The Sun
Newsletter
Summer 2023

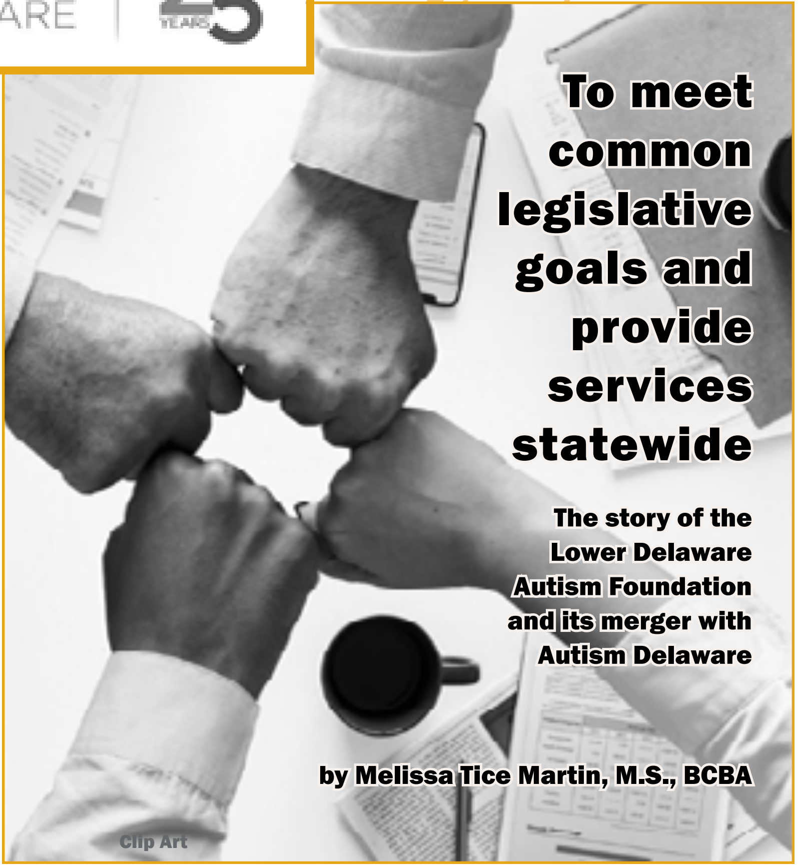
1998–2023
Autism Delaware℠

This third issue celebrating Autism Delaware's 25-year history features accounts from Melissa Martin, John Willey, Susan Patel, and Rob Gilsdorf.

Plus, each account is accompanied by a non-Autism Delaware slice of history that was also of interest to the contributor in 1998. Look for the supplemental boxes entitled "Also in 1998"!

Our mission

To help people and families affected by autism



To meet common legislative goals and provide services statewide

The story of the Lower Delaware Autism Foundation and its merger with Autism Delaware

by Melissa Tice Martin, M.S., BCBA

Clip Art

The Newark-based Autism Delaware expanded its reach across the state when the agency merged with the Lewes-based Lower Delaware Autism Foundation (LDAF) in 2010.

LDAF had been formed by a group of parents, educators, and community stakeholders with a mission to raise and distribute funding that benefits Sussex County individuals with autism and their families. The group made its debut in 2001 with a ball-and-auction fundraiser. With the success of this first event, LDAF expanded its fundraising calendar to include the half marathon–5K race–1 mile Walk for Autism, a golf tournament, and the popular Blue Jean Ball and Art Show. Mini-events included wine dinners, raffles, office drop-in activities during school breaks, and a year-end annual giving campaign.

In July of 2005, I joined the LDAF team to support the coordination of fundraising events and to expand programming for individuals with autism and their

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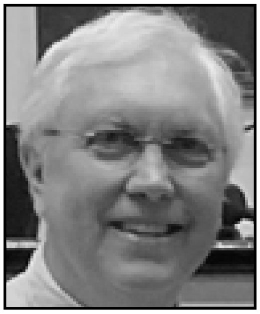
A focus on the mission and a celebrated denial



Rodger Pearce
President
Board of Directors

This year, Autism Delaware is at a monumental time in its existence. We are celebrating 25 years as an autism agency. This benchmark gives us an opportunity to pause, take a breath, and think of the incredible things Autism Delaware has done. Yes, programs have been created and best practices have been adhered to, but what must also be celebrated is the fact that Autism Delaware has maintained a focus on its mission: to help people and families affected by autism. No mission creep here!

