

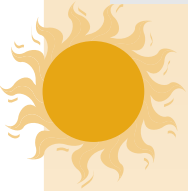
Resources

[Stay Connected to Combat Loneliness and Social Isolation.](#)

Click on the link above for an easy-to-read pamphlet that describes the downside of loneliness and ideas for staying connected.

KidsHealth from Nemours offers *Community Service: A Family's Guide to Getting Involved.*

[Click here for the two-page site.](#)



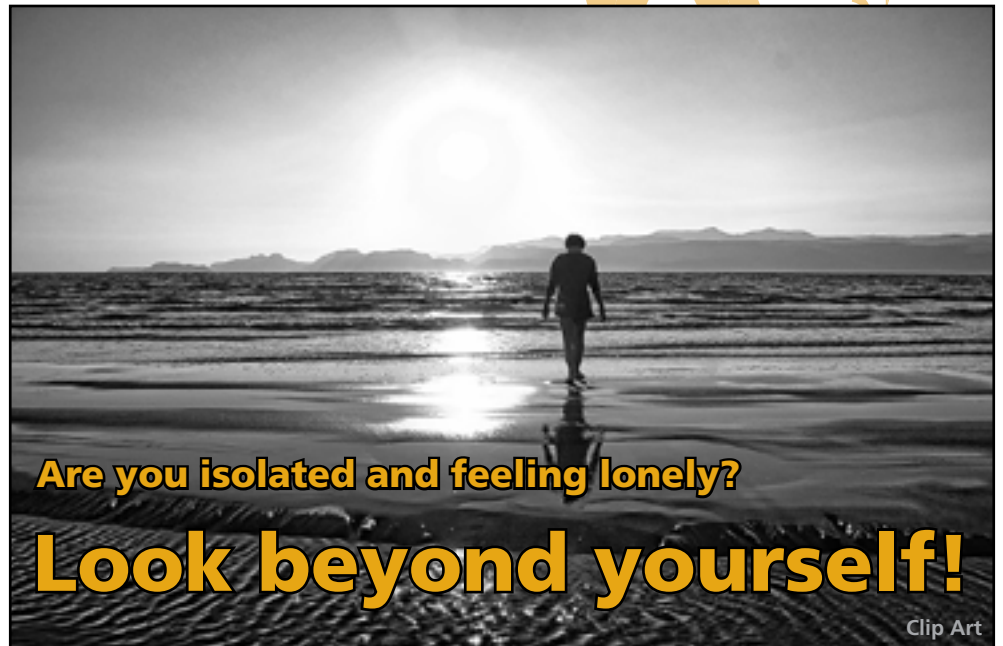
Our mission

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

The Sun

Newsletter

Winter 2022



It's not surprising that you have been isolated and feeling lonely, especially with all you've had on your proverbial plate as the parent or caregiver of a child or adult on the autism spectrum.

"Often, as the parent of a child with a disability," notes parent-advocate Cory Gilden, Ph.D., "you get stuck in your own little world and the day-to-day care of your child."

Gilden is also the research and evaluation manager of the National Leadership Consortium on Developmental Disabilities, so she understands how you can become unstuck: "By participating in advocacy, volunteering, and research efforts to advance the field, you can feel more connected and connect with more social supports and community resources. So, look beyond yourself, and become part of the autism community."

In this issue of *The Sun*:

- Parent-advocate Karen Tuohy explains how she connected with the autism community through social activities and community resources—page 3.
- Parent-advocate Jen Nardo shares how she volunteered her skills and time and found community—page 4.
- The hope that research data will benefit the autism community—page 6.
- Research goes to the movies!—page 7.
- Kyle Bryan describes how he began self-advocating and found his place in the community—page 8.
- Junior Partners in Policymaking teaches how to self-advocate—page 9.

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

An annual overview

This winter issue of *The Sun* means a new year and the promise of better days—or at least, I’ll know more than I did last year! As winter 2021 rolled around, my words to you were about autism and the new challenges (Read: COVID-19). As the parent of a young adult on the spectrum, I sympathized with other parents who suddenly found themselves working from home, reaching out for special services, and feeling alone and overwhelmed. And I made a promise: “As soon as safely possible, we hope to get back to the same level of service everyone enjoyed before the pandemic.”

