

The Sun

Newsletter

April-June 2014

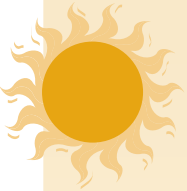
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Our mission

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



Transitioning from peds to adult PCP

Unless your child's pediatrician offers supplemental medical care to the age of 21, you will need to find an adult primary care physician (PCP) by the time your child turns 18.

Just as early intervention is critical for children with autism spectrum disorder (ASD) and parents and caregivers can nurture the skills needed for independent living, an early start to the medical transition process can help you and your child make the transition successfully.

To this end, Autism Delaware added some personal care items to a worksheet offered by Nemours Alfred I. duPont Hospital for Children (Nemours) Transition of Care and boxed them for easy access on pages 10-11. Local health-care providers also weighed in.

"I think medical transition planning is important," says board-certified pediatric neurologist Anand Gundakaram, MD, MRCPCH (U.K.). "I realize the process is challenging because many physicians who take care of adults may not have had enough training and exposure to children with autism and may not be aware of the comorbidities [coexisting health issues] associated with autism."

When to start the transition process depends on your child's developmental level. "When we talk about medical transitioning," explains Autism Delaware Resource Coordinator Heidi Mizell, "we mean learning how to be a self-advocate for your own health care and participating in the process as much as possible. This includes knowing your child's level of communication in a crisis or agitated state and help-

ing him learn how to calm himself down. Just coming to the table for a discussion about a possible procedure may be the most this child can manage."

In addition to individualizing the items listed on pages 10-11, gauge them for appropriateness to your family values. The items are age-related and included here merely to provide a well-rounded view of the many medical issues a young adult with ASD may face while living as independently as possible. The main categories are medical history and management, medication, specialized medical equipment, healthy habits, insurance and benefits, transportation, education, and, finally, adult PCP.

Assuming the role

For the first 12 to 13 years of your child's life, you have had sole responsibility for your child's health care. Now may be a good time to start letting go.

"It's hard to let go," admits Autism Delaware's Mizell. "After spending every waking moment thinking about getting what my child needs, now I'm faced with a large 23 year old who wants to live life his way. He has his own ideas, and sometimes, getting him to change his mind is really challenging."



Continued at the top of page 10

The Sun

A publication of Autism Delaware™

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**Working together,
we can create change**

Across the U.S., Autism Awareness Month is celebrated in April. For the whole month, we are inspired—by homes and buildings lit in blue, by people turning out by the thousands to the Walk for Autism, and by the increased media coverage of the autism epidemic.

But every month should be Autism Awareness Month. With one in every 88 children now affected by autism spectrum disorder (ASD), we need so much! We need more practitioners offering critical services, like speech therapies and applied behavior analysis (ABA). We need more teachers trained to support our kids in the classroom. And we need more residential options where people with ASD can select environments that best meet their individual needs and abilities. And we need much more as well.

The depth of these needs is significant, so we must come together as a community to meet them. We have to partner, collaborate, build coalitions, and take aim squarely at each issue. We need everyone at the table: individuals with ASD, families, caregivers, organizations like Autism Delaware, legislators, and state agencies like the Department of Education and the

Division of Developmental Disabilities Services (DDDS).

The Delaware Strategic Plan (known generally as “the blueprint”) brings just such a coalition together, and Autism Delaware is proud to be a part of this ongoing effort to make significant, positive changes here in Delaware.

To move us toward our goals, we need one more thing—We need you. Your voice, your experiences, your energy, and your opinions, which are critical to making change possible. Please consider getting involved. Join Autism Delaware’s Policy Committee

or the parent-teacher association or parent advisory committee at your child’s school. Help get the word out as an Autism Delaware volunteer. Or just keep in touch by giving us your feedback. Whatever you decide to do, it will help us reach our goals. All of us—working together—can create change.



Teresa Avery
Executive Director



Sean Tuohy leading about 2,000 walkers at the Wilmington walk

A service of Autism Delaware



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Autism Awareness Month

In April, Autism Delaware will join thousands of advocates around the world in celebrating Autism Awareness Month. Look for billboards and media spreading the word about what autism spectrum disorder (ASD) is, its impact in Delaware and in families, and how it affects people in so many different ways—bringing gifts as well as challenges!

