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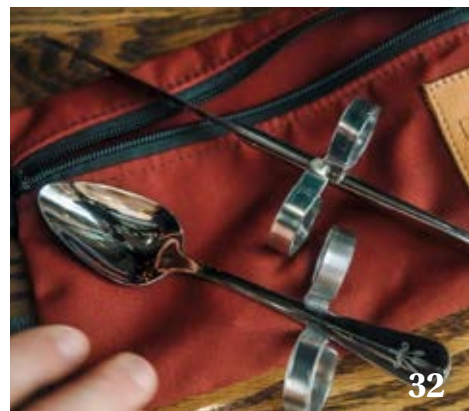
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Courtesy of George Gallego

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you'll love our sister publication — **SPORTS 'N SPOKES!**
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"By illuminating the basic signaling
biology behind spinal cord
scarring, these findings raise the
possibility of one day being able to
pharmacologically fine-tune
the extent of that scarring."

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Now in its 78th year and the official publication of Paralyzed Veterans of America, *PN* is a national, monthly magazine that covers news, health, research, lifestyle and issues of interest and concern to veterans and others with spinal-cord injury and disease. Anyone interested in submitting an article to *PN* should consult the Contributors Guidelines found on our website at pnonline.com. *PN* neither endorses nor guarantees any of the products or services advertised in the magazine. Readers should thoroughly investigate any product or service before making a purchase.

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DECEMBER

Editor's DESK

We've made it to the end of the year, and this month is usually a pretty busy one for everyone with holiday office parties, family gatherings, travel and plenty more. Gift shopping and giving is also a big part of the holiday season, and it's a good bet many presents will involve some type of technology.

We write a lot about what we term "assistive technology" in *PN* because it's a popular topic and the items we feature can have such a positive impact on our readers. Finding tech like that is one of the reasons we attend the giant electronics trade show called CES each January in Las Vegas. One of the bigger sections of CES is smart home technology. It's amazing and even a bit scary how much we can automate things in our homes, such as lights, locks, thermostats and more.

It's unknown if any smart home tech creators had people with disabilities in mind when making those items, but their affect on independent living is huge. The effect is so big that smart home tech was the subject of two separate sessions at August's Paralyzed Veterans of America Summit + Expo in Anaheim, Calif. *Navigating Smart Home Tech* (p. 18) takes you inside those sessions, which explored how smart home tech can improve patient care.

Of course, that's just one of several great articles in this month's issue. We hope you enjoy them all and maybe even get some good takeaways from them. Have an enjoyable and safe holiday season.



Andy Nemann, Managing Editor

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DIGITAL HIGHLIGHTS

SOMETHING IS BREWING

Head to pnonline.com to read about the Paralyzed Veterans of America Northwest Chapter's beer brewing endeavors.

WHO'S DRIVING?

Read about the accessibility of autonomous vehicles, including a video showing how one wheelchair user accessed a Waymo.

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Sample email



PVAfromtheTOP

ROBERT L. THOMAS JR.
NATIONAL PRESIDENT

Christmas Is Coming

We'll be here,
giving our all
to continue
delivering what
members need
during this
special time of
year, along with
the rest of
the months.

As December rolls in, we sit back and think about how quickly this year has gone, all of the challenges we've faced and overcome and feel a strong sense of accomplishment. While we tend to be ambitious at the start of the calendar year, when December arrives, we may be left feeling like we need to do better next year.

With this being the time of year for giving, and if you're feeling like you haven't achieved all or any of your goals for the year, I am suggesting one way for you to ease that burden: Perform random acts of kindness.

It has been proven through research that when people give to others, oxytocin, dopamine and serotonin are released in the body, which gives the individual a feeling of joy and happiness. Those three substances are generally known as the body's "feel-good" chemicals.

If you know of someone in your family or maybe just a family in need, try reaching

out to help relieve some of their burden. You could also donate some items to your local community center or give an unwrapped toy to your local Marine Corps Reserve Toys for Tots program.

I'm sure you can find many ways within your area to give to a worthy cause, but I also ask you keep in mind your brothers and sisters in arms who have given so much of themselves for our country.

Paralyzed Veterans of America (PVA) hasn't forgotten about these individuals. For almost 80 years, PVA has been providing programs and support. We'll be here, giving our all to continue delivering what members need during this special time of year, along with the rest of the months. However, I also want and need you to reach out to your fellow veterans.

So, if you remember the traditional nursery rhyme or classic song *Christmas Is Coming* from childhood, please hear the words:

"Christmas is coming, the goose is getting fat. Please put a penny in the old man's hat. If you haven't got a penny, a ha'penny will do, and if you haven't got a ha'penny, then God bless you." ■



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reasons & remarks

AL KOVACH JR.
EDITOR-IN-CHIEF

An Informed Citizenry Is Vital

While reading the headlines in October, I learned that two dogs were the candidates in an election, and I was intrigued.

Truth be told, a preschool in the Washington, D.C., suburbs was teaching an important component of democracy using characters from the popular kids' cartoon series *PAW Patrol*.

It gave me hope that teachers think children might actually be interested in U.S. civics at an early age. And, it might help explain why their mommies and daddies have been arguing at the dinner table about a guy named Trump and a lady named Harris.

From a field of seven original pups, this election came down to two formidable candidates: Chase, a German shepherd who wears a police uniform and serves as a police dog, and Skye, a possible mixed breed, who pilots a helicopter and serves as an air rescue pup. It's also worth mentioning that Skye did well in the polls among girls ages 3 to 4.

I'm somewhat embarrassed to admit I know so much about *PAW Patrol*, but that's because my daughters are big fans of the show. Nevertheless, educating children about how our country is supposed to function is incumbent upon parents and educators, and if they have to use some animated dogs to encourage them to learn, I'm all for it.

It'll be a while before these kids can legally vote in a real election, and they're too young to understand the three branches of government or how a bill becomes a law. Their teachers should be commended for figuring out a fun way to help the kids solve problems with classmates, deal with disappointment without seeking vengeance and appreciate the unique needs of others. This entire exercise is to teach kids that their thoughts have value, as do their classmates' opinions.

This preschool is like many others that are discovering a need to start teaching students civics early in their education. Their goal is to nurture good citizens, which is desperately needed these days when we consider the civic ignorance among students graduating from colleges in the U.S.

A survey of college students conducted earlier this year by the American Council of Trustees and Alumni (ACTA) exposes the lack of basic knowledge pertaining to how the United States governs itself. The survey reported the following disappointing statistics:

- 60% of students couldn't correctly identify the term lengths for members of the House of Representatives and the Senate.
- Only 27% knew Kamala Harris is the president of the U.S. Senate; 28% thought it was Joe Biden.
- Only 35% knew that Mike Johnson is the speaker of the House of Representatives.
- Despite two recent presidential impeachment trials, only 32% knew an impeachment trial takes place before the U.S. Senate; 30% thought it was the Supreme Court.

In an earlier survey conducted by ACTA, the questions were more specific to our elections. Even though 97% of college graduates agreed it's important to understand the U.S. election process, the survey found that:

- 22% of college graduates couldn't correctly identify when Election Day is held.
- 31% couldn't correctly define the Electoral College.
- 33% were unaware that membership in the Republican or Democratic parties isn't a requirement to run for president.

"Civic ignorance — dangerous as it is — is not unique to the present day."

— Michael B. Poliakoff, PhD



- 50% were unable to name Franklin Roosevelt as the last president to win more than two elections to the presidency.

Teaching civics in schools helps students learn the value of civic practices such as voting, jury duty and working to improve society. However, with stats like these, it's pretty clear college students need to spend more time learning about our country's 250-year history and its core values and principles.

Let's face it, if these students don't know where they came from, how can they know where they're going? With no map to guide them, how can they protect the institutions that are unique to our democracy like our electoral process? After all, it's kind of hard to defend something you don't comprehend.

According to Michael B. Poliakoff, PhD, president of ACTA, colleges seldom require their students to enroll in a course about U.S. history or how our government works.

"Civic ignorance — dangerous as it is — is not unique to the present day," Poliakoff says in a 2016 ACTA press release. "However, institutions of higher education once emphasized civic character and leadership as a core part

of instruction. The lackluster results we find among today's graduates is indeed shocking."

As we all know, our democracy is currently being tested, and this trend of civic illiteracy among college students couldn't come at a worse time. Is this scenario forecasting a perfect storm that will destroy our political institutions?

Considering the United States was founded so long ago, it's shameful that so many of its citizens have no clue how it functions.

"The framers were emphatic that an informed citizenry is a crucial precondition for the republic's survival in the United States," Poliakoff says in the release. "Colleges and universities should take note: Unless we take greater care in educating students, the deficit in civic literacy will weaken the next generation's ability to engage in the democratic process and political discourse."

I don't think we can change the adults, but there might be hope for the kids. If we stop taking our democracy for granted and begin teaching civics sooner rather than later, maybe we can prepare our children for a better future.

By the way, just for those inquiring minds, a 3-year-old girl named Janet from Virginia cast the last vote, securing a victory for Skye. Her competitor, Chase, wasn't happy that he lost, but he conceded the election gracefully and went on to thank all the volunteers who helped his campaign.

Most importantly, nobody tried to overturn the election, nobody stormed *PAW Patrol* headquarters and nobody got hurt. Maybe these kids can teach the grown-ups something about civics?

As usual, let me know what you're thinking at al@pvamag.com. ■



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Ansley To Co-Chair Air Committee

Paralyzed Veterans of America (PVA) Chief Policy Officer Heather Ansley, Esq., MSW, is helping lead a committee charged with ensuring air travel is accessible.

Department of Transportation (DOT) Secretary Pete Buttigieg announced Ansley as co-chair of the reestablished Air Carrier Access Act Advisory Committee (ACAA Advisory Committee) Sept. 20.

The ACAA Advisory Committee was established for a five-year period pursuant to the Federal Aviation Administration (FAA) Reauthorization Act of 2018 and was extended until Sept. 30, 2028, by the FAA Reauthorization Act of 2024.