And Autism Delaware has made great strides toward this promise:

- **Adult services staff** now maintains COVID testing and safety measures for participants in the Autism Delaware program known as Productive Opportunities for Work and Recreation (or POW&R, for short). Also, POW&R staff continues to provide one-on-one employment support and community resources to POW&R participants while also reaching out to businesses, agencies, and other organizations in the hope of creating much-needed community partners. Community partners are highly valued for their commitment to supporting adults on the spectrum who want to work and live full lives in their community.

For more information about POW&R, visit <https://www.autismdelaware.org/services/adult-services/>.

- **Family support staff** also maintains COVID testing and safety measures

while providing individualized help for each Delaware family affected by autism spectrum disorder (ASD). This much-needed support includes navigation through the state’s systems. And the Autism Care Team (ACT) assigns each family with a family support provider (FSP) who is also a system-wise parent.

For more information about family support services, visit <https://www.autismdelaware.org/services/family-support-services/>.

- **Fund development and engagement staff** is well aware that the need for more supports and services has increased with the COVID pandemic. The need was already great because of the ever-growing number of individuals and families affected by ASD! So, staff ramped up Autism Delaware’s fundraising effort and installed strict safety guidelines set by federal, state, and local authorities.

For this reason, staff set the date for the 2021 Walk for Autism six months later and staggered four starting times for those who chose to take part in person. (Of course, a virtual walk was also available.) Whether walkers chose Fox Point State Park in Wilmington or Cape Henlopen State Park in Lewes,

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Brendan O’Neill
President
Board of Directors

All information provided or published by Autism Delaware is for informational purposes only. Reference to any treatment or therapy option or to any program, service, or treatment provider is not an endorsement by Autism Delaware. You should investigate alternatives that may be more appropriate for a specific individual. Autism Delaware assumes no responsibility for the use made of any information published or provided by Autism Delaware.

Connect through social activities and community resources

by Karen Tuohy

People say that the first step is the hardest, and in a sense, that is true. After a long day at work, the last thing you want to do is leave the house for an activity that you're not sure will benefit you or your child.

Go anyway! Get out of the house, and join in. Not only will your child benefit from enhancing his or her social skills (such as turn-taking at bowling), but you will also benefit from connecting with members of your community.

For a community resource, I recommend Autism DelawareSM. This organization has helped and supported a tremendous number of individuals and their families in our community.

How do you become a part of this community?

It's easy! Just go to one of the many activities provided by Autism Delaware. Once you do, you will be compelled to go again and again.

When you go, you will meet people who have the same concerns and worries about their loved one's future as you do. After you get to know these people, you will discover



John Priester and Karen Tuohy at the 2019 Halloween bowling party

When new health and safety protocols have been established and put in place to protect our community, Autism Delaware will restart social recreation programs, such as Wednesday night bowling.

that they are a great source of support with a solid knowledge of resources that will address your loved one's needs. After all, these people are experiencing the same or similar issues as you.

I have often said that attending Autism Delaware bowling on Wednesday night is my mini-support group. I heard the same from a mother of one of my bowlers: She confessed to me one day that her son

did not really want to bowl that night. "You don't have to bowl," she responded, "but we need to go because I need to talk to my friends!"

Karen Tuohy works full time for the Red Clay School District, is mom to two adult children on the spectrum, and is a longtime manager of Autism Delaware's Wednesday night bowling for families affected by ASD.

Volunteering your skills and your time to a community effort, such as a nonprofit’s fundraiser, has its benefits:

- The event runs more smoothly and efficiently.
- Instead of paying for help, the nonprofit can put more of its fundraising dollars into much-needed programs and services.
- And you become a valuable part of your community.

Please know: Volunteering does not have to become a second full-time job. Organizations like Autism Delaware or your child’s school happily welcome any time that you have to offer.

Here’s how I got started:

After my son’s diagnosis of fragile X syndrome in 2000, I was devastated. I felt isolated and alone, like no one else could possibly understand what I was going through. And I had no idea how to help my son.

As I learned about the syndrome, I felt stronger and dove into helping Jake. Years later, he was diagnosed with autism—another hit, another worry.