You can raise awareness, too, in any number of ways:

- Share a good post or tweet about ASD on social media, and ask others to do the same.
- Participate in the “Light It Up Blue” campaign on World Autism Awareness Day, which is April 2. (At right, the Woodburn Mansion was lit for last year’s campaign.) Blue light bulbs are sold at many Home Depot stores.
- Take a photo of yourself and your coworkers dressed in blue, and post it on social media.
- Suggest to your company’s human resources or benefits department that it sponsor a lunch-and-learn session or other employee-training opportunity to learn about ASD.
- Place an autism ribbon magnet on your car. (Autism Delaware sells these magnets for \$5.00 each.)
- Sign up for the Walk for Autism, and create a fundraising page to tell your story. To sign up, visit autismdelaware.org.
- Come to Legislative Hall for Smart Cookie Day on April 9, or send a card to your legislators encouraging them to support policies that respect the needs and rights of people and families affected by ASD.



Smart Cookie Day 2014

Wednesday, April 9

Autism Delaware sets aside a day during Autism Awareness Month to visit the state legislature. At this time, people with autism spectrum disorder (ASD) and their families are invited to share their personal stories of ASD’s affect on their lives as well as cookies with a special message.

Plus, a resolution declaring Autism Awareness Month in Delaware will be introduced in the legislature, too!

We’re expanding our activities at Legislative Hall this year to include a meet-and-greet table where we can share information about ASD—and hand out fortune cookies containing facts about ASD. A meet-and-greet for our families, self-advocates, and legislators will also take place at Fraizer’s Restaurant in Dover. Watch our listserve, social media, and website for more details.



Some of us need a little help to reach the finish line of the Walk for Autism in Lewes.

This year, a shortcut is available that takes a mile off the route. Register at autismdelaware.org.

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.

PARENT PARENT

Written by parents
for parents



Sun contributor Dafne Carnright with her son Dylan

As parents of children on the autism spectrum, we are traveling a similar journey. One of the many experiences along the way includes your child's transition to adulthood.

I'm not talking about looking for and securing adult services, housing, transportation, or whatever else your child needs. I'm talking about the personal, emotional piece that we, as par-

ents, experience when our children begin to move into the adult world.

Some small part of us may still be assuming that the natural progression of life includes being relieved of some of the responsibility when our children become adults. However, our kids continue to need significant amounts of support throughout their lifetimes. So, we're living with our own personal emotions and feelings in this stage of the journey, possibly including exhaustion and frustration. And sometimes, we tune out for a while.

Although I'm not there myself—my son is only 12—in my work as Autism Delaware's family support and service coordinator, I talk to other parents in the community all the time and have heard some of them talk about "transition burnout." Transition burnout becomes evident when parents, knowing their children need support as adults, get overwhelmed and tired trying to arrange these services.

Parent Susan Chong says she is currently going through transition burnout. Her daughter has aged out of the Delaware Autism Program, the state's educational system for children on the spectrum. Susan is not only feeling the weight of the never-ending responsibility for her daughter's welfare but also misses being able to consult and depend on the IEP team (individualized education program through the school). "It's 100 percent my responsibility," sighs Susan.

To help ease her sense of burden, Susan relies on respite care and recreation for both herself and her daughter. Also, Susan finds strength in helping her daughter maintain contact with the classmates she grew up with because a circle of friends is important for anyone in life.

"A lot of the same emotions I had when my son was first diagnosed came to the surface again," admits parent Betsy Fisher Gray of her son Ian's transition to adulthood. "What

helps is talking to other parents and especially to a parent who is further along on this journey than you are."

Parent Kathy Magee didn't go through transition burnout in a significant way, but any time she feels tired, she reminds herself, "It could be worse. Instead, I think about the benefits in being a parent with a child on the spectrum: I always know where my child is and what he's doing, whereas the parent of a 23 year old, who is developing typically, may not know where her son is on Friday night—or what he is doing!"

To get through a slump, realize you are stuck, and allow yourself to feel your feelings; then, remember that your child needs you, and do something to get unstuck. Come to an Autism Delaware parent coffee hour or other event that connects you with a support network. Talk to other parents, or consult a professional or trusted friend. We are a resilient bunch, we parents of kids on the spectrum, and with adequate and continued support, we can thrive as well as our children throughout our lives.