Recently, the Autism Delaware Board of Directors was reviewing its guidelines for selecting new members. My curiosity was struck by one of the guidelines about the board's composition: at least one autistic person with low support needs or the family member of an autistic person with low support needs. The specificity of this wording seemed odd at first, so I asked why this guideline specifically mentions an autistic with low support needs.

The answer solidified Autism Delaware's mission for me: The agency's intent was to ensure that a range of people on the autism spectrum have seats on the board and that all are given adequate voice, not just those with high support needs.

Wow, Autism Delaware's founders had some serious forethought!

Our 25th anniversary celebration also allows us a look at how we can continue to build on the rock solid foundation of our past successes—how Autism Delaware can continue to make a difference in our community—how we can help more individuals and families. With an autism prevalence rate of one in 36, if we're not moving forward, we are falling behind.

The effort starts with fantastic staff. Yes, we have great programs and creative ideas, but our dedicated and capable staff makes it all possible. Autism Delaware is blessed to have such a staff.

I'll end this letter with a story that wraps up what Autism Delaware is all about: My daughter Hope works at Kilwin's candy store in Rehoboth Beach. She loves her work. And her direct support professionals (DSPs) have been vital to her success.

A few years back, our family wanted to get away for a short vacation. Looking forward to a vacation with her family, Hope requested the time off. A few days later, we received an email from her manager: request denied. "Denied! Why?"

The vacation time we'd chosen was during the Sea Witch Festival in Rehoboth, and Hope's manager said it was one of the busiest times of the year for the chocolate store. "Hope is extremely reliable," added her manager, "and always focused on doing a good job. Hope is really needed."

We celebrated Hope's denied vacation request by raising an ice cream cone and toasting Autism Delaware for helping Hope to become a strong part of the community. Today, the family joke is "Autism Delaware is in the business of getting their participants denied for vacation." LOL!

The LDAF–Autism Delaware℠ merger Cont’d from p. 1

families. The effort added a summer swim program, adaptive bike camp, a music program, day camp in partnership with the Children’s Beach House, the Most at the Coast Autism Educational Conference, the Educational Toys for Autism Drive, and a scholarship program supporting paraprofessionals and educators working toward continuing education credits. Plus, to encourage doctors to use early developmental screening tools, LDAF co-sponsored a physician’s awareness program with the Autism Society of Delaware (ASD), which would later become Autism Delaware.

In addition to fundraising and creating programs, LDAF was strident about local and state legislative advocacy, especially around education funding for children with autism. And LDAF shared advocacy at Legislative Hall with the ASD. The Newark-based agency’s executive director, Theda Ellis, coordinated with me to unite families and staff in working toward our common legislative goals.

Our shared efforts fostered discussion about the possibility of a merger: While the ASD’s adult employment program was of growing interest to the LDAF families whose children were becoming young adults, LDAF granted the ASD a statewide reach as well as support in advocacy efforts.

By the time our organizations merged, the Autism Society of Delaware had officially changed its name to Autism Delaware. I eagerly joined the Autism Delaware team by staffing an office in Lewes with parent-mentor Dafne Carnright. (At the time, Dafne worked as the downstate coordinator; today, she is the statewide director of family support services.) My role was to assist with growing the adult employment program in Kent and Sussex Counties.

I am proud to have had the opportunity to learn and work under the leadership of the adult employment program’s director, Katina Demetriou. I witnessed the amazing growth not only of our program participants but also of the staff who worked diligently each day to support our program participants at work in the community.

Working with Delaware’s autistic adult population from 2010 to 2020, I grew interested in applied behavior analysis (ABA)—the science of behavior—as well as in ABA’s application to learning. As the assistant director of Autism Delaware’s adult employment program, I focused on applying these principles and training the program’s staff in the use of systematic instruction, visual tools, effective prompting, shaping, and the teaching of communication responses. These tools and other ABA-based interventions helped our program participants to improve behaviors that promoted their success as employees, volunteers, and participants in the community.

I feel fortunate to have had the opportunity to serve the LDAF and Autism Delaware communities and to work with so many talented colleagues, caring volunteers, dedicated parents, and inspiring individuals with autism of all ages. And I look forward to seeing the agency’s continued progress and the innovation that will become possible for individuals with autism with the support of Autism Delaware.

