fundraisers. This is a critical position, and we're thrilled that she has accepted it.

We would like to welcome
Joanna Francis who has just joined
the Social Committee—helping
Nicole Curran and Robin Delaney
with ASD's family parties; Bob
Dunlap and Tony Casale have
joined the Recreation Center Committee; Denise Bradley is chairing
the Program & Legislative Committees; Valerie Wells is helping with
the auction; and Bob Dunlap
(again), Greg Burch and Tiffany

Schwartzberg have joined the Walk Committee. Becky Hill helped with auction invitations and it was great to see Betsey Gray home from Europe who helped along with her sister, Sarah Rogatz and Sarah's handsome and productive sons. We would also like to welcome Jeanette Johnson and Sharon McDaniel whose only connection to ASD is their desire to help out. Jeannette and Sharon will occasionally be working at fundraisers and social events to lend an extra helping hand. Thanks to all of you.

#### Parents Can Be the Key

The Department of Education (DOE) and the Parent Information Center (PIC) recently collaborated to update the booklet Parents Can Be the Key to include the recent changes in IDEA about procedural safeguards and the special education process. This is a user-friendly booklet for parents, and it is intended to go out to 15,500 special education students in Delaware. ASD is making a \$5,000 contribution to assist the PIC with printing costs so that all students with disabilities in Delaware and their families can access easy to understand information about their rights and safeguards.

#### **CLASS Act**

ASD is in the process of requesting our national delegates, Senators Carper and Biden and Congressman Castle, to cosponsor the CLASS Act (S. 1758/H.R. 3001). ASD is supporting this proposed legislation earlier in the process than we normally do; however, we believe that this legislation has the potential to make a huge difference in helping people to help themselves. The bill would create a national insurance program in which individuals with disabilities who meet functional eligibility



## Inside the ASD

(Continued from page 6)

criteria could secure certain necessary supports. Currently, individuals must limit employment and other means of building assets and income to qualify for Medicaid. The CLASS Act program would be financed through payroll deductions.

#### Potential benefits are:

- 1. It will have minimal impact on the budget and may reduce Medicaid spending
- 2. It will encourage employment, and promote integration and independence
- 3. It will offer individuals choices of supports through vouchers, and
- 4. It will allow people with disabilities to obtain supports without forcing themselves into poverty.

We believe that this fits hand in glove with the intent of the Family Support Waiver, the Medicaid Buy-in that allows individuals with disabilities to purchase health insurance through Medicaid, and other major legislation. Look for more on this important legislation in future newsletter issues.

# **Check Out the ASD Community Bulletin Board**

http://www.delautism.org/bulletinboard.htm

The ASD Community Bulletin Board is a place where individuals or groups may post announcements for services available, seeking services, individual fundraisers or social groups/activities for the autism community.

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.

To have your message posted on the ASD Community Bulletin Board, email your requests to cheryl.frampton@delautism.org. Messages will stay up on the board for 30 days. If you wish to repost your message after 30 days, you must resubmit your request. ASD reserves the right to edit posts for space and or content or may deny a post if it is deemed inappropriate by ASD.



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Making Success Personal

# TOY HAZARD RECALL INFORMATION

With all of the toy recalls, the fact that many of our children put things in their mouths long after the typical age, and with the holidays upon us, we thought we would share a website that lists all of the recent toy hazard recalls through the US Consumer Product Safety Commission.

## http://www.cpsc.gov/cpscpub/prerel/category/toy.html

Please visit the site listed above for all of the latest in toy hazard recalls. You may also contact them at (301) 504-7923 M-F 8:00 a.m.— 4:30 p.m. ET or e-mail at: info@cpsc.gov.





# Call for Volunteer Recognition

Every year both ASD and the autism community get stronger because of the efforts of great volunteers. ASD has been recognizing outstanding volunteers and employers over the past five years. It's time again to call to the membership to submit nominations for Outstanding Volunteers.

