

# The Sun

Newsletter

January–March 2014

## Inside this issue

Affordable insurance options . . . 3  
 Parent2Parent . . . . . 4  
 We need a standard . . . . . 5  
 Inside Autism Delaware™ . . . . . 6–7  
 Programs & events . . . . . 8–9



## Our mission

To help people and families affected by autism spectrum disorder (ASD)



## The process From problem to treatment

Does your child with autism spectrum disorder (ASD) struggle with a problem behavior? Does it affect your family? Do you feel overwhelmed by the treatment options? And does the thought of medicating your child concern you?

Autism Delaware posed these concerns to four local health-care professionals:

- an expert on child mental health, pediatric psychiatrist Karl W. McIntosh, MD
- an expert on the nervous system in a child, pediatric neurologist S. Charles Bean, MD
- an expert on child development, developmental pediatrician Rhonda S. Walter, MD
- an expert on patient-centered health care, nurse practitioner Veronica Wilbur, PhD, FNP-BC

All agreed that the first thing you need to know is whether the problem is related to ASD or something else.

### How do I start?

Begin researching possible doctors. When you have several who may meet your needs, make an appointment with each. Then, write a list of questions to ask. The goal is to find out what you can expect from each health-care professional.

Here are some questions to consider:

- Have you worked with patients on the spectrum before?
- How comfortable do you feel around people with ASD?
- Can you point our family in the best direction to meet our unique needs?

- Do you recommend therapy, and if so, what type?
- If a medication is needed, will you be available to help our family through the process for finding the best drug and dosage for our child?

### Define it for me, please

See page 8 for definitions of many words and terms used in autism treatment.

The best-case scenario for you and your child is a team of medical experts proficient in ASD, including a primary health-care provider who can make treatment referrals (such as a doctor, nurse practitioner, and physician's assistant). Also consider a pediatric psychiatrist for prescriptions plus a psychologist, counselor, or licensed clinical social worker who can work with the child on the problem behavior. Each health-care professional should be able to build a long-term relationship with the child.

At this point, your focus is squarely on your child as an individual living with ASD in your home, so you are the expert on your child's needs. This level of attention needs to extend to every other setting your child is part of, too. You need to gather data about your child's behavior in each setting and be able to note any differences.

And it's your job to share this with your assembled team of medical experts.

Continued at the top of page 10

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**Reflections on the journey**  
**The semi-empty nest**

At the end of this school year, Artie's and my youngest son will graduate from high school and start getting ready for college. And by this time next year, Ethan will be the only one still at home with Artie and me. Both of our other boys will be off starting their independent lives.

It's such a bittersweet time for parents: We've worked for years to prepare our children to make their own way, and now, they are heading out. We're sad to see them go, but happy and proud of the young adults they have become. Parenting a child with autism spectrum disorder involves even more work, painstaking effort, and preparation. Yet the magic age of 18 comes and goes, and your child is still at home—21 comes and goes, and your child is still at home. Many of my PONT friends (parents of neuro-typicals) are dealing with the empty nest syndrome, while we try to emotionally prepare for the semi-empty nest syndrome.

Thinking back on the journey is natural at a time like this. When Ethan was first diagnosed, we were devastated, reeling from all the information, misinformation,

and lack of information. It was overwhelming. But slowly we began to find our way.

Once we got Ethan settled at school, we started looking into what else we could do. The sense of urgency was intense. We tried many different interventions with varying degrees of success. It was important to try things—carefully and methodically—knowing that what

worked for one child might not work for another. Success stories from other parents could feel inspirational or, quite frankly, annoying. But we needed to hear their stories and determine how best to make a difference for Ethan.

But enough of reflecting back. It's time now for my family to look forward. We do plan to have a truly empty nest someday! We envision a life for

Ethan where he is living in his own home—perhaps an apartment or condo—with maybe a roommate or

**Continued at the top of page 3**



**Marcy Kempner**  
President  
Autism Delaware

*This edition of The Sun includes information about pharmaceutical interventions. Please take the time to read all of it, do your own research, and talk to other parents so that you can introduce medications or therapies that make sense for your child. If you need information or connection to other parents, call Autism Delaware and ask to speak to a parent mentor. There are many ways to improve a child's quality of life, and every effort really does make a difference.*

**A service of Autism Delaware**



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**The semi-empty nest** Continued from page 2

two along with some support staff. We talk about this often with our friends from the community who have adult children. We discuss the need for residential options at meetings of the Autism Delaware Board of Directors and at Autism Delaware Strategic Plan meetings. We know that we have a fantastic adult vocational program in POW&R (Productive Opportunities for Work and Recreation) and ask "Given our resources, how can we expand into residential services in an equally effective yet feasible way?" We are looking into all these things as an organization, and welcome your feedback and participation. Please visit our website—autismdelaware.org—take a look at our new strategic plan, and let us know what you think.

In the meantime, we Kempners will be working on embracing the semi-empty nest as the next phase of our journey. Advice, support, therapy over a few glasses of wine, all are welcome!

