

The Sun

The Voice of Autism in Delaware

Detachable Monthly Calendar

January 2006

Autism Society	of Delaware	(302) 472-2638		www.de	lautism.org
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Tappy New Year!	2	ω	4 Kent County Support Group 6 p.m.	5	6	7
8	9	10 Parent's Coffee Hour 9 a.m.	11	Adult Issues Meeting 7p.m.	13	14
15	16 No School Martin Luther King Jr. Day	ASD Chapter Meeting 7 p.m.	18	19	20	21
22	23	24 Mom's Night Out 7 p.m.	25	26	27	28
29	30	31			s for more detai visit us on line utism.com	



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Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			Kent County Support Group 6 p.m.	2	α	4
5	6	7	8	9	10	11
12	13	Parent's Coffee Hour 9 a.m.	ASD Chapter Meeting 7 p.m.	16	17	18
19	20 Presidents' Day Schools and Office Closed	21 N.C.C. Support Group 7 p.m.	22 Dad's Night Out 7 p.m.	23	Family Night at Friendly's Restaurant. Kirkwood High- way 6:30 p.m.	25
26	27	28	Check ASD web	February Exact Time and site: www.delautis	e Night (Ages 1 21, 2006	office at (302)



The Voice of Autism in Delaware

The Sun

The Autism Society of Delaware Newsletter

www.delautism.org

January/February 2006

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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.

ASD Announces 2006 Program and Events

The ASD Program Committee is really pleased to announce an exciting program of speakers covering a wide variety of topics for the coming year. They have worked to provide a balance of topics, age ranges and speakers that should have something of interest for everyone. Meetings will be in Newark, North Wilmington, and Dover. Here are the highlights:

January: Autism and Genetics – *Dr. Carolyn Schanen*, A.I. duPont
Hospital for Children.

Dr. Schanen will talk about her research on neurogenetic disorders, including autism, as well as the work her clinic is doing on the heritability of speech disorders.

February: Relationship Development Intervention (RDI)— *Libby Majewski*.

15

Libby Majewski is a certified RDI program consultant who will describe this approach that teaches children with autism to be flexible, to have a social reference in a situation, to regulate their behavior, and about conversational reciprocity and synchronized actions within everyday activities.

March: "Update on Autism Research"— *Dr. Craig Newschaffer.*

gDr. Newschaffer, Director of the Johns Hopkins Center of Excellence for Autism and Developmental Disabilities will give an overview of major research and findings in the field of autism.

April: Adults with Autism – A Panel Discussion, Facilitated by Ruth

3 Elaine Hane, Board Member of ASA Panel Participants:

Steven Shore – Board Member of ASA, Barney Vincelette and David Lerner – ASD members.

ASD is happy to present this panel of four adults who are on the autism spectrum for *Autism Awareness Month*. They will talk about their lives, their successes, their challenges, and how they have adjusted and adapted to life with autism.

May: "Brothers and Sisters" – A discussion of sibling issues — Dr. Laura
Donnelly, Brennan School of the DAP.

Dr. Donnelly will talk about siblings of children with autism and their experiences, strengths and needs, and the workshops that she offers through the DAP.

June: "National Legislation and Adult Studies"—Steve Eidelman, Edelsohn Professor of Disabilities Studies, University of Delaware.

Steve Eidelman, former director of the national ARC and current *Edelsohn Professor of Adult Studies*, will highlight national legislation; why it is important, and how it effects your child and family.



The Sun

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Kempner's Korner

By: Artie Kempner, President

Happy New Year, and I hope you're all keeping up on your resolutions. In past years I've usually resolved to eat healthier and lose weight. After consistently failing, this year's resolution is to get TALL-ER. I'll work diligently on that throughout 2006, and keep you all posted on my progress.

This month's column concerns what I believe is a great break-through for the autism community. Though it's not a research or treatment development, I do believe that *AutismSpeaks* (AS) is an organization that is going to be a major positive force in our world. Over the past couple of months, I've had meetings with *Suzanne Wright*, the cofounder (with television mogul husband, Bob), and *Mark Roithmayr*, the newly hired president and CEO.

I'm sure that many of you saw the weeklong features on autism on the *Today Show*, the *NBC Nightly News*, *CNBC* and *MSNBC* back in March. The catalyst of the series were the Wrights. In meeting Suzanne, Marcy and I feel that the autism community truly has found an inspirational, well-connected, powerful autism organization, that has the money to make a real difference in the lives of autistic people and their families. Suzanne, Bob and Mark "get it." They see the need for collaboration in order to bring our fractured community together. They see that we need that so that we will finally speak to our national legislators with one clear, and intelligent voice.

As president of ASD, and a Board member of ASA, I still believe that we are doing excellent work, both here in Delaware with ASD, and on the national level with ASA. But with the limited financial resources at ASA's disposal, there is only so much that they can do to help chapters and individuals. AutismSpeaks has been able to raise over \$30 million in a short time, and with their connections and professionalism, they'll be able to continue that wave of garnering financial support in the years to come.

