

The Sun

Newsletter

Summer 2018

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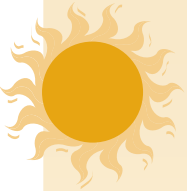
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Our mission

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



The inner struggle

What goes on inside an individual with autism spectrum disorder (ASD)? How much of his or her inner landscape is the result of ASD?

Like neurotypical people, individuals affected by autism carry their own psychological baggage and react to personal triggers, but because of their ASD, responses to the environment can sometimes be more intense. Called "acting out," an individual's response can be the result of over-stimulation, a need to avoid something he or she doesn't want to do, or an inability to express his or her needs and wants.

In this issue of *The Sun*, an expert and a parent cover methods of identifying and handling a pending meltdown. This newsletter also explains ways of communicating with your child that can result in fewer episodes of acting out.

Below, we begin with self-advocate Reese Eskridge, who shares his triggers and how he handles a potential meltdown as well as his insight into the nature of the inner struggle.

Meltdowns: inside and out

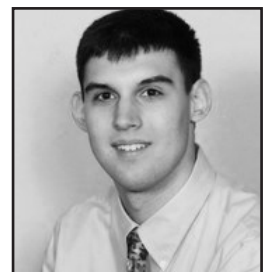
Trust me when I say that I have had plenty of meltdowns. What stands out most is the excruciating and overwhelming physical and emotional pain that occurs every time. The meltdown experience is like the stages of a volcanic eruption: It begins with pressure beneath the surface. With the added pressure of outside circumstances, or stimuli, the chance of an eruption grows—until it blows.

Just before a meltdown occurs, observable signs are like the rising smoke and tremors of a volcano shortly before it erupts. These signs,

to name a few, include heavy and fast breathing, body tightness (curling up, clenching, and so on), and change in tone and level of voice.

The stimuli most often include the following:

- unreasonably high expectations and my inability to meet them
- social exclusion
- out-of-routine or out-of-order activities



Reese Eskridge

Continued on p. 3

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Clarifying the meltdown

Do your obligations and everyday tasks ever overwhelm you? Does the feeling ever hit you all at once and paralyze you? Does your mind feel like it is in a traffic jam? You are experiencing a mental overload.

A sensory overload is similar for an individual on the autism spectrum. With all the many sights, sounds, tastes, and textures of modern life, an individual with autism may be unable to regulate the sensory input—and it's overwhelming. The result can be a meltdown.

The common misconception is that a meltdown is behavioral in nature. When my son Liam started having meltdowns, I thought he was having temper tantrums. But where a tantrum arises from an unmet need, a meltdown is a physiological response to too much.

And while a tantrum tends to be attention-getting, a meltdown can

happen with or without anyone present. Typical approaches to a tantrum will not work with a meltdown.

This issue of *The Sun* provides valuable insights on this topic from all angles: how to sense when a meltdown is coming, how to deal with a meltdown, and how a meltdown feels to the person experiencing it.

And for parents in particular, this issue shares resources and reassurance that a meltdown is not a projection of your parental ability. I hope it helps.



Pete Bradley
President
Autism Delaware
Board of Directors

Congratulations!

The following individuals are receiving scholarships for the 2018–19 school year:

Dawn Ramirez	Autism Delaware Autism Teacher Certification
Lauren Schwager	
Ian Snitch	Autism Delaware Adult with Autism Scholarship
Kaitlyn Delaney	Autism Delaware Daniel and Lois Gray Memorial Scholarship
Randi Navon	

For more information about Autism Delaware scholarships, visit <https://www.delautism.org/scholarships>.

A service of Autism Delaware



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Meltdowns: inside and out Continued from p. 1

- unnecessary punishment or discipline
- unpleasant surprises
- misunderstandings, especially those that feel derogatory
- confusion and helplessness

When an eruption does occur, I experience many emotions, including rage, confusion, fear, paranoia, anxiety, sadness, self-deprecation, isolation, helplessness, and hopelessness—all at the same time!

Fortunately, my experience and life lessons have given me ways to decompress before I melt down—and even after. Here are the seven steps that I take to prevent and remedy meltdowns:

1. Cultivate a strong sense of self-awareness.
2. Prepare for the worst, and expect the unexpected.
3. Learn all that I can before I go somewhere new, and acclimate myself by becoming familiar with the environment and the people I'll be with.
4. Make sure that others know what to expect and how they can help (or hurt) me.
5. Devote myself to daily forgiveness and mindfulness practices.
6. Constantly monitor the emotional impact that the environment, activities, and other people have on me.
7. Find the lessons to learn from each experience and the best measure to prevent and treat future meltdowns.