**Autism Delaware™ is interested in a variety of viewpoints about autism and emerging research, but reference to any treatment, therapy option, program, service, or treatment provider is not an endorsement. We publish information only for informational purposes and assume no responsibility for the use of any information. You should investigate alternatives that may be more appropriate for your specific needs.**

## ***Did you know?***

**A tax-deductible donation can be made to Autism Delaware through the United Way of Delaware. Simply enter the code on the United Way form!**

| For the<br>United Way in | the code is  |
|--------------------------|--------------|
| <b>Delaware</b>          | <b>9234</b>  |
| <b>SE Pennsylvania</b>   | <b>12598</b> |

## **Choose Health Delaware offers affordable insurance options**

Choose Health Delaware is the new state-based marketplace that offers affordable insurance options in compliance with the Patient Protection and Affordable Care Act (PPACA). Commonly known as Obamacare, PPACA requires most Americans to carry health insurance beginning January 1, 2014. The website ChooseHealthDE.com opened October 1 for those currently uninsured, underinsured, or looking for different health-care coverage.

The plans offered in the marketplace are comprehensive, including all state-mandated benefits, such as coverage for autism therapy as enacted in June 2012. The plans offer varying monthly premiums called "metal levels" (ranging from bronze to platinum) with a catastrophic plan offered to Delawareans who are under 30 or with qualifying income. The metal level also determines the share of medical expenses the policyholder is responsible for (such as deductibles and co-pays). Generally, the lower the premium, the higher the cost-share. Dental plans are also available.

If you already have health coverage through an employer, you can still shop for a plan; however, you may not be eligible for financial assistance with your premiums. This assistance includes the following:

- Medicaid for anyone whose income is up to 138 percent of the federal poverty level (FPL)  
Medicaid, including the Children's Community Alternative Disability program, can still be secured through the state Medicaid office.
- Direct subsidies for incomes between 139–250 percent of FPL
- Tax credits for incomes between 251–400 percent of FPL

Choose Health Delaware differs greatly from how most people currently shop for insurance on the open market: Instead, qualifying plans and costs are consolidated in one place for the consumer to compare. Consider all your options.

The state has a number of guides trained to assist you in addition to federally trained navigators, and any questions that come to Autism Delaware regarding the marketplace will be referred to these guides and navigators.

If you prefer to talk to a person rather than visit ChooseHealthDE.com, call 1-800-318-2596.

## **Important dates to remember**

- December 23, 2013:** Deadline to sign up for health-care coverage starting January 1
- January 1, 2014:** Date that health-care coverage becomes legally required and coverage begins, including Medicaid
- March 31, 2014:** Date that open enrollment closes for 2014

# PARENT PARENT

Written by parents for parents

Here, three Delaware parents discuss nonpharmaceutical interventions that meet the family's values or goals and worked for their children with autism spectrum disorder:

Some treatment options were easy to research while others were difficult. My husband and I found a website that evaluated these options that was very helpful. Created by a physician named James R. Laidler, MD, who has two children with autism spectrum disorder, the site is called [autism-watch.org](http://autism-watch.org) and is now run by Stephen Barrett, MD.



**Katie Murphy**

We like the site because it "provide[s] a scientific perspective on the many aspects of autism.

This website is for families of autistic children (including adult children), practitioners treating autistic patients, and anyone else with an interest in autism. [Autism Watch's] goals are to provide basic information about autism, offer scientific analysis of autism therapies, discuss the merits of the many proposed causes of autism, identify reliable sources of help and information, report improper actions to regulatory agencies, and help people seek legal redress if they have been victimized" ([autism-watch.org/about/mission.shtml](http://autism-watch.org/about/mission.shtml)).

—Beth Murphy  
Wilmington, Del.

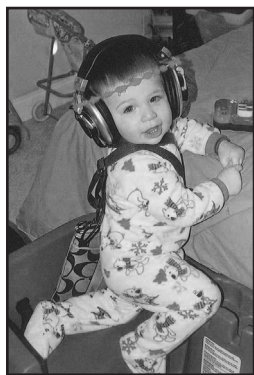
Our son was on a strict gluten-free–milk-free diet for about a year at age 5. Our family was very fortunate to have tried this diet at a time when Devin Houston, PhD, had formulated an enzyme product that prompted him to eventually become the founder of Houston Nutraceuticals, Inc. With the addition of an enzyme taken prior to a snack, our son could deviate from the diet and have the same snacks at school and special occasions as other children. After a couple years, our son was able to supplement as needed as long as foods with gluten were not eaten more than a few times straight in a row.

Our son is now 10 and can self-administer his enzymes as needed. He uses the enzymes about half of the time now during meals and snacks. He also knows if he is consuming too much wheat and will actually cut back on his own until he feels better. The use of Nutraceutical's AFP-Peptizyde enzymes have allowed our son the benefits of feeling better without strict adherence to a gluten-free diet. (He doesn't even like milk, so this is not an issue for him.)

The physical benefits are his stomach is not bloated and he doesn't have the dark circles under his eyes. The other benefits are that he doesn't feel brain fog and he is able to be more calm.

