



# The Sun

*The Voice of Autism in Delaware*

Detachable Monthly Calendar  
**September 2007**

Autism Society of Delaware

(302) 472-2638

[www.delautism.org](http://www.delautism.org)

| Sunday | Monday                                 | Tuesday                               | Wednesday | Thursday                                    | Friday  | Saturday                                  |
|--------|--|---------------------------------------|-----------|---|---|---|
|        |  |                                       |           |   |   | 1   |
| 2      | 3<br>ASD Office<br>Closed<br>Labor Day | 4                                     | 5         | 6   | 7   | 8   |
| 9      | 10                                     | 11<br>Parent<br>Coffee Hour<br>9 a.m. | 12        | 13  | 14  | 15  |
| 16     | 17                                     | 18                                    | 19        | 20  | 21<br>Asperger's<br>Teen Game<br>Night<br>6:30 p.m. | 22  |
| 23     | 24                                     | 25                                    | 26        | 27<br>ASD<br>Annual<br>Meeting<br>6:30 p.m. | 28  | 29<br>ASD<br>Mom's<br>Night Out<br>7 p.m. |
| 30     |  |                                       |           |   |   |   |



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| Sunday   | Monday | Tuesday  | Wednesday | Thursday | Friday  | Saturday   |
|--|--------|--|-----------|----------|---|--|
|  | 1      | 2  | 3         | 4        | 5   | 6  |
| 7  | 8      | 9<br>Parent's<br>Coffee Hour<br>9 a.m.<br>Dad's Night<br>Out<br>7 p.m. | 10        | 11       | 12  | 13   |
| 14<br>ASD N.C.C<br>Fall Festival<br>Bellevue<br>State Park<br>1-4 p.m. | 15     | 16<br>ASD Support<br>Group<br>7 p.m.                                   | 17        | 18       | 19<br>Asperger's<br>Teen Game<br>Night<br>6:30 p.m. | 20<br>Autumn<br>Auction for<br>Autism<br>6:30 p.m. |
| 21   | 22     | 23<br>ASD Chapter<br>Meeting<br>7 p.m.                                 | 24        | 25       | 26  | 27   |
| 28   | 29     | 30   | 31        |          |   |  |



The Voice of Autism in Delaware

# The Sun

The Autism Society of Delaware Newsletter

www.delautism.org

September/October 2007

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## Our Mission

*The Autism Society of Delaware is a chapter of the Autism Society of America. We are people with autism, their family members and friends, and professionals who work in the autism field.*

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

*We serve the entire state of Delaware.*

## Autism Society of Delaware to Award More than \$250,000 in Local and National Grants

The Autism Society of Delaware (ASD) board voted to award more than \$250,000 in grants to local and national organizations to meet a variety of needs of individuals on the autism spectrum. The board's goal is to create and enhance services in Delaware today, while also investing in the future through research and training.

### **\$200,000 to Productive Opportunities for Work and Recreation (POW&R)**

POW&R is a new service for adults with autism spectrum disorders funded by the Autism Society of Delaware. With the rates of autism growing rapidly, ASD has long considered starting adult services and has been fundraising to do this for a number of years. In preparation, ASD first completed a national study on best practices for adults with autism, then reviewed a variety of models of service and, finally, wrote a business plan. ASD anticipates underwriting POW&R for three years until it becomes self-sustaining and will continue to support POW&R with additional services that adults with autism require but that may not be funded through state or Medicaid Waiver funds.

Starting with five individuals, POW&R will work with individuals and

families to develop a plan of service that individuals control. It will use the concept of *Circles of Support*, meaning friends and family will assist in obtaining employment and developing supports. POW&R will teach job skills and provide ongoing support on the job, as well as help constituents to have fun and develop recreation skills, learn to use public transportation, or learn other things that they choose. POW&R's strength comes from working with individuals and families to create supports designed especially for each individual. As the service grows, POW&R anticipates addressing the needs of adults with Asperger's Syndrome, PDD-NOS and other related disorders. Services began for our first two adults on August 13, 2007. Contact Katina Demetriou at (302) 824-2252 for more information.

### **\$25,000 to the Organization for Autism Research (OAR)**

Every year the Organization for Autism Research conducts open grant competitions to select pilot studies for funding in autism research. These competitions promote research in the analysis, evaluation, or comparison of assessment or treatment models focusing on aspects of early education, employment, housing models and

(Continued on page 3)

Contributions for this newsletter provided by:





### The Sun

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| Theda Ellis   | Robin Ireland |
| Brenda Holsey | Jen Nardo     |

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## Kempner's Korner

By: Artie Kempner, President—ASD

This is a melancholy Kempner's Korner. I'm writing for the last time as President of ASD. No, I'm not moving or going anywhere, but I've "term-limited" out. I think this is a good thing for our organization as we have some outstanding Board members who have the qualities to lead us as we move forward. And I also recently found out that ASD isn't set up as a monarchy. I have truly enjoyed being your Board president for 8 of ASD's 10 years. It has been amazing to see the growth of the organization. We spent our first five years as an all-volunteer group, but boy, did we have great volunteers. In that half-decade we established a newsletter, website, monthly meetings, support groups, social outings and became a respected resource in the community. We have always "lived on the edge" a bit and taken some risks to help ASD get ahead.

The Autumn Auction was held in our very first year of existence, and I can vividly remember Marcy and me being concerned about losing money on the event! But thanks to a phenomenal committee, great community support and the Newschaffers' (Craig and Rebecca) auction system, we were able to net over \$10,000! And come this October 20th our TENTH auction will raise over \$100,000!!

I remember in 2000 when Pat Murphy suggested the first "Drive for Autism" golf event. Once again Marcy and I were worried about the potential to lose money on a FUNDRAISER. We got a group of folks together, made a lot of calls, sent a lot of e-mails and had a successful event with almost 100 golfers. Now we have 250 players, use both courses at the Dupont Country Club, and last year raised over \$500,000.

