

Helping People and Families Affected by Autism

# The Sun

Newsletter

January–March 2013

## Walk for Autism Teams have more fun!

Team up with family, friends, and co-workers, and have fun while raising funds and awareness at the 2013 Walk for Autism.

For ideas on how your team can get started, visit [www.autismdelaware.org](http://www.autismdelaware.org), and click the Walk for Autism box.



## Our mission

Autism Delaware™ works to create better lives for people with autism and their families in Delaware.



## Advocate for autism

The word “advocacy” is used in a variety of ways both inside and outside the disabilities community. The *World-English Dictionary* defines advocacy as “active support, especially of a cause.” But what does that mean for us in the autism community, in practice?

Any of us—from professionals to parents and from teachers to individuals—can advocate in a wide range of ways. If you want to work directly with legislators to craft the laws and regulations that benefit the autism community, consider working as a policy advocate. Health-care advocates work to assure access to appropriate medical and wellness care. Or advocate on behalf of your child or sibling with autism by attending IEP meetings and working with educators.

Advocacy can take place on behalf of a group or an individual. Parents may advocate on behalf of their children; policy advocates, on behalf of whole communities; and self-advocates stand up for their needs not only as individuals but also as members of the community.

In this issue of *The Sun*, we present articles about advocacy in two areas of interest in the autism community: health care (page 10) and education—very young children’s education (page 8) and older children’s “real world” education (page 11). We hope you find this information helpful in your decision to advocate for autism.

## Start early to train self-advocates

Ideas for starting to train self-advocates as early as age 10 to 12 (and continuing through age 21) are available in the *Tri-State Transition Slide Guide*.

This tool details self-determination, post-secondary education and training, employment, and independent living. Self-advocacy goals include knowing and describing the disability, identifying needs or fears in school and the community, and knowing what an IEP meeting is and participating in it.

A self-advocate might consider these questions:

- How do I make decisions and use community resources?
- How do I talk about my disability and the support I need?
- What are my goals, and what is my plan for reaching them?

The *Tri-State Transition Slide Guide* is scheduled for hand out at a 14-year-old student’s IEP meeting. If you need a copy, ask the educational diagnostician or transition specialist.



**The Sun**

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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.

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**On “self-advocacy”**

Self-advocacy is an essential skill for people with autism and their loved ones. I started thinking about the words and realized that, while “self” is a key part of it, the term can be misleading. Self-advocacy is not accomplished alone.

On this point, my biggest piece of advice to anyone, but particularly to those starting out on the autism journey, is that you can do a lot more than you think you can.

Most of my positions of leadership came about almost in spite of myself. Usually, some other parent decided that I was a likely candidate to take on something and handed it over. I would think I couldn’t do it, but then once it was upon me, I had no time to say “No.”

When a group of us first got together to start what would become Autism Delaware, I wasn’t planning to commit too much. Ethan was barely three years old, and I felt overwhelmed all the time. I was going to the meeting only to get information, but by the end of the meeting, my husband was voted in as president—and I suddenly became a major driving force in getting Autism Delaware started!

As we moved forward, I began to realize how much we could accomplish as a group of advocates—and how much the work and the connections with other parents made things feel more manageable. It is so important,



**Marcy Kempner and sons, Jack, Ethan, and Matt**

as a parent or person with autism, to feel empowered to make change, and nothing feels as empowering as being connected to a group of people who are going through the same thing you are, and feeling strength in their support and

their numbers. Helping people realize how much they can overcome and accomplish when they have the right support is at the heart of everything we do at Autism Delaware. And this is a great gift.

I want to acknowledge some of the people who have shared this gift with me. The amazing Marie-Anne Aghazadian helped us get started—but made sure we knew she wasn’t taking over; it was our turn to step up! Fellow parents Betsy Fisher Gray, Karen Bashkow, Kathy Hupp, and Lucy Graham have always inspired me by their belief in the potential of their children with autism. And I love working with parents of younger children, like Deanna Principe, Stacey O’Rourke, Robin Delaney, and Lisa Poyta: Their spirit and drive continue to prove to me that anything is possible.

And of course, there is Theda Ellis, who made an indelible impact on the autism community in Delaware by taking a leap of faith with a fledgling volunteer-led organization and building it into the force it is today, all because she believed in us and made us believe in ourselves. We will miss her

**Continued on page 3, column 1**

**A service of Autism Delaware**



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**On “self-advocacy”** Continued from page 2

leadership but know that she has made us better than we ever thought possible.

An adult service provider recently told me that, in her experience, the greatest predictor of success on the job for people with autism is belief that they can do it. They and their families expect to succeed.