We are very blessed to have met Dr. Houston and are extremely grateful for the work he has done to benefit others.

—Melody  
Georgetown, Del.



**Casey Gilden**

I tend to lean more toward the alternative or supplemental side than the clinical or prescription side, but that being said, I do believe things should be done under the consultation of a doctor. Plus, you need a prescription for some of the more alternative treatments.

Over the past handful of years, I've been looking at MAPS [Medical Academy of Pediatric Special-needs] doctors. They are what DAN [Defeat Autism Now] doctors used to be, doctors who are practicing in a specialized field (gastroenterology, pediatrics, and so on) but they have decided to also specialize in patients with autism. And many are at the forefront of their fields and work at prestigious hospitals.

Recently, MAPS created a system whereby doctors can get training on cutting-edge research and protocols through conferences, webinars, and workshops about autism ailments. A few years down the line, doctors will be able to claim that they are MAPS doctors with a certain degree, and patients will know that the doctors have had the appropriate training. These specialized doctors have been helping families for the past couple of decades, but now the process will be more legit. It's very exciting.

I have heard MAPS doctors speak at a conference and taken Casey to see them in private practice. And they have definitely helped my family.

—Cory Gilden  
Newark, Del.

**Updated resource guides are now available.**

**To have one emailed to you, send your email address to [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org).**



## We need a standard

Every child is a unique individual with his or her own set of traits and motivations. Every autism diagnosis is as unique as the spectrum. And no one coordinated approach or community standard exists for autism spectrum disorder (ASD).

Yet a study published October 21, 2013, in *Pediatrics* (the American Academy of Pediatrics' online journal site), notes the prevalence of prescriptions filled for children with ASD:

"Among 33,565 children with ASD, 64 percent had a filled prescription for at least one psychotropic medication, 35 percent had evidence of a psychotropic polypharmacy (two or more classes), and 15 percent used medications from three or more classes concurrently" ([pediatrics.aappublications.org/content/early/2013/10/16/peds.2012-3774.abstract](http://pediatrics.aappublications.org/content/early/2013/10/16/peds.2012-3774.abstract)).

Because these numbers stand in contrast to the lack of evidence proving effectiveness and appropriateness of drug therapy in children with ASD, the study concluded that a standard of care needed to be created.

## Why it's prescribed

According to the Autism Speaks website, relief for autism's core symptoms—communication difficulties, social challenges, and repetitive behavior—cannot be found consistently through medication ([autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms](http://autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms)).

"It's hardly surprising that few medications are available," says Autism Delaware's clinical director, Susan Peterson, PhD, BCBA-D, "considering that two core symptoms are communication difficulties and social challenges." Instead, other symptoms are addressed, such as irritability, anxiety, depression, repetitive and self-injurious behaviors, and co-diagnoses like ADD and ADHD.

**Irritability**—Two FDA-approved antipsychotic drugs are prescribed for children (aged 6 or older). The belief is that, by relieving irritability, sociability is improved while reducing tantrums, aggressive outbursts, and self-injurious behaviors. "However, both medicines tend to produce significant weight gain and diabetes risk. Therefore, their use requires close monitoring" ([autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions](http://autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions)).

**Anxiety**—The FDA has approved several selective serotonin reuptake inhibitors (SSRIs) for people without ASD—but not for adults or children with ASD. "Some studies suggest that antianxiety medications are less effective, overall, in those with autism than with other groups. It may be that the biological root of autism-associated anxiety may be different from that of anxiety in the general population. As such, individuals with autism may respond best to tailored treatments" ([autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions](http://autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions)).

## Side effect vs. allergy

A side effect, reads the fifth edition of the *American Heritage Dictionary of the English Language*, is "an undesirable secondary effect of a drug or therapy." An allergy is "an abnormally high sensitivity.... Common indication of an allergy may include sneezing, itching, and skin rashes."

A life-threatening allergy reaction can occur quickly. Called anaphylaxis, it can include hives, itching, flushing, and swelling of the lips, tongue, and roof of the mouth. According to the website *epipen.com*, "The airway is often affected, resulting in tightness of the throat, chest tightness, and difficulty breathing. These reactions can also be accompanied by chest pain, low blood pressure, dizziness and headaches."

If you have any concerns about either side effects or allergies, call your doctor.

**Depression**—Like anxiety medication, depression medication has not been studied in adults or children with ASD. Unlike it, "[s]ome research suggests that individuals with ASD are at increased risk of side effects from antidepressants. The most common side effects include sleepiness, agitation, increased irritability, restless leg syndrome, and gastrointestinal problems.... [I]t may take several trials of different medications to find one that works well with minimal side effects. Dosing needs to be carefully tailored to the individual as well" ([autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions](http://autismspeaks.org/what-autism/treatment/treatment-associated-psychiatric-conditions)).

"Antidepressants and antianxiety medications are also given for sleep disturbances and obsessive-compulsive disorder," adds Nemours' pediatric neurologist S. Charles Bean, MD. "And alpha-agonists are prescribed for sleep, agitation, inattention, and tics as well as anxiety."