Mindfulness practice

Mindful is a nonprofit that is "dedicated to inspiring, guiding, and connecting anyone who wants to explore mindfulness—to enjoy better health, more caring relationships, and a compassionate society."

Learn how to practice mindfulness at <https://www.mindful.org/how-to-practice-mindfulness>.



Are you the right therapist for me?



The following questions may help you when interviewing a new therapist for you or your child with autism:

Promoting positive outcomes and preventing harm

- How will you help me function better?
- How will you help me do the things I want to do?
- How will you help me learn the skills I want to learn?
- How will you help me learn about the things that interest me?
- How will you help me learn about my disability?
- How will you help me be accepted?

These questions are reprinted from *First-Hand Perspectives on Behavioral Interventions for Autistic People and People with Other Developmental Disabilities* (Gardiner, Finn. San Francisco: The Regents of the University of California [2017]: 6). This report was commissioned by the Office of Developmental Primary Care and the Autistic Self Advocacy Network (ASAN) of Greater Boston.

Protecting autonomy

- How will you make sure I agree to the goals of therapy?
- How will you make sure I agree to the methods you will use?
- If I tell you that I don't want to do something during therapy, will you listen to me?

Being inclusive

- How will you help me be included?
- How will you help address physical barriers I face?
- How will you help address problem attitudes about disability?
- Will you help me set healthy boundaries?
- How will you support my communication and decisions?

Being trauma-sensitive

- I have had some bad experiences in the past. How will you help me with any therapy-related fears I have?

Promoting cultural competency

- How will you respect my culture?
- How will you help me participate in my family and community?

A study of your child's meltdown

**Sun contributor
Tori Foster, PhD,
is a pediatric
psychologist and
behavior analyst
at the Swank
Autism Center
of the Nemours/
Alfred I. duPont
Hospital for
Children.**

Meltdowns, tantrums, explosions, fits: These words are commonly used by families who bring their children to the Swank Autism Center—even though these challenging behaviors are not core features of autism spectrum disorder (ASD). But if autism does not actually cause challenging behaviors, why do we see them so often among kids on the spectrum?

Everything happens for a reason. Although some behaviors are natural reflexes (like a grumbling stomach when you're hungry), most behaviors serve a purpose, or what we often call a "function." These behaviors develop over time and are learned through experience.

They are shaped by what happens before them (in behavioral terms, an "antecedent") and after them (a "consequence").

Most of our behaviors function to either get something or to get out of something. Many behaviors also function as communication. For example, two children crying loudly in the checkout line: Sophia might remember getting a hug and a treat the last time she cried, and Jackson might feel overwhelmed by the people and noise. Both children might be acting out instead of using their words, but their messages are loud and clear.

Individuals with autism have challenges with social communication and might have difficulty expressing their needs and wants. If they can get their message across in an easier way, such as by crying or hitting, they will likely do this.

Meltdowns may also result from a child's struggle with a change in routine. Or the child may be overstimulated by sights, sounds, smells, tastes, and physical feelings. Many children with ASD also have narrow and inflexible ideas about how their world should work. Although these challenges do not automatically lead to meltdowns, they might make children with autism easier to trigger. This does not mean that your child behaves badly or that you're not a capable parent; it means your child might need special support to learn more appropriate behaviors to serve the same functions.

The first step to handling a meltdown is to understand its function. Proceed the same way you would if your child suddenly came down with a fever: Try to figure out why it's happening so you know how to treat it. To this end, think about your child's likes and dislikes, and look for patterns. (See "Key questions to ask" below.) For example, if your child melts down every time you wait to be seated at a restaurant, call ahead or arrive separately so your child's wait is shorter. And make the wait more enjoyable by letting your child play with a toy or game he or she doesn't usually get to play with.