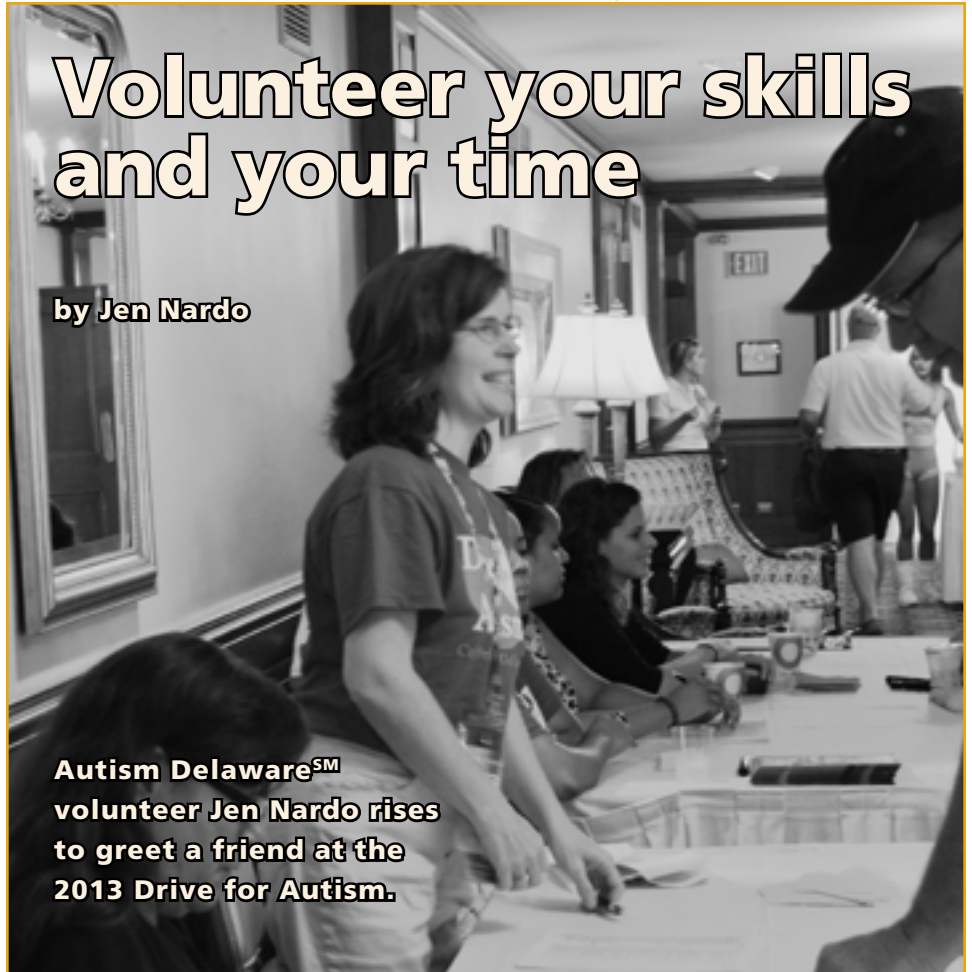
As time went on, I learned of a foundation that funds research for fragile X syndrome, and I realized I could use skills from my past work experience to help the foundation. I started organizing small fundraisers, like dances in a church basement and motorcycle runs. I felt elated to be adding to the research dollars that could bring a higher quality of life to my son.

With the autism diagnosis, I gained more local resources, mostly Autism Delaware. Feeling strong emotionally and wanting to support my son and other families, I started volunteering at Autism Delaware golf outings, for this newsletter, whatever was needed and whatever I could bring to the organization from my past work experience.

Volunteer your skills and your time

by Jen Nardo

Autism DelawareSM volunteer Jen Nardo rises to greet a friend at the 2013 Drive for Autism.



I quickly learned that Autism Delaware could use help in any form, and I talked it up to other parents. We all have skills that could aid in the running of a nonprofit that is doing its best to help us—individuals and families affected by autism.

As my son grew and started high school at the Delaware Autism Program, he also started volunteering through the vocational program at school. He worked with animals at a local pet shop, he cleaned a trampoline park and a ballet studio—wishing the ballerinas were there to watch practice—and he put away books at the library.

Through volunteering, Jake learned social skills and how to be in public and to ask for help. My son gained a confidence that allowed him to try new jobs, which readied him for the paid work he does today as an adult. And he had a great time!

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A well-respected contributor to the newsletter, Jen Nardo has been developing ideas and writing articles for *The Sun* for 13 years. She is also a longtime volunteer for Autism Delaware fundraising events, such as the Drive for Autism, and the parent of two adult sons, one neurotypical and one on the autism spectrum.