The committee is tasked with assessing the existing and emerging disability-related access barriers for passengers with disabilities; evaluating the extent to which the department's programs and activities are eliminating disability-related access barriers; and recommending actions to improve the air travel experience of passengers with disabilities. The committee will report its assessment and recommendations to the secretary.

Representing veterans with disabilities, Ansley is co-chairing the 18-person committee with Linda Ristagno of the International



Heather Ansley, Esq., MSW

Air Transport Association, which represents air carriers.

As required by the FAA Reauthorization Act, the secretary appointed 17 members to the committee in September with at least one representative from each of the following groups:

- National disability organizations
- Air carriers
- Airport operators
- Contractor service providers
- Aircraft manufacturers
- Wheelchair manufacturers
- National veterans' organizations representing veterans with disabilities

Certain categories have more than one representative to ensure multiple perspectives are represented and membership is balanced.

The DOT will appoint an 18th member to represent passengers with disabilities, in addition to the seven representatives from national disability organizations.

For more information, visit transportation.gov.

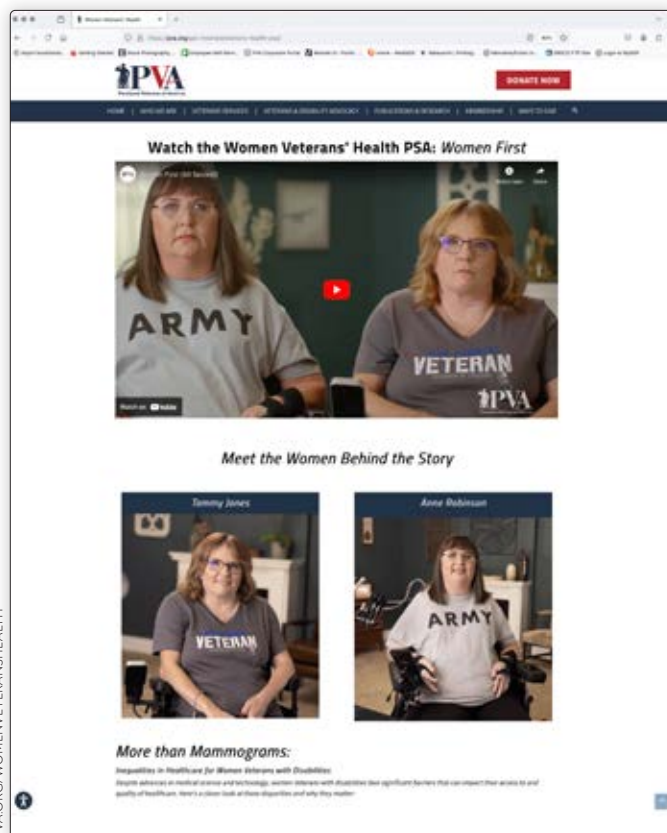
Storm Teams With PVA

An award-winning sports journalist is teaming up with Paralyzed Veterans of America (PVA) to focus on the accessibility of health care for women with disabilities.

PVA announced Oct. 3 it has launched a new public

and equipment for women with disabilities.

Coinciding with October as Breast Cancer Awareness Month, the Women First campaign highlights disparities in accessible care for women with disabilities in communities across the country. Everything from mammography machines and exam tables to doctors' offices and patient rooms are often inaccessible for women with disabilities — denying them basic



PVA.ORG/WOMENVETERANSHEALTH

awareness campaign with ESPN anchor and breast cancer survivor Hannah Storm to shed light on inaccessible medical facilities

health care services. The difference in access to care can be life-threatening.

According to the *Journal of Military, Veterans*

Catch Of The Day

Several hungry seals and a Navy destroyer provided a unique backdrop for the Paralyzed Veterans of America Cal-Diego Chapter's Sept. 18 fishing trip out of San Diego aboard the *Daily Double*.

COURTESY OF PARALYZED VETERANS OF AMERICA CAL-DIEGO CHAPTER



and *Family Health*, women service members are 20% to 40% more at risk for breast cancer than their civilian counterparts.

A website and public service announcement (PSA) highlight the need for accessible care for women. They both contrast the experience of Storm, whose life was saved by early detection of breast cancer, with that of PVA National Senior Vice President and Air Force veteran Tammy Jones and PVA National Vice President and Army veteran Anne Robinson.

After finding lumps in her breast, Jones went to a doctor for further testing. However, she couldn't get through the front door because the building wasn't accessible.


"Like any woman, if you find a lump in your breast, you want answers immediately — so when barriers like inaccessibility prevent you from lifesaving tests and treatment, it creates a horrible feeling of despair for patients with disabilities like me," Jones says in an October press release.

Meanwhile, Robinson has gone 25 years without a gynecological exam because she's unable to find an accessible obstetrician gynecologist's office in her community.

"Early detection for breast cancer saved my life, and I don't know where I'd be without access to testing," says Storm in the press release. "Women with disabilities, especially women veterans who have served this nation with honor, deserve access to the same level of care as I do. The fact that these women continue to face this

cruel reality when attempting to access even the most basic services is unacceptable. I'm proud to partner with PVA during Breast Cancer Awareness Month on this powerful Women First campaign, and I encourage everyone to join us in this fight."

The campaign website also includes a petition to demand change.

To view the PSA and sign the petition, visit pva.org/womenveteranshealth. 

Using Your Voice To Advocate For PVA

As the year winds down and Capitol Hill gears up for the January start of the 119th Congress, Paralyzed Veterans of America (PVA) wants to remind you about the importance of your voice in PVA's advocacy in Washington, D.C.

Although it was a slow lawmaking year in Congress, there were some important victories. Now, a new president has been elected, and new and returning congressional leaders are planning for the next session of Congress.

You play two important roles in shaping policy in our country: the first is through voting and electing legislators to represent your interests, and the second is by using your voice to share your stories with those legislators.

Before diving into what our future looks like, here are some of the wins important to PVA members, their families, caregivers and survivors.

A Flying Win

In May, PVA saw a historic win for the disability community through the passage of the Federal Aviation Administration Reauthorization Act of 2024.

Advocates sent more than 2,500 messages to their members of Congress seeking improvements in air travel for passengers with disabilities. The reauthorization includes several PVA-supported provisions focused on addressing the experiences of passengers with disabilities.

Sections in the new law include training requirements for assisting passengers with limited mobility and properly stowing assistive devices; analyzing and improving the Department of Transportation's (DOT) complaint process; addressing the need for more access standards and accessibility of in-flight entertainment, as well

as improved access to airline websites, applications and information communication technologies; and increasing access to seating accommodations.

The reauthorization also requires continued study into safe and secure in-cabin wheelchair tie-down systems and, if technically feasible, a study into their economic and financial feasibility; emphasizes the need for the DOT to perform a more in-depth analysis of airline-reported mishandled wheelchair data; and reauthorizes the Air Carrier Access Act (ACAA) Advisory Committee, as well as a requirement for the ACAA Advisory Committee to ensure safe transport for assistive devices powered by lithium-ion batteries.

In addition, PVA was pleased to see the inclusion of a pilot grant program to increase airport accessibility and requirements for adult changing tables; new requirements related to the availability of onboard wheelchairs; expansion of the Advanced Materials Center of Excellence to address safe and accessible air travel for passengers with disabilities; and the creation of the known service animal pilot program.

ILLUSTRATION BY DAVID HOSTETLER © GETTY IMAGES/ORNADIG



Letters To Congress

Following the Department of Veterans Affairs' (VA) July announcement of a budgetary shortfall that threatened its ability to pay disability compensation, survivor and education benefits on Oct. 1, Congress passed nearly \$3 billion in supplemental funding for the VA in September.

As a result, the VA paid critical benefits in a timely manner. Within a 10-day period, PVA had 415 letters sent to Congress members, urging them to pass legislation to ensure veterans wouldn't bear the burden of the VA's budgetary shortfall. Your voices were critical in ensuring Congress quickly passed the additional funding that prevented delays in payment.

Amplifying Your Voice

As the new year approaches and the 119th session of Congress gets underway, a renewed effort in voicing the importance of PVA's policy priorities becomes more important than ever.

Any bill that was introduced in the 118th Congress during 2023-24 that didn't make it to the president's desk will need to be reintroduced. PVA will be launching new cam-

paigms for its priorities in 2025. Please urge your Congress members to support legislation important to the disabled veteran community.

And if they haven't yet co-signed a bill, make sure to use PVAction Force (pva.org/research-resources/pva-action-force) to directly send your legislators a message to sign onto bills PVA supports. Empower your community and lend your voice toward decisions that affect your lives.

Sometime late next February or early March, PVA National President Robert L. Thomas Jr., will testify before a joint session of the House and Senate Veterans' Affairs Committees.

The annual hearing allows veterans service organizations to bring forth

issues to Congress that are important to the veterans they serve. PVA's goal is for Thomas' testimony to echo what Congress members have already heard from their constituents — meaning you.

Thomas' testimony is there to amplify your voice and spread awareness on issues important to the community. Advocacy starts with you, and PVA will use these united voices to make sure Congress continues to hear from PVA members on important issues.

Speak Life Into Issues

Grassroots advocacy allows the PVA community to use its collective strength to engage with lawmakers and ask for change. PVA members are the only ones who can tell their stories and

make an impact on the policies that affect people's everyday lives.

Be a voice of change in your community and speak out on the issues important to you and the ones you love.

Speak life into the issues and policies PVA is advocating for and help shape what tomorrow looks like. Take time in the coming year to write to your Congress members and let them know what issues are important to you and why they are important.

Together, PVA can keep pushing access forward.

Lisa Elijah is PVA's grassroots advocacy manager in Washington, D.C. ■

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research **update**

SARAH C.P. WILLIAMS

Research Points A Way To Modulate Scarring In SCI

After a spinal cord injury (SCI), nearby cells quickly rush to action, forming protective scar tissue around the damaged area to stabilize and protect it.