But the best "risk" that we ever took was when the Board decided to hire a full-time executive director. At the time we had only Cheryl Kelley (now Frampton) handling all the projects—websites, newsletter, mailings—plus a stellar volunteer group. Marcy and Jack Carney (Lt. Gov. John Carney's Dad), wrote a number of grants and thanks to Jack's persistence we got enough grant money to hire Theda Ellis. I must admit that when we interviewed Theda we failed to mention that the ASD office was located in our house. :)

Five years later we have 9 people on staff, a phenomenal new initiative called POW&R (Production Opportunities for Work & Recreation) for our adult population, a Physicians Awareness program, an Asperger's support group, Dad's Night, Mom's Night, picnic, skating parties, training seminars, and a slew of other great programs for our community.

I am so proud of what we have accomplished, and so proud to have been the President of this organization. This has been a labor of love for Ethan, and all of our loved ones with autism.

*(Continued on page 3)*

# POW&R

Productive Opportunities for Work & Recreation

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Project Director (302) 472-2638, ext 207

katina.demetriou@delautism.org

A Service of the Autism Society of  
Delaware

Karen Anderson (302) 824-2253 (cell)  
Community Specialist (302) 472-2638, ext 207

karen.anderson@delautism.org



### ASD Awards Grants

*(Continued from Cover)*

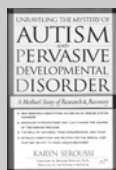
“later intervention.” The goal of this sponsored research is to promote studies that yield practical and clearly objective results that contribute to enhanced quality of life for people with autism and provide evidence-based information for use by parents, families and service providers.

### \$10,000 to Autism Speaks

In following our tradition of research funding, ASD is awarding Autism Speaks \$10,000 to be used toward funding global biomedical research into causes, prevention, treatments, and potential cures for autism. Autism is now diagnosed in up to 1 in 150 children, up from 1 in 2,500 in 1995. The increase over the years has led to a larger number of families with children with autism than ever before, and an increasing number of families coping with their adult children.

Looking for that special book? Want that cool looking autism pendant necklace you saw someone wearing at the office? Here are a few places you can find some autism-related merchandise online...

#### The Autism Shoppe



[www.theautismshoppe.com](http://www.theautismshoppe.com)  
&  
Autism Link



[www.autismlink.com](http://www.autismlink.com)

### \$10,000 to the National Association of Residential Providers for Adults with Autism (NARPAA)

NARPAA is working to establish a web-based curriculum for direct service workers that will be affordable and available to agencies, programs and services across the country. The curriculum provide basic information and knowledge about what autism is and how to work with adults with autism. This is unique because most university-based curricula address the needs of children. Now that this generation of children are becoming adults, the critical need is to increase services for adults.

### \$5,000 to Practice without Pressure (PWP)

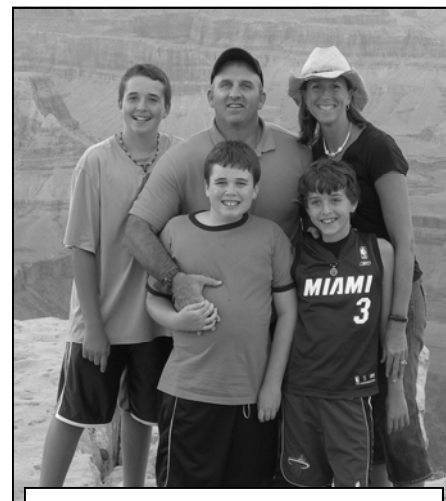
PWP works with children and adults in medical and other settings so that they will not have to be anesthetized or restrained in order to give blood, have dental work, or just have their hair cut. This award to Wilmington-based Practice without Pressure supports their mission of helping children and adults with disabilities receive quality medical, dental and personal care with dignity and respect.

### \$15,000 to Recreation Center Architectural Study

The Autism Society of Delaware, along with other community groups, is looking into the feasibility of creating a community recreation center that addresses the needs of people with disabilities and their families. The vision is to develop a fitness and recreation center that every member of the family can use, with or without a disability, and that accommodates individuals with disabilities by attending to their physical and sensory needs.

### Kempner's Korner

*(Continued from page 2)*



Artie Kempner with wife Marcy and son's Matt, Ethan and Jack.

I also need to let the few of you who don't know in on a little secret—Marcy's been the brains behind my brawn during these past ten years, so the organization has always been in excellent hands!

But you're not getting rid of me, I'm still on the Board, still honchoing the golf tournament, and will still stay very much involved with ASD. Thanks to all of you for your support, involvement and help. Now lets get to work on ASD's future success!

### Thank You Artie...

*"I long to accomplish a great and noble task, but it is my chief duty to accomplish humble tasks as though they were great and noble. The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of the tiny pushes of each honest worker."*

- Helen Keller

CKF



Please welcome the following new members to ASD...

Jules, Todd & Simon Brugel  
 Chie and Jim Kelly  
 Stacey O'Rourke  
 Julia Kirkpatrick  
 Brenda Cheeseman  
 Joanna Francis  
 Andrian Moore  
 Shirey Opalach  
 Misty Mitchell  
 Leilanie Redondiez  
 Cortney Mehalchick  
 Teon Wall Sr.  
 Prasanta & Sarita Parida

## 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.

# Social Skills Training

Over the past two years the need to learn more about social skills has come up again and again. We first helped to sponsor training by Kathy Grayson last summer, then brought in Dr. Jed Baker and Dr. Peter Gerhardt this summer for workshops. Now it's time to ensure that more professionals and parents around Delaware know and understand how important social skills are and how to teach them.

To meet this need, we applied for and received funding from Chichester duPont Foundation and the Developmental Disabilities Council. With these funds, along with ASD funding, we will be sponsoring Dr. Jim Ball to bring training to Delaware in 2008. Dr. Ball is a board certified behavior analyst (BCBA). He has served as vice president of autism services for the YCS: Sawtelle Learning Center Programs headquartered in Montclair, N.J., with programs in Collingswood, Park Ridge, Ridgewood, Paramus, and Kearny, N.J. He has also lectured nationally and internationally on topics related to autism including inclusion services, behavioral assessment, social skills training, behavior management, direct instruction, sensory issues and accountability, and has published in the area of social skills, trauma, consultation services, technology, and behavior.