Volunteer your skills and your time

Continued from p. 4

The rewards of volunteering are many. I get a feeling of fulfillment when I see a fundraiser come to life. The opportunity to be with other parents working toward the same goal reminds me that, in our autism community, we are always here for each other. And the friendships that grow from volunteering are priceless.

You'll even meet other volunteers who do not have autism in their families, yet they show up to these events year after year. They renew my faith in humanity.

Jen's 5 ideas for finding opportunities to volunteer

- Google local agencies that specialize in your child's diagnosis. Check out their websites for events, and call to see if anyone is needed to work. Get on the list as a potential volunteer for future events as your schedule allows.
- Google recreational programs for your child, and ask local agencies and other parents. Whether a group is small or large, they all need helping hands. It's a win-win situation because you help keep the program afloat for your child and other families while also becoming a needed part of the community.
- Offer your help to your child's teacher or the PTA/PTO (parent-teacher association or parent-teacher organization) at the school. If your child's teacher has a need, you can organize a way to fill it.



Jake Nardo relaxing at home

- Don't be afraid to ask local businesses to help with your projects. I have found that people want to help; they just need the opportunity.
- Check out the Delaware State Office of Volunteerism at <https://volunteer.delaware.gov/volunteers>. You may find events in which your child shows an interest. A volunteer opportunity could become a family event where your child learns important skills.

Volunteer opportunities at Autism DelawareSM!

Autism Delaware relies on volunteers to help provide a range of services, events, and resources. For more information, contact Autism Delaware volunteer and community engagement specialist Susan Campbell at Susan.Campbell@delautism.org.



Contribute to research that could benefit your community

by Carla Koss

Clip Art

Why do people take part in a research study? What do they expect to get out of sharing their experience on the autism spectrum?

“It’s possible [participants] will receive no benefit because it’s a research study,” begins clinical psychologist Vanessa H. Bal, Ph.D., “but you could contribute to research that could benefit the autism community.”

As the Karmazin and Lillard chair in adult autism at Rutgers University, New Brunswick (N.J.), Graduate School of Applied and Professional Psychology, Bal was awarded an Organization for Autism Research (OAR) grant to develop mental-health resources for college students on the spectrum. Currently, she oversees the multiple layers this feasibility study could fit into. Her team is collecting mental-health data and getting feedback from college students, covering everything from “To what extent would this study be useful?” to “Should we modify the study’s design?”

“It’s an ongoing, fluid study,” adds Bal. “We are trying to understand stressors in the college environment and strategies for dealing with that stress.”

Some stressors that the students have identified include

- sitting in a noisy classroom.

- lights that are too bright.
- someone in the room clicking their pen.
- interaction with a professor who’s challenging so the students need to advocate for themselves if an accommodation is needed.
- a deadline changes unexpectedly.

“We asked the students if they wanted to participate beginning back in August through the first two weeks of the semester,” continues Bal. “For some, it sounded good because the study fills a need in this transition [into the first year of college]; others said ‘Now is not a good time.’”

“Since the study included intervention designed to help cope with stress in college,” notes Bal, “we hope to learn the best timeline for offering the intervention.”

“The point of intervention is individualized, flexible,” says Bal. “Plus, as the study’s first participants, the students are really shaping this intervention.”

What do you tell parents who may question their child’s participation in your research study?

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Contribute to research

Continued from p. 6

“For parents: We’re monitoring the mental health of your child during the study, so if he or she shows elevated symptoms, we’ll reach out and give your child resources for more formal supports.”

In other words, the students in Bal’s research study have the opportunity to connect with more supports and community resources as well as to contribute to research that could benefit the autism community.



Clip Art

Another research project for adults on the spectrum is being offered by Rutgers University’s Vanessa H. Bal, Ph.D.

Enroll in the focus group if you have experienced depression or low-mood and prior mental-health treatment.

An opportunity also exists to be consulted by the researchers, so your autistic voice can be represented.

For more information, send an email to LifeSPANLab@gsapp.rutgers.edu.

A movie came out of a research project based at the University of California, Riverside (UCR).

Overseen by Jan B. Blacher, Ph.D., the project began because Blacher holds an abiding interest in the families of children with disabilities. She carried this interest onto the UCR college campus as the distinguished research professor in the School of Education and director of the SEARCH Autism Center.

