



### October 2008

| ASD   | (302) 224-6020 |  |  | www.delautism.org |        |                                    |
|---|----------------|--|--|-------------------|--------|------------------------------------|
| Sunday  | Monday         | Tuesday  | Wednesday  | Thursday          | Friday | Saturday                           |
|   |                |  | ASD NCC<br>Bowling Night<br>5:30 pm                                | 2                 | 3      | 4<br>Dad's Night<br>Out<br>6:00 pm |
| 5   | 6              | 7  | ASD NCC<br>Bowling Night<br>5:30 pm                                | 9                 | 10     | 11                                 |
| ASD Fall<br>Festival<br>1 pm-3 pm<br>Bellevue State<br>Park | 13             | 14<br>ASD Parent<br>Coffee Hour<br>9 am          |  | 16                | 17     | 18                                 |
| 19  | 20             | 21<br>NCC & Kent<br>Support<br>Groups<br>7:00 pm | •  | 23                | 24     | 25                                 |
| 26  | 27             | 28   | ASD NCC Bowling Night 5:30 pm Bring your costume to bowling night! | 30                | 31     |                                    |



#### Detachable Monthly Calendar

### November 2008

| ASD Newslette | r      |  | (302) 224-602   | 20  | wwv                 | v.delautism.org   |
|---------------|--------|--|---|---|---------------------|---|
| Sunday        | Monday | Tuesday                                | Wednesday   | Thursday                                      | Friday              | Saturday  |
|               |        |  | ASD NCC<br>Bowling Night<br>5:30 pm                                   |   |                     | 1   |
| 2             | 3      | 4<br>ASD Parent<br>Coffee Hour<br>9 am | ASD NCC<br>Bowling Night<br>5:30 pm                                   | 6   | 7                   | 8<br>NCC<br>Roller Skating<br>Party<br>Christiana<br>Roller Rink<br>5:15 pm |
| 9             | 10     | 11                                     | ASD NCC<br>Bowling Night<br>5:30 pm                                   | 13  | 14                  | 15<br>10th Annual<br>Autumn<br>Auction for<br>Autism<br>6:30 pm             |
| 16            | 17     | 18                                     | 19<br>ASD Bowling<br>Night<br>5:30 pm                                 | 20  | 21                  | 22  |
| 30            | 24     | 25                                     | 26<br>ASD Bowling<br>Night<br>5:30 pm<br>Bring out of<br>town family! | 27<br>Office Closed<br>Happy<br>Thanksgiving! | 28<br>Office Closed | 29  |



# Celebrating 10 Years of Service to the Autism Community

# The Sun

**ASD Newsletter** 

www.delautism.org

September/October 2008

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#### Our Mission

ASD is a community of 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.

### Happy Anniversary! The ASD Story

By: Marcy Kempner

It's our 10<sup>th</sup> anniversary so we would like to share our story with those who do not know it. ASD was started because a group of parents recognized that we needed to be organized to support families better and to improve the lives of our children with autism. In the spring of 1998 we petitioned the Autism Society of America (ASA) for the right to form a chapter. At the very first meeting, we decided the chapter should be a statewide chapter in order to capitalize on our unique qualities as a small state. We also elected Artie Kempner as President and John Fisher Gray as Vice President.

Fortunately, a group from other ASA chapters had planned their first chapter assistance workshop at the national ASA conference that summer. Delaware parents attended and brought back knowledge, assistance and networking opportunities that proved invaluable during those first few years. We quickly recognized how fortunate we are due to the presence of the Delaware Autism Program (DAP). As the only statewide public school program for children with autism in the country, the DAP provided the high quality education we needed for our kids— thus meeting that fundamental need that keeps so many parent advocacy groups from being able to focus on much else. Additionally, the DAP gave us an easy way to meet and communicate with other parents and spread the word. We also had the mentorship of parents of adults with autism who had done the impossible by getting the DAP started 20 years earlier, but who had more or less burned out on keeping a parent organization going. That guidance, particularly from Marie-Anne Aghazadian, who subsequently became the Executive Director of the Parent Information Center, was key in helping us improve and build on what had gone before.

ASD grew quickly. There were many bumps and learning experiences on the way, but the talents and the passion of the many parents who became involved helped us continue to build in a logical and professional way. Early accomplishments included a website (thanks to Cheryl Frampton) and a newsletter (thanks to Frances Ratner); public awareness efforts, meetings with informational speakers, conferences, social events for families, and local and national advocacy campaigns. And, of course, we had to figure out how to raise money through different fundraising events to make all of this possible. After a few years, though, it became obvious that while we were accomplishing so much in such a short amount of time, the all-volunteer model was only going to take us so far. So ASD embarked on its second major phase of growth - hiring professional staff.

In 2002 ASD received a grant to create the position
(Continued on page 4)

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#### The Sun

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### Thoughts From Rob

By: Rob Gilsdorf, President, ASD

Greetings. The fall weather is now with us and I am left wondering once again, "where did the summer go?" I must admit, the summer brought plenty of time to work hard, play hard and enjoy time with family and friends. I will miss the season. I do, however, welcome September each year with eager anticipa-

tion. Having Andrew back into a routine helps ease the strain of day-today family challenges. And September brings along with it the promise of a new school year and a time to reflect on the current year and plan for the next.

2008 brought both rewards and challenges for our organization. As you may know, this year marks our 10<sup>th</sup> year as an organization supporting the autism community in the state of Delaware. It is amazing to look back and realize ten years ago we started with a few volunteers and today we have twelve employees and reach thousands of Delawareans with support and services each year. While we are proud of what we have accomplished, we are also humbled by the challenges that lay ahead.....

Earlier this year, we ended our formal association with the Autism Society of America. We felt this separation was needed for us to operate more independently as we move forward to grow our organization. Unfortunately, with the separation came a legal challenge regarding the ownership of trademark rights of our two separate organizations. All issues surrounding the dispute have been resolved, the lawsuit has been dismissed without prejudice and once again, ASD is completely focused on meeting the needs of our autism community.

As I look forward, I see many ways where we can grow in our scope and effectiveness within the state. The Board of ASD is focused this fall in developing a more effective structure for organizing and delivering value to you and your loved ones. We are focused on revitalizing existing volunteer committees and creating new committee groups to focus on areas we see as critical to our future success in Delaware.