Now you have to ask, how will ASD benefit from this new organization? Right now that answer is unknown, but when they hired Mark Roithmayr, they hired someone who had a ton of experience working with *March of Dimes*. He is not just a fundraiser, but a knowledgeable, experienced chapter builder. Mark and the Wrights realize that the autism community needs more then just national exposure, they need true grassroots initiatives. ASA has never really been able to underwrite a new chapter, and that is why ASA chapters are so diverse in their ability to serve the needs of their communities. I feel that in the coming years, AutismSpeaks will be able to address that failing--and when they do—the positive effect across the autism community will better unite us all.

Artie



ASD 2006 Program

(Continued from Cover)

The Edelsohn chair is the first position of this type in the nation, emphasizing research and services for adults with disabilities.

September: Social Security and

Disability Benefits -

26 Ben Shamburger, Social Security Ad-

ministration.

Confused about Social Security? Not sure whether to apply for your child or not? Ben Shamburger will explain and clarify what SSI and other Social Security benefits are and how to apply. He can answer any questions you have.

October: Autism and Medication-

Dr. Rhonda Walter, Developmental Pediatrician

at A. I. duPont Hospital

for Children.

Dr. Walter will talk about medications and the latest research on effective medications for individuals with autism.

November: This will be a repeat of the Sibling session at

the Dover meeting.

In addition to the speakers high-lighted above, ASD will be hosting a fall conference. We are early in the planning stages, so look for information in the early summer. And finally, we have been working with Dr. Peter Doehring to enhance teacher training for students with Asperger's Syndrome and autism. Last year we were able to cosponsor both Dr. Michael Powers and Dr. Ami Klin and open those sessions to parents at little or no cost to parents. We will be continuing that partnership in 2006 as well.

In Loving Memory of

Jane Shumaker



Those we love remain with us...
In the whisper of the wind
In a soft rain that falls from heav-

en

In each sunrise
In every single star that lights
the night sky and
In every single memory we hold
within our hearts.

-Mary Chandler Huff

On December 19, 2005, Jane Shumaker, ASD Member was taken suddenly from us. Jane spent her life helping others by working as a teacher and specialist at the Delaware Autism Program. As she departed she was able to continue helping five others by saving several other lives as an organ donor.

The Autism Society of Delaware wishes to extend our condolences to the Shumaker Family and to the Delaware Autism Program for their loss.



Autism Registry Regulations Are Going Into Effect

Last year ASD was the driving force to pass legislation to create an autism registry of information about the prevalence of autism spectrum disorders in the *State of Delaware*. The Delaware Division of Public Health has finalized the regulations and we are moving towards implementation of the new autism registry in 2006.

What will the autism registry do?

The registry will collect information on diagnoses of autism spectrum disorders for children from birth through age 17. Qualified individuals will be included in the registry after their diagnosis is reported by doctors, other health care practitioners, hospitals, and clinics. Reportable diagnoses are those used by the International Classification of Diseases (ICD) used by the CDC; the *Pediatric Association* system (BPA/ICD-9), or the Diagnostic and Statistical Manual of Mental Disorders (DSM IV). The DSM IV is widely used by the mental health and educational community.

Is reporting required?

Yes. Reporting is required by any physician (including psychiatrists) or other health care practitioners including clinical and school psychologists, speech and language pathologists, licensed clinical social workers, and nurses, including school nurses who make a diagnosis. In other words, any associated health care professional who diagnoses a child with autism is required to make a report. This includes testing services (called clinical laboratories) that make formal assessments through testing, and hospitals as well. The state has developed a



one-page, easy-to-use form for reporting purposes. Reporting must be done within 30 days of the diagnosis and a continual annual reporting of the diagnosis is required in an effort to keep the registry current.

Why is this necessary?

The intent is for the registry to gather information that assists with estimating prevalence, identifying potential clusters (meaning a greater than typical occurrence of the disability in a specific geographic area), identifying risk factors, and eventually, in reviewing outcome information. As we all know, research in autism remains in the early stages and continues to be funded at lower rates than other disabilities or diseases that are much less prevalent. A registry will collect information that can be used both for research and for planning. With the growth in numbers, both schools and adult services have been struggling to meet the demand. Better information about the number of children with autism will allow for better planning and services for children and adults.

How is confidentiality maintained?

The registry will include access to medical information; however, no reporting will be allowed that will identify a child or family. One of the strongest reasons that the *Autism Society of Delaware* has supported the concept of the registry is due to the increasing problems that major research

institutions have in gaining access to critical medical and other information relating to individuals with autism. The American Health Insurance Portability and Accountability Act of 1996, known as HIP-PA, was created to ensure that all medical records, medical billing, and patient accounts meet consistent standards regarding documentation, handling and privacy. Confidentiality is very important, but in practice, HIPAA can stand in the way of research. By having a registry of all individuals with autism, researchers will have better access to more accurate data.

Those of you who are parents will soon be receiving a letter explaining the registry, the reporting form, and the requirements of the *Division of Public Health*. We encourage you to discuss the new legal requirement with the health care professional that administers to the medical needs of your loved one with autism. *Lora Lewis* of *Child Development Watch* will be available to answer physician questions, and the ASD website will offer a link to the *Division of Public Health* website as well.

For further information you may contact:

Mary Carol McCaffrey

Coordinator of Genetic Services

Blue Hen Corporate Center, 655 Bay Road, Suite 216, Dover, DE 19901 Phone: 1-800-262-3030

or (302) 741-2988 Fax: (302) 741-2995



Volunteer Recognition Awards—April 2006

Great Job!



Way to Go!