But over time, too much scarring can prevent nerves from regenerating, impeding the healing process and leading to permanent nerve damage, loss of sensation or paralysis.

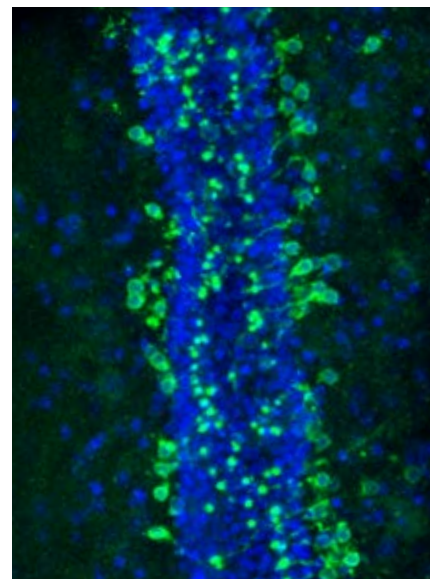
Now, University of California-San Francisco (UCSF) researchers have discovered how a rarely studied cell type controls scar tissue formation in SCI. Activating a molecular pathway within these cells, the team showed in mice, lets them control levels of spinal cord scarring.

The research appeared Sept. 18 in the British scientific journal *Nature*.

“By illuminating the basic signaling biology behind spinal cord scarring, these findings raise the possibility of one day being able to pharmacologically fine-tune the extent of that scarring,” says David Julius, PhD, the paper’s senior author, professor and chair of physiology at UCSF, and winner of the 2021 Nobel Prize in Physiology or Medicine.

Caused by physical trauma such as vehicle accidents, falls or sports collisions, SCI can damage the nerves that run down the length of the spinal cord and coordinate messages between the brain and the rest of the body. Treatments largely revolve around surgery or braces to stabilize the spine, drugs to control pain and swelling and physical therapy.

Julius and his colleagues studied the function of a poorly understood group of neurons, called cerebrospinal fluid (CSF)-contacting neurons. These



WENDY YUE/UNIVERSITY OF CALIFORNIA-SAN FRANCISCO

Cerebrospinal fluid-contacting neurons are genetically labeled with a fluorescent green marker along the length of a mouse spinal cord. These neurons are found in the ependymal layer, shown in blue, which is a thin layer of specialized epithelial cells surrounding the central canal, a hollow space in the spinal cord that is filled with fluid.

neurons are found along the hollow channel that runs through the center of the cord, and they extend into the spinal fluid that fills the channel.

An Opioid That Modulates Scarring

The team developed a new method to label these neurons, isolate them and measure which genes were active in the cells. That led them to discover that the cells express a receptor that senses k-opioids, which are naturally produced by the human body.

The group went on to identify the spinal cord cells that produce k-opioids and show how the molecules excite the CSF-contacting neurons.

Further experiments revealed that signaling through these k-opi-



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oids decreased in the aftermath of a SCI, transforming nearby cells into scar tissue for protection.

The researchers tried delivering extra k-opioids to the mice, and the scarring was reduced; but the spinal cord injuries were more severe, and the mice did not recover their motor coordination as well.

“K-opioids might give us a way, after a spinal cord injury, to pharmacologically modulate the fine balance between producing enough scar tissue and having excessive scarring,” says Wendy Yue, PhD, a former postdoctoral research fellow in Julius’ lab who is now an assistant professor of physiology at UCSF and the paper’s first author.

Importantly, k-opioids are different from commercial opioid drugs, such as oxycodone and hydrocodone, and generally not addictive.

Scientists must do more work to understand why k-opioid levels drop after SCI, as well as what the ideal levels of scarring are to support optimal healing. Further preclinical studies also would be required before testing k-opioid-related drugs in humans with SCI.

Julius says the findings underscore the importance of carrying out basic scientific research on how various cell types and signaling molecules work.

“We were not looking for a way to control spinal cord healing,” he says. “This came out of asking questions about this mysterious cell type, and then running into a mechanism that is both biologically interesting and could eventually have some therapeutic potential.”

The other study authors are Kouki Touhara, Kenichi Toma and Xin Duan of UCSF.

For more information, visit ucsf.edu/news.

Sarah C.P. Lance is an award-winning freelance science writer working for UCSF. ■

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PN is planning an article early next year about top accessible travel destinations, and we'd like your help. Briefly tell us about what places you like to visit and what makes them accessible. We may use that information in our upcoming article. Send your picks to Managing Editor Andy Nemann at andy@pvamag.com.



Researchers are developing ways to help people with disabilities use devices such as Alexa, Siri and more to enhance their care and lives.



NAVIGATING SMART HOME TECH

by Brittany Martin

From televisions, lights

and kitchen appliances to fully automated systems controlled through an app or by voice, smart home technologies are ubiquitous. They offer convenience and efficiency for everyone but can also provide greater independence, health and safety for people with disabilities.

Available everywhere from the internet to brick-and-mortar stores, there's a wide variety of smart home technology to fit almost every need and budget. However, with the rapid evolution of so many products, it can be difficult to figure out what best fits someone's abilities.

Helping people with disabilities, as well as health care providers, better understand, customize, adapt and utilize all that tech was the subject of two separate sessions at August's Paralyzed Veterans of America Summit + Expo in Anaheim, Calif.

Jaewon Kang, PhD, MSOT, reviewed her postdoctoral research that led to the development of several smart technology instruction manuals and video tutorials for older adults



BRITTANY MARTIN



From top, Jaewon Kang, Lynn Worobey, Lindsey Morris and Randy Huzinec delivered presentations on smart home technology at this year's Paralyzed Veterans of America Summit + Expo in Anaheim, Calif.

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with mobility impairments. In addition, Lynn Worobey, PhD, DPT, ATP, Randy Huzinec, PT, and Lindsey Morris, OTD, OTR/L, from the University of Pittsburgh's Rehabilitation Engineering Research Center on Wireless Technologies for People with Disabilities discussed tools for health care providers to assess their patients' requirements for smart home technology.

Clear Instructions

To make technology a little less overwhelming and intimidating, Kang, an assistant professor in the Department of Occupational Therapy at Colorado State University, worked for a year under the mentorship of Wendy Rogers, PhD, and Laura Rice, PhD, MPT, ATP, at the University of Illinois (Urbana-Champaign campus) on a project to develop and test educational materials that teach older adults with mobility disabilities how to use smart home technologies to improve their functional independence.

Kang says voice-activated digital assistants that use artificial intelligence (AI), such as Amazon's Alexa, Apple's Siri and Google Assistant, can help people with daily tasks, answer questions and provide reminders.

"So, if you have an Alexa in your home, you can simply say, 'Hey Alexa, turn on the bedroom lamp.' Then, it will turn on the lamp for you, so you don't have to physically move around in your home," Kang says. "Using such

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technology, you can easily find information like news and weather updates. You can also control your lights. You can also set up medication reminders, create grocery shopping lists, and you can call your families or friends and even play games or listen to music."

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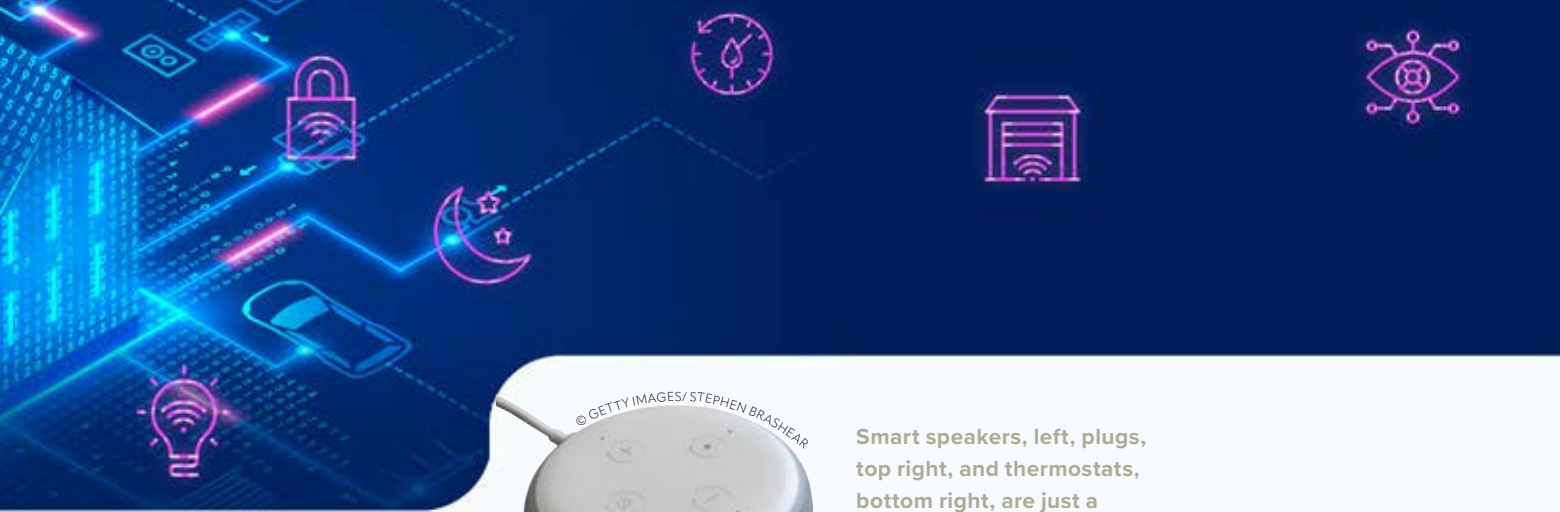


A demonstration station allows people to experiment with smart home ecosystems without going through a full setup.

However, even someone who really enjoys learning new technologies might need some time to figure out how to use these features.

"And if you're not familiar with technology, it's important to have a clear instructions," Kang says. "Unfortunately, some clinicians don't want to introduce these new technologies due to ageism. Many studies address this issue, and the reason is that many clinicians think that older adults are unable or unwilling to use this new technology."

