1998–2023 Autism Delaware™

This fourth and final issue celebrating Autism Delaware's 25-year history features accounts

from Kim Siegel, Rodger Pearce, Sarah McGuire, and Jen Nardo.

Please share your thoughts about this series of newsletters—or about any of <u>The Sun</u>'s past issues. We are always open to feedback.

Our mission

To help people and families affected by autism





hange does not always come as

spectrum can take years.

For example, the Autism Society of

Delaware (ASD) started working on a bill

in 2008 with the assistance of Delaware's

Community Legal Aid Society, Inc. (CLASI)

and Autism Speaks. (At the time, ASD

was two years away from changing its

fast as we'd like. And advocating

on behalf of our loved ones on the

The Sun

Newslett

Autumn 2023

name to Autism Delaware.) Our goal was to push insurers to cover treatments, such as <u>applied behavior analysis</u> (ABA) and auxiliary therapies for autism diagnoses. Many states across the country had already started this effort, and ASD's policy committee, made up of a group of long-time dedicated volunteers, wanted to join the push.

Advocacy

through-

out the

by Kim Siegel

years

Our effort had strong, devoted sponsors in Continued on p. 3

The Sur



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Autism DelawareSM, Productive Opportunities for Work and RecreationSM and POW&RSM, Parent to ParentSM, and Autism Care TeamSM and ACTSM are service marks of Autism Delaware Inc.

Everything we do is advocacy

S ince 2017, Autism Delaware has taken some big hits, especially in our advocacy effort. First, we lost the genius of Alex Eldreth. His totally unexpected death not only left the staff reeling but also created a massive black hole in the agency's action plan. Then in 2019, the state of Delaware shut down because of the COVID pandemic. Too many people were dying, so the most important step we at Autism Delaware could take was to also shut down—and advocate for safety in our community!

It may seem like we haven't done much since 2017, but we've learned a lot about building the appropriate infrastructure for sustainable services and the best way to move forward even during difficult times.

Plus, we found support for our unfunded services and the opportunity for more advocacy in the future. In fact, we are combining our rebuilt infrastructure with everything we've learned—going back to 1998—so that we can advocate successfully for people with autism for the next 25 years.

ike Alex did as Autism Delaware's director of policy and community outreach, I'm always considering new opportunities to advocate on behalf of our community. And I think of everything we do as advocacy.

For example, as soon as an Autism Delaware intake coordinator introduces the range of family support services available to an incoming caller, the family benefits from our advocacy. Our fully accredited staff of family navigators, family resource coordinators, and family support providers provides active communitybased support in favor of each family's specific needs.

Family support services also include Autism Delaware's advocacy effort known as Smart Cookie Day. This annual trek to the Delaware General Assembly provides a vehicle for autism advocates to tell their personal stories and voice their



Newsletter

Brian Hall, MSW Executive Director

needs on behalf of their loved ones on the spectrum. To build on Alex's foundation for coverage of the critical issues facing our community, we are in the process of hiring an advocacy coordinator. For more information about this job opening, visit <u>AutismDelaware.org/Work with Us</u>.

Like family support services, Autism Delaware's adult services program is community-based but dedicated to adults on the spectrum. From each Autism Delaware county coordinator to each participant's direct support professional, we advocate on the individual's behalf to find employment, volunteer opportunities, social and wellness activities, or personalized supported living options. And our advocacy continues in a collaborative effort in the community to ensure that each autistic individual is supported and successfully meets his or her goals.

And Autism Delaware's

communications team works to maintain appropriate and correct information that our autism community not only may benefit from but also may rely on. We are currently in the process of updating our online resource guide and website, and our long-standing newsletter, *The Sun*, continues to focus on research and best practice. Advocating especially for the parents of newly diagnosed children, the newsletter explains all

Continued at the bottom of p. 12





Advocacy throughout the years Continued from p. 1

Delaware State Senator Liane Sorenson and Del. St. Representative Quinn Johnson. Where we ran into resistance was from the state budget office. *Why?* Because one insurer had inflated the cost estimate for providing this coverage to state employees—which killed the first version of the bill.

To address this issue, Autism Speaks provided extensive consulting on cost estimates. Then-Lieutenant Governor Matt Denn also offered his help by securing another meeting with the budget office so we could present our more accurate data.