Also in 1998

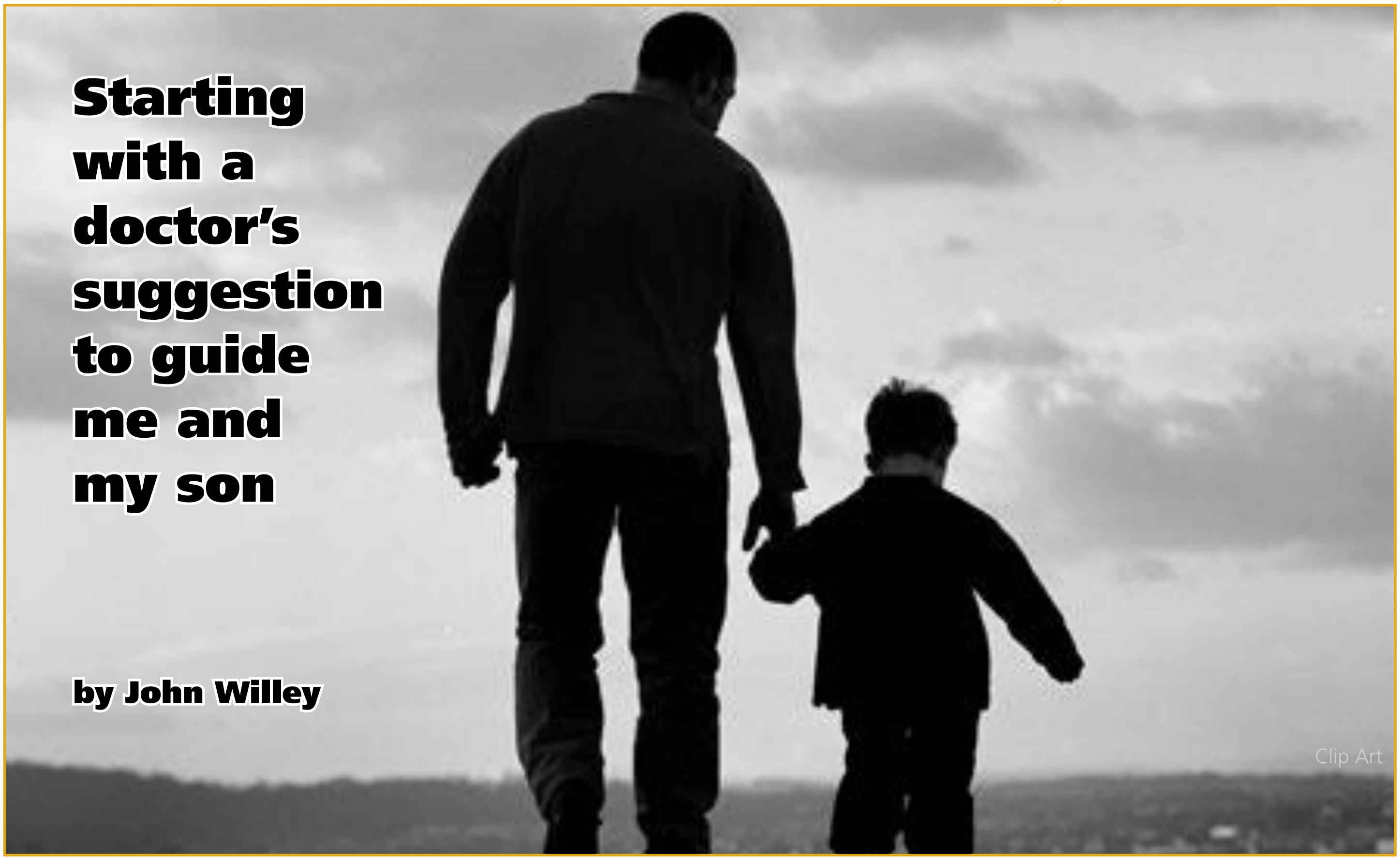

Clip Art

“The Behavior Analyst Certification Board, Inc.® (BACB®)...was established in 1998 to meet professional certification needs identified by behavior analysts, governments, and consumers of behavior-analytic services. The BACB’s mission is to protect consumers of behavior-analytic services by systematically establishing, promoting, and disseminating professional standards of practice” (https://www.bacb.com/about/).