That's why the research team developed five instruction manuals specifically tailored to older adults on how to use AI voice-activated assistants



Smart speakers, left, plugs, top right, and thermostats, bottom right, are just a few technologies that can help with daily tasks around the home.



and connected smart home technologies. By following written and visual step-by-step guidelines in various formats, users can learn how to use basic functions, set up the device, make video calls, control home devices and manage health information. Informational postcards give a brief overview, and a series of YouTube videos (youtube.com/@chart-illinois1133?si=lgWUf2cCtLxIj7dW) enhance understanding of tasks such as asking for news or weather updates, searching for information, playing music, making lists and setting and canceling alarms and reminders using an Amazon Echo smart speaker. The team also created videos on using smart light bulbs connected to Alexa, as well as smart plugs that can convert a non-smart appliance, such as a fan, into a smart device.

The project included a field trial to evaluate the benefits and barriers of integrating smart technology to assist with in-home daily activities. In post-study interviews, participants indicated they found the smart home technologies easy to use with clear instructions. The research team also found that using AI voice-activated assistants significantly reduced perceived loneliness after five weeks of use. The project's results are currently undergoing peer review for a journal, and all the training materials are available for use upon request.

"Please don't hesitate to try smart home technologies, and don't blame yourself if it's difficult to use at first," Kang says. "This is a normal process. Once you learn how to use these technologies, please encourage your friends and family members to try it, too, and think about it as fun activities and an opportunity to learn something new. Give yourself time to learn and get used to it."

Kang also urged clinicians to embrace smart home technologies in their practices and to keep it simple when explaining them to older adults.

"Tell them it's OK to find it tricky at first, but we are always here to help them and keep motivating them to give it a try and see the benefits," Kang says.

Assessing Needs

Researchers at the University of Pittsburgh are also trying close the gap between people with disabilities and technology that could enhance their care and participation.

Worobey says mainstream smart home technology can be used as assistive technology to help with tasks such as controlling lights and temperature, making phone or video calls, text messaging, shopping, preparing meals, housekeeping, ensuring security (automatic door locks, garage door openers and sensors that send an alert when doors or windows are open or closed), using transportation, taking medications, managing finances, listening to music, watching television and reading.

Morris says the team has also integrated smart technologies to address pet care, including feeders, doors and even toys, as well as vacuuming and mopping, which can save caregivers time and give them more flexibility.

"Vacuuming and mopping has been a really popular one because when we did some needs assessment studies, we had a lot of participants say that if their caregivers are running behind between clients or different things, this is a task that gets cut off the list first and foremost," Morris says.

From the health care provider's perspective, the process starts with helping a client set goals and evaluating his or her baseline functional abilities.

To help with goal-setting, the research team developed the ASSIST Functional Performance Index, which assesses a person's needs for main-



stream smart home technologies. Individuals answer a series of questions to indicate how they complete certain tasks, the amount of assistance or effort required to complete each task and their satisfaction with how each task is completed.

“Making sure it’s problem-based, so what are the activities that they’re having performance challenges with, and does the technology help to alleviate those performance challenges by compensating in the appropriate way?” Morris says.

The provider should then observe how the person completes the task.

“I’m getting to see how the environment is either facilitating or hindering their performance. A lot of times, without even asking, they’ll start to explain how their family members, caregivers, other people that are in the environment are impacting their performance, even if they’re not there in that moment,” Morris says. “Like, if they’re doing it pretty well, they might say, ‘But when my family member leaves and I don’t have anybody and I’m in bed for the night, I can’t perform this task at all.’”

Morris says the provider should determine what types of technology (i.e. smartphones, email, computers) clients currently use to get an idea how simple or complex the operation should be and which interfaces might be more intuitive. The collaboration can also include family, caregivers or other people who live in and interact with the client’s environment.

Robotic vacuums are convenient and can save people time.



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From there, providers should also assess clients’ digital literacy, such as changing settings, problem solving, learning to use new technologies and finding information on the internet. That baseline is useful to know how much training the person will need throughout the equipment trialing and selection process, Morris says.

Lastly, the client’s physical environment must be assessed to see which devices might be compatible with the space, surface materials, other devices, nearby objects, light, temperature, sound factors, location of power sources and internet connectivity.

Narrow It Down

The next step is trialing. The researchers created a smart home demonstration station, which allows clients to explore using Apple HomeKit, Google Home and Amazon’s Alexa apps to control several smart devices, including bulbs, switches, curtains, security cameras and door locks.

“So, that way at baseline, we can open up that app, let them see if that layout interface fits their needs, if it’s intuitive to them,” Morris says. “If it’s not it, we can switch over and try another one. We can do it by touch or by voice, and then also see if there’s any customizations that might be needed to make it more user-friendly, like routines, automations, and then determining where the positioning of the control devices might need to be. Also, it helps them to see what are the different functions that the device can control.”

For example, curtains and a door lock can be connected to Amazon’s Alexa.

“If you say, ‘My caregiver is here,’ what should happen is the front door should unlock and the curtain should open so you can see the person. You can also do that with the doorbell, as well,” Huzinec says.

After trialing, one of the three major ecosystems should be chosen so all devices will



BRITTANY MARTIN

communicate with each other and allow the client to use a single app to control all of them and set automations. Device packaging will have a “works with” badge to indicate with which ecosystem it’s compatible. Morris recommends selecting devices that are compatible with all three, so if the person wants to change platforms, he or she doesn’t have to purchase new devices.

There’s also a protocol called Matter that works with those three platforms, and lower-energy communication protocols like Zigbee or Z-Wave could be options for people who don’t have a regular internet connection to control devices such as fans or lights using a smart speaker or app.

Providers should also consider whether retrofit or permanent solutions are needed.

For people who rent their homes, there are removable options such as smart plugs. Retrofit options can be added onto an existing device, don’t require a contractor to install and are commonly battery-powered.

Some permanent devices need to be hardwired into an existing controller or electrical outlet. There may be less maintenance involved for permanent devices, but they may also require professional installers, which can increase time, effort and cost. Morris says some local ordinances require even a switch installation to be done by an electrician, so check with the local permits department.

“Sometimes it’s worth paying a little bit more to get that proper installation, and that’s true not only with locks, but also thermostats,” Huzinec says. “Some of the older homes don’t have a third wire called a C-wire [common wire], and you have to have that installed as well for the automatic temperature controllers.”

Other considerations for the initial setup are what type of control device (smartphone, smart speaker, wearable or smart display) will be used, whether it will be controlled by touch or voice and placement in the home.



Randy Huzinec, PT, demonstrates Amazon’s Alexa-connected smart curtains and door locks.

“It’s important to position the controller at a central point where it’s always accessible to the person when they need to use it,” Morris says. “Think about placement of devices and controls, because sometimes if they’re too close together, they’ll interfere with each other. Enable the hands-free voice assistance within a smartphone to give them an option that is a voice assistant available no matter where they’re going as they’re changing rooms. They wouldn’t have to worry about if they were facing the device or their proximity to it.”

Feedback can be either auditory or visual, which tells the person if the task was properly executed. If there’s an error, sometimes the device will provide some options to problem-solve or what to do differently to execute a task. If a device failure happens, the client must also have a backup plan and know how to troubleshoot, Huzinec says.

After initial setup, Morris says providers should follow up with clients weekly or monthly to make sure the technology is still working correctly, troubleshoot any issues and continue to evaluate if the technology is meeting the person’s needs. Over time, as people adjust to using the technology in their daily routines, some modifications may be necessary to make it as seamless and easy to use as possible.

More resources are available at wirelessrrc.pitt.edu/mst-as-at. ■



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Strong

A photograph of three women dressed in 1940s-style clothing, including sleeveless shirts, dark pants, and polka-dot dresses. They are all flexing their biceps in a 'strong woman' pose. The woman in the center is seated in a motorized wheelchair. They are standing in front of a large, circular prop that resembles a ship's porthole with rivets. The background also features large white stars on a blue field.

by Becca Hofheinz

photos by
Paralyzed Veterans
of America

Since 2019, Paralyzed

Veterans of America's (PVA) Anita Bloom Committee has focused on leadership, while also giving a voice to women veterans in their pursuit of equal health care and benefits.

Named for PVA's first female member, the committee was formed to honor Bloom and consists of 10 female members from any of the 33 PVA chapters. One of the many things the committee does is plan and execute the annual Women Veterans Empowerment Retreat (WVER).

Previously called WE Served, WVER is in its sixth year of empowering women veterans who live with spinal cord injuries or disorders (SCI/D). This year's all-expenses-paid retreat was held Oct. 5-7 at the Westin Long Beach Hotel in Long Beach, Calif.

Thirty-five women from various PVA chapters across the United States and Puerto Rico traveled to attend this year's activities. Throughout the three-day event, participants built connections, attended workshops, enjoyed yoga and meditation and learned how to take charge of their stories.

"The goal of WVER, this year and every year, is a space for our women members who are leaders in their communities or emerging leaders in their communities, to get together, trade stories, connect and learn some leadership skills, advocacy skills and resiliency skills, so they can go back to their chapters and communities and keep moving things forward," says Lindsay Perlman, PVA's director of research and education and Women Veterans Program manager.

ILLUSTRATION BY KERRY RANDOLPH / ADOBE FIREFLY

& Powerful

PVA's sixth
Women Veterans
Empowerment
Retreat gave PVA
members tools for
leadership, growth
and connection.

Perlman helped kick off this year's event, along with PVA CEO Carl Blake and PVA's first woman National Senior Vice President Tammy Jones. At the opening dinner, they shared welcoming words for all those in attendance. The event's final two days brought learning, connection and excitement.

Learning To Lead

The event featured six informational sessions where attendees learned valuable skills. PVA Chief Marketing and Communications Officer Liz Deakin focused on the value of social media. She also shared PVA's newest public service announcement, Women First,

The Women Veterans Empowerment Retreat featured a 1920s/United Service Organizations themed dinner and party.