Believe in yourself and your loved one with autism, and stay connected to other parents and advocates. Before you know it, you’ll be changing the world!

*Marcy Kempner*  
Autism Delaware™ President

**What are Delaware’s parent advisory committees (PACs) doing?**

**Sussex Consortium parent advisory committee (SusPAC) member, Chie Kelly**—“Thanks to fundraising money, SusPAC was able to feed 200 consortium staff at the annual luncheon. The event took place this year just before school started in September. In a rare moment, all the consortium staff were in one room and able to enjoy some much-appreciated one-on-one time with parents.”

**John S. Charlton School PAC president, Karen Mackie**—“The Charlton PAC’s main purpose is to advise the local educational agency. We are currently working on surveys for both parents and teachers. Our recent accomplishment as a committee has been to begin talks with the Charlton PTA started in January.”

**Seaford Delaware Autism Program PAC member, Michelle Perry**—“Some of the speakers the PAC has presented have been requested by parents. An occupational therapist gave a talk and held a Q&A session on sensory integration and diet. Vincent Winterling, Ed.D., reviewed the DAP and answered our questions. A speech pathologist discussed ways to promote communication in the home. Available services from DDDS [Division of Developmental Disabilities Services] and SSI [Social Security Insurance] were discussed as well as who is eligible for SSI benefits and preparation for post-21 challenges. And Autism Delaware services were explained by the agency’s southern Delaware service coordinator, Dafne Carnright.”

**Capital Delaware Autism Program PAC president, Kate Stomieroski**—“The Capital School District has exploded with new students in the DAP. To assist these new families, our PAC has provided numerous speakers, from psychologists and occupational and physical therapists to reps from the Parent Information Center and Autism Delaware, and we will continue to provide education and resource information. And using various campaigns, we will promote autism awareness and acceptance in our satellite schools.”

**Plan now for summer**

“With the winter months upon us, dreams of summer start taking over my house,” says parent Jen Nardo. “Having a son with autism creates some other thoughts as well: *What should he do with all his free time this summer? How do I get him outside more? Would he like to try summer camp?*”

“One thing I know for sure,” adds Jen, “is that the sooner I make plans for summer, the better. Gathering information now on available camps and activities takes the pressure off.”



Here are some ideas:

Importantly, consider your child’s likes, dislikes, and abilities. Think of the long term as well because the skills your child learns now will add to his independence as an adult. For example, does your child enjoy swimming, or is he afraid of the water? Can your child handle day camp better than an overnight stay? What if your child learns to hike and likes it? Will he have access to hiking trails in the future? And what if your child learns to surf? Would the whole family want to learn to hang ten?

Surfers Healing is an organization dedicated to teaching children with autism how to ride the waves. Led by Israel “Izzy” Paskowitz, winner of the Hang Ten Classic among others and parent of a young adult son with autism, Surfers Healing has camps throughout the year in coastal states, such as Maryland and New Jersey. For more information, visit [www.surfershealing.org](http://www.surfershealing.org).

Primal Surf in Brigantine NJ also teaches children with special needs how to surf, offering camp one morning a week in late July–early August. The instructors may be lifeguards or special education teachers as well. For details, visit [www.psurf.com](http://www.psurf.com). Or call (609) 264-1999.

Easter Seals’ Camp Fairlee Manor off Chesapeake Bay hosts three autism-only weeks during the summer. Campers are assigned individual support personnel, who have been trained by experts at the Kennedy Krieger Institute in Baltimore, and a nurse is on duty 24/7. The camp also provides a sensory room, special diets, and a range of activities, from arts and crafts to canoeing and horseback riding. For details, visit [www.de.easterseals.com/site/PageServer?pagename=DMDR\\_recreation\\_respite](http://www.de.easterseals.com/site/PageServer?pagename=DMDR_recreation_respite). Or call (410) 778-0566.

In August, Autism Delaware offers day camp at the Children’s Beach House in Lewes. Activities include kayaking, sailing (as photographed above), swimming, a low ropes course, and arts and crafts. For more information, visit [www.autismdelaware.org](http://www.autismdelaware.org). Or call (302) 644-3410.

“An established camp for children without autism may be willing to adapt a program if you ask,” notes Jen. “If you find one, don’t forget to share your find with us.”

# PARENT PARENT



**Casey Gilden today**

“It’s like he woke up!” my best friend observed, referring to my then–two-year-old son with autism, Casey. My husband and I had noticed it, too: improvements in Casey’s general awareness of the things happening around him. Instead of being fixated on noise-making toys and oblivious to his peers on a play date, Casey giggled at his buddy dancing nearby.