Melissa Tice Martin, M.S., BCBA, is a senior consultant with the Association of Behavior and Curriculum Consultants, LLC, and the vice president-elect of the Delaware Association for Behavior Analysis, an affiliate chapter of the Association for Behavior Analysis International. When Melissa is not working or learning, she enjoys participating in a book club, spending time on the beach with family and friends, and hiking with her husband Ed and Nash, their chocolate Labrador Retriever.

Starting with a doctor's suggestion to guide me and my son

by John Willey



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In 2000, a neurologist at Nemours Children's Hospital first told me about Autism Delaware℠. Dr. Marcy Yonker had diagnosed my son, Eric, as having pervasive developmental disorder–not otherwise specified (PDD–NOS)—and I told the doctor it was such a lonely feeling to be the parent of a newly diagnosed child.

At the time, the prevalence of autism was one in 150. Today, the rate is one in 36, and most people know someone on the spectrum. But 23 years ago, the only other person with autism I'd seen was Dustin Hoffman's portrayal in the movie *Rain Man.*

What are people with autism really like? I wondered. *What do they need? What helps them thrive?*

It was a relief to talk to a parent-mentor at Autism Delaware. She had experience with the systems that my son and our family now needed to navigate. Plus, she answered my long list of questions.

My son's life settled down when he attended the Sussex Consortium in Lewes. It's an integrated preschool program for three- and four-year-old children with special-education needs. I became very active in the school's parent advisory committee (PAC) and was named PAC president for several years.

I also volunteered my time at Lower Delaware Autism Foundation (LDAF). I was involved with LDAF's iCan Shine Bike Camp. This adaptive bike program was developed and put on by Richard E. Klein, Ph.D., who we called "the bike whisperer." I also served at LDAF's day camp, which took place at the Children's Beach House.

Continued on p. 5

John Willey has supported Autism Delaware as a member of its board of directors and currently sits on the agency's finance committee. His son, Eric, is now 26 years old and loves to travel. Eric joins his semi-retired father and mother, San, on road trips to visit one of his four siblings each month.

Starting with a doctor's suggestion

Continued from p. 4

When LDAF merged with Autism Delaware℠ in July of 2010, I became more involved with the combined organization because of its three stated goals:

- implement adult services in Sussex County and ensure that students with autism have an effective transition from school to adult life.
- advocate with one voice on behalf of our children when speaking to state officials, school districts, and in communities throughout the state.
- centralize expenses so the organization can provide programs and services statewide while operating efficiently.

Everyone involved with the Autism Delaware–LDAF merger was excited to work on these goals, and several other LDAF parents joined the Autism Delaware Board of Directors with me. The organization continues to work towards these goals. I'm proud to be associated with a thriving organization: When Autism Delaware thrives, Delaware's people with autism thrive.

Also in 1998

The top television programs were *ER*, *Friends*, and *Frasier*—and I enjoyed all of them!

Clip Art

The prevalence of autism

At the same time that John Willey's son was diagnosed with autism, the Centers for Disease Control and Prevention (CDC) assembled the Autism and Developmental Disabilities Monitoring (ADDM) Network.

ADDM screens developmental evaluation records. Instead of reviewing documented diagnoses or classifications, ADDM looks for behaviors that are known to be associated with autism.

Clip Art

"Because this methodology collects data from multiple health and service provision sources rather than from a single source, these data can be used to estimate a closer approximation of true population prevalence than would a single source of special education or clinical administrative data alone" (Prevalence of Autism Spectrum Disorders. CDC MMWR Surveillance Summaries. Feb 9, 2007/56[SS01]; 1-11).

According to the ADDM, autism's current prevalence rate is one in 36.

What does this prevalence rate mean?

It means more children will receive an educational classification of autism and federally mandated services from the time they are 2 years old until they are 21.

It means more adults on the spectrum will require a level of support in their work, homes, and community based on the severity of their disorder.

And it means that Autism Delaware will continue to fundraise so that adult and family support services and community engagement can be expanded across the state and across each individual's lifespan.

Finding communities of support

by Susan Patel


Clip Art

1998 was twenty-five years ago, but I remember it well: My husband Tushar and I were living in New Jersey with our six-year-old daughter Monica and five-year-old son Rohan. We had been muddling our way through the murky world of autism and disability services—and considered ourselves fortunate when Rohan had been diagnosed at two and admitted into a good early intervention program.