Paralyzed Veterans of America (PVA) Director of Research and Education Lindsay Perlman, left, and PVA National Senior Vice President Tammy Jones welcome attendees.

which focuses on women's health and the inaccessibly some women face.

In addition, Jeri Muse, PhD, DAAPM, led a session focused on attendees owning their stories to allow themselves to be the best leaders they can be. Other sessions focused on group activities, where attendees discussed challenges and worked together to learn how to overcome them.

PVA National Vice President and Anita Bloom Committee co-chair Anne Robinson, who joined via Zoom video conference, and Jones led a highly anticipated session focused on how to be a PVA leader.



Navy veteran Angela Walker, left, and Paralyzed Veterans of America Chief Marketing and Communications Officer Liz Deakin chat during the retreat.

PVA Wisconsin Chapter member and Navy veteran Angela Walker says that's what brought her back for her second WVER.

"That first year, I was really, I felt empowered and educated, and I came back this time because I wanted to find out more about becoming a leader, a woman leader, with the PVA," Walker says.

Besides learning how to be leaders, the women also received tools to help them with the process. Those included makeovers and photo shoots to supply them with a professional headshot, along with choosing from a boutique of free coats, purses, shoes and accessories to take home with them and use for future professional opportunities.



Navy veteran Rachel Rice attended her second Women Veterans Empowerment Retreat.

PVA West Virginia Chapter President and Navy veteran Rachel Rice, who has syringomyelia, a neurological disorder in which a fluid-filled cyst forms within the spinal cord, also attended her second WVER.

"I just learned so much from my last one, and it catapulted me so much further into helping out my chapter that now I am the president



Retreat attendees participated in a paint and sip night.

sustained a quadriplegic SCI in a 2022 fall, attended WVER for the first time and says she was most excited about “making connections and having a network of people to reach out to when you have questions or just, you know, to have fellowship.”

Attendees also connected through activities such as a paint and sip night. Participants were coached in painting the famous Rosie the Riveter picture, although some went their own direction

“For me, being a woman veteran is just being able to think back and know that I was strong then and I am still strong now.” — Rachel Rice

and painted whatever called to them. Laughter filled the room, as some attempted to follow along with the artist leading the paint night.

“We all are here to encourage each other. There’s no judgement, and we’re all here to support each other, and this is like our own little family,” says first-time WVER attendee Brenda Guevara, a PVA Mid-Atlantic Chapter and Navy veteran who sustained a level C5 SCI from falling on her ship while on active duty.

of my chapter, and I see our chapter going and growing so much further,” Rice says.

Building A Network

For many attendees, the retreat was a time to see old friends, while others came to make new connections. What it means to be a woman veteran with SCI/D is different for everybody, but the time together allowed participants to build a community of those who have also lived it.

“It’s a great community of women who have been to a WVER ... once you’ve been to a WVER, you are now part of a community. You are part of the WVER family,” Perlman says.

PVA Northwest Chapter member and Air Force veteran Paula Barringer, who



Air Force veteran Paula Barringer was excited about making connections at the retreat.

The retreat's closing night included a 1920s/United Service Organizations themed dinner and party, where attendees dressed up, took photos and listened to music. It was a time to celebrate the whole retreat with new friends and family.

Own The Title

While the retreat was about learning and connecting, it was also about owning the title of woman veteran.

Those newfound friends and family can provide a crucial support system. Jones knows.

"For the longest time, I didn't own the title of a veteran," says Jones, an Air Force



Navy veteran Brenda Guevara attended her first Women Veterans Empowerment Retreat.

veteran who sustained a quadriplegic SCI in a car accident at age 19 while on active duty. "The title of a woman veteran is very honorable. As a woman veteran, we volunteered to go in. We made that choice to go in."

For Rice, the title is all about strength.

"For me, being a woman veteran is just being able to think back and know that I was strong then and I am still strong now," Rice says.

For PVA Nevada Chapter Vice President and Army veteran Le'Toi Adams, who was paralyzed in 2011 due to non-Hodgkin lym-



phoma wrapping around her spine, the title means standing together.

“At one point we weren’t looked at, we weren’t seen ... for us all to show up in one building and be a voice for each other, it’s highly important,” says Adams, who attended her sixth WVER.

Meanwhile, Walker says it means being strong, resilient and responsible.

“The PVA continues to support women veterans with disabilities,” Walker says. “They continue to help us, to aid us in our health care, education and our dreams.”



Army veteran Le'Toi Adams speaks during a breakout session.



Retreat attendees took part in yoga and meditation sessions.

And Jones wants to make those dreams a reality.

“This is her PVA. Keep focused on what you want from the organization and where you want the organization to go,” Jones says. “When people see us achieving goals and making change, they don’t see our disabilities any longer. They just see the changes that we make, and that’s so strong and so powerful.”

To learn more about the PVA’s women veterans, visit pva.org/womenveterans. To sign the Women First petition calling for accessible health care for women, visit pva.org/get-involved/womens-health-psa. ■

Starting From Scratch

Running a restaurant is no small task for wheelchair users George Gallego, Yannick Benjamin and Josh George.

by John Groth

When co-founders George Gallego and

Yannick Benjamin first wheeled into the original space for what would become their restaurant, Contento, in the Brooklyn, N.Y., suburbs, it looked like a disaster.

There was no plumbing, no electricity and no storefront. Steel gates separated it from the streets. And a 10-inch step or pitch prevented them from even getting inside.

"It was uninhabitable," Gallego says.

But, in 2018, the budding restaurateurs, who both have spinal cord injuries (SCI) and are wheelchair users, saw something special.

So, they demolished the entire floor and started over — reinventing the space — and reinvigorating themselves.

"It was the utmost priority to make sure that we were going to build a restaurant that myself and George were going to be able to, like, work without any real barriers," Benjamin says. "But also just as high of a priority was to make sure that people with a disability of all backgrounds were going to come there because they knew that they were going to be treated with dignity and respect."

Two years later, they transformed that space inside a small shopping center area in East Harlem into a restaurant that provides an accessible, interesting, high-end food and wine experience. Although the restaurant has changed head chefs and menus in the last several months, it continues to earn highlights and awards.



PHOTOS THIS STRIP COURTESY OF GEORGE GALLEGO



Contento co-owners
Yannick Benjamin, left,
and George Gallego
discuss ideas at their
restaurant in
Brooklyn, N.Y.

"It was the utmost priority to make sure that we were going to build a restaurant that myself and George were going to be able to, like, work without any real barriers. But also just as high of a priority was to make sure that people with a disability of all backgrounds were going to come there because they knew that they were going to be treated with dignity and respect." — Yannick Benjamin

In fact, Contento (www.contentonyc.com) just received a Best Medium-Sized List in New York award at the Star Wine List event in New York City in March. It also has a 12-page wine list, which helped it be designated as one of the 20 best places to drink wine in New York City by Eater New York.

But it's not the only restaurant that's been started and run by wheelchair users.

On the other side of the country, five-time Paralympic wheelchair racer Josh George and his brother, Jeremy George, along with Jeremy's wife, Mckenzie, are running three

Smokin J's BBQ restaurants in California and are gaining traction.

Both groups of restaurant owners highlight accessibility, food and customer service as the hallmarks of their success.

Teaming Up

Without a push from his brother, Josh wouldn't have thought to go down the path — one that focuses on family, close friends and food.

The 2002 *SPORTS 'N SPOKES* Junior Athlete of the Year award winner attended the University of Illinois, graduating in 2007 with



JOHN GROTH

Smokin' J's BBQ

co-owner Josh

George, left, talks with a customer inside the downtown San Diego restaurant.

a degree in journalism before turning pro as a wheelchair racer.

Josh, who sustained a SCI when he was 4 years old after falling out of a 12th-story bedroom window in Falls Church, Va., made his first U.S. Paralympic team when he was 20 and stayed on the team for 18 years. He's won five Paralympic medals and is a four-time Chicago Marathon men's wheelchair division champion (2003, 2004, 2006 and 2014) and also took the 2015 London Marathon men's wheelchair division.

However, after Josh was done racing, he was stuck. While living in Australia, Josh, 40, had just broken up with his girlfriend and wasn't sure what to do next. So, 37-year-old Jeremy convinced him to move to San Diego to help with his restaurant. Their 30-year-old sister, Jennifer, has helped out at times, too.

Three years ago, Josh joined Jeremy and Mckenzie in the ownership deal. They own three Smokin' J's BBQ restaurants in California (smokinjsrealbbq.com). Over the last four years, they've opened locations in Poway, Miramar and San Diego. Josh now runs front of the house at the San Diego Smokin' J's BBQ and social media for all three restaurants.

"He basically started working out with the front of the [house] booth, coordinating all the events. He just learned all of every-

thing he needed to learn," Jeremy says of Josh. "He started learning web design, all this stuff. Whatever we needed, he learned how to do it and did it."

Smokin' J's BBQ originally started as a food truck business, with Jeremy running a 6-foot barrel smoker on a trailer. Then, Jeremy and Mckenzie decided to expand and go the brick-and-mortar restaurant route. Each location has a different vibe.

The Miramar location features all patio seating, while the Poway spot has more of a family-oriented feel, and the downtown San Diego location is geared toward young professionals with more open space, a bigger bar and outside views.

Smokin' J's BBQ features a mix of Texas and Kansas City-style barbecue. Most of the recipes are Jeremy's and stem from his cooking background and his visits to Nashville, Tenn., Memphis, Tenn., Kansas City, Mo., as well as the state of Texas. But the equipment they use more closely resembles what's used in Texas barbecue, including cooking it in big, 1,000-pound offset smokers. Jeremy says the barbecue sauce is more tangy and lighter to accentuate the meat's flavor.

The menu even has some racing ties to it. University of Illinois wheelchair track and

field coach Adam Bleakney designed more than a handful of animal characters and created the inspiration for artwork out front. His featured comic called *The American Dream* — an old man who walks around in his underwear and carries a 1980s-style TV around with him — makes an appearance on the menu, too.