We further presented the need for the bill to the Delaware Kids Caucus, a bipartisan group of state senators and representatives that promotes the health and welfare of Delaware's children (https://legis.delaware.gov/json/ BillDetail/GetHtmlDocument?fileAttachmentId= 39096).

Plus, we requested support in our valentine and Smart Cookie Day bundles that we hand-delivered to our elected officials. (<u>Click here</u> to learn how to become an autism advocate on Smart Cookie Day.)

We were sure we had the votes to pass the bill, but the senate finance committee sat on it because the chair did not want to hold a hearing on it because of the costs!

In May 2012, we threw everything we had left at getting this bill passed:

A group of determined advocates walked into the joint finance committee's budget markup hearings every day for two weeks. As the parents of children on the spectrum, they wore their autism ribbons, pins, and accessories proudly and filled the entire front row of only three rows allotted to the public. The legislators knew who they were! No matter the topic the JFC was working on, the legislators were facing constituents who wanted to talk about the need for insurance coverage for ABA and auxiliary therapies for autism diagnoses.

On the very last day of JFC's hearings, the chair agreed to speak with one of the advocating parents. I don't know what words were exchanged, but when the chair came back, he announced that he would hold a hearing. Ultimately, the bill sped through the Delaware legislature. And on August 13, 2012—after four years of advocacy effort—the bill known as SB22 was signed into law by then-Governor Jack Markell in a special ceremony held at Autism Delaware's Newark office.

A shift in direction

Back in 2006, I had learned about the effort to advocate on behalf of people and families affected by autism during a job search. Plenty of organizations needed my services as a development director, but the

Continued at the top of p. 12

Autism Delawaresm advocacy Success throughout the years

Newsletter

Since 1998, Autism Delaware's advocacy effort has changed the lives of people on the spectrum and their families:

- Senate Bill (SB) 22 required insurers to cover behavioral health treatment.
- SB100 deterred the use of seclusion and restraints in public schools.
- SB33 required schools to inform parents of their rights around a student's individualized education plan (IEP) and the available resources.
- House Bill (HB) 60 enabled savings accounts with tax advantages for disability expenses.
- HB292, renamed the Alex Eldreth Autism Education Law, expanded the Delaware Autism Program and autism resources in the schools.
- HB104, also known as the Michael McNesby Full Funding for Adults with I/DD Act, mandated increased pay rates for direct support professionals (DSPs).



Most recently, Kim Siegel was chief of staff for the Delaware Department of Natural Resources and Environmental Control, assistant director of government relations and advocacy at Mental Health Partnerships in Philadelphia, FOIA (Freedom of Information Act) coordinator and legislative affairs manager at the Delaware Department of Justice and research director for Lieutenant Governor Matt Denn.

During her eight-year stint at Autism Delaware, Kim led a successful campaign to get insurance coverage for autism therapies. She also served as a legislative fellow in the Delaware General Assembly.



y daughter Hope was born in Baltimore in 1997. From early on, I could sense something was off. Hope was delayed in most things, particularly speech and play. When I voiced my concerns to her pediatrician, he kept reassuring me: "Oh, just give it time. All kids develop at their own pace."

Because the current autism prevalence rate is one in 36, most people today are aware of autism or even know someone personally who has autism. This was not the case when Autism DelawareSM began its advocacy as an autism agency-or when I voiced my concerns to Hope's pediatrician. The lack of awareness and knowledge about autism in the medical field was reflected in the general population. Plus, when I walked into that



pediatrician's office, I was a single dad trying to raise two children by myself, so I accepted the pediatrician's view.

Nevertheless, my concerns grew heavier over time, and I was aware of Hope's formative years slipping past. By age 4, she was still only babbling. Personally, I'd been battling feelings of being a complete loser as a father when I finally said to myself "The doc is wrong. Something is amiss with my daughter."

I reached out to a speech therapist who my son Michael was seeing. Two years older than Hope, Michael was a little delayed and progressing in a program called <u>Child Find</u> in our home state of Maryland. I was able to enroll Hope in

the program, too, and she started to make progress in her speech. However, her social play remained delayed. The only people she would play with were Michael and me.