At three, Rohan got into the Douglass School, which had a strong applied behavior analysis (ABA) program. I still cry with gratitude when I think of that phone call saying he had been accepted—It was like he got into Harvard!

The ABA method of teaching is based on the philosophy of ignoring the bad and rewarding the good. Focusing on the use of effective prompts and modifying Rohan's environment made all the difference to him. He thrived—and loved going to school. While his progress was very slow, it was progress nevertheless, something we hadn't seen before.

During Rohan's first year of early intervention, I had hired student teachers to come to our home so Rohan could benefit from ABA therapy's recommended 40 hours per week. There was no insurance coverage back then, so paying these teach-

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Susan Patel was a founding board member in the nonprofit that started an adult program at the Douglass School (N.J.). Shortly after moving to Lewes in 2007, she co-founded the Sussex Consortium's afterschool program. In 2011, Susan joined the Autism Delaware℠ Board of Directors and served on the direct services and advocacy committees as well as the Autism Gala and Auction planning committee. Susan also volunteered her time and expertise in support of various fundraisers. In 2018, Susan set up an exercise class and a music appreciation class for participants in Autism Delaware's adult services program, which includes vocational programming referred to as Productive Opportunities for Work and Recreation℠ (or POW&R℠, for short).

Finding communities of support Cont'd from p. 6

ers came out of the family pocket. During that first year alone, our entire savings were wiped out.

Fortunately, our wonderful neighborhood organized a fundraiser to help pay our expenses. Plus, my husband and I assumed a strategy of divide and conquer: his job, to earn more by working as many hours as possible; mine, to take care of everything else. And for the next 11 years, we were able to hire student teachers and therapists to work with Rohan at home after school.

When Rohan turned 14, Tushar was offered a good position in southern Delaware, so we moved. Leaving the Douglass School in New Jersey was hard. As one of the first in the country founded to educate children with autism, the school had a wonderful community of support, and we knew and trusted the staff.

We also had to say goodbye to our home, our friends, and our wonderful neighborhood community. The uncertainty of what we faced in a new state—as well as a different school for my son—weighed on the family like the fog we witnessed our first day in Lewes.

But just as the sunlight melts the fog away, everything changed with the light of our new town and the people in it. We quickly saw that this community, remarkably, was even more supportive than the one we had left! We learned that eastern Sussex County had grown accustomed to seeing autistic students shopping in stores, crossing the streets in downtown Lewes, eating in restaurants, recycling, and working at jobs in the community. Therefore, most neurotypical residents were not fazed one bit by our son and his crowd. What a wonderful place to live!

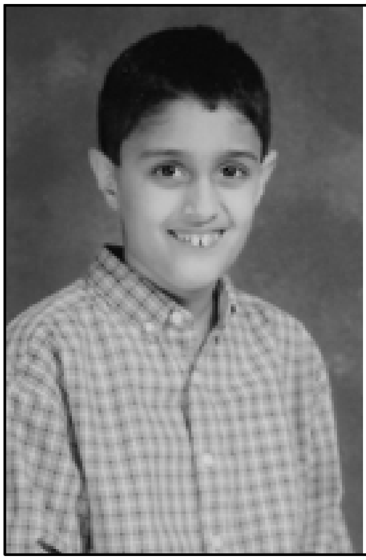
Needing specific information for Rohan's care in the First State, the Douglass School recommended Autism Delaware℠. The executive director at the time, Theda Ellis, spent hours with me on the phone, answering my many questions. Because of her expertise in the disability system—and her much-appreciated patience with me—my fears were allayed.

Another expert whose help proved invaluable was Melissa Tice Martin. At the time, Melissa was the executive director of the Lower Delaware Autism Foundation (LDAF). Both Melissa and the parents of Sussex County were beyond supportive and welcoming to my family. And my son loved attending the LDAF programs, including summer beach camp, swim program, fundraising walks, picnics, social skills classes, and a weekend social group that met monthly.

In 2010, LDAF merged with Autism Delaware. Over the years, Autism Delaware not only continued the LDAF programming that Rohan loved, but the agency also sent trained staff to Rohan's school to help define his individualized education program (IEP). Later, we needed Autism Delaware's professionals in family services to mediate a dispute with the school. As a result, Autism Delaware advocated for and achieved changes to the state procedures regarding behavioral management guidelines.

