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DECEMBER 2024
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THE STORY BEHIND THE SMILE

Jeremiah Feliciano and friends

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FAMILY AND COMMUNITY

FEATURES

ON OUR COVER

The support systems of family and community are an integral part of the holidays for those that are caring for loved ones with special needs. Through the love and diligence of his family, Jeremiah Feliciano is able to live a healthy and productive life despite his rare genetic disease. Read his story and much more in EP's Annual Family and Community Issue.
Coverage begins on page 15.

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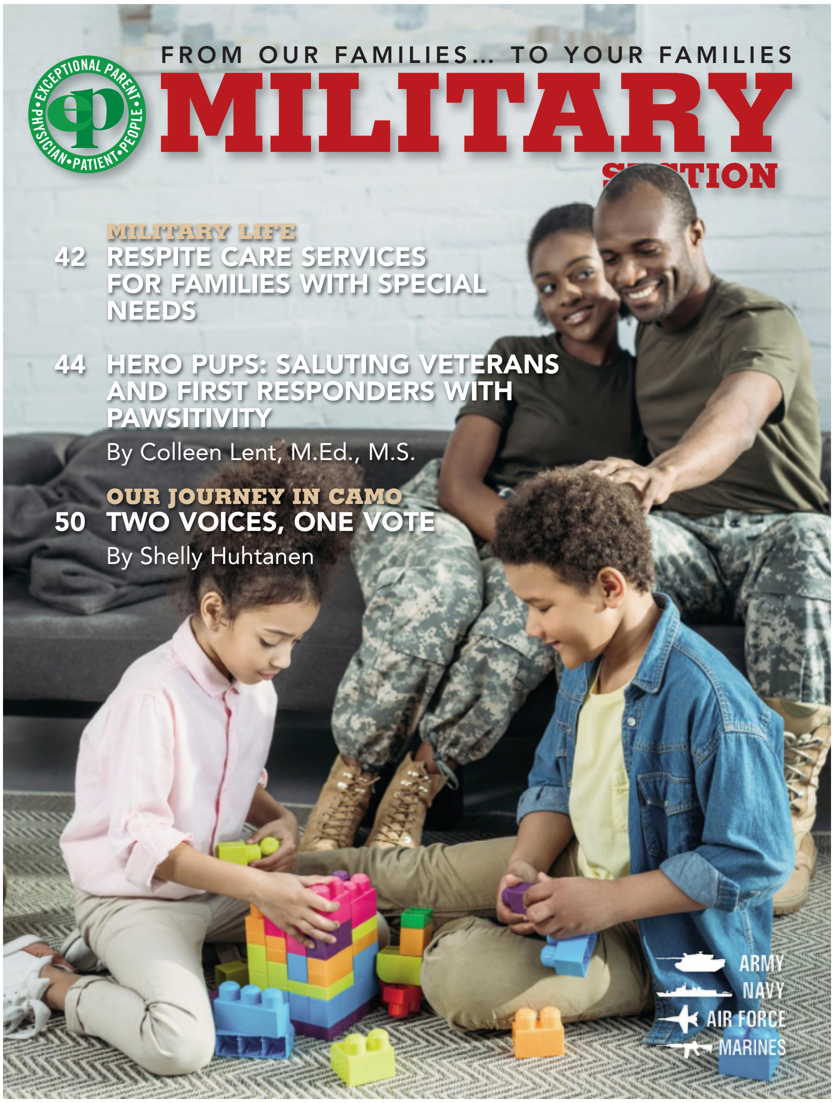

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EP Magazine thanks the authors and advertisers who allow us to keep this wonderful resource going, and keep EP for Free.

During this time of celebrations, we should take time to appreciate what we have. For those that are caring for loved ones with special needs, gratitude is often directed at family and community. Without these crucial support systems, parents would have an extremely difficult time.

Our December issue's theme is Family and Community, and we bring you several stories that highlight their importance in the lives of those featured in our articles. For Jeremiah Feliciano, the subject of our cover story, the therapists, parent advocates, specialized schools and extracurricular activities that his parents have been able to access for him, benefit him immensely.

> Without the crucial support systems of family and community, parents would have an extremely difficult time."

Brette Haines, in her article "A Transformative Experience: Supporting My Cousins with Usher Syndrome," describes her desire to be a more empathetic family member for her two cousins living with the condition, and how it has changed her outlook on many aspects of her life.

In addition, we offer several articles that aim to ease some of the stress associated with the holidays, especially for family members with disabilities. Marta Chmielowicz contributed "Autism-Friendly Tips for a Successful Holiday Season, and Kari A. Baker adds "Surviving School Holiday Parties with Your Neurodiverse Kid."

You will also find a special section that addresses holiday travel and accommodating guests with mobility issues in your home.

Respite from caregiving is an ongoing challenge. Two articles (including one specifically geared toward military families) showcase new programs that provide planned short-term and time-limited breaks for families.

Thank you readers for the comments, suggestions, and questions about *EP Magazine*. We appreciate your feedback, which helps us maintain the relevance of our magazine.

I personally want to express my appreciation for all of you who share about the magazine and EP for Free, on social media, websites, through newsletters and word of mouth! My dream is that everyone who can benefit from this outstanding content knows they can read it for free.

Feel free to contact me at **epmagazinevp@gmail.com** or **fsimon@epmagazine.com**. Follow us on **facebook.com/exceptionalparentmag**, Instagram **@epmzine** and **x.com/epmzine** and share our posts. It's easy to subscribe and get "EP for Free" – just visit our homepage **www.epmagazine.com** and click EP for Free Sign Up!

Faye Simon

Editor In Chief

THE EDITOR IN CHIEF'S DESK

Faye Simon is a certified pre-K–8 teacher with a wide range of educational experience. She has worked in deaf/blind and infant stimulation programs, taught K–2 in public schools, and was a Head Teacher and Parent Coordinator for Head Start. She is Founder and President of the volunteer-run IES Brain Research Foundation. Faye has been interviewed about *EP Magazine* and IES Brain Research Foundation multiple times including on: Mrs. D's Corner, SFN Dad to Dad Podcast, Oscar Mike Radio, Wreaths Across America Radio, Shana Siegel's Aging Answers, and Able Today Show.

Information and Support for the Special Needs Community

VOLUME 54 ISSUE 12
ESTABLISHED 1971

Publisher
Len Harac
lharac@epmagazine.com

Editor In Chief
Faye Simon
fsimon@epmagazine.com

Art Direction & Design
Leverett Cooper
lev@foxprintdesign.com

Subscriber Services
1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012
www.epmagazine.com

Customer Service/New Orders
Faye Simon fsimon@epmagazine.com
(973) 726-6218

Publishing & Editorial Office
1360 Clifton Avenue, Ste. 327
Clifton, NJ 07012

Exceptional Parent (ISSN 0046-9157) is published monthly 12 times per year including the special January EP Guide - Navigating Special Needs Resources by Exceptional Parent Magazine, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 Internet address: www.epmagazine.com. All rights reserved. Copyright ©2024 by Exceptional Parent Magazine,. Exceptional Parent™ is a registered trademark of Exceptional Parent Magazine. Postmaster: Please send address changes to: Exceptional Parent,1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012. Any applicable periodical postage paid at Clifton, NJ and additional mailing offices (USPS 557-810). Basic annual subscription for EP Digital is free. Limited edition print subscription $199.00. Subscriber Service: Direct all inquiries & address changes to: Exceptional Parent, 1360 Clifton Avenue, Ste. 327, Clifton, NJ 07012 08758. Customer Service/New Orders: E-mail: fsimon@epmagazine.com or call (973) 726-6218. Back issues incur a charge of $17 each with shipping, (January issue $20 when requested) and depend upon availability. Call (973) 726-6218. Agreement #1420542

WHAT'S HAPPENING

PEACOCK NETWORK TO PREMIERE VISIT MYRTLE BEACH'S NEW TV SERIES "TRAVELING THE SPECTRUM"

“Traveling the Spectrum,” an unscripted documentary series following three families with members on the autism spectrum as they vacation in the Myrtle Beach, SC area, is set to debut on Peacock on December 12.

SEEING THE SIGHTS: *Traveling the Spectrum* follows the inspiring stories of three families as they take sensory-friendly vacations, highlighting the transformative power of travel.

A groundbreaking new series follows the inspiring stories of three families with members on the autism spectrum as they take sensory-friendly vacations to the Myrtle Beach area, highlighting the transformative power of travel.

Traveling the Spectrum will make its nationwide debut on Dec. 12, 2024, premiering on the Peacock streaming network. Visit Myrtle Beach selected Peacock and its worldwide audience of 33 million subscribers as a way to showcase how the Myrtle Beach area's sensory-friendly accommodations and welcoming spirit are creating unforgettable experiences for families.

“Traveling the Spectrum has the potential to change the world by helping families on the autism spectrum feel more comfortable exploring new destinations,” said Stuart Butler, Chief Marketing Officer, Visit Myrtle Beach. “By following along on their vacations and hearing their personal stories, we see the unique challenges each family faces and how our community steps up to provide a welcoming, inclusive experience.”

> *“According to Autism Travel Club, Myrtle Beach is ‘the birthplace of the autism-friendly travel initiative,’ and is home to more than a dozen restaurants, attractions and stores offering accommodations and discounts to club members."*

In the six-episode season, the families embark on sensory-friendly trips in Myrtle Beach, North Myrtle Beach and Surfside Beach. All three municipalities are designated as autism-friendly destinations by Autism Travel Club, a program that connects families with autism-friendly experiences, environments and businesses.

The show will follow the Gielink, Hall and Tilk families as they navigate travel and make vacation memories at Myrtle Beach-area attractions like the Intracoastal Waterway, Pelicans Ballpark and Ripley’s Aquarium.Peacock has made. Viewers can watch the trailer, meet the cast members and learn more about how you can watch full episodes at **www.TravelingTheSpectrumShow.com**.

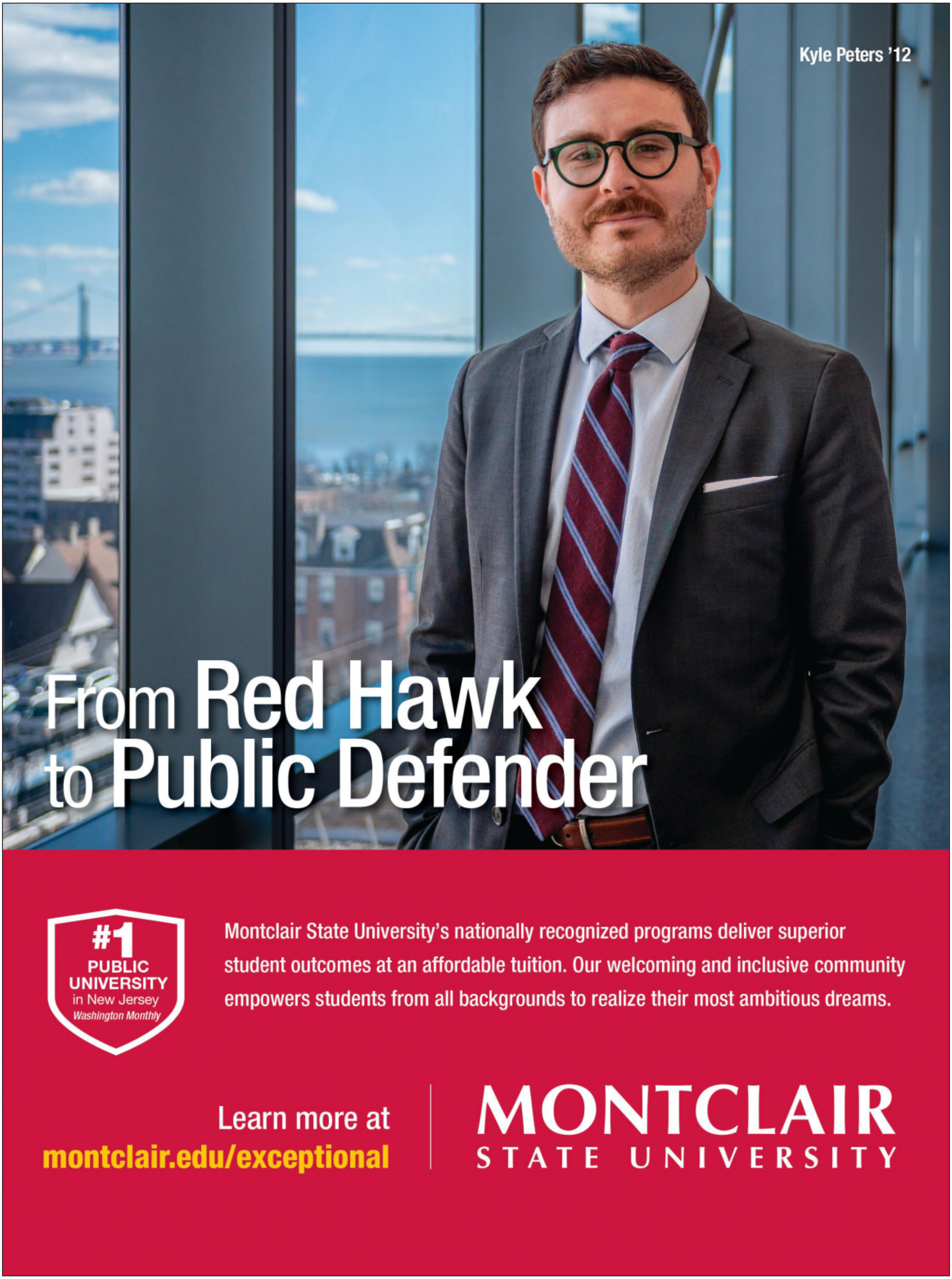
Recognized as an autism-friendly destination since 2016, Myrtle Beach and the communities along the region's 60 miles of coastline are committed to creating a sensory-friendly environment through numerous initiatives, including a sensory-friendly pledge that encourages inclusivity. Along with the television show, Visit Myrtle Beach partnered with author and illustrator Lynda Farrington Wilson to create the children’s book *Splish, Splash, Squawk! Finding Joy in a Sensory Friendly Vacation.* This valuable resource helps families prepare for a beach vacation by introducing tools and techniques to navigate new experiences they may encounter.

Of the parents of autistic children asked, 87% said they don’t currently take family vacations and 93% said they’d be more likely to travel if autism-certified options were available, according to a survey by the International Board of Credentialing and Continuing Education Standards’s website Autism Travel.

“*Traveling the Spectrum* shines a spotlight on how sensory-friendly vacations can enrich the lives of all family members,” said Becky Large, Executive Director of Champion Autism Network and the Autism Travel Club. “We're proud and blessed to be part of a community where our neurodiverse families can come to enjoy meaningful, supported, stress-free time together.”

Additional information on sensory-friendly services and programs available throughout the Grand Strand can be found at **www.visitmyrtlebeach.com/autism**.

PHOTO COURTESY VISIT MYRTLE BEACH



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WHAT'S HAPPENING

MESA, AZ CELEBRATES FIVE YEARS AS AN AUTISM CERTIFIED CITY, LEADS CHARGE FOR INCLUSIVE TRAVEL

November marked the five-year anniversary of Mesa receiving the designation as the first-ever Autism Certified City in the nation, granted by the International Board of Credentialing and Continuing Education Standards (IBCCES).

The initiative started in 2018 after Visit Mesa's President and CEO, Marc Garcia, went on a family vacation with his son who is on the autism spectrum. After an unpleasant experience, Garcia vowed to ensure that Mesa would be a safe and welcoming destination for neurodiverse travelers. In the past five years, 50 businesses and 7,921 community members have completed autism-specific training, demonstrating the community's strong commitment to inclusion as a shared core value.

OPEN ARMS: Mesa, AZ, recognized as one of the most family-friendly communities in the U.S, is rolling out the red carpet for travelers on the spectrum.

"We are incredibly proud of the progress Mesa has made in creating a welcoming environment for all individuals," said Marc Garcia, President and CEO of Visit Mesa. "Becoming the first Autism Certified City in the U.S. was just the beginning. Our community's dedication to accessibility and inclusion continues to grow, and Mesa is setting the standard for what it means to be an accessible destination for all."