Support for the caregiver

Links to a number of support networks are available on the Autism Delaware website: delautism.org/AutismResources/LearningLinks/ResourceLinks.aspx.

The Autism Delaware website also offers a list of contacts: delautism.org/AutismResources/AskforHelp/DelawareHelplineContacts.aspx.

A variety of e-groups (considered an extension of a support group) can be found at delautism.org/AboutUs/eGroups.aspx.

Autism New Jersey publishes a user friendly booklet that, despite its title, is easy for parents to understand. *Applied Behavior Analysis and Autism: An Introduction* can be ordered at behavior.org/item.php?id=340.

Sign up to receive personalized articles from Dan Coulter at coultervideo.com/articles. (Coulter is a parent and successful television writer, producer, and director, who has become a leading autism advocate.) See a sample of his work on p. 5.

For more support, see page 8 of this newsletter.

The “planning manual”

Recently, parent and *Sun* contributor Jen Nardo began the medical transition process for her son by talking to Mary Jane R. Lange, PA-C, a psychiatrist-neurologist at Nemours A.I. duPont Hospital for Children. Included in Lange’s information was a link to *Footprints for the Future*, a “planning manual” for the transition to adulthood.

To download or fill it in online, visit theamarc.org. Click on Resources; then, *Footprints for the Future*.

I found this document to be very comprehensive. It starts with personal information, like important addresses and phone numbers for the adult with a disability and his or her caregivers, and concludes with lists of family and friends, likes and dislikes, behaviors, and daily routines. In between are sections for the following:

- Medical history, such as information on insurance, physicians, the pharmacy and hospital of choice, allergies and intolerances, and medications
- Service providers
- Employment history, including volunteer activities
- Government benefits, such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), Section 8, food stamps, and transportation

- Community services and supports, such as religious organizations, recreation, and Special Olympics
- A legal section with summaries of any wills, powers of attorney, health-care proxies, trusts and trustee information, and life insurance (This section is only a summary of these legal documents and not a legal document itself.)
- If you have made final arrangements for your adult-child, there’s a section for summarizing your plans. It even provides a section for details, such as songs to be played.
- I was pleasantly surprised by the section called Map to Important Papers because it takes out the guesswork when trying to find a birth certificate or Social Security card.

If you fill in this planning manual before your child completes school, I recommend including the IEP (individualized education program) and creating a contact information page for the school, teacher, and current therapists. I also have included my son’s BIP (behavioral intervention plan) along with my take on his behaviors and how to resolve them.

I highly recommend filling this document out online. You will be able to make quick, small changes easily. Keep an updated copy with your will—and include details on how to find the document on your computer. The more information you can provide those who will be caring for your child, the better the transition to adulthood will be.

Taking care of you

by Dan Coulter

A while back, I wrote an article urging parents of kids with special needs to deal with stress by taking breaks and finding other ways to relax. Given that I’ve been burning the candle at both ends with a blowtorch recently, I thought it would be a good time to revisit the subject.

While I usually follow my own advice, I occasionally...sort of...backslide and catch myself doing things that I know are counter productive. Hey, I’m human.

In this case, however, I’ve been able to keep up with taking breaks and relaxing with exercise since the beginning of the year, even through a series of stressful events. So, if you read the first anti-stress article and need a booster shot, this is my testimonial that taking some time for yourself pays off.

I did pretty good with breaks and exercise last year. But when my wife and I took on multiple projects in our business early in 2006 on top of the demands of family life, I risked getting sucked into the “nonstop work” vortex. This vortex was, too often, my daily life while I was in the corporate world. My wife has felt its pull for years, taking on the main role of dealing with schools and doctors for our two kids with special needs. I’ve talked with lots of special needs parents who know the vortex well.

Maybe getting a bit older has given me some perspective to help deal with its pull.

Whatever the reason, I’m convinced that continuing to make taking some personal time a priority in the face of demands and deadlines (not the top priority, but a priority) has kept me sane and in much better shape than I’d be in otherwise.

One of the best assets in my stress-beater portfolio is an early morning walk. For me, it has to be early morning. Once the phone starts ringing, getting away to walk is like trying to escape a black hole’s gravity well. Walking early was a particular challenge because my wife and I tend to stay up late. There’s always lots that needs doing, and the next thing you know, it’s time for *The Daily Show* at 11 PM and we might as well stay up a bit later. It’s hard to stay up late and get up to exercise before the workday starts. One solution to this was taping *The Daily Show* to watch during lunch the next day.