Dr. Ball is a member of the New Jersey Center for Outreach and Services for the Autism Community (COSAC) Board of Trustees and a member of the COSAC Professional Advisory Board, as well as a past member of the Autism Society of America (ASA) Board of Directors. He currently serves as co-chair of the ASA Panel of Professional Advisors.

ASD will be holding focus groups of parents and employers concerning specific issues at home and in the workplace in each of the three counties. Look for groups to meet in New Castle County on October 1, in Georgetown on October 2, and in Dover on October 3.

We are looking for parents and employers to participate in separate meetings in each location. If you are interested, please contact Heidi Mizell at (302) 472-2638.

For those who may be interested in training, it will be scheduled for the spring of 2008. We will be recruiting teachers, speech therapists, social workers, psychologists, parents and anyone else who may be interested in participating. Look for more information to follow.

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

Want to share a story? Have an idea for an article? Send it to ASD today!  
[delautism@delautism.org](mailto:delautism@delautism.org). Or mail it to us,  
 (address on page 2)

Let Your Voice Be Heard!



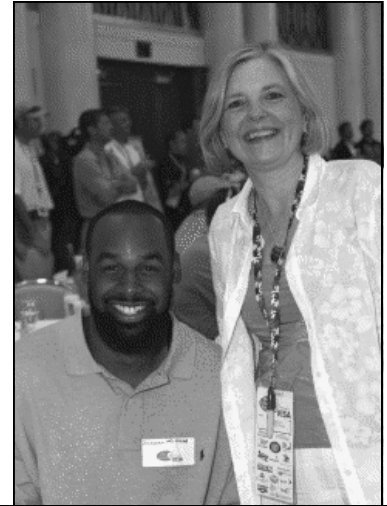
ASD reserves the right to edit for space and content.



Drive  
for Autism  
Research



Presented by:

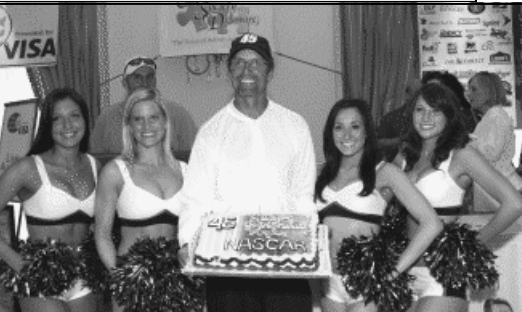
ASD Executive Director Theda Ellis with Philadelphia Eagles Quarterback Donovan McNabb.



NASCAR Driver Jamie McMurray with Delaware Autism Program Student Brendan Curran.

On May 31, 2007 at the DuPont Country Club in Wilmington, ASD held its 6th Annual Drive for Autism Research Golf Outing. This year ASD was honored to join forces with VISA as the title sponsor for the event which helped to bring this year's outing total to a record-breaking \$500,000! ASD would like to thank Jim Duncan and all of the good folks at VISA for their very generous support both financially and with the planning of the event.

ASD would also like to thank all of the other great sponsors, celebrities and students from the Delaware Autism Program who made this event such a success. There were over 250 golfers and about 60 celebrities covering several acres on two golf courses. On a personal note, I would like to thank the more than 70 volunteers who came out as early as 7 a.m. and worked as late at 9 p.m. to ensure everything was running in ship shape order for all of our very special guests. I cannot begin to tell you all of the comments I received about the professionalism of our volunteers. The country club itself has told me that this is their favorite event to run and that they have a great time working with our event staff and volunteers. We are blessed to have so many dedicated individuals, sponsors and volunteers in the autism community.



NASCAR Driver Kyle Petty celebrates his birthday with a few of the Philadelphia Eagles Cheerleaders.

To see a full list of our sponsors and pictures of the event visit us at [www.delautism.org](http://www.delautism.org).



Delaware Autism Program Student Josh Delaney with NASCAR Driver Michael Waltrip.

What is more exciting than the event itself? That would be what ASD plans on doing with the money. The ASD board voted to send out \$250,000 in grants this summer! To see who is getting what, make sure you read the cover story in this newsletter. So many of our dreams are coming true because of the dedication of this community and its friends. Again, we wish to thank everyone for their continued support. We cannot do it without you!



Philadelphia Eagles Kicker David Akers waits for his turn on the green.

Cheryl Frampton  
Event Coordinator, The Drive for Autism Research



## Inside The



### Election and Annual Meeting

Each year the Autism Society of Delaware has an annual meeting and board election. This year we will be holding the meeting on September 27, 2007 at the Special Olympics office in Newark at 6:30 pm. By now you should have received your ballot.

ASD is only as strong as its membership. This is your opportunity to speak about your key issues and to advise the board about potential future directions for the Autism Society. This year we have six well-qualified candidates for two positions on the board (see page 7). It is unusual to have so many applicants and we are thrilled that there is such a great level of interest in serving on this board. ASD makes a difference in Delaware because of the dedication of committed volunteers who serve on the board and in other capacities.

### Pencader Charter School Adopts ASD

We are excited to announce that Pencader Charter School in Wilmington, has adopted ASD as its non-profit agency of choice for students to seek service hours. Pencader has a policy that every student should provide 40 hours of community service to graduate. According to Dave Jones, principal of Pencader, this is part of the school's "overall sense of contributing back into the community in which we all live."

This student assistance will give us much needed help for our family

parties and events, typical teens to participate in *Teen Night Out*, as well as some potential office support in the afternoons. We are really looking forward to this partnership.

### Dan Prettyman Joins ASD Office Staff

For the past 18 months Dan has been coming to the ASD office twice a week to get office experience through the DAP. It's been quite a ride for us. He left us in June to work at the University of Delaware's Pencader Hall in the cafeteria. Once he was gone, we realized how much we counted on him to help us with our mailings, our parent packets, office filing, and the telephone. During that time Dan changed from being a teenager with little or no experience to being a valuable employee, so we hired him. Dan is now working six hours a week in the ASD office with no support from the DAP. Katina Demetriou has helped Dan to make that final transition into a competitive employee and both have done a great job. When you call on Tuesday or Friday afternoons, please say "Hi" to Dan, and thank him for his great contribution to ASD.