The celebration of the five-year anniversary kicked off with the "Live Life Limitless" event held at The Post on November 7th and will run through April 2025, culminating with Autism Acceptance Month. At the event, Visit Mesa reflected the city's success over the past five years and announced the launch of its Accessibility Champion Program (www.visitmesa.com/elevate/accessibility-champion-program), the first of its kind initiated by any Destination Marketing Organization. The program empowers businesses to lead in accessibility best practices and supports Visit Mesa's vision of becoming one of the most accessible cities in the nation. Participating businesses will designate a team member to lead accessibility initiatives, ensuring staff stays informed, trained, and equipped to create an inclusive environment for all guests. Here is what residents and visitors can expect over the next five months:

- ***Exclusive Hotel Offers:*** *Autism-certified hotels in Mesa will provide discounts and special packages designed to accommodate the unique needs of families traveling with autistic individuals, ensuring a comfortable and supportive stay.*
- ***Check-in Challenge:*** *Visitors can explore autism-certified attractions and collect virtual check-ins, with a special prize* for participants. This will encourage families to experience Mesa's many autism-friendly locations.*
- ***"Spec(trum) Ops" Cider and Soda:*** *In partnership with Cider Corps in Downtown Mesa, Visit Mesa will be releasing a custom cider and soda to raise awareness for autism acceptance.*
- ***Sensory Kits:*** *Autism-certified hotels and museums including the Arizona Museum of Natural History, I.D.E.A Museum and Mesa Arts Center will offer sensory kits to provide comfort for visitors with sensory sensitivities.*

Wrapping up in April, Mesa will be "lighting it up blue" for Autism Acceptance Month. The organization will be pairing up with local brewmasters for the fourth-annual release of Spectrum IPA. The limited-edition brew will be sold at select Mesa businesses with a launch party held on World Autism Acceptance Day on April 2nd. Part of the proceeds from the sale of the brew will benefit the Mesa For All Foundation (https://mesaforall.org).

In addition to autism-related programs, Visit Mesa supports a variety of initiatives aimed at improving the travel experience for all individuals with disabilities. These include Aira (www.visitmesa.com/travel-accessibility/aira-visual-info-on-demand), a guided visual interpretation service, and Threshold 360 virtual tours (www.visitmesa.com/travel-accessibility/itineraries) and AbleVu (https://ablevu.com/accessible-cities), which allow visitors to explore locations online before arriving. Visit Mesa was also the first U.S. destination to adopt the Hidden Disabilities Sunflower Program (www.visitmesa.com/travel-accessibility/hidden-disabilities-sunflower-program), a way for visitors and residents to self-identify that they have a disability that might require a little extra help. Most recently, Mesa became the first city worldwide to receive the Destination Verified Seal from Wheel the World (https://wheeltheworld.com/accessible-travel/usa/arizona/mesa), an inclusive online booking platform for travelers with disabilities.

"Our goal at Visit Mesa is to empower travelers of all abilities to confidently plan their trips to our destination," said Alison Brooks, Vice President, Marketing & Destination Experience at Visit Mesa. "For Mesa to achieve the Autism Certified City designation, while also becoming the first city in the world to receive the Destination Verified Seal from Wheel the World, shows that we are dedicated to promoting inclusive travel. Mesa is not only a limitless destination with countless rewarding travel experiences, but visitors will also feel limitless knowing that they can navigate our city without barriers."

Learn more about Visit Mesa's designation as the nation's first Autism Certified City and its mission to becoming the most accessible city at www.visitmesa.com.

PHOTO COURTESY VISITMESA.COM

WHAT'S HAPPENING

LEGO ANNOUNCES INITIATIVE FOR THOSE WITH NON-VISIBLE DISABILITIES AND SENSORY NEEDS

Just ahead of Christmas, Danish toymaker Lego has revealed a new range of its iconic minifigures which recognise the need to embrace diversity, autism and inclusion in play – but with availability slotted for next June, the new options won't be on sale in time for this year's festivities.

HIDDEN NO MORE: Lego introduces the world's first toys to feature the official Sunflower lanyard, promoting awareness and inclusion across different age groups and themes.

Valued at $8bn and the world's most successful toy brand, Lego has been buoyed by its recent success in highlighing limb-differences, skin colour variations, Down's syndrome and vitiligo, and is now seeking to raise awareness of hidden disabilites. Recent research suggests 80% of people with disabilities have a hidden disability.

According to Lego's own consumer research, about eight in 10 parents say children cared more about diversity and inclusion than their generation did; 88% of children questioned told researchers they cared about "everyone being treated equally" and want "to play with toys that teach differences" (83%).

The company said this month that it is adding the Hidden Disabilities Sunflower lanyard to characters in a variety of sets. People can also create their own minifigures wearing the special Sunflower symbol at all 55 Minifigure Factories around the world "to give fans additional opportunities to design the character they want to see themselves, a friend or family member represented as."

The firm said "the Sunflower has become a globally recognised symbol allowing individuals to discreetly share that they have a non-visible condition which may require extra support, time, space or understanding whilst going about their day – whether that be in travel, shopping, at work or in public spaces."

Created by London's Gatwick Airport in alliance with a group of charities in 2016, the Sunflower Lanyard is an initiative to help people with hidden disabilities navigate and find help in public places: as a signal of their need for extra help, users wear the lanyard and by 2020, airports in the USA and around the world now following suit.

> *"The Sunflower allows people to share that they have a non-visible condition which may require extra support, time, space or understanding."*

Lauren von Stackelberg, the Lego Group chief diversity and inclusion officer, said: "As one of the most loved toy brands, we know that our choices about which characters we make and what stories we tell about them have a big impact on how kids learn to perceive the world."

She added: "We hope that modelling a world in which all kinds of people are celebrated will help us all embrace diversity, value inclusivity and remove stigma."

The lanyard scheme is becoming a global success since it was launched in 2016.

Lego's Friends playset is aimed at older children and features an airport setting with a student wearing noise-reducing headphones and a sunflower lanyard. Themaker's Duplo First Time at the Airport, which includes a child wearing a lanyard, aims to help toddlers navigate feelings about airports, the company said.

Meanwhile, for Lego's huge following among adults, an Icons Tudor Corner set features a street scene featuring a pub, shop and flat, with a neurodivergent female character whose lanyard hangs by her front door.

Paul White, Chief Executive of Hidden Disabilities Sunflower, said the flower icon was a hugely useful tool for help among millions of adults, children and carers. He said "HD Sunflower is excited to partner with the Lego Group on raising awareness and acceptance across their fan and colleague base and can't wait to see the impact that this will create."

While the standard symbol for disability is a wheelchair, only 7% of disabled people are wheelchair-users. In all, he said that the invisible disabilities index includes 900 conditions, ranging from autism and ADHD to dementia and Parkinson's.

IMAGE COURTESY LEGO

WHAT'S HAPPENING

‘OUT OF MY MIND:” A HEARTFELT DISNEY MOVIE ABOUT COMING-OF-AGE WITH CEREBRAL PALSY

Melody Brooks, a sixth grader with cerebral palsy, has a quick wit and a sharp mind, but because she is non-verbal and uses a wheelchair, she is not given the same opportunities as her classmates.

When a young educator notices her student’s untapped potential and Melody starts to participate in mainstream education, Melody shows that what she has to say is more important than how she says it.

Disney+ recently released a trailer for its new original movie that will stream exclusively Through December. The trailer for *Out of My Mind* came out just in time to celebrate World Cerebral Palsy Day, an international day of awareness for this often misunderstood condition. The movie follows the experiences of a young girl living with cerebral palsy.

IRRESISTABLE MELODY: Based on the best-selling novel, *Out of My Mind* tells the story of Melody, a non-verbal twelve-year-old with cerebral palsy navigating sixth grade.

The movie is based on the book of the same name. Written by Sharon M. Draper, the middle-grade novel was published in 2010. It won several awards and topped many lists of best books. It was on the *New York Times* bestseller list for nine weeks. The film stars newcomer Phoebe-Rae Taylor as Melody, alongside acclaimed actors Rosemarie DeWitt, Luke Kirby, Michael Chernus, Courtney Taylor and Judith Light. Jennifer Aniston portrays Melody’s inner voice.

Out of My Mind is about Melody Brooks, a sixth grader with cerebral palsy. Melody is non-verbal, has mobility issues, and struggles to communicate with others, but her mind is sharp. Because of her physical limitations, Melody lives with the daily frustrations of people underestimating her. She is not given the same opportunities or education as other kids her age.

Melody’s life begins to change when she gets a communication device and a young teacher recognizes her natural abilities. The teacher begins an inclusion program to allow special needs students like Melody to participate in standard education classes. Her life changes as new opportunities arise, and she finds her voice.

Cerebral palsy is a neurological disorder that develops in infancy or in very early childhood. It results from abnormalities in the brain that affect its ability to control muscles and movement. Some people with CP have mild disabilities, while others are more severely affected. Cerebral palsy can affect mobility, speech, and the ability to swallow. It can cause seizures, learning disabilities, developmental delays, and many associated conditions, like mental illness, behavior disorders, and vision or hearing loss.

Cerebral palsy has no cure, but it isn’t progressive. Treatments and therapies help children live with cerebral palsy and transition to adulthood. Many people with cerebral palsy have average or above-average intelligence and live independently.

World Cerebral Palsy Day has been celebrated in October since 2012 to bring awareness to this most common movement related disorder of childhood. Children like Melody are often misunderstood because they don’t move or speak like other kids, and are at risk for discrimination and may not be given the same opportunities as other children. Awareness efforts and movies like *Out of My Mind* help people understand the condition and those who live with it. •

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IMAGE COURTESY DISNEY +

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AS SEEN ON SHARK TANK

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WHAT'S NEW FEELING FESTIVE

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BLAIN'S FARM AND FLEET
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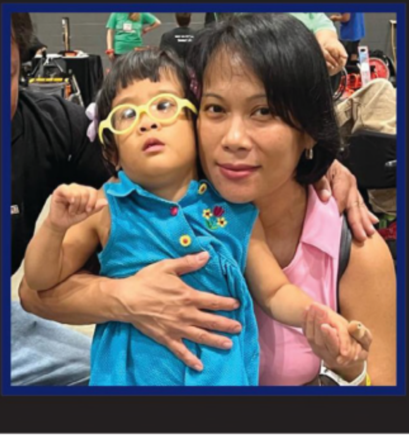

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A NEW PROGRAM HELPS FAMILIES IN MASSACHUSETTS WHO NEED A BREAK FROM CAREGIVING

BY LAUREN AGORATUS, M.A. AND ROSALIE RIPPEY

Respite is the most requested service to help family caregivers.[1]

WHAT IS RESPITE?

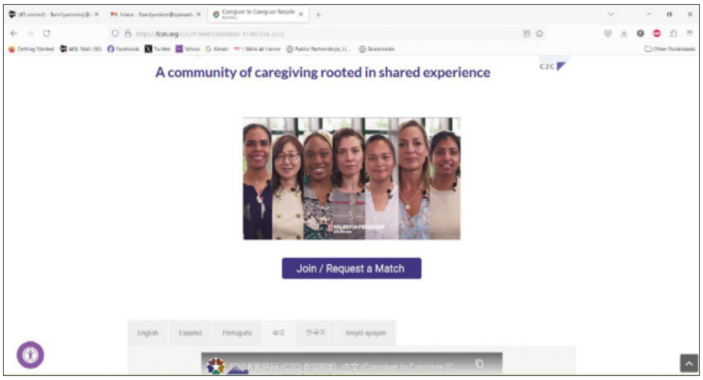
Family caregivers take care of loved ones throughout their lifespan. This can be children with disabilities who may need lifelong care, or elderly and other family members. Respite is a break from caregiving responsibilities. According to the Caregiver Community Action Network, "more people enter institutional care due to caregiver burnout, rather than deterioration of their condition". Caregivers need support to continue their caregiving duties. There is an unfortunate shortage of paid caregivers and respite providers.

A MODEL PROGRAM FOR CAREGIVERS OF CHILDREN

An innovative program from the Federation of Children with Special Needs (FSCN) is the new Caregiver to Caregiver Respite Network. This program matches families of children whose disabilities or health needs are similar, to provide respite to each other. During the matching progress, the program also considers where families live. Families can also ask to be matched with someone from their culture or someone who speaks their language. The FSCN does background checks and provides training and support throughout the match process.

HOW IT WORKS

A video in multiple languages describes the program *(see Resources)*. Families of children with disabilities can start the process by completing a form. The form can be translated into multiple languages. It asks questions about the family's background and the child's disability. It also asks more details about the child's needs in many different areas such as: healthcare, education, feeding/nutrition, assistive devices, and emotional regulation. Families are also asked to share their experiences providing care to people other than their own children, and to share any preferences or concerns that are important to them. When the program receives an application, one of the C2C Family Engagement Specialists gets to know the family and talks with them about what they are hoping for in a match. The goal is to help families find ways to help one another and get their own needs met at the same time.


A community of caregiving rooted in shared experience

GETTING STARTED: The Respite Care Match form at https://fcsn.org/c2c asks questions about the child's disability and any preferences or concerns that are important to caregivers.

The program was created by Elizabeth Bostic, proud parent of King James. Her lived experience, extensive public health research, and interviews with diverse caregivers planted the seed for Caregiver to Caregiver Respite Network.

WHO QUALIFIES

Any Massachusetts parent or primary caregiver of a child with disabilities or healthcare needs can join the Caregiver to Caregiver Respite Network. The program provides help to those with:

- *ADHD*
- *Blind or vision impaired/Deaf or Hard of Hearing*
- *Cerebral Palsy*
- *Complex medical concerns*
- *Diabetes*
- *Epilepsy/Seizure Disorder*
- *Learning disabilities*
- *Intellectual/Developmental Disabilities*
- *Mental Health concerns*
- *Physical disabilities*
- *Rare genetic disorders*
- *Traumatic Brain Injury*

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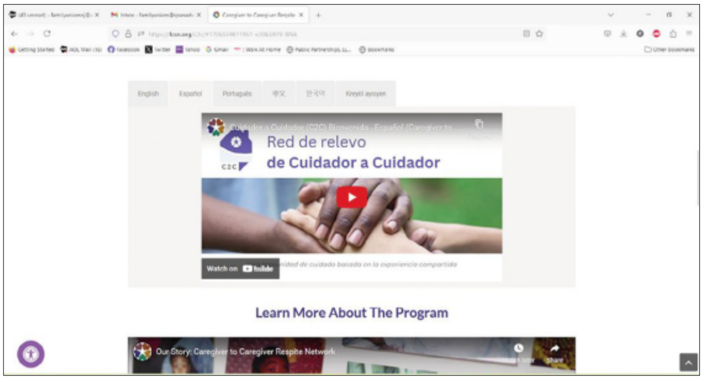
[1] https://archrespite.org/four-respite-services-selected-as-innovative-and-exemplary-in-national-search

IMAGES COURTESY FCSN.ORG/C2C

HOW THIS HELPS FAMILY CAREGIVERS

Besides helping to prevent caregiver burnout, this program helps families by connecting them to others who are going through similar experiences. Families who have been matched to one another say that the program makes them feel less alone. Benefits include:

- *Finding respite care even though there is a severe shortage of paid respite care providers*
- *Making respite care available for families whose children are younger than age 3. Traditional respite care programs do not serve families of children that young.*
- *Providing the option of being matched to someone who shares your culture or language*
- *Offering an option that anyone can access, regardless of ability to pay. Families may choose to arrange ways to pay one another for their time, or they can choose to take turns providing respite.*

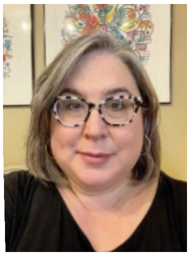


YOU'RE NOT ALONE: Providing the option of being matched to a caregiver's culture or language is another way that the program makes them feel less alone.