For my son, altering his diet was life-changing. It had been four days since Casey had ingested any casein, the protein found in milk. After removing all casein from his diet, we also removed the gluten, a protein found in many grains. At that point, Casey became obsessed with French fries, rice, and other grains, which indicated high intestinal yeast, so we consulted with various doctors and completely removed sugar and starch (both of which feed yeast) from his diet.

## Resources

Is a diet right for your child? Do you know where to start? Here are some resources to get you on your way:

### Books

*Special Diets for Special Kids: Understanding and Implementing Special Diets to Aid in the Treatment of Autism and Related Developmental Disorders*, by Lisa Lewis, PhD

*Breaking the Vicious Cycle: Intestinal Health through Diet*, by Elaine Gloria Gotschall, BA, MS

*Gut and Psychology Syndrome: Natural Treatment for Autism, ADD, ADHD, Depression, Dyslexia, Dyspraxia, Schizophrenia*, by Natasha Campbell-McBride, MD, MMedSci(neurology), MMedSci(nutrition)

### Websites

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

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

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

Because the metabolism of children with special needs works differently, we have to feed them differently. In their systems, certain foods break down more like a drug than like the fuel their bodies need. According to Patrick Elliott, DO, director of the Autism Treatment Center in Newtown Square PA and father of twin boys on the spectrum, the Food and Drug Administration (FDA) monitors foods and drugs because they are, basically, the same thing. “Food is a bunch of chemicals,” Dr. Elliott tells us. “The idea that a food can affect your mood or behavior isn’t new. Coffee is a stimulant. Caffeine is a drug. The product is one and the same.”

Dr. Elliott believes that any child with a special need should try a diet that will help heal intestinal issues, increase focus, and reduce behavioral problems. Of course, some side effects are possible when removing foods from a child’s diet. Health risks are also possible if the diet isn’t supplemented with proper vitamins and minerals. But Dr. Elliott notes that, in many cases, trying an alternative diet is well worth the short-term negatives. “It can be a miracle for some kids,” says Dr. Elliott. “To take a chance on a miracle for a kid is worth a try.”

### Gluten-free/casein-free/soy-free (GF/CF/SF)

The metabolism of people with autism cannot break down gluten and casein properly; instead, the proteins are metabolized as opiates. An intolerance to gluten and casein may show up as bowel problems, lack of focus, inappropriate laughing, or drunk-like behavior. Removal of offending foods from the diet gives the body a break from trying to do what it cannot. Soy has a similar composition to casein, so it is often removed as well.

### Specific carbohydrate diet (SCD) and gut and psychology syndrome (GAPS) diet

If your child suffers from Crohn’s disease, ulcerative colitis, celiac disease, diverticulitis, cystic fibrosis, or chronic diarrhea or seems to be addicted to carbs, SCD or the GAPS diet may be worth considering. The GAPS diet has its roots in SCD but takes it further by promoting the use of natural fats and fermented foods and removing all casein and lactose in the early stages of the diet. These diets also eliminate any sweeteners (except clear [not cloudy or crystallized] honey) including many fruits, starches (such as wheat, rice, and potatoes), and most dairy because these ingredients feed intestinal yeast and candida in the gut. To give the overworked gut time to heal, the diet is implemented in stages, starting with very easily digestible food.

### Feingold diet

Benjamin Franklin Feingold, MD, found that some children have an allergic-type response to most artificial colors, flavors, preservatives, and aspartame. By removing these from the diet, children may stop erratic, hyperactive behavior. This diet is popular with the families of children who have ADHD and other problems with focus.

### Ketogenic diet

The ketogenic diet is a high-fat, low-carbohydrate diet designed for people who experience seizures. By using fats as the primary source of energy (instead of carbs), the body produces more ketones that improve control over seizures. This diet is similar in theory to the popular Atkins diet but varies in that fats, carbs, and calories are given in a specific ratio and closely monitored.

—Cory Gilden

Parent Cory Gilden, a long-time contributor to *The Sun*, advocates for special diets for children on the spectrum. Autism Delaware™ is interested in a variety of viewpoints and does not endorse any particular program, service, treatment, or diet.

# Insurance coverage of autism in the coming months

The enactment of Senate Bill 22 (SB22) is only the first of many steps needed to improve insurance coverage for Delawareans affected by autism spectrum disorders (ASDs). Actually implementing this law—as well as the federal Affordable Care Act—will take more time, but once both are operating as intended, many individuals and families are expected to have new options for autism coverage.

## SB22

On December 11, 2012, the autism insurance reform law took effect in Delaware. Any Delaware-regulated policy that's renewed or obtained after this date must contain coverage of the therapies required by law for a child under 21 who has a medical diagnosis of ASD.