### ASD Sponsors a DSAMH Summer Institute Workshop

In July, Peter Gerhardt and Jed Baker did a lively three-day training session on adults on the spectrum, the issues they face and their need for social skills. These are two of the most well-known speakers about transition and adult issues

in the nation. We had great support from three state agencies to sponsor this training including the Division of Developmental Disabilities Services, the Department of Education and the Division of Vocational Rehabilitation. This is part of our effort to increase the ability of parents and professionals around Delaware to understand what adults need, and to be able to teach social skills. We were particularly encouraged because of the diversity of the audience which included representatives from a school district, adult service programs, state agencies, mental health providers, parents, and even one employer. It was a rare opportunity for parents and others to share experiences and ask questions.

### Introducing POW&R's Staff

It's official. August 13<sup>th</sup> has come and gone and POW&R is now open for services. It's been more than three years since ASD first entertained the idea about supporting adults on the spectrum and worked to this goal. We're proud of our goals and we're pleased to be making progress. If you are looking for actual doors and a physical space, you'll have to keep looking. If you are looking for an opportunity



to work and have fun in the community, come talk to one of the POW&R staff.

*Katina Demetriou,  
Director of  
POW&R*

Katina Demetriou is living up to the challenge of directing POW&R. Katina states that she has a passion for working with adults with autism. This must be true because she started as a volunteer with children on the spectrum while in

(Continued on page 7)





## Inside the ASD

*(Continued from page 6)*

high school, attended UD then got a graduate degree and worked as a family support counselor to families with children on the spectrum in Minnesota. On returning to Delaware in 1997, she went to work for *Chimes Delaware*, where she started as a job coach, moved to residential services, then returned to the vocational area heading up Community Services to support individuals with disabilities to get and keep their jobs.

We chose Katina, not only because of her great background, but even more based on her interactions with our parent search committee—Karen Bashkow, Ron Engard and Lucy Graham. Add Dom Squittere from the DAP and Theda Ellis of ASD and this was a formidable group. Katina had carefully thought about our values and dreams in advance and was very creative in her describing approaches to community employment and working with adults on the spectrum.



*Karen Anderson,  
Community Specialist*

Karen Anderson joined Katina on July 23 as POW&R's second staff person. Karen has a degree in Therapeutic Recreation, starting her career at the Delaware Autism Summer Recreation program. Like Katina, Karen began volunteering to work with individuals with disabilities as a teenager. All of her career experience has been with individuals with challenging behaviors and disabilities. For the past 16 years, Karen was responsible for the daily operations of work services and

employment departments at Chimes Delaware. At POW&R she will be working with folks who are referred by the Division of Vocational Rehabilitation for job assessment, placement, training, and follow-up. A particular challenge to her will be to expand POW&R's services once we are up and running to also address with needs of persons with Asperger's Syndrome. In her personal life, Karen has a family – husband Kevin, daughters Brianna and Taylor, son Chase, and dogs Dru and Smudge.

Katina and Karen are welcome additions to the ASD staff, and we encourage you to ask them any questions you may have about services available through POW&R.

*Dean Nagowski, Job Coach*

Dean, who is an accountant most of the time, will join us part time to serve in a direct staff role. His experience is as a brother and a job coach. We welcome Dean and look forward to working with him, but we won't see too much of him here at the office as he will be out and about providing support!

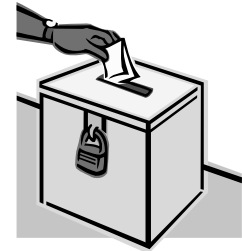
Looking for a way to help out?  
Look no further...

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



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

## ASD Election of Board Members



This is to announce the Annual Meeting and election of board members for the Autism Society of Delaware. The meeting will be held at 6:30 p.m. on September 27, 2007 at the Special Olympics office, 619 s. College Ave., Newark, DE. Descriptions of the candidates may be obtained by calling ASD at (302) 472-2638, we can either email, fax or mail a copy to you, or you may find them by visiting our website at: [www.delautism.org](http://www.delautism.org).

The candidates are:

- ◆ Robert Dunlap
- ◆ Joanna Francis
- ◆ Rob Gilsdorf
- ◆ Michael Graci
- ◆ Malisa Knox
- ◆ Thane Martin

You must be a current member of ASD to vote. If you are not sure about your membership status, or wish to become a member, please contact the ASD office and ask for Margie. She will be able to give you information on your membership status or sign you up.

Membership rights and responsibilities and instructions for voting are also available online. Please remember that it is important to vote. If you choose not to vote, your vote will be passed to the Board of Directors to vote for you via a proxy in accordance with ASD bylaws, Section 6.2.3.



# ASD Chapter Meetings

## September 27, 2007

ASD Annual Meeting

\* 6:30 - 9 p.m. Special Olympics Office, Newark **(\*Please note time change for annual meeting)**

Annual Elections of Board Members & Annual Report. Learn what ASD has been up to over the past year, and learn where ASD is going in the future. All registered members are encouraged to show up and vote for the newest openings on the ASD board. (See page 7 for details.)

## October 23, 2007

ASD Chapter Meeting

7- 9 p.m. Brennen School (DAP), Newark

Guest Speaker: Katina Demetriou, Project Director for POW&R (Productive Opportunities for Work & Recreation). Learn all about ASD's newest initiative and what it is going to do for adults with autism in the state of Delaware. Whether you have young children, teens or a child preparing to graduate in the near future, this meeting is for you. The one thing that our kids all have in common is that they are all going to grow up one day and will need to have a comprehensive game plan for a life filled with dignity, independence and happiness.