This program is brand new, but it is making a positive impact. It was started by using a major grant, and FCSN is working to secure long term funding. The model is also being documented to help other states invest in family-to-family respite care. In the meantime, the national ARCH respite locator is another resource for families.•

Special thanks to Program Director Valeryia Pedersen, as well as FCSN Executive Director Pam Nourse and Associate Executive Director Renee Williams for their assistance.
In loving memory of Beth Dworetzky.

ABOUT THE AUTHORS:



Rosalie Rippey is Director of Development and Communications at the Federation for Children with Special Needs. Her background includes two decades of leadership experience in public education and nonprofit agencies serving women, children, and families. Rosalie and her family have personally benefited from the work and mission of the Federation. She is passionate about bringing an equity lens to our work, dismantling ableism and building a more inclusive world. Through resource development and building the Federation's visibility, she hopes to give back to a community that she is proud to call her own. **rrippey@fcsn.org**

Lauren Agoratus, M.A. is the NJ Coordinator for Family Voices, NJ Regional Coordinator for the Family-to-Family Health Information Center, and Product Development Coordinator for RAISE (Resources for Advocacy, Independence, Self-Determination, and Employment). She also serves as NJ representative for the Caregiver Community Action Network as a volunteer. Nationally, Lauren has served on the Center for Dignity in Healthcare for People with Disabilities transplant committee (antidiscrimination), Center for Health Care Strategies Medicaid Workgroup on Family Engagement, Family Advisor for Children & Youth with Special Health Care Needs National Research Network, National Quality Forum-Pediatric Measures Steering Committee, and Population Health for Children with Medical Complexity Project-UCLA. She has written blogs and articles nationally, including publications in 2 academic journals (**https://pubmed.ncbi.nlm.nih.gov/?term=agoratus+l**). Lauren was named a Hero Advocate by Exceptional Parent Magazine (**www.epmagazine.com Archives June 2022**).

CONNECTING FAMILIES AND PREVENTING BURNOUT : CAREGIVER RESPITE RESOURCES

FSCN CAREGIVER-TO-CAREGIVER RESPITE NETWORK

https://fcsn.org/c2c

Request A Respite Care Match (Massachusetts families)

https://fcsn.org/c2c-match

ARCH
National Respite Network
AND RESOURCE CENTER

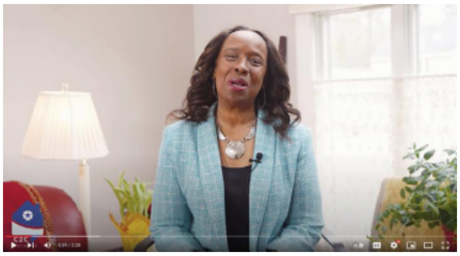
ARCH RESPITE LOCATOR

https://archrespite.org/caregiver-resources/respitelocator

CAREGIVER TO CAREGIVER RESPITE NETWORK: MEET OUR TEAM

A community of caregiving rooted in shared experience

https://youtu.be/5djtCgI-BnI



CAREGIVER TO CAREGIVER RESPITE NETWORK: OUR STORY

A video by parent who founded the program

https://youtu.be/XjUOvFIEpeg

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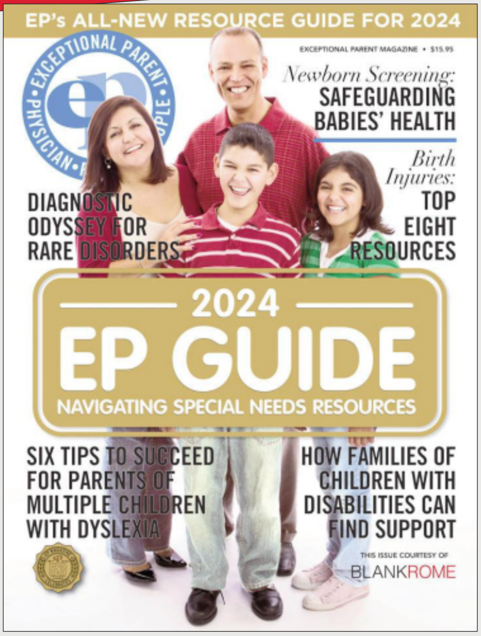
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Birth Injuries: TOP EIGHT RESOURCES

DIAGNOSTIC ODYSSEY FOR RARE DISORDERS

2024 EP GUIDE
NAVIGATING SPECIAL NEEDS RESOURCES

SIX TIPS TO SUCCEED FOR PARENTS OF MULTIPLE CHILDREN WITH DYSLEXIA

HOW FAMILIES OF CHILDREN WITH DISABILITIES CAN FIND SUPPORT

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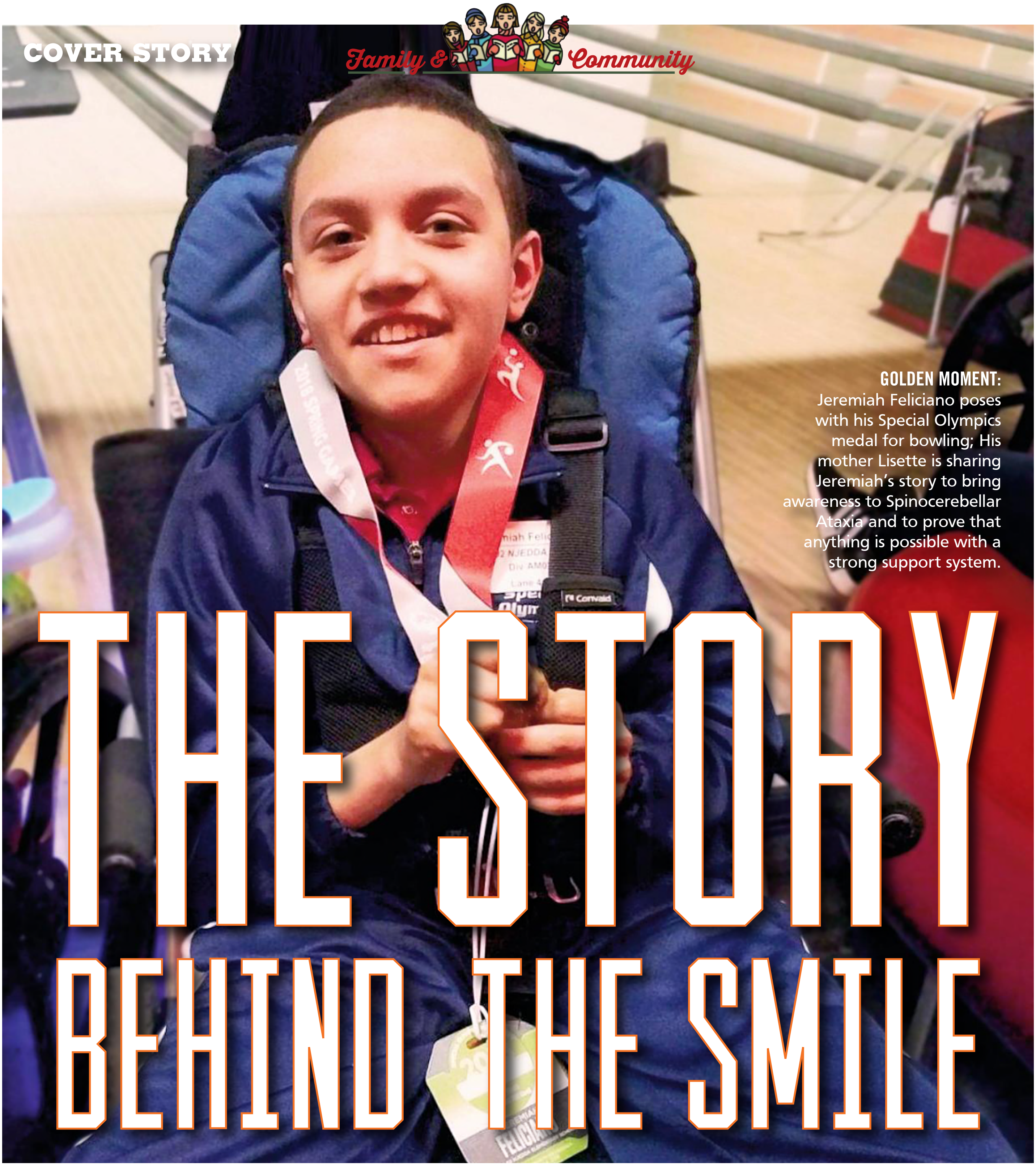
EP MAGAZINE: THE JOURNAL FOR SPECIAL NEEDS FAMILIES AND PROFESSIONALS



GOLDEN MOMENT: Jeremiah Feliciano poses with his Special Olympics medal for bowling; His mother Lisette is sharing Jeremiah's story to bring awareness to Spinocerebellar Ataxia and to prove that anything is possible with a strong support system.

THE STORY BEHIND THE SMILE

JEREMIAH'S JOURNEY WITH SPINOCEREBELLAR ATAXIA TYPE 10

BY HAILEY OCASIO

At 18 years old Jeremiah Feliciano is a son, a big brother, and most of all, a caring young man. When he was 7 years old he was diagnosed with spinocerebellar ataxia type 10 (SCA 10), an extremely rare and, as of now, incurable disease.

PHOTOS PROVIDED BY LISETTE FELICIANO

Information about spinocerebellar ataxia is limited. According to the National Ataxia Foundation, "It affects about 1 to 5 people per 100,000. SCA 10 is caused by genetic defects that lead to impairment of specific nerve fibers carrying messages to and from the brain resulting in degeneration of the cerebellum, the brain's coordination center." For individuals with this disease, the brains struggles to control movement, balance, and coordination. They may experience difficulty walking, speaking, or swallowing. Seizures can also occur, particularly during the early stages of the condition.

Although there is no specific treatment to delay or halt the progression of SCA 10, physical therapy assists with maintaining current functions, according to the National Ataxia Foundation

Jeremiah is now physically dependent on his parents. He began showing symptoms at the age of four. In preschool, he struggled with self-awareness and his surroundings, often tripped over objects, at times would shy away from the class, and showed incorrect use of his hands during artistic activities. After being evaluated by the public school child study team, he entered kindergarten as a special needs student with a language and learning disability. It was thought that Jeremiah was experiencing developmental delays, and therapies were provided. Three years later, after visiting a neurologist, his condition was confirmed. The confirmation came as a result of performing a triple MRI, picturing the brain, cervical, and lumbar parts of the spine.

AMONG FRIENDS: Jeremiah lovingly cares for his extensive collection of stuffed animals, each one individually named and cherished.

"I'm going to be honest," said Jeremiah's mother Lisette Feliciano. "When we got his diagnosis, as a mom I never really had the time to sit and dwell on what the diagnosis was. I had to jump into action. What are we going to do now, what type of services do we have to get him? It was tough at the beginning, because it is a diagnosis that we don't know much about. While his doctors are treating him and learning, we are learning at the same time."

Jeremiah was referred to Dr. D'Alessandro, Clinical Director of the Kireker Center for Child Development. Here, he has continued to partake in different types of therapies to maintain his mobility. At the age of 7, Jeremiah was mobile, but needed the use of a posterior walker due to complications of an unsteady gait. As his condition progressed, he became wheelchair bound. The Feliciano family goes above and beyond to help Jeremiah maintain his current range of motion. Doctors have told them that his mobility may decline. The family remains committed to providing him with the best possible quality of life.

After a few years in the public school system, Jeremiah's mother realized that he had outgrown the available services, and needed more advanced support, particularly in physical therapy. "I needed a parent advocate to guide me through the process," Lisette shared. She noted that it was Jeremiah's second-grade teacher who encouraged her to seek better educational opportunities for him. By the summer before third grade, Jeremiah was transferred to a specialized, out-of-district school for students with special needs. Today, he receives all the support he needs, as often as he needs it. The family has received tremendous direction from physicians and teachers guiding them towards the correct steps to ensure he receives everything he needs.

Although Jeremiah's speech is often not understood by others, his family often understands him. At school, they are using a repetition method in the classroom. If they can't understand him from the start, they try 2-3 times to see if he sounds clear enough to be understood. If that doesn't work, they have several topic cues they use to see if they can pinpoint what topic he's trying to communicate. They are also working with computer software that is used with a joystick switch, which he works quite well. It allows him to piece together what he wants to say via picture cards with names. This software can also be used by eye-gazing to select the picture cards. The teachers want to see if he would benefit more from using the joystick vs. an eye-gazing augmentative device, because using his eyes all day can become tiring.

Despite facing unique challenges in caring for Jeremiah, the Feliciano family remains resilient and dedicated. Jeremiah has a condition called dysphagia, which requires specialized attention. It affects his ability to use his oral muscles, making swallowing difficult. This can occasionally result in drooling or choking. Lisette and her family have become skilled at managing these moments. During her daily routine when Lisette takes her second child Destinee to the bus stop, she trusts the support of Jeremiah's grandparents, yet is still eager to return and assist if needed. Another aspect of their journey involves helping Jeremiah with his bathroom needs, as he requires physical support to move. Although this can present challenges in public settings, the family has developed strategies to ensure Jeremiah's comfort and care.

The Feliciano family emphasizes the importance of thoroughly exploring the education system to find the best resources for children with special needs. They encourage parents to trust their instincts when assessing whether their child is receiving the appropriate services, and to advocate for better options, if needed. It's crucial to research and discover what support is available. For the Feliciano family, enrolling Jeremiah in a school tailored for children who require specialized accommodations has been valuable. There are organizations dedicated to parent advocacy, providing an additional layer of support, and they have been beneficial to the Feliciano family. A parent advocate provides information about options, available resources, and support services that parents may not be aware of. A parent advocate should understand the intricacies of special education and the assistance available at the state level.

“I have to say, having that support helped us navigate that initial period and still helps us now” said Lisette. “His school has always been very resourceful, and they've given us different types of avenues to try to get what he needs. I am thankful that he is where he is. He is still wheelchair bound, but he is maintaining what he has. I think a lot of that has to do with the fact that he is in that school. Sometimes, it's hard for a parent because they may not know how to navigate their situation and fight for their kids' needs. Parents are their kids' number one advocates. There are times when you have to be a bit forceful and demand certain things. Otherwise, you won't be able to get your kids what they need to move forward.”

Thanks to these valuable resources, Jeremiah has had the chance to participate in several exciting activities. During his elementary school years, he competed in Special Olympics bowling. Today, he proudly owns several medals and trophies for his achievements and participation. It was a joyful experience for the family to see him included in these activities, and to witness how the programs creatively adapted the sports to meet the players' needs. Jeremiah loved being part of the sport. He attended practices twice a week to prepare for competition. Starting at the sectional level, he progressed all the way to the state level showcasing his talent.

Lisette has a great family support system that includes her husband, daughter, mom and dad. Her dad has extended himself from day one. When Jeremiah was first diagnosed, his father, David held a job that did not allow him to be available when Jeremiah left for school. Before they got a stair lift installed in the house, Lisette's father carried Jeremiah down, put him into his stroller, and helped get him ready for the bus. Later in the afternoon, he carried Jeremiah back up the flight of stairs. Jeremiah and he have a close bond. Family has definitely been a great support. The church that they attend has always been a big support in an emotional and spiritual sense.

The Feliciano family has experienced incredible blessings through their support systems. This past year, David was invited to be a four-day guest speaker at a church in Pennsylvania. He had to make the two-hour drive back and forth each day, as he was needed at home to help care for Jeremiah. Moved by this, the church's pastor approached David with an unexpected opportunity. A handicap accessible vehicle had recently been donated to the church for community use. The pastor felt compelled to reach out to the donors and ask if the vehicle could be given to the Feliciano family instead. Seven months later, David was again invited to speak at the church. The day before David left for the trip, the Pastor called to tell him to bring an extra person with him because his family would officially be receiving the fully handicap accessible vehicle.

Jeremiah is much more than a young man living with Type 10 Spinocerebellar Ataxia. He is caring, patient, kind, and the owner of a smile that lights up the room. His favorite hobby is watching TV, where his compassionate nature shines through as he roots against the villains from his side of the screen. Whether he's watching *Bubble Guppies, Peppa Pig,* or *Paw Patrol,* Jeremiah always stands up for what's right, offering encouragement to characters in need. He also lovingly cares for his extensive collection of over 40 stuffed animals, each one individually named and cherished. Some of his favorites include: Froggie the Frog, Mr. Pickles the Dinosaur, Chessie the Monkey and, of course, Mickey Mouse.