**Repetitive and self-injurious behaviors**—An opiate antagonist (approved for opioid and alcohol addictions) eases these behaviors in some children and adults with ASD. "Dopamine blockers," continues Bean, "are prescribed for self-injuring behavior and internal stresses, but they have more side effects."

**ADD and ADHD**—Conditions that can be co-diagnosed with ASD—attention deficit disorder or attention deficit hyperactivity disorder—are often treated with stimulants. Because of the stimulant's physiological actions in the body, notes Bean, side effects often occur and can include decreased appetite, irritability, emotional outbursts, and sleep disorders. Usually prescribed to address the inability to concentrate, a stimulant can further provoke anxiety and the inability to concentrate.

# INSIDE Autism™ Delaware

## Awards for education

As a statewide agency focused on helping people and families affected by autism spectrum disorder (ASD), Autism Delaware™ is a big advocate of education. Every spring, we award scholarships to both aspiring autism professionals attending the University of Delaware and adults on the spectrum who want to pursue higher education. Autism Delaware stipends are also awarded to paraprofessionals aspiring to become teachers. The 2014–15 award value is \$1,000 for selected recipients. Award winners will be announced in the spring of 2014.

The Autism Delaware Daniel and Lois Gray Memorial Scholarship was created specifically for eligible University of Delaware undergraduate or graduate students. It is awarded every spring to those who plan on becoming professionals in the autism community. Examples of applicable professions include psychologists, speech pathologists, and teachers in special education.

For adults on the spectrum, the Autism Delaware Adult with Autism Scholarship supports attendance at college or other post-secondary educational program.

And the Autism Delaware Para-to-Educator Stipend is available to an eligible paraprofessional who, in the past year, completed his or her education to become a teacher of children with ASD. The goal is to acknowledge the unique expertise these individuals bring to the autism community and how much we value them. In turn, we hope to retain these highly skilled professionals who teach and support our children.

## Community funding

Autism Delaware is now accepting grant proposals from community organizations whose objectives align with the autism agency's mission.

Autism Delaware reviews all submissions and will be responsible for approvals. If approved, the grant amount will vary with the total determined annually during the budget process. A grant can be worth as much as \$2,000.

## Year-round stipends

Autism Delaware provides year-round stipends to support attendance at autism workshops and conferences.

The \$250 stipend can be applied to registration, travel, hotel, child care, or any other related cost.

The stipend is paid once recipients submit their receipts to Autism Delaware as well as a summary of their experience at the workshop. The goal is to share what they learned with our readers.

Editor Carla Koss is available to help with your writing process if desired.

**To apply:** Noting the name of the conference, its date, and the anticipated costs, submit a request to:

Autism Delaware  
ATTN: Stipend Request  
924 Old Harmony Rd.  
Suite 201  
Newark DE 19713

Or email the request to [delautism@delautism.org](mailto:delautism@delautism.org).



## Where do I get the applications and forms?

For scholarship and stipend information and applications, grant protocol and applications, and criteria and forms to nominate an outstanding volunteer, visit [autismdelaware.org](http://autismdelaware.org). Click on "Support & Education"; then, "Scholarships, Grants, and Stipends."

All submissions must adhere precisely to the instructions and be received by March 1, 2014.

## Nominate a volunteer

Many wonderful people make a world of difference in the autism community every day. *How?* By volunteering their time and expertise. Whether they work at fundraising events and social activities, help raise awareness, or advocate for change, Autism Delaware volunteers improve the lives of all Delawareans living with autism spectrum disorder (ASD)—and their outstanding efforts deserve acknowledgment.

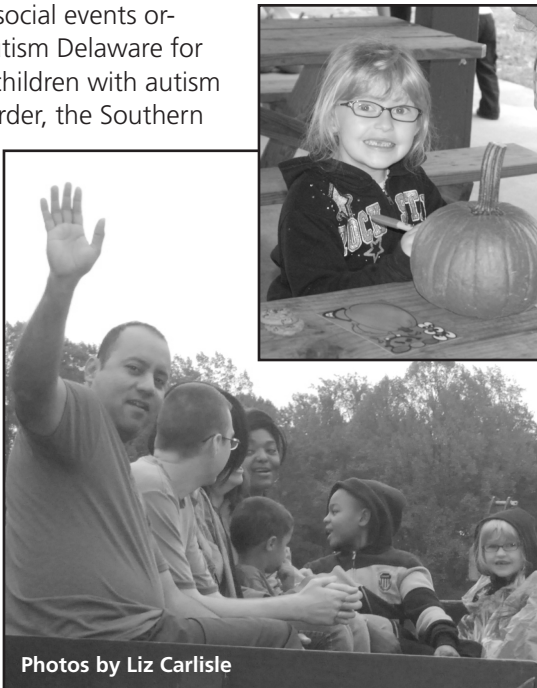
Do you know volunteers who deserve acknowledgment? Nominate them for one or more of the following awards:

- Outstanding Autism Delaware Volunteer
- Outstanding Leader in the Community
- Outstanding Employer

Award winners will be announced during the annual night of appreciation scheduled for June 2014. Last year's winners included Dover Downs Hotel, recipient of the prestigious Autism Delaware Noel Perry Award for Outstanding Employer; outstanding community leaders Grotto Pizza and retired-Del. State Senator Liane Sorenson; and outstanding volunteers Lisa Held, Toni Maestrale, Irene Rodriguez, Dee Sedlacek, Judy Mashishin, Jim and Koh Morrissey, and Barbara Butterworth.