Josh says running a restaurant is nowhere near as stressful as a major marathon or Paralympic Games race.

He says customer service issues are similar to dealing with the media. After finishing a grueling, exhausting 26.2-mile wheelchair marathon, he had only a few moments to compose himself before speaking to reporters afterward.

“And that’s sort of, you get a similar experience in restaurants, where you’re buzzing through your day. You’re doing a million things, especially as an owner. We’re wearing 50 different hats, and our headspace might not always be right in that customer service zone. But all of a sudden, if something goes wrong, like, that ability to flip the switch and immediately talk to the customer and be able to come out of one zone and into a communicative zone, like, again, that was something I didn’t realize, but we’re trained to do that as athletes because you have to do that at the end of these exhausting events,” Josh says. “You immediately have to talk to people about it right after that, and you have to switch your headspace over quickly.

JOHN GROTH

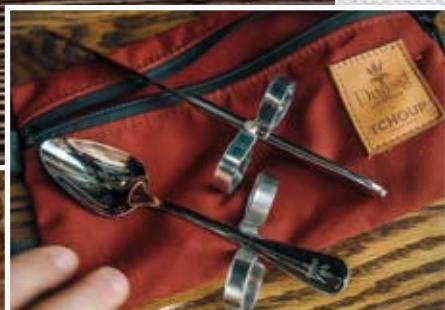


Smokin J's BBQ in downtown San Diego has ample space for wheelchair users and is one of three Smokin J's BBQ restaurants in California.



PHOTOGRAPH COURTESY OF SMOKIN J'S BBQ

Contento co-owner George Gallego shows how a wheelchair user can easily roll into an area, and the restaurant also has utensils, inset, that are designed for those with limited hand dexterity.



And that kind of worked the same here. And it was kind of cool.”

Finding Contentment

While the Georges have a family connection, Benjamin and Gallego have a mentor/mentee relationship. Gallego serves as the restaurant’s managing partner, while Benjamin is Contento’s beverage director.

When he was just 25 years old, the now-46-year-old Benjamin sustained a level T6 SCI in a car accident, and a few months later at Mount Sinai Hospital in New York, he met Gallego, who was assigned to him as a mentor. Gallego, now 56, sustained a level T10-11 SCI in March 1992 after falling three stories while inspecting a New York City construction site. The two have stayed friends all these years.

But it’s that viewing together that deepened their

bond. After checking the restaurant space out himself, Gallego convinced Benjamin to view it. They came up with a vision and then went to work.

That included plenty of projects. They had the floor leveled to make it a smooth surface. They had all the tables modified — raising the regular tables up a few more inches so anyone in a wheelchair could roll under a table anywhere and not just at the counter-height bar. They added hooks under the tables so diners, whether they have disability or not, could store purses or other items. Thanks to the help of blind disability advocate Peter Slatin, founder and president of Slatin Group LLC and Forbes.com disability writer, they also included braille signs and have braille menus for their visually impaired and blind guests.

They even made the bathroom completely accessible — with everything from



BOTH PHOTOS COURTESY OF GEORGE GALLEGO



Contento co-owners George Gallego and Yannick Benjamin wanted guests of all abilities to access the space and not be excluded.

sinks to dispensers being hands free. Originally, the bathroom included a pocket door that could slide in and out, but it kept getting off track, so Benjamin and Gallego recently had the door widened a little more and had a regular swinging door with proper handles and hooks installed, so people could lock it easily from the inside.

“We wanted to make sure that it was completely accessible,” Gallego says. “We wanted our guests of all abilities to be able to access all the spaces and not feel like they were excluded from any one space, including the bar. Something as simple as taking a regular bar height and dropping it down to a 32- to 34-inch height, or counter height, so that anyone in a manual chair, in a power chair can actually utilize the space to still feel like they are part of whatever is happening at the bar.”

They hired staff — servers, dishwashers, cooks, front of house — but added extra training on how to wait on and treat people with disabilities. Benjamin did in-person training, and he and others also did Zoom sessions with staff, teaching them what it means to be hearing impaired, spinal cord injured, sight impaired, and what those people’s needs were.

“So, there’s a lot of patience, understanding, being able to say it in a way and talk to them about it in a way that they’re going to understand,” Benjamin says.

They’ve had some new challenges in the past couple months, including hiring a new head chef and changing their main food influence.

After working as the head chef since the restaurant opened in 2021, Oscar Lorenz

decided to leave in April and focus on other projects and his family. So, Gallego and Benjamin found a new executive chef, Asia Shabazz. Born and raised in East Harlem, Shabazz brings soul food, West African and Caribbean influences to the menu.

So, instead of a menu heavy on Peruvian-dominated flavors and dishes, the menu now features appetizers like sweet potato soup, saltfish with johnny cakes and yuquita, or crispy yuca; main dishes like mofongo — a Puerto Rican dish made from green plantains — fish and grits, curry goat and hot honey fried chicken for two; side dishes that include a hot sauce trio, candied yams, mac and cheese and collard greens; and desserts like rice pudding and sweet potato pie.

“First and foremost, when you’re coming to Contento, you’re coming into somebody’s home. You’re coming to experience something. You’re coming because you want to forget about whatever’s happening on the outside. And the food is such an important role. But we never, like, really wanted to pigeonhole ourselves to one type of cuisine, because we always knew that we would just kind of always be in motion and always evolving,” Gallego says. “And so, we went from this, you know, influence of Peru to now we have the influence of the West Caribbean and West African flavors, still remaining true to these East Harlem Latin flavors.” ■

around the HOUSE

Get The Most Out Of Your Closet

Clothes are as varied as the people who wear them, and those that fit you well and express your character elevate your mood.

Your clothes closets should do the same; they should fit your unique needs in a style that brings you joy and should be easy to use. If your current storage situation is frustrating, ask yourself, 'Why?'

Is the closet inefficient and/or accessible? There may be simple design solutions to solve these issues.

Closet Access

Access is the first accessible design consideration. There are two basic closet types: reach-in, typically about 2 feet deep, and walk-/roll-in.

For reach-in closets, the door opening should be as wide as possible, so the full closet width is within reach. Bifold doors prohibit full access on either end of the closet for a wheelchair user.

For walk-/roll-ins, the door opening should be wide enough for your wheelchair to pass through with at least 32 inches of clear space (36-inch wide door). If possible, swing the door out, as doors that swing into a closet may interfere with your ability to turn around.

Closet rods or drawers shouldn't be placed behind the door. For both closet types, and if wall space allows, sliding barn or pocket doors are ideal. If renovation isn't an option and your existing closet door is an obstacle,



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Bifold doors interfere with wheelchair maneuvering space needed to access reach-in closet corners. The typical closet rod/shelf combination is out of reach from a seated position, and closet space is wasted both above and below.

remove the door and hang a stylish curtain for a simple solution.

Adjustable System

An adjustable closet system is essential and worth every penny.

Site-built, nonadjustable, painted wood systems may look good at first

An adjustable wall-hung closet system doesn't run to the floor, easily allowing wheelchair toe space. Replacing doors with a drape simplifies access into the reach-in closet. Determine the top drawer height based on your ability to reach and see into the drawer. Angled shoe shelves are less efficient than flat shoe shelves.

glance, but they're inflexible and won't accommodate your changing wardrobe and physical needs over time. You should be able to adjust shelves, drawers and hanging rod heights within the system.

Basic adjustable closet systems are wall-hung or floor-based. Wall-hung closet support sections are attached to a wall-mounted rail. Since this system doesn't touch the floor, it can easily allow a taller toe-kick space to accommodate wheelchairs.

Floor-based systems' support sections go to the floor, with either a toe kick or baseboard trim at the bottom. The standard 4-inch toe kick should be modified for a wheelchair.



Stacking two levels of short hanging space doubles your hanging volume. A pull-down closet rod brings clothes down to wheelchair level and removes shoulder stress caused from using a hook to retrieve out-of-reach items.

Efficient Use Of Space

Most people are familiar with closets where a sole shelf/closet rod combo, either wire or wood, is wall-mounted about 5½ feet above the floor.

Space is wasted both above and below, except for long-hanging items, which are typically in less demand than short-hanging items like shirts, jackets and pants. The rod is out of reach from a wheelchair.

For better use of the space, design so the top shelf/rod combo is about 7 feet above the floor. This allows you to stack two levels of short hanging space. The bottom hanging row is accessible from a wheelchair. A pull-down closet rod for the higher hanging row will bring the clothes down to you.

This accessory may not work for a reach-in closet if there's any overlap with the closet door frame. If your walk-/roll-in closet is so narrow you feel like the hanging clothes on both sides are grabbing you as you enter, place hanging clothes on only one side wall. The other side wall can be shelving, which doesn't project out as far.

Often in a walk-/roll-in closet, the shelf/rod will turn onto an adjacent wall so the hanging clothes from each side are squished in the corner and are often out of reach. Make a clean break in the system where walls meet, avoiding corner overlap.

Remember that in profile, clothes on hangers stick out about 21 inches from the wall, and you need maneuvering space in front to pull the hanger off the rod. Some systems box in corners, eliminating corner space altogether.

Drawers

Closet drawers that fully extend are great for containing clothes that don't fold neatly.

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Pullout hampers place laundry within reach and may help declutter the closet.

They can be an accessible design solution, bringing more clothes within reach, as long as placement and size are carefully planned. From a wheelchair, if the drawer is placed too high you won't be able to look down into it. If placed too low, the drawer will be out of reach or cause excessive back strain.

But the beauty of an adjustable system is these drawers can be placed to fit your needs. A drawer that pulls

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Fixed shelving is made flexible by adding incremental holes for side-support rail adjustments.

out above your knee height allows a front approach and full drawer access.

Shelving

Typical shelving units come in various depths.

Folded clothes often stack neater on a 14-inch or 16-inch deep shelf, as they often hang over the edge on a 12-inch shelf. Raised or angled shoe shelves are glamorous, but they create dead space behind the sloped shelf.