“Every April, I hold an awareness program,” explains Blacher. “It’s student-centered, but a lot of professors come. I’m often asked how to deal with students with autism.

“Out of this awareness program evolved an awareness research study with 1,200 participants that was published in the *Journal of Applied Genetics*,” continues Blacher. “The study involved talking to students on campus about how little the faculty knew about autism.

“On the flip side, the staff was interested and empathic, and saw that, if they can’t reach a student with autism, it’s their fault—not the student’s. This seemed like good information to record.

“I happened to know Eric Linthorst [the movie’s director/producer and co-writer

with Jodi Becker] and appealed to him for a way to film the study,” adds Blacher, who served as the movie’s executive producer.

“It was Eric who said ‘You have terrific material in these publications,’ so we decided to put the material on YouTube. But as Eric started filming, he suddenly stopped and said ‘This is a documentary!’”

The movie’s title is *Autism Goes to College*. “The film’s mission was to diversify who students with autism are,” defines Blacher. “All film and TV have been white, so we wanted to diversify the participants’ background and culture.

“We also put autistics in the driver seat, let them drive the research and the documentary, respected their decisions.”

Released in 2019, *Autism Goes to College (AGTC)* has been praised and designated an official selection at the SXSW Film Festival, Newport Beach Film Festival, Awareness Film Festival, Heartland Film Festival, and American Cinematheque.

The AGTC team has also created a series of podcasts. Each features an individual from the film who answers some of the questions that have come through the AGTC website.

For more information on how to view the movie and the podcasts, visit AutismGoesToCollege.org.

Share your story

by Kyle Bryan and Carla Koss (Ed.)

**Self-advocate Kyle Bryan and
Delaware Governor John Carney**

Before becoming a self-advocate, I tended to keep my autism diagnosis to myself. I felt ashamed, telling myself I was cursed with a condition that had dominance over my life. Not because of anything I had done or deserved, but like a cruel inheritance. I had no say as to whether I wanted it or not.

The shame lingered for years. It wasn't until 2010 that my walls of shame started to crumble. Through my volunteer work in the Autism DelawareSM adult services program (Productive Opportunities for Work and RecreationSM, or POW&RSM, for short) and, later, my employment at various small businesses, I met others with autism and saw how they were willing to express themselves—despite their limitations! This caught my attention because I thought my limitations were shameful.

Seeing hope for my own future, I began to open up. And once I started to share my story, an opportunity opened for me. In February 2016, a co-worker and natural support at Autism Delaware, Carla Koss, asked if I would be willing to be an advocate for [Smart Cookie Day](#). I was a little nervous at first,

so Carla suggested that I talk to then-Autism Delaware policy and community outreach director Alex Eldreth. After speaking with Alex, the anxiety went away, so he and Carla walked me through what would happen on Smart Cookie Day. Plus, I was taught how to interact with members of the Delaware General Assembly. I also learned new skills, such as how to shake hands, and practiced speaking in front of people.

I struggled at first with organization and focus, but through the mentoring I was given, my thoughts, words, and etiquette soon came together. And the work paid off! I was asked to be a team leader and assigned a group of parents and autistic children. Our task was to speak to several members of the general assembly, advocating our needs and stressing the importance of continued legislative support.

About lunchtime, the Smart Cookie Day delegation met in then-Gov. Jack Markell's office for the signing of the autism awareness proclamation. But before the signing, the governor welcomed any words that we'd like to share.

My turn came, I took a deep breath, and read aloud from the outline I had written. When I finished, the room erupted in applause! Alex and Carla were so proud of me! And the governor praised me for the clarity of my speech and the impact my words had on him.

After the governor signed the proclamation, I was approached by a number of autistic individuals, parents, and legislators who said they were also impressed by my words and thanked me for sharing my story. Some people admitted that my

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A member of Autism Delaware's Smart Cookie Day delegation since 2016, self-advocate Kyle Bryan continues to share his story and advocate for legislation that will better the lives of individuals and families affected by autism spectrum disorder.

Share your story Continued from p. 8

words were what they would have said—if they could have found the words!