## Fall program highlight of southern program schedule

One of many social events organized by Autism Delaware for families with children with autism spectrum disorder, the Southern Delaware Fall Festival attracted 60 people to Killens Pond State Park in Felton on October 19. Participants enjoyed pumpkin decorating, snacks, and hay rides to celebrate the season.



Photos by Liz Carlisle

## Mission supported by Del-One Foundation

In addition to being a tee-shirt sponsor for the Walk for Autism last April, *Del-One Foundation* formed a team of members, family, and friends who walked at both Cape Henlopen State Park and Bellevue State Park.



**Del-One Foundation Vice President Amy Resh presents Autism Delaware's development director, Troy Nuss, with a check for funds raised at the 2013 Walk for Autism.**

The *Del-One Foundation* donated \$2,000 of additional support for Autism Delaware's mission.

*Del-One Foundation* is proud to support Autism Delaware's work to ensure that all people with ASD have the opportunity to learn, grow, and live full lives as included and valued members of their communities.

A strategic plan that maps Autism Delaware's direction over the next five years was adopted by the agency's board of directors on October 22. Autism Delaware staff and supporters joined the board in drafting key steps in several essential areas, including

- family support,
- vocational services,
- clinical services,
- residential services,
- advocacy, and
- awareness.



## Strategy adopted for five-year plan

The goal is to further our efforts in helping people and families affected by autism spectrum disorder (ASD) in Delaware by the year 2018. View the complete plan at [autismdelaware.org](http://autismdelaware.org) under the heading "About Us." Select "Mission & Vision."

## The joint was jumpin'!



More than 300 people strutted their "blue jeans and bling" and boogied to the tunes of Love Seed Mama Jump at the 2013 Blue Jean Ball on September 21 in the Rehoboth Beach Convention Center.



Photos by Don Smith

The annual Autism Delaware event grossed more than \$74,000 for the programs and services essential to individuals and families living with ASD.

About 200 items were donated, including a highly prized NASCAR package for two, courtesy of Michael Waltrip Racing.



Aaron's donated the raffle item—a 55-inch LG flat-panel LED TV—won by John Hall, vice president of Bi-Rite Auto.

## Did you know?

Since the Walk for Autism first stepped off in 2007, more than \$1,000,000 has been raised for Autism Delaware programs, such as the Southern Delaware Fall Festival held in October.



# Define it for me, please

Used by health-care professionals when discussing behavior and treatment of autism spectrum disorder (ASD), the terms defined here comprise a mixture of sources: *The American Heritage Dictionary of the English Language (fifth edition)*, Autism Speaks, The National Autistic Society (UK), the National Institutes of Health's MedlinePlus, The Free Dictionary by Farlex, and WebMD.

**Agonist:** a chemical or drug that joins with a receptor to trigger a response; an antagonist blocks the agonist's trigger.

**Anesthetic drug:** a medication that decreases a symptom's effect or induces a lack of interest.

**Antianxiety:** a class of medication that calms the central nervous system and may reduce fear and tension. Known as a minor tranquilizer, can also help features of depression and decrease obsessive-compulsive disorder (OCD) symptoms.

**Antidepressant:** a class of medication that does not cure depression but may reduce sadness and withdrawn behavior. Can also help features of anxiety and decrease OCD symptoms.

**Antipsychotic:** a drug to treat psychosis (loss of contact with reality). Also known as a tranquilizer.

**Attention deficit disorder (ADD)**

**Attention deficit hyperactivity disorder (ADHD):** a syndrome signaled by impulsiveness, hyperactivity, and a short attention span. ADD and ADHD can occur in an individual without ASD or be the result of ASD, so autism professionals suggest consulting an expert in both disorders.

**Anxiety:** a state of unease that prompts self-soothing and repetitive behaviors.

**Bipolar disorder:** a mood disorder signaled by alternating periods of depression and high energy. Symptoms include pacing, impulsivity, irritability, insomnia, and rapid, loud, and nonstop talking.

**Cognitive behavioral therapy (CBT):** a therapy for identifying distorted thoughts and replacing them with positive attitudes. Primarily for verbal individuals without intellectual impairment.

**Depression:** a mood disorder signaled by sadness, inability to concentrate, sleep

problems, changes in appetite, and feelings of worthlessness and hopelessness.

**Dopamine blocker:** a class of medication that blocks the dopamine receptors in the brain to address schizophrenia, bipolar disorder, and Parkinson's disease. Dopamine is a signaling chemical known as a neurotransmitter.

**Half-life:** the amount of time a drug is in the body. If the drug has a half-life of six to seven hours, then the dosage is taken twice a day to maintain a continuous effect.