Dan Coulter and his wife Julie produce videos to help families dealing with high-functioning ASD and other special needs.

For the complete article, visit autismdelaware.org. Click Autism Resources; then, Learning Links and Local Autism Articles.

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INSIDE Autism™ Delaware

Early enrollment for summer fun

Enroll early for the best chance of placing your child in an appropriate summer program. Autism Delaware offers three programs that promise a variety of summer activities.

Autism Delaware Summer Day Camp runs August 18–21, 9:00 AM–4:00 PM, at the ever-popular Children’s Beach House in Lewes. Activities, such as sailing, kayaking, swimming, a low ropes course, and arts and crafts, provide ample opportunity for

working on communication, self-esteem, and personal and social skills, all while offering the chance to try new activities. The program is designed for children with ASD who will be enrolled in grades 3–11 in the 2014–15 school year.



Pay the \$250 fee for camp with respite funds from the Division of Developmental Disabilities Services (DDDS). Register at dhss.delaware.gov/dhss/ddds/.

For more information or an application, visit autismdelaware.org.

Autism Delaware Junior Golf Program is free to youth with ASD aged 8–21. Golf pro and coach Butch Holtzclaw teaches golf techniques (such as putting, chipping, driving, and full swing) and encourages personal skills, like sportsmanship and perseverance. Each weekly session takes place at The South Rookery Golf Course in Milton and runs for 30 minutes in the early evening on either a Monday or Thursday. Monday sessions run September 8–October 13; Thursdays, September 11–October 16.



Autism Delaware Summer Swim Club takes place at The North Rookery Golf Course’s pool in Milford. Designed for youth with ASD aged 4–21 who are toilet-trained, the program offers water and pool acclimation, development of appropriate pool conduct, recreation and fun, and—of course—swimming. Swimming is a fitness activity children can learn and enjoy throughout child- and adulthood.

The cost is \$60 for eight Tuesday sessions between June 17 and August 5 (plus one day for rescheduling in case of bad weather). Parents need to stay for each hour-long session.

Kudos!

On December 9, 2013, the Delaware State Rehabilitation Council and Division of Vocational Rehabilitation bestowed “vendor of the year” status on Autism Delaware’s adult vocational services program. Known familiarly as POW&R (which is short for Productive Opportunities for Work and Recreation), the award-winning program offers social and recreational opportunities as well as vocational services and competitive, supportive, and self-employment.

This acknowledgment comes on the heels of accolades given September 12 to two Autism Delaware direct support professionals (DSPs) for their work with people with disabilities. DSP Noel Olson received the Delaware Association of Rehabilitation Facilities (DelARF) honorable mention, and transition specialist Joe Balinski received a certificate of appreciation. The DelARF-hosted awards luncheon took place at the Executive Banquet & Conference Center in Newark. Lt. Governor Matt Denn gave the keynote address, applauding the DSPs for their outstanding effort.



Joe Balinski and Noel Olson

“I’m incredibly proud to have Joe and Noel as part of our team that supports individuals with autism spectrum disorder in the community,” says Katina Demetriou, director of the Autism Delaware POW&R program.

In addition to giving POW&R vendor-of-the-year status, the Delaware State Rehabilitation Council and Division of Vocational Rehabilitation recognized in December the hiring practices of Dover Downs Hotel & Casino. Acknowledging this positive work back in 2012, Autism Delaware had given the Noel Perry Award for Outstanding Employers to Dover Downs and Dover Motorsports. Both employers have reached out and maintained a community partnership with Autism Delaware’s POW&R program.

“We make sure,” continues Demetriou, “not only that our POW&R participants are doing the work they enjoy and are good at, but also that our community partners are getting the employees they want and need. Plus, we continue to work at minimizing the stress in the workplace to promote a positive outcome. It’s a process that works well for any employer.”

Autism Delaware’s POW&R program is always open to new ways to partner with the employment community. For more information, visit autismdelaware.org.

Much-appreciated grant money helps meet critical need

This winter, Autism Delaware received notice that two grants had been awarded to help meet the agency's many critical needs. "To help people affected by autism spectrum disorder [ASD] statewide, we need so much," notes Autism Delaware Development Director Troy Nuss. "These grants couldn't have been awarded at a better time."