By February 13, 2013, the Department of Health and Social Services must finalize the regulations concerning who may be an authorized provider of autism services—for insurance purposes, not practice. Although other licensing law may apply, providers who have not met the set standards are not restricted by this law from performing the services, but the services will not be reimbursable. Services may be delayed while providers verify their compliance with the standards, complete additional qualifications (if needed), and become part of the insurer networks.

Autism Delaware is advocating that providers already credentialed to practice (such as speech therapists, psychologists, and so on) should not have to meet additional qualifications. Because line therapists do not have existing credentialing standards, they will have to meet new ones. This step will take time, of course, and possibly delay the implementation of coverage for applied behavior analysis (ABA).

## The Affordable Care Act

Delaware is moving ahead with implementation of the Affordable Care Act and, in particular, the health insurance exchanges that are a key part of the plan. The exchanges are online marketplaces (similar to those created for Medicare prescription coverage) where individuals, families, and businesses can make side-by-side comparisons of potential insurance plans and determine eligibility for Medicaid, tax credits, or income-based subsidies. At this time, assessing the possible eligibility for the Medicaid Children's Community Alternative Disability Program through the exchanges is unclear, but Autism Delaware is advocating for it so families have more access to information about the program.

Plans sold through the exchanges must include ten essential health benefits (EHBs). Those most relevant to ASDs include behavioral health treatment, mental health and substance abuse treatment, and habilitative services. Importantly, none of these have age or annual-spending limits, although the number of visits may be capped.

Enrollment in plans through the exchanges opens in October 2013—with a significant *but*. Although the law calls for coverage of the EHBs, and Congress clearly intended to cover

autism therapy with behavioral health treatment, ASDs are not specified in the text of the law. To give states flexibility, the federal Department of Health and Human Services allows each state to choose a “benchmark” plan from existing plans—and existing plans generally do not cover or define what is meant by “behavioral health treatment” or “habilitative services.”

Autism Delaware raised these issues with the state body implementing the law, the Delaware Health Care Commission, noting the importance of providing behavioral, speech, occupational, and physical therapies to people with ASDs. When *The Sun* went to print, the commission needed further guidance from the federal government.

## Monitoring the progress

Autism Delaware will continue to monitor the progress of both SB22 and the Affordable Care Act. Because this is new ground for insurers, regulators, and families living with autism, we want the transition to be as smooth as possible while ensuring that the law is followed. Contact us with any questions or issues you face in getting appropriate coverage.

Additional information on the Affordable Care Act is available at [www.healthcare.gov](http://www.healthcare.gov) and by searching online for the Delaware Health Care Commission.

The Autism Delaware website will be kept current on both SB22 and the Affordable Care Act, so for the most up-to-date news, go to [www.autismdelaware.org](http://www.autismdelaware.org), and look under Advocacy, Issues & Positions.



**Eugene “Chief” Stoops, of the New Castle Police, Fire, Rod & Gun Club, presented Autism Delaware Executive Director Teresa Avery with a donation of more than \$6,000 in September. The funds were raised at the club’s Fifth Annual Autism Run and “Ride to Know.”**

# INSIDE Autism<sup>™</sup> Delaware

## Now accepting applications for 2013 scholarships, grants, and nominations for outstanding volunteers

### Apply for an Autism Delaware scholarship or stipend

Every spring, Autism Delaware awards a variety of scholarships and stipends to eligible individuals. The goal is to acknowledge the unique expertise these individuals bring to the autism community and let them know how much we value them.

- The Autism Delaware Daniel and Lois Gray Memorial Scholarship is available to an eligible Univer-

sity of Delaware undergraduate or graduate student who plans on becoming a professional in the autism community (such as a teacher, psychologist, or speech pathologist).

- The Autism Delaware Adult with Autism Scholarship supports an adult on the spectrum who wants to attend college or a post-secondary educational program.
- 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 autism spectrum disorders (ASDs).

Visit [www.autismdelaware.org](http://www.autismdelaware.org) for details. There, you can also download the applications. The completed forms must be received by Autism Delaware by January 31, 2013.

### Submit an Autism Delaware grant proposal

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

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.

Visit [www.autismdelaware.org](http://www.autismdelaware.org) for details. There, you can download the grant protocol and application. All grant submissions must adhere exactly to the instructions, and the



**As of January 1, 2013, Teresa Avery, MBA, is the new executive director of Autism Delaware. Avery replaces Theda Ellis who retired in December.**

completed forms must be received by March 1, 2013.