**Neuroinhibitor:** a class of medication that blocks a neurotransmitter (signaling chemical) in the brain.

**Obsessive-compulsive disorder (OCD):** a psychiatric disorder signaled by repetitive and unwanted thoughts and behavior, such as compulsive handwashing and rechecking locks.

**Off-label:** a prescribed drug with FDA approval, not for the medical problem in question, but for another, possibly related condition. In the case of ASD, other possible conditions include ADHD, sleep disturbances, and depression.

**Psychotropic medication:** a drug that alters perception, emotion, or behavior.

**Schizophrenia:** a psychiatric disorder signaled by delusions, hallucinations, disorganized thinking, and behavior indicative of a loss of contact with reality. Symptoms include withdrawal from society and impaired communication.

**Selective serotonin reuptake inhibitor (SSRI):** a class of drug used primarily to treat anxiety, depression, and OCD.

**Stimulant:** a chemical agent that speeds up physiological activity. Considered a class of medication, a stimulant is usually prescribed for children with ADD or ADHD, who have trouble concentrating.

## CALENDAR of EVENTS

### January

**4**—Sensory friendly movie: *Walking With Dinosaurs*. Penn Cinema Riverfront. 401 S. Madison St. Wilmington. 10:00 AM.

**8, 15, 22, 29**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30 PM. Register: Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.

**9**—Speaker Series: Mike Walling on employment and benefits. Appoquinimink Teacher Training Center. 118 S. Sixth St. Odessa. 9:00 AM-4:00 PM. Register: Heidi Mizell at (302) 224-6020.

**20**—Mature Aspies support group. Autism Delaware Newark office. 6:30 PM. Register: Will Morris at (302) 224-6020.

**25**—Sensory friendly roller skating. Milford Skating Center Roller Skating Rink. 1 Park Av. Milford. 5:00-7:00 PM.

### February

**5, 12, 19, 26**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30 PM. Register: Karen Tuohy at karen.tuohy@redclay.k12.de.us; (302) 633-3316.

**17**—Grandparents support group. Autism Delaware Newark office. 6:30 PM. Register: Will Morris at (302) 224-6020.

### March

**5, 12, 19, 26**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30 PM. Register: Karen Tuohy at karen.tuohy@redclay.k12.de.us; (302) 633-3316.

**17**—Dads support group. Autism Delaware Newark office. 6:30 PM. Register: Will Morris at (302) 224-6020.

**22**—Sensory friendly movie: *Muppets Most Wanted*. Carmike Cinemas in the Dover Mall. 1364 N. Dupont Hwy. Dover. 10:00 AM. Register: Tyler Anaya at (302) 644-3410.

**'Looking for parent coffee hour and teen/tween game night?'**

**See page 9.**

**For daily posting of programs, visit the Autism Delaware homepage at [autismdelaware.org](http://autismdelaware.org).**



## Parent coffee hour

### Panera Bread

3650 Kirkwood Hwy.  
Wilmington

January 14 @ 7:00 PM

February 11 @ 9:00 AM

March 11 @ 7:00 PM

*'Planning on attending coffee hour at Surf Bagel or the Holiday Inn Express?*

*Please let Dafne Carnright know at (302) 644-3410.*

### Surf Bagel

17382 Coastal Hwy.  
Lewes

January 9 @ 9:00 AM

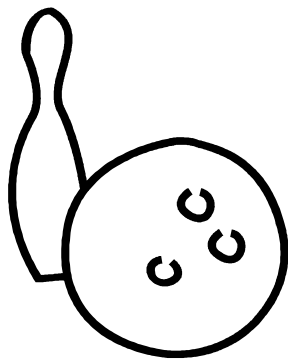
### Holiday Inn Express

• 24058 Sussex Hwy.  
Seaford  
February 11 @ 9:00 AM

• 1780 N. Dupont Hwy.  
(Behind McDonald's) Dover  
March 12 @ 9:00 AM

*Please join us!*

*The coffee is on us!*



## Bowling night

Every Wednesday

5:30–7:00 PM

### Bowlerama

3031 New Castle Av.  
New Castle

See the Calendar of Events (p. 8) for registration info.

## April 2014 Autism Awareness Month

Autism Awareness Month is a good time to advocate, educate, and fundraise for autism:

- Light up your home or office in blue on World Autism Awareness Day 2014—April 2.
- Write a *Letter to the Editor* of the local newspaper about your life with autism.
- Hold a car wash or other fundraiser to benefit Autism Delaware programs and services.

For more ideas, visit [autismdelaware.org](http://autismdelaware.org).