Volunteer awards fall into several categories. We like to honor those of you who have supported ASD, and we also recognize others who have helped the general autism community either directly or indirectly.

#### Outstanding ASD Volunteer (Individual and/or Group)

This award recognizes a volunteer or group for outstanding services that directly benefit the Autism Society of Delaware. Past examples include services that range from organizing social events to developing a cookbook.

#### **Services to the Autism Community**

This award recognizes a volunteer or group for outstanding services that benefit the autism community in general. Past examples have been the development of a bike camp or providing work sites for students. It would also be appropriate to nominate local employers that offer volunteer opportunities.

#### **Outstanding Employer**

This award recognizes an employer that has made a significant contribution to the employment of individuals with autism. This may include, among other things, the provision of supports in employment, advocacy for employment and actual employment of persons with autism.

And just because life never fits neatly into categories, if you have a nominee for someone who does not fit neatly into these categories, please contact the office and we can provide some assistance.

#### Please submit nominations by January 18, 2008.

You must be a member of the Autism Society of Delaware to nominate someone for an award.

# Marie Contraction of the Contrac

# **Volunteer Recognition Nomination**

Your Name:	Your Phone:				
Email:	ame of Person/Business you wish to nominate:				
Reason why you wish to nom	ninate this person/business:				
	·				
Nature of the Volunteer work					
	Who Was Impacted?				
Nominee's address:					
City:		Zip:			
		vening:			
,		<b>6</b>			
Please send your nomination by	/: January 31, 2008:				

Autism Society of Delaware 5572 Kirkwood Highway Wilmington, DE 19808 Attention: Volunteer Recognition or e-mail at: delautism@delautism.org

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

**Autism Society of Delaware** 

The next Mom's Night Out will be held on Saturday, January 19, 2008 at Casablanca's Restaurant in Wilmington. Come on out to celebrate the new year!

Moroccan food, male and female belly dancers...can it get any better?!?

To RSVP contact Monica McMahan at (302) 235-2101 or email m.mcmahan28@comcast.net by January 17, 2008.



February 12, 2008
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:

Mark Frampton mark@designbycher.com (302) 998-1466





# Asperger's HFA Teen Game Night Out - Space is Limited!

When? November 16 and December 14 - 6:15—8:15 p.m.

Where? Neurology Associates, 744 Christiana Road, Newark

What is it? Game night for teens ages 13 to 19

How Much? \$10 per session

Join us for an evening of fun! Board games, activities, snacks and socializing! RSVP is required. Contact Heidi Mizell at (302) 472-2638, ext 205 or heidi.mizell@delautism.org. Don't wait, space is limited to 12 participants. Feel free to bring your own board games to share!

# PARENT'S COFFEE HOUR

# The Second <u>Tuesday</u> 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!



The PAC of the DAP at the Brennen School Families eGroup.

If you have a child attending the DAP program through the Brennen school or any of its satellite classes, join today! This group is an open forum for parents to discuss issues and activities through the school and PAC. To join send a request to Deanna Principe at deannap203@comcast.net



# Parent 2 Parent

# New Levels of "Child Proof"

By: Melanie Matusheski

A recent incident reminded me to never become complacent about keeping my son safe. Robert was sitting at our kitchen island late on a Sunday night a few weeks ago. The island was cluttered with dishes and things from the pantry. His prescription bottle of Clonidine was also there. I didn't know it at the time, but apparently he sat there and slowly rubbed the label off the bottle and when he was done with that he opened the "child-proof" cap and took several of the Clonidine, many more than his usual dosage. I put him to bed without realizing what he had done. The next morning when he could barely stand up, I knew something was wrong.

Eventually, I figured out what had happened, contacted the pharmacist and school nurse and took him to the hospital Emergency Room. Because Clonidine is used as a heart medication in adults. they kept him overnight to monitor him. Fortunately, he was fine the next morning. Needless to say, though, it was a very frightening, stressful experience. I never in a million years thought he would take the Clonidine on his own. I usually crush it up and put it in a fruit rollup for him. But that was my mistake - thinking that because he had not done it in the past, he would never do it. He has been changing a lot recently. Although most of the changes are positive, I shouldn't have assumed that they would all be.