Who do you think has made a difference to the Autism Society of Delaware? Is there someone in the community you'd like to publicly honor because they made a difference to your loved one with autism?

ASD is asking for nominations for its Volunteer Recognition Awards. If you know of a business or individual who should be honored for their efforts, please nominate them for a Volunteer Recognition Award to be presented in April 2006. Your nomination should include their name, address, phone number, and a brief description stating why you think they should be honored.

Please send your nomination by: February 15, 2006:

Autism Society of Delaware 5572 Kirkwood Highway Wilmington, DE 19808 Attention: Volunteer Recognition

Or e-mail at: delautism@delautism.org

	• • • • • • • • • • • • • • • • • • • •	•••••
Your Name:		
Your Phone:	Email:	
Name of Person/Business	you wish to nominate:	
Nominee's address:		
Nominee's address: City:	State: Zip:	



Research Headlines

Autism problems explained in new research

October 25, 2005

New research from Melbourne's Howard Florey Institute (Australia) helps to explain why children with autism spectrum disorders (autism) have problem-solving difficulties.

Using functional magnetic resonance imaging technology (fMRI) the Florey scientists have shown that children with autism have less activation in the deep parts of the brain responsible for executive function (attention, reasoning and problem solving).

Research leader, Dr. Ross Cunnington, said autism was known to have a biological cause, but this neuroimaging research clearly showed the dysfunction in the brain that accounted for why children with autism have problems with their executive function.

"Discovering why children with autism have impaired executive function may help develop better therapies to improve their ability to pay attention and solve problems," Dr. Cunnington said.

"Specifically, we found that activity in the caudate nucleus, a critical part of circuits that link the prefrontal cortex of the brain, is reduced in boys with autism."

"These findings have important implications, since prefrontal brain circuits play a critical role in maintaining and focusing attention, planning and setting goals, and keeping goals in memory during problem-

solving," he said.

Dr. Cunnington, along with Ph.D. Student, Tim Silk, have also been studying children with attention deficit hyperactivity disorder (ADHD) and have found similarities in the impairment of specific executive function in children with ADHD and autism.

The autism study was conducted with boys aged 11 to 18 years who have autism or Asperger's disorder, as well teenage boys without the condition.

Autism affects one in 100 Australians and is a lifelong condition that affects the way a person communicates and relates to other people. People affected by autism typically display major impairments in social interaction, communication and behavior (restricted interests and repetitive behaviors).

The majority of people with autism also have an intellectual disability. Those with Asperger's disorder are typically of average or above average intelligence and may have relatively good communication skills but specific learning difficulties.

The Florey scientists collaborated with scientists from Monash University, the Brain Research Institute and Texas Tech University in the USA. The results of this research are soon to be published in American Journal of Psychiatry.

The Howard Florey Institute is Australia's leading brain research center. Its scientists undertake clinical and applied research that can be developed into treatments to combat brain and mind disorders in Australia, and around the world. The Florey's research areas cover a variety of brain and mind disorders including Parkinson's Disease, stroke, motor neuron disease, addiction, epilepsy, multiple sclerosis, muscular dystrophy, autism and dementia.

For more information contact: Merrin Rafferty, Public Relations and Development Manager Howard Florey Institute Email:

m.rafferty@hfi.unimelb.edu.au

http://www.hfi.unimelb.edu.au

Not
everything
that is
faced can
be changed,
but nothing
can be
changed
until it is
faced.

~ James Baldwin American Writer (1924-1987)



Inside



The Sun

Did you notice our different look this month? ASA has adopted the tagline *The Voice of Autism*, so ASD is adopting that as well, and using our own logo as the masthead. We considered changing the name, but found that people are very attached to *The Sun*, so the name stays. We hope you enjoy this new format which is printed and bound rather than copied. It should be more clear and easier to read than the copy approach that we previously used.

Mom's Night Out

The Dads have been having such a great time on their night out that the Moms want to have fun too. Enough of this committee work or support group stuff they say! We want to eat, drink, and be merry along with the dads. Member Monica McMahan has offered to put together Mom's Night Out that is just for fun on January 24. Come join other moms for a night of fun. We will be alternating the Wilmington support group night with a Mom's Night Out. Contact Monica at mmcmahan85@aol.com for more information.

Asperger's Interest Group

A major goal for this group is to develop opportunities for teens to have fun, meet others, and learn some social skills at the same time. Our first attempt will be to host a Teen Game Night on February 21. If you have a child who is still in school who would be interested in coming, please contact the office. Amy Ribbett and Shara Simpson, both speech pathologists who have

experience teaching students with autism, will be coordinating this event. Look to the e-group for more information about the time and place.

Holiday Party Highlights

More than 80 parents, friends and children showed up for our second family holiday party to watch "Ms. Vickie" perform, make holiday pins with Diane Belnavis, get their pictures taken by *Nicole Curran*, and generally just have a great time. ASD would like to give a special thank you to all the members of the social committee who helped to make this party so successful. Our thanks go to Laurie Nicoli who headed the planning and donated the cakes and drinks; to Dwayne and Monica McMahan who brought ice cream donated by Kemps, to Nicole Curran who found the entertainment, made table decorations and took photos, and to Robin Delaney for help with organizing and bringing craft items, ice and other supplies. We would also like to acknowledge Del. Vets Post #1 who donated the space and surprised us with stuffed animals for the kids. See pictures on page 17.

