



The Sun

The Voice of Autism in Delaware


Detachable Monthly Calendar

November 2006

Autism Society of Delaware

(302) 472-2638

www.delautism.org

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			1	2	3	4
5	6	7 Election Day 	8 ASD Chapter Meeting, Charlton School, Dover 7:00 p.m.	9	10	11 ASD Roller Skating Party 5:15 p.m.
12	13	14 Parent Coffee Hour 9:00 a.m.	15	16	17	18
19	20	21	22	23 Happy Thanksgiving Office Closed	24 Office Closed	25
26	27	28	29	30		



The Sun

The Voice of Autism in Delaware

Detachable Monthly Calendar

December 2006

Autism Society of Delaware

(302) 472-2638

www.delautism.org

Sunday

Monday

Tuesday

Wednesday

Thursday

Friday

Saturday

						1	2
3	4	5 Dad's Night Out 7:00 p.m.	6	7	8	9	
10 N.C.C. Family Holiday Party	11	12 Parent Coffee Hour 9:00 a.m.	13	14	15	16 Kent County Family Holiday Party	
17	18	19	20	21	22	23	
24 31	25 ASD Office Closed	26 ASD Office Closed	27 ASD Office Closed	28 ASD Office Closed	29 ASD Office Closed	30	



The Sun

Inside This Issue...

Kempner's Korner.....2

Parent 2 Parent Cont'd3

Walk the High Road for Autism.....4

Inside the ASD.....7

Mom & Dad's Nights Out
ASD Roller Skating Party
N.C.C. & Kent County Family
Holiday Parties.....9

Research Headlines.....10

ASD Calendar of Events.....11

ASD Fall Festivities.....12

Autumn Auction for Autism—
Unmasking Autism Thank You's...14

12-Year-Old Organizes Autism
Fundraiser.....15

Who We Are.....16

Call for Volunteer
Recognition.....17

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.

Parent 2 Parent

written by parents
for parents

This issue of The Sun will feature Parent 2 Parent articles.

The Fence

By: Robin Ireland

In the beginning, we moved to Woodbrook for the sense of community. Our last house was lovely but we were living in the car – driving to play dates, driving to a suitable trick-or-treating location, driving to the mailbox. My husband said it was no way to live and certainly no way to raise kids. It was, if I remember his words correctly – isolated, suburban hell.

So we packed up and moved – to a real neighborhood. With sidewalks and streetlights and kids who live next door. In Woodbrook, there are Halloween parades and Easter egg hunts and annual socials at the country club down the street – complete with a moonbounce.

Two days after Christmas that first year, the youngest of our three children was diagnosed with autism. I don't have to tell you what that's like. For weeks, I walked around in a daze, pushing down my impossible grief. On the surface, the thinnest sheet of ice. Beneath, a raging flood of tears and hysterics. Barely contained.

Only now I lived in a neighborhood where I could walk my dog at night and

know what everyone was watching on television. All of a sudden, the idea of hiding away in isolated suburban hell sounded pretty comfy. I could tackle this issue in privacy and come out when I was good and ready. When I was no longer "in a state of crisis."

First came the special pre-school and the home program and the biomedical interventions. The next step was a fence. Like a bumblebee, Luke was compelled to run from object to object. I couldn't unload groceries. I couldn't let go of his hand, even for a moment, without him darting down the driveway and into the street. In order for him to play outside, he would need to be contained. This was no longer about typical two-year-old spunk. This was something that might not go away.

Per the homeowner's association rules, I went door-to-door with my fence proposal in hand, introducing myself to my "adjacent neighbors." I told them I had a son with autism and did my best to explain autism and why we needed a fence. I tried very hard not to cry. I met the woman across the street, whose son was a Marine in Iraq. If she could shrink him back into a toddler and build a fence around him, she said, she surely would. I met the guy with the perfect yard who said he came home from work one

(Continued on page 3)





The Sun

A publication of the Autism Society of Delaware
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,
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

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), Pen-
ny.chelucci@state.de.us
Finance: Michael Graci, 302.453.8586 (h),
mjgraci@comcast.net
New Parent Support: Cheryl Kelley
(see above) & Mary Kelleher 302.761.9558 (h),
mary.kelleher@delautism.org
Public Awareness: Dwayne McMahan,
302.235.2101 (h), DMKemps@comcast.net
Social Events: Nicole Curran 302.368.2468
(h), nicolemailbox@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	Amy Justice
Brenda Holsey	Robin Ireland

Desktop Publishing: Cheryl Kelley



Kem

By: Artie Kempner

Recently, Marcy and I were invited to a fundraising dinner by a good friend of ours in New York. Our friend sent us an e-mail telling us about the evening and in it she wrote, "this organization impacts my life every day." Wow! Talk about a reason to support the cause of a friend!

That sentiment encapsulates my feelings about what we do at the Autism Society of Delaware and how we need to continue to grow. We need to IMPACT the lives of the autism community in a positive way every single day. We need to make sure that our children and loved ones with autism continue to have good school programs, inclusive recreational opportunities, job options, social supports, and all the other elements that make up a full life. We need to make sure that families are informed, educated, supported, and empowered. But if we are truly going to make an IMPACT, we have to grow our organization and our sphere of influence.