I was also interviewed by an NBC-affiliated news reporter. Seeing myself on TV and hearing the words I spoke—“that we with autism can speak for ourselves”—made me realize that something positive had happened on Smart Cookie Day. This realization spurred me to continue to participate in Autism Delaware’s advocacy effort. For the first time in my

life, I sensed that I could make a difference.

Even if I hadn’t shared my story that first time five years ago, I was able to witness the testimonials of autistic individuals. Through their bravery—sharing their stories with our state legislators and in the governor’s office—I was inspired and saw how others could be inspired as well. The self-advocates’ words created a sense of pride in myself—and the winds of change were blowing!

Self-advocacy for young adults

by Michael Harris, Developmental Disabilities Council Chair, and Daniese McMullin-Powell, Developmental Disabilities Council Vice Chair

The Delaware Developmental Disabilities Council (the Council) is proud to host Junior Partners in Policymaking (Jr. Partners). This summer program is for young adults, ages 15 to 22, with developmental disabilities. Their family members are also welcome.



- the importance of self-determination
- ways to self-advocate for the issues most important to you
- your rights in and out of school
- laws that affect important issues, such as the rights of and services for

individuals with disabilities

- how to make your own impact on public policy (laws).
- how to plan the future you want
- improving your advocacy skills
- directing your own IEP [individualized education plan] meetings
- ways to identify your interests to help you choose a career

Jr. Partners is typically held within a university setting, where participants live and learn for six days and five nights. Each day, the participants are engaged in fun, exploratory, and hands-on classes that encourage leadership and self-advocacy. In the evenings, these young leaders can get together to enjoy activities and entertainment.

At one of the sessions, participants have an amazing opportunity to practice giving mock testimony about an issue they are passionate about. Legislators who are invited to attend this session offer productive feedback.

The following include some of the areas that participants have the opportunity to learn about:

The next Jr. Partners program will be held in the summer of 2022. Specific dates and program details are still being finalized. As the information becomes available, it will be placed on the Developmental Disabilities Council website at <https://ddc.delaware.gov/>.

For an application or additional information about Jr. Partners, send an email to Stefanie Lancaster at Stefanie.Lancaster@delaware.gov.

Self-advocacy for adults

In addition to the Jr. Partners program, the Delaware Developmental Disabilities Council hosts Partners in Policymaking (Partners) for

- adults over 22 with developmental disabilities.
- parents raising young or school-aged children with developmental disabilities.
- students seeking to work in the disability community.

Partners provides up-to-date information, education, and skill-building activities concerning the legislative process and local, state, and national issues that affect individuals with disabilities.

Partners graduates are equipped with the tools to work for positive change in public policy. The overall goal of the program is to foster a partnership between those who are affected by public policy and laws and those who make public policy and laws.

For more information about Partners, reach out to Stefanie Lancaster at Stefanie.Lancaster@delaware.gov.

Meet our new staff



Melinda FitzGerald
Billing Associate, Family Support

Melinda will handle the billing process for family support's Autism Care TeamSM (ACTSM) program.

She has more than 30 years of experience in providing financial support for medical services, including work with Blue Cross Blue Shield of Delaware, Christiana-Care, and Workpro Pivot Occupational Health.



Susan Campbell
Volunteer and Community Engagement Specialist

Susan is a longtime volunteer for Autism Delaware, starting as a photographer for the Drive for Autism and moving into a planning role for the annual auction. Plus, she's active in nonprofit fundraising in the Middletown community.

In this newly created position, she will manage volunteers for Autism Delaware's fundraisers and select community needs as well as develop a strategy to enhance engagement with all key stakeholders.



Lisa Walenceus
Marketing and Communications Manager

Lisa brings more than 30 years' experience in nonprofit programming, communications, marketing, and outreach to the newly created position of marketing and communications manager.

In this role, Lisa is responsible for developing and implementing a multi-faceted marketing and communications strategy driven by Autism Delaware's mission, which is to help people and families affected by autism spectrum disorder (ASD).



Scholarships for the 2022–23 academic year

Each year, Autism Delaware funds three scholarship opportunities:

- Daniel and Lois Gray Memorial Scholarship
- Adults with Autism Scholarship
- Autism Teacher Certification Scholarship

All applications are reviewed by a committee comprised of Autism Delaware staff and board members. This committee makes decisions on an annual basis. Applications are competitive, and the number of available scholarships depends on the available funding and the assessment of the scholarship review committee.