Continued on p. 5

Key questions to ask

- **Is this behavior a pattern, or did it happen all of a sudden? Could a medical or physical factor or other change be causing it? Is my child sick, tired, or hungry?**
- **What usually happens before my child behaves this way? Does this happen at certain times, in certain places, around certain people, or in certain situations?**
 - **Is there something my child likes or does not like that is affecting his or her behavior?**
 - **Is there anything I could change about the situation to make it go more smoothly for my child?**
- **What is the typical outcome after my child behaves this way? How do I (and others) react? Could my child want this particular outcome?**
 - **What does my child get with this behavior?**
 - **What does this behavior help my child get out of?**
 - **What is my child trying to tell me?**
- **What can I teach my child to do instead that will serve the same function?**
 - **How is my child able to communicate?**
 - **What skills, strengths, and interests does my child have? How can I work these into a plan to set my child up for success?**
 - **Is this skill as easy for my child as melting down is? How can I help my child until he or she can perform the skill easily?**
 - **How can I make sure my child knows that this skill works as well as a meltdown in getting his or her needs met? How can I respond when my child uses it instead of acting out?**

A study of your child’s meltdown Continued from p. 4

When you have an idea about why your child is acting out, you might start sensing an oncoming meltdown—and know how to avoid it.

Because of difficulties with communication, children with autism often struggle when situations and expectations aren’t clear. For example, for a child to understand how long (or even short) a wait will be, use a visual timer. A first-then board (graphic shown below) can show your child that something great is coming after the wait. And if your child is enjoying a situation and may struggle transitioning away from it, use a visual schedule to show that he or she will get back to it later.

Try to make your message as clear as possible, using simple words and visual supports. To help you, see the box below entitled “Make your message clear.”

Sometimes, avoiding a meltdown is impossible. At these times, how you respond can make a big difference.

Remember: Challenging behaviors have usually been learned over time. Think about what the usual outcome of the meltdown has taught your child. If it is a good outcome, your child will keep

acting inappropriately.

To reset this pattern, save good outcomes for the times your child’s behavior is okay or good—whenever he or she is doing anything you’d like to see continue. Good outcomes include attention, items and activities your child likes, and allowing your child to get out of something he or she doesn’t like.

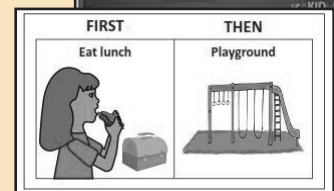
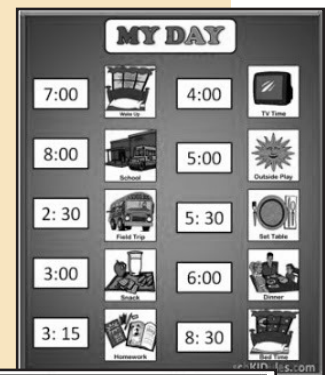
Also, teach your child that meltdowns won’t work anymore. When your child starts acting out, prompt him or her to use a more acceptable behavior. When your child behaves appropriately, immediately provide the outcome your child was looking for. This outcome might include attention and praise, a reward or activity your child wanted, or a break from the situation.

Although these challenges do not automatically lead to meltdowns, they might make children with autism easier to trigger. This does not mean that your child behaves badly or that you’re not a capable parent; it means your child might need special support to learn more appropriate behaviors to serve the same functions.

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Make your message clear

- **Keep it simple.** Make short statements, use literal and concrete language, and avoid “don’t” statements. Instead of saying “Behave” or “Stop running,” tell your child what to do, such as “Sit in this chair.”
- **Use visual supports, such as actual objects, photos, drawings or images, and written words.** Visuals can be a great way to communicate the following:
 - *What is my child expected to do?*
Examples: Mark areas with tape to show your child where to stay or place things. Use a picture to illustrate what keeping your hands to yourself looks like.
 - *How much time is left?*
Tip: Make sure to use a timer for fun, positive activities as well as negative situations so your child does not see the timer as all bad.
 - *What will happen next?* This concept can be illustrated by using a longer visual schedule (pictured top right) or a first-then board (pictured bottom right), which shows the child what is expected first and the more positive or fun thing that will happen after directions are followed.
 - *What are the options?* Hide things that are not an option: “Out of sight—out of mind!”
- **Social stories or narratives can make expectations clearer and situations more predictable for children on the autism spectrum.** For examples on how to use this tool, visit <https://www.autismspeaks.org/family-services/personalized-stories>.



From meltdowns to high praise

As a parent of a 20-year-old son on the autism spectrum, I have plenty of personal experience with meltdowns. And I've learned that meltdowns are as difficult for the child as they are for the family.

When our children lose control, they are no longer themselves. Our wonderful, loving children are taken over by the anxiety, fear, and confusion of the fight-or-flight response. This response makes our kids try to get away from the problem or to fight it. Called hyperarousal, this response is the consequence of heightened (or hyper) anxiety that makes a person feel attacked or threatened. And it can turn into a physical altercation that involves biting, hitting, kicking, and throwing things.