One newly formed committee; "School Age Issues Committee" has been formed as a result of your feedback from our recent community survey, direct discussions with some of you and our realization that there are some significant challenges approaching us within the education settings of our younger children. The goals of this new committee will focus on the issues associated with newly diagnosed families, services provided by Delaware Autism Program, and other opportunities that will support our younger children as they begin their journey in life. There is so much to accomplish and we need your help and participation. We look forward to working closely with the Parent Action Committees to identify and take action with our collective resources to assure we continue to get what our children need. Please call me if you are interested in participating, we will reach out to several of you to ask for participation as well.

I hope this note finds your family healthy and happy. Let's make sure that together, we make this upcoming year the best year of our loved ones



#### A Service of ASD

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# The Director's Chair

By: Theda Ellis, Executive Director

This fall is not just a transition season between the warmth of summer and the coming winter, it is also our transition to ASD's new name and look. As Rob reported, the lawsuit with ASA has opened the door of opportunity. We may no longer use the name Autism Society of Delaware after October 1, 2008 when we will officially become Autism Delaware, but we are not quite ready for that either. For the interim, we have called ourselves ASD—formerly a chapter of the Autism Society of America. We plan to have our new look, website, and materials ready for our 10 year anniversary, The Hidden Treasures of Autism in November. So, for about 45 days, we have a new name that we must legally use, but we don't have our materials or our look. Fortunately we are working with Dan Tipton of Tipton Communications, to "rebrand" ourselves. Keep an eye open as we totally re-introduce Autism Delaware on November 15.

I want to thank all of you who took the time to complete the recent survey and give us feedback about how we are doing and what you would like to see happen in the future. In some cases, we were already on it; in others, we are doing more than folks realize so we have some improvements to make in our communications; and of course, there are some things we can do better. Like any organization, we can't do it all, so we make choices—preferring to do a few things well rather than to take on too many things and do them badly.

During this period we also moved to larger office space. We owe a big thanks to member Dave Graham who designed five different office spaces for us before we finally secured this location. We would also like to acknowledge the three years we spent with the Parent Information Center and the great support they offered us during that period. Marie-Anne Aghazadian has been a guiding light to ASD over the years, serving as a board member, sharing office space, and offering her knowledge, experience and resources about everything, ranging from who could provide technical support to who could do our bookkeeping. We will miss that easy next door relationship but we will maintain our good collaboration as two organizations supporting individuals and families with disabilities.

We also spent the summer thinking about Southern Delaware. ASD is seriously looking at our ability to expand. The board is reviewing a proposal to open a part time office in Milford, with the intent to support ASD and POW&R activities in Kent and Sussex. This is stretching our capacity and budget along with the ever expanding POW&R services, but with your help and a great auction, I know that we can do it. I'll keep you posted – we should be making that final decision in the late fall.

Things are ever changing and never boring here at Autism Delaware.

#### New Castle Support Group is Revamping for Parents of Young Children

The New Castle monthly support group will officially be starting on October 21, 2008 at 7 pm with a new focus and a new format. This group will be specifically for parents of young children up to age nine. The meetings will be at the new office at 924 Old Harmony Road, Suite 201, Newark, DE 19711.

With these new 90 minute sessions, Kathy Hupp, who is both a parent of a son with an ASD and a licensed Social Worker, will start each session with a presentation of the topic for followed by group discussion. Kathy will be combining her experiences as a mom as well as her skills as a facilitator. Our goal is to assist parents of newly diagnosed children with information and support. Examples of sessions are described below:

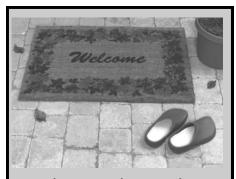
**Accepting the Reality**. Your child has been diagnosed with an ASD. Now what? The focus will be on sharing feelings relating to hearing the news and getting used to shifting perspective from having a "normal" child to the "new normal" of a child with ASD.

Managing Expectations. What will your ASD child 's educational and behavioral needs be? What is "normal."

**Coping Skills for Parents and Caregivers**. Discussion will center on what works and what doesn't work and parents can share their tips for each other.

**Dealing with Everybody Else**. We all know "the look!" It isn't easy to deal with. Discussion will focus dealing with your ASD child and extended family, friends and community members.

**Thinking Problems that Aggravate Stress and Anxiety**. Healthy mental functioning will be essential to long-term well-being as a parent of an ASD child. Learn to identify faulty thinking styles which contribute to further stress.



Please welcome the following new members to ASD...

Cherrise Berger Bonnie Bratcher Shaunttell Draper Daniel Eaker Amber Gumm Jason Hayes LaShane Norton Petra Platte Nancy Santara Naomi Seinsoth George Stephens

#### **ASD Options Policy**

All information provided or published by ASD is for informational purposes only. Reference to any treatment or therapy option or to any program, service or treatment provider is not an endorsement by ASD.

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

#### The ASD Story

(Continued from Cover)

of Executive Director, thanks to the persistent efforts of Jack Carney, whose grand-daughter has autism. Time and time again the dedication and talents of our members

would spur us forward. We initially envisioned a part-time position and planned to use space in the Kempners' house as the office. Starting out small and growing in a smart way rather than overreaching and failing has always been our guiding principle. Our search led us to Theda Ellis, who was working at the Center for Disabilities Studies at the University of Delaware, and who brought a wealth of experience and understanding beyond anything we had imagined we could find in our initial attempt. Strangely enough, she wasn't daunted by the prospect of working out of someone's home with essentially no support staff to start with, and took the leap of faith that our track record and reputation in the community meant that we would figure out some way to continue funding not only her position (we created a full time position for her in order to make it work), but the growth we were envisioning by bringing her on. Theda took on the difficult task of creating systems out of the hodgepodge of volunteer efforts that had gone before, and within two years we had office space, and two additional part time staff. The board initiated and supported increases in fundraising, beginning with the annual auction and adding a celebrity-AM golf outing.

As ASD became a professionally run organization, the informal Executive Committee that had governed it decided to become a formal Board of Directors. The bylaws were updated and we worked to improve the operating procedures of the organization. None of these efforts was easily accomplished, but it is to the credit of all those who stepped up to take leadership positions that we have always been able to work through our differences for the common good.