Spanish Language Brochure

With thanks to Yolanda Flanigan and Melinda Cicca, ASD is printing its' brochure in Spanish. This has been a long time goal that we're happy to have accomplished. Our next goal is to translate the parent packet as well. We'll be happy to make these brochures available to local organizations that support the Latino community. Please let the office know if you know of an organization that could use these.

Visioning and Strategic Planning

ASD is now seven years old and is entering the last year of our second strategic plan. We have

currently met most of our goals with a year to go. With the new board in place ASD is working hard to move from the small informal all volunteer organization that it was to the final stages of becoming a full fledged, stand alone nonprofit with a formal Board of Directors. Over the past year we have revised our bylaws, incorporated as a non-profit organization that is affiliated under the Autism Society of America but is separate from ASA, and we have expanded our Board of Directors and held new elections. The board went through training with Dr. Pam Leland of the University of Delaware in November, and will kick off a new strategic planning effort under the guidance of Mr. Bob Wright of Organizational Development Associates in February 2006.

Bob and his organization assist organizations with strategic planning ranging from large companies such as Honda, Eastman Kodak, and AstraZeneca to federal agencies such as the Department of Education to non-profits such as Children and Families First. Their purpose is to provide appropriate tools and approaches for building a shared vision, and planning strategically in a way that uses dialoque and collaborative problem solving across functional, organization, and geographic boundaries. We are looking forward to this process and the guidance that OD Associates will provide.

Social Activities

The social committee has been busy putting together the 2006 calendar. We can look forward to another night with the *Blue Rocks*, summer picnic at *Cape Henlopen*, and skating parties, along with some new events including a Halloween party and a family dinner at Friendly's. Check our webpage and e-groups for these notices.



_egislative ssues

him or her achieve their goals, sometimes working with a provider agency or making other arrangements. The

fiscal agent and family education and training are new services.

Additionally, everyone will get day habilitation (commonly known as a day, work center, community or supported employment program) and transportation. Individuals currently receiving family support also get a day program. Transportation would be a new service which is important because families generally provide transportation to adult services now, with the exception of those in special populations.

Finally, the waiver would include \$3800 per person for a range of services. These services may include personal care, respite, emergency temporary living, extended day care, environmental modifications, assistive technology, support assistance stipends, and a variety of therapies such as physical, occupational, or speech. These are the services that individuals and families would decide upon based on their individual needs.

What is the purpose of the Family Support Waiver?

The Family Support Services Waiver is intended to widen the range of services available, to increase individual and family choices, and to promote needed supports and services that are less costly and that either prevent or delay more expensive residential placements. So, one family can choose to use their funds to pay for additional respite care to allow a weekend away or a regular night out. Another family may choose to use a personal attendant to

help with getting up in the morning, and a third family might purchase a stair lift so their child who uses a wheelchair can reach the second floor bedroom.

(Continued on page 10)

What is a Medicaid Waiver?

The Social Security Act authorizes the federal government to waive certain Medicaid statutory requirements to allow states to cover a broad array of home and community-based services for targeted populations, including developmental disabilities, as an alternative to institutionalization. Waivers may include services that are not covered by the State (Medicaid) Plan such as respite care, environmental modifications, or family training.

To be a waiver participant, an individual must be medically qualified, certified for the waiver's institutional level of care, choose to enroll in the waiver as an alternative to institutionalization, cost Medicaid no more in the community under the waiver than he or she would have cost Medicaid in an institution, and be financially eligible based on their income and assets.

The DDDS HCBS Medicaid Waiver pays up to 50% of adult services in Delaware for those who are eligible for the waiver, which includes most adults who receive services. There are strict resource limitations to maintain eligibility. You may call 1-800-772-1213 (TTY 1-800-325-0778), OR CONTACT YOUR LOCAL SOCIAL SECURITY OFFICE for more information about income eligibility.

Family Support Waiver Tops the ASD Legislative Agenda

Delaware has been fortunate to be able to offer family support services over the past decade. These services are primarily provided to families whose adult children live at home. First funded with state funds in the mid 1990's, state funding has remained the same but the number of families needing assistance has grown significantly. To address this need, the Division of Developmental Disabilities Services is applying for a family support waiver to bring additional funding and services to the state. ASD recognizes that more and more students will be graduating and living at home, so we strongly endorse the concept of funding family support at a higher level.

What services would this waiver provide?

The waivers must include support coordination, a fiscal agent and/or intermediary, and family education and training. Currently individuals receive case management which is similar but not quite the same as support coordination. Case managers have responsibilities to oversee fiscal resources to ensure that individuals are not over the resource limits for Medicaid. They work with the community provider and the family to ensure that services are being provided the way they are supposed to be. The support coordinator has more overall responsibility to work with the individual and family to understand what the person wants and to help



Girls Just Wanna Have Fun... Don't Miss Mom's Night Out!!

When? January 24, 2006 - 7:00 p.m.

Where? Houlihan's Restaurant, 500 Center Blvd. Newark, DE 19702 (Next to the Christiana Mall and Pier One Imports).

www.houlihans.com Why? Because we can!

How? Call Monica McMahan at (302) 235-2101 or email:



m.mcmahan28@comcast.net

Don't miss out on our first Mom's

Night Out!