A grant from the Lydia Fund of the Chichester duPont Foundation will help provide support for Autism Delaware's existing family support initiatives:

- statewide parent coffee hours
- a speaker series
- support groups
- recreational outings (such as teen/tween game night and the summer programs described in column 1 on page 6)
- social events, such as the spring bunny train ride [pictured at right]; baseball games; sensory friendly bowling, skating, and movies; the annual picnic; and holiday parties in both New Castle and Sussex County [pictured below].



Another grant was awarded to Autism Delaware for much-needed new technology. The Crystal Trust grant will be used to create video-conferencing facilities in the Newark and Lewes offices as well as to upgrade essential technology. The new facilities will also open new channels for collaborating with other agencies in the community.

"The Crystal Trust," adds Nuss, "opens the door to more opportunities to help people and the families affected by ASD in Delaware."



We moved!

If you have been to Autism Delaware in Milton, you know that we outgrew the Sussex County office in the last two years.

In Lewes, we not only found a larger space but a more accessible one. Here, you will still be able to volunteer your time and expertise to benefit Autism Delaware events and programs. Plus, you'll be able to join Internet discussions and meetings via Skype.



The phone number remains the same: (302) 644-3410.

**New Sussex County address:
17517 Nassau Commons Blvd.
Unit 1, Lewes DE 19958**

Earning the seal of excellence

In June 2013, Autism Delaware earned the silver participant seal from the GuideStar Exchange. As an assessor of nonprofits, GuideStar looks at an organization's impact and effectiveness in meeting its mission statement.



Because Autism Delaware also demonstrated a commitment to transparency with financial information, all the criteria were met for the silver-level status.

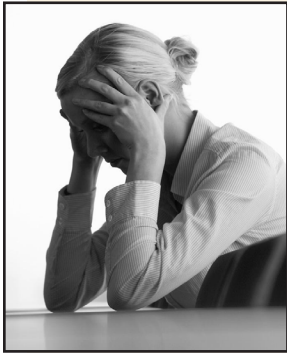
"When people see this seal," announces Autism Delaware Development Director Troy Nuss, "they know they can rely on the information being shared."

"The staff is now working to become a gold-level GuideStar Exchange participant," adds Nuss, "by charting the impact of the goals set in our new strategic plan. This includes key steps in family support, vocational services, clinical services, advocacy, and awareness, which are scheduled to be completed by 2018."

For more on Autism Delaware's strategic plan, visit autismdelaware.org. Click on About Us and Mission & Vision.

Meeting the need starts with yourself

Many parents and caregivers believe they are managing just fine as their children transition into adulthood, but based on the Autism Speaks webpage entitled Autism & Your Family, autism in the family is likely to bring up a number of reactions with uncomfortable emotions that may be undermining your best intentions at any given time:



“Parents often fail to evaluate their own sources of strength, coping skills, or emotional attitudes. You may be so busy meeting the needs of your child that you don’t allow yourself time to relax, cry, or simply think. You may wait until you are so exhausted or stressed out that you can barely carry on before you consider your own needs. Reaching this point is bad for you and for your family...”

“Acknowledging the emotional impact of autism and taking care of yourself during this stressful period will help prepare you for the challenges ahead” (www.autismspeaks.org/what-autism/autism-your-family).

So, understanding and accepting your own emotions and frustrations are important first steps.

Equating a caregiver’s reactions with the widely accepted stages of loss and grief, Autism Speaks defines the possible reactions to the stress as shock, sadness or grief, anger, denial, loneliness, and acceptance.

The webpage also offers tips to parents, siblings, and extended family members for doing something about such reactions. Written by family therapist Kathryn Smerling, Ph.D., the tips resulted from Smerling’s work with families dealing gracefully with the challenges of autism in the family.

For more, visit autismspeaks.org. In the top menu, click on What is Autism? From the side menu, click on Autism & Your Family.

Did you know?

Male U.S. citizens aged 18–25 must register with Selective Service—even men with disabilities that would disqualify them from military service.

For more information, visit www.sss.gov.

CALENDAR of EVENTS

April

2, 9, 16, 23, 30—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. Register: Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.