Soon we were improving all of our materials, including brochures, website and newsletter, and expanding our reach and distribution. We were also partnering more with state agencies and other non-profits. We created a local effort to educate physicians around early diagnosis using a national campaign called First Signs, and got state funding to do a study on best practices for services for adults with autism. We also expanded our efforts to reach beyond the traditional autism community into the Asperger's Community, starting social groups and advocating for services for individuals with Asperger Syndrome. And all along we continued to improve our core initiatives around parent and family support, information sharing through conferences, speakers, our newsletter and website, raising public awareness, advocating for legislative and systems improvements at the state and national level, and providing social opportunities for families to have some much needed fun. All this set the stage for our most ambitious project yet – creating a new system for delivering services to adults with autism.

Our national study of best practices for adult services provided a framework and spurred us to create a blueprint for the exciting

(Continued on page 5)

Next Deadline for Submissions to The Sun: October 1, 2008
Share your family's story, tips or information with everyone!
delautism@delautism.org. Or mail it to us
(address on page 2).
Let Your Voice Be Heard!



#### The ASD Story

(Continued from page 4)

new venture - POW&R - Productive Opportunities for Work and Recreation. POW&R was launched in August of 2007 after tremendous work by the ASD staff and the adult issues committee, led by Karen Bashkow. They used what they learned and envisioned a better future for our loved ones with autism, then created the kind of support service agency that would help families and individuals with autism realize those dreams. Simply put, POW&R helps connect people to jobs that fit their skills and preferences, and helps find recreational and other activities to help them lead full and productive lives. Self-determination and increasing life choices are the keys to POW&R. Once again we chose to start out small, building from just 7 clients the first year to 14 in the coming year. ASD funded and will continue to fund the considerable start up costs for POW&R, while the state Divisions of Vocational Rehabilitation and the Developmental Disabilities Services are contracting with us to support individuals and much of the operating costs moving forward. This kind of public-private partnership is another way that ASD has pioneered a new way of improving the lives of people with autism.

Finally, with so much growth and potential for much more, ASD's Board of Directors began the work in 2006 to become a separately incorporated, independent organization. We trademarked our logos for our celebrity golf fundraiser, the Drive for Autism, and for the organization to protect our assets and preserve our ability to act in the best interest of the autism community in Delaware. Once we began providing direct services through POW&R, we had outgrown the model of an ASA chapter and felt it was time to

separate from the national organization. Additionally, ASA has not provided the kind of support for chapters that was often promised over the years. By separating ourselves we could ensure that we could protect what we had built, become free to associate with other national organizations that had proven themselves to be effective, and could continue to grow and expand to better serve the autism community.

These most recent changes coincide with our ten year anniversary as an organization and open up the exciting opportunity to change our name and unveil a new look for the future. We moved to new office space, having grown out of first the Kempner's home, and then our Orchard Commons space. All these changes will ensure that we continue to grow bigger and better, and keep increasing our ability to improve the lives of people with autism and their families in Delaware. These first ten years have far surpassed our early dreams - they have been more difficult, more rewarding. more successful, more educational, more painful, more exciting, more satisfying, and generally more than anything we could have imagined. We can't wait to see what the next ten years hold - more answers, more services, more research, more treatments, more inclusion, more choices, more work to be done and more hope for a better future.

#### **ASD Staff and Volunteers**

ASD is a volunteer driven organization supported by a professional staff. It is the job of the staff to support the board and its initiatives and to support all volunteer and committees with their activities.

The staff gives advice, works in conjunction with the committees and volunteers and helps with all of the administrative duties so that volunteers have more time to do the hands on work out in the community.

#### **ASD Bowling Night**



Looking for something to do on "hump" day? Well we have just the right thing to help you get over the mid week blahs. Mark and Cher Frampton took a spin off from the Special Olympics bowling and created the very autism friendly ASD Bowling Night. Bowling nights are held on every Wednesday at the AMF Price Lanes at Prices Corner on Kirkwood Highway in Wilmington. This is the BEST part; there is only ONE rule....Please email or call Mark or Cher the Monday before bowling to RSVP. The size of the group keeps growing and we need to let the bowling alley know how many lanes to reserve. After that, NO rules!

Here is the breakdown on how it works:

- -You call or email us by Monday night. <u>markdelautism@yahoo.com</u> or (302) 998-1466
- -You arrive at the bowling alley between 5:30-6:30 p.m.
- -Parents and siblings are welcome to bowl. Autism, Asperger's, PDD-NOS, Group Homes...whomever! -There is no age limit.
- -You can come once a month or four times a month, no commitments!
- -You can bowl one game, half a game, 10 games. It is entirely up to you.
- -You pay for your games and shoe rentals. We do get a discount.
- -The snack bar is open.
- -No winner, no losers.
- -Bumpers for whoever wants them.
- -No worries if the weather is too hot, cold or wet!
- -We are usually located on the far end in the 40's and 50's. So we have a side door exit and bathrooms right behind us.
- -There is also a game room for those who need to take a break or want something a little different to do.

So that's it! Just give us a call and come out to have some fun!

# Inside The The

Our Move

ASD moved to 924 Old Harmony Road, Suite 201 in mid-August. We're about two miles from our former office on Kirkwood Highway and even closer to the Brennan School. The office was closed for a week during the move because construction was happening at both the old location and the new so we worked at home. Our new landlord, Lenape Property Management, has been great to work with, giving us a great price that includes beautiful carpet and kitchen cabinets. We also want to thank the Division of Developmental Disabilities Services for giving us work stations that they are no longer using. It's a huge help not to have to buy furniture. Ben Anderson, son of teacher Jay Anderson, brought over his Eagle Scout troop to move boxes, and Bob



Dunlap and Warren Ellis helped dismantle our current work stations, Mark Frampton patched walls and Russ Rowles and Kevin Anderson hung shelves and installed office accessories.

Our new digs feel luxurious with all the space. We now have some privacy and even a little room to grow. Come see us any time, or look for our Open House on December 5.

ASD in Sussex County

Over the past year we have been working to increase our

presence in Southern Delaware, particularly Sussex. This started with a chapter meeting last spring, and we have two more meetings scheduled for October 9, 2008 and February 13, 2009. We also cosponsored a dance for the students at the Consortium. (See photos below.)

At the October meeting we'll talk about what you would like to see happen in Sussex and what types of speakers you would like to have. ASD will also be sponsoring the new support group for parents of students in transition beginning in January 09, and we'll continue the Milford skating parties, and the family bowling events.

Look for more information about our intent to open an office to serve Kent and Sussex Counties in the next issue of *The Sun*.