I'd long ago stopped thinking

about keeping a "baby-proof" home. Now I realize I should still be thinking that way, especially when it comes to prescriptions and household items. Also, over-the-counter drugs should be kept out of reach. Vitamins, in particular, can be very dangerous if children take too many of them.

The number to call for a poison emergency is 1-800-222-1222, at the National Capital Poison Center. Their website, www.poison.org has lots of information about poison prevention and lists of harmful household items.

New Levels of "Child Proof" Safety Tips; For Parents, By Parents

By: Cheryl Frampton

As our kids get older, they can reach things that a typical toddler could not, so it is often necessary for parents to stop and reevaluate what "child proof" means to their home at different ages. If you rent you may want to ask your landlord if there is any problem with making adjustments.

- ~ If necessary, have a pantry or cabinet with a pad or combination lock to store medications, vitamins and other everyday medical supplies. A lot of our kids use edible reinforcers like M&M's, Skittles and jellybeans. Many times these reinforcers look a lot like many of the medications and vitamins we take.
- ~ Hook and eye locks are a great and cheap way to control the flow of traffic in your home. You can

# written by parents for parents

control what rooms your child has access to this way by placing the locks at the very top of doors.

- ~ If your child is tall enough to reach a hook and eye lock, try using an inexpensive door alarm. You can purchase them at any hardware store and they just stick to the door with double sided tape. These also work well on windows.
- ~ If you have a child who hits windows, a great idea is to go get a piece of Plexiglas cut to the size of the window frame (not the molding outside of the window.) Get some heavy duty Velcro and use that to stick the Plexiglas to the window. If they hit the window, they will not get hurt (at least not from broken glass) and the window will be spared. With the Plexiglas stuck on with Velcro, you can remove it to clean when necessary and this also does not prevent you from opening your windows.
- ~ Always use outlet covers, no matter what age your child is.
- ~ Turn your hot water heater down and make sure it is set no higher than 120°F. Our kids love water and if they decide to turn on the sink or tub they can receive 1<sup>st</sup>, 2<sup>nd</sup> or even 3<sup>rd</sup> degree burns if the water is set too high.
- ~ If possible, remove knobs from ovens anchor TV's to the wall or place them on the floor.
- ~ Keep all cleaning chemicals locked up and keep a list of emergency phone numbers on the fridge.

(Continued on page 12)



# **Autism Society of Delaware**

Page 11

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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 no less than 7 days in advance. Childcare registration is mandatory.

# **ASD Chapter Meetings**

- ▶ **November 14, 2007** ASD Chapter Meeting, 7 9 p.m. Charlton School, Dover (following PAC meeting) Guest Speaker: Wolf Dunaway. More information on page 8.
- ▶ December 2007— There is no Chapter Meeting in December.
- ▶ January 8, 2008 ASD Chapter Meeting, location and time TBA.

# Social Events, Public Awareness & Fundraisers

- ► November 10, 2007 ASD N.C.C. Roller Skating Party, Christiana Skating Center, Newark. 5:15 7:15 p.m. No RSVP needed.
- ► November 13, 2007 Parent's Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9 a.m. More information on page 9.
- ▶ November 16, 2007—Asperger's Teen Game Night. 6:30—8:15 p.m. Neurology Associates. Heidi Mizell, heidi.mizell@delautism.org or (302) 472-2638, ext 205. Next AS Teen Game Nights scheduled for December 14. More information on page 9.
- ▶ December 2, 2007 ASD N.C.C. Family Holiday Party, Del Vets, Wilmington. 2 4 p.m. More information in next issue of *The Sun*.
- ▶ December 2, 2007 ASD Kent County Family Holiday Party, United Methodist Church. 2 4. p.m. Contact Kate Stomieroski at beazelbeak@juno.com for inquiries. More information on page 5.
- ▶ December 12, 2007— Parent Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9 a.m. More information on page 9. The next Parent Coffee Hour will be on January 8.
- ▶ December 14, 2007—Asperger's Teen Game Night. 6:30—8:15 p.m. For more information contact Heidi Mizell, heidi.mizell@delautism.org or (302) 472-2638, ext 205.
- ► January 19, 2008 Mom's Night Out. Casablanca's Restaurant, 7:00 p.m. For contact information see page 9.
- ► April 26, 2008 Walk the High Road for Autism. More information on page 17.