His kindness extends into his daily life where he demonstrates his caring demeanor and determination by helping his parents as much as he can or, as he calls it, “doing small jobs.” Using the mobility he has, he enjoys tasks like: taking off his own hat, unzipping his jacket, and choosing his clothes when given options. Jeremiah also loves playing his bells during church services, assisting the musicians with their tunes.

We hope this story inspires others, whether facing a similar situation or not, to recognize the importance of a strong support system. Remember, you are never alone, and keeping a positive outlook can make all the difference. Your next blessing could be just around the corner. •

FURTHER READING : SCA 10 RESOURCES

National Ataxia Foundation

NATIONAL ATAXIA FOUNDATION NETWORK

About Spinocerebellar Ataxia Type 10 (SCA10)

www.ataxia.org/wp-content/uploads/2017/07/NAF-Web-Content-Publication-SCA10.pdf

ABOUT THE AUTHOR:

Hailey Ocasio is a senior at Montclair State University, majoring in Advertising with a minor in Sociology. This semester she enrolled in a class called Hawk Communications where, under the guidance of Professor Green, she had the incredible opportunity to work with Faye Simon Harac on *Exceptional Parent Magazine.* During her time with the magazine, she was excited to propose the idea of interviewing the Feliciano family. Hailey feels truly grateful to be part of this issue and wants to thank everyone involved for this amazing experience!

STRONGER TOGETHER: *(Left to right)* The author, Ethan and Gavin at the USHthis USA Summer Camp in Michigan.

A TRANSFORMATIVE EXPERIENCE:

SUPPORTING MY COUSINS WITH USHER SYNDROME

BY BRETTE HAINES

Family members like me, while well-intentioned, often struggle to fully comprehend the unique challenges and perspectives of a loved one with a disability. We may unintentionally make assumptions or offer advice based on our own experiences.

PHOTOS PROVIDED BY PAMELA AASEN

My cousin Gavin's article in the July 2023 issue of EP Magazine taught me that this can be frustrating or invalidating for them. My cousin Ethan's article in the April 2024 issue helped me realize it is important to remember that living with a disability is a personal journey, and each individual's experiences are shaped by their unique circumstances and coping strategies. Reading my aunt Pamela's articles in EP Magazine also gave me valuable insights, but I was searching for a deeper, more personal understanding of their journey. Recently, I got it!

This past summer, I had the privilege of being a mentor for the 2024 USHthis Camp. It is the first overnight camp for youth and young adults with Usher syndrome. As someone with two cousins living with Usher syndrome, and a desire to pursue a career in medicine, I was eager to learn more about their experiences and provide support to others living with this condition. Having known my cousins my entire life and spending a lot of time together, I have always been aware of the challenges they face, but living in different countries has limited my ability to fully understand their daily lives and the impact of Usher syndrome. The camp offered a valuable opportunity to share this experience with my cousins, connect with others who face similar challenges, and become a part of a supportive community for them.

A REAL ROLLER COASTER: *(Left to right)* Ethan, the author, Gavin and the author's brother Cole buckle in to an amusement park ride; "My cousins lived every day knowing they were losing vision. Somehow, they still lived such valuable and impressive lives."

Usher syndrome is the most common genetic cause of combined deafness and blindness. It is a rare genetic disorder that affects hearing, vision, and balance; three major senses in the body. My cousins were born deaf, are progressively losing their vision (because of retinitis pigmentosa), and have severe balance issues (due to vestibular dysfunction). That's the technical definition, but when I was young and learned about Usher syndrome, it meant not being able to hear without cochlear implants and having horrible balance. It was confusing, because my cousins competed in high level swimming, ran track and field, played baseball and hockey, skied, had regular speech, and were intelligent (even gifted in many ways). In some ways, I thought it was a superpower, because they seemed to be more athletic than the average individual. In a way, I was a bit jealous. They got extra attention and could just take their "ears" (cochlear implant processors) off when they didn't want to listen to anyone. Little did my younger self know just how much work went on behind the scenes for them to live this way.

In my early teenage years, I felt like I was babysitting every time my cousins visited. Having to take them out with my friends was something I knew I had to do, but didn't really want to because it was an added stress. Having to explain my cousins' needs to others when I did not even understand them myself was difficult. Instead of enjoying myself, I was concerned about explaining their disability and how my friends might treat them. I wanted to have fun with my friends and not be worried about my cousins losing an "ear." This happened often, and everyone had to stop and look for the missing processor. This happened when they were visiting and we went out boating. The wind blew one of Gavin's processors into the bay – gone forever. The anxiety this caused everyone was not something I wanted to experience again. But I did. When I was old enough to drive, I took them to town with me. When we got home, we realized one of their "ears" was missing. My friend found it in my car, but the hours of searching and thinking it was my fault was very stressful!

In my later teenage years, Usher syndrome was terrifying. My cousins lived everyday knowing they were losing vision, yet somehow they still lived such valuable lives. I became more aware of the challenges they faced and will continue to face living with Usher syndrome. It became more serious, and more devastating for me. I felt a lot of guilt when they visited, because now I knew that their vision loss was progressive, and I would notice the changes. I wanted to help them do normal teenage things, like going out or bringing them to play laser tag with my friends. I was not sure how to support them or what they needed. I wanted to help, but didn't want them to feel embarrassed or suffocated by me. I brought them with me and dealt with the stress, fear and uncertainty that I felt, because if they can live knowing they are losing their vision, I can do this.

For me as a young adult, my cousins' living with Usher syndrome is a continuous learning process. There are a lot of unknowns. If this is confusing for me, I can only imagine how much more challenging it is for someone who has been living with it. They deal with countless doctor's appointments, therapy

AT THE OLD BALL GAME: The family takes in a Toronto Blue Jays game; *(Left to right)* The author's uncle Carlito, brother Cole, Ethan, aunt Pam, mother Paula, the author's father Peter, and Gavin in front; "As their cousin, my perspective is deeply personal and shaped by my experiences and my relationship with Gavin and Ethan."

sessions to manage balance issues, and treatments to slow vision loss, all while trying to maintain sound mental health and live a quality life. I see them learning to advocate for themselves and their needs, learning to become independent, going to college, finding a sustainable career option, and finding a significant other that they can count on, as they try to live a normal life, while not entirely able to live a normal life.

This is just MY understanding of Usher syndrome. As family members, it is a constant balancing act. We wonder if we're providing the right kind of support, and if our actions are helpful or harmful. We need to adapt to their changing needs and educate ourselves to better understand their experiences. While we may never fully comprehend their challenges, we can strive to be supportive and empathetic. As their cousin, my perspective is deeply personal and shaped by my experiences and my relationship with them. Being a friend or family member of someone living with a disability is a journey that has its own challenges, its own fears. We need support and guidance, too!

One of the most admirable things about Ethan and Gavin, has been their substantial efforts to raise awareness about Usher syndrome and help families going through what they went through. Despite the challenges they faced while learning to live with Usher syndrome, they were and are committed to helping other families navigate this diagnosis. Their team of care has been amazing, yet some of them had not heard of Usher syndrome. Families deserve to feel less alone, to receive support while they grieve and benefit from the experience of others instead of having to search for all of the answers themselves.

I watched them speak numerous times, observed my aunt's involvement with creating platforms for families with a recent diagnosis, and read her articles written to raise awareness. I am proud of them for being a part of inspiring the start of a summer camp for children across the world who have Usher syndrome. Watching these initiatives from people so close to my heart, while being someone with a passion for helping people, made me desperately want to be involved. I found myself wanting to further educate myself to show them how much I care about fully understanding their journey. I wanted to help others, but my number one priority was making my cousins feel supported and understood. I wanted them to have someone in addition to their mom and dad, to lean on and trust.

I reached out to my aunt to see if I could help in any way with any of the organizations she was involved in. One of the lead hearing and sighted mentors for their USHthis Summer Camp could not make it, and I was offered the position. I was really nervous because I had no idea what to expect, or how to be a mentor for people with Usher syndrome. I knew that I wanted to do it because of my desire to learn how to better support my cousins. What I didn't know was how life changing and incredible an experience it would be.

I had the privilege of supporting campers ages 12 to 17 with

ICE TIME: *(Left to right)* Ethan, aunt Pam, the author, and Gavin at a hockey game in Canada; "I desperately wanted to be involved. I found myself wanting to further educate myself to show my cousins how much I care about fully understanding their journey."

Usher syndrome, guiding them as they forged lasting relationships and discovered accessible resources within a traditional camp environment. I also worked side by side with the young adult mentors with Usher syndrome and saw how much they inspired the younger campers. This experience was not just transformative for them, but it was a profound journey of growth for me, especially as a family member of someone with a disability. I learned the vital importance of seeing each individual as a unique person beyond their diagnosis. I had the opportunity to witness the strengths, challenges, and personal aspirations of each participant. This insight was essential for offering tailored support, and fostering a more inclusive and fulfilling camp experience.

A valuable component of camp from my experience, was the different story, personality and struggle that each person brought with them. Everyone showed different but inspirational outcomes from their Usher syndrome journey. One mentor's journey led her to become extremely passionate about nature and the environment. This is a valuable characteristic to have, but it is incredible for someone who knows they are losing their vision – to live in the moment and appreciate what they are seeing now. Another mentor's journey led her to be loud and powerful, which is also an important characteristic. It helps her advocate for herself and her individual needs while showing others the voice that they can and deserve to have.

A CLOSER LOOK : USHER SYNDROME RESOURCES

AVA'S VOICE USHTHIS CAMP
https://avasvoice.org/ushthis

USHER SYNDROME COALITION
www.usher-syndrome.org

USHER SYNDROME SOCIETY
www.ushersyndromesociety.org

HIDDEN DISABILITIES SUNFLOWER
https://hdsunflower.com

COCHLEAR AMERICAS
www.cochlear.com/us/en/home

This experience was amazing and not only changed my perspective on my own life, but strengthened me as a person. It taught me the value behind effective communication and how to articulate yourself in ways that I was not used to prior to camp. For example, if you need to make an announcement to the entire group, you would first identify yourself and your location. You would say something like, “Hey everyone, it’s Brette. I'm at the front of the cafeteria by the drink machine. Can you all hear me okay?” You would wait for people to locate you before you started speaking. Then you would speak clearly, not too fast, and you would make sure to repeat whatever directions you were giving. This gives directional cues and helps make sure everyone knows what's going on.

This was extremely valuable because it taught me how to effectively support the campers and actively listen to their individual needs, rather than making assumptions from my experience with my cousins. Before camp, I may have just jumped to grab someone’s arm thinking they needed my help. Now I know that can be quite insulting, because they may not need or want it. I learned to ask if they wanted to hold my arm while walking, or wanted me to tell them there was something out of their range of vision. Each camper was unique and illustrated the necessity of personalized support. There is not a one-size-fits-all approach to a disability.

At the beginning of camp, we each wrote a word on a piece of paper to describe what camp meant to us. I chose “inspiring,” but had no idea just how profound that inspiration would be, by the week’s end. Witnessing the campers and mentors with such a significant disability be able to open up, break out of their shells and truly enjoy themselves was an extraordinary experience. The connections they formed and the sense of family they discovered was life changing.

READ ALL ABOUT IT : EP MAGAZINE AND USHER SYNDROME RESOURCES

EP MAGAZINE
JULY 2024
Speaking Up
by Gavin Morrobel
https://reader.mediawiremobile.com
/epmagazine/issues/209001/
viewer?page=34

EP MAGAZINE
APRIL 2024
An Uncomfortable Life
by Ethan Morrobel
https://reader.mediawiremobile.com/
epmagazine/issues/208904/
viewer?page=39

EP MAGAZINE
DECEMBER 2019
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the Community
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I saw the campers gain confidence and inspiration. Many had never met anyone else with Usher syndrome, aside from perhaps a sibling. Coming together as a community where they could simply be themselves beyond their diagnosis was remarkable. While they may have Usher syndrome, they are so much more than their disability. They deserve every opportunity to thrive. This experience underscored the profound impact of genuine support, and the difference it can make in the lives of individuals with disabilities.

My favorite thing to hear when I tell anyone about my cousins is, “but they don’t look like they have a disability.” This is true until nighttime when they walk like they are intoxicated, or daytime when they walk into something, because it is out of their range of vision. Often, when I talk to people about my cousins’ disability, I add “They are incredible! They truly are the walking definition of *‘making the best of what you have despite devastating challenges you face’*”. They make it look easy, which is one of the struggles of having a hidden disability. I learned from my cousins and this experience that people often underestimate the impact of Usher syndrome, because the challenges are not immediately apparent. While they may seem ‘normal’ on the surface, they face daily challenges that most people, even family members, can’t imagine. They are constantly adapting and overcoming challenges.

Spending time with my cousins and volunteering at USHthis Camp truly transformed my perspective. I've always looked up to how they navigate life with Usher syndrome, but witnessing their strength on a day-to-day basis at camp deepened my admiration. It's incredible to consider the daily challenges they face, yet they continue to persevere with strength and determination. I feel incredibly fortunate to be a part of their journey and to offer my support, in any way I can. •

ABOUT THE AUTHOR:

Brette Haines, is a 24-year-old from New Brunswick, Canada, and a recent graduate of Acadia University in Wolfville, Nova Scotia. She actively volunteers with individuals with intellectual and/or physical disabilities and has a desire to pursue a career in the medical field someday.

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EMPOWERING PARENTS OF STUDENTS WITH DISABILITIES THROUGH SCHOOL, COMMUNITY AND FAMILY PARTNERSHIPS

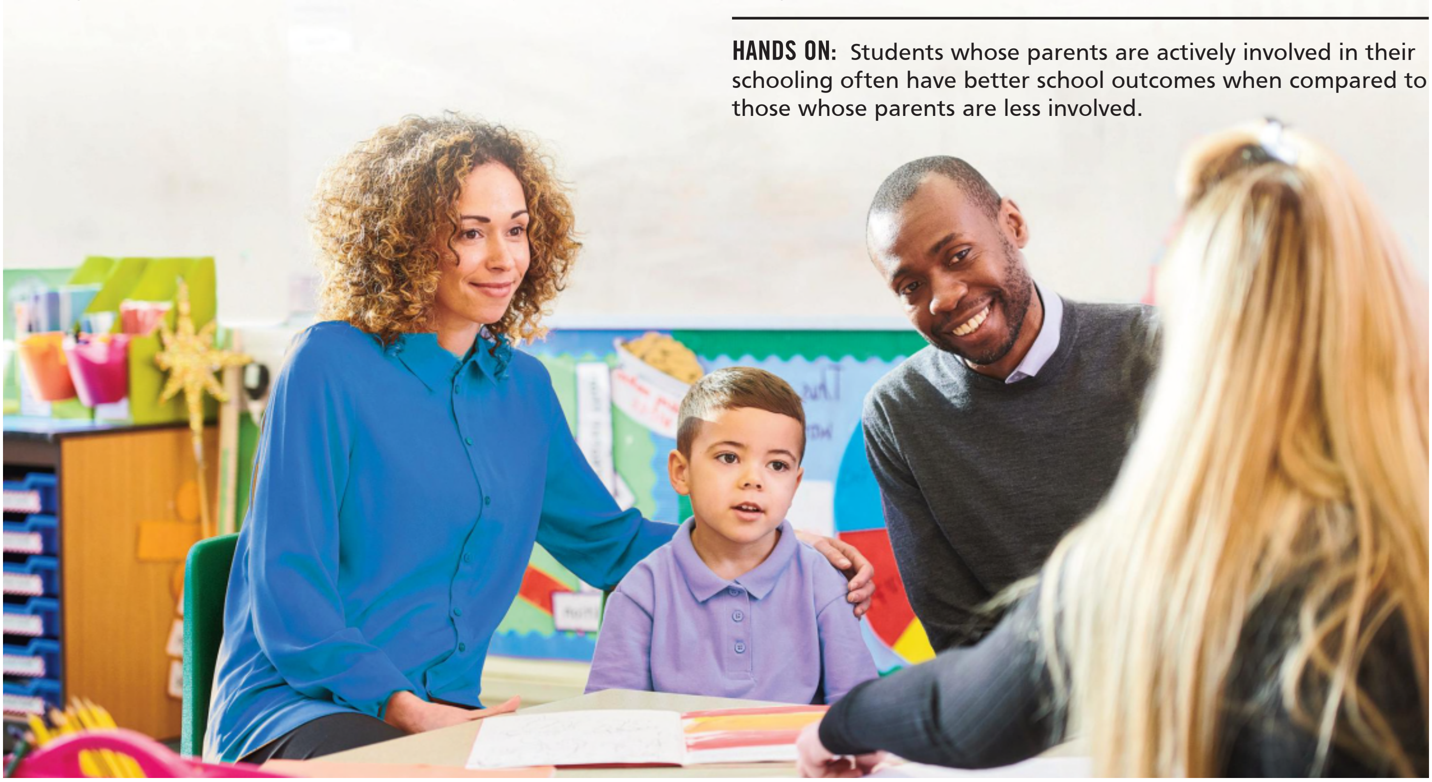
BY ROBAI N. WERUNGA, PH.D.