## November 14, 2007

ASD Chapter Meeting

7 - 9 p.m. (following the Charlton/PAC meeting)

Charlton School, Dover **(\*Please contact Lauren Padgett for childcare at the Dover meeting at: (302) 698-9317 or [alpadg@comcast.net](mailto:alpadg@comcast.net) no later than & November 7, 2007)**

Guest Speaker: Wolf Dunaway. About Wolf—Wolf has 12 disabilities that affect his physical, mental or cognitive functioning including high-functioning autism. He reports that “I was born approximately 2 1/2 months premature and well under 5 pounds. Most doctors, my biological father and many others gave up on me as hopelessly retarded. My parents were told to place me in a mental hospital, forget I exist and get on with life. I was expected to die. My father abandoned me at birth. My mother died 2 months before my fifth birthday. By age five I was an orphan in the care of loving maternal grandparents. Life growing up autistic and disabled in the 1960's was a very hard and lonely journey. The world of the purely human was confusing, mean and cold; filled with experiences that overloaded my senses—leaving me stunned. With blessings from God, lots of encouragement from good people and most of all lots of my own hard work, I became an Information Technology Specialist with the federal government at age 42. Wolf continues to work for the Social Security Administration and has been promoted since he first spoke to an ASD group in 2006.

***\*Childcare is available at all regular ASD chapter meetings and it is mandatory to RSVP for childcare services. Please call at least seven days before so we may be adequately staffed. Contact Margie Rowles—(302) 472-2638 or [delautism@delautism.org](mailto:delautism@delautism.org).***

***\* Please see page 16 regarding ASD chapter meeting childcare policy.***



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

The next Mom's Night Out will be held on September 29. For details on each date please contact Monica McMahan at (302) 235-2101 or email [m.mcmahan28@comcast.net](mailto:m.mcmahan28@comcast.net).



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

### Dad's Night Out

October 9, 2007  
Time and Location TBA  
(They always wait till the last minute to plan things!)  
Who can go? Dads, Uncles, Grandfathers or Friends of those living with autism.  
Interested? Of course you are!



Contact:  
Mark Frampton  
[mark@designbycher.com](mailto:mark@designbycher.com)  
(302) 998-1466



# ASD Fall Festival

Sunday, October 14, 2007 at Bellevue State Park in the Figure 8 Barn  
1—4 p.m. Hayrides at 2 and 3 p.m.  
Scarecrow Stuffing, Arts & Crafts, Door Prizes  
Light Refreshments  
Please RSVP by October 10, 2007 by calling (302) 472-2638 or [delautism@delautism.org](mailto:delautism@delautism.org)

Fun for the whole family!!

## PARENT'S COFFEE HOUR

***The Second Tuesday of Every Month***



Crossroads Restaurant, Route 7 & Kirkwood Hwy, Wilmington.

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

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

*Read this issue's copy of Parent 2 Parent found on page 10!*

## ASD Roller Skating Party

November 10, 2007  
Christiana Skating Center, Newark  
5:15—7:15 p.m.

Autism friendly lights and music. Parents may wear sneakers out on the rink to escort children learning to skate. Closed to the public, snack bar open. Admission is free. \$2-3 skate rentals. No RSVP needed. Just show up and have a great time!





# Parent 2 Parent

written by parents  
for parents

## Coffee Hour

By: Melanie Matusheski

Going to ASD's coffee hour has given me more than I ever thought it would. At first it was just the first step in being less isolated. More than that, though, it has answered questions, shown me that every parent's journey is different, and reminded me of how far our son has come.

We lived in a rural part of Virginia from the time our son, Robert, was two until he was seven. Our twin daughters were born when he was three and a half. It was easy to be isolated. When we moved to Delaware there were more people and more things to do, but still, with twin toddlers you don't get out much. When the girls started first grade last fall, I started going to the ASD coffee hour held the first Tuesday morning of every month at Crossroads Diner.

Every time I go I learn something new or begin to think of something in a different way. Everyone has so many of the same experiences, yet each parent is on their own unique journey. And everyone is at a different point of the process. There are parents who have a child recently diagnosed and enrolled in DAP. There are parents with issues affecting their adult children. No matter what age your child is, you'll probably find a parent with a child the same age, concerned about many of the same things you are.

There's a wealth of knowledge in all those experiences. You might

not get all the answers you want, but you'll certainly get a starting point.

*Need to know more about group homes? Call this organization. Want to find out who can really help you with transportation issues? Call this person. Have concerns about a new medication the doctor has prescribed? Oh, our son takes that medication. Want to take your child to church, but worry about him being disruptive? There's a church that has a special service . . .*

**"Every time I go I learn something new or begin to think of something in a different way."**

You also learn much about how parents deal with an autistic child as a couple. Some parents form a strong united front and tackle each obstacle together. Others are on their own with little or no support from the child's other parent. Everyone has a story; many stories, actually.

Listening to all the stories has shown me that parenting an autistic child is a lifelong process that starts off as very difficult, but for most becomes easier. It has also reminded me of how far Robert has come in the past four years. I recently heard parents talking about how their daughter becomes very stressed and upset at large family gatherings. I'd forgotten how Robert used to be the same way, but now he not only can handle large gatherings, he really has fun at them. I listen to

the frustration in parents' voices as they discuss toileting problems and remember that I also used to think our son would never be toilet trained, but he has been for the past two years. We are amazed at how far he has come in a relatively short time.

All of this knowledge and experience has led me to feel connected not only to the autism community, but to the entire community. It has also given us hope for the future. Connection and hope – two things that we didn't have for so long, but do now.

*Dare to believe —  
Because believing  
makes it so.*



*Strong, positive beliefs  
are the foundation  
upon which all great  
lives are built.  
Such beliefs are  
magical. They can  
turn the ordinary into  
the extraordinary, the  
simple into the  
profound, a single  
step into a giant leap.*



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*Childcare is available at all regular ASD chapter meetings. Please contact the office at 302.472.2638 or [delautism@delautism.org](mailto:delautism@delautism.org) no less than 7 days in advance. Childcare registration is mandatory.*

### ASD Chapter Meetings

- ▶ **September 27, 2007**— ASD Annual Meeting, 6:30 - 9 p.m. Special Olympics Office, 619 S. College Ave. Newark. Election of board members and annual report. More information on page 8.
- ▶ **October 23, 2007**— ASD Chapter Meeting, 7 - 9 p.m. Brennen School (DAP), Newark. Guest Speaker, Katina Demetriou on ASD's newest initiative, POW&R. More information on page 8.
- ▶ **November 14, 2007** — ASD Chapter Meeting, 7 - 9 p.m. Charlton School, Dover (following PAC meeting) Guest Speaker: Wolf Dunaway. More information on page 8.
- ▶ **December 2007**— **There is no Chapter Meeting in December.**