Parents/caregivers of an individual with an autism spectrum disorder are welcome. (Autism, Asperger's Syndrome, PDD-NOS). Support groups cost \$10 per session, payable at the time of the meeting. For more information on ASD's new support groups, visit us on-line: www.delautism.org or call us at (302) 472-2638.

# Support Groups

- ▶ November 20, 2007 ASD's N.C.C. Support Group Special Olympics Office, Route 896, Newark. Meetings are held on the 3rd Tuesday of every other month at 7:00 p.m. and are facilitated by Kathy Hupp. Childcare is available for the N.C.C. Support Group. You must call 7 days prior to the meeting to obtain childcare. The next New Castle County Support Group will be held on December 18, 2007.
- ▶ November 20, 2007 Kent County Support Group, Perspectives Counseling, Treadway Towers, 9 E. Loockerman St. Dover, 5:30 p.m. Dr. Janet Asay of Perspectives Counseling will facilitate the new Kent County Support Group. December date to be determined.

Other Events

- ► December 3-4, 2007 PECS Advanced Training, Pyramid
  Educational Consultants. Holiday Inn, Philadelphia Historic District, Philadelphia, PA. Contact: Stefanie
  Levendis: slevendis@pecs.com or visit their website: www.pecs.com.
- ▶ April 4-7, 2008 DAN! 2008 Spring Conference. Crown Plaza Hotel, Cherry Hill, New Jersey. More information coming in January 2008. Visit them on line at: www.danconference.com.



## Parent 2 Parent

(Continued from page 10)

#### Avoiding Misunderstandings, Reporting Injuries and Mishaps

By: Cheryl Frampton

No doubt, having a child with autism is challenging. Toss in some self-injurious behaviors (SIB) such as head banging, hitting or even running away, and it can get overwhelming fast. Sometimes our kids develop certain behaviors early and never let those pesky little habits go.

Some behaviors are phases and others just suddenly start one day out of the blue. However it happens, it always has the same effect. It leaves you feeling vulnerable, upset and shaken. What could be worse than having your child intentionally hurt himself or run away? This is worse - having Child Protective Services called because you are allegedly "abusing" your child?

Over the years I have seen it happen from time to time. While most of these unfortunate situations are eventually resolved through an investigation, this leaves the already shaken parents feeling violated and traumatized. What parents must realize is that this is not someone trying to be mean to you or "out to get you." If you look at the situation as an outsider who does not understand what is going on, all they see is this poor child who cannot talk and appears to be beaten up. Wouldn't you question such a situation if you didn't understand?

My child has a long history of

self-injurious behaviors and running. Over that time I have learned to do things that can help protect me, my son and his school from having any of these unfortunate misunderstandings.

Communicate with the school

Communication is the most important tool you have to prevent most problems. If your child develops a bruise or any other notable injury the night before, call the school nurse and explain to her what happened and ask her to please take a look at it and record the injury. It also helps to let the school know you had an incident at

home if your child has run away. They need to know what is going on at home, so keeping an open dialogue with the school nurse and your child's team is very important. If your child comes home with an injury that was not there before s/he left for school in the morning. call the school the next day and ask them to please record the injury and ask for an explana-

tion. There are times when no one is going to know what happened—that just happens—so keep that communication line open. It is also a good idea to talk to the school or other parents about ideas on how to make your home safer for your child.