Dad's Night Out

Wednesday, February 22
Time and Location TBA
(They always wait till the
last minute to plan things!)
Who can go? Dads, Uncles, Grandfathers or Friends of those living with autism. Interested?
Of course you are!
Contact: Artie Kempner
(302) 777-7273
or artie3boys@aol.com

Upcoming Dad's Night Out Dates: April 19, June 27 & August 22.





The Premiere Celebrity-Am Golf Event in the Mid-Atlantic!

June 1, 2006

DuPont Country Club, Wilmington, Delaware

Sponsorship Opportunities are Now Available!

Contact: Tournament Co-Chair, Artie Kempner (302) 983-6621 Or Event Coordinator, Cheryl Kelley (302) 472-2638, ext 203

Early Bird Registration Upgrades Available until February 15, 2006.

Want to help?
Have talents or time to offer?
Become an ASD Volunteer today!

ASD's success is due to all of our wonderful volunteers! We have several committees that always need help, including: *Adult Issues*,

Asperger's, Legislative, Social Events, and many more... Give us a call today and we will try to match you up with something that best fits your talents and interests!

(302) 472-2638.

Next Deadline for Submissions to The Sun: February 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.

Let Your Voice Be Heard!
ASD reserves the right to edit for space and content.





Legislative Issues—Family Support Waiver (Continued from page 8)

All of these are services that help the individual stay in the family home, but they look different for every family.

The waiver also makes the assumption that when individuals and their families guide the purchase of supports, it is likely they will be more cost-effective and will meet their need more effectively. If the family chooses to use the local provider agency, the family or the support coordinator becomes the negotiator for the service and the cost. Some families may choose a more intense service for a shorter time, while another family may try to extend the day as long as possible. The waiver allows this flexibility. Providers can also be fired when they don't perform. Making these choices and negotiating for services should enhance their decision making capacity, and increase the individual's satisfaction with his or her life because they are creating the life that the person wants, and that the family feels is what they need, rather than the life that a "slot" will provide.

How much will it cost?

The State of Delaware must be willing to put up four million in order to draw down four million federal dollars. In fact, with state and federal funds already in the system, the entire program would cost about \$15,000,000. However, eight million would be new state and federal funds. The additional funds are already in the system and paying for family support case managers and day programs. New monies will allow more people to be supported while living at home, and will enhance the number of services available. DDDS anticipates that 1,076 people would be served during the first year.

Informational Meetings

DDDS is holding informational meetings on the family support waiver in January. The dates and times are below.

- January 10th 2006 6 9pm –Del. Tech, Dover Terry Campus, Corporate Training Center, Room 407
- January 17th 2006 6 9pm –Del. Tech, at the Stanton Campus, room A116
- January 18th 2006 6 9pm Georgetown Owens Campus, Room 344A

We strongly encourage you to attend these meetings to learn more, ask questions and show your support. Additionally, we encourage you to write to Governor Ruth Ann Minner, www.state.de.us/governor, and contact your local legislators, www.delaware.gov, asking them to fund the Family Support Waiver. Delaware spends millions of dollars on many things. This is a wise investment of four million dollars to help our folks live at home and work in the community.

AUTISM SOCIETY OF DELAWARE VOLUNTEER RECOGNITION CELEBRATION

Cruise for A Cause

April 7, 2006

Bellevue Hall at Bellevue State Park

Join us as we pay tribute to our volunteers of the year. Have fun at our Casino Carib-



bean featuring Blackjack, Roulette, Craps and Texas Hold'em Poker. Kick back and listen to reggae music, sip rum punch and sample food from the islands.

Tickets are \$35 per person or consider sponsoring a gaming table for \$350.

Stay on board for more details...

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.



Autism Society of Delaware

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

ASD Monthly Meetings

- ▶ January 12—Adult Issues Committee Meeting, 7:00 p.m. ASD Office, Kirkwood Hwy., Wilm.
- ▶ January 17 ASD Monthly Meeting, 7:00 p.m. Brennan School (DAP), Newark. Guest Speaker, Dr. Carolyn Schanen on autism and genetics.
- ▶ February 15 ASD Monthly Meeting, 7:00 p.m. Concord Presbyterian Church, 1800 Fairfax Blvd. (corner of Foulk and Murphy Rd.) Guest Speaker, Libby Majewski on Relationship Development Intervention.

Social Events, Public Awareness & Fundraisers

- ▶ January 10 Parent's Coffee Hour, 9:00 a.m. Crossroads Restaurant, Route 7 & Kirkwood Highway. Coffee is on us! More information on page 9.
- ▶ January 24 Mom's Night Out! 7:00 p.m., Houlihan's Restaurant, More information on page 9.
- ▶ February 14 Parent's Coffee Hour, 9:00 a.m. Crossroads Restaurant, Route 7 & Kirkwood Highway. Coffee is on us!
- ► February 21 Asperger's Teen Game Night. Location and time TBA. Please call us at (302) 472-2638 or visit our website: www.delautism.org under ASD Calendar.
- ▶ February 22 Dad's Night Out. Location TBA. Contact Artie Kempner (302) 777-7273 or artie3boys@aol.com for information. More information on page 9.
- ▶ February 24 Family Night Out at Friendly's Restaurant. Exact time and details TBA. Please call us at (302) 472-2638 or visit our website: www.delautism.org under ASD Calendar
- ▶ March 14 Parent's Coffee Hour, 9:00 a.m. Crossroads Restaurant, Route 7 & Kirkwood Highway. Coffee is on us!
- ▶ March 15 ASD Roller Skating Party for New Castle County, 5:15-7:15 p.m. Christiana Skating Center, Newark. More information on page 16.