2—Parent coffee hour. Hampton Inn. Lobby. Middletown. 9:30 AM. Register: Dafne Carnright at (302) 644-3410.

5—Sensory friendly movie: *Mr. Peabody and Sherman*. Penn Cinema Riverfront. 401 S. Madison St. Wilmington. 10:00 AM.

6—Spring bunny train ride. Wilmington & Western Railroad. 2201 Newport Gap Pike. Wilmington. 2:30 PM. Register: Kris Grant at (302) 224-6020.

8—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.

11—Teen/Tween game night.

Autism Delaware Newark office. 6:30 PM.

Register: Heidi Mizell at (302) 224-6020.

Autism Delaware Lewes office. 6:00 PM. Must register by the Wednesday before the session. Register: Dafne Carnright at (302) 644-3410.

12—Sensory friendly movie: *Rio 2*. Carmike Cinemas in the Dover Mall. 1365 N. Dupont Hwy. Dover. 10:00 AM. Register: Liz Carlisle at (302) 644-3410.

—Sensory friendly movie: *Mr. Peabody and Sherman*. Penn Cinema Riverfront. 401 S. Madison St. Wilmington. 10:00 AM.

21—Spouse-Partner support group. Autism Delaware Newark office. 6:30 PM. Register: Will Morris at (302) 224-6020.

May

7, 14, 21, 28—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. Register: Karen Tuohy at karen.tuohy@redclay.k12.de.us. Or call (302) 633-3316.

9—Teen/Tween game night. Autism Delaware Newark office. 6:30 PM. Register: Heidi Mizell at (302) 224-6020.

13—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 7:00 PM.

17—Sensory friendly roller skating. Christiana Skating Center. 801 Christiana Rd. Newark. 5:15–7:15 PM.

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

23—Teen/Tween game night. Autism Delaware Lewes office. 6:00 PM. Must register by the Wednesday before the session. Register: Dafne Carnright at (302) 644-3410.

June

4, 11, 18, 25—Bowling night. Bowlerama. 3031 New Castle Av. New Castle. 5:30–7:00 PM. Register: Karen Tuohy at (302) 633-3316.

10—Parent coffee hour. Panera Bread. 3650 Kirkwood Hwy. Wilmington. 9:00 AM.

13—Teen/Tween game night. Autism Delaware Newark office. 6:30 PM. Register: Heidi Mizell at (302) 224-6020.

14—A night at the Blue Rocks & picnic. Frawley Stadium. 801 Shipyard Dr. Wilmington. 6:15 PM. Register: Kris Grant at (302) 224-6020.

16—Grandparents support group. Autism Delaware Newark office. 6:30 PM. Register: Heidi Mizell at (302) 224-6020.

20—Teen/Tween game night. Autism Delaware Lewes office. 6:00 PM. Must register by the Wednesday before the session. Register: Dafne Carnright at (302) 644-3410.

A night at the Blue Rocks

Saturday, June 14

6:15 PM

Picnic time: 5:15 PM

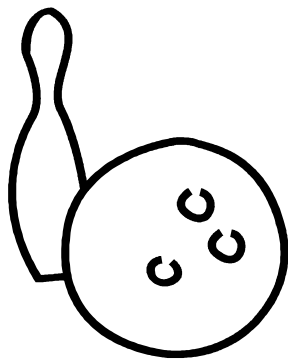
Frawley Stadium
801 Shipyard Dr.
Wilmington

Reserve your tickets today:
Kris Grant at (302) 224-6020



In addition to a ticket to the evening's Blue Rocks game, each reservation includes picnic dinner: hot dogs, hamburgers, barbecued ribs, baked chicken, mac & cheese, chips, and beverages.

The enclosed picnic area offers a great space for kids to move around freely and safely. And located at third base, it's close enough to make you feel like you are part of the action. 'Lots of games and concessions just outside the picnic area, too.



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.

New free support groups

- Spouse-Partner support group brings together the spouses and partners of people with autism spectrum disorder (ASD) to talk about their issues.
- Mature Aspie support group helps young adults with ASD work on their relationships.
- Grandparents support group offers camaraderie and information for the family's older caregivers.
- Dads support group provides information, support, and the ability to share your story.

For dates and times, see the Calendar of Events on page 8. Or visit autismdelaware.org.