The public school system was very good and took great care to help Hope, but I continued to have a nagging feeling that something was off. I just couldn't put my finger on it. And no one in the school system, at the speech therapist's office, or the pediatrician's office mentioned the word "autism"—until Hope was 6. During one of her IEP (individualized education program) meetings, the school psychologist tested her as part of the usual student assessment. After the testing, he said "I believe Hope is autistic." I had no clue what autistic meant, but finally, I had something to work with. I took my daughter

Continued on p. 5

Newsletter



A training manager with master licenses in HVAC, plumbing, and electrical contracting, Rodger Pearce is also the current president of the Autism Delaware Board of Directors. His goal is to help more individuals with autism and their families just as Autism Delaware helped his daughter Hope and his family. In his free time, Rodger enjoys watching college basketball and creating fun studies with his daughter that range from the history of bubble gum to life lessons from baseball.



Giving a voice to Hope

Continued from p. 4

to Kennedy Krieger in Baltimore to get a medical diagnosis.

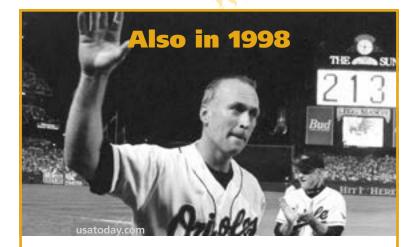
This gift of knowledge happened in 2003, yet the process for identifying and evaluating children who may need special education and related services was mandated by the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 (https://sites.ed.gov/idea/about-idea/). When I learned this fact, I had to wonder: "Was Hope tested previously?" If so, no one mentioned autism to me. Instead, when the school psychologist said "autistic," I asked if that meant my daughter was retarded. That's how little the general community knew about autism.

Shortly thereafter, I met a lovely Delaware lady, we married, and I considered moving the family to Delaware. First, I wanted to visit the school that Hope would be attending. If it was a bad fit, I wasn't moving. But I was floored by the love and concern that the Indian River School District and special-education teacher showed the kids in what would be Hope's assigned class. It was 2005: My daughter was 8 and finally blessed with an excellent educational experience.

Of course, we experienced a lot of failure in the process, but our hard work at home supported Hope's education. Hope grew and became a good student, always wanting to do her best and follow the rules. Kids were friendly to her because she has a sweet demeaner, but she was never invited to birthday parties or to join other kids for fun. She never connected with her peers on a social level.

When Hope was in the tenth grade, I grew concerned that the network of care and security that she was enjoying would disappear from her life in two years. I needed to find a new network of caring people for when Hope finished high school. During my research, I discovered Autism DelawareSM adult services, which include vocational programming known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short). What jumped out at me was the possibility for recreation, too. I wanted Hope to have fun without her old man.

I called Autism Delaware's Sussex County office and asked to speak to someone about POW&R. After telling them about Hope and my concerns as her dad, they quickly came alongside me. I felt as though they put their arms around me and said "You're not alone." What a weight of worry they lifted from my shoulders!



The Sun

Newsletter

The Iron Man of baseball took a day off! Only three years earlier, Cal Ripken Jr. had broken New York Yankee Lou Gehrig's 1939 record of playing 2,130 consecutive games—and I was sitting in the stands with my brother to witness Ripken's achievement. But the Baltimore Orioles' shortstop didn't take a day off until September 20, 1998—after playing 2,632 consecutive games and setting a new record (https://theathletic.com/2047308/2020/09/06/25-yearslater-an-oral-history-of-the-night-cal-ripken-jr-becamethe-iron-man/).

Since joining the POW&R program, Hope has been successful at her job not only because her direct support professionals (DSPs) helped her employer understand how she thinks and works, but also because Hope is doing something she loves. In fact, Hope has won employee awards for being a great worker and has held a steady job for eight years. To top it all off, she has made

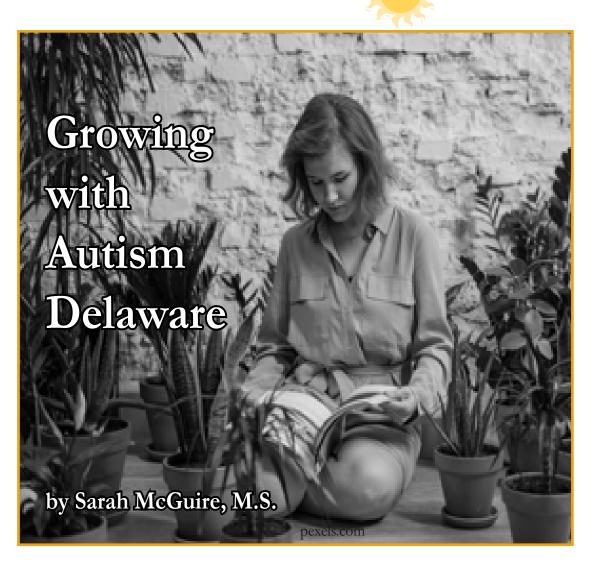
friends with her peers at POW&R. She now attends birthday and Halloween parties, goes bowling and swimming, and enjoys all kinds of fun things. Who needs her old man to have fun!