Students and staff at the Sussex Consortium enjoy getting "foot loose and fancy free" at their school dance

In April, Artie and Marcy Kempner

were invited to participate in the 3rd International Disabilities
Forum held at the
Shafallah Center in
Doha, Qatar in the

Artie Kempner

(left), Bob & Susan Wright of Autism Speaks (right) and Director of the Shafallah Center for Children with Special Needs, Hassan Ali bin Ali, in Doha. (center)

Persian Gulf. This year's forum focused on Sport and Disability and attracted innovators and interested parties from around the globe. Artie presented, along with Bob and Suzanne Wright of Autism Speaks, to a panel of seven First Ladies and other world leaders on his vision for advancing inclusive opportunities for people with disabilities in fitness, wellness and recreation. Visit: www.shafallah.org.qa to see the wonderful work being done in Qatar for children with disabilities including autism.

#### POW&R and New Staff

POW&R is preparing to grow in the coming year. Six students are partnering with Keystone to support a young man with severe issues, and we're also collaborating with Community Interactions—a day program that has recently opened to support individuals on the spectrum. We'll be helping them with the community component of services, and they will help us with sensory services. We're also happy to announce the addition of two new support staff. Matt Lindnor is a new UD graduate. Matt comes to us with a keen understanding of autism because of his 16 year old sister. His mom has served as the president of the ASA Philadelphia chapter, and he worked with Andrew Gilsdorf during his last year of school. Our second new hire is Shaheda Pine who is currently completing graduate work in counseling. Shaheda has great experience working with children at the Delaware Autism Program as a para. We are excited about their addition to staff and want to give them a big welcome.

#### International News





### Advocacy Updates

#### The Insurance Issue

This summer a group of parents started to pay attention to legislation in other states requiring coverage of various therapies (ABA, speech, occupational and physical) for children with autism. The group held a conference call with Steven Kosser, a Pennsylvania psychologist, and met with Delaware Insurance Commissioner Matt Denn. We are currently reviewing legislation from other states with the intent to decide what families want and need so that we can proceed to work on getting legislation for better insurance coverage in Delaware for children.

There is a strong argument to promote insurance coverage because the enormous financial pressure on states is affecting the quality of school and public health services. The traditional assumption has been that insurance doesn't have to contribute because ABA, speech and other therapeutic services are considered to be "educational," so they are viewed differently than medical services for children who have chronic and or severe health care needs. So, while children with asthma, diabetes, and cerebral palsy get broadly accepted speech, occupational and physical therapies paid by insurance, children with autism do not. This places the entire financial burden onto parents and school districts. Advocates around the country advise that we have to work to shift this paradigm, so that legislators see private insurance as a partner working in tandem with school districts and families. The costs can be shared and schools may be able to do more for kids when there are more partners in the process.

#### The Issues of Mandated Insurance

As we all know, health insurance is an issue for many Americans—something we have to remember as we look to insurance legislation. Craig Stoxen, Executive Director of

the South Carolina Autism Society, reports on the limitations of mandated insurance. Craig worked to get mandated insurance legislation in his state, only to learn that it still doesn't adequately respond to all the issues. His comments are based on his experience and facts from the Kaiser Family Foundation using 2006 information.

States have limited powers on placing mandates on insurance providers. No state can mandate coverage on Federal Employee/Military insurance plans; on self insured plans—even if they are being managed by a local insurance company— and according to the South Carolina and the Delaware insurance commissioners, states have a hard time enforcing mandates on policies written outside of the state.

State mandates do not include individual policies—we are not aware of any current state mandate that has included individual policies although this may change.

State mandates do not necessarily cover small businesses. Small businesses are typically considered to have 50 or fewer employees. Nationally in 2005 only 56% of private sector employers even offered health insurance to their employees.

Of the US Population, only 54% receive insurance coverage under an employer group policy, including self insured plans; 5% are covered under individual policies, 13% Medicaid, 12% Medicare, 1% other public and 16% have no health insurance.

Looking at children only (ages 0-18), 56% are covered under an employer sponsored group plan including self insured plans, 4% individual policies, 27% Medicaid, 1% other public, and 12% have no health insurance.

# POW R

#### Productive Opportunities for Work & Recreation

A Community-Based Service of Autism Delaware for Adults with Autism Spectrum Disorders



#### We see the World in a Different Way...

We envision the world where all people with autism live fulfilling lives. To do this, POW&R works with adults and their families and friends to create individualized vocational and recreational supports in the community.

POW&R/Autism Delaware 924 Old Harmony Road, Suite 201 - Newark, DE 19713 (302) 224-6020 www.delautism.org ...It's About Life

#### **Advocacy Updates**

(Continued from page 7)

Please contact the office if you are interested in and would like to work on this issue. We would also like to hear your insurance story as we gather facts for this effort.

Self Directed Support Waiver

We are very happy to announce that the Self Directed Support Waiver made it through the budget process this year, thanks to DDDS coming up with a way to self-fund the project. It is projected to come on line in the 4<sup>th</sup> quarter of the fiscal year (April 09) with 35 new individuals and 65 who are currently in the system. These individuals will receive a support coordinator and a fiscal agent, training on what these services are, a day habilitation program (such as POW&R), and up to \$2500 to purchase specific supports and services such as assistive technology or respite care. One family might build a fence while another will pay for additional therapies for their child. While the intent of the waiver is to help families of adults, it is not limited to adults.

In recent years DDDS changed their funding mechanism to give individuals and families much greater choices in who they work with as an adult service provider. This waiver will continue in that vein, opening the door for support brokers and support corporations that allow adults and their family to hire their own staff if they choose and to control their day. It can be the ultimate freedom, but it is accompanied by ultimate responsibility. Bottom line, the intent is to make the system more flexible to get what you need. Because DDDS is "self" funding, it will mean there will be fewer options for group home placements and other changes in the current service package.

Eligibility for DDDS services will be evolving to require eligibility for Medicaid, so we encourage all families to ensure your child will meet the Medicaid eligibility criteria.

This waiver is the result of three years of work on the part of a wide variety of advocates and we anticipate that this group will continue to collaborate on legislative issues.