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 and the Kent County evening support group is held on the first Wednesday of each month.

- ▶ January 4 ASD Kent County Support Group, 6:00 p.m. St. Jones Center for Behavioral Health, 725 Horsepond Road, Dover. Next Kent County Support Group, February 1 & March 1. ▶ February 21 — ASD New Castle County Night Time Support Group, Wilmington. 7 p.m. at the ASD office, 5572 Kirkwood Highway. Next N.C.C. Support Group, April 18.
- * Notice: Due to a lack of interest, the daytime Middletown support group has been discontinued. If there is anyone who is interested in having a support group in the evenings in the Middletown area, please contact ASD. (302) 472-2638.

▶ February 9, 2006 — ABC's of IEP's, by the Parent Information

Other Events

- Center of Delaware. PIC main office. Learn to formulate appropriate and measurable goals and objectives and how to monitor your child's progress through the Individualized Education Program (IEP). You must register to attend! Contact: (302) 999-7394 or www.picofdel.org
- ▶ April 26, 2006 Tony Attwood, presented by Future Horizons. Philadelphia, PA. For information call: 817-277-0727, email: teresa@futurehorizons-autism.com or visit their website: www.futurehorizons-autism.com.
- ► May 11, 2006—DOE/DATI Inclusion Conference. University of Delaware, Clayton Hall. For more information contact DATI, (302) 651-6790, dati@asel.udel.edu or visit their website: www.dati.org.



Parent 2 Parent

Our Caroline Turned Six By: Chip Davis

Last week our Caroline turned six years old. For me personally, I find the time around her birthday to be the most emotional time of the year — it reinforces the roller-coaster ride of emotions that we seem to go through as a family; the highs when she breaks through some communication or social barrier, and the lows we as a family, have known all too well, through too many instances, to mention.

Autism stinks. No—autism is hell. It is hell for the undeserving child who is afflicted with the disorder and the family who must accept it into their home. Think for a moment about what it must be like for a child to be unable to relate socially to much of the world around her, to often not be able to communicate what she is feeling, to experience fits of uncontrolled emotional hysteria simply because of a change in schedule or routine, or who, with no advance notice, and at times for no particular reason, will have a temper tantrum while in the check-out line at the grocery store or in some other public setting. Imagine what that must be like for her parents, her older brother and younger sister. Perhaps to your surprise, what I have described would not necessarily equate to a bad day, because I haven't even referenced the epilepsy and seizure issues we have been dealing with since last December. Trust me when I tell you the true definition of hell is fearing that your child is dying in your arms while you desperately await the arrival of the ambulance. I would not wish that on an enemy.

I am sharing this not because it is therapeutic per se or to evoke a level of sympathy—in fact it is quite the opposite. If my family's experience with autism is going to be, as it will likely be, a life-long battle, then I feel very fortunate and blessed to have the people in my life that are willing to confront it in

an effort to help Caroline:

 To have a wife, mother and partner who steadfastly refuses on a daily basis to give in, when in reality it would be so easy to. To be Caroline's biggest champion, while ensuring a healthy, fun, productive and normal childhood for Ryan and Hope, is something I stand in awe of on a daily basis. I often joke in

"If my family's experience with autism is going to be, as it will likely be, a life-long battle, then I feel very fortunate and blessed to have the people in my life that are willing to confront it in an effort to help Caroline."

work settings that I married over my head—that is so true because none of us could get through this without Tina - she is so incredible and so strong.

It is hard for me to speak or write about what Ryan has meant to Caroline. The day he was born, the day Tina and I became parents, was the single greatest day of my life. I know I am biased, but I can't imagine there being a better sibling for a child with special needs than our "Rye-Rye." Lord knows he has had and continues to have health challenges of his own,

written by parents for parents

but you would never know it from talking to him; his concern is always for his little sister. He supports and defends his sister like no one else. I have benefited so much from his strength and character. It is a privilege to be his father.

- Hard to say anything about little Hope that has not already been said. Firecracker...two going on twenty-one...a real kick in the pants...so easy to get along with provided you do exactly what she wants exactly when she wants you to!! All kidding aside, like her brother, Hope contributes so much to our overall family effort to create a normal household environment - a critical aspect of trying to get Caroline to live more in our world than in her own. As ridiculous as it sounds, it can be heartwarming to watch she and Caroline fight, just like normal sisters do, over toys and magicmarkers or whatever else both of them want at the same time. I truly believe that the main reason Tina was in the hospital for all those weeks in pre-term labor is because Hope wanted to enter the world as quickly as possible so that she could begin doing her part to help Caroline. I love her for that.
- As for the "Mom-Moms" and the "Pop-Pops", it would be impossible to capture all they have meant in providing love, understanding and support. Perhaps it is sufficient to say that it is only because of the way Tina and I were raised that we are strong enough now as parents



Parent 2 Parent

Our Caroline Turned Six (Continued from page 12)

ourselves to continue to handle the challenges autism presents.