As I get older, I'm thankful Autism Delaware continues to be alongside Hope. Her DSPs and I have worked together on her social skills as well as her knowledge of community safety, fire safety, money skills, and much more. At this time in Hope's life and mine, I look forward to watching my daughter have many years of fun and support, all while using her voice. Do you know someone who could benefit from Autism Delaware's adult services? Send this link to them: Autism Delaware/Adult Services



S ince connecting with Autism DelawareSM, I've witnessed the agency's growth from fewer than ten employees in one New Castle County office to a statewide agency serving thousands of people, with two office locations, and more than a hundred employees.

I've also experienced my own growth. It all began in 2008 as I started to hear about autism in the news, on television, in conversations, and in my studies as a psychology undergraduate. But wrapping my head around the concept of "autism" was difficult because I had no personal experience with it—which made me curious: What is this mysterious thing that the community was becoming more aware of?



Researching the internet, I discovered the Autism Society of Delaware (ASD) and was excited that it was a local resource with volunteer opportunities as well as a lot of information about autism.

I also met Heidi Mizell, a parent-mentor and ASD's Asperger's resource coordinator at the time. (Today, Heidi is Autism Delaware's family resource coordinator and a family navigator for New Castle County.) She signed me up as a volunteer for the agency's bimonthly game night. It became



my opportunity to learn and associate with teens and tweens on the spectrum as they played board games with their peers. And I loved it!

As a result, the focus of my undergraduate studies gravitated toward autism and sensory-related topics, plus getting to know autistic people and their families. I quickly grew to love everyone in this inclusive and accepting community—so much so that I forgot that some people aren't so accepting of autism or of disabilities in general.

fter ASD changed its name to Autism Delaware and merged with the Lower Delaware Autism Foundation in 2010, I continued to volunteer for various fundraising events, like the Autumn Auction for Autism, Walk for Autism, and the Drive for Autism.

Continued on p. 7

Newsletter

In addition to working as Autism Delaware's compliance officer and training specialist, Sarah McGuire, M.S., is an adjunct instructor in the Human Services graduate program at Wilmington University.

The Sun

Newsletter



Growing with Autism Delaware Continued from p. 6

I also began my 13-year tenure as an employee, working my way through each Autism Delaware department:

• As I mentioned previously, I supported the bimonthly teen/tween game night as an Autism DelawareSM volunteer in 2008; eventually, I facilitated the program. One of my all-time favorite things about this experience: seeing these kids grow into adults who went on to graduate from college or join Autism Delaware's adult services program.

• A couple of years after I began volunteering for game night, I was hired as an entry-level direct support professional (DSP) in the agency's community-based vocational service, which is part of our adult services program. In this capacity, I provided supported employment and day habilitation services to individuals on the spectrum.

Following the merger in 2010, the program expanded across the state and so did my work: I managed the growing contract with the state's Division of Vocational Rehabilitation as well as New Castle County's growing team of employment specialists. I also provided transition services to high school students entering the adult services program. As a result, I learned about Autism Delaware's full range of vocational services and enhanced my management skills through hands-on training.

• As the needs of the autism community continued to grow, I accepted the opportunity to continue the work started by one of the autism community's biggest advocates, Alex Eldreth. Following his unexpected death in 2017, I advocated at the state and local levels, working with stakeholders and elected officials and coordinating staff and volunteers for the agency's annual Smart Cookie Day at the Delaware General Assembly. I had some big shoes to fill, but to follow through with Alex's amazing work was an honor and an incredible learning experience.

• With the growth of the agency's services and programs came growth at the administrative level. In 2019, I was offered the opportunity to oversee the agency's quality assurance efforts, which then led to building and managing a compliance program plus all organizational training efforts.