As parents, we were "drafted" into the autism community. What we need to do is actively recruit volunteers and supporters from outside our families to help deliver our message and to spearhead the changes that are so drastically needed. To have the most IMPACT, we need to bring the autism community, the policy-makers, the business community, the school districts, the adult service providers, doctors, lawyers, caregivers and the community-at-large together. We can't be afraid to ask people to get involved. We need to ask people to get involved. Get your parents, friends, neighbors, business associates to join ASD. Give them a membership for a holiday gift. Bring them to a fundraiser or social event. We need to expand our circle of support beyond ourselves to involve everyone in the community who will IMPACT our loved ones with autism, so that we can IMPACT their ability to accept and support all of us.

We have tremendous momentum going at ASD. I'm so proud of what our organization has accomplished since 1998. I'm so proud that we have such an active volunteer group, such a vibrant staff, such strong committees and such a dedicated, forward-thinking Board. Let's work together to continue to IMPACT the autism community in a positive way every single day!



Artie



Parent 2 Parent

written by parents
for parents

day to find the boy from down the road in his kitchen eating cookies. He has autism, too. I met the lady next door, who lost her only child and her husband to a brain hemorrhage in the same year.

I met the crusty old Marine who lives catty-corner, whose grown son slid into mental illness while in college and had to move back home forever. "Everybody has something in their house," he told me. "You've got to take care of your business. People will understand."

For us, it was a double-edged sword. The board rejected our proposal until we got a government-paid disability lawyer they couldn't afford to fight. A few people said things that were toe-curlingly dreadful – like maybe I should consider an invisible fence for Luke, or that I should send a letter to all 250 people in the community informing them that I have "an autistic child." One guy remarked that his son was "even more handicapped" than mine and he would never trouble his neighbors with a fence.

I tried to explain that my son gets a sensory thrill from running, that he has no language, that I needed to do his therapy in a variety of settings or it wouldn't work. But, in the end, I simply agreed to disagree. I can play outside with my little boy. He can run in circles or in the sprinkler and I am not worried anymore.

Meanwhile, Luke teaches me about patience, unconditional love and the backbreaking joy of hard work and hope. This is, I know, the first of many battles I will fight on his behalf and I'm a tougher nut to

crack these days. I was a girl who sought approval from everyone and now I am a woman who can no longer afford to care. While there are people who hate my fence – and me for building it – I know there are others who truly understand. And they surround me on all sides.

"One guy remarked that his son was "even more handicapped" than mine and he would never trouble his neighbors with a fence."

"Fragile What?"

A Parent's Perspective of Fragile X Syndrome

By: Jen Nardo

My silent worries about my then nine-month-old were given credence when the nurse practitioner did a short developmental assessment on my son. That was the first time I heard the word "delayed" in reference to Jake. I thought he was slower than his brother, but Frankie was always ahead of or exactly in time with the textbooks. This appointment was early February 2000. In the months to come, we saw his pediatrician, a developmental pediatrician at A.I. duPont, Child Development Watch and ended with Early Intervention Services at Easter Seals.

At this point, Jake was finally able to sit on his own and could sit up from being on his back. The problem was that he was now 16 months old and showed no signs or crawling,

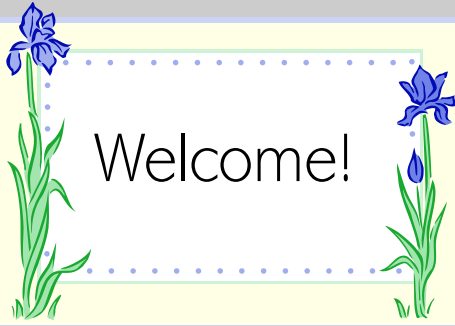
walking or talking. After two months of physical therapy, occupational therapy and speech, he showed new skills, but we wanted a cause – something to "hang our hats on." The speech therapist at Easter Seals mentioned that we might want to consult a pediatric neurologist so I made the appointment.

After several tests, his doctor's original hunch was confirmed. Jake was diagnosed with Fragile X Syndrome. I sat and cried at the kitchen table and then called my husband.

We are now 6 ½ years beyond that day and now have additional diagnoses of autism and ADHD. It has been a long road, but we feel stronger and more confident than that gray February morning.

Fragile X Syndrome (FXS) is the leading inherited cause of mental retardation. There is one gene that resides on the X chromosome and gets shut off after generations of small mutations. This gene is responsible for the production of FMR-P (Fragile X Mental Retardation Protein). Without FMR-P, the brain functions abnormally.

One in 4,000 males and one in 6,000-8,000 females are affected. One in 100-130 women is a carrier. Most, like me, have no idea until giving birth to an affected child. Mental retardation is seen in about 90% of males and 33% of females. Autism is seen in about 30% of males. Fragile X is considered the leading known cause of autism. Numbers vary, but it is estimated that 4-6% of all cases of autism are caused by Fragile X.



Please welcome the following new members to ASD...

Linda Bean
 Anthony & Kim Casale
 Jorge & Yeidi Castro
 Deborah Danner
 John & Sue Fertal
 Keith & Vivian Fleetwood
 Norma Kamau
 Yvette Kinsake
 Mark & Kim Macknis
 Diana North
 Joe & Donna Oneill
 Van Pham
 Steven Yeatman



Walk The High Road For Autism

“Walk the High Road for Autism” will be held at Bellevue State Park in Wilmington on Saturday, April 28, 2007. Bring your family, friends, and coworkers—anyone who will join you in supporting ASD and services for families affected by autism. After the walk through a beautiful section of the park and walking track, there will be a celebration with food, vendors, and activities for everyone to enjoy. To make it easy to register and raise funds, ASD has partnered with the company, Firstgiving, to offer online registration, and personalized web pages that you can send to your friends and family in order to receive on-line donations. More information can be found at www.delautism.org.