Our kids and adult children who live with autism have little control over the level of this response. We may say it's over the top, but when our children are stuck in this mode, their only goal is to make it all stop or go away.

When youngsters on the spectrum have a meltdown, they can be picked up and taken away to a safe place. If you are in the grocery store when your child drops to the floor or runs, wrap him or her up in your arms and get to the car as fast as you can. This meltdown is controllable—unless you have other children you need to grab, too. And explaining what is going on can add to the chaos. I do not believe the time to educate the public about autism is during a meltdown, because parents need to focus on their child.

The public's unknowing response to a meltdown can add to the stress level, too. When my son Jake was little, I was too aware of the general public during these tough situations. I took in all the disapproving looks and glances and "heard" all the unspoken comments about what a bad mom I was. There were times when strangers were very helpful. (They grabbed my bags or cleared the way for my hasty retreat.) But eventually, I learned that allowing outside responses to affect me was counterproductive to helping my son. I taught myself to no longer hear what other people said about my maternal skills. Now, I focus on the inner voice that tells me how to get my son out of the environment causing the hyperarousal.

As our children age and grow—sometimes taller and bigger than we parents are—meltdowns can become scarier. Jake would experience horrible meltdowns around dental appointments and, sometimes, in the

primary care doctor's office. Some visits to the hospital (for primary and dental care) ended with security guards surrounding us to keep us all safe.

The first time this happened, I was very upset. Jake bit my arm (even though I give him as much physical space as safety allows) so my emotions got in the way. The second time, I stayed calm, and the meltdown didn't last as long. From this experience, I learned that my mood and reaction can affect Jake's response, so I work at maintaining a calm response.

When Jake lashes out at me, he always apologizes afterward. I know that he would never lash out unless something felt wrong to him. So, I strongly believe that punishing my son for having a meltdown—even when I get bitten—is not a proper response on my part.

Instead, once we move through the meltdown, I talk to Jake about more appropriate behavior. We have repeated conversations over many days about his behavior. The goal is to help soften his fight-or-flight response.

In summary, seeing our children act completely out of character is scary and upsetting. I think, as a parent, it helps to understand the lack of control our kids have over their bodies' response to anxiety. During these difficult times, it's helpful for me to ignore shameful or embarrassed thinking and to focus laser-like attention on my son and his needs.

It's also helpful to desensitize our kids to the situations that make them anxious, such as the mall, grocery store, or a doctor's office. In the case of doctor visits, I suggest working with your child's medical providers to create a plan that eases your child's anxiety. When we now visit Jake's primary care doctor, we wait in an exam room instead of the waiting room.

Since we can't foresee all the possible triggers, consider bringing a family member or friend who can help carry your bags or get the car while you handle your child. And continue to teach your child the appropriate behavior for an anxiety-creating situation.

I also recommend distraction. Bring books, the DVD player, or whatever else your child loses him- or herself in. And praise your child when he or she behaves well every step of the way. Excellent behavior is worthy of high praise.

—Jen Nardo

More resources and support through the DNEA

Delawareans affected by autism now have access to more resources and support through the Delaware Network for Excellence in Autism (DNEA). Led by the University of Delaware Center for Disabilities Studies and Autism Delaware™, the DNEA represents a larger partnership between organizations, such as the Delaware Department of Education, Delaware Autism Program, Division of Developmental Disabilities Services, and Nemours/Alfred I. duPont Hospital for Children.

Through the DNEA partnership, Autism Delaware provides parent education and some professional training across the state. To this end, Autism Delaware's family services team has vastly increased parent education over the past year and will further increase program offerings that support the needs of families.

For more information, visit [Autism Delaware.org](http://AutismDelaware.org), drag down the Get Help menu, and choose Support & Activities.

Also as part of the DNEA, the Univer-



DNEA | Delaware Network for Excellence in Autism

sity of Delaware's Center for Disabilities Studies offers training, technical assistance, and information to professionals. Professional development on topics across the lifespan range from introductory sessions on autism spectrum disorder (ASD) and in-depth training on evidence-based practices to an organizational approach that includes training and coaching for administrators, managers, and direct care staff. Over the summer of 2018, trainings are being offered across the state for special-education teachers, general-education teachers, and paraprofessionals.