Office on Autism

After 18 months of meetings and work, the Legislative Task Force on Adults with Autism is available on the ASD Website at http:// www.delautism.org/TaskForce.pdf as well as the General Assembly website. With parents and agencies working as participants from around the state, the Task Force primarily looked at developing, increasing and enhancing services and supports for people with autism who have not traditionally received state or even appropriate educational services. A major recommendation is to develop an Office on Autism. This is not the first time this recommendation has been made. It was originally made almost 20 years ago as the State was developing Adult Special Populations. At that time, autism was considered very low incidence, so other groups that also had behavioral issues (such as those with Prader-Willi syndrome) asked to be included.

The benefits of an Office would be to have a central place for information, referral and training; the technical expertise to work with other state agencies and providers, and the ability and resources to address the expanding need for services for individuals with autism. Currently our adults are often put into programs designed for individuals with cognitive disabilities. With the recognition that adults with Asperger and high functioning autism go to college and can be academically successful, we now need to

develop services that address their particular needs. That simply cannot be done within a system that doesn't understand who they are or how they think. We need something new with a sole focus on autism spectrum disorders.

#### Inside the ASD

(Continued from page 6)

New Committee Forming

With the growth in the numbers of children with autism spectrum disorders, ASD will be forming a young family committee, consisting of parents of children up to age 8. The committee will report directly to the board. Its primary function will be to keep ASD abreast of the issues of young parents and to make recommendations about programs and services that young families want from ASD. The DAP is different than it was 10 years ago; the needs of families may be different as well. This will give some of you a greater voice, and keep ASD updated about current needs. We are currently recruiting five to eight young parents to participate for what we hope will be quarterly meetings. Please contact Theda Ellis is you are interested.

Thank You!

Thanks to Dr. Janet Asay

Last year, member Kate
Stomerioski brought Dr. Asay to us
and requested that we sponsor a
parent support group in Kent
County. We did that and it has
been a big success, thanks to Dr.
Asay's knowledge of children on
the spectrum. Now Dr. Asay is beginning to teach at Wilmington



### Local News

### GOOD-BYE TO DARLEY ROAD

By: Robin Ireland

It's official. The Brandywine School District has announced plans to close Darley Road Elementary School. The autism program will move to another building – as will the typical students, administrators and teachers. Nothing will change, district officials assured us. You can't fall in love with a building, my husband said. It's just bricks and mortar – what's special happened inside.

And that won't change.

Yet something inside me stirred the last time I was inside Darley Road. It was an evening meeting and

the students were gone. Construction paper projects were taped to the concrete block walls. PECS cards were scattered about, reminding children to be quiet or knock before entering.

The first time I walked into that building was three years ago, to observe Meredith Rafail's class for preschool aged children with autism. I was simultaneously thrilled to see such a lovely program and heartbroken that my child would be attending. It was the first time I saw a child – other than my own – with the telltale signs of autism. The stimming. The toe-walking. The lack of speech and eye contact. Until that time, I thought my son's habits to be uniquely odd. Now I could see why the neurologist made his diagnosis so quickly.

Luke spent two happy years at Darley Road, until the pre-school program moved to the Bush School. And, although it wasn't perfect, we came to consider Darley a second home. Most of the typical children who attend Darley Road live below the poverty line. That condition made the school a bittersweet place as well. Too few parents came for the Christmas concert. The occasional colorful word could be heard on the playground. The projects hung on the walls usually carried some form of the message "I Am Somebody."

At times, it felt like we were being hidden away. The poor and the disabled. Was Darley Road the only school that had room for our bur-

geoning program? Did they have room because every student with the ability to leave had already done so? Or were we at Darley because of Jim Grant, the kindly principal, whose cheerful

voice and generous disposition made everyone feel like part of his family? Were we at Darley because he was the only administrator willing to take us on?

We may never know.

But while Darley was open, it was a safe harbor for a bunch of kids who may have been badly neglected at home. Kids who weren't served breakfast before school. One school newsletter reminded parents not to drop off children before 7:30 a.m. because the doors were locked. It seems kids were being dropped off in the dark. A custodian let them in to play in the gym – even though it was against the rules -because he couldn't bear to let them sit outside alone.

At Darley Road, our kids were the privileged ones. The ones getting dropped off in new cars. Buckled properly into new booster seats. The ones whose parents (and grandparents) showed up at the Christmas concert with Camcorders, clapping and cheering. It made for an interesting dynamic. And when the district held hearings about which school to close, the Darley teachers showed up with tears in their eyes, begging the superintendent to spare Darley Road. Who knows what they were thinking. I can only imagine. It was clear they had become very protective of their small charges.

The final destination of BSAP (the Brandywine Specialized Autism Program) is still not known. The three potential choices are all – from a physical plant perspective – ostensibly nicer than Darley. The teachers will be the same. For the most part, same kids, too.

But there is something about Darley Road that touches a nerve in me. It was a unique place. It was a place that welcomed my son — and me — at a time when we really needed to feel welcomed. I remember Meredith making a little display called "Our Little Treasures" to introduce Luke's classroom full of toddlers to the general population. It had a pot of gold with a photograph of each child in the class around it.

Luke – and the other kids in his class - will be treasured elsewhere. Meredith is still cherished by the parents of BSAP's tiniest students, a woman who on the first day of school promised to "take care of Luke like he was my own child." Mr. Grant (whom the Catholic schoolgirl in me could never bring to call Jim even when he invited me to) will lead another school's hokey morning message every day. Somewhere, (Continued on page 14)



## Parent 2 Parent

#### Parents fall on the spectrum, too.

By: Robin Ireland

Every time I see something in the newspaper and on TV about autism, I am thankful – no matter how small the gesture.

When Alec Baldwin wore an Autism Speaks pin at the Golden Globes a few years back, I literally joined the Alec Baldwin fan club and sent him a thank you email. I laughed through my tears during the "Night of Too Many Stars" benefit on Comedy Central. As a newspaper reporter, I know that consistent media coverage of our cause is a very, very good thing.

And so it was with great excitement and enthusiasm that I watched the recent HBO documentary, *Autism: The Musical*, despite its dreadful title. The program was everything I thought it would be – funny, touching, sad - a quick tour through the usual realm of emotions. Nothing new or illuminating but very nice.

Yet, days later, I couldn't stop thinking about that show. And not about the children with autism either. It was the parents that kept creeping into my brain. Normally, the focus is on the kids. In this case, producers told the story of whole families. And I began to recognize familiar adult faces from the autism community I know and inhabit.