### Nominate an outstanding volunteer

Many generous people make a difference in the autism community every day. They volunteer their time and expertise to chair fundraising events, organize social activities, raise public awareness, and advocate for change—and they do it all to improve the quality of life for all Delawareans living with ASDs.

You can honor these volunteers and their outstanding efforts by nominating someone you believe deserves this year's award:

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

Download the criteria as well as the nomination forms at [www.autismdelaware.org](http://www.autismdelaware.org).

Be sure to submit your nominations by January 31, 2013!

## Year-round stipends

The Autism Delaware Conference Stipend is available year round for anyone who chooses to attend an autism-related workshop or conference. 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. We also ask recipients to write about what they learned at the conference in an article for *The Sun*. The goal is to share the information with our readers. Editor Carla Koss is available to help make the writing process a breeze.

**To apply:** Submit a request to Teresa Avery, c/o Autism Delaware, 924 Old Harmony Rd., Suite 201, Newark DE 19713. Or send an email to [teresa.avery@delautism.org](mailto:teresa.avery@delautism.org).

**Note:** Be sure to include the name of the conference, its date, and the costs associated with attending.

## Blue Jean Ball tickets sell out in advance

Autism Delaware saw plenty of *blue jeans and bling* at the 2012 Blue Jean Ball this year—because tickets for the September 28 festivities sold out a week in advance!



More than 300 people enjoyed the evening's festivities, which included live performances by Love Seed Mama Jump as well as an extensive auction of jewelry, sports memorabilia, housewares, and

gift certificates for services or meals at southern Delaware restaurants. Raffle winner Jessica Rodgers, of Millsboro, took home the 64GB iPad that came with a \$100 iTunes card, earbuds, case, and cleaning kit.

Held in the Grand Cru Hall of the Nassau Valley Vineyards in Lewes, the ball raised funds for much-needed programs and services statewide.

Volunteers and sponsors ensured that more of the funds raised for Autism Delaware's programs and services actually go to these supports. So, many thanks to committee co-chairs Dorian Rowe Kleinstuber, Esq., of Bethany Beach, and Koh Morrissey, of Milton, as well as to the 35 volunteers who helped set up the event, work it, and clean up afterward. And many more thanks to this year's exclusive sponsors—Hertrich Toyota of Milford, Peninsula Oil & Propane in Seaford, and Russ Palmer Builders in Lewes—and to the local restaurants that donated food and specialty cocktails—Touch of Italy, Nage, Root Gourmet, Kick n' Chicken, Lewes Fishhouse, Abbott's Grill, Bethany Blues, 16 Mile Brewery, and Moe's Southwest Grill/Carvel.



## Circle the wagons for autism!

Honorary chairs Theda and Warren Ellis donned dressy western wear for the 14th Annual Auction for Autism on November 10 at the DuPont Country Club.

Altogether, more than 180 folks joined Theda and Warren. Ace-high local talent made for a rootin', tootin' good time that also included poker, a line dancing lesson, and extensive live and silent auctions of donated items and special experiences



and adventures—just in time for the holidays! The goal was to raise funds for the wide range of programs and services needed by the growing number of Delawareans living with autism spectrum disorders statewide.

"Given the growing need in Delaware," says committee co-chair Elizabeth Fisher Gray, of North Wilmington, "we work at growing our fundraising through an extensive auction. This year, we had 135 items that were generously donated."

Volunteers and sponsors ensured that more of the funds that were raised actually go to Autism Delaware supports. Many thanks to Betsy and her co-chair, Deanna Principe, as well as the 20 volunteers who did double-duty, either setting up and cleaning up afterward or working registration and checkout.

Many thanks, also, to this year's major event sponsors:

- Edgar and Peggy Woolard
- DuPont
- Hertrich Toyota of Milford
- Skadden, Arps, Slate, Meagher, Flom & Associates, LLP

## Welcome, new members!

*As a member of Autism Delaware, you actively support our mission: to create better lives for Delawareans with autism spectrum disorders (ASDs) and their families.*

*Thank you!*

Marissa Collurafici

Kristie DeGhetto

Amy Foster

James Furr

Gary & Alisa Knapp

Sue Kutsch

Cecilia D. Machado

Steve & Laura Miller

Nirmaljit Rathee, BPEd, MA, PhD

Ms. Reaser & Mr. Harrison

Melissa Sudler

Ralph & Joanne Troisio

## Education advocacy for very young children

Workers at Child Development Watch (or Child Watch, for short) help families get support for very young children, birth to three years of age, with autism spectrum disorders (ASDs) by writing individualized family service plans. Each IFSP details the services needed not only to help a child's development but also to enhance a family's capacity to help the child's development.

When Child Watch services end at age 3, schools take over. To create a smooth transition, talk to a Child Watch worker as soon as possible.