Recent DNEA activities include trainings on assessment and behavioral consultation to more than 100 school psychologists, professional development for early childhood educators on how to recognize ASD and design

visual supports, and a training series on social communication and augmentative and alternative communication.

The DNEA will again join other agencies in presenting the Outside the Box Annual Conference on October 5–7. This conference offers professionals and families a joint learning experience in support of children who are deaf-blind, deaf and hard of hearing, and blind and visually impaired as well as children on the autism spectrum. Follow-up coaching sessions will be available to participants after these events.

The DNEA is working hard to increase the growth and knowledge of schools, clinics, and other organizations that provide services to the autism community. Training through the DNEA is largely funded by the state and typically provided at no cost to the participant.

For more information about the DNEA, visit www.cds.udel.edu/dnea. Or contact Brittany Powers at (302) 831-6839 or bblument@udel.edu.



Alex Eldreth (at left) led the effort with energy and candor until he died suddenly this past November. HB292 is now known as the Alex Eldreth Autism Education Bill. Annalisa Ekbladh (at right) took up the effort with passion and purpose until we succeeded.

Delaware Senate passes HB292

After four long years of effort, House Bill 292 was passed by the Delaware Senate on June 21. This bill updates the legislation that originally established the Delaware Autism Program (DAP).

HB292 also establishes and funds a three-year pilot program that will allow the statewide DAP director to deploy a limited number of training and technical assistance professionals to selected Delaware schools. Advocates hope that the pilot will prove the value of this assistance to teachers and students and that, eventually, funds will be available for such help at all Delaware schools—not just the six DAP districts.

Getting to this passage took the time and effort of many autism advocates. Delaware State Senator Margaret Rose

Henry (D-Dist. 2) and Del. St. Rep. Earl G. Jaques Jr. (D-Dist. 27) were absolutely tireless in their work. Knowing the work's critical nature, Marcy Kempner helped write the bill—rewrote it, and rewrote it—tweaked and re-tweaked the legislative draft, and never gave up.

Debbie Gottschalk provided professional expertise along with Verity Watson and Kim Willson from Ruggiero Willson.

Endless effort was also extended by autism advocates Marie-Anne Aghazadian, Melissa Stansell, Dawn Maloney, Kathy DeNight, Jenn Cinelli-Miller, Bill Doolittle, DAP director Vince Winterling, and Mary Ann Mieczkowski, director of the Delaware Department of Education's Exceptional Children Resources Group.

INSIDEAutism™
Delaware

This year, Autism Delaware celebrates 20 years since its founding by a group of parents who shared the common experience of autism. We're also celebrating the tenth anniversary of our remarkable adult vocational services program. Known as Productive Opportunities for Work and Recreation (or POW&R, for short), this community-based, personalized program has changed the lives of hundreds of Delawareans over the past decade.

What is known today as Autism Delaware started as two separately founded and run nonprofit organizations: the Autism Society of Delaware in the northern part of the state and the Lower Delaware Autism Foundation in the south. To provide a single, strong voice for advocacy and services across the state, the two organizations merged in 2010 under the name Autism Delaware.

Since Autism Delaware's founding, the agency has strived to support the needs of the rapidly growing number of Delawareans affected by autism spectrum disorder. For example, in 2002, 377 students had an educational classification of autism in Delaware's public schools. Today, that number is 2,109! Of course, the need for adult services has grown equally over the years—if not more rapidly.

As the need has grown, so too have Autism Delaware's services. POW&R now supports more than 150 individuals across the state. And Autism Delaware's

20 years of impact



family support team offers more than 200 programs and events each year. Our family navigators made about 1,800 family contacts last year alone!

Community support for Autism Delaware has grown over the years as well:

- Hundreds of volunteers make fundraising and family events happen every year.
- The extraordinary activity of Autism Delaware's board of directors and advisory councils helps keep the organization moving forward.
- Delaware legislators work with us to help create laws that will better support families affected by autism spectrum disorder.
- A staff of nearly 100 incredibly dedicated people strives every day to make Autism Delaware the go-to autism agency in The First State.
- More than 90 businesses across Delaware provide our POW&R participants with opportunities for employment, internship, and volunteering.
- Corporate and individual supporters from across the state and beyond generously donate the funds we need to keep running critical programs.

If you'd like to read more about our organizational history, visit AutismDelaware.org, choose the About menu and then 20 Years of Impact.

Thank you, everyone—



for supporting Autism Delaware and being part of our growing family.