Corporate sponsorships will also be available with levels suitable for very small businesses as well as to major corporations. Call the ASD office for more info on the Walk and how you can be a part of it!

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.

The Second Tuesday of Every Month

PARENT'S COFFEE HOUR

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!***



Next Deadline for Submissions to The Sun:
December 1, 2006

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.



Parent 2 Parent

(Continued from page 3)

There are many characteristics of a person with FXS including a loving personality, good sense of humor, ADD/ADHD, perseveration, impulsivity, hand flapping, toe walking, hand biting, spinning (objects or self), fleeting eye contact, poor adaptation to changes in routine, tantrums, shyness and sensitivity to touch/noises/smells. The physical features include broad forehead, large head, long face, large ears with frequent ear infections, flexible joints, low muscle tone, soft skin, flat feet, strabismus, chest indentation, mitral valve prolapse and a high incidence of seizures.

There is much more research hap-

“Children with FXS have a simultaneous cognitive style. This means that they need to see and understand the whole and not so much the parts that add up to the whole.”

pening today than in 1991 when the genetic test for FXS was created. FRAXA Fragile X Research Foundation has funded studies that have already identified a specific brain pathway (mGluR) which is defective in FXS and is implicated in autism and autism spectrum disorders. Experimental compounds exist which target this pathway, and researchers have shown that these compounds are effective in treating symptoms in FXS mouse and fruit fly models. These symptoms include cognitive impairment, anxiety, hyperactivity and sometimes seizures. Experts at the National Institute of Child Development (NICHD), National Institute of Mental Health (NIMH) and National Institute of Neurological Disorders and Stroke (NINDS) believe that the cure for FXS will be a model for curing autism. (1)

We know of specific learning challenges unique to those affected by

FXS. Children with FXS have a simultaneous cognitive style. This means that they need to see and understand the whole and not so much the parts that add up to the whole. They are keen observers who learn from seeing a whole process or skill that they can replicate through imitation. A relationship building approach works best in the classroom, and “forced responding” should be avoided. When those with FXS feel social pressure, they go into an extreme state of hyperarousal. Hyperarousal can shut down learning and language and elicit problem behaviors like aggression, tantrums, flapping, biting and perseveration. (2)

As I type this article, Jake is on the bed in my room watching the “Goodnight Show” on Sprout. He is on his head with his bottom in the air

making guttural noises and having a blast. My goal in life is to make sure that he is happy. And, I mean that in the greater sense – for him to be happy with himself, happy with his accomplishments...and maybe the latest “Go Diego Go” DVD.

(1) FRAXA literature
(2) “Hyperarousal and Fragile X Syndrome” by Tracy Stackhouse, MA, OTR and Sarah “Mouse” Scharfenaker, MA, CCC-SLP in the National Fragile X Foundation Quarterly, Issue 24, July 2006.

For more information on Frangle X Syndrome visit the following web sites:

<http://www.fragilex.org/>

<http://www.fraxa.org/>

CHOICES

By: Brenda Holsey

As parents of children with autism we have all felt overwhelmed at one point or another. Along with being overwhelmed is the need to make choices about our children. When faced with my child’s diagnosis, I remember the doctor asking me if I would be quitting work and staying home with my daughter, which for me was not an option. All the choices we have to make; stay at home or work, change of diet, medicate or not medicate, use a developmental pediatrician or a neurologist, put the child in a special school or special education, along with the challenge of getting help and information concerning those choices we need to make.

So let’s look at some of these choices, starting with a parent being at home. This is better for any child with or without autism but is it right for the family? I have read of documented cases where having a parent at home means the child does much better because she is getting that reinforcement of things learned in school and the added extra help with reading, writing, and basic developmental milestones. But does that mean the child won’t develop if one or both parents work? I would like to think that each child will succeed according to his or her own gifts, and each child has their own gifts. Even with working outside the home I have seen an improvement in my daughter and a need to focus on other areas at home. I keep these other areas in the forefront and work on them as much as possible. One thing for sure is that being at home makes it much easier to manage a restrictive diet.

So let’s talk about the casein and gluten-free diet. As a working mom it

(Continued on page 6)



Parent 2 Parent

(Continued from page 5)

serves as a source of great frustration. However, I listen to parents that have tried the diet and rave about it. My experience with the gluten-free diet started with my daughter getting sick every three to five days. After I removed wheat from her diet her illness ceased. On occasion she still gets sick and I know right away she's eating too much wheat. One thing I did notice was after she has purged is that her speech improves. Coincidence, maybe? Maybe not? Removing casein from her diet did nothing. But for other children it made a world of difference. So I try to limit her wheat and keep her on fresh fruits and vegetables and lean meats. This has kept her stomach trouble to a minimum and that is one less medication she has to take.

So what about medications. A common theme in children with autism seems to be some type of gastrointestinal trouble, hyperactivity, and bipolar disorder. Some doctors prefer ADHD meds for the hyperactivity. For my daughter these just made her mean and nasty. It turns out that she is bi-polar. Now that she is on the proper medication she's doing fine. But why the gastro-intestinal trouble? Does your child need Prevacid or Prilosec for acid reflux, or just a change in diet? Some children in the population are taking multiple drugs to control impulses, behaviors and other medical conditions. Whatever the case is for your child, research and open discussions with your child's doctors, can help.