Talk to your neighbors

Don't assume that everyone knows as much about autism as you do. Remember that time before your child was diagnosed? You didn't know much more about autism other than the movie *Rain Man*. Take time to talk to your neighbors about your child. Explain to them about autism and what behaviors your child is exhibiting. My son often likes to

scream at the top of his lungs while in the back yard. Of course, this is just for amusement, but I am sure it scares the dickens out of folks who are not aware that it is just one of his endearing behaviors. My son also likes to run off or "dart," and anyone who has had to deal with that understands how frightening it can be. This is why it is important to communicate with folks so they know how to react if your child does escape. I have always been very open to people about my son and his challenges. If you are comfortable talking to people about it, chances are people will become more comfortable in being around them.

Work with your child's primary care physician

Most of our family doctors or pediatricians are not specialists on autism, in fact, many know very little about the disorder. Make sure your doctor understands what is going on with your child. If you are seeing a pattern of bruises that don't add up to what you normally see with his behaviors, take him in for an exam and make sure the doctor documents everything. My rule of thumb having a child with no or limited communication skills has always been that I would rather go to the doctor and be wrong, than not go and be right.

Register with 911

A really simple thing to do to help the police if they are ever needed is to register your child with 911. You can go to http://ddc.delaware.gov/911Registration. shmtl. Just print, fill out and mail to the address they provide. You can also call them at: (302) 659-2349. This informs the police that a child with a disability lives at your location, so they are prepared when they arrive.

(Continued on page 13)



## Parent 2 Parent

(Continued from page 12)

#### Don't panic

If you find yourself the subject of a police or child protective services investigation, don't panic! These folks are just doing their job and making sure your child is safe. We cannot expect everyone to understand our lives. If you have been documenting all of your child's injuries and behaviors through school and home, you will have plenty of information to help them get through the process more easily. The school should be able to support your claims with their reports as well. Always keep a copy of your child's latest IEP or Behavior Management Program on hand. Just cooperate and let them do what they need to do. If you find yourself not getting through this process as smoothly as you should, call us! We will try to help where we can by informing the agency about what autism is and how it affects our families.

WE COULD LEARN A
LOT FROM CRAYONS:
SOME ARE SHARP, SOME
ARE PRETTY, SOME ARE
DULL, SOME HAVE WEIRD
NAMES, AND ALL ARE
DIFFERENT COLORS...BUT
THEY ALL EXIST VERY
NICELY IN THE SAME BOX.



Feature Article: Guaranteed Autism Spectrum Disorders Insurance Coverage – Can it fly in Delaware?

By: Robin Ireland

Everybody's talking about Jenny McCarthy – her recent appearance on Oprah and Larry King, her cover story in *People Magazine*. All of a sudden, autism is everywhere. For this, I'm grateful. Putting our cause in the public eye is never a bad thing. Still, there is something that rarely gets mentioned by our celebrity brethren.

For the most part, private insurance companies don't pay for autism therapy. Even the solid, researched-based, best practices, proven-to-help treatments like PECS and ABA. They don't pay for occupational therapy, stating that OT is covered only to "restore" function - and our children with autism "never had function to begin with." They don't pay for PT. They don't pay for speech therapy. And just try submitting an insurance form for social skills classes, music therapy or a developmental program like FloorTime or Relationship Development Intervention (RDI). There are exceptions, but in most cases, insurance is way behind the curve.

While there are scores of brilliant people working overtime to determine the cause of autism, there is virtually no debate about what autism is. Simply put, autism is a brain disorder that can be remedied – sometimes substantially – with intensive therapy. But whether those proven therapies reach every child is often a matter of cost. And so the question remains, what are we going to do about it?

In Pennsylvania, that question may be answered as early as this fall. House Speaker Dennis O'Brien (R-Philadelphia) wrote and sponsored a bill that would require private insurers to pay up to \$36,000 annually for research-based autism treatment such as ABA or other structured behavioral programs. Beyond that, the state would be required to foot the bill. The proposed legislation (HB-1150) passed the Pennsylvania house unanimously and is now being debated in the state senate chambers.