There was the mother so deeply rooted in shock and denial that she simply could not appreciate her daughter's lovely singing voice and gentle nature. Another mom was working so hard to help her child succeed that her other relationships were really suffering. There was the single mother

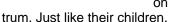
### for parents by parents

afraid that nobody would date – let alone marry – her when she was lugging such heavy baggage. There was the worn out fa-

ther who just let everyone else run the show – and another dad who clearly harbored major escape fantasies.

People were running out of patience,

yelling at their child's teacher, being role models of grace and creativity, shining good cheer wherever they went. They were people reacting to exhausting, life-changing scenarios in a variety of ways. They were people on a spec-



In that way, the show was a fantastic exercise for developing sympathetic compassion. I've met many different personalities in the autism community. Queen of denial. Grand inquisitor. Disbeliever. Protector of hope. Frantic nut job. Those with lawyers on speed dial. Those too fragile to ask for anything. Those who pick up the newer, weaker members and carry their mantle.

Most parents with severely disabled children cling to some sort of emotional edge most of the time. And we need to open our eyes and try to be more understanding and tolerant of one another.

Still, seeing it in digital clarity in my living room was a bit shocking. I expected to see my son in that show. Watch it. You'll probably see a child who looks somewhat like the one you live with, too. But which one of those parents looked like me? Or did all of them?



By: Robin Ireland

A newly published study by researchers at the University Of Texas Health Science Center at San Antonio is said to demonstrate a statistically significant link between the mercury released by coal fired electrical plants and increased autism rates.

I am not a scientist and I haven't seen the data – nor would I be equipped to properly evaluate the data even if I had. But this new study does point out something I always found fishy and more than a tad inconsistent about the autism/biomedical/environmental trigger thing. And I think I'd like to discuss it. I realize that this essay might result in my being lynched – or worse, uninvited to the ASD picnic in Lewes. But I'm going to say it anyway because I think it deserves to be said.

Why does everyone dwell on the mercury in vaccines when there is mercury – and lots of other toxic junk - all around us that seems to go unnoticed?

Could it be that it is easier to heap blame on big pharmaceutical companies or ominous-sounding government entities like the Centers for Disease Control (CDC) than it is to turn off the lights, scale down to a hybrid car or stop buying plastic bottles of water? Let me tell you about my friend. I'll call her Tara. She lives in another state and probably (hopefully) won't read this and recognize herself. She has a child with autism and has him on the full DAN protocol. She believes that the CDC is in cahoots with big pharma. She has not vaccinated her little guy since he was diagnosed, leaving him susceptible to terrible, deadly diseases like diphtheria, polio and measles.

(Continued on page 11)



#### Contaminated Food

(Continued from page 10)

She also lives in a 7,000 square foot house, drives a gas guzzling Suburban and has a house in Florida that she pays to air condition all summer long even though she's not there (so mold doesn't form and wreck the furniture). Her McMansion is lit up like an airport runway. Granted, she buys organic apples from Whole Foods and totes them home in reusable cloth bags. And she feels incredibly good about herself for doing this. But, still, come on, Can nobody else see the inconsistency in her way of living? Do you know anyone like this? Could that someone be you? Because I certainly see a little of myself in her.

Now, I'm not saying whether I think autism is linked to vaccines. It's really not germane to my larger point. I'm simply saying that our world is filled with pollutants that — even if they don't cause neurological problems like autism — are certainly not leading civilization anyplace good. And we can make changes in our lives that could lead to a healthier world. So, how about we do that? I'm as guilty as the rest of you so I'll start.

Our next car purchase will be a 40-plus mph hybrid. I will become more religious about recycling. I will turn off the lights when I leave a room. I will try not to use heat or air conditioning unless it is truly necessary. And, when it is, my house won't be meat-locker cold ever again (even though I like it that way). I will stop flushing expired medicine down the toilet so that our oceans aren't swimming in pharmaceuticals. I will even stop buying bottled water and start filtering my own.

I'm going to stop eating beef at least two days a week (The biggest reason oxygen producing trees are cut down in the rainforest is to create land for cattle ranching. The second biggest reason is so that farmers can grow corn for, you guessed it, beef).

It won't be easy but I'm going to do it. Because maybe it's time for me to own my role in creating such a polluted world and stop blaming others. Maybe leaving my porch lights on all night did more to derail my son's neurological development than anything else. At worst, my wastefulness made me a culprit to an epidemic. At best, I am using more than my share of resources, which is piggy and irresponsible.

I'm not blaming anybody but myself. I want scientists and researchers to keep looking for a cause and a cure. I'll help them in any way I can by participating in medical research studies, raising awareness whenever I am able and donating time and treasure to the people making medical advancements happen. But, in the meantime, I think I'll start making a conscious effort to keep these toxins out of our air, water and soil. And I will try to promote the concept that using less is more chic than having more.

It doesn't feel as cathartic or visceral as blaming the government, but it's a start.

#### About Robin Ireland

Robin Ireland has worked as a newspaper reporter and freelance writer for the past 15 years, covering issues such as crime, politics and health care. Her work has appeared in The Washington Post, The Los Angeles Times, The Dallas Morning News and Ladies Home Journal.

She is currently the marketing director for a private equity corporation with interests in banking and real estate. Robin lives in Wilmington with her husband, Tim, and their three children - Madeleine, Claire and Luke.

#### Inside the ASD

(Continued from page 8)

College and can no longer serve as the support group facilitator. We would like to acknowledge the work she has done for ASD, her effectiveness with the support group, and to thank her for her time and attention; for her listening skills, and for helping the families in Kent County.

So, What's Next?

It's hard to follow in Dr. Asay's shoes, but fortunately for our community, Dr. Asay lined up Deb Wright to step into them. Deb has been a teacher at the Sussex Consortium for the past 10 years, and she most recently received Master's Degree in Community Mental Health Counseling with Dr. Asay as her group supervisor. The combination of Deb's knowledge and experience with children with autism combined with her work with Dr. Asay make her an ideal choice.

We anticipate the group will continue to meet the third Tuesday of every month, beginning October 21at the Positive Futures. Contact Kate Stomerioski at beazelbeak@juno.com.

# Get Connected! Join ASD's On-Line Support eGroup



This group is for parents, guardians or any family member who has a care-taking role of an individual with autism, Asperger's Syndrome or PDD-NOS living in the State of Delaware. This will be a place to safely share your experiences and concerns. This group is set on private and only members can read and post to the group.