So what about the choice of doctor? I had Blue Cross & Blue Shield tell me that my child with autism doesn't require an alternative doctor and that a pediatrician could handle her

case just fine. I responded that I would get back to them with my attorney. Is a developmental pediatrician the best choice to help and treat a child with autism? Some may prefer a neurologist, especially when it's time to start medication. Neurologists for the most part are better versed on medications and their interactions than a developmental pediatrician may be. However, depending on your child's needs, a developmental pediatrician may be the answer to a number of questions. I'm using a developmental pediatrician and things are working out just fine.

One thing for sure, dealing with a child with autism can be overwhelming. Support groups and interaction can help. Being faced with so many choices can also be overwhelming. Take them one at a time and remember whatever the choice you make regarding, diet, medication, doctors, or educational support, do what's best for your child, yourself and your family.

*It's all right
to have
Butterflies in
your stomach.
Just get them to fly
in formation.*



-Dr. Rob Gilbert

Autism and Insurance Issues

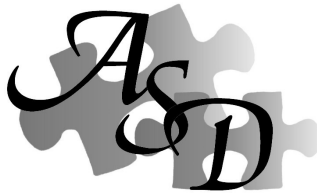
**This came to us from ASA Board member Dr. Cathy Pratt, Director, Indiana Resource Center on Autism. If anyone in Delaware is experiencing anything similar please contact the ASD office at:
(302) 472-2638 or
delautism@delautism.org**

We are working on bills for this upcoming legislative session. In preparation for this, my organization in Indiana (IRCA) conducted a Needs Assessment Survey. Once again, we have issues around insurance and waiting lists for the Medicaid waiver. We actually have an insurance mandate in Indiana and in our state statutes we have changed autism to be a neurological condition. Despite this, we have companies who turn parents down because autism is a pre-existing condition, they believe autism is a mental health disorder, or because they do not consider autism treatable. So, we have to continue to educate and push.

Another issue was the difficulty families have with getting life insurance. We will be working on that and will keep you tuned in. Also, our state legislators in Indiana have decided to write to our federal legislators and ask that they support the Combating Autism Act. And our legislators are also interested in looking at a bill that would push for certification and training for first responders. So, if any of you have gotten bills through that address this...can you please email them on. Thank you. And if anyone want the data from our Needs Assessment survey, email me directly at prattc@indiana.edu. I will send it to you as an attachment.



Inside The



Research Funds Awarded

The ASD Board unanimously elected to award the Organization of Autism Research (OAR) \$20,000. Created in December 2001 by parents, OAR's mission is to use applied science to answer questions that parents, families, individuals with autism, teachers and caregivers confront daily.

OAR defines applied research as research that directly impacts the day-to-day quality of life of learners with autism. It entails the systematic investigation of variables associated with positive outcomes in such areas as education, communication, self care, social skills, employment, behavior, and adult and community living. In this context, it extends to issues related to family support, the efficacy of service delivery systems, and demographic analyses of the autism community.

In simplest terms, applied autism research is "practical research that examines issues and challenges that children and adults with autism and their families face everyday."

OAR funds pilot studies and targeted research within specific modalities and issues affecting the autism community, primarily for studies whose outcomes offer new insights into the behavioral and social development of individuals with autism with an emphasis on communications, education, and vocational challenges.

Autism Task Force

The Legislative Autism Task Force held it's first meeting in Dover

on October 11th, chaired by Kent Riegel. Members represent parents of individuals on the spectrum who typically are not eligible for adult services, either through the Division of Substance Abuse and Mental Health (DSAMH) or the Division of Developmental Disabilities Services (DDDS). The group consists of Kent Riegel, Angie Sipple, Craig Newschaffer and Kathie Cherry who represent parents, Stephen Dettwyler of DSAMH, Dr. Joe Keyes of DDDS, Harline Dennison of Vocational Rehabilitation, Theda Ellis of the Autism Society, Cathie Field Lloyd of the provider community, and state representatives, Dick Cathcart and Valerie Longhurst .

Meetings are public so all are welcome to attend. The next meeting is scheduled for November 15, at 3 p.m. in Legislative Hall.

Holiday Activities

Over the years the number one thing that families have requested are more family activities, particularly around holidays. You may have noticed that we now have a year-round approach to family activities ranging from the Blue Rocks games in the spring to the summer picnic. We added a hayride which our social committee turned into a Fall Festival (see photos on page12) and the winter holiday party.

With the exception of the picnic, these things happen in New Castle because that's where our volunteer base is most active. ASD has always offered to support activities south of the canal, but we need some help with organizing at the local level. We're very happy to say that folks are stepping up to add to the social calendar. Dale Oberender is setting up skating parties in Milford (more on page 9) and Kate Stomerioski is putting together a holiday party in Kent County. Social events with other families is a great

way to make sure that children have opportunities to have fun, make new friends, and to feel comfortable. When everyone is able to help with a problem, it's a nice time for Mom and Dad as well. So, please take advantage of these opportunities, and even better, help us create more.

Friday Night Out

Speaking of social events, last spring ASD offered three teen nights. It was a chance for young teens to get together to eat a snack and play some games. They created their own guidelines and set of rules about the group. We will be continuing that effort, and adding a new Friday Night Out for young adults, 18 and older. Friday Night Out will meet on the third Friday of each month from 7:00 to 8:30 p.m. at Neurology

(Continued on page 8)

Kathy Ruper-

tus will be working as the facilitator of the Friday Night Out group for young adults. Kathy is currently working at the Division of Substance Abuse and Mental Health as a training officer. In her free time she is also a wife and mother, a doctoral candidate, and a therapist specializing in obsessive compulsive and other anxiety disorders. She has previously provided individual and group psychotherapy for children, adolescents and adults utilizing a cognitive-behavioral case conceptualization. She was also a co-founder and facilitator of Teen G.O.A.L., a support group for adolescents with obsessive-compulsive disorder. Kathy advises that she has always had a special interest in working with folks on the autism spectrum. Welcome to Kathy and we look forward to developing an active social group for young adults with Asperger's.