Autism Delaware staff was there for us when we needed them. And the organization continues to be there for my son. Rohan turns 30 this year and enjoys his job at Big Fish Grill in Rehoboth and the recreational support he receives as a participant in Autism Delaware's adult services program.

As a longtime member of the Autism Delaware Board of Directors, I have served in good times and bad and have faith that Autism Delaware not only will recover fully from the COVID-19 challenges but will be better and stronger for individuals and families affected by autism in Delaware.



Also in 1998

We got our first personal computer—and my son lit up. I could not believe how quickly he took to it, navigating the mouse to click on pirates and gophers while squealing with delight. He's almost thirty now and still recites phrases from those first CDs.

My journey: Changing the norm

by Rob Gilsdorf

Clip Art

I was president of the Autism Delaware℠ Board of Directors in 2010, when the Lower Delaware Autism Foundation (LDAF) merged with Autism Delaware.

Only months prior, Autism Delaware had been known as the Autism Society of Delaware, and I was overseeing a successful defense against a lawsuit filed by the umbrella group Autism Society of America (ASA). This suit was initiated because the small group of New Castle County parents who comprised our organization had decided to step out from under the ASA umbrella so that we could become an independent 501(c)(3) nonprofit agency.

We changed our name to "Autism Delaware" because it reflected our goal of becoming a statewide autism agency. And with the LDAF merger, support for this goal now extended into the southern part of the state.

Together, we began by expanding our adult services, which include vocational programming referred to as Productive Opportunities for Work and Recreation℠ (or POW&R℠, for short). We set up in Kent County in 2011 and in Sussex County in 2012. And in 2013, POW&R was nationally recognized as an "effective program."

Overall, I've been an active participant with Autism Delaware on and off for 20 years. My association was made possible because of my connections in Dover throughout the 1990s. I'd been a member of the Appoquinimink school board, and by 1998, former Governor Ruth Ann Minner appointed me to the state's board of education. In this capacity, I participated in the initiative that created the statewide directorship of the Delaware Autism Program (DAP). Subsequently, former Governor Minner appointed me to the state's public assessment and accountability advisory committee.

In my work for the state, I kept running into Marcy Kempner. The parent of a son on the spectrum, Marcy invited me to join the small group of parents who had gotten together over the Kempners' kitchen table discussions. Because of my experience and connections in the state, the group named me chair of their legislative committee, and I oversaw several efforts. To name two: We worked at setting up an autism registry and at limiting the mercury level determined suitable in vaccines.

Continued on p. 9

Rob Gilsdorf was president of the board of directors as the Autism Society of Delaware underwent a name change to Autism Delaware and began statewide expansion from 2007 to 2011. Rob also chaired the agency's legislative committee.

Currently the sales director of Veolia Regeneration Systems, Rob resides in Middletown with his wife Judi. Their 33-year-old son Andrew works part time at Autism Delaware and resides in an independent-living model created by Rob and Judi in 2015. Recently, Rob was drafted by the A-Team of Delaware to work on its housing task force.

My journey: Changing the norm

Continued from p. 8

Starting in 1982, I had an active career at DuPont—but then, my son, Andrew, was diagnosed with autism.

The diagnosis and acceptance of Andrew's autism were not easy issues for me and my wife Judi to handle. From the start, we denied the accepted norms that "Andrew would remain unmanageable," "Andrew would never progress," and "the world around Andrew would never be able to support him."

In addition to searching for "a cure" and trying to get our questions answered, Judi and I immersed ourselves in advocacy through public service, volunteerism, serving on school boards, and lobbying our local state representatives for change in Delaware.

When I joined the Kempners' kitchen table discussions, I learned that many of the parents' concerns revolved around the future because many of their kids were in the 10–13 year age range and attending DAP—where they would age out of the education program at 21. So, the parents were asking: What will happen to our kids when they are no longer supported in school?

Judi and I were already overwhelmed by the amount of information we needed to wade through just to meet Andrew's immediate needs. Now, we were facing another life-changing issue.

At that time, I focused all of my energy on Andrew—and I didn't work as diligently at taking care of myself as I should have. Instead, I sidelined my personal well-being. I allowed myself to get run-down and slipped slowly into a danger zone of fear, anxiety, and depression. And I began drinking way too much alcohol. I found myself suffering and less able to support my family as they deserved.