If a child is already three or older and an ASD is suspected, contact the local elementary school's special education coordinator or teacher, and request a psycho-educational evaluation. Point out your concerns so the evaluator can be sure to assess them in depth.

**Important:** Always follow a verbal request with a written request!

The initial evaluation must be conducted within 45 school days or 90 calendar days (whichever is less) from the date permission is given. Once determined that a child is eligible for special education, you become an important member of the child's individualized education program (IEP) team.

The Child Watch worker can help you understand the differences between the IFSP and IEP. You may also want training on special education rights. For upcoming training in your county, contact the Parent Information Center (PIC) of Delaware at [www.picofdel.org](http://www.picofdel.org).

For more on special education, read about Title 14 at [www.delcode.delaware.gov/title14](http://www.delcode.delaware.gov/title14).

## Thank you, Bank of America!

Autism Delaware now has \$25,000 in grant funding from Bank of America that specifically supports adolescent students who are severely affected by autism spectrum disorders (ASDs). This funding also provides support not covered by the Early Start to Supported Employment program to help students transition from school to work.

## CALENDAR of EVENTS

### January

- 2, 9, 16, 23, 30**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Registration:* Karen Tuohy at [karen.tuohy@redclay.k12.de.us](mailto:karen.tuohy@redclay.k12.de.us). Or call (302) 633-3316.
- 8**—Parent coffee hour:  
Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM  
Holiday Inn Express. 24058 Sussex Hwy. Seaford. 9:00 AM
- 8, 15, 22, 29**—Healthy Transitions Series. Autism Delaware Newark office. 6:00 PM. *Registration:* Heidi Mizell at [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org).
- 10**—Parent conversation hour. Harrington Parks & Recreation. Conference room. 114 East Liberty St. 9:00 AM.
- 11**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Registration:* [delautism@delautism.org](mailto:delautism@delautism.org).
- 16**—Speaker Series: The DCAS Alt 1. John S. Charlton School cafeteria. 6:30 PM. *Registration:* Dafne Carnright @ (302) 644-3410.

### February

- 6, 13, 20, 27**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Registration:* Karen Tuohy at [karen.tuohy@redclay.k12.de.us](mailto:karen.tuohy@redclay.k12.de.us). Or call (302) 633-3316.
- 8**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Registration:* [delautism@delautism.org](mailto:delautism@delautism.org).
- 12**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.
- 14**—Parent conversation hour. Harrington Parks & Recreation. Conference room. 114 East Liberty St. 9:00 AM.
- 21**—Parent coffee hour. Georgia House Restaurant. 18 S. Walnut St. Milford. 9:00 AM.

### March

- 6, 13, 20, 27**—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. *Registration:* Karen Tuohy at [karen.tuohy@redclay.k12.de.us](mailto:karen.tuohy@redclay.k12.de.us). Or call (302) 633-3316.
- 6**—Parent coffee hour. Starbucks. 4561 Delaware Route 1 (Coastal Hwy.). Rehoboth. 9:00 AM.
- 8**—Teen/Tween game night. Autism Delaware Newark office. 6:30–8:30 PM. *Registration:* [delautism@delautism.org](mailto:delautism@delautism.org).
- 12**—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM.
- 14**—IEP Clinic. Autism Delaware Milton office. 6:00 PM. *Registration:* Dafne Carnright @ (302) 644-3410.
- 14**—Parent conversation hour. Harrington Parks & Recreation. Conference room. 114 East Liberty St. 9:00 AM.
- 19**—IEP Clinic. Autism Delaware Newark office. 6:00 PM. *Registration:* Heidi Mizell at [heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org).
- 23**—Sensory friendly movie: *The Croods*. Carmike Cinemas in the Dover Mall. 1365 N. Dupont Hwy. Dover. 10:00 AM. *Registration:* Amanda Gordy at (302) 644-3410.



## Parent Coffee Hour

### Panera Bread

3650 Kirkwood Hwy.,  
Wilmington  
January 8 @ 7:00 PM  
February 12 @ 9:00 AM  
March 12 @ 7:00 PM

*Join us!*

### Holiday Inn Express

24058 Sussex Hwy.,  
Seaford  
January 8 @ 9:00 AM

### Georgia House Restaurant

18 S. Walnut St., Milford  
February 21 @ 9:00 AM

*The coffee  
is on us!*

### Starbucks

4561 Del. Rte. 1 (Coastal Hwy.)  
Rehoboth  
March 6 @ 9:00 AM



April 2013 April 2013 April 2013 April 2013 April 2013 April 2013 April 2013 April 2013 April 2013

April 2013 April 2013

April 2013 April 2013

# Autism Awareness Month

Advocate, educate, and fundraise for autism. For ideas, visit [autismdelaware.org](http://autismdelaware.org).