Inside The ASD

(Continued from page 7)

Associates at 774 Christiana Road, Newark, DE 19714. Kathy Rupertus will be facilitating. Our intent is to encourage participants to develop friendly relationships in an environment that recognizes the challenges of social skills and provides facilitation. Because social skills deficits can make it difficult for people who are otherwise competent to succeed in employment and other pursuits, participating in Friday Night Out can have real benefits beyond that of an enjoyable evening.

The size of the group is limited to 12. The cost of each session is \$10 and preregistration is required. For more information or to register,

please call Heidi Mizell at (302) 472-2638, ext 205.

Walk the High Road

So you want to support ASD but are not quite sure how because after all, the two major fundraisers can be a little "spendy". In 2007, ASD will be sponsoring *Walk the High Road for Autism* to benefit the Autism Society of Delaware. This will be an opportunity for you and your family to support us in a different way— by walking with your family and friends and raising funds to support our many activities.

The day will be fun with more family activities. With our Walk website at: www.firstgiving.org/asdwalk, you'll be able to register online and invite family and friends to donate and join you on the

Walk! See page 4 for more information.

So how do we spend this money?

Four years ago we asked you what you wanted, and you said "Family Holiday Parties." Over the past year we had a successful holiday party for 80, 40 children participated in our Spring Egg Hunt, 100 folks went to the Blue Rocks, 184 folks attended the summer picnic, and we had 125 for our Fall Festival. The funds we raise come back to you, the families, in activities and services. With this rise in numbers as well as our movement towards providing adult services, we need your continued support.

Proud to Support the 2006 Autumn Auction for Autism.



COMMUNITY COMMITMENT. COMMUNITY BANKING.



A MEMBER OF THE FULTON FINANCIAL FAMILY

302.425.3941 or 888.291.2400
delawarenational.com

Member FDIC



FULTON FINANCIAL ADVISORS™

Located at Delaware National Bank

302.425.0474

dmarkwood@fultonfinancialadvisors.com

Fulton Financial Advisors provides financial services in markets covered by Fulton Financial Corporation-owned community banks.

Securities and Insurance Products:

- Not FDIC-Insured • Not Insured by any Federal Government Agency
- No Financial Institution Guarantee • May lose value • Not a Deposit



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

The next Mom's Night Out will be held in January. Exact day and time yet to be determined. They are working on what to do and when.



No matter what we do, we always have a good time, so if you are interested in meeting up with some other mom's call Monica McMahan for details and to RSVP at (302) 235-2101 or email: m.mcmahan28@comcast.net

Dad's Night Out

December 5th, 2006
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:
Rob Scheinberg
(302) 454-8373

ASD Sussex County Roller Skating Party Saturday, December 9, 2006—Milford Skating Rink 5-7 p.m.

Closed to the general public. Admission is free. Bring family and friends. Skate rentals are \$1.50—\$3.00 depending on what type of skate you want. Easy lighting and music. Snack bar is open. No RSVP needed. Just show up and have a good time!



ASD's New Castle County Family Holiday Party

Sunday, December 10, 2006
2-4 p.m.

Del Vets on Naaman's Road, Wilmington

Holiday Crafts
Children's Entertainment
Holiday Photos

Please bring an appetizer or dessert to share. RSVP is required. Please contact the ASD by December 7 at (302) 472-2638 or delautism@delautism.org



ASD's Kent County Family Holiday Party

Saturday, December 16, 2006
11 a.m.– 2p.m.

Wyoming United Methodist Church Hall
112 Broad Street in Wyoming

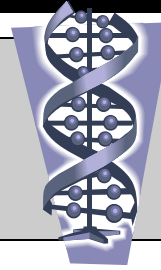
Holiday Crafts & A "Special Visitor"
Entertainment & Music

Please bring your camera and a dish to share. To RSVP please contact Kate Stomioski at (302) 734-4884 or Dafne Carnright at (302) 422-8449.





Research Headlines



Autism Costs \$35 Billion Per Year to U.S.

By: Harvard School of Public Health

It can cost about \$3.2 million to take care of an autistic person over his or her lifetime. Caring for all people with autism over their lifetimes costs an estimated \$35 billion per year. Those figures are part of the findings in the first study to comprehensively survey and document the costs of autism to U.S. society. Michael Ganz, Assistant Professor of Society, Human Development, and Health at Harvard School of Public Health, authored the study, which appears in a chapter titled, "The Costs of Autism," in the newly published book, *Understanding Autism: From Basic Neuroscience to Treatment* (CRC Press, 2006). Ganz hopes his research will help policymakers allocate scarce resources to its treatment and prevention as well as provide a useful reference for policymakers and advocates to help them more fully understand the financial impact of autism on U.S. society.