To join the group send Cheryl your request with your full name, your child's name, age, diagnosis, day time phone number and email address to:

cheryl.frampton@delautism.org





#### **ASD's Open House**

Come join us on December 5th from 11 am to 7pm to Celebrate ASD's Grand Open House and 10 Years of Serving the Autism Community!

Check out our new office & meet the staff.

Snacks and beverages will be provided.
No RSVP required.
924 Old Harmony Road, Suite 201
Newark, DE 19713

#### Dad's Night Out

Saturday, October 4th Starting at 6:00 PM

#### Delcastle Driving Range 3601 Millcreek Road

Drinks & Appetizers afterwards at

#### Tyler Fitzgerald's 5343 Limestone Road, Pike Creek

Meet some Dads, Uncles, Grandfathers or Friends of those living with autism.
Interested? Of course you are!

Contact: Rob Delaney katejosh1@comcast.net or 494-6199

### Join ASD for our Annual Fall Festival!



There will be:
Hayrides
Scarecrow building (bring some old clothes)
Arts and Crafts
Light Refreshments
& Door Prizes



#### Sunday, October 12, 2008 ~ 1:00 - 3:00 pm The Figure 8 Barn, Bellevue State Park

Reservations will be accepted until October 7th To reserve, contact the ASD office at

(302) 224-6020 or delautism@delatusim.org

This is a free event sponsored by ASD 924 Old Harmony Road
Suite 201
Newark, DE 19713

#### PARENT'S COFFEE HOUR



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

Join us at our elegant new location in

Historic Old New Castle!



Prince on Delaware 124 Delaware Street
Historic New Castle
Coffee is on ASD. Little ones not in school welcome. Invite family and friends.
No RSVP required.

#### Asperger's Teen/Tween Game Night

The Fall Schedule Out!

When: October 10, October 24, November 7, November

21, December 5 & December 19 Where: Neurology Associates

774 Christiana Rd., Newark, DE 19713

**Time:** 6:30 pm -8:15 pm

Cost: \$70 to be paid as a preregistration to ASD. Please note that you must preregister and prepay to attend.

Contact ASD's Asperger's Resource Coordinator, Heidi Mizell to preregister at 324-6020, ext. 205 See you there!!



A S

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

#### **ASD** Meetings

- ▶ October 22, 2008—Chapter Meeting: Communication Devices
- ▶ November—No meeting
- ▶ **December 5, 2008—**ASD's Grand Open House. 11 am—7pm. ASD Office, 924 Old Harmony Road, Suite 201, Newark, DE 19713 (More info on page 12.)

#### Social Events, Public Awareness & Fundraisers

- ► October 1, 2008—NCC Family Fun Bowling, Price's Lanes, Kirkwood Highway, Wilmington—5:30pm. (More info on page 5)
- ▶ October 4, 2008—Dad's Night Out, Delcastle Driving Range, 6pm then drinks and appetizers at Tyler Fitzgerald's. (More info on page 12.)
- ▶ October 8, 2008—NCC Family Fun Bowling, Price's Lanes, 5:30pm
- ▶ October 12, 2008—NCC Fall Festival, 1-3pm Bellevue State Park. (More info on page 12)
- ▶ October 14, 2008—Parent's Coffee Hour, 9am, Prince on Delaware (More info on page 12)
- ▶ October 15, 2008—NCC Family Fun Bowling, Price's Lanes, 5:30pm
- ▶ October 22, 2008—NCC Family Fun Bowling, Price's Lanes, 5:30pm
- ▶ October 29, 2008—NCC Family Fun Bowling, Price's Lanes, 5:30pm
- ▶ November 5, 2008—NCC Family Fun Bowling, Price's Lanes, 5:30pm
- ▶ November 8, 2008—NCC Skating Party, Christiana Skating Party, 5:15pm-7:15pm
- ▶ November 11, 2008—Parent's Coffee Hour, 9am, Prince on Delaware
- ► November 12, 2008—NCC Family Fun Bowling, Price's Lanes, 5:30pm
- ► November 15, 2008—10th Annual Autumn Auction for Autism, DuPont Country Club
- ► November 15, 2008—Autumn Auction for Autism—The Hidden Treasures of Autism. DuPont Country Club, Wilmington —6:30 pm
- ▶ November 27, 2008—OFFICE CLOSED
- ▶ November 28, 2008—OFFICE CLOSED

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

**Support Groups** 

- ▶October 21, 2008—N.C.C. Support Group, 7pm, Special Olympics Building, Newark
- ▶ October 21, 2008—Kent Support Group, 5:30—7:00 pm, Postivie Futures —Contact Kate Stomerioski at beazelbeak@juno.com. (More info on page 11)
- ▶ November 19, 2008—N.C.C. Support Group, 7pm, Special Olympics Building, Newark
- ▶ **November 19, 2008**—Kent Support Group, 5:30—7:00 pm

**Other Events** 

# Check out www.autismconferences.com

Here you will find local and regional conferences and events that are searchable by state.



#### Good Bye to Darley Road

(Continued from page 9)

in some other building, he'll stand by the door with a big, cheesy smile on his face, welcoming the children with, "Hola!"

But that confluence of children and teachers is gone forever. Maybe it is just bricks and mortar. But I'll never forget walking my tiny boy – in diapers and overalls – down the hallway to Miss Merry's class. I'll never forget the day I popped in unexpectedly to find Barbara Broadway, Luke's para, rocking him in a rocking chair.

Maybe Darley is just bricks and mortar. But I think it was a whole lot more.

#### To Cure or Not to Cure? That is the Question.

The following article came from ABC News Internet Ventures and ASD has no ties with them. The following article is based on the views of others and not necessarily those of ASD, their employees or volunteers.

This has been a touchy subject for many years and it is interesting to stop and read what others may be thinking or feeling throughout our community.

Controversial New Movement: Autistic and Proud. Activists Say Stop Looking for a Cure and Accept Autistic People as They Are.

By DEBORAH ROBERTS, MI-CHELLE MAJOR and JONANN BRADY June 10, 2008 — ABC News

Ari Ne'eman and Kristina Chew say they are the faces and voices of autism's future.

They're part of a controversial group hoping to radically change the way others look at autism. Their message: Stop the search for a cure and begin celebrating autistic people for their differences. It's a message that has some parents of autistic children bewildered and angry.