Belt, tie and scarf racks and wardrobe rods are designed to move out toward you, making access easier.



Avoid hanging clothes systems that turn a corner and storing shoes on wire racks above your clothes.



A closet island adds more space for reachable storage drawers and shelves, but it only works if you have ample circulation space around the perimeter. Elevate and deepen the toe kick to accommodate your chair.

If space is an issue, choose flat, adjustable shelves. Shelving also has the ability to slide out, improving accessibility and bringing more clothing or shoes within reach. For this, a deeper shelf measuring 19 inches to 22 inches is ideal to gain two times the accessible storage.

Accessible Accessories

In addition to the pull-down rod, increase functionality by adding accessories that pull out.

Tie, belt and scarf racks slide out to reveal multiple hooks. Pant racks or wardrobe rods pull out like a drawer, with rods arranged parallel or perpendicular to the wall. Pullout jewelry trays come with all sorts of compartment arrangements. Valet rods slide out when staging an outfit or placing dry cleaning temporarily. Pullout hampers and wire baskets are useful

for laundry, or you may consider planning space to park a laundry cart.

Closet Island

If you have a large space for your closet, you may consider adding an island for additional storage and clothes staging.

Make sure you have ample width for your wheelchair to avoid colliding with perimeter closet systems while maneuvering fully around the island, particularly at the corners.

The island counter height should be low enough for use from your wheelchair. Elevate and deepen the toe kick accordingly.

Other Considerations

- Be prepared when working with a closet systems designer. Measure the linear amount of hanging clothes, stacked clothes, number of shoes and anything else you wish to store.
- View a 3D image of the design before purchase.
- Regardless of the closet type, add sufficient lights for a well-lit space.
- Consider adding a full-length mirror in or near your closet.

For more information on this or any architecture issue concerning accessibility, call 202-416-7645 or email pvaarchitecture@pva.org.

Rachel Y. Krishnan, AIA, is project manager of architecture services with the Paralyzed Veterans of America Architecture Program. ■

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Paralyzed Veterans of America (PVA) has published *Accessible Home Design: Architectural Solutions for the Wheelchair User* as a detailed resource for homeowners, architects and builders. It's available for purchase by calling 800-424-8200, ext. 7645, or emailing pvaarchitecture@pva.org. The cost is \$9.99 for PVA members or \$14.99 for nonmembers. You can also purchase the book for \$14.99 on Amazon: amazon.com/s?me=A1K1VT0E51SAX3&mar_ketplacelD=ATVPDKIKX0DER or by using the QR code.



French Receives Visionary Prize

The Craig H. Neilsen

Foundation has named Jennifer French, founder and executive director of the Neurotech Network, as the 2024 Craig H. Neilsen Visionary Prize award winner.

This award honors individuals whose innovative work and dedication have significantly improved the quality of life for people living with spinal cord injury (SCI).

French's contributions to the SCI community exemplify the pioneering spirit and commitment that Craig H. Neilsen championed throughout his life, the foundation says in a September release. The Visionary Prize, accompanied by an unrestricted \$1 million award, highlights her achievements and ongoing impact.

French has dedicated her life to advancing neurotechnology and improving the quality of life for people with SCI. After a snowboarding accident in 1998 left her paralyzed from the chest down, French participated in a clinical trial for an implanted device that stimulates her hip and leg muscles, enabling her to stand. Her determination not only helped her be upright under her own power but also advanced the technology for thousands of other potential recipients, including injured soldiers returning from war.



Jennifer French

Her passion for inclusion and technological advancement shines through in her public speaking engagements, including at the National Academy of Sciences, the National Institutes of Health and various TEDx events.

As an accomplished athlete, French won a silver medal in sailing for Team USA at the 2012 London Paralympic Games. She cofounded the Warrior Sailing Program, providing wounded veterans with the opportunity to experience the freedom and empowerment that sailing offers.

She also has been an outspoken advocate for engineering innovations to help people with SCI, ensuring their voices are included within the research community.

Accommodation Ideas

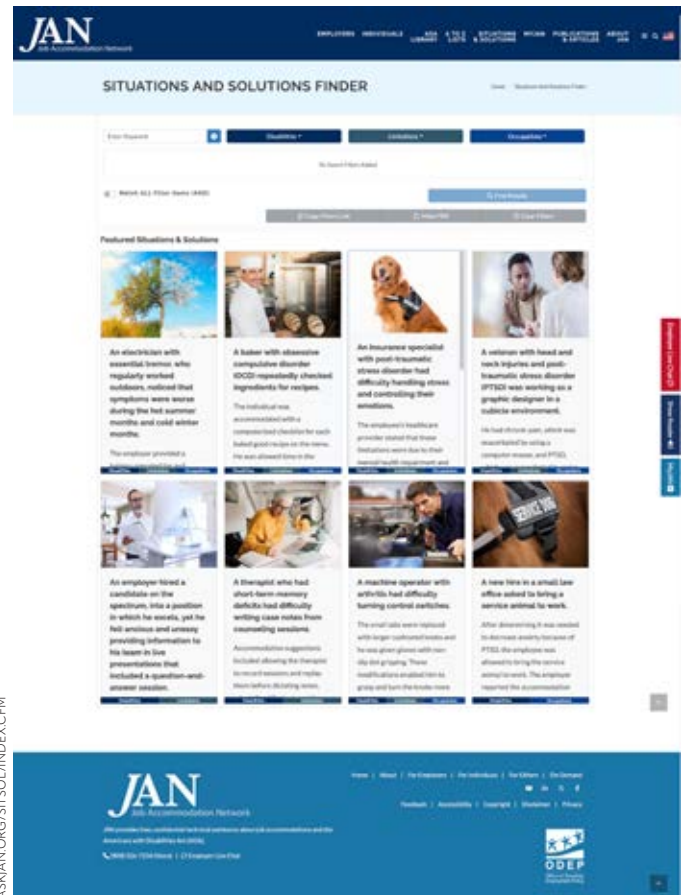
The U.S. Department of Labor (DOL) has a tool that provides access to more than 700 accommodation ideas

for workers with disabilities and their employers.

The Situations and Solutions Finder (askjan.org/sitsol/index.cfm) offers examples of workplace

results by disability, limitation and/or occupation.

An accommodation is a modification to the work environment or how a job is typically done that enables



accommodations shared by users of the Job Accommodation Network, a service of the DOL's Office of Disability Employment Policy. The database draws its examples from organizations large and small, across industries and from the private and public sectors. The tool allows users to filter and save

a qualified person with a disability to enjoy equal employment opportunities. The Americans with Disabilities Act requires employers to provide reasonable accommodations for disabled applicants and employees, when requested, unless doing so would cause an undue hardship.

“By allowing people to learn what has worked for others in similar, even if not exactly the same, situations, this new resource empowers employers, as well as employees or job applicants themselves, to ensure disabled workers have access to what they need to do their best on the job,” says Assistant Secretary for Disability Employment Policy Taryn M. Williams in a September release.

Not all examples of accommodations in the Situations and Solutions Finder may be effective for every person or workplace, as accommodations are unique to each individual, but common patterns exist to assist employers and workers in assessing options.

Best & Worst Cities Report

The personal finance website WalletHub has released its report on 2024’s Best & Worst Cities for People with Disabilities.

In order to ease the process of finding the best place to live while managing a disability, WalletHub compared more than 180 U.S. cities across 33 key indicators of disability-friendliness.

The data set ranges from wheelchair-accessible facilities per capita to rate of workers with disabilities to quality of the public hospital system.



Scottsdale, Ariz.

The top five best cities ranked overall were:

- 1) Scottsdale, Ariz.
- 2) Minneapolis
- 3) Columbus, Ohio
- 4) St. Louis
- 5) St. Paul, Minn.

Rounding out the bottom five as the worst cities for people with disabilities were:

- 178) Juneau, Alaska
- 179) Montgomery, Ala.
- 180) Jackson, Miss.
- 181) Pearl City, Hawaii
- 182) Gulfport, Miss.

To view the full report and your city’s rank, visit wallethub.com/edu/best-worst-cities-for-people-with-disabilities/7164.

Experimental ALS Drug Grant

Mayo Clinic in Florida has received a grant from the National Institute of Neurological Disorders and Stroke (NINDS) to begin an innova-

tive study that will provide hundreds of patients with amyotrophic lateral sclerosis (ALS) access to the experimental drug ibudilast over six months.

The grant totals \$22 million. Mayo Clinic will receive \$12 million and manage the distribution of the remainder to its collaborators.

The U.S. Food and Drug Administration has granted expanded access program (EAP) status to the study.

Björn Oskarsson, MD, lead investigator for the project and director of Mayo Clinic’s ALS Center of Excellence, says the primary measure of the drug’s effect on ALS progression will be a blood test that shows whether neurofilament protein levels have changed in ALS patients. High levels of neurofilament proteins may indicate damage in neurons.

About 200 patients in the program drawn from all three Mayo Clinic sites and other institutions will see their own neurofilament

light levels to determine if the drug is right for them.

This marks the first time that neurofilament light will be used in this way to guide patients and physicians to make decisions together.

“This trial will let patients monitor their own ALS condition, and we hope to confirm that this will be an effective way to evaluate progress in patients with ALS,” Oskarsson says in a September Mayo Clinic release. “This is important because it is difficult to say if ALS disease progression is speeding up or slowing down. Neurofilament light can be seen as sort of a speedometer that can give an indication whether a treatment is working or not.”

In this program, physicians treating ALS patients will join a network managed by Mayo Clinic and WideTrial, an organization focused on expanding patient access to experimental treatments through EAP. BioSEND, which

houses biospecimens collected through studies supported by or conducted in collaboration with NINDS, will hold blood samples from the study for future research and help establish an ALS biobank.

MediciNova will provide ibudilast, an anti-inflammatory drug currently used in Japan. The drug's ability to penetrate the central nervous system, block harmful proteins and stimulate cell repair makes it a possible option for ALS treatment.