"This is a medical condition and yet insurance companies have gotten away with simply denying coverage to those patients with autism – and that is not acceptable," said Bill Patton, the press secretary for Dennis O'Brien. "These families pay thousands of dollars for insurance coverage and then, when they need it most, they are turned away. We consider it a matter of civil rights – don't discriminate against one type of medical condition. That is what they're doing."

O'Brien, who has been on the forefront of the autism fight since his nephew was diagnosed with a spectrum disorder 20 years ago, faced a massive and well funded fight from the insurance industry. The insurance lobby estimated that covering autism treatment would add between four and eight percent to the cost of the average policy. O'Brien's research, which was based on states where similar laws had already been passed, estimated that the increase would be more like one percent.

The insurance lobby also argued

(Continued on page 14)



# Insurance Coverage

(Continued from page 13)

that O'Brien's bill was unfair in that it applied only to private insurance companies. Large corporations that self-insure – pay to insure themselves – would be exempt. But O'Brien's research indicated that many self-insured corporations that don't pay now will follow suit once the legal requirement is passed.

And, in many cases, self-insured companies are among the few who do cover autism treatment. Microsoft, General Electric and Home Depot already cover services for autism. At DuPont, a self-insured company and Delaware's largest employer, autism therapy such as social skills classes, music therapy, occupational therapy and speech therapy is paid at 90 percent – depending on the therapy provider.

Here in Delaware, there has been little or no discussion in the state legislature about passing a law similar to the O'Brien bill. But that could change.

"It (the O'Brien bill) certainly is an interesting idea that deserves to be looked at," said Delaware State Senator Charles Copeland (R-West Farms), who has a first cousin with autism. "There is no doubt that diagnosing and treating autism is very important. And I would be happy to start that conversation in the General Assembly."

# WHO CAN ENJOY THE SCENERY ON A DETOUR

# Who We Are

There was a day when everyone at ASD knew each other, and what was happening. Those days are long gone, as we have grown. With that in mind, we like introduce our audience to some of the parents and staff that help keep ASD alive and well and to also show you that we are just your average every day folks who face all of the same challenges you do.



Robin Ireland

#### WHAT DO YOU DO?

After working for more than a decade as a newspaper reporter, I left journalism to stay home with my children. Covering breaking news requires time and flexibility - the ability to drop everything on a moment's notice to report a story. I didn't feel I could do both jobs properly and I was fortunate enough to have had the option to stay home. I still write magazine feature articles when a topic moves me. I also began doing some freelance corporate writing and hope to expand on that this year and I am serving on the ASD Newsletter Editorial Committee.

# HOW LONG HAVE YOU BEEN WITH ASD?

Tim and I joined ASD after our son, Luke, was diagnosed with autism two years ago. Both of us are advocates by nature.

#### WHY DO YOU DO THIS?

The qualities that made me a good newspaper reporter serve me very well as the mother of a child with autism. I enjoy collecting and processing information. I'm not afraid of authority. I know how to navigate a bureaucratic maze and I am undeterred by road blocks. I think if we all channeled our unique skills into helping our children get the services they need, we could move mountains.



Nicole Curran

#### WHAT DO YOU DO?

I have two main jobs with ASD, staff photographer and Co-Chair for the Social Events Committee. As staff photographer I work to document most of ASD's social and

## Who We Are

(Continued from page 15)

fundraising events. This started six years ago at the Drive for Autism Celebrity-Am Golf Outing and I've been a standard fixture with camera in hand at events ever since! As cochair of the social events committee, I help plan and organize the New Castle County social events, as well as the annual picnic at Cape Henlopen.

# HOW LONG HAVE YOU BEEN WITH ASD?

My husband Jeff, our three sons, Austin, Brenden and Cameron, and I have been part of ASD since October of 1999. It is a big part of our lives and it has helped me grow as a person and introduced me to many other great families in the organization.