April 2013 April 2013 April 2013 April 2013 April 2013 April 2013 April 2013 April 2013 April 2013

## Healthy Transitions

Autism Delaware Newark office  
6:00–8:00 PM

### Registration:

Heidi Mizell  
[heidi.mizell@delautism.org](mailto:heidi.mizell@delautism.org)  
(302) 224-6020, ext. 205



In this series of four workshops, adolescents and young adults with disabilities (aged 14–30) are prepared for the transition from the pediatric health-care system to the adult. They learn how the transition process works and how to take responsibility for their health care. And family members learn how to support the adolescent or young adult in the transition process.

**January 8:** General transition issues

**January 15:** Insurance issues

**January 22:** Healthy lifestyles

**January 29:** Healthy relationships

## Teen/Tween game night

For 9–19 year olds  
with Asperger's syndrome

**Place:** Autism Delaware™  
Newark office

**Dates:** January 11  
February 8  
March 8

**Time:** 6:30–8:30 PM

**Cost:**  
\$30 per season  
Must be paid  
at registration

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

## Winter 2013 season

For 9–14 year olds with  
Asperger's syndrome

**Place:** Autism Delaware™  
Milton office

**Dates:** January TBD  
February TBD  
March TBD

**Time:** 6:00–7:45 PM

**Cost:**  
\$10 per session  
Must be paid  
at registration

**To register:**  
(302) 644-3410  
[dafne.carrnight@delautism.org](mailto:dafne.carrnight@delautism.org)

# Promoting self-advocacy in health care

A pilot program in Delaware currently applies a new approach to providing comprehensive primary care. Called a patient-centered medical home (PCMH), this new health-care model moves away from the familiar symptom-and-illness structure toward a home base for any child's medical and non-medical care. The relationship between the child, family, and primary care affords more comfort and convenience as well as optimal health over the child's life span.

*Why?* Because as a patient-centered model—organized around the patient (or child)—it creates an ongoing partnership with a primary care physician (or doctor) who leads a team of professionals in proactive, preventive, and chronic care management. According to the American Academy of Family Physicians, one of the largest medical organizations nationwide, “a [PCMH] integrates patients as active participants in their own health and well-being” ([www.aafp.org/online/en/home/policy/policies/p/patientcenteredmedhome.html](http://www.aafp.org/online/en/home/policy/policies/p/patientcenteredmedhome.html)). In other words, a PCMH promotes self-advocacy in health care.



## How-to guide

# Be a health-care self-advocate

### Step 1 Make an appointment with your doctor.

If you're uncomfortable about meeting a new doctor, this is normal. Make the appointment anyway. You want your doctor to know you before a problem arises. Consider your initial appointment as your baseline for your long-term health care. If you feel good today, that's great. You still need to be screened for possible future health issues. And your doctor knows and has access to the tests that will identify your health-care needs.

### Step 2 Research health-care options online.

Make sure the research is from a credible source. Here are some sources that may help you get started:

Utah-based Medical Home Portal offers a website that not only helps parents become more effective partners in their children's health care but also provides a handout for adolescents and young adults in transition. Entitled *Taking Charge of Your Health Care*, the handout focuses on three essential areas:

- Be your own health-care advocate.
- Take charge of your health-care information.

- Plan for transfer to an adult doctor.

To download a copy of the handout, visit [www.medicalhomeportal.org/link/1102](http://www.medicalhomeportal.org/link/1102).

For more information on patient-centered medical homes, visit the U.S. Department of Health and Human Services webpage, *HRSA, Health Information Technology and Quality Improvement*, at [www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html](http://www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html).

The University of Minnesota and The Arc maintain a website entitled *Self-Advocacy Online*. There, you can read stories by self-advocates, locate self-advocacy groups in each state, and learn how to get organized, develop relationships, and live a healthy lifestyle. For more, visit [www.selfadvocacyonline.org](http://www.selfadvocacyonline.org).

### Step 3 Prepare for your initial appointment by listing all your concerns.

If you have trouble in a new setting or with new people, your list of concerns will help keep you focused.

If you have memory issues, take notes during your appointment, record it, or ask someone to accompany you (to remember what is said). When you leave the doctor's office, you should understand your health risks as well as what you need to do not only to prevent a health issue but also to face a possible health issue in the future.

## Advocating for your child's "real world" education

# Education is more than academics

By Lauren O'Connell Mahler, Esq., McAndrews Law Offices, PC

If your child gets good grades but struggles socially, behaviorally, emotionally, or physically at school—or perhaps your child can't stay organized with schoolwork—could he or she be eligible for additional educational supports and services? The answer is "Yes."