When a child has disabilities, some families may feel helpless and rely on schools for support and guidance. Parental involvement is often linked to positive school outcomes for all students, including those with disabilities.

School outcomes for students, including those with disabilities, are likely to improve when parents, educators, and others in the community work together to guide and support student learning and development.

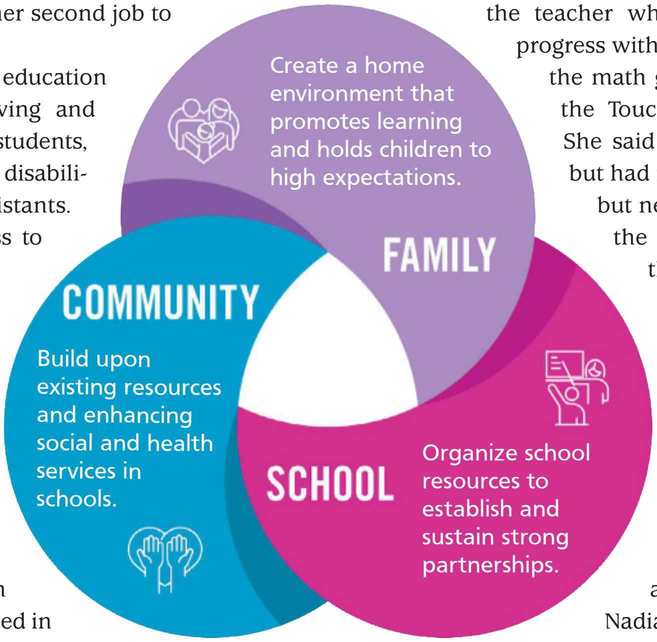
Special education professionals can play a critical role in facilitating these collaborations. For this to happen, the professionals must:

(1) *acknowledge they have a responsibility to work with and support the child's family*
(2) *value collaborative relationships with the families*
(3) *strive to make families less dependent on the professionals' advice and services, through family empowerment strategies* (Van Haren & Fiedler, 2008).



HANDS ON: Students whose parents are actively involved in their schooling often have better school outcomes when compared to those whose parents are less involved.

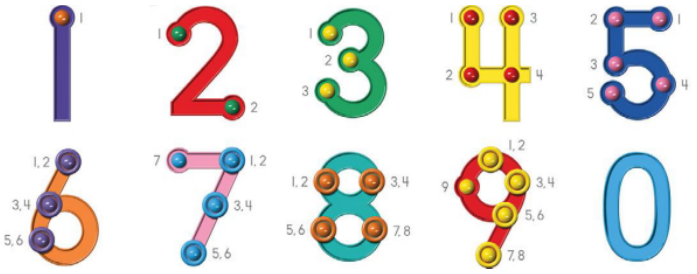
In this article, I describe a collaborative team approach that aimed to empower a parent of a student with Down syndrome[1] to participate in her daughter's learning through homework support. Participants included a community partner, school partner, and a family partner. It illustrates how these three networks can work together to improve school outcomes for students with disabilities. This relationship is what Epstein refers to as the overlapping spheres of influence and is represented in the figure below.



Family Partner: Fatima, a single mother had recently immigrated to the US as a refugee from Syria. She lost her husband during the Syrian conflict, but managed to escape. She had two daughters who attended the same school and an after-school program so that Fatima could work her second job to make ends meet.

School Partner: Nadia's special education teacher taught a self-contained Living and Learning class that consisted of 10 students, grades 3-5, with moderate to severe disabilities. She had three teaching assistants. Various specialists came to her class to support students based on their IEP goals and special needs.

Community Partner: I volunteered at the international community center, working with the after-school program facilitating homework completion for the K-5 students, including Nadia and Lamia. Lamia always had homework, but Nadia never brought work. I started bringing in work on Nadia's level. It helped her feel included in the activities. I worked on basic addition and subtraction skills using the TouchMath method *(see below)*. Nadia was excited to have her own "homework" and proud to show it off. She enjoyed using the TouchMath technique. Nadia's mother was appreciative of my efforts. She stated she would love to work with Nadia at home and support her schoolwork, but didn't know how. She said Nadia never brought home homework, but was upset that she was working with her sister and not her.



THE RIGHT TOUCH: TouchMath is a multisensory technique for teaching math that uses physical movements to represent numbers and perform calculations. In this technique, each number is represented by a set of points, or dots, that reflect its value. For example, the number 4 has four dots. Students count the dots on the numbers to learn the number concept.

The Student: Nadia, a 10-year-old with Down syndrome received special education services under the ID-Mild eligibility. She received most of her academic and social skills support in the self-contained class. Nadia was mainstreamed for specials (physical education, music, and art). She received speech as a related service, in addition to ESL support. Nadia's IEP indicated goals in reading, math, writing, and social skills.

ACTION PLAN

Information Gathering: I asked Fatima if I could talk to Nadia's teacher about ways Fatima could be involved in supporting Nadia's learning. She agreed. I set a meeting with the teacher who shared that Nadia was making progress with all her IEP goals, but struggled with the math goals. I asked if she had tried using the TouchMath strategy for basic addition. She said she was familiar with TouchMath, but had never used it. She said she had a kit, but never received adequate training, and the county had a different curriculum that was aligned with state standards that was appropriate to use to prepare her students for statewide assessments. I told her I had used TouchMath for many years, and Nadia liked it. I offered to provide an overview of the strategy and suggested Fatima use TouchMath at home, as well. She agreed.

Parental Involvement: I asked about Fatima's involvement with Nadia's learning. The teacher shared that Fatima provided information and responded to the teacher, as needed. She rarely missed scheduled meetings at school, and always signed documents sent home and returned them promptly. Homework was not sent home since Nadia's mother had two jobs, and the teacher felt sending homework would add a burden to a busy parent who spoke limited English.

Forming a Collaboration Team: The next step was establishing a team to help Nadia. I suggested Nadia's family needed to be actively involved in the collaboration effort. We decided that all communication to Fatima would be in Arabic, and we would have someone on the team to translate. I had parental permission translated to Arabic and sent home. Fatima signed the letter promptly. Our collaboration team consisted of four members.

I would oversee the entire project and the TouchMath strategy implementation, train the teacher in TouchMath, and be responsible for adjusting the TouchMath content and materials to facilitate acquisition of the strategy. I would be responsible for administering and charting results from the three assessments administered to Nadia, from the beginning to the end of the intervention process.

Nadia's teacher would be the interventionist and would be responsible for teaching Nadia the TouchMath strategy, and give her daily assessments to check for understanding. She would be responsible for communicating with Nadia's mother every day on the progress at school.

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[1] This case study involved a real family and school. To protect the participants in the project, pseudonyms are used in place of participants' names.

Nadia's mother Fatima would work with Nadia on TouchMath homework assignments sent home daily, and communicate to her teacher on the progress at home.

The Parent Liaison would translate written notes for the parent and members of the team, and would translate during meetings with Fatima.

The entire collaboration project lasted three weeks. Following the pretest, Nadia began receiving TouchMath instruction and was first assessed after one week of the intervention. Results from these assessments showed that Nadia had made notable progress. After two more weeks of instruction, I administered post-intervention assessment and scores showed a sustained upward trend of skill mastery.

Nadia's teacher felt the team approach was instrumental in helping Nadia acquire the skills fast. She liked the consistency of collaboration efforts between home and school.

For Nadia, learning how to add using TouchMath gave her confidence to pursue math tasks. Nadia referred to me as the "Polka dot teacher" and when I came to her class, she would show me her completed assignments from home and school.

Fatima was pleased with the homework for Nadia, and through the homework she was now aware of what Nadia was working on in school. She was happy to work with her at home, since it allowed them to spend time together.

THE IMPORTANCE OF SCHOOL-COMMUNITY-FAMILY PARTNERSHIPS

Parental involvement has been identified as a critical component in public education in the United States. Students whose parents are actively involved in their schooling often have better school outcomes when compared to those whose parents are less involved (Gaitan, 2004; Lee & Bowen, 2006; Okagaki & Frensch, 1998). Engaging families of children with disabilities can be challenging. Challenges are particularly amplified for parents with low income, single parents, immigrants, limited education, as well as those who speak limited English (Cartledge & Kourea, 2008; Dyress, 2011; Gaitan; Okagaki & Frensch). It is important to find ways to effectively partner with parents to positively impact educational outcomes for their children.

Many parents feel ill-equipped to be involved for various reasons. Teachers are viewed as experts, and families often fully entrust teachers to provide the right education or instruction, and unless invited, some parents tend to stay away from school, often viewing their presence as an intrusion into the teachers' space (Walker, Hoover & Sandler, 2011). It is imperative that teachers reach out to parents and ask them how and to what extent they can collaborate. Although there was positive home-school communication for Nadia, involving a community partner was essential. She brought fresh ideas that helped the teacher increase the collaboration and involve Fatima in Nadia's academic learning. Through the collaboration project, the teacher realized Fatima was willing and able to work with Nadia at home. School and supports at the community center were very important, because Fatima did not have insurance to pay for out-of-school services, and was open to all the help Nadia could get. This example is evidence that families of children with disabilities are often willing and able to collaborate with teachers and the school to promote and enhance positive educational experiences for their children. It is crucial for educators to find ways to reach out to parents and ask for their input on ways to get them involved. (Szente, Hoot, & Taylor, 2006; Trumbull, Rothstein-Fisch, & Hernandez, 2003).

A TEAM EFFORT: School outcomes for students, including those with disabilities, are likely to improve when parents, educators, and others in the community work together to guide and support student learning and development.

Without the three-pronged relationship between school, family and community facilitated by the community partner, increasing Fatima's involvement in Nadia's learning would not have happened.

It points to the critical role communities can play in promoting family engagement and school outcomes for students, including those with disabilities. Centers such as the one Nadia and Lamia attended, exist in many communities. The majority provide services and support to underserved communities. Schools could benefit leveraging the existence of these and/or similar centers, to promote parental engagement and enhance the learning of students, including those with disabilities. •

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ABOUT THE AUTHOR:

Dr. Werunga is an Assistant Professor of Special Education in the School of Education, University of Massachusetts, Lowell. Her research focus is in early academic and behavioral interventions through multi-tiered systems of support (MTSS). In addition, Dr. Werunga does research on strategies that foster and promote meaningful family-school relations and family engagement, with a focus on immigrant family empowerment. She has over 25 years' experience working with individuals with disabilities. She has taught in separate and inclusive settings, and designed instruction for students in both settings. Dr. Werunga is an active member of the council for Exceptional Children.

Surviving School Holiday Parties with Your Neurodiverse Kid

BY KARI A. BAKER

My son Brady is a smart, creative, funny thirteen-year-old with autism, ADHD, and a few other spices in his neurological soup. We started our autism journey when Brady was three, and ten years later I am incredibly proud of the young man he is becoming. I am not a mom who laments my child getting older, even though he threatens to overtake me in height. I appreciate his growing maturity and independence.

PHOTO PROVIDED BY KARI BAKER

As we approach our first holiday season with a teen, I look back with nostalgia at many, but not all, of the traditions from his early elementary school years.

For the most part, I reveled in the magic of watching Christmas through my little one's eyes. Starting the day after Thanksgiving, Brady would leap out of bed at the crack of dawn to discover where Rudy the Elf landed after his overnight visit to the North Pole. Rudy was a tad mischievous. Sometimes he made messes in my kitchen or placed himself in precarious positions. Occasionally, Rudy overslept and appeared on the same shelf as the night before. Brady would be disappointed, but out of an abundance of Christmas spirit, he would refrain from reporting Rudy to Santa's human resources department. Even elves need a day off.

> **“Your child can benefit from learning to function in an unstructured social setting, if you listen to his cues and honor his needs.”**

While most of my early yuletide memories with Brady bring on the warm fuzzies, one still stops me cold: the school holiday party. Most moms looked forward to the festively decorated room, marshmallow snowmen crafts, and reindeer games. I dreaded the gathering. I knew Brady's broad range of sensitivities and impulsiveness would be on full display. It was a recipe for disaster; his treasured routine blown to bits, loud and rambunctious kids, structured crafts, and group activities with his classmates.

When Brady was overwhelmed with visual inputs, chaotic sounds or social demands, he would sprint away from the situation with no destination in mind, just distance. I was constantly chasing after him, dragging him back to the room, and begging him to participate, while painting a smile on my sweaty face and trying to keep up the illusion that our family was just like all the others. I would leave the party exhausted, frustrated, and running dangerously low on Christmas joy.

At that time, we had not shared Brady's diagnosis with other families at the school. His autism was invisible to the naked eye, and our own fear of how others would react to his neurodiversity led us to perpetuate the illusion of typicality. Even in the face of very visible behaviors, I remained committed to my performance, pretending autism wasn't woven into every aspect of our lives.

I realize now my lack of transparency only made the situation worse. By withholding the truth, I reinforced my own shame. I assumed the other parents thought I was a terrible mother because of my inability to get Brady to conform. At the same time, I was forcing Brady to endure the unpleasant, maybe even painful consequences of my futile attempts at normalcy.

OVERPOWERING PARTY PROBLEMS : ENJOYING THE HOLIDAY SEASON IN UNSTRUCTURED SETTINGS

If you are a parent who dreads classroom parties with your neurodiverse kid, let me share some lessons I wish I'd learned sooner.

1. PLAN AHEAD

Ask the teacher to explain the agenda beforehand. Use social stories, videos, or pretend play to prepare your child for what the party will look, feel, and sound like. Eliminating the element of surprise can help.

2. SHARE CONTROL

If there are multiple activities, ask your child which he would like to do first.Follow his lead. It's okay to skip a particular craft or game if it causes your child more stress than fun.

3. OFFER BREAKS

Each time Brady ran away, I would chase him and immediately drag him back to the room. Instead, once he was safe, I should have allowed him to return when he was calm and ready.

4. BE HONEST

Acknowledge your child is struggling instead of forcing him into compliance for the sake of “fitting in.”You don't have to reveal a diagnosis if you aren't ready, but responses as simple as “Brady is sensitive to loud music,” or “Cutting and pasting is not his favorite,” are appropriate, if you feel an explanation is necessary.

It may seem easier to skip the party altogether, and believe me, I considered it. But your child can benefit from learning to function in an unstructured social setting, if you listen to his cues and honor his needs.