#### WHY DO YOU DO THIS?

I have devoted myself to ASD because ASD was there for me and my family when we needed an outlet during one of the most difficult times of our lives. I also get the opportunity to share my talents with others and to share the knowledge I have gained on the way. I enjoy watching folks enjoy themselves at our social activities that they otherwise may not have access to. I am thankful to the staff and ASD board for allowing me and my family to be a small piece in a big puzzle.

# Congratulations!

## **Rose Grover**

Winner of the 2007 Autumn Auction for Autism MAC Laptop Raffle. Thank You to Everyone Who



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Routes 202 & 1, Concordville, PA
Routes 40 & 896, Newark, DE
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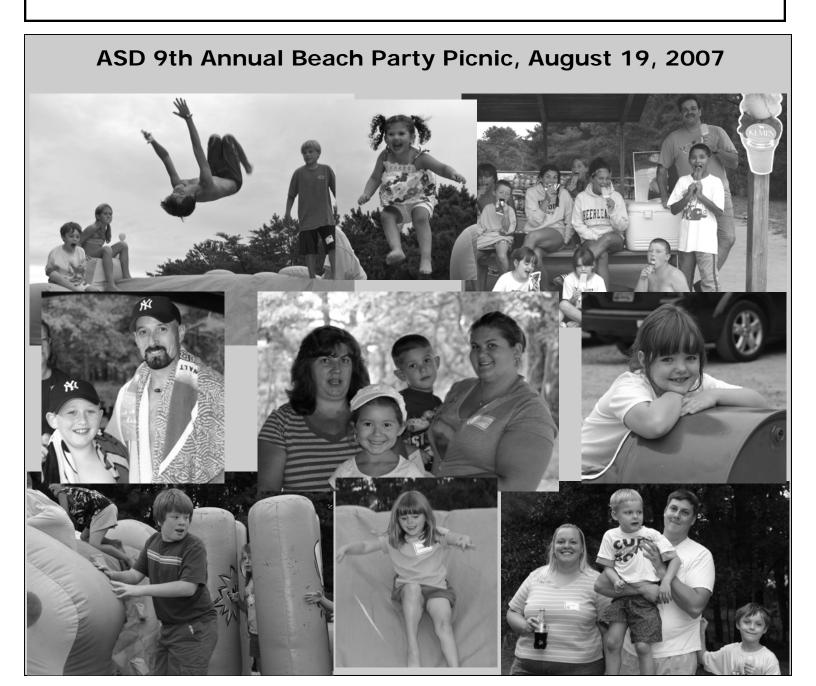


# **ASD Conference Stipends**

ASD will provide stipends up to \$200 to members who are either persons with autism, family members or professionals to attend training, conferences, and events that assist to increase knowledge or skills and that offer access to information related to a child or other family members with autism. Funds are budgeted annually, and will be awarded on a first come-first serve basis.

How do you get a stipend? You must submit your request in writing either via email or letter stating why you want to attend, what the stipend will pay for, and that it is required for the conference to be affordable. The stipend recipient must provide proof of attendance and agree to write an article for *The Sun* about the conference or training session and then ASD will reimburse once these requirements are met.

For more information about ASD's Conference Stipends and Policies contact the office at (302) 472-2638.





# Walk the High Road for Autism

Saturday, April 26, 2008
Bellevue State Park—Wilmington

Join us for a day of fun, games and, of course, supporting ASD!

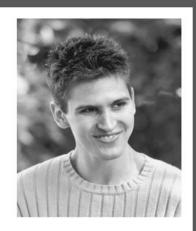
For corporate sponsorship and Walker information, please call (302) 472-2638 or visit www.delautism.org/walk.htm



# POWER

# **Productive Opportunities for Work & Recreation**

A Community-Based Service of the Autism Society of 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.

...It's About Life

POW&R/Autism Society of Delaware 5572 Kirkwood Highway ~ Wilmington, DE 19808 (302) 472-2638 www.delautism.org

# 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.) 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 5572 Kirkwood Highway Wilmington, DE 19808

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