Photo courtesy of Andrew Zeltt

Free admission!  
Sensory friendly roller skating



\$2.00 skate rental

January 25, 2014

5:00–7:00 PM

Milford Skating Center Roller Skating Rink

1 Park Av., Milford

## Teen/Tween game night

For 9–19 year olds with Asperger's syndrome

**Place:** Autism Delaware™ Newark office

**Dates:** January 10  
February 14  
March 14

**Time:** 6:30–8:30 PM

### Cost:

**\$30 per season** (includes three sessions)

Must be paid at registration

### To register:

(302) 224-6020  
[delautism.org](http://delautism.org)  
[@delautism.org](mailto:@delautism.org)

## Winter 2014 season

For 9–14 year olds with Asperger's syndrome

**Place:** Autism Delaware™ Milton office

**Dates:** January 31  
February 28  
March 14

**Time:** 6:00–7:45 PM

### Cost:

**\$10 per session**  
Must be paid at registration. Register by the Wednesday prior to the session.

### To register:

(302) 644-3410  
[dafne.carnright@delautism.org](mailto:dafne.carnright@delautism.org)

**The process** Continued from page 1

“You need to be able to talk to the team, so you need to document your concerns as you go,” recommends Heidi Mizell, Autism Delaware’s resource coordinator. “Organize the information in a way that works best for you.” Mizell endorses the care notebook handed out at workshops hosted by Delaware Family Voices. For a schedule of upcoming care notebook workshops, visit [delawarefamilytofamily.org](http://delawarefamilytofamily.org).

*Are you having a problem carrying out this process?*

The process noted here is a best-case scenario. If you find a shortage or lack of resources, contact Autism Delaware. We can help you find a resource or help advocate for one.

A first appointment with each medical expert needs to be considered a fact-finding mission. “Clinicians need to gather data so they’re aware of prior indications, behaviors, and so on,” notes Rhonda S. Walter, MD, a developmental pediatrician at

Nemours/Alfred I. duPont Hospital for Children for 23 years. “Everyone on the child’s treatment team needs to talk to each other. Be sure to tell your clinicians about all the supplements and treatments you want to try, too.”

“Parents can help improve communication by providing the specific names, addresses, and phone and fax numbers of everyone on the team,” adds S. Charles Bean, MD, a long-time pediatric neurologist at Nemours.

Once the team has determined that the problem is ASD-related, make sure your child is receiving appropriate services. “The number-one rule,” continues Bean, “is ‘Do not delay!’ If your child is under the age of three, get services as soon as possible. Even if you’re unsure of the diagnosis, it’s better to err on the side of early treatment. Children with autism need help working on core symptoms involving socialization, communication, behavior management, and education.

“It’s also important to support the family,” says Bean. “With a child with special needs, a family needs help dealing with multiple other things. Family training is needed to promote the carryover of the work done in school, and services need to extend to daycare and post-21 programs [for when the child ages out of the school system]. And all of this needs to grow with the child’s needs.”

Finally, the child needs a thorough physical, and the child’s medical history needs to be recorded. Here, Karl W. McIntosh, MD, offers two more top goals. “Number one,” lists the child and adolescent psychiatrist with Concord Behavioral Health, “is get information on how the behavior was handled in the past; and number two, evaluate what the person can and cannot do.”

**Treating the behavior**

All four of our experts also agree that a behavior problem should be treated with behavioral therapy. Examples include cognitive behavioral therapy (CBT), applied behavior analysis, and verbal behavior therapy.

“Try therapy first,” suggests nurse practitioner Veronica Wilbur, PhD, FNP-BC, associate professor and chair of the doctor of nursing program at Wilmington University, “and know what the specific behavior is you want to address. If social communication is impaired by fear, for example, is the child reacting to a particular situation in which he or she cannot process the stimuli adequately? And if the child exhibits erratic behavior, how different is it from his or her usual behavior and how is it impacting social interaction?”

Wilbur suggests that the parents create a diary of the problem behavior that includes what is being seen and when. Here are some questions to answer in the diary:

- What is the situation in which the behavior takes place?
- How often does the behavior occur in which situation?
- Is the situation familiar or unfamiliar?
- Is the behavior new? If not, how long has the behavior been going on?
- If the child takes a while to calm down, how long does he or she need?

The answers to these types of questions will point treatment in the correct direction for the individual child.

“There’s no silver bullet for anyone in psychiatry,” explains McIntosh, “and all change provokes anxiety, whether you have autism or not. During times of transition and stress, a teenager with autism suffers the same as a teenager without autism. The key is to recognize the social-emotional differences. I’ve worked with bankers who needed two years before they could say what they needed and kids with autism who needed only two weeks.

“I don’t use CBT for a person with autism,” says McIntosh of his individualized 18-year practice in psychiatry and child and adolescent psychiatry. “Nature has to be sculpted. Instead, we practice how to be in the room.”

**Deciding to medicate**

If behavioral therapy alone is not enough, physicians may recommend behavioral therapy with a complement of medication. “The goal,” defines Bean, “is not only to reduce unwanted behavior but also to make the child more available for learning. A medication may help overcome a behavior block that’s stopping the child’s advancement. You need to make sure the medication is not interfering with the behavior program and learning.”

“Medication is an adjunct to everything else,” agrees Walter. “You need to get everything else in a row before turning to medication.

“The ideal time to consider meds,” suggests Walter, “is before a symptom gets out of hand. Target the symptom that is interfering most with your child’s life, and think about using meds if the child’s symptom is stopping the day-to-day flow of family life.”