Regardless of how the class party unfolds, when you leave the campus, remember to enjoy the many wonders of the holiday season with your young child in a way that brings you both delight. Before you know it, you'll have a teenager, your elf will be retired, and your party problems will be behind you. •

ABOUT THE AUTHOR:

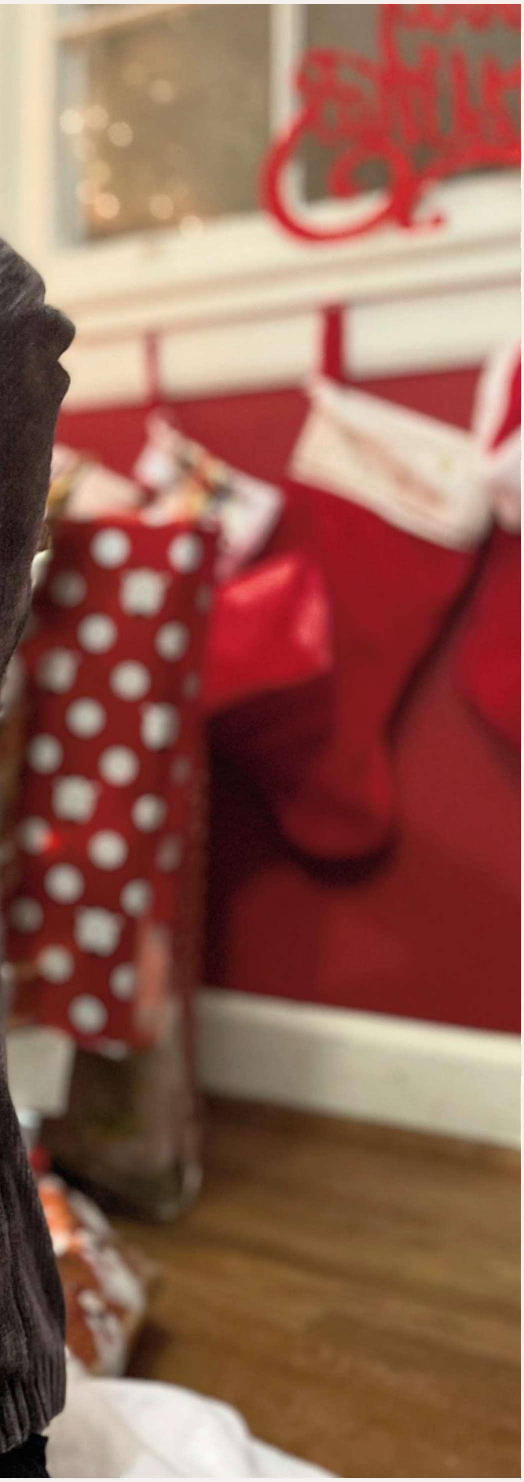
Kari A. Baker is a former financial services executive and business owner turned author, speaker, and podcaster. She is the founder of KIND Families, a community of people who love Kids with Invisible Neurological Differences and is the host of The KIND Families Podcast on Apple and Spotify. Kari became a KIND mom in 2014 when her son Brady was diagnosed with autism at age three. She started KIND Families to encourage, support, and inspire others to find purpose and promise in KIND-ness. Her first print book, *Finding KIND,* features a foreword written by Brady. For more information, please visit **www.kindfamilies.com**

Sometimes, even close relatives might not fully understand autism, so share details about your child's preferences, dislikes and habits. This helps family and friends create a welcoming, supportive environment.

AUTISM-FRIENDLY TIPS FOR A SUCCESSFUL HOLIDAY SEASON

BY MARTA CHMIELOWICZ

PHOTO PROVIDED BY MARTA CHMIELOWICZ



GOOD CHEER: You can make the holidays merry and bright for your entire family by planning ahead, creating supportive environments and embracing activities that suit everyone.

The holidays are around the corner! For many, this is a time for twinkling lights, unwrapping presents and cozy nights with family. But for people with autism and their families, the holiday season can be stressful. Changes in routine, unusual guests, unfamiliar foods and new sensory experiences can be overwhelming for those on the spectrum.

Here are some tips to help you plan a festive season that works for everyone.

PLAN AHEAD AND SET EXPECTATIONS

Whether you're hosting a holiday event or attending one, preparation is key. If you are going to a dinner party or a gathering with family or friends, ask about the timing of the meal, games or events the host has planned, the number of guests attending, and the menu.

This is also a good time to inform the host about any sensory sensitivities or specific needs your autistic family member may have. Sometimes, even close relatives might not fully understand autism, so share details about your child's preferences, dislikes and habits. This helps family and friends create a welcoming, supportive environment.

> *"Make sure you bring a go-bag of your child's favorite toys, activities and sensory comfort items wherever you go."*

People with autism thrive on routine, so letting them know what they should expect can help alleviate a lot of stress. Start by talking to your loved one early about how holiday celebrations will be different from their normal day. If you are hosting or attending an event, use a social story to walk them through the day step-by-step. You can find templates for creating your own social story on the Autism Speaks website.[1]

PROVIDE A SAFE, CALM SPACE

Holiday celebrations can be overstimulating for autistic people who may be sensitive to loud noises, bright lights, or crowded spaces. If you are hosting, it's important to understand that the way an autistic person self-soothes or enjoys themselves might look a little different than you'd expect. You might see them stimming to self-regulate their emotions. That could look different for every person, but often involves physical motions, like hand flapping, spinning or rocking.

Remember that the home they are visiting is an unfamiliar environment for them, and they might need some time to adjust. If possible, offer them a quiet, comfortable space away from the high traffic areas, where they can decompress. Keep the space low-lit and free of noise. Reassure them that it's perfectly fine to take breaks as needed.

If you're traveling or visiting family, think about ways you can bring elements of home with you. Make sure you bring a go-bag of your child's favorite toys, activities and sensory comfort items wherever you go. For children with special interests, having their favorite videos or games on hand can help them feel engaged and occupied.

BE MINDFUL OF FOOD PREFERENCES

It's very common for people with autism to have sensitivities to certain food textures or flavors, restricting their diets. They might not like traditional holiday foods, so it's important for parents and caregivers to be prepared with foods that they will happily eat.

If you are dining away from home, consider bringing one or two familiar dishes for your loved one to enjoy. Let the host know in advance that you will be bringing your own food, to avoid any surprises. Sometimes, seeing a familiar meal in a

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[1] www.autismspeaks.org/templates-personalized-teaching-stories

familiar container can be a source of comfort for autistic people.

RESPECT BOUNDARIES AND BUILD CONNECTION

Holiday events can be noisy and overwhelming, so watch for signs that your autistic guest or family member might need a break. Sometimes, people with autism struggle to communicate verbally, so you may need to pay close attention to their body language. If they look uncomfortable, don't pressure them to stay in a certain room, or engage in a conversation. Instead, focus on meeting them where they are. Shared activities, like playing a game or working on a puzzle together, can often be more meaningful than talking. Ultimately, the best tradition is simply spending quality time together in a way that feels right for them.

> *"Shared activities, like playing a game or working on a puzzle together, can often be more meaningful than talking."*

VISIT AUTISM-FRIENDLY EVENTS IN YOUR AREA

If family gatherings aren't ideal, consider sensory-friendly experiences to add to your holiday celebrations. Every year, Autism Speaks teams up with Cherry Hill Programs to host autism-friendly Santa Cares events. They allow people of all ages and abilities to enjoy the magic of Santa in an inclusive environment, welcoming to those with sensory differences. Sensory triggers are minimized by reducing crowd sizes, decreasing wait times, and ensuring lighting and music are set at comfortable levels. Santa and other staff are expertly trained by Autism Speaks to understand and cater to the needs of individuals with special needs and their families.

To find a participating location near you, visit **www.whereissanta.com**. For additional autism-friendly events, visit the Autism Speaks events calendar at **www.autismspeaks.org/events.**

By planning ahead, creating supportive environments and embracing activities that suit everyone, you can make the holidays merry and bright for your entire family.•

ABOUT THE AUTHOR:

Marta Chmielowicz leads science communications at Autism Speaks, working to advance the mission of the organization to create an inclusive world for all individuals with autism throughout their lifespan.

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Family & Community

TIPS FOR ACCOMMODATING HOLIDAY GUESTS WITH MOBILITY ISSUES

BY THEA JOHANSEN

If you're preparing to host a gathering, it's quite possible that someone dear to you will appreciate some extra support. To make your holiday celebration comfortable and inclusive for guests with mobility issues, consider the following recommendations:

OPEN THE DIALOGUE

Communication is key:

- *Never hesitate to ask, "How can I make your visit more comfortable?" when inviting a dear one with mobility issues. This simple question can make all the difference, helping you personalize your welcome.*

ACCESSIBILITY

Open your home to everyone with these simple changes:

- *Install temporary ramps for smooth entry.*
- *Rearrange furniture for clear paths.*
- *Remove rugs that may obstruct wheeled aids.*
- *Guide your guests with mobility needs, showing them the best routes to essential areas, like the restroom.*

SEATING

As hosts, we want to ensure everyone is comfortable at the table:

- *Consider chairs with armrests for added comfort.*
- *For guests in wheelchairs, adjust table heights to accommodate them seamlessly.*
- *Ensure ample space for maneuvering mobility aids or transferring to and from seats.*

ASSISTANCE

Anticipate the needs of your guests by:

- *Coordinating assistance for arrivals, seating, and restroom visits.*
- *Creating a supportive environment where help is at hand, should they need it.* •

ABOUT THE AUTHOR:

Thea Johansen is a skilled physical therapist and technical anthropologist, using her extensive knowledge and experience to help individuals attain the highest possible level of independence in the home and office environment. As a Physiotherapist, Thea has worked with rehabilitation of children and adults within the field of special care. Thea is a mobility expert at Vela Chairs.

6 HOLIDAY TRAVEL HACKS FOR KIDS!

BY NECHAMA SORSCHER, PHD

MAKING MEMORIES: Holiday travel gives your and your kids a priceless gift: time with the family!

Holiday travel is an amazing way to create memories with your children and enjoy time as a family. For parents of neurodiverse children this magical time triggers intense anxiety.

Will my child have a meltdown in the middle of a busy airport? Will we get through the day without a tantrum? How can I explain to my family that my child is not being a "spoiled brat" when he refuses to engage in family fun? Here are some ways to support your child and ensure a smooth holiday!

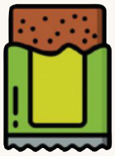
Neurodivergent children thrive on routine and predictability. Holiday travel is unpredictable! Neurodivergent children are often extremely sensitive to outside stimuli such as: noise, light, texture and temperature. Holiday travel exposes them to these aversive stimuli. No wonder they can ber cranky, stressed out and prone to tantrums! We can help by addressing these issues.

CREATING LASTING MEMORIES : REDUCING STRESS WITH PACE AND PREDICTABILITY

As a child psychologist for over three decades I have been working with patients with neurocognitive challenges. Here are my top six holiday travel hacks:

1. TRAVEL AT A SLOW PACE AND KEEP TRANSITIONS TO A MINIMUM

Holiday travel can be exhausting and overwhelming for everyone, especially for children with neurocognitive challenges. Taking it at a slow, relaxed pace avoids stress for everyone! Try to keep transitions to a minimum, as neurodivergent children struggle with shifts in the schedule and environment. Give your children as many choices as possible. For example, you can involve them in which snacks and toys to bring, what colors to wear, and what music to play. Presenting them with various options gives them the sense of being in control, reduces stress and creates calm.



2. PACK THE SNACKS!

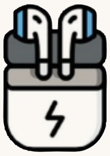
This one probably goes without saying, but make sure to stock up on snacks. It's hard to find favorite snacks when on the road or at the airport. Prepping fun, nutritious, familiar and easy to eat snacks in advance can avoid a lot of stress.

3. DRIVE WHEN POSSIBLE

Air travel involves multiple transitions that can put your child on overload. If you can, travel by car. Prepare to stop often, and go at a relaxed pace to make the journey part of the fun.

4. IF YOU MUST FLY, MAKE IT FUN!

If you must travel by air, making the experience fun can really help to bring down the stress. Lots of airlines have fun items for kids, like coloring packets or wings. Don't be afraid to ask for them. A visit to the cockpit is a magical experience. Feel free to ask the gate agent or flight attendant if they can ask the pilot for a peek at the cockpit. Some airports have children's play areas. Try to scope them out in advance, so you can plan enough time to let the kids get out some energy before the flight.



5. GET COZY AND STAY BUSY

Bring kid friendly items like coloring books, playdough, reusable sticker books, and more to keep the kids busy, while you're in the air or driving. Don't forget the headphones! Airlines don't have kid friendly headphones. Noise canceling headphones are very helpful for kids who experience sensory overload. Help them get cozy. Create a sensory cocoon for your kids with blankets, pillows, stuffed animals and toys. Your children benefit from having as much control as possible over their surroundings, so giving them the accessories to personalize their experience will help calm their nervous system.

6. AVOID SENSORY OVERLOAD

All children love details and familiarity. This is especially true for neurodivergent children. Reviewing with them every day what the plan is, will be extremely helpful to them. Creating a calendar and reviewing the schedule for each day in writing or with pictures will help them prepare mentally for the events. On the day of the flight, get there early. Give your child a checklist of all the activities. Give your child noise reducing headphones. If your child gets stressed, be calm and reassuring. Remind them of the schedule and help them take deep breaths. Creating a sensory rich experience for your child is essential for their nervous system to calm down. It can overload their circuits when they are exposed to new, unfamiliar stimuli. Give them familiar sensory experiences such as: a favorite stuffed toy, smelly erasers and fidget toys.

Your children take their cues from you. When you are calm and unflappable, it will help them follow your lead. Your goal is to create memories that will last a lifetime. You are giving yourself and your kids a priceless gift: time with the family! In the end, the specific activity or experience is insignificant, so relax, go with the flow and enjoy the time together.

ABOUT THE AUTHOR:

Dr. Sorscher, a clinical psychologist in New York City, has over three decades of experience working with patients with neurocognitive challenges, both as an evaluator and a psychodynamic therapist. Dr. Sorscher obtained her PhD in clinical psychology from Adelphi University in 1992 and a certificate in psychoanalysis and psychotherapy from NYU's Postdoctoral Program of Psychotherapy and Psychoanalysis in 2016. She has published many articles in academic journals on neurocognitive challenges, trauma, and working with neurodiverse children and adolescents. Dr. Sorscher has two new books including *Assessment and Intervention with Children, Adolescents, and Adults with Neurocognitive Challenges: A Psychodynamic Perspective*, which delineates how to best work with neurodiverse individuals, and *Your Neurodiverse Child: How to Help Kids with Learning, Attention, and Neurocognitive Challenges Thrive* for parents and teachers who work with neurodivergent children.

PART II OF II

LIVABETES

THE DIABETIC LOW ACCIDENT

CLOSE CALL: Guy's car after the accident. Now more than ever, Guy preaches the importance of paying attention to and always obeying the continuous glucose monitor.

BY LAURIE GORDON

It was Sunday, March 3rd, 2024. Time seemed to stand still as I stared out the window. To my right, I could hear the ticking of the dining room clock. With each click, I guardedly glanced at my phone. It had been nearly an hour and a half since Guy's continuous glucose monitor had stopped registering on the graph that my daughter and I have on our phones.

Prior to that had been a deluge of piercing beeps indicating a diabetic low. My daughter Ashley called him and he had promised to get a sandwich. He didn't. I called, now seeing the sugar number nearing the 40s, and pleaded with him to pull over. He didn't. Ashley was at college in Mahwah, New Jersey and I was in Stillwater. The texts between us had turned into frightened phone calls.

My husband, Guy, was diagnosed with Type 1 Diabetes in 2012. He drives from client to client with his travel gym to motivate and guide kids and teens facing some sort of adversity through the Back on Track Agency which he directs. Since kids are out of school on the weekends, working Saturdays was the norm, and that had bled into also working Sundays. Guy was working more and more, and it was taking its toll on family time and on his body.

I promised Ashley I'd "do something" if we didn't hear from Dad by noon. I knew not what. Both of us were neurotically calling and texting him to no avail. At 12:57 I received THE call. "Mrs. Gordon, this is nurse (something) and your husband is here in the Trauma Center at Morristown Memorial Hospital."

I somehow made it to Morristown, managed to park, and find

PHOTOS COURTESY LAURIE GORDON

Guy. He was in agony, and they were very concerned about brain damage from the airbag being deployed. He had, in fact, passed out from the diabetic low, so the bag hit his intestinal area rather than his head. The plan was to put him in ICU where they would wait and see if his intestinal wounds would settle down and fix themselves. I was a deer in headlights. Ashley's boyfriend got her there, and the next few hours were a blur. Hours later, we were told to go to the ICU and wait.