INSIDE Autism[™] Delaware

Fun ideas for successful fundraising

Many thanks to Todd Muñoz's dedicated team and all the dancers and contributors to the 2018 DeLAWAREness. Muñoz (top photo, second from left) started DeLAWAREness in response to his little brother's autism diagnosis. As the co-owner of Beat Addikts, Muñoz combined his love of dance and his love for his brother by bringing together organizations from five different states to raise awareness and funds through dance. The proceeds from the annual dance showcase benefit Autism Delaware. Held at the Tatnall School during National Autism Awareness Month, DeLAWAREness raised \$40,000 this year. Sharing appreciation for Muñoz's effort are Autism Delaware development director David Woods, office assistant Anne Walsh, communications coordinator Carla Koss, and acting executive director Brian Hall.

In the center photo, Jessica and Ed Bell (far left and far right) present their check in the amount of \$4,536 to Autism Delaware's southern Delaware development assistant Jim Forrest. As the owners of Homeward Tattoo and Body Piercing in Rehoboth Beach, the Bells donated the proceeds from their business on May 27 (between 6:00 PM and midnight) as well as the proceeds from the raffle tickets for prizes donated expressly for the event.

In the bottom photo, Bridgeville resident Betty Grace Eskridge (center) presents her annual fundraising check to Autism Delaware development director David Woods (far left). This year's donation amounted to \$1,000. Eskridge created and continues to run the Ride for Autism in Sussex County, a motorcycle-poker run that begins

and ends at Jeff's Tap Room. Joining the check presentation are Susie Nichols, G.L. Jefferson, and Donna Rice.



Many thanks to all the volunteers who donated their time on race weekend at the Dover International Speedway. You helped make a success of this event.

—David Woods
Autism Delaware Development Director

Do you have a fun idea for an Autism Delaware fundraiser? Would you like one?

Contact the Autism Delaware development team: (302) 224-6020.

Gratefully yours

Autism Delaware gratefully acknowledges the companies and individuals who fundraised, sponsored, and lent their support to the statewide Walk for Autism. This year's goal was to raise \$200,000 to help maintain and expand much-needed programs and services. And thanks to all of you, we did it.

Approximately 2,500 people walked on April 14 in Lewes and on April 21 in Wilmington.

At the Lewes walk, the top fundraising teams were POW&R Yellow, Lewes; Diamond State Dentistry; Stefan's A Team; and Team Alexa and Greyson.

The top fundraising teams at the Wilmington walk were Team Ethan, Tony's Team, Nemours

To our major walk sponsors, Thank you:
Hertrich Toyota of Milford
Swift Pools
The Bellmoor Inn
Dover Tents & Events
Berkshire Hathaway Home Services and Gallo Realty
John F. Kleinstuber & Associates, Inc.
Bath Fitter
Beebe Healthcare
92.7 WGMD
Cape Gazette

duPont Hospital for Children, and Team Autism Delaware, Wilmington.

Thank you also to Delaware State Representative Paul Baumbach, who walked with Team Autism Delaware, Wilmington; Del.

St. Rep. Earl G. Jaques, Jr., who walked with Trevor's Troopers; and Del. St. Rep. Kim Williams, who volunteered at sign-in.

And speaking of volunteers, thank you to all who took time out of their busy lives to help make a success of this year's Walk for Autism. Because of your effort, more of the funds raised are going to Autism Delaware's programs and services.

Thank you!



The voices of Smart Cookie Day

Among the many voices heard during Smart Cookie Day this year was Faith Aaron's. Highlighting her love for a sister on the autism spectrum, Aaron read her speech to (from left) Delaware State Representative Earl G. Jaques, Jr. (D-Dist. 27), Del. St. Senator Ernesto B. Lopez (R-Dist. 6), Del. St. Rep. Kevin S. Hensley (R-Dist. 9), Del. St. Rep. Deborah Hudson (R-Dist. 12), and Del. Governor John Carney.



Want your voice to be heard?
Contact Autism Delaware policy & program coordinator Sarah Young:
(302) 224-6020, ext. 204.



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Helping People and Families Affected by Autism

Save the date! Save the date! Save the date!



Blue Jean Ball

Saturday, September 22

Rehoboth Beach Convention Center
229 Rehoboth Avenue

Enjoy live dance music and good food while bidding on one-of-a-kind auction items at this long-time southern Delaware favorite.

Proceeds benefit Autism Delaware.

For more information, contact Autism Delaware's development team or visit

AutismDelaware.org