When the COVID-19 pandemic had everyone working from home, the administrative team began meeting virtually and more often to stay connected. As a result, the leadership team grew closer and more collaborative, which has led to building a stronger administration and compliance program.

As the agency's current compliance officer, I work with the senior leadership team and support the entire agency. My task: to ensure that important, much-needed services continue to be provided to our community not only by making the administration aware of state and federal laws and regulations and the current issues in compliance but also by directing the agency's compliance program.

hat's really kept me so captivated with Autism Delaware is the community. By far, the autism community is the most supportive and accepting community that I have been fortunate to be a part of. Some of the most accomplished people I've ever met are the advocates (including volunteers and

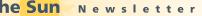
Also in 1998 I'm a music lover, and the 90s produced some of my all-time favorite songs. Here are the top 10 songs from the Billboard Year-End Hot 100 singles of 1998: 1. Next, Too Close 2. Brandy and Monica, The Boy Is Mine 3. Shania Twain, You're Still the One 4. Savage Garden, Truly Madly Deeply 5. LeAnn Rimes, How Do I Live 6. Janet Jackson, Together Again 7. K-Ci and JoJo, All My Life 8. Elton John, Candle in the Wind 1997 and Something About the Way You Look Tonight 9. Usher, Nice & Slow 10 Paula Cole, I Don't Want to Wait

> support staff) who have worked so hard over the years to make the world (or at least the state of Delaware) a better place for autistic people to learn, grow, and live full lives as included and valued members of the community.

All of my experience has been enriched by Autism Delaware's dedication to providing a spectrum of statewide services to all autistic individuals across their lifespans as well as to their families. Over my entire 15-year involvement with Autism Delaware, I've enjoyed an upfront seat to its growth, from witnessing ASD's transition to Autism Delaware in 2010 to supporting the agency's current effort to define the best way to serve the autism community in the future. In fact, my current job was created recently because of our growth!

I have nothing but gratitude for Autism Delaware's part in my own growth. And I can't wait to see where the future takes us both!







A little more than 20 years ago, my son, Jake, was diagnosed with Fragile X syndrome, and I was spending a lot of time surfing the net to answer all the questions rolling around my brain. As I was researching the syndrome, I also learned about autism and the local autism agency that, at the time, was called the Autism Society of Delaware (ASD). This organization had recently moved out of some-one's living room and into rented office space.

About four years later, Jake received a dual diagnosis: Fragile X syndrome and autism. Getting a second diagnosis was an emotionally hard blow, so I called ASD. Not only did they understand the issues I faced, but they also provided help, support, and the resources available to me and my son.

At first, I joined the other family members who attended the caregiver coffee hours. It was a great way to meet, and sharing our ideas and worries led to friendship and camaraderie. Facilitating the meetings, the ASD representatives were always informative, supportive, and kind. All questions were welcomed, and guidance was always offered. As I grew more comfortable with my son's diagnoses, I started volunteering to support ASD's fundraisers, such the annual Drive for Autism. By the time ASD changed its name to Autism DelawareSM in 2010, I had also been serving the autism community as a parent-mentor and chairing the agency's public awareness committee while writing press releases and copy for radio ads and planning publicity for National Autism Awareness Month, which takes place every April. Additional-

ly, I served on the newsletter committee, developing ideas for each issue of *The Sun* and writing articles for the Parent 2 Parent section. These days, I continue to volunteer my **Cont'd on p. 9**



Autism Delaware executive director Theda Ellis presented the outstanding volunteer award to Jen Nardo in 2008.



The parent of two adult sons, one with autism and one neurotypical, Jen Nardo is an honored recipient of an Autism Delaware Outstanding Volunteer Award for her multiple efforts as a parent-mentor,

public awareness committee chair, PR copywriter and contributor to *The Sun*, and as a volunteer and participant in the Walk for Autism and Drive for Autism.



e Sun Newsletter

A family of people who get it Continued from p. 8

time, supporting the Drive for Autism and developing ideas with the newsletter committee as well as writing articles.