### Social Events, Public Awareness & Fundraisers

- ▶ **September 11, 2007** — Parent's Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9 a.m. More information on page 9.
- ▶ **September 21, 2007**—Asperger's Teen Game Night. 6:30—8:15 p.m. Location TBA. For more information contact Heidi Mizell, [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org) or (302) 472-2638, ext 205. Next AS Teen Games nights scheduled for October 19, November 16 & December 14.
- ▶ **September 29, 2007** — Mom's Night Out. Exact time and location TBA. For contact information see page 9. Next Mom's Night Out will be held on January 19, 2008.
- ▶ **October 9, 2007**— Parent Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9 a.m. More information on page 9.
- ▶ **October 9, 2007**— Dad's Night Out. Time and location TBA. For contact information see page 9. Next Dad's Night Out will be held on February 12, 2008.
- ▶ **October 14, 2007** — ASD Fall Festival, 1 - 4 p.m. Bellevue State Park. RSVP required. More information on page 9.
- ▶ **October 20, 2007**— Autumn Auction for Autism, Greenville Country Club, 6:30 - 11:30 p.m. More information on page 17. RSVP deadline, October 12, 2007.
- ▶ **November 10, 2007** — ASD N.C.C. Roller Skating Party, Christiana Skating Center, Newark. 5:15 - 7:15 p.m. No RSVP needed. More information on page 9.
- ▶ **November 13, 2007** — Parent's Coffee Hour, Crossroads Restaurant– Route 7 & Kirkwood Highway, Wilmington, 9 a.m. More information on page 9.
- ▶ **December 2, 2007** — ASD N.C.C. Family Holiday Party, Del Vets, Wilmington. 2 - 4 p.m. More information in next issue of *The Sun*.
- ▶ **December 2, 2007** — ASD Kent County Family Holiday Party (This party is tentatively scheduled for this date, more information coming in next issue of *The Sun*.) Contact Kate Stomioski at [beazelbeak@juno.com](mailto:beazelbeak@juno.com) for inquiries.

*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.*

### Support Groups

- ▶ **October 16, 2007** — ASD's N.C.C. Support Group — South Wilmington. Meetings are held on the 3rd Tuesday of every other month and are facilitated by Kathy Hupp. Meetings are held at 7 p.m. at the ASD office, 5572 Kirkwood Highway, Orchard Commons. The next support group is scheduled for December 18, 2007.

### Other Events

- ▶ **October 26 & 27, 2007**— OAR's (Organization for Autism Research) 5th Annual Applied Autism Research and Intervention Conference. [www.researchautism.org](http://www.researchautism.org). The Westin Arlington Gateway, 801 N. Glebe Road, Arlington, VA 22203. Registration Deadline: September 25, 2007. Contact: [conference@researchautism.org](mailto:conference@researchautism.org).
- ▶ **November 2 & 3, 2007**— POAC-NoVA Presents: Functional Analysis & Treatment of Severe Behavior Disorders: Methods for Clinicians & Educators by Brian Iwata. Vienna, Virginia. Contact [workshops@poac-nova.org](mailto:workshops@poac-nova.org) or visit [www.poac-nova.org](http://www.poac-nova.org).
- ▶ **November 10, 2007** — American Sign Language Expo 2007—FREE ADMISSION! [www.aslexpo.com](http://www.aslexpo.com). Gaithersburg, Maryland.



# Walk The High Road For Autism

# Thank You!

Thanks to all who came out to support ASD at the first *Walk the High Road for Autism*, which raised \$100,000 for ASD! More than 700 people from nearly 70 teams came and enjoyed a beautiful stroll through the park followed by a celebration with food, games, and special visitors Rocky Bluewinle and Elmo.

Many thanks are due to all our sponsors as well as the UD football team and Kohls A-Team for providing so many volunteers. High Roads School staff and administrators were wonderful partners from the first day of planning through post-Walk cleanup. And finally, congratulations to the Burch Bunch, Epani's Crew, Maddie Mack's Pack and Team Casale, who each raised over \$4,000!

Mark your calendars for the 2008 Walk on April 26! The Walk Committee has already begun to plan the event and your suggestions and volunteer time are always welcomed.

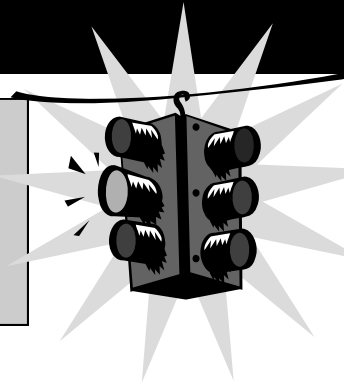




## Feature Article

### Limit Setting; An Important Preliminary

By: Corey Bowen



In the past two decades, lots of effective strategies have been explored for helping children with autism learn appropriate behavior. Centered on functional behavioral assessment (FBA), a strong emphasis has emerged, not only on the preference of rewards over punishment, but on the importance of understanding the child's motivations for acting out. This view of problem behavior, as shaped by positive and negative consequences that occur naturally in a child's world, encourages the creation of learning environments that are richer, more predictable and more carefully tailored to the sensory and communicative challenges our kids experience. It also directs our focus toward teaching skills that can help them navigate the world more effectively, rather than simply trying to make their unpleasant behaviors go away.

The benefits of these developments for children, families and professionals are enormous. They've fostered a set of educational approaches that are far more respectful and far more hopeful than the often harsh and negative approaches that prevailed in earlier times when many young people with disabilities were separated from their families and segregated in institutions.

In addition, the positive and hopeful message of the FBA approach has a strong psychological appeal to professionals. It affords us the opportunity to assure parents, often tacitly, that our goal is to help them teach their child to behave reasonably; and that further,

if we can only figure out what makes him or her tick, we can bring behavior change about with minimal discomfort.

But I'm increasingly afraid that the FBA model and the faith in stress free behavior change it seems to encourage blurs our view of a basic difficulty in our relationship with our children (with and without disabilities); that children *need* grown-ups to set clear limits on their behavior, but they don't *like* it when grown-ups do so.