Free admission!
Sensory friendly roller skating



\$3.00 skate rental

May 17, 2014

5:15-7:15 PM

Christiana Skating Center

801 Christiana Rd.
Newark

Teen/Tween game night

For teens and tweens with autism spectrum disorder (ASD) who are functionally communicative, independent, and capable of playing interactive board games

Place: Autism Delaware™ Newark office

Dates: April 11, May 9, June 13

Time: 6:30-8:30 PM

Cost: \$30 per season (includes all three sessions)
Must be paid at registration.

Register: (302) 224-6020; delautism@delautism.org

Spring 2014 season

Place: Autism Delaware™ Lewes office

Dates: April 11, May 23, June 20

Time: 6:00-7:45 PM

Cost: \$10 per session (Must be paid at registration.)
Register by the Wednesday prior to the session.

Register: (302) 644-3410; dafne.carrnight@delautism.org

Transitioning from peds to adult PCP Continued from page 1

Personal care items for your child to assume at age 12–13

Medical history and management

- Know own diagnosis and comorbidities.
- Know personal signs or symptoms that need to be reported to a doctor.
- Know family's medical history.
- List phone numbers and addresses for previous doctors, specialists.
- Know how to schedule an appointment and check in.
- Know when and how to get emergency care.
- If on a special diet, know the reason for it and what it includes.

Medication

- List the name, dosage, reason for medications.
- Know any allergies and sensitivities.

Healthy habits

- Practice good nutrition, and exercise.
- Know the effects of drugs, alcohol, and tobacco on ASD and overall health.
- Practice birth control or family planning; know how to prevent STDs.

Specialized medical equipment (communication devices)

- Know the maker's name and how to order service and supplies.

Education

- Know the school's health services.

Parents! Register with the Division of Developmental Disabilities Services (DDDS) so a case worker can manage your child's benefits.

Items to add at age 14–16

Medical history and management

- Know the history of hospitalizations, operations, and treatments, including dates, reasons, and medical recommendations.

Public transportation

- Know the availability and how to use it.

Education

- Participate in own IEP (individualized education program).
- Know eligibility for special treatment in school. (Ask about the 504 plan.)

Insurance and benefits

- Know health insurance, ID number, and how to contact the insurance agent.

Be sure your child begins carrying a health insurance card as well as a state identification card, plus a list of allergies, medications, and the phone numbers of his or her health-care providers.

"Let your child assume the role of health-care advocate," urges internal medicine and pediatric physician Jennifer LeComte, DO, FACP, FAAP. "Begin by practicing in the pediatrician's office. And practice at home."

"The biggest concern the parents have," notes pediatric neurologist Gundakaram, "is the comfort level with a new doctor. In our office, my staff is aware of the needs of children with autism. We know that these children have sensory difficulties and that a long wait in a crowded waiting room might be overwhelming. We make every effort to bring the children in as soon as they are checked in. Physicians who take care of adults with autism should understand this and sensitize their staff to the needs, too."

"Even if you decide to remain with your family doctor," says LeComte, "some transition still needs to happen for everyone moving out of pediatric-oriented care into adult care. People with autism struggle trying to find an adult doctor who is aware of the complex and comprehensive aspects of caring for a person with autism. The top five I've encountered are mental health support and behavioral health services, changes in insurance, access to home care and respite care, access to employment support and community access, and promoting medical autonomy, that is understanding your own diagnoses, medical history, and medication education."

Becoming as engaged as possible

"Transition is a daunting area. There's fear that everything will come crashing down," notes Cory Ellen Nourie, MSS, MLSP, social work coordinator in Transition of Care at Nemours. The program was established in 2010 to address the needs of transitioning young adults who, once they turn 21, cannot stay with Nemours providers.

"Our goal," states Nourie, "is to help the young adult become as engaged as possible. We assume competence and encourage the young adult to become a self-manager. Many have no idea why they take a blue pill or what they're allergic to, so we spend time discussing why they need to know their medical information and provide resources to help them get more involved."

"The program is for any child with special needs, from those who do not use words to those going to college. It's very individualized."

Any Nemours patient or parent can refer themselves to Transition of Care for assistance with the move to adult health care. Transition of Care starts working with young adults as young as 16. In general, any patient who is currently followed by a Nemours specialist, has been seen within the past three years in that subspecialty, and is over 18 can continue to be seen by the subspecialty until 21, assuming the physician feels the patient needs ongoing care.