Scholarship funds are dispersed to the winners' educational institutions in June and applied to the following semester. Scholarship winners will be announced formally at the annual Autism Delaware Volunteer Award Dinner.

Completed application materials should be sent via email to liz.carlisle@delautism.org by the application deadline.

For questions, call (302) 224-6020, ext. 208.

Application deadline: Midnight April 29, 2022

Daniel and Lois Gray Memorial Scholarship

The Gray memorial scholarship is for University of Delaware (UD) students pursuing an autism-related career in Delaware.

Who is eligible?

- full-time undergraduate and graduate students at UD
- students who are majoring in special education, psychology, linguistics, or speech pathology (or related majors) with a special interest in autism spectrum disorder (ASD)
- students with a cumulative grade point average of at least 3.0

Note: Although not available to students graduating from high school and enrolled at UD for the following academic year, we encourage them to apply when they have declared a major in a course of study that will lead to a career in an autism-related field.

Financial need is considered.

Adults with Autism Scholarship

This scholarship provides financial support to eligible adults with autism spectrum disorder (ASD) who live in Delaware and are pursuing college or another post-secondary educational experience.

Who is eligible?

Any student and Delaware resident with ASD who

- has completed high school or earned a GED, and possesses the capacity to complete a post-secondary program
- has been accepted into a post-secondary program (such as college, university, community college, trade school, or vocational training or educational program)

Autism Teacher Certification Scholarship

This scholarship was created to provide financial support for practicing teachers in Delaware's public and charter schools who wish to pursue autism certification.

Who is eligible?

Any current teacher in a Delaware public or charter school who

- is currently working with students with autism spectrum disorder (ASD) in an educational environment
- has been employed full time in a school environment for at least one full school year
- has been accepted into an autism certification program of study at a Delaware institution of higher learning

For information on how to apply for an Autism Delaware scholarship, visit <https://www.autismdelaware.org/scholarships/>.

An annual overview

Continued from p. 2

they were able to safely enjoy the community spirit that's been missing in many of our lives.

For more information on how you can help raise funds for much-needed supports and services, visit <https://www.autismdelaware.org/get-involved/make-your-own-events/>.

• **The Autism DelawareSM newsletter committee** boasts an unbroken record for getting *The Sun* out each quarter during the pandemic. This accomplishment has been a struggle as staff and volunteers worked around sudden barriers, closures, and missing resources, all due to COVID. Plus, all the volunteers are parents who were sent scrambling, like the rest of us, to set up homeschooling and find suitable resources for their kids on the spectrum.

The committee also chose to embrace COVID as yet-another aspect of life for someone with ASD and his or her family. So, *The Sun* not only continued to publish up-to-date research

and best practice on "autism" topics, but it also published articles for families suddenly faced with grief and loss, their kids' increased internet usage, and the threat of a disaster during a pandemic. And then, the committee lightened the mood with a wonderful issue on why our kids are wonderful!

I hope you have taken heart in my annual overview. As the president of Autism Delaware's board of directors, I'm proud of the staff's effort. And as a member of the autism community, I am thankful for the ways that Autism Delaware staff and volunteers have struggled and succeeded in helping people and families affected by ASD. They deserve our gratitude.

Still feeling alone and overwhelmed? This issue of *The Sun* offers a range of ways to step out of your loneliness and become a highly valued member of the autism community. To discuss any of the options, call us at (302) 224-6020.

Your shopping can help people with autism and their families!

As you shop online, please consider donating to Autism Delaware through Amazon Smile.

If you shop through smile.amazon.com/ch/20-2110190, 0.5 percent of your eligible purchases will be donated to Autism Delaware—with no fees or extra cost to you!



Where does the money go?

If you donate to or fundraise for Autism Delaware, the money supports the range of programs and services needed by individuals with autism spectrum disorder (ASD) across their lifespans as well as services needed by the families affected by ASD:

Family support services include one-on-one system navigation for both the English- and Spanish-speaking communities, plus the Autism Care TeamSM (ACTSM) program, which connects each family with a family support provider (FSP).

Adult services include community-based vocational support, day-habilitation, and social and wellness activities.

Autism Delaware also provides advocacy at the state and local levels and awareness, which includes the online resource guide, quarterly newsletter, group updates, and social media.

For details, visit [AutismDelaware.org](https://www.AutismDelaware.org).