Sex-Specific Shoulder Pain

Beckman Institute for Advanced Science and Technology researcher Josh Leonardis received funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the National Institutes of Health to study why female manual wheelchair users experience shoulder pain and pathology at greater rates than males.

Leonardis is an assistant professor of health and kinesiology at the University of Illinois (Urbana-Champaign campus) and the director of the Musculoskeletal Morphology and Biomechanics Laboratory.

"It's well-documented in literature that females experience musculoskeletal

pain at greater rates and intensities than their male counterparts, and this rings true for manual wheelchair users," Leonardis says. "We're seeing females in this cohort experiencing pain, and potentially injuries and pathologies more frequently."

Leonardis aims to reveal the sex-specific effects of wheelchair use in childhood and adolescence. He'll measure upper extremity anatomy, physiology, neuromuscular control and biomechanics with the long-term goal to optimize early detection, prevention and treatment of shoulder pain.

While Leonardis and his team

will investigate these factors over the next two years, potential solutions include improving the fit of the wheelchair, ideating optimal chair design for individuals and updating usage guidelines which haven't been amended since 2002.

"If a wheelchair user experiences pain, that severely impacts the quality of their life and economic well-being," Leonardis says. "There's a critical need to understand what causes pain and pathology and why females might face these factors more often than males to determine potential treatment options. This grant represents the first step in answering these questions."

Leonardis will use state-of-the-art 3 Tesla MRI scanners in Beckman's Biomedical Imaging Center alongside quantitative morphometrics to quantify the adaptation of upper extremities, allowing the researchers to understand the anatomical changes individuals undergo due to wheelchair use and how these changes relate to pain.

"The best way to make an impact is to be proactive," Leonardis says. "We're not looking to simply react to users' pain,



Josh Leonardis

COURTESY OF BECKMAN INSTITUTE FOR ADVANCED SCIENCE AND TECHNOLOGY

but we're aiming to understand what causes the pain so we can develop potential treatment options and prevention protocols."

Contributor:

Samantha Jones Toal/
Beckman Institute
Communications Office

Testing MS Treatment

Rutgers Health researchers in New Jersey are conducting a study with primary and secondary progressive multiple sclerosis (p-MS) patients to see if an engineered immune cell therapy can halt the progression of the autoimmune disease, according to a September Rutgers University release.

Mistargeted attacks by the body's immune system and active central nervous system (CNS) inflammation underlie MS. As CNS damage accumulates, patients typically experience increasing difficulty swallowing, balancing, breathing, coordinating movements,



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generating strength and/or controlling their bladders and bowels. They also can have increasing levels of cognitive impairment.

The cellular therapy being tested is made by altering a specific subset of immune cells taken from each patient: regulatory T cells (Tregs). Tregs typically suppress inflammation and autoimmune disease and promote repair. The engineering process enables the modified Tregs to respond specifically to CNS inflammation. After administration, the engi-

neered Tregs will circulate through the body. When they find the inflamed CNS tissue, they will activate to suppress inflammation, reset immune tolerance, limit tissue destruction and enable repair.

"The goal is to reprogram each patient's Tregs to eliminate the inflammation within the central nervous system, limiting neuronal injury and restoring healthy nerves," says Vikram Bhise, MD, a professor of neurology at Rutgers Robert Wood Johnson Medical School who will oversee the trial

in New Brunswick, N.J., in the release. "If treatment reverses disease progression, it will constitute a true breakthrough because existing treatments prevent relapses but don't work for patients with p-MS."

The phase I trial is open to patients with either secondary or primary p-MS without relapse activity, a particular genetic signature and evidence of CNS inflammation on MRI.

Abata Therapeutics is developing the therapy and financing the study to test the treatment's safety and

efficacy on at least a dozen patients at participating centers across North America.

Researchers at Abata Therapeutics will harvest Tregs from the patients' blood samples, activate them to multiply and genetically edit them in the laboratory. The engineered Tregs will be reinjected into patients.

This strategy could help patients with p-MS by preventing or stopping aggressive immune cells from attacking the nerves. ■



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November 2024

West Virginia Boccia Tournament	November 1-2, 2024	Charleston, WV
Texas Pickleball Tournament	November 9-10, 2025	San Antonio, TX
New England Boccia Tournament	November 16-17, 2024	Brockton, MA

December 2024

Nevada Bowling Tournament	December 5-8, 2024	Las Vegas, NV
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January 2025

Florida Gulf Coast Bowling Tournament	January 16-19, 2025	Tampa, FL
Racing High Performance Racing Camp	Jan. 25-Feb. 2, 2025	Tampa, FL

February 2025

Bayou Gulf States Boccia Tournament	February 1-2, 2025	Gulfport, MS
Central Florida Air Gun Tournament	February 8-9, 2025	Orlando, FL
PVA Wheelchair Rugby Invitational	February 14-16, 2025	Louisville, KY
Florida Boccia Tournament	February 21-23, 2025	Tampa, FL
Texas Boccia Tournament	TBD	San Antonio, TX

March 2025

Intro to Paracycling Camp - Stop 1	March 6-7, 2025	Phoenix, AZ
Tampa Pickleball Clinic	March 7, 2025	Tampa, FL
Mid-Atlantic Billiards Tournament	March 14-16, 2025	Midlothian, VA
Wisconsin Air Gun Tournament	March 21-22, 2025	Racine, WI
Bayou Brawl Bass Tournament	March 28-30, 2025	Westwego, LA
Long Beach Boccia Tournament	March 29-30, 2025	Long Beach, CA

SPORTS EVENT SCHEDULE

FY25

April 2025

Wheelchair Football Camp	April 3-6, 2025	Birmingham, AL
Citrus Slam Bass Fishing Tournament	April 4-6, 2025	Kissimmee, FL
Pocahontas Off-Road Spring Camp & PVA Off-Road Classic	April 9-13, 2025	Chesterfield, VA
Mid-America Billiards Tournament	April 10-12, 2025	Oklahoma City, OK
Bluegrass Bash Bass Tournament	April 11-13, 2025	Kuttawa, KY
National Air Gun Camp	April 14-18, 2025	Centreville, VA
Salt Lake City Pickleball Clinic	April 24-25, 2025	Salt Lake City, UT
Texas Bowling Tournament	April 30-May 2, 2025	San Antonio, TX

May 2025

Puerto Rico Boccia Tournament (Year-end event)	May 2-4, 2025	San Juan, PR
Land of Lincoln Bass Tournament	May 2-4, 2025	Whittington, IL
Intro to Paracycling Camp - Stop 2	May 8-9, 2025	Salt Lake City, UT
Texas Trapshoot Tournament	May 9-11, 2025	San Antonio, TX
Vaughan Trapshoot Tournament	May 23-25, 2025	Elburn, IL
Texas Air Gun Tournament	May 31-Jun 1, 2025	San Antonio, TX

June 2025

Intro to Paracycling Camp - Stop 3	June, 4-5, 2025	Milwaukee, WI
Capital Clash Bass Tournament (Year-end event)	June 6-8, 2025	La Plata, MD
Wheelchair Basketball Camp	June 6-8, 2025	Arlington, TX
Colonial Pickleball Tournament	June 14-15, 2025	Perry Point, MD
Iowa Trapshoot Tournament (Year-end event)	June 20-22, 2025	Cedar Rapids, IA
Grand Teton Outdoor Experience	June 23-27, 2025	Jackson Hole, WY



Vines Honored

Former Paralyzed Veterans of America Director of Research and Education Cheryl Vines received another wheelchair basketball honor earlier this year.

After being inducted into the National Wheelchair Basketball Association (NWBA) Hall of Fame as a contributor in April, Vines attended and was honored at October's Naismith Memorial Basketball Hall of Fame induction ceremony at the Mohegan Sun in Uncasville, Conn.

Vines was honored along with former Paralympic women's wheelchair basketball players Andrea Woodson-Smith, PhD, and Darlene Hunter, PhD, while at the Oct. 11-13 induction event. The event was broadcast on NBA TV, and all three received recognition

COURTESY OF THE NATIONAL WHEELCHAIR BASKETBALL ASSOCIATION



Andrea Woodson-Smith, PhD, left, Darlene Hunter, PhD, center, and Cheryl Vines, right, were honored at October's Naismith Memorial Basketball Hall of Fame induction ceremony.

on stage after a minute-long vignette on them.

Low-Point Rugby

After the TIRR Memorial Hermann (Houston) Texans captured the United States Wheelchair Rugby Association Low-Point Rugby national championship in September, five athletes received individual honors in October.

They included: Northridge Knights' Mike DeYoung (Top 0.5-pointer), TIRR Memorial Hermann Texans' JJ Narvaez (Top 1.0-pointer), Northridge Knights' Colton Parker (Best 1.5-pointer), Grand Rapids (Mich.) Thunder's Ryan Engelby (Most Valuable Player) and Magee/MedStar's Nate Tighe (Sportsmanship Award). ■

Pool Championships



Charles Interrante and Houston Lewis each captured titles at the Oct. 11-12 Paralyzed Veterans of America Mid-South Chapter's 9-Ball Tournament in Memphis, Tenn. Interrante won the Main Event title, while Lewis took the Second Flight title.

Main Event winner Interrante is pictured center, along with runner-up Dan Hall, left, and third-place finisher and National Wheelchair Poolplayers Association President Jeff Dolezal.

Lewis won the Second Flight, with Metyrum Wilborn in second and Sam Cooke in third.

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America's Game

The Dec. 14 football rivalry game between the Army Black Knights and Navy Midshipmen at Northwest Stadium in Landover, Md., could be one of the biggest in decades, as both teams are having stellar seasons. The matchup is always of big interest among Paralyzed Veterans of America (PVA) members, and, from left, then-PVA National President David Zurfluh, Marilou Fowler, PVA CEO and U.S. Military Academy at West Point graduate Carl Blake and his son, Jonathan, now a senior at West Point, paid a visit to the Dec. 14, 2019, game in Philadelphia. Navy won that game 31-7.

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