Through the years, I also participated in the annual Walk for Autism with my family. All the walkers, the other families, and all the Autism DelawareSM staff and volunteers, together they created "a family of people who get it"—without any explanation needed. At a time when I was worried about what others thought of Jake's behavior and my value as his mom, I never got dirty looks or rude words from this autism community. It felt freeing to be among families in the same situation as I was. Even being able to let my guard down and enjoy Jake's flapping, screaming, and squealing felt a little odd. But instead of side-eye looks, I got words of encouragement and support, such as "Mine does that, too," and "How did your IEP meeting go?" For the first time, I was with people who know. And I felt their acceptance and strength.

Autism Delaware's growth over the years has been bittersweet for me:

- Sweet because families like mine continue to find much-needed support at Autism Delaware. And sweet because children like my son benefit from the agency's adult services, which include community-based vocational programming known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short).
- Bitter because more and more families are hearing the autism diagnosis for the first time and needing help. The current autism prevalence rate is one in 36. (When Jake was diagnosed, it was one in 150.)

Because the autism community continues to grow, Autism Delaware strives to offer the range of services needed by people affected by autism across their lifespans as well as by their families. In addition to adult employment services, the agency offers family support services, awareness, and community engagement.

I am honored to continue to play a part in Autism Dela-

Also in 1998

I'm a stargazer (of the celebrity kind), and in 1998, these celebs celebrated their 25th birthdays. I also included some of what each was doing at the time:

Heidi Klum was on the cover of the *Sports Illustrated* Swimsuit Issue, in the movie *54,* and married for one year to first husband Ric Pipino.

Tyra Banks was on the covers of several magazines, including *Elle* and *Seventeen*, and looking forward to a new acting career.

Neil Patrick Harris, having wrapped up Doogie Howser five years earlier, was now in the cast of the TV movie *The Christmas Wish* and the big screen movie *The Propositior*.

In 1998 alone, Jim Parsons acted in five stage plays in his hometown of Houston, Tex.

James Marsden was in the big screen movie Disturbing Behavior, a TV episode of The Outer Limits, and a music video, Got You (Where I Want You), by the Flys.

Vera Farmiga made her feature film debut in *Return to Paradise* starring Vince Vaughn, Anne Heche, and Joaquin Phoenix.

ware's history and, most especially, to have gotten to know the wonderful families and employees who make up this organization. Those who are drawn to this work are truly extraordinary.

Help Wanted

Autism Delaware has immediate openings for full- and part-time work. To check out the job opportunities, <u>click here</u>.

More interested in volunteering? <u>Click here</u>.





INSIDE Autism[™] Delaware





The first major fundraiser to benefit the Autism Society of Delaware was held at the Riverfront Arts Center in Wilmington on October 7, 1999. Called the Autumn Auction for Autism, it celebrated the Delaware Autism Program's 20th anniversary with tributes in a formal program and featured live music by DAP graduate Autumn Graham. More than 250 people enjoyed the dinner program and raised more than \$13,000 by bidding on 153 items in a silent auction. The donated items ranged from a 1999 U.S. Open souvenir tennis ball autographed by Andre Agassi and issue of *The Sun.* "Since this was our first big fundraiser, we had no idea how the community would respond."

The community continued to respond year after year. In 2010, as the Autism Society of Delaware evolved into Autism Delaware, the northern event evolved into the Northern Fall Auction with a move, first, to the DuPont Country Club and then to the World Café Live at The Queen in Wilmington. Wherever the event was held, donors were generous with their support.

Serena Williams to a latemodel Mercury Capri Convertible.

Appropriately, the 101 businesses and individuals who donated these items received accolades and the autism community's appreciation for their generosity.

"I am overwhelmed by how generous people have been in supporting this event," noted then-event chair Marcy Kempner in the November/December 1999



Dressed for the event's 2016 theme, Disco Inferno, the partygoers inside the World Café Live at The Queen danced the Hustle, engaged in a lip sync battle, and bid on auction items from these top sponsors: The Woolard Family Foundation, AAA Mid-Atlantic, the Kempner Family, P.J. Fitzpatrick, Swift Pools, the Fischer Family, and Dover International Speedway. "Thanks to the generosity of individuals and businesses," said the 2016 events manager, Deanna Principe, "Autism Delaware can continue to provide muchneeded programs and services."

In other words, the autism community owes a lot to our event sponsors.

For the full list of all northern auction sponsors, <u>click here</u>.





Programs

This list comprises programs for October to December, which had been scheduled by *The Sun's* publication date. For the more up-to-date list, visit <u>https://www.autismdelaware.org/events/</u>.