Ganz's analysis of the costs includes direct and indirect medical costs associated with the disorder. But he believes the \$35 billion annual societal cost for caring for and treating people with autism likely underestimates the true costs because there are a number of other services that are used to support individuals with autism, such as alternative therapies and other family out-of-pocket expenses, that are difficult to measure. In addition, Ganz believes that the level of cost could be higher if there were more useful and widespread treatment options available. "Given that the federal autism research budget

has been historically less than \$100 million per year and given that research budgets for other conditions with similar numbers of affected individuals are sometimes orders of magnitude higher, I hope that my research can help focus more attention on directing more resources toward finding prevention and treatment options for autism," Ganz said. (For comparison purposes, he notes estimated annual costs of other conditions, including Alzheimer's disease (\$91 billion); mental retardation (\$51 billion); anxiety (\$47 billion); and schizophrenia (\$33 billion).)

Autism is a pervasive develop-



mental disorder (PDD) that involves severe deficits in a person's ability to communicate and interact with others. Children with autism often have trouble using their imagination, have a limited range of interests, and may show repetitive patterns of behavior or body movements. The disorder is often associated with some degree of mental retardation. Autism is the most prevalent PDD and the most common of all serious childhood disorders. It affects an estimated 1.5 million Americans and is increasing at a rate of 10-17 percent each year. It is four times more common in boys than in girls. The exact cause of autism is not known and

there is currently no cure for the disorder.

Ganz broke down the total costs of autism into two components: direct and indirect costs. Direct costs include direct medical costs, such as physician and outpatient services, prescription medication, and behavioral therapies (estimated to cost, on average, more than \$29,000 per person per year) and direct non-medical costs, such as special education, camps, and child care (estimated to annually cost more than \$38,000 for those with lower levels of disability and more than \$43,000 for those with higher levels).

Indirect costs equal the value of lost productivity resulting from a person having autism, for example, the difference in potential income between someone with autism and someone without. It also captures the value of lost productivity for an autistic person's parents. Examples include loss of income due to reduced work hours or not working altogether. Ganz estimates that annual indirect costs for autistic individuals and their parents range from more than \$39,000 to nearly \$130,000.

Since people with autism receive services from a wide variety of sources, Ganz believes future research efforts should focus on identifying those sources and linking those costs to non-financial data about the burdens of autism. These complementary sources of data can provide a richer picture that will be useful to policymakers in the future to assist them in devoting resources to address the financial and non-financial effects of autism.

All rights reserved by
www.rxpgnews.com



A
S
D

C
A
L
E
N
D
A
R

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

- ▶ **November 8, 2006** — ASD Chapter Meeting, Charlton School, Dover. 7:00 p.m. Special guest speaker, Dr. Laura Donnelly on sibling issues.
- ▶ **There is no Chapter meeting in December.**
- ▶ **January 23, 2006** — ASD Chapter Meeting, exact time and location TBA.

Social Events, Public Awareness & Fundraisers

- ▶ **November 11, 2006** — ASD New Castle County Roller Skating Party, 5:15-7:15 p.m. Christiana Skating Center, Newark. No RSVP needed. Free admission. \$2-\$3 skate rentals. Snack bar is open. Autism friendly lights and music. Bring family and friends! Closed to the general public.
- ▶ **November 14, 2006** — Parent Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9:00 a.m. Mom, Dads, Grandparents or anyone with a connection to autism is welcome to attend. Just show up and ask for the autism table. Coffee hours are held on the second Tuesday of every month.
- ▶ **December 5, 2006** — Dad’s Night Out. Time and location TBA. Please contact Rob Scheinberg, (302) 454-8373. More information on page 9.
- ▶ **December 9, 2006** — ASD Sussex County Roller Skating Party, 5-7 p.m. Milford Skating Rink. No RSVP needed. Free admission. \$1.50-\$3 skate rentals. Snack bar is open. Autism friendly lights and music. Bring family and friends! More information on page 9.
- ▶ **December 10, 2006** — ASD New Castle County Family Holiday Party. Del-Vets, Naaman’s Road, Wilmington. 2-4 p.m. More information on page 9.
- ▶ **December 16, 2006** — ASD Kent County Family Holiday Party. United Methodist Church, Wyoming. 11 a.m.—2 p.m. More information on page 9.
- ▶ **February 24, 2007** — ASD Sussex County Roller Skating Party, 5-7 p.m. Milford Skating Rink. No RSVP needed. Free admission. \$1.50-\$3 skate rentals. Snack bar is open. Autism friendly lights and music. Bring family and friends! More information on page 9.
- ▶ **April 28, 2007** — Walk the High Road for Autism Walk. Bellevue State Park. More information on page 4.

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.

- ▶ **December 19, 2006** — ASD’s Night Time 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.

Other Events

- ▶ **January 9, 2007** — Innovative and Effective Transition Partnerships and Practices for Students With Autism and Cognitive Disabilities. 6:30—8:30 p.m.—Delaware Technical & Community College, Stanton Campus. Speakers include: Melissa Catalong (Division of Developmental Disabilities Services), Warren Ellis (DDDS), Alexis Hacket (Brennen School), Katrina Demitrious (Chimes Delaware), and parents. You must register to attend! Please contact the Parent Information Center of Delaware (302) 999-7394 or visit them on line at www.picofdel.org for registration and additional information.
- ▶ **February 13, 2007** — Parent Information Center of Delaware Presents: “Hear it Here First! How the No Child Left Behind Act and the IDEA 2004 Regulations impact students with disabilities.” A Wrightslaw Program Featuring Peter and Pamela Wright. Delaware Technical & Community College, Stanton Campus. Register on line: www.picofdel.org or call 1-888-547-4412.



ASD Fall Festivities



Mark Frampton, Cheryl Kelley and Warren Ellis pose for the camera at the 8th Annual Autumn Auction for Autism on October 21, 2006 at the Greenville Country Club.