The next day, Guy had exploratory surgery to check out his knee. It seemed okay, and he needed to sleep off the anesthesia. Relieved, we recreated the timeline of what had transpired the day before as we hiked a bit in Jockey Hollow. We went back to see him in the ICU, then went home.

A SCARY STORY: *(Left to right)* Ashley, Laurie and Guy Gordon celebrating Halloween, eight months after the accident; "It was over, and we were back to being us!"

A very kind Randolph policeman with whom I had spoken on Monday had encouraged me to see what remained of the car and retrieve the remnants of Guy's travel gym. Although Ashley was 18, an adult, I will always second guess taking her along to see the sight of shattered glass and the devastation of the vehicle, and smell the lingering odor of the burst airbag. I needed her help to salvage any equipment we could. The yard manager had been the person who had brought the car there on a flatbed. The accident had been so horrific that he'd taken photos. They showed the black Honda HRV wrapped around a tree, and in the distance the battery that had flown 90 feet. "I don't know how he got out alive," the yard manager said.

We drove to the hospital to see Guy. When we entered his room, there was chaos. They needed to get Guy to the operating room IMMEDIATELY for emergency surgery. They had waited, hoping his intestines would settle, but part of his intestine had ruptured and Guy had gone septic, and an operation was needed NOW. Ashey needed to go back to college, so my mother picked her up from the hospital and drove her back to school.

Six or seven hours later, Dr. Cho emerged and escorted me to a private room to "talk." The only indication I got that Guy had not passed was Dr. Cho's calm demeanor. We sat. "Your husband made it, but he went septic. It was close. He now has a colostomy bag." Guy was in the ICU for 14 days with a new appendage; a plastic bag attached to something called a stoma, that the doctors created to let his colon and intestines heal. They had to reroute how he made stool to his front left side, into the bag. Three weeks later, he was sent home with the bag and a bad puncture wound from the seatbelt.

The next day a visiting nurse arrived at 8 am. "I'm here to teach you," she said in a cheery voice. I now had to become an expert at something I had never been trained to do. That morning, I learned how to care for my husband's stoma, release the former adhesive with a spray, remove the "wafer" (the piece that adhered around his stoma, so that the bag could connect), clean the stool filled area, spray adhesive spray, adhere a new wafer, and then replace the bag with a spritz of powder to lessen the scent. The smell was unfathomable. It stunk. His clothes stunk. That's what a colostomy does. I then had to address the wound. Two pus-filled lesions needed to be cleaned, treated with saline, and dressed. The nurse came twice a week, then once. She missed a brewing infection which our bi-weekly visit to the wound care center caught, and Guy was re-hospitalized for another week. He returned home and a woman named Sandra from an infusion agency arrived to teach me how to do yet another medical task. Saline, short infusion, saline, hour infusion, saline, then heparin.

A caregiver often goes through unfathomable situations. Guy went through his own hell. I was furious at him for putting me in this position. My work and my life had been turned upside down, and I was his one and only caregiver. What if I messed up? Why are they putting this all on me? I learned and did what I had to do, and was so thankful for friends who gave me respite (Jeffrey, Albert, Gary, Bill, Dave, Kenny and Karen), visiting on multiple occasions so I could take a deep breath for an hour. The debris and clutter of all of the medical equipment that consumed our living room reflected the debris and clutter in my mind.

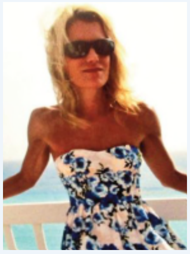
Thankfully, five months later, the doctors and our insurance approved a colostomy reversal. Although the reversal surgery took three hours more than expected, Guy made it, and was home a week later… sans colostomy bag.

All of my fears and worries had bubbled up to my consciousness. I freaked out more than once during our tenure with the colostomy bag and infectious wounds. My rock was Ashley.

Seven months later, it was Ashley who knocked me to my senses. The Ramapo College sophomore psychology major talked me down when I harped, once again, on how my husband had "let this happen to us." As I vented, she rose to her feet and said firmly, "Just hear me out! Mom, let it go. It happened. It's the past. You can't be mad anymore." I stared at her in silence, as the child became the parent. She was right. She's going to be one hell of a therapist. She already is.

Despite the horror of the accident, Guy continues to call it "Livabetes," the way he handles his Type 1 Diabetes. He teaches the kids he works with through the Back on Track Agency about his disease. He shows them how he administers shots. Now, more than ever, he preaches the importance of paying attention to and always obeying the continuous glucose monitor. •

ABOUT THE AUTHOR:



Laurie Gordon is the owner/director of Motivation Ink Services, a publicist and writing agency based in Sussex County, New Jersey. She has written for numerous magazines, newspapers and websites. She has done a host of public relations work for varying businesses, individuals and nonprofits. After she wrote a story about a devastating storm that hit New Jersey, she was contacted by and featured live on The Weather Channel. Laurie is a former US Olympic Marathon Trials qualifier who was sponsored by Nike and whose women's team won the team division at the prestigious Boston Marathon. She works with women and teens as a personal trainer. Laurie volunteers coaching children through The Bears Youth Running Program. **MotivationInkServices@gmail.com**

REMEMBER ★ HONOR ★ TEACH

Help Wreaths Across America Remember, Honor, and Teach on December 14, 2024 at 12:00 pm *(Wreath Placement Beginning at 8:00 am)* by sponsoring a wreath, volunteering, or inviting friends to help.

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and $5 from each Wreath Sponsored through this page will benefit IES Brain Research Foundation.

The Irene & Eric Simon (IES) Brain Research Foundation is a volunteer-run nonprofit whose mission is to help advance research toward treatments and cures for brain diseases and conditions. The Irene & Eric Simon (IES) Brain Research Foundation Summer Fellowship Program in Neuroscience attracts bright, motivated students to neuroscience.
These remarkable students are mentored for the summer by brilliant neuroscientists heading top-notch labs.
The Foundation will have given 116 summer fellowships as of Summer 2024.

Many fellows have gone on for PhDs or MD/PhDs in neuroscience, have published papers and even won awards.
The goal is for the student fellows to add to the work of the senior scientists towards treatments and cures for Alzheimer's, Traumatic Brain Injury, autism, MS, brain cancer, PTSD, stroke, addiction, MS, depression, Parkinson's, ALS, pain, epilepsy and other brain diseases and conditions. The Summer Fellowship Program is funded strictly by events like the Endorphin Golf Outing & Dinner being held on June 3rd 2024, and donations often made in memory or in honor of loved ones.

REMEMBER THE FALLEN   HONOR THOSE WHO SERVE   TEACH OUR CHILDREN THE VALUE OF FREEDOM

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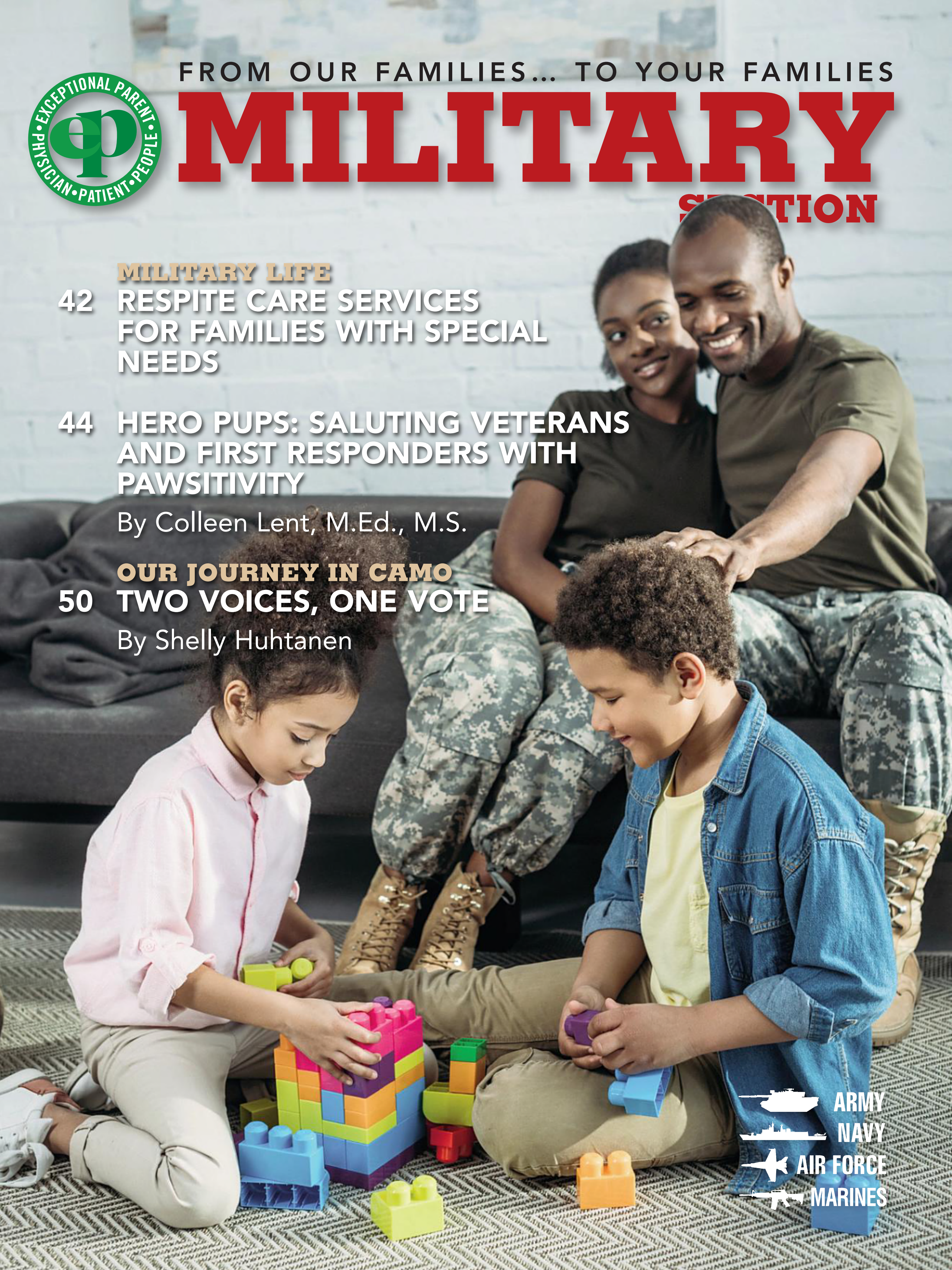

FROM OUR FAMILIES... TO YOUR FAMILIES

MILITARY SECTION

MILITARY LIFE

OUR JOURNEY IN CAMO

ARMY
NAVY
AIR FORCE
MARINES

MILITARY LIFE

RESPITE CARE SERVICES FOR FAMILIES WITH SPECIAL NEEDS

Taking care of a family member with special needs can be more than a full-time job. As a parent and/or caregiver, it's natural to want to give your all to your loved one, but everyone needs a break, whether that's to go to an appointment, run errands or just have time for yourself.

Respite care provides that temporary break by putting your family member in someone else's care. It can be hard to leave your child, teen or other family member with special needs, but taking time away from caregiving duties is essential to your well-being and benefits your loved one as well.

WHERE CAN I FIND RESPITE CARE?

Families enrolled in EFMP may receive respite care through their branch of service's EFMP respite care program if they meet standard eligibility requirements. Respite care is a program benefit, not an entitlement. Families can request additional respite care support if they experience exceptional circumstances that significantly impact the well-being of a caregiver or require additional support.

You can contact your EFMP Family Support provider (https://installations.militaryonesource.mil/search?program-service=16/view-by=ALL) for more information or assistance in locating military and community respite care resources. Other places to look for information and respite care options for children and adults include:

- Your state's Lifespan Respite Program, if available. Lifespan Respite Programs are run by state agencies to provide community-based respite for family caregivers (https://archrespite.org/ta-center-for-respite/state-respite-coalition-contacts).
- The National Respite Locator. This online tool can link you to information on respite funding and caregiver support in your state (https://archrespite.org/caregiver-resources/respitelocator).
- State Respite Coalitions. These membership organizations represent people with disabilities. Some of these organizations provide training and respite vouchers (https://archrespite.org/caregiver-resources/respitelocator).
- Nonprofit organizations related to your family member's condition may be able to refer you to respite services in your community.
- A "co-op" in which you and other families take turns watching each other's loved ones. Family support groups are a good place to meet others interested in forming a respite care co-op.

WHERE CAN I FIND HELP PAYING FOR RESPITE CARE?

There are several options where you may find help paying for respite care.

- TRICARE Extended Care Health Option offers up to 16 hours of in-home respite care to eligible military families (www.tricare.mil/Plans/SpecialPrograms/ECHO/Benefits).
- ECHO Home Health Care offers up to eight hours per day, five days a week of temporary relief for eligible military families with a family member who is homebound and requires frequent care (www.tricare.mil/Plans/SpecialPrograms/ECHO/EHHC).
- Medicaid waivers cover the cost of respite care if your family member qualifies. Check with your state's Medicaid office to learn more (www.militaryonesource.mil/special-needs/medical-needs/medicaid-waivers-for-military-families).

Your installation's Exceptional Family Member Program Family Support provider can help you navigate the EFMP respite care program, locate alternative respite care programs or locate financial assistance. You can also schedule a Military OneSource special needs consultation 24/7 by calling 800-342-9647 or through live chat. If you're overseas, view international calling options at www.militaryonesource.mil/resources/tools/international-calling-options •

– Military OneSource

Now Available: Interview with Faye Simon, Editor-In-Chief of EP Magazine

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COMFORT AND JOY: Detective Rochelle Jones and comfort dog Mason visit the Pease Air National Guard Base, 157th Air Refueling Wing, as part of their community outreach.

PHOTO COURTESY HERO PUPS AND PORTSMOUTH POLICE DEPARTMENT

HERO PUPS

SALUTING VETERANS AND FIRST RESPONDERS WITH PAWSITIVITY

BY COLLEEN LENT, M.ED., M.S.

The idea for training puppies from area animal shelters and rescues to assist veterans and first responders evolved when Laura Barker was visiting her veteran son Nick, while he was recovering from being shot in Afghanistan in 2011.

During one trek to the Naval Medical Center in Virginia, Barker noticed the transformation of another young veteran recuperating from head trauma and an amputated leg. The wounded warrior's usual gruff demeanor had softened with a smile. The visiting therapy dog responded with a repertoire of tail wags, face licks, and nose nuzzles.

Barker kept the indelible image of the veteran and his furry guest tucked into her mental back pocket. Months later, the memory resurfaced when a couple replied to Barker's advertisement for Great Pyrenees puppies that she was selling. As Megan and Jake greeted Barker at her kennel, they noticed a "Marine Mom" decal on Barker's van. This led to a serendipitous discovery. The visitors were U.S. Marine Corp veterans. Jake was grappling with anxiety and PTSD, following his service. As a volunteer search and rescue dog trainer and military mother, Barker instinctively realized that Jake and other veterans could benefit from a support dog to assist with their invisible injuries.

As Barker began researching the steps to create a nonprofit organization, she discovered that the invisible injury problem was compounded by the burgeoning percentage of veterans accepting first responder jobs after serving in the military. According to the 2015 report "Characteristics of Individuals and Employment Among First Responders" prepared for the U.S. Department of Labor, about 7% of all employed individuals in the nation served in the U.S. Armed Forces on active duty. The three major first responder categories, however, had larger shares of veterans than the 7% average. The DOL research indicates that veterans made up 25.2% of police, 18.6% of firefighters, and 10% of emergency medical technicians. This data indicates that first responders with a military background continue riding the cycle of trauma exposure without a mental break. The authors of "The Ruderman White Paper Update on Mental Health and Suicide of First Responders" released in 2018, discuss the grave aftermath of repeatedly witnessing traumatic events. "These professionals embody astounding bravery and resilience, but at the end of the day, they are only human," write the authors. Failing to destigmatize the need for mental health awareness and treatment can have fatal consequences, according to the document's researchers with the nonprofit Ruderman Family Foundation.