Family support services

- Oct. 4 Speaker Series: Planning for Your Loved One with Special Needs. R.S.V.P.: Zoom event. 7:00 P.M. Free. Host: Heidi Mizell
- Oct. 10 Parent coffee hour for Spanish-speakers. Starbucks. 3240 Fashion Center Blvd. Christiana. 6:00–8:00 P.M. Free. Contact: Ivanka Carbajal
- Oct. 25, Nov. 15, Dec. 13 Parent coffee hour. R.S.V.P.: Zoom event. 7:00 P.M. Free. Host: Heidi Mizell
- Oct. 26 Grandparent support group and coffee hour. R.S.V.P: Zoom event. 7:00 P.M. Free. Host: Heidi Mizell
- Nov. 8 Parent coffee hour for Spanish-speakers. Starbucks. Georgetown. 10:00 A.M.–12:00 P.M. Free. Contact: <u>Ivanka Carbajal</u>

Community engagement

Walk for Autism

Oct. 7. 9:00 A.M. Ft. DuPont. Delaware City. **Oct. 14.** 9:00 A.M. Hudson Field. Milton. R.S.V.P.: <u>Kris Grant</u> For more info, <u>click here</u>.

Autism Delaware's 25th anniversary gala Nov. 11. 6:00–10:00 P.M. Bally's Dover Casino Resort. 131 North Dupont Hwy. For more info, click here.

Holiday party

Dec. 9. New Castle County 12:00–2:30 P.M. \$2.00 per person. Aetna Fire Hall. 400 Ogletown Rd. Newark. R.S.V.P.: Susan Campbell

TBA

Southern Delaware holiday party: To be announced.



utism Delaware supports education by awarding scholarships annually to candidates who not only meet the scholarship's criteria but also illustrate exemplary effort in the pursuit of their education. This year's field of applicants was examined by a review team that comprised three Autism Delaware board members and a past scholarship winner.

For more information about the available scholarships, <u>click here</u>.

Having earned scholarships for the 2023– 24 school year, the following individuals are noted with their educational goals:

- Dylan Carnright—bachelor's degree in cybersecurity
- Sarah Milner—autism teacher certification
- Cynthia Ritter—autism teacher
 certification
- Michael Sturtevant—career in genetic engineering





Advocacy throughout the years Continued from p. 3

Autism Society of Delaware had a strong commitment not only to addressing needed change in public policy but also to boosting fundraising dollars. I really liked this vision! At the time, the prevalent belief in the charitable nonprofit sector was that lobbying was prohibited. Luckily, this belief was being challenged by people who knew how to lobby legally and effectively. And I was able to share this knowledge with the autism advocates.

Handed the job as development director, I was charged primarily with boosting fundraising by creating the Walk for Autism and building a development program. And because of my interest and skills in the public policy arena, I was also able to add new technical knowledge to the effort being made by the volunteer policy committee.

To this end, I began by suggesting a shift in direction for Smart Cookie Day. Instead of thanking our elected officials for supporting people with autism, I asked the policy committee to consider **calling the legislators "smart cookies" for supporting specific issues.** In other words, to personally thank the legislators who supported contracts that would cover the actual cost of autism services. In this redirection, we emphasized how legislators could support people on the spectrum and their families. Plus, asks like this were a precursor to advocacy for the now fully funded <u>McNesby Act</u>.

We also coached our advocates on how to meet with their



legislators in the Delaware Legislative Hall. And we created an evening reception to accommodate advocates who couldn't come during the day's activities.

Lasting reminders

Since leaving Autism Delaware^{5M} in 2014, I've decorated every new workspace with my photo of Gov. Markell's 2012 signing of SB22 as well as a signing pen. These lasting reminders speak to the power of grassroots activists, teamwork, and persevering through the moments when you think you can't possibly win. This one piece of legislation was not a cure-all for getting insurance coverage for all autism services, but it was a major first step that, I hope, future advocates can improve upon.

Everything we do is advocacy Continued from p. 2

language and abbreviations that may be unfamiliar. It also includes articles by parents who reach out with ideas on what worked for them as well as for providing a sense of community. And it's all published in an easily accessible format.

f you are the parent of an autistic child and want to continue this conversation about advocacy, feel free to drop me a line at <u>brian.hall@</u> <u>autismdelaware.org</u>.



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