 Last, intentionally so, is the birthday girl herself. I often think about when Caroline was diagnosed with autism, how it was the equivalent of having your heart literally crushed in a vise; being told back then that your child may never be able to communicate normally or be able to interact with you in a way you would expect.

That awful day was a little less than four years ago. I often think back to that time when I come home from work at night, walk in through the garage and have this breathtakingly beautiful child run over, jump up into my arms, look me RIGHT IN THE EYES and say "HI DADDY, HOW WAS WORK **TODAY?!**" Seems they forgot to tell Caroline that she may never be able to communicate or express herself emotionally, or maybe she just decided she would disregard that assessment and surpass expectations. Being in that moment with her is one of the most empowering things I have ever experienced - she provides a glimpse into her heart and soul —I know there is so much more there that we need to bring to the surface.

We admittedly still have very far to go with Caroline's development, but it is important to take a moment every so often to appreciate how far she has already come, and realize that no one is more responsible for that than Caroline herself.

There are many other people in

Caroline's life who deserve so much thanks and appreciation for the support she, and we as a family, have received. This letter is intended for you as one of those people - one of those family members, friends, and someone whom we may have first encountered in a professional setting who has come to mean so much more to Caroline, and to us. Let me say how grateful and appreciative I am, and our family is, for everything that you have done.

Fighting autism is a long and difficult battle. We have had some victories and some setbacks along the way, and have every expectation that the road ahead will provide similar peaks and valleys, some good days, and many difficult ones. But this fight must be fought, unconditionally and without reservation, because in the end, with the continued support of special people like you, Caroline is going to win.

Thank you so very much for all you have done to help our Caroline.

Sincerely,

Chip Davis Caroline's Dad

There are only

Two ways of

spreading light- to be

the candle or the

mirror that reflects it.

-Edith Wharton (1862-1937) Dear ASD,

I wanted to send a message your way (and absolutely should have done so sooner) to simply congratulate all of you on the success of the Autumn Action several weeks back. To no surprise, as has become the norm with ASD events, it was a first rate evening throughout, and the theme surrounding the critical role grandparents play in the lives of children with autism was nothing short of terrific. Tina and I were able to bring her parents and they were incredibly touched by such a focus (Marcy, your comments were so profound and really hit home for

When events like this one run so smoothly it is often easy to overlook how much time, energy and effort it takes to make them happen; just know that your efforts are incredibly appreciated, both with respect to the major fundraising events during the year and everything you do for ASD day-in and day-out.

On a related and personal note, I am attaching a note I scribed a few weeks ago around the time our Caroline celebrated her 6th birthday - simply a Dad's reflection on his child and all those who play such a critical role in her life. While obviously intended for a limited audience of family, friends and supporters who have been with us throughout this autism journey. through a lot of feedback I have been encouraged/pressed to share it a bit more broadly. While this admittedly gets me a bit outside of my comfort zone, if you feel it can be of any help or assistance to anyone feel free to pass it along.

Thanks again,

Chip



Parent 2 Parent

A Little Miracle
By: Susan Kelly

We were desperate to escape before blizzard like conditions paralyzed the East Coast last January. Our family of four was headed to California to visit my terminally ill stepmother of 35 years. To appease our son Mark's love of bridges, we were traveling to Central California via the Golden Gate Bridge. Some of you may understand the circuitous route.

After three hours sitting on the plane waiting to be de-iced, a layover, and a missed connection, my ever hesitant-to-travel-too-far husband was big into the I told you so mode. Our journey lasted 19 hours, but it was a now or never event and we were determined.

The entire way, Mark perseverated about buying Milano cookies when we arrived. As the day turned into night and back into day again, I gently suggested several times that we would get those cookies tomorrow and a volcanic tantrum would start to erupt. Mark was insistent that we get Milano cookies today in San Francisco! Rather than risk a boisterous outburst on a full plane of already frazzled people, I consented....at least one thousand times... that we would get Milano cookies when we got to San Francisco. Anything to keep the peace!

Our exhausted family arrived at the hotel in the wee hours of the morning. As we entered our hotel room, we rubbed our eyes in disbelief. There on the table was one glorious, complementary package of *Milano* cookies. While we tried to contain ourselves, Mark smugly snacked away.

As we mentally prepare to travel out West again this January to visit my now widowed father, that story keeps creeping into my mind.

While we are still waiting for the big miracle — a cure for autism, we're thankful for this and other everyday little miracles. To all our friends in the autism community, here's hoping for a few little miracles of your own in the New Year and hopefully the big one in our lifetime.

Correction From November/December 2005 Issue of *The Sun*

In the last issue we identified new board members and recognized former officers and board members. It incorrectly noted that Jane Graci completed a two-year term as Vice-President. She actually completed that term as Treasurer. We would like to especially thank Jane for all her work in this position.

Who We Are...

By: Cheryl Kelley

I remember back in the early days of ASD when everyone knew everyone else and who was doing what and where and why. It is really easy for those of us who work with ASD on a daily basis to forget we are no longer a small organization that does everything on someone's kitchen table or office floor. We also forget that not everyone knows who we are. Sure you hear names, and sometimes see faces, but you do not always get to connect the dots. With this in mind we decided in this issue of *The Sun* to start sharing a picture and a little bio of the people who serve ASD on a regular basis starting with the office staff.