Research released by the Substance Abuse and Mental Health Services Administration also sounds the siren on the emotional well-being of veterans and first responders. In its 2022 "Supporting the Behavioral Health Needs of our Nation's Veterans" blog, SAMHSA contends that about 5.2 million veterans are wrestling with a behavioral health challenge, with only about 50% seeking timely treatment for diagnosed mental illness. In addition, SAMHSA's "First Responders: Behavioral Health Concern, Emergency Response, and Trauma" 2018 bulletin estimates 30% of first responders face mental health challenges ranging from depression to PTSD. "This data highlights that our friends, family, and community members may be suffering in silence, and that barriers to care exist including stigma," reads an excerpt. Barker echoed the call to address these mental health challenges. She said that veterans and first responders have devoted their lives responding to the distress alarms of others, and now the public can reciprocate with compassion and support.

Barker believes progress is being made to give veterans and first responders assistance with healing the emotional scars from serving their country and communities. She cited the donation of seed money from a Florida U.S. Marine Corp family to build the nonprofit's new 9,600 square foot building that serves as a pup training and group counseling meeting spot, as one example. She said the gift symbolizes the growing support

PUP PREP: Laura Barker trains Benny as a future support dog for a veteran or first responder.

PHOTO COURTESY HERO PUPS

PERFECT PAIR: Detective and veteran Rochelle Jones tells her furry partner Mason "I trust you" before public presentations and visits.

in breaking down treatment blockades. Barker pointed to a collection of military dog tags and framed photos of veterans and first responders with Hero Pups placements, displayed throughout the two-story facility, as additional evidence. She cited the 600 volunteer hours from individuals working onsite and remotely during the first three weeks of May, as another indicator of public commitment to giving back to veterans and first responders.

Barker noted that the stairway leading to the second floor of the new Hero Pups site is wide enough to accommodate humans with wheelchairs and their canine companions. Blue cushioned chairs cradle individuals participating in group therapy sessions. A nearby queen-sized bed with a comforter and pillows provides pups practice waking their human charges from nightmares. Two lighting systems allow brightness adjustments to thwart potential triggers. Barker said that consultations with veteran organizations and therapists provided expert guidance for designing and furnishing the building.

Situated on 46 acres, the Hero Pups site also offers outdoor respite options. The four miles of wooded trails allow Hero Pups recipients to take tranquil walks with their whiskered buddies. Patio chairs and tables are available to visitors seeking a spot to share the fresh air and warm sun with flitting birds and butterflies. Garden beds are being created for green-thumbed veterans and first responders, with resulting produce earmarked for local food pantries. A flat blank side of the building serves as an oversized movie screen. There is a long dirt road leading to the site. Barker said that the road, flanked with blue and red striped wooden markers, will remain unpaved to retain the natural sensory appeal of the retreat. "We call it checking your baggage at the tree." Barker said. She added that the four-pawed Hero Pups silently communicate to the veterans and first responders that the site is a safe zone.

Police Detective Rochelle Jones served her country for three decades as a veteran and first responder. She said that handling Mason, a comfort dog donated to the Portsmouth Police Department, has resulted in immeasurable benefits to community members and fellow officers. Before pursuing a career in law enforcement, Jones served in the U.S. Army Military Police Corps as a corrections specialist for the U.S. Disciplinary Barracks in Fort Leavenworth, Kansas. Now, she is a police detective working in the city she was born and raised in. Jones said that witnessing and stopping conflict remains a routine part of her job. She and other law enforcement officers are affected by the immersion in routine traumatic scenes that include: fatal drug overdoses, sexual assaults, deadly car crashes, attempted suicides, and natural disasters.

"We're dealing with some very abnormal things," Jones said. She recalled responding to a crisis call for a despondent man threatening to jump from the Piscataqua River Bridge, as an example. Jones said that she is grateful that her training as a Seacoast Emergency Response Team crisis negotiator helped save the individual's life, but that memory of the scene lingers. "If I drive by that bridge, I'm always going to think of that inci-

PHOTO PROVIDED BY COLLEEN LENT

GAME CHANGER: Mason, Portsmouth Police Department's comfort dog; "Sometimes the best therapists have fur and four paws."

dent." Jones said. "You can work your way through it," she added. She said that she encourages her fellow officers to make a conversation "date" with themselves, to acknowledge the traumatic events that are part of the job. Jones said that she and her colleagues are thankful for the department's foresight to welcome Mason as part of its mental health wellness plan. Wearing his on-duty vest, Mason attends roll call and debriefing sessions, and completes regular department walk throughs to say hello to the entire team. Jones said that simply petting and having social interaction with the pup makes them feel good and less stressed. "Mason is a game changer," Jones said, reflecting on her partner's calming effect on the police department. "Sometimes the best therapists have fur and four paws." In addition to boosting the morale of the Portsmouth Police Department, which includes several veterans, Jones said that Mason helps the officers connect with the community during times of triumph, as well as tragedy. Mason participates in the city's annual Cops and Kids event, circulates at senior citizen socials, and visits local schools. "I want him to be exposed to as many kids as possible, before something bad happens," Jones said. She said that she feels building rapport with children will increase the likelihood that they'll reach out to an officer or other trusted adult, when they're struggling with dangerous or difficult situations, including abuse and neglect. Jones said that Mason has provided comfort to adults and children during times of crisis. She recollected responding to an "unattended" death of a young man. The father of the deceased individual arrived at the scene and remained immobilized, refusing to leave his son's side. "He was stubborn," Jones said, describing the grieving parent, who was a fellow veteran. "He was the patriarch of the family." Jones recalled asking the distraught man if he liked dogs. He said yes, and allowed Mason to climb inside his truck. As the man felt Mason's soft fur and warm breath, the tears started to roll down the veteran's face. In a calmer state, the devastated father agreed with Jones that the last memory of his son should be associated with Mason providing comfort, not the coroner completing a post-mortem exam. "Mason broke down that tough barrier," Jones said. She added that Mason's presence was invaluable with helping a heartbroken father and his family.

Nick Goulet, the recipient of a Hero Pups service dog and former lieutenant with the Berwick Fire and Rescue Department in Maine, said that he initially didn't follow the advice Jones gives to veterans and first responders, to develop a plan to process job-related trauma. Consequently, he plunged into a dark hole of despair following two tragic events. Goulet recalled being the incident commander of a car accident scene that claimed the lives of four people. This was the precursor to his PTSD symptoms. "I didn't want to say anything," Goulet said. "I didn't want to be a weak firefighter," Eventually, Goulet spoke with a counselor to help traverse the trauma that had started crowding his thoughts. Without warning, a second tragedy struck. A friend in the department filled a shift for Goulet, a schedule change that would claim the firefighter's life and shatter Goulet. Responding to an apartment fire, the fellow firefighter died while trying to rescue residents and protecting a crew member. "When Joel died, I kind of shut right down," Goulet said, referring to his fallen department brother. Goulet didn't talk with anyone about his feelings. Horrific images kept replaying. "When all these dreams and enemies catch up with us, we hit rock bottom," he said. Rock bottom for Goulet meant retreating into his basement where it was cool and dark. The longtime firefighter of 24 years said his cellar became his bunker. It was the only place he would attempt to sleep. "Upstairs, outside of the basement, I felt more vulnerable," Goulet explained. When he joined the National Junior Firefighter Program at the age of 16, he didn't foresee his quest to help others would result in a mental health lockdown, as an adult.

Seeking counseling from the nonprofit Brattleboro Retreat of Vermont, and meeting Barker at a Hero Pups fundraiser in honor of his late friend, helped Goulet come out of his self-imposed solitary confinement. Eventually, he decided to share his healing journey to help others. "I don't think firefighters understand there are these types of resources for them," he said. "They don't have to suffer." As he sat on a couch near sunny windows at the Hero Pups site, Goulet paused as his service dog Nyssa inspected a stuffed purple octopus on the nearby coffee table. Goulet said that while his companion will give the dog toy a quick sniff, she won't play with it while on duty. "When the vest goes on, the working starts," Goulet said. "She knows her job is the person she's looking at right now." Nyssa

PHOTO COURTESY PORTSMOUTH POLICE DEPARTMENT

DOG DAY: Nick Goulet. former lieutenant with the Berwick Fire and Rescue Department in Maine, and his service dog Nyssa relax outside the new Hero Pups training and respite site.

has been task trained to assist Goulet manage PTSD symptoms, ranging from nightmares to anxiousness. At night she rests by Goulet's side on his bed, placing her entire body weight against him until he falls asleep. Then, she quietly moves to her dog bed to keep vigil. When Goulet experiences a nightmare, Nyssa wakes him with a gentle nudge. If Nyssa senses Goulet becoming tense during the day, she extends her paw as a gentle reminder for him to decompress with deep breathing techniques. "We kind of have a nice system now," Goulet said. Nyssa's name, meaning new beginning in Greek, describes the gift she has given Goulet, since she was placed in his custody four years ago through Hero Pups. Goulet has resumed working as a tow truck driver with Nyssa by his side, assisting stranded motorists. Nyssa accompanies Goulet when he participates in Hero Pups fundraisers or attends outdoor concerts and plays, sitting in her own comfortable chair during spectator events. "She's my shadow," Goulet said. "It's certainly different now, because I don't feel alone."

A DOG'S LIFE : HERO PUPS INFORMATION

HERO PUPS

Support Dogs For Veterans/First Responders

https://heropups.com

Receiving its 501 (c) 3 status in 2016, Hero Pups has trained and placed 225 support dogs with veterans and first responders to counteract post-traumatic stress disorder symptoms and other psychological challenges resulting from their service.

Barker said that the generosity of volunteers and donors gives the nation's heroes a chance to embark on a new path of healing and happiness with a four-pawed trail mate, fulling the Hero Pups mission. As the U.S. Marine mother points to numerous photos of former pup trainees now serving and protecting veterans and first responders, Barker mentioned a famous quote by author C.S. Lewis: "You can't go back and change the beginning, but you can start where you are and change the ending." •

ABOUT THE AUTHOR:

As a longtime journalist and educator, Colleen Lent has written over 1,000 articles for more than 20 different publications, including *The New Hampshire Journal of Education* and *Portsmouth Herald.* She earned an excellence in teaching award from Southern New Hampshire University and a first-place health reporting award from the New England Newspaper and Press Association. Colleen holds a Master of Science degree in communications from Clark University and a Master of Elementary Education degree from Southern New Hampshire University. One of her fondest professional experiences was teaching veterans enrolled in undergraduate courses at Southern New Hampshire University and Manchester Community College.

PHOTO PROVIDED BY COLLEEN LENT

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soon becomes
later becomes
someday becomes
...when?

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OUR JOURNEY IN CAMO SHELLY HUHTANEN

Two Voices, One Vote

I picked up Broden from clinic and asked him if he wanted to come with me to vote. Not knowing quite what he was agreeing to, he said yes.

Since I can remember, my family expressed to me the importance of voting. One of the first things my parents did when I turned 18 years old, was to make sure I was registered to vote. As a military spouse, I've voted from where I lived at the time, from Alaska to South Carolina. This year was not any different. On my daily morning phone call with my dad, "Are you registered to vote? Your mom and I are going to vote early and beat the rush." I assured my dad that I was going to vote early, and reminded him that Mark had voted through an absentee ballot in Montana. When Hayden, Broden's brother turned 18, we walked with him to the voting office to make sure he had the ability to vote. My parents still tell me, "I don't care how you vote. Just get in line and vote." Unfortunately, Broden was unable this year to vote, but I'm happy to say we had the next best thing.

Through the local channels a reminder was sent out. "Early voting has started, so take time to cast your vote early, if you'd like to do so." I grabbed a sticky note and wrote a reminder to vote early to avoid the long lines. The next day, driving Broden home from clinic, I took a right onto Harden Street and saw lines of people down the street, waiting to cast their ballot. I'll admit, I got a little emotional. "Broden, look at all those people waiting to vote. It's that time!" As I crept slowly down the street to see the spectacle, I looked in my review mirror and saw Broden looking out the window to see everyone in line. Once I turned right, I gained my composure and said, "Broden, I wish you could vote, because you do have something to say."

CIVIC DUTY: Broden wearing his mom's voting sticker; "I'm grateful to live in a country where I can stand in line and, this time with my son, cast my vote."

The next day, I picked up Broden from clinic and asked him if he wanted to come with me to vote. Not knowing quite what he was agreeing to, he said yes. I grabbed my phone and searched local options for voting. I thought if I voted in the heart of downtown the lines would be too long for Broden to wait in. I thought I would try and drive to a voting site outside of town; "Broden, we're going for a little ride to see if we can find a shorter line to vote." I decided to drive to a polling site about 20 minutes away from the heart of Columbia. It was busy, but I wasn't going to leave without trying. I found a parking spot. Broden grabbed his iPad and iPhone and followed me out of the car, "Broden, keep your music low. We need to be quiet so people can focus on voting." Broden took his devices and turned the volume down. When we walked into the building the line was long, but it was moving surprisingly quickly. There were two military

PHOTO PROVIDED BY SHELLY HUHTANEN

veterans in front of us, proudly wearing their US Army retired hats. As I looked behind me, there was a woman with two boys around 8 and 10 years old. As I kept Broden in line, I looked back and saw her ensuring her boys stayed in line, too.

Before we knew it, we were at the front of the line. Our next step was to walk into a large room where I needed to show my driver's license to receive a ballot. A woman in an election vest came over to me and said, "He's going to have to turn those electronic devices completely off before you go in that room." I tried to explain to her that he was profoundly autistic, and if I forced him to turn them off he would most likely scream. After her showing indifference to his disability, I started to leave the line. I thought that maybe this was just not going to work. As I started to leave the line, the woman with the two boys stopped me. "Could your son sit in this chair over by the wall and I could watch him? You need to vote today." I turned to Broden, "Sit down over here and watch your iPad. This nice woman is going to stay with you. I'll be back in three minutes."

> "I started to leave the line. I thought that maybe this was just not going to work. As I started to leave the line, a woman stopped me. 'Could your son sit in this chair over by the wall and I could watch him? You need to vote today.'"

After quickly thanking her, I shuffled into the room and grabbed my wallet to pull my license out. After I was given a ballot, I was told to stand in another short line until a place was available for me to vote. I kept looking to my right to see if Broden was ok, and the woman periodically gave me a thumbs up. When I was close to the front of the line, I heard the woman say "No, I can't vote right now. I'm watching her son so she can vote. Just go ahead of me." I look over concerned and she mouths to me, "Vote!" I shoved the ballot in the machine as quickly as I could, so I could relieve the woman who was watching Broden. As I started to make my first selection on the ballot, I heard a chair screech across the floor. An older fellow in an election vest had dragged a chair next to me, while Broden followed him. As I looked up, the man said, "Your son is voting with you today." I thanked him. Broden spontaneously reached for my right hand and squeezed it. He continued to squeeze my right hand as I voted with my left. After I was done, I walked with Broden over to the last station to submit my ballot. The woman at the station smiled at me, "Do you want a sticker?" I smiled, took one and put it on my shirt. She smiled at Broden, "You voted too today. Do you want a sticker?" Broden looked over at her, unenthused, and said, "No." As I left the room, I saw the gracious woman who had helped me with Broden and said, "Thank you for your kindness." She smiled and said, "Happy to help."

I teach Public Speaking at USC, and I always spend a day talking about democracy. I talk about the importance of voting, because when you vote you use your voice. Yes, democracy is messy because people are messy. But I'm grateful to live in a country where I can stand in line, and this time with my son, cast my vote. My voice was heard, and as I held my son's hand, his voice was heard too. •

OUR JOURNEY IN CAMO

Shelly Huhtanen is an Army wife stationed at Fort Jackson, SC. She enjoys sharing her experiences of her day-to-day life caring for her son with autism. Shelly authored *Giving a Voice to the Silent Many* that encompasses many stories of raising a child with autism in the military. She also teaches Public Communication at the University of South Carolina and has contributed to *EP Magazine* for over 10 years.

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