I needed to be present for my family and available to deal with what my life had wrought. I began by admitting to myself, to paraphrase the Alcoholics Anonymous® first step, that I was powerless over alcohol and my life had become unmanageable.

I stopped drinking in 2015—and my life blossomed. My professional career took off, and I earned better support financially. The journey has made me much more effective and better as a person. My life opened up for me—and I have hope again!

If you are a parent who's reading this article, if my journey is resonating in you, and if you think I can help you, feel free to call me at (302) 312-1422. If you need to leave a message, I promise a rapid callback.

Also in 1998

I dreamed of some day...

running for a seat in the U.S. Congress,

Clip Art

hiking the 2,190+ miles of the Appalachian National Scenic Trail, and

riding my bicycle across the U.S.

Overwhelmed?

Get help!

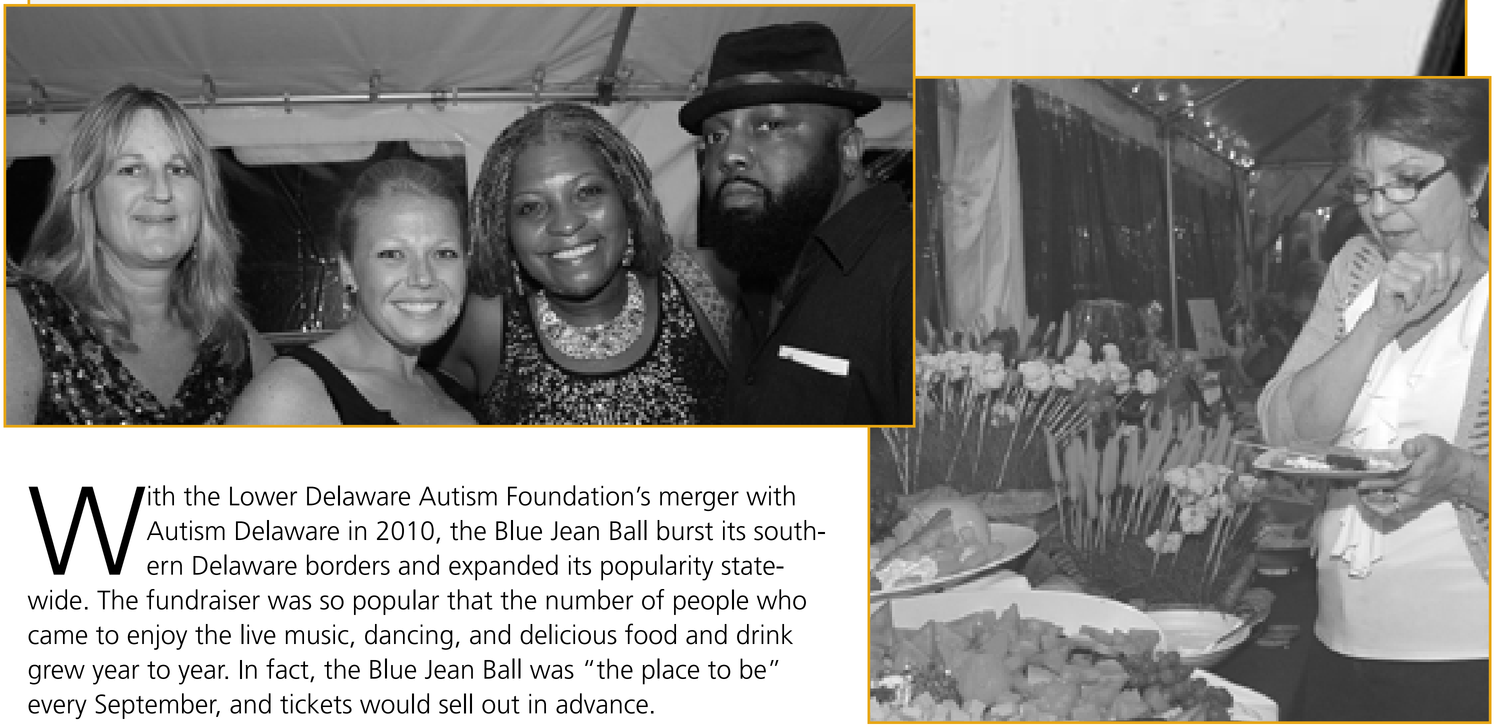
Autism Delaware℠ family support webpage: https://www.autismdelaware.org/family-support/

Send an email to Autism Delaware's intake coordinator at support@autismdelaware.org**.**

Or call (302) 224-6020, ext. 219.