Guests enjoy hearing the fortunes told by Madame Cynthia at the auction.



David Graham and daughter Sara get into the spirit on the dance floor at the auction. This year's theme was "Unmasking Autism."



Jarod Kelley and Cameron Curran take a dive in a pile of hay at the ASD Fall Festival on October 15, 2006 at Bellevue State Park.



Brendan Curran and Josh Delany meet up with a new friend at ASD's Fall Festival.



Karen Tuohy and daughter Bridgett get ready for a hayride at ASD's Fall Festival.



On October 21, 2006 at the Greenville Country Club in Wilmington, ASD held it's 8th Annual Autumn Auction for Autism—Unmasking Autism. This was our most successful auction event to date. There was lots of eating, dancing, bidding, and all around fun during the evening. If you have not had a chance to attend our auction, make sure you sign up for next year's event. Date and location will be coming out sometime in the spring of 2007.

We would like to thank all of the attendees, sponsors, auction item donors and volunteers who helped to make the evening so special.

Thank You to Our Advocate Sponsors:

Ted & Lisa Albany
Katy & Chip Connolly
Lori Loveland & Kevin Connor
Thomas & Marie Forrest
Steven & Alison Kortanek
David & Kirsten Landon
Craig & Rebecca Newschaffer
Jerome & Kelly Sullivan
Alan & Peggy Zugehar

Thank You to Our Supporter Sponsors:

Louis J. Capano
Pete Dukunchak
Chimes Metro, Inc.
Laurence DiSabatino
DiSabatino Construction

James G. Hupp
Michael P. Kelly
McCarter & English, LLP
Denis McGlynn
Dover Motorsports Inc.
William A. Oberle, Jr.
Darelle Riabov
BlueCross BlueShield of Delaware
John S. Riley
Kirk & Laura Rothrock
Walgreens

Thank You to Our Friend Sponsors:

Thomas & Pam Allingham
Julian H. Booker
Delmarva Broadcasting Co.
Theda & Warren Ellis
Paul Frese
New Castle County Government
Thomas & Sarah Goodrich
John & Betsy Fisher Gray
Nathan Reybold
Melinda South
Keystone Service Systems

Thank You to Our Patron Sponsors:

John Abood
Abood Financial LLC
Les Dukart
Dukart Management Corporation
ING Direct
Artie & Marcy Kempner

Discover Financial Services
Mary Anne Magness LeRoy
Magness Construction Company
Jeff & Sarah Rogatz
Ridgeway Captial
Gary & Ruth Rollins
AstraZeneca
Wilmington Trust Company

A Very Special Thank You to Our Silver Sponsors:

Delaware National Bank
Fulton Financial Advisors
Glazar Brothers, Inc.

Congratulations to our
Disney/Orlando Trip Raffle
Winner:

Tamara Grimstad
of Wilmington,
Delaware.

Have a Great Trip!

374 East Main Street, Newark, DE
2507 Concord Pike, Wilmington, DE
815 S. College Avenue, Newark, DE
Routes 202 & 1, Concordville, PA
Routes 40 & 896, Newark, DE
Route 40 & 7, Bear, DE
580 Middletown-Warwick Road, Middletown, DE
Concord Mall, Wilmington, DE
518 Conchester Highway, Boothwyn, PA

Owned & Operated by
Dukart Management Corporation



Did you know...

- 1 in 166 children is diagnosed with autism
- 1 in 104 boys is on the autism spectrum
- 67 children are diagnosed per day
- A new case is diagnosed every 20 minutes
- More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined
- Autism is the fastest-growing serious developmental disability in the U.S.
- Autism costs the nation over \$90 billion per year, a figure expected to double in the next decade
- Autism receives less than 5% of the research funding of many less prevalent childhood diseases
- Boys are four times more likely to than girls to have autism
- There is no medical detection or cure for autism

Source:
AutismSpeaks.org

12-Year Old Organizes Autism Awareness Fundraiser

By: Debbie Markwood

Ryan Markwood, of Lake George, New York, is a 12-year-old nephew of ASD Board Member Deb Markwood. Ryan's younger brother, Justin, age 5, was diagnosed with autism two years ago. Since then, Deb and her husband, Tom Pitts, have been active with ASD here in Delaware. Tom has volunteered on the golf committee for several years and Deb is co-chairing this year's Autumn Auction for Autism. Deb joined the Board of Directors late last year.

Ryan is aware of his Aunt Deb and Uncle Tom's activities and felt a need to do something proactive for Autism Awareness Month in his local community. He decided to raise money and awareness and saw a school bake sale as an outlet to do his part. Ryan is a 7th grade student at St. Mary's/St. Alphous School in Glens Falls, New York.

Students, parents, and faculty, cooks and consumers alike, all chipped in to make the day a great success. Ryan was hoping to raise a total of \$75.00 for the ASA, but after receiving several large donations of \$200 plus, and friends and family matching what Ryan raised, the event snowballed into profits of over \$1,000.00. Ryan donated the proceeds from his bake sale to the Albany Chapter of the Autism Society of America.

Due to his efforts, Ryan was also recently honored at an Autism Walk held in Schenectady, New York. The Mayor of Schenectady presented Ryan with an award for his outstanding accomplishments on behalf of autism awareness.

Congratulations to Ryan!



“Opportunities don't knock at all. They don't have to, they're already around us. It's up to us to see where they are and take advantage of them.”