It would be wrong to suggest that limit-setting is easy or uncomplicated. It is often strenuous and confusing, even for the parents and professionals I've admired most. It is particularly vexing when the child has autism. Given the difficulties understanding and communicating these children have, being "clear" with them is often very challenging. And for reasons I can only speculate about, disciplinary interventions like time-out or the loss of a favorite activity that may be decisive with typically developing children, may occasion a fierce behavioral escalation in a child with autism. This, further, can be particularly wrenching for parents who may be faced with the prospect of a pitched battle with their own child in their own home or (heaven forbid) in their own car.

Sometimes we allow things that are excessive or difficult because we're focusing on more important things. At other times it's natural for us to be confused about exactly what *is* excessive and unacceptable. Also, when we love some-

one, especially someone who's really different, we sometimes make a decision to accept some of their peculiar needs and idiosyncrasies. We all pick our battles for

lots of reasons. What I'm concerned about is that we sometimes try to avoid battles that are truly necessary. There are some bottom lines in life; some responsibilities so basic that if we permanently excuse someone from them, we are reducing that person's ability to live, work and play with others.

There are a number of these bottom lines. But as to the most important of them, I'm going to suggest that every adult should reserve the right to give a child in their care straightforward corrective feedback, up to or including the use of the dreaded word, "no." As in, "You *can't* do that right now." "Those are *not* your French fries." "You *don't* hit your sister." All children sometimes need correction from adults. And, since no one comes into the world enjoying correction, most children must actually learn to accept it. This is a critical challenge for us all in the autism community, since a pattern of protesting, ignoring or escaping adult correction can impact on a child's ability to learn a whole array of things, particularly as they get older and the impact of their acting out behavior becomes more dramatic. In addition, over time, this pattern inevitably changes adult behavior, causing us to lower our expectations in order to avoid a tantrum, or some other behavior that raises the stakes even higher.

In addition to being able to correct a child, there are some other lines in the sand that grown-ups

(Continued on page 14)



## Limit Setting

(Continued from page 13)

may need to draw at some point. All kids need to tolerate having their teeth brushed and their hair washed without fighting. They need to be able to transition from a favorite to a non-favorite activity without slugging someone. They need to learn to behave reasonably at a table where others are eating. They need to eat at least some nutritious foods. They need to be able to ride past a McDonald's without throwing a tantrum in the back seat. They need to walk in a shopping mall without running away from the grown-ups who brought them there. They need to learn to use bathroom fixtures in the manner intended by the manufacturer.

I'm not suggesting that problems like these will just dissolve when some adult decides not to tolerate them. As mentioned above, tough behavioral challenges may require modifications to the environment, good teaching and lots of positive reinforcement, all guided by the most thorough possible understanding of the individual child. And they may take some time. But in addition to love, ingenuity and patience, children also need clarity. And for whatever reason, it seems to me we talk about it too little.

**Heidi Mizell**  
**Asperger's Resource**  
**Coordinator for the**  
**Autism Society of**  
**Delaware**

(302) 472-2638, ext 205  
 Heidi.mizell@delautism.org

## Asperger's Syndrome

### Questions to Ask for the New School Year.

By: Heidi Mizell  
 Asperger's Resource Coordinator  
 Autism Society of Delaware

School is starting and your child may be anxious. For some individuals with Asperger's Syndrome anxiety can mean some conduct or behavior challenges. The inability to communicate effectively and all of the confusing feelings about starting a new school year can make for some challenging moments these last few weeks before school starts. If your child is starting in a new school, classroom or program consider trying to alleviate some of the anxiety before it begins. Call your school contact (educational diagnostician, teacher, school psychologist, etc.) and find out what the school procedures will be for the upcoming year. Some examples may be:

**What are the early morning and dismissal procedures** - Is there socializing? Is it monitored by an adult? If your child has a locker are they able to use it all day between classes or only at the beginning and end of the day?

**Changing Classes** - Is a bell system used? Do all the kids move at one time? Is talking allowed in the halls? Is there adult supervision?

**Teacher expectations** - How is completed work collected? How does the school to home communication work?

**Dress Code for PE** - Is there a uniform? Can the uniform be worn

under day clothes? Can sweats or shorts be worn that day eliminating the changing time altogether?

**School Discipline** - What are the school rules and what are the consequences for infractions (may be directed in your child's IEP)? Who are the disciplinarians in school and what is their understanding regarding children with an autism spectrum disorder? Are they knowledgeable about the social challenges of autism or Asperger's Syndrome?

**Important to know** - Have staff members been trained in de-escalation procedures for students with conduct and behavioral disorders? Is the staff using Positive Behavior Supports and strategies as mandated in federal law?

These are just some examples of things you can cover with your child to make the transition back to school smoother.

Next issue: *The unwritten culture of the school.*

For more information on  
 Asperger's Syndrome and  
 activities for teens with  
 Asperger's Syndrome,  
 visit the ASD website at:  
[www.delautism.org/  
 aspergers\\_syndrome.htm](http://www.delautism.org/aspergers_syndrome.htm)





# Legislative Issues



## Legislative Update

### Changes to Delaware Vaccine Law

In response to concerns by the Division of Public Health that the ban on mercury in vaccines for kids under 8 and pregnant women would have unintended consequences in the event of an epidemic or emergency, ASD worked with the Division and the Delaware Health Care Association to craft a bill which creates limited exceptions to the ban. Those exceptions are:

- When the Director of Public Health or designee determines that a mercury-free option is not manufactured or cannot be made available in a medically necessary period of time for an individual patient.
- When the Director of Public Health or designee determines there is an emergency or epidemic requiring groups to be vaccinated and a mercury-free option is not manufactured or cannot be made available.
- The Director of the Division of Public Health or their designee determines that a shortage of vaccine exists which could threaten the health of groups and a mercury-free vaccine is not manufactured or cannot be made available.

As a result of our discussions, we were also able to add a new requirement that a physician notify the person (or their parent or guardian) that they are receiving a mercury-containing vaccine which the physician believes is medically neces-

sary, and that one of the above determinations has been made which allows its use. Such determinations will be posted on the Division of Public Health website (<http://www.dhss.delaware.gov/dhss/dph/index.html>) under "What's New" to keep the public informed.