Education is intended to prepare students to become independent, self-sufficient, job-holding members of society. For students to achieve career success, attend college, or be able to care for themselves, they need more than good grades. Thus, courts have agreed that education extends beyond academic skills. It also includes the social, emotional, and physical skills needed to navigate the real world.

Experts in the medical field have recognized that psychological attributes, such as emotional control, social understanding, organizational skills, motor skills, and other non-academic abilities, are not inborn for all children. The law, likewise, recognizes difficulties in these areas as legitimate disabilities that require educational accommodations if they impact children at school. Thanks to research, we know that children with disabilities can make meaningful progress toward developing non-academic skills if given proper instruction and support.

If your child is struggling with non-academic issues at school and is not receiving special education support, ask your school for a comprehensive educational evaluation—in **writing**. Make sure that this evaluation includes testing of your child's unique issues. All areas of suspected disability should also be comprehensively evaluated:

- If your child is struggling with behavioral problems, ask that the evaluation include behavioral testing.
- If your child is struggling with social skills, ask that the evaluation examine social function or incorporate autism testing.
- If your child is struggling with organizational or task completion, ask for tests that look at attention deficit hyperactivity disorder (ADHD) and include executive functioning.

Once a child is deemed eligible for special education, his or her individualized education program (IEP) should offer the opportunity to make meaningful progress in each of the areas of need, both academic and non-academic. What kind of special education can help a child who is struggling in non-academic areas?

- For behavioral and emotional problems, a child may benefit from in-school counseling, positive behavioral supports, work with a behavioral specialist to analyze behavior, a functional behavior assessment, a behavior intervention plan, parent training and counseling, and in-school psychological services.

- For deficits in social skills, a child may benefit from participation in a structured social skills group and the chance to practice social language skills with a speech and language therapist.
- For struggles with task completion and organization, a child may benefit from direct instruction in organizational skills, agenda or binder checks, and color-coding of school materials.

For more information, visit the McAndrews Law Offices website at [www.mcandrewslaw.com](http://www.mcandrewslaw.com). Or call (302) 308-4975.

## Organize your info

If you need help coordinating your child's wide range of needs, the Care Notebook is a record-keeping system that organizes all the accompanying information you gather about your child's care. The three-ring binder is divided into five sections:

- My Child's Profile is for you to record your child's personal information.
- The Logs contains the forms you complete for doctors' appointments, hospital visits, and so on.
- The Taking Care Of section contains pages for vital information about medical equipment, medicine, daily and weekly routines, and allergic reactions.
- Evaluations and Assessments will hold important papers, such as your child's test results and IEPs.
- Reference Material comes with a glossary of acronyms and abbreviations, lists of important contacts, and other information.

A valuable tool, the notebook will help you be organized at all your child's appointments—and it's free when a family attends a Care Notebook Workshop.

### Care Notebook Workshop

**Tuesday, April 9, 2013  
6:00–8:00 PM**

**Easter Seals, 61 Corporate Circle, New Castle**

#### Hosts

Delaware Family Voices & Autism Delaware

#### For more info

**Carrie Melchisky**,  
Delaware Family Voices,  
(302) 221-5360

**Heidi Mizell**, Autism  
Delaware, (302) 224-6020



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Helping People and Families Affected by Autism

# 2013 Walk for Autism

**Saturday, April 20**

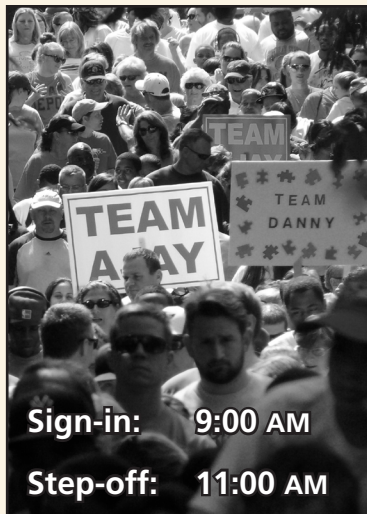
Cape Henlopen State Park,  
Lewes

Registration: Free!

(302) 644-3410

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

*Walkers fundraise to support much-needed programs and services. Raise \$100 or more, and win a prize!*



Sign-in: 9:00 AM

Step-off: 11:00 AM

**Saturday, April 27**

Bellevue State Park,  
Wilmington

Registration: Free!

(302) 224-6020

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

*A sponsor's financial or in-kind donation supports critical programs and services. Enjoy a range of benefits and recognition!*

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