Ne'eman, 20, is the founder of the Autistic Self Advocacy Network, a non-profit group aimed at advancing autism culture and advocating for "neurodiverse" individuals.

"We believe that the autism spectrum and those on it, are important and necessary parts of the wide diversity present in human genetics," Ne-eman says on the ASAN Web site.

Ne'eman was diagnosed with Asperger's syndrome, a less severe form of autism, as a child.

"I think the others around me knew I was different from as early as I can remember," he told "Good Morning America."

When Ne'eman says that looking for a cure for autism is the wrong approach to take, he understands why some parents are upset — especially those with very low-functioning, non-communicative autistic children.

"I think that one of the key issues to remember is that anti-cure does not mean anti-progress," he said.

(Continued on page17)



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ASD Celebrates 10 Years of Serving the Autism Community in Delaware

10th Annual Autumn Auction

### The Hidden Treasures Of Autism

November 15, 2008

DuPont Country Club, Wilmington, Delaware



### Honorary Chairs: Peggy & Edgar Woolard

Please join us for a fabulous evening of high spirits, fine dining, dancing and our always unique live and silent auctions.

This special night will feature a showcase of truly talented performers with autism, and

the unveiling of our new name and logo.
Black tie encouraged. Swashbuckling attire welcome!

For reservations, contact ASD at Delautism@delautism.org or (302) 224-6020

This year's raffle will be a 56"
Samsung 1080 LED DLP HDTV.
Tickets will come home with DAP students and be mailed out with Invitations.



Tickets are \$10 each. Need not be present to win. For additional tickets contact ASD.



On May 28, 2008 at the DuPont Country Club in Wilmington, ASD once again gathered with celebrities from across the sporting world which included NASCAR Drivers, NFL Players, Sports Broadcasting personalities and more for the 7th Annual Drive for Autism Celebrity-Am Golf Outing.

It was a picture perfect day with over 250 playing and a volunteer staff of about 95 individuals. Some of those volunteers were members of the Delaware National Guard who came out to support our cause and give us that extra little spit and polish we needed.

Bon Jovi's & Craig Spencer's organization, the Philly Soul, was kind enough to send us cheerleaders, the Soul Mates, to meet with some of our students. Their organization later went on to win the AFL Championship! Maybe we rubbed off on them a little bit?

Anthony Federov of *American Idol* fame made it out to start our day off by singing the National Anthem with the help of our military. We love Anthony because he was told as a child that he could never sing because he had a tracheotomy. I can assure you, the boy can sing. And like many of our children who are told what they cannot do, Anthony beat the odds and showed the world what he could do. That is the same message we want to send out to the public about our kids before they are dismissed as incapable of doing anything. Thank you Anthony!



Provide Flagrange and the Aba Phillip Cond.

Brendan Flannery poses with the Philly Soul—Soul Mates at the Drive for Autism.

We would like to thank all of the many sponsors who came out to make the day the success it was. We raised half a million dollars that day that will go to local programming and other initiatives for autism.

Without the help of every sponsor, every volunteer, every golf committee member we could not make this a reality and we want to say, Thank you. Thank you for everything you have done for us!



This year's celebrity group shot which included all of our celebrities playing that day, some of our students and POW&R clients, the Soul Mates and our Delaware National Guard.



### To Cure or Not To Cure (Continued from page 14)

'Ransom' Ad Sparks Action'

Kristina Chew, a professor at St. Peter's College in New Jersey, is one of the growing number of parents involved the movement.

When her son, Charlie, was diagnosed with severe autism, Chew said, "I was completely in a gulf. I didn't believe it for months."

Chew now believes that autism treatments and so-called cures are a waste of time. She said she'd rather see Charlie, now 11, benefit from better support services and education.

"My son is who he is. He's not going to change; he's always going to be Charlie. And at the same time, I loved him just for what he was," Chew said.

Parents like Chew and autistic adults like Ne'eman joined forces several months ago, after seeing an edgy new campaign to fight autism from the New York University Child Study Center that implied children with autism are held hostage by the disorder.

The NYU Child Study Center says the ads were about creating awareness, but Ne'eman says that instead, the ads reinforce prejudices about people with autism.

"Where does disability come from? It comes, in many respects, from a society that doesn't provide for an education system that meets our needs. From people who often discriminate or bully or even injure us, and from a society that is largely intolerant," Ne'eman said.

Ne'eman and his supporters protested so loudly, that the ads were cancelled three weeks after they were released.

Wouldn't Change Diagnosis

Many parents of autistic children say that Ne'eman and his group's views don't reflect their reality and should essentially be ignored. Lenny Shaffer, a writer with an autistic son, says of the movement, "You're a handful of noisy people who get a lot of media attention, but you don't represent a broad swath of the autism community."

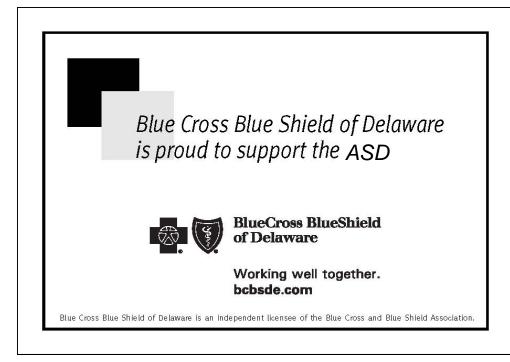
Ne'eman believes history is on his side. "I can't think of the civil rights movement throughout history that hasn't been faced with resistance and misunderstanding on the part of its detractors," he said. And the young activist says if he could go back and change his Asperger's diagnosis, he wouldn't. "If there was a magic pill that would make me neurologically typical, normal, I wouldn't take it," Ne'eman said.

But a number of experts say his path might not be the answer for many others dealing with autism. "You have to remember that this is a spectrum and you've got people who are quite high functioning and then you've got people who can't even begin to function and for whom we would love to have a cure to at least get them to a point where they would be able to function as well as the people in this movement," said Dr. Thomas Insel, from the National Institute of Mental Health.

But Kristina Chew also said she wouldn't change her severely autistic son Charlie if she could. "We really try and understand him on his own terms," she said. That is her advice for parents dealing with a child's autism diagnosis and feeling hopeless.

"Acceptance, to me, is the beginning of hope," Chew said. "I look at my son, even on the days, the most terrible, terrible days. I still knew that I love my son. That he was with us, and that he would be with us, and that the hope was really in him."

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#### **ASD**

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