-Dave Thomas





Who We Are

In each issue of *The Sun* we have been introducing you to a few of our staff and volunteers. This month we are featuring Public Awareness chair Dwayne McMahan and Physician's Awareness/ First Signs Coordinator, Heidi Mizell.



Dwayne McMahan

Who am I?

My name is Dwayne McMahan and I am the father of two great kids, Harrison, 10, who has autism and attends the Brennen School, and Savannah, 4, who keeps me on my toes. I have been married for 21 years to Monica.

What do you do?

I am the Northeast Account Manager for Kemps Ice Cream Food Service Division. We are the third largest ice cream manufacturer in the United States. Our labels include Greens, Kemps, Hagen, Hoods, Food Club, and Hytop.

How long have you been with ASD?

My wife Monica and I first toured the Brennen School while on vacation in 2004. After the tour and speaking with Cheryl Kelley, we

decided this was what our son Harrison, age 10, needed. I have been active with the ASD since January 2006 heading up the Public Awareness Committee.

Why do you do this?

Since our first visit to Delaware, the ASD has played a major part in helping us settle into a more typical family lifestyle. By introducing and socializing with other families, we don't feel like we are so isolated. Through their monthly meetings, informative guest speakers and web services, they have educated us and given us more hope for our son's future.



Heidi Mizell

Who am I?

My name is Heidi Mizell and I am both an ASD staff person and a

volunteer. I'm also a wife and mother of two, Shane who is 16 and Missy who is 10.

What do you do?

As a staff person I coordinate the Physician's Awareness Program, and as a volunteer I co-chair the Asperger's Committee and assist with Teen Night and Friday Night Out. My staff responsibilities include scheduling the team presentations on using parent reporting tools to help identify children who are at risk for a developmental delay, and I'm also part of the team as a parent presenter. Recently I received approval through Child-Care Licensing to give continuing education credits for child care providers.

How long have you been with ASD?

I've been a member for several years, and have worked since the spring of 2005.

Why do you do this?

I started as a parent volunteer on the physician's project, and one thing lead to another and I became the coordinator. Originally my connections with ASD was with Cheryl Kelley, who contacted me through the Asperger's Network of DE (which was my only e-group at the time), to continue working with ASD.

Yesterday. Today. Tomorrow.

For more than 100 years, Wilmington Trust has been privileged to provide volunteers and support to individuals and organizations who share our commitment to improving the quality of life in our communities. As we launch our second century in business, we remain steadfast in our commitment.

We are proud to support the
Autism Society of Delaware.





Call for Volunteer Recognition

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

There was a time when we knew everyone and why they were nominated. As we have grown larger, that is no longer the case; so we have adopted some guidelines for volunteer nominations.

These are volunteer awards—for anyone who has helped the autism community either directly or indirectly in a *volunteer* capacity. ASD recognizes that many professionals in our area make significant contributions; however, these specific awards are intended to recognize volunteers as opposed to able professionals such as dentists or beauticians. If you know a great doctor or attorney or beautician who has helped, please send us their names and contact information and we will include them in our Resource Guide, but we will not consider them for a volunteer award unless they are nominated for a specific volunteer service to this community.

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

Types of Awards

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 making ribbon pins for events to serving in the office to chairing a committee.

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.

This year we are also asking for more information about the nomination. Please complete the nomination form (a copy is on the next page) with this information:

- * the specific nature of the volunteer work
- * the amount of effort/time involved in the volunteer work
- * those positively impacted by the contribution
- * why this individual/group is deserving of special recognition
- * Contact Information

Employer Nominations should include:



- * Employer name and address
- * Supervisor or Manager's name
- * Information about individuals with autism who have been employed and whether it is competitive, supported, and full or part time.
- * Information about supports offered to workers
- * Other advocacy or efforts the employer has made to make them eligible for this award.

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

Please fill out the form on the next page, or e-mail to the address listed, and submit all entries no later than January 31, 2007.

Heads Up! Call now for Summer Camps

Easter Seals Camp Fairlee Manor



Camp Fairlee Manor will be sponsoring two camps for children with autism this summer.

June 17 - June 22 &
July 29 - Aug 3

25 Children Per Session
1 to 1 Care
Structured Schedule
Specialized Staff Training
Can Accommodate Special Diets

For more information contact:
Alex Humanick
(410) 778-0566



Bonded and Insured

GLAZAR
BROS. INC.

Heating and Air Conditioning

Celebrating 58 Years in Business

When you call Glazar Bros., you know you can speak to a Glazar.

Female owned and operated by a 3rd generation Glazar working hard to serve you.

Call Us Today! (302) 764-2520

Volunteer Recognition Nomination

Your Name: _____

Your Phone: _____ Email: _____

Name of Person/Business you wish to nominate: _____

Reason why you wish to nominate this person/business: _____

Nature of the Volunteer work _____

Time spent _____ Who Was Impacted? _____

Nominee's address: _____

City: _____ State: _____ Zip: _____

Nominee's Phone: Daytime: _____ Evening: _____

Please send your nomination by: January 31, 2007:

Autism Society of Delaware 5572 Kirkwood Highway Wilmington, DE 19808

Attention: Volunteer Recognition or e-mail at: delautism@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.)**

My membership fee is.....

I would also like to contribute this amount directly to ASD

Total amount enclosed (add both amounts).....

\$ _____
\$ _____
\$ _____

Date: _____

Please make your check payable to the Autism Society of Delaware to

aware (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

Non Profit Org.
U.S. Postage Paid
Permit # 317
Newark, DE