Some questions to consider are

- How is the symptom interfering with the child’s education and development?

**Continued at the top of next page**

**The process** Continued from page 10

- How is the symptom affecting behavior and causing stress in the family?
- Is it causing a true distress in the child, like agitation or discomfort?
- How could a medication enhance the child's development, education, or behavior?

**Start low, and go slow**

The process for finding the best drug and dosage involves a long-term strategy of trial and error—because no one standard exists for ASD treatment. “[W]hile the Food and Drug

Administration (FDA) has approved two drugs for treating irritability associated with the autism, it has yet to approve a medicine for treating autism’s three core characteristics” ([autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms](http://autismspeaks.org/what-autism/treatment/medicines-treating-core-symptoms)). For more, see *Why it’s prescribed* on page 5.

**For more on standards for ASD treatment, see *We need a standard* on page 5.**

“Always treat the mood first,” notes McIntosh. “Then, adjust as needed. In my opinion, if you look at the symptoms over time, you’ll find this will improve functionality and communication. If the benefits and limits are clear, you can determine a drug’s effectiveness.

“From the pharmacologic standpoint,” continues McIntosh, “the process is observational. You have to observe people to figure out the best course of treatment. If you’re dealing with anxiety, you need to educate parents to know what it looks like.

“Meds work when a relationship exists between the physician and the family,” adds McIntosh.

“Start low, and go slow,” advises nurse practitioner Wilbur about medicating children with ASD, “because a drug can have the opposite effect on a child than intended.” However, as long as the parents understand this phenomenon, there’s no need to panic when a child starts a new drug, because with only one dose in the body, it’s not concentrated enough

to bring on a side effect.

“You need to take a drug about a week for a side effect to surface,” explains Wilbur, “and a side effect tends to ease after two weeks. It may even go away.” (For an explanation on the difference between a side effect and an allergy, see the box on page 5.)

The other important point to remember, notes Bean, is the drug may fix the problem now, but the problem—and the drug’s effect in the child’s body—may change over time.

“The reason,” explains Bean, “is autism is not just one thing; it’s a spectrum with different levels of cognitive abilities; therefore, it’s a strong determiner of the medication’s ability to work.”

Parents should ask whoever is prescribing the medication to detail the possible side effects. Parents should also read the package insert that comes with the prescription.

“The handout can be scary,” admits Wilbur. “Rather than be overwhelmed by all the information, look for the possible side effects that are most common, like weight loss or gain, nausea, headache, insomnia or drowsiness.”

Once the medical expert makes sure the family understands the range of both positive responses and side effects, the parents’ job is to follow how the child responds to the medication. “The doctor needs to explain what the medication does and doesn’t do,” sums up McIntosh, “so the parents know what to look for. They need the tools to be able to observe the child’s behavior at home.”

**Tool kits!**

Autism Speaks offers a tool kit for parents considering medication. The kit provides help through the decision-making process.

For parents who have already decided to medicate, Autism Speaks offers *ATN/AIR-P Autism and Medication: Safe and Careful Use*.

Both can be downloaded at [autismspeaks.org](http://autismspeaks.org). Click on Family Services; then, Tool Kits.

**A double-edged sword**

“Medication is like a double-edged sword for someone with autism,” says S. Charles Bean, MD. “Drugs don’t always work as expected; they could have the opposite effect of what you want and make the situation worse.” Here are two examples:

**Antipsychotics and tranquilizers**—In her book *Asperger’s Syndrome and Sexuality* (Jessica Kingsley Publishers, London: 2006), Isabelle Hénault cites a 1992 study that suggests antipsychotics and tranquilizers can affect sexual function in males with a *DSM-4* diagnosis of Asperger’s syndrome. The possible side effects were erectile dysfunction and delayed ejaculation (P. Alarie and R. Villeneuve, *L’impuissance: Évaluations et Solutions*, Editions de l’Homme, Montréal: 1992).

This is important because, according to Dave Hingsburger in *Hand Made Love: A Guide for Teaching about Male Masturbation*, “a number of behaviors or attitudes lead to problematic masturbation, including... masturbation that does not end with ejaculation... [and] injury occurs from masturbation (due to overly intense stimulation) (Newmarket, Diverse City Press: 1995).”

**Stimulants**—When a child without ASD is diagnosed with attention deficit hyperactivity disorder, a stimulant is usually prescribed to help the child concentrate. But for a child with ASD who’s over-fixated inside, notes Bean, stimulants can induce anxiety and magnify the inability to concentrate.





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Helping People and Families Affected by Autism

# Walk for Autism

Two great routes—One great cause



Photo courtesy of Ken Arney

Come by yourself,  
or join a team—but  
be sure to come!  
Autism advocates  
are walking this  
spring to raise funds  
in support of much-  
needed Autism  
Delaware programs  
and services.



Photo courtesy of Andrew Zeltt

**Cape Henlopen State Park, Lewes  
Saturday, April 5**

**Fox Point Park, Wilmington  
Saturday, April 12**

# autismdelaware.org