"For many young adults with ASD," clarifies Nourie, "a subspecialist isn't treating the ASD but managing a comorbidity, such as seizure disorder or reflux. In the adult world, a PCP treats these comorbidities."

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To watch a video explaining the process, visit nemours.org/about/mediaroom/press/dv/transition-videos.html. There, you can also view videos about legal and financial, residential, and vocational planning.

Preparing for healthier results

As the medical director of the Wilmington Hospital Transition Care Practice, LeComte practices a patient-centered “medical home” model, which provides comprehensive care that is culturally sensitive and developmentally appropriate.

“I work with the patient and family to make medical decisions,” explains LeComte. “This is usually the first time the young adult is asked to participate in his or her own health care.

“Every young person,” adds LeComte, “will eventually transition to adult services and need some support selecting a physician and accessing community services. It is a process that requires time and preparation but, if done well, will result in healthier, more engaged patients and families.”

Personal care items for your child to add at 17 or older

Adult PCP

- Select a new physician, and call to make sure he or she is taking new patients.
- Be prepared to answer personal information over the phone.

Medical history and management

- Replace DDDS services with an adult medical waiver.
Call the Central Intake Unit at (866) 940-8963.
- Get a copy of medical records or know where to get them.

Insurance and benefits

- Set up continued health-care coverage.
- Know where to go for treatments and tests that are covered by insurance.
- Know when and how to get a doctor’s referral.
- Know about Medicaid or other assistance programs in Delaware.
- Contact the Social Security Administration about benefits, and make an appointment.

Practice Without Pressure

Easing transition with training and treatment

“Now what?” is the question many families ask when loved ones with disabilities age out of pediatric services. Finding an adult health-care provider who understands autism spectrum disorder (ASD) can be a daunting task—but so can preparing your child for long-term treatment goals. Practice Without Pressure has made access to health care its priority.

Working first with her young son Marc, who has Down syndrome, Practice Without Pressure (PWP) founder and chief executive officer Deborah Jastrebski created a model of support and treatment that, in the past 12 years, has helped hundreds of people with disabilities receive routine medical, dental, or personal care. Five years ago, PWP opened its center in Newark to make treatment and training accessible to people of all ages and abilities.

“For us, access to care is a collaborative process that brings the

person, professional, and caregiver together to reach treatment goals,” says Jastrebski. The success of PWP’s approach has paved the way for curricula development that will bring the process and benefits to more health-care professionals—and to people with disabilities. As PWP dentist Hope Thomas-Glavin, DDS, says, “It’s not their privilege to get treated; it’s their right to get treated.”

At PWP, practice paves the way. “For our clients who fear or avoid care, we provide our Practice Model™ in advance of treatment so that individuals learn self-management skills to make routine visits possible,” Jastrebski says.

For teens and young adults with autism spectrum disorder (ASD), the PWP approach promotes much-needed independence that can ease the transition to new procedures and health-care providers. “Moving from scared to prepared for care” is a transition that all PWP clients have in common:

- PWP helped Alexander George, age 15, to complete a dental exam after only two practice sessions. He has completed a blood draw as well.
- Artie Young, age 22, took four practice sessions to learn to complete blood draws.
- Salvatore Hailey, age 14, needed 20 practice sessions to sit for a haircut. Now, getting a haircut is second nature—as is brushing his teeth.
- PWP gave Andy M., age 12, the skills to stop running away from treatment and to complete a dental cleaning. According to mom Lynn, the practice sessions were “well worth it.”

“From my perspective,” adds Jastrebski, “helping the individual you love become confident with health-care procedures is your best preparation for [his or her] health-care future. And through PWP training, professionals will have the tools to provide that care, whenever transition takes place.”

For more information on Practice Without Pressure, contact (302) 832-2800 or requestinfo@pwpde.com.



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Helping People and Families Affected by Autism

Save the date

Saturday, November 8, 2014

**16th Annual
Auction for
Autism**

World Café Live
at The Queen,
Wilmington



**Saturday,
September 20**

2014 Blue Jean Ball

Rehoboth Beach
Convention Center

Get \$15 off the ticket price
if you register by 9/12!

autismdelaware.org