The ban and these changes apply only to those under eight or women who are pregnant. The full text of the bill, HS for HB194 (a substitute for the original HB194), can be found on the legislature's website, [www.legis.state.de.us](http://www.legis.state.de.us), using the "Bill Tracking" function.

### Family Support Waiver Unfunded Again!

We made great strides in gathering support for the Family Support Medicaid Waiver over the past two years, but it remains the challenge at the top of our legislative agenda—along with our Family Support Coalition partners because although we worked hard, it did not get support from the Governor or the Joint-Finance Committee.

Why is this important? Most funding for adult services comes from the Home and Community Based Waiver. This waiver does not include funding for therapies that adults with autism require, so if you want your child to have behavioral supports, speech therapy, or other therapies, the Family Support or some other type of Medicaid Waiver will be needed.

Adult services are not an entitle-

ment like school is. Twenty-one students graduated statewide this year and although individuals with autism have been receiving services, 74 people do not have day (vocational) services. This means that 74 people are sitting at home without a job or a place to go. Can you afford to quit your job so that you can watch your adult child? Most of us cannot. The Family Support Waiver ensures that anyone who is eligible for Waiver services will receive day services.

And finally, the Family Support Waiver offers flexibility about how funds are used, and gives a greater voice to parents to choose services needed to keep their adult child at home.

The bottom line is that the Family Support Waiver is cost effective because it helps families keep their adult children at home, ensures that needed services are available, and supports the family.

It's critical that parents look beyond the school years and become informed about funding sources that impact your child. Please call the Governor and your state legislators to say that we don't want to wait any longer. It's time to fund the Family Support Waiver now!

## Join the ASD eGroup



Want the latest updates on ASD social events, legislative issues, autism national & local news? Sign up to the ASD eGroup today!

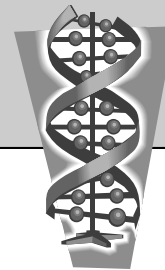
The ASD eGroup is now over 550 strong! This is a notification system, only the staff at ASD can post to the group. To sign up, send an email with request to:  
[cheryl.frampton@delautism.org](mailto:cheryl.frampton@delautism.org)



The Center for Autism and Developmental Disabilities Epidemiology (CADDE) at the Johns Hopkins School of Public Health and the Center for Autism and Related Disorders (CARD) at the

Kennedy Krieger Institute (KKI) are starting an exciting research study. The study will look at environmental factors and substances in the body to see whether they are associated with an increased risk in the development of autism. It is hoped that this study will help plan for future studies and ultimately help to better understand the genetic and environmental factors that cause autism. Eligible participants are mothers who are in their 22<sup>nd</sup> week of pregnancy or earlier who already have a child with an autism spectrum disorder (ASD). The study will follow these moms through their pregnancy. Moms are asked to bring their child with ASD to KKI for a play-based assessment, to complete a number of questionnaires and a biweekly diary. They are also asked to come into the clinic once per trimester to collect samples such as blood, hair, and saliva. At delivery the following will be collected: blood from the umbilical cord, blood from the newborn heel stick, and from the placenta. If a mom is interested, when her baby reaches age two he or she will be evaluated at CARD. The 2-year developmental evaluation is not required to participate in the study. Do you have a child with ASD? Are you currently no more than 22 weeks pregnant? Do you want to be a part of this exciting research? If so, please contact CADDE at 1-877-868-8014 or cadde@jhsph.edu.

## Research Headlines



## Important Notice: ASD Chapter Meetings & Childcare

ASD has always provided free and professional childcare at all of its regular chapter meetings. We have always asked that families call in with their childcare requests at least two days prior to a meeting. We are changing that policy because some people:

- Make reservations then don't show up
- Wait till the very last minute with childcare requests
- Show up who did not request childcare

Some children may require a 1:1 to get through the evening, which means that we need adequate notice from all parents to provide appropriate care.

In keeping with the ASD tradition of providing a comfortable and safe environment for both our parents and children, we are now requesting that:

- Families please call in no less than one week (7 days) before a chapter meeting to request childcare
- If you find your plans changing and cannot make it to a meeting after reserving childcare, please contact the office before 5 p.m. to let us know you will not be coming.

If you show up at a chapter meeting with children needing care and did not call ASD with your request, we may have to turn you away if there is not adequate care available. The safety and well-being of the children must come first. We greatly appreciate your help with this!

To request childcare for an ASD chapter meeting, call the office 7 days prior to the date of the meeting and give us your name, the number and age of children attending, and day and evening phone numbers at (302) 472-2638 or you can email: [delautism@delautism.org](mailto:delautism@delautism.org).



# October 20, 2007 Greenville Country Club

### Honorary Chairs

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

### Featuring Music by:

Club Phred  
[www.clubphred.com](http://www.clubphred.com)

### Magic by:

Chad Juros  
[www.magicalchad.com](http://www.magicalchad.com)

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

**Reservations are now available!!**

Starting at \$150.00 per person. Table sponsorships are available.

*Don't miss your chance for this exclusive and  
luxurious caribbean cruise.*



Silent and Live Auction featuring a 7-Day  
Exclusive Caribbean Cruise for Two.

Cash, Checks, Mastercard, Visa, Discover  
and American Express accepted.

To make  
reservations  
contact ASD

at (302) 472-2638. Please respond on or  
before October 12, 2007.



Same lovable MacBook.  
New lovable speed.

**ASD Autumn Auction for Autism Raffle — Apple MacBook Laptop Computer complete with Microsoft Office. Tickets are \$10.00 each. Drawing will be held at the auction. Need not be present to win. Contact ASD for ticket information.**

# Autism Society of America Membership Application

Please enroll me in the following category:

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

I am a new member    I am renewing membership

Name (s): \_\_\_\_\_

Address: \_\_\_\_\_

Phone: (h) \_\_\_\_\_ (w) \_\_\_\_\_ Email: \_\_\_\_\_

Employer or professional background: \_\_\_\_\_

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

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

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

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

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

The Autism Society of Delaware  
5572 Kirkwood Highway  
Wilmington, DE 19808

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