The Blue Jean Ball goes statewide

Clip Art



Photos are from the 2013 Blue Jean Ball

With the Lower Delaware Autism Foundation's merger with Autism Delaware in 2010, the Blue Jean Ball burst its southern Delaware borders and expanded its popularity statewide. The fundraiser was so popular that the number of people who came to enjoy the live music, dancing, and delicious food and drink grew year to year. In fact, the Blue Jean Ball was "the place to be" every September, and tickets would sell out in advance.

With such a popular stage, the number of event sponsors, food donors, and auction item donors also grew. So many individuals, organizations, restaurants, and businesses donated goods and services that there are too many to thank on this one newsletter page. But each and every one deserves the deep gratitude of the autism community. Plus, Autism Delaware is grateful for each and every sponsor because, thanks to their generosity, Autism Delaware's programs and services were able to expand across the state as well.

Click to view each list of past Blue Jean Ball sponsors: Blue Jean Ball sponsors
Blue Jean Ball in-kind food donors
Blue Jean Ball in-kind item donors

Celebrating Smart Cookie Day 2023

On April 4, Delaware Governor John Carney signed the declaration that officially named April as Autism Acceptance and Inclusion Month in the First State.

Receiving the declaration from Gov. Carney, Autism Delaware executive director Brian Hall, M.S.W., expressed his thanks on behalf of Autism Delaware.

Brian was one of 31 autism advocates who visited their state representatives to thank them for their legislative support over the years.

Photos by Lisa Walenceus

Meet Kim Covey

As Autism Delaware's new intake coordinator, Kim Covey is responsible for welcoming new clients, recording their information, and assigning the support that meets their specific needs. Before joining our family support team, Kim was first contact at an emergency restoration company. In this capacity, she dispatched work crews and coordinated with insurance carriers to make the situation as easy as possible for the customer.

Programs

This list comprises programs for July to September, which had been scheduled by *The Sun*'s July 1 publication date.

For the more up-to-date list, visit https://www.autismdelaware.org/events/.

Family support services

Jul. 26 **Grandparent support group and coffee hour**
Lewes office conference room. 9:00 A.M. Free.
R.S.V.P.: Tomara Williams

Jul. 26, Aug. 16, Sept. 27
Coffee hour for all primary caregivers
Virtual. 7:00 P.M. Free. R.S.V.P.: Heidi Mizell

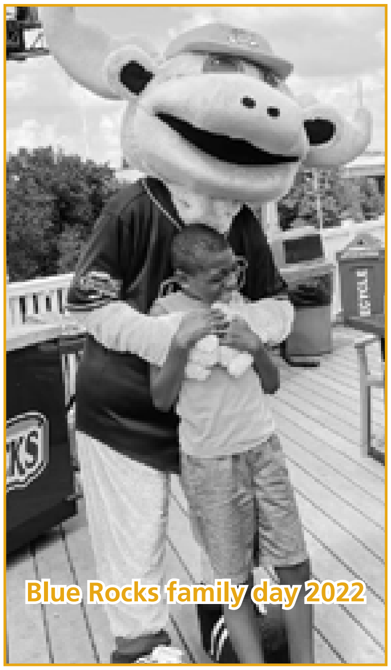
Sept. 27 **Speaker Series: Planning for Your Loved One with Special Needs** Zoom event.
12:00–1:00 P.M. Free. R.S.V.P.: Heidi Mizell

Sept. 28 **Coffee hour: "Newly diagnosed? Start here!"** Virtual. 7:00 P.M. Free.
R.S.V.P.: Heidi Mizell

Community engagement

Jul. 9
Day at the Blue Rocks
12:30 P.M.
Frawley Stadium.
$18/person.
R.S.V.P.: Susan Campbell

Aug. 13
Beach picnic
12:00 noon.
Cape Henlopen
State Park.
R.S.V.P.: Susan Campbell


Blue Rocks family day 2022

Advocate for autism acceptance and inclusion, fundraise in support of much-needed programs and services, and spend precious time with the people you love—with every step you take!

October 7
Ft. DuPont
Delaware City

October 14
Hudson Field
Milton

For more info, click here.