Theda Ellis, Executive Director



What do you do?

I direct ASD overall, and spend most of my time developing ASD's programs for individuals and families and on advocacy. I represent autism at the State Council for Persons with Disabilities, the Developmental Disabilities Council, and also work with adult agencies such as the Division of Vocational Rehabilitation and the Division of Developmental Disabilities Services. It's my job to ensure that ASD meets the goals and objectives set by the board and committees, so I write grants and put together pro-

jects such as the *Physicians' Awareness Project* and the *Adult Study*. My goals for the coming year are to develop a plan to become a support brokerage and to put together a conference for the late fall.

How long have you been with ASD?

I have had my "new" job as director of ASD for three years.

(Continued on page 15)



Who We Are

(Continued from page 14)

Why do you do this?

That's a really great question. As a young college graduate, I tried sales and investments, and decided that I wanted to work more directly with people and returned to school. The reason that I was interested in working for ASD is because it combined two things that I both love and find challenging—the chance to create something new and watch it grow, and the opportunity to work with families. The concepts of family support and self determination are very important to me, and this position allows me to do both. We work to improve systems and develop services for individuals with autism, but even more, ASD is about giving families information and the support they need to raise their children to be healthy, happy and productive adults.

Cheryl Kelley, Communications Coordinator



What do you do?

I publish ASD's newsletter *The* Sun, design and maintain the ASD website and do all of our graphic design such as logos, brochures, invitations and

posters. I am a parent mentor, spending a lot of time on the phone with parents who have a newly diagnosed child, are new to the area, or who have a special problem and need resources to find answers. I oversee the office volunteers and serve as the event coordinator for The Drive for Autism Research Celebrity-Am Golf Outing.

How long have you been with ASD?

I started with ASD in December of 1998 as a volunteer and eventually became ASD's first staff person.

Why do you do this?

I do this for many reasons. The most important reason is to help promote a better future for my son Jonathan who was diagnosed with autism in August of 1995. I also found that working with ASD has given me a great deal of support by receiving it from others and giving back to the community with the work I do. I could not imagine doing anything else! I have two boys; Jonathan, age 12 and Jarod, age 7.

Margie Rowles,



Office Manager

What do you do?

I provide office support and administration (files, ASD manuals, phones, emails, monthly updates, timesheets, etc.), database manage-

ment, membership, registration & checkout for ASD events.

How long have you been with ASD?

One year on February 7th, 2006.

Why do you do this?

I have the best of both worlds—working part-time and being available for my family, especially with my daughters' school events such as field trips and special functions. My daughters are Dalton, age 10 and Marti, age 7.

This has been the most fulfilling job I've had. Not only do I work with a bunch of great folks, the work that I

do affects tons of people. I like making a difference and doing something important.

Welcome Aboard to ASD! New Members in 2005

Heather Allen Nora & Stephen Andrews Desiree Bartlett Tawanna Bentley David Blackwell Tim Bourett Tim Briggs Steve & Keli Carr Teria Chandler Shane & Michelle Cornwell Beverly Davis Katina Demetriou Nadine Dixon Angela Dornell Ahmed Faridy Kathie Fitzpatrick Lester & Yolanda Flanigan Michael & Leanne Garrett Julian Ghanavati Andrea Guest Kademane Gururaj William & Kimberly Herbert Andrea Hill Shonna Hillard Karl & Christie Hoffman Fred Hofstettter Lisa B. Hughes John M. Kennel, Jr. Larry Jeffers Melanie Liesener FahPow & Shannon Liew Cindy & Kevin Mackesey Michael Malle Mitch & Sharrie May Gwendolyn McLaughlin Marý Kay Mills Darléna Moore Frank & Jennifer Nardo Mary Kay Olson Pernell & Stacie Parfait Paul Paugh Belinda Porter Curtis & SharonReider Gloria Rybicki Robert & Elizabeth Scheinberg Carol Schofield Rod Scott Ellen R. Stevenson Michael Terra James & Janice Venema Constance Welde Sally Wemmers Lan & Yeow Yong Lyn Ziccola



Thank You, Thank You Thank You! 2006 ASD Donors:

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*The following donations were made to ASD as a direct donation and not associated with any of ASD's fundraising events.

The Second <u>Tuesday</u> of Every Month

John & Sharon Goodill

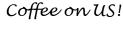
PARENT'S COFFEE HOUR

Crossroads Restaurant, 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







ASD Roller Skating Party

March 25, 2006 Christiana Skating Center, (Route 273), Newark 5:15—7:15 p.m.

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



Court of Dreams Night Saturday February 25, 2006 7:00 p.m.



Get ready to play where the Pros play! Your team can lace up, take to the court and play under the bright lights of the Wachovia Center! As an added bonus, members of the Pyramid ground are invited to play on the court for one hour before the game! Your cost: \$19.00 per person.

For more information, visit: www.pecs.com or call Debbie Bittner: (302) 994-2120.



ASD Holiday Party 2005



Autism Society of America Membership Application			
Please enroll me in the following category:Student \$15Individual \$30Family \$40Outside USA \$50Professional \$100Agency \$500Life \$1,500			
I am a new memberI 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 <i>The Sun.</i> (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) \$			
Please make your check payable to the Autism Society of Delcation 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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